

Intensification of HIV/AIDS Surveillance

*Report and Documentation of the Technical Discussions
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Intensification of HIV/AIDS Surveillance

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Part I –Proceedings¹

¹ Originally issued as document SEA/RC52/13 dated 5 Sept 1999.

1. INTRODUCTION

Technical Discussions on “Intensification of HIV/AIDS Surveillance” were held on 2 September 1999 under the chairmanship of Dr Sangay Thinley, Director of Health Division, Ministry of Health and Education, Bhutan. Dr Saw Myint, Director (Planning), Department of Health, Ministry of Health, Myanmar, was elected Rapporteur. The agenda and annotated agenda (SEA/PDM/Meet.36/9.2.1 and Add. 1) and the working paper for the Technical Discussions (SEA/PDM/Meet.36/9.2.2) formed the basis for the discussions.

1.1 Opening Remarks by the Deputy Regional Director, WHO/SEARO

Dr Samlee Plianbangchang, Deputy Regional Director, said that it was appropriate for the CCPDM to take cognizance of this issue and discuss strategies for further intensification of HIV/AIDS surveillance in SEAR, considering that the HIV/AIDS problem was acute in the developing world, particularly in the Region. Almost every country in the world had reported HIV infection and the number of people infected with HIV continued to increase steadily. The number of infected persons, however, varied according to different age groups and by gender. Highlighting the importance of surveillance programmes, he pointed out that public health interventions based on effective and appropriate planning and policy could alter the course of the epidemic in the Region based on accurate information obtained through surveillance programmes. Surveillance also ensured efficient, effective and evidence-based decisions. It was gratifying to note that the importance of initiating surveillance of sexually transmitted infections (STI) and assessment of risk behaviour on a regular basis to complement HIV/AIDS surveillance was being recognized. Dr Samlee expressed the hope that the recommendations of the Technical Discussions, duly endorsed by the Regional Committee, would guide the Member States in strengthening their efforts in HIV/AIDS surveillance and in planning public health interventions.

1.2 Introductory Remarks by the Chairman

In his opening remarks, Dr Sangay Thinley highlighted the importance of HIV/AIDS surveillance and the need for its intensification, given the alarming situation that existed in the Region with regard to HIV/AIDS. He hoped that the focused discussions by the participants would generate important recommendations on the intensification of HIV/AIDS surveillance in the countries of the Region.

1.3 Presentation by Dr Jai P. Narain, Regional Adviser, HIV/AIDS and TB, WHO/SEARO

While reviewing the status of HIV/AIDS surveillance, Dr Narain stated that though such surveillance programmes were well established in the Region, their scope and reach needed to be strengthened to respond better to the epidemic. Epidemiological surveillance data were useful to plan interventions targeted at various population groups as well as for advocacy among decision makers. The data on reported AIDS cases did not reflect the actual magnitude of the problem, due to under-diagnosis and under-reporting, coupled with the latency period of 7-10 years between infection and development of AIDS. On the other hand, HIV sentinel surveillance based on unlinked anonymous testing among various population groups, when repeated at regular intervals, provided more accurate and unbiased information on the HIV trends in a country or area. The focus now should be on improving the quality of surveillance data by strict adherence to methodology between surveys and on prompt dissemination and use of data for programme purposes.

Dr Narain noted that surveillance of HIV-related risk behaviours was not yet well established in most countries of the Region. Behavioural surveillance data are needed to assess the types and intensity of risk behaviours in various areas. The use of such data for planning and evaluating more quickly the impact of intervention strategies aimed at bringing about behavioural change could not be underestimated. While countries in the early stages of epidemic should focus on surveillance, particularly among populations with high risk behaviour, those with a

more advanced epidemic should cover both the higher as well as lower risk populations. Surveillance for sexually transmitted infections also needed to be standardized and established, together with behaviour surveillance, as a part of comprehensive HIV/AIDS surveillance programmes in the countries.

2. DISCUSSIONS

- Ⓔ During the discussions, the participants voiced their concern at the seriousness of the HIV/AIDS situation in the Region. They recognized the need to intensify HIV/AIDS surveillance to enable countries to plan and implement various interventions to combat the epidemic.
- Ⓕ It was noted that all the countries in the Region were involved in HIV/AIDS surveillance, including AIDS case reporting and HIV sentinel surveillance. Promoting and implementing intervention-linked behavioural surveillance, particularly in view of the need to bring about behavioural change in various population groups, would greatly benefit HIV/AIDS surveillance. Information obtained through surveillance of risk behaviours and STI could be also be used for advocacy and resource mobilization. The importance of collating and quickly analysing risk behaviour data for planning interventions was stressed. This included mapping, estimation of size, risk ranking and prioritizing of populations for targeting interventions.
- Ⓖ Development of a simple and standardized set of indicators for behavioural surveillance was extremely valuable. This could be developed at the national level with assistance from WHO/SEARO.
- Ⓗ Reporting of STI syndromes was considered appropriate among men. However, in view of the asymptomatic nature of STI in women, it would be useful to focus on etiological diagnosis in women, particularly data on gonococcal culture and VDRL obtained at certain sites where such laboratory facilities were available. Also, a prevalence

survey should be undertaken to establish the overall burden, at least once in three years.

- ⑥ Multisectoral involvement in HIV/AIDS surveillance was highlighted. Even though surveillance activities which provided information for public health action could be undertaken by nongovernmental organizations, the academia and research institutions, the overall coordination of these activities remained the responsibility of government.
- ⑥ The participants noted that HIV/AIDS could not be considered only as a health problem. It was also a social problem. At the same time, the danger of HIV/AIDS losing priority attention due to its being designated as a social problem rather than a health problem should be kept in mind.
- ⑥ The networking of surveillance activities at the national, sub-national and intercountry levels was also discussed. Collaboration between countries to share their experiences through the use of established mechanisms was essential to further develop HIV/AIDS surveillance in all Member Countries of the Region.
- ⑥ The participants briefly discussed the problem of HIV testing among expatriate workers as well as the ethical and public health dimensions relating to mandatory testing of various population groups. The participation bias associated with voluntary confidential testing was highlighted. It was suggested that for surveillance purposes, unlinked anonymous testing was the preferred methodology.
- ⑥ The need for the Member Countries to have a technical sub-committee for exchange of information on HIV/AIDS surveillance and the role of WHO/SEARO in setting up and supporting such an activity was highlighted.
- ⑥ Recognizing the importance of epidemiological research in prevention and control of HIV/AIDS, the participants urged enhanced support in this area. In addition, it was stressed that each country should develop and share databases on HIV/AIDS among interested parties,

both within and outside the country. WHO support to strengthen surveillance data management was also highlighted during the discussions.

