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*Public Health Surveillance:  
A Historical Review with a  
Focus on HIV/AIDS*

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## Introduction

Public health surveillance has been described as the “ongoing, systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control” (Thacker and Berkelman, 1998). This definition, however, contains two very different activities. *Case surveillance* focuses on individuals, or sometimes groups of individuals, to identify individuals with certain diseases and take action. *Statistical surveillance*, on the other hand, focuses on populations, to identify differentials and trends that can inform public health policymaking, including the allocation of resources. Both approaches incorporate different goals and objectives, data sources, and methods. In addition, different methods are used to evaluate surveillance systems in each area.

Surveillance for HIV/AIDS sits uncomfortably between these two approaches to surveillance. HIV/AIDS data systems have predominantly adopted the case surveillance perspective but have goals and objectives that are similar to those of statistical surveillance methods. The formula funding requirements of the RWCA bring this issue to the fore. Difficulties of HIV (as opposed to AIDS) case reporting make this combination particularly problematical.

In order to examine the issues raised by the use of HIV/AIDS surveillance data in allocation formulae, this paper begins with a history of surveillance activities in public health. The second section summarizes the goals and objectives of surveillance, the data and methods used, and standard approaches to the evaluation of surveillance systems. Current HIV/AIDS surveillance systems are then reviewed, and the existing evaluation

studies are summarized. The paper concludes with two case studies of surveillance activities regarding sexually transmitted diseases (STDs) and federal maternal and child health funding allocations.

### **History of Surveillance**

The first public health use of surveillance was in the Republic of Venice in the 14th century. At that time, public health authorities boarded ships to identify persons ill with bubonic plague and related symptoms and to prevent them from disembarking. In 1741, Rhode Island required tavern keepers to report patrons with smallpox, yellow fever, and cholera to local authorities. Statewide efforts began in Massachusetts in 1874. At that time, a voluntary, postcard reporting format was used to provide weekly reports on prevalent diseases. In 1878, Congress authorized the forerunner of the United States Public Health Service (PHS) to collect morbidity data for use in quarantine measures against “pestilential diseases” such as cholera, smallpox, plague, and yellow fever (Thacker, 2000).

Compulsory reporting of infectious diseases began on a national basis in Italy in 1881, and in other European countries shortly afterwards. Michigan was the first U.S. state to require reporting of specific infectious diseases, in 1893. In that same year, Congress enacted a law to provide for the collection of information each week from state and municipal authorities. By 1901, all states required “notification” and included smallpox, tuberculosis, and cholera. The list of notifiable diseases has changed over time, but the basic strategy remains in place (Thacker, 2000).

Worldwide eradication of smallpox became possible in the 1970s because of a surveillance-vaccination approach. Earlier efforts to immunize nearly 100 percent of the population failed because of logistical difficulties. The successful “ring strategy” relied on intensive surveillance to identify cases, isolation of all known cases, and immunization of individuals who may have come in contact with cases (Henderson, 1999). Based on this experience, a modified version of this approach is currently being proposed by the Centers for Disease Control and Prevention (CDC) as a national strategy for terrorist-initiated smallpox attacks.

Thus, from the start, surveillance was focused on detecting individual cases and taking action regarding the affected individuals. Control strategies include monitoring, treatment, quarantine, and contact tracing. In the United States, infectious disease surveillance (as with most public health activities) is constitutionally viewed as a state responsibility. Since the U.S. Constitution is silent with respect to health, public health is dealt with as part of the “police powers” of the state. As a result, for instance, the list of notifiable diseases varies from state to state, even to this day. The interstate commerce clause of the Constitution, however, has allowed for some federal-level efforts, especially with regard to protecting the country from infections from abroad (Gostin et al., 1997).

The basic mechanisms of case surveillance (postcard reporting to local health departments, weekly summaries in the *Morbidity and Mortality Weekly Report*, and so on) were established in the 19<sup>th</sup> century, and are generally still in place in the 21<sup>st</sup>. There are few cases these days of “pestilential diseases” for which immediate action is necessary, but the need for quick action to prevent the spread of infectious diseases does remain. For tuberculosis (TB) and STDs, for instance, one of the main goals of

surveillance is to identify infectious individuals before they infect others and thus to prevent an exponentially growing epidemic. Case surveillance has received additional prominence along with the increasing interest in emerging infections and, since 9/11, in bioterrorism. The development of electronic reporting systems utilizing the Internet (e.g., CDC's National Electronic Disease Surveillance System (NEDSS)) is under way but not yet implemented except in a few states (CDC, 2003a).

Surveillance also has a history as a statistical activity, although the term "surveillance" was not applied until the mid 20th century. In this perspective, surveillance focuses on disease in populations rather than in individuals. The earliest statistical surveillance activities made use of vital statistics, primarily derived from death certificates. The analysis of vital statistics began with von Leibnitz and Graunt in the 17<sup>th</sup> century and was extended to examine cause of death and applied to public health in the 19<sup>th</sup> century by Farr in England and Shattuck in the United States. The coverage of vital statistics became complete in the United States in the 1930s. It is now coordinated by the National Center for Health Statistics but is still a state activity (Stroup and Berkelman, 1998).

Statistical surveillance also includes health surveys based on scientifically chosen sample surveys. The first national health survey was conducted in the United States in 1935, and the National Health Interview Survey (NHIS) has been in continuous operation since 1957 (CDC, 2003b). In the 1990s, the CDC developed the Behavioral Risk Factor Surveillance System (BRFSS), a model for state population health surveys, and all states and the District of Columbia now use it (CDC, 2003c). In addition, many special-purpose surveys are now available and commonly used.

Registries are another source of data for statistical surveillance. The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) system, which operates in eleven population-based cancer registries and three supplemental registries covering approximately 14 percent of the U.S. population, uses active surveillance methods to record all incident cases of cancer as well as their treatments and outcomes (National Cancer Institute, 2003). As a result, NCI is able to estimate cancer incidence and survival rates, something that is not possible for most chronic diseases. Registries exist for other (primarily rare) conditions, but with limited coverage.

The use of medical and administrative records to analyze the utilization and outcomes of health care, sometimes known as “outcomes research,” is another form of statistical surveillance. Increasingly popular in the last few decades, outcomes research includes efforts to study health care access and utilization in small areas, as well as performance measurement and quality assessment.

