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AIDS

USE OF HIV SURVEILLANCE DATA
IN NATIONAL AIDS CONTROL PROGRAMMES

A REVIEW OF CURRENT DATA USE WITH RECOMMENDATIONS FOR
STRENGTHENING FUTURE USE

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Use of HIV surveillance data in national AIDS control programmes

A review of current data use, with recommendations for strengthening future use

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Introduction

The World Health Organization Global Programme on AIDS (GPA) now works with more than 150 countries, and 120 of those have national AIDS control programmes. Serological surveillance for human immunodeficiency virus (HIV) is a component of virtually all national programmes while sentinel surveillance for HIV infection constitutes a part of such programmes in at least 40 countries in French- and English-speaking Africa; Asia; Europe; Oceania; as well as the United States.

Over the last 2-3 years, much has been learned about the various uses of HIV surveillance data and how these data have contributed to our understanding of the current epidemic.

This paper considers four general aspects of HIV/AIDS surveillance:

- Current HIV surveillance and sentinel serosurveillance data.
- Uses and limitations of HIV surveillance data for AIDS control programmes.
- Recommended HIV surveillance activities.
- Strengthening the use of surveillance data.

1. Current HIV surveillance and sentinel serosurveillance data

In most countries HIV prevalence data are available for several areas and a few groups within those areas. These data have served to describe transmission patterns as well as variations among groups and between different areas. Thus, the basic transmission patterns and groups at highest risk have been determined for most countries.

In 1988, WHO proposed a sentinel serosurveillance method for monitoring HIV infection. This simplified scheme can be used to describe the current HIV situation and monitor future trends through repeated sampling at designated sites for selected groups (1). The sampling system described is simple and can be repeated routinely. To obtain accurate information on trends, sentinel serosurveillance utilizes methodology aimed specifically at minimizing self-selection (participation) bias. The primary objective of public health surveillance is to detect changes in the incidence, spread and distribution of disease, and therefore, is distinctly different from that of case-finding, where identification of HIV-infected individuals is essential. Unlinked or blind testing is the best method to use for eliminating or minimizing self-selection bias and protecting anonymity/confidentiality. Detailed guidelines for unlinked anonymous screening are available from WHO/GPA (2).

2. Uses and limitations of HIV surveillance data for AIDS control programmes

A great many countries collect surveillance data about the AIDS epidemic, as noted earlier; how then are HIV prevalence data being used today? Are there limitations to the use of HIV surveillance data? Are there other potential uses which deserve further exploration?

The most common uses of HIV surveillance data are for: (a) enhancing the commitment of policy makers, funders and staff; (b) targetting activities for population groups and areas; (c) programme monitoring and evaluation; (d) the development and testing of interventions; (e) resource allocation and long-range planning; and (f) the educational value for individuals.

A brief description of how HIV data are being used for these purposes follows.

2.1 Commitment (political, financial, manpower)

Unquestionably, HIV prevalence data have been extremely useful in obtaining, reinforcing, or increasing the commitment of political leaders, the health sector, and other key sectors, both national and local, to prevention and control programmes.

Many examples can be cited to illustrate the use of HIV prevalence data for advocacy, political motivation, and action by various political groups and sectors: examples include advocacy to initiate programmes and mobilize money and manpower. Quite recently HIV surveillance data were presented at multisectorial national workshops in Ethiopia and Rwanda for the purpose of gaining or further solidifying the commitment and involvement of political leaders including the political party, the military, the ministries of information and education, as well as private groups.

2.2 Targetting activities for population groups and areas

Aside from advocacy, the paramount use of HIV prevalence data is to identify high-risk behaviours and persons engaged in such behaviours to which informational, educational, or other interventions can be aimed. Examples of populations now targeted for interventions as a result of serosurveillance data include persons with multiple sexual partners in inner city areas in the United States, and intravenous drug users in Bangkok, Thailand.