- ® WHO/SEARO was urged to promote, document and disseminate experiences on “social vaccines”, such as the 100% condom programme, HIV/AIDS education in schools as a part of lifeskills approach, and education and prevention interventions among various population groups, particularly those with high risk behaviour. Such initiatives should be supported and funded through the ICP II mechanism.

3. RECOMMENDATIONS

3.1 Advocacy

In view of the crucial role surveillance plays in planning, implementing and evaluating national AIDS control programme activities, the Member Countries should give a high priority to strengthening comprehensive HIV/AIDS surveillance by allocating adequate resources, both human and financial.

3.2 Enhancing quality of HIV/AIDS surveillance data

While HIV/AIDS surveillance is well established in all countries, there is a need to improve the quality of surveillance data. To improve AIDS case reporting, it is important to train health care workers in diagnosing and reporting AIDS cases and to widely disseminate AIDS case definition to all health care facilities. HIV sentinel surveillance should be based on unlinked anonymous methodology which should be adhered to strictly in various rounds of survey. The problem of not having adequate sample size can be minimized by expanding the survey period and by carrying out surveillance only once a year instead of every six months. Moreover, countries with low HIV prevalence should carry out surveillance only among population groups with high risk behaviour.

3.3 Establishing national working groups on HIV estimates

In order to develop a consensus on current estimates of HIV in the country, a working group on HIV estimates should be established in all Member Countries. This multidisciplinary working group consisting of national experts with experience and expertise in HIV/AIDS, including epidemiologists, behavioural scientists, etc. could meet once a year to review all relevant data to prepare an estimate of HIV prevalence in the country.

3.4 Expanding surveillance of risk behaviours and STI

In addition to AIDS case reporting and HIV sentinel surveillance, the data on risk behaviour and STI should form an integral part of comprehensive HIV/AIDS surveillance. This should include geographical mapping of risk behaviour and estimation of population size. Such data should be used quickly for planning and evaluating the impact of prevention interventions. Simple and practical guidelines, including indicators to measure the risk behaviour in various population groups, should also be developed by countries in collaboration with WHO/SEARO.

3.5 Building partnerships for strengthening HIV/AIDS surveillance

While the national AIDS control programme has overall responsibility of coordinating the national response to HIV/AIDS in the country, including establishment and strengthening of HIV/AIDS surveillance, multisectoral involvement is essential to implement surveillance activities. NGOs, the private sector, the academia and research institutions, where relevant, should be involved in planning and implementing surveillance activities. This is particularly relevant in the area of behavioural and STI surveillance.

3.6 Intercountry collaboration

Many countries have, over the years, attained considerable experience in establishing HIV/AIDS surveillance. These experiences should be shared through established intercountry mechanisms. Development of a uniform methodology and networking among surveillance focal points should be considered. SEARO should provide a forum for information exchange among countries.

3.7 Data dissemination and use

Surveillance data should be more quickly analysed and made available to national programmes so that these are used for action. Ideally, surveillance data should be collected, analysed and used for action at the local level.

WHO/SEARO should assist countries in coordinating surveillance activities and assisting in data management. All national AIDS control programmes should develop HIV/AIDS databases to be shared with various stakeholders, including health workers, various governmental sectors, nongovernmental organizations, the private sector, donor agencies and, most importantly, surveillance personnel. These databases should be updated regularly.

3.8 Epidemiological research to fine-tune HIV/AIDS surveillance

Epidemiological research should be carried out periodically to evaluate HIV/AIDS surveillance programmes and to assess ways to improve the quality (completeness, accuracy and timeliness) of surveillance data in the Member Countries.

**Part II –Resolution, Agenda
and Working Paper**

Resolution¹

The Regional Committee,

Recalling World Health Assembly resolutions WHA40.26 and WHA42.33, and its own resolutions SEA/RC40/R1, SEA/RC44/R8 and SEA/RC47/R4 relating to the prevention and control of HIV/AIDS,

Realizing the importance of HIV/AIDS surveillance data in monitoring the trends of the epidemic and for planning prevention and care,

Appreciating the continuing support of WHO and its role in establishing HIV/AIDS surveillance in the Region, and

Noting with concern the inadequacy of information on the status and progress of the HIV/AIDS epidemic in the Region,

1. REITERATES the need for Member States to strengthen strategies for the intensification of HIV/AIDS surveillance and to involve, where relevant, all related sectors, including research institutions and nongovernmental agencies;
2. URGES Member States:
 - (a) to accord high priority to HIV/AIDS surveillance by providing the required human and financial resources, and
 - (b) to further strengthen national capacity for comprehensive surveillance of HIV/AIDS/STI and risk behaviour among various population groups, and

¹ SEA/RC52/R8

3. REQUESTS the Regional Director:
 - (a) to enhance support to Member States in their efforts to intensify HIV/AIDS surveillance through provision of technical and material assistance;
 - (b) to promote intercountry collaboration in surveillance activities, monitor the progress and report to the Regional Committee, and
 - (c) to assist Member States in developing national capacity in HIV/AIDS surveillance through training and strengthening of laboratory diagnostic facilities.

Agenda¹

1. Introduction
2. Objectives of epidemiological surveillance
3. HIV/AIDS surveillance in the South-East Asia Region: Current status and issues
4. Use of HIV/AIDS surveillance data for disease control
5. Role of WHO in supporting national surveillance programmes
6. Intensifying HIV/AIDS surveillance: Points for consideration
7. Conclusions

¹ Originally issued as document SEA/PDM/Meet.36/9.2.1 dated 28 July 1999

Annotated Agenda¹

1. INTRODUCTION

HIV/AIDS is a rapidly growing public health problem all over the world. From a few cases initially reported in the United States, it has now spread to every part of the globe. It is estimated that there were 33.4 million adults and children living with HIV at the end of 1998. In several countries, there are indications that the epidemic curve is stabilizing. The position is especially acute in the SEA Region as the epidemic is still growing rapidly and it is feared that the number of AIDS deaths will now start to increase exponentially.

2. OBJECTIVES OF EPIDEMIOLOGICAL SURVEILLANCE

It is essential that health planners have a clear picture of the HIV/AIDS situation in the country and some idea of the trends so as to be in a position to make projections about the health resource needs to deal with the HIV/AIDS situation in the country. It is desirable that this information is available regionwise so that planning and programmes can be focused according to the needs of the geographic area and the segment of the community concerned. Surveillance data also enable health decision-makers to evaluate the efficacy of intervention programmes.

