

HIV/AIDS Surveillance in Developing Countries

Experiences and Issues



Deutsche Gesellschaft für
Technische Zusammenarbeit (GTZ) GmbH

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Opening Words

We would like to congratulate GTZ and the authors on a very useful document. This brochure fills an important gap by blending expert discussion of strengths and weaknesses of present-day HIV surveillance methods with testimonies of practical experiences. By commissioning this review, GTZ has made a significant contribution to the ongoing debate on HIV surveillance, including the usefulness of HIV case reporting, the feasibility and sustainability of HIV sentinel sero-surveillance in resource-poor countries, and the importance of supplementing biomedical surveillance with behavioural data. GTZ is uniquely placed to do this work, as it is one of the few agencies that has a long record of providing consistent technical and financial support in this area to individual countries and projects. UNAIDS considers GTZ, with its practical experience and expertise, a key partner in this process. We look forward to our continued collaboration.

Bernhard Schwartländer, Team Leader
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UNAIDS, Geneva
26 March 1999

Preface

HIV/AIDS surveillance is one of the key elements of any HIV/AIDS programme. However, when in 1996/97 the GTZ was asked about its experience in this field, there was little systematic literature on the subject to which we could refer our colleagues. This was the major reason for our (Dr Olaf Müller, who was working at that time in the GTZ AIDS Project, and myself) idea of organising a critical review of the GTZ's involvement in HIV/AIDS surveillance, especially in HIV sentinel sero-surveillance.

HIV/AIDS surveillance was a successful focal point of GTZ's international collaboration in the first decade of HIV/AIDS work from 1987 to 1996. In nearly all of the seventeen countries where the

GTZ was supporting the National AIDS Control Programmes, surveillance, especially sentinel sero-surveillance, was a major area of activity. Thanks to these continuous efforts, some of the best systematic data sets on the development of HIV over these ten years have been collected in countries such as Uganda or Tanzania. Today, with a few exceptions (in particular our cooperation with CAREC in the Caribbean and in a few countries such as Uganda, Tanzania and Namibia) this is for diverse reasons no longer a focus of our activity.

The relative scarcity in the literature of reviews of experience with HIV/AIDS surveillance and the dynamic discussions (especially on behavioural surveillance and "second generation surveillance") of UNAIDS and AIDSCAP were instrumental in prompting us to combine the experience gathered in the GTZ-supported projects with a more general overview of the entire field of surveillance in HIV/AIDS and its conceptual, ethical and pragmatic issues.

All publications are a compromise. Some readers would probably like to see more hands-on advice on how to carry out surveillance, others would like to read more on the ethical discussion, especially in the light of the recent advances in the reduction of mother-to-child transmission (MTCT) and the promotion of this intervention by international organisations (UNAIDS, UNICEF) and bilateral agencies/donors (e.g. the French cooperation).¹

However, we hope that this brochure will contribute to the increased understanding of the technicalities of surveillance and the need for it, both on HIV sero-status and sexual behaviours; it will inform practitioners dealing with HIV/AIDS as well as others interested in the field about interesting aspects of this complex but extremely relevant issue of past HIV/AIDS surveillance work, and also convince the reader that sentinel surveillance methods will continue to be a cornerstone of work on HIV/AIDS in the future. Surveillance has its costs and its technical and often practical challenges. There are only a few countries which have made consistent use of the instrument of sero- and behavioural surveillance. This brochure would like to contribute to the discussion on the usefulness and appropriateness of these efforts in different settings of the HIV/AIDS pandemic.

Our special thanks go to Dr Gabriele Riedner who despite important changes in her professional assignments continued to provide the bulk of the work for this study, and to Dr Karl Dehne, who joined the project later, but whose international experience provided some very relevant contributions, not least in structuring the contents.

After long discussions on what would be the most appropriate form of presenting the issues and experiences the editors have opted for a combination of case studies with general theoretical reflections and discussions: three countries/regions were selected:

The Caribbean: as an example of a diversity of methods in use and under review often under overriding political considerations. GTZ has supported Jamaica over the years and is collaborating today with CAREC on the development of a regional approach.

Uganda/Tanzania: as examples for provincial/district systems in Africa showing the feasibility of such systems also in rural resource - poor settings. In both cases the technical support of GTZ was and continues to be important

Thailand: as an example for a continuous system including sero- and behavioural surveillance providing on a national scale the best data and helping managers and decision makers in their programmatic and intervention choices. GTZ was only very marginally and for a very short time involved in the Thai experience.

The example in the Caribbean and in Thailand also demonstrate the delicate line of the collaboration of an external agency with national institutions. Some of the features of the national systems like mandatory testing of young military recruits in Thailand or in Jamaica where sentinel surveillance is done today in combination with informed consent and personal identification of test results, are either against the policy of GTZ or are at least, from a technical point of view, controversial. The ultimate decision on the design of a system is always a national one and the agencies have to decide how much compromise and influence they want to exercise and where and when they have to draw a line. Technical systems like surveillance are not 'innocent'! Es-

pecially in their important ethical and human rights dimensions at times they run into conflict with the more politically instigated interests by decision makers. These conflicts exist and have to be taken into considerations and very often there is, unfortunately, not an easy clear cut all pitfalls avoiding solution. The publication also hopes to contribute to the further reflection of these issues by decision makers and managers alike.

But we would also like to take the opportunity to thank those numerous people of the 'first hour' inside GTZ, the first Coordinator of the AIDS project, Dr Thomas Rehle, those who have collaborated with GTZ, the "unknown medical technologists" (all of them were women!) in the field as well as the numerous national and local collaborators in the public health laboratories who since 1987 have worked in such diverse places as Burkina Faso, Côte d'Ivoire, Jamaica, Madagascar, Namibia, Rwanda, Tanzania, Thailand, Togo, Uganda, Zaire (Congo) and many other countries, for their contributions to the development of sentinel surveillance systems locally, training their cooperation partners and promoting better understanding of the diversity of the epidemic. None of them is with the project any longer. We would like to dedicate this work to them.

Dr. Ulrich Vogel, Team Leader
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"HIV/AIDS Prevention and Control
in Developing Countries",
Eschborn
May 1999

¹ For a more cautious and 'integrated' approach to the MTCT problematic see: H. Morr & H.-U. Wagner; 1998, Position Paper on Mother to Child Transmission of HIV - Critical Review of Prevention and Zidovudine Prophylactic Therapy, GTZ Eschborn

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1. Introduction

The development of effective approaches to HIV/AIDS surveillance in developing countries has been a major component of GTZ-supported HIV/AIDS prevention projects since 1987, when GTZ joined international efforts to combat the AIDS epidemic. During its early years (1987-91), the **GTZ Multi-Country Project of AIDS Prevention and Control in Developing Countries** focused on strengthening HIV and STD testing laboratory facilities, on training of health personnel in HIV/STD prevention and care, and on the development of HIV/AIDS and STD surveillance systems. Later the Project's emphasis shifted towards a more comprehensive approach, which included information, education and communication (IEC), and the provision of counselling and care services for those infected, their partners and families¹. Regional networks of HIV/STD prevention projects were established and strengthened, and GTZ became an important advocate for the creation of a social, legal and political environment that safeguards the human rights of people living with HIV/AIDS in many countries.

During all stages of Project development and for all components of individual country projects, the collection of valid HIV surveillance data proved indispensable. During the early years, GTZ responded to the need expressed by policy and decisionmakers to know more about the magnitude of the HIV epidemic in their countries. Later on, more sophisticated information needs emerged. For instance, in order to be able to plan for prevention programmes, it became increasingly important to follow the dynamics of HIV spread in different subgroups of the population.

As with many other public health interventions, GTZ has been advocating and supporting the implementation of strategies recommended by WHO. Until 1996 WHO guidelines and since 1996 UNAIDS/WHO guidelines on HIV/AIDS and STD surveillance have been followed.

This brochure draws lessons from 10 years of experience with HIV/AIDS surveillance in GTZ-supported HIV/STD projects in Asia, Africa and the Caribbean. Successes and limitations of different surveillance strategies in guiding the response to

the epidemics are reviewed. Efforts to improve the quality and to enhance the usefulness of HIV surveillance are presented and discussed.

Chapter 2 provides an overview of the specific characteristics of HIV surveillance and of the most important surveillance methods and tools currently in use in developing countries, including AIDS and HIV reporting, sentinel sero-surveillance and behavioural surveillance. This is followed in Chapters 3 to 5 by case studies, which describe the development of and experience with HIV/AIDS surveillance in countries in which GTZ has been involved. The countries and regions chosen not only reflect different socio-economic and cultural conditions for the spread of HIV, but also different approaches to HIV surveillance. Trinidad and Tobago, Guyana and Barbados represent Caribbean monitoring systems which have been relying almost exclusively on HIV/AIDS case reporting, for reasons associated with the small size of the countries. In contrast, sentinel sero-surveillance - the mainstay of HIV/AIDS surveillance efforts in many developing countries during the last decade - has been the most important method in Uganda and Tanzania, two resource-poor East African countries. Lastly, the chapter on Thailand, a country that was affected much later by rapidly spreading epidemics and is economically less deprived than the East African countries, provides an example of the successful combination of sero-surveillance with other methods, in particular behavioural monitoring.

Each case study is divided into four main sections: a brief description of the national surveillance system, its history, main components and specific features; a presentation and discussion of selected data resulting from surveillance; examples of how surveillance data have been used for national programme/project planning and evaluation; and key experiences and lessons learnt. In addition, the Caribbean study contains a section on factors influencing data completeness. The East African study focuses on the establishment of sentinel surveillance systems and also mentions the use of mathematical modelling for the validation of surveillance data and programme impact evaluation.

The brochure is rounded off by a brief sum-

mary of key lessons learnt and an outlook into the future of HIV surveillance in developing countries, as currently discussed among epidemiologists and

AIDS programme managers worldwide. Elements of so-called “Second Generation HIV/AIDS Surveillance” as proposed by UNAIDS are briefly reviewed.

2. HIV/AIDS surveillance in developing countries

2.1 Concepts and objectives

The modern concept of public health surveillance² evolved in the 20th century in the USA and Western Europe, but is now widely accepted in developing countries, too. Traditionally, surveillance meant the close observation of individuals exposed to a communicable disease in order to detect early symptoms and institute prompt control measures, such as detention, quarantine, vaccination and treatment³. Since the 1950s, changes in norms and values that determine the relative importance of “public” versus “individual” rights have brought about a paradigm shift. The focus of surveillance in many Western and other societies moved from the detection of disease in the individual to the monitoring of disease occurrence and risk factors in populations^{4,5}. Nowadays, surveillance is largely seen as a system for collecting information needed for advocating, designing, planning and evaluating public health action^{5,6}.

As for HIV/AIDS, the traditional concept of surveillance as “early case detection” prevailed in many countries during the early years of the HIV/AIDS epidemic. The isolation of infected individuals was an often unintended result of this approach. Today, modern public health approaches emphasising the occurrence of disease in populations predominate. In most countries, HIV/AIDS surveillance systems have a variety of aims and objectives (Box 1).

Surveillance usually refers to the intentional collection of data for monitoring purposes. In addition, surveillance systems can make use of data on HIV infection, its determinants and implications that result from other activities, such as voluntary testing and counselling, testing for diagnostic purposes or the screening of donated blood.

Box 1: Some objectives of HIV/AIDS surveillance

- ◆ To assess the magnitude of the epidemic and the distribution of infection in space and time, and to create awareness
- ◆ To identify segments of the population that are particularly vulnerable and to plan for action to reduce their vulnerability
- ◆ To aid in policy formulation and resource allocation for prevention programmes
- ◆ To predict the future course and impact of the epidemic, and to aid in the planning of care and social support of those infected
- ◆ To aid in the evaluation of prevention programmes

This brochure focuses on GTZ’s experience with HIV surveillance systems and the use of surveillance data for planning and evaluating prevention programmes.

2.2 Challenges to HIV/AIDS surveillance

Three main characteristics of HIV infection make surveillance especially difficult: its long incubation period, the often severe personal consequences of a positive HIV test result, and the complex biological, behavioural and socio-economic causation of the epidemic.

The invisibility of HIV spread

It would be ideal, if the possibility existed, to identify and thus to directly count new HIV infections, as for instance measles or diarrhoea cases are counted. Unfortunately, however, only about 1/3 of new HIV infections and sero-conversions are asso-

ciated with (mild) symptoms, most of which go unnoticed or are not recognised as HIV-related because of their unspecific nature.

HIV-related disease has a long incubation period during which infected people are and appear healthy. Unless tested for HIV antibodies, they are unlikely to become aware of their infection. HIV therefore spreads largely invisibly. There is a long time lapse of several years between the introduction of HIV into a community and the stage of the epidemic when a significant number of HIV infections and AIDS cases become clinically apparent. This makes the monitoring of the epidemic both difficult and, with regard to opportunities for prevention interventions, particularly important.

Ethical issues related to HIV testing

Another reason why the surveillance of HIV infection/AIDS differs from that of most other communicable diseases is the fact that individuals known to be infected are often severely stigmatised and discriminated against. HIV transmission is closely associated with sexual (and injecting drug use) behaviours, and sexuality is a very private sphere of life surrounded by many taboos. Homosexual, premarital and extramarital sexual relations, if unprotected, may all be seen as contributing to the spread of HIV. They are at the same time morally discredited in many societies. The consumption of injectable drugs, another risk factor for HIV infection, is illegal in most. Thus, persons known to have tested HIV positive are frequently confronted not only by ignorance and false fears of infection, but also by moralistic attitudes, rejection or even legal persecution.

Because of its enormous personal (psychological, social, economic) implications, HIV testing is only ethical if certain conditions are fulfilled so that the human rights of individuals are protected. Ethical principles of HIV testing (Box 2) are valid regardless of the purpose of testing, be it surveillance, diagnosis or any other purpose.

Box 2: Ethical principles guiding HIV testing policies

- ◆ **Voluntariness and informed consent.** HIV testing must not be imposed on any person unless the rights and health of others are

endangered. Donated blood and organs should be mandatorily tested to preserve the health of recipients.

- ◆ **Confidentiality.** AIDS and HIV diagnosis and notification policies and practices must comply strictly with the principle of confidentiality. Only in exceptional circumstances may a breach in confidentiality be considered to protect others from HIV infection (e.g. disclosure of test results to spouses).
- ◆ **Non-discrimination.** Policies and practices should ensure equal access to HIV testing, care and social support for all persons, regardless of their gender, age, occupation, nationality, religion, and ethnic group.

The complexity and diversity of determinants of HIV spread

A wide range of factors determines the patterns and speed of HIV spread. These include biological and demographic, behavioural as well as socio-economic factors. Women are biologically more vulnerable to HIV transmission than men^{7,8,9,10}, and the presence of other sexually transmitted diseases seems to act as a co-factor of transmission^{11,12,13,14,15}. Patterns of mixing between groups who inject drugs and those with different sexual practices, movements between different geographical locations⁷³, the manner in which sexual activity changes with age in the two sexes¹⁶ and patterns of sexual contact between age groups all influence patterns and speed of HIV spread¹⁷.

Economic hardship and/or armed conflict leading to migration and social disruption, poverty facilitating commercial sex¹⁸, the prevalence of injecting drug use, and the unavailability or unacceptability of condoms¹⁹ are all believed to be associated with an increased risk of HIV spread²⁰. The relative importance of each of these and other factors promoting HIV transmission varies widely in different communities. It can also rapidly change over time.

Comprehensive HIV surveillance systems should monitor not only the patterns and levels of infections, but also the determinants of HIV spread and the impact of the epidemic on individuals, the community and the society at large. Considering the opportunity costs of collecting such data, how-

ever, it is often difficult to decide which factors and indicators to measure and on which subgroups of a population and geographic areas to focus HIV surveillance efforts.

2.3 HIV/AIDS surveillance methods

2.3.1 Overview

A wide range of HIV/AIDS surveillance methods and indicators have been used to monitor the epidemic. These include measures of disease occurrence (HIV incidence and prevalence indicators) as well as indicators of risk and impact.

In the late 1980s, WHO took the lead in the development of HIV/AIDS surveillance systems, which would be low-cost and deliver the information required for the planning and implementation of prevention programmes in developing countries. AIDS and, when HIV tests became available, HIV case reporting were the first surveillance tools used. Together with AIDS and HIV case reporting, sentinel HIV sero-surveillance became the cornerstone of many national HIV/AIDS surveillance systems. Following its ethical approval by the African Ministers of Health in 1987²⁹, WHO promoted sentinel surveillance as the method of choice for the monitoring of HIV spread in developing countries.

The occurrence of other infections has occasionally been used as an indicator of HIV spread. Surveillance of sexually transmitted diseases has received attention because high rates of STD other than HIV (e.g. syphilis) are thought to be markers for the vulnerability of populations to HIV infection. Trends towards lower STD rates may reflect changes in sexual behaviour, which in turn may be the result of prevention interventions affecting both classic STD and HIV. The occurrence of HIV-associated diseases such as TB and herpes zoster have occasionally been used as markers of HIV infection.

During recent years, the importance of collecting complementary socio-demographic and behavioural information has become increasingly apparent. In order to obtain information about potential behavioural determinants of HIV spread in a society and to monitor the effectiveness of prevention programmes, the systematic measurement of various sets of sexual (and drug use) behaviour indicators has been suggested²¹. The development of standard tools for behavioural surveillance is still in process.

Efforts to map out society-level determinants of the epidemic, including migration, social cohesion, or drug demand and supply patterns have so far been limited to regional reviews and ecological studies.

