The next generation of HIV surveillance systems[1]

The diversity of HIV epidemics around the world is becoming more and more apparent, but existing HIV surveillance systems are poorly equipped to monitor trends in the spread of the virus, analyze and interpret the data collected, and disseminate information needed to take appropriate action. New, strengthened, "second-generation" surveillance systems are needed that will better capture this diversity of HIV epidemics, explain changes over time in mature epidemics, and yield information to reduce the spread of HIV and to provide care for those affected, according to a new report published jointly by the World Health Organization (WHO) and Joint United Nations Program on HIV/AIDS (UNAIDS).

Existing HIV surveillance systems: strengths and weaknesses

While they have shown a variety of weaknesses, the first generation of HIV surveillance systems also have a number of strengths on which new surveillance systems can be built. Existing systems, for example, have been crucial in a number of countries in generating a public response to HIV. This is particularly important given the many years that pass before large numbers of AIDS cases begin to appear. In some countries the publication of credible information about levels of infection has prompted political, religious, and community leaders to work to prevent further spread of HIV.

Existing surveillance systems can help target prevention efforts, by indicating who is infected and who is at risk of infection. Behavioral data can be especially useful for this purpose.

Surveillance can help in planning to reduce the impact of HIV and AIDS. Surveillance data can be used in models to estimate infection levels and the illness and death that will follow. The data can help nations to redirect resources to the areas that are most affected and to strengthen social support systems, such as for orphans.

Surveillance systems have helped countries monitor the success of their prevention and control efforts, with data both from serosurveillance and from surveys monitoring behaviors that lead to infection. In Uganda, for example, behavioral surveys showed changing behaviors over time, with increasing condom use and young people choosing to

[1] Based on: World Health Organization and Joint United Nations Program on HIV/AIDS. Second generation surveillance for HIV: the next decade. Geneva: WHO and UNAIDS; 2000. Available from: http://www.who.int/emc-documents/aids_hiv/whocdscsredc20005c.html. Accessed 10 October 2000. (Publications WHO/ CDS/CSR/EDC/2000.5 and UNAIDS/00.03).

delay having sexual relations. Serosurveillance corroborated these results, indicating lower infection rates among young women. The publication of this information promoted public support for ongoing prevention efforts among young people, an often-controversial area.

Current HIV surveillance systems suffer from a number of weaknesses. Existing systems, for example, do not make the best use of information available from other sources, such as data on sexually transmitted infections (STIs), behavioral studies, and mortality data. Many current systems have focused on the general population, by using data just from blood donors or pregnant women. While such systems have continued to indicate a low level of infection, HIV may already be at epidemic proportions in other subpopulations who are at high risk of infection, such as sex workers and their clients, drug injectors, STI patients, and men who have sex with men. Due to this surveillance system shortcoming, the epidemic may spread significantly before it is detected. Nevertheless, investigating trends in such subpopulations can be difficult, given the marginalized status that these persons often occupy in society.

Existing surveillance systems do not explain well the changes that take place as an epidemic matures and HIV prevalence begins to level off or to fall. While this is often presented as "good news," the truth may be much more complex. Such a stabilization can be due to a number of factors, including a true leveling off in new infections, rising death rates, changes in the likelihood of being tested, changes in the age structure of infection, and changes in the survival time of infected persons. One solution to these difficulties is to have surveillance systems focus their attention on new infections, which are not so affected by these factors.

Therapy can also confuse current surveillance systems, especially when the systems focus more on AIDS cases than on HIV cases. As new therapies have been introduced, the progression from HIV to AIDS has been slowed, making it harder to interpret the relationship between AIDS prevalence and HIV infection. In addition, people's willingness to be tested for HIV can be affected by changes in access to therapy and the perceived effectiveness of therapy.

Existing systems rarely change as an epidemic evolves over time, and they are unable to explain the different types of epidemics that occur in different countries. In some nations, the virus has remained contained in small, well-defined subpopulations. Elsewhere, the epidemic has spread from those subpopulations to a larger population of persons who would not consider themselves at high risk of infection. Surveillance systems need to be flexible enough to change as the epidemic evolves. For example, a country might find a growing number of HIV and AIDS cases reported among women even though it is generally believed the epidemic is concentrated among men who have sex with men. In that situation, the surveillance system needs to begin to track risk behavior and identify sources of infection in the heterosexual population. And if infection rates over one percent are consistently reported in antenatal clinics, it indicates a need to establish new or augment existing surveillance sites in rural areas, to supplement sites in urban areas.

Principles of second-generation surveillance

Rather than proposing any radically new methods of data collection, second-generation surveillance systems instead focus existing methods on appropriate populations and subpopulations and combine existing methods in ways that have the greatest explanatory power.

In developing such second-generation surveillance systems, following several key principles can greatly improve their effectiveness, according to the new WHO/UNAIDS report.