The extension of the original focus of surveillance from infectious diseases to other aspects of public health paralleled developments in our understanding of the determinants of health and of public health itself. The original focus in vital statistics on all-cause mortality in the 17<sup>th</sup> century expanded to cause-specific mortality in the 19<sup>th</sup> century as more became known about the causes of disease (Stoto and Durch, 1993).

In the second half of the 20<sup>th</sup> century, public health and surveillance began to focus on chronic diseases, and simultaneously on health risk factors as well as health care utilization, costs, outcomes, and so on. In 1979, *Healthy People* (US DHEW, 1979) brought attention to community health indicators, performance measures, and so on, and

surveillance efforts of this type have increased with publication of *Healthy People 2000* (US DHHS, 1991) and *Healthy People 2010* (US DHHS, 2000).

Surveillance of occupational morbidity and mortality, developed in concert with new regulations on workplace safety regulation, and injury surveillance became more common in the 1990s as public health turned its attention to intentional and unintentional violence. A growing focus on health care quality in the early 21<sup>st</sup> century and attendant concerns about medical errors and iatrogenic injuries in recent years (IOM, 1999, 2001b), have led to intensified surveillance efforts, along with post-marketing surveillance for medical, especially vaccine, side effects.

Despite a variety of national surveillance efforts, Birkhead and Maylahn (2000), borrowing from former House Speaker Tip O'Neill, appropriately argue that "all surveillance is local." The reason is twofold. First, as noted above, the authority for public health, and hence for surveillance, lies with the states. Second, the impetus for this authority is the need to prevent and control specific health problems in the local community. State and local authorities, because of their proximity to the population, best carry out these functions. Moreover, Birkhead and Maylahn argue, "*surveillance* is synonymous with *control* to many public health professionals, policy makers and legislators at the state and local level, and to members of the public." The increasing attention to community-level determinants of health (social and physical environment) has led states and local areas to gather and report noninfectious disease data such as community health reports, performance measures, and so on, at the "community" level.



### **Terminology**

Surveillance is currently defined as the “ongoing, systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control” (Thacker and Berkelman, 1998). However, Thacker (2000) notes that “Until 1950, the term ‘surveillance’ was restricted in public health practice to monitoring contacts of persons with serious communicable diseases such as smallpox, in order to detect early symptoms so that prompt isolation could be instituted.” It is often called “epidemiologic surveillance” or “public health surveillance” to distinguish it from military intelligence.

According to Stroup and Berkelman (1998), the focus was broadened, through the work of Alexander Langmuir, to the occurrence of specific diseases in populations rather than individuals and to issues other than infectious diseases, such as childhood lead poisoning, birth defects, injuries, cancer, diabetes, and behavioral risk factors. Langmuir limited surveillance to the collection, analysis, and dissemination of data, but others included control activities in the definition (Thacker, 2000). Former CDC director William Foege, however, stressed what he feels is an essential relationship between information and action: “The reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow.” (Stroup and Berkelman, 1998). Others, however, feel that data are important for informing policy making but may not lead immediately to action (Stoto et al., 2001).

Perhaps the connection between surveillance and control activities is based on the understanding that, in infectious diseases, the incidence of new cases is directly related to the number of existing cases. In such situations, identifying, treating, and isolating cases as quickly as possible can effectively control what would otherwise be an exponentially growing epidemic, with increases sometimes discernable on a daily or weekly basis. Chronic diseases, however, operate on a different timescale. They are more likely to be caused by environmental exposures, behavior, or genetic factors and thus do not grow exponentially as an infectious disease outbreak does. A speedy response, therefore, is not as essential as with infectious diseases. Control strategies for chronic diseases, moreover, are not as simple as for infectious diseases, and are often costly in personal and societal terms.

Surveillance systems can be classified as active or passive. The former involve an extensive effort by surveillance system personnel to contact providers and others to identify cases that have sought care but may not have been reported through normal means. Registries (see below) are common examples of active surveillance. Most case-based surveillance efforts, on the other hand, are passive, and rely on providers to voluntarily submit information to public health authorities.

Since September 11, 2001, a number of cities and states have shown interest in the development of “syndromic surveillance” systems based on existing, computerized health care data to give early warnings of bioterrorist attacks or other emerging health conditions. Syndromic surveillance - a new concept in epidemiology - is the statistical analysis of data on individuals seeking care in emergency rooms or other health care settings with pre-identified sets of symptoms thought to be related to the precursors of

diseases caused by bioterrorist attacks and emerging infections of interest. By focusing on symptoms rather than confirmed diagnoses, syndromic surveillance aims to detect bioevents earlier than would be possible with traditional surveillance systems. Because many potential bioterrorist agents initially present with “flu-like illness,” data suggesting a sudden increase of individuals with fever, headache, muscle pain, and malaise might be the first indication of a bioterrorist attack or natural disease outbreak. Syndromic surveillance is also thought to be useful for early detection of natural epidemics. The efficacy of this approach, however, has not yet been demonstrated (Stoto, Schonlau and Mariano, 2004).

### **Goals and Purposes of Surveillance**

Surveillance is an “essential public health service” (Public Health Functions Steering Committee, 1994) and is part of the “assessment” function of public health. In the Institute of Medicine’s landmark study, *The Future of Public Health*, assessment includes traditional surveillance activities and - more generally - collecting, assembling, analyzing, and making available information on the health status and health needs of the community (IOM, 1988).

In this framework, the purposes of surveillance are to assess public health status, to define public health priorities, to evaluate programs, and to stimulate research (CDC). CDC also lists a number of “uses” of surveillance: estimating the magnitude of the problem, determining the geographic distribution of illness, portraying the natural history of a disease, detecting epidemics (defining the problem), generating hypotheses, stimulating research, evaluating control measures, monitoring changes in infectious

agents, monitoring emerging and reemerging infections with laboratory data, detecting changes in health practices, and facilitating planning (CDC). Surveillance systems frequently serve multiple purposes and may be better for some than for others.

Within this list, the uses fall into two groups, as suggested by the history of surveillance. First, surveillance data are used to identify individual and local-level interventions to control epidemics. At the individual level, this includes case finding, patient tracking and linking to care, and partner notification. At the local level, interventions include identification and removal of contaminated food sources, environmental pollutants, and so on.