Dozens of countries provide examples of how HIV surveillance data have been used to direct increased attention to high-prevalence areas. In the United Republic of Tanzania, intervention efforts were increased in the Kagera and neighbouring areas. In Kenya, the

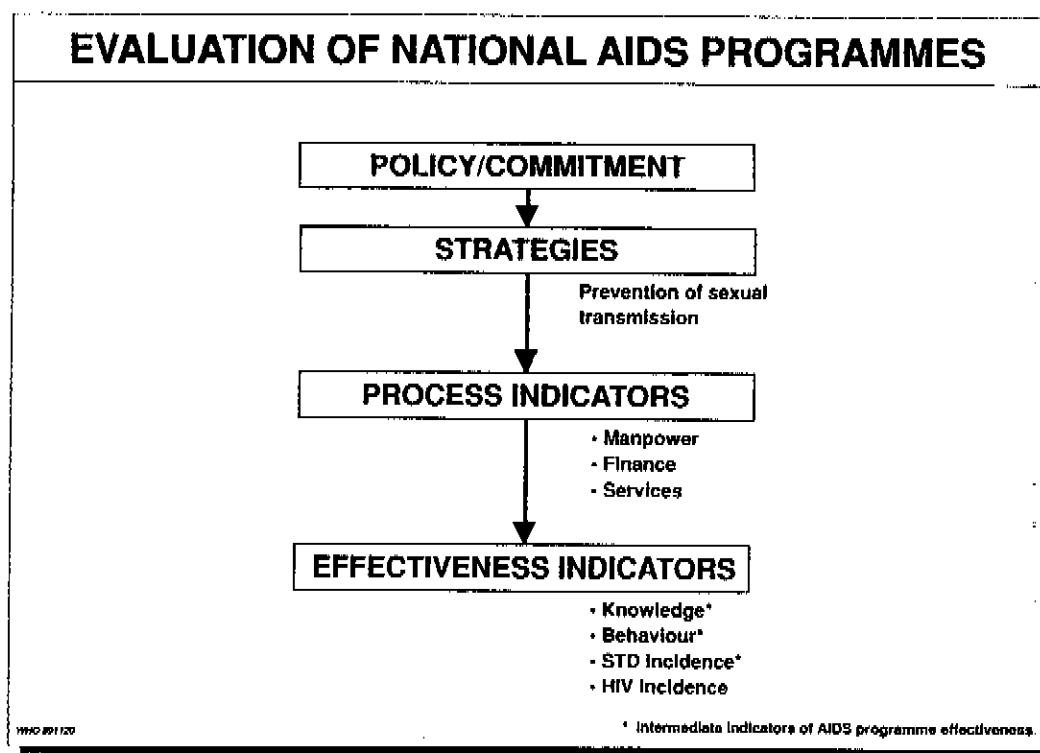
National AIDS Control Programme only recently completed a review of programme activities up to March 1989. HIV prevalence data from blood donor and survey sources were used to make specific recommendations for targetting high-prevalence and neighbouring districts in 1989-90 (3). Kenya has an ambitious programme for training counsellors: work will be concentrated in higher-prevalence provinces among high-prevalence groups. The National AIDS Control Programme in Uganda is now accelerating decentralization and district mobilization, due in part to finding a high prevalence of infection in some rural areas (4). In the United States, the Centers for Disease Control, Atlanta, reports that resources for counselling are increasingly directed to cities and specific areas where a higher prevalence of HIV infection has been identified (5). In several countries where HIV prevalence is low, surveillance data are being used to determine when systematic screening of blood donated for transfusion may need to be established. Examples include Albania, Bhutan, and Mongolia. Thus, it is obvious that HIV surveillance data play a central role in focussing preventive and control efforts.

2.3 Programme monitoring and evaluation

The most effective way to monitor the spread of HIV infection is through the use of data on geographic and population-specific incidence along with changes in prevalence. These data should also help to identify approaches that may reduce or prevent the spread of infection.

Changes in HIV seroprevalence provide the most certain indications of AIDS control programme effectiveness (Fig. 1). However, HIV prevalence data have limitations when used for evaluation purposes. First, the reasons for changes in HIV infection rates may not be apparent, and furthermore, it may be difficult to determine what proportion of such changes can be attributed to programme interventions. Second, it may take some time for control efforts to bring about changes in incidence.

Figure 1



For these reasons intermediate indicators, such as greater awareness and knowledge of AIDS, changes in behaviour, particularly those which lead to declines in the incidence of sexually transmitted diseases, should be examined. WHO/GPA is developing programme evaluation guidelines that use HIV prevalence data but in addition focus on more sensitive, intermediate indicators of effectiveness. The full utility of HIV surveillance data for programme evaluation is being explored but is not yet clear.

