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Guidelines for Conducting HIV Behavioural Surveillance

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FOREWORD

In the South-East Asia Region, the HIV epidemic is fairly advanced in its course in several nations and remains relatively low in intensity in others. In India, Myanmar and Thailand, the epidemic has become a serious addition to the nation's existing disease burden and is affecting families and communities. Adjusting policies and programmes to fit emerging epidemiological patterns and needs is an ongoing process. In this endeavour, and for advocacy among policy-makers, behavioural surveillance has an important role to play.

This document presents the principles and practical steps to implement behavioural surveillance. Most national HIV/AIDS control programmes require reasonably accurate data with which to make decisions without investing a great amount of time and resources. Various options have been presented in this document that can allow programme managers to implement behavioural surveillance programmes, according to their needs and availability of limited resources.

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Disease
CBO	Community-based Organization
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
MSM	Men having Sex with Men
NGO	Non-governmental organization
PPS	Probability Proportional to Size
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
UNAIDS	Joint UN Programme on HIV/AIDS
WHO	World Health Organization

1. INTRODUCTION

Member Countries must take timely and appropriate action to prevent the rapid and extensive spread of HIV infection among vulnerable groups, thereby reducing the danger of a widespread AIDS epidemic particularly in the general population. Where the epidemic has already reached the general population, it is essential to monitor the impact of prevention efforts to reduce the number of new infections. In order to prioritize the use of limited resources, it is essential to know which sub-populations are most vulnerable from the HIV point of view, why, and how they are linked to others. This document sets out some of the basic methods for conducting surveillance of the behaviours that put people at risk of acquiring an HIV infection. Details of various components of the methodology involved are beyond the scope of this document. Instead, individuals can acquire detailed information from local experts, books on surveys and sampling, texts on sexuality and sex research, and a few manuals specifically on HIV behavioural surveillance.

2. HIV/AIDS IN THE SOUTH-EAST ASIA REGION

In the South-East Asia Region, as of the beginning of the year 2001, HIV continues to spread rapidly to communities and sub-populations including those that were hardly affected only a few years ago. In Bangladesh, recent surveillance revealed low rates in injecting drug users (IDUs) and brothel-based sex workers. In Nepal, there has been a recent rise in HIV prevalence among IDUs after several years of low prevalence. Similar trends have been seen also in Indonesia. India is presently undergoing a phase of spread from high-risk groups to the general population in some areas. Experience shows that areas with high rates of HIV among high-risk populations, such as sex workers, can be found next to those where rates yet have remained low. High rates have been reported from Myanmar among IDUs and sex workers. Infection rates in other nations, such as Sri Lanka, Bhutan and Maldives continue to remain low, while rates in Thailand are now declining as a result of government action. The Region therefore, represents considerable variation in extent and intensity of the epidemic among the Member Countries. This situation warrants careful and repeated monitoring through HIV sentinel serosurveillance and behavioural surveillance.

3. PRINCIPLES OF SURVEILLANCE

Surveillance aims at tracking changes over time in the prevalence of a disease or its associated conditions. Sentinel surveillance does the same at specific sites known to have an associated sub-population group that is fairly stable. Individuals in the group may change over time, but the site has an ongoing association with persons representative of the particular group. In the context of the HIV epidemic, these sites are often health care facilities, clinics or drop-in centres run by government or nongovernmental organizations (NGO). HIV surveillance requires that the sample collection is completed within a specified time period for other purposes and part of the sample is tested. The samples are collected in an unlinked anonymous manner so that the result of test cannot be linked to any particular person. The prevalence rates are calculated for the group.

A sentinel site is selected in accordance with its access to the group under surveillance. WHO recommends that HIV/AIDS surveillance should be expanded to include surveillance for STIs and HIV-associated risk behaviours.

4. INTRODUCING BEHAVIOURAL SURVEILLANCE

Behavioural surveillance aims at tracking changes, through time in specified populations, in their risk behaviours and other pertinent factors, such as their access to preventive services. Behavioural surveillance is particularly useful in early stages of the epidemic, because it highlights where and in which group the infection is likely to spread. Results can be used to raise awareness of policy-makers and encourage investment in prevention before HIV infection level begins to spread rapidly. Behavioural surveillance can also yield explanations for changes in the reduced rates of HIV at later stages of the epidemic. Because results are directly applicable to the planning and implementation of prevention programmes, behavioural surveillance differs from HIV sentinel surveillance in several ways.

First, behavioural surveillance is based on social and behavioural concepts and methods. For example, it incorporates socioeconomic factors and uses both quantitative and qualitative methods. Samples consist of a social group, defined by occupation, age, or other factors contributing to HIV vulnerability. STD patients could be a good target group for HIV sentinel surveillance, but are too ill-defined socially to represent a good group for behavioural surveillance. Developing questionnaires requires familiarity with the group and its behavioural patterns, a task best accomplished through ethnographic and other

qualitative methods. Further, qualitative methods may be required to validate findings after the quantitative surveys are completed. The great value of ethnographic methods is that they bring the investigators close to the people, diminish social distance and foster empathy, all of which improve data collection through questionnaires, access to people and interpretation of results.

Secondly, behavioural surveillance is not necessarily limited to the fixed facilities only as is the usual case for HIV sentinel surveillance. This allows for better sampling with presumably less bias due to self-selection. Bias can be introduced in other ways, however, and care must be taken to avoid this.

Thirdly, behavioural surveillance always requires informed consent but is not linked to the results of HIV testing for individuals. Confidentiality and privacy should be ensured and participants are provided with information and referred to services. Informed consent is not required in sentinel surveillance because of unlinked anonymous testing.

Fourthly, because voluntary cooperation is a must for behavioural surveillance, efforts to develop rapport, enhance participation, and, ideally, develop ongoing collaborative relationships with survey populations are required. This is not so in sentinel surveillance, where the identity of the persons being tested is not known.

Fifthly, behavioural surveillance methods usually offer greater opportunity to develop more representative samples than sentinel surveillance and may therefore include sample populations which are slightly different sub-groups among the same population. For example, Injecting Drug Users (IDUs) may be accessible for bleeding only at facilities where treatment is offered. In-treatment IDUs are usually only a small proportion of those in the community and cannot be considered representative. Their average age may be different from those on the streets, or they may belong to a different socioeconomic class. Basic sociodemographic information should be collected to estimate in which direction the bias is likely to be.

Behavioural surveillance should be linked in some way to ongoing prevention efforts. This may be through collaboration with NGOs or other community-based groups, by disseminating the results to planners, programme personnel and target populations, or by actively using the results to develop new prevention programmes. The ultimate goal of all surveillance is to contribute to prevention, not just to gather information.

Sociological surveys can be simple or complex. Behavioural surveillance must be kept relatively simple in order to be practical, rapid, inexpensive and easily repeated. Both HIV prevalence and associated behaviours can change very rapidly. The results must be available relatively quickly, because they are useful for programme purposes.

The main purpose of HIV behavioural surveillance is to make quantitative estimates of the prevalence of specific risk behaviours. This type of survey cannot gather all the interesting and required information, but should focus on a few very important ones that can provide baseline data useful for designing interventions and monitoring the changes.

However, the context and meaning of risk-taking behaviours, conditions surrounding access to information and services, and reasons for positive or negative responses to prevention strategies are not easily learned from quantitative behavioural surveys.

Hence, behavioural surveillance should include both qualitative and quantitative methods. In the first stage, ethnographic, interview or focus group research methods can reveal which risk behaviours are present, and which groups of people practise them. Quantitative surveys then tell us how many of these people practise such behaviours, and how often. Further qualitative research can examine the contexts and meanings of the behaviours now documented, leading to possible intervention strategies. In other words, early qualitative research reveals that the mountain is there, while quantitative surveys measure how high the mountain is. But it takes greater in-depth and ongoing work to figure out how to climb the mountain.

5. STEPS IN CONDUCTING HIV BEHAVIOURAL SURVEILLANCE

5.1 Preparatory Stage

Step 1: Planning

A Technical Advisory Committee should be formed, composed of representatives of government, NGOs/CBOs, target populations being considered for survey, WHO, UNAIDS, and other stakeholders, such as donors. The Committee can take a long-term view of the epidemic, assess

the available evidence and plan accordingly. It should decide on the groups to be included in behavioural surveillance, and the frequency with which the surveys will take place. All decisions must be based on the best available knowledge of the current status of the epidemic, available funds and time considerations.

The government agencies represented should include those that have frequent interactions with some of the target groups, e.g. drug control, police, social welfare and others. These agencies must be involved, so that they understand the need for compassion and care and the serious damage to HIV prevention programmes that could result from discriminating and repressive measures, for example, by scattering groups with illegal practices or driving them underground. It must be ensured that the attention various groups of people receive due to the surveillance does not damage public health programmes.