The second general use of surveillance data relates to the identification of issues of concern that might lead to population-level interventions. This could include research, the development and implementation of targeted programs, professional and public education, and the allocation of resources for programs. Resources may be allocated through a federal application and review process that requires data on state or local conditions, or through block grant programs where surveillance data are incorporated into formulae determined by law.

### **Surveillance Data**

In order to support the many different purposes and uses summarized above, surveillance systems rely on a diversity of data sources. Infectious disease surveillance, for instance, still relies primarily on the system of notifiable diseases put in place in the 19<sup>th</sup> century. Health care providers are required to report all cases of a given set of diseases to their local health department. Reports are generally made, by name and with

a variety of information relating to possible risk factors, to the local health department in which the patient resides. Local health departments report to state health departments, usually by mail, and states compile reports and transmit them to the CDC for national tabulation and publication. Disease surveillance systems have generally been developed for specific diseases and differ from one another in what information is requested, how it is reported, and so on.

Not surprisingly given this fragmented system and the demands of the modern health care system, physicians' compliance with this system is limited. Moreover, some individuals may not experience symptoms or have good access to health care, and thus do not seek care. As a result, health officials acknowledge that the number of reported cases of a disease can be far below the number of actual cases. In addition, because most surveillance systems require laboratory confirmation of a diagnosis before it is reported, there can be substantial delays between the development of symptoms in an individual and reporting to and by health officials (Stoto et al., 2002).

Two recent developments may help to improve the completeness and accuracy of case reports. First, health departments are developing systems for clinical laboratories to report cases that test positive directly to state or local health departments rather than through physicians. While this may make reporting both more complete and timely, laboratories generally do not have all of the information on the cases that is necessary. Moreover, managed care organizations and other organized health care delivery systems are increasingly using out-of-state laboratories, and linking the information back to the proper local health department can be difficult (Stoto et al, 2002).

Second, CDC is developing a national electronic disease reporting system for transmitting surveillance information (CDC, 2003a). Current implementations, however, are focused on communication between local and state agencies and with the CDC, and direct links to providers are not generally available. With the increased emphasis on surveillance after September 11<sup>th</sup>, linkages to providers are being developed.

Vital records, based on individual birth and death certificates, are another important source of surveillance data. Based on individual records but generally analyzed statistically, vital records are a kind of bridge between case-based and statistical surveillance. Unlike disease case reports, however, birth and death certificates are legal documents that are essential to the persons concerned and their families, and thus there is a strong incentive for the reports to be complete. Timeliness, however, has generally not been an issue with vital statistics and the emphasis has been on completeness and accuracy in their compilation and analysis.

Registries for cancer and other diseases, as described above, provide data on disease incidence, treatments, case fatality, and health outcomes. They generally rely on active surveillance efforts, in which registry personnel regularly contact physicians, hospitals, and other health care providers to ascertain new cases and learn about developments on existing cases. Because of the cost of these efforts, registries only exist for selected diseases and in limited geographic areas. As with vital records, registry data tend to be analyzed and reported in statistical terms, and the focus is on completeness and accuracy rather than timeliness.

Sentinel surveillance efforts are specially focused, intensive efforts to identify disease incidence and case characteristics in special settings. Because influenza case

surveillance reports are very incomplete, for instance, CDC has organized a network of 650 physicians around the United States to obtain weekly reports during the fall and winter on the number of possible influenza cases seen by each provider in order to determine when the flu season has begun (CDC, 2003d). To estimate the prevalence of HIV, samples of blood from STD clinics, drug treatment programs, and other locations around the country are tested anonymously for HIV (CDC, 1998). Because the testing locations are chosen based on the expectation of high proportions of people testing positive, however, this sentinel surveillance system is not able to provide unbiased national HIV prevalence estimates (IOM, 2001a).

Population-based surveys using scientifically selected random samples provide useful data for statistical surveillance activities. The NHIS and BRFSS, as discussed above, are general-purpose surveys at the national and state levels, respectively, and many other special-purpose surveys have been developed and used at the national, state, and local levels and for special populations. Population-based surveys are designed to make estimates of the total number of cases using statistical techniques, not to identify all cases of a particular disease or health condition. The accuracy of these estimates depends on the selection of the sample, complete and accurate reporting by those in the sample, and using proper statistical methods to analyze the data. Because the individuals providing data are only a sample of the target population, attempts are generally not made to respond to cases that are identified in the survey.

The final major source of surveillance data is medical records and administrative systems. Such records have existed for many years, but they are increasingly used for both research and surveillance purposes now that they are available in computerized

form. Because medical decisions and payments are based on such documents, they are generally regarded as nearly complete. Their administrative and clinical use, however, can introduce biases. An individual's condition, for instance, may be "up-coded" to increase a hospital's or a physician's reimbursement. Such records also may not include information such as risk factors or race and socioeconomic status, which can be useful for surveillance purposes. New federal regulations established in response to the Health Insurance Portability and Accountability Act (HIPAA) restrict the use of patient information in order to protect privacy and confidentiality. Public health surveillance uses, however, are exempt from these regulations (Gostin, 2001).

### **Evaluation of Surveillance Systems**

Romaguera and colleagues (2000) suggest that surveillance systems can be evaluated along the following dimensions: simplicity, flexibility, acceptability, validity and reliability, sensitivity and specificity, representativeness, and timeliness. Each of these relates to the purposes and objectives of the surveillance system. Much of the discussion in this paper applies to case-based surveillance systems, so the discussion below indicates variants on these criteria for statistical systems. It should also be noted that the evaluation of a surveillance system is not the same as the evaluation of the statistical estimates that it produces, as will be discussed below in terms of HIV and AIDS.



**Simplicity**

The simplicity of a surveillance system relates to its structure and ease of operation. According to Romaguera et al. (2000), this includes the amount and type of information necessary to establish a diagnosis, the number and type of data sources, methods of transmitting case information and data, staff training requirements, the type and extent of analysis of the resulting data, methods of distributing reports, and the amount of time spent operating the system. One could argue, on the other hand, that simplicity is not a virtue in itself, especially if it limits the functions of the system – but may improve performance in other respects.

