

Public Health Surveillance, Confidentiality, and HIV Prevention

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In this presentation, I will examine the interaction between public health surveillance for HIV/AIDS, confidentiality, and HIV prevention. Surveillance is the process of information collection and monitoring that allows public health agencies to target and assess disease prevention and control efforts. In essence, public health surveillance provide a foundation for prevention. Central to the success of public health surveillance is the protection of confidentiality, and I will review the policies and procedures that have been used in the United States to insure the protection of confidentiality in conducting HIV/AIDS surveillance. I will also discuss how surveillance data are applied in directing HIV prevention activities, and I will discuss the relevance of protecting confidentiality to promoting health behavior change. My presentation will be based on experience in the United States; however, I will seek to emphasize principles that would be applicable more broadly.

To those who do not work in public health agencies, the term "surveillance," at least in its public health context, may not be familiar. For that reason, I will provide a brief overview of the purpose, methods, attributes, and uses of public health surveillance. Surveillance is a continuous and systematic process of collection, analysis, interpretation, and dissemination of information for monitoring health problems. Surveillance systems may function at a range of levels, from local to international. Public health agencies use the information obtained from surveillance system to guide disease prevention and control activities. Locally, surveillance may provide the basis for identifying individuals who need treatment, prophylaxis, education, or linkage to health services. More broadly, surveillance data provides a basis for shaping public health policy.

Surveillance has been described as the nervous system, or the eye and ears, of public health, providing information who is affected by specific public health problems, where problems are occurring, and when they are occurring, or in other words, describing trends. This information provides a rational basis for targeting the use of limited public health resources. Surveillance has also been described as the conscience of public health, because it can illustrate the dimension of public health problems, drawing attention to prevention needs. Thus, it is important that surveillance systems be as accurate as possible. the ability of public health agencies to conduct accurate surveillance depends on large part on their capacity to protect confidentiality.

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When new public health problems emerge or as public health agencies turn their attention to new problems, the implementation of surveillance is critical to an effective early response or activity. In the long term, surveillance is used to identify changes in the nature or extent of health problems. As a result, surveillance systems may grow from simple adhoc arrangements into more elaborate structures. This is certainly the case for surveillance systems for AIDS in the United States, where surveillance was rapidly implemented in 1981 in response to recognition of new epidemic. Surveillance data, combined with epidemiologic investigations prompted by initial case reports, identified the modes of transmission HIV and provided the basis for early prevention measures, before the etiologic agent HIV was identified. As the epidemic has evolved and the epidemiologic pattern of groups affected by the epidemic has shifted, surveillance data have continued to guide the direction of prevention resources.

The process of monitoring HIV means that governmental agencies are collecting information about individuals that can highly sensitive, not only regarding information about HIV infection but also information about sexual or drug-using behaviors. Approaches to protecting privacy and confidentiality can be addressed in different ways depending on the method of conducting surveillance. Choosing the appropriate surveillance method depends on a variety of factors, including the stage of the epidemic in a particular area, information needs, and logistic or resource constraints. In fact, conducting surveillance typically requires a balance of desirable attributes, which include the following:

Sensitivity. To what extent does the system identify all of the disease events in the population being monitored. For purposes of monitoring trends, low sensitivity may be acceptable if sensitivity is consistent over time and detected cases are representative of all cases. However, for purposes of assessing the impact of health problem, high sensitivity is desirable.

Timeliness. This attribute refers to the entire cycle of information flow, ranging from information collection to dissemination. The need for timeliness depends on the public health urgency of a problem and the types of interventions that are available.

Representativeness. To what extent do events detected through the surveillance system represent persons with the condition of interest in the population at large? Or, to what extent is a surveyed population representative of groups at highest risk? A lack of representativeness may lead to inappropriate allocation of public health resources.

Predictive value. To what extent are reported cases really cases? To what extent are measured changes in trends truly reflective of events in the community?

Simplicity. Are forms easy to complete; are procedures unobtrusive; is data collection kept to a necessary minimum; etc.

Flexibility. Can the system change to address new questions; can it adapt to evolving standards of diagnosis or medical care?

Acceptability. To what extent are the participants in a surveillance system (those who report cases, welcome staff into their hospitals or offices, complete forms, etc.)

enthusiastic about the system? Does the effort they invest yield useful information? Also, is the system acceptable to the population being monitored, and is the public health value of the information recognized as worthwhile in the community?

