

Question **2**

What are the number and characteristics of persons who know they are HIV-positive but who are not receiving primary medical care?

Efforts to measure unmet need among persons with HIV infection are under way in Louisiana. The Louisiana Office of Public Health HIV/AIDS Program has developed several strategies for identifying persons who know their status but who are not receiving primary medical care. The first project focuses on enumerating the persons who are reported as HIV infected, currently living in Louisiana, and receiving routine medical care versus those who are not receiving care. The second project is a statewide needs assessment survey, for which the most recent data were collected in 2000.

Highlights

- Of the persons living with HIV who completed the 2000 Statewide Needs Assessment and reported primary care as a need, 19% said that they needed more primary care than was available. An additional 5% reported that their need for primary medical care was not being met at all.
- Of the respondents who reported having taken protease inhibitors during the past 6 months (n=924), most said that they took them “always” as prescribed (60%) or “most of the time” as prescribed (31%). Of the respondents who were not taking combination therapy (n=233), most reported that the medications had not been prescribed (52%) or that they had not been able to tolerate the side effects (21%).

MEASURING UNMET NEED BY USING LABORATORY DATA

Louisiana’s Sanitary Code requires that laboratories report all test results indicative of HIV infection in persons residing in Louisiana (i.e., tests ordered by facilities operating in Louisiana). Once the test results have been reported to the HIV/AIDS Surveillance Program, the results can be linked to records in the HIV/AIDS case registry, which defines the population of persons living with HIV in Louisiana. Consequently, for a specified time, each HIV-infected person can be characterized as “in care” or “not in care” by the presence or the absence of a laboratory test result (e.g., CD4 cell count or measurement of viral load) during that period. This method, however, assumes that laboratory reporting is complete. Reporting is complete only if all laboratories that perform tests for HIV care facilities in Louisiana report their results to the HIV/AIDS Surveillance Program; completeness of reporting is currently being evaluated (described in the following).

A preliminary analysis of the laboratory information is being conducted to determine what proportion of persons living with HIV during 2001 sought care for HIV infection from the health care system. This analysis will detect additional issues or biases that may affect the analysis of unmet need. Later analyses will identify factors associated with accessing care and will investigate issues such as patterns of care utilization (e.g., continuity of care in the same facility, changing facilities of care) and remaining in care. An additional analysis will generate estimates of unmet need based upon a probability method that is being developed for HRSA by the University of California, San Francisco. The estimates of unmet need generated by each method will be compared to describe their differences, to assess the validity of the assumptions upon which the methods are based, and to examine their potential biases.

A comprehensive evaluation of the completeness of laboratory-based reporting is being conducted. Surveillance staff used HARS and CAREWare to generate a master list of medical facilities and health care providers in Louisiana that have cared for HIV-infected persons in the past. Each provider has been contacted by a surveillance epidemiologist to ascertain which labs the facility uses to perform HIV-related tests, as well as to determine the staff's knowledge of HIV reporting laws in Louisiana and the facility's history of reporting HIV/AIDS cases. The completed questionnaires will be analyzed to identify any laboratories not yet reporting in order to enlist them for future reporting and to describe potential biases in the estimates of unmet need.

RYAN WHITE STATEWIDE NEEDS ASSESSMENT SURVEY

A statewide needs assessment survey is conducted statewide in Louisiana every 2 years. The 2000–2001 survey was completed by more than 1,400 persons; this number represented more than 10% of the persons reported as living with HIV/AIDS in Louisiana. Information from the 2000–2001 survey provided insight into whether persons were seeking medical care, how often, and where. Additional information was collected on persons' available income and health insurance to pay for these services, extent of knowledge of their medical condition, extent of knowledge of available services and treatments, and strengths and barriers encountered when they attempted to obtain medical care. Another survey will be conducted during 2002: data on persons who indicate that they have received neither medical care nor a laboratory test (CD4 cell count or measurement of viral load) in more than 6 months will undergo additional in-depth analysis. The information gathered through the 2002 survey will provide a better understanding of persons who are not receiving care, as well as some of the potential barriers to care.

