

Second-generation HIV surveillance: better data for decision-making

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Abstract This paper seeks to outline the key elements of the expanded surveillance efforts recommended by the second-generation HIV surveillance approach. Second-generation systems focus on improving and expanding existing surveillance methods and combine them in ways that have the greatest explanatory power. The main elements of this approach include: considering biological surveillance — HIV, AIDS, sexually transmitted infections (STIs) — and behavioural surveillance as integral components, targeting surveillance efforts at segments of the population where most new infections are concentrated — which might differ depending on the stage and type of the epidemic — and providing the rationale for the optimal use of data generated for monitoring the HIV epidemic and evaluating national AIDS control programmes.

The paper emphasizes improvements in existing surveillance methodologies and discusses in detail crucial issues such as the validity of HIV prevalence data measured in pregnant women and linking HIV surveillance and behavioural data collection. In addition, a strategic partnership between second-generation surveillance and AIDS programme evaluation is proposed that stresses the complementary roles of these data collection activities in determining the effectiveness of prevention and care programmes and explaining the epidemiological trend data collected by sentinel serosurveillance systems.

In conclusion, second-generation HIV surveillance systems provide a comprehensive, cost-effective and appropriate response to the information needs of AIDS control programmes. The implementation of such systems, including a better use of the data generated by the system, will ensure that national programmes are in the best possible position to respond to the challenges of the epidemic.

Keywords HIV infections/epidemiology; Epidemiologic surveillance/methods; Sentinel surveillance; Biological markers; Behavioral risk factor surveillance system; Data collection/methods; Pregnancy (*source: MeSH, NLM*).

Mots clés HIV, Infection/épidémiologie; Surveillance épidémiologique/méthodes; Surveillance par système sentinelle; Marqueur biologique; Behavioral risk factor surveillance system (U.S.A); Collecte données/méthodes; Grossesse (*source: MeSH, INSERM*).

Palabras clave Infecciones por VIH/epidemiología; Vigilancia epidemiológica/métodos; Vigilancia de guardia; Marcadores biológicos; Sistema de vigilancia de factor de riesgo comportamental; Recolección de datos/métodos; Embarazo (*fuentes: DeCS, BIREME*).

Arabic

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Introduction

Information generated by effective surveillance systems is essential for health professionals, national governments, and international agencies to mounting an adequate national and international response to the HIV/AIDS epidemic. There are many uses of surveillance data in addition to estimating the magnitude of the epidemic and monitoring its trends. For example, the data can be used to strengthen commitment, mobilize communities, and to advocate for sufficient allocation of resources to national AIDS control programmes. Behavioural data are particularly useful for targeting interventions to individuals at higher risk or in geographical areas with a concentration of high-risk behaviour.

Surveillance data are also essential for planning and evaluating prevention and care activities and for assessing their impact. Finally, estimating the number of current and expected HIV/AIDS caseloads can be useful in planning and providing care services. This is particularly important at a time when substantial new resources are being allocated to greatly improve access to HIV treatment.

In response to these expanded needs for data collection, WHO and UNAIDS, the Joint United Nations Programme on HIV/AIDS, in collaboration with other international partners, are promoting the improvement of surveillance systems based on the “second-generation” approach. This approach considers biological surveillance — i.e. HIV sentinel surveillance,

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reporting of AIDS cases, and surveillance of sexually transmitted infections (STIs) — and behavioural surveillance to be integral and essential components of surveillance systems (1, 2). Second-generation systems focus on strengthening and improving existing surveillance methods and combine them in ways that have the greatest explanatory power. Surveillance efforts are targeted at segments of the population in which most new infections are concentrated, which might differ depending on the stage and type of the epidemic. Second-generation systems enable HIV serosurveillance and behavioural data to be used and compared concurrently, allowing national programme managers not only to better understand and explain the observed trends in the HIV epidemic but also to better assess the impact of national AIDS control programmes.

This paper describes the recommended data collection strategies, with emphasis on the key elements of the expanded surveillance efforts. It also provides the rationale for the development of technical direction and guidance in supporting countries with different types and at different stages of the epidemic to implement second-generation HIV surveillance systems. Although second-generation HIV surveillance is designed primarily for countries in the developing world, the concept of this surveillance is equally applicable to developed countries.

