

Section 1: Confidentiality

Confidentiality is defined as the protection of information that **an individual or institution has disclosed in a relationship of trust, with the expectation that it will not be divulged to others in ways that are inconsistent with the individual's or the institution's understanding of the original disclosure.**

Why is it important for health departments and service providers to maintain the confidentiality of HIV/AIDS surveillance data and information about clients and services? Because people at risk for, and living with, HIV infection have the right to know that information about them is kept confidential by everyone involved, including prevention and care program planners, service providers, and funders. Ensuring the confidentiality of information on individuals is a fundamental requirement.

What Is Confidential Information?

Confidential information is any information about an identifiable person or establishment, when the person or establishment providing the data or described in it has not given consent to make that information public and was assured of confidentiality when the information was provided.

A Breach in Confidentiality

A breach in confidentiality is a security infraction that results in the release of private information with or without harm to 1 or more persons. A breach in confidentiality may cause a person to be subject to harassment and discrimination because his or her HIV status or other confidential information became publicly linked to that person. Even the erroneous appearance of a link (e.g., someone believed to be HIV-positive because of the release of personal identifying information) can lead to these problems. Therefore, protection of confidentiality is essential to surveillance and the use of data from surveillance and other public health programs.

The relationship of the community, the health department, and care services providers hinges on trust. One way that officials and providers maintain trust is through ensuring the confidentiality of surveillance information. A breach can erode the community's confidence in public health and care systems.

Confidentiality and the Use of Data

Most states have laws to protect the confidentiality of HIV/AIDS surveillance data and other information and to protect the privacy of HIV-infected persons. These laws are supported by several federal statutes. HIV/AIDS surveillance data reported to CDC are

protected by federal assurance of confidentiality. In addition, CDC requires, as a condition of funding, that states follow strict security standards and guidelines.¹ These standards cover health department responsibilities for the ways in which HIV/AIDS data are collected, analyzed, maintained, transmitted to CDC or other state agencies, released, and disposed of.

Confidentiality and HIV/AIDS Epidemiologic Profiles

When developing your epidemiologic profile, keep confidentiality concerns in mind with all data used, not just HIV/AIDS surveillance data. Use aggregate—rather than individual—data throughout, including tables and figures. Aggregate data include summary statistics compiled from personal information that have been grouped to preclude the identification of individuals.

For your epidemiologic profile, observe local restrictions on small cell size to prevent the inadvertent disclosure of confidential information. Because it can be easy to inadvertently identify people when small numbers of cases are broken down by age, race/ethnicity, gender, or other factors, HRSA and most state HIV/AIDS surveillance programs have a restriction policy on small cell size. Follow it when presenting data in tables. Specifically, cells whose value is 3 **or fewer** are suppressed (not shown in data presentations). Contractors should become familiar with the cell-size restriction policy. When preparing the profile, writers should indicate when data were suppressed because of small cell size.

Analyze cases by geographic area within strict guidelines for the confidentiality and release of HIV/AIDS surveillance data as specified by the health department.

Confidentiality derives from an individual's right to privacy. Persons participating in HIV/AIDS and other public health surveillance activities, such as clinic clients or persons reported to surveillance, have the right to privacy regarding disclosure of information related to their HIV status. Confidentiality is protected by law and by the ethical guidelines for various professionals, including physicians, psychologists, and social workers. For purposes of the epidemiologic profile, confidential information includes anything that would identify a person as having HIV or AIDS, being a user of counseling and testing services, having TB or an STD, or participating in a public health survey (e.g., Youth Risk Behavior Surveillance System). That means that their risk behavior, HIV status, and status with respect to other diseases cannot be disclosed publicly. These data are collected with an explicit promise to the participant that the data will remain private. Breaching this promise has legal and ethical consequences for the people or organization that collected the data, anyone who discloses the data, and the person from whom the data were collected.

Source: Adapted from the American Bar Association's "Model HIV/AIDS Confidentiality Policy."

¹CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48 (No. RR-13):1–31.

Do not include in the profile or in summary data or provide to the planning group any information (e.g., name, address, month and day of birth, Social Security number) that could identify an individual.