Methods to monitor the impact of the epidemic on individuals and societies include the measurement of health sector indicators, such as hospital occupancy rates and drug consumption, and of the degree to which persons with HIV/AIDS are integrated into the society or discriminated against. Socio-economic impact studies based on AIDS case projections have been carried out in a number of countries. In general, however, the systematic monitoring of the personal and social impact of the epidemic is still in its infancy.

Limited resources and technical capacity in developing countries make the routine use of a large variety of surveillance methods impossible. Methodologies that are currently in use in developing countries are briefly described in the following. These include HIV and AIDS case reporting, sentinel sero-surveillance, and STD and behavioural surveillance.

2.3.2 AIDS case reporting

AIDS case reporting as a surveillance tool involves the systematic notification of all new diagnoses that fulfil a standard AIDS case definition to a central surveillance unit, usually situated in the Ministry of Health. The surveillance unit then compiles and analyses the data, and presents them to programme planners and decision makers. AIDS case reports usually include information on socio-demographic characteristics of persons testing HIV-positive and on the route of transmission.

AIDS case definitions

The introduction of AIDS case reporting in industrialised countries was closely associated with the definition of AIDS by the Centres of Disease Control (CDC) in 1982²². A slightly modified version of this definition was then adopted by WHO (WHO/CDC AIDS case definition) in 1986. According to both WHO and CDC, AIDS is defined by the presence of a number of indicator diseases, and a positive HIV antibody test result. When more sophisticated laboratory tests became available, which allow for the monitoring of progression towards

HIV-related immune-deficiency (CD 4 cell counts), the WHO/CDC AIDS case definition was revised to include new criteria^{23,24}.

In many developing countries, however, the WHO/CDC AIDS case definition has not been applicable, as the required laboratory facilities are not available. In 1985, a WHO-initiated meeting of African health ministers and epidemiologists in Bangui, Central African Republic, developed a definition of AIDS for surveillance purposes^{25,26} (Box 4), which is based on clinical criteria only.

The Bangui definition is relatively insensitive and unspecific, however. Evaluations have shown that around 40% of AIDS cases (according to CDC criteria) may be missed. The relatively low specificity of around 80% is due to the common presence of conditions with similar signs and symptoms, such as wasting caused by malnutrition or tuberculosis^{27,28,29}. Several African countries have therefore modified the clinical criteria, aiming to improve the definition's sensitivity and specificity. Others who could afford it have added HIV seropositivity as an additional criterion to the clinical symptoms of AIDS³⁰.

Some other regions including the Caribbean, Latin America and the Middle East have developed and adopted their own AIDS case definitions, based on assessments of the prevalence of opportunistic

infections and of the availability of laboratory facilities in their regions.

Active or passive case reporting procedures

In most countries, AIDS cases identified by the health care system are spontaneously notified to a central surveillance unit in the Ministry of Health (MoH). This type of case reporting is called "passive" reporting, as the surveillance unit plays a passive role. In contrast, "active" reporting is characterised by the active search for cases in laboratory records and hospital discharge data, for example.

2.3.3 HIV case reporting

The advent of the reliable HIV antibody test in 1985 opened up the possibility of directly measuring the prevalence and incidence of HIV infection in populations. HIV case reporting remains the cornerstone of national surveillance systems in several regions, including in the Western Pacific and Eastern Europe. In contrast, HIV case reporting plays a minor role in countries where the availability of HIV tests is restricted to a few centres, as in many African countries. As with AIDS case reporting, HIV case reporting involves standard definitions of what constitutes a "case" and routine reporting procedures.

Box 3: Bangui Definition or WHO Clinical Case Definition of AIDS in Adults

Major criteria

- Weight loss > 10%
- Chronic diarrhoea > 1 month
- Chronic fever > 1 month (intermittent or constant)

Minor criteria

- Persistent cough > 1 month
- Generalised itchy dermatitis
- Recurrent herpes zoster
- Oropharyngeal candidiasis
- Chronic progressive and disseminated herpes simplex virus infection
- Generalised lymphadenopathy

A minimum of two major criteria in combination with one minor criterion must be fulfilled in the absence of other causes of immune-depression, such as cancer or severe malnutrition.

Generalised Kaposi's sarcoma or cryptococcal meningitis alone is sufficient for the diagnosis of AIDS.

Case definitions

For surveillance purposes HIV infection is defined by the presence of HIV antibodies, detected through one serological test with or without confirmation through a second test. The exact strategy is determined by HIV prevalence, the availability of resources for HIV testing, and the performance of the HIV tests used in a specific country. For diagnostic purposes, individuals usually need to have their positive test result confirmed by a second, different type of test.

HIV testing and reporting procedures

All health facilities and laboratories that perform HIV tests are usually supposed to notify positive cases. HIV reporting data therefore usually derive from different sources, including from voluntary testing sites, blood screening, and the testing of symptomatic patients for diagnostic purposes. Despite human rights concerns, many countries that can afford it have also adopted HIV testing policies that provide for the routine screening or mandatory testing of specific population groups such as pregnant women, military personnel, registered sex workers, drug users and migrants, among others. This is not recommended by WHO and UNAIDS.

The question as to whether AIDS and HIV case reporting should be by name is often controversial. Nominal reporting may facilitate the clinical follow-up, care and support of individuals by the treating doctor, nurse or counsellor, but for surveillance purposes coded information is usually sufficient to avoid double reporting, and nominal reporting may raise unnecessary confidentiality concerns. The case study on HIV and AIDS case reporting in the Caribbean will provide further insight into this issue.

2.3.4 HIV sentinel surveillance

The ideal HIV surveillance method would allow the determination of HIV sero-prevalence and incidence rates in the entire population at any given moment. Extensive testing of large population groups - except for rare special studies - is not feasible because of the high costs it involves and for many other reasons. Therefore sentinel sero-surveillance has become the most important HIV surveillance tool in many countries.

Sentinel HIV surveillance is characterised by repeated cross-sectional sero-surveys in easily accessible populations such as antenatal care attendees, STD patients and blood donors, to monitor trends in the levels of infections in these populations³¹ (see Box 5). Some "sentinel populations", such as antenatal care attendees, are thought to represent quite closely HIV levels and trends in the general population. Monitoring of infection levels among particularly vulnerable groups (e.g. sex workers, IDUs) is often less straightforward, as these population groups are marginalised in many societies and often difficult to access. Following each round of surveys, the data from the various sentinel populations are compiled and levels and trends analysed.

HIV testing for sentinel surveillance is carried out anonymously, on blood specimens taken for other reasons, e.g. syphilis screening among pregnant women, without prior consent of the client. An important advantage of this method is the usually high validity of data, as participation bias is minimised. Experience has shown that samples collected for individual HIV diagnosis rather than surveillance provide misleading data about the true prevalence of HIV infection in a population. Those wishing to know their HIV status and thus consenting to HIV testing are highly self-selected^{32,33}.

Such testing without consent is only considered ethical, however, if it is not only anonymous but also unlinked. Unlinking means that all identifiers must be removed from the specimens to make it impossible to link test results to individual persons.

Advances in drug treatment of HIV-infected individuals during recent years and the possibility of preventing mother-to-child transmission are posing further ethical dilemmas to unlinked anonymous testing. Its benefits in terms of the collection of highly representative data therefore need to be weighed against the disadvantage for the individual that information about conditions that might be treatable is being withheld. Many policy makers therefore recommend that voluntary confidential testing is offered in parallel with anonymous unlinked testing for surveillance.

One major merit of unlinked anonymous sentinel surveillance is its low cost. No major infrastructural investments need to be made, as routine procedures can be used. Trend estimates can be

achieved with relatively low sample sizes. When combined with voluntary testing and counselling, however, costs increase considerably and one of the major advantages of the method is lost.

Box 4: Characteristics of anonymous unlinked sentinel sero-surveillance

- ◆ Serial cross-sectional surveys
- ◆ Selection of a defined, easily accessible population (e.g. women's ANC clinics)
- ◆ Use of remainders of blood specimens that are collected for other purposes
- ◆ Sequential sampling technique, whereby a defined number of eligible individuals are consecutively enrolled during the survey period
- ◆ Elimination or unlinking of identifying data from the blood specimen to ensure anonymity and confidentiality
- ◆ Repetition of the same procedure at regular time intervals

In the case studies from Uganda and Tanzania, East Africa, the specific epidemiological, logistic and managerial implications of sentinel surveillance systems are further discussed.

2.3.5 STD surveillance

Traditionally, STD surveillance has been based on the passive reporting of clinically or etiologically diagnosed cases of STD. Usually only the two STDs considered most important, syphilis and gonorrhoea, are notified.

The recent introduction of the syndromic diagnosis and treatment of STD in many developing countries has been accompanied by a corresponding change of STD case definitions, for both surveillance and case management purposes. Some countries have started reporting syndromes such as genital discharge or genital ulcer rather than specific infections.

Reported STD cases often only reflect a small proportion of the real number of infections occurring in a population, however, as many infections are asymptomatic and few symptomatic patients seek care in public health facilities and are notified. Where diagnosis is etiological, laboratory methods

may also vary between different sites and over time, making comparisons difficult. Example: Reported rates of *C. trachomatis* have shown an enormous increase in industrialised countries in the last 10 years. Although Chlamydia infections might indeed have spread during this period, a large proportion of the reported increase is probably due to the introduction of simpler and cheaper diagnostic methods. In many developing countries, diagnostic and reporting procedures have remained largely unchanged, however, and the monitoring of STD case reports can be assumed to constitute a valuable monitoring tool.

In many countries, simple laboratory tests allow for the routine syphilis screening of pregnant women, and occasionally other population groups. In other countries, sentinel sero-surveillance of syphilis which follows similar principles to those of HIV sentinel surveillance has been introduced, to observe STD trends more systematically. Syphilis sero-prevalence data resulting from such screening are regarded to be indicative of the risk of HIV infection.

2.3.6 Behavioural surveillance

The use of various behavioural surveillance methods has been promoted in recent years. Except for very few countries, however, among them Thailand, regular monitoring of sexual behaviour has not yet become part of national surveillance programmes.

During the late 1980s, WHO supported several countries in conducting large-scale KABP and partner relation surveys. However, the management of such large behavioural surveys proved difficult, and none of the study protocols was transformed into a regular monitoring tool. In 1994/95 WHO finished preliminary work on the development of protocols for the measurement of ten Priority Prevention Indicators (PPI) which would allow national programmes to monitor - among other indicators - knowledge and behaviour as a complementary measure to sero-surveillance. PPI surveys have been conducted in several countries, but have not yet been included in the routine surveillance repertoire of national AIDS programmes. The further refinement of the indicators has stagnated in recent years. Other agencies, such as USAID and GTZ, have also been actively involved in the development and use of behavioural indicators.

Lately the method known as behavioural sentinel surveillance (BSS) has been undergoing development^{34,21}, following the concept of sentinel HIV surveillance. BSS may provide a manageable approach to monitoring and tracking risk sexual behaviours at periodic intervals over time.

National HIV surveillance programmes in developing countries usually combine several of the ele-

ments and methods described, depending on the specific epidemiological situation in the countries, the human and material resources available for surveillance and the overall surveillance concept and philosophy. The case studies which follow in chapters 3 to 5 provide an opportunity to discuss at some length the experience with different surveillance methods, their strengths and limitations.

3 HIV/AIDS case reporting in the anglophone Caribbean

This case study builds on a series of evaluations of STD/HIV/AIDS surveillance systems, conducted jointly by the Caribbean Epidemiology Centre (CAREC) and the countries' Ministries of Health with GTZ support in 1997. CAREC, a sub-regional centre of the Pan American Health Organisation (PAHO), serving 21 member states, is the leading public health institution and plays a key role for HIV/AIDS programmes in the region. One of the Centre's tasks is to support the region's Ministries of Health in carrying out epidemiological HIV/AIDS and STD surveillance through its Special Programme on STD.

The study focuses on four countries which have had priority for GTZ: Barbados, Guyana, Jamaica, and Trinidad and Tobago. While surveillance systems in Barbados, Guyana and Trinidad and Tobago have many similarities, that in Jamaica is more elaborate and profits from a stronger human resource capacity. When comparing several countries to draw a regional picture, generalisations are unavoidable. Exceptions from the general rule that apply to one or the other country are mentioned whenever possible.

3.1 Main components of HIV/AIDS surveillance in the Caribbean

After the first cases of AIDS were seen in Trinidad in 1983, Caribbean countries established HIV/AIDS surveillance systems, which have been relying mainly on AIDS case notifications. HIV case report-

ing has also existed, but little use has been made of those data until recently. Sero-prevalence surveys, behavioural and other surveillance methods have had little importance until the early 1990s. In comparison to other regions of the developing world, reported AIDS (and to a lesser extent HIV) incidence has become a well-utilised and fairly reliable indicator of epidemic trends. The Caribbean example therefore provides an opportunity to document specific features and key strengths and weaknesses of AIDS and HIV case reporting as a surveillance tool.

AIDS case reporting

The first AIDS cases were diagnosed in Trinidad and Tobago and Jamaica in 1983, in Barbados in 1984 and in Guyana in 1987. With the technical support of CAREC and following the PAHO format, all Caribbean countries established AIDS case reporting systems at this early stage of the AIDS epidemic. AIDS case reporting became mandatory by law in some countries, like in Guyana, or was introduced by ministerial decree, like in Trinidad and Tobago.

Most countries in the Caribbean use the CAREC AIDS case definition which is based on a positive confirmed antibody test plus either the (African Bangui) clinical case definition or a confirmed indicator disease (CDC case definition until 1992). A few countries that have flow-cytometry facilities (Barbados) have adopted the new CDC case defini-

tion (1992), but are faced with the problem of intermittent dysfunction of the required equipment.

Standardised HIV/AIDS case report forms are used to collect information on clinical findings, socio-demographic characteristics and on the history of exposure to HIV. Case reporting is by name. Only Guyana is using a simple code for personal identifiers (e.g. initials, birth date, and location) with good results. In Jamaica named reporting is used for systematic partner notification, whereas in other countries its use is restricted to the avoidance of double counting.

Following the 1997 evaluations of diagnostic capacities in its member countries, CAREC is introducing a new report format. This includes additional risk exposure categories (e.g. crack cocaine use) and behavioural information, and alternative case definitions: a confirmed HIV-antibody test plus either i) the 1992 CDC case definition (CD 4 cell count), or ii) a modification of the previous CDC case definition, or iii) the Bangui Clinical Case Definition. The latter may be applied in the absence of HIV serology, thereby reducing non-reporting of cases where no test can be done. Nevertheless, the definition of AIDS cases as a combination of clinical signs and positive serology will remain the norm.

AIDS cases are usually reported by the treating public health facilities to a central epidemiological surveillance unit, which is responsible for data collection, analysis, storage and dissemination. In many countries this unit also performs active case finding, where surveillance nurses visit major hospitals regularly to screen discharge records for AIDS cases. Reporting compliance from the private health sector is poor.

HIV case reporting

The introduction of HIV testing in the second half of the 1980s made it possible to diagnose HIV infection in asymptomatic persons, and to use HIV case reporting as an additional surveillance tool. Reported HIV cases in the Caribbean mainly result from testing for diagnostic purposes, but also from screening for employment, insurance and visa requirements, antenatal screening (as part of a policy to reduce vertical transmission through AZT treatment) and screening of donated blood. Until recently, voluntary testing and counselling have played only a minor role. As with AIDS cases, HIV

reporting is nominal.

To date only a few countries include a systematic analysis of newly diagnosed HIV cases in their annual reports.

HIV prevalence surveys

In recent years, cross-sectional HIV prevalence surveys have been conducted among various groups, such as STD patients, ANC attendees and sex workers in several countries. Blood donors are screened in all four countries, following an assessment of their risk of HIV infection. US visa applicants are also routinely tested. The sero-surveys have been either anonymous or non-anonymous; few have been repeated at regular intervals. In other countries, the only available HIV data originated from voluntary counselling and testing. Comparisons between population groups and over time were hardly possible, which limited the value of these data for surveillance purposes.

In several countries, ethical concerns about anonymous HIV testing have caused a long-standing debate around anonymous unlinked sentinel surveillance and prevented more systematic surveillance from being implemented. These concerns are based on two grounds: firstly, that every individual has a right to be informed of her/his HIV status and, secondly, that in small island communities, such as in the Caribbean, public health authorities need to be informed about individual HIV cases in order to instigate control measures.

Despite considerable resistance, several Ministries of Health, including those of Trinidad and Tobago and Jamaica, have established anonymous sentinel HIV sero-surveillance among attendees of public ANC clinics starting from 1996, and, in the case of Jamaica, among several other sentinel groups. Since most pregnant women attend public ANC clinics in the Caribbean countries, it can be assumed that the observed rates are reasonable indicators for the extent of HIV infection in the general sexually active population.

Recently anonymous unlinked testing has been abolished and mandatory testing for all pregnant women has been introduced as a policy to reduce mother-to-child HIV transmission. AZT prophylaxis is made available to pregnant women attending antenatal care.