The agency or personnel responsible for carrying out the surveillance must be selected based on known capacity. If government agencies are selected, for example, those involved with demographic census or family planning surveys, a few persons may require specialized training. Local or external specialists in survey research on sexual and/or drug use-related behaviour may be needed to initiate the work, depending upon the extent of local experience. If nongovernmental persons or agencies are selected, senior government representatives should be associated in a formal way in all stages of the work in order that sensitive findings are kept confidential and used only for programme development and planning. As soon as possible, a single lead agency should be engaged to continue with the efforts in order to maintain continuity and consistency of methods and approach.

The Technical Advisory Committee should develop a long-term plan and select the responsible personnel or agency. A consensus workshop attended by experienced experts may be helpful in the beginning. Groups needed for the current year should be selected and criteria set for determining if they will be repeated the following year. Criteria may be set for the inclusion of new groups, and the frequency of survey with which each will be surveyed. While flexibility must be allowed, future planning is essential, allowing adequate commitment of personnel and financial resources.

Ethical clearance must be obtained after the groups to be surveyed have been identified. Surveillance of young people under the age of 18 may require parental permission in some nations.

The teams conducting surveillance should submit periodic reports to the Committee. Both sentinel surveillance and behavioural surveillance should be reported and planned together. This requires close coordination among the involved parties.

The population groups to be surveyed should be selected on the basis of the stage of epidemic and available funds.

Stage of Epidemic

Low Level

- Although HIV infection may have existed for a number of years, it has not spread to significant levels in any sub-population.
- Recorded infection is largely confined to individuals with higher risk behaviour: e.g. sex workers, drug injectors, men having sex with other men.
- Networks of risk are rather diffuse, with low levels of partner exchange or sharing of drug injecting equipment, or the virus has been introduced only very recently.

Numerical proxy: HIV prevalence has not consistently exceeded five percent in any defined sub-population.

Concentrated

- HIV has spread rapidly in a defined sub-population, but is not well established in the general population. This epidemic state suggests active networks of risk within the sub-population.
- The future course of the epidemic is determined by the frequency and nature of links between highly infected sub-populations and the general population.

Numerical proxy: HIV prevalence consistently over five percent in at least one defined sub-population. HIV prevalence below one percent in pregnant women in urban areas.

Generalized

- In generalized epidemics, HIV is firmly established in the general population.
- Although sub-populations at high risk may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of sub-populations at higher risk of infection.

Numerical proxy: HIV prevalence consistently over one percent in pregnant women nationwide

General Population Surveys

General population surveys are valuable, but may be quite expensive and complex. They can provide an estimate of age at first intercourse, age at menarche, age at marriage, overall levels of extramarital and premarital sex, male-to-male sex, sex with prostitutes, use of drugs and other behaviours of the population at large. Already established and on-going population surveys can incorporate key indicators for HIV risk, thus reducing the additional expense. Information on sexual or drug-taking risk behaviours may be obtained through self-administered questionnaire, where literacy levels are adequate. General population surveys may be door-to-door interviews, telephonic, computer-assisted, mailed with self-addressed envelopes, or in combination. A WHO module on sampling for such surveys is listed in Annex 1.

As an alternative to general population surveys, specific groups representing portions of the general population, i.e. groups not known to be at high-risk, can be surveyed. These may include workers in a particular industry, students in colleges, universities or other types of training institutions, or members of unions or other associations. The possibilities for surveys of this type are endless and depend solely on the place and mode of access. In some countries, it may be possible to survey people in public places, such as beaches or parks, while in others, it may not. If a decision is made to try such an approach, a pilot study should reveal if refusal rates will be too high, i.e. over 10%. General population surveys are seldom repeated more often than once every 4-5 years.

Surveys in High Risk Groups

Low level and concentrated epidemics require repeated surveys among sub-populations with high-risk behaviours. These are often, though not always, hard-to-reach and are stigmatized groups, such as sex workers, men who have sex with men (MSM) and IDUs. Surveying such hard-to-reach groups represents the greatest challenge, but can be accomplished by involving persons from these groups in the planning and implementation process.

Literature search on targeted groups should be carried out. Available data on key indicators should be compiled and gaps should be identified.

If little or no pertinent research has taken place, prior to the surveillance, planning will take somewhat longer. Background information must be

gathered through qualitative research methods, particularly those of ethnography. This may take a few months, but is well worth the effort. A trained ethnographer may be hired for the purpose.

Where behavioural surveillance has taken place at least once, continuity must be assured. New groups may be added, but previously surveyed groups must be retained.

Young people must be included, as a high risk population once the epidemic becomes concentrated. They can be sub-divided by age and sex groups and may be best accessed in household surveys. Special groups of young people may be accessed through youth or sports clubs, schools or churches, or even malls and other places where young people might congregate. Surveys may be repeated every 2-3 years with sample of 400 in each age-sex sub-group.

A rapid qualitative assessment of the selected population groups and their locations should be carried out. Word lists of the terms used by these groups for symptoms of sexually transmitted diseases (STDs) and various sexual practices and otherwise. Attention should be paid to available STD treatment options, existing interventions, the time schedules in these peoples' lives, people who may control or harass them, and other factors that could present barriers to the process of surveying..

Information on available resources, e.g. trained interviewers, translators, computers, data entry personnel, software and logistics for travel should be collected. Arrangements must be made to acquire what is needed. Data management requirements should not be underestimated.

A short manual for training interviewers and supervisors must be developed. This should cover basic facts about HIV/AIDS, issues surrounding vulnerability, sexually-transmitted infections (STIs) and treatment options, talking about sex and drugs, interviewing techniques and ethical issues. Using previously trained interviewers (from other similar projects or earlier surveillance surveys) greatly facilitates training efforts.

Step 2: Accessing Vulnerable Populations

Access to vulnerable populations may be easy or difficult, depending upon the attitudes of investigators. Sometimes those easiest to find may be most

difficult to interview. Previous unpleasant experience with researchers or negative media coverage can be serious barriers. NGOs or CBOs working with these groups may be protective and uncooperative at first. Persons engaging in illegal or socially undesirable activities may be frightened of being exposed. Sincere non-judgemental attitudes win friends in the end, but one must be prepared to make repeated attempts or to explain in detail the importance of these surveys in order to convince the groups. After a degree of trust is established, individuals showing the greatest interest and capacity can be engaged in the survey work. Some may be capable of becoming interviewers; many can help with the mapping. Where NGOs and community groups are cooperative, understand the purpose and value of behavioural surveillance, participate in the work itself, and receive feedback on its results, an ongoing access to the groups becomes easier.

There is one caveat with regard to involving persons implementing interventions: they frequently do not like their shameful or hidden activities to be revealed and may make a deliberate attempt to influence the interviewees to give false information. NGO workers may also try to falsify the information if they believe the results will reflect on the quality of their intervention. Government agencies, such as the police, can drive persons practising illegal acts further underground if they take punitive measures. Great care must be taken to prepare relationships and understanding with these individuals and agencies, so that surveillance is not adversely affected.

Criteria should be set to increase the likelihood of including the most at-risk persons, e.g. long-distance truck drivers as opposed to those who only work locally. Similarly, among MSM, one might choose to narrow the definition to include only those who sell sex for cash, i.e. male sex workers (MSW). The broader one defines the risk group, the larger the sample needed in order to achieve the required sample size for indicators of recent sexual activity. Ordinarily, high-risk groups should be sampled repeatedly every year or every two years.

In the South-East Asia Region, the group most countries wish to learn about are young people. Some young men and women engage in risky sexual or drug-using behaviours and this proportion is likely to increase with age. There are likely to be marked differences between the 15-19 year olds and the 20-24 year olds, requiring separate samples of about 400 for each age-sex group. The most representative indicator for these groups is the proportion that was engaging in sexual intercourse over the past year. That young

women's partners could be older men should be kept in mind while interpreting the findings. To look for trends, it would only be necessary to repeat the survey among them every five years.

In contrast to young women, a higher proportion of young men are likely to have engaged in sexual intercourse over the past year. It is important to find out what proportion of their partners are sex workers, as this information may help clarify their high-risk behaviour. If so, targeted interventions and an altered sampling strategy would be warranted. Accessing young men who visit sex workers could be accomplished at the sex venues, i.e. brothels or contact venues such as parks.

For both biological and social reasons, youth is a time of heightened vulnerability to STIs, including HIV. If an effort is to be made to prevent the epidemic from spreading widely into the next generation of adults, both in-school and out-of-school youth should be surveyed and strategies devised for sampling them through schools, sports clubs, community centres, religious groups, or at sites of congregation, such as shopping malls or cinemas. Priority should be given to target those who engage in high-risk behaviours.

Components to Implement

- (a) Existing HIV prevention interventions dealing with the selected groups should be identified. Building on familiarity developed during the formative assessments, NGO programmes or local meeting places of target group members should be repeatedly visited to develop trust and understanding of the surveillance. Where no such activity exists, meeting with people at usual gathering places identified during the initial qualitative assessment should take place on repeated occasions.
- (b) Participation in planning, mapping or interviewing, of the individuals of these groups should be arranged. Helpful, dependable and capable persons should be selected for mapping and/or interviewing. They should be paid for their work. However, people should NOT be misled into thinking that the surveillance will provide employment to a lot of people.
- (c) In consultation with people from the target groups as well as those in charge of the serosurveillance, inclusion and exclusion criteria should be finalized.

