

Summary of Approaches Used for Assessing Unmet Need: Ideas from the FY 2006 Ryan White Title I and Title II Applications

Type of Activity	Description
Demographic Analysis	
HARS-based demographics	A State with full lab reporting uses HARS laboratory data for both estimates of unmet need and demographic analysis. Tables generated include the profile of all PLWH/A in the jurisdiction, the profile of people in care, and the profile of people not in care (obtained by subtracting those in care from the total HARS database).
Demographic data from linked databases	The State Department of Public Health links and unduplicates public databases to provide the core of its unmet need estimate. It extracts demographic data on the individuals identified as in care, combining data from multiple sources to provide the most complete possible demographic profile. Typically available: PLWH/non-AIDS versus PLWA status, age, gender, race/ethnicity, zip code or municipality of residence.
Linking of HARS and other databases to obtain demographics	The State Department of Health does not use HARS laboratory data because of incomplete and/or unreliable reporting. However, it links the unduplicated data on individuals in care from its linked database with the HARS database, adding demographic data from HARS to the demographics available from the other databases. Its HARS has more reliable data on race/ethnicity than claims databases, and includes risk factor data. Claims databases have up-to-date zip code data or information on place of residence, while HARS has only residence at time of diagnosis.
Mapping	An EMA uses zip code information from its demographic analysis to prepare a map of the place of residence of individuals not in care, then categorizes communities based on their level of unmet need. Resulting information helps in targeting outreach and public education efforts.
Interpretation of incomplete demographic analyses	A grantee subtracts data on individuals found to be in care from total HARS surveillance data to obtain a profile of individuals not found to be in care. The grantee notes that lab reporting is incomplete, so some people in the "not in care" group are probably in private care. Grantee indicates that these data limitations probably lead to an overcount of PLWH/non-AIDS and White non-Hispanic MSM in the unmet need population, since these groups are especially likely to have private health insurance.
Supplemental database with demographics	The State maintains both the official HARS database and a second database of individuals known to be living in the State but diagnosed elsewhere. It also maintains demographic data on these individuals, and uses this information in preparing its demographic profile of individuals in and out of care. The State assumes in its estimate that in-migration equals out-migration. This means that it counts individuals as "in care" if they meet the Framework definition, whether or not they are in the HARS database.
PLWH/A Surveys	
Targeting of PLWH/A surveys to people not in care	The grantee or planning body conducts a <i>PLWH/A</i> survey rather than a <i>consumer</i> survey, and targets individuals both in and out of care. Participating providers include points of entry into care and entities likely to serve individuals not receiving primary care, such as homeless shelters, testing sites, and substance abuse treatment programs.

	Contacts with possible respondents are designed to protect their privacy and not identify them as HIV-positive – for example, the needs assessment is called a “community needs assessment” rather than an HIV/AIDS needs assessment.
Interviews with PLWH/A not in care	The needs assessment uses interviews rather than self-administered surveys to obtain information from PLWH/A not in care, to increase return rates. Surveys continue to be used with people in care.
Use of PLWH/A interviewers	The planning body recruits and trains PLWH/A to find and interview people not in care. Interviewers are selected for their entrée to and credibility with specific targeted communities and groups (e.g., MSM of color, Latinos, transgendered individuals, women of childbearing age, former injection drug users). Interviewers are often recruited from among PLWH/A caucus or committee members or planning body consumer members. Interviewers may receive incentives or stipends, or may be volunteers.
Statewide prevention and care survey	The State and EMAs collaborate on a statewide survey that includes questions related to both prevention and care, and targets a wide range of providers and locations to identify respondents.
Obtaining of information from individuals who have been out of care	Two States have consumer surveys that ask respondents whether they have been out of primary medical care for a period of at least 12 months at any time since diagnosis. Those who have been out of care are asked questions about why they were out of care and how they got back into care. One-fourth of respondents in one State and one-sixth in the other State report having been out of care for a year or more.
Special Needs Assessment Efforts	
Study of clients in the CARE Act system	A State works with all funded providers to identify individuals who are receiving care through Title II but are not in primary care. It finds that the percentage is small – 7% of PLWA and 3% of PLWH/non-AIDS.
Telephone survey	The grantee conducts a telephone survey of PLWH/A out of care, contacting individuals who are known to the care system (they dropped out of care or are receiving supportive services but not primary care). Response rates are higher than for personal interviews. The telephone seems to provide needed privacy and confidentiality.
Interviews with PLWH/A who are new to care	The EMA interviews of PLWH/A who are new to care (entered primary care within the last 12 months), determining whether they are newly diagnosed or formerly out of care and exploring service needs, gaps, and barriers. Analysis includes comparing their demographics to those of the overall PLWH/A population and the out-of-care population.
Mini-surveys by outreach workers	As they identify PLWH/A not in care throughout the year, outreach workers in one EMA use a mini-survey to determine basic demographics, service needs and gaps, and barriers to care. They record the data on a brief form and provide it to a central location, where the information is aggregated every few months. Findings are used annually in decision making, along with other needs assessment results and the unmet need estimate.
Unmet need-focused study conducted by outreach workers	A Planning Council uses outreach workers as the interviewers for a special study of people not in care, through arrangements with the outreach providers. Because targeted outreach focuses on particular populations, the EMA is able to obtain information on subpopulations with an unusually high rate of unmet need.
Interview by Community Health Advocates	A pilot Health Advocates program develops a Community Health Assessment that focuses on talking to PLWH in the community. The Advocates identify people not in care as part of a publicized process of obtaining community input. Individuals interviewed are also offered referrals to case management or primary care.