2.4 Development and testing of interventions

HIV prevalence and incidence data underlie the development and testing of intervention strategies that attempt to influence behaviour by helping to identify those groups and areas where such interventions are most urgently needed. Further, the interpretation of trends may suggest the type of interventions which may be successful among different risk behaviour groups.

2.5 Resource allocation and long-range planning

Past and current HIV surveillance data can be used to estimate the current and future AIDS caseload. WHO/GPA has developed an AIDS forecasting model which can provide more reliable estimates of total AIDS cases than can be obtained from the case reports of most developing countries (6). Uganda has attempted to use such estimates in replanning for 1989-90.

Switzerland, the United States of America, and many other countries have used HIV prevalence data to estimate the number of current infections; the likely future challenge to the health care system; projected costs; and the level of programme support needed to prevent further spread of HIV infection. Estimates can be calculated by the application of simple formulas or direct extrapolations where HIV prevalence data are available.

2.6 Educational value for individuals: enhancing the perception of individual risk and the likelihood of behavioural change

Dissemination of information about AIDS and HIV infection may have had an impact on individuals sufficient to have changed their behaviour, though the extent of such changes among individuals in different cultures and different educational and economic situations is unknown and undoubtedly varies. It may be possible that HIV surveillance data can be more directly used, if presented through the mass media or through individual counselling, to induce a more realistic perception of the risk of AIDS in those who continue to engage in high-risk behaviours.

3. Recommendations for HIV surveillance methods based on uses of data

The surveillance data to be collected and the procedures to be followed should be tailored to the epidemiology of HIV and the expected uses of the data. Data collection can then be expanded or limited according to programme goals and available resources.

The salient epidemiologic points which need to be taken into account for surveillance system design include: (a) HIV infections are not randomly distributed, but are associated with specific

behavioural risks so that infection rates differ substantially by geographic areas and population groups; (b) rates of HIV transmission are also influenced by social/behavioural factors; (c) HIV infections were introduced into different areas and populations at different times.

The major data uses described here are: (a) to promote political and financial commitment; (b) to direct and focus control efforts; (c) to develop intervention strategies; and (d) to promote further investigations. Only broad estimates of the HIV problem need to be useful for these purposes. Therefore, particularly where resources are limited, surveillance systems should be designed to provide only the essential data needed by the control programme. Where resources permit, additional data can be collected. Sentinel serosurveillance may be useful to estimate changes in prevalence and spread in some specific areas or population groups.

Recommended HIV surveillance activities, then, are as follows:

- 3.1** The sentinel surveillance methodology is a particularly appropriate means of collecting data from selected areas and groups and for determining the differences in HIV prevalence between groups and locations. Both high- and low-risk groups can be monitored to afford an indication of the range of HIV infection. Serosurveillance of high-risk groups is especially useful for targetting and should lead to suggesting acceptable intervention strategies.
- 3.2** Unlinked testing is the preferred method of obtaining specimens to avoid inaccurate trends. Sentinel surveillance data should represent the full range of persons served at the selected sites rather than a selected segment of the group surveilled - not for achieving more precise estimates - but to avoid potentially serious and costly mistakes. For example, if there is an increasing number of refusers over time, and if refusers are more frequently seropositive, the trend may falsely appear to be levelling off. This has already been seen in repeated studies and has led to the false conclusion that the situation is improving. This type of misleading information could result in a fall in commitment from policy makers or key staff. Therefore, methods to obtain specimens that reduce the unknown effects of self-selection bias should be used (e.g., unlinked testing). Proposed international guidelines on unlinked anonymous screening are available from the Global Programme on AIDS, World Health Organization (2).
- 3.3** Groups and areas for which only limited or no information is available should be kept under scrutiny with periodic surveys to ensure that important changes are not missed. This requires routine data evaluation which takes cognizance of the geographic distribution of HIV/AIDS as well as local awareness of high-risk behaviour. This regular review of available data should lead to the identification of important gaps in information on HIV prevalence and suggested periodic expansion of the system. Thus expansion may take the form of just 1 or 2 *ad hoc* studies performed in new locations or in new groups, using current methods.
- 3.4** Great precision in the assessment of HIV prevalence is not needed at most sites. It may be sufficient to determine, for example, if prevalence is under 1%, between 1%-5%, or in the range of 20%-40%. Large sample sizes are not required to classify groups within these broad categories. In fact, for public health purposes, it is more important to know how high HIV prevalence rates may be than to measure how low they may be. In many situations, sampling schemes that can indicate whether or not a threshold for action has been reached or exceeded may be all that is needed.