**Flexibility**

Flexibility is the ability of the system to adapt to changing needs. Flexibility allows for surveillance activities to change as more becomes known about the disease or health issue that the system is focused on. Case definitions or laboratory techniques might change, for instance, as epidemiologists' knowledge develops. Too much flexibility can interfere with statistical surveillance systems, especially in analyses focused on time trends, as changes in the surveillance system can become confused with changes in the disease itself. Flexibility across states in the implementation of surveillance systems is also not desirable, especially if the resulting estimates are to be used to allocate federal funding.

**Acceptability**

A surveillance system should be acceptable to health department staff, as well as to physicians or laboratory staff or others who are asked to report cases. If reporting is too burdensome, they may not participate. Acceptability can be assessed through interviews and surveys, as well as through the completeness and timeliness of reports. Patients' concerns are also increasingly important. Individuals with diseases such as STDs and HIV that carry the potential for stigma and discrimination are increasingly concerned about being identified to government officials, especially if the information is to be used for contact tracing or similar purposes.

**Validity and reliability**

Statistical surveillance systems can be characterized in terms of reliability and validity. *Validity* is the degree to which a system measures what it purports to measure. The NHIS diabetes question, for instance, measures diagnosed diabetes, not diabetes per se, and in that sense is valid. It is not a valid measure of the prevalence of diabetes in the population. Validity depends on the intended purpose, as will be discussed below in the context of the validity of AIDS or HIV cases as measures of the need for federal resources.

In this context, "validity" has also been used to describe the accuracy of information about reported cases, such as race and ethnicity, primary risk factors for HIV infection, and so on, as in Klevens et al. (2001).

*Reliability*, on the other hand, relates to replicability. A population-based survey with a large sample size, for instance, will yield reliable results. To continue with the

diabetes example, because the NHIS sample is large, the proportion of individuals who report being diagnosed with diabetes, whatever that means, varies little from year to year. There is sometimes a tradeoff between validity and reliability in the sense that financial constraints do not allow for the intense work needed to improve validity in surveys with large sample sizes.

### **Sensitivity and specificity**

Case definitions determine what counts as a case, and they typically focus on characteristics of the individual's illness. They can be limited to cases diagnosed at a particular place and time. A case of smallpox, for instance, could be defined in terms of fever, a characteristic rash, and other clinical characteristics, in an individual who lives in a particular community at a certain time. For most infectious diseases, laboratory confirmation is required.

Inclusive case definitions are said to be *sensitive*, in the sense that they are likely to include most of those who actually have the condition. Technically, sensitivity is the proportion of individuals with the target condition who are identified by the surveillance system. The *completeness* of a surveillance system is a common measure of sensitivity.

Sensitivity depends on people with the target condition seeking medical care, on their condition being correctly diagnosed, and on the case being reported once diagnosed. Sensitive case definitions, however, might also lead to the inclusion of individuals who have similar symptoms but not the disease of interest. Surveillance systems with low sensitivity can still be useful in monitoring trends, as long as sensitivity and specificity do

not change. Sensitivity can also refer to a surveillance system's ability to detect epidemics.

*Specific* case definitions, on the other hand are more narrowly drawn to decrease the chance that individuals who do not have the condition are included. Requiring laboratory confirmation, for instance, increases specificity. Depending on the purpose, sensitive or specific definitions might be useful. In the smallpox eradication campaign, for instance, sensitive case definitions were used to ensure that every case was found. A more specific definition might be used today to determine whether an individual with a characteristic rash has smallpox as a result of a terrorist attack. Specificity is sometimes described in terms of the "predictive value positive" (PVP), which is the proportion of identified cases that actually have the condition. High PVP is important because, at the individual level, false case reports lead to misallocation of resources for investigation, stigma and discrimination to those identified, and unnecessary medical treatment. At the population level, false positive detection of epidemics leads to unnecessary outbreak investigations.

### **Representativeness**

Surveillance systems should accurately describe the occurrence of health events over time and distribution in the population by place and person. *Selection bias* represents the systematic exclusion of certain cases. Suppose, as is commonly the case, that sexually transmitted diseases diagnosed and treated at the local public health STD clinic are more likely to be reported than those treated by private physicians. STD cases in the population with a regular source of healthcare, in this case, would be systematically

underrepresented in the surveillance system. To the extent that private patients have higher incomes and socioeconomic status, the estimates of such characteristics from the surveillance system would also be biased.

Selection bias can affect statistical as well as case-based surveillance systems. Individuals who spoke Spanish but not English, for example, would be excluded from a health survey if translators were not available. Since diabetes is relatively more common in the Hispanic population in the United States, prevalence estimates based on this survey would be biased towards lower values due to selection bias.

### **Timeliness**

Timeliness is an important issue with surveillance systems. Case-based surveillance systems as well as vital statistics and registries are based on a sequence of events: disease onset, diagnosis, receipt of a report by the responsible public health agency, and the compilation and publication of the results. Delays between any two or more of these steps will result in reporting delays. Depending on the resources available and the priority accorded to a surveillance system, any or all of these steps could lead to serious delays. There can also be a tradeoff between timeliness and completeness, as the surveillance system waits for the last few case reports to be completed before results can be published.

Timeliness is also an issue with population-based surveys. Because of the substantial effort needed to process and analyze survey responses and to publish the results, years can pass between the survey reference period and when results are

available. This problem is exacerbated when a long reference period is needed to collect enough cases for statistical reliability.

### **Practical approaches to the evaluation of sensitivity, specificity, and timeliness**

There is no “standard” approach to the evaluation of the statistical aspects of surveillance systems. Epidemiologists and statisticians have rather taken a number of specific approaches to measuring sensitivity, specificity, and timeliness, depending on the nature of the system and on the data available.

For case-based surveillance, vital statistic, and other records-based systems, the approaches can be divided into internal and external comparisons. Internal comparisons could include the following kinds of activities:

- analyzing the time from onset to diagnosis to receipt of report by the responsible public health agency, as well as to the implementation of control activities;
- calculating the percentage of completeness at a given time based on more complete data available at a later time;
- identifying duplicate reports;
- reviewing the consistency and accuracy of diagnoses and other data elements (e.g., risk factors) based on multiple reports.

The ability to make external comparisons depends on availability of other sources of data, so approaches here can be more variable. They include the following:

- surveying providers and/or reviewing medical or administrative records to identify cases to see if they were reported and, if not, find out why not;
- reviewing death certificates to see if cases were recorded while alive and when;

- checking medical records of recorded cases to see if they were true cases.

