CHAPTER 6: SURVEILLANCE AND DATA COLLECTION INITIATIVES

This chapter summarizes on-going HIV surveillance and research activities and program evaluation efforts, how surveillance and research information are linked to the strategies in the plan, and recommendations for additional surveillance and research needed to enhance HIV prevention planning and evaluation in South Carolina.

Tracking the Epidemic

The Introduction section of Chapter 1 “Epidemiologic Profile” contains a detailed description of HIV/AIDS surveillance systems in South Carolina. DHEC carefully monitors the status of HIV/AIDS and other sexually transmitted diseases enabling providers to implement strategies in communities around the state based on our best understanding of the epidemic.

In order to monitor the HIV epidemic in South Carolina, state law requires physicians, hospitals, laboratories, and other health facilities to report diagnosed HIV infection and AIDS cases to DHEC. The information obtained from health care providers includes risk factors, age, sex, race and geographic location. Health department staff conduct follow-up with persons diagnosed with syphilis and HIV infection in order to provide partner (notification) services, confidential counseling and testing services, treatment, and referral to medical and support services. Surveillance data are also used to plan and design prevention and care programs to target persons most at risk for sexually transmitted diseases and HIV infection.

Active surveillance activities include routine visits with hospitals and infectious disease physicians to identify cases and complete CDC case report forms; comparisons with other data sources such as death certificates, TB registry, and the AIDS Drug Assistance Program.

Most reports of HIV infection and AIDS are initially laboratory-based. All laboratories that conduct business in South Carolina are required to report to the health department all HIV infection or AIDS diagnosis when serum, urine, or oral fluid specimen is positive by screening test (EIA antibody), confirmatory test (Western blot) or an HIV detection test (PCR nucleic acid test, including viral load). In January 2004, laboratories were required to report all CD4 and viral load (VL) tests regardless of test results.

South Carolina also receives CDC funds for the Enhanced Perinatal Surveillance project that analyzes medical records and other data to evaluate the effectiveness of perinatal HIV prevention efforts. Staff analyze the proportion of HIV-infected pregnant women who have knowledge of their serostatus prior to delivery, proportion of HIV-infected women prescribed antiretroviral therapy during pregnancy, labor and delivery and neonatal period, proportion of HIV infected women receiving cesarean sections and selected birth outcomes. Each case of pediatric HIV infection due to perinatal transmission is analyzed to determine which prevention step was missed, and to identify follow-up training, education, or protocol development to ensure no missed opportunities for prevention.
Evaluation of key surveillance performance measures indicates South Carolina’s surveillance system meets or exceeds CDC’s performance criteria for 3 of 4 indicators: timeliness of reports, completeness of reports, and accuracy (duplication). See Table 6.1 below.

Table 6.1 South Carolina HIV Reporting Performance Compared to CDC Minimum Standards, 2008 Preliminary Data

<table>
<thead>
<tr>
<th>Performance Indicator</th>
<th>CDC Standard</th>
<th>South Carolina Performance</th>
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<tbody>
<tr>
<td>Completeness of Reporting</td>
<td>≥85%</td>
<td>97.5%</td>
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<tr>
<td>Timeliness of Reporting</td>
<td>≥ 66% within 6 months of diagnosis</td>
<td>95%</td>
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<tr>
<td>Accuracy of Reporting</td>
<td>≤ 5% duplicate case counts</td>
<td>0.02%</td>
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<tr>
<td>Identification of Transmission Risk Category</td>
<td>85% of HIV cases</td>
<td>78%</td>
</tr>
<tr>
<td></td>
<td>85% of AIDS cases</td>
<td>81%</td>
</tr>
</tbody>
</table>

Since 2005, South Carolina has received CDC funds for the HIV Incidence Surveillance project. This project measures the incidence of HIV infection in the United States; that is, the number of individuals newly infected with HIV per year. To determine incidence, new serologic (blood) testing methods were developed that distinguish between recent and log-standing HIV-1 infection. One of these tests is the Serologic Testing Algorithm for Recent HIV Seroconversion, or STARHS. STARHS is an experimental blood test that is part of an Investigational New Drug process overseen by the US Food and Drug Administration (FDA). Using both the STARHS test and information about a person’s HIV testing history, CDC was able to calculate a new estimate of actual incidence among the U.S. population, as well as subgroups such as African American women or MSM.