For example, if an AIDS control programme in a low-prevalence area, say in Asia, wanted to estimate the prevalence in the general population or in those attending antenatal clinics, would it be important to differentiate between a prevalence of 0.2%, 0.3% or 0.4%, or would it be sufficient to know simply that the prevalence is not more than 0.5% so that action could be initiated when the prevalence increased about that level? If it is sufficient to know that

prevalence has not exceeded the 0.5% threshold, then lot quality assurance sampling (LQAS) statistics can be used and costs substantially reduced since smaller sample sizes would suffice to provide that information. (Sampling frequency would be dictated by several factors described in 3.5 below.) WHO/GPA is suggesting LQAS to the collection and analysis of sentinel surveillance data in low prevalence areas. This is described in detail in the paper by Lwanga et al. (7)

- 3.5** Great precision is required at core sentinel sites where serologic studies to develop and test interventions are in progress, or where overall programme effectiveness may be assessed. Precise data are needed to demonstrate that specific interventions can be effective in reducing transmission.
- 3.6** The sampling frequency to determine trends or a threshold prevalence should be based on estimated incidence and the actions to be initiated by the programme when the threshold is reached or crossed. Frequent sampling of intravenous drug users or some populations of prostitutes may be considered worthwhile especially if their infection rates are close to the threshold and/or are rising rapidly. Less frequent sampling would suffice for groups whose infection rates are closer to those found in the general population, e.g., at antenatal clinics or at some sexually transmitted disease clinics, particularly in low-prevalence areas.
- 3.7** Whether prevalence is monitored by LQAS or more conventional methods, a basic question that must be answered is: "What action will be taken once the threshold is reached?" (For example, what is to be done when prevalence is found to be >1% or >5% in prostitutes in India or in a population of drug users in Northern Thailand, or >10% in a sexually transmitted disease clinic population in a city in the United States of America?)

A summary of these methodologic considerations is provided in Figure 2 for easy reference.

Figure 2

Recommendations to HIV sentinel surveillance methods

- 1. Sentinel serosurveillance is a high priority activity and very useful for guiding the targetting of interventions.**
- 2. Unlinked testing is preferred method of collecting specimens to avoid inaccurate trends.**
- 3. Regular review of HIV data is recommended to find gaps, in order to suggest new sites, plan expansion.**
- 4. The precision that is needed for advocacy and targetting is not great.
Therefore smaller sample sizes may be adequate.**
- 5. Greater precision may be performed at a few "core sites".**
- 6. Frequency of sampling should be dictated by estimated incidence, and as practical.**
- 7. Ask: "What action will be taken once a 'threshold' is reached?"**

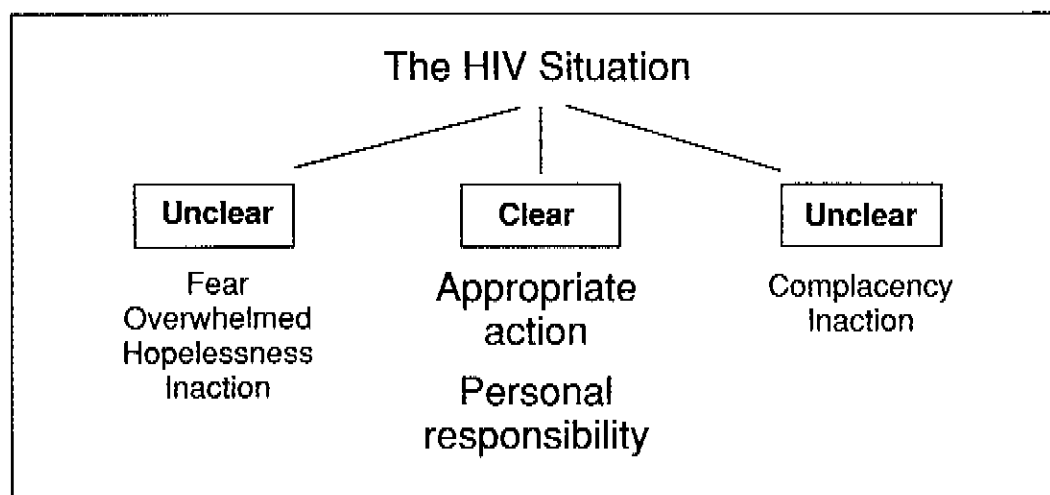
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4. Strengthening the use of HIV surveillance data

