Guidelines for Upgrading of HIV/AIDS/STI Surveillance in the Caribbean

The Third Generation Surveillance of HIV/AIDS/STI Linking HIV, AIDS and Case-Reporting, Behavioural and Care Surveillance

CARIBBEAN EPIDEMIOLOGY CENTRE (CAREC)/PAHO/WHO
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## CONTENTS

Acknowledgement iv  
Preface v  
Introduction vii  

The Need for Change: A Third Generation of HIV/AIDS/STI Surveillance 1  
A Third Generation of HIV/AIDS/STI Surveillance 7  
HIV/AIDS/STI Care and Quality of Surveillance 35  
Laboratory support for HIV/AIDS/STI Surveillance 39  
Sexual Behavioural Surveillance 45  
Ethical Issues and Human Rights Principles for HIV/AIDS Epidemiology 99  
Conclusion 105  
Annexes 107  
List of Abbreviations 111  
References 113
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Dr Carl James Hospedales, Director, CAREC

For your guidance and input into the different concepts used to develop these Third Generation HIV/AIDS/STI Surveillance Guidelines. Today, your visionary approach to public health has helped regional policy decision-makers to conceptualise care as part of prevention. Because of this vision, there is a better understanding that prevention of any health condition or control of any epidemic begins by caring for the individuals who have that condition and HIV/AIDS is no exception to this rule.
PREFACE

The Third Generation HIV/AIDS Surveillance Guidelines are the product of a collaborative effort between the “CAREC HIV/AIDS/STI Surveillance Cluster”, interested groups, and regional and international experts, including:

- National Epidemiologists
- National Laboratory Directors
- Social and Behavioural Scientists
- Clinicians (Infectious Disease Specialists, Dermatologists, Paediatricians, Obstetrician-Gynecologists, Internists and Specialists in management of HIV disease)
- National AIDS Programme Managers
- Representatives of People Living with HIV/AIDS (PLWH)
- Regional and International experts from the Canadian Public Health Association (CPHA), Health Canada, McGill University, U.S. Centers for Disease Control and Prevention (CDC), and the University of the West Indies (UWI).

At the beginning of the AIDS epidemic, CAREC promoted the use of the First Generation HIV/AIDS surveillance guidelines. They were focussed on the reporting of AIDS cases and implementation of periodic and regular HIV seroprevalence surveys among different population subsets. However, after 10 years of their implementation, serious shortcomings were identified, thus creating the need for the development of the Second Generation HIV/AIDS surveillance guidelines.

These guidelines added three essential elements to the first generation HIV/AIDS surveillance:

- reporting of HIV cases,
- classification of countries based on the level of the HIV epidemic to be used as a guide for the nature of the national response to the epidemic and
- behavioural surveillance surveys (BSS) to improve monitoring of behaviours which put individuals at risk of contracting HIV.

But, since the HIV epidemic is a rapidly evolving epidemic one, gaps were identified in the Second Generation HIV/AIDS surveillance guidelines as well. These gaps are being addressed in the Third Generation HIV/AIDS/STI surveillance guidelines.

A dilemma in the Second Generation HIV/AIDS surveillance guidelines is that the HIV epidemic in any given country can be classified based on the HIV seroprevalence rate among general population or high-risk population groups, but the national response should be adapted according to the level of the epidemic (low, concentrated or generalised). In a general context of health sector reform and decentralisation of health services and programmes, effective local responses to the HIV/AIDS epidemic are more appropriate. It is therefore important to take into account the strong possibility that the same country can harbor all three levels of the epidemic (geographic disparities). A low-level epidemic may exist in parts of a country, a concentrated epidemic in some parts and a generalised epidemic in other parts of that same country. Good examples of this scenario are the multilevel HIV/AIDS epidemics which are unfolding in Jamaica and in Trinidad and Tobago.

Thus, as intended in these guidelines, a surveillance system oriented towards local answers depending on the level of the local epidemic is the recommended approach. Therefore, the national response to the HIV/AIDS epidemic should be a mix of strategies designed and implemented according to the stage of the local HIV/AIDS epidemics.

Beyond the key components included in the Second Generation HIV/AIDS surveillance, these new guidelines put emphasis on implementation of an enhanced STI surveillance system and the audit of quality of care for people living with HIV/AIDS and STI patients. This will allow for the routine measurement of some key indicators for monitoring and evaluating national responses to the HIV/AIDS epidemic. These Guidelines promote:

- use of other sources of information e.g. Central Statistical Offices or Vital Statistics Offices
- a team approach to surveillance
- participatory approaches with community involvement and
• action-oriented approaches to demonstrate the usefulness of surveillance systems. They also require the collection of information to allow a better understanding of the sectoral impact of the HIV/AIDS epidemic.

Another important feature is that the Third Generation HIV/AIDS/STI Surveillance Guidelines (TGS) are intended to achieve comparability between Caribbean countries. Therefore, they are focussed on essential vulnerable groups which play a key role in the regional epidemic: Young People, Women, Men who have Sex with Men (MSM), People Living with HIV/AIDS (PLWHA) and Female Sex Workers (FSW). However, because of the evolving nature of the HIV epidemic, provision is made for flexibility in surveillance systems which will derive from these guidelines, and also for the inclusion of other population groups which in some specific countries may play an important role in the spread of the HIV epidemic or represent the general population and easy to reach groups such as STI patients, Intra Venous Drug Users, Tuberculosis patients and Blood Donors. In some instances, some of these groups may be too small to allow collection of a sufficient sample size to allow accurate trends assessment.

To summarise: through these guidelines, CAREC is making available to national epidemiologists, public health managers, and national decision-makers a tool which blends epidemiology with behavioural surveillance and audits of quality of care for PLWHA and STI patients. The intention is to allow for comparability between countries through targetting the same vulnerable groups among which comprehensive data is collected over time or on a continuous basis. This in turn leads to action at the local, national and regional levels and HIV/AIDS trends assessment in the Caribbean. This data collection should take place with the full participation of the vulnerable groups and under strict respect for their human rights.
INTRODUCTION

The Caribbean Epidemiology Centre (CAREC), the Caribbean’s disease monitoring agency, has the mandate to strengthen the national response to the HIV/AIDS epidemic in its 21 English and Dutch Speaking member countries with a population estimated at 6.5 million. One key component of CAREC’s regional strategy for prevention and control of the HIV/AIDS epidemic is to improve member countries’ information and surveillance systems to generate reliable data on HIV/AIDS/STI to guide decision-making, planning, implementation and evaluation.

To meet that need, CAREC developed these guidelines after numerous regional and international consultations on a new regional HIV/AIDS/STI surveillance framework. This framework will guide national epidemiologists and decision-makers to build sensitive, accurate and timely HIV/AIDS/STI surveillance systems to provide information and the opportunity to:

- better understand and monitor sexual behaviours and practices driving the HIV/AIDS epidemic in a country or within a country
- better assess HIV/AIDS/STI trends over time, direct public health actions to target vulnerable groups, and the most prevalent risk behaviours
- measure coverage and quality of care for people living with HIV/AIDS and STI patients, and
- assess the impact of HIV/AIDS prevention and control programmes

After 20 years of the HIV/AIDS epidemic in the Caribbean, some valuable conclusions could be brought to the attention of regional decision-makers about its evolution. The epidemic started as a homo-bisexual one. But, since 1985, that early pattern shifted to become a heterosexual epidemic. Nevertheless, homo/bisexual transmission continues and is well connected to the heterosexual epidemic in an environment where homosexuality is not socially accepted. From epidemiological and behavioural data, it is established that there is a multistage evolution with different geographic distributions of the HIV/AIDS epidemic both within and between CAREC Member Countries. For example, the HIV seroprevalence rate doubles the national average rate in some urban areas. Countries known as tourist destinations and those with mining industries have high HIV seroprevalence rates and a more matured epidemic compared to countries which do not have these kinds of economic activities. Therefore, to describe the HIV epidemic in any given country, surveillance systems should collect information from different sources, different vulnerable groups, different age groups and different geographic areas to satisfy needs for planning and selection of prevention and control strategies to be implemented at the national level.

In these guidelines, CAREC has taken into consideration international surveillance guidelines as well as the in-country multistage evolution of the epidemic and recommends an innovative but simplified approach to the gathering of essential information to cater for individual country needs. This process should take place in an environment where individual rights are respected, which is a prerequisite to the collection of accurate information to feed the HIV/AIDS/STI surveillance systems.

Considering its mandate under the Caribbean Cooperation in Health (CCH2) initiative, CAREC has put emphasis on care for people living with HIV/AIDS including reduction of mother-to-child transmission of HIV. Key information related to these two important areas should be collected, analysed and disseminated as part of national HIV/AIDS/STI surveillance systems. Similarly, the syndromic management of STI is recognised as an important pillar for the regional strategy to prevent and control the HIV/AIDS epidemic. Therefore syndromic reporting is being prioritised in these guidelines.

A Guide on advocacy for HIV/AIDS/STI surveillance is available to promote the involvement and support of decision-makers for HIV/AIDS surveillance as well as the importance of the use of data for planning and resource allocation on priority problems. Guidelines are available to evaluate HIV/AIDS/STI Surveillance Systems which will use the Third Generation Surveillance Guidelines as national standards for surveillance.
The Third Generation Surveillance of HIV/AIDS/STI puts emphasis on survey methodologies and minimum data requirements from each of its four components:

1. Epidemiological (HIV, AIDS and STI case reporting, AIDS mortality data using death certificates, periodic STI and HIV seroprevalence surveys among different population subgroups, HIV molecular epidemiology and STI and HIV antimicrobial resistance surveys)

2. Behavioural surveillance (periodic sexual behavioural surveys among subgroups using quantitative and qualitative methods)

3. Audit of coverage and quality of care for people living with HIV/AIDS and STI patients

4. Evaluation of specific prevention and control programmes e.g. prevention of mother-to-child transmission of HIV

This will result in a regional tracking system which allows comparability of the dynamics of the HIV epidemic between countries and within countries through the use of uniform, well-established, evidence based and adequate surveillance methodologies.
This chapter will discuss limitations of the current surveillance system in terms of HIV/AIDS/STI surveillance and new orientations of the Caribbean Cooperation in Health (phase II) which have created new demands for regional and national surveillance systems. These two elements justify the need for a new HIV/AIDS/STI surveillance system which goes beyond case-reporting and behavioural surveillance by being specific to the multistage evolution of the HIV/AIDS epidemic between regions, countries and within countries themselves. This new surveillance system will be very specific to tracking the HIV/AIDS epidemic in the CAREC Member Countries (CMCs) with emphasis at all levels, regional, country and local.

Current AIDS Surveillance Systems

Current HIV/AIDS/STI surveillance systems are heavily based on case reporting of AIDS and STI and a few HIV serosurveys initiated by CAREC to determine HIV point prevalence among pregnant women.

The AIDS surveillance systems have been able to demonstrate that in the Caribbean, from its start to the present the AIDS epidemic evolved into different but interdependent homo/bi and heterosexual sub-epidemics which are shaped by country-specific social, cultural and economic determinants. The HIV epidemic started in the Caribbean in the 1970s. The first AIDS case in the English Speaking Caribbean was reported in Jamaica in 1982, one year after the first case in the world was identified in the United States of America. In 1983, eight cases were reported from Trinidad and Tobago, all of which were gay or bisexual men. But, by 1985, female and paediatric AIDS cases represented 28% of the total cases reported to the Caribbean Epidemiology Centre (CAREC) by its member countries. This shift occurred very quickly, clearly indicating that AIDS had become a general population issue and no longer a disease solely of gay or bisexual men. By the end of 1989, 2,043 cases were reported and every single CAREC member country had reported at least one AIDS case. By the end of 1999, 19 CAREC member countries had reported 17,016 AIDS cases while 2,590 cases were reported for the year 1999 alone (Graph 1). Given the trend over the past few years and although the data for the year 2000 is not completed, it can be predicted that by the end of the year 2000 about 30,000 cases will have been reported.

This situation is the result of sexual patterns prevailing in the Caribbean:

- **socio-cultural** (early sexual initiation, multiple sex partnership and frequent sexual contacts, machismo and male dominance during the sexual act associated with his tendency to social marginalisation),

- **legal and religious taboos** (repression of same sex preference, low appreciation of condom use and prohibition of commercial sex work),

- these patterns are exacerbated by the existence of a very high internal and external migration rate.
Functioning of the Actual AIDS Surveillance Systems

Member countries report AIDS cases quarterly to CAREC. In each country each new AIDS case, according to the CAREC case definition, is reported to the National Epidemiologist or, in some instances, to the National AIDS Programme Coordinator. The reporting form usually includes information on name (or ID code), age, gender, address, marital status, socio-economic status, reported mode of transmission, date of HIV diagnosis, date of AIDS diagnosis. Sexual behaviour (number of partners, use of condoms, contact with sex workers, sexual orientation) and clinical information (major and minor signs, indicator disease) are also included. In most cases, the same form is used to report HIV diagnosis and AIDS cases. Limited information is available on who fills out the forms, where and when.

From the individual reports, the Epidemiology Units or National AIDS Programmes report to CAREC using a quarterly reporting form gathering information on gender, age groups and reported mode of transmission. Although AIDS is internationally notifiable, some countries do not have a clear national policy on AIDS reporting.

AIDS case reporting is a useful tool for surveillance of the epidemic and for assessment of access to health care. However to be an efficient tool for surveillance, reliability and exhaustiveness of reports must be ensured. This includes proper use of the AIDS case definition by well-trained professionals and full reporting of cases.

Evaluation of AIDS Surveillance Systems

Evaluations of the national surveillance systems in most countries, conducted by CAREC have shown that the level of underreporting of AIDS cases using the sensitivity estimate method varies from country to country, ranging from 10% to 70%, with an overall level of underreporting in CMCs estimated to be about 35%. The sensitivity estimate method compares the number of AIDS cases diagnosed to the number of cases reported (Graph 2).

This would give an estimated cumulative number of 26,180 AIDS cases since the beginning of the epidemic, as of December 31, 1999 in 19 CAREC Member Countries and close to 30,000 by the end of 2000. This high level of underreporting is related to the weaknesses of the surveillance systems with respect to professional skills in using the case definition and of the health care systems regarding diagnostic facilities. In addition the use of the current reporting forms, compiling many different types of information, puts an extra burden on the daily workload of health care professionals, which leads to incomplete or inaccurate or even lack of information. This applies sometimes to gender or age groups, but mostly to modes of transmission of HIV and to behavioural information. For about 18% of all AIDS cases, transmission category is not specified. Although the male to female ratio among AIDS cases ranges from 1.4 to 2.7 among CMCs, most reports maintain that most transmission in the Caribbean is via
heterosexual contact. No analysis has been conducted to verify this and no biologically plausible mechanism explains the male preponderance among heterosexually transmitted cases. This significant proportion of cases, reported as “unknown”, may therefore be related to reluctance of reporting or collecting information on sexual orientation, or simply to no collection of information (Graph 3).

Overall the current AIDS reporting system is affected by a certain level of underreporting as well as of inaccuracy and unreliability of information, with regard to mode of transmission in particular.

► Lessons Learned
Lessons Learned (cont’d)

The current system of AIDS case reporting substantially underestimates the extent of the HIV epidemic. The relationship between the rate of reported AIDS cases and the estimated population burden of HIV infection is not consistent, and thus cannot be used to develop proportionate estimates.

The current system seems to be difficult for countries to implement. Too much time is spent in maintaining the system, and collecting, transmitting, analysing and disseminating information.

The current system shows difficulties in adapting to variations in reporting sources. Only a few countries can adequately manage the data and perform analyses, and even these have difficulty with interpretation. Most physicians in the private sector do not participate in the case reporting system. This has been a consistent finding in all evaluations. Where reporting occurs, few interviews are conducted, and report forms are often incomplete.

There has been no external validation using a probability sample to verify the sensitivity of the case reporting system to detect all persons with HIV/AIDS. It is frequently stated that people do not access medical care, in order to avoid being reported and the consequent risks to confidentiality. Physicians have avoided listing AIDS or AIDS indicator diseases on death certificates in order to avoid case reporting, on request from the patient or the family. Incomplete case report forms indicate that respondents are unwilling to report their transmission risks, particularly when it comes to sexual orientation. The system has been slow to detect large changes in the epidemic (e.g. the extremely high HIV prevalence among antenatal women and CSW in Guyana). Importantly, the surveillance system has not demonstrated the ability to describe the dynamics of current transmission of HIV in the region.

The system based on case reporting does not accurately describe the occurrence of HIV infection over time, or its distribution in the population. Although HIV has a long, asymptomatic latent period, most cases in the Caribbean (of both HIV infection and AIDS) are detected only in the late stages. The surveillance system appears to reflect more the access to health care services than the occurrence of HIV. Additionally, the large number of unclassified responses (especially for transmission category) requires more in-depth interviews among a probability sample of cases to verify the actual transmission routes that are most common.

Any surveillance system based on reports of AIDS cases, regardless of how well it functions, reflects at least a 10-year lag time from the occurrence of HIV transmission. This precludes the use of surveillance data for planning and implementation of effective control measures, and also limits their usefulness to characterise current demands on the health care systems.

Case reporting remains incomplete and limits its use as the basis for the HIV/AIDS surveillance system. To continue the emphasis on case reporting and adding behavioural questions to the case report forms is unlikely to succeed. Also, it is unrealistic to solicit sensitive information about sexual behaviours and risks at the time a person receives a diagnosis of HIV or AIDS.

It is therefore necessary to adopt a new approach to AIDS case reporting by improving the diagnostic facilities at country level, including additional training on the use of the case definition. Case reporting should include limited information in order to improve the coverage of new case identification and come up with more reliable incidence rates. Additional information on AIDS cases (mode of transmission, clinical information) should be subjected to different modes of data collection e.g. use of skilful contact tracers and interviewers.

The Caribbean Cooperation in Health (CCH2)

The Caribbean Cooperation in Health 2 is the public health framework developed in 1998 by national health experts in collaboration with PAHO/CAREC and signed off by all CARICOM Ministers of Health. It is the regional programme and instrument addressing major public health issues (Communicable and Non-Communicable diseases as well as environmental issues) in the Caribbean. This regional instrument is implemented by nationals with the input of regional and international agencies working in the public health sector.

One critical success factor in CCH2 is that Caribbean countries will use regional priorities and objectives to guide national planning. There is therefore, need to collect and analyse reliable health data in a timely manner to guide new cycles of planning. The latter is essential in the development and implementation of health promotion strategies to achieve better health for Caribbean citizens.

Health promotion has become essential in a changing Caribbean. Over the last forty years non-communicable diseases (diabetes, cardio-vascular diseases, road accidents, violence and the “new” sexually transmitted disease (HIV/AIDS), all lifestyle related, have gained priority ranking over other infectious diseases as the major causes of mortality in the Caribbean.

Because of its wide perspective, health promotion is the approach that best achieves disease prevention and control. It
treats health as a primary tool in human development, focusing on public policies conducive to prevention of disease and on promotion of well-being and productivity.

Health promotion has six pillars:

- Formulating and implementing healthy public policy,
- re-orientating health services (accessibility, equity, quality and standards of quality of care and treatment),
- empowering communities to achieve well-being,
- creating supportive environments, developing and increasing personal health skills, and
- building alliances with other sectors, mainly the private sector and media.

To affect public policies in the HIV/AIDS/STI area, health promotion programmes need accurate and timely health information through disease surveillance, risk factor surveillance related to sexual behaviours and care and treatment information from strengthened care and treatment systems.

Because of its objectives, the third generation HIV/AIDS/STI surveillance is a useful tool for monitoring the effectiveness of health promotion strategies in the specific area of HIV/AIDS/STI. It will, when used as intended, help ensure that quality data for decision-making, planning and public policy formulation are produced and used by decision-makers.

**CCH2 Objectives and Indicators:**

Key CCH2 objectives and indicators related to HIV/AIDS/STI surveillance are summarised as follows:

**Objective 1:** Health information and surveillance systems strengthened to generate data for public health action.

**Indicator:** in all countries, a quarterly epidemiologic or regular review based on data generated by laboratories, behavioural and epidemiology surveillance units, produced, disseminated and utilised for public health decision-making by end of 2003 (Means of verification: Regular evaluation of surveillance systems).

**Objective 7:** Prevalence of HIV among Females 15-19 years old in the region (a sentinel population) reduced by 25% below the 1997 levels by the end of 2005 (Means of verification: Regular prevalence studies).

**Objective 8:** Incidence of Urethral discharge and genital ulcers among males aged 15-49 years reduced by 20% below the 1997 levels by the end of 2005 (Means of verification: STI reporting).

**Indicators:**

- At least 75% of reported persons living with HIV/AIDS receive appropriate clinical management in accordance with CAREC’s minimum package of care for PLWHA in all countries by end of 2003 (Means of Verification: Regular quality of care surveys).
- At least 75% of reported persons living with HIV/AIDS and 50% of persons affected by HIV/AIDS receive supportive counselling by end 2003 (Means of Verification: Regular coverage of care surveys).
- Condom usage with last non-regular sexual partner increased by 30% above 1997 level by end of 2003 (Means of verification: Regular sexual surveys).
- At least 85% of pregnant women tested for syphilis twice during the same pregnancy in accordance with current Caribbean recommendations by end 2003 (Means of verification: Regular seroprevalence surveys).
- At least 80% of syphilis positive pregnant women seeking antenatal care and 60% of their sexual partners adequately treated by end 2002 (Means of verification: Regular STI reporting with treatment information).
- 50% reduction in the mother-to-child transmission of HIV at the end 2003 (Means of verification: Regular evaluation of impact of PMTCT programmes).

Clearly, the CCH2 objectives call for strong HIV/AIDS/STI surveillance systems allowing monitoring of these indicators and tracking the HIV/AIDS epidemic. To meet this need, the most appropriate surveillance system is one which links case reporting, behavioural surveillance and information related to care provided to people living with HIV/AIDS and STI patients: the CAREC Third Generation HIV/AIDS/STI Surveillance.

For its regional surveillance and behavioural change communication programmes, CAREC focuses on targeted interventions among specific population groups, because focusing surveillance and actions on groups at high risk of HIV will have the greatest impact on the epidemic. In its HIV/AIDS/STI Strategic plan (2001-2005) CAREC identified four major vulnerable groups as targets: women (including sex workers (SW), young people, men who have sex with men (MSM) and people living with HIV/AIDS (PLWHA). These are the most appropriate groups for national and regional interventions. By acting on these four groups and achieving success, national experts and CAREC will have impacted on the regional epidemic. Other specific vulnerable or at risk groups exist such as STI and TB patients, etc. If needed, any given country could add to CAREC’s list, any other important at risk group that plays a role in the spread of the epidemic.
A THIRD GENERATION OF HIV/AIDS/STI SURVEILLANCE

**GENERALITIES**

**Definition:** HIV/AIDS/STI surveillance is defined as the systematic or periodic collection of data on cases or populations including appropriate socio-demographic, behavioural and care information.

HIV/AIDS/STI surveillance should answer the following questions:
- who has the conditions?
- when did they get them?
- where do they live?
- why have they put themselves at risk of contracting HIV and STI?
- what standards/quality of care do they receive?

HIV/AIDS/STI surveillance systems should be based on scientifically sound and well-known case definitions and well-established indicators for monitoring the epidemic and evaluating impact of interventions. They also comprise of the orderly consolidation and evaluation (Quality Assurance) of data, and prompt dissemination to those who need to know.

**Objectives:** a comprehensive HIV/AIDS/STI surveillance system is one which collects, analyses and publishes accurate and timely epidemiological, behavioural and care information. It should contribute to a better understanding of the magnitude of diseases, risk behaviours, and the quality of care received by individuals suffering from these conditions and the disease trends in different vulnerable groups and in different socio-economic strata and geographic areas. It should provide timely and cost-efficient data of sufficient accuracy for public health action.

The objectives of HIV/AIDS/STI surveillance are to monitor the spread (incidence, prevalence and underlying behaviours and factors) and the impact (health and social) of these conditions. It should support health planners and decision-makers to plan and evaluate the impact of interventions and programmes e.g. safer sex practices, reduction in incidence or prevalence of diseases, quality of care. Surveillance activities should enhance interventions to treat, counsel, increase and improve quality of life and decrease spread. The surveillance strategy should be to build strong core epidemiological, care and behavioural information systems responsive to country needs by meeting the national surveillance objectives of priority conditions such as HIV/AIDS/STI.

The overall aim of HIV/AIDS/STI surveillance is to provide health planners and decision-makers with appropriate information, which is used to reduce spread, morbidity and mortality from HIV-infection and other STI. This will also prevent expenditure by saving costs associated with treatment of these conditions, human suffering and death.

**Description of HIV/AIDS Surveillance Systems:**

**Universal reporting or case reporting:** this is the routine reporting of HIV/AIDS/STI cases in which, in principle, all health facilities, private or public, collect information on cases occurring in their facilities and report this to the central surveillance unit. There are two main critical points: regularity and completeness. In some instances, under-reporting and low quality of reported data are well documented in the routine reporting systems of HIV/AIDS/STI cases.
**Sentinel reporting:** this reporting system uses interval reporting e.g. every 4 months, or every year or two for specific conditions and specific sites for reporting. A few sites that represent larger populations are selected to report, in order to answer specific issues or questions e.g. HIV or STI prevalence, condom use, sexual practices, and quality of care for patients. Surveys could take place at health institutions and other sites frequented by the target population e.g. youth centres, brothels, etc. or in households for the general population. STI/HIV trends from the sentinel surveillance system should be used to check the quality of the routine reporting systems.

**Repeated cross-sectional behavioural surveys:** these may be used to track and map sexual behaviours, attitudes and beliefs in particular vulnerable groups e.g. youth, FCSW, MSM or the general population. These surveys provide information to be used to plan for behavioural change communication interventions to minimise spread of HIV and STI through safer sex practices. They provide early warning of the epidemiological pattern and trends, to predict the burden of the diseases and thus plan for care and support. They can help monitor the success of interventions in reducing risk behaviours. They may be combined with seroprevalence data and should be conducted at regular intervals, between 1 to 2 years depending on the stage of the HIV epidemic (see chapter on Behavioural Surveillance).

**Special studies:** these are cross-sectional aetiologic studies including anti-microbial resistance patterns. They will provide complementary information on HIV/AIDS/STI such as seroprevalence among specific groups and distribution of pathogens including opportunistic infections related to AIDS. They also include Cohort studies (prospective or retrospective) which may be undertaken e.g. among people living with HIV/AIDS to better understand standards of care and support provided to them.

**Active surveillance:** in such a system, national and local health surveillance systems actively solicit through telephone calls or visits HIV/AIDS/STI reports from health care providers, laboratories or other sources (e.g. Central Statistical Office) by regularly contacting individuals and institutions representing likely sources of STI and HIV/AIDS reports.

**Passive surveillance:** data are typically obtained through reports initiated by the health care providers. This approach requires fewer resources, but health care providers often postpone reporting or do not report at all. In many instances, this system does not give a clear picture of HIV/AIDS/STI incidence, prevalence or deaths due to these conditions.

**Other considerations:** in some countries reporting of HIV/AIDS/STI may be compulsory (by law). Often this does not result, however, in more reliable data on HIV/AIDS/STI. If compulsory reporting is not confidential, patients may be reluctant to come to a health facility for testing or treatment. Another important issue is episode reporting versus person reporting. It should be underlined that for curable STI cases every episode should be reported as a case. Registries are also used for some specific STI e.g. syphilis. For HIV the first diagnosis should be reported as a case and AIDS cases should be reported only once after diagnosis is established (see CAREC case definitions).

**FUNCTIONAL COMPONENTS OF THE HIV/AIDS/STI SURVEILLANCE SYSTEMS**

**Sources of Information:**

The following are different but often overlapping sources of HIV/AIDS/STI data:

- clinician reporting
- laboratory reporting
- early detection/screening programmes
- behavioural surveys
- special studies (cross-sectional surveys, and aetiological studies)
- registries and patient management information databases.

Data from the different sources should be compared to avoid over-reporting and to ensure that they are complementary. To facilitate an understanding of the global situation, HIV, AIDS and STI cases and underlying risk behaviours should be analysed together.

In many countries baseline data for HIV/AIDS/STI surveillance come from case reports by health care providers e.g. clinicians in a variety of facilities: clinics, health centres and hospitals. Laboratories play an important role in the surveillance of HIV/AIDS/STI. It is expected that all laboratories will report aetologic agents associated with STI or opportunistic infections as well as results of antibody testing for HIV and VDRL for syphilis. Therefore laboratory personnel should be included in the surveillance team.

For the behavioural and care surveillance, behavioural science specialists including social researchers, health educators, social workers, counsellors and members of vulnerable groups should be involved to implement surveys among specific groups.

**Flow of Information:** This describes the channel of entry of HIV/AIDS/STI information into the national surveillance systems. At this level, standardised reporting forms should be used and confidentiality should be
observed. An established and known system of transfer of
the information is essential.

Data Storage and Management: Mechanisms for
data storage and management should be established. Back
up systems for all key data should be put in place. Also at
this level, confidentiality and respect of individual rights
should be observed and storage and management should
take place in a safe place.

Data Analysis and Dissemination: A plan of
data analysis should be established. It is important to
establish the frequency of data analysis and publication so
that regularity and consistency will be observed. Mention
should be made about types of analyses to be performed. A
list of institutions or agencies to receive HIV/AIDS/STI
surveillance reports should be established, known to all
involved professionals and readily available. The data should
be written in simple style with key messages in a form easily
understood by the layperson.

Surveillance Team Functioning: The
HIV/AIDS/STI surveillance team should be a
multidisciplinary team involving:

- epidemiologists
- national AIDS programme managers
- clinicians (representatives of the medical and nursing
  associations)
- behavioural scientists
- statisticians
- laboratory staff
- counsellors and health educators.

This team under the leadership of the national
epidemiologist should agree on the objectives of the national
surveillance systems and accept their roles and
responsibilities in the systems. The team should develop
annual plans of action with a budget and identified needs for
technical support for improving the HIV/AIDS/STI
surveillance.

KEY ATTRIBUTES OF HIV/AIDS/STI
SURVEILLANCE SYSTEMS

To meet country needs, an HIV/AIDS/STI surveillance system
should have the following qualities:

Standardisation: refers to national case definitions
and for HIV/AIDS/STI standardised national patient
management protocols. At national level, conditions under
surveillance, their definitions and management protocols
including partner management should be known to every
individual involved in surveillance. Behavioural surveillance
should use key indicators (see Chapter on Behavioural
Surveillance) which are known by all individuals involved in
the surveillance systems.

Simplicity: this means that the structure of the system
is straightforward and easy to operate. Of relevance is the
amount of information necessary to make a diagnosis, the
types of data sources, qualified staff, types of data analysis,
number of users of information, and time needed to collect,
transmit and analyse case information and to maintain the
system.

Participatory: In the Caribbean, HIV is mainly a
sexually transmitted infection. Contrary to traditional STI
which are cultural symbols of masculinity, HIV/AIDS is
associated with homosexuality, a culturally rejected sexual
orientation in the Caribbean. Thus, it is very difficult for
national institutions involved in surveillance to get access to
information on these groups. To address this limitation,
these guidelines promote the involvement of vulnerable
groups including PLWHs in the data collection, analysis and
publication. CAREC’s experiences of collaboration on
research with vulnerable groups to conduct needs
assessments and studies on quality of care for people living
with HIV/AIDS have been very useful in terms of quality of
the information.

Flexibility: this means that the system has been able to
adapt to new case definitions and operating conditions.

Acceptability: this indicates that individuals,
professionals and organisations are willing to participate in
the reporting systems

Representativeness: refers to the ability of the
system to accurately describe the occurrence of cases over
time and their distribution in the population by place and
person. It assists in understanding if population groups e.g.
MSM, cocaine addicts are not captured by the surveillance
systems.

Sensitivity: compares cases known in the national
surveillance systems with the number of cases identified
and related information (demographics, behaviours, etc.) in
all national institutions involved in diagnosis, care and
treatment of HIV/AIDS/STI. To assess whether or not most
cases are detected, the sensitivity of a surveillance system
can also compare the number of reported cases with the
estimated total population living with the condition (HIV,
AIDS or STI). Overall, sensitivity refers to the system’s ability
to detect epidemics and other changes in disease
occurrence.

Timeliness: reflects the speed or delay between steps in
the surveillance system. The important step is the time
between diagnosis of an HIV, AIDS or STI case and public
health action e.g. counselling, partner referral or contact
tracing.

**Usefulness:** describes the amount of public health actions and programmes undertaken or induced as a result of the data from the HIV/AIDS/STI surveillance system.

**Sustainability:** refers to the ability of the HIV/AIDS/STI surveillance system to be guided by a planning and management process with clear responsibility for every single staff member involved and with proper budgetary allocations. A surveillance system should cultivate confidentiality and people should be motivated to participate in the systems *e.g. if the clinicians do not fully cooperate with the surveillance unit even the most sophisticated computer system cannot compensate for this.* Motivation of every single member of the surveillance team is a prerequisite for a successful surveillance system. It is also important to establish and maintain good relationships with vulnerable groups to ensure access to them and an appropriate use of the data (not for harm).

Motivation can be achieved through planning of HIV/AIDS/STI surveillance activities with the team, regular updating on surveillance output, the epidemiological situation or trends and status publications, success stories, etc. and field visits to maintain cooperation and understand difficulties facing professionals and assisting in addressing them.

These key attributes should be evaluated during the review of the HIV/AIDS/STI surveillance systems (Ref: CAREC Guidelines on Evaluation of HIV/AIDS/STI Surveillance Systems).

**SURVEILLANCE OF HIV INFECTION**

**CAREC Case Definitions of HIV Infection**

The diagnosis of HIV infection is based on laboratory confirmation using one or more of the following:

**In adults:**
Repeatedly reactive screening tests for HIV antibody *e.g.* ELISA with specific antibodies identified by the use of supplemental tests *e.g.* Western Blot, or immunofluorescence assays in persons aged more than 18 months.

Direct identification of virus in host tissues by virus isolation through Culture or Polymerase Chain Reaction: PCR or HIV antigen detection (p24 antigen).

**In Children:**
In cases of HIV positive mothers, their children may carry maternal antibodies for up to 18 months. In order to make a definitive diagnosis of HIV infection, viral material needs to be demonstrated by, for instance, a PCR test or p24Ag. Such a test should be done at least twice, at one month and at four months of age. The second PCR test should take place between four and six months of age.

In the absence of diagnostic facilities for these tests, HIV infection in infants born to HIV positive mothers is defined as the persistence of HIV antibodies beyond the age of 18 months. Antibody testing in the absence of breastfeeding should be carried out every three to six months until two consecutive negative results, or to age 18 months, if infection is ruled out by two consecutive non-reactive antibody tests.

In the special case that a non-reactive infant has been exposed to breastmilk of an HIV positive mother, HIV testing of that child should take place three months after breastfeeding is stopped.

**HIV Surveillance**

CAREC’s Third Generation Surveillance will strengthen HIV case reporting. Other strategies such as voluntary counselling and testing will be promoted to allow national medical personnel to detect HIV cases early and monitor patients for care and psychological support and measure the level of stigma and discrimination against PLWH. With the objective being to reduce impact.

The objectives of HIV case reporting are:

- To monitor trends, incidence, prevalence and burden of the HIV disease in the Caribbean
- To assist in estimating actual and future impact on health care systems and identifying the needs for health care resources
- To provide opportunities to evaluate access to and quality of care
- To make available timely information for advocacy strategies.