Acceptability is a critical attribute, since in conducting surveillance health agencies must depend on the ongoing, long-term collaboration, cooperation, and support of physicians and other health care providers, who are often the source of surveillance information. Acceptability is also critical in terms of community support for surveillance. If allowing governmental agencies to obtain sensitive information is perceived as risky, then essential community support for information collection will be lacking. This may be manifested by an inability to obtain the necessary legislative, administrative, or financial support for public health surveillance. It may also be manifested by lackluster participation by health care providers in reporting cases or in allowing entrance of public health staff into facilities, regardless of whether or not reporting is mandated. Over the long term, successful surveillance systems are built on mutual trust between public health agencies, health care providers, and affected communities. Successful surveillance systems cannot be based on adversarial relationships. A critical element in defining the acceptability of a surveillance system, and ultimately in maximizing all of the above attributes, is its capacity to protect confidentiality. If public health agencies cannot be trusted to respect and protect confidentiality, they cannot conduct effective surveillance. If there is not effective surveillance, then prevention efforts are significantly hampered.

There are many different ways to conduct surveillance for HIV/AIDS. However, I would like to review briefly two of the most commonly used methods throughout the world. Each illustrates a different approach to protecting privacy and confidentiality, and each illustrates a different strategy for information collection. These are seroprevalence surveys and case reporting.

Seroprevalence surveys seek to define the level of HIV infection in various populations, and they fall into two categories: HIV screening programs and anonymous surveys. In many countries, certain groups of people are routinely tested for HIV. For example, persons who donate blood for transfusion are routinely tested. Another approach is the anonymous, "blinded," or "unlinked" HIV prevalence survey. In this approach, groups targeted for surveillance are those who routinely have blood drawn for other purposes. These other purposes may include tests routinely done in women receiving ante-natal care, screening tests for metabolic diseases in newborns, syphilis testing in persons attending sexually transmitted disease clinics, or routine health assessments in persons entering drug treatment programs. Whenever blood tests are done, there is almost always some blood left over, and that left over blood is discarded. These surveys, in essence, intercept the left-over blood that is on its way to disposal. All identifying information is stripped from the blood specimens before HIV tests are done.

This provides a relatively simple approach to defining the extent of HIV infection in different groups. It has been widely promoted by the World Health Organization and has been adopted in many countries. It can be particularly useful in areas where HIV is emerging and not yet manifest by substantial numbers of AIDS cases. Because HIV

testing is done after any link between an individual and the particular specimen is destroyed, there is no intrusion on the privacy of individuals and thus virtually no threat to the confidentiality of information about an individual.

But this attribute is also a limitation of the blinded survey approach. Because there is no link to an individual, there is a very limited capacity to obtain information about infected persons, such as their possible mode of exposure to HIV. There is limited capacity to distinguish the number of infected persons from the number of positive blood tests, i.e., an infected person may appear in the survey sample more than once. Lastly, there is no ability to follow-back and to determine whether an infected person is obtaining needed preventive or follow-up care services. This leads to the approach that traditionally comes to mind when the term "public health surveillance" is used: reporting of cases to health departments.

Cases reporting means that when a health care provider diagnoses a case of HIV infection or AIDS, depending on the surveillance system, a report is subsequently made to a local public health agency. That report typically includes the name of the infected person, and that link to a name allows follow-back to the medical records or to the individual. This enables obtaining a profile of the individual, information on behaviors or exposures that may have led to infection, information on the manifestations of disease that have occurred, and so on. It allows culling of duplicate reports. It also allows follow-back for provision of preventive or treatment services. Obviously, this requires a much more intensive level of effort and greater resources to collect and process the information. Thus, it is less feasible in areas with very limited resources. But it is an approach that is widely used, and it requires careful attention to measures to protect confidentiality. In the United States, the categories of measures to protect confidentiality include:

Security. Protection of the physical security of surveillance data: Limiting staff access to areas where data are maintained, locks on doors and filing cabinets, passwords on computers, encryption systems.

Training. Staff who collect and manage surveillance data should receive training in the policies and procedures for handling confidential information, and in the consequences of failures to protect confidentiality.

Technical support. CDC's technical support to health department includes guidance regarding protection of confidentiality, and procedures are often reviewed during site visits by CDC staff to state or local surveillance programs.