Improving and expanding existing surveillance methodologies

Different data collection systems deliver different products, and with varying degrees of cost and complexity. A national programme must make choices about what mix of methods to adopt, with what frequency, and on what scale, if its resources are to be used in the most efficient way. These choices will reflect at what stage the country's epidemic is, as well as the country's political and social environment, existing capacity for data collection, and available resources. The current guidelines for second-generation surveillance activities provide a useful framework for an evolving national surveillance system (1,2). However, increasing the quality of surveillance data will require considerable investment in human and financial resources. Although the move towards more integrated disease surveillance systems (3) may assist in the task of building national capacities and expertise for expanded surveillance activities, there is still the need for developing a consensus on specific guidelines and recommendations to improve the collection, analysis, interpretation, and dissemination of the different types of HIV-related data.

Behavioural surveillance — emphasis on trend data

There is general consensus that behavioural data are essential to increase our understanding of what is driving the HIV prevalence and incidence trends and to improve our ability to define the response to prevention needs. Behavioural surveillance is now established as a key component of the second-generation surveillance package. Although a system of sentinel surveillance for monitoring HIV infection among selected populations has been recommended by WHO since 1988 (4), the benefits of repeated behavioural surveillance surveys for specific subpopulations were not recognized until much later. (2) As a result, many countries are still in an early phase of adapting and incorporating the proposed behavioural data collection into their national surveillance systems.

The main objective of behavioural surveillance is to track trends in risk behaviours in defined subpopulations over time,

through multiple rounds of data collection with a consistent, repeatable sampling strategy (5). This is in contrast to traditional pre/post knowledge, attitude, practice, and belief (KAPB) surveys, which focus mainly on the measurement of changes in indicators between two points in time and often lack rigorous sampling approaches. Although repeated surveys are also subject to measurement error, the feature of repeated surveys adds an element of robustness to the data obtained. Multiple rounds enable us to recover from one round of very inaccurate survey data, identifying the results of a particular round as "outliers".

Complementary qualitative research may provide additional useful information for exploring the individual, social, economic, and cultural context that determines who continues to be vulnerable to HIV infection and why. For example, if the expected changes in risk behaviours are not being observed, qualitative research (e.g. focus group discussions or key informant interviews) can assist in explaining the reasons for the lack of success (e.g. misleading messages, problems with product delivery, ineffective or inappropriate targeting). This allows national AIDS programmes to respond with appropriate modifications in ongoing prevention activities.

HIV surveillance — points for consideration

Sentinel HIV serosurveillance monitors trends in HIV infection in populations that are either representative (or a good proxy) of a larger population or of particular interest (e.g. subpopulations with known risk behaviours). In sentinel surveillance, selection of sites and population groups should be based on several considerations including feasibility, cost, availability of human resources, and the level and type of the epidemic. Ethical and practical considerations should guide the selection of populations with high-risk behaviour — e.g. intravenous drug users (IDU), men having sex with men (MSM), and sex workers — especially in societies where people are subject to imprisonment or systematic discrimination for their behaviours (6).

How representative are antenatal clinic sentinel data?

The prevalence of HIV in antenatal clinics (ANCs) continues to be the single most important source of data in HIV surveillance, particularly in countries with generalized epidemics, and it is widely used to estimate HIV prevalence in the adult population. However, ANC sentinel data are subject to several potential selection biases related to, for example, convenience sampling (sites are not randomly chosen), usage and coverage of ANC services, differentials in risk behaviours and contraceptive use, lower fertility rates among women with HIV-1 infection (7), and other sociodemographic factors such as age distribution of antenatal clinic attenders, level of education, socioeconomic status, and migration patterns. Moreover, there is insufficient understanding of the relative importance of these factors in different settings, and even less is known about how these factors may vary over time.

If the factors leading to selection biases remain the same over time, then serial data from ANC sentinel sites will provide a solid basis for analysis of HIV trends in that population. However, selection biases may change over time. Comparisons between ANC sentinel surveillance and general population serosurveys have indicated that data from pregnant women may differ significantly from the data from the general female population, and the relationship can go in different directions at different stages

of the epidemic, and for different age groups (8–11). The considerable variation in the findings suggests that extrapolations from ANC data to the general adult population should be made with caution.