¹ Originally issued as document SEA/PDM/Meet.36/9.2.1 Add.1 dated 28 July 1999.

3. HIV/AIDS SURVEILLANCE IN THE SOUTH-EAST ASIA REGION: CURRENT STATUS AND ISSUES

All countries of the Region are involved in HIV/AIDS surveillance. Generally, the national programmes have an element of AIDS case reporting. This is rather incomplete. Surveillance for HIV infection is carried out in the Region by using unlinked, anonymous sentinel surveillance. This programme is the most satisfactory component of the HIV/AIDS surveillance package. The focus now needs to be on improving the quality of data and prompt and suitable reporting and feedback to the programme managers, health decision-makers as well as to the leadership and the public.

STI surveillance is not yet on a firm footing and needs to be standardized and established as part of the general health information system. Behavioural surveillance is not yet well established in most countries of the Region. Behavioural surveillance needs to be incorporated into the national surveillance programme.

4. USE OF HIV/AIDS SURVEILLANCE DATA FOR DISEASE CONTROL

Surveillance data are required for several purposes. They can be used for advocacy and for planning. They help to target interventions in those areas where the need is greatest, and for those groups who are most at risk. By helping to project the course of the epidemic by establishing trends, surveillance data are useful for planning and resource allocation for the immediate, mid-term and long-term future. Some of the countries in the Region have made excellent use of the data for assessing the impact of interventions and for mid-course corrections in intervention programmes.

While AIDS case reports give us an idea of the present severe morbidity associated with HIV/AIDS, they really reflect what happened anywhere 5 to 15 years earlier. Measurement of HIV infection in the community gives a more proximate idea of the AIDS caseload to come.

This information can be utilized for planning, advocacy and, in some special circumstances, for evaluating the impact of the interventions. It is not possible to carry out a survey across an entire country and, in any case, the cost will be prohibitive and the data will soon become obsolete.

5. ROLE OF WHO IN SUPPORTING NATIONAL SURVEILLANCE PROGRAMMES

WHO has identified HIV/AIDS as a priority disease with great implications for public health. In consonance with this decision, HIV/AIDS has been advocated in the Region. WHO has offered technical assistance to Member Countries. In July 1999, an informal consultation on STI surveillance and on behavioural surveillance was held in the Regional Office. Later, in the same month, a workshop for programme managers was held in Bali, Indonesia, where participants were updated on surveillance issues and a plan was developed for further strengthening the programme.

6. INTENSIFYING HIV/AIDS SURVEILLANCE: POINTS FOR CONSIDERATION

6.1 Strengthening AIDS Case Reporting

One way of getting a picture of the impact of the epidemic is to keep track of the number of persons who develop AIDS. This gives an idea of the severe effects of the epidemic and helps us to plan for health care services in the near future. In all countries of the Region, there is some reporting of AIDS cases. However, the utility of the data so generated is limited by the incomplete nature of the reports. This is especially so in those countries where the epidemic is only now beginning to manifest as AIDS rather than as HIV infections. One factor that is common to most countries of the Region is the very incomplete AIDS case reporting. In general, this is due to a variety of factors which may be classified as either because a diagnosis is not made or due to a reluctance to report AIDS for reasons related to the serious social and economic considerations of a diagnosis of AIDS.

6.2 Improving the Quality of HIV Surveillance Data

Testing for HIV has serious implications because of the severe discrimination against HIV-positive persons. For these reasons, it has been decided to only advocate unlinked, anonymous testing at selected sentinel sites. The data collected periodically from the same 'sentinel' site can help programme managers to establish trends, and to use these trends as indicators for the population.

Unless the sites are carefully selected and sufficient numbers included in the sample, it will be near impossible to establish any trends. The quality of data is dependent upon strict adherence to the guidelines laid down and the quality of HIV testing.

Unless data analysis is timely and the results are fed back into the system, no care or importance will be attached to the entire exercise.

6.3 Establishing a Uniform STI Surveillance Methodology

As conventional STIs and HIV infection are both propagated by the same type of behaviour, STI surveillance gives a good index of the potential for the spread of HIV and, even more important, enables the health system to monitor the impact of prevention interventions. Unfortunately, it is difficult and expensive to diagnose several common STIs. For management, WHO has recommended the syndromic approach. However, the mere identification of syndromes, while perfectly adequate for treatment, does not give an idea about the etiology of infection. It is hoped that, as discussed at the informal consultation in New Delhi and the workshop for programme managers, held in Bali, a uniform methodology will be adopted in the Region and made a regular part of the programme. A combination of etiological and syndromic reporting is required with the etiological component being contributed from specialist clinics and the reporting of urethritis and VDRL results from the field.

6.4 Promoting Intervention-linked Behavioural Surveillance

AIDS is the result of an event that occurred 5 to 15 years earlier. HIV prevalence is the cumulative result of infections that occurred over the

last ten or more years ago. STI surveillance is a measure of the potential for HIV spread. Behavioural surveillance measures risk behaviour. It not only gives us an idea of the potential for HIV infection, but, most importantly, it gives us a measure of the impact of the behavioural change interventions that are the mainstay of HIV/AIDS prevention programmes. Behavioural data can help to interpret the other surveillance data and should be linked to interventions.

6.5 Using HIV/AIDS Surveillance Data to Estimate HIV Prevalence

Surveillance data, especially HIV data, are collected from sentinel sites. These data give an indication of the trends in infection amongst various categories. To estimate the total overall HIV load in the country, surveillance data can contribute to getting a complete picture, but load estimates do not automatically follow HIV surveillance. Many countries find it important to have a composite figure on total HIV load. Several methods have been tried for this, including mathematical modelling, back calculation and estimation by using representative group estimates.

6.6 Disseminating and Using Surveillance Data

Unless surveillance data are analysed promptly and appropriately, they can serve little purpose. It is incumbent upon the programme managers to expeditiously make all data available to decision-makers, opinion leaders, and those concerned with the programme, the media and the community. Only then will the full potential of the data be utilized.

