

Section

2

**RYAN WHITE
HIV/AIDS CARE ACT
SPECIAL QUESTIONS
AND CONSIDERATIONS**

- Question 1:** What are the patterns of utilization of HIV services of persons in Louisiana?
- Question 2:** What are the number and characteristics of persons who know they are HIV-positive but who are not receiving primary care?

Question 1

What are the patterns of utilization of HIV services of persons in Louisiana?

This section focuses on information that pertains to HRSA HIV/AIDS care planning groups. Specifically, this section characterizes the patterns in the use of services by a number of populations in the state of Louisiana. The information was provided by HRSA-funded programs as well as supplemental studies that have been conducted to examine specific aspects of HIV care in Louisiana.

In 1990, Congress enacted the Ryan White CARE Act to provide funding for states, territories, and EMAs to offer primary care and support services for persons living with HIV disease who lack health insurance and financial resources for their care. Congress reauthorized the Ryan White CARE Act in 1996 and in 2000 to support Titles I–IV, Special Projects of National Significance (SPNS), the HIV/AIDS Education Training Centers and the Dental Reimbursement Program, all of which are part of the CARE Act.

Highlights

- Ryan White CARE Act Title II clientele reflected the population in Louisiana affected by the epidemic in 2001. Sex, race/ethnicity, and age of the CARE Act clientele were similar to those of persons reported to the Louisiana Office of Public Health HIV/AIDS Surveillance System.
- During 2001, Ryan White CARE Act Title II funds were used primarily to provide case management and medical care services to the 4,125 clients enrolled in the program.
- Through the Louisiana AIDS Drug Assistance Program (ADAP), 1,440 persons received antiretroviral therapy (ART) in June 2001. Most of these persons were male, black, 19 years of age or older, and at or below 200% of the poverty level.
- Results from the Survey of HIV Disease and Care illustrate the widespread prescribing of ART (86%) and highly active antiretroviral therapy (HAART) (64%) in 1998 among HIV patients in southeastern Louisiana. Prophylaxis for *Pneumocystis carinii* pneumonia (PCP) was prescribed less frequently (indicated on the medical charts of only 58% of eligible patients). Few differences were noted in the prescribing of ART, HAART, or PCP prophylaxis, with the exception of insurance status.
- The 2000 Adult/Adolescent Spectrum of HIV Disease (ASD) study reported that HAART was prescribed to 76% of patients and that the practice did not differ substantially by patient characteristics. Overall, PCP prophylaxis was prescribed for 76% of eligible patients, and prophylaxis for *Mycobacterium avium* complex (MAC) was prescribed for a similar proportion (70%). These medications were prescribed for larger proportions of black patients than for white or Hispanic patients.
- Analysis of HIV testing delays shows that some groups may not have had access to, or may not have used, available counseling and testing services early in the course of infection.

The purpose of Title II funding is to improve the quality, availability, and organization of health care and support services for individuals and families with, or affected by, HIV disease in each state or territory. In addition, the funding provides access to needed pharmaceuticals through ADAP.

In 2001, a total of 4,125 clients received services funded through the Ryan White Title II award; of these, 871 persons were new clients. During 2001, the distribution of Title II CARE Act clients by race/ethnicity, sex, and age was similar to the distribution of these characteristics among persons known to be living with HIV/AIDS in Louisiana at the end of 2001 (Table 27).

Table 27. Comparison of demographic characteristics of CARE Act Title II clients and persons living with HIV/AIDS, Louisiana, 2001

	CARE Act clients, % (N = 4,125)	Persons living with HIV/AIDS, % (N = 13,565)
Race/ethnicity ^a		
White, not Hispanic	25	32
Black, not Hispanic	64	64
Hispanic	1	3
Asian/Pacific Islander	<1	1
American Indian/ Alaskan Native	1	
More than 1 race	3	
Unknown	5	
Sex		
Male	66	72
Female	34	28
Age (yrs.)		
<13	2	1
14–19	1	1
20–44	68	71
≥ 45	30	27

^aFor an explanation of how racial/ethnic groups were combined, see p. 11.

Most of the visits of the 4,125 Louisiana Title II clients who received services during 2001 involved case management (n = 2,231), followed by medical care (n = 770). Louisiana is unique in that it provides annual funding to 10 regional public medical centers to provide care to uninsured, low-income, or indigent patients, including those living with HIV/AIDS. Therefore, CARE Act funds are used only to supplement primary medical care in areas where gaps in services have been identified (New Orleans, Baton Rouge, and Monroe). Few clients received substance abuse or mental health services (Table 28). In 2001, the average number of visits by Title II clients was highest for case

management services (9 visits/client). Title II clients who sought dental care made an average of 3 visits related to dental care during 2001.

Table 28. Utilization of Ryan White Title II service, by type of service (N = 4,125), Louisiana, 2001

	Case management	Medical	Dental	Mental health	Substance abuse
Clients receiving service (no.)	2,231	770	467	39	13
Visits per client (average no.)	9.0	2.4	3.2	2.1	2.0

In addition to the services listed in Table 28, CARE Act funds were used to provide the following services to clients during 2001: food bank or home-delivered meals (n = 1,682 clients), emergency financial assistance (n = 1,389), transportation (n = 1,194), client advocacy (n = 816), home health care (n = 160), companion or buddy services (n = 134) and a variety of other support services (n = 1,131).

HIV MEDICAL CARE IN LOUISIANA

The prioritization and allocation of Ryan White Title II resources for HIV care require an understanding of the patterns of HIV medical care among persons living with HIV/AIDS, as well as persons already receiving care through Title II services. Monitoring the proportion of HIV-infected persons who receive recommended standards of care may help public health entities to explain differences in morbidity and mortality associated with HIV infection. Although the current HIV/AIDS surveillance system in Louisiana does not collect HIV medical care information, this information may be found in several supplemental surveillance projects that are supported by the CDC. Louisiana conducted one of the supplemental activities, SHDC, in 1998. In addition, the state has been conducting the ASD project, a survey that collects care-related data, since 1990.

AIDS Drug Assistance Program (ADAP)

Since 1987, Congress has appropriated funds to assist states in providing ART, approved by the Federal Drug Administration (FDA), to AIDS patients. With the initial passage of the Ryan White CARE Act in 1990, the assistance programs for ART were incorporated into Title II and became commonly known as ADAP. ADAP now provides FDA-approved HIV-related prescription drugs to underinsured and uninsured persons living with HIV/AIDS. For many people with HIV, access to ADAP serves as a gateway to a broad array of health care and supportive services as well as other sources of coverage, including Medicaid, Medicare, and private insurance.

In Louisiana, since June 2001, persons enrolled in ADAP have been able to receive the following classes of antiretroviral medications: nucleoside analogues, protease inhibitors, and non-nucleosides. According to the National ADAP Monitoring Project Survey, 1,440 clients were served in Louisiana during June 2001. Most Louisiana ADAP clients served during this month were male (69%), 19 years of age or older (100%), either non-Hispanic black (52%) or non-Hispanic white (48%), and lived at or below 200% of the

poverty level (Table 29). Note, however, that the National ADAP Monitoring Project Survey data are based on only 1 month of data collection (June), and the characteristics of persons receiving ADAP-funded services during this month may differ from the characteristics of the persons receiving services during the year.

Table 29. Characteristics of patients enrolled in the AIDS Drug Assistance Program (N = 1,440), Louisiana, June 2001

	Patients, %
Sex	
Male	69
Female	31
Race/ethnicity	
Black, not Hispanic	52
White, not Hispanic	48
Age (yrs.)	
<13	0
13–19	0
≥20	100
Poverty level (%)	
<100	46
101–200	54

Source. National ADAP Monitoring Project, Annual Report, April 2002.

