

Ten Questions for Reviewing and Refining Your Unmet Need Methodology

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. 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 receiving HIV-related medical care – the number 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 the Health Resources and Services Administration’s HIV/AIDS Bureau (HRSA/HAB) since passage of the 2000 CARE Act Amendments. The University of California at San Francisco (UCSF) developed a Framework for grantees to use in preparing a quantitative (numerical) estimate of unmet need, and worked with selected Title I and Title II grantees to test its Framework.

The UCSF Framework is now the basis for estimating unmet need. In the 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 the 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, beginning with the FY 2006 application.

The Mosaica Unmet Need TA Center of the Technical Assistance Contract (TAC) has developed a list of ten essential questions for grantees and planning bodies to ask while reviewing and/or refining their methodology for estimating unmet need in their jurisdictions. Answering these questions will contribute to a sound methodology for estimating unmet need – and will help you prepare a clear and understandable unmet need section in your application narrative.

1. What feedback was provided by HRSA? Do we fully understand it? What steps are we taking to revise or update the estimate?

HRSA had the Unmet Need Center of the TAC provide individual feedback to all Title I and Title II grantees on the unmet need estimate submitted as part of the jurisdiction’s FY 2005 application. Based upon the soundness of the initial estimate from that State or Eligible Metropolitan Area (EMA), the feedback included recommendations to revise or update the estimate and/or take the next appropriate action steps for assessing and addressing unmet need. Since the FY 2005 application did not require use of the actual Framework table or a narrative to explain the estimate and methodology, sometimes only limited feedback could be provided.

If your feedback was incomplete or you do not understand it, ask your Project Officer or the Unmet Need Center of the TAC to clarify the information in the report.

All Title I and Title II jurisdictions will be required to refine and/or update the estimate of unmet need in the FY 2006 application. The Program Guidance is expected to be much more specific and detailed regarding both the estimate and the narrative requested – and will ask about activities to assess and address unmet need. The planned requirements were listed in the letter sent to grantees along with the consultant report on your FY 2005 estimate.

2. Does our methodology consistently use the definitions provided by HRSA?

HRSA/HAB has developed the following 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).
- **HIV-related primary medical care** is medical evaluation and clinical care that is consistent with U.S. Public Health Service (PHS) 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.
- **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.

In estimating unmet need, it is necessary to have a “working definition” of unmet need that all Title I and Title II programs throughout the country can use, even though they may have very different data systems and data access. In using the Framework, you should use that working definition:

An individual with HIV or AIDS is considered to have an **unmet need for primary 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:

- a. Viral load (VL) testing,
- b. CD4 count, or
- c. 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. It is not enough to ask providers how many people had medical visits last year. You must use the Framework definition.

Targeting 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, including HIV testing and getting people to *learn* their status.

For more definitions, see the *Practical Guide to Measuring Unmet Need for HIV-Related Primary Medical Care: Using the Unmet Need Framework* available on-line at www.mosaica.org/unmetneedta.asp.

3. Does our method use surveillance data to estimate AIDS population size?

Population size is the number of people diagnosed with HIV disease (HIV+/aware) living in the jurisdiction during a defined 12-month time **period** or as of a specified **date** (usually the end of that time period). This includes two separate data inputs:

- a. Number of people living with AIDS (PLWA)
- b. Number of people living with HIV/non-AIDS who are aware of their status (PLWH non-AIDS/aware)

Combining (a) and (b) gives the total number of HIV+/aware individuals in your jurisdiction.

All jurisdictions are expected to use surveillance data to estimate AIDS population size unless there is a specific reason why they shouldn't or can't use it. If there is a limitation to using your State's HIV/AIDS Reporting System (HARS) surveillance data on living AIDS cases, make sure you understand and explain the limitation. If you adjusted your surveillance data, explain what you did and why.

4. What data should we use to estimate HIV population size?

If your jurisdiction has had HIV reporting for a short time (usually less than three years), you may need to use the Centers for Disease Control and Prevention (CDC) midpoint estimate instead of HIV surveillance data, or provide other adjustments.

