Chapter

5

# SPECIAL CONSIDERATIONS

This chapter is a brief consideration of several issues that may apply to only some service areas or profiles. These issues include confidentiality, special needs populations, comorbidity, and areas with low morbidity and minimal data.

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

[1] CDC. 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.

## Section 2: Special-Needs Populations

The CARE Act requires that needs assessments and comprehensive plans used by planning councils in setting priorities and allocating funds identify and address the unmet service needs of special populations.

In planning for special populations, unmet needs may refer to the service needs of persons not currently in the system of HIV/AIDS care. It may also refer to persons in the system of HIV/AIDS care whose needs are being only partially met. Determining unmet needs among special or targeted populations, which should be carried out during needs assessment, is important in determining how to direct resources to PLWH who may be disenfranchised from HIV/AIDS care services.

As of the FY 2002 application cycle, HRSA's HIV/AIDS Bureau identified the following populations as requiring special attention during the planning and resource allocations processes conducted in Title I EMAs and Title II states:

- youth 13–24 years of age
- injection drug users
- substance users other than injection drug users
- men of color who have sex with men
- white, or Anglo, men who have sex with men
- women of childbearing age (13 years of age and older)

In addition, CARE Act applicants are encouraged to identify other populations that have been significantly or disproportionately affected by the epidemic. Evidence indicating that a population has been significantly affected should be provided by the data included for underserved populations. These data should come from epidemiologic profiles and needs assessments and may also include other national and local data.

## Section 3: Comorbidity

The Reauthorized CARE Act of 2000 provides additional guidance on how HRSA's HIV/AIDS Bureau is to consider the severe-need factor in distributing Title I supplemental grant funds among Title I EMAs. The Manager's Statement, which accompanies the CARE Act Amendments of 2000, defines areas most in need of Title I funding as having "the greatest or expanding public health challenges in confronting the epidemic."

In setting service priorities and allocating CARE Act funding, Title I planning groups are required to consider epidemiologic data on comorbid conditions. They must especially consider how these conditions may increase the cost and complexity of delivering HIV/AIDS primary medical care and support services to PLWH in the EMA.

A useful epidemiologic profile provides information on HIV/AIDS prevalence among populations identified by a comorbid condition, such as STDs, hepatitis B or C, TB, substance use, or severe mental illness. It will also be important to provide information on increases or decreases in comorbid conditions among PLWH in the HIV/AIDS care system. When possible, match the cost of comorbidities with the HIV/AIDS population data to document the additional treatment costs.

## Section 4: Areas with Low Morbidity and Minimal Data

For areas with a small number of cases, data may need to be aggregated to protect confidentiality. The epidemiologists providing data for the profile should determine when aggregating data is appropriate and which aggregates are most useful.

For areas with low morbidity, geographic analysis may be particularly difficult and, in some instances, inappropriate. For example, analysis at the county level may be inappropriate because of the small number of cases. EMAs often consist of a single county or multiple counties of which one (the "dominant" county) typically has most of the cases. The numbers of cases in the other counties are generally too small for comparison with those in the dominant county or for analysis of other variables within individual nondominant counties. Consequently, the suggested analyses by "geographic area" should generally pertain only to areas (e.g., EMAs) within states, not to counties or other smaller areas within EMAs. Apply the same rationale when examining rural and urban data.

If the epidemic has remained stable in your service area, explain the data and possible reasons for this stability in your epidemiologic profile and in presentations to your community planning group. If data are available from supplemental data sources or local studies that may help explain the epidemic in your service area, be sure to include those results in your epidemiologic profile.

For service areas in which data are not available, note this lack of data in the profile.