Fig.1 Annual AIDS Incidence per 100,000 pop. in Selected Caribbean Countries

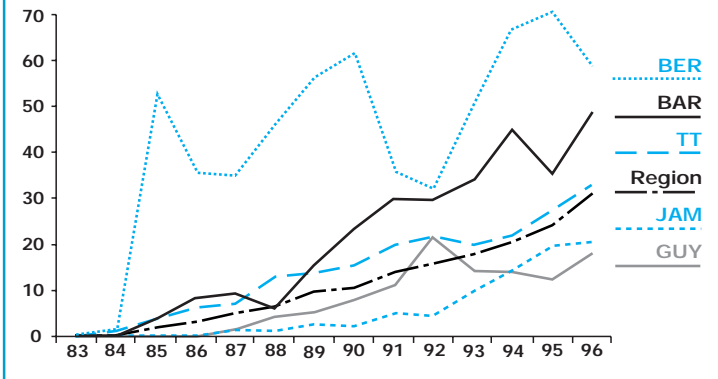


Fig. 2 Male AIDS Cases 1984-95: Transmission Categories All CAREC Member Countries

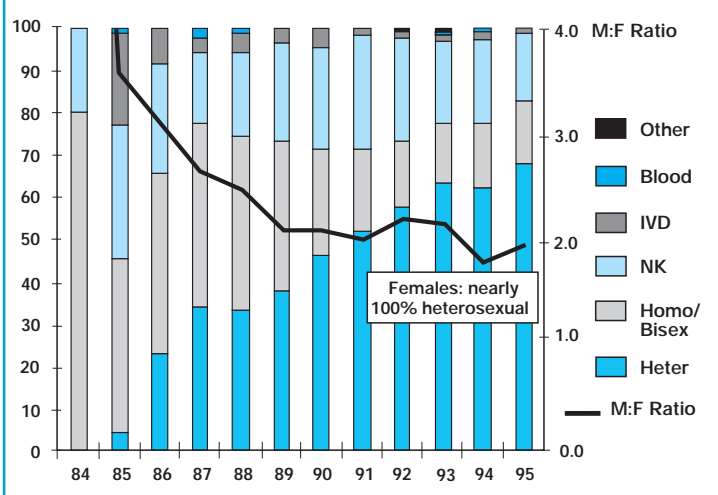
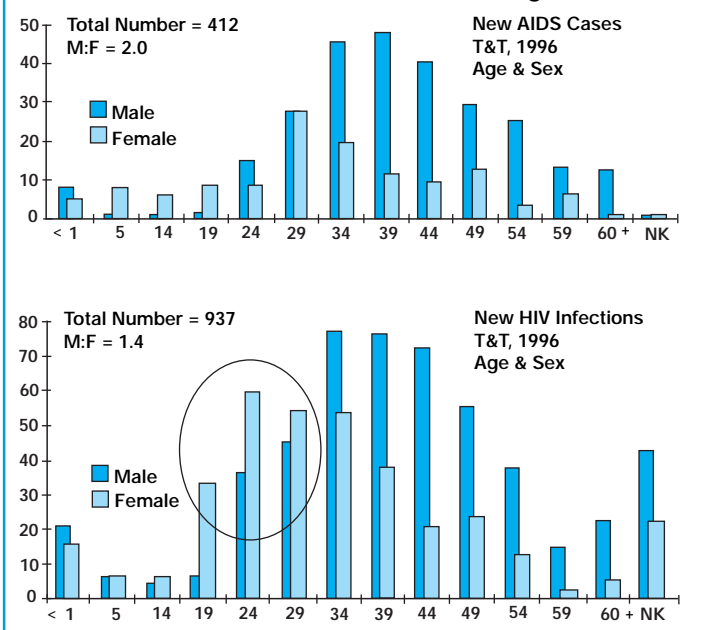


Fig. 3 Reported AIDS and HIV cases in 1996 in Trinidad and Tobago



3.2 Selected results

The magnitude of the AIDS/HIV epidemic in the anglophone Caribbean has one of the highest reported incidence rates of AIDS world-wide (27/100,000 pop. in 1996). AIDS data suggest significant differences between countries in the magnitude of the epidemic, with cumulative case rates, 1983-1996, ranging from 49 to 990 cases/100,000 population and male-to-female ratios from 1.2:1 to 3.8:1. Reported annual AIDS incidence rates have varied between 135/100,000 in the Bahamas, 67 in Bermuda, 50 in Barbados and 33 in Trinidad & Tobago to 21 in Jamaica, 10 in St. Lucia and 5 in Surinam (fig. 1).

Guyana, economically one of the weakest countries, has experienced the fastest increase in the rate of persons living with AIDS and in 1993 surpassed Trinidad and Tobago in this respect. The drop after 1993 as shown in fig. 1 was due to delayed reporting and to a high degree of under-reporting (see below).

Trends in transmission categories

Variations in the relative importance of self-reported HIV transmission categories between countries probably reflect both real cultural and socio-economic differences in sexual and drug use behaviours as well as differences in reporting.

While the majority of cases in the early years were due to homosexual transmission, hetero- and bisexual transmission have been gaining increasing importance in all countries since the late 1990s. The absolute increase of heterosexually acquired infections, however, seems to mask continuously high male-to-male transmission. In 1996, for instance, nearly a third of all cases reported in the region were in the "Unknown" category. Of these, 99% were males (fig. 2).

Several countries are confronted with rapid increases in crack cocaine use, which is believed to be associated with high-risk sexual behaviours. HIV surveillance has however largely failed to capture this risk factor, as the case reporting format used until 1998 only captured IV drug use, which is common in just a few countries. The revised report format introduced in 1998 includes this category.

Variations in the relative importance of self-reported HIV transmission categories between countries probably reflect underlying cultural and socio-

economic differences as much as the reliability of these culturally sensitive data, particularly in regard to homo- and bisexual preferences.

Comparisons between AIDS and HIV data

HIV case reporting data analysed since 1996 confirm the general trends derived from the previous analysis of AIDS case data: an increase in the reported annual number of new cases, differences between countries as well as an increase in the proportion of cases due to heterosexual transmission.

But the comparison between AIDS and HIV data also reveals important differences. For example in Trinidad and Tobago, in 1996 the male to female ratio in young adult AIDS cases was approximately 1:1, while among HIV cases it was 1:1.6. In the teenage group (15 to 19 years), the ratio was 1:5. In the same year, the largest number of new HIV infections was detected in young women aged 20-24 years and among men aged 30-34, suggesting substantial HIV transmission from older men to teenage girls (fig. 3). Generally, trends in transmission patterns, from homosexual to heterosexual spread, were more marked. HIV reporting data reflected more recent trends in transmission than previously available AIDS reporting data. The epidemic situation that they revealed immediately became a major concern for policy makers.

Prevalence data

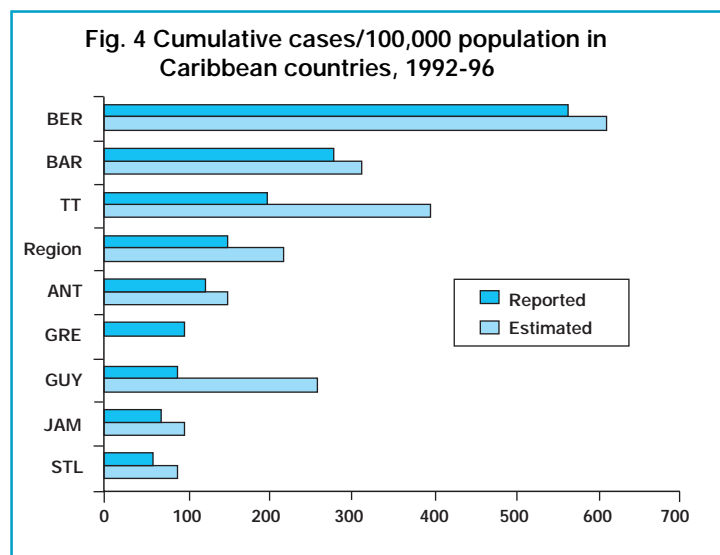
It is noteworthy that among self-selected blood donors and US visa applicants the HIV prevalence rates were usually significantly lower than among anonymously screened ANC attendees.

In Jamaica, sentinel surveillance among pregnant women, sex workers and other population groups showed significant geographic differences as well as differences between groups.

3.3 Factors influencing the quality and completeness of AIDS and HIV case reporting data

The reported number of HIV and AIDS cases is unlikely to reflect the total or true number of infected people in any given country. In the Caribbean, the proportion of AIDS cases actually diagnosed and reported has been estimated to range between 20%

(e.g. Guyana) and 90% (e.g. Barbados) (fig 4.). The estimated sensitivity of HIV case reporting was less, ranging between 10% in Guyana and 60% in Barbados^{35,36,37}.



Factors that have probably influenced the completeness of AIDS and HIV reporting in the Caribbean include the following:

Availability of HIV tests

In 1994/95, logistical problems such as interruptions of the regular supply of HIV test kits affected surveillance in several countries. In the absence of test kits, AIDS cases could not be diagnosed and were not reported. Guyana, for instance, reported significantly fewer AIDS cases than in the years before. The existing AIDS case definition, which requires laboratory tests, has therefore contributed to underreporting in countries with laboratory performance problems.

Testing strategies

In countries such as Guyana and Trinidad and Tobago, many HIV positive test results are not confirmed by second tests and therefore not reported. For instance, private laboratories may be directly accessed by patients who want to avoid the long delays in receiving test results from the public services. Following existing policies, a person testing HIV positive at a private laboratory would have to have his/her test result confirmed by a Public Health Laboratory to fulfil national HIV and AIDS case definitions. Patients concerned about

confidentiality welcome the fact that this policy is not enforced.

Confidentiality concerns

Private practitioners from several countries mentioned that they were reluctant to report cases by name. They were concerned with their patients' confidentiality. There were also strong psychological barriers against inquiring about other sensitive personal details required to fill in the report form, such as the sexual history. Therefore, even if a report was made, certain crucial types of information were often missing, for instance the transmission category.

Notification forms

Lengthy notification forms (e.g. six pages in Trinidad and Tobago) prevented physicians from notifying cases timely and completely. In order to simplify reporting, CAREC has therefore developed a unified one-page form for HIV test requests, reports of HIV/AIDS cases, and AIDS-related deaths, to be used in all CAREC member countries.

Availability of voluntary counselling and testing

The relative lack of anonymous or voluntary confidential testing services may also have contributed to under-diagnosis and underreporting. As elsewhere, people who perceive themselves at risk fear the implications of a positive HIV test result, and may not want to come forward for HIV testing.

The four countries on which GTZ has focused its attention have at least one HIV testing and counselling centre offering free HIV testing to people who wish to know their HIV status. But this service is usually available in a central "special (STD) clinic" or - in the larger countries - in one of its satellite clinics, which many people associate with a strong stigma. In Trinidad and Tobago HIV testing and counselling services are available at a few public STD clinics.

Recently some countries have adopted a more client-oriented voluntary counselling and testing strategy. For instance in Barbados, voluntary HIV testing and counselling services were introduced in ANC clinics in 1991. They have been used by an increasing proportion of clients (reaching > 90% in some clinics).

Quality of care

The perceived quality and cost of treatment are important determinants of care seeking and completeness of data in the Caribbean. In Barbados, care seeking - and, as a result, HIV reporting - have been enhanced by the availability of AZT treatment to HIV-infected pregnant women and by a clinical care system for HIV/AIDS patients, which is perceived to be of good quality and user-friendly.

Nearly all persons living with HIV, once they develop an illness, will attend the special HIV clinic provided in the main government hospital. The detection of infection has therefore most likely been on average earlier than in neighbouring countries and HIV reporting more complete.

Underreporting by private care providers

The opposite is true where the quality of public care has deteriorated. As a result the utilisation of private sector services has increased by those who can afford them. Underreporting by the private care providers sector has resulted in the biased impression in some of the Caribbean countries that the HIV/AIDS epidemic concerns predominantly lower social classes.

Contact tracing and partner notification

Under certain circumstances, contact tracing policies and practices can influence reporting completeness. In Jamaica there is a partner notification system that works well. Partners are contacted only with the prior consent of the index patient, who decides whether he/she notifies his/her partners or "contact investigators". Index patients and partners are offered confidential counselling and testing and health care services. In 1996, on average 2.5 partners per index patient were identified through this system. A significant proportion among those partners who are found to be HIV-infected did not know about their HIV status before.

Centralisation of HIV notification

AIDS case notifications have been shown to be more completely compiled and more comprehensively analysed (90%) where HIV testing and care for HIV-related disease were centralised at one clinic and laboratory, like on the small island of Barbados. In other countries, a different type of centralisation has had the opposite effect. In order to

ensure confidential handling of HIV and AIDS case databases, access has been restricted to very few persons, mostly high-level public health officials having little time to care for HIV/AIDS databases. This caused delays in data entry and analysis.

Feedback and local use of surveillance data

The quality of surveillance data has also depended on health workers' understanding of the purposes and procedures of data collection. The evaluation of surveillance systems by CAREC showed that many health workers were not aware of them. A typical statement was that the purpose of these data was to send them to the Ministry or to CAREC. Data quality was better in countries such as Jamaica where health workers received regular surveillance updates and discussed implications for their own work.

3.4 The use of surveillance information for programme planning

In most Caribbean countries reviewed in 1997, AIDS/HIV surveillance had been carried out without clearly documented objectives and had not been sufficiently informed by the data needs of national AIDS prevention and care programmes. HIV surveillance data were routinely collected, but were not analysed as to which groups of the populations were particularly vulnerable and whether earlier interventions were showing any effects. Important groups of the population were not recognised as vulnerable and/or affected, and were therefore not adequately addressed by specific interventions. In many countries, relevant information on transmission categories was not routinely collected (e.g. on crack cocaine use), or the validity of data collected was influenced by social stigma (homo- and bisexual behaviour). Opportunities were therefore missed for strategies to be implemented that could have reduced the generalisation of the epidemic.

Recently, significant efforts have been made to improve the surveillance systems and to make better use of surveillance data. The following are just a few examples of how surveillance has influenced decision making:

During 1996 and 1997, data showing the magnitude and trends of the epidemic became a power-

ful advocacy tool when experts and activists addressed cabinets, parliaments, ministers, region-wide meetings and journalists throughout the region. UN Theme Groups on AIDS played an important role in disseminating HIV surveillance data to sectors other than health to raise their active involvement in prevention. Advocacy has led to AIDS increasingly being made a priority on national development agendas, public discussion has increased and with it the political pressure for a stronger response.

- ◆ The finding in Trinidad and Tobago that young girls were increasingly becoming infected prompted concern among policy makers regarding risk behaviours of young people in general. A behavioural survey was conducted which indicated that, despite behavioural change interventions over the past decade, youth had remained a group at high risk of HIV infection. As a consequence, prevention strategies were revised to address the specific problems of youth. It was proposed to conduct regular behavioural surveillance to monitor behaviour change.
- ◆ Data showing increasing rates of HIV among adolescents also helped to resuscitate the formally suppressed discussion on sex education in schools.
- ◆ Aware of persistently high transmission rates among men having sex with men, CAREC started supporting the networking of MSM groups and promoted safer sex and the use of condoms.
- ◆ In Jamaica, the extension of sentinel surveillance to several regions resulted in the identification of a somewhat unexpected epidemiological hot spot in an economically important area (tourism). This prompted planners to design geographically focused intensive prevention programmes addressing youth, sex workers, MSM and the general public.

3.5 Key experiences and lessons learnt

The Caribbean experience has demonstrated specific strengths and limitations of national HIV/AIDS surveillance systems that rely almost entirely on AIDS and HIV case reporting. But it has also provided an insight into more general issues related to public health surveillance, programme planning

and advocacy. Surveillance is meaningless if it does not serve the needs of and is not informed by public health policy. In its STD/HIV/AIDS surveillance guidelines, CAREC defines the primary purposes as being to provide short- and long-term users with the appropriate information to prevent the spread of and reduce morbidity and mortality from HIV/AIDS.

Surveillance systems that rely on routine procedures such as the reporting of AIDS and HIV cases may be particularly sensitive to neglect and to a loss of direction, as the purpose of surveillance is easily forgotten by those doing most of the work. But the Caribbean experience has also shown that once there is an interest among policy makers and planners to better understand the epidemic and to prevent its further spread, data collection and analysis can rapidly expand and improve. HIV surveillance can significantly contribute to a focusing and strengthening of prevention programmes.

► **Clearly defined surveillance objectives are crucial for the rational collection of data, their meaningful analysis and efficient use.**

In the absence of other surveillance tools such as regular sentinel sero-surveillance, AIDS and HIV case reporting are useful tools to monitor patterns and trends of the epidemic. As in other regions, AIDS case reporting, which reflects infections that occurred almost a decade ago, was found to be too insensitive to monitor more recent patterns and trends. However, when combined with HIV case reporting, it provided valuable insights into the dynamics of the epidemics. Demographic and personal data such as on transmission categories significantly add to the value of surveillance data and need to be exploited to the greatest extent possible.

The Caribbean countries are not the only ones that have used HIV/AIDS case reporting as their main surveillance instrument. Countries in the Western Pacific, many of them small island states with similar conditions for health care service provision to those in the Caribbean countries, have been reporting HIV/AIDS cases to WHO for many years. Nevertheless, the experience from Jamaica shows that, at least in larger island countries, un-

linked sentinel surveillance should be introduced to complement case reporting. The unexpectedly high HIV rates found among sex workers and ANC attendees in certain geographic locations, for instance, would not have been detected by HIV case reporting alone.

► **AIDS and HIV case reporting can be useful instruments to monitor patterns and trends of the epidemic.**

The long list of factors that were found to have influenced the completeness of HIV and AIDS reporting data confirmed findings from other regions that underreporting is the main limitation of this method.

Inaccessible and low quality counselling and care services, confidentiality concerns and the fear of stigmatisation in the closely knit island communities, specific characteristics of the reporting systems including inappropriate AIDS case definitions and long report forms, a lack of private sector participation in surveillance and the failure to motivate health workers to provide quality data e.g. through training and feedback, and logistic constraints all contributed to a large proportion of HIV/AIDS cases going unreported.