The most recent CDC estimate of people living with HIV/non-AIDS-aware was provided to grantees through HRSA/HAB in September 2003, so you may need to update it, depending on the time period you select for your unmet need estimate. As the letter from the Division of Service Systems (DSS) to grantees in 2003 indicated, "HIV and AIDS data reported to CDC through June 2003 were statistically adjusted for delays in reporting and for unreported risk. These estimates are based on national adjustments and therefore State health departments may choose to modify them or substitute other data that may be available locally." The HIV/AIDS Bureau (HAB) and CDC suggested the following adjustment to estimates: assume that the change in HIV/non-AIDS cases since the last estimate from CDC is proportionately the same as the change in AIDS cases over the same period. For example:

- Diagnosed HIV (not AIDS) prevalence as of June 2000 (provided to grantees by DSS and CDC) = 900
- AIDS prevalence as of December 2000 = 1,000
- AIDS prevalence as of December 2004 = 1,200
- Adjustment factor = 1,200 divided by 1,000 = 1.2
- Diagnosed HIV (not AIDS) prevalence as of December 2004 = 900 x 1.2 = 1,080

Work with your surveillance department in making an appropriate adjustment. In a few years, every State should have reliable HIV reporting, but new systems and delays in reporting mean that it often takes several years before the data are reliable and reasonably complete.

5. What method should we use for the care patterns estimate?

- **Should we use HARS laboratory data?**

Care patterns are measures of how many HIV+/aware persons in your jurisdiction are receiving HIV primary medical care from any provider (not just Ryan White care providers), using the Framework's working definition of "in care." Like population size, this requires two separate inputs:

- a. Number of PLWA in care – individuals with AIDS who meet the working definition of met need for primary medical care.
- b. Number of PLWH non-AIDS/aware in care – individuals with HIV disease who know their status and meet the working definition of met need for primary medical care.

Where data are complete, HARS laboratory data are the preferred choice for determining care patterns. They provide the easiest way to estimate met need because it includes all sources of care, public and private. Some of this information is difficult to obtain from other sources, particularly the number of people receiving privately funded care (e.g., care from private physicians or health maintenance organizations, typically funded by private health insurance).

Your ability to use laboratory data to measure care patterns depends on both what is *reportable* in your jurisdiction and how fully reporting is *implemented*. To use HARS laboratory data as your only source of care patterns data, you need to be sure your system includes full reporting of all CD4 and/or viral load tests.

In many States, full lab reporting is not required. Sometimes reporting is required only of CD4 counts less than 200 and/or detectable viral loads. Some States do not require viral load reporting. Some States do require full reporting but implementation is incomplete.

If lab reporting is reliable (i.e., the required reporting is done consistently) but limited (i.e., the State does not require reporting of all CD4 counts or all viral load tests), you may still want to use surveillance data in estimating care patterns. However, you will need to supplement it with other care patterns data. Your first choice might be to seek direct reports from laboratories, because these lab reports typically include people in private care. Several States and EMAs have been able to obtain full lab reports, since the labs must collect them even if they are required to report only a subset of them. Remember, the labs don't need to give you the test results; all you need to know is whether the PLWH/A in the surveillance system had a lab report during the year. If you cannot get information directly from the labs, you will probably need to use multiple databases and unduplicate the data. Understand what

lab reporting your system includes, decide whether you can use HARS data alone or along with other data – and then make sure you include this information in your narrative.

- **Should we use a linked databases approach?**

If your HARS laboratory data is not complete, linked databases are usually the second choice. You can obtain measures of patterns of HIV primary medical care by linking information included in various client-level databases or billing databases, using adequate measures to protect confidentiality (a non-identifying unique identifier or soundex code,¹ for example). In many jurisdictions, combining data from CARE Act (ideally Titles I-IV providers), Medicaid, and the AIDS Drug Assistance Program (ADAP) will cover the largest sources of HIV primary medical care in the jurisdiction. Some jurisdictions link their incomplete HARS data with all or some of those databases. Sometimes it is possible to obtain access to client data from private providers, but often this is not possible, and an adjustment to the data will be required to include people in privately funded care.

If you obtain care patterns data from multiple data sources, do your best to unduplicate it so you don't double count people who may be included in more than one database – for example, Title I and Medicaid. Sometimes you won't be able to unduplicate data – for example, Veterans Administration (VA) data may be available only as an aggregate number. Sometimes you cannot gain access to needed databases. A jurisdiction with low HIV/AIDS prevalence may not have the computer capacity or funding to do the unduplication. If your unduplication is incomplete, describe your process or adjustments in the narrative accompanying your estimate of unmet need – and work towards an improved system in future years.

- **Should we use special studies?**

Avoid using special studies as the primary method for estimating care patterns data unless the other two options are not feasible – or unless you have access to studies that are representative of the entire population of people with HIV and AIDS.

