

Unmet Need Estimates: Dos and Don'ts for Title I and Title II Grantees

When preparing your revised Unmet Need estimate, consider these suggested “Dos” and “Don'ts.”^{*} Review them along with the consultant report on your individual grantee unmet need estimate. You may also want to review “Ten Questions for Reviewing and Refining Your Unmet Need Methodology.”

DO

1. **Do use the operational definition provided by HRSA/HAB in making your estimates.** If you prefer a more demanding or different definition, feel free to use that in addition – but be sure to provide an estimate of unmet need that is based on use of the definition provided with the Unmet Need Framework.
2. **Do use surveillance data to estimate AIDS population size unless there is a specific reason why you shouldn't or can't use it.** If there is something wrong with your HIV/AIDS Reporting System (HARS) surveillance data on living AIDS cases, explain what is wrong. If you adjusted the surveillance data, explain what you did and why.
3. **If your jurisdiction has had HIV reporting for a short time (usually less than three years), do use the Centers for Disease Control and Prevention (CDC) midpoint estimate instead of HIV surveillance data, or make other adjustments to the surveillance data.** The most recent CDC estimate of people living with HIV/non-AIDS-aware was provided to grantees in September 2003. It did not include States that have implemented HIV reporting since 1999. Your State may be able to provide a better estimate. If you want to use the CDC midpoint estimate for HIV/non-AIDS but need to update it, the suggestion from DSS and CDC was to 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.
4. **If you use HARS laboratory data for your care patterns estimate, do be sure your HARS system includes full reporting of all CD4 and/or viral load testing – or be prepared to use other data as well.** Experience from the 2005 application review suggests that the greatest challenge faced by many jurisdictions is estimating the number of people getting private care, paid for by private health insurance or by the patient. If you have full lab reporting, you have that information; if not, your task is harder. First, identify limitations in the system – such as reporting only of CD4 counts less than 200 and/or detectable viral loads. Sometimes jurisdictions assume that CD4 reporting of this type is complete for people living with AIDS, and they just need to adjust for people living with HIV/non-AIDS. This is not necessarily true. A person who has been diagnosed with HIV/AIDS may have a CD4 count above 200 with medication. Labs for that person will not be included in the reporting of a State with the cut-off of 200 – so you will not know if such individuals are in care. Getting

^{*} These suggestions were developed by the Mosaica Unmet Need TA Center, based on reviews of the 2005 Ryan White CARE Act Title I and II application unmet need estimates.

complete data on PLWH/non-AIDS from other sources can be especially difficult, because these individuals are less likely to be receiving publicly funded care and more likely to have private health insurance. You may want to link available but incomplete HARS lab data with other databases.

5. **Do be sure to include in your estimate people in “private care” – individuals with private health insurance.** As noted above, HARS lab reporting is often the best source of care patterns data on people in private care, because full lab reporting includes people regardless of the source or payer of care. If you have incomplete lab reporting, be sure to estimate the number of people in private care. This is often the most challenging aspect of the unmet need estimate. You can use local hospital discharge data to get an estimate of the number of people with HIV/AIDS who have private insurance, work with major insurance companies to get data, or obtain data from providers that serve people with private and public funding. Recognize the limitations of these sources, and wherever possible, get separate estimates for PLWH/non-AIDS and PLWA. It appears that people with HIV/non-AIDS are more likely than PLWA to have private insurance – which seems logical, since many are asymptomatic and are able to work full-time. They are also less likely to receive publicly funded care, since they may have incomes too high to qualify and are not legally “disabled.”
6. **Do avoid using special studies for your care patterns data unless they are representative of the entire population of people with HIV and AIDS in your jurisdiction.** 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. The proportion of people with health insurance in a particular clinic is unlikely to reflect the proportion of all people with HIV/AIDS who have health insurance in your State or EMA. Be particularly wary of applying estimates from one clinic or one EMA to other EMAs or the entire State, since care patterns often differ considerably by location and population group. Use surveillance data, linked databases, or a combination, instead. Use special studies to supplement them, rather than as your primary approach.
7. **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 of your data bases.** Sometimes you won’t be able to unduplicate data – for example, Veterans Administrative data may be available only as an aggregate number. Describe your process of unduplication or adjustment in the narrative accompanying your estimate of unmet need. It appears that most people getting services from VA do not also receive services elsewhere (though this may be changing), and for most jurisdictions, the numbers are relatively small. But failing to unduplicate large sets of data – for example, Medicaid and Ryan White databases – will lead to an overestimate of the number of people in care.
8. **Either do not adjust for migration at all, or adjust for both in- and out-migration.** If you can’t reliably adjust for migration, provide a written description of migration issues that might affect your unmet need estimate. Never adjust for in- or out-migration without adjusting for the other. That may be tempting, since it is generally easier and less expensive to adjust for in-migration than out-migration, but it skews your data. If you want to do

migration adjustments, get advice and assistance from your surveillance staff. In practical terms, not adjusting for either in-migration or out-migration means that:

- You count as in care individuals identified through various data sources even if they are not in your HARS database, and
- You do not adjust population data downward to estimate the number of people you feel are now living in another jurisdiction.