- (d) A pre-determined geographical area should be mapped for the presence of members of these groups with the help of guides from these groups. The entire geographical area should be well-mapped, not just the area known to project personnel or covered in an intervention. This is an essential step in preparing the sampling frames and must capture all significant variability in time and location. If time or personnel are limited, then one can limit the size of the geographical area to be covered, but one must be certain to describe the true area sampled in the final report.
- (e) Standard printed maps should be used. A city may be divided into sections, e.g. wards, and teams sent out at different times of day and night, weekdays and weekends to ascertain the accessibility of persons from the selected groups. A cut-off may be set for recording their presence, e.g. finding at least five persons at a single spot within three hours. These spots and times should be recorded and an estimate of how many would be available during a set period of time, e.g. 9-12 am, or 7-10 p.m should be made. This information should be entered into a computer database.
- (f) One must avoid interviewing only hard-to-reach persons at sites where they may congregate for HIV prevention-related reasons, e.g. to attend a clinic, to gather for safer sex education, to collect condom or to seek help with drug addiction. These persons are likely to represent only those who already recognize that AIDS is a deadly disease and are concerned about their own safety.
- (g) The sites selected each year should remain similar, but all of them need not be exactly the same. For example, during the second year of conducting the survey, mapping may indicate that the group no longer frequents some of the known sites while some new sites have developed. If at least 50% of the sites remain the same from year to year, they will be acceptable.
- (h) It must be remembered that the actual maps with the named sites do not have to be published lest the safety of the participants is jeopardized.

Step 3: Sampling

The purpose of sampling is to use a framework to select respondents in a way that can be repeated consistently year after year and measure changes that have taken place. If everyone in a group could be registered in some way, a

simple random sample would produce good estimates of the true measure of change. But, with many of the groups needed in HIV-related risk behaviour studies, such registration is unavailable and probability sampling, i.e. each person having an equal or clearly defined chance of being selected, is difficult. Good representative sampling, with trustworthy confidence intervals, can be accomplished by taking care to create sampling frames based on accurate mapping and correct calculations.

Creating the sampling frame has two basic steps. The first is the calculation of sample size. This will usually be based on estimates of the proportion of persons using condoms or not sharing needles the last time. If the survey takes place among high-risk people who have had little exposure to HIV prevention services, such proportions may be quite low. Alternatively, the indicator used may be the proportion of sex acts with the use of condoms or the proportion of injections with new clean needles. If there has been no previous behavioural surveillance (or similar survey) on which to base estimates, secondary sources and the results of the rapid assessments may be used to estimate the proportions.

One has to keep in mind that the aim is to measure change in a subsequent survey. For most purposes, a 10% change is significant. For high-risk groups, a sample size of 400 is enough to interpret the change with 95% confidence. If at least a 10% change occurs between surveys and sample sizes are adequate, the confidence intervals around each proportion will not overlap. If they do, then there really was no change or it was too small for the sample sizes to detect.

For lower risk groups, e.g. those in which only 40% of people have recently engaged in a high-risk behaviour, in order to draw a sample large enough to find 400 with such behaviour, $400/.40$ or 1000 would be needed. The lower the percentage of risk behaviours, the larger the sample size needed. Annex 2 presents a table showing the 95% confidence interval for different proportions and sample sizes. Examining this table demonstrates what happens to the width of the 95% confidence intervals with different proportions at various sample sizes and can help guide decisions about sample size estimation.

The second step is making a decision about what type of sampling strategy will be most practical in order to achieve the best representativeness possible. Some situations allow ease of good probability sampling, e.g.

brothels, gates into ports where trucks register sequentially, a network of residential injection houses, night clubs or massage parlours with sex workers on staff. Where **systematic** or **proportional random sampling** is possible, either is an easy option. Examples of these are given in Annex 3.

Some sites share the characteristic of relative stability, i.e. one can expect to find the same persons there at predictable times. If their sizes differ markedly, however, it is best to use a sampling strategy known as **probability proportional-to-size** or **PPS**. In this type of sampling, one takes a convenient number of interviews, e.g. between 10 and 20 per site and, based on the sample size required, calculates the number of sites needed. The selection of those sites is carried out in a specified way that allows larger sites to be selected more often, which builds in an automatic correction for size. This is the most practical type of sampling strategy and should be used wherever possible. See Annex 3.

It is more difficult to ensure a representative sample when there is a frequent turnover of the persons in any particular site. Street-based sex workers and IDUs fall into this category. A type of sampling that is useful for this type of situation is called **time-location sampling**. Some information is needed beforehand, however, and can be obtained during the mapping. In **time-location sampling**, the supervisor should be present to maintain the time frame and to keep track of the number of persons entering or exiting the sites for various reasons.

Some groups of people may be extremely difficult to access, except through each other, e.g. transgender sex workers, middle-class injectors or MSM. **Snowball** or **convenience samples** may be the only way they can be reached. In such a case, one can still try to achieve a wide geographical or social class coverage including samples from a variety of networks. One may set quotas or a fixed number of interviews for each known sub-group. Such a sample has no probability parameters and cannot be held as representative of the group. It may be that one is forced to do such convenience sampling the first year, but can improve on this in following years. Keeping careful records of how and where people are accessed can help define the group and develop a better approach later. Because the HIV epidemic has such serious consequences for individuals, families and nations, the information gained even from convenience sampling can be very valuable in motivating governments and other agencies to invest in prevention. It cannot be used, however, to measure change in important indicators.

Components to Implement

- (a) Using specific indicators, the sample size needed should be estimated. Secondary sources, such as previous surveys, may help to give a gross estimate. For simple random samples, detecting a change of 10% seldom requires more than 400 persons. It is always wise to set the sample size somewhat higher (e.g. 440-450) to accommodate possible refusals, absentees and persons who, in the analysis, will have to be discarded.

Where finding approximately 400 people of a specific risk group seems impossible, adequate sampling is still attainable with sample sizes of 200-300. Having smaller sample sizes simply means that future comparisons will only be able to detect larger changes, i.e. those greater than 10%, with adequate precision. Even under such statistical constraints, behavioural surveillance is worth doing.

- (b) After mapping, the sampling strategy to be used should be decided, based on the degree of mobility in the group and the number available at the mapped sites. The sampling frame should be developed according to a specific method, as suggested in Table 1 and discussed in Annex 3. Not all groups need to be sampled the same way, but it would not be wise to alter sampling strategies for the same group in subsequent years. Clear records of how the sampling strategy was designed should be kept and the sampling should be clearly described in the final report.
- (c) If the group is highly mobile, the following information will be needed about each site:
- Are there significant differences by time of day in the number of people available?
 - Are there significant differences by day of the week in the number of people available?

After this information is obtained for each site, it should be listed, along with an estimate of how many persons may be available at each time-location slot. Visiting each site numerous times may be very time-consuming and expensive. It should be adequate to visit only one or two times if members of the target group who are conducting the mapping can offer information based on their own experiences. Information from key informants must be independently checked with others for accuracy.

- (d) The sample frame must be with the help of maps and a good informant or two. Computers are very helpful. Programs such as EPI6 (EpiInfo) can help calculate sample sizes, confidence intervals and random number lists. Making a database of the information from the mapping exercise greatly facilitates designing the sampling frame. The database may have information such as site name (and code number as on the map), time period for time-location sampling and number of persons available. (Note: if the same site has different gatherings at different time e.g. on weekends vs. week days, or mornings vs. evenings, it should be listed twice).
- (e) One should be aware of and prepare for the possible influence of holidays or other unusual events. These can include strikes, failed communications, flu epidemics, police raids, floods, etc. In the real world of research, absolutely anything can go wrong (and usually does) in the flow from questions to answers. One should be flexible and be prepared on a day-to-day basis.
- (f) The following information is useful to improve the earlier sampling frame:
- How many interviewers were sent to each site?
 - How many persons of the target group were actually present at the time?
 - How many refused to be interviewed?
 - How many got away for other reasons?
 - How many were interviewed?
 - How many were rejected as duplicates?

This information should then be printed out for all the selected sites and given to the field supervisors. This information, compiled by the supervisors, will form the basis of defining the representativeness of the samples and is very important. If anything goes wrong, e.g. the team was unable to get as many interviews as planned, this information will allow the calculation of sampling weights (see Annex 3), one means by which corrections can be made to the population estimates.

- (g) If necessary, a statistician or epidemiologist should be consulted. Table 1 presents some possible examples of types of groups, modes of access to them and sampling strategies. There are often several ways one can approach sampling in any given group. The simplest and most convenient should be chosen.