The availability and representativeness of special studies is a serious concern in many jurisdictions. For example, most surveys of people with HIV and AIDS are not based on probability sampling of complete lists of people with HIV and AIDS (such as surveillance lists), so the information obtained cannot be assumed to represent the entire HIV/AIDS population in your jurisdiction. In some jurisdictions, data may be available from existing studies such as the CDC Adult/Adolescent Spectrum of Disease (ASD) studies that monitor clinical outcomes and mortality in persons with HIV/AIDS and look at the use and effectiveness of recommended preventive treatments. The Supplemental HIV/AIDS Survey (SHAS), which obtains descriptive information on persons reported to State/local health departments with HIV infection and/or AIDS, can be useful, but usually the sampling does

¹ A soundex code is a coded last name index based on the way a surname sounds rather than the way it is spelled. It is a census coding system developed so you can find a surname even if it may have been recorded under various spellings. Another approach is to develop a unique client identifier based on several factors such as birthdate, race/ethnicity, and gender.

not provide representative data for the entire jurisdiction. Both of these studies have been discontinued and are out of date – and only include certain populations and providers.

Your jurisdiction may be able to use patient chart reviews or develop your own studies. In jurisdictions where the number of providers is limited, it may be possible to survey primary care providers (including private physicians) to determine the number of clients who met the working definition of “in care” during a specified 12-month period.

6. Is each of our assumptions and/or adjustments based on the best available data?

The Framework calls for use of a very specific methodology and carefully selected State and local data sources to develop your estimate. The purpose of the unmet need estimate is to learn about care patterns – so you need to accurately measure them using the Framework, making as few assumptions as possible. Once you have measured them, you will know which assumptions you can safely make in the future.

For every assumption or adjustment, carefully review the data source and information used, identify limitations, and explain in your narrative what you did and why. Make adjustments based on data from your jurisdiction whenever possible, rather than assuming that statewide or national estimates apply to your area.

7. How do we provide separate estimates of 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 and planning bodies need separate information on people living with HIV/non-AIDS and people living with AIDS. Developing separate estimates for PLWA and PLWH/non-AIDS means obtaining separate data, and not simply assuming similar care patterns or reporting for AIDS and HIV/non-AIDS.

If you use HARS or linked databases, be sure to separately analyze care patterns data for PLWH/non-AIDS and PLWA. The data are readily available in most major databases. If you ask providers to report data on the number of clients who meet the working definition of “in care,” ask them to report the two groups separately.

Sometimes, separate data may not be available. For example, if you use the aggregate VA data available on the VA website (www.publichealth.va.gov/hrsa/data.htm), you will need to estimate the number with HIV/non-AIDS and the number with AIDS. The same is likely to be true for prison data, and sometimes for data on people in private care. Here are two sample approaches for making those adjustments:

- *Assume that the breakdown of these clients is the same as the breakdown for all PLWH/A in care.* If your other care patterns data indicates that 52% of the people in care are PLWH/non-AIDS and 48% are PLWA, apply the same percentages to the aggregate data

- assume that 52% are PLWH/non-AIDS and 48% are PLWA. Use this method if you have actual PLWH versus PLWA breakdowns for most of your care patterns data.
- *Assume that PLWH/non-AIDS and PLWA are equally likely to be in care, and that the in-care breakdown for the aggregate data is the same as your population data for all PLWH/A in your jurisdiction.* For example, if 55% of all HIV+/aware individuals in your jurisdiction have HIV/non-AIDS, and 45% have AIDS, apply the same percentages to the aggregate data – assume that 55% are HIV/non-AIDS and 45% are AIDS cases. Use this option *only* if you feel that the other care patterns data do not provide enough information for you to estimate the differences in care patterns for PLWH/non-AIDS and PLWA.

8. How can we prepare demographic analyses that help us understand who is out of care in our State or EMA?

Estimating the number of people not in care in their service area is just the first step for grantees and planning bodies in dealing with unmet need. Before they can find such individuals and get them into care, they need to know more about *who* they are, *where* they live, and why they are not in care. This usually involves two steps:

- Using client-level databases that include demographic information to carry out “subpopulation” analyses, generating provide profiles of people who are not in care, and comparing them to the entire PLWH/A in your jurisdiction
- Finding and talking to people out of care as part of your needs assessment, to understand their most important service gaps and their barriers to care.

The FY 2006 Program Guidance will ask you to describe what you have accomplished and/or are planning in both these areas.