Named reporting of HIV infection will achieve its full impact when voluntary HIV counselling and testing and adequate follow-up medical services for patients are more widely available. Understanding the important place of confidentiality in surveillance of STI including HIV for the collection of quality data, CAREC encourages its member countries to promote confidentiality and implement confidentiality measures. This will facilitate quality voluntary counselling and testing as well quality medical and care follow-up to all HIV positive patients detected by the surveillance systems. Named reporting has been advocated to avoid double counting and reporting and to allow
standardised case management as stipulated in the CAREC guidelines for the clinical management of HIV disease. Therefore, national decision makers are encouraged to make the minimum package of care available to all people living with HIV/AIDS so that good follow-up systems will contribute to minimising the spread of the disease (See section on Surveillance of Care)

**Routine HIV Case-reporting:**

Routine reporting of HIV cases should include all individuals tested for HIV antibodies for any reason. It should include individuals tested in the groups identified in the special surveys such as pregnant women, young people, STI patients, TB patients, FSWs, MSM and blood donors. However for prevalence rate determination, individuals in different groups should be considered together as denominator and the number of HIV positive individuals should be considered as numerator.

Routine HIV case reporting should include people diagnosed with HIV excluding all AIDS cases: blood donors, insurance applicants, clients of Voluntary Counselling and Testing, job applicants, health care providers, visa applicants, military or police recruits and people entering and exiting prisons, etc.

It is known that in the Caribbean the same individual can seek HIV testing at different places and at different times. Therefore, to avoid double counting, a strong national coding system developed by national epidemiologists and known by physicians and laboratory staff is necessary for patients being tested routinely for HIV. Aggregate data from such routine HIV testing (number of persons tested and number of positive tests, stratified by sex, residence, reason for testing, sector of employment and age group) may be reported without personal identifiers to the epidemiology programme in each country. Data is then analysed and published on a quarterly basis and utilised for policy formulation and planning.

Each CMC should also submit to CAREC quarterly aggregate data from routine HIV serosurveillance stratified by residence, sex, sector of employment, route of transmission and age group, for the regional surveillance perspective. CAREC will then analyse the data and provide feedback to countries (see CAREC Quarterly Reporting Form).

CAREC recommends that in all its member countries, information about the sector of employment should be collected from HIV infected individuals and AIDS cases. The value of this is three-fold:

- **to achieve a better understanding of economic or developmental sectors the most affected by the HIV epidemic at the country level**
- **to assist national decision-makers in the development of policies and prevention and care programmes for the most affected sectors**
- **to target workplace HIV care and prevention programmes and evaluate their impact.**

**Bias and limitations:**

Routine HIV case reporting gives the prevalence rate in the total population tested. It should be interpreted with caution as a selection bias may be inherent due to the limitations of services that provide HIV voluntary counselling and testing. Thus it does not represent the total number of HIV infections in the population.

Routine testing and reporting is important in individual case management but not for orientation of targeted interventions for public health programmes, as the data do not represent the distribution of the disease in the general population.

If voluntary counselling and testing is widely available and accepted, routine HIV case reporting can be used to determine the HIV prevalence in high risk and general population groups.

**HIV Surveys Among Specific Population Groups:**

Many population groups are playing an important role in the HIV epidemic. However, because of its specificity, the monitoring of the HIV epidemic should focus on major vulnerable groups at risk of being infected by HIV.

In the Caribbean, these specific groups vary from country to country, depending on socio-cultural circumstances and economic development. But also the small size of the population is another challenge to national epidemiologists because individuals in these groups move from country to country, in many instances, the reasons being the search for privacy, confidentiality, quality services or in some cases better social benefits.

There are many examples to illustrate this situation: STI or HIV/AIDS patients from Anguilla seek medical care in St Maarten, those from Dominica go to Guadeloupe, and those from St Lucia go to Martinique. FSW from the Dominican Republic, St. Kitts and Nevis, and Dominica trade sex in Antigua and Barbuda, Barbados etc.

Under these circumstances, CAREC recommends that national epidemiologists be aware of the specific national circumstances and discuss observed results before embarking on special surveys among these groups or before interpreting results of surveys.

International recommendations suggest that HIV
surveillance should focus more on groups at highest risk of infection. To achieve this end, special surveys should be conducted among populations known or suspected to have high HIV prevalence, such as Pregnant Women, Young People, MSM and FSW. At a minimum, such surveys should be conducted annually in all CMCs among pregnant women and young people.

In CAREC Member Countries with a population of 200,000 or greater, and in smaller countries where such high prevalence populations are accessible, and where logistics make the conduct of such surveys feasible, specific surveys among FSW and MSM will be undertaken by nationals and in small Islands by CAREC.

The surveys should include a brief behavioural questionnaire sufficient to allow identification of major factors associated with acquisition of HIV infection, and factors that might represent opportunities for dissemination of HIV infection to other population groups (see section on Behavioural Surveillance).

However, beyond these four groups, national epidemiological profiles may indicate that other groups such as STI patients, TB patients and blood donors are important to monitor for better understanding of the dynamics of the HIV epidemic. Information from routine screening among these groups or from surveys conducted among some of them is important to track the burden of the epidemic.

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**Minimum data requirements for HIV case reporting at country level:**

- **Number Tested by Age Group:** [1-4], [5-12], [13-14], [15-19], [20-24], [25-29], [30-34], [35-39], [40-44], [45-49], [50+]
- **Number Tested HIV Positive by Age Group:** [1-4], [5-12], [13-14], [15-19], [20-24], [25-29], [30-34], [35-39], [40-44], [45-49], [50+]
- **Route of Transmission:** MTCT, MSM, IVDU, Blood & Blood Products, Heterosexual, Others

**Patient Older than 13 Years:**

- **Sex:** Number of Males tested: Number of Females tested:  
  Number of Males HIV positive: Number of Females HIV positive:

**Sector of Employment:**

- Health Sector: including doctors, nurses, pharmacists, midwives, hospital cleaners, etc.
- Tourism Sector: including managers, receptionists, cleaners, housekeeping, gardeners, etc.

**For All Cases:**

- **Residence:** Number of individuals tested and Number HIV positive by parish or region
- **Statistical Association between age, sex, sector of employment, residence and HIV seropositivity**

**Patient Younger than 13 Years:** Number of Cases

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**National HIV Case Reporting Form**

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor’s Name:</td>
<td>……</td>
</tr>
<tr>
<td>Patient Code:</td>
<td>……</td>
</tr>
<tr>
<td>Patient’s Initials or Name:</td>
<td>……</td>
</tr>
<tr>
<td>Patient’s Mother’s Initials:</td>
<td>……</td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>…… Or Age: ……</td>
</tr>
<tr>
<td>Sector of Employment:</td>
<td>……</td>
</tr>
<tr>
<td>Residence:</td>
<td>……</td>
</tr>
<tr>
<td>Reason for Testing:</td>
<td>……</td>
</tr>
<tr>
<td>Route of HIV transmission:</td>
<td>MSM ( ) Heterosexual ( ) MTCT ( ) Blood Transfusion ( ) IVDU ( ) Others ( )</td>
</tr>
</tbody>
</table>
| Date of HIV Diagnosis: | …../…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…./…/...
HIV prevalence for each of these groups should be reported by country and summarised for the region in the CAREC Surveillance Report (CSR). Trend analysis of HIV prevalence will be conducted annually, and subsequently trends by country will be summarised and disseminated through the regional HIV/AIDS status and trend report.

After data are collected, analysis of special surveys should be conducted as soon as possible. Interpretative reports of these surveys will be provided to the CMC where the survey was conducted, presented at a community forum for persons among whom the survey was conducted, and highlighted as a special feature in the CAREC Surveillance Report (CSR). However, presentations to national decision-makers of findings of surveys and recommendations for their utilisation in policy formulation and programming, should be done jointly by CAREC staff and national epidemiologists.

The need for repeating these surveys, and the periodicity with which they are repeated, should be determined on the basis of baseline HIV prevalence and, optimally, incidence measurements.

1. Pregnant Women

This is an easy-to-reach sub-population. However to avoid or minimise bias, HIV seroprevalence surveys should include pregnant women seen in both the public and private sector. The preparatory phase of the survey should clarify the national coverage of prenatal care and the specific coverage in each sector. This will assist in organisation of the survey. Because of its closeness to the incidence rate, the HIV prevalence rate among younger pregnant women is very important for understanding the HIV epidemic among young people. It can help assess the impact of prevention programmes aimed at this vulnerable group.

Since this is a very important group representing the general sexually active population, an HIV seroprevalence study should be associated with prevalence of other STI e.g. syphilis or HBV (see section on STI surveillance) and behavioural surveillance information (see Behavioural surveillance).

**Sampling Methodology:** Two survey methodologies have been used in the Caribbean - the voluntary and linked and the unlinked and anonymous surveys. Both have their advantages and limitations. Two HIV surveillance approaches have also been used among this group: the annual pregnant cohort surveys to determine prevalence in the cohort and the sentinel surveillance systems to determine the HIV point prevalence.

Regular anonymous and unlinked HIV surveys among pregnant women do not identify individual HIV infection. However they remain important in the context of a generalised HIV epidemic such as we have in the Caribbean. They facilitate proper measurement of the HIV prevalence rate in the general sexually active population.

In the Caribbean context where voluntary counselling and testing for HIV antibodies is not widely accepted and consequently results in underreporting of HIV, anonymous and unlinked surveys among pregnant women are used as a surrogate method for public health surveillance of HIV infection. However, studies in several countries indicate that antenatal data may underestimate general population prevalence by as much as 20%.

The voluntary and linked HIV prevalence studies implemented in several countries, including the Bahamas, Barbados, Cayman Islands, and Bermuda, are subject to voluntary participation. In some instances, where the annual pregnancy cohort is small, because of the small population size, a refusal to participate in the screening process by a few pregnant women can bias the outcome of the survey.

In bigger countries, like Jamaica, Guyana, Suriname, and Trinidad and Tobago, anonymous and unlinked HIV sentinel surveillance of pregnant women is recommended. A few representative sites are selected and every year during a three to four-month period, 300 to 400 pregnant women are tested for HIV on a consecutive basis to determine the HIV point prevalence. Among pregnant women, new techniques exist for the measurement of incidence. One such example is the Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS) also called the detuned assay. With this method, new HIV infections can be identified by testing a single blood sample with a less sensitive ELISA. STARHS testing should be applied to blood samples collected as part of special surveys to determine the current incidence of HIV infection among high-prevalence groups, and those whose HIV prevalence is low to assess rates of current infection in each group. CAREC encourages that all surveys include the utilisation of the detuned assay.

**Bias and limitations:** To minimise bias, pregnant women from both the public and private sector should be included in the surveys. There are many other key elements which can influence the results of HIV seroprevalence surveys. These should be understood and analysed during the interpretation of any observed result. These include the following:

- the coverage of antenatal care services and their representativeness,
- the high general and specific maternal mortality rate,
- the low fertility rate and age. These play a role in influencing to some extent the outcome of the study because older women are not represented (menopause) and younger women are more represented, HIV reduces fertility, and some women will prefer not to become pregnant and therefore use contraceptives.
Despite these limitations, in the Caribbean, HIV seroprevalence among pregnant women is close to the rate in the general sexually active population. Thus, it remains a very important marker for monitoring of the epidemic.

2. Young People

Because of ethical and legal issues related to this group, it will be preferable to piggyback on information collected among young pregnant women or young recruits for the police or the army 15-19 and 20-24 years. For reliable HIV surveillance in this group, the focus should be on behavioural surveillance (see Behavioural Surveillance) and the utilisation of the detuned assay will help to measure HIV incidence among this group. If the detuned Assay is not available, it is recommended to over-sample the age group 15-19 and 20-24 in pregnant women being surveyed.

3. Men who have Sex with Men and Female Sex Workers

A few HIV seroprevalence surveys were conducted in this group at the early stage of the epidemic. This number has declined and in recent years only Suriname (1998) and Jamaica (1996) conducted seroprevalence surveys among MSM. Despite limitations and potential biases, the results showed a 30% HIV prevalence rate in Jamaica and 18% in Suriname, making this group one of the most affected by the HIV epidemic. For sampling, innovative approaches are recommended through involvement of peer MSM and focussing on mapping of settings where MSM gather (e.g. Gay bars).

Among female sex workers, a few HIV prevalence studies were carried out mainly in bigger countries. Experience of combined serological and behavioural surveys among this group is rare. Results of these surveys have shown that female sex workers are very much affected by the HIV epidemic (Georgetown-Guyana 31% in 2000, Jamaica 11% with 27% in St James Parish, 1996).

CAREC encourages that HIV seroprevalence in this specific group be coupled with special behavioural surveys using innovative approaches such as the use of saliva test for HIV antibodies. This allows an explanation of the seroprevalence rate measured by reported risky behaviours.

These approaches should include participation of peers, confidentiality and transparency with the group about the process and the use of data. Sample collection should be made preferably through a non-invasive method (saliva HIV test) and whenever possible the detuned Assay is recommended to determine HIV incidence. This will allow conduct of interviews while sample collection is taking place for HIV prevalence and incidence determination.

Sampling methodology and conduct of the surveys are detailed in the chapter on behavioural surveillance. In the Caribbean, seroprevalence surveys among MSM and FSW, should focus on countries with more than 250,000 population rather than in very small territories where confidentiality is almost non existent. Network sampling can be used in both the bigger and smaller Caribbean countries

Bias and limitations: because of the Caribbean socio-cultural circumstances and the small size of countries, accessibility to a marginalised group such as MSM and FSWs constitutes a real challenge. During seroprevalence and behavioural surveys, selection bias may occur. But from CAREC’s experience, these biases could be minimised when confidentiality is respected and peer MSM and FSWs are involved in the planning and implementation of surveys.

4. STI Patients

Sampling Methodology: on a consecutive basis and during a three to four month period of time, all STI patients seeking medical attention for a new STI episode should be tested for HIV antibodies on an anonymous and unlinked basis. 150 patients (10% anticipated prevalence with 5% margin of error) will be an adequate sample size to determine annual point prevalence. On annual basis, and under strict confidentiality, data collected among the 150 STI
patients seen are entered in a computer programme (Epi-Info 6) and analysed to determine associations and distribution of key variables and published as part of national surveillance reports (see minimum data requirements).

Bias and limitations: the accessibility to and acceptability of national STI services depend on many factors. Two major restrictions to these services are confidentiality issues and the negative attitude of health care providers towards STI patients. Whenever possible the HIV seroprevalence among this important group should involve both the public and private sector. If not, the results of the survey will reflect only the situation of the disease among the low socio-economic groups who cannot afford to pay service fees in the private sector. Self-treatment of STI is a prevalent phenomenon, therefore the results of such HIV prevalence among this group should take this issue into account when the interpretation of the observed prevalence rate is taking place.

5. Patients with Tuberculosis

The importance of this group may vary from country to country. Before the event of AIDS, Tuberculosis was not a major public health problem in the CMCs. However, because of its magnitude and association with Tuberculosis, the HIV/AIDS epidemic has transformed Tuberculosis into a new public health threat for the Caribbean people. In countries where AIDS incidence is high or Tuberculosis incidence is high, the double screening policy is recommended. Any Tuberculosis patient should be screened for HIV and any HIV/AIDS case should be screened for Tuberculosis. The sampling and methodology as well as the minimum data requirements outlined below will assist national epidemiologists to monitor trends of the co-infection-TB and HIV among adults and children.

**Sampling Methodology:** on an annual basis, all adults and infants with Tuberculosis who are seeking medical attention should be counselled and tested for HIV antibodies using national counselling and testing algorithms. In resource limited settings with high Tuberculosis incidence, a sample size of 150 adult patients (anticipated prevalence between 10 and 20% with a 5% margin of error) should be selected on a consecutive basis for a period of time necessary to reach the sample size. This should be repeated every year among new Tuberculosis cases. If there are several institutions involved in the treatment of Tuberculosis in any given country, they should be considered as sentinel sites for the annual prevalence estimate among Tuberculosis patients. The same methodology should be used to determine HIV prevalence among children with Tuberculosis. Results should be analysed separately and the minimum sample size should be 150.

**Minimum Data Requirements at country level:** the individual case-reporting form should reflect key variables listed below. The minimum data required from STI patients are:

**Number of cases per age group:** [15-19], [20- 24] and 25 and older

**Sex:** Total number of females: total number of males:

**Residence by parish or region:** Number of STI cases per region, parish or county

**Syndromes:**
- No of cases of Genital Discharge:
- No of cases of Genital Ulcer:

**Aetiologies:**
- No of cases of Gonorrhoea:
- No of cases of Syphilis:
- No of cases of Chancroid:
- No of cases of Chlamydia:
- No of cases of Trichomonas:
- No of cases of Donovoniasis:
- No of cases of Herpes:
- No of Bacterial Vaginosis:

**HIV test results for the 150 participants selected on a consecutive basis:**
- No of HIV positive by age group, sex, syndrome, aetiology and residence:
- No of HIV negative by age group, sex, syndrome, aetiology and residence:

Statistical Association should be determined between age, sex, syndrome, aetiology, residence and HIV+ cases.
Bias and Limitations: bias in this case is minimised as TB treatment is usually centralised in the public sector in the CMCs. It is possible to use the consecutive sampling of patients (point prevalence study) or screening of all new TB patients (cohort study) on an annual basis to conduct an HIV seroprevalence study among TB patients. The results will give a good understanding of the TB/HIV co-infection.

6. Blood Donors

All Blood donors selected are routinely tested for commonly occurring blood borne diseases. Most blood donors are males (a hard-to-reach subpopulation). Information gathered from this group will represent to some extent the burden of the HIV epidemic in the general sexually active population and specifically males.

This is a cost-effective way to gather health information readily available at the level of national Blood Transfusion Services. The methodologies summarised below will assist national epidemiologists to collect and analyse this information on an annual basis. Despite the limitation of the data, it can add strong value to the rest of information coming from other sources of surveillance (behavioural surveillance, other prevalence data) for a better understanding of the dynamics of the HIV epidemic.

Sampling Methodology: all donors should be included in the surveillance process. All selected blood donors should be counselled and tested for HIV antibodies as well as for syphilis and Hepatitis B, using national protocols.

On an annual basis, and under strict confidentiality, data collected among all blood donors are entered in a computer
programme (Epi-Info) and analysed to determine associations and distribution of key variables (see minimum data requirements) and published as part of national surveillance reports.

Bias and Limitations: Blood transfusion services have as priority to ensure blood safety. A pre-selection questionnaire is used to exclude donors with high-risk behaviours or any other past or present blood borne disease.

This selection bias leads to the underestimation of the true prevalence rate of these conditions among the general population. However, this should not discourage national epidemiologists from capturing, analysing and publishing this information, as the trends in prevalence of this subpopulation will reflect a change in the HIV trend in the general population.

Also, it is generally seen as a source of HIV information among men, since the majority of blood donors are men who represent a group which plays an important role in the spread of the HIV epidemic in the Caribbean.

To better understand the measured HIV prevalence among blood donors, it is important to include the reasons for rejection and the distribution of rejected blood donors by age and sex. A good judgement about the rejected donors will give national epidemiologists an understanding of the measured HIV prevalence through the donor pre-selection process in terms of underestimation or reflection of a true HIV prevalence rate.

Minimum Data Requirements at county level: the individual case reporting form should reflect key variables listed below in this quarterly reporting form and the minimum data required from donors are:

- Sex: Total No of women: ................. Total No of males: .................
- Residence by region or parish: number of donors by region or parish.
- Donors Rejected, then specify one major reason for rejection and number by reasons of rejection: ..............................................................
- Number of Donors Accepted, then results of laboratory tests:
  - HIV: No positive: ................. No negative: .................
  - Syphilis: No positive: ................. No negative: .................
  - HB AgS: No positive: ................. No negative: .................

Minimum data required about the blood transfusion settings are:

- No of Blood Donors per Year: ..............................................................
- No of Blood Donors Rejected per Year: .............................................
- No of Blood Donors Accepted per Year: ...........................................

Statistical Association should be determined between: sex, age groups, residence and all results of laboratory tests.

Statistical Association between: sex, age and reasons for rejection of blood donors.

Table 1: Example of Reporting of Rejected Blood Donors by Region and Reason

<table>
<thead>
<tr>
<th>REGION</th>
<th>REASON</th>
<th>MSM</th>
<th>IVDU</th>
<th>STI</th>
<th>Jaundice</th>
<th>TB</th>
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<th>Total number of HIV cases reported during this period:</th>
<th>HIV Seroprevalence rate in study(ies) concluded during this period among targeted group(s):</th>
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<tbody>
<tr>
<td></td>
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<td>Blood donors: Pregnant women: MSM: FCSW****: STI Patients: Others:</td>
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<tr>
<td>Blood and Blood Products</td>
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### Important Sector of Employment

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<tr>
<td><strong>TOTAL</strong></td>
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</tbody>
</table>

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* Mother-to-Child Transmission of HIV
* Men who have Sex with Men: homosexuals and bisexuals
** Intravenous Drug Use
**** Female Sex Workers

Sector of Employment should reflect key national sectors of employment e.g. education, banking, insurance, agriculture, mining, tourism, including self-employment.

Behavioural Co-factors such as the history of STIs, the history of Cocaine Crack Users, Commercial Sex Workers, Sex with Commercial Sex Workers (male or female) will be discussed in the component on Behavioural Surveillance.
**HIV MOLECULAR EPIDEMIOLOGY**

There are two types of HIV responsible for human infections: HIV1 and HIV2. HIV1 is the more virulent strain than HIV2, and is responsible for most of the reported cases around the world. While a few cases of AIDS in North America, Europe, and Asia have been associated with HIV2, the majority of cases occur in West Africa.

In terms of specific genetic variants called clades or subtypes, HIV1 has at least 10 different genetic subtypes (A, B, C, D, E, F, G, H, I, and an outlier group O) and HIV 2 has at least five. These subtypes may be found more frequently in certain continents, countries or regions and may differ in terms of their pathogenesis or mode of transmission. For example, Boris Renjifo, et al found that Subtype D is less frequently transmitted from mother-to-child than subtypes A and C or HIV1 inter-subtype recombinants. However, seeing the experience with the Herpes Simplex Viruses (HSV1 and HSV2) where HSV1 was considered to be the cause of oral infections and HSV2 the cause of sexual infections and with the sexual mixing of people within and between countries and continents, it is likely that most HIV subtypes will appear in most countries.

The extensive sequence variation of HIV isolates poses a considerable barrier to vaccine development. Variation in HIV arises both as a result of mutations and by recombination between different viral strains. The rapid replication of HIV-1 also facilitates the rapid generation of sequence variants. Variation in envelope amino acid sequences between different subtypes may exceed 30%. Because, a significant proportion of HIV-specific neutralising antibodies are type-specific, this sequence diversity has fostered efforts to induce broadly reactive immune responses or to utilise polyvalent AIDS vaccines.

Thus, the molecular surveillance of HIV is an important tool for understanding the viruses circulating in the Caribbean and specifically in countries where vaccine trials are taking place. Wherever resources permit, national surveillance should include periodic surveys of HIV subtypes. Therefore, CAREC as the regional surveillance agency will undertake regular molecular epidemiology studies to track down HIV subtypes circulating in the Caribbean.

**HIV RESISTANCE SURVEILLANCE:**

In populations under treatment, the development of resistance to antiretroviral agents is thought to be inevitable due to the large number of virus replication that is a feature of HIV infection. Thus the introduction of antiretroviral therapies into a community that has poor monitoring and compliance to the drugs will create an environment for developing resistance. It is therefore critical that the introduction of antiretroviral therapies to a community must be within an environment that is based on sound scientific reasoning, monitoring of response and the laboratory support to guide treatment decisions and delivered in a manner that promotes compliance and adherence to the drug therapy. HIV genotyping in new HIV cases can assist caregivers to adapt treatment regimens to the HIV resistance patterns. CAREC will work with the international community to assist member countries in conducting regular resistance monitoring studies.

**AIDS SURVEILLANCE IN THE CARIBBEAN**

The CAREC Third Generation Surveillance of HIV/AIDS/STI will continue to collect, analyse and disseminate data related to AIDS, clinical presentation at first diagnosis, and AIDS deaths.

The objectives of AIDS case and Deaths reporting are:
- To estimate the impact on health care systems and identify the needs for health care resources,
- To provide opportunities to assess access to and quality of care,
- To furnish timely information for advocacy strategies.

**CAREC Case Definition for AIDS**

*Adults & Adolescents (aged 13 years and older)*

A confirmed case of AIDS is defined as an individual, aged 13 years or older, who in the absence of other known causes of immunosuppression has a repeatedly positive screening test for HIV by an enzyme linked assay (ELISA) together with at least two major signs and at least one minor sign or at least one indicator disease.

**Major Signs**
- Involuntary weight loss of >10% of baseline body weight
- Chronic diarrhoea with at least two loose stools per day for >30 days
- Intermittent or constant fever for >30 days

**Minor Signs**
- Persistent cough for >30 days
- Generalised pruritic dermatitis
- Herpes zoster, multi-dermatomal
- Oro-pharyngeal candidiasis
- Generalised lymphadenopathy

**Indicator diseases (*does not require an HIV test*)**
- Bacterial pneumonia, recurrent (at least 2 episodes
AIDS case definition for children less than 13 years old

Mother-to-child transmission of HIV is becoming more and more an important public health issue due to the increasing heterosexual transmission of HIV. CAREC estimates that during the year 2000 between 780 and 1,070 children were born HIV infected or contracted HIV from post-natal exposure to breast milk.

During 1999, mother-to-child transmission represented 7% of all AIDS cases reported to CAREC. However, under reporting among this age group is important because of the lack of standardised case definitions and the absence of specific early diagnostic methods for HIV infection among children in the Caribbean.

It is well established that depending on the time when HIV infection takes place, AIDS can manifest itself early or later among children. When infection occurs during pregnancy, AIDS can be diagnosed in early infancy. But when infection takes place during delivery or through breast milk, AIDS can manifest itself later in childhood. Therefore for surveillance purposes, a follow-up of these children (e.g. annual cohorts of children born to HIV positive mothers) is essential to determine exactly the magnitude of mother-to-child transmission as a category of transmission in the Caribbean and its future impact on child mortality.

A confirmed case of AIDS is defined as a child less than 13 years old, who in the absence of other known causes of immunosuppression, has:

- a repeatedly HIV PCR positive test result or an HIV p24 Antigen positive (when children are less than 18 months of age); OR
- a repeatedly positive screening test for HIV antibodies by enzyme linked immunoassay (ELISA) or confirmed by Western Blot, immuno-fluorescence assay, etc. (when children are more than 18 months of age); together with at least two major signs and at least two minor signs or at least one indicator disease (see below).

**Major Signs:**
- Weight loss of more than 10% of baseline
- Failure to thrive
- Chronic diarrhoea for more than one month
- Intermittent or constant fever for more than one month

**Minor Signs:**
- Generalised lymphodenopathy
- Oro-pharyngeal candidiasis
- Repeated common infections (otitis, pharyngitis, etc.)
- Persistent cough (more than one month)
- Generalised dermatitis
- Confirmed maternal HIV infection

**Indicator Diseases:**
- Chronic lymphoid interstitial pneumonitis (more than two months)
- Chronic parotitis (more than two months)
- Common bacterial infections, severe and recurrent
- Candidiasis (oropharyngeal, trachea, lungs)
- Herpes simplex infection, disseminated, with onset after one month of age
- Isosporiasis, chronic and interstitial (more than thirty days)
- Pneumocystis Carinii pneumonia (PCP)
- Toxoplasmosis, disseminated, with onset after one month of age
- Cytomegalovirus (CMV) infection, with onset after six months
- Tuberculosis, any site
- Progressive multifocal leukoencephalopathy
- Histoplasmosis
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcus, extrapulmonary
- Cryptosporidiosis, chronic intestinal more than one month
- Lymphoma (primary) of the brain
- Lymphoma, Burkitt’s
- Lymphoma, Immunoblastic
- Kaposi’s sarcoma
Other Known Causes of Immunosuppression

- Systemic corticosteroid therapy
- Other immunosuppressive or cytotoxic therapy
- Cancer of lymphoreticular or histiocytic tissue such as lymphoma (except for lymphoma localised to the brain, Hodgkin’s disease, lymphocytic leukemia, or multiple myeloma)
- An immunodeficiency atypical of AIDS, such as one involving hypogammaglobulinaemia or angioimmunoblastic lymphadenopathy, or an immunodeficiency of which the cause appears to be genetic or developmental defect rather than HIV infection
- Exogenous malnutrition (starvation due to food deprivation, not malnutrition due to mal absorption or illness)

New AIDS Case and Death Reporting

These guidelines recommend that at regional level, AIDS case and AIDS death report forms should focus on these two situations and not to combine them with HIV reporting. In order to protect the privacy and the individual rights of people diagnosed with AIDS (as well as with HIV infection), named reporting should be encouraged only under maximum protection of confidentiality. Identifying information can be provided using an ID code (e.g. a national ID code); patient’s or mother’s initials or patient’s name so that only a few health professionals managing the patient, requesting the laboratory test, reporting the case, the national epidemiologists and public health workers should be able to trace patients back. This should be done only with the purpose of providing care and support to identified AIDS cases.

- AIDS cases report forms should include only information that is easily obtained. This should comprise identifying information (ID code) or name, gender, date of diagnosis, major signs, minor signs, presence of any indicator diseases.
- Additional information of interest (transmission category, information on behaviours, health care access, and quality of care) should be collected via interview as part of case investigations to be conducted for all AIDS cases.
- Because of risks to confidentiality (especially in smaller countries), sensitive AIDS related information on route of transmission of HIV is optimally solicited by skilful health and social professionals.
- This process may only be possible for special studies evaluating transmission risks, especially in smaller countries. In larger countries (e.g., Guyana, Jamaica, and Trinidad & Tobago) it may be possible to routinely designate a case investigator from outside the immediate community of the reported case.

Case report data should be analysed quarterly and analysis stratified by age, sex, residence, sector of employment, major signs, minor signs, and indicator diseases. Reports from these analyses (by country and aggregated for the region) should be provided to CMCs biannually, with annual summaries. Special analyses from case investigations (transmission risks, quality of care, etc.) should be reported annually.

Analysis of behavioural information among AIDS patients is of limited usefulness, because it represents risky behaviours undertaken eight to ten years ago and cannot be used for programmatic purposes.

AIDS Death Reporting

Since 1995, AIDS has been the leading cause of death in the Caribbean among people 20-44 years old and to some extent AIDS has increased child mortality. Therefore the impact of mortality due to AIDS on life expectancy at birth and on vital statistics needs to be understood in terms of a change in mortality profile (see other sources of reporting). To achieve that, it is important that all CMC improve the reporting of AIDS deaths.

In 2000, CAREC in collaboration with the Ministry of Health in Trinidad and Tobago conducted a preliminary study to estimate the level of underreporting of AIDS deaths. Findings have shown that almost 40% of the deaths due to AIDS were not reported (O’Connor, 2000).

AIDS death reporting will also assist national AIDS programmes in the monitoring of the efficacy of treatment programmes, especially the use of the CAREC minimum package of care targetting opportunistic infections, prophylactic regimens and antiretrovirals. AIDS deaths are markers of the quality of care provided to people living with HIV/AIDS. Isolation, discrimination, rejection and stigma against individuals can play a role in their survival and lifespan. Everywhere in the Caribbean, people living with HIV/AIDS are being confronted on a daily basis by social stigma.

The emphasis on reported AIDS deaths should be linked to the quality and equitable treatment and care for people living with HIV/AIDS. The reporting should be done using the AIDS reporting form and cause of death (opportunistic infections or HIV itself) mentioned on the reporting form. This should be analysed by national epidemiologists on a regular basis and presented to national decision-makers and Non-Governmental Organisations working with PLWHA.
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<td>Patient’s Mother’s Initials or Name: ............</td>
</tr>
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<td>Date Of Birth: ................................</td>
<td>Or Age: .....................................</td>
</tr>
<tr>
<td>Residence: Region or Parish or County: ...</td>
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### CARIBBEAN EPIDEMIOLOGY CENTRE (CAREC)
### QUARTERLY AIDS REPORTING FORM

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</tbody>
</table>

* Mother-to-Child Transmission of HIV
** Men who have Sex with Men: homosexuals and bisexuals
*** Intravenous Drug Use
**** Causes of Death should be analysed during quality of care surveys at country level

- Information regarding Sector of Employment should focus on major national developmental sectors including self-employment; it will assist National Decision-makers to understand national sectors the most affected by AIDS.
- AIDS case defined as patient fulfilling the following: HIV positive test with major and minor signs or an indicator disease
- AIDS death is defined as death caused by opportunistic infections of AIDS and/or HIV wasting syndrome.
**SURVEILLANCE OF SEXUALLY TRANSMITTED INFECTIONS (STI)**

STI incidence is generally considered a biologic marker indicative of risks for HIV transmission. CAREC and national surveillance systems have already undertaken STI surveillance via case reports of both STI aetiologic and syndromic diagnoses (e.g. syphilis, genital discharge, chlamydia, genital ulcer, etc.). The impact of regional and national HIV/AIDS/STI prevention and control programmes will be considerably improved within a context of enhanced STI surveillance. This is the major objective of the CAREC Third Generation Surveillance.

**Routine STI Case Reporting**

In the Caribbean several STI conditions are under surveillance and should be considered for reporting by clinicians. These conditions were selected because of their public health importance as an entity or their strong association with HIV transmission. Detecting and treating these conditions will cut the chain of transmission of STI and reduce their public health burden as well as prevent the transmission of HIV.

Most data on STI in the Caribbean have been collected and reported as part of routine disease detection activities (diagnosis, case finding, screening, partner notification). The information is used for clinical management, institutional management and public health surveillance.

STI detection activities may identify new as well as old infections. When these data are reported together, as is often the case, their interpretation is particularly difficult (e.g. Syphilis). CAREC recommends that these should be reported separately.

While all surveillance systems have biases, because of the specific nature of STI, these biases tend to be magnified for STI surveillance compared with surveillance systems for many other reportable/notifiable diseases. For these reasons, the data collected on STI through routine disease detection activities cannot, in most instances, be considered to be representative of disease incidence in the general population. The extent to which these data are useful as measures of disease burden varies widely by country and by disease. It depends heavily on the extent to which symptomatic patients present for care, on the consistency of case definitions and diagnostic methods, and on the criteria that are used for testing asymptomatic persons.

Another approach to correct this situation is the collection of population specific data. These data are of particular importance for programme planning. Therefore to correct a weakness of most STI case-reporting systems, whenever possible, they should report on a routine basis and separately, the statistics on diseases among certain groups that are the focus of public health interventions (e.g. pregnant women, female sex workers, young people, persons entering detention facilities). Reporting by subgroups has become routine for HIV serosurveys, and this should be applied to other STI.

STI case reporting will be used to determine incidence and the specific study (e.g. sentinel surveillance or screening specific groups) will assist national epidemiologists and Public Health programme Managers (AIDS programme, Mother and Child Health, etc.) to determine the prevalence of STI.

**Incidence** of disease or infection is defined as the number of new cases of diseases occurring in a population during a defined time interval.

**Prevalence** of disease or infection is defined as the proportion of persons in a population who have that disease or infection.