Table 1. Different Types of Groups and Approaches to Sampling

Type of Access	Sample Type	How	Possible Examples
Registered individuals or households, Institutional or residential	Simple random	Random number list	(a) Voter lists (b) Factory workers (c) Prisoners (d) Army barracks
Multiple institutions, unregistered	Proportional random	Proportion of total for each and proportion of needed sample size for each to be calculated, mapped; estimated or counted	(a) All the brothels in a state or country (b) All hotels with sex workers in a town (c) All massage parlours where sex is sold
Continuous at point of access	Systematic, random	Every nth person	(a) Truckers at a port (b) Migrants at a border crossing
Stable groups, similar size	Cluster, fixed number of interviews	A convenient number per cluster, randomize clusters to be set	(a) Union meetings (b) Ship crews (c) Student dormitories
Stable groups, large difference in size	Cluster, PPS	A convenient number per cluster to be set, PPS method to be used to select clusters	(a) IDUs at professional injectors' spots (b) Youth at shopping centres
Unstable groups	Cluster, time-location	To be mapped by time and day; Size available to be estimated by fixed time period; Fixed number or take-all to be selected; Sample for fixed time period; All seen and lost by any means to be monitored ; Weights to be calculated	(a) Street sex workers (b) Shifting street-based IDUs (c) Taxi stands (d) Street children

Standard cluster sampling strategies can be used after careful mapping. See Table 1 and Annex 3.

Step 4: Designing Questionnaires

Description

Many questionnaires have been designed for surveys about HIV/STD risk behaviours, but they require local adaptation.

The questionnaire must start with a statement that explains to the respondent about who is conducting the survey and for what purpose and assures him or her that there will be no name or address written on the form. The respondent must also be assured that s/he has the right to refuse or to stop the interview at any time. The respondents should be given a hint that the contents may be sensitive to them and that there is no penalty for refusing.

The questionnaire should include a short section on socio-demographic identifiers, e.g. age, sex, years of education, income, occupation. It is important to obtain some measure of the degree of in- and out-migration within a group, in order to be able to track its changing composition through the years. A few questions on levels and sources of knowledge about HIV or STDs and their prevention may be useful to develop rapport with the respondent. It must be noted that soon after educational interventions, levels of knowledge typically grow rapidly, while behaviour changes little. Such information is most useful at the early stages of the epidemic.

The principal indicators that are frequently used around the world should be included so that the results can be compared. These differ with the groups. Sex workers, their clients, young persons, and IDUs have different but related indicators. These are listed in Annex 4. They include:

- needle sharing (number of needles shared, number of persons sharing needles);
- other major risk practices associated with needle sharing (booting, front or back-loading, cocktailing);
- number of sexual partners;
- types of sexual partners;
- types of sexual activities;
- number of sexual events;

- number of events using condoms;
- number of persons using condoms;
- reported STD symptoms, and
- STD treatment seeking-behaviour.

Time periods must be built into all indicator questions, i.e. in the last day, week, month or year. Shorter time periods are generally better, but for recalled STDs in secondary risk groups, such as clients of sex workers, the last year is preferable. Alternatively, 'the last time' is a clear and easy time designation, however, it is best used when a particular practice occurred not too long ago. If a person went to a prostitute or injected drugs 10 years ago, the last time is simply too long ago to matter.

One major issue that arises repeatedly, is defining types of sexual partners. Cultures differ with regard to this factor. In some, casual, commercial, regular and legitimate sexual practices are recognized as separate categories. In others, these categories overlap, making the distinction between commercial and non-commercial sex difficult. The best way to sort this out is by in-depth discussions, for example, in focus groups, with target group members.

The questionnaire should not take more than 30 minutes to administer. For hard-to reach groups, the form should not be spread out over many sheets of paper (no more than 5-6), as a very long form is difficult to handle in the dark in parks, etc. [Note: At night, interviewers may need flashlights to work with]. Questions should be closed as much as possible e.g. Y N (yes, no) options to circle, spaces or boxes to tick, however, there should be space to write in something if absolutely necessary. Questions requiring later coding of text should not be designed. These take a great deal of time, are difficult to code for subtly different responses and are often simply not worth the effort. Skip patterns should be avoided if possible, but if they cannot be avoided, clearly mark how the interviewer will skip questions. It must be decided beforehand how unmarked questions will be handled, in order to differentiate one that is skipped, because it is not applicable, one that is skipped due to the interviewer's oversight or due to refusal on the part of the respondent. On very sensitive questions, calculating non-response rates can be quite interesting.

Questions must be clear, with no ambiguity. This is not easy to do and becomes more difficult when translated from one language to another. Sexual terms must be explicit and unambiguous. Interviewers must reveal no embarrassment as they utter these terms, a feat that requires training and practice for many people. One should ask about all types of sex acts—vaginal, anal, oral, non-penetrative; about sex partners whether commercial, non-commercial, casual, or with spouse; and about sex of partners, male, female and transgender.

Exploratory questions that are not directly related to principal indicators can also be useful. It may be valuable to learn about rates of condom breakage or levels of exposure to interventions or proportion of married clients of sex workers. Deciding whether to include a question or not, should be based on the needs of the particular stage of the epidemic. In an early stage epidemic, it is valuable to learn about the potential spread of infection through sexual networks. Asking about the occupations of sex workers' clients or the proportion of clients who are married may help to demonstrate the extent of risk and aid in planning for the future. Such questions may not have to be repeated the following year, as little change is likely to take place. After interventions are started and condom use levels rise, learning more about barriers to effective condom use, e.g. lack of accessibility, availability or affordability and breakage rates may have more direct value to prevention programmes. Many such factors can be useful and hard decisions must be made so that the overall length of the interview does not exceed one half hour.

As the HIV epidemic becomes concentrated or spreads into the general population, the types of secondary questions will change. These might include:

- Self-reported HIV test results;
- personal knowledge of people living with HIV/AIDS;
- attitudes towards people living with HIV/AIDS;
- access to HIV testing facilities, and
- knowledge of services for people living with HIV/AIDS.

Pre-testing questionnaires

Experienced survey researchers place considerable effort in adequate pre-testing. If financial resources allow, pilot surveys may also be conducted to

work out the logistics and to identify the problems that may arise. At the least, questionnaires must be pre-tested with the target groups. This is usually a multi-stage process. One experienced interviewer should pre-test the questionnaire with 5-10 persons and report feedback to those in charge. After alterations are made, several different interviewers should try it again with a few persons each. If there are different social classes or ethnic groups to be covered, trials should take place with each sub-group. The same form may be used in different cities for a single target group (e.g. IDUs), but the form will have to incorporate all the variations likely to be encountered.

For example, if the aim is to know how many persons share needles with any individual injector, one might ask "In the past week did you inject in a group?" and then follow it with "How many persons in the last group?" But, if he was the first in the group and used clean needles, he was protected, while others were placed at risk. If he was injected by a professional injector with a needle/syringe owned by the professional, then he may never know how many persons were injected with that equipment. Further, he might bring his own needle but the professional injector may use the common syringe. Many variations are possible and trying to design the right questions needs time spent on good ethnographic observation followed by trials of different ways to state the question. In the end, one will find that questions need to be phrased in very explicit and clear ways, using well understood local phrases if possible.

Components to implement

- (a) Survey instruments (questionnaires) used in previous surveys should be examined.
- (b) The domains to be covered should be listed and selected a few questions for each. The best way to ask a question could be experimented with. Whenever needed, local terminology should be used. Testing questions by asking them in different ways to target group members is essential. This stage should not be skipped.
- (c) One can try a set of questions with cooperative target group members. If translation is needed, translate; then translate back into the original language. All translations must be translated back into the original language, usually several times, before they are adequate. Great confusion can result if different versions of a questionnaire are held by different persons. This confusion can be avoided by keeping track of versions and by labelling the files and print-outs.
- (d) Questionnaires must be printed and numbered.

5.2 Data Collection

Step 5: Selection and Training of Personnel

Experienced interviewers make a difference in surveys on sensitive subjects. If sex or drug use studies have never taken place, then, of course, one must start by training the persons interested in such studies. However, since the advent of HIV and the emphasis on reproductive health improvement, some studies of this kind have been carried out, in most countries, often by academic institutions. Contacting these investigators and gaining access to their interviewers is one way to start building up a cadre of experienced interviewers. Drug use studies have been conducted less frequently in most places, but are being increasingly carried out. Contacting the local or national drug control programme may be helpful.

Staff who have non-judgemental personalities and attitudes should be selected for the survey. This is more important than most other selection criteria, even the sex of the interviewer. Gender and self-presentation, however, *are* important and must be handled sensitively. It is easier to teach people the facts about HIV and what they need to know about interviewing techniques than to change their deeply held beliefs and attitudes.

Generally, better educated people perform better in their tasks than others, but there are exceptions. In-group members who are adequately educated can be very valuable members of a team. A team can be composed of a mixed set of people, some formally well-educated, and others who are less well educated but more experienced with the target groups. All must be literate, however, and dependable. Their behaviour must be respectful to everyone and must not cause problems to the target groups, other team members or people in the community. Project leaders must make it clear that all trouble-makers will be removed if they cause problems.