Survey of HIV Disease and Care (SHDC)

The SHDC is a cross-sectional, population-based review of medical records of HIV-infected persons who have been reported to the State of Louisiana. The data presented in this profile are from January 1, 1998 to December 31, 1998. In 1998, the project was in its pilot phase; consequently, records were reviewed only for persons who received medical care for their HIV disease at facilities located in the southeastern part of the state (Regions I, II, III, IV, and IX). Data from future years, however, will be applicable statewide. Because SHDC is a population-based review, inferences can be drawn regarding the level and the types of HIV care experienced by persons who receive care at facilities in southeastern Louisiana. (See Appendix A for details of the SHDC methods.)

Prescription of Antiretroviral Therapy

In 1998, of the persons who received care for their HIV disease at facilities located in southeastern Louisiana, 86% received prescriptions for ART and 64% received prescriptions for HAART from their health care provider (Table 30). For the purpose of this analysis, HAART was defined as two nucleoside analogue reverse transcriptase inhibitors (zidovudine + didanosine, zalcitabine or lamivudine or stavudine + didanosine or lamivudine) plus at least one protease inhibitor (amprenavir, indinavir, nelfinavir, ritonavir, saquinavir) or non-nucleoside analogue reverse transcriptase inhibitor (delaviridine, efavirenz, nevirapine).

Table 30. Prescription of antiretroviral therapy (ART) and highly active antiretroviral therapy (HAART) for HIV-infected patients, by sex, race/ethnicity, and insurance status, Survey of HIV Disease and Care, Louisiana, 1998

	Prescribed ART, %	Prescribed HAART, %
Sex		
Male	87	64
Female	85	66
Race/ethnicity		
White, not Hispanic	92	70
Black, not Hispanic	83	61
Insurance status		
Private	93	76
Public	87	54
No insurance	83	66

The prescribing of ART and HAART differed somewhat by race/ethnicity and by whether patients had private or public insurance. ART and HAART were prescribed for larger proportions of non-Hispanic whites than for non-Hispanic blacks. Because of small numbers, proportions are not shown for other racial/ethnic groups. ART was prescribed for most privately insured patients, and HAART was prescribed for more than three quarters of these patients. In contrast, in 1998, HAART was prescribed for only half of publicly insured patients and two thirds of patients without insurance. ART or HAART were prescribed for similar proportions of males and females.

Opportunistic Infections

PCP was the first opportunistic infection associated with HIV infection. According to the *U.S. Public Health Service/Infectious Diseases Society of America Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus*, HIV-infected persons with CD4+ counts of < 200 cells/microliter should receive PCP prophylaxis; however, discontinuation is possible among persons taking HAART (CDC, 2002). As of 1998, according to SHDC data, PCP had been diagnosed for 6% of HIV-infected patients. PCP had been diagnosed for a

larger proportion of males (8%) than females (1%) and for a larger proportion of white patients (9%) than black patients (3%) (Table 31).

Overall, PCP prophylaxis was prescribed for 58% of patients in New Orleans in 1998. It was prescribed for larger proportions of eligible patients who were female and black than for patients who were male and white (Table 31). The prescribing of PCP prophylaxis differed by insurance status: it was prescribed for nearly twice the proportion of patients who had no insurance, compared with the proportion of those who had private insurance coverage. The difference between patients with private insurance and those who received public assistance was smaller.

Table 31. Current prescription of prophylaxis for *Pneumocystis carinii* pneumonia in HIV-infected patients, by sex, race/ethnicity, and insurance status, Survey of HIV Disease and Care, Louisiana, 1998

	Patients, %
Sex	
Male	54
Female	67
Race/ethnicity	
White, not Hispanic	45
Black, not Hispanic	60
Insurance status	
Private	34
Public	63
No insurance	70

Before or during 1998, 62% of HIV-positive patients were tested for tuberculosis by the tuberculin skin test (TST) (data not shown). Differences in the proportions of patients tested, by sex and race/ethnicity, were small: men (63%) vs. women (58%); non-Hispanic whites (64%) vs. non-Hispanic blacks (59%).

Adult/Adolescent Spectrum of HIV Disease (ASD) Project

The ASD project is a supplemental surveillance project in which data on the clinical characteristics and medical care of HIV-infected persons are collected. ASD is an ongoing, longitudinal surveillance cohort study that describes the full spectrum and progression of HIV disease among HIV-infected persons who receive health care at a participating facility. Since 1990, HIV-infected patients receiving care at the Medical Center of Louisiana at New Orleans, as well as 2 community-based early intervention clinics, have been enrolled in ASD. In contrast to the information presented from SHDC, ASD results are not generalizable to the HIV-infected population. However, ASD data may be used to examine trends in clinical characteristics and the provision of medical care over time. Results from the most recent year (2000) are presented to illustrate the

level of care received among the Louisiana ASD cohort. (See Appendix A for additional details concerning the ASD methods.)

Antiretroviral Therapy

In 2000, HAART was prescribed for 76% of the patients eligible to receive it, according to public health guidelines published in 1999 (Department of Health and Human Services and Henry J. Kaiser Family Foundation, 1999) (Table 32). The prescribing of HAART differed by patients’ sex: HAART was prescribed for more men (79%) than women (68%). Prescribing did not differ by race/ethnicity. Because of the small numbers of cases, proportions are not shown for Asian/Pacific Islanders or other races or persons of unknown race (total number includes these persons).

Table 32. Current prescription of highly active antiretroviral therapy (HAART) in HIV-infected patients, by sex and race/ethnicity, Adult/Adolescent Spectrum of Disease Project (N = 1,695), New Orleans, 2000

	Patients, %
Sex	
Male	79
Female	68
Race/ethnicity	
White, not Hispanic	76
Black, not Hispanic	76
Hispanic	75

Opportunistic Infections

ASD collects information on prophylaxis for OIs such as PCP and MAC. Patients were considered eligible for primary PCP prophylaxis if they had a history of an AIDS-related opportunistic infection or a CD4+ count of <200 cells/microliter and if PCP had not been diagnosed previously. PCP prophylaxis was defined as the prescribed use of trimethoprim-sulfamethoxazole, dapsone, aerosolized pentamidine, or atovaquone, alone or in combination, before, or in the absence of, a diagnosis of PCP. Overall, PCP prophylaxis was prescribed for 76% of all eligible patients in 2000. It was prescribed for a slightly larger proportion of eligible patients who were male than for those who were female and for a larger proportion of patients who were non-Hispanic black than for those who were non-Hispanic white or Hispanic (Table 33).

Table 33. Prescription of prophylaxis for primary *Pneumocystis carinii* pneumonia in HIV-infected patients, by sex and race/ethnicity, Adult/Adolescent Spectrum of Disease Project (N = 945), New Orleans, 2000

	Patients, %
Sex	
Male	78
Female	71
Race/ethnicity	
White, not Hispanic	69
Black, not Hispanic	80
Hispanic	69

Primary MAC prophylaxis was prescribed for 70% of eligible patients (i.e., CD4+ count of <50 cells/microliter and no prior diagnosis of MAC). This therapy was prescribed for similar proportions of male and female patients (Table 34) and for a larger proportion of black patients (75%) than for white (59%) or Hispanic (43%) patients.