**STI CONDITIONS UNDER SURVEILLANCE**

The following conditions and syndromes are under surveillance and should be reported to the national surveillance unit in every CAREC Member Country:

**Syndromes:**
- Genital Discharge (Urethral Discharge in males)
- Genital Ulcer
- Pelvic Inflammatory Disease (depending on Predictive Positive Value)
- Ophthalmia Neonatorum (depending on Predictive Positive Value)

**Diseases:**
- Chancroid
- Donovanosis (rare condition in the Caribbean)
- Chlamydial Infections
- Gonococcal Infections
- Lymphogranuloma Venerum
- Trichomonas
- Granulome Ingunale
- Bacterial Vaginosis (Gardnerella Vaginalis)
- Syphilis including Congenital Syphilis
- Herpes Simplex Infections

Others, like the Human Papillomavirus (HPV) and Candida Albicans, may not necessarily be essential in the national STI situation.
STI Syndromic Reporting

Case Definitions
The following are case definitions for STI Syndromic reporting:

Genital Discharge Syndrome
This clinical syndrome is an indicator of sexually transmitted infection.
Any male with urethral discharge which is cloudy or opaque, viscous or sticky, appearing at the urethral meatus spontaneously or after milking the urethra
OR
Any female with mucopurulent (yellowish), exudative endocervical discharge present on speculum examination.

Genital Ulcer Disease
This clinical syndrome is an indicator of sexually transmitted infection.
Any male or female with ulcers or vesicles present in the anogenital region: scrotum, penis, vulva, vagina, cervix, perianal area, or inner thighs with or without regional lymphadenopathy.

Pelvic Inflammatory Disease (PID) or Lower Abdominal Pain
This clinical syndrome is a sexually transmitted infection resulting from ascending spread of microorganisms from the vagina and endocervix to the endometrium, fallopian tubes, and/or contiguous structures.
A female with adnexal and cervical motion tenderness or bimanual pelvic examination with or without mucopurulent endocervical discharge seen on speculum examination.

Ophtalmia Neonatorum
This clinical syndrome without specific aetiological laboratory diagnosis may be an indicator of sexually transmitted infections among childbearing females. The case definition corresponds to any infant with acute redness and swelling of conjunctiva of one or both eyes, with purulent discharge in the first month of life following vaginal delivery.

STI Aetiological Reporting

Case Definitions
The following case definitions should always be used when reporting on an aetiological basis. In case of no final diagnosis on aetiologic grounds, syndromic reporting may apply.

Chancroid
Probable: Infection with Haemophilus ducreyi is sexually transmitted and may result clinically in a Genital Ulcer Syndrome.
Confirmed: A confirmed case is a case of Genital Ulcer Syndrome (see case definition) with:
Laboratory confirmation: Isolation of Haemophilus ducreyi from a clinical specimen by culture, antigen detection or DNA amplification.

Chlamydial Infections

Neonatal
Probable: Perinatal infections with Chlamydia trachomatis may result in ophthalmia neonatorum, and acute inflammatory condition of the conjunctiva among newborns. It could also result in acute pneumonia among newborns and infants.
Confirmed: A confirmed case is a case of Ophthalmia Neonatorum (see case definition) with:
Laboratory confirmation: Detection of Chlamydia trachomatis by cell culture or direct antigen method from conjunctival exudate or pseudomembrane.

Genitourinary Infections
Probable: Infections caused by Chlamydia trachomatis can be sexually transmitted and may result in urethritis, epididymitis, cervicitis, acute salpingitis (pelvic inflammatory disease), proctitis, or other syndromes (see Lymphogranuloma Venereum). Infection may be asymptomatic.
Confirmed: A confirmed case is a case of Genital Discharge Syndrome (see case definition) or any other individual with:
Laboratory confirmation: Detection of Chlamydia trachomatis by cell culture, direct antigen, PCR or LCR methods from an intraurethral (male) or endocervical swab (female).

Lymphogranuloma Venereum
Probable: Infection with L1, L2, or L3 serovars of Chlamydia trachomatis is sexually transmitted and may result in a Genital Ulcer Syndrome.
Confirmed: A confirmed case is a case of Genital Ulcer Syndrome (see case definition) with:
Laboratory confirmation: Isolation of Chlamydia trachomatis, serotype L1, L2, or L3 from a clinical specimen by cell culture or direct antigen, PCR or LCR
methods from a genital ulcer.

**Gonococcal Infections**

**Neonatal**

**Probable:** Perinatal infection with *Neisseria gonorrhoeae* may result in ophthalmia neonatorum, an acute inflammatory condition of the conjunctiva among newborns.

**Confirmed:** A confirmed case is a case of Ophthalmia Neonatorum (see case definition) with: Laboratory confirmation: Isolation of *Neisseria gonorrhoeae* from an eye swab.

**Genitourinary Infections**

**Probable:** Sexually transmitted infections caused by *Neisseria gonorrhoeae* may result in urethritis, cervicitis, acute salpingitis (pelvic inflammatory disease), proctitis, or pharyngitis. Infection may be asymptomatic.

**Confirmed:** A confirmed case is a case of Genital Discharge Syndrome (see case definition) or any other individual with:
- Laboratory confirmation: Isolation of *Neisseria gonorrhoeae* from a clinical specimen
- Observation of typical gram-negative intracellular diplococci in a urethral smear obtained from a man. Culture, PCR and LCR are other methods available for confirmation of Gonococcal infection from swab (urethral, vaginal or eye).

**Trichomonas Vaginalis**

Although there are more than 100 species of *Trichomonas*, only three of them affect humans. *Trichomonas Vaginalis* is the species responsible for urogenital tract infection.

**Probable:** *Trichomonas Vaginalis* is the most frequent parasitic sexually transmitted infection among women. The infection among men is generally asymptomatic. Infection with Trichomonas may result in genital discharge syndrome.

**Confirmed:** The diagnosis is made by direct microscopic observation of motile characteristic parasites. The preparation consists of adding physiological saline solution to a swab of vaginal secretions and analysed under a light microscope (100x). Other methods of identification exist, such as culture (Diamond’s modified medium); antigen detection (Direct Enzyme Immunoassay and Fluorescent Direct Immunoassay); and the DNA detection by PCR. These expensive methods should be used only in aetiologic surveys to determine pathogens circulating and to adapt national STI treatment algorithms.

**Gardnerella Vaginalis**

**Probable:** Up to 20% of the women diagnosed with vaginal discharge are classified as nonspecific vaginitis due to Gardnerella Vaginalis formerly *Corynebacterium vaginalis* and *Haemophilus vaginalis*. Infection with Gardnerella vaginalis may result in vaginal Discharge Syndrome.

**Confirmed:** The diagnosis is based on four key findings: a homogeneous vaginal discharge, a vaginal pH of greater than 4.5, the presence of clue cells (microscopy) and a fishy odour after addition of potassium hydroxide to the vaginal secretion (the amine test). Commercial DNA detection assays exist and may be useful but they are very expensive.

**Granuloma Inguinale**

**Probable:** Infection with *Calymmotobacterium granulomatis* is sexually transmitted and may result in a Genital Ulcer Syndrome.

**Confirmed:** A confirmed case is a case of Genital Ulcer Syndrome (see case definition) with:
- Laboratory confirmation: Demonstration of intracytoplasmic Donovan bodies in Wright or Giemsa-stained smears or biopsies of granulation tissue.

**Herpes Simplex Virus Infections (Genital)**

Infection with herpes simplex virus (HSV) types 1 or 2 may be sexually transmitted and may result in recurrent episodes of a Genital Ulcer Syndrome. Because of its chronic evolvement, only an initial episode of genital herpes should be reported.

**Probable:** A Genital Ulcer Syndrome (see case definition) with clear vesicles on an erythematous base in the anogenital area AND no previous documentation of such an occurrence.

**Confirmed:** A confirmed case is a probable case with Laboratory confirmation, Isolation of HSV1 or HSV2 from a clinical specimen by culture or DNA detection by multiplex PCR.

**Syphilis**

Syphilis is a complex, sexually transmitted infection with a highly variable clinical course resulting from initial infection with *Treponema pallidum*. Congenital syphilis may
result from untreated women becoming pregnant and infecting their offspring.

**Primary Syphilis**

**Confirmed:** A confirmed case is a case of Genital Ulcer Syndrome (see case definition) with:
- Laboratory confirmation: Nontreponemal (VDRL/RPR) and treponemal (MHATP/TPHA or FTA) reactive serology when no history of previous syphilis
- OR
- 4-fold increase in titre over the last known non-treponemal (VDRL/RPR) test
- OR
- Demonstration of *Treponema pallidum* from a chancre or in aspirated material from a regional lymph node by darkfield, fluorescent antibody, or equivalent microscopic methods.

**Secondary Syphilis**

**Suspected:** An individual with any of the following:
- localised or diffused
- mucocutaneous lesions
- generalised lymphadenopathy
- alopecia,
- loss of eyelashes and lateral third of eyebrows, iritis, splenomegaly

**Confirmed:**
- A confirmed case is a suspected case with:
- Laboratory confirmation: Non-treponemal (VDRL/RPR) and (MHATP/TPHA or FTA) reactive serology
- OR
- Non-treponemal (VDRL/RPR) serology titre greater than or equal to 1:8
- OR
- Demonstration of *Treponema pallidum* from a chancre or in aspirated material from a regional lymph node by darkfield, fluorescent antibody, or equivalent microscopic methods.

**Other Syphilis: Serological Syphilis**

An individual who does not meet the criteria for primary, secondary, or congenital syphilis with the following diagnosis:

- Laboratory confirmation: Non-treponemal (VDRL/RPR) and/or treponemal (MHATP/TPHA or FTA) reactive serology with no known previous treatment for syphilis OR 4-fold rise in non-treponemal (VDRL/RPR) serology titre.

**Latent and Tertiary Syphilis**

Their diagnosis is done occasionally through mother-to-child transmission of syphilis and generally through clinical manifestations such as cardiovascular abnormalities (thoracic aortic aneurysm and aortic insufficiency), skin lesions (localised gumma formation), neurologic manifestations (general paresis, tabes dorsalis and focal neurologic signs) as well as skeleton, testis and cartilage dysfunction and abnormalities.

**Congenital syphilis**

**Probable:** An infant (live or still birth) born to a woman with a diagnosis of syphilis who:
- is untreated OR
- does not have documentation of treatment OR
- did not have an expected decrease in serology titre after treatment OR
- was treated one month or less before delivery OR
- was treated with non-penicillin therapy OR
- an infant (live or stillbirth) with clinical evidence of congenital syphilis on physical examination or long bones X-ray OR
- an infant with a non-treponemal (VDRL/RPR) serology titre which is 4-fold greater than the mother’s titre

**Confirmed:** A confirmed case is a probable case with Laboratory confirmation: Demonstration of *Treponema pallidum* by darkfield microscopy, fluorescent antibody, or other specific stains from nasal discharges or skin lesions, or in placental, umbilical cord or autopsy material of a neonate.

**Others STI Conditions**

**Human Papillomaviruses**

These viruses are sexually transmitted and some species are associated with the presence of Genital Warts and Cervical Cancers. They can be detected by different methods, however the most sensitive and specific detection method is the DNA detection from biopsy of warts or of the cervix. For cervical cancers the best monitoring and prevention system is the Pap Smear.

**Candida Albicans:**

This fungus is not a true sexually transmitted infection. Between 85% and 90% of yeast isolated from the vagina are *Candida Albicans* strains. Many circumstances play a role in the event of an infection with *Candida Albicans* (diabetes, use of contraceptives, immunodeficiency, etc.). *Candida Albicans* can be detected by wet mount microscopy using 10% potassium hydroxide preparation added to the swab showing the presence of germinated yeast, culture or other expensive methods (Antigen or DNA detection).
Quality of STI Syndromes and Diseases as Measures of STI Incidence and Prevalence and minimum data requirements:

STI syndromes or diseases used to measure incidence or prevalence show differences in sensitivity and specificity, because their quality may differ depending on health settings, sub populations being screened or diagnosed and gender. The following tables describe these differences. National epidemiologists should use them as a guide to meet their specific needs in understanding the STI dynamics in their population. The section on essential data required will assist them to sharpen their analysis of the STI situation.

Table 2: Quality of STI syndromes as measures of STI incidence

<table>
<thead>
<tr>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
<th>UNCERTAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral discharge in Men</td>
<td>Genital Ulcer Disease in Men and Women</td>
<td>Vaginal Discharge</td>
<td>Pelvic Inflammatory Disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cervical Gonorrhoea or Chlamydia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cervicitis (clinical)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Latent Syphilis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Genital Warts</td>
</tr>
</tbody>
</table>

Table 3: Quality of STI and syndromes as measures of population prevalence in general settings where patients seek care for treatment of symptoms (primary care, antenatal, family planning clinics)

<table>
<thead>
<tr>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
<th>UNCERTAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea in women (endocervical)</td>
<td>Syphilis Serology</td>
<td>Genital Ulcer Disease</td>
<td>Cervicitis (clinical)</td>
</tr>
<tr>
<td>Chlamydia in women (endocervical)</td>
<td>Urethritis</td>
<td>Vaginal Discharge</td>
<td>Trichomonas (wet mount)</td>
</tr>
<tr>
<td>PCR for Chlamydia, Gonorrhoea and Trichomonas</td>
<td>Vaginal Discharge</td>
<td></td>
<td>Herpes Simplex Virus 2 Serology</td>
</tr>
<tr>
<td></td>
<td>Pelvic Inflammatory Disease</td>
<td></td>
<td>Chlamydia Serology</td>
</tr>
</tbody>
</table>

Table 4: Quality of STI and syndromes as measures of STI prevalence in populations examined without relation to symptoms, e.g. entry into detention facilities, military recruitment, clinic performing required sex worker examinations, population-based surveys

<table>
<thead>
<tr>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
<th>UNCERTAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea in women (endocervical)</td>
<td>Syphilis Serology</td>
<td>Vaginal Discharge syndrome</td>
<td>Cervicitis (clinical)</td>
</tr>
<tr>
<td>Chlamydia in women (endocervical)</td>
<td>Genital Ulcer Disease (non-vesicular and vesicular)</td>
<td>Pelvic Inflammatory Disease</td>
<td></td>
</tr>
<tr>
<td>Urethrits in men</td>
<td></td>
<td></td>
<td>HSV2 serology</td>
</tr>
<tr>
<td>Trichomonas by wet mount, culture or PCR</td>
<td></td>
<td></td>
<td>Chlamydia serology</td>
</tr>
<tr>
<td>PCR for Chlamydia</td>
<td></td>
<td></td>
<td>Genital Warts</td>
</tr>
</tbody>
</table>
Essential Case-Reporting data for monitoring STI incidence using syndromic reporting:

1. Syndromes

<table>
<thead>
<tr>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Urethral Discharge</td>
<td>a) Genital Ulcer Disease</td>
</tr>
<tr>
<td>b) Genital Ulcer Disease</td>
<td></td>
</tr>
</tbody>
</table>

II) Minimum data requirements:

- Clinic Identifier
- Clinic type
- Date of diagnosis
- Residence
- Sex
- Age
- Syndrome
- Treated: yes ( ) or no ( )

Essential data for monitoring STI prevalence among different subgroups:

1. Women

- Syphilis prevalence during pregnancy by serological test
- Syphilis among high risk groups by serological test
- Gonorrhoea (endocervical) by culture or non-culture test for high-risk groups
- Chlamydia (endocervical) by PCR or low and high-risk group
- Genital ulcer disease among high-risk groups

2. Men

- Syphilis among selected populations by serological test
- Urethral discharge among high-risk groups
- Genital ulcer disease among high-risk groups

3. Minimum data requirements

- Clinic identifier
- Clinic type
- Population type
- Date of diagnosis
- Residence
- Sex
- Age
- For women: record if pregnant or if specimen collected during delivery
- Presence of Syndrome
- Test result: positive, negative or unsatisfactory
- Treated: yes ( ) or no ( )
Essential data for monitoring rates of Perinatally Acquired STI

I. Diseases/Conditions:
   a) Congenital syphilis
   b) Ophthalmia neonatorum

II. Data Requirements:
   a) Site of delivery (site identifier)
   b) Date of birth
   c) Syndrome
   d) Date of diagnosis
   e) Maternal age at diagnosis
   f) Diagnosis: Gonorrhoea ( ), Chlamydia ( ), Syphilis ( )
   g) Treated: yes ( ) no ( )
   h) Number of deliveries per year at delivery site: ..................

For Congenital Syphilis:
   No. of pregnant women tested for syphilis: ..............
   No. syphilis positive: ..........................

For Ophthalmia neonatorum: No. of live births at site: ..................

Summary: at country and regional levels, STI case reports for both aetiologic and syndromic diagnoses should be **disaggregated**, and reported separately for each **sex and age**, including all genital discharge syndromes. Having only one category obscures important information, because genital discharge in males is almost always indicative of STI, while that in females can often result from other causes e.g. Candidiasis.

**SPECIAL STI STUDIES AND MONITORING**

Before implementing special STI studies, it will be necessary to clarify the following elements:

**Identification of a Technical Team and a Team Leader to develop and implement the study:**

1. Objectives of the study,
2. STI to be included in the study,
3. Laboratory and logistic supports,
4. Study design, key variables to be collected, sampling and size,
5. Recruitment and training of additional staff if necessary,
6. Study population and sites or communities,
7. Timeline (generally not more than six months),
8. Data management and analysis
9. Publication and dissemination of study results
10. Follow-up for translation of findings into policy or for use in advocacy, planning and evaluation
11. Budget

**A. STI Cross-Sectional and Aetiological Studies**

Although clinical records provide a source of surveillance data on a more or less continuous basis, it may be necessary to obtain additional data on STI. This would be the case where some STI are not routinely detected, like for instance chlamydial infection, or where the frequency and distribution of STI in a population need to be more accurately assessed. It might also be indicated to collect data in groups not covered by the routine reporting system.

To provide these additional data, or to provide baseline data for the initial development of STI programmes, it might be necessary to conduct special surveys. For instance, surveys based on sero-surveillance provide reasonable prevalence data. Examples of this are HIV and syphilis sero-prevalence surveys. As many of the groups at high risk for STI are also high-risk groups for infection with HIV, it is indicated to combine these serological surveys whenever possible.

Before embarking on special surveys, one must check whether the type of data that one is looking for is not already available, but not yet collated and analysed, through early detection of STI. Examples of these would be syphilis prevalence in blood donors, pregnant women and STI patients or gonorrhoea prevalence in clients of family planning clinics, etc.

In a number of health programmes, cross-sectional surveys are used to collect baseline data on these conditions, and through re-surveys programme impact is evaluated.
STI surveillance includes the prevalence of STI pathogens as major causes of STI health problems. In the Caribbean, this information is needed to develop or refine STI patient management protocols and national algorithms for treatment of STI patients. This is a useful tool in support of the correct application of the syndromic approach to the management of STI. This kind of research should be done on a periodic basis, for example, every three years, taking into account representativeness to ensure good geographic and demographic coverage of the particular country. This research study should be implemented under maximum availability of STI diagnostic services and methodologies (Golden Standards: e.g. PCR, LCR, WB, Culture or IFA) and can involve well-established sentinel sites in a country. They should include antimicrobial resistance studies (see next chapter) to increase the accuracy, sensitivity and specificity of case definitions used in national STI treatment algorithms.

B. Sample size and methodology to recruit study participants

Random sampling is giving to all participants the same probability of being selected. However, it has the disadvantage of being long and of complicating the recruitment, diagnosis and treatment process. Therefore, consecutive sampling until the sample size is reached is a simpler, efficient and less complicated method. It needs to be rigorous and applied to every STI patient to avoid selection bias. The sample size depends on the degree of precision to be reached, anticipated situation (anticipated prevalence) and the objectives of the study. For example, trend monitoring may require a bigger sample size and the more precise the study will be, the larger the sample size. However, it is important to underline that an STI prevalence study should be cost effective, so the minimum sample size to achieve the objectives of any given study should be chosen.

But, rounding off the sample size is recommended to ensure that the minimum size is collected, despite specimen loss, contamination or unsatisfactory results (borderlines or indeterminate).

Example: to determine the prevalence and aetiological distribution of STI, the national epidemiologist of Camaita has anticipated a prevalence rate of 5% for gonorrhea, 10% for chlamydia, 5% for syphilis, 15% for bacterial vaginosis and 15% for trichomonas vaginalis in the study population. She wanted a precision of 3% for all STI conditions. The sample size calculation should focus on the larger total needed, based on the expected prevalence rate (as mentioned in Annexe 1). In that case the sample size needed for gonorrhoea is 203, 385 for chlamydia, 203 for syphilis, 545 for bacterial vaginosis and 545 for trichomonas vaginalis. The sample size required will be 545 to ensure detection of bacterial vaginosis with a 95% confidence interval with a true population estimate between 12% and 18% (See Annexe 3 for sample size determination).

C. STI Antimicrobial Resistance Studies

These research studies are essential for the management protocols of STI. For example, gonococcal resistance to antibiotics is under international monitoring. These studies should be part of any STI aetiologic study or could be done on a periodic basis using a less expensive yet efficient consecutive sampling of 130 STI patients with specific symptoms of the disease under consideration, and seen at health facilities. For example 130 patients with gonorrhoea will be included consecutively in an antimicrobial resistance study.

Summary: CMCs should undertake these studies on a regular basis. Or, wherever necessary, CAREC will provide technical and financial support for the conduct of periodic studies on STI prevalence, aetiology, and antibiotic sensitivity, every 3 years. Such studies serve as the fundamental basis for effective syndromic management. Even when aetiologic diagnosis is possible, test results are not immediately available, to help prevent further spread of infection.

D. STI Registries

In countries where malaria is endemic, the establishment of a national standard for syphilis testing is a priority. Where sustainable, the establishment of national syphilis registries for all reactive serologic syphilis tests performed is essential. The registry would permit STI control staff to differentiate between previously treated and new infections; document rising or failing titres; and as the programme develops greater analytic capabilities, provide information leading to more in-depth case analysis. Most positive serologies are identified as a result of screening programmes, and patients may be repeatedly treated who are sero-fast or even false positive. However, CAREC recommends to countries which may wish to use registries, that they analyse the cost effectiveness of this approach. And if this cost effectiveness is low then efforts should be focused on prevention and adequate treatment of syphilis cases to minimise the impact of disease in adults as well as children.
E. Potential Study populations for prevalence studies of STI

**Low-risk sub-populations:** Pregnant women attending antenatal clinics in the public and private sector, blood donors and young people are equivalent to the general sexually active population. However prevalence rates among pregnant women and young people will give an indication of the burden of STI in the general population.

**Populations at High-risk:**
- Female sex workers
- Substance abusers — IVDU or Crack Cocaine users
- STI patients — will often include uniformed populations, migrant populations and clients of female sex workers
- men who have sex with men (MSM)
- hospitality workers and
- street children — an often forgotten group

These groups have a high STI prevalence, compared to the general population. They tend to have multiple sex partners, a high probability of getting new sex partners, and low accessibility to health care systems, thus carrying their STI longer, without treatment. They constitute the essential core groups of STI transmitters and will provide a good idea of the burden of STI in these specific population groups.
## CARIBBEAN EPIDEMIOLOGY CENTRE
### QUARTERLY STI REPORTING FORM

<table>
<thead>
<tr>
<th>NAME OF COUNTRY:</th>
<th>YEAR ................................................</th>
<th>Quarter 1 2 3 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNIT / PROGRAMME:</td>
<td>REPORTING PERIOD: 1 2 3 4</td>
<td>DATE OF REPORTING:</td>
</tr>
<tr>
<td>STI Prevalence Rate in studies concluded during this period among specific groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Number of STI Cases Reported during this period:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### STI Prevalence Rate

<table>
<thead>
<tr>
<th>Blood donors</th>
<th>Pregnant women</th>
<th>MSM</th>
<th>FSW</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>

### Total Number of STI Cases Reported during this period:

<table>
<thead>
<tr>
<th>SYNDROMES</th>
<th>AETIOLOGIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral Discharge (Males only)</td>
<td>Gonorrhoea M</td>
</tr>
<tr>
<td></td>
<td>Chlamydia M</td>
</tr>
<tr>
<td></td>
<td>Non-Specific Urethritis (NSU) M</td>
</tr>
<tr>
<td>Genital Ulcer (Males &amp; Females)</td>
<td>Syphilis M</td>
</tr>
<tr>
<td></td>
<td>LGV M</td>
</tr>
<tr>
<td></td>
<td>HSV M</td>
</tr>
<tr>
<td></td>
<td>Chancroid M</td>
</tr>
<tr>
<td>Vaginal discharge (Females Only)</td>
<td>Gonorrhoea F</td>
</tr>
<tr>
<td></td>
<td>Chlamydia F</td>
</tr>
<tr>
<td></td>
<td>Trichomonas F</td>
</tr>
<tr>
<td></td>
<td>Bacterial Vaginosis F</td>
</tr>
<tr>
<td></td>
<td>Unspecified F</td>
</tr>
<tr>
<td></td>
<td>Others F</td>
</tr>
<tr>
<td>No Syndrome, but Laboratory test positive (Males &amp; Females) (serology positive)</td>
<td>Syphilis M</td>
</tr>
<tr>
<td></td>
<td>HSV M</td>
</tr>
<tr>
<td></td>
<td>Chlamydia M</td>
</tr>
</tbody>
</table>

### Infants

<table>
<thead>
<tr>
<th>INFANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmia Neonatorum</td>
</tr>
<tr>
<td>Gonorrhoea</td>
</tr>
<tr>
<td>Chlamydia</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Congenital Syphilis</td>
</tr>
</tbody>
</table>

---

HSV: Herpes Simplex Virus Infections  
Only the first episode should be reported  
LSV: Lymphogranuloma venereum  
FSW: Female Sex Workers  
MSM: Men who have Sex with Men  
*Count based on persons to avoid duplication
The CAREC Third Generation Surveillance promotes the surveillance of care for STI patients as well as for people living with HIV/AIDS in the Caribbean. This surveillance should be participatory and confidential.

There are four components of the surveillance of care surveys:

- one will focus on the institutional readiness to face the increasing demand for services because of the increasing number of people living with HIV/AIDS.
- the second component will focus on care receivers i.e. people living with HIV/AIDS who should be involved in every step of the surveys.
- the third will focus on the prevention of mother-to-child transmission of HIV and
- the fourth component will assess care for STI patients and flow charts used to treat STI cases.

Care and Quality of Care Surveillance and recommendations

Availability and quality of care are increasingly important, in particular because effective interventions, both to prevent opportunistic infection and to prevent progression of HIV disease, have become available. Discrimination, lack of adequate health care services and confidentiality may serve as discouraging factors for individuals seeking HIV diagnosis and care. Therefore, many persons are diagnosed late in the course of their HIV disease. In the meantime their health status has deteriorated substantially and they may have transmitted HIV to other people.

An important feature of the proposed surveillance strategy is to collect information that is generated during the delivery of basic health care services. Availability and access to health care will unquestionably influence the adequacy of surveillance information.

Care for STI Patients at the Institutional Level

For STI, many approaches will be used to measure quality of care: informal conduct of surveys in the treatment channels and the assessment of the availability of essential drugs to treat STI on a syndromic basis. The following surveys will be strengthened in CMGs through the Third Generation HIV/AIDS/STI Surveillance:

1. For STI management, CAREC will conduct audits biannually to assess the availability of medications which are necessary to implement syndromic management. These audits will be carried out within health institutions selected randomly in member countries.

2. CAREC will conduct in-country periodic audits of completed STI reporting forms, medical charts or existing national treatment guidelines to determine appropriateness of treatment of persons who present with STI syndromes.

Evaluation of Flowcharts

Validity, cost-effectiveness, and feasibility are evaluated in the assessment of a flowchart.

a. Assess Validity: this is accomplished by looking at the sensitivity and specificity of a diagnosis by comparing it to a gold standard diagnosis. Sensitivity is defined as the proportion of infections detected by a flowchart (A/A+C). A low sensitivity means that only a small number of individuals infected will be diagnosed by the use of the flowchart (D/B+D). A low specificity means that many negative cases will be wrongly diagnosed as being positive. Therefore, the ideal flowchart will be highly sensitive and specific.
The positive predictive value — the proportion of positives confirmed by laboratory testing — of a flowchart can be calculated using the following formula: \( \frac{A}{A+B} \). The negative predictive value — the number of negative results confirmed by laboratory diagnosis — can be calculated using \( \frac{D}{C+D} \).

**b. Determine your sample size:** a minimum number of patients will be required to test the validity of a flowchart; this can be determined using the formula below:

\[
N = \frac{(1.96)^2 \times P \times (1-P)}{L^2}
\]

Where \( N \) = your sample size, \( P \) = expected sensitivity (positive predictive value may be used). \( L \) = desired precision of the proportion. This is the range above and below your desired sensitivity. 1.96 represents a 95% confidence level.

For example, if you want a sensitivity of 80%, that is, your flowchart will correctly identify people suffering from a particular syndrome 80% of the time, and a precision of 5%, then your range of sensitivity will be 80 plus or minus 5.

For this example, \( p = .80 \) and \( L = .05 \).

Calculating cost-effectiveness:

a. Determine cost per patient, this can be calculated as follows:

\[
C = (P_d \times \text{cost of diagnosis}) + (P_t \times \text{cost of treatment})
\]

Where \( C \) = cost per patient, \( P_d \) is the proportion of patients who will undergo diagnosis and \( P_t \) is the proportion of patients who will be treated. Cost of diagnosis is equal to costs resulting from any laboratory tests (i.e. Gram stains), gloves, disinfectant and any other costs related to an examination. Cost of treatment is the cost of medication needed.

This information, when compared to costs incurred from aetiologic diagnosis can be useful in demonstrating the amount of resources that can be saved if syndromic diagnosis is utilised. However, it is important to realise that this approach can be cost-effective only when health care providers are appropriately trained and only when valid flowcharts are used.

For STI care-seeking behaviour, community based surveys are important ways to understand the underreporting of STI. Selected key pharmacies representative of the urban and rural areas should be surveyed on a periodic basis. This will complete information available in the national reporting system and will assist with understanding the magnitude of STI in communities. The physician-based surveillance of STI syndromes is another way to achieve this objective. The denominator in both cases should be clients seen at the institution for the period of the survey. The numerator is the number of persons seeking STI treatment.

Another valuable way to use this information is to compare the adjusted number of STI cases seen at the different pharmacies with the number of STI reported by national epidemiologists.

**Audit of Care and Treatment of PLWHA**

**A. Steps Undertaken at the Institutional level:**

1. CAREC, together with CMCs and the Caribbean Regional Network of People Living with HIV/AIDS (CRN+) developed a minimum package of care i.e. an inventory of basic health care services that all agree should be available to persons diagnosed with HIV infection. These are included as standards of care for counselling skills, health personnel training, and referral networks.

2. CAREC will assess the availability of standardised essential services during periodic evaluations of surveillance activities in its member countries. This will be achieved through cohort surveys, e.g. patients diagnosed during a specific year, retrospective studies among persons diagnosed with HIV/AIDS and special surveys.
3. CAREC will use data generated from national AIDS case reports — major and minor signs and indicator diseases at initial diagnosis — to determine the prevalence of specific AIDS-related infections.

4. CAREC will monitor specific prophylactic treatment regimens e.g. Cotrimoxazole for prophylaxis against *toxoplasmosis* or *pneumocystis carinii* pneumonia, or Isoniazid prophylaxis for tuberculosis, through surveys among health institutions and people living with HIV/AIDS.

5. CAREC adapted a survey instrument to assess institutional readiness based on the WHO indicators developed for measurement of institutional capacity (structure and human resources) to provide care for people living with HIV/AIDS.

B. Survey among the PLWHA Community:

Coverage — the proportion of people with HIV disease who are receiving care — is an important aspect of quality of care. However, in the case of HIV/AIDS there are difficulties in calculating this indicator because in many countries an accurate estimate of the total number of PLWHA is not available. In countries where a good estimate of the number of PLWHA exists, the indicator can be calculated with the number of people receiving care as a numerator and with the estimate of the total number of PLWHA as the denominator. Where accurate estimates of the number of PLWHA do not exist, calculation of this indicator is of very limited usefulness. Nonetheless, CAREC recommends that coverage of care be calculated by using the following formula:

\[
\frac{\text{No. of persons (PLWHA) receiving standard care}}{\text{No. of persons diagnosed with HIV using Laboratory, Medical Records, Registries or Patient Management Information database as a source of information}}
\]

Depending on the country situation, random sampling can be used within a cohort of individuals tested HIV+ and identified, for example, in national laboratory records or in the confidential national HIV/AIDS registries. As an alternative, a snowball sampling approach can be used. In instances, where antiretroviral treatment is introduced and patient management information is in place, these databases should be used to audit quality of care provided to people living with HIV/AIDS. However, face-to-face and observational studies will be useful to complement database audits of quality of care.

Major indicators to be measured by national epidemiologists for impact of treatment and the essential package of care for people living with HIV/AIDS are:

- The reduction in the number of new AIDS cases
- The reduction in frequency of hospitalisation of PLWHA
- The reduction of incidence of opportunistic infections in individuals living with HIV
- The reduction of STI incidence in PLWHA
- The increase of safer sex practices in PLWHA
- The improvement of knowledge about HIV case management among health care providers
- The reduction in reported stigmatisation towards PLWHA in health care systems.

In the Caribbean, the “snowball or network sampling” methodology may be the best way to conduct surveys among people living with HIV/AIDS, despite the fact that it is a non-probability sampling method with potential selection bias. Another useful method is multi-stage cluster sampling. This could target Community Based Organisations (CBOs) involved in care for PLWHA as they may constitute the sites or locations where respondent group members congregate. If these are numerous, it is important to map them as primary sampling units (PSUs) and compile a list from which a random selection can be made. Then a list of individuals is compiled from PSUs selected and individuals chosen at random, preferably, or consecutively — two-stage sampling design. For the sample size determination, it is important to be in a position to measure changes between two proportions in terms of quality of care for people living with HIV/AIDS and their protective behaviours (for sampling methodologies see Behavioural Surveillance component).

For selection of the PSUs, it is important to take into account variability related to the movement of the target population. If the population is fixed, conventional clusters may be used, but if the presence of the respondents is time-bounded e.g. many PLWHA attend when it is dark and not during the day, then to achieve representativeness, the selection should be from time-location clusters.

CAREC has developed and tested an instrument to conduct surveys among people living with HIV/AIDS regarding their perspective on the quality of care provided to them in the health care systems; the social reaction to their condition; and their own protective behaviours (Lambourne, Isaacs and Joseph, 2000). The survey instrument was developed and tested in Trinidad and Tobago with the full support and collaboration of PLWHA members of the Caribbean Regional Network of PLWHA (CRN+) (see CAREC Guidelines on Evaluation of HIV/AIDS/STI Surveillance Systems).
Surveillance of Impact of PMTCT Programmes

Reduction of mother-to-child transmission of HIV is one of the CCH2 priorities. Many CAREC member countries have implemented this prevention approach to reduce HIV incidence among children. In the Caribbean every year, an estimated 2,600 to 3,900 children are born to HIV positive mothers. Through this approach at least 780 new HIV transmissions can be averted among children. To measure the impact of MTCT, CAREC has developed and tested a surveillance instrument to assist national decision-makers and health planners. Through this instrument, the CAREC Third Generation Surveillance brings surveillance closer to action and measurement of impact. Therefore, it is recommended that member countries gather data required for the survey, which CAREC will administer on a yearly basis to measure the impact of PMTCT programmes (see CAREC Guidelines on Evaluation of HIV/AIDS/STI Surveillance Systems).