7. CONCLUSIONS

Working Paper¹

1. INTRODUCTION

AIDS first appeared on the scene in the early 1980s when reports began trickling in of unusual infections and malignancies in otherwise healthy young men. The only common trait that they shared seemed to be their sexual orientation. Soon the agent responsible was identified and eventually named the Human Immunodeficiency Virus or HIV. It was also established that the sexual route largely spread the infection, heterosexual spread being responsible for 80-90% of the new infections. Since that small beginning, HIV/AIDS has spread to all parts of the globe and has already become one of the major causes of death in many parts of the world.

The epidemic is in different stages of development. In some parts of the world, such as the USA and Southern Europe, there are indications that the prevalence may have started to decline. In other parts of the world, the growth of infection has slowed down and started to level off. In yet other areas, the infection is growing very rapidly. The infection curve in South-East Asia is still in the stage of rapid increase. Even within countries, the prevalence of infection is not uniform as the AIDS epidemic comprises many outbreaks. The risk factors and the overall disease epidemic could vary from region to region and from area to area within a country.

¹ Originally issued as document SEA/PDM/Meet.36/9.2.2 dated 28 July 1999.

As of 1 June 1999, more than 115,421 AIDS cases had been reported from the South-East Asia Region (Table 1). It is estimated that nearly 5.5 million people with HIV, or 18% of the world total, are in the South-East Asia Region. Unlike other parts of the world, the epidemic in our Region is still growing sharply. WHO estimates that the number of infections will continue to rise well into the next century and there will be 8 to 10 million infections by the year 2000. Although HIV came late in the Region and the epidemic started only in the mid to late 1980s, it has rapidly taken a firm hold of the population in most countries of the Region. Starting out in populations whose lifestyles were conducive to the spread of a sexually transmitted infection and in many countries heralded by the use of injectable drugs, the epidemic is beginning to spread out into the general population.

Table 1. AIDS and HIV infections in South-East Asia
as of 1 June 1999

Bangladesh	10	3/97	21,000	16
Bhutan	1	8/98	<100	<16
DPR Korea	0	11/96	<100	<1
India	6,252	3/98	4,000,000	418
Indonesia	237	5/99	25,000	12
Maldives	5	3/98	<100	<25
Myanmar	2,312	3/98	440,000	760
Nepal	183	1/98	25,000	66
Sri Lanka	77	3/98	6,000	32
Thailand	106,344	1/99	950,000	1,345
Total	115,421		~ 5,600,000	> 358

* 1996 population estimates for all countries except Bhutan are based on UN population figures for mid-1994, with annual growth rates applied as appropriate.

It is obviously very important to keep track of the epidemic. Information about the extent of the disease is needed so that governments, civil society and national AIDS control authorities can respond meaningfully, efficiently and appropriately to the epidemic. Accurate information also makes it possible to plan appropriate interventions and to assess their effect. Without reliable epidemiological surveillance information, advocacy is hampered.

2. OBJECTIVES OF EPIDEMIOLOGICAL SURVEILLANCE

Public health surveillance is described as the systematic collection, analysis and dissemination of data on the occurrence of a disease or condition in order to guide decisions towards its prevention and/or its management. It is emphasized that surveillance collects data for action, and that action is an essential part of the surveillance process. In the context of HIV/AIDS, current concepts of HIV/AIDS surveillance include STD surveillance, and now, surveillance of behavioural patterns.

**Action is an essential part of the
surveillance process**

The objectives of HIV/AIDS surveillance therefore are:

1. To detect and describe the geographical and demographic distribution of HIV infection and other STIs and their determinants;
2. To monitor the progression of the HIV/AIDS epidemic;
3. To plan HIV prevention activities and health and social services for people living with HIV infection and AIDS;
4. To evaluate the impact of specific elements of national AIDS control programmes;
5. To estimate the present and future impact of the pandemic;

6. To provide comparative data on the global and regional scope of the epidemic, and
7. To increase public and political awareness of the disease, leading to political commitments and resources to combat the epidemic.

In summary, surveillance helps to generate national commitments to HIV as well as target prevention activities and plan responses.

3. HIV/AIDS SURVEILLANCE IN THE SOUTH-EAST ASIA REGION: CURRENT STATUS AND ISSUES

To get a complete picture of the HIV epidemic, several separate activities have to be implemented. AIDS case reporting reflects current HIV-related morbidity and transmission of the infection 5-10 years earlier or even further back. Data on HIV can give a more immediate idea about the load of infection. Because of the long period between acquiring infection and developing AIDS, the impact of the epidemic is often not immediately visible as the prevalence of HIV is affected slowly and minimally. While the prevalence is easily measured through various surveys periodically, the incidence of HIV infection is difficult to detect or measure on a routine basis as it involves the serial measurement of infection in a defined cohort.

As conventional STIs and the majority of HIV infection are both spread by the same means, studies of STIs give a very good surrogate measure of the potential for the spread of HIV in a given population. As prevention and control measures advocated for conventional STIs and HIV are exactly the same, changes in the prevalence of STIs indicate the impact of control interventions. In view of the essentially short duration of the incubation period of STIs, changes in incidence are easy to detect and can be related to current interventions.

In the absence of vaccines or other bio-medical interventions for preventing HIV infection, all prevention efforts are primarily focused on

behavioural change. It follows therefore that measurements of behavioural patterns are the most immediate and sensitive indicators of the potential for the spread of HIV infection and also of the impact of prevention programmes. Behavioural surveillance is therefore also an important component of the total effort to get information about HIV/AIDS.

A complete public health surveillance of the epidemic therefore requires that information from all components be used to complement each other. AIDS case surveillance and HIV surveillance, together with STI and behavioural surveillance, present a complete picture of the epidemic, both in terms of disease distribution as well as of the related risk factors.