Table 34. Prescription of prophylaxis for *Mycobacterium avium* complex in HIV-infected patients, by sex and race/ethnicity, Adult/Adolescent Spectrum of Disease Project (N = 449), New Orleans, 2000

	Patients, %
Sex	
Male	70
Female	72
Race/ethnicity	
White, not Hispanic	59
Black, not Hispanic	75
Hispanic	43

HIV Testing Delays

With the current availability of antiretroviral medications, which have often been successful in treating HIV-infected persons, it is important that people be tested early for HIV so that they can benefit from these advances in treatment. However, a significant number of people are not tested until they are immunosuppressed or sick. Of the persons who had a positive result from a confidential HIV test during 1996–2000 and were reported to the state’s HIV/AIDS Surveillance Program, one third had an AIDS diagnosis within 3 months of their first positive HIV test result. Table 35 shows the time between a person’s first positive confidential test and AIDS diagnosis, by demographic and risk characteristics. These data should be interpreted cautiously,

Table 35. Proportions of persons with AIDS diagnosis, by time between first positive HIV test result and AIDS diagnosis (N = 6,956), Louisiana, 1996–2000

	AIDS diagnosis, %		
	At time of first HIV+ test result	≤ 3 Months ^a	≤ 12 Months ^b
Overall	22	32	37
Gender			
Male	25	36	41
Female	15	23	27
Race			
White, not Hispanic	27	38	41
Black, not Hispanic	20	30	35
Exposure category			
Male-to-male sex	30	43	48
Injection drug use	24	37	44
Male-to-male sex and injection drug use	19	34	38
Heterosexual contact	17	27	32
Other	24	34	35
Unspecified	18	26	30
Age (yrs.)			
0–14	10	15	16
15–24	7	12	14
25–34	21	31	36
35–44	26	39	45
≥ 45	31	43	48
Public health region			
I	23	33	38
II	17	28	34
III	29	39	42
IV	19	30	34
V	27	37	39
VI	16	28	33
VII	23	36	39
VIII	22	34	40
IX	29	38	43

^aIncludes persons given AIDS diagnosis at time of first positive test result.

^bIncludes persons given AIDS diagnosis within 3 months of, or at time of, the first positive HIV test result.

however, because a person may have been tested earlier, but anonymously. In groups with higher rates of anonymous testing (e.g., white males), these data may overestimate the true proportion of persons who are tested late.

Among persons who were tested confidentially during 1996–2000, men were tested later than women, and white persons were tested later than black persons. For groups in which larger proportions were tested anonymously, these estimates of HIV testing delays are likely to overestimate the proportion who enter care late. Moreover, estimates of late testing and delayed access to care seem to be inconsistent with other surveillance data

(not shown) that indicate that the greatest declines in new AIDS cases and AIDS-related mortality have occurred among whites and men.

Reference

Department of Health and Human Services and Henry J. Kaiser Family Foundation. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents, May 5, 1999. Available at: <http://www.hivatis.org>.

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

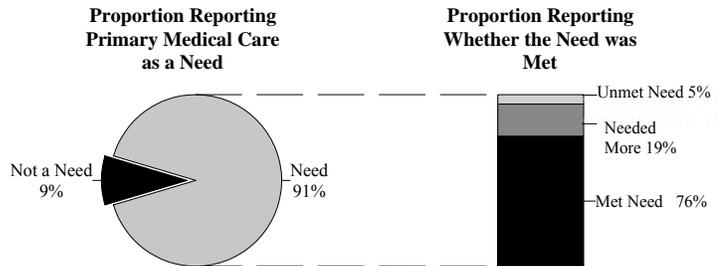
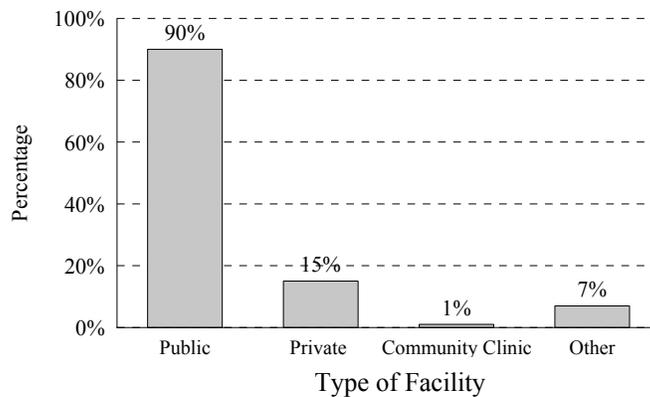


Figure 48
Receipt of Primary Care by HIV-Infected
Persons (n=1,151), by Type of Facility
 Ryan White Needs Assessment, Louisiana, 2000-2001



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

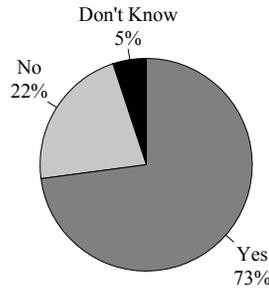
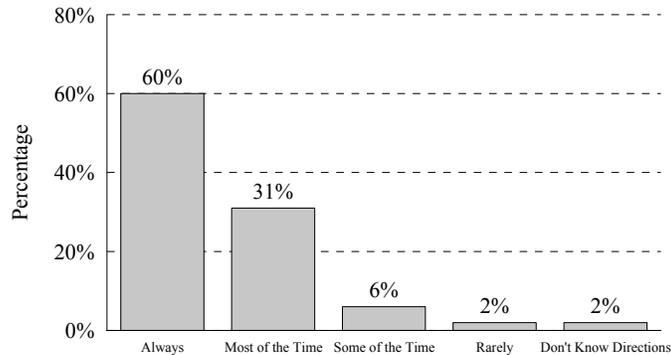


Figure 50
Adherence to Directions for Combination Therapy (n=924 patients)

Ryan White Needs Assessment, Louisiana, 2000-2001



APPENDIX A: DATA SOURCES

- Core HIV/AIDS Surveillance
- Supplemental HIV/AIDS Surveillance Projects
- Behavioral Surveys
- STD Surveillance
- HIV Counseling and Testing Data
- Substance Abuse Data
- Vital Statistics Data
- Population Data
- Ryan White CARE Act Data

Core HIV/AIDS Surveillance

AIDS Surveillance

Overview: AIDS is a reportable condition in all states and territories. Since 1993, all states and territories base their reporting practices on the 1993 CDC case definition for AIDS surveillance. The AIDS Surveillance system was established to monitor incidence of the disease and the demographic profile of AIDS cases; describe the modes of HIV transmission among persons with AIDS; guide the development and implementation of public health intervention and prevention programs; and to assist in the evaluation of the efficacy of public health interventions. AIDS surveillance data are also used to allocate resources for Titles I and II of the Ryan White CARE Act.

State and local health departments actively solicit disease reports from health care providers and laboratories. Standardized case report forms are used to collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status, and referrals for treatment or services

Population: All persons who meet the 1993 CDC AIDS surveillance case definition

Strengths: This is the only source of AIDS information that is available in all areas (states). The data reflect the effect of AIDS on communities and trends of the epidemic in communities. AIDS surveillance has been determined to be >85% complete. The data include all demographic groups (age, race/ethnicity, sex).

Limitations: Because of the prolonged and variable period from infection to the development of AIDS, trends in AIDS surveillance do not represent recent HIV infections. Asymptomatic HIV-infected persons are also not represented by AIDS case data. In addition, incomplete HIV or CD4+ T-cell testing may interfere with the completeness of reporting. Further, the widespread use of HAART complicates the interpretation of AIDS case surveillance data and the estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt the progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infections.

HIV Surveillance

Overview: Since the human immunodeficiency virus was identified and a test for HIV was licensed, CDC and other professional organizations have recommended the reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities. As part of ongoing, active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, and establish liaisons with laboratories that perform HIV testing of samples. Moreover, HIV/AIDS surveillance programs routinely evaluate the completeness of HIV reporting and conduct follow-up on HIV cases that are of epidemiologic importance.

Population: All persons who test positive for the human immunodeficiency virus (HIV)

Strengths: HIV surveillance data represent more recent infections, compared with AIDS surveillance data. Previous evaluations have estimated that HIV infection reporting in Louisiana is >85% complete for persons who have tested positive for HIV. Consequently, HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, identifies emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, or women) that may not be evident from AIDS surveillance. Additionally, HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services and can be used to anticipate unmet needs for HIV care.

Limitations: HIV surveillance data may underestimate the level of recently infected persons because some infected persons either do not know they are infected or have not sought testing. Persons who have tested positive at an anonymous test site and have not sought medical care, where they would be confidentially tested, are not included in HIV surveillance statistics. HIV surveillance data represent infections in jurisdictions where reporting laws for HIV are in place. HIV reporting laws differ by jurisdiction; therefore, consultation with local surveillance staff is advised on how to interpret local HIV surveillance data. Furthermore, reporting of behavioral risk information may not be complete.