Service Needs/Availability

In the 2000-2001 Statewide Needs Assessment, respondents were asked to report their need for 26 different services during the past 6 months. Respondents indicated whether they needed the service and received it, received the service but needed more than was available, needed the service but could not get it, or did not need the service. Primary

medical care was rated the most needed service: 91% of the respondents reported a need for this type of care.

Although 95% of these persons received some primary medical care during the past 6 months, nearly one fifth of patients (19%) said that they needed more than was available. An additional 5% reported that their need for primary medical care had not been met at all (Figure 47). Respondents reported that the reasons they did not receive adequate care included rescheduling difficulties, inadequate medical staffing, difficulty in accessing acute care at their local HIV/AIDS clinic, and transportation problems. Of the persons who received primary medical care, most (90%) reported they obtained primary care services at a public medical center (Figure 48).

Figure 47
Need for Primary Medical Care Services
(n=1,366)
 Ryan White Needs Assessment, Louisiana, 2000-2001

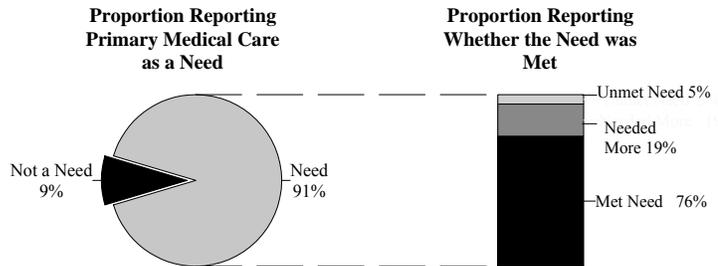
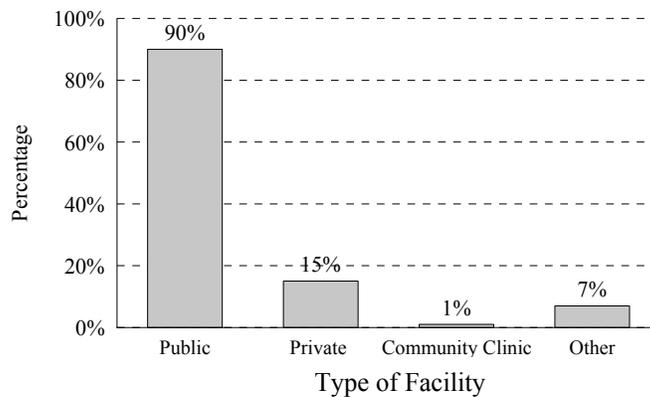


Figure 48
Receipt of Primary Care by HIV-Infected
Persons (n=1,151), by Type of Facility
 Ryan White Needs Assessment, Louisiana, 2000-2001



Note: Percentages do not sum to 100% because respondents were asked to report all primary care providers.

In addition to primary medical care, the following services were rated as the most needed by respondents: medications (78%), dental care (61%), case management (56%), and food bank or vouchers (53%). Some of these service needs were not met as well as others. Of all services, the highest level of unmet need was for dental services (17%).

Antiretroviral Therapy (ART)

Of the respondents, 73% reported that they had received a prescription for combination therapy medications during the past 6 months (Figure 49). Of those who reported taking protease inhibitors (n = 924), most indicated that they took the medications “always” as prescribed (60%) or “most of the time” as prescribed (31%) (Figure 50).

Of the respondents who were not taking combination therapy (n = 233), most reported that the medications had not been prescribed (52%) or that they had not been able to tolerate the side effects (21%). Only 1% throughout the state reported that they had not been able to fill prescriptions (either combination therapy or other therapy). Most respondents (69%) said they got medications from an HIV/AIDS clinic in a public medical center.

Figure 49
Combination Therapy in Past 6 Months
(n=1,348 patients)

Ryan White Needs Assessment, Louisiana, 2000-2001

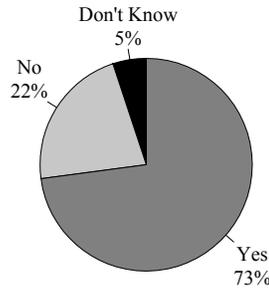


Figure 50
Adherence to Directions for Combination Therapy (n=924 patients)

Ryan White Needs Assessment, Louisiana, 2000-2001

