

Introduction to HIV/AIDS and sexually transmitted infection surveillance

MODULE 4

Introduction to respondent-driven sampling

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Introduction

How to use this module

What you should know before the course

This training course describes how to plan and implement a respondent-driven sampling (RDS) survey. The course is intended for university and ministry of health staff, public and private public health researchers, and surveillance officers, who will be involved in the planning, organizing, monitoring or implementing of biological and/or behavioural surveillance surveys on HIV/AIDS and associated risk factors in key populations at higher risk of HIV exposure.

This module is part of a set of four modules that have been designed with a focus on the World Health Organization's (WHO) Eastern Mediterranean Region. The modules were designed for use in training workshops. The other modules are:

- Module 1: Overview of the HIV/AIDS epidemic with an introduction to public health surveillance
- Module 2: Surveillance of HIV risk behaviours
- Module 3: Surveillance of most-at-risk populations.

Similar training modules have been developed for WHO's African, Americas, European and South-East Asia regions. Although the overall framework of the modules is the same, each region has different patterns of HIV epidemics and distinct social and cultural contexts. Also, different countries may have different HIV surveillance capacities and different needs. Thus, these modules were developed taking into account the specific context of the HIV epidemic in the countries of the Eastern Mediterranean Region.

The modules are also intended for use in the countries of the Joint United Nations Programme on HIV/AIDS (UNAIDS) Middle East and North Africa Region. For the purpose of this training course, all countries in the WHO Eastern Mediterranean Region plus Algeria are therefore the intended audience. We refer to these collectively as Eastern Mediterranean Region/Middle East and North Africa (EMR/MENA) countries.

Module structure

This module is divided into units. The units are convenient blocks of material for a single study session. The module can also be used for self-study.

Each unit begins with warm-up questions to help you start thinking about the material you will be learning. Based on your past knowledge and experience with behavioural

surveillance, you may be easily able to respond correctly to some of the questions. You may have a more difficult time responding to other questions. Answer the questions as best you can. You can keep your answers to the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will be able to return to the warm-up questions and change your answers. At the end of the unit, the class will discuss the warm-up questions and you can check your answers.

Most units also have exercises and case studies for you to think about. These are designed to stimulate small group discussion among course participants. Answers are not provided.

As you study this module, you may find terms that are unfamiliar to you. These terms are defined in the glossary found in Annex 1. The glossary also contains definitions of acronyms.

Annexes

More information is provided in the following annexes:

- Annex 1 Glossary
- Annex 2 Useful links
- Annex 3 Answers to warm-up questions
- Annex 4 Formative assessment protocol, consent forms and questionnaires
- Annex 5 Generic protocol for conducting RDS surveys among people who inject drugs, men who have sex with men and female sex workers
- Annex 6 RDS survey forms
- Annex 7 Standard operating procedures
- Annex 8 Laboratory standard operating procedure forms.

Additions, corrections, suggestions

We welcome feedback on this training module. Please send your suggestions for any changes or additional information that might be included to the following address for possible inclusion in future editions.

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Unit 1

Introduction to
respondent-driven
sampling

Overview

What this unit is about

This unit provides an introduction to and background for respondent-driven sampling (RDS), a method for sampling hard-to-reach (also referred to as hidden) populations and key populations at higher risk of HIV exposure (also referred to as vulnerable populations and most-at-risk populations). Some of the topics presented in this unit will be discussed in more detail in later units.

Warm-up questions

1. Give as many answers as you can to this question: Why are HIV/AIDS public health workers interested in surveillance of hard-to-reach populations such as people who inject drugs, men who have sex with men or sex workers?
2. At the beginning of an RDS survey, researchers recruit a handful of participants who serve as the _____ based on pre-existing contact with the survey group.
3. Which choice below is incorrect? Circle your answer.
Hard-to-reach populations often:
 - a. cannot be identified by any means
 - b. lack sampling frames
 - c. are rare in the population
 - d. have behaviours that are stigmatized and/or illegal.
4. True or false? RDS is usually slower and more expensive than the other sampling methods, but is used because it is more accurate. Circle your answer below.

True

False

5. Match the sampling methodology with its definition by putting the correct letter in each space.

- | | |
|--|---|
| _____ Snowball or related chain-referral methods | a. Researcher recruits individuals from specific locations. |
| _____ Time-location sampling | b. Individuals in an institution, such as a prison, are sampled. |
| _____ Institutional sampling | c. One individual recruits as many participants as possible for the survey. |
| _____ Stratified sampling | d. Individuals are recruited based on their strata and their actual representation in the population. |

6. True or false? An RDS sample without the proper analysis adjustments is nothing more than a very good snowball sample. Circle your answer below.

True

False

Introduction

What you will learn

This unit provides a brief introduction to sampling hard-to-reach populations/key populations at higher risk of HIV exposure using RDS and introduces the assumptions and key concepts and definitions needed to understand RDS recruitment and statistics. By the end of this unit, you should be able to:

- describe the difference between a probability and non-probability sampling method
- explain how a survey is conducted using RDS
- identify some of the differences between a chain referral convenience sample and RDS
- describe the assumptions needed for RDS recruitment and analysis
- explain the differences between functional and analytical assumptions in RDS.

Why is sampling needed?

Sampling is that part of statistical practice concerned with the selection of individuals from a survey population that are intended to yield some knowledge about a total survey population, especially for the purposes of statistical inference.

Sampling methods are classified as either probability or non-probability.

- In probability sampling, each member of the population has a known probability of being selected. Probability sampling includes random sampling, systematic sampling and stratified sampling, and it yields unbiased estimates.
- In non-probability sampling, members are selected from the population in some non-random manner. Non-probability sampling includes convenience sampling, judgment sampling, quota sampling and snowball sampling, and it often yields biased estimates.

The advantage of probability sampling is that sampling error can be calculated. Sampling error is the degree to which a sample might differ from the population. When inferring to the population, results are reported plus or minus the sampling error. In non-probability sampling, the degree to which the sample differs from the population remains unknown.

In countries with increasing HIV incidence, public health workers trying to control the spread of the epidemic are interested in hard-to-reach or hidden populations such as people who inject drugs, sex workers and men who have sex with men. For these populations, public health workers need to:

- monitor risk behaviours
- estimate proportions of characteristics, behaviours and prevalence of HIV and other infections within the subpopulation
- describe the composition of the population at risk for HIV infection
- measure access to services and HIV prevention coverage
- observe trends over time using the same sampling method.

These subpopulations often:

- lack sampling frames
- are rare in the population
- have behaviours that are stigmatized and/or illegal

- do not necessarily want to be identified by researchers or others.

This prevents researchers from obtaining unbiased estimates of important indicators because of the difficulty of using probability sampling methods.

Chain referral sampling methodologies

Chain referral sampling methodologies have been commonly used as an easy and low cost way to recruit the hard-to-reach populations listed above. Chain referral sampling is a non-probability method in which hard-to-reach populations are asked to provide referrals to other members of their group. Typically, this method continues until the final sample size is attained or when an entire network of the population is sampled. Although this method can easily and rapidly identify numerous participants, it is prone to sampling biases because not everyone has an equal probability of selection [1, 2, 3]. Specific problems in chain referral sampling are the potential for certain groups to be either over- or under-represented depending on the number of connections a recruiter has to other population members.

RDS attempts to overcome the limitations associated with chain referral methods, while retaining several of its advantages including:

- using an initial group of participants to initiate peer recruitment
- having peers refer their peers
- in many situations, relatively easy and rapid recruitment.

RDS overview

Introduction

Used for the first time in 1994 among people who inject drugs in the United States, RDS is now utilized around the world in numerous surveys among hard-to-reach populations [4, 5]. RDS belongs to a class of sampling method known as link tracing and adaptive sampling designs which are useful in situations where traditional probability sampling methods are unfeasible. RDS uses several theoretical premises borrowed from sociological statistics to mitigate the biases associated with a chain referral sample. Specifically, RDS utilizes a branch of the social sciences known as social network theory. Social network theory attempts to map relationships and characteristics shared by groups. Information about the social networks of persons recruited into an RDS survey is used to determine the probability of each recruit's selection and to mitigate the biases associated with over- or under-sampling certain groups.

Social networks

A social network in RDS is a social structure of individuals who are connected by one or more specific types of interdependency, such as relationships of activity (sexual, working, drug using), friendship, kinship, common interest, etc. RDS peer-to-peer recruitment relies on populations being connected through social networks.

For example:

- people who inject drugs have strong social networks because they often buy drugs and inject with other people who inject drugs
- men who have sex with men form strong social networks since they have sex and socialize with other men who have sex with men
- sex workers form social networks through their work, living and social activities.

The characteristics of social networks are described in more detail in Unit 2.

How RDS works

Introduction

RDS comprises two parts: a recruitment strategy and an analysis component. Before a survey may be classified as using RDS, the recruitment and analysis must take into account social network sizes and who recruited whom.

The careful collection of personal network size information and tracking who recruited whom is critical for analysis of RDS data. Without the necessary analytical adjustments, RDS is just a very good chain referral sample.

The following information must be collected from each participant in order to analyse RDS data:

- Personal social network size—this is the number of people the respondent knows within the survey population.
- Participant's coupon number—this is the number on the coupon with which the participant was recruited. Seeds are selected by survey staff and therefore do not get a coupon. However, seeds will have a coupon number.
- Coupon numbers of recruits—these are the numbers given to the recruits of each participant. They are used to link the recruiter to his or her recruits.

RDS uses two types of structured incentive:

- an incentive for being interviewed (primary incentive)
- an incentive for recruiting peers to be interviewed (secondary incentive).

All of these concepts are discussed in later units of this module.

RDS recruitment steps

Once the preliminary steps of holding planning meetings, obtaining clearance for research with human subjects (ethics review) and conducting formative assessment are complete, it is time to gather a sample using RDS. The RDS recruitment steps are as follows:

1. Researchers select a location accessible and acceptable to the survey population. They ensure that the site is discreet and will not attract undue governmental or community concern.
2. Based on formative assessment, researchers identify and recruit a handful of participants who serve as the seeds (initial survey participants) from the survey population. Most

- past surveys have used somewhere from 3 to 15 seeds or, in more difficult recruitment situations, as many as 29 seeds [5]. Seeds need not be selected randomly, but a diverse selection of seeds will help ensure reaching diverse members of the population.
3. Seeds complete the survey process (interview, provision of biological specimens, etc.) and receive a set number of coupons to use in recruiting their peers (other population members who they know).
 4. The recruits of the seeds produce wave 1; the recruits of wave 1 produce wave 2; and so on. This process continues until the sample size is reached. The seed and its corresponding waves are referred to as a chain.
 5. All participants receive an incentive for completing the interview (primary incentive) and another incentive for recruiting their peers to participate in the survey (secondary incentive).

Figure 1.1, a graphic illustration of a sample survey with only one seed, shows what may happen as each wave progresses.

The objective in RDS is to generate long recruitment chains made up of several recruitment waves of participants so that the final sample characteristics will be independent of those selected as seeds.

For a larger survey, if there is an initial selection of twelve seeds, and each of these seeds recruits two peers, and each of the two peers recruits two more peers over three waves, then the sample will exponentially expand as follows:

- 12 seeds
- Wave 1: 12 seeds select 2 peers each = 24 peers
- Wave 2: 24 peers select 2 peers each = 48 peers
- Wave 3: 48 peers select 2 peers each = 96 peers

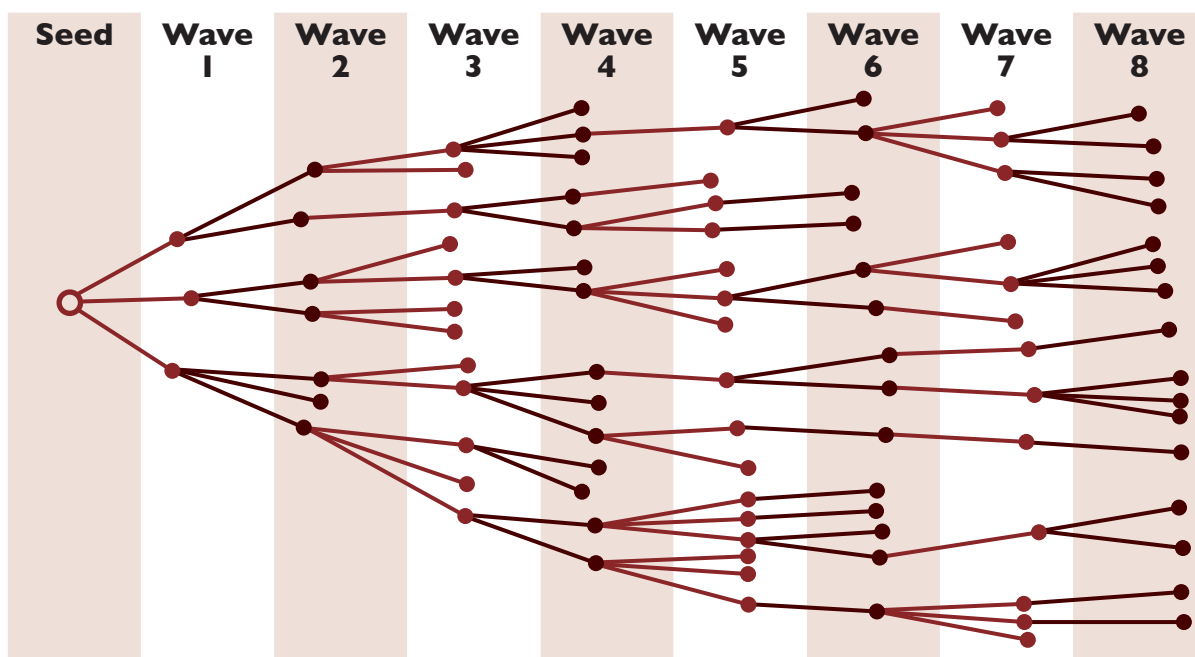


Figure 1.1 Recruitment chain of eight waves generated from one seed

Source: Johnston LG, Sabin K. Sampling hard-to-reach populations with respondent driven sampling. *Methodological Innovations Online*, 2010, 5(2):38–48.

This creates recruitment chains totalling 180 individuals (12 seeds + 24 + 48 + 96)

Note: It is almost impossible to predict the number of coupons that will be used by each participant during the course of a survey. In general you can expect to never achieve 100% use of coupons distributed. For a survey that issues up to three referral coupons to survey participants, the redemption of at least 33% of coupons or more is preferred. This means that for every three coupons that are issued, at least one coupon is redeemed at the survey site.

Sampling should end based on the calculated sample size (see Unit 3 on sample size calculation). In some cases, when populations are not socially networked or when formative assessment has not been conducted to assess recruitment potential in a population, sampling may end prematurely as recruitment chains cannot be sustained.

Although it is important in the sampling process to reach a stable composition with respect to key characteristics (equilibrium), equilibrium is only calculated on the final sample and not during the sampling process (see Unit 5 for more about equilibrium).

Note: Do not end the sampling process once you have reached equilibrium since the attainment of equilibrium is the point at which your sample finally becomes independent of the non-randomly selected seeds and multiple waves are needed beyond the point of equilibrium.

The final attainment of waves is based upon the maximum number of waves in the longest chain [4]. Some RDS surveys have reached up to 20 waves or more. It is common that one seed becomes a “super” recruiter producing more waves in the chain than any other chain in the sample. It is not uncommon that one seed produces a very long chain and comprises one third of the sample whereas other seeds produce 2, 3 or 4 waves. Some seeds may not recruit anyone.

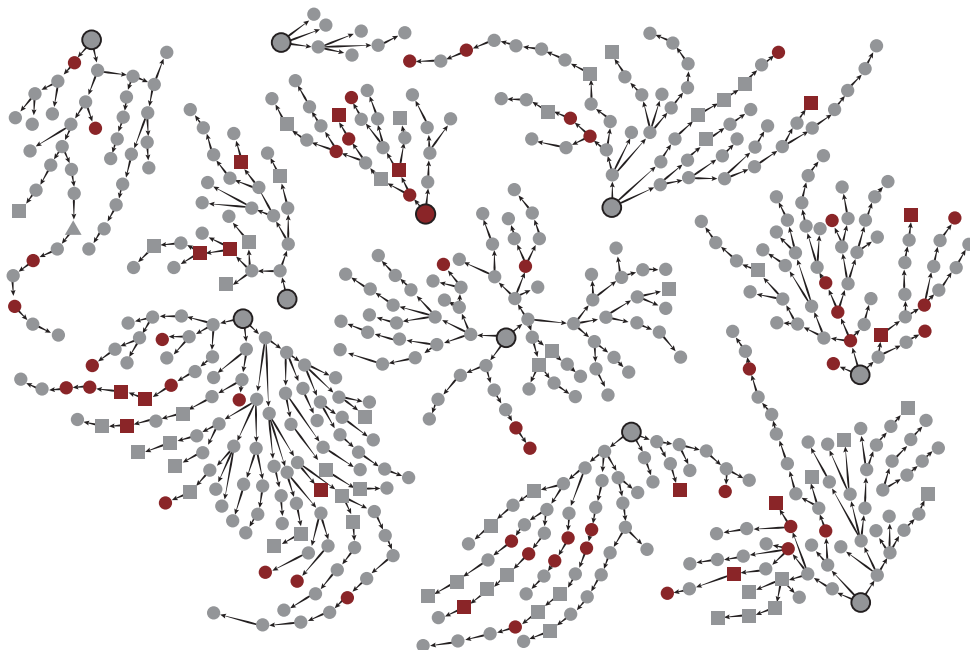


Figure I.2 Recruitment chain from a survey conducted among men who have sex with men in Zanzibar, Tanzania, 2007.

Figure 1.2 shows the recruitment chains from ten seeds of a sample of 509 men who have sex with men from a survey conducted in Zanzibar, Tanzania, in 2007 [6].

RDS functional and analytical assumptions

Introduction

It is important to have some knowledge about assumptions before conducting a survey using RDS methods. There are two types of assumption in RDS: functional and analytical [7].

Functional assumptions

Three functional assumptions must be met during RDS recruitment. Each of these assumptions should be reviewed before considering RDS. If these assumptions are not met, a number of problems may result, including failure to accumulate a large number of respondents.

1. Respondents know one another as members of the survey population.

RDS recruitment is premised upon populations being linked by pre-existing contact patterns and reciprocal relationships (recruit and recruiter know each other). To be successful recruiters, respondents must know others that meet the eligibility criteria.

Recruitment quotas (provision of a set number of recruitment coupons for each participant) maximize the probability that respondents recruit persons with whom they already have a relationship rather than approaching strangers. Previous applications of RDS demonstrate that relationships between recruit and recruiter involve some form of ongoing personal relationship in approximately 98% of cases [8].

RDS assumes that group members can most effectively recruit other members of their group [9]. Essentially, peer-to-peer recruitment is believed to increase credibility and encourage participation, especially among populations that prefer to be hidden and are hard to reach.

2. Respondents are linked by a network composed of a single component.

The sample population must be large and dense enough to sustain recruitment. While respondents may know others that meet the eligibility criteria for a survey, if they do not know multiple people who fit the description, recruitment will not be sustained. To ensure numerous network connections, respondents can recruit those with whom they have “weak links” such as acquaintances and “strong links” such as friends and family members.

3. Sampling occurs with replacement.

Sampling with replacement is one of the statistical requirements for some RDS estimators to be valid. Theoretically, sampling with replacement means that all members of the population have multiple chances to participate. Most surveys do not allow respondents to participate more than once, as a very small number of respondents may overwhelm the sample.

Instead of allowing respondents to participate more than once, the RDS method requires that the sampling fraction (the number of people in the sample divided by the total number of people in the survey population) be small. If the sample size required to create valid estimates is high, it is possible that achieving the target sample size would be impossible because respondents would not have a pool of eligible people in their network that have not already participated.

Analytical assumptions

Analytical assumptions must be assessed to measure the level of bias in the final estimates. When these assumptions are met, the population estimate is purported to be asymptotically unbiased, so bias is negligible, i.e. on the order of $1/(\text{sample size})$. Asymptotically unbiased estimates are those that become increasingly exact as they approach a limit (equilibrium) [10]. Not all assumptions can be proven and some assumptions may not be completely met.

1. Respondents can accurately report their personal network size, defined as the number of relatives, friends and acquaintances who fall within the survey population.

Because respondents recruit each other, it is important to know how many people could potentially recruit each respondent. There are multiple paths to each respondent: those with larger social network sizes are more likely to be recruited than those with smaller social network sizes. Those respondents with small social network sizes are given a higher weight because there are few recruitment paths that lead to them.

The social network size question should reflect the pool of people that the respondent could recruit from the survey population. The accurate measurement of personal social network size depends on many factors including how the question is structured, how well the interviewers are trained to probe for accurate responses to this question and the impact of recall bias.

2. Peer recruitment is a random selection from the recruiter's network.

The assumption of random recruitment has not been formally tested. There are areas where random recruitment may be violated:

- random coupon distribution: participants do not distribute their coupons randomly among different subgroups within their social network
- coupon acceptance: those approached do not accept coupons randomly
- coupon redemption: those who accept a coupon do not enrol in the survey randomly.

Non-random coupon distribution occurs when seeds are homogenous on an important variable (e.g. men who have sex with men seeds identified through a men who have sex with men organization) and therefore recruit from among their own subgroup (e.g. "out" men who have sex with men) without reaching into other important subgroups ("hidden" men who have sex with men). Non-random coupon acceptance occurs when one subgroup (e.g. out-of-treatment people who inject drugs) is more reluctant to accept a coupon compared to another group (e.g. in-treatment people who inject drugs).

The random recruitment assumption is plausible only if members of the survey population have reasonably easy and comfortable access to the survey site, an appropriate time frame is used for the network-size question, and appropriate incentives are employed.

However, non-random recruitment, if it occurs, will not necessarily bias the RDS estimator as long as recruitment is not correlated with any variable important for estimation [11].

3. **Each respondent recruits a single peer.**

This assumption is required because the Markov-chain model assumes a linear structure [12]. A Markov-chain model is a system which is in a certain state at each “step” (or wave), with the state changing randomly between steps. Basically, the changes of state of the system are called transitions, and the probabilities associated with various state-changes are called transition probabilities. Research has shown that allowing multiple recruits results in an approximation of the Markov model assumptions [13]. Most RDS surveys begin with multiple recruits (recruiters give out more than one coupon) because recruitment tends to die out when only one recruit is allowed at the beginning of a survey.

Examples of RDS surveys

RDS survey populations

In addition to sampling people who inject drugs, men who have sex with men and sex workers, RDS has also been used in other socially-networked populations including:

- Jazz musicians and other artists [14]
- youth at risk, child labourers, child prostitutes, “beach boys” [15]
- high-risk heterosexual men [16, 17]
- University students [18].

Lessons from EMR/MENA

A number of RDS surveys among key populations at higher risk of HIV exposure have been conducted in EMR/MENA (see Table 1.1).

Female participants seem to be difficult to recruit and more exploratory research is needed to identify and appropriately address the existing barriers.

For example, during extensive formative assessment among people who inject drugs in one country, half of the females who were contacted did not come for their interviews. Stigma associated with injecting among women was most probably the reason for the unwillingness to participate in formative assessment.

During the RDS survey itself, it was harder to reach women who inject drugs than men owing to weaker networking among them. Men who inject drugs took drugs in group gatherings and generally had larger and stronger networks.

Table I.1 Examples of RDS surveys from EMR/MENA

Survey location	Time frame (survey population)	Target sample size	Reached sample size
Tehran, Islamic Republic of Iran	2006/2007 (people who inject drugs)	726	549
Tehran, Islamic Republic of Iran	2007 (men who have sex with men)	120	102
Cairo, Egypt	2006 (people who inject drugs)	406	413
Alexandria, Egypt	2007 (men who have sex with men)	406	267
Beirut, Lebanon	2007/2008 (people who inject drugs)	290	81
Beirut, Lebanon	2007/2008 (female sex workers)	800	135
Beirut, Lebanon	2007/2008 (men who have sex with men)	530	101
Aden, Yemen	2008 (female sex workers)	250	244
Khartoum, Sudan	2008 (female sex workers)	251	321
Hargeisa, Somalia	2008 (female sex workers)	146	237
East Jerusalem Governorate, occupied Palestinian territory	2010 (people who inject drugs)	350	199

Using RDS data to estimate the population size

RDS data can be used as one data source in population size estimates. The multiplier method is one of the most commonly used methods for population size estimates. To employ this method, we need to have information from two sources: the first is usually from an institution or service-based site, such as a voluntary counselling and testing (VCT) site, that the target group members are in contact with, and the second from a community-based survey (such as an RDS survey) that asks questions about the usage of these specific services. These two data sources should correspond to one another, in respect to the geographical area and definitions of key populations.

For example, people who inject drugs can be asked whether they were in treatment during the last year. If the Ministry of Health has information that there were 1000 people who inject drugs in treatment in the capital city during the last year, and if 30% of people who inject drugs in the RDS survey said that they were in treatment, that would give an estimate of $1000/0.30 = 3333$ people who inject drugs in that city.

Multiplier methods based on use of services should be employed at the local level. This means that when we carry out an RDS survey in a local area, we should ask participants which VCT sites they have visited in the past 12 months (or another time period). The next step involves collecting data from these VCT centres on the number of people who

inject drugs (or other target group) who sought services there in the past 12 months, and finally calculating the approximate size of their population in that area. One disadvantage of this method is that service-based data on risk categories are likely to be biased and to contain an unknown number of duplicates.

For more information about estimating population sizes see:

UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance. *Guidelines on estimating the size of populations most at risk to HIV*. Geneva, World Health Organization, 2010.

Unit I exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want based on your study of this unit.

Small group discussion

Get into small groups to discuss the question below. If you are working on your own, write the answer to the question.

Describe any previous experience you have had with sampling methods in your country. Compare the strengths and weaknesses.

Apply what you have learnt/case study

Try this case study individually. We will discuss it in class later.

An RDS survey is planned to determine HIV status and risk factors among sex workers in Menaland. All funding is in place and tentative dates for conducting RDS are scheduled. In contacting organizations working with sex workers in the area, it is learnt that most of the sex workers are trafficked, heavily controlled by pimps and hidden away in brothels. Sex workers do not attend formative assessment interviews and pimps become suspicious. Sex workers are not able to leave their brothels and do not form social networks with other sex workers.

- a. Would RDS work in this context?
- b. What other sampling method would you suggest? Why?

Unit 2

Formative
assessment for RDS

Overview

What this unit is about

This unit provides an introduction to conducting formative assessment to plan a survey using RDS. Also, the unit provides an overview of the key formative assessment topics for RDS.

Warm-up questions

1. True or false? Formative assessment is an important part of developing an RDS survey. Circle your answer below.

True

False

2. Which of the following methods are useful for conducting formative assessment:
 - a. focus group discussions
 - b. key informant interviews
 - c. observations
 - d. mapping
 - e. all of the above.
3. The data collection method that involves the use of graphics (such as maps, drawings and pictures) and other visual materials is known as _____
4. True or false? A rapid assessment and response approach to gathering formative assessment data is usually too expensive to use for planning RDS surveys.

True

False

5. List one key topic that would be important to include in a formative assessment to plan a survey using RDS?

Introduction

What you will learn

This unit provides an introduction to conducting formative assessment to plan a survey using RDS. By the end of this unit, you should be able to:

- know the importance of conducting formative assessment in advance of an RDS survey
- select methods for collecting formative assessment data
- identify key topics for informing an RDS survey
- select questions to guide your formative assessment
- understand how to gather formative assessment data quickly and efficiently.

What is formative assessment?

Formative assessment is research conducted before the quantitative survey begins. Researchers conduct focus groups, in-depth interviews, mapping or observations of the survey population and individuals who work with them to learn more before the survey begins. Originally, it was said that one advantage of RDS is that formative assessment is not required. However, researchers who conduct RDS in international settings find that formative assessment is an essential step in ensuring a successful outcome for the survey. Formative assessment should be incorporated into every RDS survey.

Formative assessment involves talking with human subjects and therefore must go through an ethical review process that will involve the development of a protocol. Ethical review for formative assessment is necessary before collecting data. Annex 4 has an outline of a formative assessment protocol that can be used as a template.

Formative assessment

Benefits of formative assessment

Aside from learning more about the population being surveyed, formative assessment may answer certain questions that you have at the beginning of the survey. Formative assessment can help:

- decide whether RDS is an appropriate sampling method for the population being studied (is the survey population socially networked?)
- identify subpopulations of interest and help select subsets for seeds
- identify individual seeds
- define logistical issues (appropriate incentive, interview locations and so forth)
- inform materials development e.g. coupons, survey questions.

Methods for gathering information

There are several complimentary methods that can be used to gather formative data in preparation for an RDS survey. The most widely used methods are:

- reviewing existing information
- in-depth interviews

- focus group discussions
- mapping
- observation
- key informant (or expert) interviews.

Not all of these methods need to be used in preparing for an RDS survey, but a mix of methods will produce a better understanding of the population and context. Table 2.1 provides a list of the definitions and the potential usefulness of several data collection methods for formative assessment.

Table 2.1 Data collection methods for formative assessment

Data collection method	What it involves	It can be useful because it helps you to...
Reviewing existing information	Involves review of new and existing data sources such as strategy and policy documents, media commentaries and overviews, results of previous HIV and risk behaviours research surveys, scientific literature reviews, published nongovernmental organization documents, and routinely collected data from community organizations, religious groups, law enforcement agencies, treatment centres, ministries of health, hospitals and clinics	<ul style="list-style-type: none"> ● understand what is already known (or reported to be known) ● compile a profile of social, political and economic factors that may constrain or facilitate a survey ● identify key informants to contact and where they might be found ● identify gaps in knowledge to develop questions for the questionnaire
In-depth interviews	Involves interviewing members of the survey population	<ul style="list-style-type: none"> ● identify impediments to the survey ● locate other key persons and organizations to interview ● understand the population's social networks ● gain information about possible survey site locations, incentive levels and other logistical components ● learn about key community members that must be included in planning/implementing the survey ● identify seeds and members for advisory groups ● validate and cross-check findings from other data sources and hypotheses ● explore acceptance of the survey (e.g. biological testing, coupon recruitment)

Data collection method	What it involves	It can be useful because it helps you to...
Focus group discussions	Involves interviewing a number of individuals collectively because they have had a common experience, come from a similar background or have a particular skill or knowledge	<ul style="list-style-type: none"> ● understand the population’s social networks ● explore beliefs, attitudes and behaviours about HIV and risk, and research in general ● gain ideas for further investigation or to develop questions for the questionnaire ● gain information about possible survey site locations, incentive levels and other logistical components ● learn about key community members that must be included in planning/implementing the survey ● identify seeds and members for advisory groups ● validate and cross-check findings from other data sources and hypotheses ● judge reactions to possible aspects of the survey (e.g. biological testing, coupon recruitment)
Mapping	Involves the use of graphics (such as maps, drawings and pictures) and other visual materials to collect data	<ul style="list-style-type: none"> ● identify where survey population members congregate (e.g. clinics, brothels, parks, secluded places, sex venues, gay clubs/bars, markets, bus and train stations) ● identify behavioural indicators (e.g. discarded syringes or condoms) ● identify boundaries affecting research (e.g. ethnic divisions, health or peer outreach boundaries, areas “unofficially” controlled by groups or gangs or likely to be raided by the police) ● understand traffic flow and important transportation routes ● identify where to locate survey sites
Observation	Involves observing general movements and activities of the survey population	<ul style="list-style-type: none"> ● identify where survey population members congregate ● identify behavioural indicators (e.g. discarded syringes or condoms) ● identify boundaries affecting research ● understand traffic flow and important transportation routes ● identify where to locate survey sites

Data collection method	What it involves	It can be useful because it helps you to...
Key informant (or expert) interviews	Involves interviewing members of institutions, organizations and government agencies who know something about or work directly with the survey population	<ul style="list-style-type: none"> ● gain access to key survey population members ● understand the population's social networks ● learn about behaviours and knowledge about HIV and risk in the community ● gain ideas to develop questions for the questionnaire ● gain information about possible survey site locations, incentive levels and other logistical components to the survey ● learn about key community members that must be included in planning/implementing the survey ● identify seeds and members for advisory groups ● validate and cross-check findings from other data sources and hypotheses ● assess level of interest and desire to be included in survey planning and implementation

As in all qualitative research, use information from more than one source in order to assess the validity of the information you are getting.

Discussing Table 2.1

Now try the questions below.

- a. Have you participated in focus group discussions or conducted interviews or heard about these activities where you work? What is useful about each method? What may be some problems associated with each method?
- b. What questions do you think would be useful to ask in a formative assessment when planning an RDS survey among men who have sex with men? Among female sex workers? Among people who inject drugs? What methods would be most useful in obtaining this information?

Lessons from EMR/MENA

In one EMR/MENA country, formative assessment included visits to 29 different venues (bars, clubs, streets, beaches) and conducting structured interviews with 61 female sex workers and 54 key informants. Sex workers reported knowing on average 19 other sex workers, with a median network size of 9 female sex workers. The suggested incentive levels varied widely and it was later decided to keep the incentive at the lower level but to pay each participant for travel costs separately and to offer certificates of HIV status, for which each sex worker normally had to pay a considerable amount at regular intervals.

In another EMR/MENA country, formative assessment included an extensive survey of people who inject drugs. The survey included in-depth interviews with 40 key informants, 9 focus group discussions with 66 people who inject drugs and a review

Table 2.2 Overview of formative assessment methods

CITY, COUNTRY (population)	METHODS			
	In-depth interviews	Focus group discussions (number)	Expert interviews (number)	Observation and mapping
Hodeidah, Yemen (female sex workers)	62 in-depth interviews with female sex workers/ 17 in-depth interviews with pimps	None	<ul style="list-style-type: none"> ● Nongovernmental organizations providing services to female sex workers (6) ● Public health institutes (4) ● Criminal investigation police (1) 	Observation of female sex worker venues
Banja Luka, Bosnia and Herzegovina (people who inject drugs)	None	Six people who inject drugs recently enrolled in treatment (1)	<ul style="list-style-type: none"> ● POENTA syringe exchange project (2) ● Viktorija drug treatment/ counselling nongovernmental organization (2) ● Public Health Institute (1) ● Department of Infectology Clinic (1) ● Social Psychology Department, Banja Luka University (2) 	Observation and mapping of people who inject drugs and locations where users and former users spend time
Bangkok, Thailand (female sex workers)	13 in-depth interviews with female sex workers	None	<ul style="list-style-type: none"> ● Public clinic serving a large female sex worker population (2) ● three nongovernmental organizations working with female sex workers (5) 	Observation and mapping of street-based female sex workers
Podgorica, Montenegro (female sex workers)	4 in-depth interviews with female sex workers	None	<ul style="list-style-type: none"> ● Anti-trafficking nongovernmental organization safe house (1) ● Montenegrin Association Against AIDS (2) ● Juventas youth cultural centre (3) ● Trafficked women shelter (1) ● Drug treatment unit at a mental health centre (2) ● Public Health Institute (2) ● Police anti-drugs centre (2) ● International Organization for Migration (1) ● Montenegrin Women's Lobby (1) ● Centre for Social Work (1) 	Observation visits to two brothels (few other venues known)
Accra, Ghana (men who have sex with men)	None	8–10 men who have sex with men (4)	<ul style="list-style-type: none"> ● men who have sex with men service providers (12) 	Observations at men who have sex with men venues (and mapping)

Source: Johnston LG, et al. Formative research to optimize Respondent Driven Sampling surveys among hard to reach populations in HIV behavioral and biological surveillance: Lessons learned from four case studies. *AIDS Care*, 2010, 22(6):784–92.

of existing published and unpublished literature. Key informants were people who inject drugs, their families, advocates, physicians, policy-makers and police. The survey provided descriptions of people who inject drugs' demographics, their self-defined networks and their HIV risks.

Lessons from EMR/MENA

There have been cases where funding or implementing agencies were interested in carrying out RDS surveys without detailed formative assessment specific to RDS needs. Formative assessment in one case indicated that the incentive made available by the funding agency was low but additional funds could not be secured. As a result, recruitment was slow and the final sample size was much smaller than initially planned.

Examples from the field

Table 2.2 is an example of formative assessment methods conducted in preparation for RDS integrated biological-behavioural surveillance surveys. Note that not all surveys use the same methods.

Key formative assessment topics for RDS¹

Main topics

Aside from general questions you might have about the survey population, HIV prevalence and risk behaviours, stigma and discrimination, etc., formative assessment for RDS should address four main topics:

- social network properties
- acceptability of RDS to the survey population
- seed selection
- survey procedures.

Social networks

The exploration of social networks is essential for determining whether RDS peer-to-peer recruitment can be sustained by the survey population. There are several aspects of social networks to consider for optimizing RDS including “degree” (number of ties within a social network), whether networks form isolated “cliques” or subgroups, and if so whether there are “bridges” which can be targeted to ensure connections between these cliques. Bridges ensure that important subgroups within a social network are sampled (e.g. bisexuals in a social network of men who have sex with men or female sex workers working in distinct areas in a city). In the absence of bridges between cliques, the final survey population could form two or more independent samples (social network structures) that need to be analysed as such or important subgroups may be missed altogether.

¹ Much of this section is borrowed from: Johnston LG, et al. Formative research to optimize Respondent Driven Sampling surveys among hard to reach populations in HIV behavioral and biological surveillance: Lessons learned from four case studies. *AIDS Care*, 2010, 22(6):784–92.

It is also important to understand the strength of ties (weak or strong) within social networks. Having both weak and strong ties can assist in RDS recruitment, whereas just having strong ties may indicate less social diffusion throughout the network. Ties can be assessed by measuring the number of ties there are within a social network (degree) and should be linked through multiple types of relationship (e.g. friendships, acquaintances, co-workers, room-mates) and activities. Ideally, degrees should be large enough (≥ 3) to sustain recruitment and develop the long recruitment chains needed for RDS analysis.

Social networks should also be assessed for both their geographical and temporal density. For example, a long distance truck driver may know many other long distance truck drivers but if they are spread out across an entire country they may not contact each other in a period of time that will be conducive to RDS recruitment during a specific data collection period.

Acceptability of RDS

The peer recruitment sampling used in RDS relies on its acceptability to the survey population. Acceptability may be influenced by stigma or legal sanctions associated with survey population behaviours, confidence that survey staff can maintain confidentiality, level of trust in the organizations conducting the survey or in institutions generally, incentive levels and the convenience of the location of the survey and operating hours. Some of these factors are outside the control of researchers; others can be addressed by tailoring survey logistics appropriately as discussed below.

Seed selection

Seeds should comprise survey population members with large degree (many ties) made up of multiple types of relationship, activity and subgroup. “Good” seeds will improve recruitment effectiveness by supporting the survey goals and persuading others to participate. Seeds with diverse characteristics and social relationships within a social network will speed up the recruitment of a social mix of participants representing the survey population.

Survey procedures

Formative assessment can assist in determining acceptable incentives for enrolling in a survey and recruiting peers, finding appropriate survey locations, setting the hours and days of operation and the type and sex of the survey staff, and providing important information about coupon design (colours, pictures, map, language and literacy considerations).

Formative assessment interviewing

Interview formats

Interviewing is the systematic collection of data through asking questions and carefully listening to and recording or noting the answers. Interviews can take place in any location,

at any time, and with different individuals or groups of people. They may be formal or informal.

There are two types of interviewing format: unstructured (or semi-structured) and structured. These formats will help dictate what types of questionnaire (unstructured, semi-structured and structured) you will use. Most qualitative research will use unstructured or semi-structured interviewing techniques and questionnaire formats. Table 2.3 describes the two formats and their respective advantages and disadvantages.

Table 2.3 Description of unstructured and structured interviewing formats

Interview type	What it is	What else	Advantages	Disadvantages
Unstructured interview	Uses a loose interview guide and an open-ended question format to encourage interviewees to offer their opinions, knowledge and experience freely.	Requires careful thought about which questions to ask, how they should be phrased and when to use probes and prompts; interviewers need good facilitation and communication skills.	<ul style="list-style-type: none"> ● Flexibility, allowing for follow-up of interesting responses and investigation of underlying motives. 	<ul style="list-style-type: none"> ● Inexperienced interviewers may introduce bias by using poorly worded questions ● Can encourage the respondent to talk about irrelevant and unimportant issues ● The uniqueness of each interview may make interpretation difficult.
Structured interview	Uses a more detailed interview guide and questionnaire format so that interviewees respond to direct and specific questions.	Often undertaken after exploratory research, allowing findings from other methods to identify topics that the team wishes to investigate further.	<ul style="list-style-type: none"> ● Offers more control over interview topics and format ● Data from a common interview format is easier to interpret ● Keeps interviews within a more manageable time frame ● Easier for inexperienced interviewers. 	<ul style="list-style-type: none"> ● Adherence to the guide may prevent collection of unexpected but relevant information.

Possible questions about social networks

Table 2.4 presents some possible questions about the social networks of the survey population.

Table 2.4 Questions about social networks

Social networks	Questions
Do survey population members form a social network?	<i>Do you know or spend time with other survey population members?</i>
Do the survey population members have large degree? (This question is tied to the survey eligibility criteria)	In a survey of male current drug injectors, ≥ 18 years, living in city A, ask: <i>How many men do you know who also know you, they currently inject drugs, they are ≥ 18 years and they live in city A? How many of these men have you seen in the past month?</i>
Do the survey population members form diverse social network ties?	<i>Please tell me about how your (survey population) friends and acquaintances interact with each other. What activities do they do together?</i> <i>Do (survey population) go out together when they are not working/injecting?</i>
What is the structure of the social network? Are there cliques and if so, can you find bridges to include them?	If you suspect that survey population members form distinct geographical social networks, ask: <i>Do you know survey population members who work in/are from other parts of the city?</i> If you suspect that survey population members form distinct social network types, ask: <i>Do you know survey population members who are of a type different from you [e.g. older versus younger men who have sex with men; street versus bar based female sex workers]?</i>

Possible questions about survey acceptability

Table 2.5 presents some possible questions about whether the population will be willing to participate in the survey.

Table 2.5 Questions about willingness to participate

Willingness to participate	Questions
Are survey population members willing to participate in an RDS survey?	<i>Would you (or your peers) be willing to participate in this survey?</i> <i>Why or why not?</i> <i>What seems most/least interesting about this survey?</i> <i>Would you be willing to recruit your peers into this survey?</i> <i>How many coupons out of three could you give to your peers that they would actually redeem?</i> <i>What might prevent your peers from participating in the survey?</i> <i>Will you (or your peers) participate if the survey includes HIV/STI tests?</i> <i>How would you encourage a friend to join the survey? Especially one who is reluctant?</i>

Possible questions about seeds

Table 2.6 presents some possible questions about how to identify seeds for the survey.

Table 2.6 Questions about seeds

Seeds	Questions
How do we find good seeds? If there are cliques, can your seeds access bridges to include them?	<i>Can you think of any survey population members who would make good seeds (describe seeds)?</i>
	<i>Do you know different types of survey population members (who are diverse in age, income, risk, etc.)?</i>
	<i>What would be the best way to locate survey population members to be seeds for our survey?</i>
	<i>Are there nongovernmental organizations or other groups that work with survey population members?</i>
	<i>Have other outreach programmes used survey population members to contact other survey population members?</i>
	<i>Can you help us contact survey population members?</i>

Possible questions about survey procedures

Table 2.7 presents some possible questions about survey procedures.

Table 2.7 Questions about survey procedures

Procedures	Questions
Incentive: What is the appropriate incentive given the survey population and country context?	<i>Do you think _____ (local currency or item of monetary value) is sufficient to encourage survey population members to participate in a survey?</i>
	<i>About how much would transport cost to get to the survey site?</i>
Survey logistics: During which hours and days and under which circumstances would survey population members participate in a survey?	<i>What hours/days are most convenient for survey population members to participate in a survey?</i>
	<i>Is it convenient for survey population members to get around in this city?</i>
	<i>How can survey population members get to the survey site?</i>
	<i>Is it easy for survey population members to get here on public transport?</i>
	<i>Do you think survey population members are willing to be interviewed at the same survey site during the same hours as other members?'</i>
	<i>What type of survey site would be most comfortable for survey population members to go to?</i>

Procedures	Questions
Staffing: Who are appropriate staff and when can they work?	<p><i>Do you prefer men, women or transgender staff conducting the survey?</i></p> <p><i>Describe the type of person with whom you would feel most comfortable answering personal questions?</i></p> <p><i>Describe the type of person with whom you would feel most comfortable taking biological specimens from you (e.g. a rectal swab)?</i></p> <p><i>Is there a local nongovernmental organization that you know of with people willing to work in this survey?</i></p>
Coupon design: How should the coupon be designed?	<p><i>Do most of your peers read?</i></p> <p><i>What colours are appropriate for the coupon?</i></p> <p><i>Coupons are about the size of _____, do you think they should be smaller or larger?</i></p> <p><i>What kinds of information should be included on the coupons?</i></p> <p><i>Do you think a map on the coupon is helpful for finding the survey site?</i></p>

¹ This is important if you are conducting simultaneous surveys.

Using a rapid assessment approach

Adapting a rapid assessment and response (RAR) approach may be useful when gathering data in preparation for an RDS survey [19, 20, 21]. Below are some of the significant features of a rapid assessment which make it useful for quickly gathering formative assessment data.

- Speed, timeliness and cost-effectiveness—most RAR surveys can be completed within 12–16 weeks and use techniques that cost less than surveillance and large surveys.
- Strengthening local responses—RAR fosters the involvement and participation of the community and survey populations.
- Use of existing information—RAR uses existing information to describe and understand the local situation and uses this description to identify gaps in knowledge. The gaps are then filled using other research methods to collect new data.
- Use of multiple methods.
- Inductive approach—induction is the process of drawing conclusions and developing hypotheses from the data collected, and searching for information that confirms, denies or modifies these conclusions and hypotheses. This allows for the building of ideas and conclusions from the data collected, not from pre-existing theory generated in other contexts.
- Multilevel analysis—this comprises an analysis of individual, community and structural contexts. It analyses the influence of each of these factors on the risks and vulnerabilities of key populations at higher risk of HIV exposure.
- Reliability, validity and triangulation—RAR uses a number of methods and data sources to collect and analyse information.
- Adequacy for response—the purpose of an RAR survey is to gather enough information in order to respond effectively.

Summary

It is always a good idea to conduct some formative assessment in preparation for an RDS survey. There are many ways to collect formative assessment data depending on your resources and contacts. Formative assessment is useful for understanding social networks and assessing whether the RDS methodology and survey protocol will be acceptable to the survey population. Formative assessment is also helpful for identifying seeds and to plan logistics. Formative assessment need not be an expensive and time-consuming process if you chose to use a rapid assessment format to collect your data. Annex 4 provides outlines for a formative assessment protocol.

Unit 2 exercises

Apply what you have learnt/case study

Get into small groups to discuss the questions below. If you are working on your own, write down your answers.

1. You are visiting a province where a local health official has recently attempted to use RDS to sample 400 people who inject drugs in the region. When you interview the health official, you find out that he has never worked with people who inject drugs before and that there is no recent published work on people who inject drugs in the area. The health official had heard from a friend in the police department that most people who inject drugs in the province could be found near a particular railroad crossing and started the survey with this information.

Four seeds were recruited from men hanging around the crossing. A survey site was established in the health clinic, with the hours and days of operation based on the clinic's hours. The health official's son designed a coupon for distribution.

After three weeks, only 10 people who inject drugs were recruited into the survey, and the health official decided to close the survey site. He could not understand why people who inject drugs would not want to enrol in a survey entitled, "HIV survey in people who inject drugs". The survey was seen as a failure and the health official may never use or recommend RDS again.

- a. Do you agree with the health official that the survey failed?
 - b. Did the health official know enough about the population to initiate the survey?
2. Despite the lack of success with the first RDS survey of people who inject drugs above, the local health official has decided to try the methodology again and decides to bring you in to help conduct formative assessment. First he wants you to point out what went wrong with the first survey and then to tell him how you would go about learning more about the population.
 - a. What are the potential problems in the survey outlined above?

- b. What additional information would you have wanted to know about people who inject drugs in this province before starting the survey?
 - c. How would you go about learning more about this population?
3. What are some formative assessment questions that you would want to ask before conducting a survey of people who inject drugs using RDS?

Unit 3

Sample size
calculation for RDS

Overview

What this unit is about

In practice, the sample size for RDS is calculated using formulas used for other types of sampling and then multiplying it by the appropriate design effect. There are two types of sample size calculation used in RDS surveys: to estimate the prevalence of a characteristic based on some pre-specified precision (estimates at a single time point) or to test changes in an estimate over time. Because integrated biological-behavioural surveillance looks at trends and assumes that surveys will be conducted more than once, the latter sample size calculation is often used. Calculating a sample size requires some consideration about which measurements to include in the calculation. These considerations will vary based on the extent of existing knowledge about the population of interest and the survey goals.

Warm-up questions

1. True or false? The design effect is an adjustment for how much a cluster or other type of sampling method differs from a simple random sample. Circle your answer below.

True

False

2. The $Z_{1-\alpha}$ score is a statistic that corresponds to the level of significance desired. What would be the level of significance used to correspond to a 95% confidence level?
3. Which of the following is not a consideration for a sample size calculation for integrated biological-behavioural surveillance surveys?
 - a. Design effect
 - b. Estimated proportion (to test prevalence at one time)
 - c. Desired level of change in the measures of interest (to test change over time)
 - d. Level of significance desired
 - e. Size of the population
 - f. Level of power desired
4. What would be a good indicator to use to measure a change in proportions over time (from one survey round to the next)?

5. True or false? A design effect of 2 is always appropriate for all sample calculations for surveys using RDS. Circle your answer below.

True

False

Introduction

What you will learn

One of the first steps in designing a survey is to calculate a sample size. There are important parameters to think about when calculating a sample size. By the end of this unit, you should be able to:

- know how to calculate two types of sample size for an RDS survey
- understand the purpose of a design effect in the sample size calculation
- select an appropriate indicator to measure change over time
- select the level of significance and power for a sample size calculation.

RDS sample size calculation

Sample sizes vary greatly among surveys using RDS. In a review of 123 RDS surveys that reported their calculated sample size, sample sizes ranged from 100 to 800 and averaged 275 [5].

As in most surveys, the sample size for RDS is typically calculated either:

- to test prevalence at one time based on the prevalence of a characteristic based on some pre-specified precision (e.g. to estimate the prevalence of HIV among persons who have injected drugs in the past six months, over the age of 18 years and living in city X);

or

- to test changes in an estimate over time (e.g. to estimate whether condom use at last sex with a regular partner has increased from survey round 1 to round 2 among persons who have injected drugs in the past six months, over the age of 18 years and living in city X).

Most integrated biological-behavioural surveillance surveys are intended to provide point estimates and are to be repeated over time with the same sampling method. In this regard, many RDS survey sample sizes are calculated based on both the desired precision in the estimate (sample calculation 1) of a characteristic such as HIV prevalence and also on the power for detecting a change in that characteristic over time (sample calculation 2) [22].

Sample size calculation to test prevalence

Sample size calculation 1

The sample size needed to conduct integrated biological-behavioural surveillance surveys can be based on the number of participants needed to accurately measure HIV prevalence in a population. This is referred to as sample calculation 1.

The general formula for the needed sample size (n) is:

$$n = D \frac{Z_{1-\alpha}^2 P(1-P)}{d^2}$$

n = Sample size required per survey round

D = Design effect

$Z_{1-\alpha}$ = The z score for the desired confidence level, usually 1.96 for 95% confidence

P = Expected proportion

d = precision (usually set at 5%)

Example of sample size calculation 1

Suppose you are planning a survey to estimate the prevalence of HIV among persons who have injected drugs in the past six months, over the age of 18 years and living in city X using RDS. You estimate HIV prevalence in this population to be 20% ($P = 0.2$). You set the design effect at 2 ($D = 2$), confidence at 95% ($Z_{1-\alpha} = 1.96$) and precision at 5% ($d = 0.05$).

$$D = 2$$

$$Z_{1-\alpha} = 1.96; (1.96)^2 = 2.58$$

$$P = 20\%$$

$$d = 0.05; (0.05)^2 = 0.0025$$

By plugging in these data, the final sample size is 330.24 or rounded down to 330.

$$330.24 = 2 \frac{2.58 \times 0.2 (1-0.2)}{0.0025}$$

Sample size calculation to test changes in an estimate over time

Sample size calculation 2

The sample size needed to conduct integrated biological-behavioural surveillance surveys can be based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. This is referred to as sample calculation 2.

The general formula for the needed sample size (n) is:

$$n = D \frac{[Z_{1-\alpha} \sqrt{2P(1-P)} + Z_{1-\beta} \sqrt{P_1(1-P_1) + P_2(1-P_2)}]^2}{(P_2 - P_1)^2}$$

Where:

- n = Sample size required per survey round
- D = Design effect
- $Z_{1-\alpha}$ = The z score for the desired confidence level, usually 1.96 for 95%
- $Z_{1-\beta}$ = The z score for the desired power, usually 0.83 for 80%
- P_1 = The proportion of the sample reporting indicator baseline
- P_2 = The proportion of the sample reporting indicator at round 2
- P = $(P_1 + P_2)/2$

Example of sample size calculation 2

Suppose you are planning a survey of persons who have injected drugs in the past six months, over the age of 18 years and living in city X using RDS. You want to measure whether condom use at last sexual intercourse with a casual partner will increase from 20% in the baseline survey to 30% or greater in the next survey round. You set the design effect at 2 ($D = 2$), confidence at 95% ($Z_{1-\alpha} = 1.96$) and power at 80% ($Z_{1-\beta} = 0.83$). By plugging in these data, the final sample size is 582.

Solution:

- $D = 2$ (moderate)
- $Z_{1-\alpha} = 1.96$ (95% confidence level)
- $Z_{1-\beta} = 0.83$ (80% power)
- $P_1 = 20\%$ condom use in year 1
- $P_2 = 30\%$ condom use in year 2
- $P = (0.20 + 0.30)/2 = 0.25$

$$582 = 2 \frac{[1.96\sqrt{2 \times 0.25(1-0.25)} + 0.83\sqrt{0.20(1-0.20) + 0.30(1-0.30)}]^2}{(0.30 - 0.20)^2}$$

Table 3.1 presents calculated sample sizes using sample size calculation 2.

Table 3.1 Sample sizes to detect a change in the proportion of an indicator between survey rounds using a 95% confidence level, 80% power and a design effect of 2.0.

Indicator level (P_1) at round 1	Indicator level in round 2 (P_2)	Sample size needed with a design effect of 2.0
0.10	0.20	395
0.10	0.25	197
0.20	0.30	581
0.20	0.35	274
0.30	0.40	706
0.30	0.45	322
0.40	0.50	768
0.40	0.55	343
0.50	0.60	768
0.50	0.65	336
0.60	0.70	706
0.60	0.75	301
0.70	0.80	581
0.70	0.85	239
0.80	0.90	395
0.80	0.95	149

Sample size considerations

Introduction

There are several important considerations for calculating a sample size in integrated biological-behavioural surveillance surveys using RDS. These considerations include:

- design effect
- estimated proportion (to test prevalence at one time)
- desired level of change in the measures of interest (to test change over time)
- level of significance desired
- level of power desired.

These considerations are described below.

Design effect

The design effect is an adjustment for how much a cluster or other type of sampling method differs from a simple random sample. Effectively, the design effect multiplies the sample size by the factor of D to account for the loss of diversity by using a sampling method other than a simple random sample.

Whereas the calculation in a simple random sample essentially uses 1 as its design effect (reflecting no change to the calculated sample size), RDS requires a minimum of 2 as its design effect (reflecting a doubling of the calculated sample size). The interpretation of a design effect of value 2 is that only one-half as many sample participants would be needed to measure a given statistic if a simple random sample were used instead of RDS with its design effect of 2.0 [23].

Design effects vary from survey to survey, and even within the same survey will vary from question to question. For example, if a recruitment chain of men who have sex with men comprises men associated with a gay nongovernmental organization, the design effect would be high for characteristics that are the same for all members of the nongovernmental organization (e.g. self-identity as gay) and would be low for characteristics that are different for different members of the nongovernmental organization (e.g. education, age).

In sum, using RDS to gather a sample requires a larger sample size than a simple random sample. Although most RDS surveys now use a design effect of at least 2, some analyses of RDS data indicate that design effects may need to be larger, possibly as large as 10 [24, 25, 26].

The bigger the D , the larger the sample size needed.

Estimated proportion

P is an indication for a proportion. The P is used differently depending on the sampling formula used. It is the proportion (prevalence) that will be estimated during the survey (sample calculation 1). This may be tricky, especially when nothing is known about the population being studied. Often the goal of the survey is to determine the proportion of something and therefore it may seem difficult to have to provide an estimate of something which you do not yet have. In this case, P may come from guessing or from other similar countries that have gathered this proportion on a similar population. An investigator may get several P s and will need to make the best judgment about which P seems most reasonable.

Detecting changes over time

P_1 and P_2 are the measures of interest for which you wish to see a change between survey rounds (sample calculation 2). For example, you wish to show that condom use at last paid sex act for sex workers increased from 20% in 2006 (P_1) to 30% or greater in 2007 (P_2). P_1 is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be. P_2 is ideally set at the goal you would like to achieve (e.g. a 10% or greater increase in condom use). In practice, it is usually set at the smallest change you think is meaningful. For example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful.

The smaller the change you wish to detect, the larger the sample size needed. Also, the closer P_1 and P_2 are to 50%, the larger the sample size needed.

Which measures to use for P

The estimated proportion for a sample size calculation (sample calculation 1) for integrated biological-behavioural surveillance surveys is often based on the prevalence of HIV.

For detecting changes in proportions over time (sample calculation 2), HIV prevalence is a poor indicator since changes in HIV prevalence are impacted by many factors aside from the rate of new infections and it is not time sensitive since it takes a lot of time to see any impact from prevention and intervention programmes. More meaningful proportions to measure over time are based on condom use (i.e. increase or decrease of condom use at last sex with a regular partner) or programme use (i.e. increase or decrease in methadone treatment usage from round 1 to round 2).

What to do if you have no prior data on your population

If there is absolutely no data available upon which to base measures for P , as is often the case in sampling hidden populations for the first time, then 50% is often suggested as P . In sample calculation 1 the sample size using 0.5 for P would be 516 (precision at 5%, confidence at 95% and design effect at 2) and for sample calculation 2 using 0.5 for P_1 to detect a 15% change over time would be 336 (power at 80%, confidence at 95% and design effect at 2).

Which measure to use in the subsequent rounds of integrated biological-behavioural surveillance surveys

In subsequent rounds of integrated biological-behavioural surveillance surveys, the proportions to use for calculating sample sizes should be based on the proportions you found in the previous rounds assuming there are no major changes in the survey design.

Level of significance

The $Z_{1-\alpha}$ score is a statistic that corresponds to the level of significance desired. Usually, a significance level of 0.05 (or, equivalently, a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a “two-tailed” statistic).

The smaller the significance level (i.e. higher confidence level), the larger the sample size you will need.

Level of power

The $Z_{1-\beta}$ score is a statistic that corresponds to the power desired in the calculation to detect changes in estimates over time (sample calculation 2). Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (increase) or down (decrease) from year to year (a “two-tailed” statistic).

The higher the power, the larger the sample size you will need.

Summary

There are two commonly used sample size calculations for surveys using RDS. One method estimates the prevalence of an indicator, often HIV, and the other measures changes in indicators, often programme or condom usage, over time (survey rounds). The formulas to calculate sample sizes require some a priori knowledge about the population in order to select the most appropriate formula parameters. However, several guidelines exist that are useful in deriving the most suitable sample size for a given population and country context.

Unit 3 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want based on your study of this unit.

Apply what you have learnt/case study

Get into small groups to discuss the questions below. If you are working on your own, write down the answers to the questions.

A university has just completed formative assessment for a possible integrated biological-behavioural surveillance survey among men who have sex with men using RDS. They have been contracted by the Ministry of Health in the country to implement the first round of the survey among the men who have sex with men population. The purpose of this surveillance activity is to track important changes in the HIV epidemic over time i.e. between rounds of surveillance. They have asked you, an in-country surveillance officer at the Ministry of Health, to assist with determining the needed sample size for the survey.

Between yourself and the university, the following parameters are known to help calculate the desired sample size:

- Data from a similar survey conducted in a similar neighbouring country indicate that the estimated proportion of condom use with anal intercourse among men who have sex with men is 60%.
 - The magnitude of change that is desired to detect the proportion of condom use with anal intercourse among men who have sex with men is a 10%–15% increase or decrease based on the ability to assess meaningful implementation of prevention programmes between survey rounds.
 - A 95% significance level is desired.
 - A power of 80% is desired.
- a. Based on the information provided above, are you able to calculate the sample size needed? If so, what would be a logical sample size to aim for?

- b. What additional information would be helpful to know in order to calculate the sample size?
- c. After you determine the sample size needed, what are some additional factors to consider before you and the university agree on the desired sample size to aim for?

Unit 4

Designing and
planning an RDS
survey

Overview

What this unit is about

In any survey, preparation is very important to ensure that the recruitment and data collection processes run smoothly. This section will provide an overview of some of the key steps involved in the preparation of an RDS survey.

Warm-up questions

- 1 True or false? Unlike other types of surveys, surveys using RDS methods do not require review by an ethical review committee. Circle your answer below.

True

False

- 2 A _____ describes the procedures that must be followed during the RDS survey and should anticipate problematic situations and include contingency plans for these situations.

- 3 True or false? Monitory and advisory committees can be useful when something goes wrong in an RDS survey. Circle your answer below.

True

False

- 4 Which of the following documents is not necessary to have during the planning and preparation stages of your RDS survey?
 - a. survey protocol
 - b. operations manual
 - c. final report of findings
 - d. forms for managing the survey
 - e. questionnaire

Introduction

What you will learn

By the end of this unit, you should be able to:

- plan the survey steps
- define the roles and responsibilities of a technical working group
- define the elements of an RDS survey protocol and operations manual
- describe some of the ethical considerations associated with an RDS survey
- understand the importance and different types of community partnerships
- identify the types of staff needed to plan and implement an RDS survey.

Time needed for preparation

As with any survey, ample time is needed for preparation. When planning an RDS survey consider the amount of time needed to: come to a consensus within your working team (sometimes referred to as a technical working group) about the steps involved in an RDS survey; develop a protocol and submit it to an ethical review board; develop an operations manual and other materials; develop and pilot a questionnaire; and decide on staff and advisory groups.

Planning the survey steps

Planning the survey steps will be helpful in developing necessary materials, including the protocol. The steps in a typical RDS are shown below.

As discussed in Unit 1, a participant in an RDS survey will usually participate on two separate occasions. The first occasion is for enrolment and to receive the primary incentive (see Figure 4.1). The second occasion is to get a secondary incentive (see Figure 4.2) for having recruited eligible peers who have completed the survey steps for the first incentive, and in some situations to conduct a follow-up questionnaire and to obtain test results and post-test counselling. These steps can be modified to suit the needs of your survey.

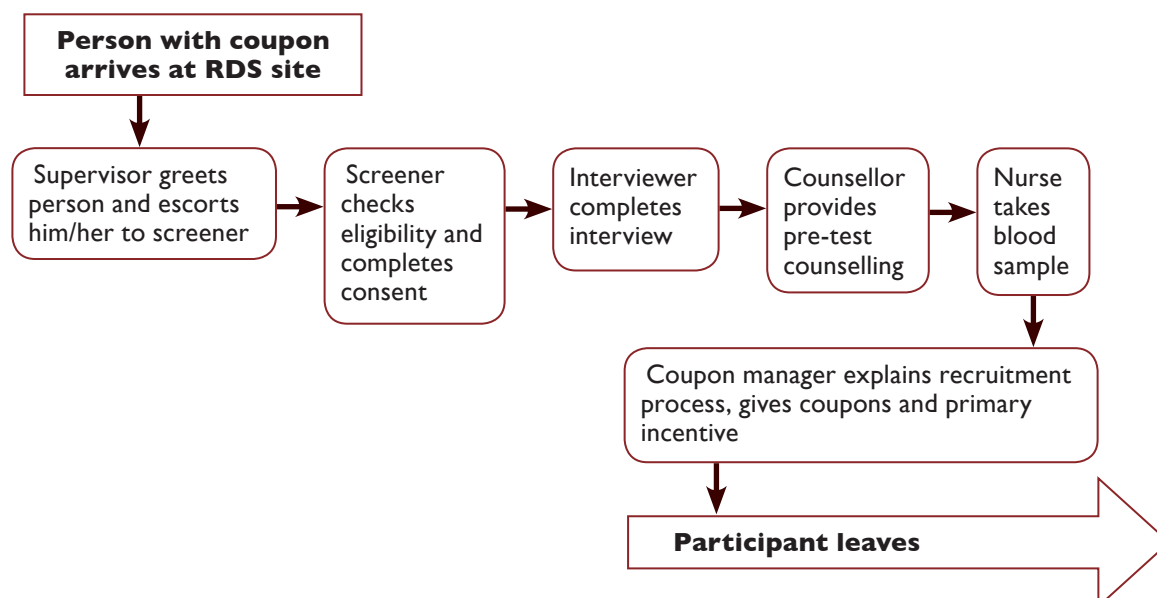


Figure 4.1 Example of survey steps for the primary incentive

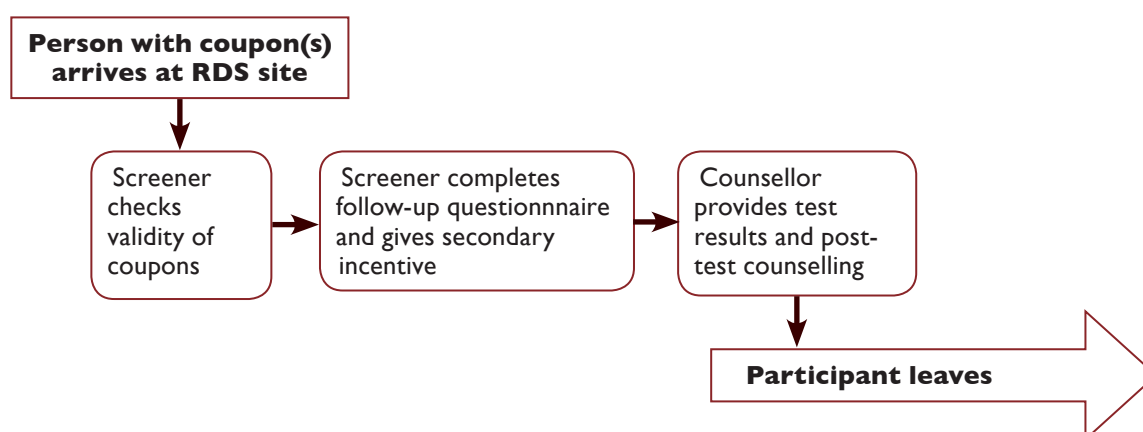


Figure 4.2 Example of survey steps for the secondary incentive

Setting up a technical working group

A technical working group is an interdisciplinary collaboration of stakeholders and technical personnel, often from the ministry of health, national laboratories, nongovernmental organizations, universities and other relevant agencies, to provide input and offer expertise during the planning phases of the survey. The technical working group should include highly experienced persons who can offer relevant input into decision-making. The specialties of those serving on a technical working group may include:

- programme managers with experience in survey research, questionnaire design, prevention and intervention services, and other relevant expertise.
- statisticians
- laboratory personnel
- qualitative researchers
- quantitative researchers

- specialists in HIV/AIDS and other infections
- VCT personnel
- high-level staff working with populations at higher risk of HIV exposure
- political decision-makers.