Population-based studies carried out periodically in the catchment areas of ANC sentinel sites can help evaluate the sources of bias in different country settings (11, 12). Cross-sectional, population-based HIV surveys are best suited to provide representative prevalence data at the population level, but they are usually expensive and difficult to implement. Recently, population-based prevalence data on HIV have been collected by adding HIV testing to regular population-based health surveys — usually carried out every 3–5 years — such as the Demographic and Health Surveys (DHSs) (13). Although this might be a feasible solution in some countries, such surveys are not carried out frequently enough to be considered a timely source of HIV trend information, although they can contribute important data that may be used to “calibrate” the results obtained from pregnant women (14, 15).

Linking HIV surveillance and behavioural data collection

Linking HIV surveillance and behavioural data collection in antenatal clinic attenders would seem an efficient way to correlate HIV serostatus with specific behaviours or behavioural changes. However, pregnant women are not considered to be a suitable population for behavioural surveillance because asking women in the later stages of pregnancy about their sexual behaviour and condom use will not generally yield results that are typical of the sexually active population at large. Adding HIV testing to population-based studies such as the DHSs may allow the linking of core behavioural data to HIV test results. However, the cost and complexity of collecting HIV and behavioural data from the same people in population-based studies are notable, and interpretation of the obtained information is complicated by the potential biases introduced by this survey procedure and the risk of correlating present behaviours with past infections (16).

An alternative solution would be to establish an association between behaviour and HIV prevalence at the community level by collecting data from the same source population. For example, repeated behavioural surveys could be conducted in a random selection of households in the catchment area of selected key ANC sentinel sites, such as large urban antenatal clinics. A minimum set of sociodemographic data should also be collected from all ANC attenders at the selected sentinel sites, including data on age, parity, time since last birth, level of schooling, occupation, and length of time living in the area (as an indicator of migration). These parameters can be compared with those collected in the population-based behavioural surveys, allowing any systematic differences between the two groups to be identified and adjusted for in the analysis.

AIDS cases — from passive reporting to active sentinel AIDS surveillance

The reporting of AIDS cases continues to play an important role in advocacy. In most developing countries, however, inconsistent application of case definitions, poor diagnostic facilities, and heavy underreporting due to weaknesses in the health system and/or unwillingness to record an AIDS diagnosis because of stigma or loss of benefits have all contributed to very inadequate case reporting. This clearly has limited the utility of passive case reporting as a tool to track the magnitude of the AIDS epidemic, or even trends over time. Integrating AIDS case reporting in

national disease surveillance systems has the potential to increase the completeness of reporting but will limit the amount of information that can be linked to AIDS cases (3).

To overcome these limitations, it is suggested that an active sentinel system be set up for AIDS-related morbidity and mortality in selected hospitals with high caseloads (17). The AIDS sentinel system will be focused on a small number of facilities and is expected to provide additional quality information on several parameters such as the age and sex distribution of AIDS cases, AIDS incidence and AIDS-specific mortality, major risk exposures, and the distribution of AIDS-related opportunistic infections as well as treatment outcomes. Such information is crucial in assessing care needs and documenting changes in the age and sex distribution of HIV infection over time.

STI surveillance — biological markers for risk behaviour

Strong biological and epidemiological evidence has long pointed to the critical cofactor role that STIs play in facilitating/increasing HIV transmission and acquisition (18). Technical documents have been prepared to provide practical guidance in establishing STI data-collection systems and assessing the outcome of STI control efforts (19–21). Monitoring trends in STIs in the general population or specific target groups is the primary purpose of STI prevalence surveys, and the availability of accurate diagnostic tests for several common STIs has made such population-based surveys more feasible.

The prevalence and/or incidence of selected STIs has been suggested as a proxy measure for the effectiveness of HIV prevention programmes because STIs are markers of high-risk sexual activity. An STI with high infectivity, short incubation and infectiousness periods, and little resulting immunity would be a sensitive marker for recent unprotected sexual contact. As such, effective interventions for HIV prevention, directed at sexual risk reduction, should reduce STI prevalence and incidence rates more rapidly than the prevalence and incidence of HIV infection, given that HIV is a lifelong viral infection with a comparatively lower transmission probability. Bacterial STI measures would therefore be useful indicators of recent changes in sexual behaviour for HIV — or lack, thereof (22).

This common sense notion of STIs being a marker for the effectiveness of HIV prevention programmes is actually quite complex (23). First, STIs is a term that refers to a diverse group of about 30 pathogens — bacterial, protozoal, and viral — each with unique biological features of infectiousness, host response, and associated patterns of sexual contact. Second, effective treatment will have a dramatic impact on the incidence of treatable STIs. Consequently, one cannot attribute changes in STI incidence solely to changes in behaviour. Finally, STI changes must be put in the context of longer-term trends, where such data are available. Thus, although information on STI prevalence and incidence rates is essential information for STI control programme purposes, the use of STI data in combination with behavioural surveillance data to “validate” observed trends in risk behaviours should be approached with caution.