Policies. Laws, regulations, rules, and policies govern access to surveillance information, define public health uses of the data, and severely limit or prohibit uses outside of the public health arena. Penalties for violation of confidentiality procedures can result in loss of employment. Federal support for surveillance programs in state health departments emphasizes the protection of confidentiality as a criteria for funding.

Limiting transmission identifying information. For HIV and AIDS reports, identifying information is retained by local or state health departments, but names are not

forwarded to CDC at the national level. Instead, names are coded in a way that allows identification of duplicate reports of an individual from more than one state, but does not permit identification of an individual in the national data base.

Limiting detail as information is presented. Guidelines for dissemination of data limit detail that is allowed in cross-tabulations of data, in public reports, or in preparation of public access data sets provided by CDC to other researchers. For example, data are aggregated in published tables so that the identity of an individual could not be inferred.

Respecting and protecting the confidentiality of surveillance data, however, is often not enough to win the public's confidence in surveillance systems. We have learned that perceptions about confidentiality are powerful in shaping public concerns about, or acceptance of, information collection by health departments. For example, the public often does not distinguish different parts of government, it is all "the government." The role of different parts of the health care system may not be distinguished from public health agencies. Violations of privacy or rights that occur completely outside the domain of public health surveillance can substantially undercut support for information collection by government agencies.

An issue that is less directly related to individual confidentiality, but is related to the overall theme of this conference, concerns the identification and description of "high-risk groups." On one hand, there is a need to apply public health resources where the need is greatest. This requires the identification and description of that need. As with many health problems, in the United States and elsewhere, health status in general and HIV risk in particular, is greatest among groups that are disenfranchised or marginalized within society because of race or ethnicity, poverty, gender, sexual behaviors, or drug use. In some instances, the behaviors that place individuals at risk for HIV infection may be illegal. As a result, the very information that can be used to advocate for these populations and to direct public health resources to them can inadvertently lead to further ostracism, particularly when it concerns an infection such as HIV that carries the risk of stigmatization. This means that we as public health advocates must be sensitive in how we use and present the powerful information we collect. We want our information to lead to improvements in health and not to barriers to health.

Before turning to the attributes of effective prevention measures, I would like to add a few additional points regarding the use of surveillance information. In some instances, surveillance data can be used in formulas for allocating resources, but more commonly the process of allocating resources and setting priorities is much more complex. For example, surveillance data may show that a problem is currently greatest in one group but increasing more rapidly in another. How prevention resources are allocated between these groups reflects community values, the status of existing programs serving these groups, and the level of effort needed to effectively serve what may be very different populations. Increasingly in the United States, these priorities are being defined locally with the involvement of representatives from communities affected by HIV, and in this regard we have much to learn from the precedents in other countries. In providing guidance to this process, we have emphasized the use of surveillance data as a foundation

to the deliberations. This process involves bringing together people with very different perspectives, including those who come from the world of data and those from the world of personal experience. Both are important, and we have seen that the willingness to embrace surveillance information is shaped by perceptions of its integrity, a key dimension of which is the level of trust of public health agencies. Much of the precedent for defining that trust is based on protection of confidentiality.

Lastly, I would like to make a few points about effective HIV prevention, which largely means changing behaviors. The discussion of confidentiality and privacy is often framed in terms of a balance between protecting individual rights versus protecting community health. But this construct is limited for HIV, because protection of confidentiality and respect for privacy are necessary components of overall efforts to promote long-term, sustained behavior change. Our colleagues in the behavioral and social sciences tell us that changing behaviors requires a number of steps. For the individual, having knowledge about HIV prevention is just a first step. There must also be an awareness and acknowledgement of risk, a motivation to change behavior, a sense of self-worth, the skills and capacity to initiate and sustain behavior change, a supportive environment, and social norms that promote healthy behaviors. Fear of discrimination or fear of reprisal that may arise from failures to protect confidentiality are clearly barriers in this path to changing behaviors. In addition, programs must have "cultural competency," which includes a sensitivity to the culture of the audience, its needs and values. Disregard for the value of confidentiality can be a barrier to achieving this cultural competency.

In conclusion, protecting confidentiality is an essential element in effective public health surveillance systems and enhances respect for the information that is obtained. This protection can be achieved through anonymous surveillance methods or through rigorous adherence to policies and procedures when identifiable case reporting methods are used. Protection of confidentiality is an essential part of the psychological and social climate that support behaviors which lessen the risk of HIV transmission and that characterizes effective HIV prevention programs