Typical goals of a technical working group include:

- developing the formative assessment and survey protocol (the formative assessment protocol is described in Unit 2; the survey protocol is described below)
- developing survey materials and an operations manual
- questionnaire development and piloting
- making decisions about the steps involved in, and the timing of, the survey
- making decisions about eligibility, sample size, incentive level, location of the survey site(s), etc
- providing responses to questions posed by ethical committees about the protocols
- interpretation and decision-making based on findings from formative assessment
- technical advice on collection and processing of biological specimens
- input into budgetary issues
- decisions about staffing
- finding members for partnership groups (see below).

The lifespan of the technical working group can last anywhere from several months to several years.

Developing survey documents

Survey documents

There are several survey documents that are essential to planning and implementing an RDS survey. Common survey documents include:

- survey protocol
- operations manual
- survey management forms
- questionnaire.

Each of these documents is discussed below.

Survey protocol

A survey protocol describes every step of a survey and is a good tool to have while preparing for and conducting an RDS survey. The survey protocol is usually submitted as part of the ethical review process. A survey protocol describes:

- the survey goals and objectives
- the survey design and methodology to be utilized
- the survey population and sample size
- the procedures to be followed throughout the survey
- plans for data monitoring, management and analysis
- how to protect participants' rights during the survey

- the rules to be followed by the research team
- how and where biological samples will be collected, processed and analysed.

An example of an RDS survey protocol is provided in Annex 5.

Forms for managing the survey

Think about the steps involved in conducting your RDS survey and prepare the forms that will be needed to ensure quality collection of data. A thorough discussion of survey management and its related forms is presented Unit 12. Examples of these forms are provided in Annex 6.

Questionnaire

The questionnaire will need to be developed and piloted during the preparation stage of your RDS survey. Unit 9 provides detailed information about the types of questions you will need to add to your questionnaire specific to RDS and necessary for analysing RDS data. A sample questionnaire is provided in Annex 6.12.

Operations manual

A field operations manual describes the standard operating procedures that must be followed during the RDS survey. A good field operations manual anticipates problematic situations and includes contingency plans for these situations. An example of RDS integrated biological-behavioural surveillance survey standard operations procedures are provided in Annex 7, and an example of standard operating procedures for biological HIV and STI testing and the related forms are provided in Annex 8.

Ethical review

As in all surveys involving human subjects, especially among key populations at risk of HIV exposure, there are serious ethical considerations when preparing for and conducting an RDS survey. Every effort must be made to ensure that the survey design and interview process will not negatively impact upon the population you are working with.

Review of your documents by an ethical review committee is required in all surveys involving human subjects. The review is an important and necessary step in preparing for an RDS survey and should be completed before **any** data collection begins.

All survey documents, questionnaires and procedures need to be completed prior to ethical review and submitted with the ethical review application.

Ethical review requirements vary depending on the funding, research and supporting institutions involved in the survey. Review and respond to the ethical review requirements of the institutions involved in your survey.

Survey partnerships

Key partnership groups

It is useful in any survey to form partnerships with important community members and stakeholders during survey preparation and implementation. Depending on the need, it may be worthwhile to form groups that can meet regularly throughout the survey preparation and implementation process. The examples that follow describe some groups, such as teams or councils, that have been used during RDS surveys.¹

Community monitoring committee

This can comprise community members of the survey population and, in some cases, those who work with members of the survey population. The purpose of the community monitoring committee is to monitor the community's survey perceptions and to address any incorrect information or misperceptions.

Lessons learnt

During an RDS survey of female sex workers in one city, recruitment stopped abruptly. It was learnt from the community monitoring committee made up of local female sex workers that the female sex worker population was not participating in the survey because they had been told by other female sex workers that they were required to provide large quantities (a bottle) of blood to participate in the survey. In reality, the female sex workers were asked to provide a "Vacutainer" (5 ml) of blood, which through translation was interpreted as "a bottle". The survey team was able to use this information to improve how female sex worker recruiters explained the blood collection to other female sex workers (recruits) and to emphasize that only a small amount of blood would be collected from those who participate in the survey. Furthermore, an empty Vacutainer was kept at the screening desk so that female sex workers who were enrolling in the survey could see the actual size of the container that would hold the blood. Within a few days, female sex workers were again enrolling in the survey.

Community advisory committee

This could comprise members of the survey population, staff from nongovernmental organizations working with the survey population, local HIV/AIDS organization staff and other stakeholders. The purpose of the community advisory committee is to monitor the survey and provide input when responding to adverse events. This group would also be responsible for safeguarding the community and minimizing harm to participants prior to and during the survey.

Lessons learnt

In one country, an RDS survey participant complained that a survey team member had used sexually inappropriate language (language inconsistent with the purview of the

¹ Suggested reading: *Behavioral surveillance surveys: guidelines for repeated behavioral surveys in populations at risk of HIV* (Chapter 2). Arlington, VA, Family Health International, 2000.

questionnaire or other aspects of the survey) with her. News of this event could have spread through the community and deterred other survey population members from participating in the survey. The committee met to discuss how to respond to the situation and how to redress the concerns of the participant who complained. The community advisory committee decided to provide targeted training to the entire survey staff about appropriate language for the survey site, to counsel and monitor the offending survey team member and to provide a personal apology to the offended participant.

Lessons from EMR/MENA

In one large city with expensive public transportation it was decided that a mobile van would be used in addition to a fixed site in order to cover a large area. Members of the community advisory committee were instrumental in reaching an agreement with the police that would allow data collection in all assigned parking lots. Although RDS recruitment using a mobile van later became unfeasible, it demonstrated the importance of the involvement of the community advisory committee in the survey.

Identifying key staff

Key staff should be identified early in the development of the survey. They include those who will be:

- coordinating and planning the survey
- supervising the survey
- managing the survey site
- screening and assisting participants
- conducting interviews
- providing pre- and post-test counselling
- collecting biological specimens
- managing coupon issuing and recruitment
- entering and managing data
- undertaking data analysis
- writing the report.

Some surveys will be using computerized surveys and will not need interviewers.

Surveys using computerized questionnaires should have a computer specialist to fix computer problems and staff to help participants use the computer. Surveys with a biological component will need laboratory technicians.

Unit 11 lists the types of staff needed at an RDS survey site and their possible roles and responsibilities.

Planning the survey steps can be helpful in determining the number and types of staff needed for an RDS survey.

Preparing for field work

Table 4.1 provides a checklist for preparing for any survey.

Table 4.1 Checklist for implementing fieldwork (of any kind)

Check	Activity
<input type="checkbox"/>	Define clear goals and objectives
<input type="checkbox"/>	Select outcome measures
<input type="checkbox"/>	Establish survey population:
<input type="checkbox"/>	<ul style="list-style-type: none"> ● define population
<input type="checkbox"/>	<ul style="list-style-type: none"> ● develop inclusion/exclusion criteria
<input type="checkbox"/>	<ul style="list-style-type: none"> ● determine size of survey population (this may not be possible when sampling hard-to-reach populations).
<input type="checkbox"/>	Logistics planning:
<input type="checkbox"/>	<ul style="list-style-type: none"> ● plan community acceptance/involvement
<input type="checkbox"/>	<ul style="list-style-type: none"> ● determine staffing
<input type="checkbox"/>	<ul style="list-style-type: none"> ● plan field organization.
<input type="checkbox"/>	Select sampling/enrolment methods
<input type="checkbox"/>	Establish data handling procedures
<input type="checkbox"/>	Establish quality control procedures
<input type="checkbox"/>	Calculate sample sizes appropriately
<input type="checkbox"/>	Develop detailed protocol
<input type="checkbox"/>	Develop a protocol
<input type="checkbox"/>	Develop, write and pilot the questionnaire
<input type="checkbox"/>	Conduct formative survey (pilot questionnaire, garner community support, submit to Institutional Review Board for research determination or to exempt protocol)
<input type="checkbox"/>	Submit final protocol, instruments, and consent forms to appropriate human subjects' review committees
<input type="checkbox"/>	Develop field manual/standard operating procedures
<input type="checkbox"/>	Develop database
<input type="checkbox"/>	Provide training for all staff

Source: Adapted from Smith PG, Morrow RH, eds. *Methods for field trials of interventions against tropical diseases: A toolbox*. Oxford, Oxford University Press, 1991.

Summary

There are several important considerations when planning an RDS survey. A technical working group of qualified persons can be extremely useful in making decisions and performing tasks such as protocol, survey material, operations manual and questionnaire development. The protocol is useful for ensuring that all components of the survey are realistic and that all of the proposed survey steps are acceptable for review by an ethical committee.

Unit 4 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions. If you are working on your own, try the questions now.

1. Have you participated in an ethical review process in past projects? If so, what was the process? How long did it take?
2. Why do you think an ethical review is important or not important before conducting a survey? What do you think might be different, ethically, with RDS?

Apply what you have learnt/case studies

1. Your data collection using RDS from a survey on sex workers in your city is complete. You begin the data analysis process. The demographic data look good. The phone rings. It is the manager of the sexually-transmitted infection (STI) clinic that serves sex workers in the city. She asks how the survey went. You reply that it went well and express your gratitude for her assistance in making it a success. In response, she asks if you would mind providing her with a few numbers regarding sex workers' use of her clinic for her next board of directors meeting. You realize that you did not collect data for several of the questions she is asking about.
 - a. How could you have avoided this embarrassing situation during the planning stage?
 - b. What are some of the things you can do to ensure that your questionnaire includes the questions that will be necessary for analysis.

2. You are two weeks into your survey of sex workers in city Z. All of your seeds have recruited other sex workers and recruitment seems to be going well with about 10 interviews completed every day. All sex workers so far are agreeing to provide the 7 ml of blood for HIV and other STI testing. One day, no sex workers come into the survey. This occurs for the following two days and you start to become worried
 - a. Why do you think the sex workers stopped coming to your survey?
 - b. How will you try and find out?
 - c. What can you do to continue with the survey?

Small group discussion

Answer the questions below on establishing contacts with nongovernmental organizations and key populations at higher risk of HIV exposure.

1. Why is it important to establish contacts with nongovernmental organizations and key populations?
2. How can they help you with the survey?
3. How can they hinder your survey?
4. How would you establish contact with nongovernmental organizations and key populations?
5. How would you involve them in the survey?
6. Would you contact police authorities?

Unit 5

Identifying and
recruiting seeds

Overview

What this unit is about

This unit discusses how to identify and recruit seeds, including the importance of seed selection and how to choose the correct number of seeds. The unit also provides “lessons learnt” information from actual surveys to help in decision-making when planning a survey.

Warm-up questions

1. True or false? Seeds are members of your survey population that are randomly selected to begin the RDS recruitment process. Circle your answer below.

True

False

2. If you want to collect a sample size of 400 people who inject drugs, the correct number of seeds to choose is:
 - a. five
 - b. ten
 - c. twenty
 - d. none of the above
 - e. there is no one correct number
3. Provide two characteristics that are important for seeds to have.
_____ and _____.
4. Describe one potential problem that could arise in your recruitment process if too few seeds were selected at the beginning of your survey.
5. True or false? The selection of seeds is an exact science whereby there are specific parameters based on sample size and survey population that can be used to ensure that you have the correct number of seeds for your survey. Circle your answer below.

True

False

Introduction

What you will learn

By the end of this unit, you should be able to:

- describe the importance and characteristics of seeds for RDS
- identify and recruit seeds
- define the parameters to help you select an appropriate number of seeds.

What are seeds?

Seeds are non-randomly selected members of the survey population who initiate the RDS recruitment process. From each seed, a recruitment chain is expected to grow. Seeds play an extremely important role in conducting an RDS survey.

Number of seeds to choose for your survey

Currently, there is no precise method for choosing the “correct” number of seeds. However there are parameters based on previous experience that will help you select the best possible number of seeds.

A literature review of 123 RDS surveys conducted around the world (outside of the USA), found that the average reported number of seeds used was 10 (range, 2–32, median 8) and that the average number of unsuccessful seeds was 1.6 (range 0–19, median 0, interquartile range [IQR] 0–2) per survey [5]. Of 86 surveys with available data, 35 (41%) had at least one unsuccessful seed.

Here are some guidelines for choosing the number of seeds:

- If there are too few seeds, or if seeds are not effective recruiters, new seeds may have to be added later on in the survey. This is fine, but it may increase the time needed for the survey to reach sample size. In the literature review mentioned above, 31 (43%) out of 72 surveys with available data reported adding seeds beyond the originally selected seeds.
- If there are too many seeds, it may result in short recruitment chains and the possibility that equilibrium is not attained.

Factors in the survey that will impact the number of seeds selected include:

- Number of connections among survey population members: if the population has many connections (large social networks) then there is a good indication that recruitment will be easily sustained. In this situation, fewer seeds may be needed.
- Sample size: the larger the sample size, the more seeds that may be needed.
- Population of interest: based on past surveys, people who inject drugs are often effective recruiters and therefore seem to need fewer seeds than other groups such as men who have sex with men and sex workers. In addition, people who use drugs tend to have more successful seeds. In a literature review of 86 surveys, the median proportion of unsuccessful seeds per survey was lower among surveys of injecting and non-injecting

people who use drugs (0%, IQR 0%–5%) than among sex workers (20%, IQR 14%–30%); there was no significant difference in the median proportion of unsuccessful seeds per survey between men who have sex with men and injecting and non-injecting people who use drugs or men who have sex with men and sex workers [5].

- Level of stigma (discrimination) or illicitness of the survey population: high levels of stigma may indicate that seeds may not recruit anyone. Consider starting with extra seeds to account for those who may not recruit anyone.
- The resources and time frame allotted to the survey: you may need more seeds to speed up the time in which sample size is achieved.
- Types of seed available: seeds should have large network sizes and be well connected to other members of the survey population. If these types of seed are not available, it may require more formative assessment and community involvement to ensure RDS will work.
- Level of community outreach, services and interaction with the survey population: if community services are already working with the survey population, effective seeds can usually be found easily. Having good seeds who will recruit others will mean that fewer seeds are needed overall.
- Level of diversity within the survey population: if there are several types of subpopulation that need to be included in the survey, seeds from each of these types may be needed.
- Level of geographical diversity in the target area: if there are distinct neighbourhoods or districts that have tightly-knit networks, recruitment may not spill into other districts in a timely manner. In this situation, seeds from diverse neighbourhoods/districts may be needed.
- Number of survey sites, interviewers at a given survey site and the number of hours and days the survey site(s) is open.

Seed diversity

The theories underlying RDS state that the sociodemographic characteristics of the seeds have no significant impact on the final sample composition [4, 13]. However, selecting diverse seeds will improve the chances of quickly reaching equilibrium.

It is a good idea to consider all of the diverse characteristics of importance in each of the populations you plan to sample. General seed diversity can include:

- HIV and other infection status (positive and negative)
- risk behaviour (high and low risk)
- geographical spread within the recruitment area (if in a large city, try and get seeds from different locations within the city)
- income and employment status (high wage earners and low wage earners, unemployed and employed)
- gender/sex
- age (young and old)
- marital status.

Specific seed diversity considerations are displayed in Table 5.1.

Table 5.1 Suggested diversity criteria for people who inject drugs, men who have sex with men and sex workers

Population	Diversity characteristics
People who inject drugs	<ul style="list-style-type: none"> ● Number of years injecting ● Drug preference ● Needle sharing and not sharing ● Sex workers and non-sex worker
Men who have sex with men	<ul style="list-style-type: none"> ● Sexual orientation self-identity (bisexual, gay, homosexual, heterosexual, etc.) ● Gender identity (male, female, transsexual) ● Exclusive sex with males and sex with females in addition to males ● High risk and low risk sexual behaviours (e.g. condom use during anal penetrative sex, multiple sex partners) ● Places where men who have sex with men meet other men who have sex with men (e.g. meeting at cruising spots, online)
Sex workers	<ul style="list-style-type: none"> ● Type of sex worker (where they usually solicit clients such as the street, through the telephone, at a brothel, etc.) ● High risk and low risk sexual behaviours (e.g. condom use during last vaginal sex with a client) ● Usual types of client (new or regular clients) ● Injecting and non-injecting drug use ● Supporting other people (family members and children) and just supporting self

Selecting seeds to overcome isolated subpopulations and bottlenecks

Introduction

RDS requires that the social network of the population being sampled comprises one complete social network component [7]. Barriers to social mixing may be physical (e.g. lack of access to transportation in a large city) and/or social (e.g. cultural, linguistic, or socioeconomic differences). Such barriers may lead to isolated subpopulations and bottlenecks, which affect the validity and precision of RDS estimates.

Isolated subpopulations

Isolated subpopulations occur when the barriers to social mixing across subgroups of the survey population are so great that cross-over between subgroups within a social network is obstructed. Common types of isolated subpopulations include:

- Sex worker type: when street based sex workers do not interact with brothel-based sex workers [27].
- Men who have sex with men sexual self-identity: when transsexual/transgender groups do not necessarily form connections to gay, homosexual and bisexual types of men who have sex with men.

- Men who have sex with men income levels: when higher income men who have sex with men are not connected to lower income men who have sex with men [28].

It is essential to identify potential isolated subpopulations during formative assessment (see Unit 2) and to select appropriate seeds to overcome these isolated subpopulations.

Bottlenecks

Bottlenecks occur when recruitment becomes “trapped” within a certain subgroup or clique within the survey population. Unlike isolated subpopulations, members of the clique are socially linked to other members of the survey population; however, recruitment becomes bottlenecked because members of the clique tend to recruit persons in their own clique. Bottlenecks are disadvantageous to RDS because the bottlenecked cliques are more homogenous than members of the larger survey population thereby reducing the precision of the RDS estimates [12].

When cliques are not identified early on, more recruitment waves may be needed for the sample to recruit outside of the clique. In a survey of men who have sex with men conducted in Chile, all recruitment seeds were selected from two well established nongovernmental organizations providing services to men who have sex with men. All of these seeds were part of a large and well-connected clique of homosexual and gay-identified men who have sex with men (those who reported not having sex with a female in the past year).

In the two RDS recruitment graphs displayed below the bottleneck is evident. In Figure 5.1, men who have sex with men are displayed based on sexual orientation self-identity. The blue boxes are self-identified homosexuals, pink are gays, yellow are bisexuals and green are other. In Figure 5.2, men who have sex with men are displayed based on reported sex with a woman in the past year.

Take a look at the two figures and try to assess whether there seems to be a clique.

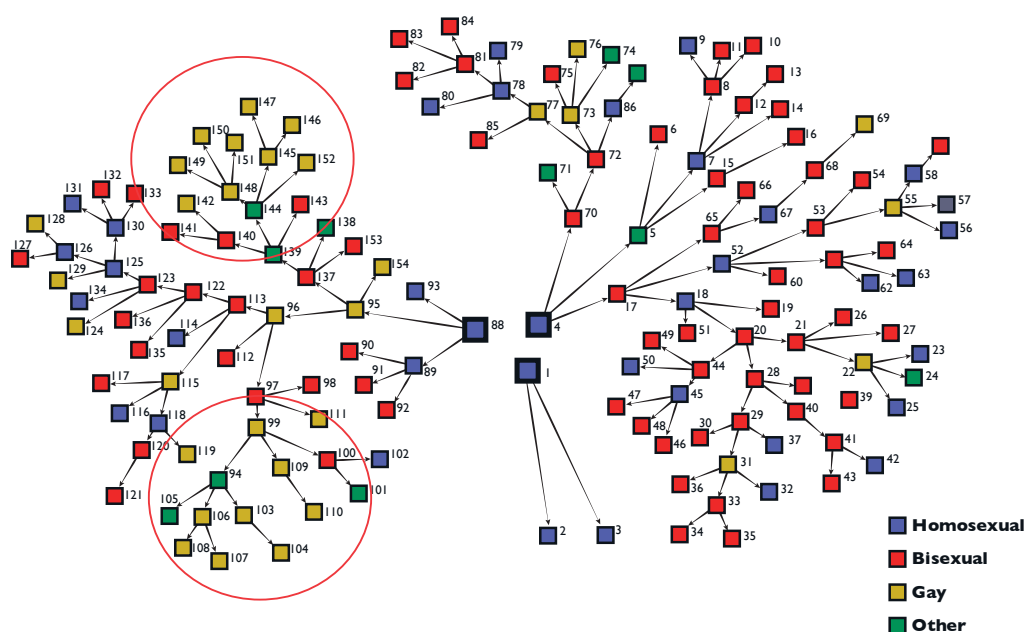


Figure 5.1 Men who have sex with men self-identity¹

¹ Thanks to Isabel Matute, Ministry of Health, Santiago, Chile, for the use of these graphics.

Figure 5.1 shows that the clique of self-identified homosexual and gay men who have sex with men are just beginning to recruit outside of their clique. The self-identified bisexual and other (self-identified heterosexual) men who have sex with men are just starting to be recruited when sampling stopped and are mostly clustered on the outer edges of the recruitment chains.

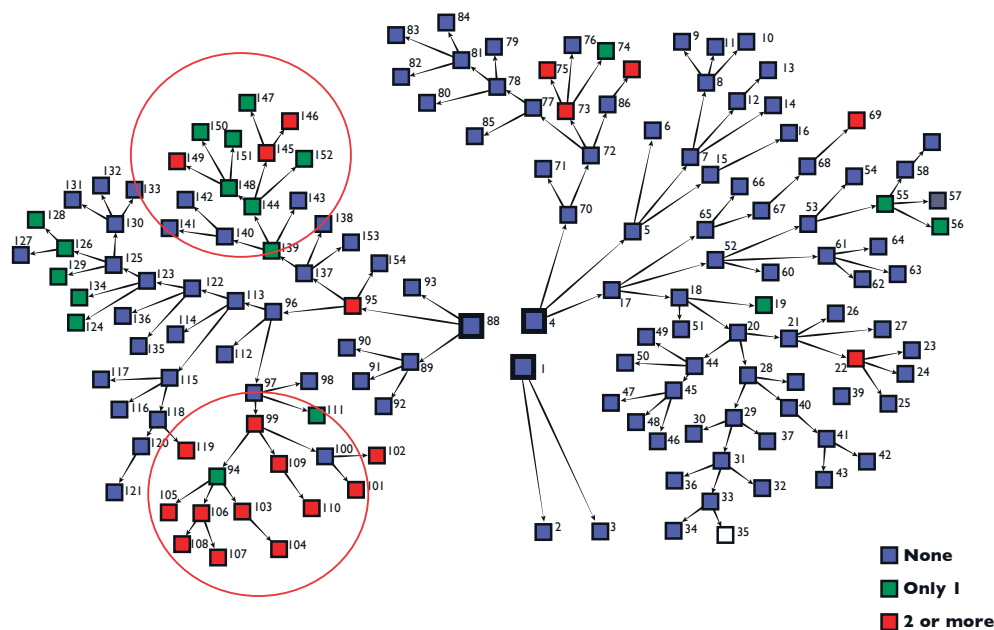


Figure 5.2 Men who have sex with men who reported having sex with a woman in the past year

Figure 5.2 shows that the clique of men who have sex with men who reported having sex only with men is just beginning to recruit outside of their clique. Men who have sex with men who reported having sex with women were just starting to be recruited when sampling stopped and are mostly clustered on the outer edges of the recruitment chains.

If you were involved in this survey, what recommendations would you make about the seeds? What recommendations would you make about the sample size? Would you have continued sampling if you noticed this before the survey ended? How could this situation be avoided in future surveys?

Network cross-over across survey sites

Another possibility for isolated subpopulations is when one sampling area has more than one survey site. For instance, in the large sprawling city of Bangkok, Thailand, three interview locations were needed to accommodate sex workers who were not willing to travel long distances to enrol in an RDS survey. However, in order to avoid having three distinct social networks (and therefore, three distinct samples) based on the survey site locations, it was important to ensure that recruitment occurred across the survey sites. Cross over can be ensured by the proper selection of seeds and monitoring of the recruits that make up each seed's recruitment chain.

In Figure 5.3 below, nine seeds have been selected. For instance, seeds 1, 2 and 3 are being initiated from survey site 1. At least one of the seeds starting from survey site 1 was selected based on their ability to recruit another sex worker in their social network who was located at either site 2 or site 3. This process was repeated in the seed selection at survey sites 2 and 3 to ensure that all sex workers in the survey formed one complete social network component (based on geographical diversity).

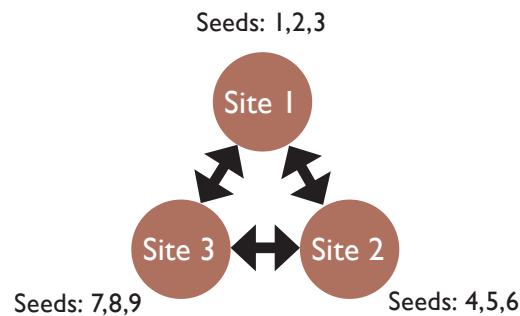


Figure 5.3 Recruitment cross-over among survey sites, Bangkok, Thailand, 2007

Source: Johnston LG. *Formative research in advance of conducting biological-behavioral surveillance using RDS methods: Thailand case study*. Presented at the Second Global HIV/AIDS Surveillance Meeting, Bangkok, Thailand, March, 2009.

Characteristics of good seeds

Select seeds based on their ability to recruit others into the survey. A good seed should have a large social network. That is, he or she should be well-connected to members of the peer group of interest.

This type of seed speeds the growth of recruitment chains since he/she is more likely to have a large pool of peers to recruit. This improves the chances that peers with diverse characteristics are recruited early on so as to avoid bottlenecks and the exclusion of isolated subpopulations. This in turn speeds the point at which equilibrium (the point at which the sample characteristics no longer significantly change, no matter how many more people are recruited into the survey) is reached.

When seeds are selected with the help of peer educators, service providers and nongovernmental organizations working with the population, this increases the chances that the seeds have large social networks. Ideally, seeds should be “sociometric” stars. They should not only be willing to recruit their peers, but also be well-regarded by their peers. Seeds who are well-regarded are more likely to influence their peers to be recruited into the survey.

Seeds should also be enthusiastic about participating in the survey and be able to convey that to their peers. Keep in mind that the only participants over which you have some control are the seeds, so try and do your best to select seeds that have these characteristics.

Lessons learnt

In one country, men who have sex with men had never been sampled using RDS. It was expected that some seeds would not recruit anyone. Therefore, a couple of extra seeds were selected at the beginning of the survey to avoid having to add more seeds later on. However, it was also important not to select so many seeds that the sample size was reached before the waves had a chance to reach equilibrium.

Table 5.2 presents the seed number ($n = 10$) and the corresponding survey location, age, HIV status, place of residence, self identity, maximum number of recruits, maximum number of waves and percentage of the sample produced by that seed's recruits.

- The sample size was calculated to be 350; but the final sample comprised 362 men who have sex with men.
- The survey had two survey sites and the survey covered one city made up of three areas: Castle Rock, High Tower and Newman.
- In the final sample, two of the ten seeds did not recruit anyone. These were seed numbers 03 and 10.
- The maximum number of recruitment waves was 13 (seed 8).

Table 5.2 Characteristics of men who have sex with men seeds, 2010

Seed	Survey site	Age	HIV status	Place of residence	Self-identity	Maximum number of recruits*	Maximum number of waves*	Percentage of sample*
Seed 1	Site 1	49	positive	Castle rock	gay	71	9	19.9%
Seed 2	Site 2	31	negative	High tower	homosexual	13	4	3.9%
Seed 3	Site 1	25	positive	Newman	bisexual	0	0	0%
Seed 4	Site 1	22	negative	High tower	homosexual	8	4	2.5%
Seed 5	Site 2	43	negative	Newman	bisexual	84	12	23.5%
Seed 6	Site 1	23	negative	Castle rock	heterosexual	28	12	8.0%
Seed 7	Site 2	45	negative	High tower	gay	3	2	1.1%
Seed 8	Site 1	41	negative	Newman	homosexual	53	13	14.9%
Seed 9	Site 2	34	negative	Castle rock	bisexual	93	9	26.3%
Seed 10	Site 1	48	positive	High tower	homosexual	0	0	0%

*excluding seeds

- However, seed 9 recruited the most participants (93), comprising 26.3% of the sample.
- Seed 6 produced a recruitment chain of 12 waves, yet only made up 8% of the sample.
- Equilibrium was reached by wave three or four on the main variables of interest for this survey, which were:
 - age
 - HIV status
 - place of residence
 - self-identity
 - condom use at last penetrative anal sex (not shown in table).

Seeds 5 and 9 recruited the most recruits. It is not unusual that one or two seeds recruit the majority of all recruits in a sample. It is acceptable to add more seeds during the course of the survey if a large number of seeds do not recruit anyone or if a socially important group is discovered, from which no seeds were drawn and no one is enrolling.

1. What other features do you notice about the recruitment by the ten seeds displayed in Table 5.2?
2. Are there other variables that you think are more important than those listed above for establishing equilibrium? What are they?
3. What are some of the issues you would want to consider in selecting seeds for men who have sex with men? Are there other issues that come to mind when considering the selection of seeds for sex worker or people who inject drugs surveys?
4. What are situations where it would be beneficial to add extra seeds to a survey of people who inject drugs, sex workers or men who have sex with men?

Educating seeds

Seeds should understand and be committed to the goals of the survey. It is essential that the seeds feel enthusiastic about their role in the survey. This will increase the chances that seeds:

- report favourably about the survey
- accurately explain the survey goals
- use all three of their coupons to recruit the first wave.

If possible, before the RDS survey begins, host a “kick-off” meeting with the seeds to educate them about the survey goals and to inform them of their importance to the success of the survey. You should:

- provide food and beverages
- consider providing a short presentation on the survey goals and process.
- encourage the seeds to be enthusiastic
- create a sense of trust and partnership with them.

Because the first wave learns about the survey from the seeds, the first wave of recruits will, in turn, be more likely to report favourably about the survey, accurately explain the survey goals and use all three of their coupons to recruit the second wave.

Although a kick-off meeting can be helpful in the success of your survey, it is sometimes difficult to organize the seeds to attend such an event. Even if you are not able to schedule

a kick-off meeting for your seeds, it is important that they feel that their role is central to the success of the survey.

When considering a kick-off meeting, keep in mind that some seeds may not want to participate because they do not want others to know that they are participating in the survey. It is important to inform all seeds that they will be attending a meeting whereby other seed participants will be present and then to respect someone's decision not to attend.

Using seeds to improve the survey

Seeds can help improve the survey process. Seeds will be the first people who undergo the interview, specimen collection and coupon explanation process. At the end of the survey process, a member of the survey team should ask the seeds what they thought of the process and if they have any advice about how to improve it. This is a good time to address any final problems in the survey process.

Seeds should be informed that they will be part of the evaluation of the survey if you decide to involve them in this manner. This will also help them feel that they are respected and are playing an important role in the survey. Constructive feedback and suggestions from seeds and all other participants should be taken seriously.

Sample recruitment patterns

Diverse seeds and participants

Figures 5.4 and 5.5 provide examples of recruitment patterns. Recruitment graphs can be helpful to show how survey participants are linked together in their social networks.

Figure 5.4 displays the recruitment chain of eight sex worker seeds in Hai Phong, Viet Nam. The larger shapes represent the seeds. The black square shape represents karaoke-based sex workers; the blue square shape represents street- and park-based sex workers; the red circle shape represents hotel- and guesthouse-based sex workers; and the triangle shape represents phone- and internet-based sex workers.

The seed selection in this sample appears to be well-diversified by sex worker type. There is one phone-based sex worker seed, two hotel-based sex worker seeds, three karaoke bar-based sex worker seeds and two street-based sex worker seeds. There also appears to be a good mix of different types of sex worker within each of the recruitment chains.

Discussing Figure 5.5

Look at Figure 5.5 and try to answer the following questions.

- a. Find the longest recruitment chain. How many waves were reached in the longest chain?
- b. Find the shortest recruitment chain. How many waves were reached in the shortest chain?

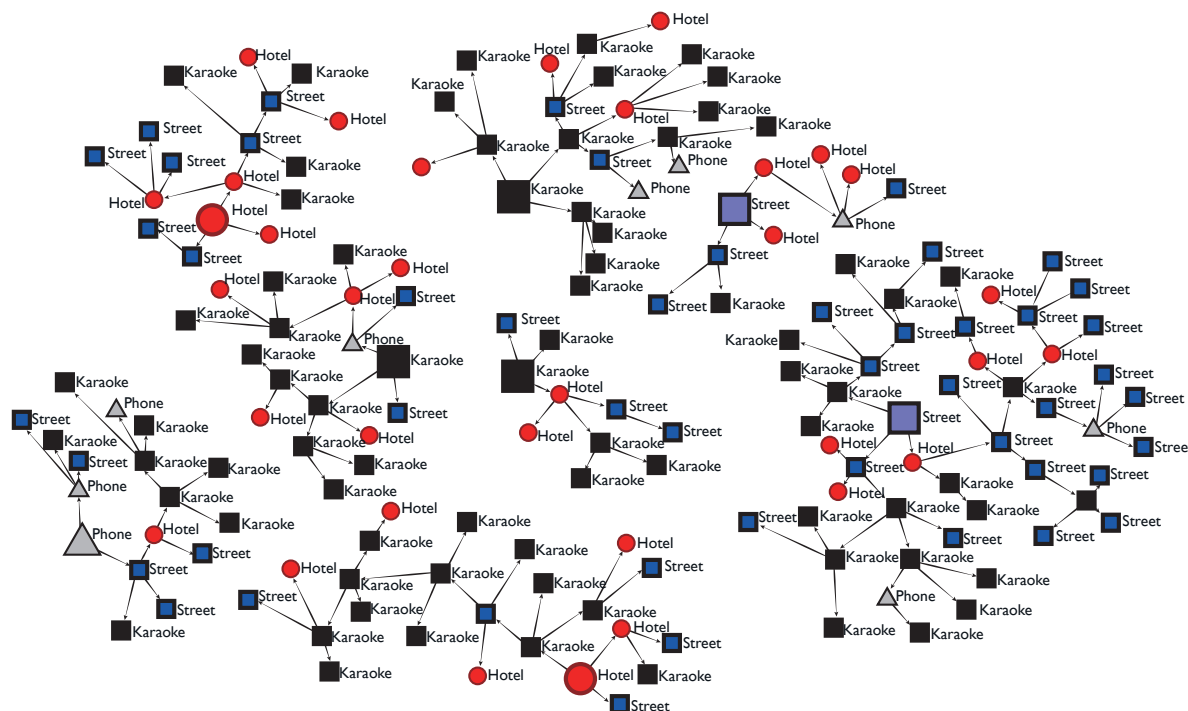


Figure 5.4 Recruitment graph of sex workers by type, Hai Phong, Viet Nam, 2004.

Source: Johnston LG, Sabin K. Sampling hard-to-reach populations with respondent driven sampling (In English). *Methodological Innovations Online*, 2010, 5(2):38–48.

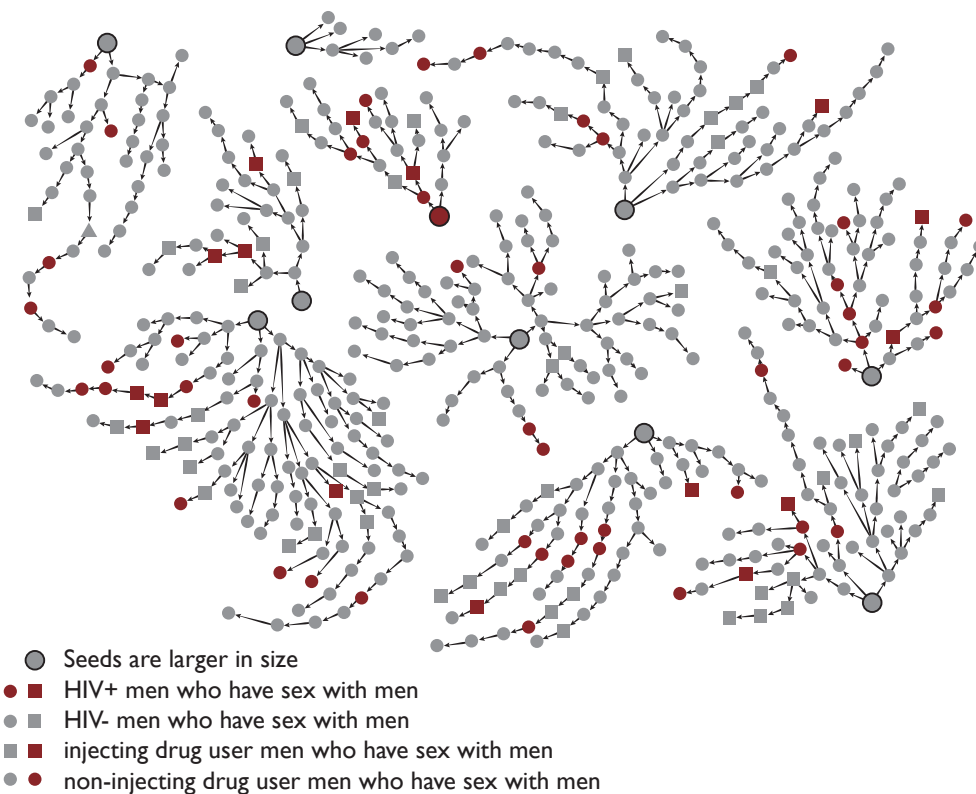


Figure 5.5 Recruitment graphic of men who have sex with men by HIV status and injecting drug use, Zanzibar, 2007

Source: Johnston LG, et al. HIV risk and the overlap of injecting drug use and high-risk sexual behaviours among men who have sex with men in Zanzibar (Unguja), Tanzania. *International Journal of Drug Policy*, 2010, 21:485–492.

- c. Using the legend under the figure, can you determine the HIV status of each seed? What is the injecting drug use status of each seed?
- d. Can you try to determine the approximate proportion of HIV positive men who have sex with men who also inject drugs in this sample?
- e. What may be some reasons that some recruitment chains are far shorter than others?

Summary

There is no exact number of seeds specified for any one sample. Selecting seeds will depend on a number of factors including the survey sample size, number of diverse characteristics held by the sample population and the number of ties connecting the sample population's social networks. Research indicates that past RDS surveys have used an average of 10 seeds. Depending on your survey population, for a sample size of 400 no more than 6 to 8 seeds are usually necessary.

Seeds should:

- be well-liked and respected by other members of the survey population
- be effective communicators
- have large network sizes
- be diverse with respect to geographical, demographic and key outcome variables
- understand the survey and its goals.

Seeds are an extremely important part of the survey. If they leave the survey site having had a negative experience, they will not recruit anyone. Because seeds are often known by the survey team, it is very important to ensure their confidentiality.

In some cases, seeds that do not recruit anyone with their coupons can be contacted by the survey team to inquire why they have not done so.

If seeds have distributed their coupons, they can be contacted and asked to follow up with their recruits to encourage them to enrol in the survey. Remember that some seeds may not recruit anyone.

Unit 5 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. If you were to conduct a survey using RDS in a major city in your country, what are some of the outreach groups or organizations that you could use in your area to help you recruit seeds for a men who have sex with men survey? For a sex worker

survey? For an injecting drug user survey? What kind of involvement do these groups or organizations have with these populations in your area?

2. What types of diverse characteristics would you want to include in the seeds you select. For a men who have sex with men survey? For a sex worker survey? For a people who inject drugs survey?
3. How would you find out if your seeds are sociometric stars? What are some questions you could ask them and in what type of setting would you ask those questions?
4. Describe a kick-off event you would have to educate and motivate your seeds. Where would you do it? What kinds of activities would you have? Would you have refreshments? In addition to the seeds, who would you invite? What would you do if none of the seeds you invited to the kick-off event showed up?

Apply what you have learnt/case study

Try this case study individually.

You selected 10 seeds to initiate your recruitment. All seeds attended your kick-off celebration, completed their survey and received their three coupons in order to recruit their peers. Three weeks into the survey, no one linked to three of your seeds has shown up for an interview. Some of your other seeds have already produced three waves. What would you do?

Unit 6

Selecting and
managing survey
sites

Overview

What this unit is about

This unit provides guidelines and suggestions that are useful for selecting the most appropriate RDS survey sites based on your survey needs. This unit will also discuss management issues related to having more than one survey site.

Warm-up questions

1. True or false? One of the advantages of RDS is that participants come to you to be interviewed instead of you having to seek out participants to interview. Circle your answer below.

True

False

2. Participants should feel comfortable at the survey site. List at least two characteristics of a survey site that makes the site comfortable.
3. Which of the following types of site may not be appropriate for a survey site?
 - a. rented storefront on a busy public street
 - b. mobile van parked across from a public park
 - c. rented house in a quiet residential neighbourhood
 - d. private area of a large bar or restaurant
 - e. public health clinic.
4. What are two reasons that more than one survey site may be needed?
5. True or false? For safety reasons, survey sites should never be open at night. Circle your answer below.

True

False

Introduction

What you will learn

By the end of this unit, you should be able to:

- identify different types of survey site for conducting RDS
- describe the advantages and disadvantages of each type of survey site
- describe the reasons for having more than one survey site and the limitations of this
- understand the guidelines for establishing hours of operation for the survey site
- develop a safety plan for your survey site.

Site selection issues

This unit will help you evaluate advantages and disadvantages when selecting an RDS survey site. The selection of appropriate survey sites depends on the:

- size and type of your survey population
- number of staff and staff responsibilities
- space available to the research team
- survey budget.

Characteristics of survey sites

Choosing a survey site

Currently there are no specific criteria for selecting RDS survey sites. However, an RDS survey site should have at minimum:

- an interior waiting room and reception area away from the interviewing or biological testing area
- private spaces for interviews
- private space for VCT
- private space for the collection of biological specimens
- a bathroom.

This unit offers guidelines and suggestions based on past experiences that are useful for selecting the most appropriate RDS survey sites based on your survey needs. Although no two survey sites will be exactly the same, Figure 6.1 presents a diagram of what an ideal survey site might look like.

This survey site assumes one screener (to screen for eligibility and enrol participants), three interviewers (to conduct the interviews), one VCT counsellor (to provide pre- and post-test counselling for those having an HIV test), one nurse or phlebotomist (to draw a blood sample or collect other biological specimens) and one coupon manager (to explain the coupon recruitment system and to provide coupons to participants). Usually the screener or the coupon manager provides the primary incentive.

This survey site also assumes a large waiting room, a bathroom (also useful for self-collection of vaginal or rectal swabs) and a kitchen (optional) for serving tea or other refreshments.

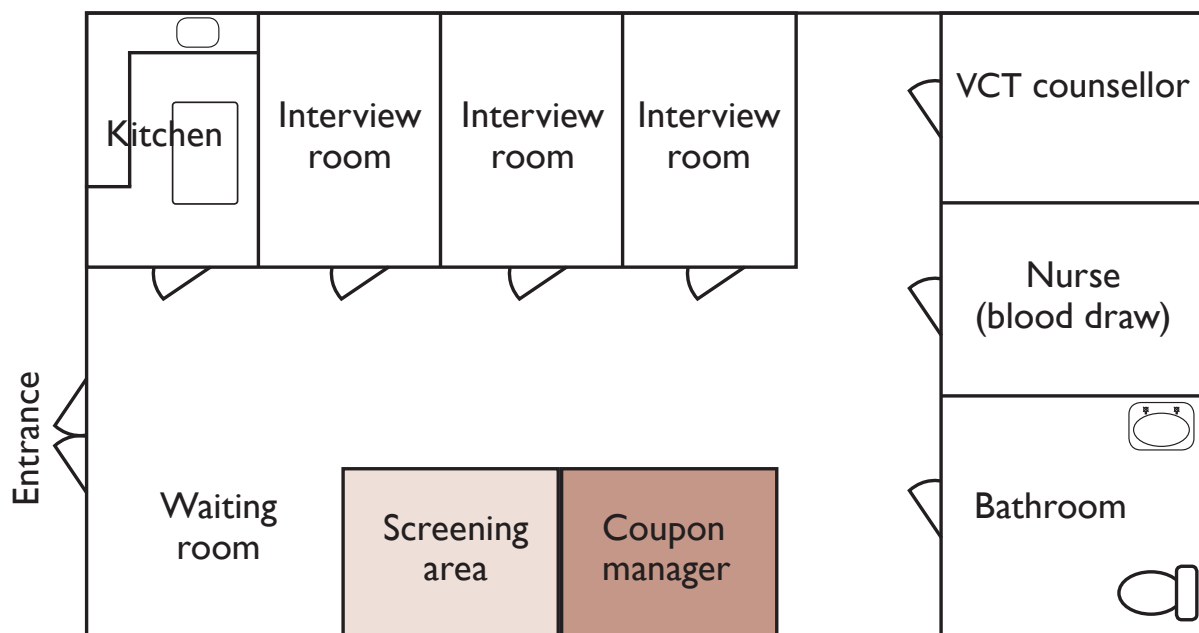


Figure 6.1 Map of survey site

Survey sites should be:

- accessible
- quiet and private
- spacious
- safe
- comfortable
- clean.

Each of these characteristics is discussed in Table 6.1. More than one site may be selected for interviewing, depending on sample size, availability of sites and the size of the recruitment area.

Discussing Table 6.1

Look at Table 6.1 and think about your own experience to answer the following questions:

- a. Have you been involved in conducting interviews in the past? Have you been interviewed by someone else? Describe the survey site where you were interviewed or you conducted interviews. Was it a comfortable interviewing space? What were the advantages and disadvantages to the site?
- b. Describe what you think would be the ideal survey site if you were to conduct RDS in your area. Can you think of a specific site? How would you find a good site? What kinds of questions would you have to ask to make sure a site was appropriate for an RDS survey? What kinds of things can you do to the waiting area to make it more comfortable for participants that have to wait for long periods of time (e.g. 30 minutes)?
- c. What do you think would be the differences in an RDS site that is interviewing men who have sex with men, people who inject drugs or sex workers? Would you want to conduct simultaneous RDS surveys among men who have sex with men, people who inject drugs and sex workers at the same survey site? Why or why not?

Table 6.1 Descriptions of important site characteristics for RDS surveys

Needed characteristic	Description
Accessible	<ul style="list-style-type: none"> ● Site should be: <ul style="list-style-type: none"> ○ easy to find ○ affordable to get to ● Several possible appropriate settings may exist e.g. cafes or health settings
Quiet and private	<ul style="list-style-type: none"> ● Site should <ul style="list-style-type: none"> ○ ensure participant confidentiality ○ limit distractions ○ allow for participant traffic that will not attract undue community concern ● Avoid highly visible locations or using large signs for advertising the survey site ● Choose an unassuming location; it may be less of a deterrent for survey participants
Spacious	<ul style="list-style-type: none"> ● Site should have enough space: <ul style="list-style-type: none"> ○ to safely store biological specimens ○ to ensure that specimens are kept out of sight of participants and non-staff members ○ to store completed questionnaires ○ to allow private rooms or spaces for each interviewer or computer terminal, if using audio computer-assisted survey instruments (ACASI), to conduct interviews confidentially ○ so that participants can comfortably wait to be interviewed
Safe	<ul style="list-style-type: none"> ● Site should be located in an area where participants and staff feel safe: <ul style="list-style-type: none"> ○ far from police stations or other law enforcement organizations that may intimidate participants ○ with sufficient outdoor lighting for staff and participants to feel safe entering and exiting the survey site ● Site should have sufficient space to safely guard important items: <ul style="list-style-type: none"> ○ Storage of data and forms ○ Storage of equipment (computers, telephones, etc.)
Comfortable	<ul style="list-style-type: none"> ● Site should: <ul style="list-style-type: none"> ○ have enough chairs for participants to use while waiting ○ be properly heated and cooled ○ have ample tables, computers, chairs for participants to use during the interview ○ have an inviting, welcoming atmosphere ○ provide refreshments, especially if blood is drawn ○ contain a bathroom
Clean	<ul style="list-style-type: none"> ● Site should: <ul style="list-style-type: none"> ○ be a healthy environment for staff and participants ○ maintain high standards of cleanliness when collecting biological specimens ○ have a place to wash hands ● Keep work areas and paperwork neat

Choose discreet sites

Survey sites must be discreet and not attract undue community concern. For instance, if you select a survey site for people who inject drugs that is located in a family-oriented residential area, neighbours may become concerned and insist that you close down the survey site before your survey is completed.

Consider budget

Depending on the budget allocated for survey sites and how hidden the survey population is:

- surveys with adequate budgets can rent private space to conduct interviews
- surveys with smaller budgets allocated for survey sites can use private spaces located in pre-existing sites such as cafes, coffee shops or health settings
- in countries where services are available to members of the survey population, the use of these service provision sites, such as condom distribution sites and VCT centres, as survey sites, may be appropriate.

Lessons from EMR/MENA

Formative assessment and budgetary constraints are of crucial importance in the choice of an RDS site and how it is equipped. In one survey, limited funds dictated a maximum of four computers for audio computer-assisted survey instruments (ACASI) interviewing and the recruitment flow exceeded the site capacity. Having more computers would have helped to reduce the number of participants waiting to be interviewed (an appointment system was not feasible).

Sites should be spacious

It is important to screen all potential participants before you allow them to go into the interview area. Make sure there is adequate space for this activity. There should also be a waiting area for incoming participants before they are allowed into the interviewing area. To accommodate staff and waiting participants, find a location that has a waiting room available inside or nearby and escort participants to and from the waiting room, if necessary.

Maintain confidentiality and safety

Interviewers should have private rooms to maintain confidentiality and privacy during an interview.

- If you are using computer-assisted survey instruments (CASI) or ACASI, use partitions or arrange the computers so that no one other than the interviewee can see the screen.
- Lock doors to survey sites to secure project materials and equipment.
- Lock file cabinets in the survey site to maintain confidentiality of any information collected.

Miscellaneous issues

Remember to consider the maintenance of the survey site. There may be costs related to electricity, proper lighting, cleaning, storage and other items.

The checklist in Table 6.2 includes suggested items to have readily available at the survey site. Make notes about your particular situation.

Table 6.2 Checklist for survey site materials

SURVEY MATERIALS	
Check	Item
<input type="checkbox"/>	Handheld or desktop computers (if using ACASI/CASI)
<input type="checkbox"/>	Paper copies of your survey (even if you are using ACASI/CASI), including the eligibility form, network questions and the core questionnaire
<input type="checkbox"/>	Test kits and other paraphernalia (if taking biological specimens)
<input type="checkbox"/>	Maps if your questionnaire includes questions about important geographical areas (e.g. In what area of town do you buy drugs? Where do you solicit clients?)
<input type="checkbox"/>	Recruitment/referral coupons
<input type="checkbox"/>	Consent forms or scripts
<input type="checkbox"/>	Recruitment process script
<input type="checkbox"/>	Interviewer guide
<input type="checkbox"/>	Response flashcards (if needed)
<input type="checkbox"/>	Incentives
<input type="checkbox"/>	Appointment book
<input type="checkbox"/>	Calendar for determining expiry dates
PROGRAMME MANAGEMENT/QUALITY ASSURANCE	
Check	Item
<input type="checkbox"/>	Coupon tracking forms
<input type="checkbox"/>	Security incident forms
<input type="checkbox"/>	Receipt book

OFFICE SUPPLIES	
Check	Item
<input type="checkbox"/>	Lockable filing cabinets or cases
<input type="checkbox"/>	Paper (regular and stock), envelopes
<input type="checkbox"/>	Pens, pencils, stapler, scissors, masking tape, paper cutter
<input type="checkbox"/>	Binders, folders, hanging folders
<input type="checkbox"/>	Stamps, post-it notes
<input type="checkbox"/>	Chairs for staff, interviewees and for those who are waiting
<input type="checkbox"/>	Stamp or embosser for coupons
<input type="checkbox"/>	Refreshments
<input type="checkbox"/>	Cleaning supplies

EQUIPMENT NEEDS	
Check	Item
<input type="checkbox"/>	Computers
<input type="checkbox"/>	Internet access for networking multiple sites
<input type="checkbox"/>	Printer, ink cartridges
<input type="checkbox"/>	Media: diskettes, zip drives
<input type="checkbox"/>	Telephone/fax, answering machine

RISK REDUCTION MATERIALS	
Check	Item
<input type="checkbox"/>	Condoms, lubricants, bleach kits, hygiene kits
<input type="checkbox"/>	Pamphlets on safer sex and injecting, HIV/AIDS, STIs and hepatitis
<input type="checkbox"/>	Referral information for drug treatment and VCT
<input type="checkbox"/>	Posters

Choose your survey site well

Select survey sites carefully. One of the worst things that can happen to your survey is that you lose the survey site during the course of your survey. If this happens, you will have to:

- find another site quickly
- inform your survey population that you have moved to another survey site.

Ultimately, you will lose participants and your survey will be delayed.

Lessons learnt

Such an event occurred during an RDS survey conducted among “sugar daddies” (older men who provide gifts and money to younger girlfriends in exchange for sex) in a South African township. Four weeks into the survey, the survey site, a wing in a health care clinic, was burgled. In response, the community and the health care clinic authorities told RDS staff to leave. It took the RDS team two weeks to find another survey site. Extra expense was required to develop new coupons and great effort was needed to try and convince previous participants to continue participating in the survey. In the end, none of the coupon numbers of the participants from the original survey site showed up at the new survey site. New seeds were selected and the survey began anew.

Types of survey site

Selecting survey sites

RDS usually uses fixed survey sites. The different types of survey site that have been used for past RDS surveys are discussed below. There are reasons to select or avoid each of these types of survey site. Selection of an appropriate site will depend on your own survey needs and on formative discussions with members of your survey population.

Established health sites

Established health sites may include general health clinics, STI facilities or VCT sites. This type of survey site is useful for surveys with limited budgets. The health site will often lend, rather than rent, space for the purposes of the survey.

These types of survey site are often discreet. They may already be known and used by the survey population. However:

- in situations where the survey population is highly suspicious of the government, using government-run health establishments as survey sites may hinder participation
- in some cases, STI clinics and VCT sites may also discourage participation, since some members of the survey population, especially those who are more hidden (such as bisexual men who have sex with men or part-time sex workers), may not want to be seen at one of these sites.

Lessons from EMR/MENA

In Khartoum, Sudan, an established public health clinic was used as an RDS survey site for an RDS survey among men who have sex with men. This established health clinic was centrally located, enclosed with walls and had extra rooms in which to conduct interviews. Furthermore, the clinic was provided to the Ministry of Health (those conducting the survey) at no cost.

In another EMR/MENA country, a drug treatment clinic located within a large clinic in the centre of the city was used for an RDS survey among people who inject drugs. The site was near areas where people who inject drugs lived, they felt comfortable in that setting and the survey was successful.

Established nongovernmental organization sites

Some communities may have nongovernmental organizations already working with key populations at higher risk of HIV exposure that have extra space to lease. Similarly to established health sites, established nongovernmental organization sites are usually discreet.

In addition, established nongovernmental organization sites may:

- be centrally located in public areas where people come and go without being noticed
- have staff that are familiar with the survey population or have research skills that could be useful to your survey
- have staff that can be trained as interviewers or to conduct formative assessment
- have existing credibility in the community
- have computer systems that can be used for conducting CASI.

Lessons from EMR/MENA

In a survey conducted in Hodeidah, Yemen, among female sex workers, a pre-existing nongovernmental organization office that provides reproductive and family planning services was used as an RDS survey site. Some of the useful properties of this site were that the organization:

- mainly served female populations so the survey population did not attract the undue attention of neighbours
- had VCT facility with staff trained in counselling and testing
- had part-time staff who were familiar with research techniques and survey management as well as dealing with the survey population, some of whom were hired for the survey
- was not functioning during the hours in which the survey wanted to conduct interviews (16.00–20.00 and on weekends)
- charged a minimal rent to the survey, which helped it supplement its own funding needs.

Established public sites

These types of survey site may include bars, cafés, restaurants and hotels. Select public establishments carefully in order to avoid disturbing regular clientele.

Choose appropriate public establishments. The patrons should not look too different in appearance from members of the survey population. For instance, a four star restaurant would probably not work well for interviewing people who inject drugs.

Establish a well-planned protocol to quickly address situations at the survey site if survey population members arrive and are drunk, high or threatening.

- In some cities, restaurants or bars may have side rooms or may have an area that can be partitioned off where interviews can be conducted.
- Hotels can serve as discreet survey sites and will sometimes offer lower rates for booking rooms for interviewing for long periods of time.
- If you choose to use a private establishment, clearly communicate the goals of your survey to the manager. Ensure that he or she understands and agrees to your use of the rooms/spaces.

There are several benefits to using established public sites:

- For security—a hotel room may include a locked safety box for secure storage of incentive money.
- To decrease participant intimidation—survey population members may be less intimidated by entering a place where people often go to socialize, have meetings, and eat and drink.
- For participant comfort—interviewees or survey staff may buy drinks or food in hotels, cafés, restaurants or bars.

Rented storefront sites

A rented storefront (or an empty commercial space in a building) may be the most discreet type of survey site but is probably the most expensive option.

Survey sites that are located in areas where your survey population lives or spends time (such as areas of high drug use) can be less expensive to rent, but may not be safe.

If the survey site is to be set up in a new location, check first to see if the city has any zoning restrictions for use of the space. Also, consider the cost of furnishing the rented storefront space.

But there are benefits to rented storefronts:

- a high level of control can be retained by research staff over interviewing arrangements, such as hours of operation, types of participants being interviewed and methods for dealing with difficult participants
- once the survey is over, rented storefronts are easy to close up.

Rented private apartments

A rented private apartment is much like a rented storefront. A rented private apartment may be located in a more residential area than a storefront and may have more oversight from a non-commercial landlord. It is important to know the residential zoning laws in the country and city where you will be conducting the survey to ensure that you can carry out the survey activities that you are proposing.

Lessons learnt

In a survey among female sex workers conducted in Khartoum, Sudan, the only viable option for an RDS site was to rent a private apartment. Survey coordinators found a large private apartment located on the first floor of a four story apartment building that:

- was surrounded by a wall (ensuring privacy to the participants)
- was located one block from a busy and central traffic intersection
- had several spacious rooms in which to discreetly screen, interview and collect biological specimens from participants
- had a large area that could serve as a waiting room.

The landlord who lived on the second floor was informed about the survey and the nature of the survey population. Accordingly, he proposed to put a sign on the apartment door (“Women’s Research Centre”) in order to avoid undue attention from the neighbours. The survey went well and participants felt comfortable in the apartment.

In a second example in Serbia and Montenegro, survey coordinators wanted to rent an apartment in which to conduct interviews and collect blood from a finger prick. After searching for apartment spaces, it was later learnt that biological specimens (including a finger prick) could not be collected outside a registered health facility. The survey coordinators had to look for some other space in which to conduct the RDS survey.

Mobile sites

A large converted bus or van can be used as a mobile interview/intervention site [29]. This type of survey site is useful for travelling to different locations to conduct interviews. Mobile sites may require substantial upfront costs and logistical effort, including:

- the cost of the vehicle and license
- a conversion cost to make it suitable for conducting interviews
- ensuring that participants know where the site will be located on a given day
- maintenance costs.

If you plan to use a van, obtain a parking permit and identify a fixed parking location for each area where you will be conducting interviews.

Having a consistent location is beneficial for staff and recruiters; they can provide directions to the field site. Depending on the available parking space in specified areas, it may be necessary for a staff member to reserve the location a few hours to a day in advance of the actual scheduled operating hours.

There is potential for mechanical problems with a van, so alternate plans of action should be developed for times when the van is unavailable due to unforeseen circumstances or regular maintenance.

If you choose to use a mobile site, make sure it is discreet. Many survey population members would not be interested in entering the mobile survey site if it had a sign that read, “HIV behavioural surveillance survey site for people who inject drugs”.

As with other types of survey site, mobile sites could result in community and police curiosity that could eventually reduce survey confidentiality and privacy. Discuss the survey with the police and make sure you choose locations where the participants and community members are similar in appearance.

There are benefits to mobile sites. Mobile sites may be:

- sold when the survey is over to partially recover some of the initial cost
- useful in widely-dispersed populations or in areas with poor transit systems.

Conducting interviews outside a survey site

Although RDS is usually conducted in a fixed location, there are situations where a participant will want to be interviewed away from the site. This may occur in situations where the participants feel particularly vulnerable and stigmatized. In this case, the interviewer will have to use a paper questionnaire or a handheld CASI system. If collecting biological specimens, consider some means to collect these outside the survey site.

- For safety reasons, if a potential participant calls the survey site and requests an off-site interview, the interviewer should meet the potential participant at a public location.
- If the meeting does not occur at a public location, the interviewer should go with another person.
- As in any interviewing situation where a staff member meets an interviewee at an off-site location, the interviewer should inform the site manager where they are conducting the interview and have a cell phone with them in case they need to call for help.

Lessons learnt

In a district-wide survey of people who inject drugs, RDS staff learnt that some people who inject drugs from a town located 45 minutes from the fixed RDS site were not willing to travel so far to participate in the survey. The RDS staff, including the laboratory technicians and the doctor, rented a small space in this town to conduct interviews for a period of four days (and collect blood and urine samples and genital swabs). Of course, all survey participants had to have a coupon and meet the eligibility criteria.

In an RDS survey of sex workers in Brazil, some survey participants were afraid to go to the fixed RDS survey site. The recruitment coupon provided a private phone number so that those participants could call an RDS staff member to request an interview at a mutually convenient location. Interviewers wore identifiable caps in order to be easily recognized by participants.

Number of survey sites

Deciding on number of sites

Depending on the sample size, the availability of survey sites and the size of the recruitment area, more than one site may be selected for interviewing. If you are conducting a survey in a large metropolitan city where participants will need to travel great distances to reach a survey site, you may want to consider having more than one survey site. In a review of 114 RDS surveys 81% used a single site and the maximum number of sites used in one survey was five [5].

Lessons learnt

When you select multiple survey sites, it is important that they are not so far away from each other that you are sampling from a separate social network. You want to be able to capture your original network without them having to travel too far. It is important

to understand the geographical boundaries of the social networks of your population of interest and their willingness to travel.

For instance, an RDS survey was being considered in the Caribbean islands of Saint Kitts and Nevis. These islands comprise one state and the survey populations are socially-networked through travel between the islands for work, shopping and social activities. As Saint Kitts and Nevis are separate islands, it was important to have a site on each island, since it would be difficult for some members of the survey population from Saint Kitts to travel to Nevis, and vice versa. A survey site was therefore placed in each of the islands.

Managing multiple sites

Having more than one RDS survey site may require more staff. Furthermore, having multiple survey sites also increases the chances of someone participating more than once in the survey.

Multiple survey sites require stricter coupon management, especially if the coupon identification numbers are made up at the time of an interview, resulting in the possible duplication of coupon identification numbers. If multiple sites can be networked by a computer system, then coupon numbering can be easily managed. However, networked computer systems are not available in some settings.

To manage multiple RDS survey sites, it is important that the survey supervisors meet as often as possible (perhaps every day) with RDS staff to avoid duplication of the coupon identification numbers. Use a coupon numbering system like the one described in Unit 7 to avoid duplication of coupon numbers.

Ensuring cross-over among survey sites

Multiple survey sites can create bottlenecks which could decrease the possibility that the network comprises one complete network component, an important assumption in RDS. For example, in a large sprawling city, three survey sites might be needed to accommodate people who are not willing to travel long distances to enrol in an RDS survey.

However, in order to avoid having three distinct social networks (and therefore, three distinct samples) based on the survey site locations, it is important to ensure that recruitment occurs across the survey sites (e.g. that people who would normally go to site 1 would recruit someone who would go to site 2 and someone who would normally go to site 3 would recruit someone who would go to site 1 and so on). Encouraging this type of recruitment is most easily managed through the selection of seeds (see the section on network cross-over across interview sites in Unit 5).

Hours and days of operation

Determining hours

Determine the hours of operation through formative assessment. Different types of survey population have different hours when they will be willing to be interviewed. For instance:

- sex workers may work late into the night, so opening the survey site early in the morning would not be convenient for this population
- sex workers may not be willing to be interviewed during their peak hours of business
- some men who have sex with men may have full time day jobs that would prevent them from attending an interview during normal work hours.

Determining days

To avoid having potential participants arrive after the survey site is closed, determine the appropriate week days for having the survey site open. Display days and hours at the survey site and on the coupon.

- Always open and close the site at specified times.
- During lunch and other breaks, close the survey site and do not conduct interviews. Keep in mind that some participants may want to be interviewed during the normal time for lunch breaks.
- Schedule only a certain number of interviews so that the interviewers are not overwhelmed.

Survey sites can be open any number of days during a week. In past surveys, some survey sites were open seven days a week and others were open four days a week.

If there is more than one survey site, researchers should decide whether to:

- have each site open at the same time or on separate days of the week during the same data collection period
- open on weekends, which, especially in the evenings, may be most convenient to survey population members since many will want to attend an interview during times when they normally run errands, go shopping or during periods of free time
- have drop-in times or ask interviewees to make an appointment by telephone before arriving at the survey site
- consider having a separate day available just for secondary incentives and test results.

Summary

RDS survey sites must be:

- accessible, easy to find and affordable to get to
- discreet so as not to attract undue community concern
- quiet and private to ensure confidentiality and to limit distraction
- clean, comfortable and safe for staff and participants
- spacious enough so that biological specimens and completed questionnaires can be kept out of the public view
- pleasant, so participants feel comfortable inviting their peers to participate in the survey.

Select survey sites carefully. One of the worst things that can happen to your survey is that you lose the survey site during the course of your survey. If this happens, you will have to:

- find another site quickly
- inform your survey population that you have moved to another survey site.