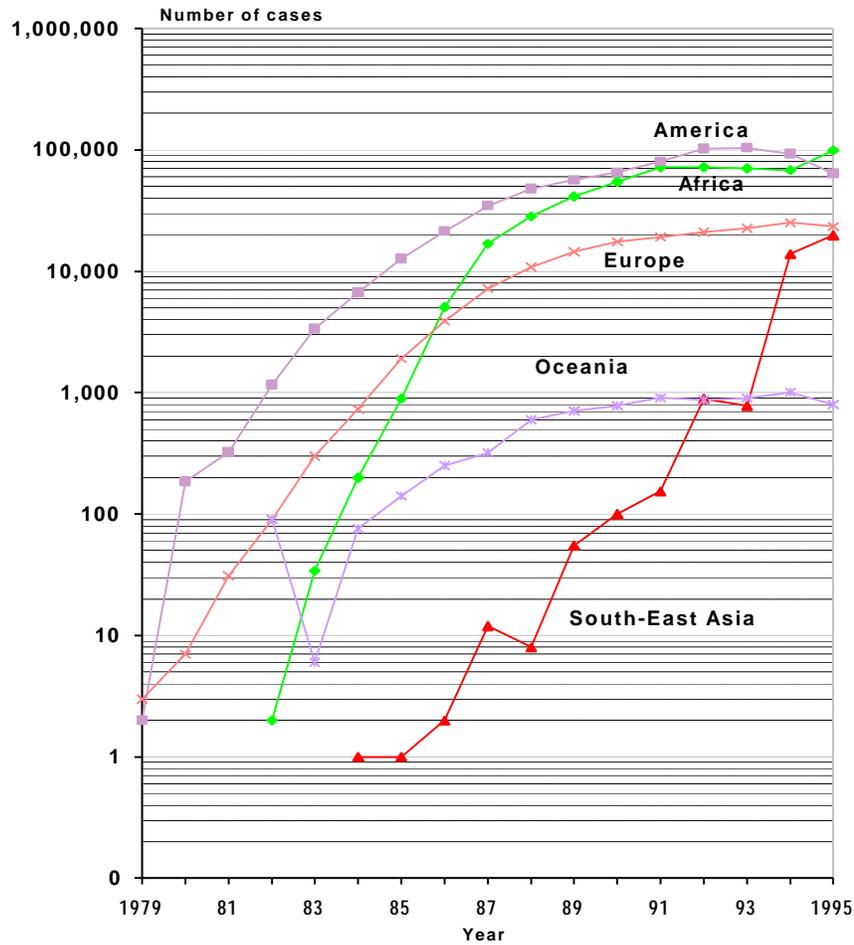
3.1 AIDS Case Reporting

For many reasons, it is important for the health system to have a good idea of the number of persons with AIDS. When complete, AIDS case reports can provide information on the demographic and geographical characteristics of the population affected by the epidemic and on the relative importance of the modes of transmission. This information is of great value for planning prevention interventions. AIDS case data also indicate the extent of serious morbidity associated with HIV infection and the potential impact on health services. This information is necessary for short-term planning of health care at the national level. Data on AIDS cases can also be used for advocacy and raising public awareness. Finally, as long as case definitions and surveillance systems are taken into consideration, the data can be used for international and intra-national comparison.

3.1.1 Current status of AIDS reporting in the Region

Unfortunately, for a variety of reasons the reporting of AIDS cases is generally incomplete. It was reported that even in a country like Thailand, only about 30% of the cases of AIDS are actually reported to the health authorities (Figure 1). The reasons for this rather unsatisfactory state are easy to understand.

Figure 1. Trends in reported AIDS cases, by Region, 1979-1995



In many situations, diagnosis of AIDS is not made as the index of suspicion is low. Patients are treated for opportunistic infections and that infection is assumed to be the primary illness. This is especially true in the developing countries where the commonest opportunistic infections are common diseases, such as tuberculosis. Other respiratory illness where the organism is not isolated may just be diagnosed as pneumonia.

- ⑥ In many situations, HIV laboratory diagnostic facilities in the form of voluntary counselling and testing services are not easily accessible and the diagnostic criteria for AIDS being used requires a positive antibody test.
- ⑥ For reasons of confidentiality and protection of patients' rights, and for the protection of the patients' family, the diagnosis may not feature on the case sheet or other linked hospital record. The case may therefore be reported by the hospital administration in terms of the infection that led to admission.
- ⑥ AIDS case definitions, as they are currently applied in some countries, require a positive HIV test. In the absence of HIV testing facilities in the concerned institution, health care providers do not make a diagnosis of AIDS.

3.1.2 Major issues to be addressed

Among major issues relating to AIDS case reporting is the fact that it does not reflect the current magnitude of the epidemic and suffers from gross under-diagnosis and under-reporting of cases. There are also reporting delays.

In the absence of a widely known and accepted AIDS case definition, health care providers remain reluctant to diagnose and report cases of AIDS. As far as AIDS case surveillance is concerned, the definition prescribed should have the following attributes. It must be able to identify cases of severe HIV-related disease with a high degree of sensitivity and specificity. The definition must be simple to understand and applicable in all health care facilities, and be suitable for both national and international comparisons. Laboratory HIV testing and other tests, such as CD4 cell counts, will improve the sensitivity and specificity of the diagnosis. However, the accepted definition must also cater to the needs of the more peripheral areas where laboratory facilities for HIV and immunological testing are not routinely available and where precise etiological diagnosis of many opportunistic infections cannot be made.

The provisional clinical case definition for AIDS, or the “Bangui” definition which was developed in 1985, was modified in 1992 by WHO and does not require HIV testing to identify a case of AIDS. This definition is widely used in many countries and provides a good level of information. Most parts of this Region accept the ‘Bangui’ definition for AIDS case surveillance but many authorities have modified this by the addition of HIV test results. It is correct that the addition of HIV tests increases the sensitivity and specificity of the definition; however a provision must be made for those facilities that do not have ready access to HIV testing.

3.2 HIV Surveillance

AIDS case reporting gives information on infection that occurred a median of 7-10 years earlier. HIV surveillance, on the other hand, gives information on the current status of the infection in the community. There are several types of surveillance that have been carried out to determine the extent and trend of HIV infection in the community.

3.2.1 Current status of HIV surveillance in the Region

Soon after HIV tests became available in the mid-1980s, people started reporting the results of HIV tests as sero-prevalence data. Some countries even tried to estimate the prevalence of infection by carrying out random surveys in the community. It soon became evident that these surveys were not cost-effective and generated information that soon became obsolete at a high cost. It also became apparent that many such surveys gave highly inaccurate estimates of the total HIV load because of the fact that HIV infection is not randomly distributed in the population, but rather was highly clustered around certain behavioural characteristics. Participation and selection bias also played their part in making results unreliable.

During the late 1980s, WHO advocated testing of specific population groups periodically using an unlinked anonymous methodology. When repeated every six months or one year, using similar methodology, this process provides trends of HIV prevalence in the same population group. It was suggested that sentinel surveillance be carried out in those

with high-risk behavior (HRB) as well as among groups representing the general population provided rates in HRB were found to be high.

Sentinel surveillance is the systematic and periodic cross-sectional surveying of the prevalence of HIV antibodies in selected populations. Sentinel sites are chosen keeping in mind that they must be available to be resurveyed periodically. Sentinel surveillance is recommended by WHO as the principal methodology for collecting information on the geographical, demographic and temporal distribution of HIV infection.