Surveillance and programme evaluation — a strategic partnership

Our efforts to monitor and respond to the global HIV/AIDS pandemic are complicated by the temporal and geographical evolution of the many subepidemics at the regional or country level. Interpretation of epidemic trends is made more difficult by our

poor understanding of how different social, behavioural, and epidemiological factors influence the dynamics of the epidemic in different settings. When reductions in HIV prevalence and HIV incidence are observed at the population level, the following key questions arise. Are the observed changes a reflection of the natural progression (natural history) of the epidemic? Are the observed changes a product of a “spontaneous” change in behaviour? Are the observed changes a result of prevention interventions?

The relationship between HIV incidence and prevalence grows increasingly complex as the epidemic matures and prevention efforts try to mitigate it at the same time. Changes in HIV prevalence may be suggestive of the long-term impact of multiple HIV/AIDS prevention interventions, but it is very difficult to prove a causal relationship with one or more specific interventions. In fact, many other factors could also account for such changes (Box 1). The difficulties in establishing evidence of a relationship between a change in behaviour and epidemic decline is further compounded if we add the claim that the documented behavioural change is caused by intervention effects. This may not necessarily be the case. In particular, evidence has shown that when evaluating the impact of interventions that lead to changes in behaviour in the face of growing numbers of people with AIDS-related illnesses, secular trends toward risk reduction will occur (24).

The interpretation of HIV trends will be even more challenging in the coming years when antiretroviral (ARV) treatment becomes more widely available for infected individuals. Increased access to ARV treatment will increase the survival time of HIV-infected people and, at the same time, it may have multiple, potentially altering effects on HIV transmission by increasing the pool of HIV-infected persons, disinhibiting prevention behaviours (25), and by perhaps decreasing infectiousness through reduction in viral loads.

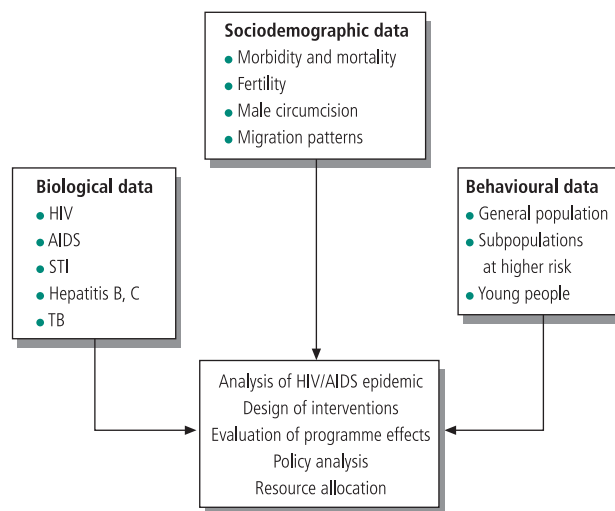
In view of these challenges, there is now an emerging consensus among evaluation and surveillance experts that national AIDS control programmes need to collect HIV data in conjunction with behavioural, socioeconomic, and sociodemographic data (Fig. 1). In fact, some of these data are often already routinely collected by other programmes or institutions (e.g. National DHSs, National Census, tuberculosis programmes, etc.). A joint planning and coordination process with these programmes is crucial to ensuring that resources and expertise are used as efficiently as possible.

Although programme evaluation and surveillance activities do overlap, they are not the same and they serve different purposes. However, programme evaluation and second-generation surveillance systems play essential, complementary roles in determining

Box 1. Factors contributing to observed declines in HIV incidence and/or prevalence

- Saturation of the epidemic among susceptible individuals
- Increasing AIDS-associated mortality, especially in mature epidemics
- Decrease in new HIV infections as a result of a change in behaviour:
 - effect of interventions
 - spontaneous (e.g. having a friend or relative with HIV/AIDS)
- Decrease in the prevalence of biological cofactors that can facilitate HIV transmission e.g. sexually transmitted infections (STIs):
 - effect of interventions
 - AIDS-related mortality in groups with high STI levels
- Population differentials related to in- and out-migration patterns
- Sampling bias and/or errors in data collection

Fig. 1. Types of data needed for improved analysis and decision-making



WHO 04.1

whether or not prevention and care programmes have been successful. The combined analysis of these datasets serves a dual purpose: it provides information for better interpretation and explanation of the epidemiological data and it will enable a more valid assessment of programme effects on the course of the epidemic in a given setting to be carried out. Fig. 2 illustrates the different levels of programme monitoring and evaluation efforts and shows that behavioural and biological surveillance systems provide essential data for assessing programme outcomes and programme impact (26).

