

Estimating Unmet Need for HIV-Related Primary Medical Care: The Basics

Overview

The CARE Act Amendments of 2000 require Ryan White CARE Act Title I and Title II grantees and planning bodies to determine how many people in their service areas know they are HIV-positive but are not receiving regular HIV-related primary medical care. All CARE Act Titles and programs have a responsibility to support this process and to help with the next steps – identifying these individuals, assessing their service needs and barriers, finding ways to locate them, and getting them into care.

This summary provides a brief plain language introduction to the legislative and administrative requirements and expectations related to estimating unmet need, defines some key terms, and presents and describes the Unmet Need Framework developed by the University of California at San Francisco (UCSF) and used by the HIV/AIDS Bureau. For more information on using that Framework for estimating unmet, see *A Practical Guide to Measuring Unmet Need for HIV-Related Primary Medical Care: Using the Unmet Need Framework*, available in English and Spanish on the HRSA/HAB website at <http://hab.hrsa.gov/tools/unmetneedsp/toc.htm>.

The Project Officer training scheduled for April 7 will provide a more in-depth description of the Framework, its use, findings from the first estimates provided by Title I and Title II grantees, and ways in which Project Officers can help grantees from all Titles and programs understand and deal with unmet need.

Estimating Unmet Need: Legislative Requirements and HRSA Expectations

The CARE Act Amendments of 2000 emphasize the critical importance of dealing with the unmet need for HIV-related primary medical care among people who know they are HIV-positive but are not receiving such care. The Act:

- Directs the Secretary of Health and Human Services to develop epidemiologic measures “for establishing the number of individuals living with HIV disease who are not receiving HIV-related health services” and to prepare State and national estimates of unmet need as input to Congress about the need for continued appropriations for HIV/AIDS treatment.
- Directs Title I and Title II grantees to:
 - “determine the size and demographics of the population of individuals with HIV disease,” and to
 - “determine the needs of such populations, with particular attention to individuals with HIV disease who know their HIV status and are not receiving HIV-related services” and “disparities in access and services among affected subpopulations and historically underserved communities.”

There are three steps to the process of dealing with unmet need:

1. *Estimate* the number of people in each Title I or Title II service area who know they are HIV-positive but are not in care.
2. *Assess* the service needs and barriers to care for such people, including finding out who they are and where they live.
3. *Address* unmet need by finding these individuals and getting them into care.

Estimating unmet need is the first step in this process – and has been a major focus of HRSA/HAB since passage of the 2000 CARE Act amendments.

Definitions

The box provides some basic HRSA/HAB definitions related to unmet need:

Definitions Related to Unmet Need

- **Unmet Need for Health Services** (also referred to as **unmet need**) is the need for HIV-related health services by individuals with HIV who are aware of their HIV status, but are not receiving regular primary health care.
- **In care:** A person is considered to be **in care** when s/he is receiving regular primary HIV-related medical care (clinical evaluation and clinical care). This medical care should meet U.S. Public Health Service guidelines for the treatment of HIV/AIDS.
- **Primary medical care** is medical evaluation and clinical care that is consistent with U.S. Public Health Service guidelines for the treatment of HIV/AIDS. Such care must include access to anti-retrovirals and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.
- **Other primary health care** includes HIV-related health services other than primary medical care – oral health care, outpatient mental health care, outpatient substance abuse treatment, nutritional services, and specialty medical care referrals.
- **Non-medical supportive services** are other services that contribute to the ability of PLWH to access and remain in primary medical care.
- **Service gaps** are *all* service needs for *all* PLWH except primary health services for those who know their status and are not in care. The term **unmet need** is used only to describe the unmet need for HIV-related primary health care.
- **Estimating unmet need** means determining the approximate number of individuals in your service area (EMA, region, or State) who are HIV-positive (AIDS or HIV/non-AIDS), know their status, and are not receiving regular primary medical care.
- **Assessing unmet need** means determining the characteristics, service needs, gaps, and barriers of the individuals who are not in care – and seeing how they compare to the those of the overall population of people living with HIV and AIDS in your service area.
- **Addressing unmet need** means finding people who are not in care, getting them into primary medical care, and keeping them in care.