Major indicators to be measured in terms of impact of prevention of mother-to-child transmission of HIV are:

- Increase in the number of children born HIV negative to HIV positive mothers
- Increase in the number of pregnant women and partners who have participated in PMTCT programmes, to determine acceptance of the programme (uptake)
- Reduction in the number of repeaters
- Impact of counselling programmes

OTHER SOURCES OF INFORMATION:

Central Statistical Offices: in the majority of the CMCs, medical authorities issue death certificates to families, for every death occurring. Although many families do not wish that medical authorities put AIDS as the cause of death on the certificates, they accept opportunistic infections or syndromes as causes of death. Death certificates are therefore an important instrument to assess underreporting of AIDS deaths and AIDS cases because they capture information that meets the criteria for the AIDS case definition (the ICD 10 classification), specifically taking into account the AIDS related opportunistic infections and age. This information becomes more important when it measures age-specific mortality. The CAREC Third Generation Surveillance recommends that Central Statistical Offices (CSOs) be considered as key sources of information on AIDS mortality and that they should be included in the evaluation of national HIV/AIDS/STI surveillance systems to determine the level of underreporting of AIDS deaths.

Pharmacies: in the Caribbean, it has been documented that self-treatment of STI patients is common. Therefore, pharmacies should be included in epidemiological surveillance systems as important sites to be used by national epidemiologists during regular surveys to find out about clients who buy STI drugs over the counter to try to treat their infection. Whenever possible, surveys should include information on demographic variables such as age, gender and residence and the reasons for seeking treatment. This can be documented or reported for survey purposes on a syndromic basis, e.g. genital ulcer, urethral discharge, vaginal discharge, etc.
The clinical or public health laboratory may be the site that first detects an outbreak, or a change in disease patterns, or an emerging disease. The laboratory generates critical information used by epidemiologists to track disease patterns, identify new diseases, identify health problems and develop strategic interventions used by clinicians to confirm diagnoses, manage patients and supply information required for disease surveillance; and used by researchers to identify, analyse and resolve health problems.

The laboratory is thus a key component of the surveillance system in that it generates diagnostic and research data that contribute to the foundation on which HIV/AIDS control & prevention programmes are built. As a result of laboratory action, trends can be more readily assessed, resistance patterns can be tracked, effective and timely health policies can be developed and the quality of care can be greatly improved through early and reliable diagnoses and treatment.

Laboratory staff must therefore play an integral role in the surveillance team. They must be included in the planning and development of surveillance interventions and they must fully appreciate the objectives of surveillance action and the importance of managing laboratory data to allow for the provision of accurate and timely information.

Since a significant percentage of data feeding into the surveillance system is generated by the laboratory, the quality of laboratory data, namely, the accuracy, reproducibility and timeliness of laboratory data impacts the quality of surveillance data and by extension, the effectiveness of surveillance action.

**Laboratory Quality:**

**Determinants of a laboratory’s reliability:**

The reliability of a laboratory’s results is dependent on the standards that govern its operations. In the absence of adherence to established standards, error may be a frequent occurrence in laboratories. The Surveillance Team can help to ensure that laboratories produce high quality results by working together with laboratories to implement systems governed by recognised standards. In the absence of a national accreditation or licensing mechanism, laboratories must take responsibility for implementing and maintaining strong Quality Assurance (QA) programmes that ensure the quality of their complete service, from managing the patient and sample to providing reports or other information to clients. Key components of a Laboratory’s QA programme must include:

- Standard operating procedure manuals that are formatted to allow for clear, easy-to-follow instructions and that are used routinely by all laboratory staff to ensure that testing is conducted in the right way by all of the technologists all of the time.

- Effective quality control that involves the monitoring of every HIV/STI test run with appropriate controls, charts or graphs. Run data should be analysed and validated before results are dispatched to clients.

- Proof of participation in External Quality Assessment Programmes for HIV/STI laboratory testing. These programmes may be provided at a cost or free-of-charge by CAREC and its partners.
• The conduct of evaluations and statistical analyses of the data for all new HIV/STI assays before implementation, as part of a routine algorithm, to ensure that the test result is a reliable indicator of the presence or absence of HIV infection.

• Adequately trained and competent staff.

**HIV/STI Test Performance:**

The performance of an HIV or STI assay is defined by its ability to correctly identify infected or uninfected individuals. Test performance in a laboratory is dependent not only on the inherent assay characteristics but on the characteristics of the population to be screened and on the quality of the laboratory’s testing process. An assay’s performance may vary from laboratory to laboratory, thus all HIV and STI test algorithms should be evaluated within the laboratory setting before implementation for routine testing. Test performance is generally characterised through the measurement of test sensitivity, specificity, and negative and positive predictive values. These are defined as follows:

**Sensitivity**
The sensitivity of a test is the frequency with which it identifies proven positive samples as reactive. Therefore, a test with a high sensitivity produces few or no false negative results but may produce false positives i.e. there will be no persons or only a small number of people who, if infected, will not be detected by the test.

\[
\text{Sensitivity} = \frac{\text{True Positives}}{\text{True Positives} + \text{False Negatives}} \times 100
\]

**Specificity**
The specificity of a test is the frequency with which it identifies proven negative samples as non-reactive. Therefore, a test with high specificity produces few or no false positive results but may produce false negatives i.e. there will be no persons or only a small number of people, who if not infected, will test positive.

\[
\text{Specificity} = \frac{\text{True Negatives}}{\text{True Negatives} + \text{False Positives}} \times 100
\]

**Negative Predictive Value**
The negative predictive value is the likelihood that a sample identified as non-reactive (negative) by a test is truly negative.

\[
\text{Negative Predictive Value} = \frac{\text{True Negatives}}{\text{True Negatives} + \text{False Negatives}} \times 100
\]

**Positive Predictive Value**
The positive predictive value is the likelihood that a sample identified as reactive (positive) by a test is truly positive.

\[
\text{Positive Predictive Value} = \frac{\text{True Positives}}{\text{True Positives} + \text{False Positives}} \times 100
\]

Generally in a:
Low prevalence population

\[\text{True Positives} < \text{False Reactives}\]

High prevalence population

\[\text{True Positives} > \text{False Reactives}\]

It is important to remember that for a given sensitivity and specificity, the probability that a test identifies the true infection status of an individual changes in accordance with the prevalence of the infection in the population studied. With increasing prevalence of infection, the proportion of false positives decreases.

For surveillance purposes the testing strategy (selection of test - incorporating only one test or also a second confirmatory test), will depend upon the accuracy required in the survey population being tested. It is essential that rates of false reactivity i.e. false positive tests and positive predictive values are estimated for each testing strategy and in each survey population. However, it should be noted that, in general, the cost of surveillance testing increases if some false results cannot be accepted.

**Laboratory Support for HIV/STI Surveillance Studies:**

The Laboratory staff member designated to oversee collaborative surveillance studies should develop the laboratory component of the study protocol. The protocol
must outline in great detail procedures and responsibilities for:

• sample collection and handling
• sample transport
• sample accessioning and processing
• sample storage and testing
• quality control procedures
• safety procedures
• data recording, collation, processing and reporting, and
• maintenance of confidentiality of study information.

The principal investigator must periodically monitor the progress of studies through observation and discussion with laboratory staff conducting the study to ensure that the study protocol is being adhered to and especially that there is compliance with sampling, quality control and safety procedures.

The types of samples collected for studies will depend on the specific diseases that are being monitored and the tests that are being used. Clinical guidelines and laboratory procedure manuals should be consulted for instructions on relevant and appropriate sampling and testing methods. The study protocol must outline:

• the participant enlistment protocol
• mechanisms for the procurement of supplies
• budgets supporting study expenditure
• staff competencies & responsibilities
• collection vials and transport and/or shipping mechanisms to be used (based on IATA guidelines for shipping)
• the sample logging and data recording formats to be used for the specific study (unlinked, anonymous or other)
• the appropriate sample storage conditions
• the test algorithms and specific assays to be used
• the turn-around-time for testing
• the standard quality control procedures applicable for the specific test
• safety considerations to be observed
• systems for the maintenance of confidentiality of study data
• data collation formats
• data analysis and/or reporting

**Appropriate Samples for HIV Surveillance & Diagnosis:**

<table>
<thead>
<tr>
<th>Sample</th>
<th>Suitable For</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole blood, plasma,</td>
<td>Surveillance, clinical diagnosis, blood donor screening, PMTCT programmes,</td>
</tr>
<tr>
<td>serum</td>
<td>research</td>
</tr>
<tr>
<td>Dried blood spots</td>
<td>Surveillance, clinical diagnosis, research, PMTCT programmes,</td>
</tr>
<tr>
<td>Oral fluid</td>
<td>Surveillance, PMTCT programmes, clinical diagnosis, research</td>
</tr>
<tr>
<td>Urine</td>
<td>Performance issues still to be resolved</td>
</tr>
</tbody>
</table>

**Cautions for HIV Sampling**

The *recommended* matrix (type of filter paper) should be used for the collection of dried blood spots.

Oral fluid samples can only generate reliable results if tested with the ELISA that is *recommended by the manufacturer*. Only the recommended ELISA should be used.

**Appropriate HIV testing Strategies:**

All HIV tests or algorithms to be introduced and utilised by national laboratories should be *appropriately evaluated* before being implemented for routine testing.

While not relevant for the conduct of surveys, it is important to note that both CAREC and WHO recommendations state that *in the absence of clinical signs of AIDS*, all persons who are diagnosed as HIV positive for the first time *must* have a new sample drawn and re-tested to ensure that laboratory error has not occurred. Laboratory error can occur in the best of laboratories.
### HIV Indeterminate Reactions:

The reasons for indeterminate reactions may include, among others:
- Early HIV antibody formation
- Loss of core-specific antibody late in infection due to severe immunosuppression
- Autoantibodies e.g. ANA & rheumatoid factor
- Recent immunisation e.g. tetanus boosters

#### The HIV Indeterminate Reactor:

- Low-risk persons who exhibit a non-reactive ELISA result on repeat testing do not need further follow-up.
- High-risk individuals should be re-tested over a 6-month period. If they continue to exhibit an indeterminate reaction on a western blot test (or other supplemental test) they are confirmed as HIV uninfected.
- Supplemental tests such as the HIV-1 p24 antigen or the PCR test for the detection of plasma HIV-1 RNA or HIV-1 proviral DNA, may be used to give a more definitive result.

### Diagnosis of HIV Infected Children:

Optimally, identification of infants at risk of HIV infection should be accomplished through prior recognition of HIV infection in their mothers during pregnancy. This would allow for adequate care and management of both the mother and the HIV-exposed or infected baby and more positive patient outcomes. Almost all babies born to HIV positive women may be HIV positive at birth due to maternal antibodies that have crossed the placenta to the foetus. They may be present in babies up to 18 months of age. Therefore, antibody testing is not a reliable diagnostic tool for a definitive confirmation of paediatric infection in children younger than 18 months.

However, infants born to HIV positive mothers who demonstrate initially positive serology may be confirmed as uninfected if they have two or more HIV-antibody negative test results at 18 months. If antigen tests are available e.g. PCR, infants may be tested at 1 and at 4 – 6 months and can be diagnosed as HIV positive or negative if at least two consecutive tests are positive or negative respectively. PCR assays are therefore among the most sensitive and specific assays for identifying HIV infection in children.

<table>
<thead>
<tr>
<th>Reason For Testing</th>
<th>Confirmatory Testing Strategies &amp; Interpretation</th>
</tr>
</thead>
</table>
| Clinical diagnosis (adults) | **Non-infected:** one ELISA or Rapid/Simple Test (negative)  
**Infected:** Traditional Algorithm: one ELISA or Rapid/Simple Test positive, Supplementary Test e.g. Western Blot positive  
**Alternative Algorithm:** a combination of two or more: ELISA tests (at least two positive) or Rapid/Simple Tests (at least two positive) or ELISA and Rapid/Simple Tests (at least two positive) |
| Clinical diagnosis (child = 18 months) | **Non-infected:** One Polymerase Chain Reaction (PCR) test at 1 month, repeated at 4 months (both negative)  
**Infected:** One Polymerase Chain Reaction (PCR) test at 1 month, repeated at 4 months (both positive) |
| Clinical diagnosis (child > 18 months) | **Non-infected:** one ELISA or Rapid/Simple Test negative  
**Infected:** Traditional Algorithm: one ELISA or Rapid/Simple Test positive + Supplementary Test e.g. Western Blot positive or  
**Alternative Algorithm:** a combination of two or more: ELISA tests (at least two positive) or Rapid/Simple Tests (at least two positive) or ELISA and Rapid/Simple Tests (at least two positive) |
| Blood donations | One ELISA or Rapid Test: If reactive, the blood must be discarded.  
If negative the blood may be transfused |
| Monitoring treatment | Repeated plasma HIV-1 RNA tests and CD4+ counts prior to treatment and at 3-4 month intervals after a stable response has been achieved or Alternative Algorithms |
| Surveillance studies | A combination of two or more: ELISA tests or Rapid/Simple Tests or ELISA and Rapid/Simple Tests |
| Research | As indicated by research objectives |
**Appropriate Samples and Testing Methodologies for STI Surveillance & Diagnosis**

<table>
<thead>
<tr>
<th>STI Pathogen</th>
<th>Sample</th>
<th>Testing Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Treponema pallidum</em></td>
<td>Blood</td>
<td>Non-treponemal tests e.g. RPR, VDRL</td>
</tr>
<tr>
<td></td>
<td></td>
<td>FTA-ABS, MHA-TP</td>
</tr>
<tr>
<td><em>Neisseria gonorrhoeae</em></td>
<td>Urine</td>
<td>LCR, PCR</td>
</tr>
<tr>
<td></td>
<td>Urethral swabs</td>
<td>Culture; Non-amplified DNA probe (GenProbe); LCR; PCR;</td>
</tr>
<tr>
<td></td>
<td>Endocervical swabs</td>
<td>Culture; Non-amplified DNA probe (GenProbe); LCR; PCR;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Culture; Non-amplified DNA probe (GenProbe); LCR; PCR;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>LCR; PCR</td>
</tr>
<tr>
<td><em>Chlamydia trachomatis</em></td>
<td>Urine</td>
<td>PCR; LCR; Culture; Non-amplified DNA probe (GenProbe); Direct</td>
</tr>
<tr>
<td></td>
<td>Urethral swabs</td>
<td>Fluorescent Antibody test; EIA</td>
</tr>
<tr>
<td></td>
<td>Endocervical swab</td>
<td>PCR; LCR; Culture; Non-amplified DNA probe (GenProbe); Direct</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fluorescent Antibody test; EIA</td>
</tr>
<tr>
<td><em>Trichomonas Vaginalis</em></td>
<td>Vaginal Swabs</td>
<td>Wet preparation, Culture</td>
</tr>
<tr>
<td></td>
<td>Urine</td>
<td>Wet preparation</td>
</tr>
</tbody>
</table>

**Cautions for STI Sampling and Testing:**

Endocervical swabs collected for gonorrhoeal culture should be streaked on to culture plates immediately and incubated at 35-37°C in a CO₂ enriched atmosphere or transported in appropriate transport or growth media to the laboratory where samples should be plated within 6 hours to avoid rapid deterioration of viability. Swabs for GC recovery should not be refrigerated.

Blood should not be allowed to sit on the clot for too long especially if temperatures are high. Samples should be spun and the serum removed and refrigerated if testing is to be delayed. Serum should always be removed from the clot before testing.

Fresh samples should be used to make wet preparations for the diagnosis of trichomoniasis. In older samples, these parasites may be non-motile or very distorted and difficult or impossible to identify.

All samples collected must be transported under the specific conditions outlined in the laboratory’s procedure manual.
G
ood quality surveillance yields information that is useful in reducing the spread of HIV and in providing care for those affected. Behavioural surveillance provides information which may be used to reduce the spread of HIV, as sexually transmitted infections by definition are transmitted by interpersonal behaviour. It may be used to provide early warning of the epidemiological pattern and trends, to predict the burden of the disease and thus plan for care and support. It can help monitor the progress of interventions in reducing risk behaviours.

There is a need to provide data which allows trends to be assessed over time and for comparisons to be made in behaviours between geographical areas and groups. This will enable policies and interventions to be optimally effective by facilitating the allocation of resources where they are most needed and where they will have most impact.

By identifying the extent of risk behaviour and the groups most at risk, the data enable the design of targeted interventions. Behavioural data should be used to support/guide behavioural interventions; for example, showing young people the true extent of risk behaviours has been shown to be effective in motivating behaviour change through a “peer norms” effect. Sometimes the extent of harmful behaviour is not as extensive as popularly thought and this fact can be utilised to encourage and help sustain safer behaviour. On the other hand, data showing the extent of risk behaviours can serve as a clarion call to action for policy- and decision-makers, and lead to the more effective allocation of resources.

This chapter draws on the recommendations and guidelines for behavioural surveillance of a number of agencies, particularly UNAIDS, WHO, Family Health International (FHI) and the US Centers for Disease Control and Prevention (CDC). Occasionally their recommendations are repeated, and where this takes place the source is acknowledged. Their guidelines are intended to be used in a wide variety of contexts across the world. However, the Caribbean has unique features and challenges and this chapter takes these into account in tailoring behavioural surveillance guidelines and recommendations to the needs of the region. Local Caribbean examples are used wherever possible. The aim is to synthesise a large quantity of information on best practice which is available from international agencies, while being sensitive to local Caribbean realities.

Definition and aims of HIV/ AIDS/ STI Behavioural Surveillance

Behavioural surveillance has been defined as repeat cross-sectional surveys of behaviour in a representative population (UNAIDS/WHO, 2000). Its aims are:

- To provide early warning of the burden of disease by identifying risks
- To identify the extent of behaviours which continue to drive an established epidemic
- To identify the population groups most at risk and thus target interventions, and
- To help monitor the success of interventions

Repeated studies are needed in order to meet each of these aims. It is necessary to show trends and changes in behaviours and their distribution by social and demographic groups and geographic areas.

Many existing behavioural studies in the Caribbean, as elsewhere, have focussed on providing information for a single behavioural intervention or communications campaign. They have been oriented to particular research
questions, such as, “Which media should be used to transmit AIDS messages?” The most popular kinds of
research conducted in the Caribbean region have been Knowledge, Attitudes, Beliefs and Practices (KABP) surveys. These have been used to guide communications campaigns but have had limited use in informing national AIDS policy. Because most of the surveys have been one-off activities, they have not enabled comparisons over time.

Just as medical scientific thinking has progressed, the thinking of social and behavioural scientists has changed over time with regard to the types of data which will enable the most effective responses to the HIV epidemic. The need for a mapping of risk behaviours over time and between groups is now seen as crucial.

The need for comparability means that behavioural surveillance involves primarily **quantitative methods** of data collection. Quantitative research provides answers to pre-defined questions. It is ideal for achieving reliability and comparability through utilisation of standardised procedures and questions and representative sampling techniques. It lends itself well to **description**, which is the basic purpose of a surveillance system.

Behavioural surveillance involves **surveys** in a **cross-section of a representative population**. This means that sampling techniques should be used to generate the most representative sample possible, and sample sizes should be sufficiently large to generate statistically reliable estimates for the population as a whole. In practice it may not be possible to conduct random sampling, and sample sizes may be restricted. This is primarily because behavioural surveillance often involves conducting surveillance with vulnerable groups, and ethical and practical considerations preclude the use of optimally representative methods. These methodological issues, and ways to address them, are considered below.

While behavioural surveillance utilises primarily structured questionnaire surveys, qualitative behavioural research can play an important role in the surveillance system. Qualitative research methods, such as focus groups and depth interviews, may be used to explore reasons why people behave in particular ways. Such information is crucial to the design of effective behavioural interventions. It is widely recommended that data from a range of behavioural studies should be integrated into the surveillance system. Section 2.3 discusses the role of qualitative research within this system.

**Types of surveys**

Two main types of structured questionnaire surveys should be utilised in behavioural surveillance for HIV; household surveys with the general population and behavioural surveillance surveys with vulnerable groups.

### 2.1 General population surveys

A common approach in the Caribbean has been to conduct household surveys with the general population on Knowledge, Attitudes, Beliefs and Practices (KABP) related to HIV. Household surveys can give a good picture of risk behaviour in the general population. They are most useful in countries with generalised epidemics that are sustained by significant levels of sexual mixing between men and women in the general population. For example, if a large proportion of people have more than one sex partner per year, infections are likely to spread quite rapidly, and household surveys will be able to detect changes in numbers of partners.

A generalised epidemic is defined by UNAIDS/WHO as follows:

**Principle:** In generalised epidemics, HIV is firmly established in the general population. Although 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.

**Numerical proxy:** HIV prevalence consistently over one per cent in pregnant women.

According to this definition, a number of CMCs now have a generalised epidemic, with HIV prevalence estimated to be around two per cent overall according to various surveys among pregnant women. A review of KABP surveys revealed that between 11% and 34% of adults over 15 in various CMCs had had more than one partner over the past year. This minority is substantial and those with multiple partners are more likely to spread infection to others, including those with only one partner. This is especially likely as only a minority of adults always use condoms, ranging between 7% and 29% in KABP surveys in CMCs (Allen et al, 2001).

Under these circumstances, periodic surveys of behaviour in the general population are appropriate. Specific surveys on HIV risk may be conducted, or questions on HIV risk behaviour may be included in other general population surveys such as Demographic and Health Surveys (DHS). A few key indicators of HIV risk should be included in every survey, as shown in the “indicators” section below.

An advantage of household surveys is that they are usually based on solid sampling methods, and statistical analysis is generally reliable, and data can be compared over time with some confidence.
A disadvantage of household surveys is that they are time consuming and expensive, particularly when they include a random sample of households that is representative of the whole country or large region. Because they are so expensive, it is rarely possible to conduct this sort of survey more than once every four or five years (FHI, 2000).

**It is recommended that household surveys including key indicators of HIV risk behaviour be conducted at least every five years in each Caribbean country.**

One way to reduce the cost is to include the key indicators in other surveys which are regularly conducted by the Central Statistical Office.

Household-based surveys are useful for advocacy, given that policy-makers are often interested in the aggregate picture for the general population. They can be used to interpret trends in HIV infection. They can orient programme design and monitor behaviour following prevention campaigns. However, it is difficult to assess the effect of a single intervention using this method. Rather, these surveys show the aggregate effect of HIV/AIDS prevention activities at the national level (UNAIDS/WHO, 2000).

### 2.2 Behavioural surveillance surveys with vulnerable groups

Household surveys are less useful in looking at behaviours that are quite rare in the general population but are concentrated in certain sub-populations and which contribute to HIV risk. An example is use of crack cocaine which might be high among groups such as out-of-school youth, the homeless and commercial sex workers. Groups at high risk may not be included in sufficient numbers in household surveys to yield statistically significant information about their behaviour. Mobile populations such as economic migrants or those who gather in institutions such as prisons or barracks may also be missed or underrepresented in household surveys. Yet these groups may be highly vulnerable to infection and be of interest to those who wish to design and evaluate HIV prevention activities for them.

Behavioural surveillance surveys (BSS) aim to concentrate attention on behaviours and sub-populations that contribute most to the potential spread of HIV. Adolescents and young people are highly vulnerable to infection, and indications are that the highest rates of incidence are in the age group 15 to 24, with severe social and economic repercussions for Caribbean societies. Various studies in CMCs have shown rates of HIV infection well in excess of 10% among commercial sex workers and men who have sex with men (see chapter on Surveillance of HIV Infection). Thus, in the Caribbean, we can say that the epidemic is both generalised (more than one per cent in pregnant women) and concentrated (substantially higher in certain sub-populations). The situation calls for a combination of general population surveys and behavioural surveillance surveys (BSS) with vulnerable groups.

Behavioural surveillance surveys in the Caribbean should prioritise three high-risk groups:

- Young people
- Female Sex Workers (FSWs)
- Men who have sex with men (MSM)

Specific guidelines for the conduct of surveys with these groups are provided below.

Other groups may be at high-risk in particular Caribbean contexts. Depending on local circumstances, BSS may usefully be conducted with groups including the following:

- Incarcerated populations (prisoners)
- Private minibus operators (“Maxi-taxi” drivers, conductors and touts)
- Uniformed male military and security personnel (army, police, security guards)
- Migrant workers
- People employed in the tourism sector
- Homeless people
- Street children
- Informal commercial importers (“hucksters” and “higglers”),
- Unemployed people and
- Miners.

Some of these groups are subject to discrimination; for all, there are challenges in gaining access to survey respondents. Ethical and practical guidelines for working with vulnerable groups are presented below.

While international behavioural surveillance guidelines often recommend surveys among intravenous drug users (IVDUs), this is not recommended in the Caribbean, as IVDUs are very rare in this region, with the exception of Bermuda. The inclusion of questions about drug use in surveys with other vulnerable groups will enable estimation of the extent and rate of increase of IVDU and may suggest the need for surveillance with this group in future.

#### 2.2.1 Choice of populations for behavioural surveillance surveys

In the absence of behavioural interventions, risk behaviours are unlikely to change. If they do change in response to societal trends such as urbanisation, these changes tend to be slow and incremental. Thus it makes little sense to establish BSS among groups for whom there is no current or planned programme of prevention, care or support which enables behaviour change. BSS is meaningful as part of an integrated HIV prevention and care programme. Where an
ongoing programme of prevention and support exists or is planned for a particular population group, BSS should be established for this group.

In some CMCs, National AIDS Programmes (NAPs) have conducted interventions in schools and have a strong and co-operative relationship with the Ministry of Education and school authorities. In these countries, BSS may be conducted among young people in school. If there are plans to develop programmes with out-of-school youth, behavioural surveillance may also incorporate a sample of these young people, using a variable to distinguish in and out-of-school youth for comparison purposes.

In a few CMCs, NAPs have established a trusting relationship with groups of men who have sex with men and/or sex workers. For example, they might have carried out training for leaders and facilitators of the group, or have a promotion programme involving group members distributing condoms to their peers. Under such circumstances, the NAP can work with key people in the MSM or FCSW community to develop systems of behavioural surveillance.

A further crucial factor is the relative contribution of different groups to the spread of HIV. The groups which contribute the most should be prioritised. Care should be taken to use existing data, including research reports and publications, which can indicate which sub-populations are most at risk. Press reports and interviews with people likely to have information on sexual and drug-taking behaviour can also inform preliminary decisions. The process of choosing sub-populations can include a rapid assessment stage confirming that members of the group are sufficiently numerous and they do engage in high-risk behaviours.

**Key factors in the choice of groups for behavioural surveillance are:**

- The estimated extent of their contribution or potential contribution to the spread of HIV in the local situation
- A relationship of trust and cooperation between the survey implementers, the group and “gatekeepers”, e.g. school authorities
- Existing or planned behavioural interventions with this group

In order to be sensitive to changes in behaviour, BSS should be conducted once a year or at least biannually with each group.

Note that behaviour change tends to be quite rapid in a tightly-knit community of people who interact frequently. This applies to most populations at high risk.

It is important to note that certain groups are inappropriate for behavioural surveillance. These are groups which encounter services as a result of behaviour which could put them at risk of HIV, such as multiple partners and sex without a condom. STI patients and pregnant women who adopt safer sexual practices will drop out of the population attending the clinics. Thus successive surveys at clinics will not reveal the impact of interventions. In addition, the sexual practices of pregnant women are generally not typical of their behaviour when they are not pregnant.

### 2.3 The Role of Qualitative Research in Behavioural Surveillance

The aim of this section is to highlight the utility of qualitative research within the HIV surveillance system. It has an important role in designing BSS and in translating the results of behavioural surveillance into effective interventions.

To explain behaviours measured in behavioural surveillance surveys, a variety of research methods may be used. These include utilising data from the surveys to explore statistical links between sexual behaviour and factors thought to be associated with them, e.g. attitudes and demographic characteristics. It should be noted that statistical association does not of itself amount to explanation. Say, for example, that in a survey of youth we find that propensity to use condoms among the sexually active rises with age. Since age does not explain condom use, further research may be needed to discover the barriers preventing younger people from utilising condoms, as well as the factors which enable higher condom use among older youth.

Qualitative research can assist in providing such explanations. Focus groups and depth interviews may be conducted following behavioural surveillance surveys in order to explain particular findings. Qualitative research methods are most appropriate to questions of why? and how? Examples of appropriate hypothetical research questions are as follows:

1. Why is condom use with non-regular partners higher among younger than among older male adults?
2. How can condom use be increased among older men?
3. There has been a rise in condom use among female sex workers with their clients over the last three years. How has the rise been achieved?

Respondents to qualitative research may be drawn from vulnerable groups and from among service providers. The respondents for research on the first question above would be male adults stratified by age group. Separate focus groups may be conducted for older and younger males exploring attitudes to condom use. Such groups may also be used to provide a partial answer to question 2 above.

What do older men themselves think are the best ways to increase condom use among them? The question may also be addressed to service providers. Can condom providers
Questions may be formulated which ask about associations between drug use and sexual behaviour. An example of such a question would be:

“In the last three months, did you use crack cocaine to get high before having sex with a man?”

In short, qualitative research may be employed to:

- **Explain** patterns of behaviour revealed in BSS (the *why*)
- Identify the **processes** through which behavioural change has been achieved (the *how*)
- Identify the units to be measured in BSS (*what* should we be measuring?)

A variety of techniques may be used, including participant observation, unstructured depth interviews and focus groups. The following table contrasts some of the main features of qualitative and quantitative research:

<table>
<thead>
<tr>
<th>Quantitative Research Questions</th>
<th>Qualitative Research Questions</th>
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Good for:

- **Descriptive** data
- **Monitoring** behaviour
- **Reliability**

Good for:

- **Discovery**
- **Explanation**
- **Process**
- **Experience**
- **Validity**
3. Steps in setting up and conducting behavioural surveillance

This section largely follows the recommendations of FHI (2000), with specific considerations being given to the Caribbean context. It outlines a series of necessary steps for the effective functioning of behavioural surveillance. The steps are as follows:

1. Build partnerships
2. Build agreement on the survey process
3. Define measurement objectives
4. Operationalise definitions of populations of interest
5. Select and map sites
6. Construct a sampling frame
7. Develop the survey protocol
8. Pre-test and adapt survey instruments and survey procedures
9. Train interviewers
10. Supervise Data Collection
11. Guide Data management
12. Guide Data analysis
13. Use the data to improve HIV/STI prevention, care and support

The process of behavioural surveillance is not as linear as this series of steps might suggest. Information gathered in one step may lead to the review of decisions made at other steps.

Note that steps 1 to 8 are concentrated in the period before the first survey round. Once the procedures have been established, the second and subsequent rounds are less time and labour intensive, concentrating on steps 9 to 13. For steps 9 to 13 the workload will diminish over time as they become routine and a bank of people is established with experience of conducting behavioural surveillance.

Step 1: Build partnerships

We showed above that a relationship of trust and cooperation with people from vulnerable groups and “gatekeepers” is a prerequisite to BSS. Partnerships must be built with these groups and others who will be involved in conducting surveys and utilising the data. A number of groups and individuals should agree on the goals of the data collection as well as the practicalities. This will ensure that surveillance produces results that are usable and are used.

Public health officials and other government agencies

Behavioural surveillance is most likely to occur under the leadership of the national AIDS programme or the national epidemiologist. Besides managing the HIV surveillance system (both behavioural and serological), public health officials are likely to be prime users of the data in order to improve national prevention and care programmes.

It is important to recognise that leadership does not mean that public health officials necessarily have to implement the surveys themselves. Surveys and data analysis may be conducted by a range of institutions, including local universities and NGOs. But if the results of data collection are to meet their needs, programme officials will want to maintain a leading role in overseeing the methodology as well as in disseminating the data and lobbying for its effective use.

Public health officials are well placed to seek support from other quarters of government. Formal approval for research with human subjects should be sought from national authorities. Other ministries may be “gatekeepers”, and should be involved and consulted to ensure access to target groups. Education officials can help provide a sampling frame and secure the support of school Principals for surveys among students, for example.

Organisations and individuals providing services to communities at risk

In CMCs, support for people in high-risk groups is often provided by non-governmental organisations. For instance, a women’s organisation may be involved in training sex workers to negotiate safer sex. A religious organisation may provide food and other resources to the homeless and unemployed. Private minibus operators may be organised into a trade union, which may or may not have formal legal status.

For people engaged in illegal or highly stigmatised activities, there is often no organisation providing support. It may be that an individual provides services, formally or informally, to people at risk. For instance, a professional counsellor may see a substantial number of people in vulnerable groups, especially if the clients know that they are HIV positive. Often such professionals waive their fees for especially needy people. In another case, a person from a vulnerable group, for example a gay man, may informally provide support to others. He gains a reputation as someone who MSM can approach in times of trouble.

Formal and informal counsellors and people in NGOs have an important contribution to make in planning BSS activities, for the following reasons:

• They have a deep and sensitive understanding of the group, and can provide effective suggestions for research methods. They can help prevent unethical or risky research practices.

• They have good access to communities that are otherwise difficult to reach. The trust that they have
established with communities provides a platform from which successful behavioural surveys — and interventions — can be launched.

- They may become involved in carrying out the research themselves. They may possess the skills to manage and oversee the fieldwork process and train fieldworkers. In other cases it may be worth investing in training them to a level from which they can manage the process, given the strong relationships they already have with the community.
- They will be important users of the data in orienting their own work with the vulnerable group. They are likely to be more effective and consistent users of the data if they are involved at an early stage.

Vulnerable Groups or Communities at risk of HIV

The full and active participation of all quarters of government and NGOs will be of no value unless communities at risk are themselves willing to participate in behavioural surveillance. They are only likely to participate if they believe that the exercise will benefit them and their communities. The translation of data into better service provision is the weakest link in what should be a circular chain of programming, surveillance, evaluation and improved programming. Partly in order to ensure the continued co-operation of communities at risk, it is important to plan from the beginning how data will be translated into programmes.

The more BSS answers questions raised within the community itself, the more community members are likely to act on the information it generates. It is therefore important to consult them about the questions to be included in the survey. These may not be identical to the key indicators presented below, so it is important to explain the importance of these indicators to them and to be open to discussion. Community members are likely to suggest additional questions, and managers should respond to their needs for information. They are best placed to know the world they inhabit. Key individuals can provide essential information, helping to delineate the community and facilitate access.

They can also shed light on the power structures that operate within a community. For BSS to succeed, those planning data collection have to deal not only with individuals at high risk, but with the men and women that hold the keys to their community. The “gatekeepers” may be brothel owners, pimps, night club owners, union leaders or school principals. They may stand to gain or lose from a better understanding of risk behaviour and from prevention efforts in the communities they influence. Certainly, they can stand in the way of a successful data collection exercise. Planners of BSS must consult key power brokers about their concerns, and clarify the benefits that better HIV prevention efforts can bring to them and the communities.

Organisations involved in research

Often individual government departments do not have sufficient human resources to conduct behavioural surveillance. Certain skills, for example in survey research, may be in short supply. There may not be enough staff to conduct fieldwork, data entry and analysis. Therefore it is important to involve organisations with a track record of behavioural research. These may include any or all of the following:

Central Statistical Office or National Statistician

Government statisticians should be involved wherever possible in advising on survey design. They may be able to assist in supervising fieldwork and recruiting fieldworkers. Statistical departments may conduct data entry and analysis.

Market research organisations

Market research organisations can advise on survey methods and recruit personnel including fieldworkers. Some have experience in conducting surveys (occasionally on health) in several Caribbean countries.