Ordinarily, an interviewer can carry out two interviews per hour, unless the samples are snowball samples requiring appointments and travel. Based on this, the number of interviewers will be determined. However, it is wise to include a few extra in the original training sessions to take care of drop outs, sickness or dismissal.

Using the previously developed training manual, new interviewers must be trained for at least five full days, and experienced interviewers for three days. They must learn how to talk about sex with ease. They should have a day or more to practice interviewing, followed by in-depth feedback sessions.

Inadequately trained interviewers are a serious liability. Maintaining a roster of trained persons to hire year after year, or, if at all possible, keeping a group of these persons working on research related to HIV on an on-going basis, greatly builds capacity and improves the quality of data.

Persons who can serve as supervisors, should be selected to exercise control over sampling, review the forms, handle problems that arise during fieldwork and do any necessary coding.

One note of caution: one should not be surprised if a number of people who begin as surveillance interviewers become dedicated to prevention and take jobs in intervention programmes. This is to be expected and encouraged.

Components to implement

- (a) Interviewers already experienced in surveys on sensitive issues, if available should be identified. If not available, interested and capable people should be found.
- (b) Screening should be carried out for attitudes as well as technical capacity. Recommendations from previous employers should be reviewed in order to find appropriate people. In-group members who are educated can be very useful, if committed and dependable.
- (c) Adequate time and energy should be invested in training so that all team members understand the basics about HIV and STDs, how to talk about all kinds of sexual or drug-using practices, what prevention programmes seek to do, and some aspects of the lives of the target groups they will be interviewing. They should be taught about ethical issues in taking interviews, interviewing techniques, and how to elicit true information. Using persons who participated in earlier assessments or mapping helps to build knowledge and capacity.
- (d) A few more than the immediate need should be trained, and a roster of trained people kept for the future with the possibility of calling on them to participate in future surveys. If possible, they should be helped in remaining employed in HIV-related research or interventions.
- (e) Ethical considerations include privacy, confidentiality and responding to the need for information. One way of developing skill to provide information is to train interviewers in giving a short educational talk with condom demonstration and distribution. This is highly valued by the

participants. A card or leaflet explaining where they can access more information and services can also be prepared, so that the research is viewed as helpful and non-exploitative.

- (f) Supervisors of teams need an extra day of training and written instructions, preferably in the form of a checklist. They need the sampling frames and forms that will help them record any needed information in the field. They should have a notebook in which they can record a narrative of each day's events.

Step 6: Carrying out the fieldwork

The fieldwork requires strategic planning and administrative help. Salaries, travel arrangements, travel allowances, accommodation, vehicles, materials and equipment must all be organized. Delays can harm the survey and lower morale among team members.

Arrangements for communication with project leaders must be set up and adequate attention paid to the safety of survey teams. If female interviewers must work after dark, in some locales they may need a car and some mode of protection.

Some situations require that notification be given to the local police or other authorities. The National AIDS Programme or Department of Health may be able to help in this regard. Otherwise, a simple letter explaining the purpose of the survey should be carried by the team. Each team member should have in his/her possession some form of identification, preferably with a photo. This should not however, be displayed prominently.

Privacy must be assured and this is not easy in some situations. Persons should not be interviewed within earshot of others. In order to assure privacy, it may be necessary to take the respondent aside. Respondents should not be paid for the interview. However, where the norm has been established for respondents to be paid, there may be little choice but to offer payment. Survey leaders should experiment ahead of time with what is likely to work best for each group at each locale.

In the beginning of the survey, supervisors should meet with their team members daily after the fieldwork in the beginning and, later, every few days to discuss the experience and solve any problem. Problems they cannot

solve should be brought to the project leader's notice promptly. Interview forms should be reviewed repeatedly until no further questions or recording problems emerge. If coding is required, this must be done daily and the completed forms handed in to a person in charge of registering them.

Components to implement

- (a) Arrangements should be made for travel, funds, and needed materials ahead of time. Clipboards are usually necessary; carry bags and other items are required in many situations.
- (b) Identification documents must be arranged for all team members.
- (c) Supervisors should be reminded to record a narrative of each day's events and conditions.
- (d) Letters of explanation to authorities who might be concerned about unknown persons appearing in their territories should be prepared and sent or carried.
- (e) Methods of communication and protection for team members should be arranged.
- (f) Problems must be anticipated when teams reach a specific site and a back-up site to go to, if at all possible, should be given to them. This should be accommodated in the sampling frame.
- (g) One must prepare for the means by which privacy can be assured to respondents.

5.3 Data Analysis

Step 7: Compiling data

The first step in managing the data is the collection of the completed questionnaires. Each day, the supervisor of each team should collect and review the forms and place them in labelled envelopes. Supervisors or specially trained personnel must be given responsibility for coding. The forms should be protected and transferred to the site at which data will be entered into the computers. Depending upon the situation, this can be done daily, weekly or somewhat less often. Supervisors must be made responsible for the safety of the data until it reaches the computer operators.

Data can then be entered in a database programme such as Dbase, Foxpro, Excel, Access or Quattro Pro. EpiInfo, SAS and SPSS have data entry modules or can utilize files from other database programmes. Provisions for data entry and analysis should be part of the original planning. When the questionnaires are completed, the database files can be constructed. If coding is required, it may be best for supervisors to complete it. If very extensive, different persons may be required to do it, but consistency must be assured. A codebook for each sample is required. Data should be entered twice and checked with an appropriate programme, e.g. the Validate module of EpiInfo6. Corrections can then be made and analysis begun.

Most surveys will generate a great deal of data. Adequate personnel should be hired or contracted to complete the work in as short a time as possible. As this will require a bank of computers and persons, it may be most practical to contract the task to a suitable organization.

Supervisors' narratives should be typed and read as soon as possible. All information regarding the sampling should also be entered into the computer.

Components to implement

- (a) Supervisors should check each form in the field and assure consistency and completion. Wherever possible, supervisors might repeat a small proportion of interviews with the same persons to validate responses.
- (b) The forms collected daily from all team members should be listed and placed in envelopes for protection. Nothing should be altered on forms after the original completion. Corrections can be done in red ink.
- (c) Coding should be completed before forms go to data entry. Code lists must be kept and consistency assured. It is conventional to use 99 or 9999 for missing data. Care must be taken to keep true numerical data separate from numbers that represent coded responses.
- (d) Database files can be constructed after questionnaires are finalized, ready for entry as soon as forms are delivered from the field and coded.
- (e) All data must be double-entered and files compared for validation. After final corrections are made, analysis can begin.
- (f) All required typing of reports should be completed.

Step 8: Conducting analysis and confirming results

A plan for data analysis should be prepared as soon as the questionnaires are completed. In fact, ways of analyzing the data are implicit in the ways the questions are asked. If the indicator is the proportion of sex acts with the use of condoms, then the first question in a particular series must ask about the number of these acts, followed by the number of acts with the use of condoms so that the proportion can then be calculated. It is important to keep the denominators in mind, i.e. the number of persons or the number of acts. It is also important to keep the time periods clear. When comparing across samples, for example, if male sex workers were asked about clients in the past week and comparisons are to be made with female sex workers, the same time period must be referred to.

Generally, a single survey does not need complex statistical analysis. Frequencies, a few cross-tabulations, proportions, means and/or medians will be adequate for most uses. Comparison between two or more surveys requires adequate attention to confidence intervals and the sampling frames used. If they can be compared, then tests such as chi-square or a chi-square for trend should be adequate.

The percentage of refusals should be noted for each sample and reported.

One is not expected to confirm all results of the surveys, however, sometimes some strange or doubtful results appear and require investigation. First, all form and data-related problems should be examined. Often coding or data-handling mistakes are responsible and can be corrected. If these are not the cause, then one must go back to the people involved and find out if the results are true or not. First examine the field notes of the supervisors. Were there problems reported for some groups or at certain sites? Sometimes survey in a site may have to be repeated and the previous results discarded. Such a problem should be caught during the fieldwork period.

Sometimes a particular interviewer always gets markedly higher (or lower) results than others for the same group. Such inter-observer error can be examined statistically and if it appears to be serious, all the work of that interviewer may have to be discarded. One cannot selectively throw out just some of the person's work. Again, good supervisors should be picking up these problems during the fieldwork.

If none of these issues is the source of a doubtful result, focus group discussions and key informant interviews should be conducted with the target group. Annex 1 lists several good references on focus group discussions. For our purposes, the following example should be helpful.

Let us say that there was a needle exchange in some of the sites selected for an IDU survey, while other sites did not have such an intervention. The rates of needle/syringe sharing at the needle exchange sites would be lower than those at the sites without needle exchange, but if the same or similar rates were found at both sites, something might be wrong. A focus group discussion could be devised for this situation to examine:

- If there was a spread effect from the needle exchange sites to the others, i.e. people were changing behaviour even without a specific intervention, and
- If people were giving socially acceptable answers because they had learnt that they should be using clean new needles, even though they were not really doing it very often.