The evaluation of statistical surveillance systems based on surveys typically focuses on establishing the adequacy and appropriateness of the methods used in the surveys. These include the adequacy (especially the representativeness) of the sampling frame; the adequacy of the questionnaire as determined through pilot testing, and so on; the execution of sampling and survey as documented through completion rates, both overall and by subpopulations; errors in data entry as well as the need for data cleaning; and the use of appropriate statistical methods, for example the use of correct sampling weights in complex surveys.

External comparisons are also possible for statistical surveillance systems through aggregate level comparisons between independent systems. For instance, the responses to similar questions on the NHIS and the BRFSS can be compared.

### **HIV/AIDS Surveillance**

Surveillance for HIV and AIDS is among the most complex and carefully evaluated surveillance efforts in the United States. It includes different and mostly separate systems for AIDS and HIV. The system is largely case based, but many of the more important applications are statistical in nature.

#### **AIDS case reporting**

Since the beginning of the epidemic, surveillance efforts have emphasized determining the number and characteristics of individuals diagnosed with AIDS. The present national AIDS surveillance system, which was implemented prior to the

identification of HIV as the etiologic agent of AIDS and the development of an antibody test to determine HIV infection, was originally based on epidemiological investigations of an end-stage syndrome (Gostin et al., 1997).

Each state requires that all patients diagnosed with AIDS be reported by name to the local, state, and/or territorial health departments. These reports are then forwarded (without names but with unique identifiers) to the CDC, where a national surveillance database is created and analyzed. This surveillance system provides uniform data on trends and distribution of individuals diagnosed with AIDS. Standard records for each case include information on age at diagnosis, sex, race and ethnicity, state of residence (and metropolitan area, if relevant), mode of exposure to HIV, month of AIDS diagnosis, date reported, and other information.

AIDS case surveillance was set up in 1982, before there was a test for HIV, and even before HIV was known or the name Acquired Immunodeficiency Syndrome (AIDS) was invented. Epidemiologic analysis of reported AIDS cases alone established that AIDS was transmitted sexually and through blood products and identified a series of risk factors (homosexual sex, multiple partners, IV drug use, etc.) that were useful in developing early prevention strategies.

The system evolved over time, primarily by changing its case definition to reflect the growing clinical understanding of the disease and of appropriate laboratory tests. The case definition was also expanded in 1993, in part to enable more individuals to be eligible for federally funded treatment programs. The basic reporting responsibilities and procedures, however, remain unchanged (Schwarcz et al., 1999).



**HIV case reporting**

Until the era of potent antiretroviral therapies, AIDS case reporting, although imperfect, provided a relatively accurate picture of trends in HIV infection, especially relative HIV prevalence in groups defined by geography, race and ethnicity, and primary mode of infection. Estimates of HIV incidence and prevalence were made by statistical techniques, such as calculating backward from reported AIDS cases according to well-established patterns of disease progression (Brookmeyer and Gail, 1994). Recent developments in therapy for HIV and AIDS have at least temporally decoupled HIV infection and its progression to AIDS. As a result, the timing of the progression from HIV infection to AIDS and from AIDS to death is increasingly difficult to predict, making HIV incidence and prevalence estimates based on AIDS cases much less accurate (CDC, 1999). As a result of these developments, AIDS case reporting is no longer adequate to monitor trends in HIV infection.

HIV (as opposed to AIDS) case surveillance started in some states in the 1980s for contact tracing and to link people to care. This approach was not common at that time, however, because no effective treatment was available and also because of difficulties with contact tracing, especially given the need to protect cases' privacy and confidentiality.

In response to concerns about the limitations of the current AIDS surveillance system in providing accurate information about trends in the HIV epidemic, CDC now recommends that all states and territories extend their AIDS surveillance activities to include case reporting of HIV infection (CDC, 1999). In August, 2003 Georgia became the last state to implement an HIV reporting system.

HIV case reporting is said to have a number of benefits. In its official guidance on HIV surveillance, the CDC maintains that HIV case reporting will produce a more realistic and useful estimate of resources than use of AIDS case reports alone (CDC, 1999). Accounts of HIV case reporting in the popular press sometimes suggest that such a system will identify a larger number of infected individuals, and thus lead to greater federal funding for states who adopt such a system. The possibility that federal treatment funds might be allocated according to the number of individuals living with HIV rather than AIDS, raised during Congressional debate about the Ryan White Care Act reauthorization in 2000, caused great concern in areas such as San Francisco with “mature” epidemics.

Data from existing HIV reporting systems, however, are incomplete in several important ways. In contrast to the AIDS case reporting system, which is relatively complete, the HIV reporting system collects data only from persons who (a) choose to be tested and (b) do so at a non-anonymous testing site (i.e., where the HIV test result is linked with identifying information, including patient and provider names). Thus, HIV case reporting data exclude individuals who are infected but have not been tested, as well as those who utilize anonymous testing sites or home collection test kits (CDC, 1999). Because of this selectivity, HIV case reporting by name is unrepresentative of the larger population of infected persons. Further, because reported HIV cases could represent infections that are anywhere from a few weeks to a few years old, the data would reflect the time that individuals chose to be tested rather than when the individual became infected. As a result, HIV case reporting data provide only partial information about HIV

prevalence, rather than information about new HIV infections (HIV incidence) (Johri et al., 1998).

In *No Time to Lose*, the Institute of Medicine (IOM, 2001a) concluded that a new surveillance system focused on HIV incidence is needed in order to more effectively guide HIV prevention planning, resource allocation, and evaluation decisions at the national, state, and local levels. To the extent possible, the system would provide the most accurate and timely estimates at the state and local level and for the population groups at highest risk for HIV infection. In particular, the committee recommended that CDC “create a surveillance system that can provide national population-based estimates of HIV incidence. The recommended surveillance system would estimate new HIV infections using blinded serosurveys of well-characterized sentinel populations (e.g., drug users in treatment and people attending STD clinics, tuberculosis clinics, and clinics serving women of reproductive age), surveys that characterize the populations served by those sites, and new testing technologies that are able to distinguish new and old HIV infections. The same approach might also be used to estimate HIV prevalence.