Non-governmental organisations

A few Caribbean NGOs have been involved in social research projects including surveys. Alternatively, among members of the NGO may be people who have conducted such research and are qualified to do so. If the NGO has a strong link or affinity with a particular vulnerable group, it is valuable to draw on these skills.

Universities and institutions of higher learning

Higher education institutions with a social science faculty or course, such as the University of the West Indies, generally teach research methods and are involved in survey research. Academics involved in such teaching and research can advise on survey methodologies and may be useful allies in supervising and providing training for the surveys. There may be specialised research agencies within the institution, e.g. the Sir Arthur Lewis Institute of Social and Economic Studies (SALISES) at the University of the West Indies. Such agencies often have a bank of fieldworkers with whom they work, and who may be recruited in BSS.
It may be useful to consult academic researchers when it comes to the stage of writing the research results. These researchers have experience in presenting data for publication. Communications specialists may be employed to tailor the presentation of results to specific audiences.

**Funders of HIV prevention activities**

While the funders of HIV programmes include local taxpayers, in practice the demand for evaluation often comes from international investors in prevention. Public health officials managing a surveillance system may be sensitive to the needs of major donors by taking their concerns into account in designing BSS. This may entail including particular geographical areas or population sub-groups in the surveillance system. It should be stressed, however, that BSS is designed to be a routine exercise which meets the long-term needs of the NAP. The concerns of individual organisations funding particular short-term projects should remain secondary to long-term national needs.

**Mechanisms to sustain partnerships**

It may be a good idea to formalise the consultation process. A mechanism that appears to work well is a technical working group including members of the groups mentioned above. The working group should meet regularly during the design phase, and continue to meet at less frequent intervals during implementation and analysis to review progress and plan for effective use of the data.

**Step 2: Build agreement on the survey process**

Together, the groups listed above need to come to agreement on the following issues:

- Which information will be collected from the groups chosen for behavioural surveillance?
- Who will do the data collection and analysis?
- What mechanisms will be used to ensure that information gathered will be used to benefit the communities involved?

**Step 3: Define measurement objectives**

Surveillance planners must articulate clearly:

- what exactly they want to know
- how they plan to measure it and
- how the information will be used to help improve prevention, care and support.
- who will be involved in using each of these pieces of information to inform their work?

Failure to state objectives clearly at this stage may lead to wasted resources and lost opportunities in the data collection phase. It is important to define the likely users and uses of the data at the beginning. It is necessary to define how results will be used to:

- identify sub-populations at risk
- pinpoint risky behaviours
- design interventions to reduce risk
- plan for care and support needs and
- measure progress over time

Based on exactly what are the basic questions in need of answers, indicators should be selected at this stage. It is recommended that the standardised indicators and associated questions and measurement time periods below be used, while these may be supplemented by additional indicators chosen by the technical working group.

**Step 4: Operationalise definitions of populations of interest**

For household surveys of the general adult population, the “universe” to which results will be extrapolated is the entire national population (or the population of a particular area, such as a city or county) of a particular age band (e.g. 15-24).

For BSS with vulnerable groups, once respondent groups have been chosen, the sampling universe must be defined. The universe is the population to which results may be extrapolated. An example of a respondent group might be sex workers, and the sampling universe could be those who work in brothels and on the streets.

After defining the sampling universe, the sampling domains must be identified. A sampling domain is a specific population segment or subset for which survey estimates are desired. For example, there may be a wish to compare the behaviour of street-based and brothel-based sex workers. Further, brothel-based female commercial sex workers (FCSW) may be broken down into urban and rural. In order to ensure that statistically significant changes can be monitored over time in particular domains, and that significant differences between domains can be detected, sample sizes are calculated per domain (see section below on sampling).

The sampling universe needs to be precisely operationally defined. In many Caribbean countries, the atmosphere of homophobia is such that very few men openly and publicly declare themselves as gay. How, then, should MSM be defined? At this stage it is important to consult key informants from the respondent group as they will be in a position to advise on the culturally and practically most appropriate definition.

Ideally, behavioural data for specific sub-populations should be monitored on a national basis, with sufficient sample sizes to allow for separate estimates for different regions. This type of data can help explain differences in levels of HIV
infection between one region and another, and help target interventions according to geographic needs. Regardless of whether coverage is national, regional, or for only a subset of regions, it is important to recognise that the generalisability of findings is limited to those areas included in the universe for the survey effort.

Many factors (including cost, feasibility and political expediency) will influence the geographic coverage of BSS. One important consideration is the distribution of sero-surveillance efforts. It is advisable to conduct BSS in the same geographic area as HIV sero-surveillance for a given sub-population. Where sero-surveillance efforts use population-based sampling approaches for a given hard-to-reach population, the same sampling frame and sampling design can be used for both HIV surveillance and behavioural surveillance.

Step 5: Select and map sites
BSS must identify places where vulnerable groups are accessible. This generally involves a mapping of sites where the behaviours take place or where people “pick up” partners, such as brothels, nightclubs and beaches. The process of site selection and mapping is outlined in section 4.

Step 6: Construct a sampling frame
See section 4 of these guidelines.

Step 7: Develop the survey protocol
The survey protocol lays out the methodology to be used for the survey. It includes:

- A description of the goals and objectives of the survey
- Details of the methodology including:
  -- adescription of the chosen target populations and sites
- Ethical considerations, e.g. how will confidentiality be assured?
- Sampling design.
- A description and justification of the indicators selected (see section 5)
- Identification of agencies responsible for fieldwork, data entry, data analysis and report writing
- Procedures for recruiting, training and supervising fieldworkers
- The fieldwork process
- Procedures for transfer of data from fieldworkers to the agency responsible for data entry and analysis
- Storage and security of data
- Data entry methods (e.g. software package used)
- Plan of data analysis
- Data dissemination plan

Appendices should include the questionnaire to be used, plus auxiliary materials such as interviewer guides used for training and as an on-site reference for field staff.

Step 8: Pre test and adapt survey instruments and survey procedures
Aspects of the survey process which should be piloted include selection of respondents, feasibility of completing interviews with selected respondents, length of time necessary to complete an interview, how many interviews can be completed in a day, role of the supervisors (how they will maintain quality control) and storage and transport of completed questionnaires.

Note that pre-testing should be carried out before the first round of behavioural surveillance. The aim is to establish a system to be used repeatedly over a number of years. It is not advisable to wait until the first survey is underway to discover problems. Methods will then have to be modified for the next round, which defeats a major purpose of behavioural surveillance; to measure change over time by using consistent methods.

Step 9: Train fieldworkers
The attitude of interviewers can greatly influence the outcome of a survey, especially one that asks about illegal or stigmatised behaviour. To increase the likelihood of honest responses, interviewers must be thoroughly trained in open and non-judgmental questioning techniques, and in accurate recording of responses. (See section 5 for further details.)

Step 10: Supervise Data collection
Only after the above steps have been completed should the first round of behavioural surveillance be conducted. Note that most of the steps are restricted to the period before the first survey round. In subsequent rounds, the work will become progressively less consuming of time and labour, as a result of the establishment of a clear system before the first survey begins.

Data collection and supervision should follow the procedures outlined in the survey protocol. Supervisors should spot check questionnaires for completeness and accuracy of data recording. They should be vigilant when interviewer fatigue begins to take its toll. They should be available for consultation and support of the interviewers as the survey progresses.

Step 11: Guide Data entry and management
Methods and responsibilities for data entry should be established by the survey protocol. The accuracy of data entry should be checked by verifying that it accords with the contents of a sample of completed questionnaires.
Once data entry errors have been reconciled, the data should be checked for values that are “out of range” (i.e. values that are impossible as they are outside the range of defined codes) and/or are inconsistent with other information gathered in the interview (e.g. respondents who report never having had sex also reporting condom use). Most inconsistencies may be avoided by careful questionnaire design, with jumps to avoid questions which might result in inconsistency. If interviewers have disregarded instructions to jump questions, a check file for data entry can ensure that inconsistencies are not carried through into the data set.

**Step 12: Guide Data analysis**

Analysis may include the calculation of statistics such as medians and averages as well as frequencies and percentages. The analysis stage entails the calculation of standard errors of the survey estimates and the conduct of tests for the statistical significance of trends over time and/or differences in behaviour between domains (see section 6).

**Step 13: Use the data to improve HIV prevention, care and support**

This final step is the one that justifies the entire behavioural surveillance effort. Primary responsibility for decisions about how the data are used will rest with public health officials in the NAP. However, the technical working group, which includes members of the respondent groups themselves, should advise on how the data should be disseminated and may be involved in the dissemination process. Respondent groups should receive the results in an easily accessible form, explained by somebody they trust.

### 4. Sampling approaches

Sampling methods will determine the usefulness of the results of behavioural surveillance. To be useful, the results should apply not only to the survey respondents, but to the wider group which they have been selected to represent. The objective of sampling strategies is to ensure that the selected respondents are representative of their population group to the maximum extent possible. Results can then be generalised from the respondents to the population group as a whole.

Behavioural surveillance is concerned with trends over time, therefore sampling strategies should be replicable over time. If they are not, then any changes observed may simply be the result of different sampling strategies. Therefore it is important to design an appropriate sampling method before the first survey round.

#### 4.1 Calculation of sample size

This subsection deals with the calculation of sample size according to the changes which behavioural surveillance is aiming to detect.

In discussing sample size, it is important to note that the size requirements relate to particular survey **domains**. Usually, in HIV behavioural surveillance, separate estimates are required for males and females. In youth studies, it is often advisable additionally to provide separate estimates for the age groups 10-14, 15-19 and 20-24. The genders and age groups are domains and an adequate sample size must be allowed for each domain.

Sample size requirements accord with the number of domains. For example, the sample size for an unstratified survey of youth has been calculated as 200. It is decided that the analysis should be stratified by gender (2 domains) and age group (3 domains). The sample size for an unstratified sample would thus need to be multiplied by 6: the required sample size would be 1200.

Sample size calculation may be considered a complex technical matter, therefore survey managers are advised to always consult a statistician. Basic guidelines are presented here.

Behavioural surveillance is concerned with detecting change over time, so the sample size needs to be sufficiently large to detect changes with a high degree of certainty. Sample size requirements presented in this section are somewhat larger than those required to measure a variable or indicator at a single point in time.

Most HIV behavioural indicators are proportions, e.g. the proportion of the sample that used a condom at last sexual intercourse. The sample size requirements presented here are designed to measure a change in proportion of a given magnitude in a given direction (e.g. an increase in condom use or a reduction in the proportion with two or more partners). Sample sizes required to detect changes of the same magnitude in either direction would be larger. Behavioural surveillance is undertaken in the context of prevention efforts that aim to produce a change in a given direction.

Four basic pieces of information are required to calculate required sample size:

1. An estimate of the proportion of the target group in the domain currently engaging in the behaviour (P1)
2. The target proportion engaged in the behaviour at some future date (P2). The magnitude of change to be detected is P1 - P2.
3. How sure you want to be that a change of a certain magnitude would not have occurred by chance. This is known as the level of statistical significance.

4. How sure you want to be that you will observe a change of that magnitude if it did in fact occur. This is known as the level of power.

The formula for calculation of sample size is complex and is given in Appendix II. The following table shows required sample sizes for given combinations of P1, P2, significance and power. Note that many surveys conventionally adopt a significance level of 95% and a power level of 90%. This means that one can be 95% certain that the estimated change did not occur by chance, and 90% certain that a change of that magnitude will be detected. Survey planners are advised to adopt these conventions where economically possible. As shown in Table 1, relaxing these stringent conditions by lowering the levels of significance and power reduces the required sample sizes and thus the likely costs of the survey. Note, however, that lower levels of significance and power translate into lower levels of generalisability to the target group as a whole.

In some rare cases in very small Caribbean territories and when studying behaviour in small sub-populations, it may be possible to include all members of a target group in a survey. In these cases the research enterprise is, strictly speaking, a census rather than a survey. The results are those for the target group as a whole rather than being estimates of values for this group. Sample size calculations and tests for the significance of change over time are not required in these cases.

An important challenge is estimating the value of P1, the proportion of the population which engages in the behaviour of interest. Other surveys or anecdotal information can be consulted for guidance.

Table 5 provides sample sizes sufficient for detection of change of 10% and 15% for given levels of P1. Ten per cent is a sufficient level of sensitivity to change for HIV behavioural surveillance. Most behavioural targets require a change of 10% or more by a given date. Requiring smaller changes to be detected (e.g. 5%) would necessitate larger sample sizes.

For some behavioural indicators, the denominator is not the total number of respondents but some fraction of this number. For example, indicator 6 for adults age 15-49 below is “condom use in last commercial sexual encounter”. The denominator in this case is not all respondents, but, rather, the number who have given or received money for sex in the last twelve months. In such cases it is necessary to inflate the sample size to ensure that there are sufficient people in the denominator group to enable a change of a given magnitude to be detected. The sample size should be inflated by a factor of one divided by the proportion of respondents estimated to have the behaviour indicated in the denominator.

An example will serve to clarify. Say that it is estimated that 50% of men have given or received money for sex in the last twelve months. Of these men, approximately 60% are thought to have used a condom at last sex at the beginning of the survey, and the aim of the behavioural programme is to push this up to 75%. Using a 95% significance level and a 90% power level for a change from P1 = 60% to P2 = 75% gives a sample size of 330. This sample size needs to be inflated by a factor of 1/0.5 = 2 to account for the fact that only half of men are estimated to have given or received money for sex in the past year. The sample size required for men would therefore be 660.
Behavioural surveys invariably have more than one indicator and at least ten are recommended for each vulnerable group in these guidelines. It is not necessary to have estimates of the proportion of people in each domain engaging in each of the behaviours for every one of the indicators before calculating sample size. As a rough rule of thumb, utilise the indicator with the rarest form of behaviour in the denominator. Looking at the ten key indicators for each vulnerable group presented below, these might turn out to be:

- For adults: the proportion of men reporting sex with males (the denominator in adult indicator 4)
- For youth: the proportion of males reporting sex with males (the denominator in youth indicator 5)
- For sex workers: the proportion reporting anal sex in the last 6 months (the denominator in sex worker indicator 6)
- For MSM: the proportion reporting anal sex with a commercial partner in the last 6 months (the denominator in MSM indicator 6)

The sample size should then be calculated as in the example above. Note that required sample sizes are highest when \( P_1 \) approaches 50% and lowest when \( P_1 \) approaches zero or 100%. To be on the safe side when values of \( P_1 \) cannot be estimated, set \( P_1 \) at or near 50% to ensure that the sample size chosen will be sufficient to satisfy the measurement objectives.

It is important to note that this discussion of sample size requirements has not distinguished between surveys to be undertaken using probability sampling methods and those using non-probability methods. Conventional tests of statistical significance should not, strictly speaking, be used.

### Table 5: Sample size requirement for selected combinations of \( P_1, P_2, Z_{1-α} \) and \( Z_{1 - b} \)

<table>
<thead>
<tr>
<th>Combination of ( Z_{1-α}/Z_{1 - b} )</th>
<th>1-sided significance level/per cent power</th>
</tr>
</thead>
<tbody>
<tr>
<td>( P_1 )</td>
<td>( P_2 )</td>
</tr>
<tr>
<td>Increase in proportion</td>
<td></td>
</tr>
<tr>
<td>.10</td>
<td>.20</td>
</tr>
<tr>
<td>.10</td>
<td>.25</td>
</tr>
<tr>
<td>.20</td>
<td>.30</td>
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<td>.20</td>
<td>.40</td>
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<td>.20</td>
<td>.45</td>
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<td>.30</td>
<td>.50</td>
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<td>.40</td>
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<td>.80</td>
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<td>.70</td>
<td>.85</td>
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<tr>
<td>.80</td>
<td>.90</td>
</tr>
<tr>
<td>.80</td>
<td>.95</td>
</tr>
</tbody>
</table>

Source: FHI (2000); WHO - Adequacy of Sample Size in Health Studies (1990)
in the analysis of non-probability surveys. However, given that the use of non-probability sampling methods may be unavoidable in some settings, as a practical matter the best that can be done in such situations is to take steps to minimise bias in the survey data. This implies assuming that the data have distributional characteristics similar to data gathered using probability-sampling methods. Sample sizes for non-probability samples should therefore also follow the guidelines above.

The following subsections outline ways to select the sample of the chosen size. Section 4.2 presents an overview of the choice of sampling methodology. Section 4.3 shows ways in which sample frames may be created. Section 4.4 shows how to select clusters from a sample frame in multi-stage cluster sampling. Section 4.5 shows how to select respondents within clusters.

4.2 Choice of sampling methodology

Probability sampling methods are the preferred choice for behavioural surveillance wherever feasible. With probability sampling, every person in the defined universe may be selected with a known (non-zero) probability. Using random sampling ensures that each person in this universe has an equal chance of selection. Standard statistical tests measuring change over time or differences between domains assume that probability sampling has been used. For general population household surveys, and for some youth surveys which sample from well-established institutions such as schools, utilising probability sampling techniques is quite straightforward. Techniques used in these cases are outlined below.

However, some populations of particular interest to behavioural surveillance, such as sex workers and MSM, are not easily accessible through conventional household or institutional sampling techniques. The challenge in conducting behavioural surveillance with these groups is to devise sampling plans that are both feasible and capable of producing unbiased estimates (or, more realistically, estimates with minimal levels of bias) for populations that are not easily “captured” in household surveys.

As a practical matter, this will require:
• the use of conventional, probability sampling in non-conventional ways and
• the occasional use of non-probability sampling methods such as snowball or network sampling in situations where probability methods are not feasible.

Non-probability methods should only be used where probability sampling is not feasible, i.e. for some populations whose members are not accessible at definable physical sites and for whom it is not possible to develop a list or sampling frame. Some MSM, for example, may not attend gay bars or NGO meetings and may only be accessible through referral by other MSM. In the Caribbean situation of high levels of stigmatisation of certain behaviours, there may be few or no clearly defined locations such as gay bars where high risk groups meet on a regular basis. Network sampling may be necessary to ensure the representation of people who do not attend sites associated with particular behaviours.

Probability sampling commonly entails the selection with known probability of “clusters” or “primary sampling units” (PSUs) where members of the target group are located. At a later stage, members of the group are selected with known probability from the cluster. This technique, known as multi-stage cluster sampling, is more economical than simple random sampling from the entire population of interest. Random sampling from the target population as a whole entails a larger amount of time and expenditure on travel to reach potential respondents in many different locations. Selecting fewer locations cuts down on this expenditure and time. Clusters should be randomly selected from the full list, or sampling frame, of clusters.

The first step in conducting multi-stage cluster sampling is to identify the clusters, or locations, where members of the target group may be located. Some types of target group members may be associated with sites in a fixed manner, while others come and go freely from sites. In-school youth, for example, are generally available as survey respondents in schools during school hours. On the other hand, out-of-school youth may congregate in certain places (such as basketball courts or shopping malls) at certain times of day or night. In the latter case it is necessary to identify not only the places but also the times when members of the target group attend the site. The result is what is known as a “time-location cluster”.

If behaviour associated with risk of HIV is expected to differ between times, the same location may be included more than once in the sampling frame of clusters. The day (or week, or month) must be divided into discrete time intervals according to variations in respondent behavioural type. The cluster in this case becomes the site during each of the risk periods specified, and each of these clusters is entered separately into the list of clusters for the sampling frame. For example, if sex workers are thought to have a more rapid turnover of partners during periods of high demand following payday than at other times of the month, a single block of a red light district, say Block A, might be entered as three time-location clusters as follows: “Block A, week before payday”, “Block A, week after payday” and “Block A, rest of the month”.
Fig. 1 below presents a decision-tree to facilitate the choice of sampling methodology according to the characteristics and expected behaviour of the target population.

Are the target members accessible at a physical site?

Yes

Are the target group members associated with site in a fixed manner, or do they come and go freely?

Yes

Associated with site in fixed manner

No

Snowball sampling

Come and go freely from site

Use time location cluster sampling

Is it possible to get an estimated Measure of Size for the site?

Yes

1st stage: Select clusters with probability proportional to size (PPS)
2nd stage: Select equal number of respondents from each cluster

No

1st stage: Select clusters by equal probability (EP)
2nd stage: Subsample fixed proportion from each cluster

Is average by number of target group members during a fixed time interval small (i.e. 15 or fewer)

Yes

1st stage: Select time-location cluster by equal probability (EP)
2nd stage: Select equal number of respondents from each cluster during equal time period

No

1st stage: Select time location cluster by equal probability (EP)
2nd stage: Subsample fixed proportion from each cluster during time period for each cluster
So far we have examined different types of sampling and offered guidance on the strategy to be used in particular circumstances. If a decision has been made to use a cluster sampling approach (whether using straightforward location clusters or time-location clusters), the next step is to identify the clusters themselves from which a sample will be drawn. The following section outlines ways to create a sample frame of clusters.

4.3 Mapping to create a sampling frame

Mapping means describing the times and locations where people with defined risk behaviours may be found. Clusters are delineated on the basis of such descriptions. Mapping may also provide qualitative, descriptive information on types of behaviour which can assist in the selection of indicators for monitoring.

In some instances the lists for the different stages of sampling are readily available and it is not necessary to conduct a mapping exercise. For general population household surveys, geographical districts are the potential clusters at the first stage of sampling. Electoral districts are often used as first-stage clusters. Households are used as clusters at the second stage. The final stage is to select respondents of the appropriate age from the households.

A survey of in-school youth might use lists of schools separated by gender and with measures of size for the number of students in each school and each class, which can be obtained through the Ministry of Education.

In many instances when conducting surveys with vulnerable groups, sampling frames are not so readily available. Consider the case of a CSW survey. A list of establishments where the workers solicit clients may be required, along with an estimate of the number of sex workers who frequent the establishments at different times of the week.

Mapping aims to identify sites/locations and times where sufficient numbers of respondent groups may be found on a regular basis for use as clusters. Key informants and members of the respective respondent groups themselves should be consulted in a systematic fashion to construct a sampling frame of sites that is as complete as possible. The process of gathering this information is known as ethnographic or social mapping. This means that those creating the maps use basic ethnographic techniques in their construction; for example, key informant interviewing and spending time “walking the community” in the company of key informants.

Sampling frames should cover the entire geographic and temporal universe defined for a given survey effort and include the large majority of sites and times where respondent group members congregate in significant numbers. If not, survey estimates are prone to bias to the extent that the characteristics and behaviours of target members excluded from the possibility of selection are different from those who were surveyed.

In some locations, creating the sampling frame might only involve creating lists of sites and times. In other instances, mapping may entail actual sketching of the specific geographic area. The resulting map would not need to have precise dimensions and distances, but rather be a rough drawing including such things as main streets, main features of the landscape such as notable buildings and parks, and, most importantly, markings indicating the main places where respondent group members are likely to be found. It is important to allow sufficient time, human resources and budget for mapping and sample frame development, a process which may take up to two months before the first survey round.

Note that the sampling frame should be updated with each new survey round, as certain characteristics may have changed; for instance some establishments where sex workers solicited for clients may no longer be used by them or may have gone out of business, while new establishments are now used.

Care must be taken in mapping members of sub-populations engaged in illegal or stigmatised activities. Commercial sex workers, drug users and MSM fall into this category. Mapping of these groups requires extensive rapport and trust-building which can best be achieved by working with group members as part of the planning team. Confidentiality of the information, with very limited circulation of the maps, is crucial. NGOs working with the target group may assist in mapping.

In some cases, police officers have helped in mapping exercises. This is most common in surveys of sex workers. While the support of the police for survey activities can be important in ensuring success, it is preferable that this support remains passive. For example, it is a great help to have police officers commit not to harass individuals contacted by survey teams. It is less helpful to have them actively involved in mapping, since association of the survey team with law enforcement authorities may greatly increase the refusal rate and bias the responses of those who choose to respond to the survey.

4.3.1 Targetted (snowball) sampling

In some instances it is not possible to construct a comprehensive sample frame. Some or all members of the target group may simply not congregate in sufficiently large numbers at specific places or times. An example may be some MSM who do not (or very rarely) go to bars, clubs or meetings where concentrations of MSM are to be found. In
such cases the only way to include such people in the survey is via referral, usually from other people in the target group. It is particularly important to establish rapport and trust with members of the community in order to gain access to potential respondents who may not attend sites precisely because they fear the consequences of public disclosure of their sexual practices. Confidentiality is highly important here.

Non-probability methods such as snowball sampling are a last resort, to be used in situations where it is not possible to construct an adequate sample frame. The basic form of non-probability sampling recommended for behavioural surveillance is a modified form of snowball sampling referred to as targeted sampling. The idea in snowball sampling is to compensate for the lack of a sampling frame by learning the identities of members of a given “network” of persons who engage in a given risk behaviour through key informants and other respondent group members. Typically, the data collection process begins by interviewing key informants and group members known to the researchers to learn the identities of other group members and where they might be found. The people are contacted, data collected, and these persons are asked to provide information on how and where additional group members might be found. Leads from each wave of referrals are followed up until a sample of a pre-determined size has been reached.

An important limitation of snowball sampling is that “lead” sub-population members are more likely to provide information on other group members who are in their own social, economic and/ or sexual network. To the extent that behaviours of interest differ across networks, this poses a potential bias problem.

The targeted sampling approach extends the ideas of snowball sampling to include an initial ethnographic assessment aimed at identifying the various networks that might exist. The networks are then treated as sampling strata, and quota samples are chosen within each stratum using “snowball sampling” techniques.

It may be discovered during the ethnographic assessment stage that some members of the target group may be found at particular locations and times while others can only be accessed via snowball sampling techniques. For instance some MSM may congregate in certain bars, while others do not attend such locations. In such circumstances two types of sampling strategies may be used with the same target population; two- stage cluster sampling and targeted snowball sampling. It is important to treat the groups sampled by the two different methods as separate domains for the purposes of sample size calculations and statistical estimates, because behaviour is likely to differ between the two groups.

4.4 Selection of clusters

In cluster sampling, the preferred way of selecting clusters is known as selection of clusters with probability proportional to size (PPS). Using PPS ensures that each person in each cluster has an equal chance of being included in the sample. In the absence of PPS, a person in a cluster of 50 people is twice as likely to be selected as a person in a cluster of 100 people, for example. The method of choosing clusters with PPS is presented below. It relies on an estimate of the number of people in each cluster, known as the measure of size (MOS). Note that the measure of size does not need to be an exact count. A rough approximation for each site is good enough. Strenuous efforts should be made in the mapping stage to obtain a measure of size for each cluster. This is because results generated from PPS are self-weighted and therefore are robust estimates for the target population as a whole.

In cases where a MOS is not available, a simple random selection of clusters may be performed, known as selection of clusters by equal probability (EP).

4.4.1 Selection of clusters with probability proportionate to size

As the number of clusters in a sampling frame is sometimes large, the recommended procedure for choosing clusters is through systematic sampling, where one cluster is chosen at random and every cluster thereafter is automatically selected, based on a calculated sampling interval. This procedure is shown in figure 2 below. A worked example is in table 6.

This procedure is followed until the list has been exhausted.

Note: in selecting sample clusters, it is important that the decimal points in the sampling interval be retained. The rule to be followed is when the decimal part of the sample selection number is less than .5, the lower numbered cluster is chosen, and when the decimal part of the sample selection is .5 or greater, the higher numbered cluster is chosen.
If sample clusters are selected with probability weighted according to their size as described above, and an equal number of individuals is chosen per cluster at the second stage, the end result is a **self-weighted sample**. This means that every person in the universe described by the sampling frame has the same probability of being selected into the final sample. This design eliminates the need to weight the data during analysis.

The number of clusters to be chosen depends on the sample size requirement in terms of number of respondents needed. The same number of respondents will be selected from each cluster to reach the overall sample size, so the number of clusters will be the sample size divided by the number of respondents to be selected per cluster. As a general rule, it is better to select a larger number of clusters and a smaller number of respondents in each than vice versa. This will enhance the reliability of the estimates.
4.4.2 Selection of Clusters with Equal Probability

Where no measure or educated estimate of size is available, each cluster should have an equal probability (EP) of being selected. Procedures for choosing clusters with EP are described in fig. 3, and an example is provided in table 6.

Once the clusters have been selected with EP, a fixed proportion (rather than a fixed number) of individuals should be included in the survey – for example every third person in the cluster. This will result in a self-weighted sample. The advantage of this is that it avoids the necessity of complicated weighting procedures at the time of data analysis. The disadvantage is that as the size of the population associated with the cluster is not known beforehand, this approach will result in an unpredictable final sample size.

Table 7: Selection of a systematic-random sample of primary sampling units with equal probability – an example

<table>
<thead>
<tr>
<th>NO.</th>
<th>Selection</th>
<th>Primary sampling unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>X</td>
<td>Planned no. of clusters = 40</td>
</tr>
<tr>
<td>002</td>
<td>X</td>
<td>Sampling interval = 170/40 = 4.25</td>
</tr>
<tr>
<td>003</td>
<td></td>
<td>Random start between 1 and 4.25 = 2</td>
</tr>
<tr>
<td>004</td>
<td></td>
<td>Cluster selected = 002, 006, 011, 011</td>
</tr>
<tr>
<td>005</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>006</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>007</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>008</td>
<td></td>
<td>170 (Last)</td>
</tr>
</tbody>
</table>

Note: in selecting samples clusters, it is important that the decimal points in the sampling interval be retained. The rule to be followed is when the decimal part of the sample selection number is less than .5, the lower numbered cluster is chosen, and when the decimal part of the sample selection is .5 or greater, the higher numbered cluster is chosen. In the above example, the sample selection number for the third sample cluster was 10.5, and thus cluster 011 was chosen for the sample.

Source: FHI (2000)
4.5 Selection of respondents

Once clusters have been selected, the final stage of sampling is to select respondents in each cluster. As noted, when PPS sampling has been used to select clusters, an equal number of respondents from each cluster should be selected until the sample size is reached. When EP sampling has been used to select clusters, a fixed proportion of respondents should be selected.

To maximise the generalisability of results, more clusters with smaller numbers of respondents selected from each is the best option, especially when the expected homogeneity of behaviour within each cluster is high. As a general rule, no more than 20-25 subjects per cluster should be selected. Sampling more than 40 individuals per cluster should be avoided. A minimum of 20 clusters per respondent group is recommended, and more is desirable when feasible.

Individuals should be selected using a random procedure. Where individuals can be identified in advance on a list such as a school register or an electoral list, each can be assigned a number. Numbers can then be selected using a random number table until the required sample is reached. Alternatively, systematic sampling methods can be used, as shown in tables 6 and 7 above. Here, the size of the list is divided by the sample size to calculate the sampling interval. A number between zero and the sampling interval is randomly selected as the random start number. The sampling interval is added several times to this start number, and each time the individual is selected whose number corresponds to the sum.

Where time-location clusters are used, sampling must take place over a fixed time interval in every cluster: typically, one hour. Where the average number of target group numbers per time-location is expected to be 15 or less, it is recommended that all individuals who appear at the selected sites and times be selected for the sample. This will result in a self-weighted sample.

When sampling vulnerable groups such as MSM it will rarely be possible to list all of the individuals who congregate at the cluster site ahead of time. Therefore, an approach which is as systematic as possible should be used for random selection of respondents. On arrival at the site the team could rapidly list and number the target group members by some visible characteristic (such as “man in red shirt” or “woman with big gold earrings”).

If PPS sampling has been used to select clusters, systematic sampling can be used to select the required number of target group members. Alternatively, and if feasible, two sets of slips of paper could be marked with consecutive numbers up to the number of members of the target group present. Group members may be asked to select a piece of paper each and thus assign themselves a number. The second set of slips of paper could be put into a hat, shaken and numbers drawn out one by one until the required number of respondents is selected. If EP sampling has been used, every person on the list of target members present should be selected, to reach a fixed proportion of target group members per cluster.

5. Indicators and questions

This section presents ten key indicators of HIV risk behaviour for each of four groups to be included in surveys:

1. The general population aged 15-49
2. Young people
3. Female sex workers (FSWs)
4. Men who have sex with men (MSM)

It is recognised that individual countries may wish to define the questions to be included in behavioural surveillance. At the same time there is value in accepting international guidelines, based on a wealth of experience in many countries. The indicators below aim to strike a balance between the need for indicators based on Caribbean social realities and that for comparability using widely accepted standards. Only ten key indicators and sets of questions are presented for each of the four groups above. Adhering to this minimum set of indicators will ensure that there is a minimum of standardised information for comparison. A standardised minimum data set will facilitate understanding of the information within and between countries, as well as the emergence of a Caribbean-wide picture of behaviour related to HIV. Such a picture is necessary for the programming of policies and interventions at the regional level by agencies such as CAREC and CARICOM. It will assist regional and international agencies in gaining a picture of local needs and help them to respond efficiently and appropriately.

The use of ten key indicators and associated questions of course does not satisfy the range of needs for behavioural information for each country. They represent a basic minimum which may be supplemented. There is insufficient space here to provide a comprehensive list of indicators and questions which might usefully be included in surveys with every respondent group. More detailed guidelines, including full questionnaires, are available from various sources. (see the references at the end of these guidelines).

These indicators were chosen by a multidisciplinary team of professionals involved in HIV surveillance at CAREC (the HIV/AIDS/STI surveillance cluster).

- The following criteria were used for selection of indicators and questions:
  - Internationally recommended best practice
• Appropriateness to what is known about the profile of risk behaviour in the Caribbean. A number of existing surveys and other studies were reviewed for this purpose
• Experience of CAREC and other institutions in utilising the indicators and questions in Caribbean surveys

In addition, the following WHO/UNAIDS criteria for indicators were applied:

**Actionable:** The indicator provides information needed by managers to assess performance and orient programmes

**Available:** The indicator has already been utilised in the Caribbean or can realistically be utilised

**Sensitive:** The indicator measures change in the behaviour of interest

**Specific:** Indicators do not measure anything else but what they are intended to measure

**Reliable:** Repeated surveys using the same questions are equally likely to produce accurate results

**Valid:** The indicators measure the behaviour they are intended to measure

It is suggested that the criteria above be applied by survey planners who wish to utilise indicators in addition to those below.

For each of the key indicators, an explanation and definition is provided, followed by suggested wording for related survey questions.

It should be noted that the wordings below are suggestions only and they may be adapted or changed in line with local cultural meanings and understandings. The suggested wording is based on international and regional guidelines (see the source for each question) but some of these have not been tested in the Caribbean. It is especially important, therefore, to pilot whichever questions are chosen and revise and re-test those which do not give a valid indication of the behaviour in question. Some vulnerable groups may have specific local words for behaviours (particularly sexual behaviours), and these should be used if they enhance understanding of the question. It is not appropriate to use such words if they are derogatory or profane, as this will tend to bias responses.

Coding of responses should be consistent throughout the questionnaire. For instance, if the code “1” is allocated to the response “Yes” and “2” to “No”, this should be done for questions with “Yes/No” responses throughout the questionnaire. A useful convention is to allocate the code “8” to “Don’t know” and “9” to “No response”, or “88” and “99” for questions with 10 or more response categories.

### 5.1 Indicators and questions for the general population aged 15-49

The indicators selected for the general adult population are as follows:

1. Number of non-regular sex partners in the last 12 months
2. Condom use at last sexual intercourse with a non-regular, non-commercial partner
3. Consistent condom use with non-regular, non-commercial partners
4. Condom use in men who have sex with men
5. Commercial sex in the last year
6. Condom use in last commercial sexual encounter
7. Use of crack/ cocaine or other illegal drug
8. Knowledge of HIV prevention methods
9. No incorrect beliefs about AIDS transmission
10. Attitudes to people living with HIV/AIDS

#### 1. Number of non-regular sex partners in the last 12 months

**Definition**

Option 1: Median number of sex partners in the last 12 months who are not spousal or cohabiting, and who are not commercial partners.