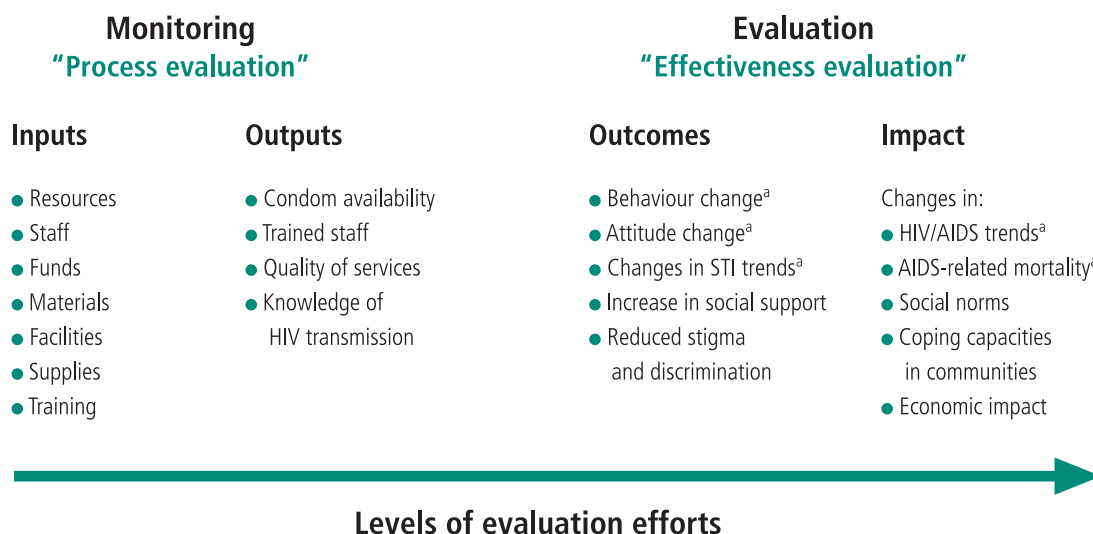
Surveillance, monitoring, and evaluation are essential components of national AIDS programmes and should be adequately funded. However, it is crucial that national programmes seek to strike a sensible balance between the resources allocated for surveillance and funding of prevention and care programmes. In general, we would recommend that at least 10–15% of the HIV/AIDS budget be committed to programme evaluation and second-generation HIV surveillance activities.

It also is important to realize that prevention programmes have to be implemented for sufficient amounts of time and on a large enough scale to have an impact on personal behaviour, social norms in communities, and on the epidemic. Documenting those successful national prevention efforts is a prime task of surveillance and programme evaluation systems and is instrumental in generating public support for continued prevention and care programmes.

Conclusions

Epidemiological and behavioural surveillance systems have evolved and continue to evolve in response to the changing dynamics of the epidemic, the increased knowledge about HIV infection, and the evolving needs of national prevention and control efforts. Information generated by effective surveillance systems is essential for health professionals, national governments and international agencies in mounting an adequate national and international response to the HIV/AIDS epidemic. In addition to being used for estimating the magnitude of the epidemic and monitoring its trends, surveillance data are essential for advocacy, strengthening commitment, mobilizing communities,

Fig. 2. Framework of monitoring and evaluation efforts



^a Information provided by second-generation HIV surveillance systems.

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advocating for sufficient allocation of resources to national programmes, and assisting in targeting interventions to people or places with high-risk behaviours.

The proposed epidemiological and behavioural surveillance components will substantially improve the ability of national programmes to meet several important objectives:

- To provide key epidemiological information on the course of the epidemic by monitoring trends over time.
- To build a strategic partnership between second-generation surveillance and national HIV/AIDS/STI programme evaluation for improving the design of targeted interventions and the assessment of their effectiveness.
- To form linkages with other sectors, agencies, and/or research institutions involved in data collection, data analysis, and data dissemination.