4.1 Use for commitment

Current projections suggest that the number of AIDS cases will increase several-fold over the next 5-10 years despite control efforts or expenditures. In several very hard-hit countries the effects of projected increases are already being seen. Increased caseloads and deaths can cause fear; a feeling of being overwhelmed or paralysed; and fatalism. Fatalism or complacency among politicians and donors, already too evident in some places, must be avoided. Political commitment is, after all, not stable. Efforts are also needed to mobilize forces to forestall the overwhelming of health services: several leading health officials from Africa and elsewhere have voiced such concerns. It is hoped that wider dissemination of data on HIV prevalence and trends may clarify the actual situation and ensure continued commitment. Uncertainties in HIV information may lead to either complacency or inaction (e.g. if the situation is believed improving), or fear and hopelessness (e.g., if the situation is believed overwhelming) (Fig. 3).

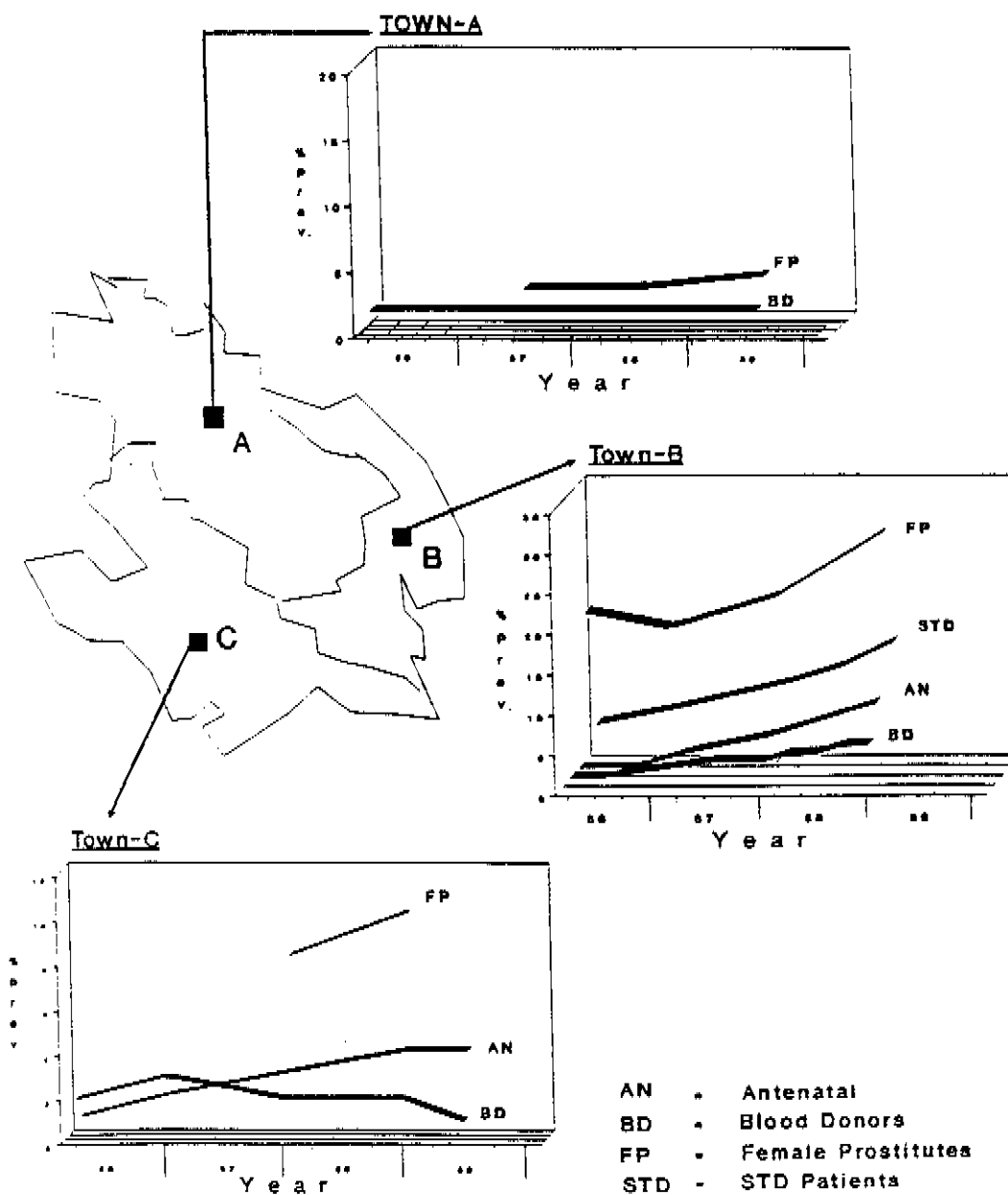
Figure 3. Clarification of the HIV situation to combat fear and complacency and to raise commitment