Unit 6 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. Think about the cities where you might conduct an RDS survey and consider what kinds of survey site you could have access to. What are the advantages and disadvantages of each site?
2. If you were to conduct a survey on sex workers, people who inject drugs and men who have sex with men in your country, would you use the same site to interview all three groups? Why or why not?

Apply what you have learnt/case studies

Try these case studies.

1. Three weeks after initiating the RDS survey in Beirut, the public health survey site was overcrowded with people who inject drugs. Upon finding out that they would have to wait or return for an interview, many of the participants started threatening the interviewers. The safety of staff and survey materials became an issue. Neighbours from nearby buildings filed complaints to the local police because of people who inject drugs waiting outside the survey site.

- a. What would you do in this situation?
-
2. An RDS survey conducted in Sana'a did not have much money available for a survey site and had to think of some creative ways to reduce the costs for renting space. The research staff decided to use spare rooms located in a restaurant. They were able to reduce costs by negotiating with the restaurant manager that the survey incentives would include vouchers for meals in the restaurant. The restaurant manager agreed to the proposal and reduced the survey's cost of renting the spare rooms.
 - a. Can you think of other creative ways to reduce the costs of renting space?
 - b. Can you think of problems associated with the type of situation mentioned above?

Unit 7

Coupon design,
coding and
management

Overview

What this unit is about

Coupons must be easy to track but not easily reproduced by members of the survey population. They must contain a unique RDS identification code, so that each coupon can easily link recruiters with recruits. Coupons should be carefully developed, easy to read and have a pleasant appearance so that survey participants realize that the coupons have value.

Warm-up questions

1. True or false? There is only one way to design an RDS coupon and each country should use the same coupon used in previous surveys. Circle your answer below.

True

False

2. List at least two pieces of information that are essential to have on a coupon.
3. Why would a survey want to use more than one colour on a coupon?
 - a. to make the coupons more attractive so participants will be more willing to accept them
 - b. to manage the different waves of survey participants
 - c. to track where the coupons were distributed
 - d. to easily distinguish between two different groups (such as sex workers and people who inject drugs) being interviewed simultaneously in the same survey site
4. True or false? After the seeds are selected, only persons with valid coupons are eligible to participate in the survey. Circle your answer below.

True

False

5. Circle the one response below that is incorrect. Tracking coupons during a survey is important because:
- a. it ensures that incentives are paid out to the correct person
 - b. it can help track the number of waves completed in the survey
 - c. it can help you locate the person who gave you the coupon if you have to find them
 - d. it is important for analysing the sample data
 - e. depending on the identification system you use, it can help to determine which seeds are producing and which are not.

Introduction

What you will learn

Coupons are very important in conducting an RDS survey. By the end of this unit, you should be able to:

- explain the purpose and use of coupons in RDS
- describe important design elements in a coupon
- design a coupon
- use coupon identification methods
- select a coupon identification method
- explain how to track and manage coupons.

The purpose of coupons

Correct coupon design and use are essential for successful participant recruitment and accurate data collection in any RDS survey. RDS coupons:

- provide information about the survey, survey site time and location to potential recruits
- link information about recruits and their recruiters through the unique RDS identification code system
- help track recruitment progress and manage incentive payments.

How many coupons to print

It is important to produce enough coupons to last the duration of the survey. Usually it is wise to print as many coupons as the sample plus twice as many more. For example, for a survey of 400 participants, print 400 coupons plus at least 800 extra coupons. Even though everyone may receive three coupons to recruit others, many coupons are never redeemed.

Coupon design

Essential elements

A coupon must have the following elements:

- unique RDS identification code or number
- survey site location
- telephone number (if telephone is available)
- days and hours of operation
- expiry date (the period of time during which a participant is expected to recruit a peer and the peer redeems the coupon).

It is also essential that coupons be legible and easily understood, even for those who may be illiterate. Furthermore, the coupon should include text with a font large enough to be easily read.

Coupons are usually printed on hard-stock paper so that they are not easily destroyed. If

using polished paper, make sure that the paper can retain markings with pens (e.g. that the pen marks do not smudge).

Coupon design options

There are many options for developing coupons. The coupon that you design will depend on many factors, such as the:

- languages used by the population
- level of literacy of the population
- age group of the population (i.e. younger populations may need different instructions)
- number of sites being used
- number of populations you are sampling (e.g. simultaneous sex worker and people who inject drugs surveys at the survey site)
- type of paper you have available
- number and types of organization logos you may want to include on the coupon.

The coupons described in this unit have been tested, are easy to track and are being used in other RDS surveys around the world. Please use these coupon samples as a tool for designing your own coupon.

Formative assessment will be very helpful for designing appropriate coupons. Also, try to get feedback about, and/or involvement in the design of, coupons from the population being sampled.

Simultaneous surveys

If more than one RDS sample is being collected at the same time, such as having a simultaneous survey of sex workers and people who inject drugs, make the coupons a different colour for each sample. For example:

- yellow coupons for people who inject drugs
- blue coupons for sex workers
- green for men who have sex with men.

This will make the coupons easily identifiable.

If conducting surveys of more than one population at the same time, it is possible that someone who participates in one survey will be able to participate in one of the other surveys. For instance, if someone fulfils the eligibility criteria of a men who have sex with men survey and has a valid coupon they can enrol in the men who have sex with men survey. However, if this person is also injecting drugs and fulfils the eligibility criteria for a people who inject drugs survey and has a valid coupon, they can also enrol in the people who inject drugs survey. Anyone who has a valid coupon, fulfils the eligibility criteria and has not yet enrolled in the survey should be enrolled.

Coupon size

The coupon should neither be so small that it will get lost nor so large that it will be difficult to carry around.

One suggestion is to make the coupon no larger than the size of two credit cards, one placed above the other. This is about 8.5 cm × 10 cm.

Another option is to make the coupon the same size as, and look similar to, the local currency.

A further option is to make the coupon the same size as a business card that can be easily carried around in a purse or wallet where other business card-sized items may go.

Expiry period

The expiry period is the time frame during which a participant is expected to pass a coupon onto his or her recruit and the recruit redeems the coupon at the survey site. In four surveys conducted among female sex workers and men who have sex with men in two EMR/MENA countries, almost 75% of participants in all populations were able to pass out their coupons and have their recruits redeem those coupons at the survey site within two days. Many surveys begin with an expiry date of ten days to two weeks depending on the number of days the survey site is open during a week.

There are several reasons to have an expiry period on the coupon. These include the following:

- It encourages recruiters and recruits to redeem their coupons faster (or at least before the expiry date runs out).
- It assists in the management of coupons and estimation of the number of people who may enrol in the survey. For instance, the expiry date will allow staff to determine how many valid coupons are remaining in the community and to assess how many of those coupons will likely be redeemed based on the experience of the previous days or weeks.
- It allows for the closure of the survey with no more valid coupons remaining in the community. Keep in mind that any eligible person arriving at the survey site with a valid, unexpired coupon should be accommodated even if the sample size has been reached and the survey has ended. These persons have come in good faith to participate in the survey and not accommodating them by allowing them to participate or giving them an incentive may result in causing dissatisfaction or hurting future research with this population.

A common question about the expiry date is whether to accept someone who comes into the survey after the date has expired. The expiry date is set arbitrarily and is basically a mechanism to help ensure the survey's smooth implementation. When an eligible person comes into the survey with a coupon that is expired, the staff can consider allowing this person to participate without harming the RDS methodology.

A couple of things to consider are:

- if recruitment is fast and there are already too many people enrolling, then you may decide to deny the person access and to remain firm with the expiry date
- if recruitment is progressing slowly, then you may decide to allow the person access and to be flexible with the expiry date.

Activation period

The activation period is the time from when the participant leaves a survey site until the time they are allowed to pass out their coupons. Activation periods are usually from 24 hours to 3 days. The activation period was developed to slow down recruitment and to encourage random recruitment.

The reason for having an activation period is for cases where it is suspected that participants will pass out their coupons to the first peers they find after exiting the survey site. In some surveys, people wanting to be recruited will wait outside the survey site to get a coupon and then immediately enrol in the survey. This has occurred most commonly in surveys of people who inject drugs and may be an indication that the incentive is too high.

Sample two-part coupon top and bottom

Two-part coupon

One way to design your coupon is to have two parts that can be easily separated:

- One part of the coupon serves as the referral coupon that a recruiter provides to the peer who is recruited into the survey. The referral coupon has also been called the recruitment coupon, invitation voucher or peers' coupon. The recruit keeps this part of the coupon and uses it to enrol in the survey.
- The other part of the coupon serves as the payment coupon. The payment coupon has also been called the receipt coupon, return voucher or reimbursement coupon. It is kept by the recruiter who uses it to claim an incentive for having recruited a peer into the survey.

Both parts of the coupon have a unique identification code or number for the person being recruited printed on them. This coupon system eliminates the need to collect names for incentive collection.

Some surveys may choose to use an official coloured stamp directly over the section that is to be separated. When the coupon is torn in half, one half of the stamp is on each part of the coupon. This reduces the possibility that someone will duplicate a coupon or if coupons are lost (prior to the stamp being placed on the coupon) that someone can redeem it.

Figures 7.1 through 7.4 are samples to help you design your own coupon. Based on formative assessment, you may learn that there are other types of information that you want to include on your coupon.

These sample coupons assume that the survey will include a primary and secondary incentive. There are some RDS surveys that have not used a primary and/or secondary incentive. Incentives are discussed in the next unit.

Top front of coupon

Coupons can be printed on both sides. The referral coupon (top front portion) can contain information for the participant's recruits as shown in Figure 7.1 (the numbers in the list below correspond to elements of the coupon in the figure). Include these items:

1. A unique RDS identification number or code for the recruit (referred to as the coupon number below). This keeps track of who recruits whom.
2. The title of the sponsoring organization or a non-stigmatizing title of the survey. This coupon is entitled "Good Health Survey". Do not use titles such as the "National AIDS Project" or the "Survey to Test for HIV among Men Who Have Sex with Men". This could discourage participants from carrying the coupon. Survey names used in the past include "Men's Health Survey", "Health Assessment for Women" or "Project for Health Improvement".
3. Location and address of the survey site.
4. Contact information, including phone number if available.
5. Hours and days for enrolment.
6. Space for project staff to write in activation and/or expiry dates of the coupon.

Coupon number _____	→ 1. Coupon number
<u>Good Health Survey</u>	→ 2. Non-stigmatizing title
Address: 25, Karsom Street, building next to Trust Hospital	→ 3. Survey site location
Ask for: Ahmed (055-222-7777) or Martine (033-777-2222)	→ 4. Contact information
Drop in or make an appointment Drop-in hours: Monday through Saturday: 1200–1900	→ 5. Drop-in hours
PLEASE BRING THIS COUPON	
Coupon expires on _____	→ 6. Expiry date

Figure 7.1 Example of the top front of a referral coupon

Top back

The referral coupon (top back portion), shown in Figure 7.2, could display the benefits of participating in the survey and reasons why someone cannot participate in the survey. Items to include are:

1. Instructions
2. Reasons to participate
3. Map showing location of the survey site
4. Reasons for non-acceptance.

Optional (not shown here):

5. Space for project staff to write in coding such as interviewer ID.

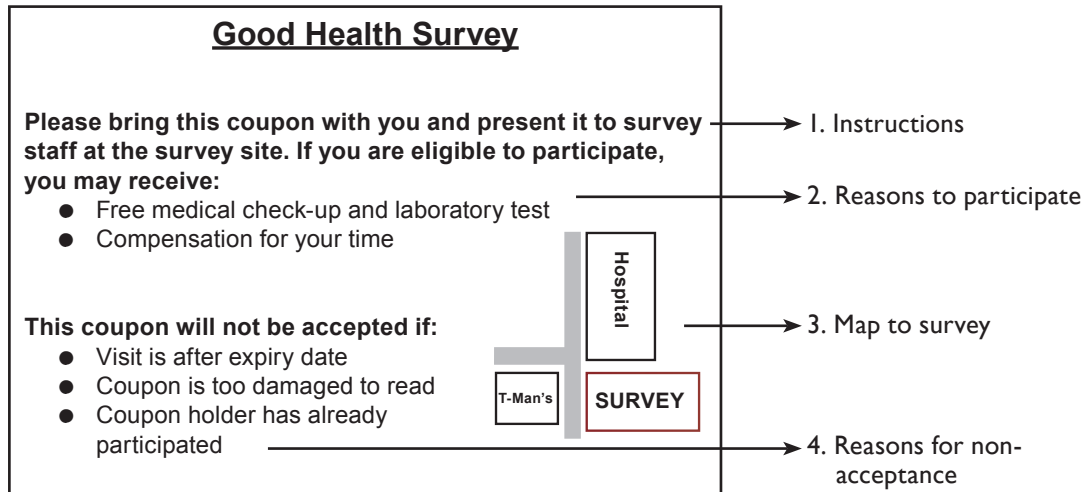


Figure 7.2 Example of the top back of a referral coupon

Bottom front

The payment coupon (bottom front portion) is used by participants who recruited someone else (Figure 7.3). The recruiter will need to retain the payment coupon in order to receive a secondary incentive for recruiting someone into the survey. Items to include are:

1. Coupon number (this keeps track of who recruits whom)
2. Name of project
3. Survey site location
4. Contact information including phone number, if available
5. Hours and days for receiving secondary incentives
6. Instructions
7. Expiry date (date when survey will finish).

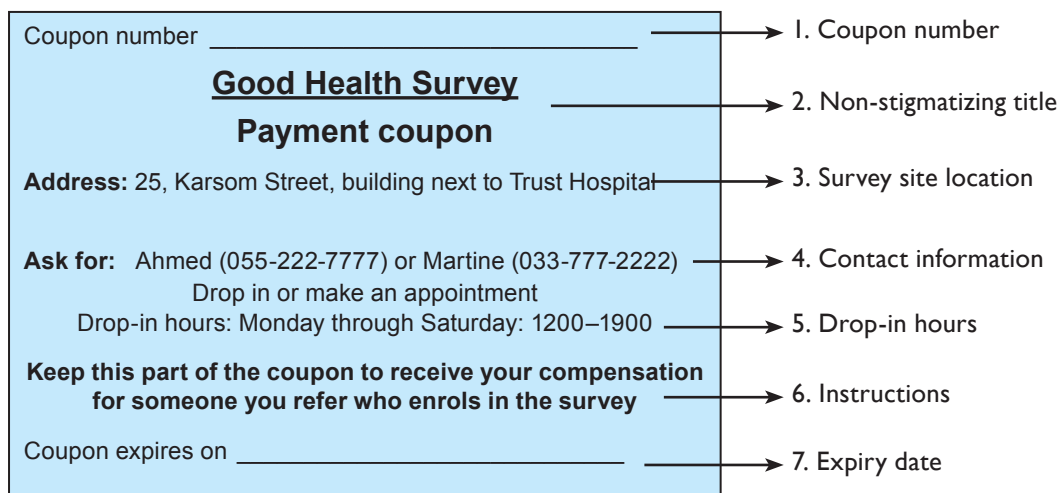


Figure 7.3 An example of the bottom front of a referral coupon

Bottom back

You can include information on the bottom back portion, as shown in Figure 7.4:

1. Name of project
2. Circumstances under which this coupon will be accepted
3. Circumstances under which recruiter will not receive incentive.

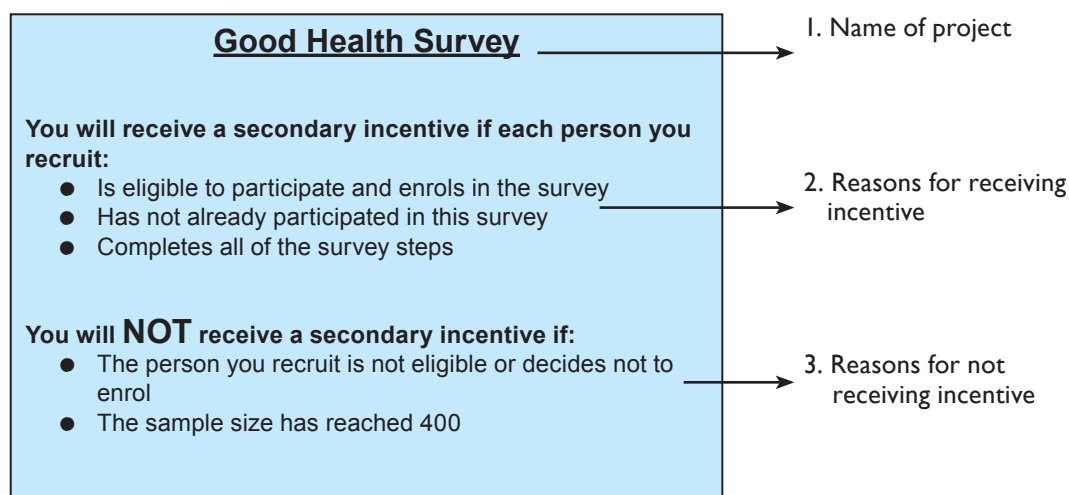


Figure 7.4 Example of the bottom back of a payment coupon

Lessons learnt

In two surveys in EMR/MENA, the survey team made the colour of the referral coupon different from that of the payment coupon in order to avoid confusing the survey participants.

Figures 7.5, 7.6 and 7.7 provide samples of the front and back of actual coupons used in RDS surveys.

The colour of the referral coupon (front) is different from that of the payment coupon (front).

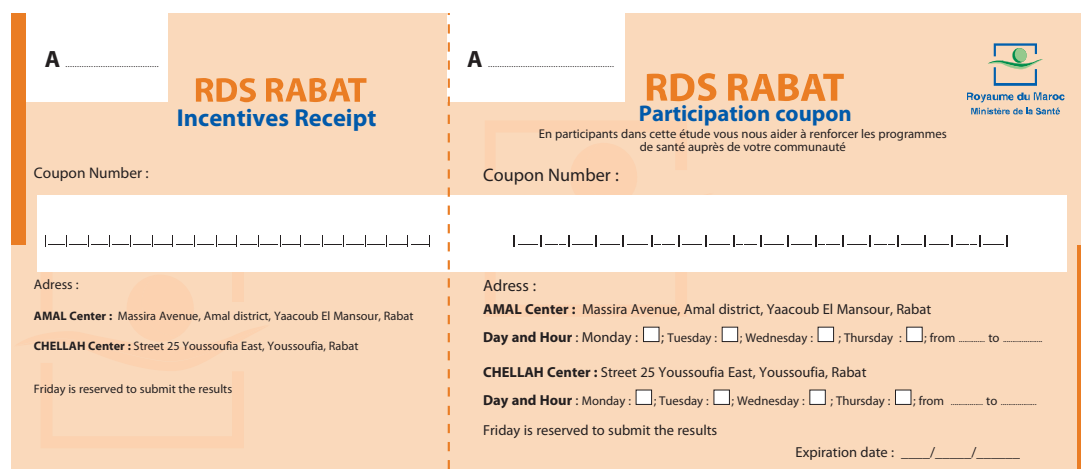


Figure 7.5 Example of a coupon used in an RDS survey among sub-Saharan migrants conducted in Rabat, Morocco, in 2013 (front part)¹

¹ Coupon used in a survey of sub-Saharan migrants in Rabat, Morocco, reproduced here courtesy of Dr Kamal Alami, UNAIDS, Morocco, and Dr Aziza Bennani, Ministry of Health, Morocco.

Coupon identification methods

Selecting a coupon identification method

All coupons will contain numbers and/or letters to manage who recruited whom. The type of coupon identification method will depend on how the survey is being conducted.

- If you are using a computerized system, any type of coupon identification method is acceptable as long as the coupons are properly tracked to record who recruited whom.
- If you do not have a computerized system, some systematic coupon identification method may be useful to manage the coupons and recruitment progress.

Two types of coupon identification method are described below:

- systematic coupon identification codes
- sequential coupon identification codes.

Systematic coupon identification

This coupon identification method is useful when there are no computers at the survey site to manage enrolment and coupons. This method has been used in numerous countries where staff want to easily identify how recruitment is progressing.

Depending on the number of seeds, this method starts with a unique number provided to the seed. For instance, in a survey with 10 seeds, the first two digits on each coupon will be 1, 2, 3, through to 10.

For example, Seed 1 has the number 1, then...

Seed 2	2
Seed 3	3
...	
... to Seed 10	10

Most RDS surveys only allow for recruiters to recruit up to three peers, so the numbers following the seeds' numbers are 1, 2 or 3 as shown in Figure 7.8.

For instance, if seed number 5 is interviewed and given three recruitment coupons, then the recruits for seed number 5 would receive the following numbers:

51
52
53

If a recruit with coupon 53 is interviewed, then he or she will receive coupons with the identification numbers of 531, 532 or 533. This process occurs according to the number of waves produced by each seed. So coupon 533 represents the second wave produced by seed 5.

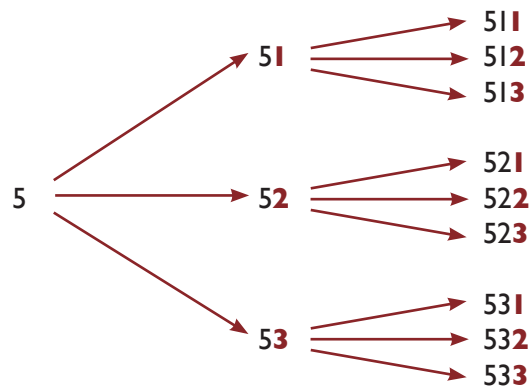


Figure 7.8 The coupon numbering method for seed 5

How coding helps manage your seeds

Coding the coupons in this manner makes it easier to manage:

- which seeds are efficient recruiters
- which seeds do not recruit anyone
- the number of waves completed by each seed.

The first digit identifies the seed, the second digit is wave one, the third digit is wave two and so on.

If someone with coupon number 533122 enters the survey, it is easy to see that seed number 5 has recruited five waves. This is useful, especially if you want to end your recruitment for each seed at a certain wave.

Seed numbering

Since the numbers 1, 2 and 3 are so important (if only three recruits are allowed), we recommend that if you have more than ten seeds to skip numbers 11, 12 and 13 for seeds and to use 14, 15, 16 instead. If there are more than 20 seeds, skip numbers 21, 22 and 23 for seeds and use 24, 25 and 26 instead. This will limit confusion when, for instance, coupon number 112323 comes into the survey. Can you tell if this coupon is from seed 11 with four waves? Or is it from seed 1 with five waves?

Beyond the seed no numbers in the identification code should be larger than 3, if allowing up to three recruitment coupons. If a number beyond the first two digits is larger than 3, you can detect and correct the mistake.

Putting the code on the coupon

Because the coupon identification number is unique to each participant, it must be written directly onto the coupon or onto a label that is affixed to the coupon. Do not pre-print these numbers onto coupons or onto labels because 1) many coupons go unused which will be a waste of coupons, and 2) as the numbers become long it takes too long to find them amongst the pre-printed coupons or labels.

If using the two-part coupon design, the identification number of the recruiter will be written or affixed onto both the referral part and the payment part. The coupons will be managed in a ledger or computerized system to link the recruiter to his or her recruit.

A recruiter who goes to the survey site to collect an incentive for recruiting peers will need to present the payment coupon(s) (e.g. the bottom portion of the coupon if using the design described above) which he/she received after participating in the survey.

Each of the payment coupons will show the identification code of the recruit, not that of the recruiter. Staff are responsible for verifying the identification codes of recruiter and recruit. Staff can either:

- look for the appropriate coupon identification number in the computer or the ledger book or
- use the recruit's number to derive the recruiter's number by taking off the final digit (for example, a recruit with number 11223 was recruited by number 1122).

Figure 7.9 gives an example of how to determine the recruiter's identification number.

If a recruit has a payment coupon number of 212...



Figure 7.9 Determining the recruiter's identification number

Discussing Figure 7.9

- a. What is the primary seed's number in Figure 7.9?
- b. How many waves have occurred based on these coupon numbers?
 - 212
 - 52312
- c. Complete Table 7.1 below to show the three coupons you would give to the participant who had the unique coupon numbers given.
 - Assume that each participant will receive three recruitment coupons.
 - The first coupon has been done for you.
 - If you are not sure how to answer, explain why you are not sure.

Table 7.1 What coupon numbers will you assign?

Recruiter	Coupon 1	Coupon 2	Coupon 3
311111	3111111	3111112	3111113
122			
101102			
83332			
122532			

Note: Some of these coupons are incorrect. Try to identify which of these are not valid and explain why they are not valid.

Advantages and disadvantages

There are advantages and disadvantages to using this coupon identification method.

The advantages include:

- when no computer is available at the survey site, it is an intuitive method for managing who recruited whom
- it is useful for easily managing recruitment progress and making decisions about adding new seeds or reducing coupons
- it is easy to see to which seed a recruit belongs and the wave number of that recruit.

The disadvantages include:

- it requires very careful tracking of numbers and when numbers get long (e.g. 1112221111222) there can be errors.

Sequential coupon numbers

The sequential numbering method involves using 4-digit numbers starting from 1000 up to the number needed for the total number of coupons needed for your survey. This method allows coupons to be pre-printed. Coupon numbers are unique and sequential. Seeds may be given other coupon numbers to identify them as seeds. These numbers may be below the numbers given to participants (i.e. below 1000).

In addition to the 4-digit numbers, some surveys use letters in order to identify different populations studied or survey locations.

To manage coupons with this method, they should always be given out in order of their coupon numbers. Any break in the series of coupon numbers should be documented in a coupon tracking log and a reason for the break provided. For example, if coupons are lost or misplaced, these should not be replaced; the numbers should be made void and recorded in the log. On the other hand, if coupons are merely damaged, replacement coupons should be made with the same coupon numbers and the damaged coupons destroyed.

Advantages and disadvantages

There are advantages and disadvantages to using this coupon identification method.

The advantages include:

- numbers are easy to use with a computer coupon tracking system (RDS coupon manager), which also allows for printouts of recruitment progress
- numbers can be pre-printed onto coupons
- numbers are short (only 4 digits).

The disadvantages include:

- you cannot intuitively monitor recruitment progress
- you need to carefully manage numbering since the numbers are not intuitively linked
- it may not be as useful in settings without computerized systems in each survey site.

Identification coding using unique information

Some surveys have used identification codes comprised of several pieces of unique information known to the participant. These are not necessarily coupon identification numbers, but rather separate codes to ensure that participants are who they say they are. This is useful for when participants collect their test results and secondary incentives. The code is unique to the participant (and therefore cannot be made up by someone trying to impersonate the participant) and should be easily remembered by the participant when prompted. In addition, the code can be modified to include pieces of data specific to the country and the group being sampled. Finally, the pieces of information used to make up this code cannot be used to find a participant once he or she leaves the survey site.

One example of this type of coupon identification system is the following:

- first two letters of participant's last name
- first letter of participant's first name
- first letter of participant's mother's first name
- month participant was born (two digits)
- last two digits of participant's year of birth
- participant's gender (useful for people who inject drugs surveys where both males and females are participating)
- first letter of participant's racial/ethnic group (may not be appropriate for all settings).

In this example, if the participant's last name is Magumo, first name is Charles, mother's first name is Clara, month of birth is May, year of birth is 1984, gender is male and ethnic group is Kinbutu, this person's coupon identification would be:

MACC0584MK

Because this code is unique to each participant, it must be written directly from or into a ledger or onto a label that is affixed to forms or into a ledger.

Coupon distribution

As shown in Figure 7.10 below, it is uncommon that all three coupons will be passed to recruits. Even if the coupons are all passed out, all three recruits may not come to enrol in the survey. There are three coupon recruitment steps that occur before someone enrolls in an RDS survey: 1) coupon distribution by the recruiter; 2) coupon acceptance by a recruit; and 3) coupon redemption by the recruit.

Keep in mind that it is only necessary for one recruit to enrol in each wave of the survey to continue the progression of a recruitment chain. Once seeds are interviewed and provided with three coupons to recruit their peers, the survey may progress slowly. But as recruits start to enrol in the survey and, in turn, receive three coupons to recruit their peers, the survey should move along much faster.

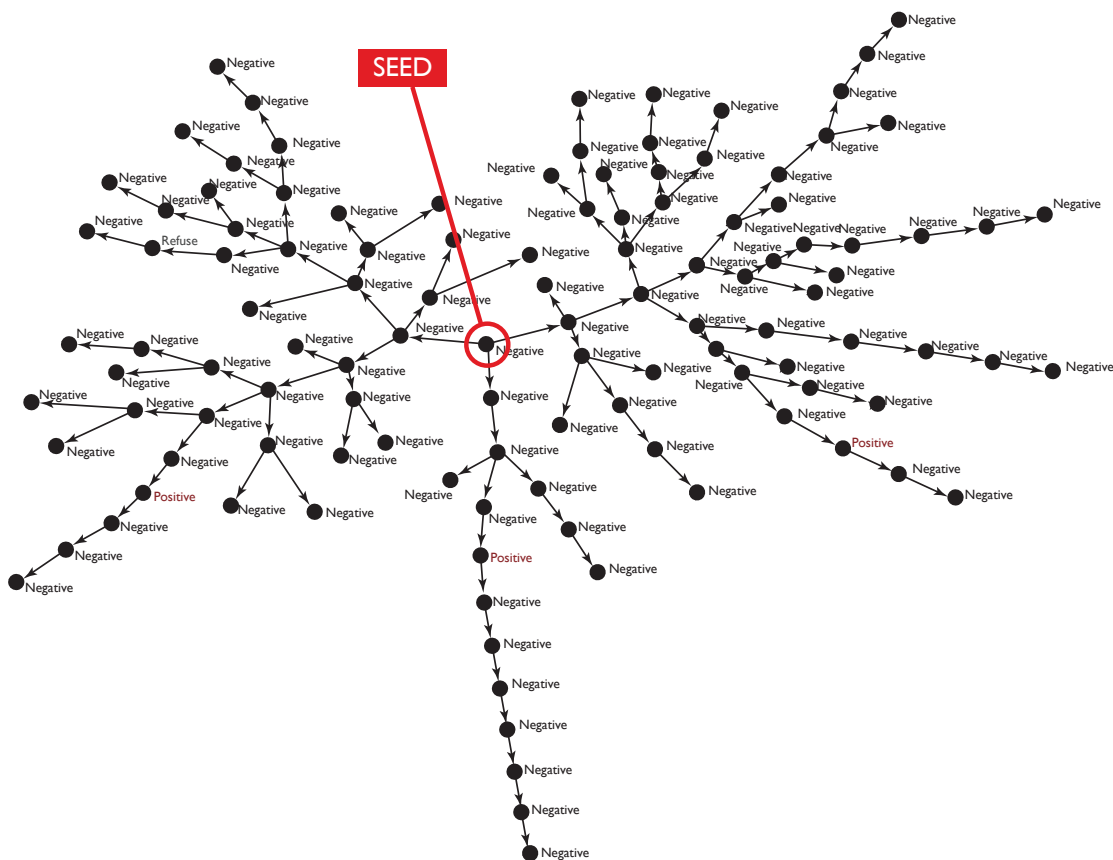


Figure 7.10 Recruitment chain from one seed with HIV status labels

Discussing Figure 7.10

- Find the participants with fewer than three recruits.
- Find the longest recruitment chain. How many waves are in the longest recruitment chain?

Coupon management

Coupon management systems

You will need to develop a tool to keep a record of the coupons collected and distributed. Coupon management is an essential part of any RDS survey. Use coupon management to:

- track who recruited whom
- ensure that incentives are paid to the correct person
- track the number of waves completed in a survey
- track which seeds are producing and when to add new seeds
- assess when to reduce the number of coupons (see Unit 13)
- assess when to end the survey by discontinuing the distribution of coupons as you approach the sample size
- analyse recruitment patterns.

A computerized RDS coupon manager can be accessed at:

<http://globalhealthsciences.ucsf.edu/prevention-public-health-group/global-strategic-information-gsi/surveillance/surveillance-resources/rdscm>

At this website, you will find the RDS Coupon Manager (RDSCM) installer, RDSCM installation and coupon manager backup tips and a guide on how to use RDSCM.

Although a computerized database is the most efficient manner in which to track coupons, not all countries have computers available for managing coupons. If an extra computer is not available for this purpose, a paper coupon management system can be used (see Unit 12). Numerous countries have successfully implemented their RDS surveys without the use of computers in the survey site. See Unit 12 for details on coupon databases.

Coupon management questions and answers

Question (Q): Who gives instructions to recruiters on how to recruit?

Answer (A): Preferably, only the coupon managers provide such instructions to recruits. In some cases, the site manager, principal investigator or other trained staff can provide instructions as well.

Q: How many coupons should be given out?

A: The site manager will receive guidance on this from the principal investigator and provide that guidance to staff. The number of coupons may change over time. Most of the time participants will be given three coupons per recruit. Later in the survey, it may be two coupons, then one coupon and near the end of the survey, zero coupons.

Q: What points shall the coupon manager discuss with the recruiter?

A: The coupon manager should follow the recruitment script provided in Annex 6.6 or some version of it. The recruiter should be informed about which people to recruit, what to tell the peers about the survey, under what conditions they would not receive a secondary incentive for recruitment and that coupons should be randomly distributed. Explanations of recruitment may vary based on the survey protocol.

Q: Which people should recruiters consider for recruiting?

A: Recruiters should only give the coupons to people with whom they have reciprocal relationships (people they know and those people know them). They can have strong (close friend, sexual partner, roommate, etc.) and weaker (acquaintance, neighbour, etc.) ties with their recruits. Recruiters should be confident that these recruits are members of their own population group.

Q: Who should recruiters not give a coupon to?

A: Recruiters should not give coupons to:

- *strangers (even if otherwise eligible) and people they know, but who do not know them*
- *people who are not members of the same population group*
- *people who do not live in the survey area*
- *people who are below the age limit set for the survey.*

Q: Can recruiters give coupons to family members, sex partners or other people they are very close to?

A: Yes, all people they know personally and who are members of the same population group can be given coupons.

Q: How should recruiters choose among the people they know? Should they give preference to certain peers?

A: Explain to them that, ideally, they should choose randomly among the people they know who are also members of the population group. Another way of “choosing” peers is to hand out the coupon on a first come first serve basis i.e. the first eligible peer they know personally and meet after receiving the coupon. In any case, do not encourage a recruitment pattern based on other factors, such as the closeness of their relationship to them, or someone who wants to test, or wants an incentive, etc.

Q: Can recruiters give more than one coupon to the same person?

A: No. If a recruit shows up at the survey office with two or more coupons, retain all coupons, use only one, and declare the other coupon(s) invalid. There also cannot be a double incentive for having two coupons. (The coupon manager should write “Void” across the face of the invalid coupon and file in the “Void” coupon file).

Q: Can a recruiter photocopy a coupon to recruit extra people?

A: No, only original coupons can be used. Photocopied coupons are invalid.

Q: What should the recruiter tell the potential future recruit?

A: The recruiter should tell his/her recruit what the survey is about and what can be expected. He/she should emphasize the benefits of taking part and how good an experience it will be, including:

- *free anonymous HIV testing*
- *testing for several other infections*
- *referral for care and treatment if they test HIV-positive*
- *referral for treatment or on the spot treatment if they have another infection*

- counselling on how to stay healthy
- a safe non-judgmental environment
- no names recorded.

Q: Should the recruiter keep a copy of the coupon or a portion of the coupon? (There are two answers below based on the survey protocol you are using)

A1: If using a two-part coupon, then the recruiter gives out one part of the coupon (“the referral coupon”) and keeps the other part of the coupon (“the receipt coupon”). The numbers on the coupons are linked to a database, if using a serial coupon identification method, or can easily be read, if using the systematic coupon identification method, to determine who recruited whom.

A2: If using a one-part coupon whereby unique serial numbers are stored in a computer system, then the answer is no, the whole coupon should be given to the peer. It will be known in the database who was given which coupon (number). If the recruiters want to note down for themselves which coupon (number) they gave to whom, they can do that.

Q: What if the recruit tells the recruiter that he or she has just tested for HIV anyway, or if they say they know that they are infected or on treatment already?

A: Prior HIV testing, regardless of the test result, has nothing to do with eligibility for this survey. All people can join as long as they meet the eligibility criteria, regardless of whether they previously were tested or not, whether they are HIV-infected or not, or already on treatment or not. The recruiter should explain to the peer that this survey is not just about HIV. By participating they can learn how to stay safe and healthy. Many surveys will also offer tests for other important diseases and provide treatment for these. If not yet under care, HIV-infected persons can be referred to health-care providers who will give them care and treatment as necessary. If they have tested negative before it may be worthwhile to test again.

Q: What should the recruiter be told about the secondary incentive?

A: Tell the recruiter that we appreciate his or her help in recruiting. To show this appreciation we will give them an incentive (tell them how much) when they return to the survey site for each eligible recruit they refer to the survey and who joins the survey. They cannot be given an incentive if:

- the coupon does not find its way back to the survey
- the coupon holder is not eligible.

By the time the recruiter returns to the survey site to collect the secondary incentive we hope to already know how many eligible recruits they have referred to the survey and will pay out the secondary incentive accordingly. For the two-part coupon, the recruiter must bring in his or her part of the coupon, the “receipt coupon”.

Q: If, at the time of the recruiter’s return visit no coupon was redeemed, can the recruiter get another chance and be given some more coupons and try again?

A: As a general rule, no. However, the recruiter should be encouraged to go back to his or her recruit(s) and try to get them to enrol in the survey.

Q: What if a coupon holder comes to the office only after the recruiter’s return visit?

A: That is fine. The recruiter will have to come back another time to get paid for this recruit.

Q: What if the coupon holder says that he or she wants to collect the recruiter's secondary incentive, perhaps to save them from having to come to the office again?

A: Only recruiters can be paid for their own recruitment.

Summary

Coupon distribution is an essential part of monitoring and encouraging recruitment in an RDS survey. Coupons are unique and specific to the country and population under study. For instance, there are different types of coupon (one-part and two-part), numbering systems and pieces of information that need to be provided in a coupon. Coupons must have an attractive but hard-to-replicate design, a unique RDS coupon number to link recruits to recruiters, the period during which they are valid, a title that is not stigmatizing and does not jeopardize the safety or identity of the coupon holder, and information on how to access or contact the survey site.

Unit 7 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions. If you are working on your own, answer the questions below.

1. What do you think would be a good design for coupons for your country? What colour and size? What kinds of information would you include?
2. What are some ways to display information for members of the survey population that may be illiterate?
3. Can you think of any additional pieces of information or design issues not provided in the samples provided in the unit that you would want to have in your coupon? What are they?
4. Draw an example of a coupon that you would consider using in your country or in an imaginary country.

Apply what you have learnt/case study

Try this case study individually or as a role play.

You are conducting research on men who have sex with men in a city in EMR/MENA. A man comes into the survey saying that he has lost the coupon given to him by someone who is a man who has sex with men. He can describe the coupon and swears that he had the coupon just a couple of days ago.

- a. Do you let him into the survey?

A participant comes into the survey to be interviewed. You ask him for his coupon and he shows you that he has ten coupons.

- b. What do you say to him?
- c. Do you let him into the survey?
- d. What do you do with his extra coupons?

Unit 8

Incentives

Overview

What this unit is about

One of the more difficult parts of implementing a survey using RDS is to determine the proper incentive level. Generally, RDS participants (including seeds) receive an incentive for completing the interview process (the primary incentive) and another incentive (the secondary incentive) for recruiting eligible peers to participate in the survey.

When considering the incentive, it is important to keep in mind that RDS is also based on another type of incentive whereby the relationship between the recruiter and the recruit creates a moderate level of peer pressure. It is expected that the recruit will be more interested in accepting a coupon and participating in the survey because he or she is being asked to do so by someone he or she knows.

Warm-up questions

1. True or false? All RDS surveys should use the same incentive level, regardless of the population under surveillance. Circle your answer below.

True

False

2. There are usually two types of incentive in an RDS survey.
 - The incentive a participant gets for enrolling in the survey and completing an interview is usually called the _____ incentive.
 - The incentive a participant gets for recruiting his or her peers into the survey is usually called the _____ incentive.
3. Which choice below is incorrect? Circle that answer.

An incentive can be in the form of:

 - a. money
 - b. gifts
 - c. vouchers for food or groceries
 - d. telephone cards
 - e. illegal drugs.
4. What is a problem that can occur if your primary incentive is too high?

Introduction

What you will learn

This unit provides information to assist you in selecting the correct incentive for an RDS survey.

By the end of this unit, you should be able to:

- describe the types of incentive used in RDS surveys and when they are distributed
- describe guidelines for determining an incentive for your survey
- give examples of different kinds of incentive.

Use of incentives in RDS surveys

Types of incentive

Incentives for RDS are best looked at as a remuneration that shows respect for participants' time and effort in recruitment and their judgment to use remuneration for personal needs [30].

In RDS surveys, an incentive is a token of appreciation for:

- taking an hour of someone's time to complete the interview (some interviews can take up to one hour)
- recruiting their peers.

Although money has been the type of incentive most often used in past RDS surveys, other forms of incentive may be used. In place of money, you may decide to use:

- food vouchers
- gifts (e.g. make up, accessories)
- T-shirts
- school supplies
- telephone cards.

Some researchers believe that incentives are unethical and that they interfere with the participation rates for those surveys that cannot afford an incentive.

Lessons learnt

In a systematic review of a 107 RDS surveys that reported using primary incentives, the majority of surveys (89, 83%) used cash incentives, 11 (10%) gave cash equivalents (e.g. food stamps, grocery vouchers) or small goods with minimal monetary value and 3 (3%) gave condoms and lubricants; 4 (4%) claimed that they did not offer any primary incentive [5].

Seventy-two of the reviewed surveys reported using secondary incentives. Among these, 58 surveys (74%) reported using cash incentives.

In addition to incentives, surveys offered a wide range of additional services, such as free HIV testing and counselling, referral for clinical follow-up, and condoms, lubricants, information and educational materials.

Incentives based on pre-existing relationships

Discussion about the level of the incentive often forgets a key component of RDS methodology: that recruitment is based on a pre-existing relationship between the recruiter and the recruit.

It is therefore important to keep in mind that RDS also involves another type of incentive: the relationship between the recruiter and the recruit that creates a moderate level of peer pressure. It is expected that the recruit will be more interested in accepting a coupon and participating in the survey because he or she is being asked to do so by someone he or she knows. In the end, whether someone redeems a coupon to enrol and thereby receive the primary incentive is a matter of individual choice.

However, the addition of the secondary incentive encourages “group mediation” whereby a recruit’s failure to redeem a coupon results in the recruiter’s failure to receive a secondary incentive [31]. The resulting moderate form of peer pressure (and non-material rewards such as peer approval [4]) is designed to:

- encourage recruits to participate for reasons other than the primary incentive
- encourage the recruitment of peers that are eligible and are more likely to redeem their coupon
- reduce non-response by recruits.

Why people participate

There are several reasons why people participate in surveys. The most obvious reason is to obtain the incentive. However, evidence has shown that this is not always the case. Many RDS surveys incorporate a question in the questionnaire which assesses why someone accepted a coupon and decided to enrol in the survey (this is also discussed in Unit 9). An example of this question is shown in Table 8.1.

Table 8.1 Question about why someone accepted a coupon and decided to enrol in the survey

<p>What is the main reason that you accepted a coupon and enrolled in this survey?</p> <p><i>Do not read out answers, circle one answer</i></p>	<ol style="list-style-type: none"> 1. For the incentive 2. For HIV test results 3. For hepatitis B test results 4. For hepatitis C test results 5. For syphilis test results 6. For all test results 7. Recommendation from person who gave coupon 8. The survey seemed interesting/useful 9. I have free time 10. Someone forced me 97. Other: Specify _____
--	--

This question was incorporated into a survey of drug users (DU), female sex workers (FSW) and men who have sex with men (MSM) in the Dominican Republic in 2008. Figure 8.1 displays the participants' responses to this question. As you will note, the majority of the participants in each group responded that the main reason they accepted a coupon and enrolled in the survey was to receive their HIV test results: 10% of drug users, 3% of female sex workers and 5% of men who have sex with men responded that the main reason was to receive the incentive.

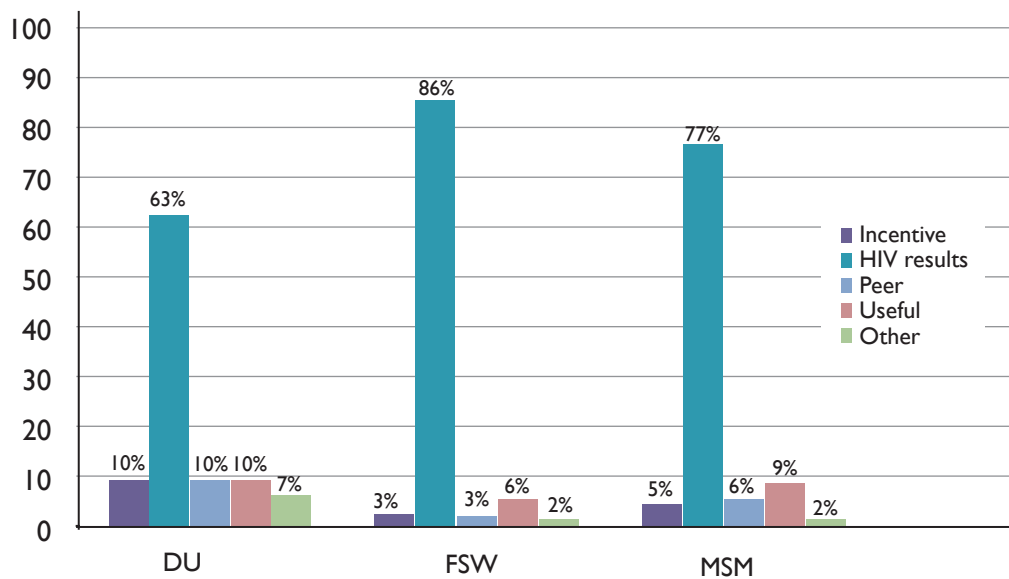


Figure 8.1 Drug user, female sex worker and men who have sex with men responses to the question “What is the main reason why you accepted a coupon and enrolled in this survey?”

Source: Johnston LG, Giles K. *Respondent behavior in respondent driven sampling using data collected from the Dominican Republic, 2008*. Paper presented at the Centers for Disease Control and Prevention Respondent Driven Sampling Workshop for the Dominican Republic and Latin America, October 2009.

Incentive amounts

Avoiding extreme incentives

Incentive amounts vary depending on a number of factors, including:

- survey budget
- standard of living in the survey country
- governmental policies (some countries do not allow monetary incentives; others have a pre-established cap on the amount of incentive that can be given to participants in a survey)
- population of interest
- institutional review board (IRB) issues (restrictions by an ethics committee).

Incentives should not be so low that important segments of the population will not participate. On the other hand, an incentive should not be so high that it increases the

chance that someone will sell or barter their coupons. In addition, high incentives will probably increase the chances that persons who are not members of the survey population pretend to be members of that population.

Determining the correct incentive amount

To determine the incentive amount appropriate for a survey population and location, conduct formative assessment (see Unit 2) with a variety of sources who work closely with these populations, including:

- members of the survey population
- outreach workers
- nongovernmental organizations with ties to the survey population
- governmental staff.

Figure 8.2 illustrates a hypothetical amount of money needed to reach a certain proportion of the population of interest. Imagine that an incentive of US\$ 5 attracts only 50% of the population you are trying to reach.

- If the incentive is US\$ 5, this amount would attract street-based sex workers (one of the lower paid type of sex worker) but would not attract many of the higher paid types of sex worker.
- If the incentive is increased to US\$ 10, a survey would attract more types of sex worker, but would not attract all of the types of sex worker in the survey population.
- However, with an incentive of US\$ 15, a survey attracts all types of sex worker, including the more hidden and higher paid sex workers such as call girls.
- If the incentive is US\$ 20, a survey could end up attracting females who are not sex workers but who would be willing to pretend to be sex workers in order to collect the incentive.

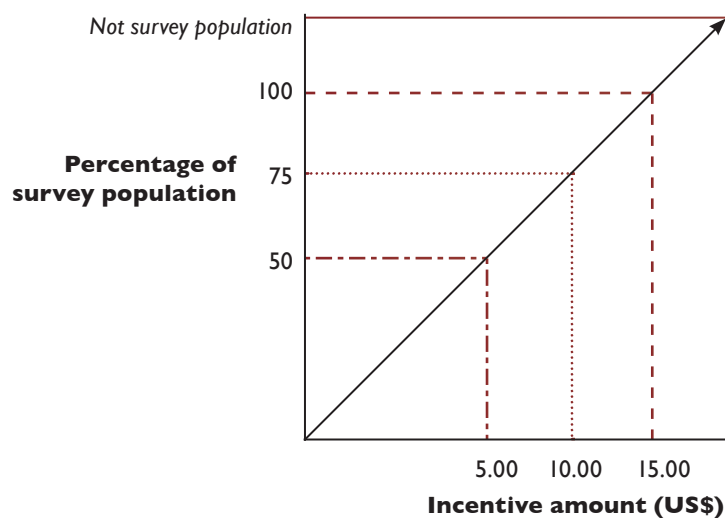


Figure 8.2 Determining incentive amount

Discussing Figure 8.2

Answer the following questions based on your experience and the information in Figure 8.2.

- a. How would you determine the appropriate incentive amount if you were surveying sex workers in your area?
- b. How would you find information about what an appropriate incentive would be?
- c. What would you do if you started your survey and within a couple of weeks found out your incentive was too high for your survey population? What would be some indications that an incentive amount is too high for your survey population?

Lessons learnt

In several surveys, the incentive selected was too high. For instance in a survey of people who inject drugs in East Africa, the incentive level was based on past surveys that used an incentive to get participants to talk to interviewers. Although the previous survey of people who inject drugs used a peer referral system, it involved researchers contacting referred peers and setting up a time for the researcher to meet with them. This survey did not provide an incentive for recruiters who referred their peers.

Although the incentive for the RDS survey was based on the same incentive as the previous survey, it was obvious to the RDS technical advisors that the incentive was too high. Once the survey started, several factors indicated this: persons who did not inject drugs were willing to pretend that they injected drugs just to receive the incentive; people who inject drugs quickly learned that they could sell coupons to others and make a small profit; and a small group of people who inject drugs started pressuring participants with recruitment coupons to give up their coupons for a small fee so that they could give them to peers who would share part of the primary incentive once the coupons had been redeemed.

Once these activities were discovered, the incentive was decreased by half. Although this seemed to mitigate several of the problems mentioned above, several biases were probably already introduced into the sample by the time the incentive was reduced.

Splitting incentives

Surveys that have two parts, such as a behavioural survey component and a biological component, may choose to split the incentive so that participants receive a portion of the incentive if they complete the survey and another portion if they complete the biological component.

The decision to split the incentive comes about when surveys have an “opt out” for biological testing. This means that those who do not want to do the biological testing can still enrol in the survey by only completing the behavioural questionnaire. In this situation, some surveys have given the entire incentive regardless of whether someone completes both the questionnaire and the biological testing, while other surveys have

given one part of the incentive for those completing the questionnaire and the other part for those providing a biological specimen.

One disadvantage with the former option is that future participants may quickly learn that they can get the same amount of incentive by only completing one part of the survey, thereby spending less time at the survey site in return for the same money. Another disadvantage is that the survey might end up with a lot of missing data for test results, which is not a very good outcome for a survey to measure HIV prevalence.

A disadvantage with the latter option is that some ethical committees may perceive that participants are being “paid” for providing a biological specimen. One way to avoid this situation is to define the survey as the successful completion of both behavioural and biological components of the survey. Those who want to only do the behavioural and not the biological components of the survey are not enrolled and do not receive any incentive.

Monetary incentives used in past surveys

Past RDS surveys have determined the appropriate incentive level based on the local costs of items such as:

- the price of a moderate dinner
- the price of one week’s worth of groceries
- the cost of public transportation for one week
- the costs associated with travelling from one side of the city to the other side of the city.

In past surveys, secondary incentives have usually been worth less than primary incentives [5]. However, recruiters may receive the secondary incentive up to as many times as the number of coupons given out in the survey, so the total of the secondary incentives may end up being worth more than the primary incentive.

Incentives for sex workers are especially difficult to determine since this population is being recruited in relation to the type of paid work they do. Therefore, many sex workers expect to be reimbursed for their participation in the survey equal to the time they would have spent with a client. In many cases, this would be prohibitively costly for a research project. RDS researchers should consider other non-monetary types of incentive (perhaps in addition to money) for sex workers.

Some populations may be more interested in receiving an HIV/STI test and results, having a medical examination, receiving treatment for an STI and other health benefits than in receiving a monetary incentive. This is especially true among sex workers and men who have sex with men.

It may be worthwhile to consider whether a reasonable reimbursement for travel costs should be all or part of an incentive.

A list of incentive amounts and types are displayed in tables in Malekinejad M et al (2008) [5], a review of 107 RDS surveys that reported their incentive amounts and types conducted outside of the United States.

Claiming an incentive

Primary incentive claim

There are several steps involved for a participant to claim an incentive. In order for a participant to claim the primary incentive, he or she must:

- have a coupon (except for the seeds)
- fulfil the survey eligibility criteria
- provide informed consent
- complete the interview process
- when required, provide a biological specimen for HIV testing.

The coupon manager (or some other staff member) can provide a receipt to each participant who receives an incentive. The steps involved in collecting the primary incentive are thoroughly discussed in Unit 10.

Secondary incentive claim

A participant may receive an incentive for each individual (usually no more than three) he or she recruits that fulfils the eligibility criteria, the survey requirements and in some cases has successfully completed the survey procedures.

A participant who has distributed a coupon to his or her peers may travel to the survey site expecting to collect a secondary incentive only to find that the persons he or she recruited have not yet participated in the survey. In this case, ask the recruiter to find their recruits and encourage them to enter the survey.

Claiming a secondary incentive usually requires an extra visit back (in addition to the visit during which the participant completed the interview process) to the survey site or some other location where the secondary incentive is claimed.

Separate times for secondary incentives

When recruiters come to collect a secondary incentive during enrolment hours, staff may become overwhelmed having to respond to enrolees and recruiters at the same time. It is suggested that separate days and/or hours be set aside just to accommodate secondary incentives.

Follow-up questionnaire

When a participant comes back to claim a secondary incentive it is now customary to ask some questions about the recruitment process. A useful question is whether a recruiter tried to recruit someone who refused to accept a coupon and the main reason why that person refused to accept a coupon. This is an excellent way to explore the reasons why some people are not participating in a survey. This is discussed in more detail in Unit 9.

Managing incentive distribution

When you use monetary incentives, large amounts of cash will be stored in a secure location and be accessible to specified RDS survey staff members.

A coupon manager (or some other staff member) should be responsible for the management and distribution of incentives. Each survey site should have a receipt system to account for the distribution of incentives. Having a receipt system does not mean personal identifiers, such as signatures, need to be collected.

Depending on the survey site's computer access, incentives can be monitored in a computerized database or by using paper incentive tracking forms. Tracking incentives using pen and paper systems are described in Unit 12.

It is very important to ensure that the distribution of an incentive (primary and secondary) is linked to the coupon number of the participant who receives the incentive.

Summary

Standard RDS surveys provide two incentives: the primary incentive for enrolling in and completing the survey process and the secondary incentive for successfully recruiting peers into the survey. Incentives can be cash, gifts or useful items or services. Determining the appropriate incentive type and amount can be challenging. An incentive that is too high may encourage non-members to masquerade as target population members in order to receive the incentive, whereas an incentive that is too low may not attract participants to the survey. The formative assessment can provide helpful information on appropriate types and amounts of incentive.

Unit 8 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. What are some types of non-monetary primary incentive that you would consider using for an RDS survey in your country?
2. Would you use the same type of incentive for men who have sex with men as you would use for sex workers or people who inject drugs?
3. Do you think a secondary incentive is necessary to conduct an RDS survey?
4. Why does RDS have a secondary incentive?

5. What level of secondary incentive, in comparison to primary incentives, would you think are appropriate for men who have sex with men, sex worker and/or injecting drug user populations in your country?
6. Would you allow recruiters to bring in and wait for their recruits to complete the interview process so that they could receive their secondary incentive?
7. What are some of the disadvantages to managing the distribution of secondary incentives in this way?
8. What are some of the advantages?

Apply what you have learnt/case studies

Get into small groups to discuss this case study.

1. In a survey conducted in North Africa, some men who have sex with men showed up at the survey site with payment coupons (the part of the coupon that is linked to someone they recruited) for recruits they did not recruit. When queried, these men claimed that the persons who actually recruited peers for whom they were collecting the secondary incentive were too busy to come to the survey site. They stated that they were there to collect the secondary incentive on behalf of the actual recruiters.
 - a. What would you do in this situation? Would you give these people the secondary incentive?
 - b. Why is this situation a potential problem?

Your supervisor expects everyone who returns to the survey site with recruitment coupons to complete a follow-up questionnaire about the people the recruiter tried to recruit but who refused to accept a coupon.

- c. What would you do in this situation if someone besides the actual recruiter came to the survey site to collect the incentive?

Try this case study individually.

2. In one country in EMR/MENA, RDS was used to sample men who have sex with men for an integrated biological-behavioural surveillance survey.
 - Participants in the capital city could receive a maximum of US\$ 15.50 through a dual incentive system and reimbursement for transport as shown in Table 8.2.
 - To put this into perspective, a transgender male sex worker in the capital city typically earns less than US\$ 1 for one act of anal sex.

Table 8.2 Survey incentives

Incentive	Capital city (US\$)	Two towns (outside the capital) (US\$)
Participation	3.00	2.00
Per recruit (maximum three recruits)	3.00 (each recruit)	2.00 (each recruit)
Fees for transport to clinic and VCT	3.50	2.50
Total possible	15.50	10.50

The survey site, a nongovernmental organization-run men's health clinic, was immediately overwhelmed by the response.

- The nongovernmental organization had selected 10 low socioeconomic status seeds. Each seed was asked to refer up to three recruits.
- The potential to earn US\$ 15.50 drew 60 men on day two. Some had received referral coupons, others had not.
- At 08:00 on day three, 100 men were waiting to be enrolled in the survey. Clinic hours were 09:00 to 17:00.

The clinic environment was chaotic with a mix of participants, non-participants and those trying to claim their incentive. The survey team was unable to control participant flow and the environment became disruptive.

To ensure receipt of the recruitment incentive, some men who have sex with men referred men they did not know but who were loitering in the clinic or outside. Almost 30% of recruits reported not knowing their recruiter.

Long waiting periods encouraged some men to leave the site and recruit substitutes to answer the questionnaire for them (breaking the biological and behavioural data link).

Some men who have sex with men visiting the capital city from the provinces pretended to be residents so they could be eligible to participate.

A systematic pattern of referral was noticed after the first week:

- Either 0 or 3 coupons were received, not 1 or 2.
- Some recruits arrived with a large number of coupons.
- One participant tried to redeem 25 coupons and became hostile and aggressive when his request was rejected.

Men who have sex with men of higher socioeconomic status apparently were either not recruited or chose not to participate.

This case study illustrates some of the problems that may occur when large incentives are offered. Consider and respond to the following questions:

- a. Why do you think higher socioeconomic status men who have sex with men did not take part in the survey?
- b. How would you get higher socioeconomic status men who have sex with men to take part in the survey?

- c. What are some of the most obvious problems with this survey?
- d. How do you obtain a representative sample of the survey population and not a sample biased by those in most need or desire for the incentive?
- e. How do you motivate members of the survey population to participate while offering only a small incentive to compensate them for their time?
- f. Would RDS work better in this population if a non-monetary incentive were offered?

Unit 9

Specific questions
for RDS surveys

Overview

What this unit is about

It is essential to add a question to measure the size of each participant's social network. This measurement is known as "degree". In addition to this question, there are many other specific RDS questions that are currently being used in surveys around the world. These questions are useful for evaluating the strength of peer relationships and the survey recruitment process and acceptability.

Warm-up questions

1. What is the most important type of question to be asked of RDS participants for the purposes of analysing RDS data?
2. True or false? One of the advantages of RDS is that only a few extra questions need to be added to the survey's main questionnaire. Circle your answer below.

True

False

3. Which of the following pieces of information are we interested in obtaining from participants about other members of their population (circle all that apply)?
 - a. the names of at least three close friends
 - b. how many of their peers have HIV
 - c. the number of members of the survey population a participant knows personally
 - d. how many members of the survey population a participant has seen during a given period of time

4. Recruiters should distribute coupons to someone in their network. Therefore, recruiters should not distribute a coupon to a _____.

5. True or false? A good time to ask participants about why someone did not accept a coupon is when he/she returns to the survey site to collect a secondary incentive. Circle your answer below.

True

False

Introduction

What you will learn

This unit provides the structure and probing techniques for the questions required to measure each participant's social network. The unit also provides examples of questions that are useful for evaluating the RDS sample, the relationships between recruits and recruiters, and why people do and do not participate in the survey. These questions can be incorporated into the existing survey instrument or used as a separate instrument.

By the end of this unit, you should be able to:

- understand why the questions on social network size are important for RDS
- develop the social network size questions for an RDS survey
- describe why questions about the recruiter are important
- develop questions to assess why people do and do not participate in the survey.

Social network size questions

Introduction

For the purposes of an RDS survey, questions on each participant's social network size (or degree) are essential for data analysis. A participant's social network size sets up the probability of someone being selected into the survey and should be estimated as accurately as possible by including **all** of the criteria used in eligibility. Only those members of a participant's social network who meet the criteria should be recruited into the survey, as analysis is based on each of them having an equal probability of being included in the survey.

We want to know:

- how many survey population members the participants know personally who have engaged in the same behaviour being studied as used in the eligibility criteria
- if the recruiter has seen the people they know in the past week to six months (more about how to decide how long is discussed below)
- if they are in the same age group as used in the eligibility criteria
- if they live, work or socialize in the geographical boundary of the survey as used in the eligibility criteria.

When we ask social network size questions, the respondents are only requested to provide a number without any information on network characteristics or names. Surveys on the accuracy of participants' reporting of social network sizes have found high reliability for recall over short time periods with appropriate probes [32].

Variations on this question

Sometimes additional questions are asked about a participant's social network size in order to conduct further analysis to look at population characteristics or to test certain RDS assumptions (e.g. random recruitment). For instance:

- people who inject drugs could be asked how many females they know who inject drugs, men who have sex with men could be asked how many bisexuals they know or sex workers could be asked how many telephone-based sex workers they know
- participants could be asked how many people they know who are not eligible, such as the number of people they know who are below the age of the survey eligibility
- participants could be asked how many people they know who are of a certain ethnicity or from a particular tribe.

What does it mean to “know” someone?

There are many definitions of what it is to “know” someone. Basically, to know someone means that you recognize the person, know a name by which to address them and would greet them if you saw them on the street and that this relationship is reciprocal [33, 34, 35].

Having a reciprocal relationship is essential and ensures that they are not people that you know but who do not know you (for instance, you might know a celebrity or a world leader but they do not know you) or are people known through other people but whom you have never met personally (such as a friend of a friend).

There can be weak and strong ties in knowing someone. For instance, weak ties can be acquaintances or co-workers. Strong ties may include family members, sexual partners or those with whom you have friendships.

It is important that “knowing” someone is understood in the same way by everyone and that language and cultural contexts be considered. For instance, in countries where the social network size question must be translated from English to another language, it is important that the correct terminology for “knowing” someone is used.

Lessons learnt

When conducting formative assessment to estimate the social network size of people who inject drugs in an Arabic-speaking country in North Africa, the interviewer (an English-speaker) was asking the translator (an Arabic-speaker) to ask focus group participants how many people they know, who also knew them, that injected drugs in the previous three months and whom they had seen in the past two weeks. Based on previous knowledge about the injecting drug user population in this city, the interviewer found the social network sizes to be very small (2–5 persons).

With further probing the interviewer discovered that the word being used for “knowing” someone was understood as knowing the persons phone number and home address, therefore signifying only strong ties. After further discussion and a better explanation that “knowing” someone should include strong and weak ties, a more appropriate word in Arabic was found and subsequently used in the final questionnaire to measure social network sizes.

The social network size question can be used as a basis from which to ask other questions, such as:

How many of those people you mentioned as part of your network would you consider inviting to this survey? (The answer to this question could be more accurate than the response to the original social network question.)

Researchers are also discussing whether the original social network question accurately measures someone who is a member of that participant's network.

- Should someone's social network comprise only those people they know by name or can they include acquaintances or those known by sight?
- In addition to the original social network question, you may want to ask for the number of people in the participant's network who:
 - they trust
 - they discuss important issues with
 - they spend social time with.

Appropriate time frame for the social network question

In earlier RDS surveys, participants were asked to estimate the social network sizes of survey population members whom they had seen in the previous six months. Experience has now shown that it is better to select a shorter time period to maximize the potential that survey participants report accurate current network sizes.

The recommendation is to use short, rather than long, time periods. With short time periods, participants are more likely to remember how many network members they have seen. For instance, some surveys will want to use the time reference of the "past two weeks" or "past one month", rather than the "past six months". As long as the same time frame is used consistently in the same survey, the network sizes will be appropriate for RDS analysis.

To increase the chance that the time period used for your network questions is appropriate, conduct formative assessment with members of your survey population (see Unit 2).

You want to determine participants' estimated network size based on whom they have seen during a particular time period (such as the previous week, previous two weeks or previous month). One suggestion is to use a period of time in order to obtain network sizes of between 3 and 25. However, for the purposes of analysing RDS data, a network size as large as 250 or more is valid, as long as the same time reference to measure each participant's social network size is used systematically throughout the survey. Table 9.1 shows an example of how to structure the social network size question.

Getting accurate responses to the social network question

Introduction

Because the network size question is open-ended and often difficult to answer, there are several suggestions for how to obtain the most accurate response. These include:

- training interviewers well

- always asking this question face-to-face
- using systematic probing
- breaking the question into several sub-questions
- ensuring that the question cannot be skipped in the survey.

Training interviewers well

Properly asking the social network size question requires adequate training. All interviewers for the social network size question should understand the following:

- the importance of the social network size question to the overall success of the survey
- that without the proper measurement of each participant's social network the analysis cannot be correctly completed.

Training should involve practicing the network size question through role play techniques involving actual survey population members or persons pretending to be survey population members. Trainers should ensure that every person who will be responsible for asking the social network size question be evaluated for their ability to elicit responses that are as accurate as possible.

Asking the question face-to-face

Even though some surveys use computerized surveys, the social network question must be asked in a face-to-face format. Only an actual person can identify facial expressions and body language to see if someone is providing enough thought to properly respond to the question. Furthermore, when someone has trouble responding to this question, an actual person can assist in eliciting a response through probing.

Probing

Using systematic probes is helpful (and sometimes necessary) to get the most accurate response. Interviewers should be adequately trained to use probes without introducing bias by steering the participant towards a particular response.