A focus group discussion guide for such a meeting might look like the following:

We are here to learn from you about any recent changes in people's behaviour. There are no right or wrong answers and we simply want your opinion as you know a great deal more about these things than we do.

- (1) In the past year have people around here been hearing more about the disease called AIDS?
- (2) What kind of information have you all been hearing?
- (3) Do you think any of your friends have changed their behaviour because of learning about AIDS?
- (4) Have any of you changed your behaviour recently ?

It would not be wise to discuss what practices they might have changed. Let them tell you. Do not mention your findings or you will be giving them the answers they think you want to hear.

A few focus group discussions held at 3-4 sites without needle exchanges and one or two at needle exchange sites could then be followed with 2-3 key informant interviews. A key informant would be a person with very special

knowledge of the situation, one who is there frequently and has personal experience with the sites and people involved. Such persons should be interviewed completely privately and out of earshot of anyone else. They must be assured that their names are not being recorded and that their statements are completely confidential. They can be asked the same questions as those in the focus group discussions. Then, after hearing their responses, one can tell them what was said at the focus groups. Do they think this is the true picture of the situation? If they do, and if almost everyone gives a similar set of responses, you have your answer. If they do not think you have been told the truth, ask them why people would be giving false answers. There may be very good reasons, e.g. someone has threatened them that they will not get something (their drugs, new needles, an intervention) if they reveal the truth - or they simply feared that this might happen. People often have unrealistic fears of the repercussions of their behaviour. If your interviewers said they were from the government, sex workers and IDUs might fear that they will be blamed for the epidemic if they reveal how much risk they are placing themselves and others at. They may fear that they will be arrested.

You can see from this example that it is VERY IMPORTANT to train the interviewers on all of these issues.

If you find that there are false results, do not be afraid to report them and that they were false. Explain how you tracked down the problem and what caused it. This will allow for correction next time.

Components to implement

- (a) After data are cleaned, frequencies should be calculated. Outliers (very unusual responses, e.g. a man with 4,000 partners last month) should be discarded after careful examination as should any nonsensical responses (e.g. four sex acts with no partners the previous day).
- (b) Measures of central tendency (means and standard deviations, medians) should be calculated for all numerical data (numbers of partners, etc.). Medians are needed for variables with high variation, e.g. age or income. Proportions that are important as indicators should then be calculated. If calculating the sample weights per site reveals a three-fold difference or more between the lowest and the highest weights, standardization may be required. Simply add another variable to each record and add the standard weight for that site. Most statistical packages can adjust any statistics accordingly.

- (c) Other data that are not part of indicators can then be examined, sometimes as cross-tabulations against the indicators. It is possible to re-group some into quartiles or other reasonable quantities for the cross-tabulations. Usually complex inferential statistics are not required or even statistically justified, unless care is taken to control for primary factors, such as age, education or other variables that could confound whatever is being examined.
- (d) For repeated surveys, groups that have follow-up data should be examined for sample size and method comparability. Proper modes of comparison must be selected and used. Be very cautious about reporting as significant any resulting difference between surveys that are not at a significance level of $P < .01$ or even greater. If a difference is tested and found to be significant at $P < .05$ and design effects were not calculated into the analysis, the resulting interpretation could be false. Simply stick to $P < .01$ and you need not worry about design effects.
- (e) Strange or doubtful results must be investigated.
- (f) After assembling all information on sampling, as well as the narrative reports, a description of the sampling strategy, the locations [without their actual names if the activities are illegal] and settings should be written up. These should be checked by supervisors for accuracy.

5.4 Data Dissemination and Use

Step 9: Presenting results

Be prepared to 'sell' your results. For most users, simple tables or graphs are adequate to present the findings. One should not pack too much information into one figure. The sampling must be described well so that future surveys can be made comparable. Results may be written up differently for different audiences. For national policy-makers and programme managers, the key findings should be highlighted in attractive presentation materials, for oral as well as written presentations. An executive summary, explaining methods and findings in a tabular form may be most useful for wide dissemination. For scientific audiences, a lengthier document with greater detail can be written.

Components to implement

- (a) A series of 5-8 slides (overheads) should be constructed with the most important indicators shown graphically.
- (b) Tables should be constructed for the written documents as well.
- (c) A summarized version of the methods and findings should be written for wide dissemination. Depending on the setting, dissemination may be a major event or small one. The results should reach those who can act on them quickly in as comprehensible a form as possible. This includes the participants, i.e. the groups interviewed. Whenever possible, results should be fed back to them through the organizations associated with them.
- (d) A more detailed scientific presentation can be written for publication. While the most immediate consumers of the behavioural data are programme managers and participants, documentation of scientific literature on HIV/AIDS is important and has a valuable role to play in the management of the pandemic.

Annex 1

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An example of an ongoing national survey

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- (23) MACRO International Inc. Contact: Project Director, M. Vaessen, 111785 Beltsville Drive, Calverton, MD 20705, USA: fax:1-301-572-0999; email: vaessen@macroint.com

Countries that have used the AIDS module of DHS are listed on the website: <http://www.macroint.com/dhs>.

Annex 2

SAMPLE SIZE AND THE 95% CONFIDENCE INTERVAL

The following table is taken from *The Social Organization of Sexuality: Sexual Practices in the United States*, by Laumann E Gagnon J, Michael R and Michaels S. University of Chicago Press, 1994, p.48. It is a very useful table for non-statisticians because it shows clearly what happens when sample sizes change in relation to various proportions of an indicator found in the population. It is relevant only to the 95% confidence intervals as these are the most conventional and expected in scientific literature. The confidence interval is based on the fact that, if you repeated your sampling many times from the same population, you would get slightly different results each time, but these results would be distributed normally (a normal or Gaussian distribution). The table shows the width of a 5% variation on either side (plus or minus) of a given proportion at various sample sizes, e.g. if the proportion of sex workers using a condom with the last client was 20% and your sample size was 400, then you could report the finding as 20%, CI= 16.1%-23.9%. [Calculated as $.20 - .039$ and $.20 + .039$]. This means that we can be certain that 95% of the time repeated samples would fall between 16.1% and 23.9%. This applies to proportions only; for means, use standard deviations to express the variance in the population.

Table. Width of one side of a 95% confidence interval for the estimate of a proportion

Sample Size	Population Proportion					
	.50	.30	.20	.10	.05	.01
25	.196	.180	.157	.118	.085	.039
100	.098	.090	.078	.059	.043	.020
200	.069	.064	.055	.042	.030	.014
400	.049	.045	.039	.029	.021	.010
800	.035	.032	.028	.021	.015	.007
1000	.031	.028	.025	.019	.014	.006
1500	.025	.023	.020	.015	.011	.005
2000	.022	.020	.018	.013	.010	.004
3000	.018	.016	.014	.011	.008	.004
5000	.014	.013	.011	.008	.006	.003

Annex 3

EXAMPLES OF TYPES OF SAMPLING

Systematic random sampling

In a situation where people stream through a portal, one has to prepare by counting how many come through on several occasions and average the amount. For example, at the gate into a particular international port area, an average of 2500 long-distance truck drivers register daily. If a sample of 400 is needed, then one should simply pick a random number to start and then follow with every sixth person ($2,500/400=6.25$), until one reaches 400.

Proportional random sampling

There are four brothels in town. In order to sample them as a whole, it is necessary to go to each and conduct simple mapping and counting. The following results are obtained: A=620, B=220, C=880, D=300, for a total of 2,020 women. First the proportions of the total each brothel represent is figured out. Brothel A: $620/2,020=0.307$, or brothel A=31% of the total. A sample size of 400 is needed. 31% of 400=123. Continuing with each brothel, figuring out what proportion of the total each represents and then transferring that to what proportion of 400 each will have to supply to the sample, one obtains the figures: A=123, B=44, C=174, D=59. Of course, when one gets there, a random starting number is picked and then every nth room is visited (depending how many we need at each brothel) for an interview. At brothel A, it would be every fifth woman.

But in some rooms there is more than one woman, so one needs a way to figure out which one to take. This is also easy, because on the top of each questionnaire a simple device called a Kish table (Kish, 1965) can be printed. Each of the questionnaires is numbered and one takes the last digit in the questionnaire serial number and finds it across the top of the table, while looking at the right hand column showing the total number of women in the room. If the questionnaire is number 305, and there are three women in the room, one would need to interview woman number 2. Which one is she? One has to mentally order and label the women upon arrival, by height or by age or some consistent characteristic.