### **Other HIV/AIDS surveillance activities**

To help improve the design and evaluation of prevention strategies, additional surveillance information is needed on behaviors that put people at risk for HIV. Currently, assessment of HIV risk behaviors is conducted on three levels. First, CDC and the states regularly conduct behavioral surveillance of the general U.S. population, using such instruments as the NHIS, BRFSS, the Youth Risk Behavior Surveillance System, and the National Survey for Family Growth. These surveys provide very general

information about HIV testing and some sexual and drug-use-related behaviors, but are very limited in the amount of data they can provide regarding specific risk practices, particularly among high-risk subgroups, such as injection drug users and men who have sex with men. Behavioral surveys conducted among HIV-infected populations may provide information on practices that increase risk for viral transmission to sex and drug-using partners, but they do not yield data on at-risk, uninfected persons. Behavioral assessments among high-risk populations fill this void but often are constrained in their representativeness and generalizability due to sampling biases (e.g., as with convenience sampling).

### **Evaluations of AIDS and HIV Surveillance Systems**

Evaluations of AIDS and HIV surveillance systems have tended to focus on the completeness of reporting—the degree to which all individuals with these conditions are reported to public health authorities. To a lesser extent, they have studied the accuracy of the elements of the report such as sex, primary risk factor, and place of residence. To the extent that characteristics such as sex and primary risk factor are systematically misreported in AIDS reports, estimates of the prevalence of HIV or AIDS in people with those characteristics will also be biased. Delays in AIDS case reporting have also been systematically studied.

Evaluations of these surveillance systems usually do not directly address the dimensions identified by Romaguera et al. (2000)—simplicity, flexibility, acceptability, validity and reliability, sensitivity and specificity, representativeness, and timeliness. However, information from the existing studies of completeness, accuracy, and delays in

reporting, taken together with analyses of trends in AIDS and HIV case reports, do shed light on these issues. This section summarizes the existing evaluations of AIDS and HIV surveillance systems in their own terms, and then interprets the results in the context of the use of surveillance data for allocating federal funds.

### **Completeness and accuracy of AIDS case reporting**

Completeness studies rely on the comparison of AIDS case reports with an external source of AIDS cases that should have been reported, typically based on medical or administrative records or death certificates. The external source may also be incomplete, so capture-recapture methods (which estimate the number of cases in neither source by making statistical assumptions about the number of cases reported in the first, the second, and both sources). Accuracy studies typically look at the correspondence between reported characteristics of cases who appear in both sources, so the results may not be representative of individuals who appear in only one or neither source.

Klevens et al. (2001) reports on three relatively recent CDC-funded assessment studies in Massachusetts, Louisiana, and San Francisco. In Louisiana and San Francisco, the reference source was generated by sampling hospitals, clinics, and individual physicians thought likely to see AIDS cases and reviewing their records. In Massachusetts, the reference source was generated from the state's Uniform Hospital Discharge and Medicaid claims data sets. They found that completeness varied by location and by setting. In Louisiana, AIDS case reports were 99% complete and varied little by setting. In San Francisco, case reports were 95% complete overall, but varied from 100% in hospitals to 92% in private clinicians' offices. In Massachusetts, case

reporting was 93% complete overall, and 95% complete in the Medicaid setting.

Combining the results from the three sites, Klevens et al. (2001) found that completeness ranged from 98% among Blacks to 83% in Asian populations. They also found that completeness ranged from 87% in IV-drug users (IDUs) and 83% in men who have sex with men (MSMs) to 67% in cases with heterosexual transmission as their primary risk factor.

Using methods similar to those of Klevens et al. (2001), Jara et al. (2000) found an overall completeness rate of 93% in Massachusetts, and odds ratios for being unreported of 1.72 (95% C.I. 1.20-2.46) for females and 1.49 (95% C.I. 1.00-2.33) for IDUs.

Investigators found similar results in AIDS case reports before the 1993 change in the definitions of AIDS. Reporting on 5 separate studies in New York City, Greenberg et al. (1993) found completeness rates ranging from 77% to 89%, with a mean of 84%. By race and ethnicity, completeness ranged from 86% in Whites and 83% in Blacks to 82% in Asians and 43% in those whose race was not known. According to risk group, Greenberg et al. (1993) found completeness rates ranging from 87% in MSMs and 82% in IDUs to 77% in those with “other” risk factors and 70% in those with unknown risk factors. Completeness ranged from 86% in those who resided in Manhattan to 81% for those in Brooklyn.

Summarizing studies that compare AIDS case report to death certificates, Buehler et al. (1992) found completeness rates ranging from 96% in Maine and Arizona to 83% in Los Angeles County and 80% in Duval County (Florida). Comparing AIDS reports to hospital discharge and other medical and administrative records, Buehler et al. (1992)

report on studies finding 98% completeness in Connecticut and Maryland, but only 68% completeness in Tennessee and 62% completeness in North Carolina.

In summary, completeness of AIDS case reporting is high – typically more than 90% and approaching 100% in some groups – but as low as 80% in other areas and population groups. Variation of this sort is more important for allocation decisions than is having a high average level of completeness. Completeness rates may also have changed over time, although there are no longitudinal studies to confirm this.

### **Completeness of HIV case reporting**

Although there is great debate about the relative strengths and weaknesses of name and non-name HIV case reporting, there are few studies that evaluate the completeness and accuracy of either type of HIV case reporting. Studies comparing the two types of HIV case reporting have focused on the uniqueness of the codes used instead of names, the availability of information to create a code, and the repeatability of the process of creating a code (Solomon et al., 1999). However, both types of reporting have the same critical problem—only people who have been tested for HIV at non-anonymous sites can possibly be included. The completeness of HIV case reporting, therefore, is typically calculated as the proportion of HIV positive individuals known to the health care system who are reported to public health authorities.

Mayer et al. (1994) have analyzed the completeness of reporting in HIV-infected hospitalized inpatients in South Carolina. Hospital discharge data for 1986 through 1990 were searched for patients with any HIV-related discharge code who did not meet the AIDS case definition. Of 396 HIV-infected hospitalized patients during this period, 313,

or 79%, were reported to the state HIV registry. This proportion varies from 81% in Black women to 76% in White men. There are more substantial differences in mode of HIV exposure, varying from 85% in MSMs and 81% in IDUs to 61% in blood product recipients.