As often occurs, when someone is asked the network size question, such as “How many people of a certain type do you know, they know you, you have you seen them in the past month, they are 18 years or older, and they also live in your city?” The initial response may either be “I do not know” or someone may give you a very quick response that will most likely be inaccurate.

Interviewers should be thoroughly trained on how to elicit accurate responses from participants when asking this question. The participant will need to think before he or she can answer accurately. Often the participant will look away and appear as if they are counting in their heads. If someone responds “I do not know” to this question or with a response that has not involved an adequate amount of thought, then it is best to probe to get a best guess.

One way to start the probe is to say “What is your best guess?” The next thing you might want to offer is a piece of paper and a pencil that the participant can use in adding up the number of peers he or she has. If this does not work, then you could suggest a number

such as “20”. The participant can be prompted to stop and think and they can respond, “20 is too high (or too low)” or “I don’t think the correct number is 20”. You can then ask, “Is the number closer to 15?” The participant can respond “yes” or “no”. You can go from there until you get a number that the participant deems most accurate.

Breaking up the question

Most surveys now break the social network size question into several parts. For instance, in Table 9.1, there are four separate questions to establish the social network sizes of people who inject drugs. The first question is the broadest question. The response to this question need not be accurate but allows the participant to start thinking about how many people he or she knows. The next question asks how many of those in the previous question they have seen in the past one month. This allows the participant to start to narrow down the number of persons in their social network. The difference between the first question and the second question is usually the largest. The third question is usually close to or the same as the question directly above. The final question asks how many of them are in the same area as the survey. This is the final network size question and should be as accurate as possible as it will be used in the analysis of data.

Table 9.1 Social network size question in several parts

How many people do you know (you know their name and they know yours) who have injected drugs in the past six months? <i>(Participants must provide a response—it cannot be zero)</i>	Number _____
How many of them have you seen in the past one month? <i>(Participants must provide a response—it cannot be zero)</i>	Number _____ <i>(Must not be larger than number above)</i>
How many of them are 15 years and older? <i>(Participants must provide a response—it cannot be zero)</i>	Number _____ <i>(Must not be larger than number above)</i>
How many of them live/work in survey area? <i>(Participants must provide a response—it cannot be zero)</i>	Number _____ <i>(Must not be larger than number above)</i>

Note: It is impossible for someone to have a network size of zero since every participant should know at least one peer (i.e. the person from whom they received a coupon). Even though a seed did not receive a coupon from a peer, seeds should not have a network size of zero since they are selected by the research team.

Also note that in the second, third and fourth questions, the response cannot be larger than the previous response.

Lessons learnt

In several surveys, it was not noticed until all of the data had been collected that the interviewers did not understand the purpose of the social network size question and, as a result, did not ask it properly. An example of one response is in Table 9.2.

Table 9.2 Example of responses to the social network size question

How many people do you know (you know their name and they know yours) who have exchanged sex for money in the past six months?	Number <u>30</u>
How many of them have you seen in the past one month?	Number <u>15</u>
How many of them are 18 years and older and live/work in city Z?	Number <u>19</u>

1. Do you see anything wrong with these responses? What is wrong? Why is it wrong?
2. What are possible reasons why this (and other) responses are like this?
3. What would you do in this situation (remember, all your data are collected and you are ready to analyse it)?

Reasons why people participate

Many surveys now include a question in the questionnaire or as part of the eligibility criteria asking participants the main reason why they accepted a coupon and enrolled in the survey. The question is often asked in the manner shown in Table 9.3, but there may be other ways of asking this question and more types of responses warranted.

Table 9.3 Question about why someone accepted a coupon and decided to enrol in the survey

What is the main reason why you accepted a coupon and enrolled in this survey?	1. For the incentive
<i>Do not read out answers, circle one answer</i>	2. For HIV test results
	3. For the clinical exam
	4. Recommendation from person who gave coupon
	5. The survey seemed interesting/useful
	6. I have free time
	7. Someone forced me
	97. Other: Specify _____

Although it is logical to think that most people enrol in the survey to receive the incentive, this is not always the case. In a survey of men who have sex with men conducted in Dhaka, Bangladesh, in 2006, the main reason most frequently cited by participants for accepting a coupon ($n = 523$, seeds not asked) included “for clinical consultation and blood test” ($n = 334$, 57.9%) [36]. This was followed by “for receiving money (transport costs)” ($n = 102$, 28.5%), “to respect friends request” ($n = 34$, 7.0%), “interesting and useful survey” ($n = 52$, 6.2%), and “to while away my time” ($n = 1$, 0.1%). Similar responses have been found in numerous other surveys that have asked this question.

Questions about recruiters

Introduction

Other questions useful in RDS surveys describe the type of relationship the participant has with his or her recruiter. Questions about the participant's recruiter could be incorporated into the existing behavioural questionnaire.

The need to recruit randomly

RDS assumes that, on average, recruiters recruit their peers randomly. This does not mean that recruiters should randomly pick a number, such as the number three, from a hat and then distribute a coupon to every third peer until he/she has passed out all three coupons. When a survey participant is given a coupon and asked to recruit one of his/her peers, the coupon should be distributed to someone chosen in a non-preferential manner from his/her personal network.

Specifically, the interviewer informs a recruiter not to distribute all their coupons to their closest friends, family members or to the first people they see after leaving the RDS survey interview. Nor should recruiters recruit strangers since recruits should be someone from the recruiter's personal social network (the recruiter knows the recruit and vice-versa).

Sample questions about recruiters

Several useful questions can be added to the existing behavioural questionnaire to assess random recruitment. These questions include:

- How would you best describe your relationship with the person who referred you to this survey (the person who gave you this coupon)?
- How close are you to your recruiter?
- How often do you see your recruiter?
- About how long have you known your recruiter?
- Does your recruiter live in the same neighbourhood as you?

Experience with this type of question

The responses to these questions are important for understanding your sample and whether recruitment occurred in a non-preferential manner. For instance:

- If most of your final sample is comprised of those who classified their recruiters as "strangers", then it indicates that recruiters did not recruit people who were part of their social network.
- If your entire final sample is comprised of recruits who classified their recruiters as "best friends", then it indicates that recruiters did not recruit in a non-preferential manner from their social network.
- If your entire final sample is comprised of recruits who classified their recruiters as "sex partners", then the interpretation of the final data may be that the survey is about a sexual network and not a general network of the population.

So far, analysis of these questions in RDS surveys have shown that very few recruits were either strangers or very close (i.e. family member or best friends) to their recruiters. No more than 3% of your sample should know their recruiter as a stranger. On average, recruit–recruiter relationships were varied.

Table 9.4 shows the type of question you might want to ask about recruiters and the response you might receive. Unlike the social network size questions, questions about the participant’s recruiter are not essential for analysis. However, these questions can help determine if the assumptions related to RDS methodology have been met.

Table 9.4 Recruiter questions and desired responses

Recruiter question	Possible response
<p>1. How would you best describe your relationship to the person who referred you to this survey, that is, the person who gave you this coupon? <i>(Do not read the responses to the participant.)</i></p>	<p>Could include:</p> <ul style="list-style-type: none"> ● A stranger, someone they met for the first time ● Someone they know, but not closely ● A close friend, someone they know very well ● A sexual partner ● A family member or relation <p>and, depending on survey population:</p> <ul style="list-style-type: none"> ● A dealer ● A pimp/gatekeeper
<p>2. How close are you to your recruiter?</p>	<p>Could include:</p> <ul style="list-style-type: none"> ● Very close ● Somewhat close ● Not very close
<p>3. How often do you see your recruiter?</p>	<p>Could include:</p> <ul style="list-style-type: none"> ● Every day ● Once a week ● Once a month ● Less than once a month
<p>4. About how long have you known your recruiter? Options may be:</p> <ul style="list-style-type: none"> ● open-ended <i>(for example, six months, three years and so forth)</i> or ● closed-ended <i>(for example, less than six months, more than six months but less than one year, one to two years, more than two years)</i> 	<p>Open-ended responses</p>

Questions about recruitment

Coupon rejecters

The final type of question that can be used in RDS surveys are those that ask recruiters about their relationship with, and perceptions of, people who refused a coupon (“coupon rejecters”).

One of the opportunities that RDS offers is that participants return to the survey site to collect a secondary incentive for recruiting their peers. This is an excellent time to ask them about those who rejected a coupon to assess some level of non-response. Bear in mind that this will not be an accurate indication of non-response since some participants never return to the survey site to retrieve their secondary incentive. Unlike the network size question, these questions are optional, but highly recommended.

Why people do not accept a coupon

RDS methodology anticipates that non-response bias is low relative to other methods used to sample hard-to-reach populations because peers are recruiting peers [4]. In comparison to other sampling methods, RDS peer recruitment is more likely to encourage participation because it uses a mixture of motivators. Peers are motivated to participate through:

- the promise of a modest incentive for completing the interview
- social influence or mild peer pressure from the recruiter (who will receive a secondary incentive for recruiting his or her peers)

Table 9.5 Questions to measure RDS non-response

Recruiter question	Desired/expected response
1. What was the main reason given by those to whom you tried to give a coupon but refused to accept a coupon?	Responses could include: <ul style="list-style-type: none"> ● too busy ● already had a coupon
2. What was the main reason given for refusing to accept a coupon?	<ul style="list-style-type: none"> ● already participated in the survey ● not a sex worker (or injecting drug user, or man who has sex with men) ● younger than 18 years (or other age cut off) ● did not sell sex/inject drugs in past month ● fear of being identified as sex worker/injecting drug user/man who has sex with men ● site is too far away ● not interested ● afraid of the HIV test ● afraid of the HIV test results ● incentive is not worth the time.

- a personal benefit of getting tested and test results
- some sense of civic duty.

To find out why people do not accept a coupon from a peer, researchers must actively seek information about members of the population who were offered, but refused, a coupon. Table 9.5 provides some possible questions and responses (an example of a questionnaire that asks follow-up questions about recruitment is found in Annex 6.10).

This question helps researchers to measure differences between those who responded and those who did not.

For instance, if it is found that numerous people who inject drugs did not accept a coupon because the survey site was too far away, then this should be corrected for the next survey.

If many people are not accepting coupons because they have already participated in the survey, then this may be an indication that you are saturating the population.

Summary

All RDS surveys must include the personal social network size question which is based on the eligibility criteria components describing the sample population. Given that the network size question is open ended and comprises many parts, it is recommended that it be asked face-to-face and as a sequence of questions. Interviewers should be trained to assess accuracy in responses to this question by observing participant's facial expressions and body language and the speed at which they answer. In addition, there are other questions to ask in order to verify that the survey and the sample meet the functional and analytical assumptions of RDS. Recommended questions assess reciprocity and closeness of recruitment relationships, the legitimacy of coupon receipt, and motivations for participating or refusing to participate in the survey. These questions can be added to the existing or follow-up questionnaires or to the screening form.

Unit 9 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. What are some reasons for wanting to assess non-response in RDS surveys?
2. Write three questions you could use to assess why someone refused to accept a coupon. What factors would you consider when determining the strengths and limitations of each of the questions you created to measure non-response?
3. Develop three questions you could use to determine the network size of each

participant in a survey of men who have sex with men that uses RDS methods for recruitment. What factors would you consider when determining the strengths and limitations of each of the questions you created to measure network size?

4. (For ACASI users) In one survey of people who inject drugs, eligibility criteria included injection of illicit drugs in the past six months. Within the survey instrument, administered by ACASI, the lead drug use question asks if the participant injected drugs in the past 30 days. All drug injecting questions followed this question. However, if the answer to the lead question was “I did not inject in the past 30 days”, the entire module was skipped. When data analysis began, it was discovered that 30% of the respondents were missing all responses to injecting behaviour questions because they reported no injecting in the past 30 days. What steps can you take to avoid this happening to you? (This happened in a survey. Also, people who inject drugs learned that if they said no to this question, the survey could be completed much more quickly, making the problem worse.)

Apply what you have learnt/case study

Try this case study.

1. You are conducting a survey of men who have sex with men in your community for the first time ever using RDS methods and you are tasked with developing the survey instrument that will be used. A local nongovernmental organization partner has already conducted some formative assessment for this survey but you have not yet seen the report from the formative assessment. You have a standard instrument for HIV risk behaviours that was used to generate data for national level monitoring indicators for your National AIDS Control Programme.
 - a. Develop a work plan that includes the steps you will have to take to generate the survey instrument. Include a rough timeline with each step to help you guide the process.
 - b. In addition to the standard instrument that you have from the National AIDS Control Programme, what other sources of information would be helpful to you as you begin to draft the survey instrument? What types of information should you search for? How would you go about searching for this information?
 - c. Now the nongovernmental organization partner has shared with you a draft report from the formative assessment that was conducted. What kinds of information are you interested in gathering from this formative assessment?

Unit 10

The RDS survey
process

Overview

What this unit is about

This unit describes the steps involved in the RDS survey process. It also provides examples of participant flow diagrams and instructions on how to conduct various survey activities.

The RDS survey process usually involves two visits to the survey site. During the first visit, an individual arrives with a valid coupon and leaves with a primary incentive. On the second visit, the participant usually leaves with a secondary incentive. Planning the steps in an RDS survey will help to ensure efficient participant flow and clearly defined roles and responsibilities for survey staff. Staff should be familiar with each survey step, from the moment an individual first arrives at the survey site to the time they leave with their incentive.

This unit covers:

- survey process overview
- first site visit activities
- second site visit activities
- personal safety issues.

Warm-up questions

1. True or false? It is best to explain the recruitment process to a participant only after they have completed the interview? Circle your answer below.

True

False

2. Upon arriving at the survey site for an interview, a participant must present a valid _____.
3. What can you tell a recruiter who arrives at the survey site to receive a secondary incentive for recruiting a peer, but the peer has not yet enrolled in the survey?
 - a. Find the person to whom he/she gave the coupon and remind him/her to come into the survey.
 - b. Return to the survey site in another week to see if the person to whom he/she gave the coupon has enrolled into the survey.
 - c. Give the recruiter another coupon so he/she can recruit another person.
 - d. Both a and b.
 - e. All: a, b and c.

4. True or false? Sometimes a person who is eligible to receive a secondary incentive for having recruited one of their peers cannot get to the survey site to pick up their secondary incentive. In these situations it is all right to allow a friend of the recruiter to receive the incentive on the recruiter's behalf. Circle your answer below.

True

False

5. Which of the following responses is incorrect when dealing with an angry and potentially violent participant?
- Stay calm and listen to the complaints of the participant.
 - Use a code word to call someone to help you.
 - Yell back at the participant to show that you cannot be intimidated.
 - Make sure you know where the exits are and try to position yourself near the exit.

Introduction

What you will learn

By the end of this unit, you should be able to:

- list the steps involved in an RDS survey (respondent flow)
- describe the responsibilities of each step
- list the steps to provide recruiters with their primary and secondary incentives
- list the steps to collect biological specimens
- design and use appointment vouchers
- know how to respond to safety threats.

Interviews should be pleasant

RDS staff should ensure that survey participants' experiences at the survey site are as pleasant as possible. Serve refreshments to participants and make every effort to ensure that they feel welcome. It is also important that you serve refreshments if you are collecting venous blood from participants, as some participants may feel weak after giving blood. This is important because you want to ensure that each participant goes out and recruits their peers. If a participant has a bad experience at a survey site, they will not want to recruit their peers.

Survey procedures

This unit provides two flowcharts, Figure 10.1 and 10.2, which represent two possible interactions with RDS participants. Each figure has a set of detailed procedures outlined in Tables 10.1, 10.2 and 10.3.

The RDS survey steps described here can be modified to suit the layout of your survey site.

Procedure I: The RDS survey process

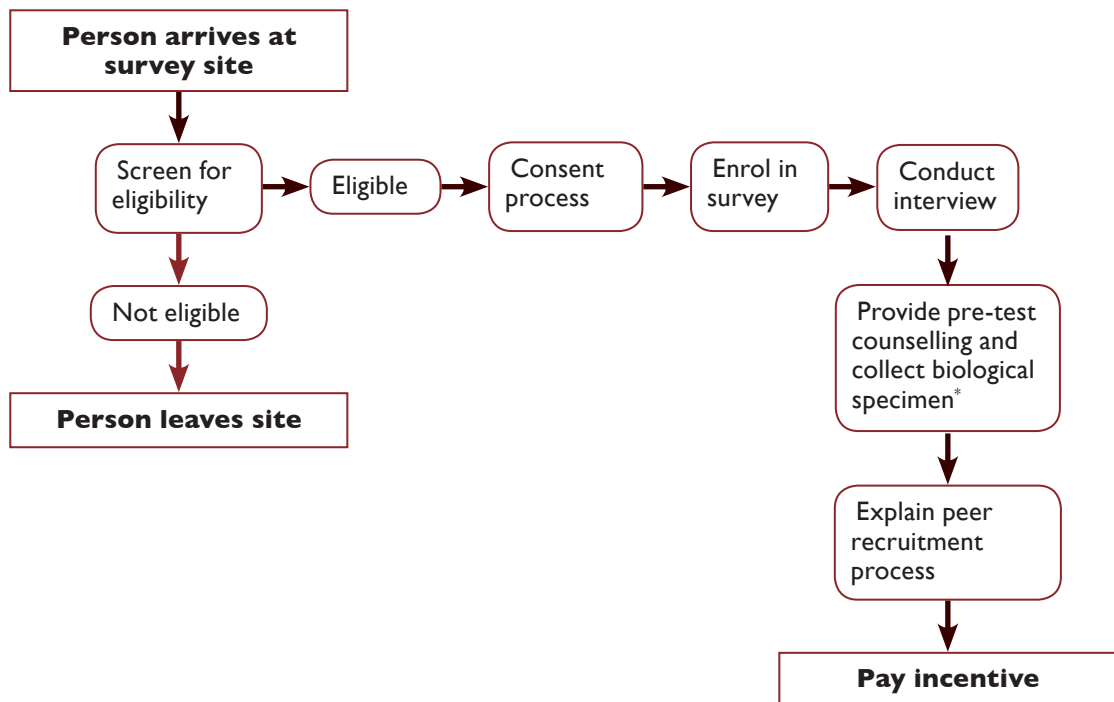
Respondent flow

Figure 10.1 illustrates the RDS interview process and Table 10.1 explains each step of the process. You may use the procedure as a checklist. Simply copy and update it to reflect your survey protocol.

Procedure process checklist

If the procedures are complicated in your survey, it is helpful to have a checklist that can be checked off and signed by staff as a participant completes the survey flow.

Once the participant completes each of the survey steps (eligibility, interview, biological specimen collection, pre- and post-test counselling, explanation of the recruitment process, recruitment coupons, etc.) he/she can submit the completed checklist to receive an incentive.



* If giving post-test counselling and HIV rapid test results, do so after explaining the peer recruitment process.

Figure 10.1 The RDS survey process (respondent flow)

This can help staff remember the flow of the survey and provide the necessary paperwork to ensure that the participant has completed each of the survey steps needed to receive a primary incentive.

A sample procedure process checklist is provided in Annex 6.1.

Screening participants

It is very important that participants are properly screened before they are enrolled in the survey.

- Each survey site should have a proper screening area in which potential participants can be screened before they are allowed to enter the survey area.
- Having a screening area near, but not in, the survey/testing area can reduce the chance that a disgruntled or disruptive person disturbs enrolled participants or staff.

Screening process

During the screening process, the person who is screening must ensure the potential participant:

- has a proper coupon (accurate identification number, colour, expiry data, activation date)
- is actually a member of the survey population
- is willing to provide informed consent (including that he or she understands his or her rights in relation to the survey).

If each of the screening steps is fulfilled, the person is enrolled in the survey and can proceed to the interview.

Verifying membership in the survey population

Use staff members who have already worked closely with the survey population to determine if the participant you are screening is actually a member of the survey population. They will be best equipped to know the nuances of the behaviours associated with the survey population.

People who inject drugs may have visible track marks that can be checked by the screening person. For people who inject drugs, the screener may ask the following questions:

- When did you last inject drugs?
- What did you last inject?
- In which part of your body do you usually inject?
- Can you show me where you last injected?
- How much do you usually buy (heroin) and how much does it cost? (The screener should be aware of the current cost of drugs in the area.)

It is much harder to ensure that a sex worker is actually a sex worker and that a man who has sex with men is actually a man who has sex with men.

For sex workers, screeners may ask the following questions (the screener should be aware of the appropriate responses to these answers):

- When did you last exchange sex for drugs, money or other goods?
- Where do you usually find your clients?
- How much do you charge?
- How do you negotiate your price?

For men who have sex with men, screeners may ask the following questions (the screener should be aware of the appropriate responses to these answers):

- How often do you sleep with men?
- Do you enjoy receptive sex with a man?
- Do you enjoy penetrative sex with a man?

Many times, men who do not have sex with men may be put off by these types of questions and it may become obvious that an imposter is uncomfortable responding to these questions.

It is best to ask the questions above in correct local terminology. Keep in mind that the screener should not be overly concerned about excluding people he or she is in doubt about. If the sample size is large enough and a few people who are not actually members of the survey population get into the survey, it should not bias the results of your survey too much.

It will also help if incentives are not so high that people who are not members of the survey population are motivated to fake membership in a stigmatized population to enrol (and receive the incentive) in the survey.

The step-by-step RDS survey process and providing the primary incentive

Table 10.1 describes each step of the survey process, including providing the primary incentive. Use the table as a checklist. Simply copy and update it to reflect your survey protocol.

Table 10.1 The RDS survey process, including the primary incentive

Step	Do this...
1	When someone arrives at the survey site, ask to see if they have a coupon (if they do not have a coupon, tell them that they need to receive a coupon from a peer in order to enrol).
2	Ensure that the coupon is valid and has a proper coupon number. Check the coupon number and make sure the expiry date has not passed.
3	Screen participant: <ol style="list-style-type: none"> Ensure participant meets all of the eligibility requirements. Explain the survey to participant. Be able to answer any questions the participant may have about the survey.
4	Perform consent process: <ol style="list-style-type: none"> Review the consent form with the participant. Answer all of the participant's questions. Have participant verbally agree to consent and have staff member sign and date consent form on his or her behalf or have participant provide some written indication that they consent (by using a pseudonym). Because this is a survey of stigmatized populations, it is best to have participants give verbal consent and have a staff member sign and date the consent form on the participant's behalf. This will depend on the decision of the ethical review board.
5	Ask the social network size questions (this can be done as part of the screening process or during the interview depending on how the flow of participants is managed).
6	Conduct the interview. <ol style="list-style-type: none"> Use an appropriate behavioural surveillance assessment questionnaire. Conduct the interview: self administered or face-to-face. If using a self-administered computerized survey, staff will set participant up on the computer by entering the coupon ID number and/or other necessary information. <p>Complete the interview.</p> <ol style="list-style-type: none"> For paper questionnaires: Review the questionnaire to ensure that all questions have been answered. Go back to skipped questions to see if participant is willing to answer that question now. For CASI/ACASI: Ensure that the entered data have been saved. <p>Complete the paperwork (for paper questionnaire).</p> <ol style="list-style-type: none"> Ensure that the coupon number is recorded on the questionnaire. Place the completed questionnaire in a file (or secure place) and set aside until transported to data entry office.

Step	Do this...
7	Conduct pre-test counselling and collect biological specimens (this part is discussed in Unit 14).
8	Conduct an exit interview to see if participant is feeling alright.
9	<p>Explain the recruitment process.</p> <ol style="list-style-type: none"> Advise participant to safeguard the payment coupons and that he/she will need to present the coupon(s) to receive incentives for recruiting peers. Advise participant that they will not receive their incentive if someone tampers with the coupon or forges it. Explain the activation and expiry dates (if you are using them).
10	<p>Provide the primary incentive to the participant.</p> <ol style="list-style-type: none"> Provide participant with HIV information and any other educational materials or referrals. Record the identification code or numbers of the coupons provided to the participant in the appropriate space on the coupon tracking form. Be sure to thank participant for his or her time!
11	<p>If providing a rapid test result, have this be the very last step.</p> <ol style="list-style-type: none"> Provide post-test counselling. Provide test result.

Collecting biological specimens

If collecting biological specimens, it is important to know the HIV testing laws of the country in which you are collecting the specimen. Determine if there are regulations about where biological specimens can be collected (e.g. health care setting) and who can collect them (e.g. registered nurse, medical technician). Table 10.2 describes the steps involved in collecting a biological specimen. Simply copy and update it to reflect your survey protocol.

Table 10.2 Collecting a biological specimen

Step	Do this...
1	<p>Consent. Make sure the participant has consented to provide a biological specimen (see step 4 in Table 10.1).</p> <ul style="list-style-type: none"> ● Ensure that the participant understands and agrees to the items contained in the consent form in order to enrol in the survey. ● The participant may choose to only complete the interview and not the biological test (if conducting a biological test). ● Some surveys require that participants complete both the interview and the biological test to be eligible for the survey. ● Participants may decline to provide a biological specimen at the beginning of the interview. At the end of the interview, enquire again if the participant is now willing to provide a specimen. ● If a participant who originally declined to provide a specimen changes his/her mind, ensure that the consent form is updated to reflect this.
2	<p>Counselling. If a participant agrees to provide a biological specimen and to receive the test results, the participant requires pre- and post-test counselling.</p>
3	<p>Specimen collection and storage. Collect a biological specimen (saliva, blood, other).</p> <ul style="list-style-type: none"> ● Label the specimen with a laboratory number that can be linked to the participant's coupon identification number. It may be a good idea to label the specimen with some other identifier such as birth date to ensure the results get to the correct person. The specimen will also be identified by the date it was taken. ● Place the specimen in a secure location, well away from public view.
4	<p>Testing. Use the appropriate test kit for the biological specimen.</p> <ul style="list-style-type: none"> ● For rapid tests, results can be read within 20 minutes after collecting the specimen. Results should not be seen by the participant until you are ready to discuss them. ● If you collect specimens that require laboratory testing and confirmation, the specimen must be properly processed and stored until it is sent to the appropriate laboratory.
5	<p>Recording the results. Record the rapid test results properly.</p> <p>Enter the results into the database when the result is read or received from the HIV testing laboratory.</p>
6	<p>Returning the results/post-test counselling. Provide test results or not, depending on your survey (it is optimal to provide test results if at all possible, because RDS provides a perfect opportunity to access key populations at higher risk of HIV exposure).</p> <ul style="list-style-type: none"> ● If providing test results to participants on site, provide HIV post-test counselling. ● Some tests require processing at an off-site laboratory. If this is the case, participants will need to return to the interview site to get their test results. ● Offer special hours for participants to receive test results or arrange a future appointment during which participants can receive test results. ● If test results and post-test counselling are not provided on site, provide participants with a voucher to get a free HIV test at the collaborating VCT site.
7	<p>Thanking the participant. Be sure to thank the participant for his or her time!</p> <ul style="list-style-type: none"> ● Provide the participant with HIV information and any other educational materials that you think are important.

Discussing Figure 10.1 and Tables 10.1 and 10.2

Look at Figure 10.1 and Tables 10.1 and 10.2 and answer the following questions:

- Review the recruitment process script found in Annex 8. What types of question might a participant have about the survey? What are some of the answers you would provide for these questions?
- What are the laws concerning biological HIV testing in your country? Could you collect a rapid HIV test sample in a non-medical setting? Could a rapid HIV test sample be collected by non-medical staff? What kinds of rapid HIV tests are you aware of?

Procedure 2: Collecting secondary incentives

Respondent flow

Figure 10.2 illustrates how recruiters collect secondary incentives (respondent flow).

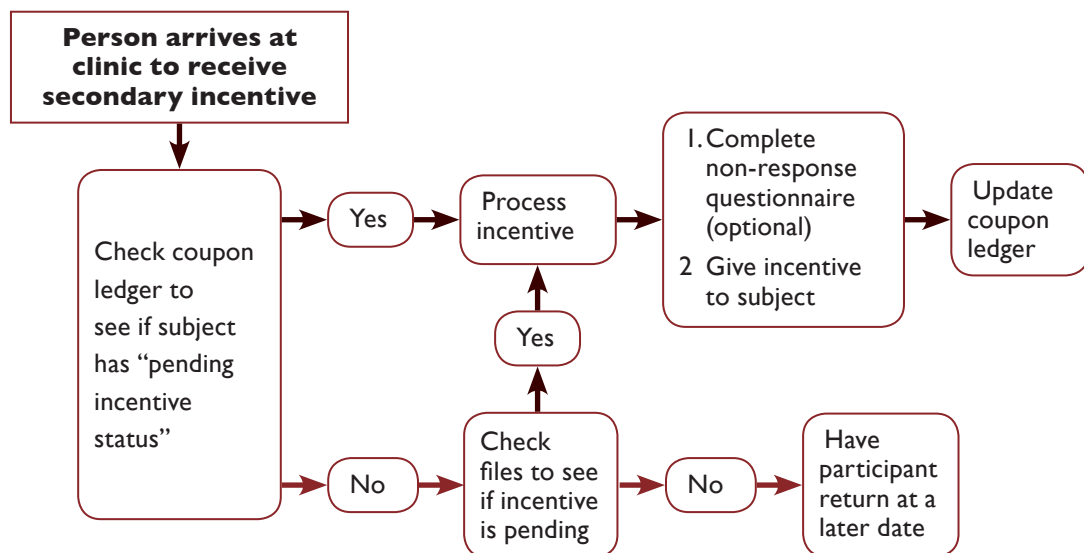


Figure 10.2 How recruiters collect secondary incentives (respondent flow)

Providing a secondary incentive

Table 10.3 explains each step of the process for obtaining the secondary incentive. You may use the procedure process as a checklist: copy and update it to reflect your survey protocol.

Table 10.3 Providing a secondary incentive

Step	Do this...
1	<p>Ask the recruiter for the payment coupon(s).</p> <ol style="list-style-type: none"> Ensure that the recruiter provides you with the appropriate coloured and numbered coupon for the secondary incentive he/she is claiming. Try to ensure that the person collecting the secondary incentive is the actual person who distributed the coupons to recruit their peers. Sometimes people who want their secondary incentive quickly will bring their recruits with them to the survey site and wait for the recruits to finish the interview. Encourage the recruiter to return in an hour or around the time you think his/her recruits will finish with the survey process. Do not give out the secondary incentives to a recruiter before the recruits have completed the entire survey. It is often a good idea to give out secondary incentives on a different day than when participants are enrolling in the survey. Encourage recruiters to collect their secondary incentive sometime after the expiry date on the recruitment coupons. This way, you will be certain that any recruit that received a coupon and wants to enrol in the survey will be sure to have enrolled.
2	<p>Ensure that the recruiter's recruits have enrolled and completed the survey. If the recruit has not enrolled in the survey, inform the recruiter and suggest that he/she do one of the following:</p> <ol style="list-style-type: none"> Find the person to whom he/she gave the coupon and remind him/her to come into the survey. Return to the survey site in another week to see if the person to whom he/she gave the coupon has enrolled into the survey. Return to the survey site once the expiry date on the coupon has expired. If the recruit has enrolled in the survey, inform the recruiter and proceed to the next step.
3	<p>Conduct an interview with the properly-identified recruiter using the follow-up questionnaire (optional)</p> <ol style="list-style-type: none"> Put the proper identification code or number on the questionnaire. Place the completed questionnaire in a file (or secure place) and set aside until transported to data entry office.
4	<p>Provide the participant with a secondary incentive for each of his/her recruits who enrolled and completed the survey process.</p> <ol style="list-style-type: none"> Record the identification code or numbers of the coupons provided to the participant in the appropriate space on the coupon tracking form (see an example in Annex 6.2). Thank the participant for his/her time.

Lessons learnt

Recruitment of people who inject drugs in an RDS survey conducted in a small island nation was going very well. From the beginning a steady flow of participants were enrolling in the survey with about 20 participants enrolling daily.

However, a few weeks into the survey, staff became overwhelmed having to accommodate enrolees and participants who were returning to the survey site for their secondary incentive. The staff was more concerned about ensuring that participants who were enrolling in the survey were accommodated first. After all, the survey only had a few

more weeks to reach its sample size and staff did not want to lose enrolments by having to make them wait.

Participants who were waiting for the secondary incentive became frustrated and disruptive as they noticed that people with referral coupons (those wanting to enrol) who came in after them were being accommodated first. Although this was not an appropriate way to treat those wanting secondary incentives, it was more important to the survey to enrol participants than to give out secondary incentives.

During a weekly meeting the staff came up with the idea of having dedicated times or days just for secondary incentives. It was decided that every Tuesday would be dedicated for secondary incentives. In addition, Tuesdays were dedicated for providing test results for hepatitis B and C since many participants were not choosing to get their test results. It was thought that by encouraging participants to get their secondary incentive on the same day as their test results that more participants would get their test results.

Dedicated days for secondary incentives

Based on the situation described above, it is highly recommended that a dedicated day (or dedicated hours) be used for the sole purpose of providing secondary incentives and conducting the follow-up questionnaire for those who tried to give out a coupon to someone who did not accept it. This will mean that staff do not have to choose whether to accommodate enrollees before having to accommodate participants wanting their secondary incentive.

In addition, if test results are provided on a day other than the day of enrolment, then consider having a dedicated day for the provision of test results as well. Appointments for secondary incentives and test results can be made on the day of enrolment. In some cases, having the secondary incentive on the same day as the test results will increase the number of people getting their test results. Also, it will:

- increase anonymity
- allow participants to make just one trip to get both secondary incentives and test results
- allow staff to focus on responding to these participants.

Appointment vouchers

Introduction

An appointment voucher can be used for two purposes:

- to provide an appointment date and time to the seeds
- to provide an appointment date and time to participants who drop-in and who cannot be interviewed at that time.

Usually the appointment voucher is provided by the site supervisor or screener, or whoever is managing the flow of participants coming into the survey site.

When deciding how many appointment vouchers to reproduce for the duration of the

survey, keep in mind that most people will not be making appointments and therefore will not need a voucher. For a survey of 400 participants, usually no more than 50–75 appointment vouchers will be needed.

Front of the appointment voucher

All appointment vouchers should contain this information on their front (see Figure 10.3):

- unique RDS number (coupon number)
- name of the project (optional, but do not use an outwardly stigmatizing name such as “AIDS prevention for people who inject drugs”)
- location and address of the field site (in the blank space after ‘You have an appointment at’)
- space for project staff to write in screening/interview appointment date and time at the survey site
- telephone number of survey site in case person needs to cancel or change appointment time or date (if telephone is available)
- expiry date (this is the final estimated expiry date for the survey so that people do not show up at the survey site six months after the survey has ended).

Coupon number:

Appointment voucher

You have an appointment at

Time Date

Telephone: xx-xxx-xxxx

This card will no longer be valid on

Figure 10.3 Survey appointment voucher

Back of the appointment voucher

All appointment vouchers should contain this information on their back:

- map showing how to get to interview location
- information about the survey.

Appearance of voucher

The physical appearance of the appointment voucher should differ from that of the coupons used to recruit participants. The following are recommendations for the physical appearance of the appointment voucher:

- Print the appointment vouchers on a different coloured paper than the colour used for the coupons.
- Cut the appointment vouchers to a size a little larger or smaller than the coupons.

Peer-driven interventions

Some projects provide interventions to participants through the RDS recruitment process. When a participant enrolls in an RDS survey, he or she can receive important health information (e.g. how to clean syringes and proper care for abscesses among people who inject drugs), which can be passed on to peers during the recruitment process. The behavioural questionnaire may include questions that evaluate such information sharing. Past RDS surveys involving peer-driven interventions among people who inject drugs have demonstrated that this method of information transfer can produce very positive outcomes [29, 37, 38, 39, 40].

Personal safety issues during the interview process

Introduction

Each survey site should develop local safety procedures and train field staff on those procedures. Staff can avoid trouble through common sense and advanced planning. Staff must be alert to their own safety and to that of their co-workers at all times. By adopting the recommendations below, staff will be able to effectively recruit and interview participants while still maintaining their personal safety.

Plan ahead

- Have a screening table that blocks any potentially-disruptive persons from entering the interviewing area. During screening you can assess the person's behaviour.
- Have an emergency action plan. Know what you are going to do ahead of time in case things suddenly go wrong.
- Know who to contact in case of emergency. Always know the location of all exits from any point in the survey site.
- During interviews, position yourself closest to the door. You do not want an unruly participant to be stationed between you and the exit.
- Consider developing a code word to call for assistance from a co-worker. You might use something like the phrase "bring the red folder". For example, if a staff member is not comfortable interviewing a participant by themselves or needs help with an uncooperative participant, they would ask one of their co-workers to "bring them the red folder" to indicate that they need assistance.

Be alert

- Be aware of your surroundings. If a threatening situation arises, remove yourself from the location immediately. Leave quickly, but do so carefully and in a relaxed manner.
- Use all of your senses to assess a situation. If something just does not feel right, do not

discount that feeling. If your intuition tells you that you are not in a safe situation, get assistance from another staff member.

- Approach every potential participant in a welcoming manner (most people will not pose a safety problem), but be cautious if you have concerns about an individual.

Use common sense

- Limit the amount of cash available in the field site (including participant incentives).
- Avoid wearing or carrying articles that look valuable. Jewellery, expensive watches and purses invite theft.
- Do not leave any valuables or project materials in your car, unsecured or in view.

If you feel threatened

Aggressive/threatening individuals: If you are directly confronted, employ verbal de-escalation techniques:

- position yourself at an angle and allow extra space between you and the other person
- do not smile
- let them vent
- listen to and acknowledge their concerns
- avoid becoming defensive
- lower your voice, tone and tempo
- respond to valid complaints.

Sexual harassment: If a respondent makes sexual advances to you or is sexually harassing you, you have the right to terminate the interview.

- If you feel the respondent is behaving inappropriately, first remind them that you are only there to interview them and that you are not interested in any sexual offers.
- If the respondent continues, tell them that you are going to end the interview if they cannot stay focused on the questions.
- If this does not work, end the interview.

Drunk, high or drowsy respondents: A respondent may not be able to complete the interview or give accurate responses for a variety of reasons.

- If they have had little sleep or have recently used alcohol or drugs, they may be unable to give coherent answers to questions, may fall asleep or appear to be very drowsy during the interview.
- If you have begun the interview and the participant is no longer giving coherent answers, stop the interview, thank the respondent for their time, and enter a description of what happened in the interviewer comments.

Develop field incident reporting procedures

- Set up local safety guidelines and procedures for incident reporting prior to starting work at the field site.
- In the event that an incident occurs at your site, know who to notify.

- Complete a field incident report (Annex 6.11) and submit it to your project officer.
- Consider having a security guard.

Summary

The RDS survey process involves several steps which usually include a first and second visit. The exact steps are unique to each survey and survey site. It is helpful to map out these steps in the standard operating procedures across all survey sites so that the survey staff is familiar with them. Additionally, it is a good idea to be prepared for situations that might arise such as having to set up appointments with participants and dealing with safety issues at the survey site.

Unit 10 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. What do you think are the advantages and disadvantages of providing HIV results to participants in an RDS integrated biological-behavioural surveillance survey?
2. Do you have VCT services available in your country? What kinds of services do your VCT sites provide? Do you think people in your community feel comfortable using the VCT services? What are some ways in which an RDS behavioural surveillance survey could reinforce the efforts of VCT in your country?

Apply what you have learnt/case studies

Try these case studies individually.

1. Your survey started two weeks ago and already there are 10 to 15 people who inject drugs waiting for an interview when you arrive at the survey site. You only have two other staff members (one who usually sets the participant up on the ACASI and the other who explains the recruitment process). You are the screener.
 - a. What do you do with all of these participants?
 - b. Some of the participants see that it is crowded at the survey site and start to get angry about waiting. One person in particular starts to raise his voice at you and you feel threatened. What do you do? What do you tell this person?
 - c. What are some ways you can prepare for this situation in advance?

2. In reviewing the first week of process data in a survey of men who have sex with men, you note a disproportionate number of refusals to participate from one screener. You review their screening sheets and notice that nearly all refusers meet the eligibility criteria. You discuss the issue with all of the screeners and they seem to be doing their job correctly. The next day, you listen to the screeners doing their work through a screen.

Screener 1, who has a high acceptance rate, describes the survey and then asks the eligibility questions according to the script. Screener 2, who has the lower acceptance rate, does the same.

Next, you step around the screen and observe.

- a. Can you guess the differences between the screeners?

- b. What can you do to rectify the situation?

3. Your survey site is set up with several stations: check-in, screening, interviewing, specimen collection, coupon distribution and incentive distribution.

Towards the end of the first week, when the daily number of interviews begins to increase, movement through the office becomes a bit chaotic. Participants become confused and frustrated while trying to get to the next station. Some try to go from check-in directly to collect their incentive. The coupon manager is unable to ascertain whether these participants have completed the survey and pays them.

- a. What can you do to facilitate an organized flow of participants through the survey process?

Unit II

Staffing

Overview

What this unit is about

This unit provides information about the type, number, and roles and responsibilities of RDS survey site staff members.

Warm-up questions

1. List the different staff members that might be required to undertake an RDS survey.
2. List two responsibilities of the coupon manager?

3. True or false? Each staff member should only perform their own roles and responsibilities and not assist other staff members in performing their roles and responsibilities. Circle your answer below.

True

False

4. Fill in the blank space.

The _____ is usually responsible for making sure that persons trying to enrol in the survey are eligible.

Introduction

What you will learn

By the end of this unit, you should be able to:

- outline how to staff an RDS survey site
- describe the different staff roles and responsibilities
- have a clear indication of the types and number of staff needed to conduct your survey.

Staffing an RDS survey

Staff positions and responsibilities

There are several factors to consider when determining staff for an RDS survey.

Below is a list of potential staff members and a brief description of their primary responsibilities:

- Site manager—someone to manage activities in the survey site including the flow of participants.
- Screener—person who conducts the screening process with someone who arrives to the survey site with a valid coupon (the screener may also fulfil other activities such as explaining the survey to the participant, conducting the consent process and asking the social network size question).
- Interviewer or, if using a computerized survey, someone to explain how to use the computerized system.
- Pre- and post-test counsellor—person who will conduct HIV pre- and post-test counselling (described in more detail in Unit 14).
- Biological testing team (pre- and post-test counsellor, nurse, phlebotomist, laboratory technician)—includes someone qualified to take a blood or other types of biological specimen (described in more detail in Unit 14).
- Coupon manager—someone who manages the coupons, including explaining the recruitment process and giving out properly numbered coupons; this person may also pay out the incentive since he or she is the last person a participant usually sees.

In addition there are some off-site positions that should be considered:

- Survey coordinator—someone involved in survey preparation and ongoing coordination of the survey.
- Survey supervisor—someone who understands the protocol and RDS methodology well and who oversees the quality of the survey process, ensures that the staff is following the protocol and is able to make informed decisions that could impact outcomes.
- Data manager and data entry clerk—persons responsible for developing the database, reviewing questionnaires and inputting data.
- Statistician—someone who is responsible for cleaning, coding and analysing the data.

Staffing and the RDS survey respondent flow process

Figure II.1 displays a simple flow chart for the RDS survey process for collecting the primary incentive and the associated staff responsibilities. These positions and responsibilities will be described in more detail below.

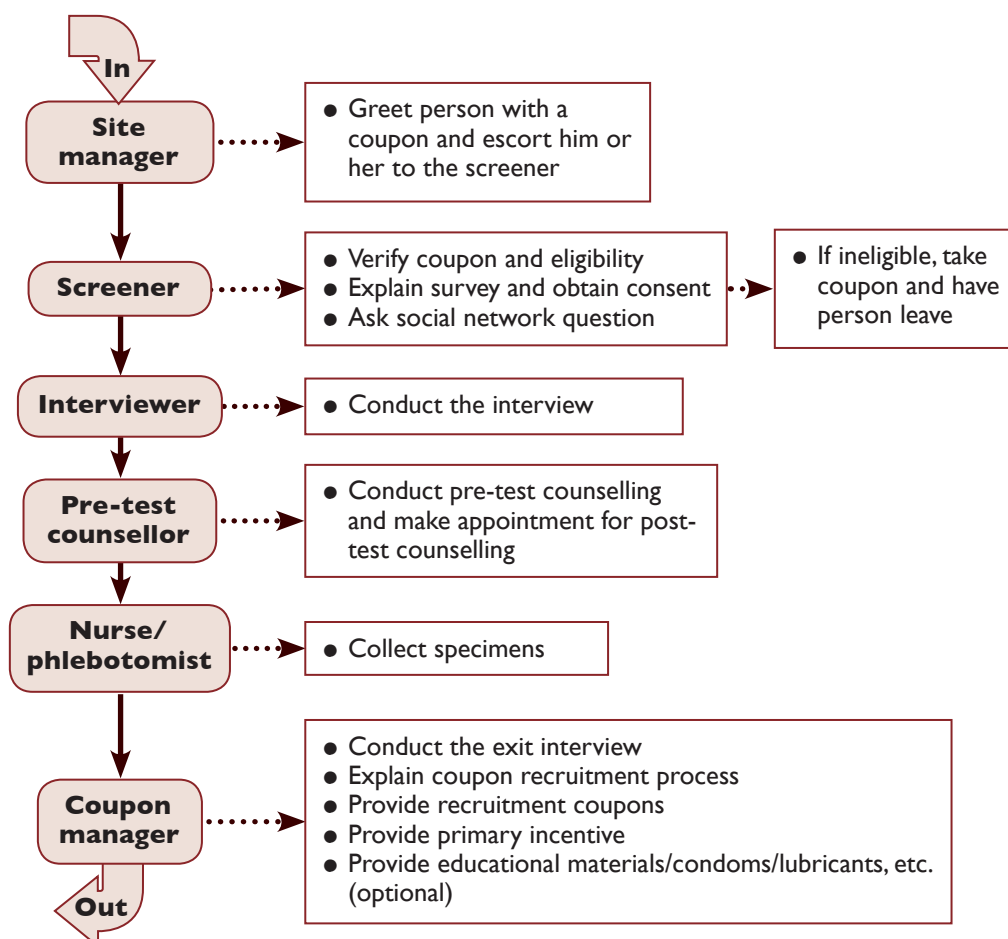


Figure II.1 Flowchart for RDS survey process and staff roles for collecting the primary incentive

Figure II.2 illustrates the RDS secondary incentive process and the staff members responsible for each step in the process. This scenario assumes that participants are allowed to go to the survey site at any time to collect the secondary incentive. Another scenario for collecting the secondary incentive is to have dedicated days for this as discussed in Unit 10.

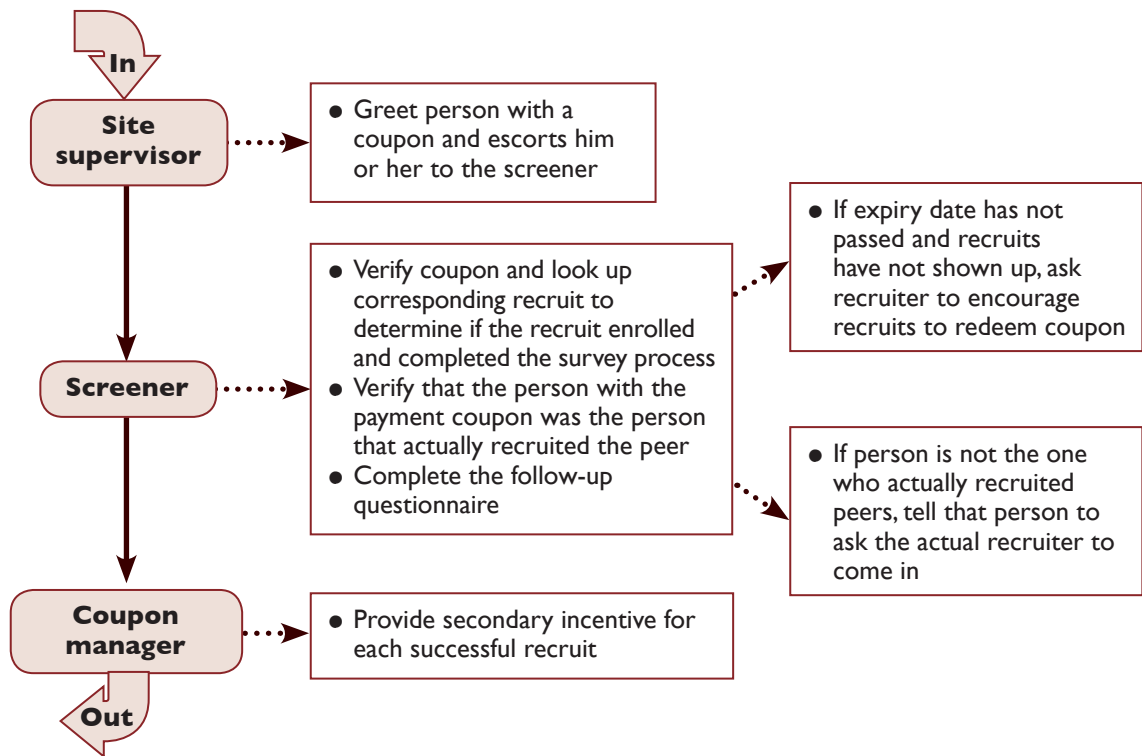


Figure 11.2 Flowchart for RDS survey process and staff roles for collecting the secondary incentive

The specific steps, based on the flow chart in Figure 11.2, for the collection of the secondary incentive are provided in Table 11.1. Although the flow chart divides the tasks up between the screener and the coupon manager, either position could fulfil all of the steps needed to process the secondary incentive.

Table 11.1 Specific responsibilities for the secondary incentive

Step	Do this...
1	Verify that participant is actual recruiter.
2	Collect payment coupon from participant.
3	Verify that the recruit was enrolled in the survey: <ul style="list-style-type: none"> ● If expiry date on referral coupon has past and participant has not yet enrolled in survey, recruiter receives no secondary incentive. ● If expiry date on the payment coupon has not passed and participant has not yet enrolled in survey, tell recruiter to return at a later date.
4	Complete follow-up questionnaire (discussed in Unit 12; example provided in Annex 6.10) if recruiter reports that someone refused to accept a coupon.
5	Update accounting system for secondary incentives.

Cross-train staff

The responsibilities listed above are interchangeable and not exhaustive. For instance, a coupon manager should be able to step into the screener position if the need arises. In addition, some surveys merge the screener and the coupon manager position into one position.

It is always a good idea to cross-train your staff so at least one other person has the capacity to fulfil the role of another, especially if you want to be prepared for a staff member quitting the survey before it is completed.

Roles and responsibilities

Several staff members will need to be present during survey operation hours. As there are numerous steps involved in conducting an RDS survey, at least one screener and coupon manager, and several interviewers (no less than three), will most likely be needed in addition to the site manager. If using a computerized survey, fewer staff will be needed.

The number of RDS staff members needed at one survey site depends on the:

- number of steps in the survey process
- sample size (expectation of the number of people to be interviewed)
- duration of the survey
- hours of operation
- number of hours a site assistant can effectively work and other factors.

Survey coordinator

Background

The survey coordinator helps set up the survey and is most important during the period before data are collected. The survey coordinator should understand the survey protocol and methodology or should invite someone who does to present the survey methods to partners and stakeholders.

Role and responsibilities

The survey coordinator's responsibilities can involve survey preparation, scheduling and attendance at planning meetings with survey partners and stakeholders (including the technical working group), and liaison functions for survey contracting and finances. Furthermore, the survey coordinator can help establish and coordinate the community advisory boards (community monitoring and advisory committees and the technical working group, see Unit 4).

The survey coordinator can ensure that all ethical, legal and safety requirements are met to a satisfactory standard, in conjunction with local partners, stakeholders, and law enforcement and government bodies. For instance:

- Does the government have strict rules about collecting biological specimens and importing test kits?
- Is there a certain type of building where surveys can be conducted?

The survey coordinator can also be responsible for setting up interviews and focus group discussions during formative assessment, identifying survey staff and setting up and delivering parts of the RDS survey training course. When there is a biological component to the survey, the survey coordinator may be helpful in acquiring licenses as necessary, getting importation clearance for all biological test kits and identifying laboratories where tests can be performed.

The survey coordinator can work with local professionals to determine relevant HIV/AIDS services for referrals of persons testing positive for HIV (or other infections) and to establish referral pathways and procedures for post-exposure prophylaxis and reports of adverse events at sites.

During the collection of data, the survey coordinator can have an expanded role in maintaining regular communication with the site manager and other staff, partners and stakeholders. The survey coordinator may also be an ideal person to take on the responsibility of survey supervisor or some other staff position.

Lessons learnt

In an eastern European country, the survey coordinator wanted to rent an apartment for an RDS survey. The survey coordinator thought an apartment would be more comfortable for participants and provide a higher level of privacy and anonymity than would a public building. However, on further investigation, it was found that government regulations required that all business (the survey was classified as a business) had to be conducted in a public building. The survey coordinator ended up conducting the survey in extra office space provided by a local nongovernmental organization.

Survey supervisor

Background

Survey supervisors need to have a thorough understanding of all components of RDS, including enrolment and eligibility procedures, interviewing processes, management and payment of incentives, and the steps involved in the collection and management of biological specimens. Most importantly, the supervisor should oversee the quality of the survey process, ensure that the staff are following the protocol and be able to make informed decisions that could impact outcomes.

Role and responsibilities

Each survey should have a survey protocol (see Annex 5) and an RDS field operations manual (see Annex 7). The protocol should contain specifics about the population under survey, the sample size, the survey design and an overview of the survey process. The operations manual should contain all of the specific procedures related to the day-to-day

operations of the survey. These are important tools that the supervisor should utilize when overseeing a survey; they will help to ensure the quality of the survey.

Survey supervisors should have a thorough understanding of the survey protocol and RDS methodology. A survey will often have technical assistance to ensure that the RDS methods are followed. For times when a supervisor is not sure about a methodological issue, there should be an RDS technical advisor that the survey supervisor can contact for help.

Lessons learnt

In one RDS survey of people who inject drugs, the survey supervisor and staff became overwhelmed with the number of people coming to the survey site for an interview. The survey supervisor did not have a clear understanding of the RDS methodology and told the staff to stop giving out coupons and to begin setting up appointments. The site assistants started making appointments based on when people came into the survey. Some of the appointments were made for three weeks from the time a participant came into the survey. After a little time, the staff realized that by stopping the distribution of coupons for everyone at the same time, some chains only reached two waves and that the appointment schedule they had created had reduced the chances that those with two waves would be able to recruit more waves.

If the survey supervisor had understood RDS methodology better or had called for technical advice, he/she could have followed some of the following suggestions:

- See whether it is possible to hire more staff or to extend the hours of operation.
- Have walk-in periods as well as a period of time available for appointments.

Meeting with staff

The survey supervisor should set up a meeting schedule to discuss survey issues, problems and progress. It is advisable for the survey supervisor to meet weekly with the entire survey staff, and more regularly with the site manager, to address any problems or ongoing issues and to maintain quality assurance. Some issues, if not dealt with quickly, can have a negative impact on RDS methodology.

Lessons learnt

In one country, an RDS survey of sex workers and people who inject drugs was being conducted at the same time. Three weeks after interviewing the initial sex worker and people who inject drugs seeds, the survey site was bustling with participants wanting to enrol in the survey. What the supervisor did not realize was that the RDS staff was only enrolling and interviewing people who inject drugs and that no sex workers, except for the seeds, had come into the survey. Had the supervisor been aware that sex workers had not yet enrolled in the survey, he/she could have had time to contact the sex worker seeds to:

- encourage them to pass out their coupons
- or if they had passed out their coupons, to encourage the seeds to encourage their recruits to enrol in the survey.

The supervisor could have added more seeds. Three weeks had already passed, so the supervisor did not have enough time to ensure collection of the predetermined sex worker sample size.

Managing RDS staff

Survey supervisors have broad management responsibility of the RDS staff, including the screeners, interviewing staff, coupon managers, the nurses who may be collecting biological specimens and any other staff members at the survey site. It is the survey supervisor's responsibility to ensure that staff have clearly understood working hours and are conducting their jobs effectively. All staff must be respectful and professional towards the participants and provide participants with an environment that is comfortable and safe at all times.

Survey supervisors should also pay attention to the well-being of staff and to be available to them if they have questions or concerns as a result of the survey. The survey supervisor should be available to staff by telephone for most of the opening hours of the survey site and should have regularly scheduled hours where he or she is physically present at the site.

Site manager

Background

Similarly to the survey supervisor, the site manager should have a thorough understanding of the survey components and methods and should be very familiar with the protocol and operations manual. The site manager has many responsibilities and should be someone who can multitask, gets along well with others and can think quickly on their feet.

Role and responsibilities

Site managers have overall responsibility for the day-to-day management of the survey and for ensuring that staff have the support they need to conduct their jobs and that participants complete the survey process. The site manager must be at the survey site during all (or most) hours of survey operation and will often be moving around the survey site rather than seated in an office.

In addition the site manager will:

- ensure that the survey site always has a supply of coupons, questionnaires, incentive money or items, survey forms and other materials necessary to conduct the survey
- greet respondents and escort them to the screener
- make appointments if the survey site becomes too crowded
- ensure that participants are escorted to the next step in the survey
- keep completed materials and questionnaires in a secure location
- oversee transport of completed materials and questionnaires to the data manager
- if using a computerized survey, ensure that the computer systems are functioning, review the data from the completed surveys and back up data daily
- manage incentives and oversee the person distributing the incentive (often the coupon manager)

- oversee the safety of the participants and RDS staff and intervene on behalf of staff to diffuse a disruptive situation or to escort a participant from the survey area
- meet with staff and the survey supervisor to identify any issues or problems with the survey
- hold a staff debriefing meeting at the end of each day of operation
- report any adverse situations or questions about methodology to the survey supervisor
- write up field notes and provide updates or weekly reports to a central office or funding source
- oversee the smooth ending of the survey and closure of the survey site.

Site managers should be cross-trained to take on other survey responsibilities. For instance, in some sites, the site manager will also be an interviewer or will be involved in screening participants for eligibility.

Screener

Background

Screeners are very important to the RDS survey. Usually the screener will be the first RDS staff member with whom a participant will interact. The screener should be pleasant and friendly and make the participant feel welcome.

Screeners will normally assess eligibility criteria by asking screening questions to ensure that a participant is a member of the survey population. Screeners should have some knowledge of, and experience working with, the survey population.

Screeners will explain the survey, respond to questions and obtain consent from participants. Screeners may also be interviewers who will conduct interviews with participants and can also take on more responsibilities such as asking the social network size question. Finally, the screener plays an important role in maintaining the safety of the RDS survey staff and participants.

Role and responsibilities

A screener should have a desk positioned near or in the waiting area, blocking entry to the interviewing and laboratory areas of the survey site. Table II.2 displays some of the specific responsibilities performed by the screener.

Other tasks for the screener include:

- maintaining the flow of participants in the waiting room
- ensuring that participants are screened on a first come, first served basis
- making appointments
- answering the phone (if there is one) and responding to callers' questions or interest in making an appointment
- knowing when to call on the site manager if necessary
- assuring quality of coupon tracking
- assisting the coupon manager in updating the coupon tracking form.

Table 11.2 The specific responsibilities of the screener (reorder steps as needed)

Step	Do this...
1	Greet potential participant.
2	Check the validity of each coupon (has coupon been tampered with, is it a real coupon, does it have a valid coupon number, etc.?).
3	Retain coupon (this can be stapled to the consent or some other form or be put into a special envelope).
4	Ask eligibility questions and enter this onto a screening form (see Annex 6.3 and 6.4 for examples of two types of screening form). If participant is not eligible, fill in the ineligibility form (optional, see Annex 6.5).
5	Verify membership in the survey population; for example: <ul style="list-style-type: none"> ● ask to see scarring for people who inject drugs ● ask a few questions to determine membership in the survey population (sample questions for female sex workers, for example, are found in the screening form in Annex 6.4).
6	Explain the survey.
7	Complete consent (Annex 6.6): if the person refuses to participate, fill in the refusal form (optional, see Annex 6.7).
8	Fill out and explain the client checklist form (optional, see Annex 6.1).
9	Enter ID number in database, on tracking form (see Annex 6.2).
10	Turn the participant (if a valid member of the population) over to the interviewer, who escorts client to interview area.

Screener materials

The screener should have the following forms (see Annex 6) in front of him or her:

- consent forms
- screening forms
- check list forms
- non-eligibility forms
- refusal forms.

The screener should make up several folders containing all of the necessary paperwork, ready when participants arrive to enrol in the survey. The screener will need the following items nearby:

- stapler (to staple coupon to a form)
- pens
- large envelopes or files to keep confidential paperwork
- appointment vouchers
- calendar
- if available, a computer in which the screener can input and look up important survey information.

Screening process

During the screening process, the person who is screening must ensure that potential participants:

- have a proper coupon (accurate coupon identification number, colour, expiry date, activation date)
- are actually a member of the survey population and eligible to join the survey (meets inclusion criteria)
- is willing to provide informed consent (including that he or she understands his or her rights in relation to the survey).

If each of the screening steps is fulfilled, the person is enrolled into the survey and can proceed to the interview.

Lessons learnt

Having a dedicated screener positioned near the waiting area, was developed in response to situations that arose in Hanoi, Viet Nam, during an RDS survey among people who inject drugs.

In Hanoi, the survey sites were run by interviewers and a site manager. Interviewers were called upon to screen participants, validate coupons, and then conduct the interview. As the survey progressed, participants wanting to be interviewed were overwhelming the survey site.

Interviewers had to be called out of interviews being conducted with other participants to help the lone site manager attend to up to 25 participants on a given day. Some participants became disruptive and entered the interviewing area, disrupting the anonymity of the other participants and threatening the safety of the RDS staff and participants.

A screener was hired whose sole responsibility was to:

- screen potential participants for eligibility
- note the order of potential participants who came into the survey site (to ensure first come, first served)
- give realistic estimates of waiting times
- make appointments with those who could return at a later time
- screen out drugged or drowsy or potentially disruptive participants; anyone who was not fit or eligible to participate in the survey would not get beyond the waiting area into the interview and laboratory areas.

Interviewer

Background

Interviewers should have good active listening (nodding when appropriate, relaxed positioning, appropriate facial expressions and so forth) and probing skills. Interviewers also need to know how to make people feel comfortable when asking sensitive questions.

Role and responsibilities

Once the participant is screened (is eligible and provides consent), he or she is escorted to the interview room by the screener or the site manager (or some other designated staff member). Table 11.3 displays some of the specific responsibilities performed by the interview.

Computerized surveys

If using a computerized survey, someone will need to be responsible for getting the participant set up on the computer. In this situation, the interviewer or other responsible person will need to correctly enter the participant's identification code/coupon number and explain how the computer survey works by walking the participant through a few practice questions.

Table 11.3 Specific responsibilities of the interviewer

Step	Do this...
1	Greet participant, build rapport.
2	Either add the correct identification code or coupon number onto the questionnaire or into the computerized survey.
3	Conduct interview.
4	Ask network size questions (the network size question can also be asked by the screener during screening)—see Unit 9.
5	Check off procedure process checklist (return checklist to participant). (See Annex 6.1)
6	Escort participant to the doctor/laboratory technician (or next step in the survey protocol).

Interviewer materials

The interviewer will need the following items nearby:

- pens or pencils
- large envelopes or files for confidential paperwork
- questionnaires (paper or computer).

Coupon manager

Background

The coupon manager is often the last person the participant will see before leaving the survey site. The interaction between the coupon manager and the participant should be as pleasant as possible.

The coupon manager should make a point of doing an informal exit interview by asking “how was your experience here?” The coupon manager should be prepared to listen to complaints or concerns the participant might have. If the problem is serious, the coupon manager needs to involve the site manager.

Role and responsibilities

The coupon manager ensures that a participant has completed all of the steps of the survey (this is done easily by looking at the client checklist form, see Annex 6.1) and will manage and distribute the primary incentive. The coupon manager will label the coupons or ensure that the coupon has the correct coupon number to track who recruited whom. He or she will apply an expiry date (and, in some surveys, an activation date) and explain the coupon recruitment process to the participant (see Annex 6.8).

Primary incentive

The task of providing the primary incentive could be easily fulfilled by the coupon manager especially since he or she is often the last person the participant sees before leaving the survey site. Formal management of the incentives could still be overseen by the site manager.

The specific responsibilities performed by the coupon manager are displayed in Table 11.4.

Table 11.4 Specific responsibilities performed by the coupon manager

Step	Do this...
1	Confirm participant has completed all survey steps; otherwise, have participant complete step(s).
2	Conduct exit interview (e.g. ‘How was the survey process for you?’).
3	Produce/put coupon number on recruitment coupons.
4	Explain recruitment process to participant (see Annex 6.8).
5	Give out the primary incentive.
6	Distribute educational material.

Coupon manager materials

The coupon manager will need the following items nearby:

- pens or pencils
- large envelopes or files for confidential paperwork (e.g. the returned checklist forms)
- coupons
- incentives
- the incentive financial reporting form (Annex 6.9)
- educational materials.

The biological testing team technician

Background

The biological testing team may consist of a pre- and post-test counsellor, a phlebotomist/nurse (someone to collect specimens) and a laboratory technician to process on-site laboratory results. Biological specimens may consist of dried blood spots, venous blood, saliva, urine, rectal swabs and vaginal swabs (read more about biological testing in Unit 14). The biological testing team should:

- attend RDS training on the survey process and methods
- work with the survey supervisor to ensure that the appropriate equipment is available for the testing room.

Role and responsibilities

For details on the roles and responsibilities of the biological testing team see Unit 14 and for the steps involved in collecting biological specimens see Table 10.2.

Data manager and data entry clerk

Background

The data manager oversees all aspects of the database and, along with the data entry clerk, is responsible for data quality and input. They should be familiar with the:

- database
- skip and coding patterns of the database
- questionnaire.

They should be able to identify and address problems with database structure and format.

Role and responsibilities

Data managers and data entry clerks should input data and flag inconsistencies or incomplete questionnaires for return to site managers and interviewers for correction. They should:

- take time to ensure that the data are correct
- ensure there are no suspicious responses and the questionnaires have been completed
- double enter data.

If you are using a computerized survey, there is no need for a data entry person. However, it will be necessary to have someone who ensures that the computerized survey software is working and that there are no software problems during the survey.

Statistician

Background

The statistician is responsible for cleaning, recoding and analysing the data. The statistician may also be involved in checking data during the data collection process. The statistician should be familiar with the different estimators needed for RDS analysis and know how to use RDS-specific analysis software (RDSAT, RDS Analysis) as well as other data analysis software programs such as R, SPSS, STATA and SAS.