**Numerator:** Number of respondents who have had sex with one or more non-regular partner(s) (i.e. non-spousal, non-cohabiting and non-commercial) in the last 12 months

**Denominator:** Total number of respondents
How to measure it

Option 1 is calculated from data from question GP1.2c presented in a table of frequencies. The median is the number of partners coinciding with the 50th percentile; half of the sample had this number of partners.

Option 2 is calculated from the number of respondents reporting one or more partners (question GP1.2c) divided by the number of respondents (sample size).

For both options 1 and 2, separate estimates should be generated for males and females, in each case taking care to include only the number of male or female respondents as the denominator for option 2. Estimates should also be provided for the sample as a whole.

Of the two options for measurement presented above, the median is the more sensitive indicator, as it will measure changes from higher to lower numbers of partners and vice versa. Option 2 is useful for showing the proportion of the population engaged in these relatively high-risk partnerships.

What the indicator measures

People with non-regular partners are more likely to link into a wider sexual network. HIV prevention programmes try to discourage high numbers of partners and to encourage mutual monogamy. This indicator aims to give a picture of the proportion of the population that engages in relatively high-risk partnerships and that is therefore more likely to be exposed to sexual networks where HIV can circulate.

In the Caribbean context, it may also be useful to examine the data from question 1.2a, the number of regular partners. Various Caribbean studies have indicated that a significant proportion of Caribbean men cohabit with more than one woman, sometimes providing resources for several households. Women rarely live with more than one man, but often have a series of cohabiting relationships. This pattern encourages the spread of HIV.

Many Caribbean studies with adults have asked about the number of sex partners without distinguishing between regular, commercial and non-regular partners. A typical question is:

How many sex partners have you had in the past 12 months? |___|___| Number

While this question has the advantage of simplicity, it is not encouraged as the levels of risk from each type of partnership are different and should be distinguished. Caribbean studies reveal that the majority of people have zero or one partner per year.
– this applies to men as well as women, though men report higher numbers of partners (Allen et al, 2001). Using this question is therefore unlikely to give a sensitive indication of change and programmatic success.

2. **Condom use at last sexual intercourse with a non-regular, non-commercial partner**

**Definition**

*Numerator:* Number of respondents who used a condom the last time they had sex with a non-regular (i.e. non-spousal, non-cohabiting and non-commercial) partner  
*Denominator:* Number of respondents who have had sex with at least one non-regular partner in the last 12 months

**Suggested Question**

<table>
<thead>
<tr>
<th>GP2.1</th>
<th>Think about your most recent non-regular, non-commercial partner. The last time you had sex with this person, did you or your partner use a condom?</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
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<td></td>
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**Note:** This question should be preceded in the questionnaire by a set of questions defining what is meant by “non-regular” partner, i.e. question 1.2 a-c.

**How to measure it**

The indicator is the number who used a condom last time according to question 2.1, divided by the number of respondents with 1 or more non-regular partners according to question 1.2 c. It may be expressed as a percentage.

The indicator should be measured for males, for females and for the sample as a whole.

**What the indicator measures**

AIDS programmes promote condom use in casual partnerships. This is a sensitive and reliable indicator of progress in meeting the objective of 100% condom use in non-regular sexual intercourse. Many years of use have proven the indicator to be very robust. A rise in this indicator is an extremely powerful indication that condom promotion campaigns are having the desired effect.

Asking about the most recent sexual act with a non-regular partner minimises recall bias and provides a good cross-sectional picture of levels of condom use. However, this indicator cannot provide measures of consistency of use, which are provided by the following indicator.

3. **Consistent condom use with non-regular, non-commercial partners**

**Definition**

*Numerator:* Number of respondents who used a condom every time they had sex with any non-regular (i.e. non-spousal, non-cohabiting and non-commercial) partner over the past 12 months  
*Denominator:* Number of respondents who have had sex with at least one non-spousal, non-cohabiting and non-commercial partner in the last 12 months

**Suggested Question**

<table>
<thead>
<tr>
<th>GP3.1</th>
<th>With what frequency did you and all of your non-regular, non-commercial partner(s) use a condom during the last 12 months?</th>
<th>Every time</th>
<th>Almost every time</th>
<th>Sometimes</th>
<th>Never</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

**Note:** This question should be preceded in the questionnaire by a set of questions defining what is meant by “non-regular” partner, i.e. questions 1.2 a to c.
How to measure it

Respondents are asked whether they have had sex in the last 12 months, and if so, whether they have had sex with a spouse or regular partner, with a non-regular partner, or with a commercial partner (questions 1.1 and 1.2 above). They are later asked how frequently they used a condom with non-regular partners over the past year. The indicator is the number who used a condom every time according to question 3.1, divided by the number of respondents with 1 or more non-regular partners according to question 1.2c. It may be expressed as a percentage.

The indicator should be measured for males, for females and for the sample as a whole.

What the indicator measures

AIDS programmes promote condom use in casual partnerships. This question records the consistency with which adults adhere to this recommendation.

An indicator of frequency of condom use has been included in many adult studies in the Caribbean (though a distinction between regular and non-regular partners is regrettably rarely made in these studies). It has been used more often than condom use at last sex.

Depending on the respondent’s level of sexual activity, this indicator may refer to many different acts of intercourse with many different partners. It may therefore be subject to recall bias. It is a less robust indicator than condom use at last sex, but nevertheless fairly reliable and very useful in giving a broader picture of condom use.

By only including people who say they always use condoms with every non-regular partner, this indicator sets the standard for consistent condom use very high. This may result in the indicator being measured at low levels for some years.

It has been suggested that respondents who report that they use condoms “almost every time” be included in the numerator. This is not recommended as it tends to decrease the reliability of the indicator.

4. Condom use in men who have sex with men

Definition

Numerator: Number of male respondents who used a condom last time they had anal sex with a man
Denominator: Number of male respondents who have had sex with a man in the last 12 months

Suggested Set of Questions

<table>
<thead>
<tr>
<th>GP4.1</th>
<th>(Ask of men) Mean just talked about your female sexual partners. Have you ever had any male sexual partners?</th>
<th>Yes</th>
<th>No</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP4.2</td>
<td>Have you had sexual intercourse with any of your male sexual partners in the last 12 months?  (sexual intercourse defined as penetrative anal sex)</td>
<td>Yes</td>
<td>No</td>
<td>No response</td>
</tr>
<tr>
<td>GP4.3</td>
<td>Think about your most recent male partner. The last time you had sex with this person, did you or your partner use a condom?</td>
<td>Yes</td>
<td>No</td>
<td>Don’t know</td>
</tr>
</tbody>
</table>

Source: FHI (2000)

Note: This question should be preceded in the questionnaire by a set of questions which first ask whether the man has had sex in the last 12 months (question 1.1 above), then ask the man about the number of female sex partners (questions 1.2 a to c above).
How to measure it

This indicator expresses the proportion of homosexually active men (those who have had sex with a man in the last 12 months) who used a condom last time they had sex with a man. It may be expressed as a percentage.

Note that the questions on male-to-male sex should be preceded by questions on male to female sex. This is important in putting respondents at ease.

What the indicator measures

This is a sensitive indicator of protective behaviour among MSM. Because it refers only to the last sexual partnership with a man, it minimises recall bias. Programme success may be measured by an increase in this proportion over time.

Male to male transmission of HIV appears to be substantial in the Caribbean. Men continue to comprise the majority of cases of HIV/AIDS in the region, and comprise two-thirds of adult AIDS cases reported during 1982-98. It is unlikely that male cases are transmitted exclusively during sex with females, as females are biologically more susceptible. The proportion of cases reportedly transmitted through heterosexual intercourse among males has increased since the advent of the epidemic; the importance of male transmission is reflected by the continued higher proportion of males in the infected population and the substantial and growing proportion of male cases. This has created doubt about the veracity of self-reported mode of transmission.

The wording and ordering of questions on male homosexual behaviour must be very carefully considered, as homosexuality is highly stigmatised in the Caribbean. It is advisable first to ask men whether they were sexually active in the last year, then ask about their female partnerships. Only after this should the interviewer ask about male partnerships. Given the level of homophobia, some men may be offended and are less likely to answer truthfully if they are first asked about sex with men. Asking about sex with women then about sex with men indicates to the respondent that the interviewer is simply asking about different sorts of sexual encounters rather than passing judgement on sexual practices and orientation.

It is important to emphasise that the concern is with risky sexual behaviour, and not with sexual orientation. A few Caribbean surveys have sought to identify the proportion of the population which is homosexual, by asking questions such as

Have you ever had a homosexual relationship?
[ ] Yes [ ] No [ ] No response

Not surprisingly giving prevailing social attitudes, the proportion responding “Yes” is usually very small (no more than 3% in any survey reviewed). Asking whether a man has had male sexual partners, only after asking him about female sexual partners, is more likely to give valid and reliable results. The proportion of men who have ever had sex with a man, and the proportion practising anal sex with men, may be calculated by dividing the number of men who respond “Yes” to questions 4.1 and 4.2 by the number of male respondents. However, the aim is not to decrease these proportions (which would be discriminatory) but rather to estimate the size of the MSM population, and thus to orient interventions towards them.

5. Commercial sex in the last year

Definition

Numerator: Number of respondents who have given or received money for sex in the last 12 months  
Denominator: Total number of respondents

Suggested Question

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>GP5.1</td>
<td>In the past 12 months have you given or received money for sex?</td>
</tr>
<tr>
<td></td>
<td>Yes [ ]</td>
</tr>
<tr>
<td></td>
<td>No [ ]</td>
</tr>
<tr>
<td></td>
<td>Don’t know [ ]</td>
</tr>
<tr>
<td></td>
<td>No response [ ]</td>
</tr>
</tbody>
</table>

Source: UNAIDS/MEASURE evaluation (2000)
How to measure it

This indicator shows the proportion of the population exchanging money for sex in the past year. Separate estimates should be provided for males and females and for the population as a whole.

What the indicator measures

Qualitative and to a lesser extent quantitative research in the Caribbean has revealed that exchange of sex for money and material things (e.g. clothes, jewellery) is substantial in the general population. This behaviour is risky; those who receive money or things tend to take more partners as they seek resources, while those who give money will tend to be exposed to large sexual networks.

This indicator does not include exchange of sex for material things (as opposed to money) as this is likely to be a common practice in monogamous relationships as well as non-regular partnerships. Where an estimate of the proportion of the population buying sex is required, this may be calculated from information in question GP1.2b above and the sample size. A frequency table generated from answers to GP1.2b will yield the number of respondents who bought sex from one or more partners in the past year. Separate estimates should be provided for males, females and the total sample. While the vast majority of people buying sex from commercial partners are likely to be male, it is of interest also to calculate the proportion of females who buy sex from males.

6. Condom use in last commercial sexual encounter

Definition

Numerator: Number of respondents who used a condom last time they had sex with a partner who gave or received money
Denominator: Number of respondents who have given or received money for sex in the last 12 months

Suggested Question

<table>
<thead>
<tr>
<th>GP6.1</th>
<th>The last time you had sex with someone and exchanged money, did you or this partner use a condom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

Source: UNAIDS/MEASURE evaluation (2000)

Note: This question must be preceded by question GP5.1 above

How to measure it

This indicator is the number of people who report that they used a condom at last commercial sex, divided by all those who report they have given or received money for sex in the last year.

Separate estimates should be provided for males and females and for the population as a whole.

What the indicator measures

This is a sensitive and robust indicator of protective behaviour among people who exchange sex for money. A significant increase in this indicator demonstrates success in promoting safer sex in this at-risk sub-population.

7. Use of crack/cocaine or other illegal drugs

Definition

Numerator: Number of respondents who have used any illegal drugs
Denominator: Number of respondents
**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>GP7.1</th>
<th>Marijuana (ganja, weed, grass, pot)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP7.2</td>
<td>Cocaine (crack, coke, snow)</td>
</tr>
<tr>
<td>GP7.3</td>
<td>Amphetamines (speed, ice)</td>
</tr>
<tr>
<td>GP7.4</td>
<td>Hallucinogens (LSD, acid, PCP, dust)</td>
</tr>
<tr>
<td>GP7.5</td>
<td>Heroin</td>
</tr>
</tbody>
</table>


**How to measure it**

The indicator is the proportion of respondents who answered “yes” to any questions about use of specific illegal drugs (questions GP7.1 to GP7.5). Survey planners should choose questions on the illegal drugs thought to be used in their country. It may be necessary to conduct a rapid assessment to identify these. Even where it is felt that particular drugs are not used in that country, it may be worth asking respondents whether they use it, in order to monitor emerging patterns. For instance, heroin use is thought to be very rare in the Caribbean (except in Bermuda), but including a question on its use will enable its detection at an early stage. It may be useful to ask about abuse of substances such as steroids and sniffing glue which are not illegal but which may be associated with higher sexual risk-taking. Separate estimates should be provided for males and females and for the population as a whole.

**What the indicator measures**

Research has repeatedly shown that people who consume illegal drugs are at high risk of HIV. This may be because they generally inclined to take risks, because they are willing to sell sex for drugs, or because they become sexually permissive while under the influence of drugs. Often sexual behaviour is influenced by all three of these factors. In the case of intravenous drug use (injecting) there is a high risk of direct injection of the virus into the blood stream.

Some Caribbean countries are transit points in the illegal drug trade, notably the trade in cocaine. There is also a flourishing internal trade in these drugs in many countries. Marijuana use remains relatively high. It may be surmised that the region faces significant HIV risk associated with consumption of illicit drugs.

It may be thought that consumption of illegal drugs is outside the remit of National AIDS Programmes. While NAPs may not have the necessary expertise in prevention and control of drug use, there is a responsibility to monitor their use as part of an expanded national response to HIV. They should work in partnership with national drug control agencies to ensure that this risk is reduced.

Regarding injecting drug use, it may be useful to add the following question to monitor emerging trends:

**Suggested Question**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you injected an illegal drug (shot up with a needle) during the past 12 months?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. Knowledge of HIV prevention methods

Definition

**Numerator:** Number of respondents able to identify mutual monogamy between HIV negative partners **and** consistent condom use as methods of reducing the risk of contracting HIV, in response to prompted questions.

**Denominator:** Total number of respondents

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP8.1 Can people protect themselves from the virus that causes AIDS by using a condom correctly every time they have sex?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP8.2 Can people protect themselves from HIV by having one uninfected faithful partner?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How to measure it**

The indicator is the number of respondents answering “Yes” to question GP8.1 **and** “Yes” to question GP8.2, divided by the number of respondents.

Separate estimates should be provided for males and females and for the population as a whole.

**What the indicator measures**

Early assumptions that knowledge about AIDS and how to prevent it would lead to behaviour change have proven optimistic. However, there is no doubt that knowledge is a prerequisite to behaviour change. Most AIDS programmes targeting the general population promote mutual monogamy and condom use as the primary ways of avoiding HIV infection. This indicator measures the extent to which those messages have reached the general population.

Many KABP studies have revealed that levels of HIV knowledge in the Caribbean are high. Most have reported on percentages correctly answering about individual prevention methods. In general population studies conducted from 1992 and 1999, between 75% and 96% of respondents in individual Caribbean countries agreed that condom use protects from HIV. Between 82% and 95% agreed either that people could protect by having one faithful partner or that HIV can be transmitted by sex with an infected person. The suggested indicator is more rigorous by including in the numerator only those respondents who correctly identify **both** mutual monogamy and condom use as prevention measures. The number identifying both is likely to be lower than the percentages identifying one alone, and the indicator will more sensitively measure changes in knowledge about HIV. It should be presented in conjunction with data from general population indicator 9 on “no incorrect beliefs about HIV transmission”.

9. No incorrect beliefs about HIV transmission

Definition

**Numerator:** Number of respondents who, in response to prompted questions, correctly reject the two most common local misconceptions about AIDS transmission, and who know that a healthy looking person can transmit AIDS.

**Denominator:** Total number of respondents

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP9.1 Can a person get HIV from mosquito bites?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP9.2 Can a person get HIV from sitting on a toilet seat after someone who is infected?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP9.3 Do you think that a healthy looking person can be infected with HIV, the virus that causes AIDS?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How to measure it

This is calculated as the number of people who answered “No” to GP8.1 and “No” to GP8.2 and “Yes” to GP8.3, divided by the number of respondents. In other words, to be counted in the numerator for this indicator, a respondent must correctly reject both misconceptions, and must know that a healthy-looking person can transmit AIDS.

Separate estimates should be provided for males and females and for the population as a whole.

An increase will indicate programme success.

What the indicator measures

This indicator gives a good picture of the level of false beliefs that may impede people’s determination to act on correct knowledge. When the data are disaggregated by misconception, they provide valuable information for programme managers planning information, education and communication campaigns, telling them which misconceptions must be attacked, with which subpopulations.

General population studies have shown that between 6% and 50% of people in various Caribbean countries believe that mosquitoes can transmit HIV. Substantial proportions believe that people can contract HIV by sitting on a toilet seat after it has been used by a person with HIV infection. While contact with mosquitoes and toilet seats can result in infection with other diseases, the same is not the case for HIV, which cannot survive under these conditions. Similarly, while people with other diseases show clear symptoms, the same is not true of HIV before it becomes AIDS. Nevertheless, between 5% and 55% of people in various Caribbean countries believe that you can identify somebody with HIV “by looking”. Incorrect transmission beliefs have been shown to be associated with higher risk taking behaviour (FHI, 2000).

Survey planners should use the two most common misconceptions about transmission in their country. While transmission via mosquitoes and toilet seats are common transmission beliefs across the Caribbean, there may be other beliefs which are more important in individual countries. All countries should utilise question GP8.3, though the exact wording may vary locally.

10. Attitudes to people living with HIV/AIDS

Definition

Numerator: Number of respondents expressing positive attitudes to people living with HIV/AIDS
Denominator: Number of respondents

Suggested Set of Questions

<table>
<thead>
<tr>
<th>GP10.1</th>
<th>If a member of your family became sick with the AIDS virus, would you be willing to care for him or her in your household?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>[ ]</td>
</tr>
<tr>
<td>No</td>
<td>[ ]</td>
</tr>
<tr>
<td>Don’t know</td>
<td>[ ]</td>
</tr>
<tr>
<td>No response</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GP10.2</th>
<th>If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>[ ]</td>
</tr>
<tr>
<td>No</td>
<td>[ ]</td>
</tr>
<tr>
<td>Don’t know</td>
<td>[ ]</td>
</tr>
<tr>
<td>No response</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GP10.3</th>
<th>If you knew that a shopkeeper or food seller had the AIDS virus, would you buy vegetables from them?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>[ ]</td>
</tr>
<tr>
<td>No</td>
<td>[ ]</td>
</tr>
<tr>
<td>Don’t know</td>
<td>[ ]</td>
</tr>
<tr>
<td>No response</td>
<td>[ ]</td>
</tr>
</tbody>
</table>


How to measure it

This is an indicator based on answers to a series of hypothetical questions about men and women with HIV. It reflects what people are prepared to say they would do when confronted with various situations involving people living with HIV. The aim is to increase the proportion answering “Yes” to all three questions.
Only a respondent who reports an accepting or supportive attitude on all three of these questions enters the numerator. The denominator is all people surveyed.

What the indicator measures

Stigma and discrimination are of concern to AIDS programmes for two main reasons. First, because they can make life unbearable for those who live with the disease. And secondly, because they affect prevention and care efforts. People who have been exposed to HIV through their behaviour or that of their partner may be unwilling to be tested or to change their behaviour in any way for fear of being suspected of being HIV-infected. If they are indeed infected, they may continue to spread the virus and will not be able to access adequate care. Where stigma is high, people avoid HIV tests that could provide an entry point for necessary care and support. Active discrimination has consequences for prevention, too. If a person is fired from their job because they are HIV-infected, they may have to resort to survival strategies such as selling sex, which further fuel the epidemic. Thus stigma and discrimination have the power to obstruct prevention and care efforts.

Programmes aim to combat active discrimination by changing laws to support those living with HIV and AIDS and by ensuring that the laws are enforced. They seek to change attitudes towards infected people and their families. They seek to break the silence surrounding the disease, partly by involving people living with HIV and their communities in an active response. This indicator provides an important measure of these efforts which improve both prevention and care.

A low score on the indicator is a fairly sound indication of high levels of stigma, and for that reason alone it is worth measuring. There are, however, difficulties in interpreting indicators based on hypothetical questions, and a high score on the indicator is harder to understand. Changes in the indicator could reflect a reduction in stigma or simply a growing awareness that people should not discriminate. Raising awareness that discrimination is wrong in itself, however, constitutes an important step in programme success (UNAIDS, 2000).

5.2 Indicators and questions for youth

The age group chosen for youth studies is important, as this will affect the results of the survey. If respondents are older, they are more likely to have had sex and to have had larger numbers of partners, for instance. CAREC recommends that surveys with young people be conducted with respondents age 10 to 24. Caribbean surveys have repeatedly shown that substantial proportions of young people are sexually active by age 10 – a few have shown that half of sexually experienced boys have had sex by this age. At the other end of the age spectrum, levels of HIV infection in the Caribbean have been shown to be highest between ages 15 to 24.

For school-based surveys which do not include youth out-of-school, it is recommended that young people age 10 to 18 years be selected as respondents. A school-based survey with 10 to 18 year olds in 9 Caribbean countries (PAHO, 2000) showed that median age at first sex (for those who had ever had sex) was less than 10 years for males, 14 for females and 13 for the sample as a whole.

Surveys may be conducted with children under 10 years. However, the wording and format of questionnaires must be carefully considered and piloted to ensure that children of this age understand and can easily respond to questions.

Use of standard age groups will improve comparability between studies. Caribbean studies of youth sexual behaviour have used many different age groups, making comparisons over time and among territories difficult.

All the youth indicators below should be calculated separately for males and females as well as for the sample as a whole.

The indicators selected for youth are as follows:
1. Number of sex partners in the last 12 months
2. Age at first sex
3. Age mixing in sexual relationships
4. Condom use at last sexual intercourse
5. Involuntary sexual relations (rape) in the last 12 months
6. Commercial sex in the last year
7. Use of crack/ cocaine or other illegal drugs
8. Knowledge of HIV prevention methods
9. No incorrect beliefs about HIV transmission
10. Attitudes to people living with HIV/AIDS

1. **Number of sex partners in the last 12 months**

**Definition**

**Option 1:** Median number of sex partners in the last 12 months

**Option 2:**

*Numerator:* Number of respondents who have had sex with more than one partner in the last 12 months

*Denominator:* Number of respondents who have ever had sex

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y1.1</td>
<td>Have you ever had sexual intercourse?</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Y1.2</td>
<td>How many sexual partners have you had in the last 12 months?</td>
</tr>
<tr>
<td></td>
<td>PARTNERS</td>
</tr>
</tbody>
</table>


**How to measure it**

Option 1 is calculated by presenting data from question Y1.2 in a table of frequencies. The median is the number of partners coinciding with the 50th percentile; half of respondents had this number of partners.

Option 2 is calculated from the number of respondents reporting two or more partners divided by the number of females or males who have had sex (question Y1.1).

Of the two options for measurement presented above, the median is the more sensitive indicator, as it will measure changes from higher to lower numbers of partners and vice versa. Option 2 is useful for showing the proportions of young people exposed to more risk through multiple partnerships. The indicator may be reported separately for those aged 10-14, 15-19 and 20-24.

**What the indicator measures**

Prevention messages for young people tend to begin with abstinence and often focus also on mutual monogamy. But because sexual relationships among young people are frequently unstable, relationships that were intended to be mutually monogamous may break up and be replaced by other relationships. Particularly in high HIV prevalence epidemics, serial monogamy is not greatly protective against HIV infection. This indicator measures the proportion of young people that have been exposed to more than one partner in the last year. That is, the proportion for whom the “one, mutually faithful partner” message has failed.

2. **Age at first sex**

**Definition**

**Option 1:** Median age at first sex (the age by which one half of young people have had first sexual intercourse)

**Option 2:** Percentage who has had sex by age 16.

**Suggested Question**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y2</td>
<td>Have you ever had sexual intercourse?</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

Note: Question Y2 is identical to question Y1.1
**How to measure it**

This measure is constructed from data on current virginity status on young people, NOT from retrospective questions about age at first sex. Most questionnaires include questions such as “How old were you when you first had sex?” These data are not used in the construction of this indicator. This is because they exclude people who have not yet had sex, and therefore tend to bias the median age downwards.

To calculate the median, age of respondent and responses to “Ever had sexual intercourse?” are cross-tabulated. The table will show percentages responding “Yes” to having ever had sex against each year of age. When the cumulative percentage reaches 50%, this is the median. Note that where less than 50% of respondents report having ever had sex, it will not be possible to calculate the median.

Option 2 may be calculated from the same table by reading across from age 16 and calculating the cumulative percentage having had sex before this age. Alternatively, select all respondents aged under 16, and calculate the percentage who have ever had sex. The threshold age of 16 has been selected because this is the legal age of consent to sexual intercourse in many Caribbean territories.

Caribbean studies with 10 to 24 year olds, which have invariably used retrospective questions, have shown median age at first sex to be around 15 years. This is the median age at first sex of those who are sexually experienced, and not of young people as a whole. Studies with younger sample age, not surprisingly, tend to show lower median ages at first sex for the sexually experienced. If a younger age group is selected, a younger threshold age for option 2 may be chosen. It is important to be consistent in choice of sample age group.

Studies across the Caribbean consistently show lower reported age at first sex among boys than girls. Thus it is particularly important to disaggregate the data by gender.

**What the indicator measures**

A major programme goal in many areas is delaying the age at which young people first have sex. Clearly, young people are protected from infection by abstinence. But there is evidence to suggest that a later age at first sex also reduces susceptibility to infection per act of sex, at least for women. An upward shift in the indicator suggests that programmes promoting abstinence among young people are working.

Programme success is indicated by rising age at first sex, or a falling percentage of 10-24 year olds who have had sex by age 16.

### 3. Age mixing in sexual relationships

**Definition**

The percentage of sexually experienced young people whose first sexual encounter was with someone who at that time was at least 10 years older than they were.

**Suggested Questions**

<table>
<thead>
<tr>
<th>Y3.1</th>
<th>At what age did you first have sexual intercourse?</th>
<th>Age in years</th>
<th>Don’t know/ can’t remember</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y3.2</td>
<td>I would like you to think about that first time you had sex. How old was your partner?</td>
<td>Age in years</td>
<td>Don’t know/ can’t remember</td>
<td>No response</td>
</tr>
</tbody>
</table>

*Source: MEASURE DHS+ (2000)*
How to measure it

Age at first sex is subtracted from age of partner at first sex to calculate a variable representing the age difference between the partners. Data from this variable is presented in a table of frequencies. The indicator is the percentage of sexually experienced respondents (question Y1.1) whose partner was at least 10 years older when virginity was lost.

What the indicator measures

One of the principal forces driving the spread of HIV is age-mixing. Often, the virus is introduced into a new pool of uninfected young people when people in that age group have sex with people in an age group that is already heavily infected. Most commonly, but not exclusively, the younger partners are girls, the older partners men. These types of partnerships are especially good at spreading the virus since, for physiological reasons, there is a high risk of infection per act of sex between a young, uninfected girl and a more mature infected man.

In some countries this pattern of mixing is common enough to have been given a name: the “sugar daddy syndrome”. AIDS programmes sometimes try to address it directly from both ends: through IEC campaigns aiming to make sex with younger people socially unacceptable among older men, and through initiatives to increase young peoples’ negotiating power. This indicator measures progress made towards reducing the proportion of young people having sex with substantially older people.

4. Condom use at last sexual intercourse

Definition

*Numerator:* Number of respondents who used a condom the last time they had sex

*Denominator:* Number of respondents who have had sex in the last 12 months

<table>
<thead>
<tr>
<th>Suggested Set of Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y4.1</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Don't know</td>
</tr>
<tr>
<td>No response</td>
</tr>
<tr>
<td>Y4.2</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Don't know</td>
</tr>
<tr>
<td>No response</td>
</tr>
</tbody>
</table>

*Source: FHI (2000); WHO-GPA (1994)*

How to measure it

Those that report using a condom the last time they had sex enter the numerator. The denominator is the number of respondents who have had sex in the last 12 months. An increase indicates success. The indicator should be measured for males, for females and for the sample as a whole.

What the indicator measures

In many high HIV prevalence epidemics, it is clear that a high (and rising) proportion of HIV infections take place among young unmarried people, but reluctance to provide services to decrease risk among young people is sometimes intense. Some national programmes are beginning to actively promote the provision of services to young and unmarried people. This indicator tracks their success in reducing the risk of HIV infection in premarital sex by increasing condom use.

5. Unwanted/Involuntary sexual relations (rape) in last 12 months

Definition

*Numerator:* Number of respondents who have had involuntary sexual relations in the last 12 months

*Denominator:* Total number respondents
**Suggested Question**

| Y5 | During the last 12 months, did any of your sexual partner(s) force you to have sex with them even though you did not want to have sex? | Yes | | No | | Don't know | | No response | |

Source: FHI (2000)

**How to measure it**

This indicator is the number of respondents answering “yes” to Y5, divided by the number of respondents. It expresses the proportion of respondents who have involuntarily had sex over the past year.

Separate estimates should be generated for males and females and for the age groups 10-14, 15-19 and 20-24.

**What the indicator measures**

Sexual abuse of young people is of serious concern in the Caribbean. Involuntary sexual relations are reported (though infrequently to the police authorities) by both females and males. This is a measure of the extent of involuntary sexual activity among young people. It may indicate the need for skills training among young people to avoid situations that could put them at risk and assertiveness training so that they can successfully refuse unwanted sexual advances. Concerted IEC campaigns may be needed to reduce the acceptability of forcing young people to have sex.

6. **Commercial sex in the last year**

**Definition**

*Numerator:* Number of respondents who have given or received money or things for sex in the last 12 months  
*Denominator:* Total number of respondents

**Suggested Question**

| Y6 | In the past 12 months have you given or received money or things (such as clothes) for sex? | Yes | | No | | Don’t know | | No response | |


**How to measure it**

This indicator shows the proportion of young people exchanging money or things for sex in the past year.

Separate estimates should be provided for males and females and for the population as a whole.

**What the indicator measures**

Research in the Caribbean has revealed that exchange of sex for money and material things (e.g. clothes, jewellery) is substantial among young people. This may be influenced by the lack of legitimate income-earning opportunities for them. Those who receive money or things tend to take more partners as they seek resources, while those who give money or things will tend to be exposed to large sexual networks. Sex for material gain tends to exacerbate the risks associated with frequent turnover of partners among youth.

7. **Use of crack/ cocaine or other illegal drug**

**Definition**

*Numerator:* Number of respondents who have used any illegal drug  
*Denominator:* Number of respondents
How to measure it

The indicator is the proportion of respondents who answered “yes” to any questions about use of specific illegal drugs (questions Y7.1 to Y7.5). Survey planners should choose questions on the illegal drugs thought to be used in their country. It may be necessary to conduct a rapid assessment to identify these. Even where it is felt that particular drugs are not used in that country, it may be worth asking respondents whether they use it, in order to monitor emerging patterns. For instance, heroin use is thought to be very rare in the Caribbean (except in Bermuda), but including a question on its use will enable its detection at an early stage.

It may be useful to ask about abuse of substances such as steroids and sniffing glue which are not illegal but which may be associated with higher sexual risk-taking.

What the indicator measures

Young people, in an experimental phase of life, are susceptible to using mood-altering drugs, and are thus susceptible to HIV. See general population indicator 7 for more information on the importance of measuring illegal drug use.

8. Knowledge of HIV prevention methods

Definition

Numerator: Number of respondents able to identify mutual monogamy between HIV negative partners and consistent condom use and abstinence from sex as methods of reducing the risk of contracting HIV, in response to prompted questions. Denominator: Total number of respondents

Suggested Set of Questions

<table>
<thead>
<tr>
<th>Y7</th>
<th>Some people have tried a range of different types of drugs. Which of the following, if any, have you tried?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Y7.1</td>
<td>Marijuana (ganja, weed, grass, pot)</td>
</tr>
<tr>
<td>Y7.2</td>
<td>Cocaine (crack, coke, snow)</td>
</tr>
<tr>
<td>Y7.3</td>
<td>Amphetamines (speed, ice)</td>
</tr>
<tr>
<td>Y7.4</td>
<td>Hallucinogens (LSD, acid, PCP, dust)</td>
</tr>
<tr>
<td>Y7.5</td>
<td>Heroin</td>
</tr>
</tbody>
</table>

Sources: FHI (2000); PAHO (2000)

How to measure it

The indicator is derived from answers given for three primary sexual prevention methods for young people. It is the number of respondents answering “Yes” to question Y8.1 and “Yes” to question Y8.2 and “Yes” to question Y8.3, divided by the number of respondents. Separate estimates should be provided for males and females and for the population as a whole and
data should be disaggregated by age groups: 10-14, 15-19 and 20-24 years old.
The indicator components should also be reported separately to show changes in specific knowledge areas.

What the indicator measures

The indicator is the same as general population indicator 8, except that it includes abstinence as a method of preventing HIV.
HIV prevention and life skills training aimed at young people generally try to equip them with skills to delay sex until they feel
it is appropriate, as well as to encourage safe sex for those who choose to be sexually active.

Note that correct knowledge is particularly critical at a young age when young people are under pressure to have sex. Yet
Caribbean surveys have shown young people to be no better informed, and sometimes less informed, than the general
population. For instance, in response to prompted questions, between 50% and 95% of young people in individual Caribbean
countries agreed that people can protect themselves from HIV. This compares with between 75% and 96% in general
population surveys.

9. No incorrect beliefs about HIV transmission

Definition

_Numerator_: Number of respondents who, in response to prompted questions, correctly reject the two most common local
misconceptions about AIDS transmission, and who know that a healthy looking person can transmit AIDS.

_Denominator_: Total number of respondents

<table>
<thead>
<tr>
<th>Suggested Set of Questions</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y9.1 Can a person get HIV from mosquito bites? Y9.2 Can a person get HIV from sitting on a toilet seat after someone who is infected? Y9.3 Do you think that a healthy looking person can be infected with HIV, the virus that causes AIDS.</td>
<td>Yes [ ] No [ ] Don't know [ ] No response [ ] Yes [ ] No [ ] Don't know [ ] No response [ ] Yes [ ] No [ ] Don't know [ ] No response [ ]</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: FHI (2000)

How to measure it

This is calculated as the number of people who answered “No” to Y9.1_and_ “No” to Y9.2_and_ “Yes” to Y9.3, divided by the
number of respondents. In other words, to be counted in the numerator for this indicator, a respondent must correctly reject
both misconceptions, and must know that a healthy-looking person can transmit AIDS.

Separate estimates should be provided for males and females and for the population as a whole. The data may be
disaggregated by age groups: 10-14, 15-19 and 20-24 years.

An increase will indicate programme success.

What the indicator measures

This indicator gives a good picture of the level of false beliefs that may impede young people’s determination to act on correct
knowledge.

Youth studies have shown that between 10% and 60% of young people in various Caribbean countries believe that mosquitoes
can transmit HIV, higher than the range of 6% to 50% in the general population. Given the association of misconceptions with
risk, it is particularly important to reduce misconceptions among young people.
Survey planners should use the two most common misconceptions about transmission among young people in their country. It may be necessary to conduct a rapid assessment to pick up new beliefs among the youth.