Total women in room	Last digit of questionnaire #									
	1	2	3	4	5	6	7	8	9	0
1	1	1	1	1	1	1	1	1	1	1
2	2	1	2	1	2	1	2	1	2	1
3	1	2	3	1	2	3	1	2	3	1
4	1	2	3	4	1	2	3	4	1	2
5	4	5	1	2	3	4	5	1	2	3

If one gets refusals, one goes on with the sampling frame as planned, i.e. the next fifth room. One should not replace refusals as one does not know why they are refusing and one might introduce a bias, particularly if one has a lot of refusals. If one finds the woman is not at home, then one can take the next room as replacement, continuing on with the original sampling units (every fifth one) after that.

PPS

Suppose one maps a city and finds 78 spots where drug users can be found injecting. The mapping team made an estimate of how many men will be there each day and found considerable variation. Some have 100 men and others only 20. Because these are residences where professional injectors perform the service of injecting, the situation is a stable one. Each day at spot A, there are 35 men coming for injections between 9 and 12 am. In the afternoon, somewhat fewer men come, and they are the same as those who came in the morning. One does not want to return twice because there will be too many duplicates. One estimates that the team can get 18 interviews at each site (three interviewers, working three hours with a half-hour interview). If one needs 400 interviews, then one must go to 22 sites. One needs a way to select the sites so that larger ones have a greater chance of being selected, i.e. their probability of being selected is proportional to their size. The way to do that is to calculate a sampling interval. One adds up the total number of men one can expect to find at all 78 sites. Say that it is 2,300. One divides 2,300 by 22, and gets 104.5-this is the sampling interval. The sites and their available men are listed as:

Site#	Available men
1	35
2	89
3	66

4	70
5	85
6	120
7	20
8	48

One then sums each cumulatively, as follows:

Site #	Available men	Cumulative	Selected or not
1	35	35	S
2	89	124	
3	66	190	S
4	70	260	S
5	85	345	
6	120	465	S,S
7	20	485	S
8	48	533	

Picking a random start number between 1 and 104.5 (our sampling interval; please keep the decimal in the calculation), e.g. 32, one starts there and selects the site in which 32 is located, site #1. Then one adds 104.5 to 32, and gets 136.5. This number falls within the range for site #3. (it is over 124, the upper limit for site #2.) Next one adds 104.5 again to 136.5 and gets 241. One selects site #4. Continuing: $241 + 104.5 = 345.5$ and $345.5 + 104.5 = 450$. Site # 6 was selected twice, as expected, because it is much larger than the others. Continuing, one adds $450 + 104.5 = 554.5$, and so on until one finishes. One will have 22 selections as planned and the larger sites will be selected more often than the smaller ones. One can return to those sites selected twice and get 18 interviews each time.

As in all sampling, one must be careful to avoid getting duplicates, i.e. interviews with the same person twice. One must have the supervisors watch who is being interviewed and train the interviewers to ask first if the person has already been interviewed by someone within the past few days (or weeks, as appropriate). Obviously, the sooner one completes the survey, the less likely one will have problems with duplicates.

Time-location sampling

The mapping showed 54 sites around the city where sex workers could be found out on the streets. At two of them, there was a significant difference by day of week, with more women out on Fridays. At six of them there were women available during the day (between 12 and 4 pm) as well as at night between 7 and 11 pm. [NOTE: The time periods MUST be kept equal.] In total, one then can list 62 different possible time-location units. These are labelled on the maps by number. The rough estimates of the number of women at each time-location unit average to 20, although the range is between 5 and 80. If one needs a sample of 400, then one needs 20 sites, out of the 62 possibilities. But because one knows the situation is unstable, one will expand the number to 25, to be safe. Using a random number list (EpiInfo and many other computer programs can generate these), one selects the time-location units accordingly and one sends the team of four women plus supervisor to each site selected for a set duration of time (4 hours).

At this point there are two options:

Option 1: The take-all option

The interviewers can be instructed to try a *take-all* approach (without duplications). They will only go to each site once and get everyone they can in the time period, i.e. 4 hours-no more or less. This is a gamble as one can never know how many sex workers will actually be there, but any that *are* present have an equal chance of being interviewed, which keeps the sampling self-weighted. One might end up with more than 400; if one completes the set of selected sites and have less than 400, one can simply generate another set of sites from those previously not selected.

One problem with this type of sampling is that, if any site is likely to have 40 or more persons available within the time interval, a small team may not be able to interview them all. The team may have to be expanded for those sites. It is NOT a good idea to do the mapping far ahead of the actual survey as the situation might change too much in the interim.

Another problem is related to the type of group. If these are sailors, for example, they might be quite busy and want to wait until another time. If they are sex workers, they would probably want to leave with a client if one becomes available and the team would lose the interview. If they are injecting

drugs, many would want to leave after they inject and before the team could interview them all. Sometimes, offering a cup of tea or drink while they wait makes a real difference in capture rates.

In any event, the supervisor MUST keep a record of all sex workers seen during that time period. If necessary, standardized weighting can then be done during analysis.

Option 2: Fixed number of interviews

Alternatively, one can fix a set number of interviews to be achieved at each site. It is very important that the number of available persons from the target group at each site is identified correctly and recorded for the exact time period (e.g. 4 hours). If the number of possible persons available is small at many sites, then one would have to set a low fixed number of interviews, e.g. 6, which may require selecting a much larger number of sites. This, however, may be preferable if one has enough interviewers and can send just one or two to each site. This option is reasonable if the numbers of persons available at these sites are similar. If there are very large differences, standardized weighting may be required.

Checking for self-weighting:

The idea behind these time-location approaches to sampling is that each individual will have an equal chance of being selected at the site, i.e. the sample is self-weighted. In order to check if this assumption is being violated, one must calculate the weights for each site using a simple formula and the information gathered in the field. Example:

- The number of sites originally mapped was 52 and the number selected was 32. $32/52 = 0.615$. This may be called "a"
- Site 1 had 20 persons available for the interviews, but the team only got 14. $14/20=0.7$ may be called "b". "a" and "b" may be multiplied: **a x b**, or 0.43. The sample weight = $1/ab$ or 2.32.

This may be done for each site. It is very easily done in all database and spreadsheet programs by formula. The minimum and maximum weights should be examined. If the difference is less than three-fold, self-weighting was not violated.

If it was violated, then the weights must be standardized and that figure added to each record. Note: the standardized weights for each site will be different and must be applied to the records for each individual interviewed at that site. When analysis is carried out in SPSS or almost any other statistical package, the option to do a weighted analysis may be selected and the weight added into the analysis as a variable.

To standardize weights

All the weights be calculated as before. Each one should be multiplied the number of times the interviews were actually done at the site. For Site 1, this would be 2.32×14 , or 32.48. This may be called **a**. All of these should be added up for all sites. Say the total comes to 1322. This may be called **b**. Then, for each site **a** should be divided by **b**. For example at Site 1, the result would be $32.48/1322$, or 0.0246. That is the standardized weight. On all the records for people interviewed at Site 1 a new variable has to be put in the database file and the number 0.0246 entered.

Annex 4

RECOMMENDED INDICATORS

*[It is not necessary to include all of the following indicators in any one group. Many measure the same thing in different ways. The most suitable indicator for the target group may be selected and the same ones used in repeated surveys. One can always add another, but the previous ones should not be removed. Some that are especially useful or commonly used around the world are marked with an *]*

For injecting drug users

- * Proportion of IDUs not sharing even one needle/syringe in past week and/or month;
- * Proportion of IDUs using needle/syringe and then giving (lending, etc) to others within the last week and/or month;
- * Proportion of IDUs using needle/syringe previously used by some one else within the last week and/or month;
- * Proportion of needle/syringes used in the last week and/or month previously used by someone else, and
- * Proportion of needle/syringes cleaned with bleach (or boiling) in last week and/or month.

Less common but useful indicators

- Proportion of injections in the last week and/or month received from professional injector;
- Proportion of injections in the last week and/or month in which front or back loading was employed;
- Proportion of IDUs selling sex for drugs within the last week and/or month, and
- Proportion of IDUs reporting abscesses within the last month and/or year.

All sex-related risk questions that apply to clients of sex workers also apply to IDUs.

For sex workers (male, female or transgender)

- Average number of clients the previous day and/or the last week ;
- Average number of days worked as sex worker the last week;
- Proportion of sex workers using condom with the last client;
- Proportion of the previous day's (penetrative) sex acts covered by condoms;
- Proportion of sex workers using condoms for all commercial sex acts (penetrative) the previous day (or last week);
- Proportion of sex workers using condom the last time with main partner;
- Proportion of sex workers using condom the last time with non-paying partner (if different from main partner);
- Proportion of sex workers using condoms for all sex acts (penetrative) with non-paying partners (or main partner) the last week or the last month;
- Proportion of sex workers seeking STD treatment the last time with trained providers;
- Proportion of sex workers seeking STD treatment the last time with traditional practitioners, and
- Average number of days between the recognition of STD symptoms and seeking treatment the last time.

Less common but useful indicators

- Proportion of sex workers currently injecting drugs;
- Proportion of sex workers reporting broken condoms in last month;
- Proportion of sex workers reporting participation in HIV intervention programme;
- Proportion of bonded sex workers in brothel;
- Median age of sex workers;
- Proportion of sex workers reporting violence against them, and
- Proportion of sex workers having anal sex and/or group sex in the last week.