Enhanced Perinatal Surveillance

Overview: Perinatal HIV/AIDS surveillance is the ongoing and systematic collection of information on HIV-infected pregnant mothers and perinatally exposed and HIV-infected children. Extensive medical record abstractions are conducted for all HIV-exposed children and their mothers, and the children are followed up until their infection status is determined. These data address the prevention of perinatal transmission, including prenatal care, HIV counseling and testing during pregnancy, and the use of zidovudine or other antiretroviral medications for pregnant mothers and neonates. The data also address questions regarding treatment issues for HIV-infected women and their children.

Population: All HIV-exposed children and their mothers

Strengths: Enhanced perinatal surveillance data provide perinatal-specific information that can be used to examine patterns in HIV testing and in the use of zidovudine in clinical practice, as well as to identify barriers to the implementation of Public Health Services guidelines. Perinatal surveillance data may also be used to help ascertain mother-infant pairs by matching data in the HIV/AIDS registry to the state birth registry each year.

Limitations: Perinatal data may underestimate the number of mother-infant pairs because some pregnant women may not know they are HIV infected and others may not have been tested for HIV. Perinatal data includes only those women who have had a positive confidential HIV test result. HIV-exposed infants must be followed up until sufficient laboratory information is available, so infants who are lost to follow-up cannot be classified as infected or not infected.

Supplemental HIV/AIDS Surveillance Projects

Adult/Adolescent Spectrum of HIV Disease (ASD)

Overview: The Adult/Adolescent Spectrum of Disease (ASD) project is an ongoing, longitudinal surveillance cohort study that describes the full spectrum and progression of HIV disease, including severe illness and death. Information on AIDS-defining conditions, other illnesses and symptoms, treatments, and lab parameters are abstracted from medical records onto a standardized form. In addition, gynecologic information (e.g., Pap smear, cervical cytology) is collected for women. Data are collected for the 12 months preceding ascertainment and re-abstractions are done every 6 months until the patient dies or is lost to follow-up.

Population: ASD participants must be ≥ 13 years, have a diagnosis of HIV infection, and receive health care at a participating facility in the funded area. In each funded area, facilities serving HIV-infected persons (clinics, hospitals, neighborhood health centers, private medical practices, and emergency departments) are selected to participate as project sites. At each project site, all HIV-infected women and persons belonging to a racial/ethnic minority group are included.

Strengths: ASD data describe the spectrum of HIV disease that is documented in the medical chart. Data have been available since January 1990. ASD data are useful for assessing the prescription of prophylactic and antiretroviral treatment over time and for assessing the level of AIDS-defining conditions for case definition purposes. As of December 2001, more than 50,000 persons had been included in the ASD project.

Limitations: ASD data describe morbidity among persons who received medical care for HIV infection at a participating site (i.e., not population-based). The morbidity information on the medical chart may not be complete. Gynecologic information may be underreported because this information may appear elsewhere (e.g., women may have been cared for by gynecologists rather than HIV specialists). ASD data rely on the thoroughness of diagnostic testing and recording.

HIV Testing Survey (HITS)

Overview: HITS assesses HIV testing patterns among persons at high risk for HIV, evaluates reasons for seeking or avoiding testing, and examines knowledge of state policies for HIV surveillance. In addition, HITS collects behavioral risk information from persons at high risk for infection. The data can also be used to evaluate the representativeness of HIV surveillance data by determining the characteristics of persons who delay testing, are tested anonymously, or are not tested at all.

HITS is an anonymous, cross-sectional survey of populations at high risk for HIV infection. The core populations include MSM, IDUs, and heterosexual adults. To recruit HITS participants, the study is conducted in several cities in a state (generally) at 3 venues: gay bars, street locations in areas of heavy drug use, and STD clinics. At a minimum, 100 persons in each population group are interviewed; thus, states have a minimum sample of 300 persons. Persons who are not tested or who report that they are HIV-positive are interviewed.

In 2001, HITS was conducted in New Orleans (Orleans Parish), Baton Rouge (East Baton Rouge Parish), and Monroe. The sample of 300 persons was distributed among these 3 areas: 50 persons in each population group in New Orleans, 40 in Baton Rouge, and 10 in Monroe.

Population: Regardless of the venue, persons who are at least 18 years of age, able to give informed consent, and have been a resident of the state for at least 1 year are eligible for a HITS interview. In addition, behavioral criteria apply to each risk group: men at MSM venues are eligible if they have had sex with a man within the past 12 months; injection drug users must have injected drugs within the past 12 months; and high-risk heterosexual clients at an STD clinic are eligible if they are at the clinic because of a suspected STD, have not been treated during the past 90 days, are not at the clinic because of referral or follow-up, and have not had homosexual sex within the past 12 months.

Strengths: HITS collects public health information from groups at high risk for HIV; the information includes HIV testing attitudes, history and behaviors, as well as knowledge of testing and risk behaviors.

Limitations: HITS is a cross-sectional survey and relies on a convenience sample for participation. Information collected is self-reported and may be subject to recall bias. Further, HITS data may not represent the entire high-risk population of an area. For example, in Louisiana, information on MSM was collected in only 3 areas of the state (New Orleans, Baton Rouge, and Monroe) and therefore may be limited in its representativeness. Furthermore, data on MSM were collected only in gay bars; MSM who frequent gay bars may not be representative of the entire population of MSM.

Survey of HIV Disease and Care (SHDC)

Overview: SHDC, a cross-sectional review of medical records of HIV-infected persons reported to HARS, was developed to obtain population-based estimates of the clinical characteristics of persons receiving medical care for HIV infection. SHDC collects demographic and clinical information, including the proportions of patients receiving

therapy recommended by current treatment guidelines and of those who receive preventive services. Information in the medical records of sampled patients are reviewed for the preceding 12 months and documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. Among sampled providers, a listing of their HIV-infected patients is prepared and then sampled systematically with a random start. Women and racial/ethnic minorities are oversampled.

Strengths: SHDC is designed to collect data from a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. Women and members of racial/ethnic minority groups are oversampled to ensure that population-based estimates in these populations are valid. SHDC extracts information from a variety of record sources in order to obtain information on the prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history. Data from SHDC are used to estimate the proportion of persons who received appropriate standards of care for their HIV disease.

Limitations: SHDC is a cross-sectional review, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data obtained is dependent on the completeness of documentation in the patient's medical record. SHDC's sampling frame is patients who have sought medical care; therefore, population-based inferences about HIV-infected persons who are not in care cannot be made. Although SHDC collects some behavioral information, self-reported adherence to therapies documented in the medical chart may not be known. In addition, data from SHDC may underestimate the amount and type of medical care a patient received if the patient received medical care from more than 1 provider. For example, gynecologic care may be underreported because women may seek this care from a provider who is not an HIV specialist.

Behavioral Surveys

MSM Outreach Survey (MOS)

Overview: During 1995–2000, outreach surveys were conducted across Louisiana at bars that serve MSM. The survey was a 1-page, self-administered questionnaire distributed by outreach workers from local CBOs. Each CBO surveyed 50 to 150 MSM twice per year at 1 to 2 bars where they conducted outreach activities. Every person at the bar was approached. However, if the bar was very busy, workers chose a representative sample of persons at the bar (e.g., they approached every third person who entered the bar). Respondents were asked about sex partners, history of condom use, history of receptive and insertive anal sex, and HIV status.

Population: MSM men who attend bars that serve gay and bisexual men

Strengths: Data on HIV-related behaviors among MSM are very limited. The MOS is one of the only sources of statewide behavioral data for MSM. Because the survey was

conducted every year for 6 years, trends in risk behaviors can be analyzed. Information collected from the MOS is useful for planning prevention strategies for MSM.