Surveillance systems should be appropriate to the epidemic state, that is, answering the needs of a particular country situation at a particular point in its epidemic evolution.

Surveillance systems should evolve as the epidemic changes, such as by expanding the reach of the system or changing its focus. However, as countries change their surveillance systems, they need to consider the tradeoff between gaining new types of information and losing comparability with earlier data sets.

Surveillance systems should be efficient, focusing resources where they can provide the most useful information. This will often mean tracking behavior and infection in subpopulations whose members are at high risk of contracting or passing on HIV infection.

Biological and behavioral data need to be combined and compared in order to maximize the system's explanatory power. Two sets of data pointing in the same direction make a more convincing case than just one type of data.

Information from other sources should be integrated into the HIV surveillance system, such as from the surveillance of tuberculosis and of STIs, and from the death registration system.

Finally, the information coming a surveillance system must be applied effectively. The data generated should be used to identify the subpopulations

at risk, to pinpoint behaviors which continue to expose people to infection, and to design interventions that reduce risk behavior. The data can also be applied in planning for future care and support needs and to measure a country's progress over time in slowing the spread of the epidemic.

Epidemic states: low-level, concentrated, and generalized

HIV epidemics around the world can be divided into three basic states: low-level, concentrated, and generalized.

In a low-level epidemic, HIV infection may have existed for many years, but it has never spread to significant levels in any subpopulation. Infection largely occurs among persons with higher risk behavior, such as sex workers, drug injectors, and men who have sex with men. It may be that the virus was only recently introduced, or the risk networks may be diffuse, with low levels of partner exchange or sharing of drug-injecting equipment. In numerical terms, HIV prevalence has not consistently exceeded five percent in any subpopulation.

In a concentrated epidemic, HIV has spread rapidly in one or more subpopulations but has not become well established in the general population. The future course of the epidemic is determined by the frequency and nature of links between the highly infected subpopulations and the general public. Numerically, HIV prevalence is above five percent in at least one subpopulation but is still below one percent among pregnant women in urban areas.

In a generalized epidemic, HIV is firmly established in the general population. Although some subpopulations may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain the epidemic. In numerical terms, HIV prevalence is consistently over one percent among pregnant women.

Surveillance in low-level and concentrated epidemics

The issues that countries face in tracking HIV and risk behavior differ in different epidemic states. Further, large and diverse countries may need to tailor their surveillance systems to needs at the regional and local level, so as to produce data to help shape local responses within a national framework.

With low-level epidemics, HIV is often not considered a priority. Even when prevalence rises in some subpopulations, countries may fail to recognize the danger since such populations are often marginalized and overlooked. Nevertheless, without a surveillance system in place, countries are unable to identify changes in risk behavior that can lead to a wider epidemic.

To identify this increasing risk, surveillance systems will need to rely on behavioral data collection and on such other risk markers as STI levels. The surveillance systems need to investigate "bridging populations," or persons in higher-risk subpopulations who interact with people of lower risk in the general population. This might include, for example, men who have sex with both men and women, and married clients of sex workers. Sometimes these bridging populations are concentrated in certain occupational groups, such as mine workers, farm laborers, soldiers, and truck drivers and other transport workers. Behavioral studies can look at such questions as whether these higher-risk persons use condoms with some partners but not with others. HIV serosurveys among these groups can provide early warnings of the impending spread of infection to a wider population. In addition, data indicating that these individuals interact with persons of lower risk can help build support for prevention measures.

Tracking HIV in marginalized subpopulations can be difficult. If members of those communities fear that information about their behavior will be used against them, they will either refuse to participate in studies or will lie to the investigators. Ensuring fully informed consent and absolute confidentiality can promote cooperation. The information that is collected should be shared with the communities, to help them mobilize against the spread of HIV and to cope with its consequences. Whether to share such information with the general public is a more difficult issue. In the early stages of an epidemic, the general reaction may be to call for restrictive measures against the subpopulations with higher risk. Rather than eventually reducing the spread of the virus, such steps simply drive risk behavior further underground and make prevention and care programs more difficult.

With concentrated epidemics, surveillance will need to be expanded. Behavioral studies with the general population, especially young people, can gauge the potential for more widespread infection. Such surveys can also provide a baseline for assessing future behavioral changes. Surveillance should also be initiated with pregnant women, to investigate whether bridging-population links are helping to establish the epidemic in the general population.