- To ensure sustainability of surveillance activities by fostering national ownership and commitment, advocating for appropriate levels of resource allocation, and identifying synergies with integrated disease surveillance systems.
- To prepare for additional and/or future surveillance and data collection needs.

Second-generation HIV surveillance systems provide a comprehensive and appropriate response to the information needs of AIDS control programmes. Their implementation, including a better use of the data generated by the system, will ensure that national programmes are in the best possible position to respond to the challenges of the epidemic. ■

Conflicts of interest: none declared.

Résumé

Systèmes de surveillance du VIH de deuxième génération : de meilleures données pour décider

Le présent article vise à présenter une vue d'ensemble des principaux éléments des opérations de surveillance élargie recommandées par les systèmes de surveillance du VIH de deuxième génération. Ces systèmes s'attachent à améliorer et à élargir les méthodes de surveillance actuelles et à les associer de manière à en maximiser le pouvoir explicatif. Ce système s'articule autour de trois axes : considérer la surveillance biologique – VIH, SIDA, infections sexuellement transmissibles (IST) – et la surveillance comportementale comme des parties intégrantes, cibler l'action de surveillance sur les segments de la population où se concentrent la plupart des nouvelles infections – qui pourraient être différents selon le stade et la nature de l'épidémie – et expliquer le bien-fondé de l'utilisation optimale des données recueillies pour suivre l'épidémie de VIH et évaluer les programmes nationaux de lutte contre le SIDA.

Le présent article souligne les améliorations apportées aux méthodes de surveillance actuelles et examine en détail les questions cruciales telles que la validité des données de

prévalence du VIH mesurées chez les femmes enceintes et le lien entre la surveillance du VIH et la collecte des données sur le comportement. Il est en outre proposé d'instaurer une alliance stratégique entre la surveillance de deuxième génération et l'évaluation des programmes de lutte anti-SIDA pour souligner les rôles complémentaires de ces activités de collecte de données au moment de déterminer l'efficacité des programmes de prévention et de soins et d'expliquer les tendances épidémiologiques que font ressortir les données rassemblées par les systèmes sentinelles de sérosurveillance.

En conclusion, les systèmes de surveillance de deuxième génération du VIH permettent de répondre de manière globale, économique et adaptée aux besoins d'information des programmes de lutte contre le SIDA. L'application de tels systèmes, y compris une meilleure utilisation des données générées par le système, garantira que les programmes nationaux sont le mieux à même de répondre aux défis posés par l'épidémie.

Resumen

Vigilancia del VIH de segunda generación: mejores datos para la adopción de decisiones

Se esbozan en este artículo los elementos clave de la vigilancia ampliada recomendada en la estrategia de vigilancia del VIH de segunda generación. Los sistemas de segunda generación se centran en la mejora y ampliación de los métodos de vigilancia existentes y los combinan mediante fórmulas que les confieren la máxima potencia explicativa. Los principales elementos de este enfoque incluyen la consideración de la vigilancia biológica -VIH, SIDA, infecciones de transmisión sexual (ITS)- y la vigilancia del comportamiento como componentes integrados, la focalización de las actividades de vigilancia en los sectores de la población donde se concentran la mayoría de las nuevas infecciones -lo que depende del tipo y fase de la epidemia- y la aportación de los criterios necesarios para hacer un uso óptimo de los datos generados por las actividades de vigilancia de la epidemia de VIH y de evaluación de los programas nacionales de control del SIDA.

En el artículo se hace hincapié en las mejoras de las actuales metodologías de vigilancia y se analizan detenidamente

aspectos cruciales tales como la validez de los datos de prevalencia del VIH medidos en las mujeres embarazadas y la vinculación de la vigilancia del VIH al acopio de datos sobre el comportamiento. Además, se propone una alianza estratégica entre la vigilancia de segunda generación y la evaluación de los programas contra el SIDA en la que se subraya el carácter complementario de esas actividades de reunión de datos a la hora de determinar la eficacia de los programas de prevención y atención y de explicar las tendencias epidemiológicas configuradas por los datos recopilados por los sistemas de serovigilancia centinela. En conclusión, los sistemas de vigilancia del VIH de segunda generación constituyen una respuesta idónea, integrada y costoeficaz, a las necesidades de información de los programas de control del SIDA. La implantación de tales sistemas, incluido un mejor uso de los datos generados, garantizará que los programas nacionales se hallen en una situación inmejorable para responder a los retos que plantea la epidemia.

Arabic

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