Limitations: MOS data are self-reported; thus, the information may be subject to recall bias. Because these data were collected in bars, the data are representative only of MSM who go to gay bars and cannot be generalized to all MSM.

Street Outreach Survey (SOS)

Overview: SOS has been administered by CBOs in every region of the state since 1995. The survey was a 1-page, self-administered questionnaire distributed each quarter by outreach workers at 3 sites where they actively conducted street outreach activities. These sites were in neighborhoods with 1 or more of the following characteristics: high rates of HIV/STDs, high levels of drug use, exchange of sex for money or drugs, or "crack" houses. Questionnaires were collected between 3:00 p.m. and 8:00 p.m. at outdoor locations (i.e., street corners, bus stops, public housing developments, and locations outside convenience stores and apartment complexes). The survey was generally conducted at the same sites each quarter. Every person at the site was approached, but a representative sample of persons was selected if the site was very busy (e.g., every third person was approached). Respondents were asked about sex partners, history of condom use, drug use, HIV testing history, and exposure to prevention programs.

Population: High-risk persons in neighborhoods where street outreach activities are actively conducted

Strengths: This survey provides data on the sexual and drug-use behaviors of persons at particularly high risk for HIV. These persons are likely to be missed by other survey approaches (e.g., BRFSS telephone survey). Because the survey is conducted every year, trends in risk behaviors can be analyzed. Data from the SOS may be used to help plan prevention strategies for persons at high risk for HIV and STDs. The data can also be used to determine the extent to which persons have been exposed to prevention activities and to monitor and evaluate state and local prevention programs.

Limitations: SOS data are self-reported; thus, the information may be subject to recall bias. These data represent persons at particularly high risk for HIV and are not generalizable to the general population in the local community.

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: The BRFSS is a state-based random-digit-dialed telephone survey of adults that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. Each month, a sample of households is contacted, and 1 person in the household who is 18 years or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents to the BRFSS questionnaire are asked a variety of questions about their personal health behaviors and health experiences. A sexual behavior module was added to this survey in 1994, 1995, 1996, 1998, and 2000.

The questions in this module, for adults (aged 18-49), concerned number of sex partners, condom use, and treatment for STDs.

Population: All noninstitutionalized adults, 18 years and older, who reside in a household with a telephone

Strengths: Data from the BRFSS survey are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state. Information collected from the BRFSS survey may be useful for planning community-wide education programs.

Limitations: BRFSS data are self-reported; thus, the information may be subject to recall bias. Because BRFSS respondents are contacted by telephone, the data are not representative of households that do not have telephones. In addition, BRFSS data are representative of the general noninstitutionalized adult population in an area, not just persons at highest risk for HIV/AIDS. The extent of HIV behavioral risk information collected by the BRFSS questionnaire is limited, and inferences can be made only at the state level.

Youth Risk Behavior Surveillance System (YRBSS)

Overview: The YRBSS was established to monitor 6 high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and young adults in the United States. YRBSS was developed to collect data that are comparable nationally, statewide, and locally. It is a self-administered questionnaire that is given to a representative sample of students in grades 9 through 12 at the state and local levels. In Louisiana, the survey is administered at the state level and in Orleans Parish public schools. However, only the survey administered to Orleans Parish high school students includes questions related to sexual behavior. The Orleans Parish Youth Risk Behavior Survey (YRBS) collects information on 6 categories of behaviors; sexual behaviors that contribute to unintended pregnancy and STDs, including HIV, constitute 1 category. Questions are also asked about exposure to HIV prevention education materials, sexual activity (age at initiation of sexual activity, number of partners, condom use, past drug or alcohol use), contraceptive use, and pregnancy history.

Population: A representative sample of students in grades 9 through 12 at the state and local level

Strengths: In New Orleans, YRBSS samples adolescents in public schools and is population-based. The YRBS questionnaire is administered to students anonymously during school. Repeated attempts are made to contact students who are not in attendance. Inferences from YRBSS estimates can be drawn about behaviors and attitudes of adolescents in school, which makes the information useful for developing community-wide prevention programs aimed at younger persons. YRBSS uses a standardized questionnaire so that comparisons can be made across participating jurisdictions. Jurisdictions have the option of asking specific questions to meet local needs.

Limitations: The YRBSS project relies upon self-reported information; therefore, reporting of sensitive behavioral information may not be accurate (may be underreported or overreported). Also, because the YRBSS questionnaire is administered in school, the data are representative only of students and cannot be generalized to all youth. For example, students at highest risk, who may be more likely to be absent from school or to drop out of school, may be underrepresented in this survey, especially among upper grades. The questionnaire does not include questions about homosexual or bisexual behavior.

STD Surveillance

STD Case Reporting

Overview: The Louisiana Office of Public Health STD Control Program conducts statewide surveillance to determine sexually transmitted disease (STD) incidence and to monitor trends. It also conducts partner counseling and makes referrals for examination and treatment in order to reduce the spread of STDs. In Louisiana, chancroid, chlamydia, gonorrhea, lymphogranuloma venereum, and syphilis are reportable STDs.

Population: All persons with an infection that meets the CDC surveillance case definition for the infection and who are reported to local health department

Strengths: STD surveillance data (e.g., data on rectal gonorrhea) can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of, or changes in, a specific behavior. STD data are widely available at the state and local level. Because of shorter incubation time periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (e.g., ulcerative STDs) can facilitate the transmission or the acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms, such as unprotected sex.

Limitations: STDs are reportable, but state requirements for reporting differ. The reporting of STDs from private-sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk.

HIV Counseling and Testing Data

Counseling and Testing System (CTS)

Overview: The Louisiana Office of Public Health provides funds for the HIV CTS at more than 150 sites in Louisiana. These sites include CBOs, drug treatment centers, and STD, prenatal, family planning, and TB clinics. The CTS collects information on counseling and testing services delivered, as well as the characteristics of clients receiving the services. The characteristics include demographics, insurance, risk information, and testing information (data, testing history, test result). However, no personal identifying information is collected. All sites offer both anonymous and confidential testing. However, 84% of persons that were tested in 2000 were tested confidentially.

Population: All clients who receive confidential or anonymous HIV testing services at a counseling and testing site funded through a CDC cooperative agreement

Strengths: CTS provides standardized data, available at the local level, on clients who are tested for HIV. The data may offer insights into HIV infection rates in an area's high-risk population. The CTS testing data may also highlight the effect of prevention programs focused on specific populations.

Limitations: CTS collects test-based, rather than person-based data. Information is collected only from persons who seek counseling and testing services or agree to be tested after consultation with a counselor at a testing site. Therefore, estimation of HIV statewide seroprevalence is not possible with CTS data because the clients self-select for testing. However, at sites where testing is universal, persons who are HIV-positive may reflect the prevalence in that population. Because a person can repeatedly seek testing, it is not possible to distinguish persons who have been tested multiple times; however, a variable called previous HIV test on the client abstract form allows prior testing to be quantified. Because the CTS gathers data on HIV testing or program activities, changes in testing patterns may reflect changing program priorities rather than the testing patterns of individuals.

Substance Abuse Data

Treatment Episode Data Set (TEDS)

Overview: TEDS is a national data set maintained by the Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA). Data are obtained annually on more than 1.5 million records of treatment admissions for substance abuse. TEDS comprises data that are routinely collected by states to help monitor their individual substance abuse treatment programs. TEDS collects information on client demographics, information about the number of prior treatments, the usual route of administration for each problem substance, frequency of use, age at first use, and services provided. Facilities that report TEDS data usually receive state funding for the provision of substance abuse treatment.

Population: Persons admitted to substance abuse treatment facilities that report to TEDS

Strengths: Although TEDS does not represent the total demand for substance abuse treatment, it does include a significant proportion of all admissions to substance abuse treatment. It includes admissions that constitute a burden on public funds.