Table 1 summarizes the recommendations on HIV surveillance in low-level epidemics, and

TABLE 1. Surveillance for HIV in low-level epidemics

Main questions	Core surveillance	Additional surveillance/Studies
Are there groups with risk behavior?	• Formative research and mapping of groups with potential risk behavior • Analysis of available STI surveillance data[a]	• Mapping to cover a larger geographical area, and to be conducted more frequently • Size estimates of groups with potential risk behavior
What are the main risk behaviors?	• Risk behavior surveys in groups considered at high risk for HIV infection	• Increased geographical coverage of risk behavior surveys • STI prevalence and incidence studies in groups with risk behavior
How much HIV infection is there?	• HIV serosurveillance in identified groups with risk behavior • Analysis of available blood donor HIV screening data	• Larger coverage and increased frequency of HIV serosurveillance in identified groups with risk behavior • HIV serosurveillance in pregnant women in urban areas
Who else might be affected, and to what extent?	• AIDS case reporting	• Risk behavior surveys focused on potential bridging populations

[a] STI = sexually transmitted infection.

TABLE 2. Surveillance for HIV in concentrated epidemics

Main questions	Core surveillance	Additional surveillance/Studies
How much HIV infection is there?	• HIV serosurveillance in groups with risk behavior • Annual HIV serosurveillance in pregnant women in urban/high-exposure areas • Analysis of available blood donor HIV screening data	• Wider geographical coverage and increased frequency of HIV serosurveillance in identified groups with risk behavior • HIV serosurveillance in bridging populations and in pregnant women
What are the main risk behaviors and how do they change over time?	• Repeated risk behavior surveys in groups with risk behavior • Repeated risk behavior surveys in bridging populations • Analysis of STI data in groups with risk behavior and in bridging populations[a]	• Wider geographical coverage and increased frequency of repeated behavioral surveys in groups with risk behavior and in bridging populations • Surveys of health-seeking behavior for STIs
Who else might be affected, and to what extent?		• Repeated risk behavior surveys in the general population in all areas • HIV case reporting

[a] STI = sexually transmitted infection.

Table 2 provides a similar summary for concentrated epidemics.

Surveillance in generalized epidemics

With generalized epidemics, heterosexual transmission is the dominant mode for the spread of HIV, and small shifts in the general-population prevalence can lead to massive burdens for health care systems. The time for an early warning has passed, and the surveillance systems must instead focus on strengthening their capacity to track and explain trends and to indicate the effectiveness of prevention programs (Table 3). Repeated behavioral surveys can examine the extent to which changes in behavior might contribute to trends in prevalence. Surveillance systems among pregnant women especially need to focus on the youngest age groups, where HIV prevalence most closely reflects the rate of new infections.

With such broader epidemics, surveillance systems will need to make more efforts to investigate men in the general population, who are often inadequately covered by many of the standard HIV

TABLE 3. Surveillance for HIV in generalized epidemics

Main questions	Core surveillance	Additional surveillance/Studies
What are the trends in HIV infection?	• Annual HIV serosurveillance in pregnant women in urban and rural areas • Increased sample size in high-volume sites to enable analysis by age groups • AIDS case reporting	• HIV serosurveillance in pregnant women in a larger number of sites • HIV serosurveillance in groups considered at high risk (e.g., sex workers and their clients) • Population-based HIV prevalence studies to validate surveillance data
Is behavior changing? Do recorded changes help explain trends in HIV infection?	• Repeated behavioral surveys in groups considered at high risk of HIV infection • Analysis of STI surveillance data in groups considered at high risk of HIV infection[a] • Repeated risk behavior surveys in the general population, with a focus on young people • Analysis of STI surveillance data in the general population	• Larger coverage of behavior surveys
What is the impact of HIV?	• Vital registration data • Surveillance of TB and other HIV/AIDS-related illnesses	• Other death data, from census and other studies • Studies of access to care

[a] STI = sexually transmitted infection.

surveillance approaches. Surveillance in rural areas also needs to be strengthened, as does the collection of data on HIV-associated morbidity and mortality for use in planning appropriate preventive and supportive services.

SINOPSIS

La próxima generación de sistemas de vigilancia del VIH

La diversidad de la epidemia de VIH en el mundo es cada vez más evidente, pero, según un nuevo informe publicado conjuntamente por la Organización Mundial de la Salud y el Programa Conjunto de las Naciones Unidas sobre VIH/SIDA, los actuales sistemas de vigilancia del VIH están mal preparados para seguir las tendencias de propagación del virus, analizar e interpretar los datos recogidos y diseminar la información necesaria para actuar adecuadamente. Son necesarios nuevos sistemas de vigilancia de "segunda generación, fortalecidos, que capten mejor la diversidad de la epidemia de VIH, expliquen sus cambios en el tiempo y proporcionen información para reducir la propagación del virus y atender a los afectados. La epidemia de VIH se puede dividir en tres categorías básicas (bajo nivel, concentrada y generalizada), de acuerdo con las cuales cada país deberá adaptar la adquisición de información a partir de la serovigilancia, de las encuestas sobre conductas de riesgo y de otras fuentes de información.