Roles and responsibilities

The statistician should:

- run frequencies to check data accuracy and if inaccuracies are found work closely with the data manager to clean them
- recode data
- conduct analysis using the appropriate weighted estimators and software.

Examples of staffing in different surveys

Table 11.5 provides examples of past surveys and the number of staff given the survey population, sample size, number of survey sites, interview method and hours of operation. There is also information about the number of weeks it took to reach the sample size.

Table 11.5 RDS staffing from previous surveys

Survey location	Survey population	Sample size	Number of survey sites/ interview method	Hours of operation	Number of staff (on duty at one time)	Time to reach sample size
Teheran, Islamic Republic of Iran	People who inject drugs	549	1/ACASI	Saturday–Thursday 09:00–16:00/ Friday 09:00–12:00	<ul style="list-style-type: none"> ● 2 screener/coupon manager ● 1 ACASI technician ● 1 laboratory technician 	11 months
Cairo, Egypt	People who inject drugs	429	1/face-to-face interview	Sunday–Thursday 11:00–16:00	<ul style="list-style-type: none"> ● 7 staff members 	14 weeks
Alexandria, Egypt	Men who have sex with men	267	1/face-to-face interview	Sunday–Thursday 11:00–16:00	<ul style="list-style-type: none"> ● 6 staff members 	10 weeks
Khartoum, Sudan	Female sex workers	321	1/face-to-face interview	Saturday – Thursday 10:00 – 16:00	<ul style="list-style-type: none"> ● 1 screener ● 4 interviewers ● 1 laboratory technician ● 1 coupon manager/ site supervisor ● Total = 7 staff members 	3 weeks
Hodeidah, Yemen	Female sex workers	300	1/face-to-face interview	Saturday – Wednesday 16:00 – 20:00	<ul style="list-style-type: none"> ● 2 screeners ● 4 interviewers ● 2 coupon managers ● 1 laboratory technician/counsellor ● 1 site supervisor ● Total = 10 staff members 	10 weeks

Survey location	Survey population	Sample size	Number of survey sites/ interview method	Hours of operation	Number of staff (on duty at one time)	Time to reach sample size
Ho Chi Minh City, Viet Nam	People who inject drugs, sex workers	400 each group	3/face-to-face interview	6 days a week, 10:00–17:30	<ul style="list-style-type: none"> ● 3 interviewers at each site ● 1 supervisor at each site ● total = 12 staff members 	10 weeks
Belgrade, Serbia	People who inject drugs	400	1/ACASI	7 days a week, 15:00–21:00	<ul style="list-style-type: none"> ● 1 screener ● 2 interviewers ● 1 site supervisor ● total = 4 staff members 	8 weeks
Dhaka, Bangladesh	Men who have sex with men	530	1/face-to-face interview	6 days a week, 11:00–19:00	<ul style="list-style-type: none"> ● 1 screener ● 3 interviewers ● 1 coupon manager ● 1 site supervisor ● total = 6 staff members 	10 weeks
Dimapur, India	Sex workers	400	2/face-to-face interview	6 days a week, 10:00–18:00	<ul style="list-style-type: none"> ● 1 screener ● 3 interviewers ● 1 coupon manager ● 1 site supervisor ● total = 12 staff members 	8 weeks

Summary

An RDS survey will involve several staff members. Each staff member should not only know how to fulfil their own responsibilities but also know something about the responsibilities of their co-workers (with the exception of a trained professional such as a nurse or phlebotomist, VCT counsellor, etc.).

Unit II exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions. If you are working on your own, write the answers to these questions.

1. Make a list of the type of staff members you would need for an RDS survey of 500 people who inject drugs. Describe each of the duties those staff members would have.
2. Describe how you would budget and organize staff at the survey site knowing that by the end of the survey, there could be up to 50 participants enrolling in the survey on a given day.
3. If you were conducting an RDS survey in your country, how would you find appropriate staff to hire? What are some of the qualifications you would want in your survey staff?
4. What would you do if your screener quit the survey before it was over? What would you do if your site manager quit the survey before it was over? What are some ways you can be prepared for a situation like this before it happens?
5. Create an organogram (a tree or hierarchical structure of job tasks) of who supervises whom and list the responsibilities of each staff member.
 - a. If an interviewer has a question on biological testing, who does he or she ask?
 - b. If a coupon manager has a question about whether a coupon is valid, who does he or she ask?

Unit 12

RDS survey
documentation and
management

Overview

What this unit is about

Managing the steps in a survey is very important for ensuring that the recruitment and data collection processes run smoothly. Having the proper forms will make it easier to efficiently and effectively manage the survey processes. This unit provides suggestions about, and examples of, forms used to document and manage an RDS survey.

Warm-up questions

1. True or false? Computers can replace the use of any forms during the collection of data? Circle your answer.

True

False

2. A _____ is a form that helps the survey staff keep track of all of the steps the participant needs to complete before he or she can receive their primary incentive.
3. Which form is most useful in monitoring the reasons why someone was not eligible to enter an RDS survey? Circle your answer.
 - a. checklist form
 - b. consent form
 - c. ineligibility form
 - d. refusal form
 - e. financial reporting form
 - f. both c and d
4. True or false? Completed forms should be reviewed, double checked and compared with other forms during the course of the RDS survey to ensure that information about a participant is consistent and to catch errors. Circle your answer below.

True

False

Introduction

What you will learn

In addition to the behavioural questionnaire, all RDS surveys involve the careful management of process data. From the time a person is screened until the time they receive their secondary incentive on their second visit to the survey site, there are important pieces of information that need to be recorded. This unit provides all the forms needed to manage data during an RDS survey. Even if you have a computerized system to manage data collection, it is always a good idea to use paper forms as a backup. All of the forms presented here are suited for RDS survey sites that do not have computers or those sites that wish to have a paper back-up in addition to computerized systems.

The forms presented in this unit are templates for you to modify to suit the needs of your specific survey (also see Annex 6). By the end of this unit, you should be able to:

- use a form to manage the flow of participants to ensure that each participant completes each step of the survey
- know which forms assess those who are ineligible or refuse to participate
- know which forms are needed for managing coupons and incentives
- determine which forms are needed based on whether there is a computer available in the survey site
- learn about managing data in a centrally-located computer database.

Forms specific to managing and processing the biological specimen collection and laboratory coordination are discussed in Unit 14.

Managing data in an RDS survey

Introduction

Managing data in an RDS survey is really no different than managing data in any well-run research survey. Reviewing other resources, beyond this unit, on setting up an efficient and reliable data management system is highly recommended [41, 42]. Data should be entered into a computer database as soon as possible after it is collected.

Having office space

It is important to have dedicated office space for data management. The data management office should have enough space for computers, tables for paperwork and for reviewing completed questionnaires, locked file cabinets for securely storing forms, and desks for data managers and data entry specialists.

It has been found that data entry specialists are more likely to edit computerized data without going through the source documents if these documents are not easily accessible [41]. If the data are not being entered directly by the participant into a computerized survey format, it is best to enter all behavioural data in one designated location.

If using a computerized system to screen and enrol participants, then having enough space to accommodate the computer and all paper forms is necessary.

Data systems development

Data systems development includes designing, developing, implementing and improving the performance of data management software. Most RDS data will be stored in a computer database based on the structure of the questionnaire and forms. Almost any type of database program can be used to store RDS data.

Past surveys have used data storage programs such as the Centers for Disease Control and Prevention's Epi Info (see www.cdc.gov) or Microsoft Access.

Database design

A well-designed database will reduce programming time during cleaning and analysis. A database should have efficient skip patterns, programmed error checks and data tables with key variables that can interlink within the database. Developing modules for addressing issues such as error identification, data correction and processing, and data linkage will require substantial amounts of time.

Computerized surveys

Using computerized survey methods is extremely useful and efficient. The entire questionnaire is electronically stored as the participant or interviewer enters data. In order to set up computerized surveys at the site, a room with networked, password-protected computers may be needed. Computer types used in RDS surveys include those that sit on top of a desk or those that are held in the participant's palm (hand-held computer systems). You will need to:

- Instruct the participant how to use the computerized system. A set of questions that are unrelated to the survey can be included to serve as a tutorial before participants begin responding to the questionnaire. These questions should introduce the participant to different types of response such as: choose one, choose more than one, yes/no, a time span. For example, one question may be how many pets do you have?
- Enter the participant's correct identification code or number into the computer system.
- Be available to respond to any questions during the interview process.
- Enter a password to save the data at the end of the participant's interview.

It is important that questionnaires that are formatted into a computerized survey method be piloted and that the computer system has the correct filters and skips. There are software programs that can be used for formatting surveys for a computer such as:

- Questionnaire Development System™ (see <http://www.novaresearch.com/QDS/>)
- iForm (see <https://www.iformbuilder.com/>)
- Entryware Designer (see <http://w2.techneos.com/kb/default.asp?ToDo=>).

Lessons learnt

In a survey conducted among female sex workers in Bangkok, participants were interviewed using a computerized survey on a hand-held computer. Because the screen was rather small, some of the female sex workers had trouble reading the questions. Staff quickly realized that some of the participants needed reading glasses to be able to read the screen. Several pairs of reading glasses were purchased and made available to those needing them.

Documentation management and flow

Many RDS surveys require numerous steps during the survey process. In most RDS surveys a participant will have to:

- complete the eligibility and consent process
- complete an interview
- have pre-test counselling
- provide a biological specimen
- learn the coupon recruitment process
- receive a primary incentive.

A variety of forms are needed to track each of these important steps and to manage the recruitment processes and payment of incentives. The flowchart presented in Figure 12.1 is an example of how the forms are used at each step of an RDS survey. This diagram assumes the provision of HIV test results on the day of enrolment and the provision of other test results on the day the participant returns for their secondary incentive. The flow of participants and use of forms described here can be modified depending on the needs of each specific survey. Forms are highlighted in each of the steps.

Storage of forms

Storage systems

Each survey site should have an easy and safe storage system for retaining paper and electronic forms. Blank forms need to be within easy reach of the appropriate survey staff members, e.g. blank checklist forms and consent forms should be in easy reach of the screener.

Information from management forms can be entered directly into a computer database if available. For sites that do not have a computer system, these forms can be stored and entered into a management database at a later time. Even though there may be an on-site computer system whereby data can be entered directly into the computer as it is collected, it is strongly recommended that paper forms also be used to record data just in case data are lost on the computer.

Storing paper forms

Each staff member should know the filing system for paper forms. This system should be easy to follow. Always store the forms in a locked file cabinet. Filing completed forms in individual participant files labelled with the coupon number will enable easy access for adding biological test results and retrieving participant folders when needed for the second survey visit. If there is no on-site computer management database, try and input data from the forms into a computerized database in a central location as soon as possible after it is collected.

During the interview process, the survey site tends to get very busy, so forms may need to be stored in a temporary, secure location until their data can be entered into a computer management database or stored in a locked filing cabinet.

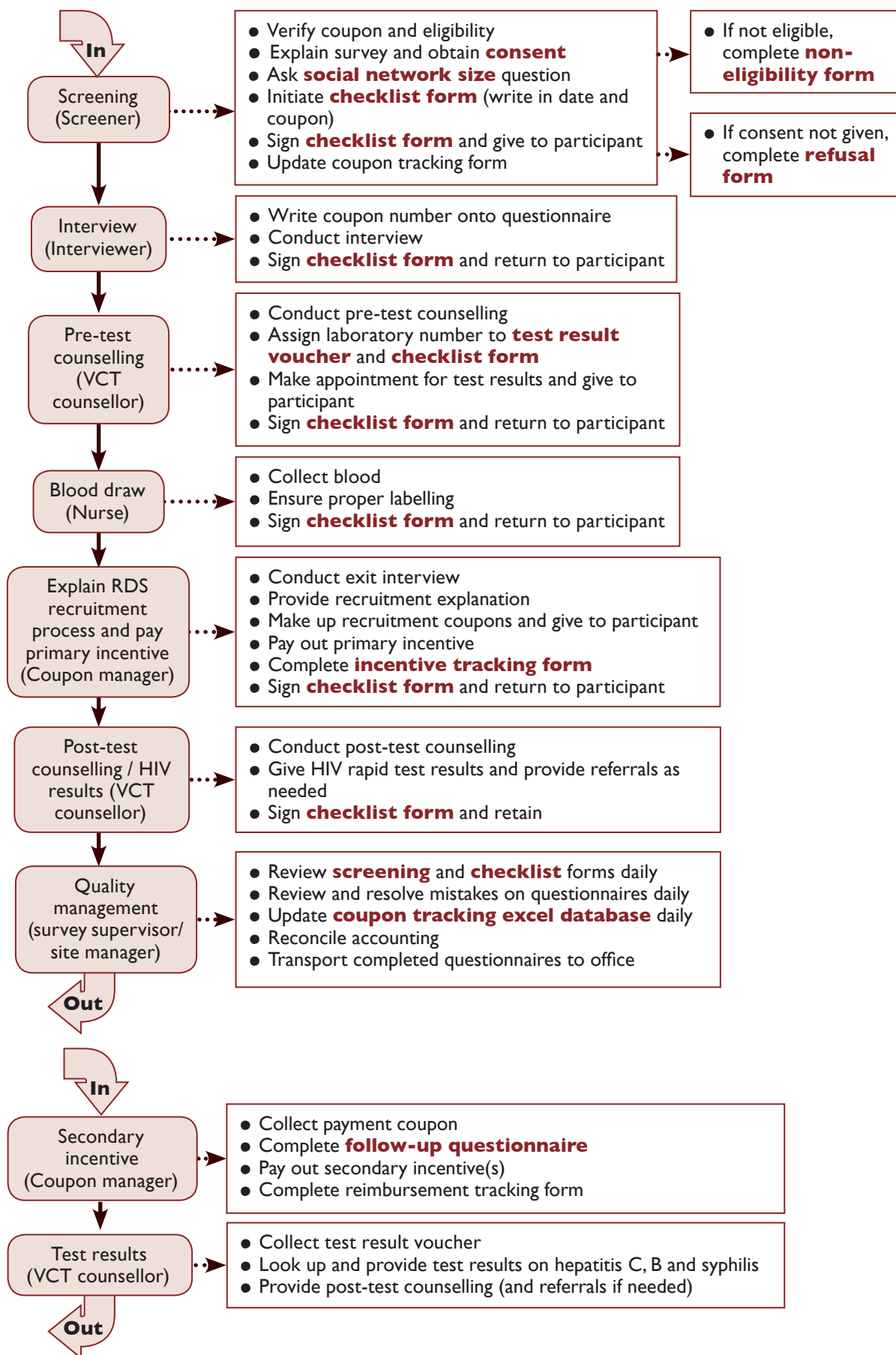


Figure 12.1 Flowchart of an RDS survey protocol, staff roles and corresponding forms

Once forms are completed, they should be accessible to those who may need them. If forms are entered into a computer management database, they should be easily accessible to appropriate staff members in case the forms need reviewing. Forms may need to be reviewed when a participant's information on one form does not correspond to that on another form or to the information contained in the participant's questionnaire, or when the computer management database is not working.

Electronic data storage

Data from forms should be entered into a computerized management database for ongoing oversight of the survey. There are several programs available to do this. This can be useful for storing important bits of information and for tracking:

- identification codes or coupon numbers that have been redeemed
- dates of coupon redemption and distribution
- expiry dates on distributed coupons
- number of waves completed
- number of valid coupons outstanding
- amount of incentive owed to participants for successful recruitments.

If there is no on-site computer management database that collects this data throughout the day, data from forms can be entered into a computer at the end of the day (in a central location where there is a computer) or during the site working hours when it is not too busy. This computer should be password protected to ensure safe storage and confidentiality. All forms should be initialled once they are entered into the database to indicate that they have been reviewed and can be stored in a more permanent storage location. It is very important to back up any data that is stored.

Description of forms

Introduction

Each of the forms described below are simply titled to reflect their purpose. Some forms may need to be renamed to suit the needs of specific surveys. Depending on the number of sites and the number and type of populations being sampled, different forms may be useful. The contents of each of the forms described in this unit can be modified to meet the needs of a specific RDS survey. Examples of each type of form are presented in Annex 6. The following RDS survey forms are described in this unit:

1. Checklist form—follows each participant from the moment he or she enrolls in the survey until the time he or she completes the survey (Annex 6.1).
2. RDS coupon tracking form—tracks who recruited who by recording the identification codes or numbers of each participant's coupon; this is essential data to collect (Annex 6.2). If there are no computers at the survey site, participants' coupon numbers can be uploaded in an RDS tracking database at a later time. This database is described later in this unit. It stores useful pieces of data that can be used throughout the survey to monitor the flow of participants, the length of recruitment chains and recruitment effort, and to reduce the number of coupons given to participants as the survey progresses.

3. Screening form—this form is used to screen persons who have a valid coupon and are interested in enrolling in the survey (Annex 6.3 and 6.4).
4. Ineligibility form—summarizes why a participant was found ineligible at screening (Annex 6.5).
5. Information sheet and consent form—explains the purpose, requirements, risks and benefits of the survey and asks the participant for acknowledgement of informed consent. The referral coupon is stapled to this form and they are filed together (Annex 6.6).
6. Refusal form—summarizes why a participant refused to participate (Annex 6.7).
7. RDS network size questionnaire—administered face-to-face by a survey staff member, it gathers information on the participant's network size and characteristics, a necessary element for RDS analysis; this is mandatory for all RDS surveys and can be either embedded in the main behavioural survey or as part of the screening form (Annex 6.4).
8. Recruitment explanation script—contains all of the information needed about the coupon recruitment process (Annex 6.8).
9. Financial reporting form—tracks the payment of primary and secondary incentives (Annex 6.9).
10. Another form to consider using in an RDS survey is the follow-up questionnaire (Annex 6.10). This form assesses reasons why peers do not accept coupons and is administered face-to-face every time a participant returns to the survey site for their secondary incentives.

Checklist form

The explanation of this form starts with a short case study that can be discussed in small groups.

Read the following case study and respond to the question that follows it.

Your survey site is set up with several steps: check-in, screening, interviewing, pre-test counselling, specimen collection, coupon distribution and incentive distribution. Towards the end of the first week when the daily number of interviews begins to increase, movement through the survey site becomes chaotic. Participants become confused and frustrated while trying to get to the next step in the survey. Some try to go from screening directly to collect their incentive. The coupon manager is unable to determine whether these participants have completed the survey and goes ahead and gives them an incentive.

What would you do to facilitate an organized flow of participants through the survey process?

If there are many steps in the survey process and different staff members are responsible for each step, it is helpful to have a checklist that can be checked off and signed by staff as a participant completes each survey step.

- Once the participant has completed each of the survey steps (eligibility, interview, explanation of the recruitment process, recruitment coupons, biological specimen, pre-test counselling, post-test counselling), he/she can submit the completed checklist to receive an incentive.

- This can help staff remember the steps in the survey and provide the necessary paperwork to ensure that the participant has completed each of the survey steps needed to receive a primary incentive.
- The RDS survey form in Annex 6.1 provides a sample procedure process checklist.

The checklist form (see Figure 12.2) should contain each of the steps to be completed by the participant and is carried by the participant throughout the survey process. Once the participant completes a specific step, the staff overseeing that step will check off and sign the box to the right of that step. This will be an indication to the staff member overseeing the next step that the previous step has been completed. The final step in the RDS process is payment of the incentive.

In the example checklist in Figure 12.2, the following information is collected during the RDS survey process:

1. Date—enter the date when the potential participant is being interviewed.
2. Identification or coupon number—write in the coupon number. Ensure that the coupon number is correct and matches that of the coupon brought in by the potential participant.
3. Network size—this could be useful when the coupon manager explains the coupon recruitment process to encourage recruiters to recruit from their social network (see Annex 6.8 for the coupon explanation script).
4. Eligibility—does the potential participant meet all eligibility requirements? If not, then the staff member completes the ineligibility form (described below). If yes, then go to the next step in the checklist.
5. Consent—check and sign this section once the participant reads, understands and gives consent for participation.
6. RDS network size questionnaire—check and sign this section once the participant responds to the network size questions. This is very important for RDS data analysis and must be completed face-to-face. For more information about this questionnaire, see Unit 9. For this example the network size question is being asked by the screener.
7. Interview (computerized or paper)—check and sign this section once the participant completes the entire questionnaire.
8. Pre-test counselling—the VCT counsellor checks and signs this section when the pre-test counselling is completed.
9. Test result voucher—this is provided by the pre-test counsellor as a receipt with the time and date the participant is to return for test results (see Unit 14). The laboratory number can be added to have an extra paper trail to ensure that the correct coupon number is connected with the correct laboratory result.
10. Collection of blood or other biological sample—check and sign this section once the sample is collected.
11. Recruitment coupon explanation—the coupon manager checks and signs this section to record that the participant has received the recruitment information.
12. Recruitment coupons—this section is checked and signed once the participant has received the recruitment coupons.
13. Primary incentive—once the participant has completed all of the necessary steps in the survey process, he or she will need to present the completed (checked and signed sections indicating that all required steps have been completed) checklist form to a designated survey staff member in order to receive his or her primary incentive.
14. Post-test counselling—in this example the participant is receiving his/her test results

Date:		Social network size																					
Coupon number:		<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>																					
SIGNATURE																							
RECEPTIONIST	The participant is eligible and enrolled	<input type="checkbox"/> Yes	<input type="checkbox"/> No ¹																				
	Informed consent completed	<input type="checkbox"/> Yes	<input type="checkbox"/> No ²																				
	Participant provided network size <i>(Fill in the network size at top of form)</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
INTERV.	The participant has completed the questionnaire	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
VCT	Participant received pre-test counselling	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
	Participant received test result voucher	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
NURSE	Blood sample taken	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
COUPON MGR.	Participant received coupon explanation	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A																			
	Participant received recruitment coupons	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A																			
	Primary reimbursement paid	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
VCT	Participant received post-test counselling	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
	Participant received test results	<input type="checkbox"/> Yes	<input type="checkbox"/> No																				
Notes:																							

1 – Please fill non-eligibility criteria form

2 – Please fill refusal form

Form has been entered into database

Figure 12.2 Example of a checklist form

on the same day of enrolment. The VCT counsellor checks and signs this section when the post-test counselling is completed.

15. Test results received—the VCT counsellor checks and signs this section when the tests are provided to the participant. At this point the VCT counsellor will retain the checklist form and the participant will depart.

Other pieces of data to collect are the time the participant enrolled and the time the participant finished the survey steps.

RDS coupon tracking form

The coupon tracking form is important for tracking who recruited whom and for managing the number of coupons redeemed and the number of valid coupons remaining in the community. This form records the identification codes or coupon numbers of redeemed coupons and of recruitment coupons.

Some type of paper coupon management system should be utilized even if there is an on-site computer system tracking this information. Figure 12.3 is an example of a handwritten coupon log.

SEED 3

COUPON TRACKING FORM
(Complete a new form for each seed)

	COUPONS GIVEN OUT (PUT IN COUPON NUMBERS)					
	DATE	AGE	PARTICIPANT COUPON NO.	COUPON 1	COUPON 2	COUPON 3
1	16/5	32	33	331	332	333
2	16/5	19	331	3311	3312	3313
3	16/5	21	32	321	322	323
4	16/5	25	31	311	312	313
5	17/5	36	311	3111	3112	3113
6	17/5	42	312	3121	3122	3123
7	17/5	24	333	3331	3332	3333
8	17/5	44	323	— INELIGIBLE		—
9	17/5	18	313	3131	3132	3133
10	17/5	22	3311	33111	33112	33113
11	18/5	33	33111	331111	331112	331113
12	18/5	35	3112	31121	31122	31123
13	18/5	41	3113	31131	31132	31133
14	18/5	19	33112	331121	331122	331123
15	18/5	22	31121	311211	311212	311213

Figure 12.3 Sample of a handwritten coupon log

Screening form

Before someone can enrol in the survey, they should be screened to determine their eligibility. The screening form is based on the eligibility criteria. The format of the screening form for a survey on female sex workers can be similar to that shown in Figure 12.4.

Often the screening form may include extra questions, such as the network size questions

SCREENER NAME	COUPON NUMBER	DATE		
		_____	_____	_____
1	This person is 15 years or older <i>(Probe: How old are you?)</i>	Eligible <input type="checkbox"/>	Ineligible <input type="checkbox"/>	
2	Has exchanged sex for money with more than one client in the past six months <i>(Probe: When was the last time you exchanged sex for money?)</i>	Eligible <input type="checkbox"/>	Ineligible <input type="checkbox"/>	
3	Lives and/or works and/or studies in area of survey <i>(Probe: In what general area do you live, work or study?)</i>	Eligible <input type="checkbox"/>	Ineligible <input type="checkbox"/>	

Figure 12.4 Example of questions for a screening form

(see Unit 9) and questions about how the participant received their coupon and/or about the participant's relationship to their recruiter (an example of a screening form with the social network size questions is in Annex 6.4; an example of a screening form with extra assessment questions is found in Annex 6.3).

Ineligibility form

The ineligibility form, as shown in Figure 12.5, can track the characteristics of your sample by identifying why some people were not eligible for your RDS survey. The form can be modified to reflect the eligibility criteria in your survey.

For instance, in a survey on people who inject drugs, aged 18 years and older, who have injected in the past month and live in a certain area, the reasons for ineligibility would be:

- is not a person who injects drugs
- is a person who injects drugs but has not injected in the last month
- is under 18 years
- does not live in the required area
- does not have a valid coupon.

Other useful information to collect could be:

- coupon number (take the coupon away from the ineligible person)
- date
- sex of person
- survey site (if more than one)
- approximate age.

Information sheet and consent form

The information sheet and consent form may vary by survey. An example of an information sheet and consent form is included in Annex 6.6. Information sheets should explain

the steps of the survey and remind participants about confidentiality and anonymity. Consent forms are necessary for all research involving human subjects. Consent forms basically explain the survey process and requirements, confidentiality and rights assured to participants.

INELIGIBILITY FORM
PEOPLE WHO INJECT DRUGS

To be completed by the Screener

Instructions: Please indicate the **principal reason** why someone does NOT meet the inclusion criteria to participate in the survey.

Ineligibility codes

1. Under age 15
2. Did not inject drugs within past one month
3. Does not live/work/study in area of survey
4. Coupon not valid
5. Does not have a coupon
6. Already participated
7. Other — specify

NUMBER	COUPON NUMBER <small>(Take away coupon and write number in this column)</small>	DATE	REASON FOR NON-ELIGIBILITY <small>(Write the code in this column)</small>	IF OTHER, SPECIFY	SCREENER SIGNATURE
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					

Figure 12.5 Example of an ineligibility form for people who inject drugs

Refusal form

The refusal form, as shown in Figure 12.6, is useful for tracking the characteristics of your sample by identifying why some people refused to complete the RDS survey. This form can be modified to reflect the nature of your survey.

Possible reasons for refusing to participate in a survey could be that the person:

**REFUSAL FORM
FEMALE SEX WORKERS**

To be completed by the Screener

Instructions: Please indicate the **principal reason** why someone does NOT want to participate in the survey.

Refusal codes

1. Did not want to sign consent
2. Did not want to answer questions
3. Fear of being identified as female sex worker
4. No time
5. Did not want to give blood
6. Other – specify

NUMBER	COUPON NUMBER <small>(Take away coupon and write number in this column)</small>	DATE	REASON FOR REFUSAL <small>(Write the code in this column)</small>	IF OTHER, SPECIFY	SCREENER SIGNATURE
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					

Figure 12.6 Example of a refusal form for female sex workers

- did not want to give a biological specimen
- did not want to answer questions
- was afraid of being identified
- did not have time.

Other useful information to collect could be:

- coupon number (make sure to take the coupon away from a person who refuses to participate to avoid him or her giving the coupon to someone else; if they say they will come back at a later date, make an appointment and hold on to the coupon for them until they return)
- date
- sex of person
- survey site (if more than one)
- approximate age.

RDS network size questions

These questions are vital to the analysis of RDS data and need to be asked face-to-face. Sometimes these questions are part of the larger behavioural questionnaire and at other times they are in a form of their own. The RDS network size questions and structuring are described in more detail in Unit 9.

If the screener rather than the interviewer will ask these questions, you might consider embedding them in the screening form mentioned above.

Recruitment explanation script

The coupon explanation script is useful for helping the appropriate staff member correctly explain the recruitment process to a participant. See Annex 6.8 for an example of a recruitment explanation script. In some surveys, a recruitment script or information sheet is handed out to the participant to review when they leave the survey site.

Financial reporting form

The financial reporting form, as shown in Figure 12.7, is important for tracking the payment of primary and secondary incentives. Since most RDS surveys are anonymous and confidential, no personal identifiers (such as someone's signature for receipt of an incentive) should be recorded. The staff member responsible for managing the payment of incentives will need to account for all incentives given to participants, as well as ensure that there is enough money at the survey site to pay out incentives.

Financial management of incentives relies on the strict tracking of coupon numbers to ensure that the correct incentive is given to the correct participant. See Annex 6.9 for an example of a financial reporting form.

Coupon database

If on-site computers are available, coupons and other information can be tracked in an electronic database. A commonly-used electronic database is the RDS Coupon Manager (RDSCM).

RDSCM is free and available on the internet for download. The latest version, version 1.02, can be found at <http://www.respondentdrivensampling.org>

However, the older version, version 3.0, is available at <http://globalhealthsciences.ucsf.edu/prevention-public-health-group/global-strategic-information-gsi/surveillance/surveillance-resources/rdscm>

This web site also has step-by-step instructions for using RDSCM version 3.0. Version 3.0 is only compatible with Windows XP but has the necessary functionality and is flexible in its use. The latest RDSCM version, version 1.02, is compatible with Windows 7 but has many fields that are permanent and it is likely to be inapplicable to most international RDS surveys. For this and other reasons, a majority of RDS surveys still use RDSCM version 3.0.

PRIMARY AND SECONDARY REIMBURSEMENT TRACKING FORM

Instructions: Coupon manager must complete this form each day for each seed. The date primary reimbursement was given (first column) is the same date the participant was interviewed.

Seed number: _____ Date: _____ Coupon manager _____
Signature

Date primary reimbursement given	Coupon number	Running total for primary reimbursement	RDS coupons given	Date secondary reimbursement given	Running total for secondary reimbursement
			1. 2. 3.	1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.	1. 2. 3.
			1.	1.	1.

Figure 12.7 Example of a financial reporting form

RDSCM can be useful for storing important elements of coupon information and for tracking:

- coupon ID numbers that have been redeemed
- linkages between a recruiter and his/her recruits using coupon numbers
- dates of coupon redemption and distribution
- expiry dates on distributed coupons
- number of valid coupons outstanding
- amount of incentive owed to participants for successful recruitments.

In some situations where there is not a dedicated computer at the survey site, a central database of identification codes or coupon numbers should be maintained to manage recruitment progress. Figure 12.8 shows an example of fields to include in the database. This example assumes a systematic coupon numbering system and the distribution of three recruitment coupons to each participant.

COUPON NUMBER OF THE PARTICIPANT			NEW COUPONS GIVEN OUT *NE is not eligible				INCENTIVE GIVEN OUT DATE				LAB	INELIGIBLE	NETWORK
No	participation date	coupon #	coupon 1	coupon 2	coupon 3	expiration date	primary incentive	second incentive 1	second incentive 2	second incentive 3			
1	13/4/07	1	11	12	13	27/4/07	27/4/07	28/4/07	28/4/07		T-001		5
2	13/4/07	2	21	22	23	27/4/07	27/4/07	28/4/07	28/4/07	28/4/07	T-002		4
3	13/4/07	3	31	32	33	27/4/07	27/4/07		28/4/08		T-003		10
4	13/4/07	4	41	42	43	27/4/07	27/4/07	28/4/07	28/4/07	28/4/07	T-004		3
5	13/4/07	5	51	52	53	27/4/07	27/4/07				T-005		5
6	14/4/07	6	61	62	63	28/4/07	28/4/07				T-006		8
7	14/4/07	7	71	72	73	28/4/07	28/4/07				T-007		5
8	14/4/07	8	NE* 81	82	83	28/4/07	28/4/07				T-008		8
9	14/4/07	11	111	112	113	28/4/07	28/4/07				T-009		11
10	14/4/07	12	121	122	123	28/4/07	28/4/07				T-010		2
11	14/4/07	21	NE 211	212	213	28/4/07	28/4/07				T-011		2
12	14/4/07	22	221	NE 222	NE 223	28/4/07	28/4/07				T-012		4
13	14/4/07	23	231	232	233	28/4/07	28/4/07				T-013		5
14	16/4/07	32	321	322	323	30/4/07	28/4/07				T-014		7
15	16/4/07	41	411	412	413	30/4/07	28/4/07				T-015		2
16	16/4/07	43	431	432	433	30/4/07	28/4/07				T-016		8
17	16/4/07	51	511	512	513	30/4/07	28/4/07				T-017		3
18	14/4/07	61	611	612	613	28/4/07	28/4/07				T-018		10
19	16/4/07	81	811	812	813	30/4/07						X	
20	16/4/07	82	821	822	823	30/4/07	28/4/07				T-019		4
21	16/4/07	211	2111	2112	2113	30/4/07						X	
22	16/4/07	212	2121	2122	2123	30/4/07	28/4/07				T-020		9
23	16/4/07	213	2131	2132	2133	30/4/07	28/4/07				T-021		16
24	16/4/07	221	2211	2212	2213	30/4/07	28/4/07				T-022		6
25	16/4/07	222	2221	2222	2223	30/4/07						X	

Figure 12.8 Example of an RDS coupon tracking database in Microsoft Excel

Data can be stored in a Microsoft Excel or other type of database depending on the survey needs and software availability. Data included in the database above are the date of enrolment, the enrolling participant’s coupon number and recruitment coupon numbers, the date of expiry on the coupon, the dates for receiving the primary and secondary incentives, the corresponding laboratory number, whether the participant was eligible or not (an “x” indicated the person was ineligible) and the social network size of each participant.

Formulas can be easily embedded into the database to automatically generate recruitment

coupon numbers and to check their consistency (to see if the same number has shown up more than once and if a coupon number has come in that was never distributed as a recruitment coupon number) and expiry dates.

Data management

Management of data forms

The data management team should maintain a log of data forms. This will contain information about the number of forms delivered on a given day, when the forms were delivered, who delivered the forms, who received the forms and the coupon numbers of the forms that were delivered. The time interval between the delivery of the forms and entry of the data from those forms should be short. This will help to:

- reduce the chances of losing the form
- quickly address any errors in the forms with the RDS survey staff.

Checking for data errors

There are generally two types of data error: data and keystroke errors. Data errors are due to incorrect data collected in the field and keystroke errors occur during data entry. Data errors should be monitored by well-trained staff and site managers during all stages of data collection. Keystroke errors will be mitigated through double data entry, close supervision of well-trained data entry staff and data checking by the database manager.

Correcting errors

Data errors should not be unilaterally corrected by data entry staff, but rather through a standardized data operating protocol. A protocol on managing data errors should list all anticipated errors and provide possible resolutions for these errors. Keep a log of errors that are corrected, and why and how they were corrected. It will be easier to correct data errors if data are entered as soon as possible after being collected.

Data dictionary

A data dictionary, also known as a codebook, is very important for ensuring correct entry of data. The data dictionary provides a description of the data and can include:

- column identification numbers
- column descriptions
- column type (string, numerical, etc.)
- column length
- column length for decimal places
- minimum and maximum value of the variable
- other values for variables (missing, unknown, etc.).¹

¹ Ali M et al. Organizational aspects and implementation of data systems in large scale epidemiological studies in less developed countries. *BMC Public Health*, 2006, 6:86.

Data security

Because RDS surveys often recruit stigmatized populations, data should not be linked with personal identifiers. As most RDS data have no personal identifiers and participants are usually linked to it by either their unique coupon number or by a survey identification code, there should be no method for anyone to connect any of the data to an actual person.

Nevertheless, all data should be password protected and accessed only by authorized users. All entered and un-entered questionnaires, logs of data activities, data printouts, etc., should be kept in a locked and secure file cabinet.

Computers should have antivirus software installed in them and a daily or weekly backup copy of all data entered should be kept.

Summary

As in all surveys, careful management of survey data is essential. From the time a person is screened until they complete their second visit, there are important pieces of information that need to be recorded. Forms are available to track the survey process and record data, and will vary in type and the information asked for depending on the survey design.

Unit 12 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Small group discussion

Get into small groups to discuss these questions.

1. Look at the different forms and think about which ones would be useful for an RDS survey that you would conduct in your country. What are some other pieces of information you would want to add to these forms to make them more useful to you?
2. What are the different types of filing systems that you could use to store paper forms? How would you store electronic forms? Which staff member in your survey would be responsible for managing the filing systems? How would you secure your forms?

Apply what you have learnt/case study

1. Two weeks into an RDS survey using a computerized survey you get a printout of all the coupon identification numbers that have entered the survey. You notice that some of the numbers are duplicated and that some of the numbers do not correspond with what you have listed on your paper copy. You also notice that the computer printout shows 52 participants when you thought there had been 55 participants.

- a. In addition to the identification numbers printed out from the computer file, what other pieces of information from the computer printout would you want? How would you ask to sort the data?
 - b. What other sources of data would you use to understand the discrepancies? Which forms could be useful in your efforts?
 - c. What could be some of the reasons why there are coupon number discrepancies in the computer database?
2. You have determined that two missing files from the computer somehow did not get saved into the database and are lost. The biggest problem is that one of the missing files is from a seed and the other is from someone in wave 1. You are worried that you have lost this important data but know that the first two days of the survey were very busy and that staff were using the computerized screening system for the first time. What could you do in this situation?

Unit 13

Controlling sample
growth and ending
RDS recruitment

Overview

What this unit is about

This unit provides methods for ending an RDS survey and for controlling the rate at which the sample grows.

Warm-up questions

1. True or false? Depending on your sample size and the number of seeds you select, you can determine the exact number of weeks needed to conduct your RDS survey. Circle your answer below.

True

False

2. What are some of the problems that may arise when someone arrives at the survey site with a valid coupon and are told to leave because the survey has ended?
3. The RDS recruitment process allows each seed to give three coupons to participants, allowing the sample size to grow _____, not linearly.
4. Which choice below is incorrect? Some of the suggestions for ending an RDS survey include:
 - a. staying open for an extra couple of weeks to inform post-survey recruits that the survey has ended
 - b. as soon as the sample size is reached, closing the door to the survey site and putting a sign on the door saying that the survey has ended
 - c. continuing to provide HIV information and materials to post-survey recruits
 - d. informing all participants during the survey that no more interviews will be conducted once sample size is reached (and inform them of the sample size)
 - e. using expiry dates.
5. True or false? Sample size growth can be controlled by reducing the number of coupons given out to participants as the survey progresses. Circle your answer below.

True

False

Introduction

What you will learn

By the end of this unit, you should be able to:

- describe the potential problems that can arise when ending an RDS survey
- explain ways to effectively end an RDS survey
- describe how to control the rate of recruitment.

How long should recruitment take?

Reaching sample size

It is hard to estimate how long it will take to reach the predetermined sample size. The time needed to reach sample size depends on the:

- size of the sample
- population of interest
- number of seeds you start with
- incentive level
- density of the survey population's networks.

Other factors may impact the time it takes to complete recruitment:

- the comfort and accessibility of the survey site
- the hours of operation
- how well the survey staff treats the participants
- the degree of enthusiasm the participants have about the survey
- the number of interviewers available to accommodate participants.

Lessons learnt

When an RDS survey is being conducted for the first time, there is no way to estimate the amount of time it will take to complete recruitment.

- One survey of people who inject drugs with 20 seeds took 8 weeks to reach a sample size of 400.
- Another survey of people who inject drugs starting with 8 seeds took 6 weeks to reach a sample size of 400.

In past surveys, researchers found:

- The rate of recruitment for sex workers is often slower than for people who inject drugs.
- A large number of seeds may result in a faster recruitment process but may also reduce the chances of producing lengthy recruitment chains, thereby reducing the chances of reaching equilibrium.
- An overly generous incentive may increase the rate of recruitment to the point of overwhelming survey sites and may also lead to participants selling their coupons and falsifying their membership in the survey population.

If the population is densely networked, the rate of recruitment may be faster. This is difficult to predict unless surveys on the population's networks have been previously conducted.

Remember that participants who feel enthusiastic about the survey and are well treated by survey staff will be more inclined to invite their peers to the survey. Having a survey site that is comfortable, accessible and secure will encourage participants to recruit their peers.

In past RDS surveys, a sample size of 400 adequately networked people who inject drugs, sex workers or men who have sex with men could be reached in fewer than two months (see Table 13.1), so allow for at least this amount of time.

Table 13.1 Past examples of the time it takes to reach sample size

Survey location	Survey population	Sample size each site	Time to reach sample size	Initial seeds
Alexandria, Egypt	Men who have sex with men	267	10 weeks	25
Cairo, Egypt	People who inject drugs	429	12 weeks	25
Hodeidah, Yemen	Female sex workers	300	10 weeks	6
Khartoum, Sudan	Female sex workers	321	3 weeks	8
Viet Nam: ● Ho Chi Minh City ● Hanoi ● Hai Phong (people who inject drugs only)	People who inject drugs, sex workers	400	10 weeks	20
Beijing, China	Men who have sex with men	326	14 weeks	1 (note: single seed not recommended)
Zagreb, Croatia	Men who have sex with men	360	14 weeks	9
Belgrade, Serbia	People who inject drugs	400	8 weeks	8
Dhaka, Bangladesh	Men who have sex with men	530	10 weeks	8
Manaus, Brazil	People who inject drugs	499	12 weeks	7
Dimapur, India	Sex workers	400	8 weeks	6

Ending an RDS survey

Potential problems

Some of the first RDS surveys used rented storefront locations as survey sites. Once the sample size was reached, the site was easily closed. Individuals who showed up for an interview once the survey ended found a sign on the door indicating that no more interviews were being held.

Some recruits who had a valid coupon, took time to travel to the survey site and were prepared to spend an hour or so completing an interview were unaware and disappointed that the survey had ended. Some of these people also probably felt resentful. Situations like this could damage future survey opportunities with the target population. It could also create resentment among other research groups who want to conduct their own research activities with these populations and have to overcome the negative residue left from the survey.

Group discussion

What are some ways you can think of to end an RDS survey without causing problems?

Ending recruitment

One suggestion for ending an RDS survey is to inform all participants that the survey will end once the sample size is reached.

- Add this information on the coupons: “Once 400 participants have been interviewed, no more interviews will be conducted.”
- Ensure that coupons have expiry dates to indicate the period of time during which a recruit can enrol in the survey.
- Make the coupons expire after a set time period e.g. two weeks from the time the participant receives his or her recruitment coupons. The expiry date can be written directly onto the coupon so that the survey staff and the participant know the exact date when the coupon expires.
- As the sample size is being reached, the amount of time given for expiry can be reduced to ensure that participants will not come into the survey after it has ended.
- Stop giving out coupons when you are close to reaching sample size.
- Post signs to indicate that the survey is nearing the end. You can say something like the following: “75 more interviews before the end of the survey”.
- Produce a coupon tree that is visible to all which shows the coupon numbers and the recruitment growth.

Keeping the site open after reaching sample size

Keep the survey site open for a couple of weeks beyond the time the sample size was reached.

- A survey staff member should be present to explain why coupons are no longer being accepted and interviews no longer being conducted.
- If VCT was provided as part of the survey, a counsellor could also be present to offer post-survey recruits who show up at the survey site with a valid coupon to pay for their counselling or information about local HIV services or to discuss health issues.
- RDS survey protocols should consider including reimbursement for post-survey recruits' travel to the site and back to their home, even if the survey is closed.
- Post-survey recruits who have a valid coupon could be provided with a voucher for food or personal items.

If the coupon expiry dates accurately estimated the date on which the survey would end, then there should be very few or no people coming to the survey site once the survey ends.

Extra time for secondary incentives

Survey sites must stay open beyond the time that sample size is reached in order to ensure that participants have enough time to collect their secondary incentives. These incentives are given to thank participants who successfully recruited others.

It is difficult to determine how long a survey site should remain open beyond the end of the survey to accommodate those who have not redeemed their secondary incentive.

You could use a tracking system that counts the number of expected secondary incentives to be redeemed. But experience has shown that many participants never collect their secondary incentive.

One method for ensuring that participants collect their secondary incentive in a timely manner is to tell them to collect their secondary incentive no later than one week (or some other time period) beyond the expiry date on the coupon they gave to a peer.

- If the recruited peer has not come in by the date of expiry, then the recruiter will not be eligible to collect their secondary incentive.
- Information about whether someone has come in should be recorded in the coupon database (see Unit 12).

Controlling sample growth

Unredeemed coupons

In one survey, over 400 unredeemed coupons remained in the community once the survey ended. This occurred because an RDS sample grows exponentially, leading to two problems:

- difficulties with the flow of participants at the survey site
- an abrupt end to recruitment once sample size is reached, resulting in numerous unredeemed coupons remaining in the community.

Coupon reduction

The effects of exponential sample growth could be eliminated if the sample size were allowed to grow more linearly. To do this, you would limit the number of coupons distributed as the survey progresses:

- Survey supervisors would track the recruitment chains of all seeds and stop distributing three recruitment coupons once a recruitment chain reached a certain wave (such as the fourth wave).
- When a recruitment chain reached the fourth wave, interviewers would begin giving two recruitment coupons instead of three.
- By the sixth wave and for all the waves that follow, interviewers would give only one recruitment coupon.

If your survey is nearing its sample size, stop distributing recruitment coupons [36].

Coupon activation

Coupon activation can slow down the rate of recruitment as well. This works by assigning an activation date (usually a few days from the date the coupon was given to a participant) on the coupon. The participant/recruiter is asked to wait until the activation date before giving the coupon to a peer (someone he or she recruits). The recruit must also wait until after the activation date to redeem his or her coupon at the survey site.

Problems with slow recruitment

In cases where recruitment in the survey is going more slowly than was anticipated, the number of coupons should not be reduced during the survey. All those who completed the survey should get three coupons until the sample size is reached.

If recruitment is slow during the first month of the survey, this might imply that some seeds are not recruiting at all. The solution is to add new seeds if some seeds are not successful recruiters.

A coupon manager plays a crucial role in explaining to potential recruiters how coupons should be distributed and should try to make them enthusiastic about negotiating with his/her peers for inclusion in the survey. Recruiters should mention to their peers that the survey offers the possibility to get HIV/STI testing and counselling, HIV-related information, free condoms and lubricants, and primary/secondary incentives.

Do not plan to implement an RDS survey during major holidays (Ramadan, vacation time, etc.).

It is also important to remember that sex workers' interest in participation and incentives is higher during seasons when the demand for their services is low.

Closing the survey site

The methods for closing a survey site are no different for RDS than for any other survey that is located in a stationary location.

As previously mentioned, the RDS survey site must remain open beyond the end of the survey to respond to post-survey recruits and to pay out secondary incentives (and, if applicable, to provide test results). The survey budget should include time and staff for this and also for cleaning and closing down the survey site.

As with any survey, confidential materials should be either shredded or transported and stored in a secure location. All data from computers should be downloaded, transferred to a secure location and deleted from any computer that remains at the survey site.

Summary

It is difficult to know how long recruitment will last. The length of time for recruitment will depend on a variety of factors. When recruitment gets closer to reaching the target sample size, it is good practice to start slowing down recruitment before ultimately closing the survey office. It is important that recruitment ends slowly, deliberately and systematically rather than suddenly and unexpectedly. Utilize a number of strategies including coupon reduction. Clear and open communication with the survey population is critical to manage the expectations of coupon holders and those who have already participated and are expecting to return for a follow-up visit.

Unit 13 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want.

Small group discussion

Get into small groups to discuss these questions. If you are working on your own, write the answers to these questions.

1. In your local situation, what would be a good method of ending an RDS survey?
2. Would you consider coupon reduction? Why or why not?
3. How long beyond the time the survey ends would you consider leaving open the survey site?
4. What would you say to participants who show up with a valid coupon once the survey ends? Would you consider giving them something for their time or travel?

Apply what you have learnt/case study

Try this case study individually.

1. A health officer was planning a survey of sex workers using RDS. He was asked by his supervisor how long it would take to survey 500 sex workers in the district. The supervisor was concerned about the cost and redirection of staff to the project for its duration. The health officer needed to estimate the rate of recruitment. Since this had not been done in his country before, he emailed some people he knew had used RDS to recruit sex workers. Their answers varied:

- 14 weeks for 400
- 8 weeks for 300
- 16 weeks for 350.

Next he asked how many seeds they started with and the coupon return rate. What else might he ask?

2. Your supervisor has returned from a meeting where she heard a “horror” story about an RDS-based survey of people who inject drugs in the capitol. The survey site was overwhelmed by people who inject drugs seeking to be interviewed. Some became unruly and a couch was broken in a small fight. The site was shut down for a couple of days in the hope of restoring order. She wants to know if you know why this would have happened and how you plan to avoid a similar situation.

- a. How would you control coupon use?
- b. How would you control coupon distribution?
- c. What other steps might be taken to insure an ongoing positive relationship with the community of people who inject drugs when the survey shuts down?

Unit 14

Biological testing and
test results

Overview

What this unit is about

Most HIV surveillance surveys include biological specimen collection and testing. The addition of biological testing involves consideration of HIV testing and counselling, collection of specimens to test other infections such as hepatitis B and C, and STIs, and the provision of test results and referrals for treatment and care. This unit provides suggestions regarding, and examples of, the steps and additional forms needed to include a biological component in a behavioural surveillance survey. In Annex 8 there is an example of laboratory technician standard operating procedures as well as forms for managing biological testing and test results.

Warm-up questions

1. True or false? All surveillance surveys collect biological specimens in order to test for HIV? Circle your answer below.

True	False
------	-------
2. When conducting an HIV test it is necessary to have a trained professional provide _____ and when giving HIV test results is it necessary to have a trained professional provide _____.
3. Which one of the following is a type of specimen not normally collected during an integrated biological-behavioural surveillance survey?
 - a. blood
 - b. saliva
 - c. hair
 - d. anal swab
 - e. vaginal swab.

Introduction

What you will learn

An important objective in most HIV surveillance surveys among key populations at higher risk of HIV exposure is to gather estimates on the prevalence of HIV and other infections. There are numerous considerations and decisions to make when including a biological component in any survey. A biological component will involve decisions about which tests to conduct and the method to use in conducting them, the manner in which biological specimens will be collected from the population, the procurement of biological test kits, coordination with local or national laboratories, the hiring of extra professional staff such as trained pre- and post-test counsellors and phlebotomists and/or nurses and the addition of adequate space at the survey site.

By the end of this unit, you should be able to:

- develop additional steps for an RDS survey to include the collection of biological specimens and provision of test results
- know some of the different testing procedures used in HIV testing
- describe the different types of forms to manage biological testing
- design and use vouchers and coupons for test results and referral to care and treatment
- access useful resources for HIV testing and pre- and post-test counselling.

Collection of biological specimens

Considerations

The majority, but not all, HIV surveillance surveys of key populations at higher risk of HIV exposure collect biological data. Out of 123 RDS surveys reviewed between 2004 and 2007, 107 (87%) reported collecting both HIV biological and behavioural data concurrently, and the remaining 16 (13%) reported only collecting behavioural data [5]. Surveys may not be consistent in the methods by which biological specimens are collected. In the same review of RDS surveys, of those that reported collecting biological specimens and reported the method of collection, 44 (36%) collected venous blood, 6 (5%) collected oral fluid and 25 (21%) collected urine, penile or vaginal swabs [5].

There are several considerations when planning biological specimen collection and testing. The selection of HIV testing approaches for surveillance depends on national policies and laboratory capacity. Where feasible, HIV testing should be conducted in settings where referrals to follow-up care and treatment are provided. Linked anonymous testing (with informed consent) is the approach most often used in integrated biological-behavioural surveillance surveys among key populations at higher risk of HIV exposure [43]. Informed consent for HIV testing within a surveillance survey must follow the country's relevant policies and guidelines.

These include:

- types of test kit to use
- types of test to conduct
- how to collect specimens

- facility in which to collect the specimens
- adequate laboratory facility in which to conduct certain tests
- which testing algorithm to use for HIV testing
- type of staff needed and their roles and responsibilities
- types of form needed.

Planning for the biological component of an integrated biological-behavioural surveillance survey should include professionals involved in laboratory testing and science, test kit procurement and HIV testing specialists and policy planners.

Linked anonymous testing

Linked anonymous testing involves linking the results of the HIV test with the person tested and allows the person to receive his or her HIV test results without providing personal identification (however, some sociodemographic information can be used). This method requires obtaining informed consent and providing pre-test and post-test counselling. Linked testing may or may not occur in a clinical setting.

Linked HIV testing can be either confidential or anonymous. Confidential means that only the person tested and some qualified health professionals know the results of the test. Anonymous means that no personal identifiers are used to associate the test result to a specific person. Linked testing implies that the testing is anonymous since the link is some non-personal identification, such as a code or a number, to link the tested person to his or her results.

For most HIV integrated biological-behavioural surveillance surveys, linked anonymous and confidential testing involves a staff member obtaining informed consent and providing pre-test counselling prior to specimen collection. The specimen is then labelled with a code not linked to any personal identifying information. After HIV testing is performed, the test results are given to the person, along with post-test counselling.

Specimen selection

Many types of specimen can be used with HIV and other infections testing technologies for biological surveillance:

- whole blood
- plasma, serum
- oral fluids (vaginal or anal)
- urine.

The choice of specimen collected depends on logistics, populations, sites selected and the HIV testing strategy. Specimens must be collected, tested and stored in an appropriate manner in order to obtain accurate and reliable results. For biological surveillance activities, specimens are usually collected and stored prior to HIV testing at a regional or national laboratory. Serum, plasma and dried blood spot specimens can be stored and tested at a later date; specifications for storage will depend on the type of specimen collected. Specimens not tested on site at the local level will need to be transported to a regional or national laboratory for testing. The methods by which specimens are

transported will depend on the country's infrastructure. Few countries have courier systems linking health-care facilities and laboratories. More frequently, the field surveillance staff members themselves transport the specimens from the local to the national laboratory.

For specific information about collecting, processing and storing blood, serum and plasma specimens see UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance [43].

Providing pre- and post-test counselling

Provisions for pre- and post-test counselling, provided by trained staff, must be included in any survey that plans to perform HIV testing and provide results to participants. Each country will have specific guidelines and training procedures for HIV pre- and post-test counselling. In addition, counselling staff should be trained on the specific health concerns of key populations at higher risk of HIV exposure.

More information about pre- and post-test counselling can be found at: <http://www.who.int/hiv/topics/vct/en/index.html>

Having adequate space

If you are collecting biological specimens for your RDS survey, it is important to select an appropriate site. It is highly recommended to collect biological specimens at the same site in which you conduct interviews. Determine whether you can collect biological specimens in a non-medical setting. If not, this limits where you can establish survey sites.

It is important to ensure that the survey site has adequate space for the collection and storage of specimens. The space should allow for:

- a private area to collect a biological specimen (saliva using a swab, blood using a finger-prick or needle)
- proper bio-waste disposal receptacles
- a proper area for processing and storage of tests (a place hidden from view of the participants so they cannot see the results)
- adequate space to store supplies such as test kits, alcohol, cotton, paperwork and other materials
- a refrigerator/freezer for storing specimens, if necessary.

Follow universal safety precautions. See Centers for Disease Control and Prevention [44], Secretariat of the Safe Injection Global Network [45] and UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance [43] for guidance.

Selection of HIV test and testing strategies

For surveillance as well as diagnostic purposes in low- and middle-income countries, technologies that identify HIV antigen are expensive and technically more difficult. In most industrialized countries, current diagnostic testing procedures use an enzyme immunoassay (EIA) to screen a specimen and, if it is reactive, the result is confirmed by testing the specimen with a western blot test.

However, surveys have shown that the testing algorithms using EIAs and rapid tests are as reliable for confirmation as those using western blots. In addition, compared with western blots, EIAs and rapid tests are less expensive, do not require as high a level of technical expertise to perform and interpret, and produce fewer indeterminate results.

Therefore, UNAIDS and WHO recommend alternative testing strategies using combinations of EIAs and rapid tests to confirm initial reactive test results. The tests should be highly sensitive and specific to provide reliable detection of antibodies in a specimen. EIAs and rapid tests contain antigens to both HIV-1 and HIV-2, and can therefore detect antibodies to both HIV types. Some tests are capable of discriminating between HIV-1 and HIV-2. EIAs and rapid tests are recommended for both HIV surveillance and diagnostic purposes because they are the most accurate and cost-effective.

For further information and guidance on the selection of HIV tests and recommended testing strategies refer to *Guidelines for using HIV testing technologies in surveillance: selection, evaluation, and implementation: 2009 update* [43].

Laboratory forms and codes

Labelling specimens

The specimen container (i.e. plastic tube, cryovial or filter paper) must be labelled with a specimen code at the time of collection and processing. If labels are used, make sure the label is placed on the side of the tube, not on the cap. Also make sure that the label can withstand freezing and getting wet. For freezing using cryovials, there are pre-printed cryolabels available.

Integrated biological-behavioural surveillance survey site managers should provide the field staff responsible for specimen collection with a series of labels (pre-printed or blank) and/or permanent markers and the codes to be used. For unlinked anonymous testing, label the tube only with a new specimen code and not with any personal identifying information.

Coding specimens

Specimen codes should be easy to use and easy to link to other sources of data, such as the participant coupon identification number. It is important to work closely with the participating laboratory to decide how the specimens should be coded.

One example of specimen coding is to use three digits ranging from 001 to the sample size (e.g. 400). In the example provided in Figure 14.1, the code includes the first letter of the population (I) being studied, followed by the first letter of the city (P) in which the survey is being conducted. The rest of the code uses serial numbers starting with 001 and ending at the sample size of 200.

LAB NUMBERS-IDU, PROSPECT CITY				
IP001	IP046	IP091	IP136	IP181
IP002	IP047	IP092	IP137	IP182
IP003	IP048	IP093	IP138	IP183
IP004	IP049	IP094	IP139	IP184
IP005	IP050	IP095	IP140	IP185
IP006	IP051	IP096	IP141	IP186
IP007	IP052	IP097	IP142	IP187
IP008	IP053	IP098	IP143	IP188
IP009	IP054	IP099	IP144	IP189
IP010	IP055	IP100	IP145	IP190
IP011	IP056	IP101	IP146	IP191
IP012	IP057	IP102	IP147	IP192
IP013	IP058	IP103	IP148	IP193
IP014	IP059	IP104	IP149	IP194
IP015	IP060	IP105	IP150	IP195
IP016	IP061	IP106	IP151	IP196
IP017	IP062	IP107	IP152	IP197
IP018	IP063	IP108	IP153	IP198
IP019	IP064	IP109	IP154	IP199
IP020	IP065	IP110	IP155	IP200
IP021	IP066	IP111	IP156	
IP022	IP067	IP112	IP157	
IP023	IP068	IP113	IP158	
IP024	IP069	IP114	IP159	
IP025	IP070	IP115	IP160	
IP026	IP071	IP116	IP161	
IP027	IP072	IP117	IP162	
IP028	IP073	IP118	IP163	
IP029	IP074	IP119	IP164	
IP030	IP075	IP120	IP165	
IP031	IP076	IP121	IP166	
IP032	IP077	IP122	IP167	
IP033	IP078	IP123	IP168	
IP034	IP079	IP124	IP169	
IP035	IP080	IP125	IP170	
IP036	IP081	IP126	IP171	
IP037	IP082	IP127	IP172	
IP038	IP083	IP128	IP173	
IP039	IP084	IP129	IP174	
IP040	IP085	IP130	IP175	
IP041	IP086	IP131	IP176	
IP042	IP087	IP132	IP177	
IP043	IP088	IP133	IP178	
IP044	IP089	IP134	IP179	
IP045	IP090	IP135	IP180	

Figure 14.1 Specimen codes for a survey in Prospect City

If pre-printing labels, make enough for each of the forms you will need for processing the specimens and laboratory results. For instance, you will want to print four of the same coded labels if you want to put the label on the 1) vial, 2) the transport form for transporting the specimens from the RDS survey site to the laboratory, 3) the in-house tracking form to manage specimens and 4) on the voucher the participant will use to retrieve his or her results.

Recording specimens and test results

A separate laboratory logbook or line listing form will be needed to manage HIV specimens and test results. The logbook or form should be accessible only to laboratory and surveillance staff; it should be secured in a locked drawer or cabinet when not in use to ensure confidentiality of the person’s test results as well as their participation in the integrated biological-behavioural surveillance survey. For unlinked anonymous testing, the logbook or form should contain only the new specimen codes and corresponding HIV test results; no participant’s personal identifying information should be included.

Figure 14.2 is an example of a specimen collection form. Information to collect on this form includes the location of the survey site, the initials of the supervisor and the initials of the VCT counsellor (this form assumes that the person collecting the blood is the VCT counsellor). For each participant, additional information to gather includes the coupon number or the participant identification number, birth date (as a validation, but still retains anonymity), date of specimen collection and the specimen (or laboratory) number. Examples of this form and other forms are provided in Annex 8.

SPECIMEN COLLECTION FORM — GUIDELINES									
(To be filled in duplicate)									
Technician name: _____				Date: _____					
Site/City: _____				Region: _____		Transfer batch number: _____			
No.	Participant ID code	Lab number	Time blood collected	Blood collected yes/no	Blood adequate yes/no	Serum obtained	Number of cryovials	Time serum obtained	Comment
1.									
2.									
3.									
4.									
5.									
6.									

Figure 14.2 Example of a specimen collection form

Transferring specimens to the laboratory

When transferring specimens to the laboratory, it is useful to have a form to help manage the number of specimens being transferred and their specific laboratory numbers. It may be a good idea to have two copies: one to leave at the laboratory and the other to keep at the survey site.

Figure 14.3 provides an example of a specimen transfer form. Some of the information is filled in by the sender (RDS survey site) and some of the information is filled in by the recipient (the laboratory).

The information to be recorded includes: a transfer batch number which can be simply coded as 01 for the first transfer, 02 for the second transfer and so on; the total number of serum samples, cryovials or other type of samples being sent from the survey site to the laboratory and the total number of samples being received by the laboratory (the numbers in these spaces must, of course, match); and the name and signature of the sender and date the specimen is being sent, as well as the name and signature of the recipient and the date the specimen is received.

Finally, there is a space for applicable comments to be completed by both the sender and the recipient. This can be useful if specimens are undamaged when they leave the survey site but are damaged during transport.

Keeping a log book at the survey site

It is a good idea to keep a log of specimen transfers at the survey site. Such a form can include the total number and batch of serum samples and/or cryovials sent, the date these specimens were sent, the signature and any comments of the sender and the date the specimen transfer form was received from the laboratory. Figure 14.4 presents an example of a specimen transfer log book.

SAMPLES TRANSFER FORM — GUIDELINES

(To be filled in duplicate)

Site/City: _____

Region: _____

Transfer batch number	
Total number of serum samples being transferred (from site to lab)	
Date (sent from site)	
Name (sender)	
Comments (sender)	
Signature (sender)	
Total number of serum samples received (at lab)	
Total number of cryovials received (at lab)	
Date (received at lab)	
Name (recipient)	
Signature (recipient)	
Comments (recipient)	

Figure 14.3 Example of a specimen transfer form

SITE SPECIMEN TRANSFER LOG BOOK (KEEP AT SURVEY SITE)

(To be copied into specimen logbook)

Site/City: _____

Region: _____

Transfer batch number	Total number of serum specimens	Total number of cryovials	Date (specimens sent from site)	Name and signature (sender)	Comments (sender)	Date (Specimen transfer form received from lab)
01						
02						
03						
04						
05						
06						

Figure 14.4 Example of a specimen transfer log book

Refusing to provide a specimen

Some participants will not want to provide a blood (or other) specimen. If completion of the survey includes consenting to the behavioural and biological parts of the survey, then these persons will not be eligible to participate. However, if the survey allows participants to enrol and take only the behavioural part of the survey but not the biological part, then it may be useful to record why some people refuse to provide a specimen.

REFUSAL FORM					
To be completed by the VCT counsellor.					
Instructions: Please indicate the MAIN reason why someone does NOT want to give a blood sample.					
Main reason for not giving blood					
<ol style="list-style-type: none"> 1. Afraid it will hurt 2. Afraid of being HIV positive 3. Afraid of being positive for hepatitis B, hepatitis C or syphilis 4. Afraid of all test results 5. Afraid someone will find out that I had HIV test (afraid it will not be confidential) 6. Do not have time 7. It is dangerous to your health 8. No cure for HIV 9. It is against my religion to give blood 10. Just had an HIV test and do not want to do it again 11. Other (specify) 					
Number	Coupon number (Take away coupon/write number in this column)	Date	Reason for not giving blood (Write the code in this column)	If other, specify	RDS staff signature
1					
2					
3					
4					
5					
6					
7					
8					
9					

Figure 14.5 Example of a form for those who refuse to give blood

Figure 14.5 provides an example of a form to record why someone refuses to provide a specimen. This form asks for the main reason why that person refused to provide blood based on a list of responses. The list provided in this example may not be exhaustive and can vary based on the specific survey.

HIV and other infection test result appointment vouchers

Introduction

It is highly recommend that HIV and other test results be provided to the participants as part of the survey.

Depending on the testing method, some test results can be provided to participants within 30 minutes after providing a specimen. If specimens must be transported to a laboratory for testing, then results may have to be provided to participants up to two weeks after they provide a specimen.

Whether test results are provided the same day as the participant enrolled in the survey or at a later date, it is essential that the testing and provision of results be accompanied with HIV and other STI pre- and post-test counselling.

If participants must return to the survey site at a later date, a test result voucher should be given to the participant indicating when and where he/she can receive their results.

Elements in a voucher for test results

As shown in Figures 14.6 and 14.7, test results appointment vouchers can be similar to previous appointment vouchers. As with the appointment vouchers, important information includes:

- a unique RDS identification number or code
- name of the project (do not use an outwardly stigmatizing name such as “AIDS prevention for people who inject drugs”; nor do you want to call it the “Test results voucher”)
- location and address of the field site
- space for staff to write in the appointment date and time
- phone number of a staff member in case participant needs to cancel or change appointment time or date
- expiry date: this is the final estimated expiry date for the survey so that people do not show up at the survey site six months after the survey has ended.