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To obtain continued political and financial commitment for national and local AIDS programmes, HIV surveillance data must be effectively formatted and presented to those individuals who make the decisions. Selected individuals who need to be informed about HIV surveillance data should include politicians, potential funders, public health planners, physicians and other health personnel at national and local levels, health promotion and prevention staff, as well as individuals, groups and communities at risk and those less at risk. (A possible format for presentation to politicians and planners might be that described in Fig. 4).

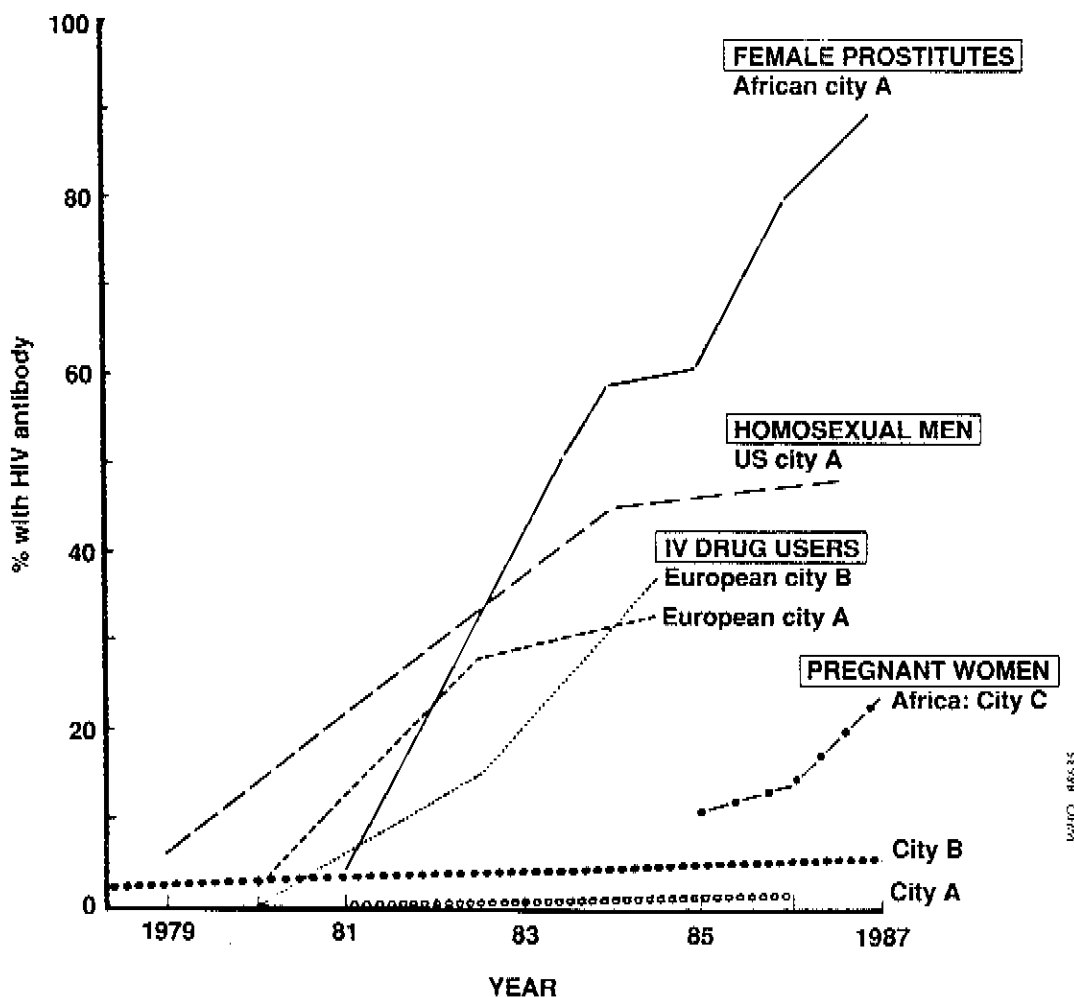
Figure 4. An example of trends in HIV serosurveillance data for 3 cities in an African country