In this way, you assume that in-migration equals out-migration.

9. **Do provide separate estimates of unmet need for people with HIV/non-AIDS and people with AIDS.** The two groups have different care needs and appear to have very different levels of unmet need in many States and EMAs. Separate data will provide you more useful information for decision making. In addition, the HIV/AIDS Bureau needs to provide separate estimates to the Congress. Wherever possible, obtain separate patterns of care estimates, since that is the only way to really understand patterns of care in your jurisdiction. Where this is not possible, use a defensible and consistent formula for splitting HIV/non-AIDS and AIDS cases.
10. **If you are concerned about confidentiality and Health Insurance Portability and Accountability Act (HIPAA) requirements, do become familiar with those requirements.** Go to <http://www.hhs.gov/ocr/hipaa/> for more information. Generally, the key is not to use data with people's names attached. Unique identifiers are generally the best approach to address this issue.
11. **If your unmet need is higher among people living with AIDS than for people living with HIV/non-AIDS, do review your data carefully and try to find out why.** Usually, unmet need is higher among people with HIV. If your AIDS estimate is higher, look at the year of diagnosis for people identified as not in care. Some jurisdictions have found that people with AIDS they have listed as out of care actually either have moved out of the service area or have died. One way to explore this is to compare data for people diagnosed before a specified date – such as 1990 or 1995 – with the National Death Index and the Interstate Duplication Project.
12. **Do be sure to document your process, assumptions, and limitations.** Fill in the time periods and provide understandable lists of data sources in your Unmet Need Framework table. The FY 2006 Program Guidance will require a narrative explanation that enables HRSA/HAB and other users of your estimates to understand how you developed them and whether they have important limitations. Such information is particularly valuable for planning bodies and other entities responsible for setting service priorities and allocating CARE Act resources.

DON'T

1. **Don't say that you have zero unmet need.** Distrust very, very low estimates (and very, very high estimates). Zero unmet need is highly unlikely, given what we know about co-morbidities and other barriers to care. Even if you have a superb system of care and sufficient funds to provide outreach, transportation, and every other form of support, some people

won't be in a position to take advantage of primary care services. If you get an extremely low number, check your methodology.

2. **Don't use fractions in your estimate** – you're talking about whole people.
3. **Don't rely solely on Ryan White client data in estimating the number of people who are out of care.** The CARE Act is the provider of last resort, and many people obtain primary care from other sources. If you cannot obtain all needed care patterns data from surveillance lab reports, then you will probably need to use linked databases to estimate unmet need. If so, include in your estimate major providers or payers such as Medicaid and ADAP, as well as the client-based CARE Act database.
4. **Don't simply take the word of an epidemiologist or some other expert about the level of unmet need – use the Framework.** Experts provide a great resource, but the Framework calls for use of a sound methodology and carefully selected data sources to develop your estimate.
5. **Don't assume that estimates of unmet need or care patterns taken from national studies or other States apply in your State or EMA – or that studies or estimates for the whole State or a single EMA apply in the State's other EMAs.** Jurisdictions vary greatly in the epidemiology of their epidemics and in the systems of care and the care patterns of people with HIV and AIDS. If you plan to apply national or other external data to your State or EMA, be sure you can demonstrate that the data apply to your service area.
6. **Don't simply assume similar care patterns for PLWH/non-AIDS and PLWA.** Their care patterns appear to vary considerably in most jurisdictions. Wherever possible, get separate data for PLWH/non-AIDS and PLWA in care and learn about actual care patterns. Then perhaps you will be able to make informed assumptions in the future – for example, that PLWH/non-AIDS are X% more likely than PLWA to have private insurance, or Y% less likely to be in care. Avoid making those assumptions until you can verify them with data from your jurisdiction.
7. **Don't provide two or three unmet estimates calculated in different ways** – choose what you feel is the most reliable estimate or calculate an average and explain what you did. It is useful to consider and test more than one estimation method and state the limitations of your methods. However, HRSA/HAB wants to receive a single estimate, and you need a single estimate as a foundation for further needs assessment and decision making.
8. **Don't view estimating unmet need as just “another HRSA requirement.”** Estimating unmet need provides valuable information about the epidemic in your jurisdiction – information that will help you improve your system of care, get people into care, and keep them in care. Unmet need estimates are an important step in this process.

Contact the Mosaica Unmet Need TA Center by telephone 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.