Limitations: TEDS is based on records of admissions and does not represent individuals. Because of this, a person admitted to treatment twice within the same calendar year would be counted as 2 admissions. Also, because most states cannot identify persons who have been assigned a unique identifier at the state level to protect their confidentiality, TEDS is unable to follow individual clients through a sequence of

treatment episodes. TEDS does not represent the total substance abuse treatment burden or the prevalence of substance abuse in the general population.

Drug Abuse Warning Network (DAWN)

Overview: DAWN is an ongoing, national data system that collects information on drug-related deaths from the offices of participating medical examiners. Data are also collected on drug-related visits to hospital emergency departments from a nationally representative sample of short-stay general hospitals throughout the coterminous United States. Emergency department estimates are produced for 21 large metropolitan areas and for the nation. Drug-related death data are collected in more than 40 metropolitan areas.

DAWN was established to provide national, state, and local areas with data for program planning and policy development; to identify substances associated with drug abuse deaths; to monitor drug abuse patterns and trends; to detect new drugs of abuse; and to assess adverse health outcomes associated with drug abuse

Population: Persons who died at 6–97 years of age and whose death was drug induced or drug related. Also, the decedent must have used the substance because of dependence, to commit suicide, or to achieve psychic effects.

Strengths: DAWN provides ongoing data on the patterns of drug-induced and drug-related deaths from a large number of areas in the United States. Standardized data collection and data management procedures are used to ensure the accuracy of DAWN data. Because of concerns about the accuracy of the data, the methods were revised and new protocol modifications were implemented in 2001.

Limitations: Participation in DAWN is voluntary; thus, counts of drug-abuse deaths do not represent the entire service area if participation is not universal. DAWN collects only information about drug-abuse episodes that have resulted in a death classified as a drug-induced or drug-related death. Finally, because DAWN relies on death-investigation case files for reporting, drugs may be underreported (if not reported) or drug information may not be specific (if drug name is recorded differently).

National Household Survey of Drug Abuse (NHSDA)

Overview: The NHSDA is an ongoing source of statistical information on the use of illicit drugs by the US civilian population aged 12 or older. The survey collects data by administering questionnaires to a representative sample of the population. Face-to-face computer-assisted interviews are conducted at the respondent's residence. Information obtained by the NHSDA questionnaire includes use of cocaine, receipt of treatment for illicit drugs, and need for treatment because of illicit drug use during the past year; use of alcohol, tobacco, or marijuana during the past month; and perceived risk for binge drinking, marijuana use, or smoking.

The NHSDA uses a 50-state sampling design; for the 8 states with the largest populations, the sampling design provides a sample large enough to support direct state estimates. For the 42 remaining states and the District of Columbia, small-area

estimation techniques are used to calculate state estimates. Youths and young adults are oversampled so that each state's sample is approximately equally distributed among 3 age groups: 12–17 years, 18–25 years, and 26 years or older.

Population: Noninstitutionalized civilian US population aged 12 years or older

Strengths: NHSDA is a national, standardized survey of drug-use behaviors among the general population. To increase the level of honest reporting, information has been collected since 1999 by using a combination of computer-assisted interviewing methods. This provides respondents with a more private and confidential means of responding to questions about substance use and other sensitive behaviors.

Limitations: Direct state-level estimates are available for only 8 states; other states must rely on statistical estimates. NHSDA estimates represent behaviors in the general population; thus, the survey may underestimate the level of substance use in the population at highest risk for HIV infection. Further, data from the NHSDA are self-reported and are subject to recall bias, which may result in the underreporting of a sensitive behavior.

Vital Statistics Data

Birth Data

Overview: The National Center for Health Statistics (NCHS) receives information on births and deaths in the United States through a program of voluntary cooperation with state government agencies (e.g., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. States use a standard form (U.S. Standard Certificate of Live Birth) to collect birth data and report this information annually to NCHS. The birth certificate form collects demographic information on the newborn and the parents, insurance, prenatal care, prenatal risk factors, maternal morbidity, mode of delivery, pregnancy history, and clinical characteristics of the newborn.

Population: All live births in Louisiana

Strengths: Vital records contain data on all births in an area. Because reporting is approximately 100% complete, inferences can be made about the population of live births in a service area. The revised birth certificate collects additional information on maternal insurance status, smoking, and morbidity, which may be useful for allocating prevention resources.

Limitations: Birth certificate data are often not complete for data that are obtained from patient medical records (e.g., smoking history, morbidity).

Death Data

Overview: NCHS receives information on births and deaths through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. A standard certificate of death is used to record death information on each decedent. A

death certificate bears demographic information about the decedent, the underlying cause of death (using an *ICD-10* code [*International Classification of Diseases*, 10th rev.]), and contributions of selected factors to the death (e.g., smoking, accident, or injury).

Population: All deaths that occur in Louisiana

Strengths: The reporting of deaths in Louisiana is universal and 100% complete. The data are widely available and can be used to determine the effect of deaths related to HIV infection in a service area. Standardized procedures are used nationwide to collect death certificate data.

Limitations: Deaths resulting from, or whose underlying cause was, HIV infection may be underreported on death certificates. Clinical information related to HIV or AIDS may be missing. Death records are not available as promptly as AIDS case reports are.

Population Data

U.S. Bureau of the Census (Census Bureau)

Overview: The Census Bureau collects and provides timely information about the people and the economy of the United States. The Census Bureau's Web site (<http://www.census.gov>) includes data on demographic characteristics (e.g., age, race, Hispanic ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the proportion of persons living at or below the poverty level. Tables and maps of census data are available for all geographic areas to the block level. Summaries of the most requested information for states and counties are provided, as are analytical reports on population change, race, age, family structure, and apportionment.

Population: U.S. population

Strengths: A wide range of online statistical data on the U.S. population is available in different formats (e.g., tables, maps). State- and county-specific data are easily accessible. Links to other Web sites with census information are provided.

Limitations: The downloading of some large files may require a significant amount of time.

Louisiana State Census Data Center

Overview: This data center is administered by the State of Louisiana. The Web site for the center (<http://www.state.la.us/census>) includes current population estimates and projections; socioeconomic, income, and poverty status information; demographic profiles and rankings; and geographic units from which census data are obtained (parishes, cities, and metropolitan areas). Parish population trends are also provided.

Population: Louisiana population

Strengths: A wide range of online statistical data on the Louisiana population are available in different formats (e.g., tables, maps). Links to local affiliates of the state census data center and to other Web sites with census information are provided.

Limitations: The downloading of some large files may require a significant amount of time.

Ryan White CARE Act Data

Title I and II Statewide HIV/AIDS Needs Report

Overview: Every 2 years, Ryan White Title I and Title II programs administer a detailed survey to persons living with HIV/AIDS in Louisiana. The purposes of the survey are to gain a greater understanding of the current level of HIV/AIDS service needs and to provide insight into consumers' perceptions of the availability and quality of HIV/AIDS services throughout the state. Representatives and consumers from Titles I and II jointly developed the methods and the instrument for the statewide needs assessment. The 2000–2001 survey included a variety of demographic questions (residence, age, race, gender, income levels and sources, and type of health insurance coverage), as well as questions about HIV-related primary care, illness severity, and experiences with combination therapy. Respondents were also asked specific questions about housing, transportation, child care, drug or alcohol abuse, and needs and opinions regarding various medical and social services. Each region in the state received a predetermined number of surveys according to the response goal (a minimum of 10% of persons known to be living with HIV/AIDS in a given region).

Population: Persons living with HIV/AIDS who agreed to complete the needs assessment survey. The sample population was weighted heavily toward persons who were in care (potential respondents were encountered in primary care clinics, social service agencies, community health centers, Medicaid enrollment centers, substance abuse or mental health treatment facilities, homeless or transitional shelters, and local jails). Most of the participants received services through the Ryan White–funded service delivery system, although some sought services at Veteran's Administration hospitals only, private clinics, or other private providers.