Community discussion groups	The PLWH Caucus works with the Needs Assessment Committee of an EMA to arrange community discussion groups with specific themes related to unmet need, such as “barriers to care,” “why people drop out of care, and ” from testing to care.” Knowledgeable individuals from targeted subpopulations are recruited to participate – and asked to recruit and bring at least one HIV-positive person they know who is out of care or has been out of care. The session is open only to invited participants to protect confidentiality.
Key informant interviews	Needs assessment includes interviews with selected “key informants” from specific subpopulations. They have extensive knowledge of service needs, gaps, and barriers to care in those subpopulations.
Provider interviews	The needs assessment effort includes interviews with providers about a number of topics, including factors that cause PLWH/A to delay entry into care or drop out of care. Focus is on staff that have direct contact with PLWH/A, such as case workers, peer advocates, and outreach workers.
RARE Study	A Title I Planning Council conducts a RARE (Rapid Assessment, Response, and Evaluation) study targeting people with HIV and AIDS who are not in care. PLWH/A hired for the project serve a key role in finding individuals not in care.
Follow up on clients who drop out of care	A primary care facility contracts with a community-based organization to do individualized follow up on former clients who have not received services in at least six months, determine their reasons for dropping out of care and what is needed to get them back into care, and accompany them to an appointment where appropriate.
SPNS study	An EMA obtains funding through Special Projects of National Significance (SPNS) to identify people out of care from a particular population group. The study examines barriers to care and strengths of the service delivery system from the perspective of this group.
Foundation-funded study	The EMA obtains a grant from a health-focused foundation for a study of “HIV Aware Not in Care.”
Chart reviews	The State uses Field Surveillance Specialists to conduct chart reviews in health care provider facilities funded under all four CARE Act titles. The Specialists identify and determine the demographics of PLWH/A who are not currently in care but have an identified health care provider. The information is used for follow up with these individuals, to determine barriers to care and help them return to care – and for decision making about priorities, allocations, and the system of care.
Not-in-Care Supplement to the MMP	One State reports participating in a CDC-sponsored Not-in-Care Supplement to the new Morbidity Monitoring Project (MMP), which collects data on PLWH/A in six metro areas and 20 States. The project identifies and contacts persons diagnosed with HIV or AIDS and not initiating medical care (using CD4 counts or viral load tests as evidence of care), to investigate barriers to care.
Focus groups of “non-adherent clients”	One State reports success in using focus groups with “non-adherent clients,” PLWH/A who were in care but have not had a medical appointment in the past six months. Most grantees and planning bodies have found it difficult to get people not in care to focus groups. This group may be less concerned about anonymity than individuals who have never been in care.