In a similar study in Louisiana, Klevens et al. (1997) found that completeness of HIV reporting was 97% of patients identified in hospitals, 99% of patients identified in clinics, and 96% of patients identified in private physicians' offices.

Solomon et al. (1999) have evaluated the non-name-based HIV case reporting system in Maryland using similar methods. Of 645 unique individuals who were reported to have tested positive for HIV in 1996 at confidential testing sites, 566, or 88%, matched to the state HIV registry. In another analysis, individuals in the state's AIDS registry who had received a HIV test during 1996 were compared to the HIV registry. Of these 495 individuals, 420, or 85%, matched. These results suggest that non-name-based HIV case reporting is similar to name-based reporting in terms of completeness (defined as the proportion of HIV positive individuals known to the health care system who are reported to public health authorities).

CDC has evaluated the completeness of HIV- case reporting in Maryland and Texas by matching individuals reported to the state AIDS registry with HIV diagnoses from July 1994 to December 1996 to the state HIV registry. The completeness of HIV case reporting, measured in this way, was 50% in Maryland and 26% in Texas. In Maryland, the records from the AIDS registry were also compared to records of individuals testing positive at non-anonymous counseling and testing sites, yielding a completeness rate of 52%. These rates are not comparable to those in the previous



paragraphs since the denominator is composed of individuals who were diagnosed with AIDS 1.5 to 3 years after the HIV testing rather than individuals who received medical care during the same time period as their HIV test. We are aware of no similar estimates for name-based HIV case reporting states, but the same bias would likely be present.

In summary, when compared to the number of individuals in care for HIV-related illness, HIV case reports are only slightly less complete than AIDS case reports, although the variability from state to state in the completeness rate may be somewhat higher. Far less is known about the completeness of HIV reporting relative to actual HIV infection. However, limited data from Maryland and Texas, in conjunction with estimates that one-third or more of those infected with HIV do not know it (IOM, 2001a), suggest that the completeness of HIV case reporting is substantially lower than for AIDS. There is almost no empirical evidence about the variability of the completeness rate from state to state, but since it depends strongly on HIV-infected individuals needing and receiving care, as well as the efficiency of reporting systems that vary from state to state, the variability is likely to be higher than for AIDS case reporting.

### **Timeliness of AIDS case reporting**

By comparing reported cases to an external source, timing studies identify the lag between the first diagnosis of a case and its report to CDC. Hardy et al. (1987) reviewed death certificates from 1985 in Washington, DC, New York City, Boston, and Chicago, and matched them to the AIDS surveillance registries in each city. The estimated completeness of AIDS case reporting ranged from 83 % to 100 %. In 1988, CDC estimated that only 85% to 90% of AIDS cases were reported to CDC within one year of

diagnosis and that this proportion was declining. The median reporting delay, for example, had increased from 2 to 3 months since the previous year (Morgan, cited in National Research Council, 1989, p. 33).

Brookmeyer and Liao (1990) and Pagano and colleagues (1994) have developed more sophisticated statistical methods for estimating and adjusting for AIDS reporting delays. Applying these methods to AIDS cases in the United States before 1987 (when there was a major change in the surveillance case definition), Brookmeyer and Liao (1990) found significant geographical variation. Delays were shortest in the Northeast and longest in the South. An overall trend towards longer delays with year of diagnosis contributed to longer delays in the Northeast. Pagano and colleagues (1994) found similar effects in data reported in 1990. If these differentials in reporting delays have persisted, they would contribute to a systematic bias against the Northeast in estimating the proportion of AIDS cases, even if a uniform correction for delay in reporting was made at the national level.

Klevens et al. (2001) looked at the timeliness of reporting before and after the 1993 change in the CDC definition of AIDS in three locations. In 1993 CDC expanded the case definition for AIDS to include individuals with CD4+ t-cell counts of less than 200 cells/ $\mu$ L or less than 14% of total lymphocyte and three additional conditions among HIV-infected persons. The objective of the change was to better reflect persons with HIV-related immunosuppression, and thus at highest risk of HIV-related morbidity. In California, there was a substantial decrease in the median delay, from 14 to 3 months. The change in the median delay in Louisiana and Massachusetts was less (one month more or less, respectively). After 1993, however, the median delay differed substantially

across state, varying from 6 months in Massachusetts to 3 months in California and Louisiana.

We are not aware of any statistical studies of the timeliness of HIV case reporting.

### **Assessment**

As indicated above, surveillance systems should be evaluated in terms of simplicity, flexibility, acceptability, validity and reliability, sensitivity and specificity, representativeness, and timeliness. Whether the data and statistical estimates that emerge from such systems are appropriate for a particular policy use, however, is a different question. Of particular concern in the current study, for instance, is whether state-by-state counts of AIDS cases are appropriate measures to be used in funding allocation formulae (as is currently the case with the Ryan White Care Act), or whether counts of HIV cases might be more valid. There are a number of aspects to this question.

First, implicit in this use of the data is the assumption that one or another measure is a good proxy for the level of need for the funds to be distributed. For instance, until recently, it has been implicitly assumed that the need for federal assistance was proportional to the number of individuals with AIDS living in a state. This is in turn built on assumptions that all of these individuals need the same level of care, and that no one else needs care for HIV-related illness. Congressional deliberations about the reauthorization of the Ryan White Care Act in 2000, however, questioned these assumptions, and suggested that the number of individuals living with HIV might be a more appropriate indicator of the relative level of need. This would be true if all of these individuals need the same level of care and no one else needs care for HIV-related illness.

It would also be true under the somewhat less restrictive assumption that the distribution of need for care among HIV-infected individuals was the same in every state.

Second, it must be noted that the counts of individuals living with AIDS (or HIV) are not based directly on reported cases, but are estimates derived from these counts. In particular, the cases reported in a given year are estimates of *incident* cases, i.e., those diagnosed in that year. The RWCA formula requires estimates of the number *living with* AIDS, which must be derived from incident cases coupled with information on survival.

Third, because the RWCA allocates a fixed sum of money, the distribution of AIDS (or HIV) cases, not the absolute level, matters. Statistical adjustments are routinely used to account for incompleteness and delays in AIDS reporting (Green, 1998), but they assume that the patterns of delays in missing reports are constant over time and in the geographic areas being compared. To the extent that completeness and patterns of delay vary from state to state, the resulting estimates will contain errors, but a consistent level of underreporting of AIDS (or HIV) cases does not constitute a bias.