Populations particularly suitable for sentinel HIV surveillance are persons attending STI clinics, drug treatment centres, and other groups at higher risk. Women attending antenatal clinics and young military recruits represent populations at lower risk or the general population. To facilitate unlinked anonymous testing, sentinel sites are chosen where blood is already being drawn for a non-HIV-related reason. Generally, clinic or health centre-based sentinel sites are preferred as they permit the testing of blood/sera drawn for any routine purpose without linking the result to the identity of the person. This methodology is referred to as unlinked anonymous testing and is the preferred method for sentinel surveillance. An aliquot of serum separated from that taken for routine haematology etc. is sent for testing without any personal identifiers. The methodology is important as it avoids participation bias, which otherwise is a problem in such surveys. As no attempt is planned to link the person being tested with the test result, this technique also obviates the need to take informed consent, nor is confidentiality an issue. Moreover, sentinel surveillance for HIV does not involve randomized selection of sentinel sites making it operationally easy to implement. The data from different sites should not be aggregated.

Sentinel surveillance for HIV serves to monitor trends for HIV prevalence in selected populations, determine the geographical spread of infection and provides data which can be held to estimate the current HIV load and to make projections for the future. However, the utility of HIV surveillance data can greatly decrease if the methodology is not followed stringently.

3.2.2 Issues to be addressed

HIV sentinel surveillance is being implemented in all countries of the Region except DPR Korea. However, the extent of population covered and the quality varies greatly within the Region. This is greatly influenced by the size of the centres and the stages of the epidemic. Sentinel surveillance using unlinked anonymous testing is a powerful methodology that addresses several of the common causes of bias and inaccuracy of the data generated by surveys. The specified methodology must be adhered to by all concerned. It is important that care is taken to choose sites that are stable and can be used from year to year. The sites must also have the potential to recruit an adequate number of samples in defined period.

3.3 STI Surveillance

There is broad acceptance that collection and dissemination of surveillance data on STIs are essential to identify groups at high risk, establish realistic disease control objectives and evaluate the overall effectiveness of syndromic management in managing sexually transmitted diseases. Inputs on the prevalence and incidence of STI are therefore an essential component of the total surveillance efforts for HIV/AIDS. In all practical aspects, HIV/AIDS is also a sexually transmitted infection. Both conventional STIs and HIV are spread by unprotected sex and prevention messages that relate to HIV are exactly the same as measures directed towards the control of conventional STIs. In addition, the presence of a STI increases the risk of both acquiring and transmitting HIV infection.

STIs are also a good surrogate marker for the risk of acquiring HIV and, therefore, of the impact of HIV primary prevention interventions.

3.3.1 Current status of STI surveillance in the Region

Surveillance of STI in the South-East Asia Region remains weak; there is a lack of reliable and accurate data on the prevalence and incidence of

common sexually transmitted diseases in most countries. As a result, the magnitude of STIs and the trends cannot be quantified with any degree of confidence. The situation is further compounded by the lack of consensus on the approaches to be used to measure the disease burden and due to the inadequate laboratory diagnostic facilities available in most countries.

Based on country reports, it is clear that the incidence and prevalence of STIs and complication rates are high in most countries of the Region, except in Thailand, where the incidence of STIs has been declining over the years.

The priority for the Region now is to establish a reliable but simple and practical STI surveillance programme using a standardized approach and format. In this regard, draft STI surveillance guidelines prepared by the Regional Office have been discussed during an informal consultation with a view to adopting the same for South-East Asia. Consistent availability of reasonably accurate data on STIs will guide and assist STI/AIDS control programmes in evaluating the impact of control strategies, e.g. based on syndromic management of STIs and IEC interventions targeted at individuals with high-risk behaviour. Such data will also help in rationally planning for future strategies.

Monitoring of gonococcal antimicrobial susceptibility patterns is important for developing and changing treatment options as a part of STD syndromic management.

(a) Reporting of STIs from sentinel sites

Reporting of STIs by all institutions or from carefully selected sentinel sites scattered across the country, on a continuous basis, should provide data that can be analysed, reported and disseminated on a regular basis. Patient load and the willingness to participate in reporting are other important considerations when selecting sentinel sites. While in men, reporting of syndromes, particularly genital ulcer and urethral discharge, will be most practical, in women, STI being mostly asymptomatic, syndromic reporting would not be useful. Hence, reporting by etiology, particularly of syphilis and, if possible, cultures for gonorrhoea and chlamydia could be considered.

Although etiological reporting is an important part of the STI surveillance, this is necessarily restricted to a few treatment facilities that have a laboratory and clinical resources to make such diagnoses.

(b) Prevalence surveys

Periodic surveys in various population groups help to establish a baseline and thereafter in monitoring STI over time. These surveys could be carried out in populations accepted to be at high risk as well as those who are a part of the general population. Examples of high-risk female populations are female sex workers. Clinics situated in the proximity of CSW (commercial sex workers) concentrations, and thus including a sizable proportion of sex workers in their clientele, is an example of a suitable high-risk site for females. Male high-risk populations are typically sampled from STI clinics. Another example of high-risk population is those using injectable drugs (IVDU). Surrogates for the general or low-risk population include pregnant women (ANC attendees) and recruits into the military and paramilitary forces.

(c) Special surveys/studies

As in the case of other forms of surveillance, special surveys can be used as an important supplemental source of valuable information. Examples of these include investigations into treatment seeking behaviour, community prevalence of STIs, validation of syndromic management flow charts and other such studies. Monitoring of gonorrhoeal anti-microbial susceptibility has been established in the Region, which could provide very useful surveillance information that can be used to decide choice of treatment for STD syndromes.

3.4 HIV-related Risk Behavioural Surveillance

In the chain of events that culminates with a person developing AIDS, the earliest point is the behaviour that puts an individual at risk of getting a sexually transmitted disease, be it one of the conventional STIs or HIV. In the absence of a specific vaccine or other bio-medical intervention,

prevention efforts are focused on promoting behavioural change to eliminate or minimise the risk of acquiring HIV infection. It stands to reason therefore that monitoring behaviour would give a direct measure of the efficacy of educational interventions directed at preventing HIV/STIs. In addition, a measure of the prevalence of risk behaviour can serve to indicate the potential for the spread of HIV/STI.

Behavioural surveillance aims at capturing data regarding levels of risk behaviour so as to give some gauge of the potential for spread of HIV in the population concerned.