4.2 Targetting interventions

With respect to the use of data for targetting specific population groups, the most urgent practical consideration is to ensure that silent HIV "explosions" or highly threatening situations are detected promptly. Changes in prevalence or incidence of up to 15% per year have been noted in groups of prostitutes; of 10%-20% per year in homosexual men; and of 5%-20% in intravenous drug users (Fig. 5). In Bangkok prevalence has increased from less than 1% to >40% in a year in a group of intravenous drug users. In Kenya, 40% of a cohort of prostitutes seroconverted in less than a year while on a study protocol. More must be done at these places immediately, yet, these are certainly not the only populations now seroconverting at such rapid rates.

Figure 5. Examples of trends observed by serial studies for different population groups and countries

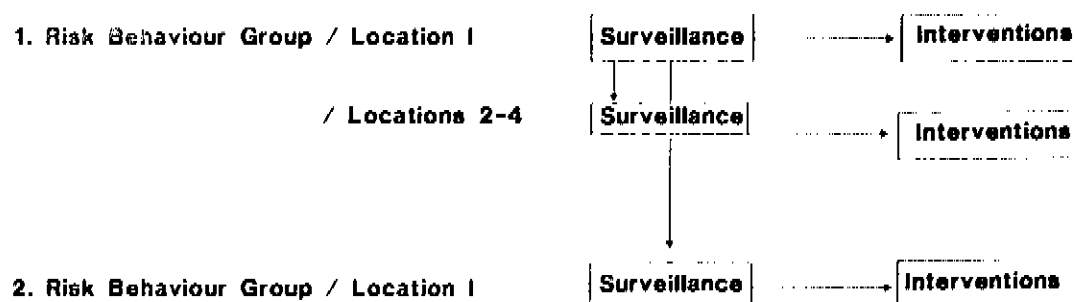


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Immediate expansion of surveillance and intervention activities are clearly needed in most places. However, a basic question remains about whether or not HIV control programmes are using the surveillance data available to them. This is not an academic question. Most disease control programmes have routinely collected surveillance data but have not applied them directly to field operations. Exceptions include smallpox, malaria, and, currently, measles control in the United States.

The transmission characteristics of HIV are such that control programme operations could be led to respond directly to surveillance data which demonstrate uneven geographical and population characteristics of those affected as well as the occurrence of outbreaks. If control programmes responded in a systematic and progressive way to such data, a simple framework could be proposed, which might look something like Fig. 6.

Figure 6. One possible framework for systematic and progressive application of serosurveillance data to HIV/AIDS control decisions and actions



When prevalence in the highest-risk groups (e.g., STD patients or prostitutes) in the areas of highest prevalence reach a predetermined threshold (e.g., 5% or 1%), interventions such as intensified counselling or counselling and voluntary testing programmes could be intensified. At the same or a different threshold, surveillance could be expanded to other populations and/or areas. Such an approach to phased surveillance and intervention is being taken by several countries. A control programme could arbitrarily determine its threshold for expanding surveillance and initiating interventions as resources permitted and experience dictated.

4.3. Intervention development

HIV surveillance data could provide the basis for intervention development by ensuring that interventions judged appropriate are designed, implemented, and evaluated in those areas where they are most needed and will have the maximum effect.

4.4 Monitoring and evaluation

The role of HIV surveillance data in monitoring and evaluation is threefold.

- a) Surveillance data provide the means to monitor the spread of the epidemic.
- b) Surveillance data enable programme managers to review and revise programme operations for adequacy and relevance to the spread of the epidemic. These data also serve as a basis for continually directing control efforts toward the most threatened populations, especially as changes in prevalence in different populations are detected.
- c) Surveillance data are necessary for the evaluation of programme effectiveness, though additional indicators may be helpful.

4.5 Estimating case load, resource planning

Serologic surveillance data can be used: a) to estimate the current and future caseload; b) to provide local and national programmes with a cross check on available AIDS case totals; and c) to furnish a rational basis for planning and requesting resources. More complete and accurate planning for care is urgently needed for the support of patients and their families.