Underreporting has the potential to seriously threaten the representativeness of case reporting data, to restrict comparative analyses between countries and to reduce the usefulness of HIV/AIDS reporting as a surveillance tool in general. The seemingly high degree of underreporting of a homo- and bisexual exposure risk in the Caribbean was the clearest illustration of this inherent weakness of case reporting. Up to 40% of AIDS cases were attributed to “unknown” risks, nearly all of them in men. The frequently quoted notion that the Caribbean AIDS epidemic has turned from an initially homosexual transmission pattern to a predominantly heterosexual one may therefore be largely incorrect. It is important to overcome this reporting bias in order to better understand the interdependence of the two patterns and to develop appropriate interventions.

► **Underreporting often severely hampers the usefulness of case reporting as a routine surveillance tool.**

The Caribbean experience with case reporting also sheds light on the issue of nominal reporting. Case reporting by name may facilitate the follow-up of affected individuals for counselling and care by the treating doctor or nurse, but confidentiality often becomes a major concern for both health care providers and patients. The fear that confidentiality might be breached is probably among the most important reasons why HIV-infected persons and those at risk avoid public services or do not attend services at all in the Caribbean. Nominal reporting therefore contributes to underreporting.

For surveillance purposes, coded information (rather than reporting by name) which allows dou-

ble counting to be avoided would be sufficient. It has been argued that nominal registries should only be kept by institutions that make use of such sensitive information, for example the treating doctor. A modification of national surveillance regulations which would allow for coded reporting would therefore probably constitute the single most important measure to improve HIV surveillance in the Caribbean.

► **AIDS and HIV case reporting by name has more disadvantages than advantages and should be replaced by coded reporting.**

4. Sentinel surveillance in rural Uganda and Tanzania

GTZ became actively involved in technical assistance to the AIDS prevention and control efforts of national AIDS programmes in Tanzania in 1988 and in Uganda in 1991. GTZ support to Mbeya Region in Tanzania and Kabarole and Bundibudgyo Districts in Uganda has since been covering all relevant aspects of HIV prevention and care programmes: STD services, care for people with AIDS, voluntary HIV testing and counselling, the promotion of safer sexual behaviour, condom distribution/social marketing and support to self-help projects. In urgent need of information about the distribution of HIV and the vulnerability to HIV of different groups of the population, the GTZ projects emphasised the establishment of HIV testing facilities and HIV/AIDS surveillance from the onset.

4.1 Establishing sentinel surveillance

Before the establishing of sentinel surveillance, limited AIDS case reporting data and various cross-sectional prevalence studies had already revealed that HIV infection was present in both urban and rural areas. The first AIDS cases had been diagnosed in Uganda and Tanzania in 1983, and soon after in all other East African countries. In 1985/86, HIV preva-

lence surveys among pregnant women, blood donors and sex workers in several countries revealed that the HIV epidemic had already spread substantially among vulnerable groups and the general population^{38,39,40,41,42,43,44}. Little was known, however, about patterns and trends.

In 1986, challenged by the rapid spread of the epidemic in this region, WHO took the lead in developing appropriate surveillance tools. Guidelines for anonymous unlinked sentinel HIV sero-surveillance were issued⁴⁵, and in the same year East African governments supported by WHO established National AIDS Control Programmes (NACPs) and adopted sentinel sero-surveillance as the main surveillance tool to supplement AIDS case reporting. It then still took several years before the first sentinel surveillance programmes were effectively implemented in rural areas.

In the Tanzanian as well as in the Ugandan project ambitious schemes involving five sentinel populations (ANC attendees, blood donors, general outpatients, TB patients and STD patients) in three different geographical strata (urban, semi-urban and rural) were designed, and sentinel sites selected accordingly.

Major obstacles that had to be overcome included the low priority initially attributed to AIDS/HIV surveillance by the responsible local authorities, a lack of adequately trained personnel, weak supervision and, at times, low staff morale. Sentinel surveillance only became feasible and successful when all these issues were adequately addressed.

Training. A two-step training programme for on-site health workers was designed consisting of an initial two-day workshop for staff responsible for surveillance at the sentinel sites followed by training “on the job” during surveys at the respective peripheral health facilities. During the introductory workshop, staff acquired understanding of conceptual issues, such as the rationale of unlinked anonymous testing, as well as practical skills, such as the selection of survey participants, sample collection and storage, record keeping and unlinking of personal identifiers. Training on surveillance was usually combined with training on other relevant issues in relation to HIV/STD prevention and care. On-the-job training was conducted repeatedly during the starting period of each new survey round. A senior laboratory technician of the reference laboratory visited each sentinel site for two to four days to initiate the survey and to train staff on site. Experience over several years showed that neither attendance at the workshop nor “on-the-job training” alone, but only a combination of the two, was effective in ensuring good performance of health workers.

Supervision. Despite intensive training, problems occurred concerning the strict adherence to survey protocols. Sentinel sites that were not supervised regularly (e.g. monthly) during survey periods frequently delivered inconsistent data. For example in 1989, an unexpectedly high HIV prevalence was observed at a rural site in Mbeya Region, when ANC clinic staff had intentionally selected predominantly young pregnant women coming from certain villages, whom they perceived to be at an increased risk of HIV infection. There have been many other occasions when timely supervision provided the only opportunity to rectify surveillance procedures.

Restriction to fewer sites and populations. At sites which could not be supervised properly, sen-

tinel surveillance could hardly be maintained. Judging that the quality of surveillance data was more important than the quantity, the project management decided after the first rounds to reduce either survey sites or populations to a more manageable size. Remote rural sites, which were more difficult to supervise and which because of low clinic attendance had faced difficulties in enrolling sufficient numbers of patients, were excluded from the scheme. In Tanzania the frequency of surveys was reduced from two to one per year, while in Uganda the project manager decided to reduce the number of sentinel groups and to focus on ANC attendees, only for similar reasons of cost and feasibility.

Expansion to neighbouring districts. In 1992, at the request of the National AIDS Programme, the project in Mbeya Region extended its support for HIV sentinel surveillance to two neighbouring regions. Syphilis screening and treatment of pregnant women were introduced at the same time as sentinel surveillance. Unfortunately the ANC clinics were not able to sustain the screening activities, because of shortages of reagents and drugs. The lack of regular syphilis testing negatively affected HIV surveillance, as health workers had no chance to get used to standard procedures.

Other methods of surveillance. Projects in both countries combined sentinel surveillance with other surveillance methods, such as AIDS reporting and STD surveillance. In Kabarole, behavioural data and mathematical modelling methods were used to explain data obtained from sentinel surveillance. Sentinel surveillance data that were difficult to interpret were also compared with data from a survey among the general population. Since 1992 the project has also collected information on socio-demographic characteristics (education and marital status) from ANC attendees and on sexual behaviour from pupils of 15 secondary schools⁴⁶.

The cost of sentinel surveillance. After an initial substantial investment in the establishment of the surveillance systems, the cost of routine sentinel surveillance in Tanzania and Uganda did not exceed 2% of the total annual budget of the regional and district AIDS programmes. Fig. 5 shows for Uganda

that the cost of external consultants accounted for a large proportion of total costs.

4.2 Selected results

Stabilising HIV prevalence rates in Mbeya

In Mbeya, Tanzania, the first sentinel surveillance round conducted in late 1988/early 1989 showed that the HIV epidemic had already spread to both urban and rural areas. Among pregnant women, prevalence rates were found to be as high as 10% in urban areas and below 5% in rural areas (fig. 6). Rates among other sentinel populations varied between 10% in blood donors and 15% to 30% among STD patients in various locations.

From 1989 to 1997, HIV continued to spread among all sentinel populations and in all locations, with the epidemic curves showing their steepest slopes before 1991. As expected, patients with sexually transmitted diseases were infected at higher rates than ANC attendees and blood donors. Prevalence among all three sentinel groups was found to be extremely high at the border to Malawi. Very high numbers of infections were found at several market places. In general, urban populations were more severely affected than rural ones, and women were infected at higher rates and at a younger age than men.

By 1992, prevalence among ANC attendees started stabilising in most areas. But despite stabilising overall trends, substantial HIV transmission was still occurring among young women. HIV prevalence among ANC attendees aged 15-19 years ranged between 20% in urban and 10% in rural areas (fig. 7).

Simultaneously with increasing HIV rates, a downward trend of syphilis rates was observed in ANC attendees from 1991 onwards (fig. 8).

Decline of HIV prevalence among teenagers in Kabarole

In Kabarole district in Uganda, sero-surveillance showed a different course of the HIV epidemic. In 1991, when sentinel surveillance was introduced, the epidemic curve had already passed its peak. HIV prevalence had started decreasing in ANC attendees, from 23% in 1991 to 17% in 1995, which was mainly due to falling prevalence among the youngest age group (15-19 years) (fig. 9).

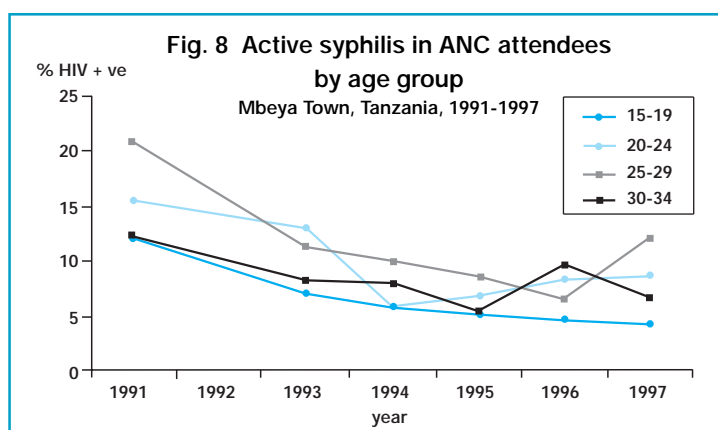
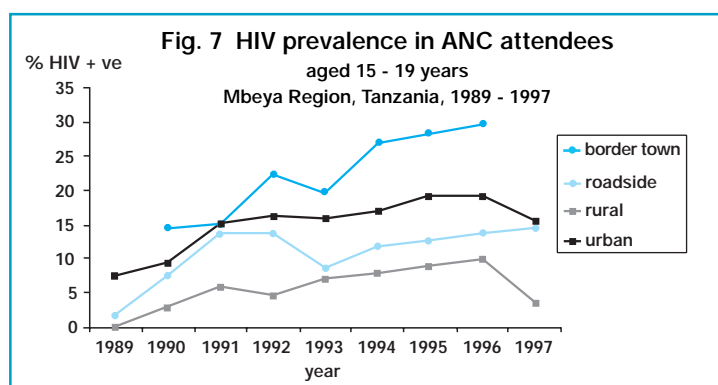
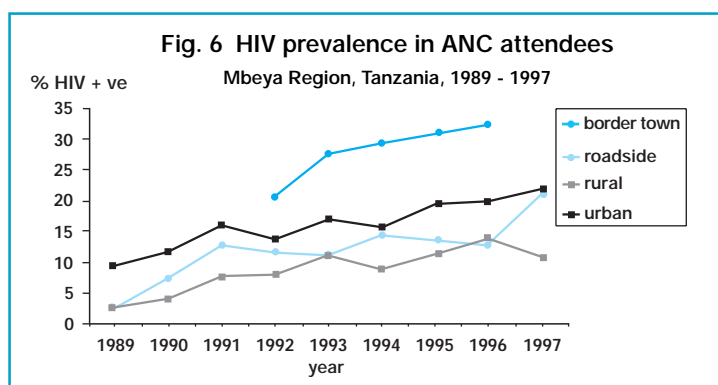
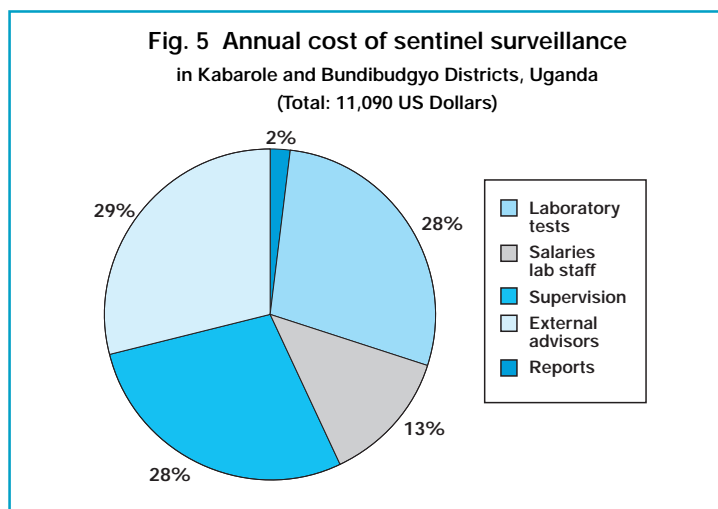


Fig. 9 HIV prevalence in ANC attendees by age group
Fort Portal, Uganda, 1991-1997

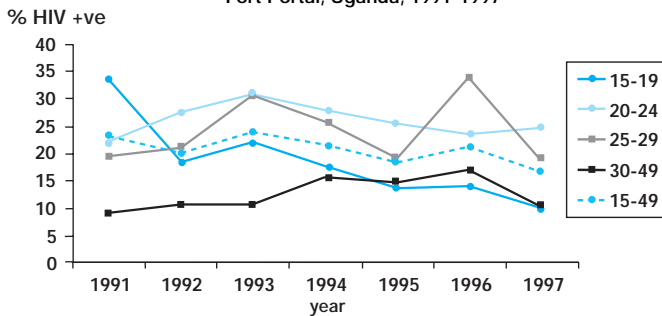
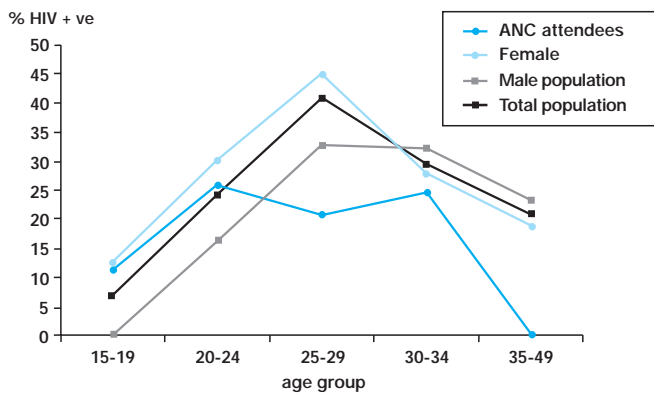


Fig. 10 Comparison between sentinel and population-based data. Kabarole district, Uganda, 1995



Representativeness of pregnant women for the general population in Kabarole

In Uganda, as elsewhere, infection rates among women attending antenatal care were believed to closely reflect those in the general population. To investigate whether this assumption holds, the Kabarole project decided to measure HIV prevalence during a representative household survey. Overall, the comparison found only slightly lower prevalence rates in pregnant women than in the general (pregnant and non-pregnant) female population. Only 25-29-year-old pregnant women were much less likely to be infected (fig. 10).

Various explanations have been offered for differences in HIV prevalence between ANC attendees and general population samples. ANC attendees may be at higher risk of HIV infection than a representative sample of pregnant and non-pregnant women because they only include women who are sexually active. Women who started having sex at a young age are over-represented. On the other hand, ANC attendees may be at a lower risk, because

women who are infertile due to chronic infections which may also be associated with HIV-related morbidity are excluded. The latter was considered to explain partially the lower HIV prevalence of pregnant women aged 25-29 in Kabarole.

Results from Kabarole, Uganda, have been compared with published data from Mwanza, Tanzania, and Zambia. HIV prevalence among ANC attendees underestimated the rate in the general population samples in Kabarole as well as in Tanzania⁴⁷ and in Zambia⁴⁸. Interestingly in Zambia the youngest pregnant women (15-19 years) were infected at higher rates than women of the same age group in the general population.

Representativeness of blood donors for the general population in Mbeya

HIV trends among blood donors have also sometimes been interpreted as reflecting trends in the general (male) population. Nevertheless, persons who voluntarily donate blood and undergo the HIV test associated with the donation are often a very biased sample of the general population.

Between 1988 and 1995, HIV prevalence among blood donors in Mbeya increased from 10 to 16%, but whether this increase reflected a real trend in the general population remained unclear. Most blood donors were recruited from amongst the family of the patient requiring transfusion. The majority was male. With the increasing awareness of AIDS among the population, the motivations of people to donate blood seemed to have been changing. On the one hand, potential donors who were at risk and did not want to undergo HIV testing refused to donate blood. On the other hand, individuals who perceived themselves at HIV risk used blood donation as an opportunity for HIV testing. These mechanisms must have either resulted in an under- or over-representation of HIV-infected individuals among blood donors over time.

Association of educational status and HIV infection

The HIV decline in Uganda has been evaluated further. An important finding was that between 1991 and 1997 the relative risk of HIV infection among ANC attendees with primary and, in particular, secondary education decreased while the risk among those without schooling increased (fig. 11).