In common with other forms of surveillance, a universal and ongoing measurement is not possible. Repeated cross-sectional surveys on behaviour are relatively expensive as they need considerable time per person interviewed. The frequency of such surveys must therefore be carefully considered. Periodic surveillance every two years appears to be a pragmatic possibility. As in HIV and STI surveillance, it is desirable to select sentinel sites so that the risk behaviour in the selected population can be monitored on a temporal basis.

In the Region, there have been only some attempts to initiate a system of behavioural surveillance. Such studies have been done, but they have often been in the nature of in-depth investigations planned on an individual basis. Few, if any, examples are available of a planned long-term surveillance incorporating a design for repeated surveys to give an idea of temporal trends, especially programmes that have been integrated into the national surveillance plan. Examples of repeated surveys exist in several countries. In India, two waves of behavioural survey have been done in Tamil Nadu and similar programmes are being initiated in some other states, such as Maharashtra. Similarly, behavioural surveys have been done in Bangladesh and Myanmar. A periodic exercise has been conducted in Thailand where the data have resulted in changes in the intervention plans.

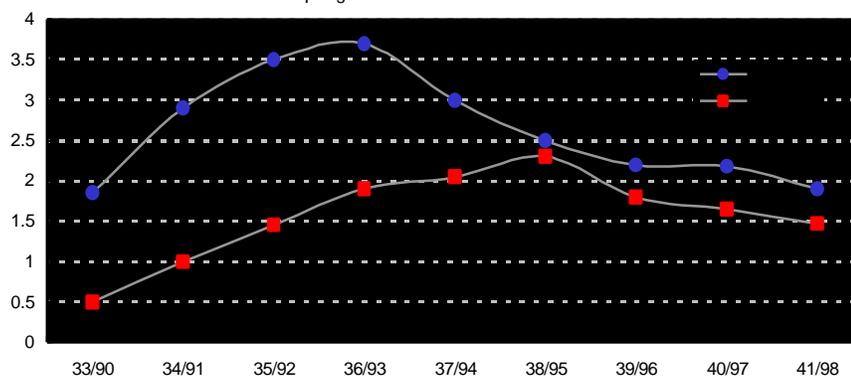
This is an area that must be strengthened in the Region. It complements the data obtained by the other forms of surveillance and offers perhaps the best estimate of the immediate impact of behaviour change interventions.

4. USE OF HIV/AIDS SURVEILLANCE DATA FOR DISEASE CONTROL

Even though the surveillance of HIV/AIDS/STIs has not yet achieved the standards expected except in a few Member Countries, there are many examples where surveillance data have been found to be of great value in steering the response to the epidemic.

In Thailand, HIV surveillance is being carried out in each province and among various population groups. Data are then used for advocacy and planning purposes in each province. Among excellent examples of surveillance are data from HIV sentinel surveillance of army recruits which have provided an accurate measure of the need for and then of the success of the behavioural change interventions in the general population. Studies on behaviour suggested that exposure to HIV from unprotected sex in brothels may well be the prime source of infection (Figure 2). This behavioural data led to the development and implementation of the 100% condom use policy. The reduction in HIV prevalence amongst recruits has been used as an index to show the efficacy of this policy.

Figure 2. Trend of HIV prevalence rate in conscripts and pregnant women in Thailand



In India, the results of the first 'national' round of sentinel HIV surveillance vividly brought home the changing nature of the epidemic. It became clear that in some states the epidemic was no longer confined to those segments of the population generally considered being at risk. The significant prevalence of HIV infection found in antenatal mothers has led to a rethinking of the intervention policy. The results have also made it possible to clearly differentiate between those states where the epidemic was in very early stages and others where the situation was more serious. This has repercussions on the allocation of resources and the design of the response.

HIV sentinel surveillance data also indicated that factors fuelling the epidemic may vary from area to area. For example, in Mumbai and Chennai, rates of HIV among sex workers and STD patients were found to be high indicating that heterosexual transmission is predominant in these areas. Data from an IDU site in the north-east of India demonstrated the explosive nature of the spread of HIV in drug injectors beginning 1989.

Sentinel surveillance data also contributed to the development of differing HIV prevention strategies in Maharashtra, Tamil Nadu and similar states focusing on intervention to bring about sexual behavioural change, and in Manipur and other north-eastern states in India where harm reduction strategies were given a priority.

In Myanmar, surveillance data show that as a result of IEC and community-based interventions with the involvement of family, behavioural change is occurring among injecting drug users and HIV infection rates have come down to nearly 50% from 66-73% reported prior to 1994.

Similarly, in Bangladesh, the high prevalence of STIs, together with behavioural data in certain sections of the population, has brought home the realization of the susceptibility to the rapid spread of HIV infection once the virus gains a foothold in the population.

5. ROLE OF WHO IN SUPPORTING NATIONAL SURVEILLANCE PROGRAMMES

Since 1988, when the Global Programme on AIDS was formed, WHO has been supporting countries in establishing and strengthening HIV/AIDS surveillance. In January 1996, when UNAIDS was established, WHO, now in its role as one of the co-sponsors, has again identified surveillance as one of its core areas of work in support of Member Countries. This decision has been taken with due consideration to the WHO mandate and its comparative advantages *vis-a-vis* other co-sponsors.

WHO priority areas

- STD management and control
- Safety in blood transfusion
- Care of people living with HIV/AIDS
- Epidemiological surveillance

As a consequence of this decision, WHO stands ready to provide technical support to Member Countries in HIV/AIDS surveillance activities.

In 1990, the Regional Office had organized an inter-city workshop on HIV/AIDS surveillance where training modules on HIV sentinel surveillance were introduced. Subsequently, the Regional Office developed guidelines entitled "Carrying out HIV sentinel surveillance: A guide for programme managers" which describe in a simple and straightforward manner the steps for planning and implementing HIV sentinel surveillance. Support was provided to various national programmes in HIV/AIDS surveillance. Many countries regularly send reports on a quarterly basis to WHO and feedback is provided regularly, including through the quarterly Newsletter, AIDS Watch.

The Regional Office has also developed guidelines on STI surveillance as well as on HIV-related risk behaviour surveillance, which were finalized during an informal consultation held in New Delhi recently.

With the change in the pattern of the epidemic and the problem acquiring a sharper focus, a workshop was held in Indonesia from 27 to 30 July 1999 to review the status of HIV/AIDS surveillance and to recommend necessary steps for further strengthening HIV/AIDS surveillance in the Region. The participants were members of the National AIDS Control Organizations responsible for surveillance in their respective countries. The concepts of surveillance will need a new emphasis now that the epidemic is firmly entrenched in almost all the countries of the Region. STI surveillance needs greater emphasis and behavioural surveillance needs to become part of the overall surveillance programme in the Region.