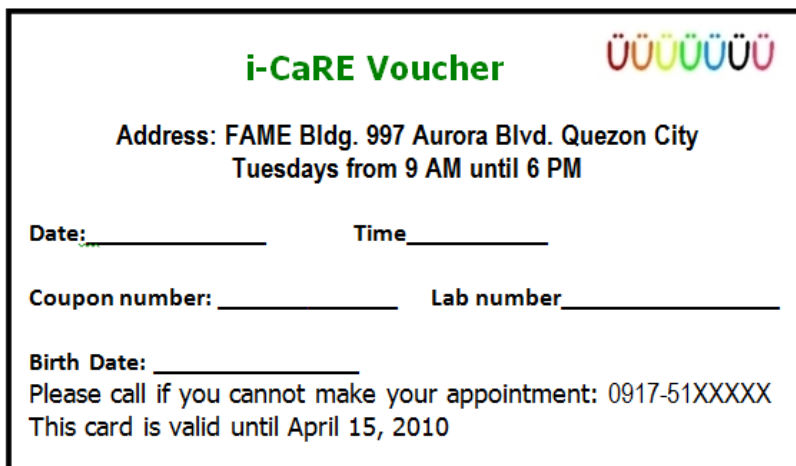


Figure 14.6 Example of a voucher for test results

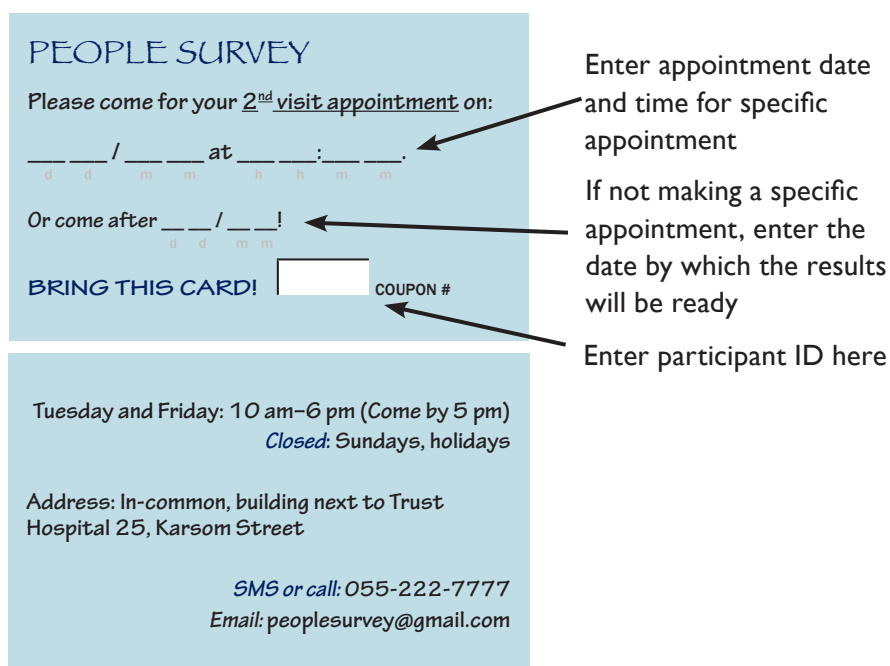


Figure 14.7 Example of a voucher for test results

How many to print

When you are deciding how many test result vouchers to print for the duration of the survey, keep in mind that most, if not all, of your sample may want an appointment to receive test results. Not everyone will keep their appointment or want to receive their test results once they leave the survey site. For a survey of 400 participants, have 400 plus at least 75 extra vouchers printed.

HIV and other infection test results

Introduction

Post-test counselling is essential when providing test results. Bear in mind that the RDS survey site should create a comfortable and safe environment for key populations at higher risk of HIV exposure to receive services that either may not be available to them or for which they feel too stigmatized to access. Providing testing and test results during your RDS survey is an excellent opportunity to reach these populations.

Test results

Test results can be transferred by the laboratory through email, some computerized file or through a paper form system. Regardless of method, test results will usually be given to the participant in a form. Figure 14.8 is an example of a test result slip that is kept at the survey site.

In this example, the form is for HIV and syphilis test results and is completed by the laboratory technician at the RDS survey site based on the test results received by the laboratory. Two copies of this form are produced, one of which stays at the RDS survey site, while the other is offered to the participant. The laboratory technician then writes the result of the HIV test (e.g. positive, negative or discordant and type 1, 2 or 1/2) and the date (day-month-year) on which it was tested.

TEST RESULT SLIP (SITE) FOR HIV AND SYPHILIS — GUIDELINES	
(To be filled in duplicate)	
Site/City:	_____
Region:	_____
Participant ID (Label)	
HIV test result	
Date tested (HIV test)	
Syphilis test result	
Date tested (syphilis test)	
Name of technician	
Signature of technician	
Comments	

Figure 14.8 Example of a test result slip

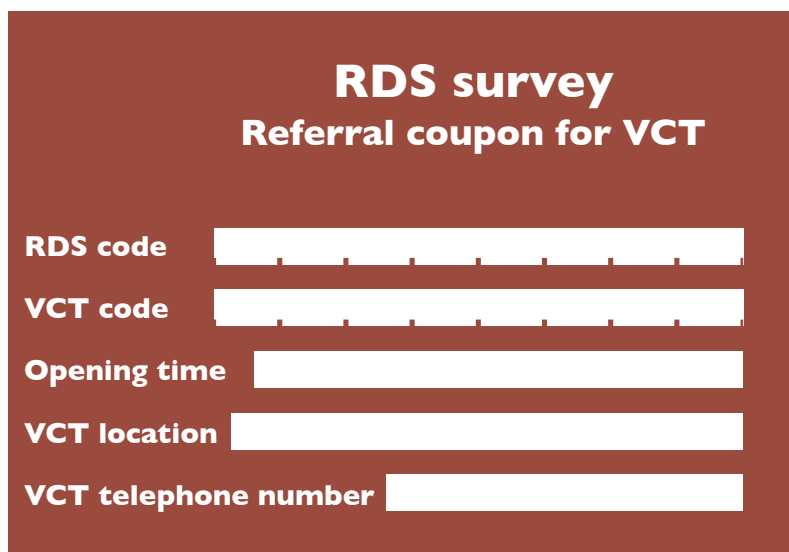
Using your staff to provide services

If the RDS staff is properly trained, they may be instrumental in providing some general information on HIV/AIDS. This may include:

- basic knowledge on HIV/AIDS and HIV transmission
- HIV/AIDS treatment and care, opportunistic infections and STIS
- drug treatment
- local support programmes.

Some surveys try to link the RDS coupon number to the care and treatment referral coupon to assess the proportion of RDS participants who were positive for HIV or some other infection and accessed services after participating in a survey. As shown in Figure 14.9, some of the information to include on a treatment and care referral coupon includes:

- name of research (VCT is in the title since it is assumed that the general public does not know what this means; however, feel free to use another name for the coupon)
- address and telephone number of VCT
- participant's RDS coupon number
- code of participant in VCT
- VCT site hours of operation
- information about the services offered by the VCT centre.



The image shows a sample VCT referral coupon form. It has a dark red background with white text and input fields. The title is 'RDS survey Referral coupon for VCT'. Below the title are five rows of input fields, each with a label to its left: 'RDS code', 'VCT code', 'Opening time', 'VCT location', and 'VCT telephone number'. Each input field is a white rectangle with a thin border and a small vertical tick mark on the right side.

Figure 14.9 Sample VCT referral coupon

Summary

The majority of behavioural surveillance surveys of key populations at higher risk of HIV exposure collect biological data to determine prevalence of HIV and/or other infections. There are several considerations when planning biological specimen collection and testing. The selection of HIV testing approaches for surveillance depends on contextual factors such as country policies and laboratory capacity. Some factors to consider beforehand are:

- the testing algorithm to use for HIV and other infection testing
- the specimens to be collected
- the type of test kit to be used
- the tests to be run on the specimens
- the type of facility needed to collect specimens
- the availability of adequate laboratory facilities to conduct the tests
- the staff needed to collect specimens and their roles and responsibilities
- the types of form needed to link and monitor tests
- tracking the flow of biological data.

Many types of specimen can be used for biological testing of HIV such as blood, oral fluids or urine. The choice of specimen collection and testing method depends on testing algorithms in effect in a country, the capabilities of the RDS survey and laboratory site(s) and staff, and acceptability among the population being surveyed. Specimens must be collected, tested and stored in an appropriate manner in order to obtain accurate and reliable results. Furthermore, specimens must be accurately coded, labeled and logged to ensure the results of the specimen make it into the RDS survey data and back to the participant, if applicable.

Provisions for pre- and post-test counselling by trained staff must be included in any survey that plans to perform HIV testing. If results are to be provided to participants, a system for referring patients testing HIV positive for care and treatment services must also be in place. Linked HIV testing is commonly-used to link the results of the HIV test to the person tested without releasing any personal identifying information about the person being tested. Linking can be done as either confidential (some personal identifying information is collected) or anonymous (no personal information is collected).

Unit 14 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want to make.

Apply what you have learnt/case study

Try this case study individually.

In one country a female sex worker participant who had already completed the interview was escorted to the nurse for pre-test counselling and an extraction of 7 ml of venous blood. The female sex worker happened to be weak and anaemic and did not have adequate veins for blood collection. After several attempts the nurse gave up and escorted the participant to the coupon manager who informed the participant that because she had not completed all of the necessary steps in the survey (each participant was required to fulfil both the behavioural and the biological components to be eligible for the survey), she was neither entitled to the incentive nor any recruitment coupons.

- a. Do you think the coupon manager was correct in denying this participant her incentive and recruitment coupons?
- b. Why or why not?
- c. If no, what should the coupon manager have done?

Later in the week, no one was enrolling in the survey and the survey came to a standstill. In a meeting to determine why no female sex workers were enrolling, the coupon manager and nurse informed the site manager about the incident with the female sex worker who was not able to give blood.

- d. If you were the site manager, how would you respond to this information?
- e. What could you do to encourage female sex workers to start enrolling in the survey again?

You find out that the female sex worker participant that was not able to provide the blood, and was therefore denied her incentive and recruitment coupons, was very upset by this experience and that she told other female sex workers about how poorly she was treated and warned them not to go to the survey. Unfortunately, this female sex worker was very influential with other female sex workers and was able to stop all female sex workers from enrolling in the survey.

- f. What would you do to fix this situation?

Small group discussion

Get into small groups to discuss these questions.

1. What do you think are the advantages and disadvantages of providing HIV results to participants in an integrated RDS biological-behavioural surveillance survey?
2. Do you have VCT services available in your country? What kinds of services do your VCT sites provide? Do you think people in your community feel comfortable using the VCT services? What are some of the ways in which an integrated RDS biological-behavioural surveillance survey could reinforce the efforts of VCT in your country?

Unit 15

Introduction to RDS
analysis

Overview

What this unit is about

It is essential to have a basic understanding of RDS analysis before initiating a survey using RDS methods. This will assist in ensuring collection of the essential data needed for the analysis. A detailed presentation of the statistical theory upon which RDS is based is beyond the scope of this manual. Further information about RDS estimators can be found in several articles on RDS, most of which are published in social science journals [4, 7, 10, 11, 12, 13, 46].

Although some investigators have developed their own software programs to analyse RDS data, the RDS Analysis Tool (RDSAT, see www.respondentdrivensampling.org), a statistical package developed by Heckathorn and colleagues, and RDS Analyst (www.hpmsg.org), offer a free and relatively straightforward way to analyse RDS data. A guide to using RDS Analyst and also NetDraw (a free software program for graphing network data) can be found in a supplement to this module.

Warm-up questions

1. True or false? RDS approximates random sampling in that survey population members do not recruit their peers randomly from their personal social network. Circle your answer below.

True

False

2. True or false? To analyse RDS data you must collect data on each person's self-reported network size. Circle your answer below.

True

False

3. True or false? Homophily is the point at which your sample proportions (e.g. HIV-positives versus HIV-negatives) change very minimally, even though you may continue to sample from the population. Circle your answer below.

True

False

4. Which of the following is the best definition of homophily with respect to RDS (select one).
 - a. The statistic that describes the preference one has towards someone like oneself or different from oneself.
 - b. The harmonic mean of all of the sampled degree values.
 - c. The final sample is independent of the characteristics of the non-randomly selected seeds.
 - d. The degree to which the population estimates differ from the sample estimates.

5. RDS controls for biases in the sample by giving less _____ to proportions with large average network sizes and more _____ to proportions with small network sizes.

6. True or false? There is only one estimator for analysing RDS data. Circle your answer below.

True

False

Introduction

What you will learn

This unit describes key features of RDS analysis. By the end of the unit, you should be able to:

- understand the underlying assumptions behind RDS analysis
- explain the key concepts of RDS analysis
- identify the estimators and sources of bias addressed by RDS analysis
- know the data needed for RDS analysis and how to collect it.

Weighted analysis for RDS in general

RDS is believed to approximate random sampling because survey population members recruit their peers randomly from their personal social network. However, sampling weights in RDS differ from standard weights in that each variable requires its own weighting.

The probability of selection is based on each participant's probability proportional to degree (social network size) and is measured by asking each participant the number of people they know who fulfil the inclusion criteria for the survey and whom they have seen in a defined period of time. Simply put, each sample element is weighted by the inverse of its probability of selection so units with a small chance of being selected have more weight. In other words, the group with a reported larger average social network size is assigned less weight and the group with the smaller reported average network size is assigned more weight during analysis.

For instance, in the example of RDSAT output presented in Table 5.1, the analysis is partitioned by two groups (Group 0 and Group 1). The network size for Group 0 is larger than the network size for Group 1 and the population weight for Group 1 is larger than the population weight for Group 0.

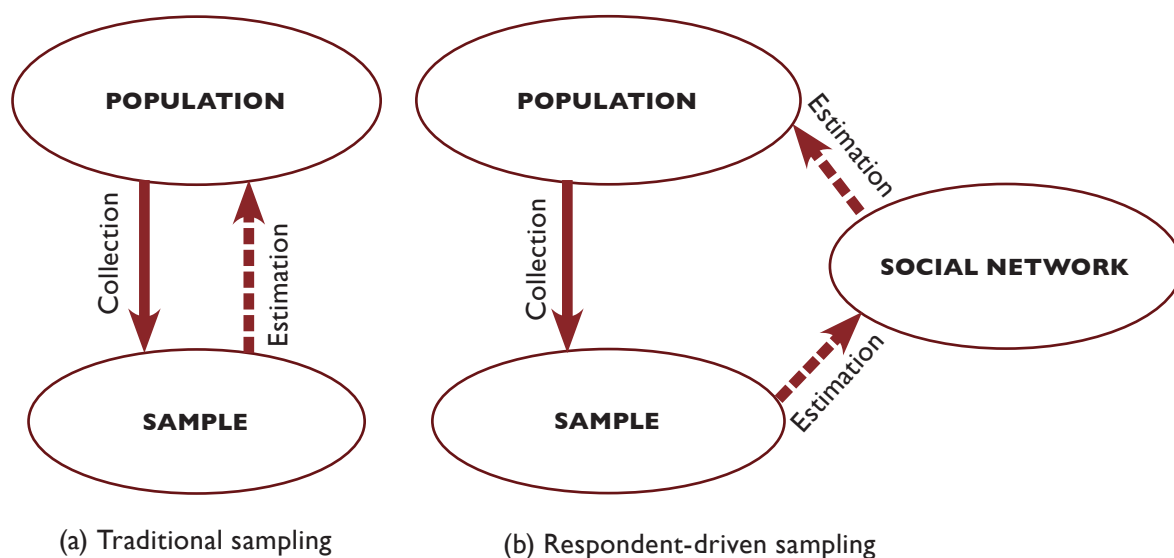
Table 15.1 Example of the multiplicity mean network size and population weights from RDSAT 6.0

	Group 0	Group 1	Total
Mean network size, N (multiplicity)	14.435	8.398	
Population weights	0.989	1.573	

RDS estimators

Unlike traditional sampling, which makes inferences directly from the sample to the population, RDS makes inferences based on data from the social network of the sample as shown in Figure 15.1.

- First, the sample is used to estimate properties of the social network connecting the population.
- Second, information about the social network is used to estimate the proportion of the population in different groups (such as those who are HIV-positive or HIV-negative).



Source: [10].

Figure 15.1 RDS makes inferences based on data from the social network of the sample

A chain referral sample, in and of itself, is not generally representative of the survey population. Data properly collected using RDS methods must be weighted. The estimates produced from RDS data will be referred to as “weighted estimates”. Essentially, weighted estimates are an adjustment of the difference between the composition of the sample and the composition of the survey population (adjusted estimates should represent the social network of the population from which you are sampling). The weighted estimates are used to make inferences about the survey population. Representative samples should allow you to say, for instance, “50% of injectors in city X (the population from which you sampled) share needles” instead of saying “50% of injectors in my sample share needles”.

Analytical computation of currently-used estimators can be found in the literature on RDS analysis [4, 7, 10, 11, 12, 13, 46].

In addition to social network sizes, the current estimators use information on who recruited whom. This is used to estimate the probability that a person of one type may recruit a person of another or same type and combines it with the average personal network size (described above) of each respondent by using the self-reported social network size information. These measures are combined to estimate the proportion of the population falling into one of two (or more) distinct subtypes (e.g. female and male).

Required data for analysis

To analyse RDS data you must collect data on each person's self-reported network size and who recruited whom. Below is a table (Table 15.2) which explains what to collect, how it is collected and why it is important.

Table 15.2 Required data to collect for analysing data with RDSAT

What to collect	How it is collected	Why it is important
Social network size of each participant	This is measured through the participant's self-reported number of peers in his or her priority population	This is used to apply statistical weights to mitigate biases due to differential network sizes, whereby those with larger network sizes have a smaller probability of selection and vice versa
Participant's unique identification number	This is usually collected through a coupon tracking system and is the unique number of the coupon the participant was recruited with	This provides information about who recruited whom so that transition probabilities (the probability of a female to recruit a female versus a male) can be calculated. This also provides information about homophily (the tendency of people to recruit people similar or different from themselves)
Recruit's unique identification number	This is also collected through a coupon tracking system and is the unique number from the coupons the participant is given to recruit others	This provides information about who recruited whom so that transition probabilities (the probability of a female to recruit a female versus a male) can be calculated.

Sources of bias addressed by RDS

Introduction

There are several sources of bias common to the chain referral sampling upon which RDS is based [1, 2, 3].

Non-random selection of initial survey participants

Similarly to snowball sampling, RDS initiates recruitment with non-randomly selected survey participants, known as seeds. But the RDS methodology results in a reasonably randomly drawn sample: survey participants should be recruited through numerous waves (> 6) of random selection from within peer networks.

The sampling begins with a non-random (or purposive) selection of seeds from the survey population.

- RDS seeds who have completed an interview explain the process to their peers who decide for themselves whether or not they wish to participate.
- Not all participants will use all of their recruitment coupons. Participants with small personal networks will generally be able to find at least a couple of peers to recruit, avoiding the chance that recruitment chains will terminate prematurely.

- If participants use at least one coupon, the recruitment chain will continue to lengthen and will have the potential to expand exponentially over time.
- The increased number of waves allows the target sample size to be attained and ensures a broad array of participants have the opportunity to recruit their peers.
- Not all recruitment chains will have the same number of waves. The number of waves in a sample is usually based on the chain with the maximum number of waves.

Differential recruitment

Differential recruitment can lead to one group being oversampled. For instance, men who inject drugs often recruit more people on average than women who inject drugs. If women who inject drugs are more hidden and less willing to enrol in a survey, they may be differentially recruited and, in this case, under-represented in the sample. Although the quota system of recruitment coupons by which peers are provided with a set number of coupons, usually three, with which to recruit peers will reduce this form of bias, some variation may remain.

Differential recruitment can be impacted by volunteerism (over-sampling of cooperative participants) and masking (under-sampling of reclusive respondents). Having incentives for enrolment and recruitment, and a recruitment quota whereby no more than a set number of peers can be recruited, helps to minimize these biases.

- Incentives are a combination of material and social benefits which help to ensure that recruits are motivated regardless of stigma and illicit behaviours. This helps provide diversity and a sample that extends into the more hidden areas of a social network.
- Each recruiter is usually allowed only up to three coupons to recruit their peers. This helps to avoid over-sampling of members of the survey population who are the most cooperative and most social.

In addition, RDS ensures that peers approach their peers, rather than having researchers approach those who have been identified as members of a hidden population. Recruited peers can decide for themselves whether to come forth to participate in an interview. Survey participants recruit their peers, providing credibility for the survey and positive peer pressure to participate.

Once the data are collected, if over-sampling occurs in one of the groups, most estimators will weigh the sample to compensate for differential recruitment by mathematically projecting what the sample composition would have been had all groups recruited with equal effectiveness.

Differential social network sizes

Differential social network sizes in chain referral sampling can lead to over-representation in the sample since those with larger social network sizes have more opportunities to recruit others. Self-reported social network size information is used to weight data to account for biases associated with differential social network sizes. In doing so, those with larger social network sizes are given less weight, while those with smaller social network sizes are given more weight.

In-group affiliation

“In-group affiliation” or “homophily” is when people tend to purposefully recruit others with characteristics similar to themselves. This occurs because people are most often connected to people with characteristics similar to themselves [47, 48, 49]. Most chain referral methods are subject to in-group affiliation because they do not allow for numerous recruitment waves.

Lengthy chains are important for a variety of reasons. Longer chains result in:

- deeper penetration into the social network structure
- more diverse and representative samples
- achievement of equilibrium.

Surveys using RDS have demonstrated that:

- at least four to six waves are usually needed to reach equilibrium, but keep in mind that equilibrium is the point at which your sample first becomes random so numerous waves beyond the point of equilibrium are needed
- selecting a diverse set of initial seeds can speed the approach to equilibrium
- Having an appropriate number of seeds for the sample size will allow recruitment chains to become lengthy (see Unit 5)
- reducing your coupons as recruitment continues will help ensure lengthy chains (see Unit 13).

Markov processes

A first-order Markov process is a mathematical theory. RDS analysis assumes that recruitment follows a Markov process whereby coupons are distributed at random in a closed system until a steady state (equilibrium) is reached [12]. Each wave of the recruitment chain is said to represent a particular state. In other words, all characteristics (such as age, condom use, HIV status) of each individual in a recruitment wave are static at the point at which the wave is reached. For instance, at wave three of a particular seed there could be ten recruits, five of which are female and five of which are males. This state (females and males) cannot change.

There are two important characteristics of a Markov process used by RDS:

- First, there are a limited number of specific states (e.g. male/female/transgender, HIV-positive or negative status) that participants can assume.
- Second, any participant’s recruits are to some degree a function of their type, such as their HIV status.

Beginning with the seed, up to three recruitments are allowed by each participant in the survey. Each participant who distributes some or all of his/her coupons contributes to a recruitment chain made up of waves. Each of these waves represents a step in a Markov process.

Equilibrium

Introduction

Equilibrium, which is derived from concepts developed for stochastic Markov chain models, indicates that the final sample is not biased by the purposive selection of seeds [50]. For instance, the estimate of HIV is likely to change as more people are recruited into the sample. However, the survey will reach a point where the ratio of HIV- positive to HIV-negative participants (or some other characteristic) remains constant (stabilizes) no matter how many more people are recruited into the survey. Equilibrium is assessed in the analysis phase of RDS. Purposively selecting a diverse set of seeds will increase the speed at which equilibrium is reached.

Attaining equilibrium

Attaining equilibrium assumes that at each step (wave) the sample proportions will shift as the sample grows. This shift will ultimately gravitate towards equilibrium whereby the sample proportions no longer change depending on which state (variables such as sex, HIV status) you are analysing.

At some point each characteristic (variable) in the sample will converge at the point of equilibrium, the “equilibrium proportion estimate” (EPE). Equilibrium is the state whereby limited sample variation (a good default is within 2% of the sample composition) will occur even though more waves are produced after equilibrium is attained [4, 10]. Recruitment chains must be long enough to reach equilibrium to ensure that the bias introduced from the initial selection of seeds is eliminated.

There is some debate on the accurate use of equilibrium. Often the attainment of equilibrium is interpreted as an indication that the sample has a sufficient number of waves to justify analysis. Another interpretation is that only the waves after reaching equilibrium are unbiased by the seeds, suggesting that only those participants in the waves beyond equilibrium are suitable for analysis [13]. Yet another interpretation is that for surveys in which the majority of recruits originate from one seed analysis should occur only on the longest chain [51]. Recent analyses using actual and simulated data have found that the gain from analysing only data obtained after reaching equilibrium was not worth the loss due to reductions in sample size resulting from throwing out earlier waves [18, 46].

The statistical computation for deriving equilibrium is found in Heckathorn (2002) [13].

Note: When assessing equilibrium it is important to have a good understanding of your sample. Even though you may have reach equilibrium on variables of interest that does not necessarily mean you have a random sample. One survey of men who have sex with men in Estonia only attained 59 participants out of the 300 sample size yet attained equilibrium on several key variables of interest. Due to the small number of men who have sex with men recruited, the sample was obviously not random.

In Figure 15.2, it is possible to estimate the wave at which the sample reached equilibrium for a three category variable. On the vertical axis is the percentage and on the horizontal

axis are the waves. To be conservative, the equilibrium simulation begins with 100% of the sample in one category state (and therefore, the others have to be zero). In this example, the maximum number of waves for this sample was 13, although equilibrium was reached by the eighth wave.

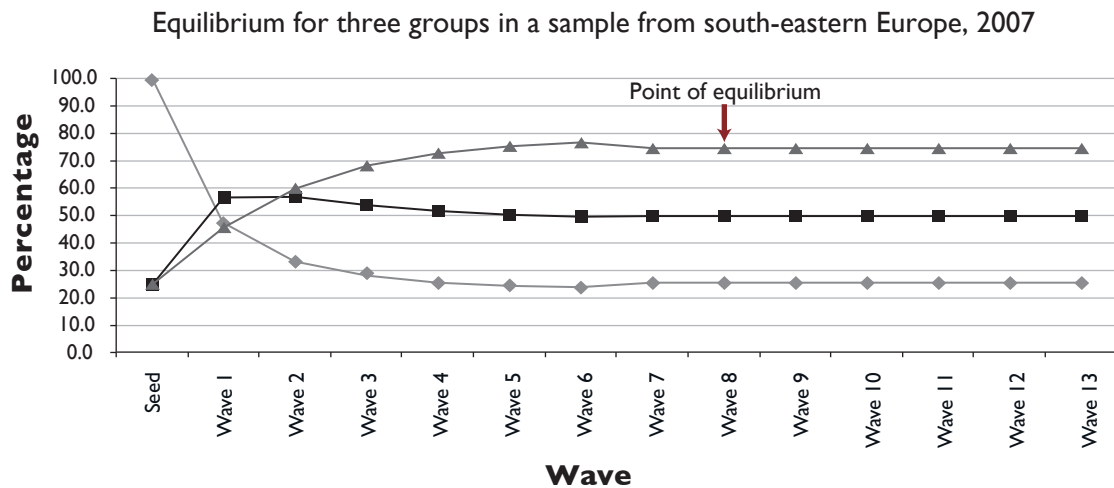


Figure 15.2 Equilibrium point for a three category variable

Summary

Data gathered using RDS methods must be analysed with a specialized data analysis software that will properly weight network sizes and adjust for the biases described above. An RDS sample without proper adjustment is nothing more than a very good snowball sample (and not a representative sample). Therefore, RDS has two essential parts: acquiring data using the RDS recruitment methods and analysing that data with proper adjustments (weighting) for differential recruitment patterns, social network sizes and in-group affiliation.

Unit 15 exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of the unit. Make any changes you want based on your survey of this unit.

Apply what you have learnt/case study

Try this case study individually

In Table 15.3 below, the sample sizes and the number of initial recruits are shown.

Table 15.3 Sample size and number of initial recruits

Sample size		Initial recruits	
Negative	241	Negative	3
Positive	66	Positive	0

Table 15.4 Recruitment and estimation

Recruitment count (selection proportion, S)	HIV status of recruit		
	Negative	Positive	Total
HIV status of recruiter			
● Negative	129 (0.872)	27 (0.173)	156 (I)
● Positive	24 (0.585)	17 (0.415)	41 (I)
Total recruits	153	44	505
Recruitment proportions	0.777	0.223	I
Population proportion estimate (PPE)	0.769	0.231	
Sample proportion estimate (SPE)	0.785	0.215	I
Equilibrium proportion estimate (EPE)	0.772	0.228	I
Estimated mean network size, N	3.66	3.61	
Homophily, H_x	0.249	0.239	
Standard error of PPE	0.035	0.035	
Sampling weights	0.98	1.072	

Table 15.4 shows that the sample reached equilibrium because the percentage of HIV-positives in the sample (21.5%), the SPE, closely approximates the EPE (22.8%).

Similarly, the SPE and EPE for HIV-negatives are similar (SPE = 78.5%, EPE = 77.2%). Therefore any bias introduced by the seeds could be negligible.

Note that all three forms of potential bias in an RDS sample are present in the sample data:

- Differential recruitment bias: HIV-negatives make up 82.7% (129/156) of participants recruited but make up 76.9% (153/197) of the sample. HIV-positives make up 41.5% (17/41) of participants recruited but make up 22.3% (44/197) of the sample. With this

information, one can see that HIV-negatives are over-recruited and HIV-positives are under-recruited. This is an example of differential recruitment patterns. Given that HIV-negatives recruited more effectively other HIV-negatives compared to HIV-positives, HIV-negatives were more effective recruiters and were over-sampled. To see how bias is adjusted for in the analysis, you can see that the PPE for HIV-negatives has been adjusted downward from 78.5% (SPE) to 76.9% (PPE), and the PPE for HIV-positives has been adjusted upwards from 21.5% (SPE) to 23.1% (PPE).

- Homophily bias: Upon examination of the homophily index values (Hx) in the table one can see that the groups are not equally insular. HIV-negatives demonstrate slightly more insularity (higher homophily) than do HIV-positives (24.9 versus 23.9). Because HIV-negatives are more insular, they may have been over-sampled. This bias is known as differential homophily.
- Network size bias: The table shows that the two HIV groups have unequal network sizes (N). The average network size for HIV-positives is 3.61 and for HIV-negatives is 3.66. HIV-negatives appear to be slightly over-sampled.

Now we will calculate the PPE mate for each of the groups. The PPE formula is:

$$(1) \quad P_a = \frac{S_{ba}N_b}{S_{ba}N_b + S_{ab}N_a}$$

Whereby:

- P_a = estimate proportion of group A
- S_{ab} = proportion of group A selected by group B
- S_{ba} = proportion of group B selected by group A
- N_a = network size for group A
- N_b = network size for group B.

Based on this equation, HIV seroprevalence (%) can be calculated based on the recruitment and network size data in the table. Here S_{ab} is the proportion of Bs recruited by As, and S_{ba} is the proportion of As recruited by Bs. For example, where group A is HIV-negatives, and group B is HIV-positives, $S_{ab} = 0.173$ (27/156), $S_{ba} = 0.585$ (24/41), $N_a = 3.66$, and $N_b = 3.61$.

$$(2) \quad P_a = \frac{0.0773 \times 8.928}{(0.0773 \times 8.928) + (0.878 \times 10.208)} = 0.0715$$

- Using the table above, compute the P_b PPE for HIV-positives.
- How do the SPE and PPEs differ? Were HIV positives over- or under-sampled?

Calculating the EPEs from the data in the table.

The EPE for group A (HIV-negatives), P_a , is given by:

$$E_a = S_{ba} / (S_{ba} + S_{ab})$$

We already calculated $S_{ab} = 0.173$ (27/156), $S_{ba} = 0.585$ (24/41),

Therefore $E_a = 0.585 / (0.585 + 0.173) = 77.2$

- c. Now calculate E_b and verify this value against the value in the table.

References

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Annex I

Glossary

Glossary

ACASI	Audio computer-assisted self-interviewing.
AIDS	Acquired immunodeficiency syndrome.
CASI	Computer-assisted self-interviewing.
CDC	Centers for Disease Control and Prevention.
Chain referral sample	A non-probability sampling method in which existing survey participants recruit future participants from among their acquaintances. Findings cannot be extrapolated to represent the survey population.
Coupon	Used in RDS surveys to provide incentives to participants. Typically, the coupon has two parts that can be easily separated: <ul style="list-style-type: none">● One part of the coupon serves as the referral coupon that the recruiter uses to recruit a peer into the survey.● The other part of the coupon serves as the payment coupon. It is kept by the recruiter and he or she will use it to claim an incentive for having recruited a peer into the survey. Both parts of the coupon have the unique identification number of the recruitee printed on them. The dual system eliminates the need to collect names for incentive collection.
Checklist form	The form is used to keep track of each participant from the moment he or she comes in to the survey site with a coupon until he or she is paid their primary incentive. This form is useful when there are many steps involved in completing an RDS survey.
Coupon manager	An RDS staff member responsible for giving coupons and explaining the peer recruitment process to participants. The coupon manager may also provide primary and secondary incentives to participants.
Coupon rejecters	People who were offered a coupon by a recruiter but declined to take it.
Coupon reduction	The reduction of coupons as the survey progresses. Coupon reduction helps control the flow of participants and number of coupons in the community as more waves are created. An example of coupon reduction is to systematically reduce the number of coupons distributed to participants at wave three from three coupons to two coupons, and then to reduce the number of coupons distributed to participants at wave five from two coupons to one coupon.
Data smoothing	Data smoothing is an analytical tool used to fill potentially empty cells of a recruitment matrix with the average across the diagonal. Data smoothing has effect on greater than two category proportions.
Degree	The number of people in an individual's social network. Degree is also referred to as social network size.

Differential recruitment	The patterns that occur when some recruiter subtypes systematically recruit more people from one subtype than from another subtype.
Equilibrium	The point at which the sample characteristics no longer change, no matter how many more individuals enter into the sample. Equilibrium is also referred to as convergence and stabilization.
Equilibrium proportion estimates (EPE)	An estimate of the sample proportion of two (or more) distinct groups at the time of equilibrium.
FHI	Family Health International.
Formative assessment	Research conducted before a survey begins. Researchers conduct focus groups, in-depth interviews, mapping or observations of the survey population and individuals who work with them to learn more before the survey begins.
HIV	Human immunodeficiency virus.
HIV behavioural surveillance	The monitoring of people's behaviours in relation to HIV/AIDS.
Homophily (or the index of clustering)	The statistic that describes the mixing patterns in networks. Homophily can be positive or negative, ranging from -1 to 1 depending on whether an individual preferentially attaches to others of his/her own type or, alternatively, avoids them.
Incentive	This is a reward or reimbursement given to participants in an RDS survey. There are typically two types of incentives: a primary incentive and a secondary incentive. <ul style="list-style-type: none"> ● A participant receives a primary incentive for enrolling in the survey and completing the interview process. ● The same participant receives secondary incentive(s) for recruiting his or her eligible peers into the survey.
In-group affiliation	This is group similarity based on characteristics (ethnicity, age, socioeconomic status, etc.) of interest.
Institutional sampling	This is a sampling method that involves sampling individuals in institutions such as a prison, a drug treatment programme, hospitals, etc.
IRB	Institutional review board.
Integrated biological-behavioural surveillance	Monitors HIV and other STI prevalence through biological testing (urine, saliva, blood) in addition to monitoring peoples' HIV risk behaviours.
Kick-off meeting	This is a meeting hosted for seeds before an RDS survey begins. It is an excellent opportunity to educate seeds about the survey goals and process, inform seeds of their importance to the success of the survey, and to encourage them to be enthusiastic. The meeting should be festive and may include food and beverages.
Lessons learnt	This is information recorded (learnt) from previous surveys that is useful in making decisions when planning an upcoming survey.
Markov process (as applied to RDS)	A theory which states that biases introduced into a chain referral sample by the non-random selection of an individual (seed) are weakened with each recruitment wave and ultimately eliminated.
Masking	Sampling bias whereby reclusive respondents are under-sampled.
Non-probability sample	A sampling method that involves selecting members from the survey population in a non-random manner (there is no known probability of selection). These types of sampling methods (snowball, judgment, quota, etc.) are not usually representative of the survey population from which the sample was taken.
Non-random mixing	The tendency for people to preferentially recruit others like themselves.
Operations manual	A survey document that describes the steps and procedures involved in a survey. An operations manual can also be referred to as a procedural protocol or survey manual or some other title. A sample operations manual is provided to accompany this module.

Peer	A peer is someone who is linked to another person(s) based on similar characteristics. Several peers can make up a social network. For instance, people who inject drugs form peer relationships with other people who inject drugs through the sharing, buying and using of drugs.
PPE	See population proportion estimate .
Population proportion estimate (PPE)	This estimate is the correction of the difference between the composition of the sample and the composition of the survey population (sample proportions should represent the population). PPEs are used to make inferences about the survey population.
Probability samples	In this sampling method, each member of the survey population has a known probability of being selected. Probability sampling methods include random sampling, systematic sampling and stratified sampling. The advantage of a probability sampling method is that sampling error can be calculated.
Protocol (or survey protocol)	A survey document that describes the methodology and procedures in a survey. A generic protocol is provided in Annex 5.
RDS	See respondent-driven sampling .
RDS Analyst	Software for analyzing RDS data.
RDSAT	Respondent-driven sampling analysis tool.
Reciprocity (in RDS)	One of the assumptions of RDS. Connections are reciprocal; meaning if individual A recruits individual B, then B may also recruit A.
Recruitment chain	Made up of a seed and all of his or her recruits.
Recruitment matrix	Describes the pattern of recruitments within the sample. The sample is divided into disjoint subtypes (such as HIV positive versus HIV negative) and the number of recruitments from each type to each type is measured. These data are summarized in a matrix with the recruiter's type in the axis rows and the recruit's type in the columns.
Respondent driven sampling (RDS)	The sampling method that relies on social network properties to sample hard-to-reach populations.
Safety protocol	The protocol that describes how to respond to, avoid or document field incidents or adverse events.
Sample proportion estimates (SPEs)	These estimates are the proportions for two (or more) distinct groups from the sample.
Sampling	A statistical practice concerned with the selection of individuals from a survey population, such as people who inject drugs, sex workers and men who have sex with men. It is intended to yield some knowledge about a total survey population, especially for the purposes of statistical inference. Sampling methods are classified as either probability or non-probability.
Sampling error	The degree to which a sample might differ from the population. When inferring to the population, results are reported plus or minus the sampling error. In non-probability sampling, the degree to which the sample differs from the population remains unknown.
Sampling frame	The source from which a sample can be drawn. It is a list of all those within the survey population who can be sampled and may include individuals, households or institutions. Sampling frames of hard-to-reach populations cannot be developed since the size of the population is unknown.
Screenener	The screener is responsible for determining a participant's eligibility before he or she is able to participate in the survey. The screener is also important for ensuring that those who have false coupons, are potentially disruptive, are not actual members of the survey population or are too high or drowsy from drugs to be interviewed are not allowed into the main survey area.

Seeds	These non-randomly selected members of the survey population initiate the RDS recruitment process. From each seed, a recruitment chain is expected to grow.
Snowball sampling	A non-probability sampling method in which existing survey participants recruit future participants from among their acquaintances.
Social influence	This is a form of mild peer pressure from the recruiter who will receive a secondary incentive for recruiting his/her peers.
Social network	This is a social structure made up of members of a peer group. Social networks may be connected through risk behaviours such as injecting and sharing drugs and selling sex.
Sociometric stars	These are seeds that are not only willing to recruit their peers, but are well-regarded by their peers. Such seeds are more likely to influence others to be recruited into the survey.
SPE	See sample proportion estimates .
STI	Sexually transmitted infection.
Targeted sampling	This sampling method recruits individuals from specific locations. Time-location sampling is an example of targeted sampling.
Time-location sampling (TLS)	This is a sampling method that recruits individuals from specific locations during specific time periods. Time-location sampling can be a probability sample based on the accuracy of the sampling frame in including all the venues and the size of the survey population that frequents these venues. Time-location sampling is also referred to as venue-based sampling, venue-time-based sampling, time-location cluster sampling and time-space sampling.
Transition probability	This probability is estimated from the recruitment matrix. The rows of the recruitment matrix are added up, providing the total number of recruitments made by each type. The number of recruits in each cell can be divided by the row total to determine the transition probability.
VCT	Voluntary HIV counselling and testing.
Volunteerism	This is a form of bias that involves the over-sampling of cooperative participants.
Waves	In RDS recruitment, a seed recruits his or her peers who make up the first wave of a chain. The first wave peers recruit peers who make up the second wave of a chain, and so on. The waves make up a chain and the grouping of chains makes up the sample.

Annex 2

Useful links

Useful links

- <http://www.who.int/hiv/pub/surveillance/en/>

This link has UNAIDS and WHO guidelines for various aspects of conducting HIV surveillance.

- <http://www.respondentdrivensampling.org>

This link has RDSAT programs for analysing RDS data, information about RDS and some key journal articles.

- <http://www.hpmrg.org>

This link has the RDS Analyst software program for analysing RDS data.

- http://globalhealthsciences.ucsf.edu/PPHG/surveillance/surv_modules.html

This link has materials for conducting biological and behavioural surveillance, including some materials on RDS.

- <http://www.lisagjohnston.com>

This link has numerous journal articles available for downloading and RDS materials, manuals and slides.

- <http://www.princeton.edu/~mjs3/research.shtml>

This link provides more statistical information including references to key journal articles and innovations in population size estimations with RDS.

Annex 3

Answers to warm-up questions and case studies

Answers to warm-up questions

Unit 1

1. Give as many answers as you can to this question: Why are HIV/AIDS public health workers interested in surveillance of hard-to-reach populations such as people who inject drugs, men who have sex with men or sex workers?
 - *To monitor risk behaviours*
 - *To estimate the proportions of characteristics and behaviours, and the prevalence of HIV and other STIs*
 - *To describe the composition of the population at risk for HIV infection*
 - *To measure access to services and HIV prevention coverage.*
 - *To observe trends over time.*
2. At the beginning of an RDS survey, researchers recruit a handful of participants who serve as the seeds based on pre-existing contact with the survey group.
3. Which choice below is incorrect? Circle your answer.
Hard-to-reach populations often:
 - a. cannot be identified by any means
 - b. lack sampling frames
 - c. are rare in the population
 - d. have behaviours that are stigmatized and/or illegal.

a
4. True or false? RDS is usually slower and more expensive than the other sampling methods, but is used because it is more accurate. Circle your answer below.
False

5. Match the sampling methodology with its definition by putting the correct letter in each blank space.

<u>c</u> Snowball or related chain-referral methods	a. Researcher recruits individuals from specific locations.
<u>a</u> Time-location sampling	b. Individuals in an institution, such as a prison, are sampled.
<u>b</u> Institutional sampling	c. One individual recruits as many participants as possible for the survey.
<u>d</u> Stratified sampling	d. Recruit individuals based on their strata and their actual representation in the population.

6. True or false? An RDS sample without the proper analysis adjustments is nothing more than a very good snowball sample. Circle your answer below.

True

Unit 2

1. True or false? Formative assessment is an important part of developing an RDS survey. Circle your answer below.

True

2. Which of the following methods are useful for conducting formative assessment?

- a. focus group discussions
- b. key informant interviews
- c. observations
- d. mapping
- e. all of the above

e

3. The data collection method that involves the use of graphics (such as maps, drawings and pictures) and other visual materials is known as mapping.

4. True or false? A rapid assessment and response approach to gathering formative assessment data is usually too expensive to use for planning RDS surveys.

False

5. List one key topic that would be important to include in formative assessment to plan a survey using RDS?

- *social network properties*
- *acceptability of RDS to the survey population*

- *seed selection*
- *survey logistics (incentive, survey site location, etc.).*

Unit 3

1. True or false? The design effect is an adjustment for how much a cluster or other type of sampling method differs from a simple random sample. Circle your answer below.

True

2. The $Z_{1-\alpha}$ score is a statistic that corresponds to the level of significance desired. What would be the level of significance used to correspond to a 95% confidence level?

0.05

3. Which of the following is not a consideration for a sample size calculation for integrated biological-behavioural surveillance surveys?

- a. Design effect
 - b. Estimated Proportion (to test prevalence at one time)
 - c. Desired level of change in the measures of interest (to test change over time)
 - d. Level of significance desired
 - e. Size of the population
 - f. Level of power desired
- e*

4. What would be a good indicator to use to measure a change in proportions over time (from one survey round to the next)?

programme utilization, condom use

5. True or false? A design effect of 2 is always appropriate for all sample calculations for surveys using RDS. Circle your answer below.

False

Unit 4

1. True or false? Unlike other types of survey, surveys using RDS methods do not require review by an ethical review committee. Circle your answer below.

False

2. A protocol describes the procedures that must be followed during the RDS survey and should anticipate problematic situations and include contingency plans for these situations.

3. True or false? Monitory and advisory committees can be useful when something goes

wrong in an RDS survey. Circle your answer below.

True

4. Which of the following documents is not necessary to have during the planning and preparation stages of your RDS survey?
- survey protocol
 - operations manual
 - final report of findings
 - forms for managing the survey
 - questionnaire

c

Unit 5

1. True or false? Seeds are members of your survey population that are randomly selected to begin the RDS recruitment process. Circle your answer below.

False

2. If you want to collect a sample size of 400 people who inject drugs, the correct number of seeds to choose is:
- five
 - ten
 - twenty
 - none of the above
 - there is no one correct number.

There is no one correct number. The number will vary depending on the sample population, past use of RDS, the country and city context, etc.

3. Provide two characteristics that are important for seeds to have.

_____ and _____.

large social network sizes, interest in the research, able to recruit others, important diversity characteristics, communicates well, is respected by others in the population, fulfils eligibility criteria

4. Describe one potential problem that could arise in your recruitment process if too many seeds were selected at the beginning of your survey.

Recruitment chains are too short

5. True or false? The selection of seeds is an exact science whereby there are specific parameters based on sample size and survey population that can be used to ensure that you have the correct number of seeds for your survey. Circle your answer below.

False

Unit 6

1. True or false? One of the advantages of RDS is that participants come to you to be interviewed instead of you having to seek out participants to interview. Circle your answer below.

True

2. Participants should feel comfortable at the survey site. List at least two characteristics of a survey site that makes the comfortable.

- *private*
- *accessible*
- *spacious*
- *quiet*
- *confidential/anonymus*

3. Which of the following types of site may not be appropriate for a survey site?

- a. rented storefront on a busy public street
- b. mobile van parked across from a public park
- c. rented house in a quiet residential neighbourhood
- d. private area of a large bar or restaurant
- e. public health clinic

c

4. What are two reasons that more than one survey site may be needed?

- *The sample geographical area is large; participants from one side of town may find it difficult to get to a survey site on the other side of town*
- *You cannot find a survey site large enough to accommodate the sample size*

5. True or false? For safety reasons, survey sites should never be open at night. Circle your answer below.

False

Unit 7

1. True or false? There is only one way to design an RDS coupon and each country should use the same coupon used in previous surveys. Circle your answer below.

False

2. List at least two pieces of information that are essential to have on a coupon.

address of survey site, unique ID number, hours of operation, etc.

3. Why would a survey want to use more than one colour on a coupon?
- to make the coupons more attractive so participants will be more willing to accept them
 - to manage the different waves of survey participants
 - to track where the coupons were distributed
 - to easily distinguish between two different groups (such as sex workers and people who inject drugs) being interviewed simultaneously in the same survey site

d

4. True or false? After the seeds are selected, only persons with valid coupons are eligible to participate in the survey. Circle your answer below.

True

5. Circle the one response below that is incorrect. Tracking coupons during a survey is important because:
- it ensures that incentives are paid out to the correct person
 - it can help track the number of waves completed in the survey
 - it can help you locate the person who gave you the coupon if you have to find them
 - it is important for analysing the sample data
 - depending on the identification system you use, it can help to determine which seeds are producing and which are not

c

Unit 8

1. True or false? All RDS surveys should use the same incentive level, regardless of the population under surveillance. Circle your answer below.

False

2. There are usually two types of incentive in an RDS survey.
- The incentive a participant gets for enrolling in the survey and completing an interview is usually called the primary incentive.
 - The incentive a participant gets for recruiting his or her peers into the survey is usually called the secondary incentive.

3. Which choice below is incorrect? Circle that answer. An incentive can be in the form of:
- money
 - gifts
 - vouchers for food or groceries
 - telephone cards
 - illegal drugs.

e

4. What problem can occur if your primary incentive is too high?
People who are not part of the population will participate just to get the incentive

Unit 9

1. What is the most important type of question to be asked of RDS participants for the purposes of analysing RDS data?
Social network size
2. True or false? One of the advantages of RDS is that only a few extra questions need to be added to the survey's main questionnaire. Circle your answer below.
True
3. Which of the following pieces of information are we interested in obtaining from participants about other members of their population (circle all that apply)?
- the names of at least three close friends
 - how many of their peers have HIV
 - the number of members of the survey population a participant knows personally
 - how many members of the survey population a participant has seen during a given period of time
- c and d*
4. Recruiters should distribute coupons to someone in their social network. Therefore, recruiters should not distribute a coupon to a stranger.
5. True or false? A good time to ask participants about why someone did not accept a coupon is when he/she returns to the survey site to collect a secondary incentive. Circle your answer below.
True

Unit 10

1. True or false? It is best to explain the recruitment process to a participant only after they have completed the interview? Circle your answer below.
True
2. Upon arriving at the survey site for an interview, a participant must present a valid coupon.

3. What can you tell a recruiter who arrives at the survey site to receive a secondary incentive for recruiting a peer, but the peer has not yet enrolled in the survey?
- Find the person to whom he/she gave the coupon and remind him/her to come into the survey.
 - Return to the survey site in another week to see if the person to whom he/she gave the coupon has enrolled into the survey.
 - Give the recruiter another coupon so he/she can recruit another person.
 - Both a and b.
 - All: a, b and c.

a, b and d

4. True or false? Sometimes a person who is eligible to receive a secondary incentive for having recruited one of their peers cannot get to the survey site to pick up their secondary incentive. In these situations it is all right to allow a friend of the recruiter to receive the incentive on the recruiter's behalf. Circle your answer below.

False

5. Which of the following responses is incorrect when dealing with an angry and potentially violent participant?
- Stay calm and listen to the complaints of the participant.
 - Use a code word to call someone to help you.
 - Yell back at the participant to show that you cannot be intimidated.
 - Make sure you know where the exits are and try to position yourself near the exit.

c

Unit II

- List the different staff members that might be required to undertake an RDS survey.
Survey coordinator, survey supervisor, site manager, screener, interviewer, coupon manager, pre- and post-test counsellor, nurse/phlebotomist, laboratory technician, data manager, data entry clerk, statistician
- List two responsibilities of the coupon manager. _____
Explains the coupon recruitment process, provides the participant with recruitment coupons, manages the distribution of coupons.
- True or false? Each staff member should only perform their own roles and responsibilities and not assist other staff members in performing their roles and responsibilities. Circle your answer below.
False
- Fill in the blank space. The screener is usually responsible for making sure that persons trying to enrol in the survey are eligible.

Unit 12

1. True or false? Computers can replace the use of any forms during the collection of data? Circle your answer below.

False

2. A checklist is a form that helps the survey staff keep track of all of the steps the participant needs to complete before he or she can receive their primary incentive.

3. Which form is most useful in monitoring the reasons why someone was not eligible to enter an RDS survey? Circle your answer.

- a. checklist form
- b. consent form
- c. ineligibility form
- d. refusal form
- e. financial reporting form
- f. both c and d

c

4. True or false? Completed forms should be reviewed, double checked and compared with other forms during the course of the RDS survey to ensure that information about a participant is consistent and to catch errors. Circle your answer below.

True

Unit 13

1. True or false? Depending on your sample size and the number of seeds you select, you can determine the exact number of weeks needed to conduct your RDS survey. Circle your answer below.

False

2. What are some of the problems that may arise when someone arrives at the survey site with a valid coupon and are told to leave because the survey has ended?

- *It can lead to distrust and resentment from members of the survey population who want to participate in the survey*
- *It can lead to resentment by the recruiters who gave out the coupons to a peer member*
- *It can lead to resentment among other research organizations who want to work with that population in the future*
- *It can damage future research prospects with members of the target community*

3. The RDS recruitment process allows each seed to give three coupons to participants, allowing the sample size to grow exponentially, not linearly.

4. Which choice below is incorrect? Some of the suggestions for ending an RDS survey include:
- a. staying open for an extra couple of weeks to inform post-survey recruits that the survey has ended
 - b. as soon as the sample size is reached, closing the door to the survey site and putting a sign on the door that the survey has ended
 - c. continuing to provide HIV information and materials to post-survey recruits
 - d. informing all participants during the survey that no more interviews will be conducted once sample size is reached (and inform them of the sample size)
 - e. using expiry dates.

b

5. True or false? Sample size growth can be controlled by reducing the number of coupons given out to participants as the survey progresses. Circle your answer below.

True

Unit 14

1. True or false? All behavioural surveillance surveys collect biological specimens in order to test for HIV? Circle our answer below.

False

2. When conducting an HIV test it is necessary to have a trained professional provide pre-test counselling and when giving HIV test results is it necessary to a trained professional provide post-test counselling.

3. Which one of the following is a type of specimen not normally collected during an integrated biological-behavioural surveillance survey?

- a. blood
- b. saliva
- c. hair
- d. anal swab
- e. vaginal swab

c

Unit 15

1. True or false? RDS approximates random sampling in that survey population members do not recruit their peers randomly from their personal social network. Circle your answer below.

False

2. True or false? To analyse RDS data you must collect data on each person's self reported network size and who recruited whom. Circle your answer below.

True

3. True or false? Homophily is the point at which your sample proportions (e.g. HIV-positives versus HIV-negatives) change very minimally, even though you may continue to sample from the population.

False

4. Which of the following is the best definition of homophily with respect to RDS (select one).

- a. The statistic that describes the preference one has towards someone like oneself or different from oneself.
- b. The harmonic mean of all of the sampled degree values.
- c. The final sample is independent of the characteristics of the non-randomly selected seeds.
- d. The degree to which the population estimates differ from the sample estimates.

a

5. RDS controls for biases in the sample by giving less weight to proportions with large average network sizes and more weight to proportions with small network sizes.

6. True or false? There is only one estimator for analysing RDS data. Circle your answer below.

False

Annex 4

Formative
assessment protocol,
consent forms and
questionnaires

Formative assessment protocol, consent forms and questionnaires

If conducting formative assessment to design your RDS survey, you may want to add the following sections to your protocol. Ethical review is needed to conduct formative assessment. This section, which includes 1) information about conducting formative assessment in conjunction with an RDS survey and 2) consent and questionnaires for interviews and focus group discussions, can be adapted to meet the needs of your specific survey.

4.1 Formative assessment phase

The formative assessment phase will allow us to better understand (*put population here*) networks, sexual and drug use preferences and practices, and knowledge and beliefs about HIV/AIDS. The formative assessment will have four areas of focus: 1) social network properties; 2) acceptability of RDS to the survey population; 3) seed selection; and 4) survey procedures. Each focus area is described in more detail below (for more information see: Johnston LG, et al. Formative assessment to optimize Respondent Driven Sampling surveys among hard to reach populations in HIV behavioural and biological surveillance: Lessons learned from four case studies. *AIDS Care*, 2010, 22(6):784–792).

1) Social network properties: The exploration of social networks is essential for determining whether RDS peer-to-peer recruitment can be sustained by the survey population. There are several dimensions of social networks to consider for optimizing RDS including degree (number of ties within a social network), whether networks form isolated cliques or sub-networks, and if so whether there are bridges which can be targeted to ensure connections between these cliques. Bridges ensure that important subgroups within a social network are sampled (e.g. bisexuals in a social network of men who have sex with men or female sex workers working in distinct areas in a city). In the absence of bridges between cliques, the final survey population could form two or more independent samples (social network structures) that need to be analysed as such, or important subgroups may be missed altogether. It is also important to understand the strength of ties (weak or strong) within social networks. Having both weak and strong ties can assist in RDS recruitment, whereas just having strong ties may indicate less social diffusion throughout the network. Ties can be assessed by measuring the number of ties there are within a social network (degree) and should be linked through multiple types of relationship (e.g. friendships, acquaintances, co-workers, room-mates) and activities. Ideally, degrees should be large enough (≥ 3) to sustain recruitment and develop the long recruitment chains needed for RDS analysis.

2) **Acceptability of RDS to the survey population:** The peer recruitment sampling used in RDS relies on its acceptability to the survey population. Acceptability may be influenced by stigma or legal sanctions associated with survey population behaviours, confidence that survey staff can maintain confidentiality, level of trust in the organizations conducting the survey or in institutions generally, incentive levels, and the convenience of the location of the survey site and operating hours. Some of these factors are outside the control of researchers; others can be addressed by tailoring survey logistics appropriately as discussed below.

3) **Seed selection:** Seeds should comprise survey population members with large degree (many ties) made up of multiple types of relationship, activities and subgroups. “Good” seeds will improve recruitment effectiveness by supporting the survey goals and persuading others to participate. Seeds with diverse characteristics and social relationships within a social network will speed up the recruitment of a social mix of participants representing the survey population.

4) **Survey procedures:** Formative assessment can assist in determining acceptable incentives for enrolling in a survey and recruiting peers, finding appropriate survey locations, setting the hours and days of operation and the type and sex of the survey staff and providing important information about coupon design (colours, pictures, map, language(s) and literacy considerations).

The formative assessment phase of this survey will be through rapid assessment using qualitative methods and tools common to ethnographic studies, including:

- reviewing existing information
- in-depth interviews
- focus group discussions
- mapping
- observation
- key informant (or expert) interviews.

These qualitative methods are briefly described in the box below.

Reviewing existing information	Involves review of new and existing data sources such as strategy and policy documents, media commentaries and overviews, results of previous HIV and risk behaviours research studies, scientific literature reviews, published nongovernmental organization documents, and routinely collected data from community organizations, religious groups, law enforcement agencies, treatment centres, the ministry of health, hospitals and clinics
In-depth interviews	Involves interviewing members of the survey population
Focus group discussions	Involves interviewing a number of individuals collectively because they have had a common experience, come from a similar background or have a particular skill or knowledge
Mapping	Involves the use of graphics (such as maps, drawings and pictures) and other visual materials to collect data
Observation	Involves observing general movements and activities of the survey population
Key informant (or expert) interviews	Involves interviewing members of institutions, organizations and government agencies who generally know something about or work directly with the survey population

Analysis plan and theoretical approach for formative work

Sampling frame/recruitment

Participants will be recruited for focus groups using a purposeful sampling technique, which is the intentional recruitment of participants who are best suited to provide a full description of the phenomenon been studied.

Sample size for the focus groups and interviews

The issue of sample size in qualitative research is not set *a priori*, but based on when data saturation is reached: the point at which further analysis of the data does not yield any new information or does not add anything new to the theory being derived from the data. It is estimated that at least (*put number here*) focus groups (with 5–8 participants in each group) and up to (*put number here*) key informant (and/or in-depth) interviews per site will be adequate to reach data saturation.

Focus group moderator and interview guide

Focus groups will be conducted by moderators with the aid of interview guides that will be used to elicit individual responses within the context of a group. All focus groups will be audio taped and transcribed, and each will last up to one hour.

Structure of the focus groups

The composition of each focus group will be relatively homogenous in terms of relevant sociodemographic characteristics in order to encourage individuals to freely share their ideas and perceptions. All focus group sessions will be conducted in a quiet room dedicated for this purpose. After a brief introduction of the survey by the moderator and after obtaining written consent from each participant, permission will be asked to audio tape the session. The objectives of the session will be outlined and discussion facilitated with the aid of the interview guide. It is anticipated that each session will last no more than 90 minutes. Two trained research assistants will moderate all sessions. During the sessions, the moderators will generate memos as the discussion unfolds to help formulate follow-up questions and probes. At the end of each session, responses will be transcribed and analysed. Moderators will also write up their impressions about the session, its main themes and the comments and reactions of participants.

Key informant (and/or in-depth) interviews

These interviews will be used to confirm, refine and augment the information generated from the focus group data. Trained research assistants will conduct all interviews using the same interview guide as in the focus groups. The screening strategy and sampling technique will be the same as used with the focus groups. All interviews will be audio taped and transcribed, and each will last up to one hour.

Analysis plan

The information generated from this formative phase will be transcribed and stored in a common word processing format in order to facilitate analysis. This is not a

formal qualitative survey, but rather an assessment to inform the design of a survey. Therefore, data analysis will comprise the review and assessment of the key themes, direct responses and ideas that emerge from the data collection to directly guide survey design (e.g. appropriate hours to have the RDS survey site open, the amount for incentives, acceptability of HIV testing, size of social networks).

4.2 Key informant participant information sheet

(Title of survey here) *(English version)*

Principal investigators: *(add principal investigators here)*

The name of this survey is “*(add title here)*”. This information sheet explains the survey to you in writing. An interviewer will also talk about the survey with you today. We would like you to ask **any** question about **any** part of the survey that you do not understand. After you have heard about what is involved we will ask you to decide if you want to participate or not. We will give you a copy of this information sheet to take home with you.

Participation in research is entirely voluntary. If you agree to take part in this survey you can withdraw at any time, and you do not have to take part if you do not want to.

A. Purpose

The *(add the names of the implementing organizations here)* is planning for a survey in the future on *(add population here)* who may be at high risk for HIV infection because they *(add behaviour here)*. The survey will test participants for HIV and other infections and risky behaviours. You are being asked to be in the survey today because you have ideas and opinions that can help us to plan this future survey. Today, we are asking people to do a special interview, called a key informant interview *(or in-depth interview)*. This will help us to learn about the best way to plan our future survey.

B. Procedures

1. If you agree to be in this survey as a “key informant” you will meet with a trained interviewer and have an informal discussion for 1–1.5 hours.
2. During the discussion, we will inform you about the future survey we are planning and will ask you for your opinion about:
 - the social connections of people who *(add behaviour here)*
 - ways to encourage people who *(add behaviour here)* to take part in a survey
 - reasons people who *(add behaviour here)* might not want to take a test for HIV and ways to encourage them to take the test.
 - the best payment for doing the survey.
3. You do not need to answer all the questions in the interview if you do not want to. If a question makes you feel uncomfortable or you do not know the answer, it is alright to tell the interviewer that you do not want to answer the question. You can also stop the interview at any time without any penalty.
4. The interview is anonymous. We will not record your name or anything else about you that could identify you. Only the survey staff ever see or know the information you give us.
5. We will take notes on paper and also tape-record the interview so we can listen to it later. At the end of the survey, the notes and tape recording from the interview will be destroyed.
6. We will provide you with refreshment during the interview.
7. At the end of the interview we will give you *(add amount here)* as a token of thanks.

C. Discomforts and risks

Because the interview is about men who are at risk of HIV because of behaviour that is sensitive, illegal and stigmatized, some of the questions might make you feel uncomfortable.

If other people in your community find out that you are in this survey, you could suffer from a loss of privacy or discrimination in your community. To protect you from this, your name will not be asked for or written down at any point in this survey. No one on the staff will tell anyone else that you took part in the survey, the place where the interview takes place will be private and unmarked, and there will not be a written list of people who were interviewed at any time. In addition, no one will ask about your own behaviours, and you should not share this information during your interview.

D. Benefits

The information you give us may help us to plan a better survey for *(add population here)* who may be at high risk for HIV infection because they *(add behaviour here)*. This could benefit *(add country here)* society through improved health and social programmes.

E. Incentive

You will be given *(add amount here)* for your participation in the interview.

F. Persons to contact

The people in charge of this research are *(add names and affiliations here)*. You can call them with any questions or concerns about the survey. You can contact *(add phone numbers and email addresses here)*.

If you have any questions about your rights as a survey participant, about ethical matters, or wish to complain you can call the Chairperson of the Ethical Review Board who reviewed and approved this survey *(add phone numbers and contact persons here)*.

G. Confidentiality statement

What you tell us is confidential. No one except the survey staff will have access to the interview notes or tape recordings.

H. Right to refuse or withdraw

Participating in this interview is voluntary. You have the right to refuse to discuss any questions. You can leave the interview at any time.

I. Agreement

Do you have any questions?

Moderator: Answer the participant's questions about the interview before proceeding to the next question.

You have read and/or had read to you the explanation of this survey, you have been given a copy of this form, had a chance to ask questions and you know that you can refuse to participate. I am going to ask for your consent to do this interview. By saying yes, you agree to do the interview. By saying no, you decline to do the interview. Do you agree to take part in the interview?

Date/initials of moderator: _____ to confirm affirmative verbal consent

I have explained to the participant the survey purpose and procedures and we have discussed all the risks that are involved. I have answered questions that the participant had to the best of my ability.

Date: _____ Signature of moderator: _____

4.3 Focus group participant information sheet

(Title of survey here) *(English version)*

Principal investigators: *(add principal investigators here)*

The name of this survey is “*(add title here)*”. This information sheet explains the survey to you in writing. An interviewer will also talk about the survey with you today. We would like you to ask **any** question about **any** part of the survey that you do not understand. After you have heard about what is involved we will ask you to decide if you want to participate or not. We will give you a copy of this information sheet to take home with you.

Participation in research is entirely voluntary. If you agree to take part in this survey you can withdraw at any time, and you do not have to take part if you do not want to.

A. Purpose

The *(add the names of the implementing organization here)* is planning for a survey in the future on *(add population here)* who may be at high risk for HIV infection because they *(add behaviour here)*. The survey will test participants for HIV and other infections and risky behaviours. You are being asked to take part in the survey today because you have ideas and opinions that can help us to plan this future survey. Today, we are asking people to be in a special discussion group called a “focus group”. This will help us to learn about the best way to plan our future survey.

B. Procedures

1. If you agree to take part in this survey you will come to a group discussion with 6–8 other people from your community. The discussion will take about 90 minutes and will be led by a trained facilitator. In the discussion everyone will be asked to talk about the following issues:
 - information about the social connections of people who *(add behaviour here)*
 - ways to encourage people who *(add behaviour here)* to take a survey
 - reasons people who *(add behaviour here)* might not want to take a test for HIV and ways to encourage them to take the test
 - the best payment for doing the survey.
2. You do not need to talk about anything that is asked or discussed during the focus group if you do not want to. If a question makes you feel uncomfortable or you do not want to say anything in the group, you can remain silent. You can also leave the focus group at any time without any penalty to you.
3. The focus group is anonymous. We will not record your name or any characteristics that might identify you at any time during the group. The group leader will tell all participants not to use their name or anyone else’s name during the discussion. No one except the survey staff will have access to the information you provide to us.
4. During the discussion, we will take notes on paper and the facilitator will tape-record the discussion so that our team can listen to it later. We will not ask for your name or any other information that might identify you or connect you to what you said during the focus group.
5. We will provide you with refreshment during the focus group.
6. At the end of the focus group we will give you *(add amount here)* as a token of thanks.