Results from mathematical modelling

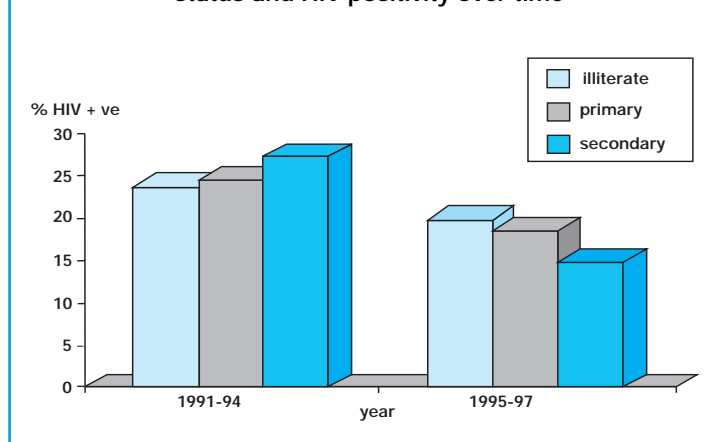
Mathematical simulations confirmed that the trends observed in Uganda deviated from the predicted natural course of the HIV epidemic and were consistent with a significant change in sexual behaviour. For instance, an increase in condom use from 0% to 75% among groups with high sexual activity, or significant reductions in the number of partners, would have resulted in the observed reductions in HIV sero-prevalence.

4.3 Interpretation of HIV sentinel surveillance data showing stabilising or decreasing trends

The trends observed in Uganda and Tanzania fit into the picture of the course of the HIV epidemic in East Africa, which is formed of many confluent sub-epidemics with varying patterns of HIV spread. Increasing, stable and decreasing trends are all observed simultaneously. In Mbeya, sentinel surveillance indicated stabilising HIV prevalence (and decreasing syphilis prevalence) among ANC attendees while, in Uganda, HIV prevalence in ANC attendees was found to be decreasing. Despite the use of complementary surveillance methods, however, the interpretation of data showing such trends was found to be particularly difficult. Two main questions were raised by the findings: whether the reported declines in prevalence also reflected declines in new infections (incidence), and whether the observed trends were due to changes in sexual behaviours, and hence a result of HIV prevention, or due to other factors.

During the early phases of the HIV epidemic, prevalence trends were almost uniformly rising and could be assumed to largely reflect the speed with which new HIV infections occurred. Almost everybody was still susceptible and new HIV infections occurred in all age groups, according to age- and sex-specific patterns of sexual behaviour and associated HIV risk. With the passage of time, however, new infections in older people could be expected to decline, as the greatest risk of HIV infection had already been experienced earlier and thus many are already infected. In mature epidemics, such as in Uganda and Tanzania in the late 1990s, therefore, new HIV infections tend to occur predominantly among young people. Overall HIV prevalence in the

Fig. 11 Changes in the association between educational status and HIV positivity over time



population may level off or fall as well, as many HIV-infected individuals eventually die.⁵¹

In Mbeya, in the light of continuing substantial HIV transmission among adolescents, little could be said with confidence about the programme's impact on the HIV epidemic. Two explanations for the observed decline in syphilis rates were considered: changes in sexual behaviour and/or an increased coverage of effective syphilis treatment. As no simultaneous decline in HIV prevalence among female adolescents had occurred, major changes in sexual behaviours in the 15-19-year age group were considered unlikely. The decline in syphilis rates was more likely due to the gradual introduction of syphilis screening and the treatment of pregnant women and their partners.

In Kabarole District, Uganda, as in many other locations in Uganda^{50,51}, the main feature of HIV sero-prevalence trends in ANC attendees in recent years has been a decline in HIV prevalence in teenage pregnant women, with relatively stable rates of HIV infection in other age groups. Evidence from behavioural studies as well as epidemiological modelling suggests that this decline might indeed have been due to changes in adolescents' sexual norms and behaviours.

School AIDS education, condom social marketing and other prevention programmes supported by the Ugandan national AIDS programme and GTZ may have played an important role in lowering the risk of HIV infection. Behavioural monitoring in secondary school students suggested significant changes in sexual behaviour, including increased condom use.

Although behavioural change was by far the most plausible reason for the observed HIV trends, available data did not, however, allow the complete exclusion of alternative explanations, for example the decline being a mere reflection of biological factors (the natural course of the HIV epidemic).

4.4 The application of sentinel surveillance findings for programme planning and evaluation

Since its introduction in Mbeya and Kabarole in the late 1980s and early 1990s, sentinel HIV surveillance has produced a wealth of high quality data, which have served to initiate, strengthen, evaluate and redirect local prevention and care programmes. The data generated locally have also been used for advocacy and planning purposes at the national level and internationally.

The following are just a few examples of how surveillance findings have contributed to programme planning in Mbeya and Kabarole:

- ◆ In Mbeya, the rapid increase in HIV prevalence in young pregnant women during the early 1990s demonstrated the importance of providing prevention services for youth. Activities undertaken included teachers' training, support to youth clubs and theatre groups.
- ◆ The extremely high HIV prevalence found in the border town Kyela led to the further investigation of local risk determinants through a KABP study among barmaids, followed by the implementation of a 'barmaid' peer education project.
- ◆ The high number of reported AIDS cases at several market places along the Trans African Highway was used to mobilise resources for a "High Transmission Area Intervention Project" targeted specifically at truck drivers and sex workers.
- ◆ High levels of HIV infections among blood donors led to attempts to introduce risk assessments, before donation, to defer donors at higher risk of infection. Pre- and post test counselling were introduced. Risk assessments were largely unsuccessful, however, mainly due to a reluctance of laboratory staff to ask sensitive questions about sexual behaviours. High HIV prevalence in STD patients indicated that improved STD treatment services may be a useful contact point to people at high risk.

- ◆ The initially already high and rapidly increasing prevalence found in rural areas suggested that prevention interventions should not be restricted to towns and truck stops on the highways. HIV/STD prevention messages were therefore disseminated through women's groups and agricultural extension projects as well as drama and film shows to rural areas where the vast majority of the population lives.
- ◆ The falling HIV prevalence rates among young women in Kabarole motivated project staff to continue with and reactivate their prevention work among adolescents in and out of school.
- ◆ The project intensified its support for activities of anti-HIV youth clubs and peer education projects among pupils and in youth organisations.
- ◆ The distribution of condoms via outlets that were easily accessible for youth became a priority of the condom social marketing project.

4.5 Key lessons learnt from sentinel sero-surveillance programmes in East Africa

The experience of many national AIDS programmes in developing countries is that establishing and sustaining a functioning sentinel surveillance programme is difficult. Many programmes have only managed to conduct initial rounds of surveys, or failed to repeat surveys at regular intervals. As a result, information on HIV prevalence remained patchy and inferences on HIV trends over a longer period could not be made with confidence.

The Mbeya and Kabarole examples show that the establishment of sentinel surveillance is feasible and that programmes can be sustained over many years, given a sufficient degree of commitment by local decision makers, adequate training and supervision of field staff, and minimum support in terms of supplies and equipment. In Mbeya in Tanzania, sentinel surveillance has provided decision makers with reliable HIV data at regular intervals for almost a decade, and in Kabarole in Uganda for about half a dozen years. At the beginning, the main challenge was to introduce a concept that was entirely new to health personnel and policy makers. Training and advocacy were essential. Later, regular in-service training and supervision and continuity in financial support paid off.

Regular sentinel surveillance was achieved at relatively low cost. At about US\$ 11,000, the annual budget did not exceed 2% of the overall budget of the district for HIV/STD prevention and care. If the costs for external consultants could be avoided by building local capacity in data management, analysis and presentation, costs could be reduced further by about one third.

➤ **HIV sentinel surveillance is feasible and sustainable in rural Africa.**

Both practical experience and epidemiological reasoning showed that repeated sero-surveys among ANC attendees were the most successful and cost-effective surveillance strategies in high prevalence areas.

ANC attendees were not only the most consistently accessible group of the population, but also proved to be most representative for the general (female) population. Stratified analysis of surveillance data provided ample opportunity to detect age and geographic differentials, and led to further investigations through behavioural inquiries and modelling.

➤ **Monitoring levels of HIV infection among ANC attendees proved to be the single most useful surveillance strategy.**

Nevertheless, neither in Tanzania nor in Uganda were sero-surveillance data sufficient on their own to prove programme effectiveness in terms of behavioural change. It was only when they were combined with behavioural data from among youth and mathematical modelling that causal effects became much more plausible. In Tanzania, behavioural data were largely lacking, and syphilis surveillance produced contradictory results.

When sentinel surveillance programmes were initially set up, many AIDS programmes expected that HIV prevalence curves would directly reflect the success or failure of their interventions and could thus be used for programme impact evaluation. Recent experience and epidemiological knowledge suggest that the interpretation of stabilising and declining prevalence is more complex. The above examples clearly demonstrated the value of complementary socio-demographic and behav-

oural information for the interpretation of surveillance findings in high prevalence areas such as East Africa.

➤ **Sentinel sero-surveillance data need to be combined with behavioural information where and whenever possible.**

5 Comprehensive HIV surveillance in Thailand

The Thai HIV/AIDS epidemic is one of the most extensively and completely documented infectious disease epidemics in the world. From the time of the first HIV outbreaks among men who had sex with men in the late 1980s, the Thai Ministry of Public Health's national surveillance system has been capturing the evolution of the HIV epidemic.

Openness with the national and international public about the state and the magnitude of the HIV problem has been the key to the success of the Thai AIDS programme. Both the government and the private sector have shown a remarkable commitment and flexibility in responding to the diversity of risk situations in this fast developing society. Surveillance has significantly contributed to this success. Through a wide range of methods, information was gathered which was crucial to create awareness of the trends and patterns of the HIV spread and of risk behaviours, and which guided planning for prevention and care. This case study summarises the main lessons learnt from the Thai experience with a comprehensive surveillance system.

GTZ support for Thailand's efforts to combat the HIV epidemic started in 1989. GTZ has had two collaborating partners: the Epidemiological Division of the Ministry of Public Health (MOPH) with its provincial health teams, and the Population and Community Development Association (PDA), a national NGO. The MOPH part of the project concentrated on epidemiological and behavioural research in several provinces in Northern and Southern Thailand. The project has also been supporting peer education among various population groups as well as training and care activities.

5.1 Development of the Thai national HIV surveillance system

The HIV/AIDS epidemic began in Thailand in the mid-1980s with the first recorded HIV infections among men having sex with men (MSM). During 1985 to 1987, several small-scale sero-surveys were conducted in populations with assumed high levels of risk behaviours, such as male and female sex

workers and injecting drug users, but few infections were detected. At that time, many still hoped that HIV/AIDS would not become a major problem for Thailand. Except for AIDS and HIV reporting, no consistent monitoring system existed.

Sentinel surveillance

In 1988, testing in public drug treatment clinics revealed outbreaks of HIV infections among injecting drug users in Bangkok. Concerned that HIV might spread from IDUs via sexual transmission to other high-risk populations and from there to the general population, the Ministry of Public Health initiated sentinel surveillance among male and female sex workers and STD patients in 14 out of 73 provinces. ANC attendees and blood donors were also included in the surveillance system at that early stage, because their surveillance would provide an early warning system for the spread of HIV into the general population.

HIV prevalence among female sex workers remained low until 1989, when almost half of the brothel-based sex workers in Chiangmai were found to be infected. Again, the Ministry of Public Health reacted quickly by expanding sentinel surveillance to cover several high and low-risk populations (pregnant women, blood donors, sex workers, male STD patients, injecting drug users) to 31 out of 73 provinces in the second round of surveys and to all provinces, starting from the third round. Data are collected on HIV status, age, sex and residence. Sex workers are asked about condom use. Surveys were carried out regularly every 6 months until 1995, when stabilising HIV trends were found among standard sentinel groups and fast changes in infection levels were no longer expected. To contain costs, the frequency of sentinel surveys was then reduced to one per year.

Surveys among military recruits

In addition to HIV sentinel surveillance, non-anonymous samples of about 60,000 21-year-old military recruits from all over the country are tested for HIV every year. In order to gain an insight into the geo-

graphical patterns of HIV spread, data are aggregated according to the most recent place of residence.

Cohort studies

Furthermore, several cohorts of military recruits, female sex workers, men having sex with men, STD clinic attendees and blood donors have been followed to determine the rate of new HIV infections and potential risk factors associated with HIV infections.

National behavioural survey

By 1990, one third of the provinces reported HIV infection among ANC attendees, and it became obvious that a) the geographical reach of the epidemic had become extensive and b) HIV was now predominantly transmitted heterosexually. The increase in heterosexual transmission of HIV led the Ministry of Public Health to carry out a nationwide sexual behaviour survey in 1990⁵², which demonstrated that a substantial proportion of the male and female population were at high risk of infection. This first national behavioural survey, the "Survey of Partner Relations and Risk of HIV Infection in Thailand", was conducted using a modified version of the WHO Partner Relations core questionnaire. Data on key sexual and drug injecting behaviours, such as the onset of sexual activity, condom use, number and type of sexual partners including commercial sex and homosexual activity, STD experience, needle sharing and disinfection practices, were collected from a sample of more than 2,800 men and women.

During the early 1990s, awareness of the HIV/AIDS threat rapidly increased, as prevention activities dramatically expanded. Surveillance now acquired yet another dimension: it was supposed to monitor measurable changes in drug use and sexual behaviours as a result of HIV prevention efforts. In 1993, the national behavioural survey was repeated, and a behavioural surveillance system was established in Bangkok.

Regional and local surveillance efforts

By the mid-1990s, with an increasing regional diversity of patterns of HIV spread, provincial HIV programmes felt the need for and made efforts to collect locally relevant information. As each locality

was found to have its own population at risk, for instance fishermen on the seacoast, migrant workers from rural mountainous areas and factory workers in industrial areas, sentinel sero-surveillance protocols were adapted to include these groups rather than relying on standard sentinel groups only. To date only a few provinces have been able to establish their own sentinel surveillance programmes however, as skills in survey design, implementation and analysis are limited.

Sentinel behavioural surveillance

In 1995, behavioural surveillance was extended to 19 further provinces. Following the methodology of classical HIV sentinel sero-surveillance, anonymous behaviour surveys have since been conducted annually, to track sexual behaviour among 15-29-year-old military conscripts, male and female factory workers, male and female secondary school students and ANC attendees. In Bangkok, the system has involved short face-to-face interviews to follow a limited number of behavioural key indicators including commercial sex, sex with non-regular sex partners and condom use with regular and non-regular sex partners. Around 1,400 males, 3,100 females and 800 female sex workers are interviewed during each round. In the provinces, information has been collected among the same groups, using a single-sheet anonymous self-administered questionnaire.

STD case reporting

In addition to HIV sero-surveillance and behavioural surveillance, STD case reporting data have been used to monitor HIV relevant trends in sexual behaviours. Government clinics and hospitals report STD cases via the provincial surveillance unit to the Venereal Disease Division of the MOPH, where the reports are compiled. Private care providers do not contribute to the reporting.

5.2 Selected findings

Trends in HIV sero-prevalence

Different levels and trends of HIV prevalence have been observed in the various groups surveyed within the framework of the sentinel sero-surveillance system (fig. 12), reflecting subsequent waves of the epidemic. Between 1989 and 1990, HIV prevalence among IDUs in Bangkok rose from 1%

to around 40%. One year later a similar rapid rise in infections among IDUs was seen in several provinces throughout the country. After 1989, HIV prevalence in IDUs did not further increase, but remained stable at between 30% and 40%.

Since the beginning of systematic surveillance in 1989, HIV prevalence among sex workers has been rising steadily all over the country. HIV infection levels among brothel-based sex workers (direct sex workers) and those based in non-brothel establishments, like bars and night-clubs (indirect sex workers), have been remarkably different. In 1995, for instance, the nation-wide average HIV prevalence among direct sex workers exceeded 30% and seemed to be still rising, while that in indirect sex workers reached 12% and appeared stable. The increase in infections among men attending STD clinics has resembled the trends in indirect sex workers and has appeared to be levelling off at 10%.

Data from pregnant women and blood donors had already been collected at a time when the HIV

epidemic appeared to be confined to highly vulnerable populations, such as drug users. Although the inclusion of low-risk populations in the surveillance scheme at an early stage of the epidemic involved significant additional costs, this investment soon paid off. Prevalence among pregnant women rose from nearly 0% in 1989 to 2.4% in 1995, and remained relatively stable at 2% in 1996. HIV prevalence in blood donors has remained relatively low and even dropped in recent years. This decline may reflect increasing self-deferral of those perceiving themselves at HIV risk rather than a decline in the general population.

There were considerable geographical differences in HIV prevalence levels among 21-year-old military conscripts, with the North experiencing a more severe epidemic than other regions. Since 1993, an impressive drop in HIV prevalence has occurred in this group. In the highly affected Northern provinces HIV prevalence dropped from above 7% in 1993 to below 4% in 1995 (fig. 13)⁵³. Conscripts represent a narrow age range, and trends may therefore not reflect those in the general male population. Army personnel in Thailand might be relatively well protected from infection during their service. One study showed that the risk of HIV infection increased immediately after discharge from the military.

Trends in HIV incidence

Findings from cohort studies provide a diverse picture. Incidence in male gay bar workers in Chiangmai has been relatively high, at an average of 12/100 person years (py) over the period from 1991 to 1994⁵⁴. Incidence in STD clinic attendees appeared to have remained stable in two cohorts in the North of the country at 4.0/100 py and 3.2/100 py. A retrospective analysis of data from 11,000 repeat blood donors shows that incidence had been falling constantly from about 1.7/100 py in 1989/90 to 0.5/100 py in 1994⁵⁵.

Sero-prevalence trends in military recruits also provided some evidence of falling incidence. The drop in observed HIV prevalence among military recruits (which implies that on average 21-year-old men today contract fewer HIV infections than a few years ago) was also confirmed by the cohort studies⁵⁸.