Demographic analyses provide an understanding of the characteristics and place of residence of people with unmet need – and often show how they are similar to or different from the overall HIV/AIDS population or people who are in care. There are several ways to do demographic analyses – and HRSA/HAB does not require any particular approach. Unmet need estimates often use databases that provide not only care patterns but also demographic information about people with HIV and AIDS. Typically, this includes information on:

- Gender
- Race/ethnicity
- Age or age category
- Method of transmission
- Place of residence (city and often ZIP code)

If you gather not only numbers but also demographic information when you do your estimate of unmet need, you will be able to do some demographic analysis of the people who are not in care using the same databases. Then you will be able to provide a *breakdown* of people not in care according to those characteristics – for example, to look at the number and percent of people with unmet need who are male and female, are of various racial/ethnic backgrounds, live in particular geographic areas, and fit particular transmission or risk groups. UCSF has developed technical instructions for using this method, which is one type of demographic analysis.

In addition to preparing a profile of people not in care, it is important to compare this group with people in care or with the total HIV/AIDS population living in your jurisdiction, using information usually included in your epi profile. This comparison helps you determine whether particular subpopulations or residents of particular geographic areas are especially likely to be out of care – important information for your grantee and planning body in identifying barriers to care and planning how best to address unmet need.

Often, demographic data on people in or out of care is incomplete. For example, you may have demographic data from your HARS and Ryan White client database, but not from billing databases like Medicaid. Demographic analyses can be useful even if they are not complete – just be sure you know and document their limitations.

In addition to demographic analyses, most jurisdictions will also need to include assessment of unmet need as part of the needs assessment. This means finding people who are not in care, learning what services they most need, and learning why they are not in care so you can help to overcome those barriers. It is important for planning bodies to understand the concept of unmet need and their own jurisdiction's estimates, including any limitations. If the current needs assessment obtains data primarily from current CARE Act clients, you will need to add a component that seeks out and interviews people not in care. (For help in doing this, see “After the Estimate of Unmet Need – What Comes Next? Assessing and Addressing Unmet Need,” available on the Mosaica Unmet Need website.)

The FY 2006 application is expected to ask grantees to describe any demographic or subpopulation analyses of the people not in care in the jurisdiction based on the results of the Unmet Need Framework. It will also ask grantees to discuss the demographics and location of persons who know their HIV status and are not in care and their service needs, gaps, and barriers to care.

9. How are we using our estimate in decision making and in addressing unmet need?

Your estimate of unmet need is not designed simply to meet HRSA requirements. Grantees and planning bodies should be using unmet need estimates and assessments to get people into care and retain them in care.

The FY 2006 application is expected to ask grantees to discuss the following:

- Plans to find people not in care and get them into primary care
- How the results of the Unmet Need Framework were used in planning and decision making about priorities, resource allocations, and the system of care

10. How can we best collaborate with other titles and programs on unmet need?

Collaborating with other Ryan White Titles and programs helps you in estimating, assessing, and addressing unmet need. This process should involve all Ryan White Titles and programs as well as other service providers, some of them not funded through the CARE Act but serving people with HIV and AIDS.

Many States and EMAs have formed cross-title working groups to estimate unmet need, and are now working with them to assess and address unmet need as well. Collaboration can strengthen your work on unmet need:

- In estimating unmet need, Title III and IV providers can provide data on their clients “in care,” and may provide valuable estimates of the proportion of clients who have private health insurance. Sometimes these providers have done special studies that will help you with other estimates and adjustments.
- In assessing and addressing unmet need, you will need the help of all Titles and programs to identify people out of care so you can learn about their service gaps and barriers to care and get them into care. Providers that may not be CARE Act-funded, such as homeless shelters, counseling and testing sites, and substance abuse treatment programs can provide valuable help in finding people out of care – so you can learn about their needs and get them into primary medical care and other needed services.
- In addressing unmet need, all Titles need to help in getting people into care. Often, most primary care is provided by Title III and Title IV programs. They represent a key referral source for Title I and Title II programs. Limited resources are a challenge for all Titles, and cross-title collaboration can help ensure that PLWH/A get help to enroll in Medicaid or obtain care from other sources.

The FY 2006 application is expected to ask grantees to discuss any plans for cross-title collaboration in both assessing and addressing unmet need.

For technical assistance, contact the Mosaica Unmet Need TA Center of the TAC at 1-877-UNMNEED (1-877-866-6333) or by e-mail at unmetneedta@mosaica.org.

For helpful materials, go to www.mosaica.org/unmetneedta.asp