Understanding the Framework

The Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB) asked UCSF to develop a Framework for grantees to use in preparing a quantitative (numerical) estimate of unmet need. Several Title I and Title II grantees tested the Framework. In May 2003, HRSA/HAB informed grantees that they would be expected to estimate unmet need. In their FY 2004 grant applications, grantees were required to describe their plans for estimating unmet need, including potential data sources, timeline, and personnel who would be involved. In their FY 2005 grant applications, grantees were required to provide an estimate of unmet need using the Framework. Grantees will be expected to improve and update their estimates in future grant applications.

The Framework is based on a logical concept: If you can determine the total number of people in your service area who know they are HIV-positive – people living with HIV/non-AIDS and AIDS (PLWH/A) – and if you can determine and subtract from that total the number of such people who are receiving primary care, the difference is the number of people who have an unmet need for primary care. In other words, you assume that the individuals you cannot identify as “in care” are “out of care”:

The total number of diagnosed PLWH/A minus the number of PLWH/A receiving medical care equals the number of diagnosed PLWH/A with unmet need.

The concept is clear and straightforward. The challenge is in the implementation – in estimating the total HIV-positive/aware population and the number of people who are “in care.”

Four other pieces of information can help you understand the Framework and explain it to grantees and planning bodies.

1. **The Framework asks for the number of people in the service area who know they are HIV-positive – people who are “HIV+/aware” – and not the total number of people with HIV or AIDS – the “true HIV or AIDS prevalence.”**

Targeting of individuals who “know their HIV status” but are not in care makes sense for CARE Act grantees because people are not going to request or receive HIV-related primary medical care until they know they are HIV-positive. In addition, the CARE Act focuses on providing care for people who know their status, while the Centers for Disease Control and Prevention (CDC) provides funding for HIV prevention.

2. **The Framework asks grantees to separately estimate the number of people living with HIV/non-AIDS and the people living with AIDS who are in and out of care.**

Care needs and patterns are generally quite different depending on disease progression. Because the unmet need estimate is used in planning and decision making, grantees need separate information on people living with HIV/non-AIDS and people living with AIDS.

3. **The Framework uses a relatively simple “operational” or working definition of “in care” and “out of care.”**

HRSA/HAB requires shared definitions that grantees from every state and EMA area can use. The definition of “in care” needs to be straightforward and practical, requiring information that is likely to be available in both high-incidence and low-incidence States, in both urban centers and rural areas. The Framework definition of “in care” is *not* intended to be a definition of high quality care that meets Public Health Services guidelines. The box shows the working definitions for estimating unmet need based on the Framework:

**Using the Framework: Working Definitions of Unmet and Met Need
for HIV Primary Medical Care**

For purposes of the Framework, an individual with HIV or AIDS is considered to have an **unmet need for care** (or to be **out of care**) when there is no evidence that s/he received *any* of the following three components of HIV primary medical care during a defined 12-month time frame:

1. viral load (VL) testing,
2. CD4 count, or
3. provision of anti-retroviral therapy (ART).

A person is considered to have **met need** (or to be **in care**) when there is evidence of *any one or more* of these three measures during the specified 12-month time period.

A grantee may choose to use these definitions and *also* different or more demanding definitions. But all grantees are expected to use the basic definitions so HRSA/HAB will have estimates from all EMAs and States using the same definitions of unmet need.

4. **Doing the initial estimate is just the first step – then grantees need to assess who these people are, where they live, and what their service needs and barriers are.**

Estimating unmet need helps grantees understand the size and proportion of the PLWH/A population that is not in care. This information can help them better target their resources and services – but only if they also *assess* unmet need. That means doing demographic analyses and other needs assessment in order to understand *who* is not in care, *where* they live, *what* services they need besides primary care, and *why* they are not in care. It is also important to understand whether certain populations or subgroups are more likely than others to be out of care. This assessment of unmet need should be a part of the grantee’s overall needs assessment.

Using the Framework

The table at the end of this summary provides a sample Framework with made-up numbers. Project Officers will receive copies of their grantees’ unmet need estimates from Mosaica’s Unmet Need Technical Assistance Center, along with an assessment of the estimate’s strengths and weaknesses, comments on the methods used, and suggested next steps. To be able to use this

report, Project Officers need to be familiar with the format of the Framework and with the types of information included. They are as follows:

1. **Estimated Population Size:** The first two rows of the Framework ask the grantee to enter the number of people living with AIDS (Row A) and the number of people living with HIV/non-AIDS who are aware of their status (Row B). Every EMA and State has an estimate of total living AIDS cases available through the State HIV/AIDS surveillance system, the HIV/AIDS Reporting System (HARS). Every State is now doing HIV reporting, so in a few years the estimate of HIV/non-AIDS/aware will also be available through HARS. However, in some States, HIV reporting is too recent to be reliable. Those jurisdictions can either use an adjusted estimate from CDC or some other estimate.
2. **Care Patterns – Estimated Number of People in Care:** The next two rows of the Framework (C and D) provide the estimated number of people with HIV/non-AIDS and AIDS who are in care. This is generally more complicated to estimate than the population size. The *Practical Guide* describes several approaches, and EMAs and States have used a variety of methods. Most often, they use one of the first two approaches listed below, or a combination of approaches:
 - **Surveillance data:** In some States, laboratories are required to report all CD-4 counts and viral load tests to the State surveillance system, *and* the database allows for recording all these lab tests in the computerized system. In such States, grantees can determine from these data how many people with HIV/non-AIDS and how many people with AIDS in the system had a CD-4 count or viral load during the specified 12-month period. Normally laboratories are required to report all tests, regardless of whether people are getting care through private physicians or public sources. The sample Framework table on the following page uses this method. In the future, hopefully more and more States will be able to use this single source of care patterns data for estimating unmet need.
 - **Linked databases:** Where the surveillance system does not receive and record all CD-4 and viral load tests, grantees must use other sources of data. They can obtain data on care patterns by linking billing or service information included in various databases that record information by client (client-level databases). This requires developing a unique client identifier that protects client confidentiality and then electronically combining and “unduplicating” the data to avoid double-counting clients who received care from more than one of the data sources. Typical databases include Medicaid, the AIDS Drug Assistance Program (ADAP), and Ryan White client-based systems (such as CAREWare), preferably with data from all Titles. Since such databases typically include only people receiving care through public sources, this approach usually requires some adjustment to take into account PLWH/A who are receiving medical care through private sources. The linked databases approach requires access to all the databases as well as appropriate computer skills and capacity.
 - **Special studies:** A few EMAs and States have used special studies to estimate the number of PLWH/A in care. For example, some have used chart reviews of a sample of clients at various primary care sites. However, finding a special study that gives reliable estimates of the total population in care is difficult. This approach is not likely to provide a solid estimate unless the study is based on a probability sample of the entire population

of people diagnosed and living with HIV and AIDS. For example, data on care patterns from a survey conducted as part of an EMA’s needs assessment are not likely to be reliable unless the sample was drawn from the surveillance database. More often, such surveys are not based on a sampling process and reach primarily people who are known to the Ryan White system. Such people are more likely to be in care than the entire population of PLWH/A in the service area – so such a survey is likely to underestimate the number of people who are out of care.

Project Officers do not need to guide grantees through the process of estimating unmet need. However, Project Officers from all Titles and programs should be familiar with the Framework and the general approaches grantees are likely to use in completing the Framework. Any Project Officer who wants more information or training on estimating unmet need may request it from Mosaica’s Unmet Need TA Center, at unmetneedta@mosaica.org or 1-877-UNMNEED.

A Sample Completed Unmet Need Framework

Input	Value	Data Source
Population Sizes		
A. Number of persons living with AIDS (PLWA) as of December 31, 2003	2,500	HIV/AIDS Reporting System (HARS)
B. Number of persons living with HIV (PLWH non-AIDS/aware) as of December 31, 2003	3,500	HIV/AIDS Reporting System (HARS)
Care Patterns		
C. Number/percent of PLWA who met the definition of “in care” during 2003	2,000	Laboratory Reports from HARS (CD-4,VL)
D. Number/percent of PLWH non-AIDS, aware who met the definition of “in care” during 2003	2,100	Laboratory Reports from HARS (CD-4,VL)
Calculated Results		
E. Number and Percent of PLWA who were not “in care” during 2003	500 20%	A-C E÷A
F. Number and Percent of PLWH non-AIDS, aware who were not “in care” during 2003	1,400 40%	B-D F÷B
G. Total Number and Percent of HIV+/aware not “in care” in 2003 (quantified estimate of unmet need)	1,900 32%	E+F G÷(A+B)

Title I and Title II programs have primary responsibility for using the Framework and developing these estimates, but they need access to client data from other Titles. *Assessing and addressing unmet need* are best accomplished through cross-title collaboration. Grantees from all Titles can work together in finding and assessing the needs and service barriers for people not in care, and getting people into care – with services funded through the CARE Act or other sources.