In August 2008, CDC released an updated estimate of the number of new HIV infections per year, as 56,300 (using 2006 data; estimates for more recent years will be calculation using the new methods, as data become available). The new estimate is over 16,000 more infections per year than was previously estimated; however, this number does not represent an actual increase in the numbers of HIV infections, but reflects a more accurate way of measuring new infections. The South Carolina HIV/AIDS Surveillance Program also calculated a new estimate for the State, using these new methods; we estimate that in 2006, there were approximately 990 new HIV infections in South Carolina. This number is different than the number of new cases diagnosed in 2006. That year, there were less than 800 new HIV cases diagnosed; however, not all of these new diagnoses were newly infected. Information of this nature can help prevention programs target their prevention efforts more effectively, focusing on populations that are recently infected. Incidence data can also be used over time to evaluate the success or impact of prevention efforts in slowing HIV transmission among certain populations.

Since 2005, South Carolina has also participated in a surveillance effort by CDC to determine the prevalence of antiretroviral drug resistance (ARVDR) among newly diagnosed persons with HIV infection in public health settings or settings collaborating with public health departments. A
routine test is conducted to detect the presence of genetic mutations associated with HIV ARVDR. Clients receive the ARVDR results from their clinical caregiver, which are then used to determine appropriate antiretroviral treatments for the client.

From 2004 to 2009, South Carolina participated in the Medical Monitoring Project (MMP), an enhanced surveillance project consisting of patient interviews and medical record abstractions. The interviews gathered information about the experiences and needs of people receiving care for HIV, including behaviors, treatment and health status. This project was the first of its kind, and provided the opportunity to truly identify gaps in access to care, treatment, prevention efforts, and meeting the needs of people living with HIV/AIDS. The project was discontinued in South Carolina as of June 2009; when the MMP data are received from CDC, they will be shared with the HPC as well as Ryan White HIV care advisory groups and providers.

Surveillance staff analyzes HIV (and other STDs) surveillance data and disseminates findings to multiple prevention and care providers, media, community organizations, and others. Surveillance data are used extensively to develop the Epi Profile for HIV prevention community planning; data files are produced for local HIV prevention planning efforts; data by Ryan White service area are produced for care planning. Numerous custom reports are produced for legislators, local agencies, media, and others for grant writing, policy decisions, state health publications, progress reports and program planning and evaluation efforts.

STD/HIV/AIDS surveillance reports are completed and posted on the South Carolina Department of Health and Environmental Control web site two times per year, located at: [http://www.scdhec.gov/health/disease/sts/index.htm](http://www.scdhec.gov/health/disease/sts/index.htm). This Web site includes data reports from the counseling and testing sites, and the Supplemental HIV/AIDS Surveillance (SHAS) Project conducted in South Carolina between 1991 and 2002. Reports are run for various demographic indicators (age, sex, race, and geographical areas) and behaviors (modes of transmission).

**Linkage of Surveillance Data to HIV Prevention Programming**

As mentioned above, surveillance data were used extensively to determine priority populations, identify unmet needs, describe risk behaviors and evaluate specific prevention efforts. These data are reflected throughout this prevention plan.

In addition, surveillance data are used to determine prevention and care funding allocations to public health regions, HIV prevention contractors and HIV services providers.

One of the goals of a prevention system is to reach people who may have no knowledge of their risk of HIV infection. A key strategy to reach people is partner services (PS). Surveillance data are essential to initiate PS in South Carolina. All newly reported cases are provided to local disease intervention specialist (DIS) staff for follow-up partner services. Newly reported persons are contacted confidentially and referred for counseling and voluntary PS. Named or identified sex and needle-sharing partners are contacted and referred for HIV counseling and testing services.
Many persons contacted, particularly women, have no awareness of their past or current HIV risk or that of their partner. Because they do not perceive their risk, they are unlikely to actively seek information on HIV or get tested. For many persons, partner services are essential for them to learn of their risk, take steps to reduce it and to learn their HIV status. Counseling and testing data indicate that partners of HIV infected persons consistently have the highest positivity rates. Almost 10.5 percent of partners tested in DHEC clinics were positive in CY2006, indicating the effectiveness of PS in targeting at-risk individuals. Referrals to medical care, support groups, substance use treatment, and community-based organizations are provided to clients at the time of PS.

Finally, perinatal surveillance data on HIV–exposed infants is used by local case managers to refer mothers/infants to the Ryan White Part D children’s care system and to monitor if subsequent testing has been done for final HIV status determination. About 25 percent of HIV exposed infants will become infected without proper treatment; with treatment the risk drops to 2 percent or less. Most infants’ true HIV status can be determined by 18 months of age.