Strengths: The needs assessment is a valuable tool for understanding consumers' perceptions of care in Louisiana. The survey instrument is flexible and can be modified to accommodate new questions as services and care recommendations change.

Limitations: The survey was administered only to persons who visited one of the care sites during the 8 weeks in which the survey was administered. Respondents also had to be willing to participate in the survey. Persons who were not in care during that time, not in care at all, or who were unwilling or unable to complete the questionnaire were not surveyed. Thus, the survey provides a measure of the needs of persons who were receiving some type of care but does not adequately address the needs of those who were not seeking care at all. Because the survey also deals with perceptions of care, many of the responses are qualitative and cannot be generalized to the statewide population.

Ryan White Title I CAREWare

Overview: Since 1993, the HIV/AIDS Program of the Louisiana Office of Public Health has collected data on persons served through Louisiana Ryan White Title I funding. Until 1999, data for Consortia-funded services were collected through the DOS-based ToolBox data collection system provided by the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA). This data collection system was not designed to obtain information about persons who received pharmaceuticals through the state-administered AIDS Drug Assistance Program. In 1996, the HIV/AIDS Program contracted with a local computer programmer to design and implement a comparable data system for persons receiving funds through ADAP. In late 1999, the ToolBox data collection system became obsolete because of “Y2K” noncompliance. The ADAP data collection system was then expanded into a more comprehensive database that was named Louisiana CAREWare.

This database includes key information on all persons receiving assistance through any of the programs funded by Ryan White Title II as well as through programs funded by State Formula HOPWA. Such programs include Health Insurance Continuation, Home-Based Care, Consortia-funded Services (e.g., case management, transportation and medication assistance, child care, mental health therapy counseling); pharmaceuticals provided through ADAP; State Direct Services (legal services, 3 primary care contracts and a copayment and deductible assistance program); and limited emergency rent, mortgage and utility payments. Information collected from service providers throughout the state includes basic demographic and risk information on each of the clients, eligibility verification data (current address, current income, HIV/AIDS diagnosis, Louisiana Medicaid number), the type of services received, the date and quantity of services received, the cost of these services, and other pertinent information (history of substance abuse or mental health treatment, veteran status and, for women, current pregnancy status). The data collected are used by the HIV/AIDS Program staff to perform monthly service delivery and fiscal monitoring activities, conduct an annual disparity analysis, track regional utilization trends for quality assurance purposes, and to meet the HAB/HRSA requirements set forth in the Annual Administrative Report and in the new CADR. It is also the expectation of the HIV/AIDS Program that providers use these data internally to consistently assess and reassess their agency’s performance.

Population: All HIV-infected persons receiving services funded by Ryan White Title II. To be eligible for Ryan White Title II services, a person must be living with HIV/AIDS, be a resident of Louisiana, and have an income that is equal to or less than 200% of the current year’s federal poverty level. The only exception is the Health Insurance Continuation Program, for which financial eligibility may be as high as 300% of the federal poverty level.

Strengths: CAREWare is a comprehensive database that includes key fields of information on all persons receiving Ryan White Title II services. The CAREWare database is an important tool for monitoring which Ryan White resources are being used, how often, and by whom. CAREWare is now the model data collection system provided

to grantees free of charge by the HIV/AIDS Bureau at HRSA. It has been modified specifically for the HIV/AIDS Program. Louisiana CAREWare also provides opportunities to review information on comorbidity and to track the changing needs of the client population from year to year. The program is able to eliminate duplicate records of clients in a particular service or service area and can also eliminate duplicate records of clients of all services and in all geographic regions. This provides a more accurate picture of how many people seek care through services provided by Ryan White Title II.

Limitations: The Louisiana CAREWare data are provided or downloaded monthly; therefore, it is not a “real time,” or Web-based, data collection system. In addition, the customized fields established for Louisiana CAREWare make future versions of this database provided by HAB/HRSA incompatible with the system the HIV/AIDS Program has developed. The data in Louisiana CAREWare also cannot be generalized to all HIV-infected persons living in the state because it collects data only on persons who (1) know their HIV serostatus, (2) are not eligible for health coverage through private insurance or Louisiana Medicaid, (3) are currently seeking care and treatment services through Ryan White Title II–funded providers, and (4) are financially eligible to receive services. Historically, the population data in the Louisiana CAREWare database have comprised approximately 30% of persons known to be living with HIV/AIDS in the state.

APPENDIX B: MAP OF LOUISIANA

Geographic Guide to Louisiana Public Health Regions and Metro Statistical Areas (MSA)



Public Health Regions

Urban Parishes (MSAs)

I New Orleans		VI Alexandria		New Orleans	
Jefferson	Plaquemines	Avoyelles	Lasalle	Jefferson	Plaquemines
Orleans	St. Bernard	Catahoula	Rapides	Orleans	St. Bernard
II Baton Rouge		Concordia	Vernon	St. Tammany	St. James
Ascension	Pointe Coupee	Grant	Winn	St. John the Baptist	St. Charles
Iberville	East Feliciana	VII Shreveport		Baton Rouge	
E. Baton Rouge	West Feliciana	Bienville	Natchitoches	E. Baton Rouge	Ascension
W. Baton Rouge		Bossier	Red River	W. Baton Rouge	Livingston
III Houma		Caddo	Sabine	Houma/Thibodaux	
Assumption	St. James	Claiborne	Webster	Lafourche	Terrebonne
Lafourche	St. Mary	Desoto		Lafayette	
St. Charles	Terrebonne	VIII Monroe		Acadia	Lafayette
St. John the Baptist		Caldwell	Madison	St. Martin	St. Landry
IV Lafayette		East Carroll	Morehouse	Shreveport	
Acadia	St. Landry	West Carroll	Ouachita	Bossier	Webster
Evangeline	St. Martin	Franklin	Richland	Caddo	
Iberia	Vermilion	Jackson	Tensas	Lake Charles	
Lafayette		Lincoln	Union	Calcasieu	
V Lake Charles		IX Hammond/Slidell		Alexandria	
Allen	Calcasieu	Livingston	Tangipahoa	Rapides	
Beauregard	Cameron	St. Helena	Washington	Monroe	
Jefferson Davis		St. Tammany		Ouachita	

GLOSSARY

AIDS (acquired immunodeficiency syndrome): An HIV-infected person receives a diagnosis of AIDS after the development of 1 of the CDC-defined AIDS indicator illnesses (see *opportunistic infection*) or on the basis of the results of specific blood tests (i.e., a CD4⁺ count of less than 200 cells/microliter or a CD4⁺ percentage of less than 14). A positive HIV test result does not mean that a person has AIDS.

antiretroviral therapy (ART): Anti-HIV treatments designed to reduce the levels of HIV in a person's body.

ASD (Adult/Adolescent Spectrum of Disease): Study funded by the CDC and conducted in Louisiana since 1990. (For additional details on the study's purpose and methods, see Appendix A.)

bias: Refers to results that do not represent true findings because of a systematic error in the data. For example, if persons feel uncomfortable reporting that they have engaged in high-risk behaviors, these behaviors will be systematically underreported. Consequently, conclusions about the occurrence of such behaviors would be considered biased.

CDC: The Centers for Disease Control and Prevention, in the U.S. Department of Health and Human Services, is the lead federal agency for protecting the health and safety of the people of the United States. CDC accomplishes its mission through developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve public health in the United States. The CDC provides most of the funding for HIV prevention and HIV surveillance activities in Louisiana.

denominator: Divisor; the term of a fraction, usually written under or after the line that indicates the number of equal parts into which the unit is divided; used to calculate a rate or ratio. For example, in the fraction $\frac{3}{4}$, four is the denominator.

epidemiology: Study of how diseases or health conditions are distributed in a population. Consequently, an epidemiologist may analyze public health data to determine how a disease is transmitted and to recommend interventions, to identify segments of a population at risk of acquiring a disease, or to monitor disease trends and predict the course and effect of a disease.

exposure categories: To monitor how HIV is being transmitted, HIV/AIDS cases are classified as one of several exposure (risk) categories developed by the CDC.