Fig. 12 HIV prevalence in different populations. Thailand 1989 - 1997

Source: Epidemiology Unit of the MoH

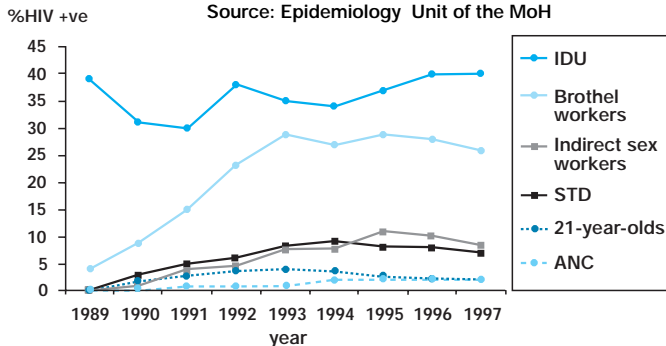
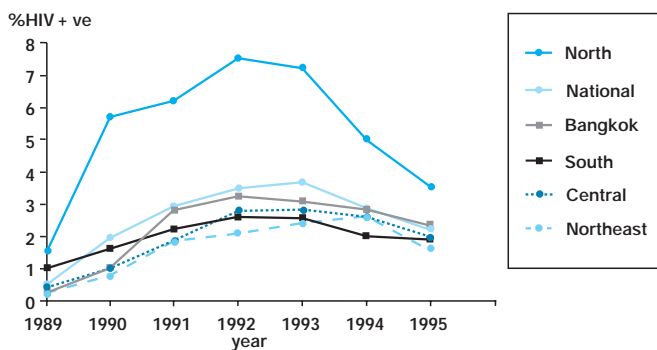


Fig. 13 Mean national and regional HIV infection levels in military conscripts

Source: Jugsudee et al. 1996, Royal Thai Army⁵³



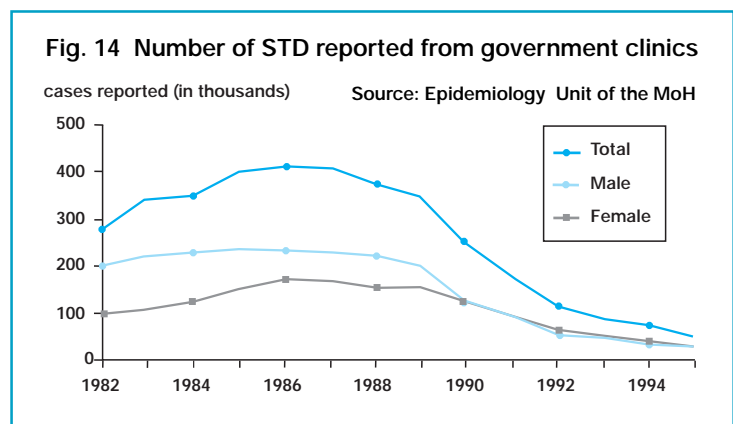
A review of the different trends suggested that in the late 1980s and early 1990s HIV infections had probably grown very rapidly in high-risk populations. Since 1991, the rate of new HIV infections has slowed down. Certain parts of the population, including sex workers, men having sex with men and STD clinic attendees, are still experiencing high rates of new HIV infections, although at lower rates than during the early years of the HIV epidemic.

STD incidence trends

The total number of male STD cases annually reported by public STD clinics to the Venereal Disease (VD) Division is shown in fig. 14. An increase during the early 1980s was followed by a slight decline during the late 1980s and a much more dramatic decline during the first half of the 1990s. Between 1990 and 1995 the reported number of STD cases declined from above 400,000 to below 50,000, although the number of clinics that reported had increased⁵⁹. The early decline between 1986 and 1989 has been attributed to the introduction of effective drugs for gonorrhoea treatment⁵⁷, but the massive drop that occurred between 1989 and 1992 was most likely caused by a combination of changes in sexual behaviour and improved STD services. Ultimately, however, the available data do not allow the possibility to be ruled out that the number of STD cases seen at government facilities may have only declined because STD treatment shifted from public sector services to the private sector.

Behavioural trends

Reported condom use in brothels rose from below 50% in 1989 to over 90% by 1992⁵⁹, but remained lower in indirect sex work sites. The proportion of men that admitted having visited sex workers halved between 1990 and 1993. The reliability of the data on condom use has been questioned, because high social expectations to report 100% condom use might have resulted in over-reporting. A review of methods assessing condom use among sex workers concluded, however, that although some over-reporting had certainly occurred, interviews with clients of sex workers had generated results that were consistent with those obtained from interviews between sex workers and re-



searchers acting as clients. The trends in condom use reported by male clients of sex workers were therefore plausible.⁵⁸

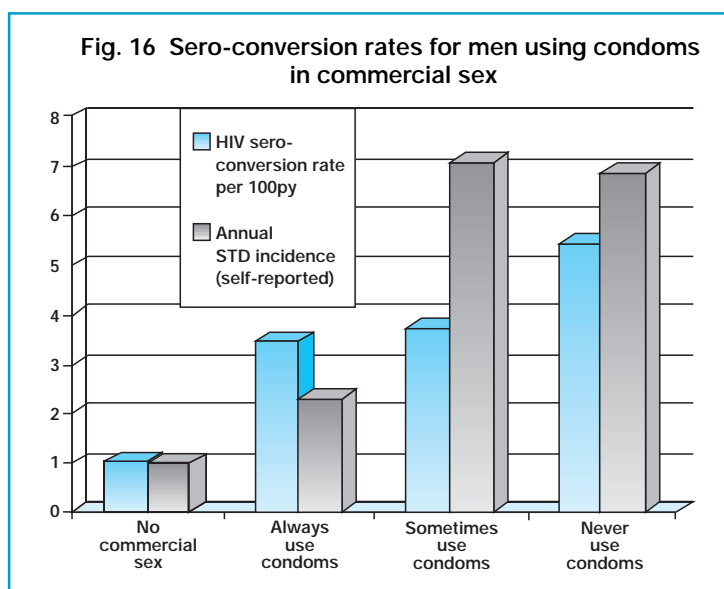
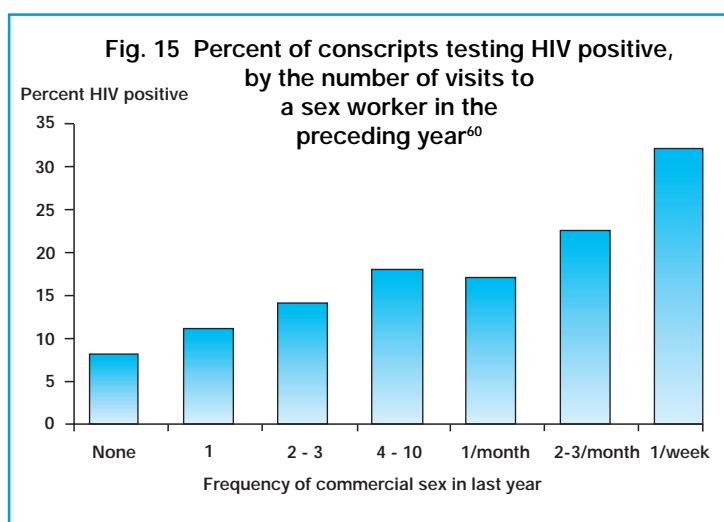
Other behavioural trends are less encouraging. There are indications that casual sex among young people is increasing. Condom use is consistently low in non-commercial sexual relationships with casual partners among young people.

Behavioural surveys among Bangkok's drug users have shown a drop in rates sharing equipment, from 66.5% in 1989 to 24% two years later. Unfortunately, in 1995 the practice of needle sharing had increased again to 43%.

While behavioural surveillance among most sentinel surveillance proved successful, behavioural surveys among ANC attendees turned out to produce unreliable data. The context of antenatal care appears not to be suitable for women to answer sensitive questions about risk behaviour.

Links between epidemiological patterns and behaviour

Thai surveillance data show that HIV infection rates have been falling in some population groups, and that risk behaviours have become less common. There is also evidence to suggest a causal link between the two. Across studies, commercial sex has been found to be a major risk factor for infection⁵⁹. Data from military conscripts, for instance, showed an association between HIV seropositivity rates and the frequency with which they had visited sex workers⁶⁰ (fig. 15). In cohort studies, sero-conversion among a priori HIV-negative military recruits was also strongly related to the number of contacts with sex workers. HIV risk in sex workers themselves depended on the number of clients a day⁶¹.



In cohort studies among clients of sex workers, condom use was found to be protective against infection^{62,63} (fig. 16).

Further links between behavioural and epidemiological findings included:

- ◆ A decline in STD symptoms among indirect sex workers in Bangkok that coincided with the adoption of 100% condom use policies⁶⁴. Levels of unprotected commercial sex among military conscripts in different provinces that were predictive of the relative ranking of HIV prevalence in these regions.
- ◆ The observed decline in STD case reports in 9 randomly selected provinces, which corresponded with a decline in the number of men having visited sex workers in these provinces⁶⁵.

5.3 Use of surveillance data in programme planning and evaluation

From the very beginning of HIV surveillance in Thailand, data were used for strategic planning. During the late 1980s, the main issue was whether low levels of infections justified a major societal effort to fight the epidemic. Later, surveillance data were mainly used to determine priorities for prevention programmes and to evaluate their impact.

The first outbreak among injecting drug users was unfortunately not taken sufficiently seriously. IDUs were perceived as an isolated group that would not spread HIV to the general population. In contrast, when increasing HIV rates were detected among sex workers and this information was brought to the attention of top decision makers, the national response quickly moved from denial and hesitation to action. The importance of commercial sex in Thai society was confirmed by the first national behaviour survey in 1990, which documented that visits to sex workers by Thai men are common, and which revealed the significance of unprotected sexual encounters for the further development of the HIV epidemic. With the early discovery of increasing HIV rates among ANC attendees and blood donors, it became apparent that the whole of Thai society was threatened by the epidemic. The surveillance showing these trends proved extremely useful in motivating decision makers to commit public funds to HIV prevention activities.

After that, surveillance continued to support prevention planning in several ways:

- ◆ Data from several provinces demonstrated that the HIV epidemic did not merely consist of a small outbreak in one province, but that HIV spread to all corners of the country. Consequently, the Thai government and society launched a vigorous prevention campaign. The famous 100%-condom-use campaign in brothels was launched and enforced in partnership with brothel owners and sex workers. STD treatment was substantially expanded⁶⁵. Mass media educated the public on how to prevent HIV infection with the support of Thai advertising and marketing agencies. Peer education programmes in factories and community-based programmes using participatory approaches were launched

by numerous NGOs, and private businesses conducted HIV prevention programmes in their workplaces.

- ◆ Rising HIV rates in military conscripts confirmed the importance of putting HIV on the national agenda. HIV was perceived to threaten the country's security, as a substantial proportion of conscripts had already been infected.
- ◆ In order to get more detailed information on trends in HIV infection among different types of sex workers, the surveillance programme started to distinguish between so-called direct and indirect sex workers. This became especially important, as the 100%-condom-use campaign only reached brothel-based sex workers effectively, and there were concerns about low condom use and sustained HIV transmission outside brothels. Surveillance data soon confirmed the need to specifically target commercial sex outside licensed brothels.
- ◆ Later, data showing a correlation between HIV infection and the number of commercial sex encounters of military conscripts demonstrated the need to specifically target prevention interventions at these groups.
- ◆ Surveillance data also showed that the Northern part of the country was most affected by the epidemic. A centre was established to co-ordinate prevention programmes in this area, with a special budget. Surveillance information thereby helped to direct resources to most affected areas.
- ◆ The full coverage of provinces with sentinel surveillance made it possible that each province had information on local HIV rates, which could be used to create awareness and commitment by local government and community leaders. Locally generated data also proved useful in creating AIDS awareness among the population, especially among men with risky behaviours - a precondition for behavioural change.
- ◆ Surveillance was also useful to show the overall effect of prevention activities in the country. During the 1990s, data had indicated a gradual reduction of HIV risk in some population groups. HIV prevalence declined gradually among military conscripts, and STD notifications to the Ministry of Health dropped substantially, suggesting a partial success in prevention efforts.

- ◆ Behavioural surveys served to evaluate the success of the 100% condom campaign and other related prevention activities. The surveys showed that condom use in commercial sex had become the norm, numbers of clients had been cut in half, new HIV infections in men had dropped and STD fallen almost by 80% nationwide. But behavioural surveys also revealed that unsafe sex remained a problem to some extent in all population groups, especially with non-regular partners other than brothel-based sex workers. Thus, monitoring behaviour has added another warning piece of information to policy makers and people.
- ◆ A further positive outcome of the efforts put into behavioural surveillance is the development of culture and gender-sensitive communication about sexuality and AIDS: The fact that Thai women - like women in many other cultures - are more reluctant to talk freely about their sex lives than men made experiments with different interview methods and sensitive communication necessary.

5.4 Key experiences and lessons learnt

The Thai HIV surveillance system, through its unique combination of epidemiological and behavioural surveillance, has been successful in the early detection of sub-epidemics in different groups and locations, and in providing a comprehensive picture of the HIV epidemic and its determinants. It has helped enormously in guiding the Thai government in the development of a vigorous response to a major public health threat - this is the most important experience to be reported here.

Thailand is the first developing country to have established such a comprehensive HIV/AIDS surveillance system. The following are some of the key lessons learnt:

An important feature of the Thai surveillance system is its dynamic and flexible response to the challenges of an ever-changing epidemic situation. Initially, the Thai sentinel surveillance system was established to cover injecting drug users and sex workers at a few sites, which were thought to be epicentres of the HIV epidemic. As soon as HIV infections rose in female sex workers, the Ministry of Public Health expanded surveillance to groups representing different subgroups of the general popu-

lation with varying levels of HIV risk, such as pregnant women, blood donors and STD clinic attendees. The expansion took place just in time to detect countrywide rapid HIV spread in the general population and to use these findings to bring about a strong response.

There was also flexibility in the choice of methods other than sentinel surveillance. Whenever required to arrive at a better understanding of the epidemiological situation, methods such as (non-anonymous) screening of military conscripts, national behavioural surveys, behavioural sentinel surveillance, cohort studies and STD surveillance were used to supplement sentinel HIV surveillance.

➤ Flexibility in the choice of survey populations and methods is essential.

The Thai experience showed that STD case reporting can effectively complement HIV surveillance. STD case notifications already started declining significantly 3 years before the first signs of a stabilisation or decline in HIV prevalence in military conscripts emerged. Trends in reported STD incidence therefore probably reflected reductions in risk behaviour much earlier and more effectively than HIV prevalence trends.

➤ STD surveillance can contribute to the early detection of changes in sexual behaviour.

Given that Thailand is currently the only developing country with an elaborate behavioural surveillance system, it is noteworthy that behavioural surveillance in this country has proven both feasible and successful. Several rounds of behavioural surveys have already been completed, without any indication that insurmountable operational problems might arise in the future. Sexual and HIV risk behaviour surveys aim to obtain valid information on very sensitive and often tabooed topics in a standardised manner. The Thai experience showed that behavioural surveillance is in principle feasible.

Behavioural surveillance data proved to be successful both in giving early warning about the potential of a further spread of the epidemic and in assessing and explaining declines in infections. An inherent limitation of HIV sentinel sero-surveillance is

that it can only identify populations at risk of HIV infection once the first HIV infections have already occurred and can be detected by serological tests. Behavioural surveillance has the advantage that it can provide warning in advance of impending HIV epidemics among subgroups in the population. In Thailand, it has also been widely and successfully used to validate epidemiological findings suggesting a decline in new infections, and to evaluate the impact of prevention programmes.

➤ Behavioural surveillance has proven feasible and successful, both as a sensitive early warning tool and in guiding prevention interventions.

6. Current HIV/AIDS surveillance systems and the future of HIV/AIDS surveillance in developing countries

6.1 Weaknesses and strengths of surveillance systems based on case reporting and sentinel surveillance

AIDS and HIV case reporting

As the three case studies have shown, HIV surveillance systems in developing countries vary in their choice of approaches and complexity. While most of the Caribbean countries have relied on AIDS and HIV case reporting as the main monitoring tool, in the two other examples case reporting has played only a minor role.

AIDS and HIV case reporting have their own specific strengths and weaknesses. A strength of AIDS case reporting is that it delivers tangible evidence of the presence of the epidemic. For example in both East African countries and Thailand, where case reporting preceded the introduction of sentinel sero-surveillance, increasing numbers of reported AIDS cases drew attention to the presence of an HIV threat. In Tanzania, it contributed to the planning of prevention programmes, for instance by highlighting the rapid spread of HIV along major transport routes, where AIDS cases were accumulating. Depending on the completeness of reporting, AIDS case reporting also provides a basis for estimating the burden of HIV-related disease and the demand for health care.

The main drawback of AIDS case reporting is that AIDS cases represent infections acquired several years in the past. As the Caribbean experience painfully demonstrated, the analysis of AIDS case reporting data can only provide a very limited understanding of current HIV transmission patterns. Hence it is hardly relevant for short- or medium-term impact evaluation. In contrast to AIDS case reporting, reporting of HIV cases can provide an insight into recent HIV transmission patterns. As soon as available HIV reporting data started being analysed in the Caribbean, programmes were enabled to refocus their interventions on those most vulnerable.

Nevertheless, as the Caribbean examples also

showed, a weakness of both AIDS and HIV reporting in many developing countries is (often severe) underreporting. The completeness of reporting was not only affected by the quality of reporting itself and by the diagnostic skills of health personnel, but also by the degree to which infected persons seek care in public health services and the availability of test kits. The usefulness of HIV case reporting is severely compromised where financial constraints do not allow for the testing of all those seeking to know their sero-status. HIV case reporting is probably more meaningful in small island communities with a largely functional health care system, in the earlier stages of the epidemic, than in large resource-poor countries, and in those where HIV prevalence is high.