C. Discomforts and risks

Because the interview is about *(add population here)* who are at risk for HIV because of behaviour that is sensitive, illegal and stigmatized, some of the questions might make you feel uncomfortable. If other people in your community find out that you are in this survey, you could suffer from a loss of privacy or discrimination in your community. To protect you from this, your name will not be asked for or written down at any point in this survey. No one on the staff will tell anyone else that you took part in the survey, the focus group location will be private and unmarked, and there will not be a written list of people who attended. The group leader will tell all participants not to use their name or anyone else's name during the discussion. In addition, no one will ask about your own behaviours, and you do not need to share this information.

D. Benefits

The information you give us may help us to plan a better survey for *(add population here)* who may be at high risk for HIV infection because they *(add behaviour here)*. This could benefit *(add country here)* society through improved health and social programmes.

E. Incentive

You will be given *(add amount here)* for your participation in the interview.

F. Persons to contact

The people in charge of this research are *(add names and affiliations here)*. You can call them with any questions or concerns about the survey. You can contact them at *(add phone numbers and emails here)*.

If you have any questions about your rights as a survey participant, about ethical matters, or wish to complain you can call the Chairperson of the Ethical Review Board who reviewed and approved this survey *(add phone numbers and contact persons here)*.

G. Confidentiality statement

What you tell us is confidential. No one except the survey staff will have access to the interview notes or tape recordings.

H. Right to refuse or withdraw

Participating in this interview is voluntary. You have the right to refuse to discuss any questions. You can leave the interview at any time.

I. Agreement

Do you have any questions? Moderator: Answer the participant's questions about the interview before proceeding to the next question.

You have read and/or had read to you the explanation of this survey, you have been given a copy of this form, a chance to ask questions and you know that you can refuse to participate. I am going to ask for your consent to do this interview. By saying yes, you agree to do the interview. By saying no, you decline to do the focus group. Do you agree to take part in the interview?

Date/initials of moderator: _____ to confirm affirmative verbal consent.

I have explained to the participant the survey purpose and procedures and we have discussed all the risks that are involved. I have answered questions that the participant had to the best of my ability.

Date: _____ Signature of moderator: _____

4.4 Example of an interview guide for interviews with government officials, nongovernmental organization staff, etc.

Note: not all questions may be relevant to all interviewees.

Survey population characteristics

- How do you define *(put survey population here)*?
- What languages do they speak? How literate are they? What is their age distribution?
- Which are the areas they frequent? What hours?
- Which commercial venues do they frequent? What hours?
- What is their access to public health services?
- What do you know about their sexual behaviours?
- What do you know about drug use among them?
- What types of diversity are there among each of the groups *(e.g. different venues where sex workers solicit clients; different self-identities among men who have sex with men)*?
- How well do they know each other? By name? By sight? Are there subgroups within these populations that are separated from each other? How are they separated?
- How are they organized among themselves?

Service provision

- How many organizations provide services for them? Can you give us their contact details?
- What services is your organization providing to them?
- When and where do you provide them?
- Is our planned incentive appropriate? Should we pay it out in cash or goods?
- Where should we refer them for further care and treatment?
- Are you interested in working with us, e.g. can we refer them to you if they need further help?

Other

- Would HIV and STI tests be acceptable? Would they see getting the results, counselling and treatment (for STIs) as a benefit?
- In your opinion, how interested would they be in participating in the survey?
- Do you think our planned benefits are such that we would have to deal with impersonators?
- Where should we look for seeds to start the sampling?
- Can you advise us how we can confirm true *(put survey population here)* or identify impersonators?
- Are the authorities, especially the police, making your work difficult?
- What types of discrimination and stigma do these groups face?

4.5 Example of an interview guide for focus group discussions or in-depth interviews

Note: not all questions may be relevant to all survey populations

We will ask you questions about yourself and your peers. When I say “peers”, we mean people you know and they know you. They can be “colleagues”, “peers”, “acquaintances” or “family members” who *(describe behaviour of the survey population here)*.

Survey procedures

We will start by giving a brief explanation of the planned survey: In this survey we plan to interview people who *(describe behaviour of the survey population here)* about HIV and sexual practices. We also want to give free HIV testing and free screening for sexually transmitted infections (STIs), and treatment, if necessary. We will tell you how to protect yourself from HIV and other diseases. We plan to ask you to find peers who can participate in the survey. There are no costs and we will not collect any names or other personal information that can be used to identify a person.

- How likely is it do you think that people would join a project like this? What sounds most interesting about this project? Why? What sounds least interesting about this project? Why?
- What do you think would prevent your peers from coming to see us? How can we overcome such reasons?
- Do you think free and anonymous HIV testing, care and referral services are important to you or your peers?
- What if we also ask you and your peers to screen for other STIs: how do you feel about this?
- How would you feel about receiving free testing and treatment for STIs?
- We want to collect urine for testing of sexually transmitted diseases: how would people feel about that?
- For women: We want to collect some fluid from the vagina. After receiving instructions, you would do that by yourself, in a bathroom. It is quick and painless. Would you mind doing that? How would your peers feel about doing that?
- For men: We want to collect some fluid from the anus. After receiving instructions, you would do that by yourself, in a bathroom. It is quick and painless. Would you mind doing that? How would your peers feel about doing that?
- It is important to get test results for these tests? Why?
- What other services would your peers like? Why?
- The whole procedure (interview, counselling, blood draw, etc.) will take 1–2 hours. Do you think that is acceptable?
- If the survey included taking an HIV test, how likely do you think it is that your peers would join? What about you?
- If someone tests positive for HIV, where should we refer him/her to get treatment and care?
- How shall we inform your community of the results of our survey?

Questions about social networks and recruitment

Let me describe how we want to find people to be interviewed. We will give you up to three coupons to give out to peers who are like you. For each peer who shows up with a coupon from you, you will get a small amount of money or a gift. Your recruit will also be interviewed, get free HIV testing and STI screening and treatment, be told about HIV and how to prevent it, and get coupons to give out to his/her peers. Your peers who join will be asked to do the same thing as you do.

- Would you be willing to pass a coupon to a peer and ask him/her to join the project? Do you think your peers would be willing to do the same?
- How many people who are also (*describe behaviour of the survey population here*) do you know, and they know you, you know their name and they know yours, and you have seen them in the past one week? In the past one month?
- If you wanted to, is it easy for you to contact them? Do you have their phone numbers? How often do you see them?
- Could you tell me about how your peers interact? (What kinds of activities do they do together?)
- Do people who are also (*describe behaviour of the survey population here*) know each other?
- Please describe the different types or groups of (*describe behaviour of the survey population here*). Do they have separate names/titles?
- Are there groups of people who also (*describe behaviour of the survey population here*) you do not have any contact with? Who are they? Why?
- How likely do you think it is that you could recruit your peers?
- What information should we include on the coupon?
- How many coupons out of three do you think you can give to your peers and they would actually show up?
- How many days would it take until your peers would come to us to join the survey?

Questions about seeds

This survey will start with a few persons who can easily find recruits. These persons are known as “seeds”.

- Do you have something like peer leaders in your community? What do you call them? Do you know some of them personally?
- Can you think of any of your peers who would make good seeds (who know a lot of other (*describe behaviour of the survey population here*), speak well, are well liked by their peers, and would be interested in our survey goals)?
- Can you think of peers who live/work in different areas, and have different ages, incomes, or are of different types? Do you know peers who know many other (*describe behaviour of the survey population here*) who have diverse characteristics?
- What is the best way to find seeds?
- Can you help us locate seeds?

Questions about logistics

This survey will also include an incentive for completing the questionnaire and testing, and then for recruiting peers. We are thinking of having *(add amount here)* as the incentive for participating in the survey and *(add amount here)* for recruiting up to three peers.

- Do you think this is appropriate?
- Instead of paying small amounts of money, should we give participants gifts such as clothes, cosmetic kits or food, along with money to cover transport? What do you think about that?
- What other things should we give? Condoms? Lubricant?
- What would be a convenient location for the survey site? Why is that? What areas should we avoid?
- We may also ask other groups to participate *(name them)* – would it disturb you to wait in the same room as them?
- What hours of the day and days of the week would be most convenient for you and your peers to come to the survey site?
- Would you and your peers prefer men, women or transgender persons as staff during the survey?
- What languages do most of your peers speak? Can you read? Can most of your peers read? Can people easily read a map? Do you think a map on the coupon is helpful for finding the survey site?
- What colours are appropriate for the coupon? Coupons are about the size of *(add size here)*. Do you think they should be smaller or larger? What kinds of information should be included on the coupons?
- Are there any groups or persons we should talk with during the planning stages of this survey? Are there groups or persons who may hinder this survey? Are there groups or persons who may be especially helpful in planning this survey?

Annex 5

General protocol for
conducting respondent-
driven sampling surveys
among people who
inject drugs, men who
have sex with men and
female sex workers

General protocol for conducting respondent-driven sampling surveys among people who inject drugs, men who have sex with men and female sex workers

The protocol below is intended as an example and can be altered in any way to meet the needs of your specific survey. Some parts of this protocol that need to be modified are in *italics*.

This protocol has undergone rigorous review by governmental and university ethical review boards in the United States and local ministries of health.

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List of annexes

(At a minimum, you should have the following appendices; you can use your own or those provided in the appendices of the module)

- Annex X Recruitment coupon draft (test result voucher, appointment voucher, etc.)
- Annex X Eligibility screening form (and any other forms to be used in data collection management)
- Annex X Information sheet and consent form for full survey
- Annex X Survey instrument
- Annex X Data and specimen flow chart
- Annex X Laboratory specimen forms (and any other forms used for biological specimen collection, control and transport)
- Annex X Table shells for primary data analysis

1. Title of the project: PROTOCOL FOR INTEGRATED BIOLOGICAL-BEHAVIOURAL SURVEILLANCE SURVEYS USING RESPONDENT-DRIVEN SAMPLING AMONG *(add population here)*

Working title: THE *(add survey name here)* SURVEY

Clarification of titles: The full protocol title reflects the survey's survey population *(add population here)*, the primary measures of HIV and other markers of infectious diseases with related risk behaviours, the sampling design (respondent-driven sampling [RDS]), and the long-term goal of enhancing public health surveillance activities in *(add country here)*. Given the legal status of *(add population here)* in *(add country here)*, the working title deliberately avoids reference to *(add population here)* and will be used on the verbal informed consent form/information sheet and other materials to minimize exposure of the survey population. For simplicity, the specific survey is hereafter referred to as *(add survey name here)*. The term "integrated biological-behavioural surveillance surveys" refers to an overarching approach to tracking the HIV epidemic and related factors among key populations at higher risk of HIV exposure.

2. Investigators and institutional affiliations

The current survey will be implemented by employees and agents of *(list all agencies, organizations, universities, etc., that will be involved)*

Country X AIDS Commission

Principal investigator 1: *List name and academic titles here; List the person's position and organizational affiliation and their responsibilities in the survey (e.g. responsible for overall scientific oversight, survey implementation and conduct, the interpretation of findings, and the use of data for programme planning).*

Principal investigator 2: *List name and academic titles here; List the person's position and organizational affiliation and their responsibilities in the survey (e.g. responsible for overall scientific oversight, survey implementation and conduct, the interpretation of findings, and the use of data for programme planning).*

Co-investigators: *List names and academic titles here; List the person's position and organizational affiliation and their responsibilities in the survey (e.g. responsible for coordination of technical agencies/implementing partners and stakeholders, field monitoring and supervision monitoring).*

Country X Institute for Medical Research

List name and academic titles here; List the person's position and organizational affiliation and their responsibilities in the survey.
List name and academic titles here; List the person's position and organizational affiliation and their responsibilities in the survey (e.g. laboratory coordinator and responsible for the counselling and testing, collection of biological samples in the field and related laboratory analyses).

List name and academic titles here (e.g. responsible for quantitative and statistical analysis).

Nongovernmental organization providing services to key population

List name and academic titles here (e.g. responsible for field coordinator and supervisor).

List name and academic titles here (e.g. key population HIV research specialist).

3. Location and funding source

Location: City Y, Country X project headquarters, see below for proposed survey sites

Funding: County X Ministry of Health

4. Abstract

This protocol describes survey activities among *(add population here)* in several locations in *(put country here)* to measure HIV prevalence and other sexually and non-sexually transmitted

infections, related risk behaviours, and access to prevention and care services. The overall approach is based on standardized methods for integrated biological and behavioural surveillance surveys used around the world with adaptations to the *(put country here)* context. The survey will use respondent-driven sampling (RDS) for recruitment of *(add population here)* through peer-referrals using non-identifying codes to link recruiter to recruit and collecting social network size data for statistical adjustments. *(Add population here)* over the age of *(put age here)* residing in *(put country here)* will be eligible. The survey will be entirely anonymous with verbal informed consent; at no time will identifying information be collected.

This protocol is based on information from *Introduction to respondent-driven sampling (2007)* developed by Centers for Disease Control and Prevention/Family Health International. (See: http://globalhealthsciences.ucsf.edu/PPHG/surveillance/other_modules.html).

Proposed procedures include:

- a face-to-face risk behaviour questionnaire
- rapid HIV testing using dried blood spot (DBS) processing with confirmatory testing of positive specimens and/or collection of blood to test for HIV and *(list other infections here)*
- HIV/STI pre- and post-test counselling.

Participants may consent to or decline each part of the survey (e.g. survey, rapid testing, blood draw). Persons testing HIV-positive on rapid testing and those with reactive tests will be referred to collaborating care and support services. As it is primarily a surveillance effort, the sample size of *(put sample size here)* per location is based on providing 80% power to detect a significant ($p < 0.05$) 10% change in condom use between the proposed survey and future rounds of integrated biological-behavioural surveillance surveys with *(put population here)* using a chi-square test and assuming a design effect of 2.0. Findings of the surveys will be disseminated to stakeholders to advocate for needed services for *(put population here)*, develop appropriate prevention and care interventions, guide future research and assess the impact of the response to the HIV epidemic over time.

5. Background and justification

(Describe the epidemic and why it is important to conduct an integrated biological-behavioural surveillance survey among the population selected; a closing paragraph is provided below)

To effectively design HIV/AIDS policies and interventions, reliable estimates of HIV prevalence, non-sexually and sexually-transmitted infections, and related behavioural, social and environmental factors that affect infection transmission among *(put population here)* in *(put country here)* are needed. To monitor and evaluate the reach of programmes for *(put population here)* and their aggregate impact over time, repeated representative surveys of the population of *(put population here)* are needed. However, to date there has not been a standardized set of surveillance activities to track the epidemic among *(put population here)* in *(put country here)*. This protocol therefore proposes to conduct a series of cross-sectional surveys among *(put population here)* in several locations in *(put country here)* using RDS that will assist with the development of an integrated biological-behavioural surveillance survey as an integral component of a comprehensive HIV surveillance system. Data from the survey itself and the formative assessment will enrich our understanding of *(put population here)* and their health needs in *(put country here)*.

6. Survey objectives

1. To measure the prevalence of HIV, *(list other infections here)* and their associated risk behaviours among *(put population here)* in *(put country here)*.
2. To assess use of, and access to, health and social welfare programmes among *(put population here)* and identify means to increase their coverage and uptake in *(put country here)*.

3. To enhance local capacity to conduct integrated biological-behavioural surveillance surveys (*put population here*) in (*put country here*).

7. Survey methods

7.1 Overall survey design: RDS

Worldwide, (*add population here*) comprise a relatively rare and highly stigmatized population making them hard-to-reach through conventional population-based survey methods. In response, specialized surveillance methods have been developed that attempt to approximate probability-based sampling through peer referral (e.g. RDS). RDS has been used worldwide in integrated biological-behavioural surveillance surveys to recruit hidden and hard-to-reach populations.^{1,2} This survey will use standard RDS procedures to recruit (*add population here*).³

The theoretical premises of RDS have been explained in detail previously.⁴ In brief, RDS begins with the selection of “seeds” that are known members of the survey population who are instructed to recruit a limited number of their peers from their social network, who in turn are enrolled (if eligible) and instructed to recruit other peers and so on. The number of recruits per person is usually restricted to three in order to ensure that chains progress through diverse social networks. Coupons are used to link who recruits whom through the use of codes.

A primary incentive is given for completion of the survey and secondary incentives are given for each successfully recruited peer. RDS reduces the biases inherent in referral methods through statistical adjustments that attempt to account for social network size and similarity among persons within social networks. Although sampling begins with a purposely chosen set of initial subjects, known as “seeds”, the composition of the final sample approaches independence from the starting point. Recruitment progresses to produce numerous waves of recruits and ends once the sample size is met (see Figure A5.1).

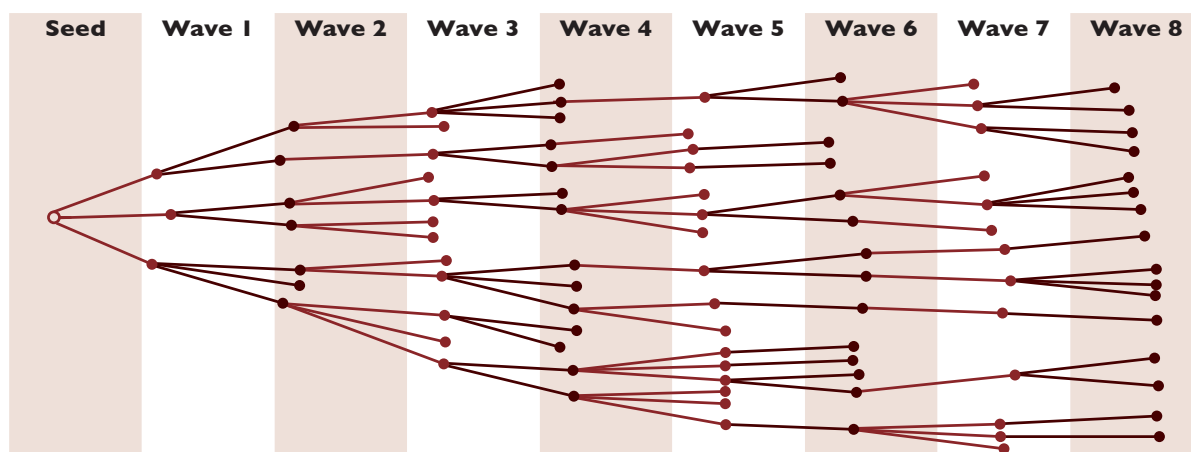


Figure A5.1 Recruitment chain of eight waves generated from one seed⁵

¹ Malekinejad M et al. Using respondent-driven sampling methodology for HIV biological and behavioural surveillance in international settings: a systematic review. *AIDS and Behavior*, 2008, 12(Suppl. 1):105–130.

² Johnston LG et al. Implementation challenges to using respondent-driven sampling methodology for HIV biological and behavioural surveillance: Field experiences in international settings. *AIDS and Behavior*, 2008, 12(Suppl. 1):131–141.

³ Johnston LG. *Conducting respondent driven sampling (RDS) studies in diverse settings: A training manual for planning RDS studies*. Atlanta, GA, Centers for Disease Control and Prevention/Arlington, VA., Family Health International, 2007 (see: http://globalhealthsciences.ucsf.edu/PPHG/surveillance/other_modules.html).

⁴ Heckathorn DD. Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems*, 1997, 44:174–199; Heckathorn DD. Respondent-driven sampling II: Deriving valid population estimates from chain-referral samples of hidden populations. *Social Problems*, 2002;49:11–34.

⁵ Source: Johnston LG, Sabin K. Sampling hard-to-reach populations with respondent driven sampling. *Methodological Innovations Online*, 2010, 5(2) 38–48. See: <http://www.methodologicalinnovations.org>

Each eligible participant who presents to one of the RDS survey sites with a valid coupon will be enrolled into the survey. The steps for the primary incentive will involve: screening for eligibility; completion of consent; face-to-face interview; pre-test counselling; extraction of blood for testing; explanation of the coupon recruitment process, provision of up to three coupons and a primary incentive (see Figure A5.2).

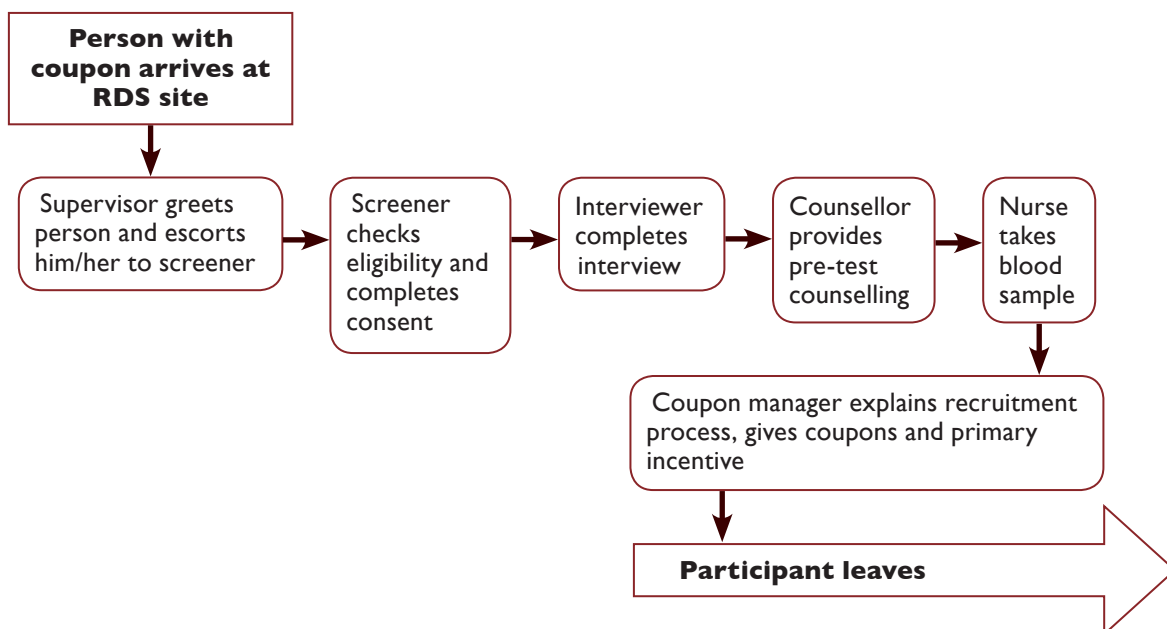


Figure A5.2 Survey steps for the primary incentive

The steps for the secondary incentive will involve: completion of a follow-up questionnaire; secondary incentives for recruitment of eligible peers who enrol in the survey; post-test counselling, and test results (see Figure A5.3).

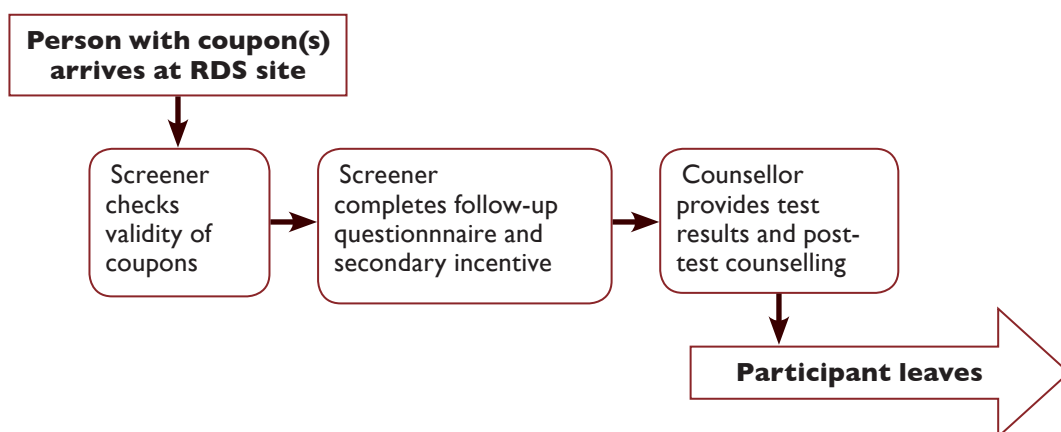


Figure A5.3 Survey steps for the secondary incentive

Specialized analysis (e.g. using RDSAT or RDS Analyst software) is used to produce population prevalence estimates and 95% confidence intervals of variables adjusting for unequal probabilities of inclusion due to varying social network sizes and the similarities in characteristics of persons within their social networks. To conduct analysis, the survey must link recruiter to their recruits and ask the number of persons in the participant’s

social network who would be eligible and recruitable for the survey. Advanced aspects of the analysis of RDS data, such as adjusted multivariate analysis, are currently under research and we will keep abreast of the most up-to-date accepted standards during the analysis phase.

7.2 Selection of survey locations

The following survey locations are selected based on the size of the population in each of these locations *(add rationale why certain cities are selected. Examples are that they are the largest cities in the country, they are tourist areas and prone to sex work, they are port cities, they are drug using hot spots, etc.)*.

7.3 Participant eligibility criteria

Eligibility for this survey is: *(add all components of eligibility here, including the sex, behaviour to be measured, age and catchment area of survey)*.

7.4 Sample size and power estimates

The sample size estimate is based on the surveillance purpose of tracking important changes in the epidemic over time i.e. between rounds of integrated biological-behavioural surveillance surveys. In the proposed survey, each site will constitute a separate survey with the sample size needed to track changes at each location. The needed sample size is *(add sample size here)* participants per survey location. The estimation is based on the following formula and assumptions:

$$n = D \frac{\left[Z_{1-\alpha} \sqrt{2P(1-P)} + Z_{1-\beta} \sqrt{P(1-P_1) + P_2(1-P_2)} \right]^2}{(P_2 - P_1)^2}$$

Where:

D = design effect of 2.0.

P_1 = the estimated proportion of the key variable or behaviour at the time of the first survey.

P_2 = the estimated proportion of the behaviour at the next round of integrated biological-behavioural surveillance, so that $(P_2 - P_1)$ is the magnitude of change we wish to be able to detect. In this case, we would like to be able to detect a 10% to 15% increase *(to XX%–XX%)* or decrease *(to XX%–XX%)* based on the ability to assess meaningful programme effort between surveys.

$P = (P_1 + P_2)/2$.

$Z_{1-\alpha}$ = the z-score corresponding to desired level of significance (we use 95% significance level and corresponding two-sided z-score).

$Z_{1-\beta}$ = the z-score corresponding to the desired level of power (we use 80% power and corresponding two-sided z-score).

Based on the calculation above, the needed sample size is *(add the results of the calculation here)* participants per survey site.

8. Survey procedures and logistics

8.1 Survey offices

One to two discreet office spaces in survey locations will be used to administer interviews and counselling in private, collect specimens and provide service referrals. The location will have central access and be quiet and secure. Only survey staff, investigators and recruits with coupons will be granted access beyond the reception area. The office will have enough rooms to serve several recruits concurrently and avoid overcrowding. To avoid public stigma, signs will not reveal the actual purpose of the office. The survey office will remain open up to four weeks after the last enrolment to ensure all participants can receive results, referrals and secondary incentives.

8.2 Selection of seeds

Seeds are the initial participants who start the chains of recruitment among their social networks. Seeds are purposely selected to reflect the diversity of social networks in the location in order to logistically enable the survey to reach equilibrium in a feasible time period. In theory, the characteristics of the starting seeds are irrelevant if chains progress long enough. However, in practice time constraints dictate that seeds should be selected from each of the major subpopulations identified in the formative assessment (i.e. to avoid “bottlenecks” between distinct groups or areas). Seeds must meet the survey eligibility criteria and will be given coupons and instructions in peer recruitment. Seeds will be oriented and motivated at the survey start to promote a feeling of survey ownership and enthusiasm about the project. Formative assessment will identify approximately (*add number here*) seeds. More seeds may be added during the course of data collection if recruitment speed is slower than anticipated or too many chains die out. To ensure rapid recruitment, ideal seeds should be well connected within their networks (among their peers), well regarded by their peers, sympathetic to the survey’s goals and diverse with regard to:

- sexual identity
- socioeconomic status
- geographical location
- age, area of residence
- selling of sex
- drug use
- ethnicity
- language.

8.3 Interview scheduling

Potential participants will receive a coupon from their recruiter that provides the survey site location, a phone number to call and hours of operation for drop-in. Upon returning the call, the next available interview slot will be offered to match the participant’s convenience, accommodating drop-ins as soon as possible. If there are too many drop-ins, recruits will be offered to schedule an appointment for a later time and date and will be given an appointment voucher.

If a non-recruit were to present at the survey site without a coupon, staff will inform them that it is the office of a “health survey” and escort them off the site, so that anonymity is preserved.

8.4 Coupon management

The coupon is essential to link the recruiter to their recruits and is necessary for the analysis of RDS data to adjust for network size and homogeneity within social circles. Being in possession of a valid coupon is an eligibility criterion. Issuance and receipt of coupons will be monitored electronically. Initially, participants will be given three coupons each. This number may be reduced to two, and thereafter one, as sampling progresses and recruitment needs to be slowed and stopped as the sample size is reached. Once the sample size approaches the target, and equilibrium has been achieved, no coupons will be handed out to remaining recruits.

The coupon will be designed in consultation with community representatives present at the stakeholders meeting to appeal to the population, include images recognized by *(add population here)* and have a consistent survey logo. No information that would directly divulge the focus of the survey will appear on the coupons. Coupons will have the following elements: serial number (which becomes the recruit's survey ID code), the name of the survey, telephone number to call, days and hours of operation for drop-in, activation date (date before which the coupon may not be used for enrolment) and expiry date (date after which coupon should not be used). In practice the activation and expiry dates are flexible. Information on the coupon will be in *(list languages)*. A coupon may be invalid if expired, tampered with, unreadable, or already used. Invalid coupons will be retained and stamped "Void". Valid coupons of recruits undergoing screening for eligibility will be retained and stamped "Used". Recruits who are re-scheduled for a future visit have their coupons returned to them. Re-scheduled visit dates may be past the coupon expiry date without rendering the coupon invalid. See Annex X for draft coupon *(attached draft coupon as an annex)*.

8.5 Survey ID codes

The proposed survey will be completely anonymous. Linkage of the various data components will be done through non-identifying unique survey codes. Multiple codes are associated with each individual and used for different purposes:

1. **Coupon/survey code.** The coupon code will be assigned by the coupon manager. The coupon code becomes associated with the questionnaire and with all other forms including test results.
2. **Recruiter coupon code.** In addition to their own coupon identification (ID) number, each participant is given three uniquely numbered coupons to recruit others. The linkage between recruiter and recruit is preserved for statistical analysis.
3. **Unique testing code (UTC).** *(This is optional)* The UTC is an alphanumeric code created by elements of information known to the participant. The UTC is used to unduplicate participants and verify individuals presenting for results disclosure and is only temporarily retained for the survey. A UTC will be created for every participant. The specific elements of the UTC for the proposed survey will be reviewed for acceptability and modified accordingly during the formative assessment, but may include the following elements:
 - the first 2 letters of the participant's first name
 - the first 2 letters of the participant's mothers name
 - the participants age in years at time of initial interview
 - the first two letters of the district of residence.

8.6 Eligibility screening

The coupon manager will examine the coupon (dates, originality) presented by the potential recruit. The UTC will confirm that the recruit had not been enrolled previously. The recruit's eligibility will be assessed through a short personal interview to screen for eligibility (see Annex X) covering the eligibility criteria listed above. Where doubts about eligibility remain, staff or volunteers may pose additional (non-standardized) questions to confirm true eligibility.

8.7 Verbal informed consent

Eligible recruits will be able to read and have read to them the verbal information sheet (see Annex X for English language full survey information sheet) (*add languages here*) (accommodating others as described above) with the opportunity to have any questions answered by the interviewer. Informed consent will cover all procedures, potential risks, benefits and who to contact in (*add country here*) to report complaints or concerns. The information sheet allows for separate consent or declining of components of the survey including:

- completion of the questionnaire
- venous blood draw for (list tests).

A copy of the information sheet will be offered to participants (see Annex X).

8.8 Survey data collection

Standardized data collection instruments adapted for (*add population here*) will be used for quantitative data collection (for a draft to assess the scope of questions considered see Annex X). Data items will include indicators needed for tracking the HIV epidemic and the national response among (*add population here*), conforming to international standards (e.g. UNGASS indicators, local key performance indicators), national programme needs, and comparability with similar surveys in the region. These instruments collect data on demographics, behaviours potentially correlated with HIV, symptoms of STI, and HIV-related knowledge, attitude, practices, stigma, discrimination and perceptions.

The proposed questionnaire originates from previously-used surveys worldwide (*list other surveys used*).¹ The questionnaire will undergo a development and review process in several stages. First, the instrument will be reviewed by stakeholders and the technical working group. A second phase of development will occur through administering the questionnaire with interactive feedback by key informants during the formative assessment. The questionnaire will be administered face-to-face by a trained interviewer with answers recorded on paper.

8.9 Recruitment of peers

Following completion of the above procedures, the coupon manager will explain the handling of the peer recruitment coupons and the recruitment process to participants. Three coupons will be given to the recruit (fewer to slow and end recruitment) to use in inviting eligible peers. Interested peers will receive the referral coupon and will call for an appointment or present themselves at the survey office. Survey participants who indicate they are not interested in recruiting will still be encouraged to take the referral coupons in case they change their mind about recruiting. As the survey approaches the needed sample size, the number of recruitment coupons will be reduced to two, then one, then zero.

¹ *Behavioural surveillance surveys: guidelines for repeated behavioural surveys in populations at risk of HIV*. Arlington, VA., Family Health International, 2000.

8.10 Laboratory testing

Serological testing for markers of infectious diseases will use *(add country here)* Ministry of Health approved assays following standardized protocols by the national reference laboratories of *(add name here)*. Rapid tests will be done on site, serological tests will be done at the *(add name here)* laboratories in *(add city here)* within a two week turn-around. *(Add the number of tests conducted here)* tests are proposed for this survey with two types of specimen: rapid test and dried blood spots and blood for serum. *(add amount of blood to be collected here)* ml of blood will be drawn. Participants may separately consent for each specimen. Specimens are collected after pre-test counselling.

8.11 Pre-test counselling

Upon completion of the survey and prior to collection of specimens for laboratory testing, participants who consent to testing will receive pre-test/risk reduction counselling for HIV and STIs. National guidelines for the development and implementation of HIV counselling, testing and referral services will be followed with adaptations made specifically for the *(add population here)* population. This includes certification of counsellors following successful completion of a two-week mandatory training and supervised counselling. We will also conduct a survey team specific training on *(add population here)* counselling issues. Pre-test counselling will include an explanation of HIV infection and transmission, the meaning of test results, risks associated with sexual and injection behaviours, as well as means to prevent and treat HIV, STIs and non-sexually transmitted infections.

8.12 Post-test counselling and linkage to services

Receiving test results will be strongly encouraged, but not mandatory for survey participation. Results disclosure, post-test counselling, and referral to treatment and care will be provided immediately following the rapid tests for HIV and syphilis to all participants who do not opt out of receiving their results. Post-test counselling messages will be tailored to recruits' HIV results and risk profiles. Post-test counselling will include goals, means and strategies for behavioural risk reduction, maintenance of risk reduction and explanation of risk reduction methods (e.g. condom use). Counselling of HIV-infected participants will include an assessment of psychosocial needs, a discussion of living with HIV-infection, treatment and care, and issues related to discrimination. HIV transmission to partners will also be discussed and strategies for behavioural change will be addressed. At all locations conducting HIV testing in this proposal, collaborations have been developed between *(list programmes here)* for linkage to care. For all participants, *(add what participants will receive, such as condoms and lubricants)* will be provided free of charge. We will follow-up with the collaborating providers at regular intervals to determine whether participants have accessed treatment and care.

For participants consenting to the blood draw for *(add infection here)* testing, results will be available within *(add time frame here)*. Prior to leaving the project site, participants will be given an appointment date on their test result voucher to return on for these results, disclosure counselling, and needed referrals for treatment and care. Results will be given upon presentation of their test result voucher or UTC; drop-ins for results return will also be accommodated provided that they can produce the the test result voucher or UTC. The return of results will be recorded.

8.13 Staff training

The survey staff, including (but not limited to) counsellors, interviewers, survey supervisor and site manager, will participate in a formalized *(add time frame here)* week mandatory training. All staff, including the above mentioned and coupon and data managers, will also be trained on the protocol implementation using a standard operating procedures (SOP) manual that is

being developed. This manual will cover training on the protocol, data management, ethics, safety, human subjects and confidentiality. Staff will be trained on formative assessment as outlined in the data management sections.

9. Data management and analysis

9.1 Data management

Interviewers will receive training on the administration of the questionnaire, question by question in English and (*add languages here*). Consistency checks will be in place to catch errors during the interview as well as detection of illogical data values. At the end of each interview, the interviewer will check the questionnaire for completeness clarifying any uncertainties with the participant. At the end of each day, the survey supervisor will review completed questionnaires soliciting clarifications from the interviewers and providing feedback. Completed questionnaires will be double entered into standardized software with built-in error checks (e.g. range values, internal consistencies) and compared with reconciliation against original forms that will be kept in a secure locked cabinet.

Management of codes from both survey results and HIV and other test results will be performed by the site manager, coupon manager and data manager on a daily basis. Continuous quality checks will be performed to ensure that code numbers are recorded properly for each participant. Merging of data sources (i.e. the laboratory and survey responses) will be conducted under the supervision of the investigators and lead data manager. All databases will be encrypted and password protected. Data (i.e. laboratory and survey) will be entered, merged, analysed and stored at (*enter name of organization*) as implementing partner in the survey.

9.2 Analysis overview

The analysis of RDS data requires adjustment for social network size and homophily within networks. The methods of analysis, including multivariate analysis, are under development and we will keep abreast of the latest developments. At present, we will use RDS Analysis Tool (RDSAT) version 6.0 for analyses (see www.respondentdrivensampling.org). An RDS coupon manager will be used to track recruit processing and coupons; UTC will be used 1) to identify duplicate recruits, 2) to confirm correct ownership of a recruit's coupon (ID number), and 3) to re-establish the ID number of recruits who present themselves for follow-up without a coupon. RDSAT is software developed for analysis of RDS data which produces population point prevalences and 95% confidence intervals for key indicator variables.

RDSAT also produces survey weights. The data (along with the individual survey weights) can then be exported into standard statistical packages (e.g. SPSS or Stata) for more complex analysis.

As primarily a surveillance effort, the primary analyses will be the adjusted population point estimates of disease prevalence and key risk behaviours (e.g. HIV, STIs, unprotected sex), (objective 1), and prevalence of use and access to programmes (objective 2) by each site (i.e. data will not be aggregated across locations). Stratified analyses will also be conducted within sites to identify subpopulations at higher risk. Using the RDSAT exported weights, conventional analyses (e.g. logistic regression) will be conducted to identify significant predictors of HIV and STI infection and risk behaviours.

10. Ethical considerations

10.1 Potential harm and measures to mitigate harm

A primary ethical concern of this survey is that participation in the survey may reveal that respondents are engaging in illegal and stigmatized behaviours, including commercial sex work, illegal drug use and same sex sexual activity. Inadvertent disclosure of information collected from the survey may subject persons to discrimination and potential harm. HIV serostatus may also subject participants to stigma and discrimination if inadvertently revealed to persons outside the survey. To help minimize the risk of these disclosures, the survey will be entirely anonymous—at no time will names or identifying information be collected.

Diagnosis of HIV infection may also subject participants to psychological and emotional stress. To minimize these harms, we will use trained counsellors. Participants will also be referred to HIV treatment, care and support services. Dealing with reports of rape and other violence will be handled in consultation with local human rights law organizations and relevant services.

10.2 Age of respondents

This activity will recruit only persons age 18 or older; no minors will be included.

If minors are included, please modify the following to help explain how minors will be protected:

United Nations General Assembly indicators suggest reporting on HIV/AIDS indicators in many groups from ages 15–24. The Government of *(add country here)* is required to report on these rates. Including adolescents aged 15–17 years raises legal and ethical concerns about informed consent in institutional review boards in the United States and other countries where the age of majority is 18 years. The age of majority in *(add your country here)* is also 18 years of age, however...

Example: the legal age of marriage *(you may need to find some other legal premise for recruiting minors)* for females in *(add country here)* is *(give age here)* years of age and the national guidelines for voluntary counseling and testing (VCT) emphasize the particular vulnerability of adolescents under age 18 stating that “adolescents who are married, have children or practice unsafe sex shall be categorized as ‘mature minors’ and permitted unrestricted access to VCT programmes”.

Example: the importance of this survey for delivering prevention and services in the population of 15–17 year olds is considered a high priority by the *(add implementing governmental organizations here)* whose surveillance, as well as demographic household surveys and AIDS indicator surveys in *(add country here)*, all include youth age 15 and older.

Example: given that *(add population here)* are unlikely to live with or nearby their parents and understanding the risks related to identifying them to family members or spouses, we propose to include “emancipated” minors aged 15–17 in this survey. We define an emancipated minor as one not currently living under the direction or auspices of parent or guardian, and not otherwise supported by a parent or guardian. This information will be self-reported and questions for verification are built into the survey tool.

To further protect minors and all survey participants, no identifying information will be collected. All participation will be confidential and anonymous with referrals to local resources provided to all survey participants who wish to receive services and support.

10.3 Approvals and consultations

This project proposal will be submitted for review and approval to the institutional review board of *(list the review board here)* in *(add country here)*. Survey personnel will be trained in ethics and good clinical practice. Investigators with membership on the local institutional review board will recuse themselves during institutional review board review and approval meetings (except where permitted for purposes of information gathering at the request of the board).

10.4 Reporting adverse incidents

Adverse incidents will be reported to the *(add country here)* institutional review board. Potential incidents may include protocol violations, security incidents harming recruits or staff, breaches of confidentiality, or adverse physical or mental reactions to HIV counselling and/or testing.

10.5 Data security and privacy

The survey is entirely anonymous; no personal identifying information will be collected. Access to the recruit interview and testing electronic data will be limited to the data/coupon manager, site manager, data analyst and investigators. Data files will be password protected. Any hard copy recruit data will be stored in locked file cabinets and access will be limited in the same manner as for electronic data.

10.6 Potential benefits

The primary benefits of the proposed survey will accrue to *(add population here)* communities in *(add your country here)* by producing reliable data on their health and social welfare needs. Potential individual benefits include the provision of the following free of charge:

- counselling and testing for HIV *(list other infections to be studied)* with referral to treatment and care
- provision of *(add what will be provided to participant e.g. condoms and lubricants, health information)* and referral services specifically available for *(add population here)*
- HIV-infected participants will be referred for treatment and care; antiretroviral therapy is freely available and increasingly accessible in many areas of *(add country here and confirm that this is accurate)*.

10.7 Incentives

Incentives for participation are common in integrated biological-behavioural surveillance surveys using RDS methodology. RDS relies on survey participants to identify, approach and inform future recruits. To propagate recruitment chains, nominal primary incentives are offered for completing the survey and secondary incentives for each recruit. Furthermore, participants need to travel to the survey site for the interview and are asked to return for one or more visits for test results disclosure and to collect secondary incentives. Some benefits offered through survey participation (e.g. HIV testing and counselling, diagnosis and treatment) may be perceived as compensation.

Past RDS surveys suggest that incentives should reflect the price of a moderate meal, payment for a round trip on public transportation, or one day's minimum wage. Based on these parameters, RDS survey participants will receive *(add proposed amount here)* for participation and *(add proposed amount here)* for each successful recruit (no more than three recruits). The precise amount of the primary and secondary incentive will be re-assessed in the formative assessment period and the IRB will be informed of any changes prior to recruitment of subjects.

II. Projected time line

This surveillance project will start in *(add month and year here)* with the expectation of all phases being complete within twelve months. The following table outlines the current plans for surveillance in each site for the first year beginning with receipt of all ethical approvals.

SURVEY ACTIVITY	MONTH OF SURVEY											
	1	2	3	4	5	6	7	8	9	10	11	12
Formative assessment												
Questionnaire design and piloting												
Database development												
Printing of coupons and survey forms												
Rental of survey site(s), hiring staff												
Technical and ethical training of survey personnel												
Data collection												
Data entry												
Analysis and report writing												

12. Dissemination of findings

Survey implementers and stakeholders will be informed of the findings of this surveillance survey through a final dissemination meeting as soon as primary results are available. Means of dissemination will include presentations at meetings and workshops, as well as reports and publications at national and international conferences and in the peer-reviewed literature. Data will also be used to inform and engage *(add population here)* communities in taking ownership and responsibility regarding the prevention of HIV/AIDS.

Annex 6

Examples of RDS
survey forms

6.1 Client checklist form

To be filled out by authorized personnel

Date:		Location:		Social network size:		
Coupon number:						
				Signature		
SCREENER	Participant is eligible and enrolled	<input type="checkbox"/> Yes	<input type="checkbox"/> No ¹			
	Participant signed informed consent (behavioural)	<input type="checkbox"/> Yes	<input type="checkbox"/> No ²			
	Participant signed informed consent (biological)	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
	Participant provided network size (Fill in the network size at top of form)	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
INTERVIEWER	Participant completed the questionnaire	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
	Participant received pre-test counselling	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
	Participant received test result voucher	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
PHLEBOTOMIST	Blood sample taken	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
SCREENER	Participant recieved coupon explanation	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A		
	Participant received recruitment coupons	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> N/A		
	Primary reimbursement paid	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
Notes:						

1 – Please fill non-eligibility form

2 – Please fill refusal form

Form has been entered into database

6.2 Coupon tracking form

(Complete a new form for each seed)

SEED:		Coupons given out (<i>put in coupon numbers</i>)				
	DATE	AGE	PARTICIPANT COUPON NUMBER	COUPON 1	COUPON 2	COUPON 3
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						

6.3 Female sex worker screening form (visit 1)

“Hello. My name is _____. I would like to first thank you for taking the time to participate in the survey. This survey is about HIV knowledge and behaviours of female sex workers. But before we start the survey, I need to first find out if you are eligible to participate. If you are eligible to participate, I will explain the survey in more detail. Let me also tell you that everything you tell us will be completely confidential. We will not take your name and no one will be able to link your responses to you personally. Do you mind if I start?”

1.	Person conducting this screening	<input type="text"/>
2.	[Date]	_____ _____ _____ (dd) (mm) (yyyy)
3.	[Is this person a seed?]	1 Yes 2 No
4.	[Skip if seed] [Does the candidate have a valid coupon?]	1 Yes 2 No → Ineligible
5.	[Coupon number person came in with]	<input type="text"/>
6.	Are you able to speak and understand _____ languages?	1 Yes 2 No → Ineligible
7.	Have you participated in this survey before?	3 Yes → Ineligible 4 No
8.	How old are you now?	Age in completed years: _____ [<18 years → Ineligible]
9.	In which city do you live/stay currently?	01 xxxxxx 02 xxxxxx 03 xxxxxx 04 xxxxxx 09 Outside XXXXX, Eligible (indicate): _____ 10 Outside XXXXI, Ineligible (indicate): _____ → Ineligible
10.	Have you had sex with a man in exchange for money, drugs, goods, or services in the last 3 months?	1 Yes 2 No → Ineligible
11.	Remember that your response is completely confidential and the person from whom you received the coupon will not know your response. Has anyone forced you in any way to participate in this survey against your will?	1 Yes → Ineligible 2 No 9 No response

Screener must NOT read the next two questions out loud	
12. [Is the recruit too high or too drunk to give consent or complete the questionnaire?]	1 Yes → Ineligible 2 No
13. [Is the recruit mentally impaired and not able to give consent or complete the questionnaire?]	1 Yes → Ineligible 2 No

Complete if recruit is deemed eligible	
14. How much money do you typically get for only vaginal (penetrative) sex? <hr/> How much money for the entire evening?	Recruit answered with ease: 1 Yes 2 No 9 No response
15. Where do you typically solicit for clients?	Recruit answered with ease: 1 Yes 2 No 9 No response
16. How much money did you get for your last client and for what service?	Recruit answered with ease: 1 Yes 2 No 9 No response
17. How did you find your last client? Where did you have sex with him?	Recruit answered with ease: 1 Yes 2 No 9 No response

Screener must NOT read the next two questions out loud	
18. [How confident are you, the screener, in the answers provided by the participant?]	1 Very confident 2 Confident 3 Not confident at all
19. [Specify why screener is “Not confident at all”.]	1 Not female sex worker 2 Does not live in/around survey area 3 Other. Specify: _____

Screener message: “You are eligible for this survey. Would you like to participate? Let me review what the survey is about and go over the consent form with you.”

6.5 People who inject drugs ineligibility form

To be completed by the team leader

Instructions: Please indicate the **principal reason** why someone does **not** meet the inclusion criteria to participate in the survey.

INELIGIBILITY CODES

1. Under age 15
2. Did not inject drugs within past six months
4. Does not live in area of survey
5. Coupon not valid
6. Does not have a coupon
7. Already participated
8. Other, specify: _____

	COUPON NUMBER <i>(Take away coupon/ write number in this column)</i>	DATE	REASON FOR INELIGIBILITY <i>(Write the code in this column)</i>	IF OTHER, SPECIFY	TEAM LEADER SIGNATURE
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					

6.6 Participant information and informed consent form

Title of the survey: Behavioural and biological surveillance of key populations at higher risk of HIV in XXXX

You are being asked to take part in a survey about HIV, sexually transmitted infections (STIs), and sexual behaviours. Some people may be at higher risk of HIV and STIs than others because of their drug use or sexual practices or because they do not have enough information about these diseases. I am part of a survey team that is trying to understand what puts people at higher risk for HIV and STIs in XXXX. This will allow us to design better health services and programmes for people at high risk for HIV and STIs.

This survey is being conducted by the XXXXX, along with the Ministry of Health (National AIDS Control Programme) and XXXXXX.

This document is a consent form. If you decide to participate in this survey, you will be asked to sign this form. You will be given a copy to keep. Please take your time to review it. You are free to ask questions at any time. Please ask the survey staff to explain any words or information that is not clear to you.

Purpose of the survey

The purpose of the survey is to know what proportion of people at high risk are infected with HIV or have another infection transmitted through sex.

Procedures

If you agree to participate in the survey, you will be asked to do the following:

1. Have an interview about your behaviours and knowledge about HIV.
2. Have an HIV test that will involve a quick fingerstick to take a small amount of blood.
3. Have about 5 ml (about 1 teaspoon) of blood drawn from a vein in your arm.
4. Recruit some of your friends to participate in the survey.

Let me explain some of these things I just mentioned in more detail.

Interview

You will also be asked to do an interview about your sexual and drug use behaviours, what types of partners you have, your perceptions and experiences with stigma and discrimination and your knowledge about HIV. The interview is completely confidential and will not have any personally identifying information linked to it. You will complete the interview in a private room, where a trained interviewer will ask questions and record your answers on a computer. If you feel uncomfortable with or embarrassed about some of the questions that are asked, you may refuse to answer them. You can also stop the interview at any time. If you do stop the survey, it will not have any bad consequences for you. The interview will last about 30–45 minutes.

HIV counselling and testing

If you agree to participate, we will conduct a rapid HIV test. But before we do the test, you will be counselled by a trained counsellor about the risks of getting HIV or STIs and how to prevent them. After the counselling, we will take about three drops of blood from your finger by pricking the tip of your finger. You will be able to watch the test being conducted and observe the test results yourself within 15 minutes. Further counselling will also be available after you see the test results. You may choose not to see the test results or be counselled afterwards.

Storage and other testing

If you agree, we will keep left-over blood samples at the University of XXXXX laboratory for up to five years. Later, we may do some more tests on your samples to know more about HIV infections and for the development of new laboratory tests for STIs. We will obtain permission from the XXXXX Ethics and Research Committee for future testing. Your name will not be on any of the left-over samples, so we cannot contact you with the results of any future tests. You may choose not to store your left-over samples for future testing and still participate in this survey.

Recruiting your peers

We will ask for your help in asking people like yourself to join this survey. We will give you some recruitment coupons to recruit other people like yourself into the survey. If they enrol in the survey, you will receive XXXXX for each person who enrolls. We ask you to come back after X weeks to check if the people you recruited have enrolled in the survey. We will give you a full explanation of these procedures at the end of your visit today.

Risks and benefits of participation

A risk involved in participating in the survey is that you could be seen being involved in this survey by others, which may identify you as part of a population at higher risk for HIV exposure.

The risks of blood draws and fingerstick tests may include some pain, bleeding, swelling, bruising or infection where the needle entered the skin. You may feel some lightheadedness or fainting feeling, but this is very rare.

There is also the possibility that answering personal questions about sexual activity and your personal habits will make you feel uncomfortable, embarrassed or stressed. You may also feel distressed if you test positive for HIV.

Benefits of participation

On the other hand, the benefit of your participation is that you will contribute useful information to public health programme managers so that they can design and provide appropriate programmes and services for HIV and STI prevention and care to people like yourself in XXXX. Another possible benefit is that you will be examined at survey visits for infections and will receive treatment for those that are found.

Alternatives

You may choose not to participate in this survey and you may seek testing and/or treatment from a different practitioner. You may also seek other means to reduce your risks of becoming infected with STIs and HIV.

Confidentiality

Your opinions and experiences are important to us, and we want you to feel comfortable being truthful in answering our questions. It is important that we have a complete picture of the way people behave. The survey staff will do everything possible to keep your participation in this survey private. Your survey records will be kept in locked areas. Information gathered in this survey may be used in reports, published papers or presented in public, but your name or other personal identifier will never be used. Your name will be known by only a few of the survey staff.

Your name will not be attached to any answers you give to the survey questions or to your blood, urine or swab samples. Your samples will be identified only by a number, so it will not be possible for the people surveying your samples to know who you are. Even though we will do everything possible to keep the results of the survey private, there is a very small possibility that someone who should not have this information may see it.

Costs

You will not be charged nor will you have to pay for your participation in the survey.

Time involved and compensation

We understand that you are taking time to participate in this survey. For this first visit, you will receive XXXX for your time and transport costs. For the second visit, you will receive XXXX for transport costs, as well as XXXX for each person you assist in recruiting for this activity up to a maximum of X peers; the total amount you may receive at the second visit will be XXX.

Voluntary participation/withdrawal

You can choose whether or not to be in this survey. If you volunteer to participate, you may choose to refuse any question you do not want to answer and you can withdraw from this survey at any time. Also, the investigator can withdraw you from the survey if circumstances arise which warrant doing so.

Questions

You are free to ask questions at any time about the survey and your rights as a participant. You will not be giving up any of your legal rights by signing this consent form.

You have the right to contact the survey investigators if you have any questions, concerns or complaints: XXX is leading the survey team with the XXX, and may be contacted at XXX. The survey investigator from the Government of XXX is represented by XXX and may be contacted at XXX. If you feel that you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, you may call XXX, at XXX (*list affiliation here*).

Age and consent

- 1) Are you 18 years of age or older?
 Yes (Go to 2) No (Not eligible)

- 2) Do you consent to participate in the overall survey, including survey interview and the HIV testing?
 Yes No (not eligible to continue)

- 3) Do you consent to allow left-over blood to be stored for future research?
 Yes No

Thank you.

_____ | _____ | _____
Signature of interviewer Date

(This is verbal consent)

6.7 Refusal form (people who inject drugs)

To be completed by the team leader

Instructions: Please indicate the **principal reason** why someone does **not** want to participate in the survey.

REFUSAL CODES

1. Did not want to sign consent
2. Did not want to answer questions
3. Fear of being identified as injecting drug user
4. No time
5. Did not want to give blood
6. Other, specify: _____

	COUPON NUMBER <i>(Take away coupon/ write number in this column)</i>	DATE	REASON FOR REFUSAL <i>(Write the code in this column)</i>	IF OTHER, SPECIFY	TEAM LEADER SIGNATURE
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					

6.8 Script for explaining the recruitment process

Please follow these guidelines when using coupons and explaining the recruitment process to a survey participant.

“Here are three (*two or one*) coupons for you to use to recruit other people you know who (*mention behaviour*). Please make sure that the persons you give the coupons to are (*add your eligibility criteria here*) and have not received this coupon from someone else (*i.e. have not participated in this survey before*).”

“Let us go back to the question about how many people like you that you know and they know you and you have seen them in the past one month. The number you gave was _____.”

“When deciding whom to give the coupons to, do not give any coupons to strangers. Can you think of three (*two or one*) people you listed in the question above to whom you can give your coupons? If possible, try and give the coupons to different types of people who you know (*e.g. different ages, different levels of income, from different locations in this city*).”

“Please inform your recruits that this survey is anonymous and confidential and that the information provided is used for developing health programmes. If someone accepts the coupon, tell them the address where they can go to be interviewed and inform them that they can call the number on the coupon to make an appointment. Also, explain to them that the survey will take at least one hour. You can also explain that if they choose, they can receive their HIV and other test results and receive pre- and post-test voluntary counselling.”

“Please look at the coupon. Each coupon has two parts with a unique number filled in. This is the special number of the person to whom you will give the coupon. There is also an expiry date on the coupon. Please tell your recruit to come into the survey before this expiry date.”

“Please give the top portion (*recruitment coupon*) to the person you are recruiting. The bottom part (*reimbursement coupon*) is for you to keep in order for you to claim your reimbursement for recruiting one of your peers.”

“Once you give a coupon to a peer, and they enrol into the survey and complete the interview, you can pick up your reimbursement at the same time you pick up your test results.”

“Only you can recruit peers with your coupons. If you have another person recruit peers for you, you will become ineligible to receive your reimbursement. Remember to keep the bottom portion of the coupon because you will not be able to claim your incentive without it.”

“Thank you for your participation. Do you have any questions?”