10. **Attitudes to people living with HIV/AIDS**

**Definition**

*Numerator:* Number of respondents expressing positive attitudes to people living with HIV/AIDS  
*Denominator:* Number of respondents

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y10.1</td>
<td>If a member of your family became sick with the AIDS virus, would you be willing to care for him or her in your household?</td>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
<td>No response</td>
</tr>
<tr>
<td>Y10.2</td>
<td>If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?</td>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
<td>No response</td>
</tr>
<tr>
<td>Y10.3</td>
<td>If a student has HIV but is not sick, should he or she be allowed to continue attending school?</td>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
<td>No response</td>
</tr>
</tbody>
</table>

*Source: UNAIDS (2000); MEASURE DHS+ (2000); FHI (2000)*

**How to measure it**

The indicator is the proportion of the population answering “Yes” to all three of the questions above.

**What the indicator measures**

The indicator is based on three realistic scenarios which young people may face in encountering PLWHA in everyday life. (See adult indicator 10 for more information about the issues in measuring stigma and discrimination).

5.3 **Indicators and questions for Female Sex Workers (FSWs)**

The indicators selected for FSWs are as follows:

- Knowledge of HIV prevention methods
- No incorrect beliefs about HIV transmission
- Condom use at last sex with a client
- CSW carrying a condom at time of interview
- Consistent condom use with clients in the last month
- Condom use at last anal sex
- Use of crack/cocaine or other illegal drugs in the last six months
- Exchange of sex for drugs
- Attitudes to people living with HIV/AIDS
- Sex workers seeking voluntary HIV tests

1. **Knowledge of HIV prevention methods**

**Definition**

*Numerator:* Number of respondents identifying consistent condom use as a method of reducing the risk of contracting HIV, in response to a prompted question  
*Denominator:* Total number of respondents surveyed
**Suggested Question**

<table>
<thead>
<tr>
<th>Suggested Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW1 Can people protect themselves from HIV, the virus that causes AIDS, by using a condom correctly every time they have sex?</td>
<td>]</td>
<td>]</td>
<td>]</td>
<td>]</td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

**How to measure it**

People who answer affirmatively to the question on condom use are included in the numerator. The denominator is all respondents.

**What the indicator measures**

While many factors other than knowledge influence the behavior of sex workers, accurate knowledge is a prerequisite to safer practices. This indicator measures knowledge of the only primary prevention method relevant to sex workers; consistent condom use.

It is expected that this indicator will be at very high levels in most sex worker populations. However, disaggregation by location of sex work or type of sex worker may point to information gaps. For instance, sex workers in a poorer area of a city or immigrant sex workers may have lower than average levels of knowledge.

2. No incorrect beliefs about HIV transmission

**Definition**

**Numerator:** Number of respondents who, in response to prompted questions, correctly reject the two most common local misconceptions about AIDS transmission, and who know that a healthy-looking person can transmit AIDS  

**Denominator:** Total number of respondents surveyed

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Suggested Set of Questions</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW2.1 Can a person get HIV from mosquito bites?</td>
<td>]</td>
<td>]</td>
<td>]</td>
<td>]</td>
</tr>
<tr>
<td>SW2.2 Can a person get HIV from sitting on a toilet seat after someone who is infected?</td>
<td>]</td>
<td>]</td>
<td>]</td>
<td>]</td>
</tr>
<tr>
<td>SW2.3 Do you think that a healthy looking person can be infected with HIV, the virus that causes AIDS?</td>
<td>]</td>
<td>]</td>
<td>]</td>
<td>]</td>
</tr>
</tbody>
</table>


**How to measure it**

This is calculated as the number of people who answered “No” to SW2.1 and “No” to SW2.2 and “Yes” to SW2.3, divided by the number of respondents. In other words, to be counted in the numerator for this indicator, a respondent must correctly reject both misconceptions, and must know that a healthy-looking person can transmit HIV.

**What the indicator measures**

This indicator is identical in principle to adult indicator 9 and youth indicator 9. However, it is worth mentioning that there may be transmission and prevention myths specific to the world of sex workers. These should be explored in the survey planning stage, and used to replace more generally held misconceptions where appropriate.
3. Condom use at last sex with a client

Definition

**Numerator:** Number of sex workers who report using a condom with their most recent client  
**Denominator:** Total number of sex workers surveyed

<table>
<thead>
<tr>
<th><strong>Suggested Question</strong></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The last time you had sex with a client, did you and your client use a condom?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

How to measure it

Sex workers are asked whether they used a condom with their most recent client. The indicator is the number of sex workers who say they used a condom with their most recent client, divided by the total number of sex workers interviewed.

What the indicator measures

The indicator measures the success of campaigns to promote condom use in commercial sex, from reports given by sex workers. Referring to the last client minimises recall bias. This is a robust measure of levels of condom use with clients.

4. FSWs carrying a condom at time of interview

Definition

**Numerator:** Number of sex workers who can show the interviewer that they have a condom with them  
**Denominator:** Total number of sex workers surveyed

<table>
<thead>
<tr>
<th><strong>Suggested Set of Questions</strong></th>
<th>Yes</th>
<th>No</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW4.1 Do you have a condom with you now?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SW4.2 Can you show it to me?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: Guyana National AIDS Programme, Red Thread Women’s Development Programme and CAREC (2001); FHI (2000)*

How to measure it

The number of sex workers answering “Yes” to question 4.2 is divided by the number of survey respondents.

What the indicator measures

This provides a concrete indication of condom use, since sex workers who are able to show a condom to the interviewer are also more likely to use condoms with clients. The indicator has been used in a number of sex worker surveys including a 2000 survey in Georgetown, Guyana where 41% of respondents showed a condom to the interviewer.

5. Unwanted/Involuntary sexual relations (rape) in last 12 months

Definition

**Numerator:** Number of respondents who have had involuntary sexual relations in the last 12 months  
**Denominator:** Total number respondents
**Suggested Question**

| SW5 | During the last 12 months, did any of your sexual partners force you to have sex with them even though you did not want to have sex? | Yes [ ] | No [ ] | Don't know [ ] | No response [ ] |

*Source: FHI (2000)*

**How to measure it**

This indicator is the number of respondents answering “yes” to SW5, divided by the number of respondents. It expresses the proportion of respondents who have had sex involuntarily over the past year.

**What the indicator measures**

Involuntary sex, or rape, prevents sex workers from adopting sexual practices, including condom use, which are safer for herself and her partner. This form of abuse engenders a feeling of helplessness, reducing confidence in the ability to control sexual encounters and thus the likelihood that women will take preventive action. This measure of the extent of involuntary sexual activity among sex workers may indicate the need for skills training among them to avoid situations that could put them at risk and training so that they can successfully negotiate the terms of sexual encounters. It may indicate the need for interventions with clients. The indicator will measure the success of such efforts.

6. **Condom use at last anal sex**

**Definition**

**Numerator:** Number of sex workers whose partners used a condom at last anal intercourse  
**Denominator:** Number of sex workers who had receptive anal intercourse in the last 6 months

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>SW6.1</th>
<th>In the past six months, have you ever taken anal sex?</th>
<th>Yes [ ]</th>
<th>No [ ]</th>
<th>Don't know [ ]</th>
<th>No response [ ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW6.2</td>
<td>Last time had anal sex, did your partner use a condom?</td>
<td>Yes [ ]</td>
<td>No [ ]</td>
<td>Don't know [ ]</td>
<td>No response [ ]</td>
</tr>
</tbody>
</table>

*Source: Guyana National AIDS Programme, Red Thread Women's Development Programme and CAREC (2001)*

**How to measure it**

The measure is the number responding “Yes” to SW5.2 divided by the number responding “Yes” to SW5.1.

**What the indicator measures**

There is a high risk of HIV transmission during anal intercourse. Sex workers whose partners use a condom during this type of sex have a substantially lower risk. The aim is to increase this indicator.

This set of questions would need to be worded appropriately in the local context. In Georgetown, Guyana, for instance, respondents were asked if they take “sex in the back”, which has the local meaning of anal sex. In other contexts this same expression may simply mean vaginal sex from behind. Ideally, the colloquial term used by sex workers themselves should be used.
7. Use of crack/ cocaine or other illegal drugs in the last twelve months

Definition

**Numerator:** Number of respondents who have used any illegal drug in the last twelve months  
**Denominator:** Number of respondents

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>SW7</th>
<th>Some people have used a range of different types of drugs. Which of the following, if any, have you used in the last twelve months?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW7.1</td>
<td>Marijuana (ganja, weed, grass, pot)</td>
</tr>
<tr>
<td>SW7.2</td>
<td>Cocaine (crack, coke, snow)</td>
</tr>
<tr>
<td>SW7.3</td>
<td>Amphetamines (speed, ice)</td>
</tr>
<tr>
<td>SW7.4</td>
<td>Hallucinogens (LSD, acid, PCP, dust)</td>
</tr>
<tr>
<td>SW7.5</td>
<td>Heroin</td>
</tr>
</tbody>
</table>

Sources: FHI (2000); PAHO (2000)

How to measure it

The indicator is the proportion of respondents who answered “yes” to any questions about use of specific illegal drugs (questions SW7.1 to SW7.5). Survey planners should choose questions on the illegal drugs used by sex workers in their country. It may be necessary to conduct a rapid assessment to identify these. The local names for these drugs should be used. It is important not to mention that the drugs are illegal as this will lead to substantial underreporting.

It may be useful to ask about abuse of substances such as steroids and sniffing glue which are not illegal but which may be associated with higher sexual risk-taking.

What the indicator measures

Drug use contributes to the risks taken by sex workers. In the Caribbean, some people become involved in or continue sex work in order to finance a drug habit. Under the influence of drugs, sex workers may relax their standards for safer sex. NAPs should work with drug prevention agencies in programmes that target sex workers and which aim to decrease this indicator.

Regarding injecting drug use, it may be useful to add the following question to monitor emerging trends:

<table>
<thead>
<tr>
<th>Have you injected an illegal drug (shot up with a needle) during the past 12 months?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Sex workers are often among the first populations to become involved in new drug use trends, and may influence the drug taking behaviour of clients. Given the high level of risk of transmission through IDU, it is worth monitoring trends in key populations at risk.

8. Exchange of sex for drugs

Definition

**Numerator:** Number of respondents who have exchanged sex for drugs in the last 12 months  
**Denominator:** Total number of respondents
What the indicator measures

Selling sex for drugs provides an additional level of risk, as it further reduces sex workers’ capacity to control what takes place during sexual encounters. In the Georgetown sex workers’ survey, it was found that FSWs who exchanged sex for drugs were significantly more likely to be infected with HIV than those who did not. The level of HIV infection among these women was an astounding 59%, as against 31% for the sample as a whole (Guyana NAP, Red Thread and CAREC, 2001). This finding reinforces the point that NAPs and drug prevention agencies have a responsibility to work together.

9. Attitudes to people living with HIV/AIDS

Definition

Numerato r: Number of respondents expressing positive attitudes to people living with HIV/AIDS

Denominator: Number of respondents

Suggested Set of Questions

<table>
<thead>
<tr>
<th>SW9.1</th>
<th>If a member of your family became sick with the AIDS virus, would you be willing to care for him or her in your household?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SW9.2</th>
<th>If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SW9.3</th>
<th>If you knew that a shopkeeper or food seller had the AIDS virus, would you buy vegetables from them?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
</tr>
</tbody>
</table>


How to measure it

Only a respondent who reports an accepting or supportive attitude on all three of these questions enters the numerator. The denominator is all people surveyed.

What the indicator measures

See general population indicator 10.

Note that prejudicial attitudes to PLWHA can be damaging to sex workers as they are associated with the view that HIV infections are associated with other types of people: “It cannot happen to me”. People with such views pay less attention to messages about safer sex. Given the high rates of infection among sex workers, prejudice will lead to an unsupportive environment for those who do find themselves to be infected.

10. Sex workers seeking voluntary HIV tests

Definition

Numerato r: Number of respondents who have ever voluntarily requested an HIV test, received the test and received their results.

Denominator: Total number of respondents.
**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>SW10.1</th>
<th>I don't want to know the result, but have you ever had an HIV test?</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SW10.2</td>
<td>Did you voluntarily undergo the HIV test, or were you required to have the test?</td>
<td>Voluntary</td>
<td>Required</td>
<td>No response</td>
<td></td>
</tr>
<tr>
<td>SW10.3</td>
<td>Please do not tell me the result, but did you find out the result of your test?</td>
<td>Yes</td>
<td>No</td>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

**How to measure it**

The measure is the number who answered “Yes” to SW10.1, “Voluntary” to SW10.2 and “Yes” to SW10.3, divided by the number of respondents.

**What the indicator measures**

The indicator is a summary measure of the coverage of quality VCT services among sex workers. This coverage will go a long way to determining whether testing services are achieving their aims of providing an entry point to care and support and promoting safer behaviour. This indicator aims to show the reach of voluntary HIV testing services in a key group at risk.

**5.4 Indicators and questions for men who have sex with men (MSM)**

MSM are defined operationally as men who have had sex with men within the last year. Strategies for identifying these men are discussed in the section on sampling.

The indicators selected for MSM are as follows:

1. Number of male anal sex partners in the last six months
2. Female partner(s) in the last year
3. Age at first sex with male partner
4. Condom use at last anal sex
5. Consistent condom use in anal sex with male partners
6. Condom use at last anal sex with a male commercial partner
7. Involuntary sexual relations in the last twelve months
8. Use of crack/ cocaine or other illegal drug
9. Knowledge of HIV transmission and prevention
10. Attitudes to people living with HIV/AIDS

**1. Number of male anal sex partners in the last six months**

**Definition**

*Numerator:* Number of respondents who report anal sex with more than one other man in the last 6 months

*Denominator:* Total number of respondents surveyed

**Suggested Question**

<table>
<thead>
<tr>
<th>MSM1</th>
<th>How many men have you had anal sex with in the last six months?</th>
<th>NUMBER</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
</table>

*Source: FHI (2000)*
How to measure it

If the response to MSM1 is more than 1, the respondent enters the numerator. The denominator is all respondents.

What the indicator measures

Many interventions with MSM aim both to decrease the overall number of partners and to increase condom use in all partnerships. This indicator attempts to measure changes in anal sex with multiple partners, and therefore exposure to sexual networks that increase the risk of HIV transmission.

The six-month time reference period differs from that used for other groups. This is because in most cases where BSS is used with MSM, the sampling strategy tends to focus on cruising areas and other areas where men congregate to seek or meet male partners. This means that these men are likely to have a high turnover of partners. The time reference period is reduced to six months to provide for more accurate recall.

2. Female partners in the last year

Definition

*Numerator:* Number of respondents who have had sex with a woman in the last 12 months

*Denominator:* Total number of respondents

Suggested Set of Questions

<table>
<thead>
<tr>
<th>Suggested Set of Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MSM2.1</strong> We have been talking about your male sex partners. Have you ever had any female sex partners?</td>
</tr>
<tr>
<td><strong>MSM2.2</strong> Have you had sexual intercourse with any of your female partners in the last 12 months?</td>
</tr>
<tr>
<td><strong>MSM2.3</strong> How many female partners have you had intercourse with in the last 12 months?</td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

How to measure it

The number of respondents who answer “Yes” to MSM2.2 is divided by the total number of respondents.

What the indicator measures

The indicator measures the proportion of MSM who also have sex with women. In the numerator is counted any MSM who has had sex with a woman as by definition he will have had at least two partners in the last year. This indicator thus provides a further indicator of multiple partnership, as well as an indication of active bisexual behaviour. Men who have sex with both men and women are at high risk by linking into both MSM and heterosexual sexual networks. They provide a bridging population for the spread of HIV into the general population.

In the homophobic social climate of the Caribbean, many MSM have relationships with women in order to retain social respectability. Some are married to women (Russell-Brown and Sealy, 1998). Programmes should seek to reduce the number of sexual partnerships, whether with males or females or both, in order to reduce the spread of HIV. They should also seek to reduce discrimination towards MSM: this will help stabilise sexual partnerships and enable MSM to adopt safer sex practices.

Dividing the number of female partners (MSM2.3) by the number who have ever had sex with a woman (MSM2.1) provides the average number of female partners per man with bisexual behaviour. This is a further useful measure, showing the average number of women who are linked to MSM sexual networks by each man with bisexual behaviour.
3. Age at first sex with male partner

Definition

Median age at first sex among MSM aged 15 to 24 years.

**Suggested Question**

<table>
<thead>
<tr>
<th>MSM3</th>
<th>At what age did you first have sexual intercourse with another male?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AGE IN YEARS</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

How to measure it

The sub-sample of MSM aged 15-24 are selected. For these men, data on age at first sex (MSM3) are presented in a table of frequencies. The median is the age at first sex coinciding with the 50th percentile.

What the indicator measures

Research has revealed that many Caribbean MSM have their first sexual experience with a male at a very young age. Some were sexually abused or raped by an older man (Russell-Brown and Sealy, 1998). Raising the age at first sex between males will tend to reduce risk by enabling these sexual encounters to take place under conditions of safety, mutual consent and negotiation. This indicator will show the age at which MSM become sexually active and reveal whether it is necessary to target interventions at male adolescents and children as well as the older men who may have sexual relations with them.

The median age of first sex for the sample as a whole will tend to be associated with the age distribution of the sample. Therefore a standard age group should be selected for measurement of this indicator. The age group 15-24 has been selected as younger men will have a higher level of recall of their first sexual experiences. This MSM age group also enables comparisons with data on the same age group of males and females in BSS with young people. To generalise from this indicator to the population of MSM in this age group as a whole, the size of the sample of MSM 15-24 must be sufficiently large (see chapter on sampling).

A retrospective question on age at first sex is used for this indicator. This contrasts with the situation for surveys with young people in which the median is calculated by combining data on current age with data on virginity status. As MSM by definition are sexually experienced, it is not necessary to use the same method of calculation as is used in BSS for youth as a whole.

4. Condom use at last anal sex with a non-commercial male partner

Definition

**Numerator:** Number of respondents who report condom use at last anal sex with a non-commercial male partner

**Denominator:** Number of respondents who report anal sex with at least one non-commercial partner in the last six months.

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>MSM4.1</th>
<th>How many men have you had anal sex with in the last six months?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NUMBER</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MSM4.2</th>
<th>Of all these partners, how many were:</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMMERCIAL</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MSM4.3</th>
<th>- Commercial (partners with whom you had sex in exchange for money)</th>
</tr>
</thead>
<tbody>
<tr>
<td>OTHER</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MSM4.4</th>
<th>The last time you had sex with a non-commercial partner, was a condom used?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td></td>
</tr>
</tbody>
</table>

Source: FHI (2000)
How to measure it

The numerator is the number of men reporting that a condom was used the last time they had anal sex with a non-commercial partner (MSM4.4). The denominator is all men who reported having anal sex at least once in the last six months with a non-commercial partner (MSM4.3).

What the indicator measures

The single most common intervention among MSM is the promotion of condom use during anal sex. This indicator measures progress towards increasing the proportion of acts of anal sex that are protected against HIV transmission. Focusing on the last sexual act minimises recall bias. This is a robust and sensitive indicator of condom use.

5. Consistent condom use in anal sex with non-commercial male partners

Definition

*Numerator:* Number of respondents who used a condom ever time they had anal sex with non-commercial male partners over the last six months  
*Denominator:* Number of respondents who have had anal sex with a non-commercial partner at least once in the past 6 months

**Suggested Question**

<table>
<thead>
<tr>
<th>MSM5</th>
<th>With what frequency did you and all of your clients use condoms over the last 30 days?</th>
<th>Every time</th>
<th>Almost every time</th>
<th>Sometimes</th>
<th>Never</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*

How to measure it

The indicator is the number of respondents answering “Every time” to question MSM5, divided by the number of respondents who have had anal sex with a non-commercial partner at least once in the past 6 months (MSM4.3).

What the indicator measures

This provides a measure of consistent condom use in anal sex between men. It is similar to general population indicator 3.

6. Condom use at last anal sex with a male commercial partner

Definition

*Numerator:* Number of respondents who report condom use at last anal sex with a male partner who they are paying cash for sex  
*Denominator:* Number of respondents who report anal sex with at least one male commercial partner in the last 6 months.

**Suggested Question**

<table>
<thead>
<tr>
<th>MSM6</th>
<th>The last time you had sex with a commercial partner, was a condom used?</th>
<th>Yes</th>
<th>No</th>
<th>Don't remember</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: FHI (2000)*
How to measure it

This is the number of men replying “Yes” to MSM6 divided by the number reporting at least one male commercial partner to MSM4.2

What the indicator measures

Unprotected sex with a commercial partner carries a higher risk of HIV transmission than with a non-commercial partner. This is because male sex workers tend to have a higher turnover of partners, so unless they consistently use condoms they are repeatedly exposed to the risk of infection. This indicator should be presented alongside MSM indicator 5 to compare condom use levels with the two types of partners.

7. Unwanted/Involuntary sexual relations (rape) in last 12 months

Definition

Numerator: Number of respondents who had involuntary sexual relations in the last 12 months
Denominator: Total number respondents

Suggested Question

| MSM7          | During the last 12 months, did any of your sexual partners force you to have sex with them even though you did not want to have sex? | Yes | ] | No | ] | Don't know | ] | No response | ] |

Source: FHI (2000)

How to measure it

This indicator is the number of respondents answering “Yes” to MSM7, divided by the number of respondents. It expresses the proportion of respondents who have involuntarily had sex over the past year.

What the indicator measures

Qualitative research reveals that male rape is quite common among MSM, and adds to their feeling that they cannot control their sexual lives (Russell-Brown and Sealy, 1998). Involuntary sex, or rape, prevents MSM from adopting safer sexual practices. This form of abuse engenders a feeling of helplessness, reducing confidence in the ability to control sexual encounters and thus the likelihood that men will take preventive action. This measure of the extent of involuntary sexual activity among MSM may indicate the need for skills training among them to avoid situations that could put them at risk and training so that they can successfully negotiate the terms of sexual encounters. The indicator will measure the success of such efforts.

8. Use of crack/ cocaine or other illegal drugs in the last twelve months

Definition

Numerator: Number of respondents who have used any illegal drug in the last twelve months
Denominator: Number of respondents
Suggested Set of Questions

<table>
<thead>
<tr>
<th>MSM8</th>
<th>Some people have used a range of different types of drugs. Which of the following, if any, have you used in the last twelve months?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>MSM8.1</td>
<td>Marijuana (ganja, weed, grass, pot)</td>
</tr>
<tr>
<td>MSM8.2</td>
<td>Cocaine (crack, coke, snow)</td>
</tr>
<tr>
<td>MSM8.3</td>
<td>Amphetamines (speed, ice)</td>
</tr>
<tr>
<td>MSM8.4</td>
<td>Hallucinogens (LSD, acid, PCP, dust)</td>
</tr>
<tr>
<td>MSM8.5</td>
<td>Heroin</td>
</tr>
</tbody>
</table>


How to measure it

The indicator is the proportion of respondents who answered “yes” to any questions about use of specific illegal drugs (MSM8.1 to MSM8.5). Survey planners should choose questions on the illegal drugs used in their country. It may be necessary to conduct a rapid assessment to identify these. The local names for these drugs should be used. It is important not to mention that the drugs are illegal as this will lead to substantial underreporting. It may be useful to ask about abuse of substances such as steroids and sniffing glue which are not illegal but which may be associated with higher sexual risk-taking.

What the indicator measures

Drug use contributes to the sexual risks taken by MSM, as for other sub-populations. (See sex worker indicator 8 for more information).

9. Knowledge of HIV prevention

Definition

Numerator: Number of respondents who correctly identify avoiding anal sex and using condoms during anal sex as means of reducing the risk of HIV infection, in response to prompted questions.  
Denominator: Total number of respondents surveyed

Suggested Set of Questions

<table>
<thead>
<tr>
<th>MSM9.1</th>
<th>Can people protect themselves from HIV by avoiding anal sex?</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSM9.2</td>
<td>Can people protect themselves from HIV by using a condom correctly every time they have anal sex?</td>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
<td>No response</td>
</tr>
</tbody>
</table>

Source: FHI (2000)

How to measure it

The number of respondents who answer “Yes” to MSM9.1 and “Yes” to MSM9.2 is divided by the number of respondents.

What the indicator measures

IEC campaigns for MSM often promote non-penetrative sex and condom use during anal sex as ways of avoiding HIV infection. This indicator measures the extent to which these messages have reached their target audience.
To be of additional use to programme managers, data for this indicator may be disaggregated by prevention method, showing up strengths and weaknesses in IEC campaigns.

Clearly, there are other ways of preventing male-to-male HIV transmission besides those specified in the indicator. The two specified are those which can more realistically be changed than others in the Caribbean context. The “mutual monogamy” message, for instance, is less effective in a social context where homosexuality is so heavily stigmatised that it is extremely difficult to sustain a homosexual relationship, and where many MSM are also married.

10. Attitudes to people living with HIV/AIDS

This should be used to complement the surveillance of quality of care for PLWH.

**Definition**

*Numerator:* Number of respondents expressing positive attitudes to people living with HIV/AIDS.

*Denominator:* Number of respondents

**Suggested Set of Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSM10.1 If a member of your family became sick with the AIDS virus, would you be willing to care for him or her in your household?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM10.2 If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM10.3 If you knew that a shopkeeper or food seller had the AIDS virus, would you buy vegetables from them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


**How to measure it**

Only a respondent who reports an accepting or supportive attitude on all three of these questions enters the numerator. The denominator is all people surveyed.

**What the indicator measures**

See general population indicator 10.

Given the high rates of infection among MSM, prejudice among them will contribute to the harshly unsupportive environment for those who do find themselves to be infected. They will not find the care and support they need in the MSM community.

5.5 Questionnaire construction and administration

The questions relating to the indicators above are intended for use in questionnaires which include a variety of other questions. If used along with information on gender and age of respondents, they will yield a dataset which provides a minimal basic set of information necessary for tracking progress in addressing the behavioural determinants of the epidemic.

Internationally standardised questionnaires for use with the general population, young people, MSM and FSWs are available from different sources (e.g. FHI, WHO/UNAIDS etc.). The questions above have been drawn from these sources and in some cases adapted to the Caribbean context. It is recommended that survey designers review standardised questionnaires and
modify them according to local needs, using the questions recommended above. Questionnaires that have been successfully used in Caribbean KABP studies may also be adapted using the key indicators and questions above.

In adapting questionnaires, note that they should follow a basic sequence of types of information, as follows:

- Questionnaire identification number
- Cluster identification code (if cluster sampling has been used)
- Location of interview. Fields may be completed for the city (e.g. Bridgetown), the county (e.g. St. Michael) and the site (e.g. Bobby’s Bar, Nelson Street). Location identifiers are important in mapping the geography of behaviours.
- Introductory statement by the interviewer. The interviewer should read a prepared statement which tells the interviewee about the purpose of the survey and asks whether the person has been interviewed before for the same study. Those who have been interviewed before should be excluded.
- In self-completion questionnaires, an introduction will be written on the questionnaire. Nevertheless, there should also be a verbal introduction by the survey administrator.
- Confidentiality and consent: the interviewer reads a prepared statement which assures the respondent of confidentiality and asks for their verbal consent. The interviewer signs the questionnaire to certify that informed consent has been given.
- Survey administrators tell survey participants about methods of assuring confidentiality and let them know that no part of the questionnaire is compulsory. They also tell them why the survey is important in terms of benefiting people in that community. Interviewer name, code, date of interview, sex and socio-demographic characteristics of respondents and their age should be recorded by the interviewer, from observation and by asking a question.

Other socio-demographic information that may be collected include level of education, number of years of schooling, religion, ethnicity and marital status.

1. Sexual history: numbers and types of partners
2. Sexual practices with different types of partners (including condom use)
3. Knowledge and beliefs regarding HIV/AIDS
4. Attitudes to PLWHA.

In designing survey questions, pay attention to the following issues:

**Time reference periods:** Precise time frames have been set for the indicators above. For instance, young people are asked about number of sex partners *in the last 12 months*. Time frames: must be carefully considered, balancing the ability of respondents to remember against allowing enough time for less common behaviours to be recorded. Time frames chosen must be consistent from one survey to the next.

**Formulation of questions:** Questions must appear neutral and non-judgmental. There may be some local terms for sexual activity which are considered lewd, obscene or derogatory. Such terms should be avoided as they are likely to provoke underreporting of certain behaviours. On the other hand, a technical and scientific term may not be understood locally and in this case a local term with the same meaning should be chosen.

The following check list may be used to improve questionnaires:

- Qualitative research before the survey to learn about the characteristics of sub-populations and how best to approach them
- Verification that the language in the questionnaires is clear to the people being interviewed, and that the questions are answerable
- Pre-testing and adaptation of questionnaires according to problems encountered in the field
- Use of self-administered questionnaires when surveying literate populations.

Interviewers and survey supervisors should be carefully trained, ensuring that they are thoroughly familiar with each question, its intended meaning, how to code responses and how to follow skip patterns. Written guidelines for interviewers and supervisors are very useful in providing an easily accessible reference while in the field. As well as technical issues to do with the questionnaire, interviewers should be taught approaches to enhance the validity of the data.

Growing experience in collecting data on sexual behaviour shows that people do not generally lie. They are, however, more likely to tell the truth in some situations than others. The following are approaches to enhance the validity of responses:

- Interviews should be conducted in private, ensuring that people cannot overhear the conversation.
- Confidentiality must be assured. This is not simply a matter of including a statement on confidentiality in the questionnaire. Interviewers must be told never to take the names of interviewees, data must be stored in a secure place and penalties must be imposed on fieldworkers who divulge information from interviews.
• Interviewers should be friendly but non-judgmental. Balancing the two takes practice and may be achieved through role-play.
• Interviewers should not express surprise or disapproval at any response or comment made by the respondent. They should read every question exactly as written and in sequence.
• Interviewers should have similar characteristics to those of interviewees. Thus young people should conduct youth BSS etc. This will generally help establish rapport and trust. However, in very small societies, respondents may be particularly concerned about confidentiality. In this case it may be advisable to employ fieldworkers from outside the immediate community or from abroad. As experience of conducting BSS across the Caribbean grows, a cadre of experienced fieldworkers may carry out surveys in more than one country.

6. Analysis and interpretation of results

Three types of analysis are important for behavioural surveillance:
• Calculation of chosen indicators
• Assessment of changes in indicators over time
• Exploration of relationships between variables

Each of these is examined below.

This section assumes that analysts have access to statistical computer packages such as Epi-Info, SPSS, SAS or STATA. These packages ease the analysis process by conducting statistical tests using standardised formulae. These formulae are not presented here: they are available in statistical textbooks. Rather, this section presents basic information on the tests, their purposes, assumptions and limitations. Note that the tests are based on the assumption that probability sampling methods have been used (see section 4).

6.1 Calculation of chosen indicators

Section 5 gave instructions on how to calculate each of the ten key indicators, or variables of interest for HIV behavioural surveillance in the Caribbean, for each of four target groups. It is important to note that for a few of them, the denominator is not the number of respondents in total but the number reporting a certain behaviour. For these indicators, those reporting the behaviour in the denominator should first be selected, then the indicator calculated.

In HIV behavioural surveillance, most indicators consist of proportions (e.g. the proportion of adults who had one or more non-regular sex partners over the last 12 months). Because behavioural surveillance asks questions of just a sample of the universe of possible respondents, the estimated proportion with the behaviour in question may not reflect the true proportion of members of the target group with this behaviour. It is therefore useful to calculate confidence intervals around the indicator. Confidence intervals give us a range within which we assume the true value lies.

Typically, the level of confidence used in calculating this range is set at 95%. For example, if a survey shows that 22% of male youth aged 15-19 have used an illegal drug in the past twelve months, and the 95% confidence interval has been calculated between 16 and 28%, this means that we are 95% confident that the true value lies between these values.

As the sample size becomes larger, the confidence intervals become narrower, and we can be more confident about the precision of our estimates. The confidence interval is based on the standard error of a percentage. The standard error (SE) is calculated as follows:

\[ SE = \sqrt{\frac{p(100 - p)}{n}} \]

Where \( n \) is the sample size in the denominator of the indicator and \( p \) is the percentage in which the outcome variable is observed (i.e. the indicator itself).

The 95% confidence interval is calculated as follows: 95% CI = \( p \pm 1.96 \times SE \)

For example, say that 40% of a sample of 375 female youth express positive attitudes to PIWHA (youth indicator 10). The CI would be:

\[ = 40 \pm 1.96 \times \sqrt{\frac{(40 \times 60)}{375}} \]
\[ = 40 \pm 4.96 \]
\[ = 35.04 \text{ to } 44.96 \]

Thus we can be 95% confident that between 35% and 45% of female youth have positive attitudes to PIWHA.

6.2 Assessment of changes in indicators over time

Each time a behavioural surveillance survey is conducted, fresh calculations of each of the indicators should be
conducted. These will show estimated changes in indicators, e.g. whether condom use has gone up, number of partners has gone down etc. To assess whether the estimated changes are likely to reflect real changes in the target population as a whole, tests should be conducted to measure the significance of changes over time. These tests are based on confidence intervals. If there is little or no overlap in the confidence intervals around the indicators in two time periods, we can say that there has been a statistically significant change over time.

Various tests of trend are available. One simple way to compare proportions between time periods is to conduct a Chi-Square test, with time period as the explanatory variable (with values of “Year 1” and “Year 2”), and with the indicator as the dependent variable. Say we wish to find out whether a rise in condom use at last sex from 25% in year 2001 to 33% in 2003 is significant. The chi-square statistic will be based both on the magnitude of change and the sample size in each year. Chi-square statistics are presented alongside their p-values in statistical computer programmes. A p-value of less than or equal to 0.05 indicates that we can be 95% confident that the change over time has not happened by chance.

6.3 Exploration of relationships between variables

In behavioural surveillance, comparisons in values of indicators between domains are important. For instance, surveys with the general population and youth should include separate calculations of indicators for males and females. For example, we might wish to know whether our data give support to the idea that males have a greater propensity than females to have multiple partners. Answers to such questions will help target interventions to people in the different domains and also measure the success of targeted interventions.

At the simplest level, calculation of the indicators by domain shows whether there is a difference in behaviour between two or more domains. But we would also wish to know whether the differences between groups happened by chance or whether they reflect real differences within the broader population of interest. Note that tests of the significance of differences between domains are best performed when there is an adequate sample size per domain - see the section on sampling above.

The most appropriate test for differences in proportions between domains is the Chi-Square test. The domain variable, say, “Gender” or “Age group” is treated as the explanatory variable, while values of the indicator (e.g. “used a condom at last sex” and “did not use a condom at last sex”) are treated as dependent. The domain variable and the indicator variable are cross-tabulated, and the Chi-Square statistic calculated. A p-value of the Chi-Square statistic of less than or equal to 0.05 indicates that we can be 95% confident that the difference in behaviour between domains has not happened by chance.

In some cases the variable of interest is continuous rather than categorical. Continuous variables, such as number of partners per time period, do not have a set of fixed response categories, but rather a wide range of consecutive numbers as potential responses. There may be a wish to compare estimates of a continuous variable between domains. In this case, a statistical test called the F-test can compare means of the variable between domains. For example, it can test whether male adults have on average more partners per year than female adults. Again, a p-value of the F-statistic of less than or equal to 0.05 indicates that we can be 95% confident that the difference in behaviour between domains has not happened by chance.