The various other HIV surveillance methods described differ in their ability to capture rapid changes in transmission patterns and trends (Table 1, page 36).

Sentinel surveillance

Largely because of the inherent limitations of case reporting and the high costs of other potentially suitable methods such as population-based surveys, HIV sentinel surveillance was developed by WHO's Global Programme on AIDS and affiliated research institutions more than a decade ago. Among many other national programmes and projects in developing countries, GTZ supported projects in East Africa, Thailand and other countries, not reviewed in this brochure, as well as national programmes in larger Caribbean islands such as Jamaica, and introduced unlinked anonymous sentinel sero-surveillance as their main monitoring tool. Many surveillance systems, particularly those in resource-poor Africa, have relied almost entirely on sentinel HIV surveillance.

As both the East Africa and Thailand studies showed, sentinel surveillance data can be used to advocate political commitment and the allocation of resources, to prioritise interventions, and to evaluate prevention programmes. Sentinel surveil-

Table 1:
Different surveillance methods relate to different objectives and time perspectives

Method/type of data	Time perspective of surveillance
<ul style="list-style-type: none"> • STD case reporting • Annual condom turnover • Behavioural surveillance 	<ul style="list-style-type: none"> • to monitor short-term trends (year to year) • to assess efficacy of interventions
<ul style="list-style-type: none"> • HIV case reporting* • HIV sentinel surveillance • Behavioural surveillance 	<ul style="list-style-type: none"> • to monitor medium-term trends (- 5 yr.) • to focus interventions and monitor their impact
<ul style="list-style-type: none"> • AIDS case* and death reporting 	<ul style="list-style-type: none"> • to monitor long-term trends (5-15 years) of incidence and transmission patterns • to assess social cost and impact

* AIDS and HIV case reports may include:
 - clinical information, e.g. clinical stage, case definition criteria;
 - sociodemographic information, e.g. education, occupation;
 - behavioural information, e.g. no. of sex partners in last 12 months, lifetime, sex partners, condom use.

lance can provide a relatively early warning mechanism and a basis for prevention planning. In both East Africa and Thailand, sentinel surveillance was highly successful in keeping track of HIV seroprevalence rates in various population groups and locations.

In spite of its relative simplicity and overall appropriateness in resource-poor settings, however, sentinel surveillance was found to be partially unsustainable and produced inconsistent data in rural areas in Uganda and Tanzania, despite long-term support provided to the projects by GTZ. During a workshop on HIV surveillance in Nairobi in 1997, many experts cautioned that poor testing procedures and inadequate quality control compromised the usefulness of data from sentinel surveillance systems in many other African countries.

Among the factors identified to have impeded the establishment and maintenance of rural surveillance systems, two appeared to be most important:

- ◆ the lack of understanding among senior health planners and decision makers of the importance of surveillance as an HIV prevention and care planning tool and thus the low priority given to it, and
- ◆ the lack of skilled epidemiology personnel at both central and lower service levels.

In GTZ's experience, the need for data was, in the eyes of local decision makers, too often associated with requests by external organisations. It was

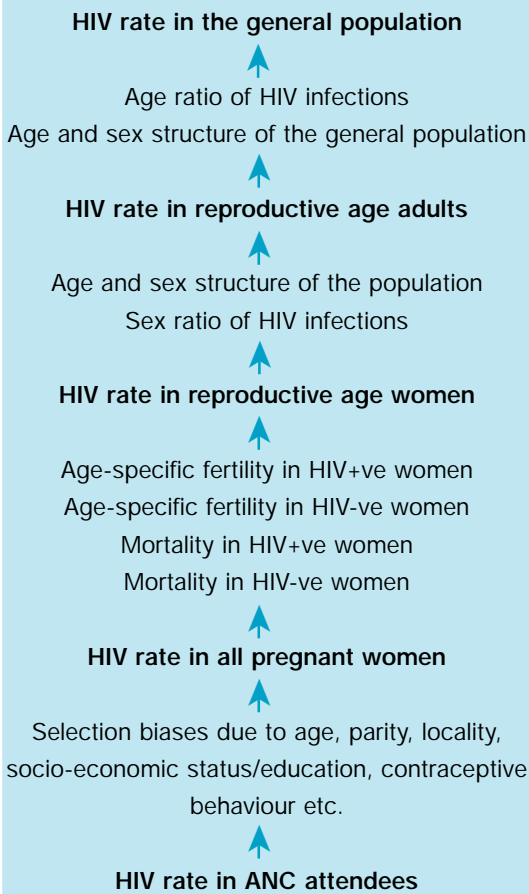
also common experience in GTZ-assisted projects that as long as specialised foreign personnel was in place, who actively pursued the collection of data, the surveillance system was maintained. As soon as this personnel left, however, systems tended not to be maintained any longer, despite the fact that national counterparts had been trained. This experience was made in countries as diverse as Burkina Faso, Côte d'Ivoire, Jamaica, Malawi and Togo.

Another constraint identified was gross understaffing of epidemiological divisions of Ministries of Health. For instance, in Namibia in 1996, there was a severe shortage of epidemiology personnel in the Ministry of Health, which resulted in external consultants handling the first three rounds of the national HIV sero-surveillance virtually on their own. As the East African case study showed, external consultants account for a large proportion of the costs of sentinel surveillance.

Other limitations of HIV sentinel surveillance that became apparent both in the Eastern African projects and in Thailand were not related to poor implementation, but were inherent in its methodology. These include:

- ◆ The representativeness of sentinel populations such as pregnant women for the general population varies and is not known unless data from general population studies are available for comparison. The potential biases that might interfere with the representativeness of ANC attendees are shown in Box 5.

**Box 5:
Factors influencing the representative-
ness of ANC attendees for the general
population**



- ◆ In mature epidemics like the ones in Uganda and Tanzania, prevalence data derived from sentinel surveillance are insufficient to explain trends in new infections (incidence). Therefore, after years of efforts to contain the spread of HIV, AIDS prevention programmes in Uganda and Tanzania were at a loss to know whether new HIV infections were indeed stabilising or declining.
- ◆ Existing sentinel surveillance data proved insufficient to explain why HIV levels were different in different areas or groups within the same countries and between countries, or to explain why trends had been stabilising or declining, in other words whether differentials and trends were due to behavioural or other (biological) factors.

Despite its inherent methodological limitations and the described problems with its implementa-

tion, sentinel surveillance has proved to be the most robust and effective HIV surveillance method, and it is safe to say that most of what we know about the patterns and trends of the HIV epidemic in Africa and in many other countries in Asia and Latin America has resulted from sentinel surveillance. To date sentinel surveillance is still the only affordable surveillance method that allows the calculation of HIV prevalence rates and their comparison over time and space.

6.2 Elements of a “Second Generation of HIV Surveillance”

The described limitations and failures of case reporting and sentinel surveillance have led epidemiologists and programme managers to believe that “first generation” HIV/AIDS surveillance systems based on case reporting and sentinel surveillance should be further developed and supplemented to overcome their shortcomings. UNAIDS is taking the lead in the development of a “second generation of HIV surveillance”. Recent experience with behavioural surveillance in Thailand has played a major role in considerations to develop a “new HIV surveillance”.

HIV surveillance systems have been evolving in two directions: optimisation of existing methods and diversification. For instance, in the Caribbean, CAREC has helped national surveillance programmes to analyse HIV reporting data that had not been exploited and to introduce more appropriate report forms. Proposals also exist to introduce coded reporting. All these measures might improve the quality of surveillance, without modifying its basic approach. In East Africa and Thailand, changes in the number of sentinel sites and sentinel populations, and continuing efforts to improve data collection through training and supervision can be interpreted as optimisations of the existing sentinel surveillance system.

The other direction, diversification, refers to the introduction of new methods into routine surveillance systems. For instance, despite substantial resistance from among policy makers, Jamaica – which had relied on case reporting – introduced sentinel surveillance in 1992. The East African programmes have experimented with combining existing with new approaches, for instance when using population-based sero-surveys and mathematical

modelling, to validate sentinel surveillance findings. Few of these methods seem suitable, however, to be introduced as a routine surveillance tool. The one approach that may have the potential to evolve into a standard instrument is behavioural surveillance. The Thai case study showed that the establishing of such surveillance is indeed feasible.

In the following sections the various elements of “Second Generation HIV Surveillance” are discussed in more detail.

6.2.1 Improve sentinel surveillance and case reporting

While advocacy for political support and adequate funding at a national level are crucial, there are many opportunities in the periphery to improve the performance of existing surveillance programmes. The following recommendations are based on the lessons learnt in GTZ projects over the last ten years:

- ◆ As shown, for instance, in the Tanzania and Uganda studies, it may be advantageous to concentrate resources and efforts on a few selected populations and on sites where the required minimum of managerial and technical capacity exists to produce reliable data. Data quality rather than quantity should be the main consideration when designing a study.
- ◆ The basic capacity to conduct sentinel surveillance can be further strengthened and sustained through systematic quality control of data collection procedures and laboratory testing. For this purpose the capacity of managers and reference laboratories at a central level to perform regular supervision and quality control may require strengthening.
- ◆ On site, the use of dried blood samples on filter paper may be introduced to overcome storage problems.
- ◆ Data management (data input, analysis and presentation) at the national and local level depends in many countries on a few specialists. Simple recording systems that do not use complex report forms and do not require multiple data transfers reduce the likelihood of errors and incomplete reporting.
- ◆ The development of simple packages for local statistics and data presentation and increased

support for the development of skills in data management may be useful.

The collection of AIDS/HIV reporting data should continue to supplement sentinel surveillance. Measures to improve the completeness of HIV and AIDS reporting therefore deserve their own efforts.

- ◆ AIDS and HIV case reporting, such as in the Caribbean, would benefit from a shift in policy away from nominal reporting.
- ◆ In areas where passive case reporting has been unsuccessful, attempts to actively supplement this information may be valuable. Surveillance staff could conduct periodic reviews of hospital data, lists of persons receiving medication, and laboratories to compare their registries with reported HIV/AIDS cases.
- ◆ Most of the simple measures proposed to strengthen sentinel surveillance also refer to case reporting.

The following principles apply to both case reporting and sentinel surveillance and, in fact, to any other surveillance:

Feasibility and simplicity. It is better to have a simple system that is functional than a complex one that is not. Data collection and management procedures should be adapted to the capacity of the weakest site.

Continuity. To accurately assess trends over a given time period, changes in data collection methods should be kept to a minimum.

Standardisation and consistency. Training and supervision need to ensure that those who collect and process data are familiar with standard procedures (case definitions, eligibility criteria for the selection of survey participants, standard testing protocols, etc.).

Acceptability. For staff to fully collaborate, they need to (a) understand the rationale for the data collection and accept its usefulness. They need to be given (b) timely feedback; (c) reporting procedures need to be simple and not too time-consuming; and (d) responsibilities and lines of communication need to be clear.

Use of data. Data compilation and presentation serve two purposes: information and motivation. Surveillance reports should be issued regularly

and contain a summary of recent surveillance findings, clear and simple graphic presentations of data alongside their interpretation and the discussion of conclusions. Those responsible for data collection and reporting, policy and decision makers, researchers, advocacy groups and media representatives should all be included in the distribution list.

6.2.2 Validate sentinel surveillance data Measure HIV incidence

In order to follow epidemic trends, incidence measures are more meaningful than prevalence. Measuring or estimating incidence has therefore been proposed as one of the objectives of efforts to establish “Second Generation” HIV surveillance systems.

HIV tests used for HIV sentinel surveillance, e.g. among ANC attendees, do not allow for the distinction between recent and old infections. Nevertheless, levels and patterns of new infections can, in principle, be estimated from serial prevalence data^{66,67,68}. Prevalence trends in young age groups should reflect, with reasonable accuracy, trends in the rate of new infections (incidence), because exposure to sexually transmitted HIV has been short and infections must have occurred recently. Estimating incidence from ANC data in older age groups is more problematic, because exposure to sexual experience and HIV risk is more varied. Estimates also heavily depend on assumptions regarding the differential mortality and mobility and, if ANC data are used, fertility of HIV-positive compared with HIV-negative women. In younger women, biases due to differential mortality and fertility are less relevant. It has therefore been proposed to concentrate sentinel surveillance on younger age groups to capture trends in new infections.

Sexual behaviour and the associated HIV risk develop rapidly in teenagers and change significantly during this short phase of life. Comparisons between 15- and 19-year-olds have revealed significant differences in risk behaviour and in levels of HIV prevalence⁶⁹.

To be able to conclude on trends in new infections among 15-19 year olds it is therefore important to know the exact age composition of this group and – if changes in the composition occur over time – to control for those changes in the analysis.

Nevertheless, this approach to estimating incidence levels and trends has several disadvantages which make implementation and interpretation of results difficult. First, the most frequently studied sentinel group are pregnant women, who, as has been shown earlier, may not be representative of the general population. Importantly, adolescent pregnant women may be even less representative than older women. For instance, if an IEC programme succeeded in reducing teenage pregnancy and/or in delaying first sexual intercourse among young women, those who still became pregnant and attended ANC clinic would certainly be a very biased sample of all women of that age group.

Secondly, for the analysis of narrow age band data to produce valid results, adequate sample sizes are required (a minimum of 250 persons per age group per survey). Even with much larger age groups, it has been difficult to achieve such sample sizes in the past, as ANC clinic attendance is so low in many areas. It has therefore been suggested to concentrate on a few key sites in densely populated urban areas and to over-sample young age groups (15-24 years) there, at the cost of sacrificing sites in areas where operational costs are high and recruitment for testing is low. As sexual behaviour greatly varies, local research is required to determine the most relevant age range, for the estimation of incidence in any given population. Lastly, age reporting is notoriously poor in many developing countries and may hamper efforts to obtain more accurate data.

Cohort studies are an alternative opportunity to measure HIV incidence and to collect data on the natural history of HIV infection and its association with demographic variables, such as fertility and migration. But they are expensive and difficult to carry out in developing countries. Because of their considerable expense and logistical complexity, it is unlikely that many such studies can be conducted. Therefore full advantage should be taken of ongoing studies, whenever possible.

Determine HIV trends in the general population

There are basically three possibilities to build on sentinel surveillance data to track the HIV epidemic in the general population and to validate findings among ANC attendees.

1. To compare socio-demographic characteristics of sentinel populations with that of the general population

The representativeness of pregnant women can be assessed by comparing their socio-demographic characteristics with those of the general population. General population information may already be available from other sources, such as demographic and health surveys. If not, surveys need to be conducted to collect minimum data such as age, marital status and education. In areas with a high proportion of migrants, data on the length of stay in the area or in the place of origin should be added. General population samples should ideally be drawn from the catchment population of clinics, where sentinel surveys are conducted.

2. To complement existing surveillance information with data on those parts of the general population which are not covered by sentinel surveillance

Complementary information can be obtained through additional sero-surveys among specific subgroups of the general population, which are not covered by sentinel surveillance, such as men, residents of a particular province or sex workers. For example factory cohorts or military recruits may be relatively easily accessible groups which, if not yet part of routine sentinel surveillance, might be tested episodically using similar methods. Improved availability of saliva tests might result in higher participation in voluntary testing and similar sensitivity and specificity as in anonymous testing. When blood testing was replaced by saliva testing in Zambia⁷⁰, participation rose sharply.

3. To measure HIV prevalence directly in the general population through repeated (over time) population-based sero-surveys

Although population-based sero-surveys have the potential to deliver highly representative information, they have not become an essential component of routine HIV surveillance systems. They are costly and logistically demanding. In addition, ethical concerns with regard to voluntarism, informed consent and confidentiality loom large in this kind of testing. Adequate

counselling services and confirmatory tests would have to become available for those study participants who prefer to be informed about their sero-status. As with surveys among specific subgroups of the population, general population surveys may become more feasible with the use of saliva HIV tests. It has been suggested to combine major surveys, such as demographic and health surveys (DHS), with saliva or urine testing on HIV, though such a combination would pose many ethical problems.

6.2.3 Introduce behavioural surveillance

Behavioural surveillance has increasingly been recognised as a key element of HIV/AIDS surveillance systems. In Uganda and Thailand, as well as in many other countries, behavioural information has contributed to the better understanding of the dynamics, the underlying causes and the consequences of the epidemic and of the effectiveness of interventions to prevent its spread. The study of sexual and drug use behaviours can provide advance warning of an impending HIV epidemic among certain subgroups of the population, and profiles of risk and vulnerability obtained through behavioural research can guide prevention programmes. The observation of behaviours may also help to evaluate the effects of prevention programmes, as behavioural trends become attributable to specific interventions.

While therefore little doubt exists that behavioural surveillance is useful in principle, further research is needed into how best to collect behavioural data in the context of HIV/STD prevention systematically over time and how to integrate behavioural surveillance into national HIV surveillance programmes. Challenges also remain with regard to the selection of appropriate indicators and concerning the need to supplement indicator surveys with qualitative data. So far, only a few countries in Asia and Africa have experimented with establishing a behaviour monitoring system³⁴.

Types of surveys

To study the pattern of risk behaviour and how it alters with time and place, basically three different types of periodical studies have been proposed.

1. **Periodic cross-sectional large-scale surveys**

The implementation of periodic (e.g. every three to five years) nation- or region-wide cross-sectional behavioural surveys among a representative sample of the total population at reproductive age may serve to map out dominant behaviours, sexual mixing patterns and potential risk groups. Data from national behavioural surveys can be related to and complemented by national demographic and health survey data.