6. Instructions: complete the following for each person who refused (e.g., P1, P2, P3, etc) to accept a coupon

What is the <u>principal</u> reason why these persons did not accept a coupon?					
	P.1	P.2	P.3	P. 4	P. 5
6.1 Very busy/Did not have time					
6.2 Afraid of being identified as an injector					
6.3 Incentive is too low					
6.4 The survey site is too far away					
6.5 Not interested					
6.6 Afraid to receive test results for HIV					
6.7 Afraid to receive test results for syphilis					
6.8 Afraid to receive test results for <i>Chlamydia</i> infection					
6.9 Afraid to receive test results for hepatitis C					
6.10 Afraid to give blood					
6.11 Did not inject drugs in past six months					
6.12 Is not person who injects drugs					
6.13 Is under the age of 15 years					
6.14 Already has a coupon					
6.15 Already participated in the survey					
6.16 Other (specify)					

6.11 Field incident report

Project area:	
Name of person filing report:	
Position: <i>(check all that apply)</i>	<input type="checkbox"/> Supervisor <input type="checkbox"/> Screener <input type="checkbox"/> Coupon manager <input type="checkbox"/> Interviewer <input type="checkbox"/> VCT counsellor <input type="checkbox"/> Laboratory technician <input type="checkbox"/> Other <i>(specify)</i> :
Location of incident: <i>(name and address)</i>	
Date of incident: <i>(dd/mm/yy)</i>	_____ Time of incident: _____
Description of incident and actions taken:	
Incident reported locally to <i>(check all that apply)</i>	
<input type="checkbox"/> Supervisor	Date: _____ Time: _____ <input type="checkbox"/> a.m. <input type="checkbox"/> p.m.
<input type="checkbox"/> Police	Date: _____ Time: _____ <input type="checkbox"/> a.m. <input type="checkbox"/> p.m.
<input type="checkbox"/> Other <i>(specify)</i>	_____ Date: _____ Time: _____ <input type="checkbox"/> a.m. <input type="checkbox"/> p.m.
Incident report to project officer:	Date: _____ Time: _____ <input type="checkbox"/> a.m. <input type="checkbox"/> p.m.
Comments: <i>(other information relevant to the incident)</i>	
Signature of person filing report:	Date: _____
Give this completed form to:	

I. RESPONDENT’S BACKGROUND

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
101.	When were you born?	DAY _____ MONTH _____ YEAR _____	
102.	How old are you?	AGE IN COMPLETED YEARS _____ DO NOT KNOW 88	
103.	Have you ever attended school?	YES 1 NO 2 NO RESPONSE 99	→ 105
104.	What is the highest level of school you completed? DO NOT READ LIST CIRCLE ONLY ONE RESPONSE	Primary incomplete 1 Primary (year 1–6) 2 Middle incomplete 3 Middle (year 7–9) 4 Higher incomplete 5 Higher (year 10–12) 6 Above higher 7 Technical school 8 Other _____ 97 (Specify)	
105.	How would you describe your current civil status? READ LIST CIRCLE ONLY ONE RESPONSE	Married, living with spouse 1 Married, living with other sexual partner 2 Married, not living with spouse or other sexual partner 3 Not married, living with sexual partner 4 Not married, not living with sexual partner 5 NO RESPONSE 99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
106.	<p>Is there anything else you do to earn money outside of exchanging sex for money?</p> <p>READ LIST</p> <p>CIRCLE ALL MENTIONED</p>	<p><u>YES</u> <u>NO</u> <u>DK</u> <u>NR</u></p>	
		Private business (own or for wage)	1 2 88 99
		Household/domestic	1 2 88 99
		Manual labour	1 2 88 99
		Hair stylist	1 2 88 99
		Sales/service worker	1 2 88 99
		Illegal activities	1 2 88 99
		No other income besides exchanging sex for money	1 2 88 99
		Other _____ 97	(Specify)
107.	<p>Other than exchanging sex for money, what is the <u>main</u> thing you do to earn money?</p> <p>DO NOT READ LIST</p> <p>CIRCLE ONLY ONE RESPONSE</p>	Private business (own or for wage)	1
		Household/domestic	2
		Manual labour	3
		Hair stylist	4
		Sales/service worker	5
		Illegal activities	7
		No other income besides exchanging sex for money	8
		Other _____ 97	
		(Specify)	

II. SEXUAL HISTORY: GENERAL SEX WORK QUESTIONS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
201.	At what age did you first have sexual intercourse? (By sexual intercourse I mean penetrative vaginal or anal sex)	AGE	
		DO NOT REMEMBER	88
		NO RESPONSE	99
202.	At what age did you first exchange money for sexual intercourse?	AGE	
		DO NOT REMEMBER	88
		NO RESPONSE	99

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP																																																																						
203.	<p>When you started exchanging sex for money, what was the <u>most important</u> reason?</p> <p>DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE</p>	<table border="0"> <tr><td>Need money to help family</td><td>1</td></tr> <tr><td>Didn't know any other work to do</td><td>2</td></tr> <tr><td>Grew up in sex work environment</td><td>3</td></tr> <tr><td>Need money to pay debt</td><td>4</td></tr> <tr><td>Was forced/pressured</td><td>5</td></tr> <tr><td>Like to do/pleasure/hobby</td><td>6</td></tr> <tr><td>Friends/family were doing it (peer pressure)</td><td>7</td></tr> <tr><td>Good income</td><td>8</td></tr> <tr><td>Abandoned by husband</td><td>9</td></tr> <tr><td>Abandoned by family</td><td>10</td></tr> <tr><td>Extra income</td><td>11</td></tr> <tr><td>Other _____</td><td>97</td></tr> <tr><td colspan="2" style="text-align: center;">(Specify)</td></tr> </table>	Need money to help family	1	Didn't know any other work to do	2	Grew up in sex work environment	3	Need money to pay debt	4	Was forced/pressured	5	Like to do/pleasure/hobby	6	Friends/family were doing it (peer pressure)	7	Good income	8	Abandoned by husband	9	Abandoned by family	10	Extra income	11	Other _____	97	(Specify)																																														
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204.	<p>In the <u>past 30 days</u> where did you meet your clients?</p> <p>READ LIST CIRCLE ALL MENTIONED</p>	<table border="0"> <thead> <tr> <th></th> <th style="text-align: center;"><u>YES</u></th> <th style="text-align: center;"><u>NO</u></th> <th style="text-align: center;"><u>DK</u></th> <th style="text-align: center;"><u>NR</u></th> </tr> </thead> <tbody> <tr><td>Own home</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Friend's home</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Wedding/Funeral/Family event</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>At school</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Guesthouse</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Hotel</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>On the streets</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>By telephone</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Through agent</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Internet</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Brothel</td><td style="text-align: center;">1</td><td style="text-align: center;">2</td><td style="text-align: center;">88</td><td style="text-align: center;">99</td></tr> <tr><td>Other _____</td><td></td><td></td><td></td><td style="text-align: center;">97</td></tr> <tr><td colspan="5" style="text-align: center;">(Specify)</td></tr> </tbody> </table>		<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>NR</u>	Own home	1	2	88	99	Friend's home	1	2	88	99	Wedding/Funeral/Family event	1	2	88	99	At school	1	2	88	99	Guesthouse	1	2	88	99	Hotel	1	2	88	99	On the streets	1	2	88	99	By telephone	1	2	88	99	Through agent	1	2	88	99	Internet	1	2	88	99	Brothel	1	2	88	99	Other _____				97	(Specify)					
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(Specify)																																																																				
206.	<p>In the <u>past 30 days</u> where have you had vaginal or anal sexual intercourse with someone who paid you for sex?</p> <p>READ LIST CIRCLE ALL MENTIONED</p>	<table> <thead> <tr> <th></th> <th><u>YES</u></th> <th><u>NO</u></th> <th><u>DK</u></th> <th><u>NR</u></th> </tr> </thead> <tbody> <tr><td>Unoccupied buildings</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Own home</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Friend's home</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Playground/cemetery</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>At school/university</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Guesthouse</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Hotel</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>On the streets</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>At the beach</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Brothel</td><td>1</td><td>2</td><td>88</td><td>99</td></tr> <tr><td>Other _____</td><td></td><td></td><td></td><td>97</td></tr> <tr><td colspan="5" style="text-align: center;">(Specify)</td></tr> </tbody> </table>		<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>NR</u>	Unoccupied buildings	1	2	88	99	Own home	1	2	88	99	Friend's home	1	2	88	99	Playground/cemetery	1	2	88	99	At school/university	1	2	88	99	Guesthouse	1	2	88	99	Hotel	1	2	88	99	On the streets	1	2	88	99	At the beach	1	2	88	99	Brothel	1	2	88	99	Other _____				97	(Specify)					
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(Specify)																																																																				

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
207.	In the <u>past 30 days</u> where have you most often have vaginal or anal sexual intercourse with someone who paid you for sex? DO NOT READ LIST CIRCLE ONLY ONE RESPONSE	Unoccupied buildings 1 Own home 2 Friend's home 3 Playground/cemetery 4 At school 5 Guesthouse 6 Hotel 7 On the streets 8 At the beach 9 Brothel 10 Other _____ 97 (Specify)	
208.	Do you have someone who helps you find clients? (agent, pimp)	YES 1 NO 2 NO RESPONSE 99	
209.	Does anyone in your family know that you exchange sex for money?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	

III. NUMBERS AND TYPES OF PARTNERS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
301.	In total, how many different sexual partners have you had in the <u>past one month</u> ?	TOTAL PARTNERS DON'T KNOW 88 NO RESPONSE 99	
302.	Among these partners that you have had in the <u>past one month</u> , how many were “regular partners” (your spouse(s) or live-in sexual partners)	REGULAR PARTNERS DON'T KNOW 88 NO RESPONSE 99	
303.	Among these partners that you have had in the <u>past one month</u> , how many were “non-regular partners” (Sexual partners that you are not married to and have never lived with and did not have sex in exchange for money)	NON-REGULAR PARTNERS DON'T KNOW 88 NO RESPONSE 99	
304.	Among these partners that you have had in the <u>past one month</u> , how many were “one-time clients” (someone with whom you exchanged sex for money or goods only one time)	ONE TIME CLIENTS DON'T KNOW 88 NO RESPONSE 99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
305.	Among these partners that you have had in the <u>past one month</u> , how many were “regular clients” (someone with whom you exchanged sex for money or goods on a regular bases such as once a week, once a month, etc.)	REGULAR CLIENTS DON'T KNOW 88 NO RESPONSE 99	

IV. REGULAR NON-PAID PARTNERS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
401.	CHECK 302: HAD SEX WITH REGULAR PARTNER DURING PAST ONE MONTH <div style="text-align: right;"> <input type="checkbox"/> 402 </div>	DID NOT HAVE SEX WITH REGULAR PARTNER DURING PAST ONE MONTH <div style="text-align: right;"> <input type="checkbox"/> </div>	→501
402.	Think about your most recent regular sexual partner. How many times did you have sexual intercourse with a regular partner in <u>past one month</u> ?	NUMBER OF TIMES DON'T KNOW 88 NO RESPONSE 99	
403.	The <u>last time</u> you had sex with a regular partner did you and your partner use a condom?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	→406
404.	Why didn't you and your partner use a condom that time? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE PROBE ONLY WITH “ANYTHING ELSE?”	Not available 1 Too expensive 2 Not pleasurable for respondent 3 Not pleasurable for client 4 My partner and I are HIV positive 5 My partner and I are HIV negative 6 Used other contraceptive 7 Didn't think of it 8 Trust partner 9 Wanted to have a child 10 Too high or drunk 11 Claims to be allergic to condoms 12 No sexual infections 13 Other_____ 97 (Specify) DON'T KNOW 88 NO RESPONSE 99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
405.	<p>What is the <u>main reason</u> you and your partner did not use a condom that time?</p> <p>DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE</p>	<p>Not available 1</p> <p>Too expensive 2</p> <p>Not pleasurable for respondent 3</p> <p>Not pleasurable for client 4</p> <p>My partner and I are HIV positive 5</p> <p>My partner and I are HIV negative 6</p> <p>Used other contraceptive 7</p> <p>Didn't think of it 8</p> <p>Trust partner 9</p> <p>Wanted to have a child 10</p> <p>Too high or drunk 11</p> <p>Claims to be allergic to condoms 12</p> <p>No sexual infections 13</p> <p>Other _____ 97</p> <p>(Specify)</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	
SKIP TO SECTION V			
406.	<p>ASK ONLY THOSE WHO RESPONDED "YES" TO Q. 403</p> <p>Who suggested condom use that time?</p> <p>DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE</p>	<p>Myself 1</p> <p>My partner 2</p> <p>Joint decision 3</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	
407.	<p>With what frequency did you and all of your regular partner(s) use a condom in the <u>last one month</u>?</p>	<p>ALWAYS 1</p> <p>MOST TIMES 2</p> <p>ABOUT HALF THE TIME 3</p> <p>OCCASIONALLY 4</p> <p>NEVER 5</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	

V. NON-REGULAR NON-PAYING SEXUAL PARTNER

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
501.	<p>CHECK 303: HAD SEXUAL INTERCOURSE WITH A NON-REGULAR NON-PAYING SEXUAL PARTNER IN PAST ONE MONTH</p> <p style="text-align: right;"><input type="checkbox"/> 502</p>	<p>HAVE NOT HAD SEXUAL INTERCOURSE WITH A NON-REGULAR NON-PAYING SEXUAL PARTNER IN PAST ONE MONTH</p> <p style="text-align: right;"><input type="checkbox"/></p>	<p>→601</p>

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
502.	Think about the non-regular sexual partners you have had in the <u>past one month</u> . How many times did you have sexual intercourse with non-regular sexual partners in <u>past one month</u> ?	NUMBER OF TIMES DON'T KNOW 88 NO RESPONSE 99	
503.	The <u>last time</u> you had sex with a non-regular partner did you and your partner use a condom?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	→506
504.	Why didn't you and your partner use a condom that time? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE PROBE ONLY WITH "ANYTHING ELSE?"	Not available 1 Too expensive 2 Not pleasurable for respondent 3 Not pleasurable for client 4 My partner and I are HIV positive 5 My partner and I are HIV negative 6 Used other contraceptive 7 Didn't think of it 8 Trust partner 9 Wanted to have a child 10 Too high or drunk 11 Claims to be allergic to condoms 12 No sexual infections 13 Other_____ 97 (Specify) DON'T KNOW 88 NO RESPONSE 99	
505.	What is the <u>main reason</u> you and your partner did not use a condom that time? DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE	Not available 1 Too expensive 2 Not pleasurable for respondent 3 Not pleasurable for client 4 My partner and I are HIV positive 5 My partner and I are HIV negative 6 Used other contraceptive 7 Didn't think of it 8 Trust partner 9 Wanted to have a child 10 Too high or drunk 11 Claims to be allergic to condoms 12 No sexual infections 13 Other_____ 97 (Specify) DON'T KNOW 88 NO RESPONSE 99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP														
SKIP TO SECTION VI																	
506.	<p>ASK ONLY THOSE WHO RESPONDED “YES” TO Q. 510</p> <p>Who suggested condom use that time?</p> <p>DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE</p>	<table border="1"> <tr><td>Myself</td><td>1</td></tr> <tr><td>My partner</td><td>2</td></tr> <tr><td>Joint decision</td><td>3</td></tr> <tr><td>DON'T KNOW</td><td>88</td></tr> <tr><td>NO RESPONSE</td><td>99</td></tr> </table>	Myself	1	My partner	2	Joint decision	3	DON'T KNOW	88	NO RESPONSE	99					
Myself	1																
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DON'T KNOW	88																
NO RESPONSE	99																
507.	<p>With what frequency did you and all of your a non-regular partner(s) use a condom in the <u>last twelve months</u>?</p>	<table border="1"> <tr><td>ALWAYS</td><td>1</td></tr> <tr><td>MOST TIMES</td><td>2</td></tr> <tr><td>ABOUT HALF THE TIME</td><td>3</td></tr> <tr><td>OCCASIONALLY</td><td>4</td></tr> <tr><td>NEVER</td><td>5</td></tr> <tr><td>DON'T KNOW</td><td>88</td></tr> <tr><td>NO RESPONSE</td><td>99</td></tr> </table>	ALWAYS	1	MOST TIMES	2	ABOUT HALF THE TIME	3	OCCASIONALLY	4	NEVER	5	DON'T KNOW	88	NO RESPONSE	99	
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OCCASIONALLY	4																
NEVER	5																
DON'T KNOW	88																
NO RESPONSE	99																

VI. ONE-TIME CLIENTS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP								
601.	<p>CHECK 304: HAD SEXUAL INTERCOURSE WITH A ONE-TIME SEXUAL CLIENT IN PAST ONE MONTH</p> <p style="text-align: right;"><input type="checkbox"/> ↓ 602</p>	<p>HAVE NOT HAD SEXUAL INTERCOURSE WITH A ONE-TIME CLIENT IN PAST ONE MONTH</p> <p style="text-align: right;"><input type="checkbox"/></p>	→701								
602.	<p>Think about the one-time clients you have had in the <u>past one month</u>. How many times did you have sexual intercourse with one-time clients in <u>past one month</u>?</p>	<p>NUMBER OF TIMES</p> <table border="1"> <tr><td>DON'T KNOW</td><td>88</td></tr> <tr><td>NO RESPONSE</td><td>99</td></tr> </table>	DON'T KNOW	88	NO RESPONSE	99					
DON'T KNOW	88										
NO RESPONSE	99										
603.	<p>The <u>last time</u> you had sex with a one-time client did you and your partner use a condom?</p>	<table border="1"> <tr><td>YES</td><td>1</td></tr> <tr><td>NO</td><td>2</td></tr> <tr><td>DON'T KNOW</td><td>88</td></tr> <tr><td>NO RESPONSE</td><td>99</td></tr> </table>	YES	1	NO	2	DON'T KNOW	88	NO RESPONSE	99	→606
YES	1										
NO	2										
DON'T KNOW	88										
NO RESPONSE	99										

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
604.	<p>Why didn't you and your partner use a condom that time?</p> <p>DO NOT READ LIST</p> <p>MULTIPLE ANSWERS POSSIBLE</p> <p>PROBE ONLY WITH "ANYTHING ELSE?"</p>	<p>Not available 1</p> <p>Too expensive 2</p> <p>Not pleasurable for respondent 3</p> <p>Not pleasurable for client 4</p> <p>My partner and I are HIV positive 5</p> <p>My partner and I are HIV negative 6</p> <p>Used other contraceptive 7</p> <p>Didn't think of it 8</p> <p>Trust partner 9</p> <p>Wanted to have a child 10</p> <p>Too high or drunk 11</p> <p>Claims to be allergic to condoms 12</p> <p>No sexual infections 13</p> <p>Other _____ 97</p> <p>(Specify)</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	
605.	<p>What is the <u>main reason</u> you and your partner did not use a condom that time?</p> <p>DO NOT READ OUT THE LIST</p> <p>CIRCLE ONLY ONE RESPONSE</p>	<p>Not available 1</p> <p>Too expensive 2</p> <p>Not pleasurable for respondent 3</p> <p>Not pleasurable for client 4</p> <p>My partner and I are HIV positive 5</p> <p>My partner and I are HIV negative 6</p> <p>Used other contraceptive 7</p> <p>Didn't think of it 8</p> <p>Trust partner 9</p> <p>Wanted to have a child 10</p> <p>Too high or drunk 11</p> <p>Claims to be allergic to condoms 12</p> <p>No sexual infections 13</p> <p>Other _____ 97</p> <p>(Specify)</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	
SKIP TO SECTION VII			
606.	<p>ASK ONLY THOSE WHO RESPONDED "YES" TO Q. 603</p> <p>Who suggested condom use that time?</p> <p>DO NOT READ OUT THE LIST</p> <p>CIRCLE ONLY ONE RESPONSE</p>	<p>Myself 1</p> <p>My partner 2</p> <p>Joint decision 3</p> <p>DON'T KNOW 88</p> <p>NO RESPONSE 99</p>	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
607.	With what frequency did you and all of your one-time time clients use a condom in the <u>last twelve months</u> ?	ALWAYS 1 MOST TIMES 2 ABOUT HALF THE TIME 3 OCCASIONALLY 4 NEVER 5 DON'T KNOW 88 NO RESPONSE 99	

VII. REGULAR CLIENTS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
701.	CHECK 305: HAD SEXUAL INTERCOURSE WITH A REGULAR CLIENT IN PAST ONE MONTH <div style="display: inline-block; vertical-align: middle; margin-left: 20px;"> <input type="checkbox"/> 702 </div>	HAVE NOT HAD SEXUAL INTERCOURSE WITH A ONE-TIME CLIENT IN PAST ONE MONTH <div style="display: inline-block; vertical-align: middle; margin-left: 20px;"> <input type="checkbox"/> </div>	→801
702.	Think about the regular clients you have had in the <u>past one month</u> . How many times did you have sexual intercourse with regular clients in <u>past one month</u> ?	NUMBER OF TIMES DON'T KNOW 88 NO RESPONSE 99	
703.	The <u>last time</u> you had sex with a regular client did you and your partner use a condom?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	→706
704.	Why didn't you and your partner use a condom that time? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE PROBE ONLY WITH "ANYTHING ELSE?"	Not available 1 Too expensive 2 Not pleasurable for respondent 3 Not pleasurable for client 4 My partner and I are HIV positive 5 My partner and I are HIV negative 6 Used other contraceptive 7 Didn't think of it 8 Trust partner 9 Wanted to have a child 10 Too high or drunk 11 Claims to be allergic to condoms 12 No sexual infections 13 Other _____ 97 (Specify) DON'T KNOW 88 NO RESPONSE 99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
705.	What is the <u>main reason</u> you and your partner did not use a condom that time? DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE	Not available	1
		Too expensive	2
		Not pleasurable for respondent	3
		Not pleasurable for client	4
		My partner and I are HIV positive	5
		My partner and I are HIV negative	6
		Used other contraceptive	7
		Didn't think of it	8
		Trust partner	9
		Wanted to have a child	10
		Too high or drunk	11
		Claims to be allergic to condoms	12
		No sexual infections	13
		Other _____	97
(Specify)			
DON'T KNOW	88		
NO RESPONSE	99		
SKIP TO SECTION VIII			
706.	ASK ONLY THOSE WHO RESPONDED "YES" TO Q. 710 Who suggested condom use that time? DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE	Myself	1
		My partner	2
		Joint decision	3
		DON'T KNOW	88
		NO RESPONSE	99
707.	With what frequency did you and all of your regular clients use a condom in the <u>last twelve months</u> ?	ALWAYS	1
		MOST TIMES	2
		ABOUT HALF THE TIME	3
		OCCASIONALLY	4
		NEVER	5
		DON'T KNOW	88
		NO RESPONSE	99

VIII. DRY SEX AND ANAL SEX

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
801.	Have you ever had dry sex? (When we say 'dry sex' we mean when a woman makes her vagina dry and then have sexual intercourse)	YES	1
		NO	2
		NO RESPONSE	99
			→807
			→807
802.	Have you had dry sex in the past 30 days?	YES	1
		NO	2
		NO RESPONSE	99
			→807
			→807

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
803.	In the <u>past 30 days</u> , when you last had dry sex, did you use a condom?	YES 1 NO 2 NO RESPONSE 99	→805 →805
804.	In the <u>past 30 days</u> , how often have you used condoms during dry sex?	ALWAYS 1 MOST TIMES 2 ABOUT HALF THE TIME 3 OCCASIONALLY 4 NEVER 5 DON'T KNOW 88 NO RESPONSE 99	
805.	In the <u>past 30 days</u> , the last time you had dry sex, what was the <u>primary</u> reason why you had dry sex? DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE	Client paid more money for it 1 I like the way it feels 2 It prevents pregnancy 3 It prevents HIV 4 It is useful for vaginal tightness 5 Mama or other agent made me do it 6 Client likes it but did not pay more money 7 Other _____ 97 (Specify) NO RESPONSE 99	
806.	In the <u>past 30 days</u> , the last time you had dry sex, what was the <u>primary</u> method you used to get dry? DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE	Panadol 1 Detergent 2 Soap 3 Vinegar 4 Hot water 5 Alcohol 6 Other _____ 97 (Specify) NO RESPONSE 99	
807.	Have you <u>ever</u> had anal sex?	YES 1 NO 2 NO RESPONSE 99	→901 →901
808.	Have you had anal sex in the <u>past 30 days</u> ?	YES 1 NO 2 NO RESPONSE 99	→901 →901
809.	In the <u>past 30 days</u> , when you last had anal sex, did you use a condom?	YES 1 NO 2 NO RESPONSE 99	→811 →811

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
810.	In the <u>past 30 days</u> , how often have you used condoms during anal sex?	ALWAYS 1 MOST TIMES 2 ABOUT HALF THE TIME 3 OCCASIONALLY 4 NEVER 5 DON'T KNOW 88 NO RESPONSE 99	
811.	In the <u>past 30 days</u> , the last time you had anal sex, what was the <u>primary</u> reason why you had anal sex? DO NOT READ THE LIST CIRCLE ONLY ONE RESPONSE	Client paid more money for it 1 I like the way it feels 2 It prevents pregnancy 3 It prevents HIV 4 It is useful for vaginal tightness 5 Mama or other agent made me do it 6 Client likes it but did not pay more money 7 Other _____ 97 (Specify) NO RESPONSE 99	

IX. GENERAL CONDOM USAGE AND ACCESS QUESTIONS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
901.	Do you have any male condoms now?	YES 1 NO 2 NO RESPONSE 99	 →903 →903
902.	How many male condoms do you have on-hand <u>right now</u> ? Would you please show them to me?	Number of condoms on-hand _____ DON'T KNOW 88 NO RESPONSE 99	
903.	In the <u>last twelve months</u> , have you been given male condoms through an outreach service, drop-in centre or health facility)?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
904.	Do you know of any place or person from which you can obtain male condoms?	YES 1 NO 2	→906

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP	
905.	Which places or persons do you know where you can obtain female condoms? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE PROBE ONLY WITH “ANYTHING ELSE?”	Pharmacy	1	
		Market	2	
		Hospital	3	
		Polyclinic	4	
		Guest house/hotel	5	
		Peer educator/outreach worker	6	
		Friend	7	
		HIV testing centres	8	
		Other_____ 97 (Specify)		
906.	Have you <u>ever</u> heard of a female condom?	YES	1	
		NO	2	→1001
		DON'T KNOW	88	→1001
907.	Have you or your partner <u>ever</u> used a female condom?	YES	1	
		NO	2	→1001
		DON'T KNOW	88	→1001
908.	Do you know of any place or person from which you can obtain female condoms?	YES	1	
		NO	2	→1001
909.	Which places or persons do you know where you can obtain female condoms? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE PROBE ONLY WITH “ANYTHING ELSE?”	Pharmacy	1	
		Market	2	
		NGO A	3	
		Polyclinic	4	
		Guest house/hotel	5	
		Peer educator/outreach worker	6	
		Friend	7	
		VCT centres	8	
		Other_____ 97 (Specify)		
		NO RESPONSE	99	

X. SEXUALLY TRANSMITTED INFECTIONS (STIs)

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP	
1001.	Have you <u>ever</u> heard of diseases that can be transmitted through sexual intercourse?	YES	1	
		NO	2	→1007
		DON'T KNOW	88	→1007
		NO RESPONSE	99	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP	
I002.	<p>If a man has a sexually transmitted disease other than HIV/AIDS, what signs/symptoms might he have?</p> <p>DO NOT READ LIST</p> <p>MULTIPLE ANSWERS POSSIBLE</p> <p>PROBE ONLY WITH “ANYTHING ELSE?”</p>	Abdominal pain	1	
		Genital discharge	2	
		Foul smelling discharge	3	
		Burning pain on urination	4	
		Genital ulcers/sores	5	
		Itching	6	
		Other_____	97	
		(Specify)		
		DON'T KNOW	88	
		NO RESPONSE	99	
I003.	<p>If a woman has a sexually transmitted disease other than HIV/AIDS, what signs/symptoms might she have?</p> <p>DO NOT READ LIST</p> <p>MULTIPLE ANSWERS POSSIBLE</p> <p>PROBE ONLY WITH “ANYTHING ELSE?”</p>	Abdominal pain	1	
		Genital discharge	2	
		Foul smelling discharge	3	
		Burning pain on urination	4	
		Genital ulcers/sores	5	
		Itching	6	
		Other_____	97	
		(Specify)		
		DON'T KNOW	88	
		NO RESPONSE	99	
I004.	<p>What action should one have to take when s/he has a sexually transmitted infection?</p> <p>DO NOT READ LIST</p> <p>MULTIPLE ANSWERS POSSIBLE</p> <p>PROBE ONLY WITH “ANYTHING ELSE?”</p>	Seek treatment	1	
		Notify partner(s)	2	
		Complete treatment	3	
		Use condom until cured with treatment	4	
		Use condom until signs/symptoms go away without treatment	5	
		Abstain from sex until cured with treatment	6	
		Abstain from sex until signs/symptoms go away without treatment	7	
		Other_____	97	
		(Specify)		
		DON'T KNOW	88	
NO RESPONSE	99			
I005.	<p>Do you know where you could receive sexually transmitted infection treatment if you had one?</p>	YES	1	
		NO	2	→I007
		DON'T KNOW	88	→I007

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
1006.	If yes, where can you go to get sexually transmitted infection treatment?	NGO A 1 NGO B 2 Hospital 3 Private clinic 4 Other _____ 97 (Specify)	
1007.	Have you had an unusual genital discharge during the <u>last twelve months</u> ?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
1008.	Have you had a genital ulcer/sore during the <u>last twelve months</u> ?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
IF RESPONDENT ANSWERS 'NO' TO BOTH 1007 AND 1008, SKIP TO 1101			
1009.	The <u>last time</u> you had a genital/anal sore, ulcer or unusual discharge what did you do? READ LIST MULTIPLE ANSWERS POSSIBLE		
		<u>YES</u> <u>NO</u> <u>DK</u> <u>NR</u>	
	Did not do anything	1 2 88 99	
	Went to government health establishment for examination and treatment	1 2 88 99	
	Went to private health establishment for examination and treatment	1 2 88 99	
	Went to pharmacy to buy drugs	1 2 88 99	
	Went to traditional healer for examination/treatment	1 2 88 99	
	Treated myself at home	1 2 88 99	
	Told my sexual partner about the symptoms	1 2 88 99	
	Stopped having sexual intercourse when having the symptoms	1 2 88 99	
	Used condoms during sexual intercourse	1 2 88 99	
	Other _____ 97 (Specify)		

XI. KNOWLEDGE ABOUT HIV TRANSMISSION PREVENTION

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
1101.	Have you ever heard of HIV, the virus that causes AIDS?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1102.	Can you tell me the ways in which one can prevent the sexual transmission of HIV? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE	Abstinence	1
		Being faithful	2
		Condom use	3
		Other_____97 (Specify)	
1103.	Can having sex with only one faithful, uninfected partner reduce the risk of HIV transmission?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1104.	Can using condoms reduce the risk of HIV transmission?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1105.	Can a healthy-looking person have HIV?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1106.	Can a person get HIV from mosquito bites?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1107.	Can a person get HIV by sharing a meal with someone who is infected?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1108.	Can HIV be transmitted by shaking a hand of someone who is infected?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99
1109.	Can a person get the HIV virus by getting injections with a needle that was already used by someone else?	YES	1
		NO	2
		DON'T KNOW	88
		NO RESPONSE	99

XII. PREVENTING MOTHER-TO-CHILD-TRANSMISSION OF HIV (PMTCT)

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I201.	Can a pregnant woman infected with HIV or AIDS transmit the virus to her child?	YES	1
		NO	2 → I301
		DON'T KNOW	88 → I301
		NO RESPONSE	99 → I301
I202.	When can the virus that causes AIDS be transmitted from the mother to her child? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE	During pregnancy	1
		During delivery	2
		During breastfeeding	3
		DON'T KNOW	88
I203.	Can the risk of transmitting the HIV virus from the mother to her child be reduced?	YES	1
		NO	2 → I301
		DON'T KNOW	88 → I301
		NO RESPONSE	99
I204.	What can a pregnant woman do to reduce the risk of transmission of HIV to her unborn child?	Take medication (Antiretroviral)	1
		Other _____	97
		(Specify)	
		DON'T KNOW	88

XIII. HIV COUNSELLING AND TESTING

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I301.	Do you know where you can go if you wish to receive an HIV test?	YES	1
		NO	2 → I303
I302.	If YES, where can you go to get an HIV test?	NGO A	1
		NGO B	2
		Hospital	3
		Private clinic	4
		Other _____	97
(Specify)			
I303.	Have you ever been tested for HIV?	YES	1
		NO	2 → I311
I304.	Have you been tested for HIV in the <u>last twelve months</u> ?	YES	1
		NO	2
I305.	Did you get pre-test counselling before you had your <u>last</u> the HIV test?	YES	1
		NO	2
		DON'T REMEMBER	88
I306.	Was your <u>last</u> test voluntary?	YES	1
		NO	2

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I307.	Did you receive the results of that test?	YES 1 NO 2	→ I312
I308.	Remember that your responses are confidential and that you do not have to tell me anything you do not want to tell me. Could you tell me the result of your last test?	POSITIVE 1 NEGATIVE 2 NO RESPONSE 99	
I309.	Did you get post-test counselling when you received your test results?	YES 1 NO 2 DON'T REMEMBER 88	→ I312 → I312
I310.	Why did you not find out the result? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE	I had to come back for result 1 Fear of knowing status 2 Negative attitude of health staff 3 Concerned about confidentiality 4 Still waiting for results to be ready 5 Other_____ 97 (Specify) NO RESPONSE 99	→ I312 → I312 → I312 → I312 → I312 → I312 → I312
I311.	You said you have never taken an HIV test, what are the reasons for not taking a test? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE	Testing center too far away 1 I do not have HIV (have never done anything that puts me at risk) 2 Do not want to change behavior if positive 3 Do not trust HIV testing staff 4 I already think I am positive 5 Costs too much 6 Requires too much time 7 Don't know where to go 8 Afraid that someone will find out I took test 9 Other_____ 97 (Specify)	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I312	What are the benefits of having HIV counselling and testing? DO NOT READ LIST MULTIPLE ANSWERS POSSIBLE	Plan future	1
		Avoid infection	2
		Protect an unborn child	3
		Get treatment (antiretrovirals)	4
		Learn to live with HIV	5
		Receive food support	6
		Receive material support	7
		Receive HIV care	8
		No benefit	9
		Other_____	97
		(Specify)	
		NO RESPONSE	99

XIV. ALCOHOL AND DRUG USE

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I401.	Have you <u>ever</u> consumed alcohol?	YES	1
		NO	2 → I404
		NO RESPONSE	99 → I404
I402.	Have you consumed alcohol during the <u>past six months</u> ?	YES	1
		NO	2
		DON'T KNOW	88 → I404
		NO RESPONSE	99 → I404
I403.	How often did you have alcohol during the <u>past six months</u> ?	ONLY ONCE	1
		2-3 TIMES	2
		ABOUT ONCE A WEEK	3
		2-3 TIMES A WEEK	4
		4-6 TIMES A WEEK	5
		ABOUT ONCE A DAY	6
		2-3 TIMES A DAY	7
		4 OR MORE TIMES/DAY	8
		DON'T KNOW	88
		NO RESPONSE	99
I404.	Have you <u>ever</u> used illegal non-injecting drugs?	YES	1
		NO	2 → I409
		NO RESPONSE	99 → I409
I405.	Have you used illegal non-injecting drugs in the past <u>six months</u> ?	YES	1 → I409
		NO	2 → I409
		NO RESPONSE	99

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
1406.	How old were you when you <u>first</u> time you used illegal non-injecting drugs? ESTIMATE BEST ANSWER	AGE IN COMPLETED YEARS DO NOT KNOW 88 NO RESPONSE 99	
1407.	Which of the following types of non-injecting drugs have you used in the <u>past six months</u> ? READ LIST CIRCLE ALL MENTIONED	Used in the <u>past one month</u> <u>YES</u> <u>NO</u> <u>DK</u> <u>NR</u>	
	Marijuana, gandia	1 2 88 99	
	Hashish	1 2 88 99	
	Glue	1 2 88 99	
	Ecstasy	1 2 88 99	
	Codeine	1 2 88 99	
	Crack	1 2 88 99	
	Tranquilizers (Artan, Trimadol, Valium, Robinal)	1 2 88 99	
	LSD	1 2 88 99	
	Opium	1 2 88 99	
	Heroin (smoked)	1 2 88 99	
	Subutex	1 2 88 99	
		Other _____ 97 (Specify)	
1408.	Which non-injecting drug did you use <u>most often</u> in the <u>past six months</u> ? DO NOT READ LIST CIRCLE ONLY ONE RESPONSE	Marijuana, gandia 1 Hashish 2 Glue 3 Ecstasy 4 Codeine 5 Crack 6 Tranquilizers (Artan, Trimadol, Valium, Robinal) 7 LSD 8 Opium 9 Heroin (smoked) 10 Subutex 11 Other _____ 97 (Specify)	

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP			
I409.	Have you <u>ever</u> used illegal injecting drugs?	YES 1				
		NO 2	→ I50I			
		NO RESPONSE 99	→ I50I			
I410.	How old were you when you <u>first</u> injected drugs?	AGE IN COMPLETED YEARS				
		DO NOT KNOW 88				
		NO RESPONSE 99				
I411.	Which of the following types of injecting drugs have you used in the <u>past six months</u> ? READ LIST MULTIPLE ANSWERS POSSIBLE	Used in the <u>past six months</u>				
			<u>YES</u> <u>NO</u> <u>DK</u> <u>NR</u>			
		White heroin	1	2	88	99
		«Brown sugar»	1	2	88	99
		Buprenorphine (Subutex)	1	2	88	99
		Brown and Subutex	1	2	88	99
		Other _____ 97 (Specify)				
I412.	Which injecting drug did you use <u>most often</u> in the <u>past six months</u> ? DO NOT READ LIST CIRCLE ONLY ONE RESPONSE	White heroin 1				
		«Brown sugar» 2				
		Buprenorphine (Subutex) 3				
		Brown and Subutex 4				
		Other _____ 97 (Specify)				
I413.	On average, during the <u>past six months</u> how often did you inject drugs?	ONLY ONCE 1				
		2-3 TIMES 2				
		ABOUT ONCE A WEEK 3				
		2-3 TIMES A WEEK 4				
		4-6 TIMES A WEEK 5				
		ABOUT ONCE A DAY 6				
		2-3 TIMES A DAY 7				
		4 OR MORE TIMES/DAY 8				
		DON'T KNOW 88				
		NO RESPONSE 99				
I414.	The <u>last time</u> you injected drugs; did you use a needle/syringe that had previously been used by someone else?	YES 1				
		NO 2	→ I50I			
		DON'T KNOW 88	→ I50I			
		NO RESPONSE 99	→ I50I			

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I415.	Think about the times you injected drugs during the <u>past six months</u> . How often was it with a needle/syringe that had previously been used by someone else?	ALWAYS 1 MOST TIMES 2 ABOUT HALF THE TIME 3 OCCASIONALLY 4 NEVER 5 DON'T KNOW 88 NO RESPONSE 99	

XV. STIGMA AND DISCRIMINATION TOWARDS PEOPLE LIVING WITH HIV/AIDS

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I501.	Would you be willing to share a meal with a person you knew had HIV or AIDS?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I502.	If a male relative of yours became ill with HIV, the virus that causes AIDS, would you be willing to care for him in your household?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I503.	If a student has HIV but is not sick, should he or she be allowed to continue attending school?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I504.	If a female relative of yours became ill with HIV, the virus that causes AIDS, would you be willing to care for her in your household?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I505.	If a teacher has HIV but is not sick, should he or she be allowed to continue teaching in school?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I506.	If you knew a shopkeeper or food seller had the HIV virus, would you buy food from them?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	
I507.	If a member of your family became ill with HIV, the virus that causes AIDS, would you want it to remain secret?	YES 1 NO 2 DON'T KNOW 88 NO RESPONSE 99	

XVI. PERSONAL STIGMA AND DISCRIMINATION AND INCARCERATION

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP																																								
1601.	<p>In the <u>last twelve months</u>, how many times do you believe you have been refused the following kinds of services because someone believed you exchanged sex for money?</p> <p>READ LIST MULTIPLE ANSWERS POSSIBLE</p>	<table border="1"> <thead> <tr> <th></th> <th><u>YES</u></th> <th><u>NO</u></th> <th><u>DK</u></th> <th><u>NR</u></th> </tr> </thead> <tbody> <tr> <td>a. Health care</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>b. Employment</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>c. Education</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>d. Religious service</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>e. Restaurant service</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>g. Police assistance</td> <td>1</td> <td>2</td> <td>88</td> <td>99</td> </tr> <tr> <td>Other _____</td> <td></td> <td></td> <td></td> <td>97</td> </tr> </tbody> </table> <p>(Specify)</p>		<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>NR</u>	a. Health care	1	2	88	99	b. Employment	1	2	88	99	c. Education	1	2	88	99	d. Religious service	1	2	88	99	e. Restaurant service	1	2	88	99	g. Police assistance	1	2	88	99	Other _____				97	
	<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>NR</u>																																							
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g. Police assistance	1	2	88	99																																							
Other _____				97																																							
1602.	<p>In the <u>last twelve months</u>, how many times have you had verbal insults directed at you because someone believed you exchanged sex for money?</p>	<table border="1"> <tbody> <tr> <td>No times-did not happen</td> <td>00</td> </tr> <tr> <td>NUMBER OF TIMES</td> <td></td> </tr> <tr> <td>DON'T KNOW</td> <td>88</td> </tr> <tr> <td>NO RESPONSE</td> <td>99</td> </tr> </tbody> </table>	No times-did not happen	00	NUMBER OF TIMES		DON'T KNOW	88	NO RESPONSE	99	<p>→1604</p> <p>→1604</p> <p>→1604</p>																																
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DON'T KNOW	88																																										
NO RESPONSE	99																																										
1603.	<p>Who was the person(s) who last directed a verbal insult at you?</p> <p>DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE</p>	<table border="1"> <tbody> <tr> <td>Do not know the person(s)</td> <td>1</td> </tr> <tr> <td>Social acquaintance</td> <td>2</td> </tr> <tr> <td>Friend</td> <td>3</td> </tr> <tr> <td>Family/relative</td> <td>4</td> </tr> <tr> <td>Client</td> <td>5</td> </tr> <tr> <td>Sexual partner</td> <td>6</td> </tr> <tr> <td>Police</td> <td>7</td> </tr> <tr> <td>Drug dealer</td> <td>8</td> </tr> <tr> <td>Other drug user</td> <td>9</td> </tr> <tr> <td>Co-worker (someone you work with)</td> <td>10</td> </tr> <tr> <td>Other _____</td> <td>97</td> </tr> </tbody> </table> <p>(Specify)</p>	Do not know the person(s)	1	Social acquaintance	2	Friend	3	Family/relative	4	Client	5	Sexual partner	6	Police	7	Drug dealer	8	Other drug user	9	Co-worker (someone you work with)	10	Other _____	97																			
Do not know the person(s)	1																																										
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Other drug user	9																																										
Co-worker (someone you work with)	10																																										
Other _____	97																																										
1604.	<p>In the <u>last twelve months</u>, how many times have you been hit, kicked, or beaten because someone believed you exchanged sex for money?</p>	<table border="1"> <tbody> <tr> <td>No times-did not happen</td> <td>00</td> </tr> <tr> <td>NUMBER OF TIMES</td> <td></td> </tr> <tr> <td>DON'T KNOW</td> <td>88</td> </tr> <tr> <td>NO RESPONSE</td> <td>99</td> </tr> </tbody> </table>	No times-did not happen	00	NUMBER OF TIMES		DON'T KNOW	88	NO RESPONSE	99	<p>→1606</p> <p>→1606</p> <p>→1606</p>																																
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NO RESPONSE	99																																										

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
I605.	Who was the person who last hit, kicked, or beat you? DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE	Do not know the person 1 Social acquaintance 2 Friend 3 Family/relative 4 Client 5 Sexual partner 6 Police 7 Drug dealer 8 Other drug user 9 Co-worker (someone you work with) 10 Other _____ 97 (Specify)	
I606.	Have you ever been forced to have sexual intercourse when you didn't want to?	YES 1 NO 2 NO RESPONSE 99	→ I609 → I609
I607.	In the <u>last twelve months</u> , have you been forced to have sexual intercourse when you didn't want to?	YES 1 NO 2 NO RESPONSE 99	→ I609 → I609
I608.	In the <u>last twelve months</u> , the <u>last time</u> you were forced to have sex, who forced you? DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE	Do not know the person(s) 1 Social acquaintance 2 Friend 3 Family/relative 4 Client 5 Sexual partner 6 Police 7 Drug dealer 8 Other drug user 9 Someone you work with 10 Prison staff 11 Other prisoner 12 Other _____ 97 (Specify)	
I609.	Were you arrested during the <u>last twelve months</u> ?	YES 1 NO 2 NO RESPONSE 99	→ END → END

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
1610.	The <u>last time</u> you were arrested, what was the main reason? DO NOT READ OUT THE LIST CIRCLE ONLY ONE RESPONSE	Being on drugs/having drugs in possession 1 Being in possession of syringe 2 Being drunk 3 Aggravated assault 4 Theft 3 Exchanging sex for money 5 Being a woman in an uncommon location 6 NO RESPONSE 99 Other _____ 97 (Specify)	

THANK YOU

Annex 7

Standard operating
procedures

7.1 Example of standard operating procedures (SOPs): first visit

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)*
Arrival at survey office Recruit arrives.	—	<ul style="list-style-type: none"> ▸ Recruit: Coupon ▸ Office: Direction signs to the survey office and to the reception 	Entrance to survey office	<1
Welcome Recruit enters survey office and walks to the waiting area/entry area. Greet participant.	Site manager/receptionist	<ul style="list-style-type: none"> ▸ Reception sign for desk 	Entry area	<1
Coupon request Request to see coupon.	Site manager/receptionist	<ul style="list-style-type: none"> ▸ Coupon 	Entry area	<1
Initial coupon validation Ensure that the coupon is survey-related; Check the coupon's expiry date. <ul style="list-style-type: none"> ● If a coupon is not valid (i.e. not one of our own), ask the person to leave. ● If person does not have a coupon, list them on the ineligibility form. 	Site manager/receptionist	<ul style="list-style-type: none"> ▸ Coupon ▸ Ineligibility form (Annex X) 	Entry area	<1
If there is a waiting period <ul style="list-style-type: none"> ● Tell person how long the wait will be. ● If the wait is too long, offer an appointment time. ● If person wants to wait, give them a number to hold his/her place in the waiting line. ● Have person wait in the waiting room until screener can see him/her. ● Person keeps coupon with him/her. If there is no waiting period <ul style="list-style-type: none"> ● Escort person to the screener. 	Site manager/receptionist	<ul style="list-style-type: none"> ▸ Chairs in waiting room area ▸ Water or other refreshment 	Entry area	<1

* These are approximate time estimations.

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>If there is a waiting period</p> <ul style="list-style-type: none"> Select the next person in the waiting line based on the numbers given out. 	Screener		Screener desk	
<p>Meeting with the screener Participant folder:</p> <ul style="list-style-type: none"> Retrieve a previously assembled participant folder with the following survey materials: <ul style="list-style-type: none"> Participant checklist form Consent form (2 copies). Greet recruit. Ask for recruit’s coupon (keep coupon). <p>Repeaters If it is suspected that recruit has already participated:</p> <ul style="list-style-type: none"> Inquire if the recruit has already enrolled in the survey. If yes, remind the recruit that he/she may only participate once in this survey. No financial compensation is given. Complete ineligibility form. If the recruit denies that he/she participated in the survey before, process recruit and alert other staff to be aware. 	Screener	<ul style="list-style-type: none"> Participant folders Pre-printed labels Checklist form (Annex X) Consent form (Annex X) Coupon management form (Annex X) Ineligibility form (Annex X) 	Screener desk	<1
<p>Meeting with the screener (continued)</p> <ul style="list-style-type: none"> Write coupon number on folder or affix pre-printed label¹ onto folder. Write coupon number on coupon management form. <p>Screening</p> <ul style="list-style-type: none"> Write coupon number on folder or affix pre-printed label onto screening form and administer screening. Conduct screening. <p>Not part of population</p> <ul style="list-style-type: none"> If recruit is deemed not part of the population, explain that he/she is not eligible, complete the ineligibility form and escort him/her out of survey site. 	Screener	<ul style="list-style-type: none"> Ineligibility form (Annex X) Labels (optional) Screening form (Annex X) 	Screener desk	5

¹ If using pre-printed serial numbers, browse through the stack of label sheets to find the one that matches the participant's coupon ID number. Paste a label on the outside of the folder and put the sheet back into the folder.

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>Meeting with the screener (continued)</p> <p>Informed consent for eligible recruits</p> <ul style="list-style-type: none"> ● If the recruit is deemed eligible as per the survey criteria for participation, review the consent form with the recruit and ask if the recruit consents to the survey procedures. ● Answer any questions the recruit has about consent. ● Write coupon number on folder or affix pre-printed label onto two consent forms. ● Give one copy of consent to participant and keep other copy in participant folder. <p>If participant has questions</p> <p>Briefly review the remaining first visit procedures with the recruit, reminding him/her that all staff will answer questions along the way:</p> <ul style="list-style-type: none"> ● Survey data will be collected in the interview. ● Pre-test counselling will occur after the interview is administered. ● Blood (or other fluid) will be taken. ● Coupons for peer-recruitment and incentive distribution will be given at the end of the survey. <p>If participant is eligible but does not provide consent</p> <ul style="list-style-type: none"> ● Probe for reasons. Complete refusal form. ● May consider rescheduling for another time. 	Screener	<ul style="list-style-type: none"> ▸ Consent form (Annex X) ▸ Refusal form (Annex X) 	Screener desk	7

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>Meeting with the screener (continued)</p> <p>Client checklist</p> <ul style="list-style-type: none"> ● Complete the appropriate sections of the checklist form. ● Explain the form to the participant (i.e. he/she needs to hold onto the form throughout the recruitment process and must show it at the end of the survey to get the incentive). ● Give the checklist form to the participant. 	Screener	<ul style="list-style-type: none"> ▸ Checklist form (Annex X) 	Screener desk	5
<p>Participant waits for next available interviewer</p> <ul style="list-style-type: none"> ● If interviewer is available, escort participant to the interviewer room. ● If the interviewer is not available, have participant wait in waiting room. 	Screener → Site manager/ receptionist	<ul style="list-style-type: none"> ▸ Availability sign for the interviewer's room door ("In session" or "Available") 	Screener desk → Interviewer or waiting room	<1
<p>Interview</p> <p>Participant initial interaction with the interviewer</p> <ul style="list-style-type: none"> ● Greet participant. ● Build rapport. ● Review the checklist form to verify enrolment. ● If everything so far has been successfully completed, write or affix participant ID number on questionnaire. <p>Behavioural questionnaire</p> <ul style="list-style-type: none"> ● Conduct interview. 	Interviewer	<ul style="list-style-type: none"> ▸ Behavioral questionnaire 	Interviewer room	45
<p>Interview end</p> <ul style="list-style-type: none"> ● End interview and thank participant for the interview. ● Complete the appropriate section of the checklist form and return to participant. ● Escort participant to waiting area or pre-test counsellor. 	Interviewer → Site manager/ receptionist		Interviewer room → Pre-test counsellor or waiting room	<1

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>Participant escorted to counsellor</p> <ul style="list-style-type: none"> ● Greet participant. ● Build rapport. ● Review the checklist form to verify completion of interview. ● Conduct pre-test counselling (e.g. briefly explain the next procedures for HIV/STI testing. Clarify issues surrounding pre-test HIV and STI counselling). ● Ask if participant has any questions. ● Set an appointment to get test results if more tests are conducted. ● Complete a test result voucher for test results and give to participant. ● Complete the appropriate section of the checklist form and return to participant. ● Escort participant to laboratory technician. 	Counsellor	<ul style="list-style-type: none"> ▸ Availability sign for the counsellor's room door ("In session" or "Available") ▸ Test result vouchers (See Annex X) ▸ Calendar to make test result appointment 		5
<p>Testing</p> <ul style="list-style-type: none"> ● Greet participant. ● Build rapport. ● Review the checklist form to verify completion of pre-test counselling. ● Follows SOP for blood (or other) collection. ● Fill out specimen collection form in duplicate (one to be sent with sample to laboratory and other to be stored at site laboratory). ● Conduct rapid HIV test as per the testing guidelines SOP. ● Inform participant that rapid HIV test requires approximately 20 minutes to complete. ● Record HIV test results onto site test result slip in duplicate (one copy accompanies samples to laboratory and one is kept) and test result log book. 	Laboratory technician	<ul style="list-style-type: none"> ▸ Phlebotomy materials ▸ Specimen collection procedures SOP ▸ Specimen collection form (duplicate) (Annex X) ▸ Rapid HIV test kits ▸ Site test result slip (duplicate) (Annex X) ▸ Site test result log (Annex X) 	Laboratory testing room	5

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>Specimen labeling and laboratory documentation</p> <ul style="list-style-type: none"> ● Label and prepare specimen for transport to laboratory. ● One copy of specimen collection form goes to laboratory along with specimen. ● Two copies of the specimen transfer forms are completed. ● Complete specimen transfer log book before samples are sent to laboratory. <i>(Note: Refer to specimen collection SOPs)</i> ● Complete the appropriate section of the checklist form and return to participant. ● Send participant to coupon manager or waiting room. 	Laboratory technician	<ul style="list-style-type: none"> ▸ Specimen labels ▸ Laboratory transport log (Annex X) ▸ Specimen collection SOP (Annex X) ▸ Specimen collection form (Annex X) ▸ Samples transfer form (duplicate) (Annex X) ▸ Site sample transfer log book (Annex X) 	Laboratory testing room	2
<p>While participant is waiting for rapid test results</p> <p>Coupon recruitment explanation and issuance:</p> <ul style="list-style-type: none"> ● Greet participant. ● Conduct informal exit interview: “How did everything go today?” ● Resolve any problems the participant might have. ● Review the checklist form to verify completion of testing and all of the other steps. If steps are not completed try and find out why. ● If steps are completed, make up recruitment coupons based on coupon number listed on top of checklist form. ● Explain coupon recruitment process using the participant’s recruitment coupons as an example. ● Give coupons to participant. ● Pay out incentive. ● Keep checklist form. 	Coupon manager	<ul style="list-style-type: none"> ▸ Blank coupons ▸ Coupon recruitment script (Annex X) ▸ Incentives ▸ Cash reimbursement log (Annex X) 		10

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>HIV post-test counselling and HIV test results</p> <ul style="list-style-type: none"> ● Examine rapid HIV test. <i>(Note: In case of a discrepancy, the counsellor follows the national guidelines manual)</i> ● Provide HIV test results and post-test counselling. <p>HIV-positive results</p> <ul style="list-style-type: none"> ● Inform participant of the different HIV/AIDS care and support clinics (refer to a list of service providers) and about risk reduction strategies. ● Refer participant to a service for treatment and care. ● Make up and provide a referral voucher. <p>HIV-negative results</p> <ul style="list-style-type: none"> ● Discuss risk reduction strategies with participant and come up with a risk reduction plan. <p>Prevention materials</p> <ul style="list-style-type: none"> ● Irrespective of HIV status, provide list of service providers, and HIV prevention literature and materials (condoms, lubricants) as per agreed quantities. ● Counsellor reminds participant that he/she will have to come back for a second visit to receive other test results. 	Counsellor			5–15
<p>Participant exits</p> <ul style="list-style-type: none"> ● File participant folder with all forms (checklist, completed questionnaire, consent, etc.). ● Thank participant for his/her time and kindly encourage him/her to return for his second visit. 	Site manager			<1
<p>Daily quality checks by the site manager</p> <ul style="list-style-type: none"> ● Periodically review participant folders, laboratory forms and other forms. Specifically, all forms and specimen collection containers need to have participant ID labels. ● Quality checks may be conducted at the time of preparing daily specimen transports to the laboratory or more frequently based on need and time available. 	Site manager			

7.2 Standard operating procedures (SOPs): second visit

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
Arrival at survey office <ul style="list-style-type: none"> Participant arrives. 	—	<ul style="list-style-type: none"> Office: Direction signs to the office and to the reception 	Entrance to survey office	<1
Welcome <ul style="list-style-type: none"> Participant enters survey office and walks to the waiting area/entry area. Greet participant. 	Site manager/receptionist	<ul style="list-style-type: none"> Reception sign for desk 	Entry area	<1
Results appointment card request <ul style="list-style-type: none"> Request participant's results appointment card.¹ Check the appointment time and date. If there is a problem with the appointment card or the participant does not have the results appointment card, contact the coupon manager to continue with validating the participant's status in the survey. 	Screeener	<ul style="list-style-type: none"> Results appointment card (Annex X) 	Screeener desk	<1
Reimbursement/incentives <ul style="list-style-type: none"> Request receipt coupon (if using two part coupon). Check the coupon tracking forms/database to verify if participant's recruits enrolled into the survey. Pay out incentives for those recruits that enrolled in and completed the survey. Thank participant for efforts in giving out the coupons (if applicable). Ask if participant has any questions about recruitment, as needed. Update the reimbursement log. 	Screeener	Recruit <ul style="list-style-type: none"> receipt coupon Screeener <ul style="list-style-type: none"> Reimbursement log (Annex X) Coupon tracking forms or databases 	Screeener desk	2–5
Follow-up questionnaire <ul style="list-style-type: none"> Complete the follow-up questionnaire. Escort participant to waiting area. 	Screeener	<ul style="list-style-type: none"> Follow-up questionnaire (Annex X) 	Screeener desk → site manager/receptionist	7

¹ Not all participants will want to get their test results; it is best to take care of all logistics before participants get test results.

OPERATION	PERSON RESPONSIBLE	MATERIALS NEEDED	PLACE	TIME (MIN.)
<p>Escort participant to the counsellor</p> <ul style="list-style-type: none"> ● If counsellor is not available, ask participant to wait in the waiting room. ● If counsellor is available, escort participant to the counselling room for post-test counselling and results communication. 	Site manager/ Receptionist	▶ Waiting room	Site manager/ receptionist → counsellor	1–10
<p>Post-test counselling</p> <ul style="list-style-type: none"> ● Greet participant, invite him/her to sit, and build rapport. ● Look up test results. ● If the participant accepts to receive the results, give the results as per national guidelines. 	Counsellor	▶ Participant laboratory results (Annex X) ▶ Referral list ▶ Referral voucher (Annex X)	Counsellor room	10
<p>Test results</p> <p>If participant is positive</p> <ul style="list-style-type: none"> ● Review list of service providers available to participant in the nearby area. ● Explain services provided in the survey-affiliated facilities and provide referral vouchers. ● Examine HIV test results from first visit. If participant tested HIV positive during first visit ask if participant has any further questions and whether participant accessed referred services. 	Counsellor	▶ Referral list ▶ Referral voucher (Annex X)	Counsellor room	5
<p>All participants</p> <ul style="list-style-type: none"> ● Offer condoms and lubricants and prevention literature. <p>Participant exits</p> <ul style="list-style-type: none"> ● If participant is able, allow him/her to leave. ● Thank him or her for their participation. ● Update test results database. 	Counsellor	▶ Condoms ▶ Lubricants ▶ Prevention literature ▶ Referral voucher (Annex X)	Counsellor room	2

Annex 8

Laboratory
standard operating
procedures forms

8.1 Example of specimen collection and handling procedures for HIV and STI testing

Scope: The following standard operating procedures (SOPs) describe procedures for collection and handling of blood specimens for testing. These SOPs are for laboratory technicians who are responsible for specimen collection, handling and testing. Samples are only collected from survey participants who provide informed consent.

Collection of blood

1. Materials and equipment required

- Vacutainer tubes (5 ml red-top, with clot activator and gel separator)
- serum tubes/cryovials
- Vacutainer needles and needle holder
- sample rack
- spirit swabs
- dry cotton swabs
- sticking plasters
- participant identification (ID) labels
- disposable latex gloves
- tourniquet
- sharps disposal container (bleach bottle)
- plastic waste bio-hazard disposal bags
- sample transport containers for cryovials (racks and cool boxes)
- black plastic bag
- benchtop centrifuge
- liquid hand sanitizer
- pipettors
- pipette tips.

2. Forms needed

- Specimen collection form
- Blood refusal form.

3. Sample required

- Total of 5 mls of whole blood.

4. Phlebotomy procedure

- Blood collection shall be performed only by laboratory technicians.
- Location: survey office laboratory.

Blood draw:

1. Explain to the participant that a blood sample is to be collected. Address participant by their name (only if participant agrees to use his/her name). Ensure client is comfortably seated in the survey office laboratory with adequate lighting.
2. Assemble the Vacutainer needle and holder together in readiness for the procedure.
3. Have ready swabs, sticking plaster and tourniquet.
4. Put on a new pair of gloves.
5. Select the site and vein using the spirit swab provided and allow it to dry.
6. Apply tourniquet and locate a suitable vein in the arm.
7. Insert Vacutainer needle into the vein and release the tourniquet allow 15 seconds before drawing blood. Tourniquet must be removed after no more than one minute.
8. Draw 5 mls of blood into a red-top Vacutainer tube
9. Gently invert the tube 5–10 times immediately after blood collection to reach a proper mix of the additive in the tube and blood. Turn the filled tube upside-down and return to upright position – this is one complete inversion. (Note: do not shake the tubes!)
10. Put the red top Vacutainer tube into sample rack
11. Remove needle and apply dry swab to site. Ask client to fold their arm.
12. Drop needle and holder into the sharps container.
13. If first attempt does not yield enough blood try again on the other arm. If the second attempt does not yield blood, try again. Make no more than three attempts at blood draw per participant.
14. If the participant refuses to give blood or if the blood draw is unsuccessful, fill in the blood refusal form.

Specimen labelling and documentation:

1. Label the red-top Vacutainer (5ml) with the pre-printed participant ID label in front of the client.
2. Document blood collection in the specimen collection form.

Client care:

1. Check that bleeding has stopped at injection site.
2. Apply sticking plaster; advise client to leave this in place for at least three hours.
3. Thank client and tell him to go and wait at the reception, where the counsellor will come for him for his post-test counselling.

First aid:

1. Some people feel faint after a venipuncture. If this happens remain calm. Ask client to remain seated, bend down and place their head between their knees for about three minutes. Thereafter move them to a lying down position. Full recovery should occur in ten minutes.
2. Should bleeding continue at the venipuncture site, apply firm pressure for two minutes. Do not rub the injection site. When no fresh drops of blood appear, apply sticking plaster.

3. Should the laboratory technician prick themselves with a used needle, do not panic. Wash the site in running water, clean with spirit, apply a sticking plaster. Report to the site manager who will arrange for further evaluation.

5. Specimen processing

Specimen processing is done by the laboratory technician after the blood collection is complete and the participant has left the laboratory.

Serum preparation:

1. The blood sample should be centrifuged 30 minutes after blood collection and no later than two hours after collection.
2. Place the red-top Vacutainer tube (5 ml) into a centrifuge, make sure the tube is counterbalanced, and spin tubes for 10 minutes at 1800 rpm (revolutions per minute). Do not use brakes to stop the centrifuge.
3. Remove the red-top Vacutainer tube from the centrifuge, taking care not to disturb the cell layer. Inspect serum for turbidity. Turbid samples should be centrifuged again to remove remaining insoluble matter.
4. Put the centrifuged Vacutainer tube in upright position in a rack.
5. Label the serum tube with the pre-printed participant ID label.
6. Collect the serum from the centrifuged Vacutainer tube into the labelled serum tube using the pipette and pipette tips.
7. Document serum collection in the sample collection form.
8. Use part of the serum to perform the HIV and syphilis tests.
9. Store the remaining serum in the freezing compartment of the refrigerator for sites far from the laboratory and transport to laboratory every three days; store in the non-freezing part of the refrigerator for sites near to the laboratory with daily transportation to laboratory.

Testing for HIV and syphilis

1. HIV test procedure (according to test kit manufacturer's recommendations)

2. Syphilis test procedure (according to test kit manufacturer's recommendations)

3. Waste disposal and site clean-up

1. Ensure site is clean and has no blood or serum droplets. If there are any droplets please clean with spirit swabs before you remove your gloves.
2. Place all used needles and needle holders in the sharps containers.
3. Place all wrappings, used gloves, used swabs, pipette tips and other waste into the bio-hazard bags, tie up and return to carrier box.
4. Wastes should be categorized as follows:
 - Non-contaminated waste → plastic bag
 - Contaminated waste → bio-hazard bag
 - Sharps → bleach sharps container.

Specimen storage and transport

1. Materials required

- cool boxes
- serum tube racks/holders
- plastic re-sealable zipper storage bags
- refrigerator
- thermometer and temperature log
- ice packs.

2. Forms needed

- specimen transfer form
- site specimen transfer log book
- specimen collection forms
- site test result slips
- laboratory test result slips
- temperature log.

3. Specimen storage

1. All serum specimens are stored in the refrigerator (2°C–8°C) for sites near to the laboratory and in the freezing compartment of the refrigerator for sites far from the laboratory.
2. Laboratory technician checks the refrigerator temperature twice a day (morning and afternoon), every day. Temperature readings are recorded in the temperature log.

4. Prepare specimen for transport to laboratory

1. For sites near to laboratory, specimens are prepared for transport every day, while for sites far from the laboratory specimens will be prepared for transport three times a week.
2. Laboratory technician prepares specimen cool box for transport to laboratory (ice packs are not necessary for sites in the same city as the laboratory, but required for sites far from the laboratory).
3. The cool box should have the following designation:
Add address here
4. Laboratory technician collects specimens (in serum racks) from the refrigerator and checks to make sure that all have appropriate labels and places them in the cool box.
5. Laboratory technician prepares the specimen transfer form (in duplicate) and fills the site specimen transfer log book.
6. The specimen collection forms, a copy of the site test result slips and both copies of the specimen transfer form are placed in a plastic re-sealable zipper storage bag to accompany the specimen in the cool box.
7. For sites in the same city as the laboratory the driver will transport the specimen and paperwork to the laboratory. The driver then picks up any available laboratory test results slips and a completed copy of the specimen transfer form in a sealed envelope and returns them to the site receptionist/screener.

8. For sites far from the laboratory, the cool box (containing the specimens and paper work) will be transported to the offices of the commercial transport operator for transfer to the country laboratory. The cool box will be collected by laboratory staff (at the office of the transport operator) who will send back to the site receptionist/ screener a cool box containing any available laboratory test results slips and a copy of the completed samples transfer form (from the previous transfer).
9. Note: The cool box needs to be handled with caution. It should always stay upright; vigorous movements need to be avoided.

5. Laboratory staff contact information

- Primary contact: *Add primary contact here*
- Secondary contact: *Add secondary contact here*
- Sample reception office: *Add contact here.*

Safety

I. Biosafety precautions

- Follow universal precautions. Assume that blood and body fluids from all patients are infectious. Handle all specimens as at biosafety level 2.
- Wear gloves for handling blood or body fluids. Change gloves when attending to each new client and whenever they become contaminated, and wash hands after handling specimens. Do not handle door knobs, telephones or other community objects while wearing gloves.
- Wear protective clothing (laboratory coat, etc.) while working with potentially infectious materials. Wear closed-toe shoes (no sandals).
- Laboratory surfaces should be decontaminated with a 10% bleach solution following any spill and at the completion of work activities. If a Vacutainer is broken or blood is spilled, cover with 10% bleach and absorbent paper and let sit for 10 minutes. Double-glove, wipe up and dispose of paper and gloves in an infectious waste container.
- Dispose of contaminated materials in a plastic bio-hazard bag.
- Personnel should wash their hands after removal of protective clothing and before leaving the survey office.

8.2 Example: Refusal to give blood

To be completed by the VCT counsellor

Instructions: Please input the **main** reason why someone does **not** want to give a blood sample.

MAIN REASON FOR NOT GIVING BLOOD

1. Afraid it will hurt.
2. Afraid of being HIV positive.
3. Afraid of being positive for syphilis.
4. Afraid of all test results.
5. Afraid someone will find out that I had HIV test (Afraid it will not be confidential).
6. Do not have time.
7. It is dangerous to your health.
8. No cure for HIV.
9. It is against my religion to give blood.
10. Just had an HIV test and do not want to do it again.
11. Other, specify: _____

	COUPON NUMBER <i>(Take away coupon/ write number in this column)</i>	DATE	REASON FOR REFUSAL <i>(Write the code in this column)</i>	IF OTHER, SPECIFY	RDS VCT COUNSELLOR (INITIALS)
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					

8.3 Example: Test result slip for HIV and syphilis tests that are done at the laboratory

(To be filled in duplicate)

Site/city of specimen origin: _____ Region: _____

Participant ID	
HIV test result	
Date tested (HIV test)	
Syphilis test result	
Date tested (syphilis test)	
Name of laboratory technician	
Signature of laboratory technician	
Comments	

Instructions

1. Form to be filled in duplicate by laboratory technician at the laboratory, after HIV and syphilis tests have been done.
2. One copy is sent to the site manager (to be put in the participant folder for post-test counselling during second visit), while the other copy is kept at the laboratory.
3. Participant identification (ID): remove label from participant folder and stick on form (do not write).
4. Test result and date: write the result of the HIV test and the date on which it was done.
5. Test result and date: write the result of the syphilis test and the date on which it was done.
6. Name and signature of technician: write name and signature.
7. Comment: write any other relevant information about the sample that was tested.

8.4 Example: Test result slip for rapid HIV and syphilis tests done at the RDS survey site

(To be filled in duplicate)

Site/city of specimen origin: _____ Region: _____

Participant ID (label)	
HIV test result	
Date tested (HIV test)	
Syphilis test result	
Date tested (syphilis test)	
Name of technician	
Signature of technician	
Comments	

Instructions

1. Form to be filled in duplicate by laboratory technician on site, after HIV and syphilis tests have been done.
2. One copy accompanies serum sample to laboratory and the other is put in the participant folder.
3. Participant folder is returned to receptionist.
4. Participant ID: remove label from participant folder and stick on form (do not write).
5. HIV test result and date: write the result of the HIV test (e.g. positive, negative or discordant and type 1, 2 or 1/2) and the date (dd-mm-yyyy) on which it was done.
6. Syphilis test result and date: Write the result of the syphilis test (e.g. positive, negative or discordant) and the date (dd-mm-yyyy) on which it was done.
7. Name and signature of technician: write name and signature.
8. Comment: write any other relevant information about the sample that was tested.

8.5 Example: Site specimen transfer log book (keep at RDS survey site)

(To be copied into specimen log book)

Site/city: _____ Region: _____

Transfer batch number	Total number of serum specimens	Total number of cryovials	Date (specimens sent from site)	Name and signature (sender)	Comments (sender)	Date (specimen transfer form received from laboratory)
01						
02						
03						
04						
05						
06						

Instructions

- Format to be copied into a notebook kept in the site laboratory and filled in by the site laboratory technician (sender) after every batch of samples transfer to laboratory.
- Transfer batch number: The number for the first batch of transfer is 01, second is 02, third is 03, etc.
- Total number of serum sample: Sender must write the total number of participants whose serum samples are being transferred to laboratory.
- Total number of cryovials: Sender must write the total number of cryovials transferred to laboratory.
- Sender name and signature, date and comment: Sender must also write his/her name, signature and date samples are being transferred to laboratory, together with any relevant information about the samples being transported.
- Date (sample transfer form received from laboratory): Record date on which a copy of the completed specimen transfer form is received from laboratory.

8.6 Example: Specimen collection form and guidelines

(To be filled in duplicate)

Technician name: _____ Date: _____

Site/city: _____ Region: _____ Transfer batch number: _____

No.	Participant ID code	Laboratory number	Time blood collected	Blood collected Yes/No	Blood adequate Yes/No	Serum obtained Yes/No	Number of cryovials	Time serum obtained	Comment
1.									
2.									
3.									
4.									
5.									
6.									
7.									
8.									
9.									

Instructions

- Form to be filled by site laboratory technician in duplicate after participant’s blood sample has been collected and serum transferred into cryovials (serum tubes).
- One copy accompanies the samples being transferred to the laboratory (for verification of samples), while the other copy is stored in the cabinet in the site laboratory.
- Transfer batch number: write the code number of the batch of samples when they are being sent to the laboratory, e.g. the code for the first transfer is 01, second is 02, etc.
- Participant ID: remove label from participant folder and stick on form (do not write).
- Time blood collected: write the time that the participant’s blood was collected.
- Blood collected and serum obtained: write “yes” or “no” as the case might be.
- Blood adequate: write “Yes” if blood collected is at least 3 mls, otherwise write “no”.
- Number of cryovials: write the number of cryovials filled with participant’s serum.
- Time serum obtained: write the time that the participant’s blood was centrifuged and serum obtained.
- Comment: write why blood was not collected, serum not obtained, blood or serum not adequate or any other relevant information about sample.

8.7 Example: Samples transfer form and guidelines

(To be filled in duplicate)

Site/city: _____ Region: _____

Transfer batch number	
Total number of serum samples being transferred (from site to laboratory)	
Total number of cryovials being transferred (from site to laboratory)	
Date (sent from site)	
Name (sender)	
Comments (sender)	
Signature (sender)	
Total number of serum samples received (at laboratory)	
Total number of cryovials received (at laboratory)	
Date (received at laboratory)	
Name (recipient)	
Signature (recipient)	
Comments (recipient)	

Instructions

1. Form to be filled in duplicate by site laboratory technician (sender) before samples are transferred, and also by laboratory technician (recipient) after samples are received at laboratory.
2. Both forms should accompany the samples being transferred.
3. One copy of the fully completed forms is kept by recipient (at laboratory) and the other copy is sent back to the sender (on site).
4. Transfer batch number: sender should write the code number of the batch of samples being transferred to laboratory e.g. the code for the first transfer is 01, second is 02, etc.
5. Total number of serum sample (site to laboratory): sender must write the total number of participants whose serum samples are being transferred to laboratory.

6. Total number of cryovials (site to laboratory): sender must write the total number of cryovials being transferred to laboratory.
7. Sender name and signature, date and comment: sender must also write his/her name, signature and date samples are being transferred to laboratory, together with any relevant information about the samples being transported.
8. Total number of serum sample (received at laboratory): recipient must write the total number of serum samples received at laboratory.
9. Total number of cryovials (received at laboratory): recipient must write the total number of cryovials received at laboratory.
10. Recipient name and signature, date and comment: the recipient must also write his/her name, signature and date samples are received at laboratory, together with any relevant information about the samples received.

Surveillance is the systematic, regular collection of information on the occurrence, distribution and trends of a specific infection, disease or other health-related event. HIV surveillance is designed to collect and integrate data reported from a variety of sources, including behavioural surveillance, case reporting, seroprevalence surveillance, and sexually transmitted infections surveillance. The goals of second generation HIV surveillance are to help countries better understand the HIV epidemic trends over time, to better understand the behaviours driving the epidemic, to focus on subpopulations at highest risk for infection and to better use surveillance data for planning the response to the epidemic.

HIV surveillance in the Eastern Mediterranean Region needs to be strengthened in order to fill the gaps in our understanding of the dynamics of the epidemic and to be in a better situation to plan appropriately for an effective response. This training course is part of a series of 4 training modules and has been adapted to the regional context from a module originally developed by the Centers for Disease Control and Prevention, USA. It describes how to plan and implement a respondent-driven sampling (RDS) survey. The course is intended for university and ministry of health staff, public and private public health researchers, and surveillance officers, who will be involved in the planning, organizing, monitoring or implementing of biological and/or behavioural surveillance surveys on HIV/AIDS and associated risk factors in key populations at higher risk of HIV exposure. Countries are free to further adapt these modules or to translate them into local use.