6. INTENSIFYING HIV/AIDS SURVEILLANCE: POINTS FOR CONSIDERATION

Given the changing dimension of the HIV/AIDS epidemic and based on experiences gained in the Region, the role of surveillance must be further strengthened as we enter the new millennium. Therefore, the agenda for future strategies to intensify HIV/AIDS surveillance in the Region must include elements directed at each of the identified components of the comprehensive plan for HIV/AIDS surveillance.

6.1 Strengthening AIDS Case Reporting

As discussed earlier in the document, AIDS case reporting is generally incomplete and often irregular in the Region. Clear and unambiguous case definitions and adequate training are key interventions that have the potential to improve the completeness and reliability of AIDS case reports.

To improve AIDS case reporting, several linked activities are indicated:

- Ⓔ Mechanisms and policies must be enacted to make AIDS case reporting a part of the accepted pattern, preferably integrated into the general morbidity reporting format.
- Ⓕ Uniform AIDS case definitions acceptable in a country must be widely propagated to all health care workers. These must be laid down separately for situations where testing facilities are available and for other situations when care is given in the absence of HIV testing facilities.
- Ⓖ Health care providers must be trained to recognize AIDS, to diagnose it using the relevant national case definitions and to report cases to appropriate public health authorities.
- Ⓗ Steps should be initiated to ensure confidentiality; reporting should not require data on personal identifiers.
- Ⓘ All training programmes for physicians and other health care providers should ensure that the teaching curriculum contains reference to this important need.

6.2 Improving the Quality of HIV Surveillance Data

Most countries of the Region have adopted the methodology of HIV sentinel surveillance, as advocated by WHO. However, much work needs to be done to ensure that the data generated in different situations are not only of a high standard but that the data are analysed appropriately and reported expeditiously.

- Ⓔ To make the best use of resources in countries with a low level of the epidemic, sentinel surveillance should concentrate on populations with high-risk behaviour. Regular monitoring of lower risk population (such as women attending antenatal care) is only recommended once HIV prevalence in higher risk groups becomes 2% or higher.
- Ⓕ In countries with advanced epidemic, on the other hand, surveillance should cover both higher and lower risk population in urban as well as rural areas. Monitoring of HIV prevalence in antenatal clinics and

among military recruits often provides useful data suggesting the level of epidemic in the general population.

- Ⓔ Most importantly, however, for data to be compared over time, and trends to be monitored, the methodology used at each survey must be strictly and consistently adhered to. Also, adequacy of sample size requires particular attention at many sites. Finally, national programmes must collect, collate and analyse data on HIV available from other resources, such as blood donor screening, *ad hoc* surveys and from research projects implemented in the area.

6.3 Establishing a Uniform STI Surveillance Methodology

Some system for the collection of data on STIs exists in most countries. However, the data gathered are of limited value even for the country collecting them and have almost no international value. There is an urgent need to propagate the idea of using a standardized and reliable methodology for STI surveillance.

- Ⓔ Regular collection and analysis of data from selected STI clinical services can provide important information on disease prevalence and patterns. This information can be of considerable use in intervention planning.
- Ⓔ Moreover, special STI surveys, such as prevalence surveys, carried out every 2-3 years could provide key information for STI programmes. However, these surveys need considerable resources.
- Ⓔ Monitoring antibiotic susceptibility in the country would help decide treatment regimens for managing STDs using a syndromic approach. Hence surveillance of *Neisseria gonorrhoea* for antimicrobial susceptibility should be an integral component of STI surveillance.

6.4 Promoting Intervention-linked Behavioural Surveillance

Behavioural surveillance is important in identifying levels of risk behaviours in various populations, and monitoring changes in behaviour

over time. These data provide information for essential planning and evaluating intervention programmes.

- Ⓡ Behavioural surveillance should be an integral component of the national surveillance programme on HIV/AIDS and STI.
- Ⓡ In countries with a low HIV prevalence, behavioural surveillance should focus on populations considered at higher risk for HIV and in lower risk populations to establish the extent and type of risk behaviour in the general population. In countries with advanced epidemic, behavioural surveillance should cover various population groups to ascertain the potential for HIV spread from population with high-risk behaviour into the general population.
- Ⓡ While population at high risk must be studied more frequently, say, each year, those at lower risk must be monitored for behavioural change every three years.

6.5 Using HIV/AIDS Surveillance Data to Estimate HIV prevalence

There is a need to develop guidelines for using the existing data to prepare HIV estimates through consensus in the countries of the Region. Building national capacity to do this work, and to carefully analyse data on relevant populations while arriving at estimates consistent with the data is essential. A working group must be established in each country so that estimations are acceptable to all stakeholders. This can be achieved through consensus among national experts drawn from various disciplines, such as epidemiologists, behavioural scientists, policymakers, etc. This would not only lend credibility to the process of estimating HIV prevalence, but also help in the use of such data for advocacy and planning interventions.

6.6 Disseminating and Using Surveillance Data

Use of data for action is most essential. To do so, surveillance findings should be disseminated through periodic national and state/provincial meetings, through newsletters distributed to all sectors active in combating

HIV/AIDS including NGOs working with higher risk populations as well as provincial and community level personnel involved in HIV activities and national policymakers and ministry officials. Most importantly, however, feedback to those carrying out surveillance at the ground level is essential for maintaining their motivation to do a good job.

7. CONCLUSIONS

The changing scene of HIV/AIDS has made it necessary to rethink the issue of surveillance in the Region. Accordingly, the needs and scope of HIV/AIDS surveillance have evolved over the years. Indeed, therefore, in addition to the traditional focus on AIDS case and HIV sentinel surveillance, Member States need to emphasize STI surveillance and the tracking of risk behaviour. WHO will continue to play an important catalytic role in this area and support national AIDS control programmes in their endeavour to further strengthen HIV/AIDS surveillance in the Member Countries. Only such an efficient, yet single surveillance system can provide the evidence for rational interventions and monitoring both the epidemic and the efficacy of the interventions. The need to utilize limited national and international resources more efficiently also mandates that decisions are based on evidence.

Scarce financial resources mandate that evidence-based decisions are made for maximising efficiency in response to the HIV/AIDS epidemic. This is possible only through a strong and efficient surveillance programme.