- Male-male sexual contact refers to men who have sex with men (MSM); that is, homosexual or bisexual contact.

- Injection drug use refers to the use of forms of drugs that require injection. Although it may be valuable to know that a person has used illicit drugs through other routes, this information would not be enough to classify a case as an exposure through injection drug use.
- High-risk heterosexual contact refers to heterosexual contact with a partner who is at increased risk for HIV infection, i.e., a homosexual or bisexual man, an injection drug user, or a person with documented HIV infection.
- Hemophilia/transfusion/transplant cases are those resulting from a transfusion of blood or blood products before 1985.
- Perinatal HIV cases are cases of HIV infection in children resulting from transmission from an HIV-positive mother.
- Unspecified, or no identified risk (NIR), cases are those in persons who have no reported history of exposure at the time of the report date. This category includes persons for whom the surveillance protocols to document risk behavior information have not yet been completed, persons whose exposure history is incomplete because they have died, persons who have declined to disclose their risk behavior or who deny any risk behavior, and persons who do not know the HIV status or risk behaviors of their sex partners.

HAART (highly active antiretroviral therapy): Aggressive anti-HIV treatments that usually include a combination of protease and reverse transcriptase inhibitors, which interrupt the HIV life cycle and whose purpose is to reduce a person's viral load to undetectable levels.

HITS (HIV Testing Survey): Study funded by the CDC and conducted in Louisiana in 2001. (For additional details on the study's purpose and methods, see Appendix A.)

HIV (human immunodeficiency virus): The virus that causes AIDS. A person who has contracted the virus is said to be HIV-positive or HIV infected.

incidence: Refers to the number of new cases of a disease that occur in a population during a specified time, usually a year. Even though HIV data are often presented as "new cases of HIV," these data do not represent new infections (true HIV incidence) because a person may not be tested for HIV during the same period that he or she became infected. On the other hand, incidence can be calculated for diseases (e.g., some STDs). These diseases have clear symptoms that are detectable when a person becomes infected and that cause a person to be tested or to seek treatment shortly after infection.

numerator: Dividend, the term of a fraction, usually written above or before the line that indicates the number of parts that are to be divided; used to calculate a rate or ratio. For example, in the fraction $\frac{3}{4}$, three is the numerator.

opportunistic infection (OI): HIV infection can weaken a person’s immune system to the point that it has difficulty fighting off certain infections. These types of infections are known as opportunistic infections because they take the opportunity a weakened immune system gives to cause illness. Some examples of opportunistic infections are *Pneumocystis carinii* pneumonia (PCP) and Kaposi’s sarcoma (KS). Opportunistic infections are CDC-defined AIDS indicator illnesses, which means that an HIV-infected person receives a diagnosis of AIDS after the development of 1 of them.

parish: A civil division of the state of Louisiana corresponding to a county in other states.

perinatal: The word means “around birth” and is used to describe events that occur during labor and birth, and immediately after delivery. When used to describe HIV transmission, however, this word applies more broadly and describes any time that a mother may transmit HIV to her child— while she is pregnant, during birth, or through breast-feeding.

prevalence: Refers to the total number of persons with a specific disease or condition at a given time. HIV prevalence data are generally presented as “persons living with HIV.” HIV prevalence data provided by HIV surveillance programs underestimate the true HIV prevalence because HIV-infected persons who have not yet been tested or reported to the health department are not included.

proportion (percentage): A proportion is a type of ratio in which the numerator is included in the denominator. Because the numerator is a subset of the denominator, a proportion can be thought of as a ratio of a part to the whole. A proportion is usually expressed as a percentage.

rate: Type of ratio that includes a specification of time. In epidemiology, rates express the probability of, or risk for, disease or other events in a defined population during a specified period, often 1 year.

ratio: The value obtained by dividing one quantity by another. For example, the fraction $\frac{3}{4}$ is a ratio and can be expressed verbally as “three divided by four.” Both rates and proportions are specific examples of ratios.

reporting delay: The time lag between the diagnosis of a new case of HIV or AIDS and the report to the health department. Currently in Louisiana, 86% of HIV cases and 87% of AIDS cases are reported to the HIV/AIDS Surveillance Program within 6 months of diagnosis. Because of reporting delays, surveillance estimates of cases diagnosed in recent periods underestimate the actual number of cases diagnosed in those periods. Consequently, data for recent periods are adjusted to account for the anticipated number of cases diagnosed, but not yet reported. For AIDS cases, the HIV/AIDS Reporting System (HARS) was used to generate

reporting delay fractions. For HIV cases, multiple years of data were reviewed to calculate the estimated percentage of cases in persons reported within specified periods (e.g., 1 year, 2 years) after the diagnosis of HIV infection. The estimates were then adjusted upward to account for the reporting delay.

Ryan White CARE Act: The Ryan White Comprehensive AIDS Resources Emergency Act was created to provide federal assistance to increase the availability of primary health care and support services for persons living with HIV disease, to increase access to care for underserved populations, and to improve the quality of life of those affected by HIV infection. The CARE Act was first enacted by Congress in 1990 and was reauthorized in 1996 and 2000.

HRSA implements the CARE Act and directs assistance through the following channels:

- Title I provides support to eligible metropolitan areas (EMAs) with the largest numbers of reported AIDS cases, to meet emergency service needs of persons living with HIV.
- Title II provides support to all states and territories to improve the quality, availability, and organization of health care and support services for persons living with HIV and their families.
- Title III supports early-intervention outpatient HIV services through funding to public and private nonprofit entities.
- Title IV funds public and private nonprofit entities to conduct projects to coordinate services to children, youth, women, and families with HIV/AIDS.
- Part F provides support for Special Projects of National Significance (SPNS) to develop and evaluate innovative models of HIV/AIDS care, for AIDS Education and Training Centers (AETCs) to conduct education and training for health care providers, and for the HIV/AIDS Dental Reimbursement Program to assist with providing oral health services to HIV-infected patients.

surveillance: In a public health context, refers to the intentional collection of data on diseases or other important health conditions in order to monitor where the condition occurs and to determine the risk factors associated with the condition.

testing (anonymous, confidential): In Louisiana, a person can choose to be tested anonymously or confidentially for HIV infection. Positive results of anonymous and confidential HIV tests are reported to the health department, where the information is maintained under the strictest security and confidentiality measures. Persons who are tested anonymously do not provide their names when they are tested. Persons who are tested confidentially do provide their names when they are tested.

ABBREVIATIONS

ADAP	AIDS Drug Assistance Program
ART	antiretroviral therapy
ASD	Adult/Adolescent Spectrum of Disease
BRFSS	Behavioral Risk Factor Surveillance System
CADR	CARE Act Data Report
CBO	community-based organization
CDC	Centers for Disease Control and Prevention
CTS	Counseling and Testing System
DAWN	Drug Abuse Warning Network
HAART	highly active antiretroviral therapy
HARS	HIV/AIDS Reporting System
HITS	HIV Testing Survey
HOPWA	Housing Opportunities for People with AIDS
HRSA	Health Resources and Services Administration
IDU	injection drug user
MAC	<i>Mycobacterium avium</i> complex
MOS	MSM Outreach Survey
MSA	metropolitan statistical area
MSM	men who have sex with men
NHSDA	National Household Survey of Drug Abuse
OMB 15	Office of Management and Budget Directive 15
PCP	<i>Pneumocystis carinii</i> pneumonia
SAMHSA	Substance Abuse and Mental Health Services Administration
SHDC	Survey of HIV Disease and Care
SOS	Street Outreach Survey
STD	sexually transmitted disease
TB	tuberculosis
TEDS	Treatment Episode Data Set
YRBSS	Youth Risk Behavior Surveillance System
ZDV	zidovudine