Finally, the estimates resulting from an AIDS (or HIV) case reporting system will be biased if the reporting process in some states is *consistently* incomplete. The evaluation studies summarized above suggest that there are differences between states, but studies have not been done to see if the differences are consistent over time. Case reporting is a process, however, and the number of cases reported depends on characteristics of the reporting system as well as on the actual number of people with AIDS or HIV infection. For instance, Klevens et al. (2001) report that the revision of the AIDS case definition had a major impact on AIDS case reporting. In the first three months of 1993, there were 204% more cases reported than in the corresponding period

in 1992, as cases became eligible because of the change of definition. The number of cases meeting the earlier case definition, however, increased by 21% during this same period, suggesting that any change in the reporting process has implications on final estimates. The implementation of HIV case reporting in California in 2002 seems to have led to an increase in AIDS reporting – as much as 32 percent in Los Angeles County (Ornstein, 2003). To the extent that the reporting process varies consistently from state to state, considerable bias can be introduced. HIV case reporting is far less uniform in its application than AIDS case reporting, so the amount of bias in estimates of HIV prevalence is likely to be greater.

### **Case Studies in Surveillance**

In order to illustrate the basic concepts of surveillance systems and the ways in which surveillance data have been used, the final section of this paper describes two case studies in detail. Case-based surveillance for STDs has long been a central part of the public health response to these diseases. Statistical surveillance data have been used for many years to guide the allocation of federal resources for maternal and child health programs in the United States, including the use of funding allocation formulae.

### **Sexually transmitted diseases**

Case identification and contact tracing have been essential parts of the U.S. strategy for control since Surgeon General Thomas Parran championed this approach in 1936. In this strategy, individuals diagnosed with syphilis not only are treated for their disease, but the health department is notified. Health department personnel interview the

“source cases” to identify their recent sexual partners. These individuals are then contacted and offered treatment.

This approach is based on two facts. First, the incubation period for syphilis is long, averaging 3 weeks and ranging from 10 to 90 days. Second, treatment reduces infectiousness. As a result, the identification and treatment of “source cases” can help to break the “chain of transmission” by preventing further transmission from source cases and by identifying and treating exposed partners before they develop symptoms.

Gonorrhea and chlamydia, however, have shorter incubation periods (< 1 week and 1-2 weeks respectively), so therapy of “incubating cases” is not possible. When the case identification and treatment logic was applied to these conditions, therefore, the rationale had to be changed to locating asymptomatic infected female partners of male source cases to provide early treatment to prevent complications.

After AIDS was identified as a sexually transmitted disease in the early 1980s, some public health officials sought to use a similar case identification and treatment control strategy. The incubation period for HIV, however, is long (on the order of years), and infected people are infectious during this period, so waiting until someone develops symptoms is too late to break the chain of transmission. Moreover, effective treatments were not identified until the late 1980s. As a result of these factors, the justification for case identification and treatment developed for syphilis did not apply to AIDS. After effective treatments did become available, the same rationale as for contact tracing for gonorrhea and chlamydia, i.e., to identify asymptomatic cases (male or female) and provide early treatment, did carry more force.

More recently, the focus of STD surveillance has grown to include questions such as whether syphilis is present in a community. Recent analyses, for example, have shown that syphilis in the United States is concentrated in a small number of areas. In fact only 21 counties and one city have 50 percent of the cases. It is mainly cities of the Southeast and those with minority populations that are the most heavily affected (CDC, 2003e). This analysis suggests that syphilis can be eradicated in the United States, and that attention should be focused on the areas and populations with highest prevalence. Similarly, recent surveillance data from San Francisco and other cities reporting a sudden increase in syphilis in young men suggest a change in sexual behavior that could also put these men at risk for HIV infection, and lead to specially targeted behavior change programs. Current uses of case surveillance data includes resource allocation, therefore, but not according to a formula such as those discussed below.

### **Maternal and child health programs**

Title V of the Social Security Act Maternal and Child Health Services Programs administered by the Maternal and Child Health Bureau (MCHB). Although Title V was enacted in 1935, MCHB's roots going back to 1912. As part of the part of the Health Resources and Services Administration in the Department of Health and Human Services, MCHB "provides leadership, performance, and accountability to ensure the delivery of health care services to all mothers, infants, children, adolescents, and children with special health care needs in the Nation – including those with low incomes, diverse ethnic or racial backgrounds, or isolated populations with limited access to care." The Bureau's budget is approximately \$700 million per year, most of which is distributed to the states.

Funds appropriated by Congress for MCHB programs are distributed to the states as follows. Roughly 85 % is distributed directly to the states according to a formula that depends on the *number of low income children in the state* as well other factors as of 1983, including the *number of births*, the *proportion of the population that is rural*, and *state financial need factors*. Prior to 1983, annual data for these variables were used in a formula to allocate funds. The remaining 15 % is set aside for distribution through programs for maternal and infant home health visiting programs, projects designed to increase the participation of obstetricians and pediatricians in MCHB programs, integrated maternal and child health service delivery systems, maternal and child health centers, and maternal and child health projects in rural areas. In the distribution of these funds, preference is given to activities in states or local areas with relatively high *infant mortality rates*.

Although not part of the funding allocation formula, states are also required to report annually on expenditures by activity and type of individual served, the number of individuals served, a variety of health outcome measures, and a set of “performance measures.” The performance measures include 18 national “core” measures plus 7 to 10 “developmental” performance measures negotiated between the states and MCHB. For example, some of the core measures are:

- percent of children through age 2 who have completed recommended immunizations;
- birth rate for teenagers age 15 through 17;
- percent of children without health insurance;
- percent of very low birth weight births;



- percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

While state funding does not formally depend on these measures, the measures themselves, plus the performance improvement system that they are a part of, are required for federal funding. All of these data are part of the annual grant application, available to federal officials making decisions about eligibility and need especially for the discretionary component of the funding.

One result of MCHB's approach to the allocation of funds to the states is the need for broad and extensive surveillance data. Many different types of data from a variety of sources (see italicized terms above) are required. Moreover, for allocation to the states to be fair, the systems generating these data must be similar in all of the states.

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