2. **Intervention-linked KABP surveys**

Such smaller KABP surveys may accompany interventions as baseline and follow-up surveys, for instance among school youth. Indicators may be selected following local research or according to regional or nationally defined standards.

3. **Behavioural sentinel surveillance (BSS)**

Behavioural sentinel surveillance consists of repeated anonymous cross-sectional questionnaire surveys of population subgroups currently or potentially at risk of HIV infection (Box 6). Drawing largely on the experience of Thailand, researchers are presently developing protocols and guidelines for behavioural sentinel surveillance^{34,71}.

If behavioural surveys are conducted in the catchment population of HIV sentinel sites, data on key behavioural indicators can be related to results from sero-prevalence surveys. This may help to interpret trends in HIV prevalence.

BSS may become a component of routine HIV/AIDS surveillance systems in developing countries in the future.

Box 6

Characteristics of behavioural sentinel surveillance:

- ◆ Serial cross-sectional behavioural surveys
- ◆ Structured interviews among anonymous respondents
- ◆ Questionnaires consisting of small numbers of questions on key behavioural indicators such as age at first sexual intercourse
- ◆ Selection of defined, easily accessible populations, such as school pupils and students, as

well as of particularly vulnerable populations such as sex workers, men who have sex with men, STD patients, truck drivers and migrant workers

- ◆ Selection of sites so as to include target areas for prevention programmes and to allow for the linking of behavioural with sero-survey data
- ◆ Repetition of surveys at short regular, e.g. annual, intervals

Indicators

As an in-depth analysis of all behavioural determinants of the epidemic is too complex for surveillance purposes, trends should be monitored in behaviours that have a direct impact on the transmission of HIV. The choice of “key behavioural indicators” depends on the predominant modes of transmission in a country. For example, in sub-Saharan Africa, sexual mixing patterns and the number of sexual partners, the frequency of sexual practices such as anal heterosexual intercourse, sex during menses, and condom use may be monitored. In Latin America and the Caribbean, where HIV is frequently transmitted through male homosexual and bisexual activity and injecting drug use, these behaviours would need to be monitored, in addition to indicators of heterosexual transmission. In Asia, where the frequency of commercial sex contacts may play a larger role in determining the course of the epidemic than elsewhere, the number of contacts males have with sex workers as well as indicators of condom use may be monitored.

Key behavioural indicators include:

- ◆ Age at sexual initiation (first intercourse). If age at first sex rises, a decrease in HIV infections in adolescents is expected.
- ◆ Age at first-ever marriage. Since married persons tend to have fewer partners than single people, marriage tends to reduce the risk of infection.
- ◆ The gap between age at first sex and age at first marriage indicates the length of time young people are at a relatively high risk of HIV infection.
- ◆ Number of sexual partners. The risk of HIV infection increases with the number of sexual partners a person has. There is also evidence that concurrent partnerships have a greater influ-

ence on the spread of HIV than sequential partnerships⁷².

- ◆ **Mixing patterns.** The degree of mixing between different socio-demographic and behavioural subgroups in the population has a significant impact on the course of the HIV epidemic. Non-assortative mixing (like with unlike), for instance sex of a girl with an elder man (age disparity of partners) or of a married man with a sex worker, involves a higher risk of HIV transmission than assortative (like with like) mixing.
- ◆ **Use of condoms in various types of partnerships.** Here it is of interest whether condoms are used at all (“ever use”), whether they are used consistently (“consistent use”) and during last intercourse and whether they are used with regular or irregular partners.

The collection of data on migration patterns and drug use may be considered complementary to sexual behaviour information, as both are factors that have been shown to significantly influence sexual behaviour⁷³. Injecting drug use is an important risk factor on its own.

The need for local qualitative research

There are many challenges to successful behavioural surveillance, the most important one of which would appear to be the diversity of human behaviour itself. The identification of standard indicators, for instance, is complicated by the fact that concepts such as “regular”, “casual” or “commercial” sexual relations, sex worker and even marriage vary widely between different cultures and languages. Furthermore, it is difficult to obtain valid data on socially discredited risk behaviours such as contact with sex workers or extramarital sex. For example there is considerable evidence in many populations that adult women underreport their number of sexual partners. In contrast, men may exaggerate their number of partners. Sensitivities and taboos concerning anal sex, homosexuality, commercial sex or premarital sex vary enormously between different locations. The advantages of standardising behavioural indicators within and across countries and cultures for the sake of comparability should therefore not override relevance to local conditions. Unless validated by in-depth qualitative research, indicator surveys may not be meaningful at all.

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TECHNICAL ANNEX

The methodologies of unlinked anonymous sentinel sero-surveillance and behavioural sentinel surveillance

The technical annex describes the methodology of unlinked anonymous sentinel sero-surveillance and behavioural sentinel surveillance in more detail than in the main part of the brochure. It includes advice and information on basic methodological questions that are crucial for the effective implementation of sentinel surveillance, such as the criteria for the choice of survey populations and sites, the type of data to be collected, sampling methods, and laboratory testing strategies. Information that has already been given in the main part of the brochure is only referred to.

1. Unlinked anonymous sentinel sero-surveillance

When designing a sentinel HIV sero-surveillance system, the following questions need to be answered:

- ◆ Which populations should be included?
- ◆ How many and which sites should be selected?
- ◆ Which information on the survey participants besides the HIV status should be collected?
- ◆ At what time intervals should surveys be carried out?
- ◆ What data collection procedures should be followed?
- ◆ What laboratory testing procedures should be followed?
- ◆ How should data be analysed and presented?

The selection of survey populations

The following criteria should be considered when selecting a population group for sentinel surveillance:

Easy accessibility

1. Anonymous unlinked sentinel surveillance is usually health-facility-based (because of the easy access to blood specimens that are collected for other purposes), and sentinel populations are selected among users of health facilities. In contrast, access to injecting drug users is often difficult.
2. **Coverage of transmission routes**
Important transmission routes should be covered:

sexual transmission (e.g. through ANC attendees and STD patients), mother-to-child transmission (indirectly through ANC attendees) and transmission through blood and blood products (through blood donors and IDUs).

3. Representativeness

Ideally the groups chosen should reflect the dynamics of the HIV epidemic in both the general sexually active population and in groups with an increased risk of HIV infection. Antenatal care attendees and blood donors are the two groups which have been chosen most frequently, as they are thought to represent the general population most closely. Their representativeness depends on many factors, e.g. blood donor selection mechanisms or ANC clinic user rates among pregnant women (see chapters 4.2 and 6.1).

STD patients are often used as rough indicators for HIV rates in groups that are at increased risk of sexually transmitted HIV infection.

4. Stable socio-demographic characteristics

To make HIV prevalence rates in consecutive surveys comparable, the composition of the groups in relation to socio-demographic characteristics (age, sex, socio-economic status) should not change over time.

The choice of survey sites

Criteria for the selection of health facilities are: that they draw blood from patients/clients as part of routine services, that they have reliable laboratory facilities for the correct preparation and storage of specimens, that attendance rates of the selected group are high, that they are easily accessible for supervision, and that on-site staff is willing to co-operate and capable of conducting surveillance.

Different geographic strata (urban, rural) should be represented among the selected sites.

Type of data collected

Information is collected on only a few socio-demographic variables. Those are: "sentinel group", "sex", "age" and "location". From ANC attendees, in addition, information on "parity" should be collected.

Duration and frequency of surveys

Ideally the entire sample should be collected during a period of not more than 8 to 12 weeks in order to avoid the same individual being included more than once in a survey.

Time intervals between surveys depend on the stage of the epidemic. During the phase of rapid spread in a population or subgroup, quarterly to 6-monthly surveys may be useful. When an endemic equilibrium has been reached, annual surveys are sufficient to detect new increases or decreases in prevalence.

Sample size, sampling scheme

WHO recommends a sample size of 300 individuals per sentinel group and site. In practice, it is often not feasible to achieve those sample sizes, especially at smaller clinics, e.g. in rural areas.

Samples are collected consecutively from members of the survey population. Inclusion and exclusion criteria for survey participants must be clearly defined. For example, with regard to antenatal care attendees, women attending for the first time during the current pregnancy are included, but those on a repeat visit are excluded.

If trends of HIV infection over time in specific demographic subgroups (by age group or by sex) are of interest, then sample sizes must be determined for each subgroup. A minimum of 50 samples per subgroup should be collected.

As already mentioned, sample sizes must be sufficiently large to provide a reasonably accurate esti-

mate of prevalence at each sentinel site. Surveillance results are never exact measurements, but are ranges within which one can be reasonably confident that the true prevalence rate falls. The upper and lower limits of this range are called limits of precision or confidence intervals (CIs). The narrower the range, the more precise the results will be in describing the true prevalence rate in the selected sites and populations. Two prevalence rates are considered to be statistically significantly different only if their confidence intervals do not overlap.

Table A1 provides an overview of the precision of expected results based on the sample size and the prevalence rate.

Laboratory testing strategies

Modern ELISA tests are highly sensitive and specific (above 99%). The probability that a test accurately identifies the true infection status depends not only on its sensitivity and specificity, it also depends very much on the prevalence of HIV infection in the population. With increasing prevalence, the proportion of positive test results that are falsely positive decreases, but the proportion of negative test results that are falsely negative increases. For surveillance purposes it is important to minimise the possibility of overestimating HIV prevalence by counting a large number of false positives, especially in populations with low prevalence of HIV infection.

Table A1:
Precision of prevalence estimates in sentinel populations depending on sample size

	Sample Size N=100		Sample Size N= 50		Sample Size N= 1,000	
	Prevalence	95% CI	Prevalence	95% CI	Prevalence	95% CI
Number Positive						
1	1.0%	0.0 - 3.0	0.2%	0.0 - 3.0	0.1%	0.0 - 3.0
5	5.0%	0.7 - 9.3	1.0%	0.7 - 9.3	0.5%	0.1 - 0.9
10	10.0%	4.1 - 37.8	2.0%	4.1 - 37.8	1.0%	0.4 - 1.6
20	20.0%	12.2 - 27.8	4.0%	12.2 - 27.8	2.0%	1.1 - 2.9
50	50.0%	40.2 - 59.8	10.0%	40.2 - 59.8	5.0%	3.6 - 6.4
100	100.0%	98.5 - 100.0	20.0%	98.5 - 100.0	10.0%	8.1 - 11.9

At a prevalence of 10% the positive predictive value (PPV)¹ of one ELISA alone is already 90%, which is sufficient for surveillance purposes. WHO recommends for areas with HIV prevalence rates below 10% that specimens reactive to the ELISA test be retested with a second ELISA from a different type. Because HIV-2 can be found on four continents, the HIV testing reagents that are used for HIV sentinel surveillance should detect as far as possible the presence of antibodies to both HIV-1 and HIV-2.

Analysis and presentation of data

Prevalence rates and their 95% confidence intervals are determined for each population and subgroup of interest. As a next step prevalence rates of consecutive surveys over time are compared, and the statistical significance of trends needs to be assessed. Statistical techniques are to include the standard chi square analysis, chi square analysis for trend, test for difference in proportions and multiple regression analysis.

In addition, differences in prevalence rates between surveys, locations and groups and subgroups can be explored.

Data are presented in simple tables indicating prevalence rates including confidence intervals and line or bar charts.

2. Sentinel behavioural surveillance

As sentinel behavioural surveillance was originally developed following the principles of sentinel sero-surveillance, there are many similarities in the design of the two surveillance methods. Therefore, at the planning stage for behavioural sentinel surveillance, the questions that are raised are almost exactly the same as for sero-surveillance. Naturally, more emphasis is put on the selection of behavioural information to be collected and the development of tools, such as questionnaires.

The selection of survey populations and sites

The selection of survey populations and sites depends on the purpose of behavioural surveillance.

The purpose may either be to evaluate the impact of HIV prevention interventions on the behaviour of the target populations or to complement data on HIV prevalence trends from sentinel sero-surveillance with behavioural information to facilitate their interpretation. In general, as with sentinel sero-surveillance, groups selected for behavioural surveillance should be easily identifiable and accessible.

If the evaluation of the impact of prevention interventions is the purpose of behavioural surveillance, populations and sites are selected in the target areas of those interventions. For example: if projects are targeting sex workers and their clients in several cities and truck stops in a country, then certain brothels, night-clubs, bars etc. in those places are selected. If vocational students or military personnel are the focus of interventions, then vocational schools and military barracks or training camps should be the survey sites.

If, for example, the interpretability of HIV prevalence trends among ANC attendees should be improved through information on behavioural trends, then the ideal would be to collect behavioural information directly from ANC attendees during sero-surveys. But the principle of anonymity makes it impossible to find an ethically acceptable way of collecting sensitive behavioural information and linking it to blood samples. Instead, one tries to sample women with the same socio-demographic characteristics as surveillance clinic attendees and men likely to be their sexual partners, living in the catchment area of ANC clinics.

For the initial survey round sites should be selected at random from a list of eligible sites. According to the experience of an AIDSCAP project in Bangkok, Thailand, random sampling of sites and individuals is important to prevent a biased selection. For example, if only those brothels with convenient access are chosen, then these sites might have better management and higher condom use rates than brothels with difficult access. A full range of sites provides a variation in risk level that may help to explain why risk occurs or changes over time.

¹ The diagnostic accuracy of a laboratory test or a combination of laboratory tests in a population is expressed as the predictive value of a test result. The positive predictive value of an HIV test is the probability that a person is really HIV-positive if he/she tests positive with the respective test, and the negative predictive value is the probability that a person is really HIV-negative if the respective test gives a negative result.

For follow-up surveys either the same sites can be chosen or a new random selection can be carried out.

Survey intervals

The time between surveys is determined by the speed at which behaviour is changing and by the local capacity to carry out surveys and analyse data, as well as budget considerations. In the early stages of interventions aiming at behaviour change, when the speed of behaviour change is not known at all, intervals of 6 months are recommendable. Longer intervals (12 to 24 months) are likely to be sufficient later.

Information to be collected and questionnaire development

Information should be collected on the key indicators, which need to be determined. Examples include: age at first intercourse, age at first-ever marriage, type and number of sexual partners, sexual mixing patterns, use of condoms in various types of partnerships (see chapter 6.2.3).

Questionnaires should be as short as possible. Their development should follow standard social science methods. The major steps include formative research to identify variables to be included in the questionnaire, drafting and pre-testing questions, and compiling the complete questionnaire with introductions, skips and guidelines for interviewers.

Data collection procedures

Care should be taken that not only questionnaires are culturally appropriate, but also data collection procedures. They may include self-administered questionnaires and structured interviews or a mixture of both. An interview should not take more than 30 minutes. For example in Bangkok the following experience was made: when surveying women with a structured questionnaire, it was important to begin with less sensitive questions. Then, at an appropriate point in the interview, the interviewer passed a self-administered questionnaire containing only those questions relating to the respondent's sexual behaviour and left the room. The respondent put the questionnaire in a box with only a code number as identification. The

interviewer then returned to finish the questionnaire.

As questions in behavioural surveys concern sexuality, which is a sensitive and very personal domain, interviewers need to be non-judgemental about the respondent population and well trained.

Sample sizes

For all target groups it is essential to have adequate sample sizes of subgroups engaging in the behaviour(s) of interest. As a rough guide, the desired minimum number of eligible respondents with the specific behaviour of interest should be 50 in each subgroup of interest. Thus the required sample size depends on the prevalence of the behaviour of interest in the survey population and varies widely. An example from behavioural sentinel surveys among vocational students in Bangkok²:

An important question in that survey was what proportion of male students had sex with sex workers during the past year. Behavioural data from other sources suggested that the answer would be approx. 30%. A sample of 200 students would therefore yield 60 respondents with the behaviour of interest "sex with sex workers". Among female students, researchers were interested in the percentage of single women who had sex in the past year. They estimated that 99% of female students were single, of whom 13% had ever had sex and 35% of those had sex in the past year. Thus 1,300 interviewees would yield 60 respondents with the behaviour of interest "sex in the past year".

Analysis and data presentation

BSS data provide information on the proportion of the sentinel population engaging in the behaviour of interest. Those proportions may change over time. Simple statistics should be used to rule out apparent trends that are due to chance variation. Statistical techniques to determine whether changes over time are significant include the standard chi square analysis, chi square analysis for trend, test for difference in proportions and multiple regression analysis.

Data can be shown in time trend tables or graphs.

² AIDSCAP evaluation tools. Module 4. FHI/AIDSCAP 1995

Abbreviations and acronyms

AIDS	Acquired Immune Deficiency Syndrom
ANC	Antenatal care clinics
ANT	Antilles
AZT	Azidothymidin
BAR	Barbados
BER	Bermuda
BSS	Behavioural Sentinel Surveillance
CAREC	Caribbean Epidemiology Centre
CDC	Centres of Disease Control
GRE	Grenada
GTZ	Gesellschaft für Technische Zusammenarbeit (GTZ) GmbH
GPA	Global Programme on AIDS
GUY	Guyana
HIV	Human Immune Deficiency Virus
IEC	Information, Education and Communication
IDU	Intravenous Drug User
JAM	Jamaica
KABP	Knowledge Attitude Behaviour Practice
MoH	Ministry of Health
MoPH	Ministry of Public Health
MSM	Men having Sex with Men
MTCT	Mother-to-Child-Transmission
NACP	National AIDS Control Programme
NGO	Non Governmental Organisation
PAHO	Pan American Health Organisation
py	person years
PDA	Population and Community Development Association
SPSTD	Special Programme on STD
STD	Sexually Transmitted Diseases
STL	St. Lucia
T&T	Trinidad & Tobago (TT)
TB	Tuberculosis
VD	Venereal Disease
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation



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