More sophisticated analyses examine the combined effect of a number of explanatory variables on a particular dependent variable. For instance, we might wish to explore which combination of factors explains condom use at last sex, and how much each factor contributes to determining condom use. Multivariate analysis is used to examine the relationship between a number of different explanatory variables to an outcome variable. It looks for interactions between explanatory variables.

The most appropriate form of multivariate analysis where the dependent variable is categorical is logistic regression. Logistic regression is virtually always performed by computer, and standardised software packages are available to assist in this process. It enables the calculation of odds ratios for values of explanatory variables. The odds ratio is the likelihood that someone of a certain category displays the behaviour indicated in the dependent variable, compared with somebody who is not in that category. Odds ratios are expressed in relation to one level of the explanatory variable.

For example, say we have chosen condom use at last sex as the variable we want to explain (the dependent variable). Youth age 10-14 are the reference group, the odds ratio for youth 15-19 is 1.4, and the odds ratio for youth 20-24 is 2. This means that youth age 15-19 are 40% more likely to have used a condom at last sex, while youth age 20-24 are twice as likely, as compared with youth 10-14. Examining the p-value for this variable enables one to determine whether the age group of respondent makes a significant contribution to explaining condom use at last sex as compared with other potential explanatory variables.
6.4 Integration of behavioural surveillance with other parts of the surveillance system

AIDS statistics can only indicate patterns of infection some time, perhaps years, ago. HIV surveillance may be restricted to some “sentinel” populations whose representativeness is limited. Assessment of sexual behaviour may serve as an early indicator or proxy for HIV incidence. Samples may be obtained of populations which are difficult to reach in HIV prevalence studies, or which are more representative. For all these reasons, behavioural surveillance should be integrated into the regular HIV/AIDS surveillance system, and treated as a central and essential part of this system.

Behavioural surveillance planners should also be involved in the planning of HIV/AIDS surveillance, to ensure that the types of data collected and types of analysis performed are complementary. For example, if behavioural data analysis is stratified by particular age groups, HIV/AIDS data should also be stratified by these same domains, comparing behaviour and HIV prevalence and incidence between groups.

HIV behavioural surveillance data should be combined with other sources of social and behavioural information to provide a comprehensive picture of factors affecting the epidemic. If, for instance, behavioural surveillance shows that condom use differs significantly by age group, it is useful to explore what are the barriers and facilitating factors to condom use for youth of different ages using various sources of information, for example, as follows:

- Collecting data on official and unofficial restrictions on selling or giving condoms to people under the legal age of sexual consent
- Interviews with condom providers in pharmacies, family planning clinics and health centres
- Observation of the behaviour of service providers when young people of particular age groups ask them for condoms
- Data on the price of condoms and income levels by age group
- Qualitative research, such as depth interviews and focus groups, with youth of different ages, asking them to identify barriers and facilitating factors for condom use.

7. Disseminating and using the data

Behavioural surveillance data should be used in decision-making by a wide variety of agencies, professionals and people in vulnerable groups, as part of an expanded response to HIV/AIDS. It bears repeating that deciding how the data are to be used should be one of the early steps in the planning process for behavioural surveillance. Pieces of information which might prove persuasive to decision-makers may not get collected unless data use is planned before data collection begins. Nevertheless, it is recognised that some potential audiences and ways in which the data are used will not be anticipated in the design stage, and there is a need for flexibility in responding to unanticipated demands.

HIV and STI surveillance data should be combined with results from behavioural surveillance to produce a number of reports from the surveillance system:

- A full technical report of the sentinel surveillance systems for HIV and STIs.
- A full technical report of the behavioural surveillance system. This should include details of methodology as well as results. Much of the information contained in the survey protocol (see section 2) should be included. The presentation of key indicators should not be restricted to the values for the sample as a whole. Estimates should be provided for the different domains of interest (by gender, age group etc.) along with confidence intervals. The sample sizes used to make the estimates, including the number of people in the denominator of certain indicators, should be presented.
- A non-technical review of the national HIV epidemic, combining data from the technical reports with other sources of information. Examples of such information include studies of condom availability and access, qualitative studies of women’s sexual decision-making power, the employment prospects of young people, the economic climate, attitudes to and legislation regarding homosexuality etc. “Situation and response analyses” which follow UNAIDS guidelines are currently being produced by a number of Caribbean countries to guide the process of strategic planning for the epidemic. Behavioural surveillance data can contribute highly pertinent data to such analyses and can track progress in implementing the resulting plans.
- A schedule of meetings with members of the community from which data were gathered and NGOs which work with them or represent them. Members of the target group should be primary recipients of the data in a form that they can understand and use. Care must be taken in explaining the implications of the findings for the community and the individuals within it. Short
briefing papers on the main results should be
distributed if members of the audience are
literate. These meetings may be an opportunity to
begin the process of behaviour change. Great
care should therefore be taken in designing the
way in which the information is put across.
Presenters should refrain from passing judgement
on particular behaviours, but should explain the
nature and magnitude of HIV risk as shown by the
data, and provide basic information on strategies
to avoid risk. Members of the community should
be involved in presenting the data. This should
be feasible if community members have been
involved in planning and implementing the
survey. Feedback should be sought, along with
the community’s suggestions for next steps to
address the HIV epidemic.

• A short news release focussing on the main
results of the behavioural surveillance and HIV/
STI surveillance systems, to accompany the
release of the technical report. A media briefing
session may be held to explain the implications of
the findings for media audiences. It may be
necessary to conduct media sensitisation sessions
so that the media become allies and refrain from
sensationalising the issues, thus potentially
damaging the relationships which have been
carefully nurtured with vulnerable groups who
participated in the surveys.

• A series of “issues briefs” which package data for
the use of different audiences and sectors. For
example, a briefing for the Ministry of Education
would concentrate on key indicators of
knowledge, attitudes and behaviour for youth of
various school age groups. This may be
combined with data on HIV prevalence in youth of
school age, and other information relating to the
vulnerability of young people, such as
employment prospects, access to counselling and
guidance professionals, Health and Family Life
Education, etc. Where possible, those producing
the data (e.g. NAPs) should plan to meet with
various Ministries, governmental and non-
governmental agencies to plan a series of steps
arising from the results of the surveillance
system.

These reports and mobilisation activities
should:

• Include vulnerable groups in a process of
reflection which empowers them to use the
information in making individual decisions (e.g.
to use condoms in subsequent sexual
encounters) and in collective decisions (e.g. to
lobby brothel owners to provide condoms to sex
workers and their clients).

• Encourage policy-makers to promote HIV
prevention. Some officials, especially those
outside the Ministry of Health, have yet to
perceive the importance of HIV/AIDS to their own
work and personal lives. Data should therefore
be carefully packaged according to the interests
and needs of particular agencies in the public and
private sectors. One effective example of the use
of behavioural data is a study conducted by
CAREC with the Health Economics Unit at the
University of the West Indies, which projected the
cost of the HIV epidemic based on information
from a behavioural survey. The results showed
the impact on the economy of current trends in
sexual behaviour. After showing the economic
impact to a number of Caribbean government
representatives, a number of them have increased
their focus on HIV activities.

• Encourage the allocation of resources to HIV
prevention. Demonstrating that behaviours do
change following prevention activities, both in
groups with high-risk behaviours and the general
population, is one of the most effective ways of
increasing support for prevention activities.
Behavioural data can indicate success in
interventions and pinpoint continuing needs for
support by private firms, development
organisations and international founders as well
as governments.

• Make the public aware of the threat posed by HIV.
Behavioural surveys in the general adult
population as well as in selected population
groups can illustrate the extent of continuing risk
behaviour. This awareness is a first step to more
cautious behaviour.

• Improve prevention programmes. Tracking
behaviour over time enables the identification of
behaviours that have changed following
interventions and those which remain
entrenched. It also enables the identification of
which sub-groups are most at risk. It therefore
facilitates the development of interventions which
efficiently focus on the key risk groups and
behaviours. behaviours that remain unchanged
despite efforts to promote safer alternatives need
a new approach, perhaps one which pays more
attention to the social and economic context which
conditions personal behaviour.
In presenting data, the following guidelines are useful:

Maximise the information in data tables. The title of the table should name the indicator in question, including the time reference period, and the group or sub-groups for which the data is presented. The sample size for each indicator and domain should be provided as well as the values of the indicator itself. The text can pick out the most salient points which arise from the data. Providing more data in the table than that which is discussed in the text enables readers to pick out further pieces of information according to their own interests and priorities.

Present data graphically where possible. Graphics are often easier to understand and clearer to people than tables or text. They allow people to see directly the differences between groups and changes over time. The following diagram simply shows data on the proportions who reported they had ever had sex, by gender and age group, for a study of young people in Tobago. Bar charts are a useful way to present differences in proportions by domain.

![Bar chart showing percentages of young people who have ever had sex, by gender and sub-sample, Tobago 1999](chart.png)

ETHICAL ISSUES AND HUMAN RIGHTS PRINCIPLES FOR HIV/AIDS EPIDEMIOLOGY

At the beginning of the HIV/AIDS epidemic, epidemiological surveillance reported mainly AIDS cases, their categories of transmission, demographic information and some additional information on HIV prevalence in special groups or populations. There is a need for more accurate data to help understand the complete picture of the epidemic. Therefore, these Third Generation HIV/AIDS/STI Surveillance Guidelines put more emphasis on HIV case reporting; better knowledge of HIV incidence and prevalence, sexual behavioural risks factors, and the quality and coverage of care provided to people living with HIV/AIDS (PLWHA).

However reporting of HIV and AIDS cases, surveillance of sexual behavioural risk factors and the accurate measurement of quality of care and support, raise a number of ethical issues and concerns about human rights protection of PLWHA.

For example, reporting of new HIV cases needs to get people motivated to get tested for HIV. The ethical context of the testing procedures must ensure full confidentiality and that the testing process will not threaten the protection of individual rights of people who are willing to know their HIV status. Collecting behavioural information on persons diagnosed with HIV, as well as evaluating the care and support for PLWHA, also need a strong ethical context in order to protect confidentiality regarding their HIV status, sexual orientation and practices.

Taking these points into consideration, questions related to ethics and human rights and HIV/AIDS will be outlined in the following text. However, we cannot minimise human responsibilities in this process so that the public health goals will be achieved. A right balance between the two notions — human rights and responsibilities (individual and professional) — is necessary to control the HIV/AIDS epidemic.

A. Are Human Rights Critical to an Effective Response to HIV/AIDS?

Human rights and public health share the common objective of promoting and protecting the rights and well being of all individuals. In the context of the HIV/AIDS epidemic, the promotion and protection of human rights is necessary to achieve the public health goals of:

- Reducing vulnerability to HIV infection
- Lessening the adverse impact of HIV/AIDS on those affected and
- Empowering individuals and communities to respond to HIV/AIDS.

HIV prevention programmes with coercive or punitive features result in reduced participation and increased alienation of PLWHA and those at risk of infection. People may not seek counselling, testing, treatment and support if this means facing discrimination, lack of confidentiality or other negative consequences. Coercive public health measures drive away the people most in need of such services, and therefore fail to achieve the public health goals of prevention through behavioural change, care and health support.
The spread of HIV is disproportionately high among groups that already suffer from a lack of human rights protection and from discrimination, or that are marginalised by their legal status. These vulnerable groups include women, children, people living in poverty, minorities, indigenous people, migrants, refugees and internally displaced persons, people with disabilities, sex workers, men who have sex with men, injection drug users, prisoners. Lack of human rights protection disempowers these groups. On the contrary, when human rights are protected, fewer people become infected and PLWHAs and their families can better cope with the disease.

B. Human Rights Principles Relevant to HIV/AIDS

- The right to non-discrimination, equal protection and equality before the law;
- The right to life;
- The right to the highest attainable standard of physical and mental health;
- The right to liberty and security of person;
- The right to freedom of movement;
- The right to seek and enjoy asylum;
- The right to privacy;
- The right to freedom of opinion and expression and the right to freely receive and impart information;
- The right to freedom of association;
- The right to work;
- The right to marry and to found a family;
- The right to equal access to education;
- The right to an adequate standard of living;
- The right to social security, assistance and welfare;
- The right to share in scientific advancement and its benefits;
- The right to participate in public and cultural life;
- The right to be free from torture and cruel, inhuman or degrading treatment or punishment.

C. International Consultation on HIV/AIDS and Human Rights (1996) - Recommendations

In response to the alarming HIV/AIDS situation the II International Consultation on HIV/AIDS and Human Rights concluded the following:

- Public health interests do not conflict with human rights. On the contrary, it has been recognised that when human rights are protected, fewer people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS;
- A rights-based, effective response to the HIV/AIDS epidemic involves establishing appropriate governmental institutional responsibilities, implementing law reform and support services and promoting a supportive environment for groups vulnerable to HIV/AIDS and for those living with HIV/AIDS;
- In the context of HIV/AIDS, international human rights norms and pragmatic public health goals require States to consider measures that may be considered controversial, particularly regarding the status of women and children, sex workers, injecting drug users and men having sex with men. It is, however, the responsibility of all States to identify how they can best meet their human rights obligations and protect public health within their specific political, cultural and religious contexts;
- Although States have primary responsibility for implementing strategies that protect human rights and public health, United Nations bodies, agencies and programmes, regional intergovernmental bodies and non-governmental organisations, including networks of PLWHAs, play critical roles in this regard.

D. Ethical principles to guide formulation and implementation of HIV/AIDS health policy

- **Well-being/Beneficence:** HIV/AIDS policies should be designed for the general good, and the benefits of the proposed policy should be weighed against the harms. There should be no infliction of harm on people, including PLWHAs or suspected of it.
- **Equity/Distributive Justice:** The burdens and benefits of HIV/AIDS policy should be distributed equitably among the population. No groups or individuals should be discriminated against in the context of HIV/AIDS. All people and groups should be treated fairly and equally and have equal access to available information, prevention methods, treatment and research results.
• **Respect for Persons:** Individuals have the capacity and right to make choices and decisions about their bodies, personal integrity, and actions as long as they do not diminish rights of others. Aid should be free from unjustified interference by others, including in the context of HIV/AIDS. People of diminished autonomy who are dependent or vulnerable should be protected against harm or abuse.

• **Confidentiality:** People have a right to keep confidential any information which is highly personal and the divulgence of which could be detrimental for them, including information about their HIV/AIDS status. Professional ethics requires that professionals (lawyers, health care workers, insurance, social workers) maintain strict confidentiality concerning all personal information obtained from clients in the context of their professional work.

• **Obligation to treat:** Medical ethics require that health professionals must treat, to the best of their ability, all persons seeking their medical attention without discrimination and without prejudice based on the origin or nature of the patient’s illness, including HIV/AIDS. Informed Consent: Respect for the integrity and autonomy of the individual means that informed consent should be obtained before the administration of medical tests, drugs, treatment or participation in research, including those that are related to HIV/AIDS.

• **Elements of Informed Consent:** The individual must be a competent individual who has the capacity to make decisions. S/he must have received all necessary information, and arrived at a decision without coercion, inducement or intimidation. If s/he does not have capacity to give free consent, s/he should be protected by supplementary measures.

• **Information Essential to Informed Consent:** Information concerning HIV testing, treatment and research should be explained in a language the individual will understand. All benefits, risks, problems, and alternatives should be fully explained. No information should be withheld that would cause a reasonable person to refuse. The person should understand that they are free to refuse and/or withdraw at any time without penalty. The degree to which confidentiality can be maintained should also be explained to the person.

E. Are Human Rights Universal?

A number of countries or communities object that the Universal Human Rights Declaration is a western vision of human rights and therefore doesn’t apply to them. The declaration has a universal nature, but universalism is not accepted everywhere and by all States. It is the very human rights concept being thrown back into question. Countries most in favour of cultural “differentialism” or of another vision of human rights, are also those ignoring or violating human rights.

Human rights are universal because all human beings have fundamental rights that cannot be denied, otherwise humanity itself is denied. Everywhere the integrity of the human person is to be respected. Everywhere human beings have the right not to be tortured, killed or mutilated, not to be reduced to slavery, to receive care, to have access to education and culture. Everywhere human beings must be able to think and speak freely. From this, a core of rights is valid for all and in every society. Whether this is expressed culturally in very different ways, does not justify, on behalf of cultural diversity, undermining what constitutes fundamental rights of human beings.

Freedom of religion, for example, is one of the fundamental rights and indeed a major step in the history of humanity. But excision in women, on behalf of religious or cultural tradition, is a violation of the rights of the human person. God’s name cannot be used to violate human rights. On the other hand, if social and economic rights are to be better protected in a tribal structure, because it is true to the tradition, there are only advantages. The universality of human rights does not imply that all societies must be built on the western individualistic model, which is not necessarily what brings most satisfaction to the human being.

F. Moral Responsibility of Modern Epidemiology

There is a moral and professional obligation to identify the consequences on health and on physical or mental status of individuals and populations, resulting from human rights violations. Human rights violations are pathogens, impacting on health. A pathogenesis has to be identified for prevention and cure purposes.

Organising and categorising in “groups at risk”, not only is not really useful, but the common use of this terminology increases fears towards persons belonging to these groups, as well as the lack of confidence of these persons in health care systems. The use of “groups at risk” also reinforces the idea that AIDS is other people’s problem.
Epidemiological concepts must be used with caution, particularly when it is about populations already socially fragile, stigmatised or marginalised. The dialogue with affected persons has to be inclusive and active, avoiding categories or generalisations, which not only are inefficient and inaccurate, but also are a source of potential obstacles for prevention. This is crucial in terms of relationships between the epidemiologist and the population under study. Studies should be conducted “with” populations, instead of “on” populations. The starting point should be the choice of issues to study: are they seen as important by the population? What form of participation in the elaboration of the study is to be considered? Then, what is the responsibility for confidentiality of data and towards participants with regards to their voluntary consent and for the dissemination of results? There are many epidemiological studies showing risk factors for a particular disease. Most of the time participants only get this information if they read newspapers, listen to the radio or watch television.

Another responsibility for epidemiology is the development of a real epidemiology of social risk factors. This requires an effort to go beyond classical factors of analysis, such as “poverty” and “socio-economic conditions”. There is a need for identifying and evaluating the relationship between social status, human rights, conditions furthering or jeopardising human dignity and health conditions, diseases, handicaps, and premature deaths.

Finally this human rights approach of epidemiology should contribute more actively to the transformation of “individual tragedies” into “social injustices”. The usual common sense interprets diseases, handicaps and deaths as individual tragedies, seen as fate in individual life. It is only when the event is placed in a social context that the “individual tragedy” can become “social injustice”, raising issues of human rights and dignity.

Twenty years ago, for example, accidents used to be looked at as unpredictable tragedies, acts of fate, therefore unavoidable. Today, the epidemiological understanding of the heterogeneous distribution of accidents has changed the approach, looking at accidents as predictable and accessible to prevention. The epidemiological analysis identifies expressions of a social system creating conditions, in which some are sick, handicapped or dead, while others are healthy and alive. When risk factors, preventable diseases, or premature deaths show a heterogeneous distribution, it may be because of weaknesses and inequalities in individual rights and dignity. Epidemiology must identify abuses in human rights and human dignity that may be hidden behind every heterogeneous distribution of causes of morbidity and mortality.

Looking at health as “physical, mental and social well-being status” and at public health as an effort to “ensure conditions for persons to live in good health”, the achievement of the public health’s goal — based on epidemiology — needs a transformation of society. Technicians of epidemiological methodology might be placed in a new role of transforming tragedies into injustices, being pathophysicists of the social body, in order to identify social risk factors and their pathogenesis. They will then contribute to social transformation with a new vision of health, based on human rights, global interdependence and solidarity.

Success Story: the Antigua and Barbuda Government rules out screening of immigrant workers: In June 2000, Antigua and Barbuda ruled out screening prospective immigrant workers for the HIV virus, saying that to do so would be discriminatory and complicated. “At present, we are not advocating that because it could be discriminatory, it’s an invasion of their privacy and being HIV positive does not affect a person’s ability to work,” Head of the National AIDS Secretariat Felicity Aymer told CANA yesterday.

G. Human Responsibilities and Legislative Framework

G.1. HIV/AIDS and Human Rights Guidelines for Public Health

Caribbean states should review and reform public health legislation to ensure that they adequately address the public health issues raised by HIV/AIDS, that the provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations. Public health legislation should include the following components:

1. Public health laws should empower professionals to provide a comprehensive range of services for the prevention and treatment of HIV/AIDS: relevant information and education, STI and sexual and reproductive health services, condoms availability, access to voluntary counselling and testing, drug rehabilitation and adequate treatment for HIV/AIDS-related illnesses and prophylactic measures.

2. Apart from surveillance testing and other unlinked testing done for epidemiological purposes, public health legislation should ensure that HIV testing of individuals should only be performed with the specific
informed consent of that individual. Exceptions to voluntary testing would need specific judicial authorisation, granted only after due evaluation of the important considerations involved in terms of privacy and liberty.

3. In view of the serious nature of HIV testing and in order to maximise prevention and care, public health legislation should ensure that pre- and post-test counselling be provided in all cases.

4. Public health legislation should ensure that people not be subjected to coercive measures such as isolation, detention or quarantine on the basis of their HIV status. Where the liberty of persons living with HIV is restricted, due process protection (e.g. notice, rights of review/appeal, fixed rather than indeterminate periods of orders and rights of representation) should be guaranteed.

5. Public health legislation should ensure that HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality.

6. Public health legislation should ensure that information relative to the HIV status of an individual be protected from unauthorised collection, use or disclosure in the health-care and other settings and that the use of HIV-related information requires informed consent.

7. Public health legislation should authorise that health-care professionals decide, on the basis of each individual case and ethical considerations, whether to inform their patients’ sexual partners of the HIV status of their patient. Such a decision should only be made in accordance with the following criteria:

- The HIV positive person in question has been thoroughly counselled;
- Counselling of the HIV positive person has failed to achieve appropriate behavioural changes;
- The HIV positive person has refused to notify, or consent to the notification of his/her partner(s);
- A real risk of HIV transmission to the partner(s) exists (e.g. continued unprotected sexual intercourse);
- The HIV positive person is given reasonable advance notice;
- The identity of the HIV positive person is concealed from the partner(s), if this is possible in practice;
- Follow-up is provided to ensure support to those involved, as necessary.

8. Public health legislation should ensure that blood, tissue or organ donation is free of HIV and other blood-borne diseases.

9. Public health law should require the implementation of universal infection control precautions in health-care and other settings involving exposure to blood and other body fluids. Persons working in these settings must be provided with the appropriate equipment and training to implement such precautions.

10. Public health legislation should require that healthcare workers undergo a minimum of ethics and/or human rights training in order to be licensed to practise medicine.

11. Public health should encourage professional societies of health-care workers to develop and enforce codes of conduct based on human rights and ethics, including HIV/AIDS-related issues such as confidentiality and the duty to provide treatment to PLWHA.

G.2. International, Community and Individual Responsibilities towards HIV/AIDS

To a rights-based approach to deal with HIV/AIDS issues among PLWHA, it is important to apply a responsibility-based answer to the epidemic. This responsibility-based approach will include international, national, community and individual responsibilities towards the prevention and control of the epidemic. The human rights issues were discussed above in terms of duties to be carried out at the international, national and community levels to empower PLWHA. This last chapter will focus on a few general responsibilities and specific individual responsibilities.

- Compassion requires that people respond to the suffering of others, including those with HIV/AIDS, with sympathy, mercy and a willingness to help.
- Solidarity requires that people come together to respond to the suffering, as well as the injustice, caused by HIV/AIDS.
- Tolerance requires respect for the equal worth, dignity and autonomy of people affected by HIV/AIDS, including those with different beliefs, opinions, and lifestyles.
- Responsibility means that every individual, community, institution and nation must act responsibly towards HIV/AIDS to prevent its spread and to care for those infected and otherwise affected.
• All empowered individuals and communities should have available to them or look for the necessary information to make good decisions about their health, including how to avoid HIV infection and how to cope with its consequences.

• All individuals should have the ability to protect themselves from infection by being able to refuse unsafe sex and to cope with HIV/AIDS if they or someone in their family is infected.

• PLWHA should specifically refuse to be part of the problem and accept to be part of the solution by refusing to participate in the spread of the disease and avoiding their own re-infection.

• Public health laws should make provision for penal corrections for PLWHA who do not adhere to self-protection practices and knowingly infect other community members through sexual and other contacts.

• Public health laws should make provision for penal corrections for individuals who knowingly refuse to use scientifically proven protective measures when having sexual encounters with PLWHA, thus exposing themselves as well as others to infection and re-infection.

• Public health laws should encourage PLWHA to participate in and adhere to their management. Since HIV disease is a chronic condition, good collaboration between patients and care providers is paramount for the positive outcome of the treatment regimens (palliative care, advice on hygiene and diet practices as well as antiretroviral treatment).
A s the HIV epidemic progresses in the Caribbean, it has become increasingly clear that a multi-pronged approach towards surveillance is the recommended way of tracking. This calls for the design of comprehensive surveillance systems to achieve the objectives of prevention and control programmes. The Third Generation HIV/AIDS/STI surveillance guidelines offer a comprehensive framework to implement surveillance systems which go beyond “collection of cases” or “counting numbers”. After twenty years of its existence, the HIV epidemic has demonstrated its ability to rapidly evolve. Therefore, there is a clear need for proactive surveillance systems that combine prevention strategies with care and treatment strategies i.e. linking epidemiological surveillance with behavioural surveillance and audit of quality of care and treatment of people who have HIV/AIDS/STI conditions.

In developing these guidelines, CAREC has collaborated with Caribbean and international professionals and experts, using best practices in the region and in some cases tailoring international recommendations to meet the regional needs for new surveillance systems. Therefore, these guidelines are the sum of Caribbean experiences and international best practices on HIV/AIDS/STI surveillance. They make concrete recommendations on steps to set up procedures for such a surveillance system, sampling procedures, key markers to be monitored, data analysis, dissemination and utilisation of surveillance results.

The different sections in the guidelines provide recommendations and guidance on ways to establish effective surveillance for a communicable and chronic disease like HIV/AIDS and to monitor the impact of prevention and control programmes. Generally, upward or downward changes in HIV incidence and HIV/AIDS prevalence follow on from upward or downward changes in STI incidence and prevalence which follow on from upward or downward changes in risky sexual behaviours. This inter-link demonstrates how important the multi-pronged approach towards surveillance is for the prevention and control of the HIV/AIDS epidemic. It is also important to underline that quality information is the result of a supportive environment conducive to better involvement of people who have health conditions. Thus, respect for human rights and involvement of individuals and communities are important to the implementation of efficient surveillance systems.

The main lessons which emerge from these Third Generation HIV/AIDS/STI surveillance guidelines are as follows:

1. Team work, collaboration and partnership between a range of individuals and institutions is vital to achieve efficient surveillance systems.

2. There is need for consistency, with clear and systematic procedures which are routinely used or replicated overtime to collect and analyse HIV/AIDS/STI information.

3. Involvement of vulnerable groups will achieve ownership of surveillance outcomes, thus, they can be easily and effectively used as part of interventions and strategies among these groups.

The implementation of these guidelines may be considered as a challenge for the Caribbean, because of its limited human resources. However, by seizing all existing opportunities at the national (National Universities, Offshore Universities, Statistical Offices, senior staff in other relevant
ministries, etc.) and regional levels (CAREC/PAHO/WHO and the University of the West Indies), that challenge will be easily addressed. Adhering to these guidelines will bring about better tracking, thus improving understanding of the epidemic and facilitating comparison of surveillance information over time and between groups within and among countries. Inter-country comparison will assist regional and international agencies such as CAREC/PAHO/WHO in responding effectively to the needs of individual Caribbean countries.
Annexe 1 - SAMPLE SIZE DETERMINATION

Minimum Sample Size for a Prevalence Survey according to expected Prevalence Rate

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<th>5%</th>
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<td>-</td>
<td>235</td>
<td>457</td>
<td>865</td>
<td>1537</td>
<td>2017</td>
<td>2305</td>
<td>2401</td>
</tr>
<tr>
<td>5%</td>
<td>-</td>
<td>-</td>
<td>73</td>
<td>139</td>
<td>246</td>
<td>323</td>
<td>369</td>
<td>385</td>
</tr>
<tr>
<td>10%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>35</td>
<td>62</td>
<td>81</td>
<td>93</td>
<td>97</td>
</tr>
<tr>
<td>15%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>28</td>
<td>36</td>
<td>41</td>
<td>43</td>
</tr>
</tbody>
</table>

This represents the 95% confidence interval. For example, if the true prevalence was 10% and we took a sample size of 139 we would be 95% certain that the prevalence rate measured in the sample would be between 5% and 15% (i.e. 10± 5%). In general, do not accept a sampling error of greater than 5%.

To work out the required sample size for values not shown in the table, use the following formula: \( N = \frac{pq}{(E/1.96)^2} \)

- \( N \): the minimum sample size required
- \( p \): the maximum expected prevalence rate or anticipated population proportion
- \( q \): \( 100 - p \)
- \( E \): margin of the sampling error tolerated
- \( 1.96 \): standard errors of the population proportion.

For example: the Nayagu national epidemiologist is undertaking an HIV seroprevalence survey among TB patients. She assumed an anticipated HIV prevalence rate at 20% (p) among these patients, q will be 100 - 20 = 80, the margin of error chosen is ±5, then the minimum sample size required will be 246.

If at the end of the survey she observes an HIV prevalence rate of 18.5%, the real prevalence among the TB patients is between 14% (18.5% - 5) and 24% (18.5% + 5) within a 95% confidence interval.
Annexe 2 – A calculation of the required sample size for a given sub-population for each survey round (n) is given by:

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

Where:

- **D** = design effect;
- **P_1** = the estimated proportion at the time of the first survey;
- **P_2** = the target proportion at some future date, so that \((P_2 - P_1)\) is the magnitude of change you want to be able to detect;
- \(\bar{P}\) = \((P_1 + P_2)/2\);
- **Z_{1-a}** = the z-score corresponding to the desired level of significance
- **Z_{1-\beta}** = the z-score corresponding to the desired level of power.

*Source: FHI (2000, page 47)*
### Annexe 3: Sample Size needed based on Estimated Prevalence of STI and desired precision using 95% confidence interval calculation

#### Table 8: Sample size based on estimated prevalence of STI and desired precision using a 95% confidence interval calculation

<table>
<thead>
<tr>
<th>Estimated prevalence of STI</th>
<th>Precision ± 0.5% Sample size</th>
<th>Precision ± 1.0% Sample size</th>
<th>Precision ± 1.5% Sample size</th>
<th>Precision ± 2.0% Sample size</th>
<th>Precision ± 2.5% Sample size</th>
<th>Precision ± 3.0% Sample size</th>
</tr>
</thead>
<tbody>
<tr>
<td>1%</td>
<td>1522</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2%</td>
<td>3012</td>
<td>753</td>
<td>335</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td>4472</td>
<td>1118</td>
<td>497</td>
<td>280</td>
<td>179</td>
<td></td>
</tr>
<tr>
<td>4%</td>
<td>5901</td>
<td>1476</td>
<td>656</td>
<td>369</td>
<td>237</td>
<td>164</td>
</tr>
<tr>
<td>5%</td>
<td>1825</td>
<td>811</td>
<td>457</td>
<td>292</td>
<td>203</td>
<td></td>
</tr>
<tr>
<td>10%</td>
<td>1537</td>
<td></td>
<td>865</td>
<td>554</td>
<td>385</td>
<td></td>
</tr>
<tr>
<td>15%</td>
<td></td>
<td></td>
<td>1225</td>
<td>784</td>
<td>545</td>
<td></td>
</tr>
<tr>
<td>20%</td>
<td></td>
<td></td>
<td></td>
<td>984</td>
<td>683</td>
<td></td>
</tr>
<tr>
<td>30%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>897</td>
</tr>
</tbody>
</table>

**Precision 0.6%, 1.6%**

*Source: WHO-1999*
LIST OF ABBREVIATIONS

AIDS  Acquired Immuno-Deficiency Syndrome
BSS  Behavioural Surveillance Surveys
CAREC  Caribbean Epidemiology Centre
CARICOM  Caribbean Community and Common Market
CBO  Community Based Organisations
CCH2  Caribbean Cooperation in Health – Phase 2
CDC  U.S. Centers for Disease Control and Prevention
CMC  CAREC Member Countries
CMV  Cytomegalovirus
CPHA  The Canadian Public Health Association
CRN+  Caribbean Regional Network of People Living with HIV/AIDS
CSO  Central Statistical Office
CSW  Commercial Sex Worker
DHS  Demographic Health Survey
DNA  DeoxyriboNucleic Acid
EIA  Enzyme Immuno Assay
ELISA  Enzyme-linked Immuno Sorbent Assay
EP  Equal Probability
FCSW  Female Commercial Sex Worker
FHI  Family Health International
FSW  Female Sex Worker
FTA-ABS  Fluorescent Treponemal Antibody Absorption test
HIV  Human Immuno-deficiency Virus
HSV1  Herpes Simplex Virus Type 1
HSV2  Herpes Simplex Virus Type 2
ICD  International Classification of Disease
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
</tr>
<tr>
<td>IFA</td>
<td>Immuno Fluorescence Assay</td>
</tr>
<tr>
<td>IVDU</td>
<td>Intra Venous Drug User</td>
</tr>
<tr>
<td>KABP</td>
<td>Knowledge, Attitude, Beliefs and Practices</td>
</tr>
<tr>
<td>LCR</td>
<td>Ligase Chain Reaction</td>
</tr>
<tr>
<td>LGV</td>
<td>Lymphogranuloma venereum</td>
</tr>
<tr>
<td>LSD</td>
<td>Lysergic Acid Diethylamide</td>
</tr>
<tr>
<td>MHATP/TPHA</td>
<td>Microhaemagglutination Assay/Treponema Palidum Haemagglutination Assay</td>
</tr>
<tr>
<td>MOS</td>
<td>Measure of Size</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother-to-Child Transmission</td>
</tr>
<tr>
<td>NAP</td>
<td>National AIDS Programme</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>PAHO</td>
<td>Pan American Health Organization</td>
</tr>
<tr>
<td>PCP</td>
<td>Pneumocystis Carinii Pneumonia</td>
</tr>
<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>PPS</td>
<td>Probability Proportional to Size</td>
</tr>
<tr>
<td>PSU</td>
<td>Primary Sampling Units</td>
</tr>
<tr>
<td>QA</td>
<td>Quality Assurance</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribo-Nucleic Acid</td>
</tr>
<tr>
<td>RPR</td>
<td>Rapid Plasma Reagin</td>
</tr>
<tr>
<td>SI</td>
<td>Sampling Interval</td>
</tr>
<tr>
<td>STARHS</td>
<td>Serologic Testing Algorithm for Recent HIV Seroconversion</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>SW</td>
<td>Sex Worker</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UWI</td>
<td>University of the West Indies</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>VDRL</td>
<td>Venereal Disease Research Laboratory</td>
</tr>
<tr>
<td>WB</td>
<td>Western Blot</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WHO-GPA</td>
<td>World Health Organization – Global Programme on AIDS</td>
</tr>
</tbody>
</table>
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CAREC-Special Programme on Sexually Transmitted Infections (SPSTI) partners in the battle against HIV/AIDS:

Canadian International Development Agency (CIDA)
European Union-Caribbean Community (EU-CARICOM)
German Technical Cooperation (GTZ)
United Kingdom Department for International Development (DFID)
United States Agency for International Development (USAID)

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