For MSM

- Average number of different sex partners in the last month and/or last year;
- Proportion of anal intercourse among all sex acts during the last week and/or month;
- Proportion of men having any anal intercourse without condoms in last week and/or month;
- Proportion of all sex acts (penetrative) in the last week (or month) covered by condoms;
- Proportion of all sex acts (penetrative) with casual or commercial partners in the last week (or month) covered by condoms;
- Proportion of all sex acts (penetrative) with main partner in the last week (or month) covered by condoms;
- Proportion of men using condoms for all sex acts (penetrative) the last week and/or the last month);
- Proportion of men using condom the last time with commercial (casual, or main partner);
- Proportion of men with urethral discharge in the last year;
- Proportion of men seeking STD treatment the last time with trained providers;
- Proportion of men seeking STD treatment the last time with traditional practitioners, and
- Average number of days between the recognition of STD symptoms and seeking treatment the last time.

Less common but useful indicators

- Proportion of MSM currently injecting drugs;
- Proportion of MSM having sex with a female in the last month and/or year;
- Proportion of men selling sex to men in the last month;

- Proportion of MSM participating in HIV prevention intervention;
- Proportion of MSM reporting broken condoms in the last month, and
- Proportion of sample reporting anal discharge (pus) or pus with blood currently or within the past year;

For presumed clients of sex workers

- Proportion of sample having any commercial sex within the last month and/or year;
- Average number of different commercial partners within the last month/and or year;
- Proportion using condoms for all commercial sex in the last month and/or year;
- Proportion of sex acts (penetrative) with commercial partners covered by condoms in the last month and/or year;
- Proportion of group having sex with casual, non-commercial partners within the last month and/or year;
- Average number of non-commercial or casual partners within the last month and/or year;
- Proportion using condoms the last time with casual, non-commercial or main partner (should separate these partner types)
- Proportion purchasing sex from male or transgender sex workers in last year;
- Proportion of men with urethral discharge in the last year;
- Proportion of men seeking STD treatment the last time with trained providers;
- Proportion of men seeking STD treatment the last time with traditional practitioners, and
- Average number of days between the recognition of STD symptoms and seeking treatment the last time.

For the general population

[Usually, non-regular implies extramarital; among single persons, it might refer to any sex partners, depending upon local norms]

- Median age at first intercourse (or proportion having intercourse before age 18);
- Median age at marriage;
- Proportion reporting having any non-regular partners within the last year;
- Average number of non-regular partners in the last year;
- Proportion using condom with non-regular partner the last time;
- Proportion of men purchasing sex within the last year;
- Proportion of women exchanging sex for cash;
- Proportion of women exchanging sex for goods, protection or other services within the past year, and
- Proportion of men reporting urethral discharge within the past year;

Annex 5

SAMPLE SECTIONS OF QUESTIONNAIRES

An example of a possible introduction

I am working with [x agency] and the Ministry of Health, [x country]. We are trying to find out how we can help people avoid getting the sickness called AIDS. We need to ask you some very personal questions. Nothing you tell me will be used for anything but the purposes of this survey. Your name or address will never be written down. You can refuse without any problem and you can stop the interview at any time after we start. What you tell me will be kept strictly confidential. Because we sincerely want to help all the people of [x country] avoid AIDS, if you agree to giving the interview, it is really important that you are willing to be very truthful. Is it alright to begin?

An example of a set of questions for the socio-demographic background:

For street sex workers:

1. Age _____
2. Location code _____
3. Are you sleeping on the streets? Y _____ N _____
4. Years completed education _____
5. How long have you been in sex work?
Years _____
Months _____
(only if less than 1 yr)
6. How long have you been working on
this city's streets?
Years ____ Months ____
(only if less than 1 yr)
7. Bonded (all income taken) Y _____ N _____
8. Marital status:
Single ____ Married ____
Separated ____ Divorced ____
Widowed ____
Living with partner _____

9. No of children living with you? _____

10. No of children living elsewhere _____

For IDUs:

1. Age _____

2. Location code _____

3. Living on streets? Y_____ N_____

4. Completed years of education _____

5. Main source of income in last six months Rickshaw_____ Selling _____
Salary _____ Other_____

- Monthly income _____

- Marital status Single_____ Married_____
Separated___ Divorced_____
Widowed_____
Living with partner _____

An example of a set of questions for risk-taking behaviours:

For street sex workers:

We will now talk about the past seven days .

1. In the past seven days, how many days did you NOT have clients?

2. In the past seven days, how many different clients did you have? _____ (count all in groups)

3. What was the total number of bouts of sex? vaginal_____ anal_____
oral (on man to climax)____
non-penetrative,
to climax_____

4. In the past seven days, how many times were you able to use condoms for these bouts of sex? vaginal_____ anal_____
oral (on man to climax)____

5. In the past seven days, did you ask any of your clients to use condoms? all____ some____ none____

6. With how many of these men did you actually use condoms ? _____

Now let's talk about regular clients.

7. In the past seven days, how many *regular* clients did you have? _____

8. Did you ask any of these men to use condoms? all____ some____ none____

9. With how many of these men were you able to use condoms ? _____

Now let's talk about yesterday.

10. Yesterday how many clients did you have? _____

11. Yesterday how much money did you make? _____

12. With the last client, how many bouts of sex? Used condoms for all__
some____
none____

13. How many of your last five clients were drinking alcohol? ____
taking drugs ____

14. How many times did a group of men hire you together- in the past seven days____ past
month____

15. The last time, how many men were there? _____
How many used condoms? _____ -

Now we will talk about husbands, boyfriends, or lovers (non-paying partners).

16. Do you have a current steady main partner or husband? Y____ N____

17. Does your main partner (or husband) have another wife? Y___ N____
18. Does he sometimes have other women too? Y___ N___
don't know___
19. Has he ever injected drugs? Y___ N ___
don't know___
20. (If yes), Is he currently injecting? Y____ N ___
21. In the past seven days, how many non-paying partners did you have sex with? _____
22. How many times did you have intercourse with these men ? vaginal____ anal___ oral to climax___
non-penetrative to climax_____
23. In the past seven days, did you ask any of these personal partners to use condoms? all ___some___ none___
24. How many of these times were you able to use condoms ? vaginal___ anal____ oral_____
25. Do you have condoms with you now? Y____ N _____
Seen by interviewer? Y___ N _____
26. Have you ever injected drugs? Y___ N _____
27. [If yes], Are you currently injecting? Y___ N _____
28. Have you ever had a condom break? Y___ N _____
[If yes], How many in the past month? _____

For IDUs, About injecting:

1. How long have you been using any kind of drugs? years ___
months____
(If less than 1 yr)
2. How long have you been injecting drugs? years____
months____
(If less than 1 yr)

3. Which drug are you injecting most of the time? Tidijesic____ Pethidine____
Heroin____ Other____
4. How many times did you inject in the past seven days ? _____
past month?_____
5. Of these times, how many were performed by a professional injector in the past seven days? _____
in past month?_____
6. How many of the last seven days' injections were: intravenous _____
intramuscular?_____
7. How many times did you use a needle/syringe after someone else used it in: past seven days _____
past month?_____
8. How many times did you pass on a new needle/syringe you just used to someone else in: past seven days _____
past month?_____
9. How many of your injections were cocktails in: past seven days _____
past month?_____
10. How many times did you boot the injection in: past seven days _____
past month?_____
11. How many times were the injections front (or back) loaded in: past seven days _____
past month?_____
12. The last time you injected with others, how many people shared the same needle/syringe? _____
past month?_____
13. The last time you injected with others, did you clean the needle/syringe between people? Y__ N __
14. How cleaned? water_____ cloth_____
leaves_____ blow_____
suck_____ other_____

15. Have you had any abscesses on your skin in the past year? past month? Y___ N___
Y___ N___

About sex:

16. How many times have you purchased sex from a sex worker in the past month? _____ year_____
17. (If any) In the past month, how many were: female___ male____
transgender [use local term] ____
18. (If any) In past year, how many were female___ male____
transgender [use local term] ____
19. (If any) The last time you purchased sex from any sex worker, did you use a condom? Y___ N___
20. How often have you sold blood for money in the past month? _____
past year_____
21. Have you sold sex for money or drugs in the past month?_____
past year?_____
22. How many different partners have you had who you did not pay (girlfriend, wife, lover) in past month?____
past year?_____
23. In last month, how many of these partners were female___ male____
transgender [use local term] ____
- In last year? female___ male____
transgender [use local term] ____
24. (If married) Was one of these females your wife? Y____ N____
25. (If married) Do you use condoms with your wife? always___sometimes___ never_____
26. The last time you had sex with a non-paid partner, did you use a condom? Y____ N____
27. Do you have condoms with you now? Y____ N____
Seen by interviewer?4 Y____ N____