4.6 To enhance perception of risk

New and additional ways of presenting HIV data to communities and individuals should be explored, and in particular, methods which might enhance the perception of individual risk.

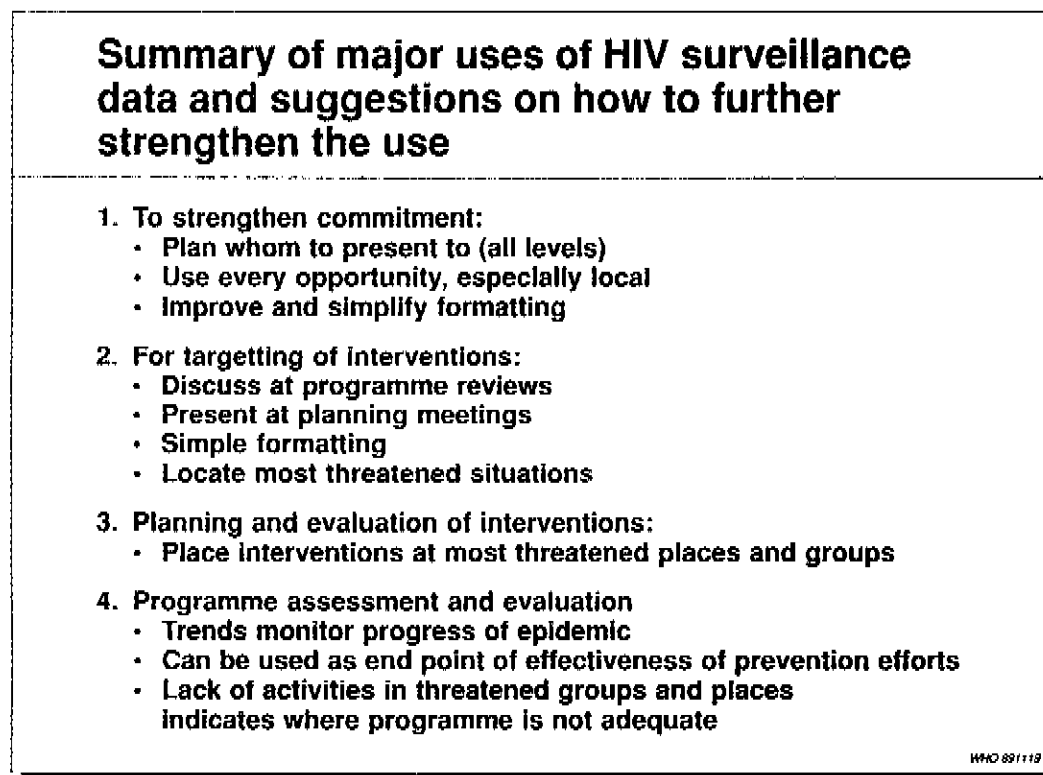
4.7 Other uses

Other possible uses for sentinel surveillance data which are beyond the scope of this paper include:

- a) the systematic use of HIV and other surveillance data for national and local programme decision making;
- b) the use of surveillance data to educate the populace about personal risk in order to influence behaviour;
- c) operational research on group risk versus individual perception of risk; and
- d) possible links between sentinel HIV surveillance systems and sentinel systems for knowledge, behaviour, and STDs.

A summary of suggestions on how to strengthen the use of HIV surveillance data is provided in Figure 7.

Figure 7



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Conclusions

In general, HIV surveillance data are used to motivate and guide decisions and actions. The principal uses of HIV surveillance are: to define the extent of the problem; to increase commitment to HIV prevention and control; to ensure that programmes are appropriately targeted; and to stimulate a regular assessment, and if necessary, a redirection of programme operations.

Public health planners, programme directors, health promotion and prevention personnel, and epidemiologists should consider more carefully when surveillance systems are initiated, what data are really needed for programme operations. In particular, they should consider when and what additional data are needed, what degree of precision is required, and most important, whether the data already available are being used to their fullest potential.

Wherever possible, the decisions and actions to be taken at different HIV prevalence thresholds should be specified. Many places have long since crossed the threshold of needed intervention.

As the HIV pandemic spreads to new areas and new populations, existing data must be used to the maximum extent to direct programmes to the most threatened populations and ensure the most effective interventions.

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