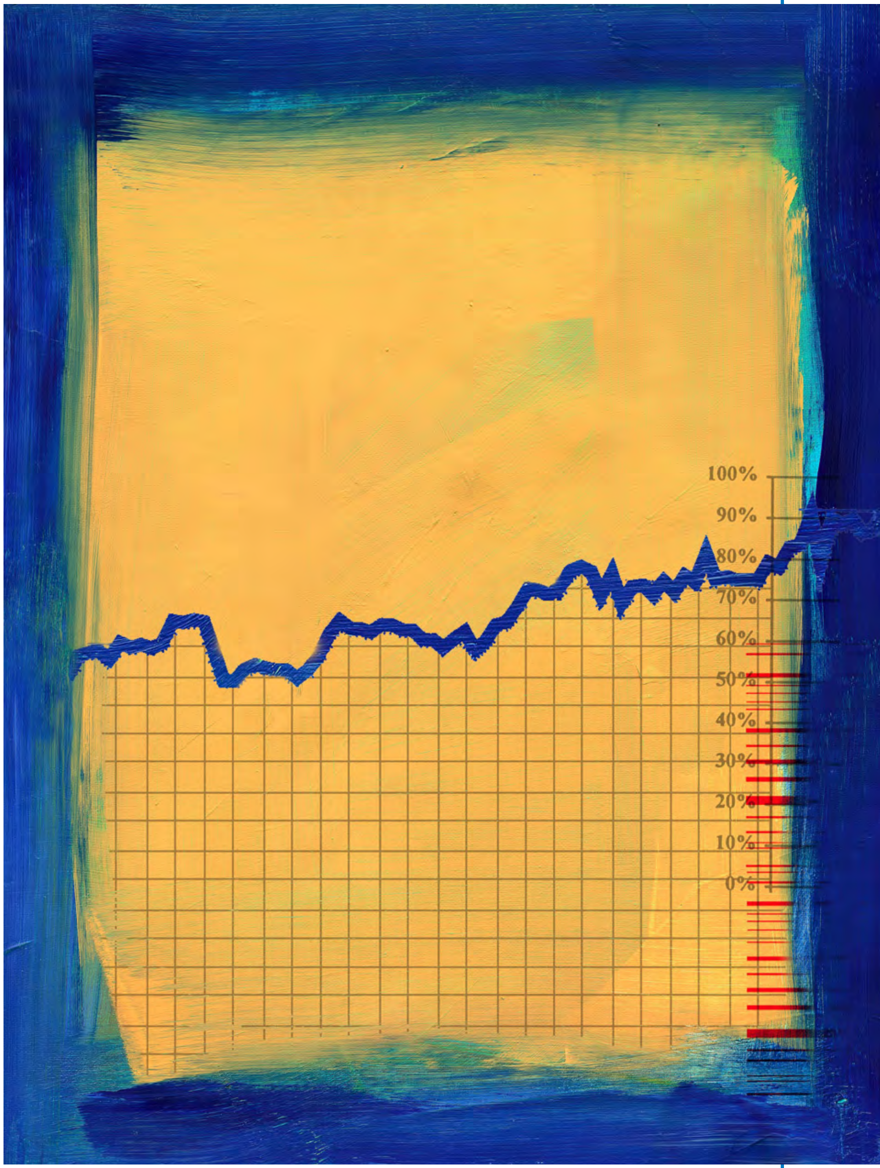
Using Data to Measure Public Health Performance



A Guide for Ryan White HIV/AIDS Program Grantees

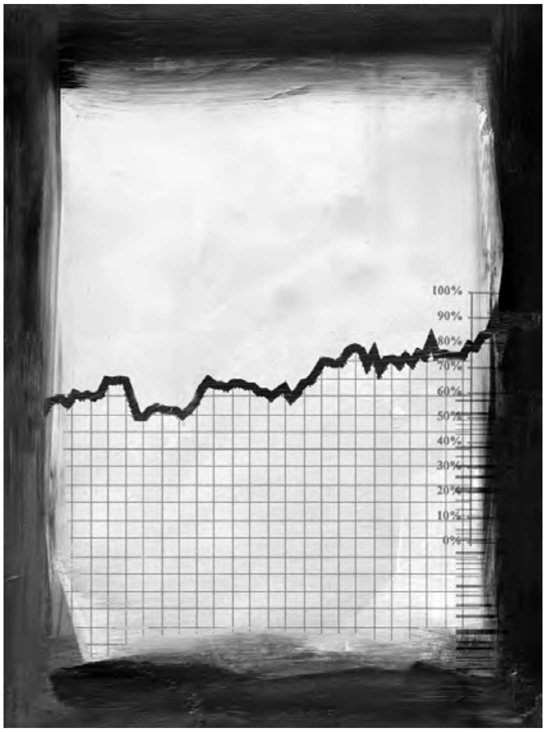
2010

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration

U.S. Department of Health and Human Services
Health Resources and Services Administration, HIV/AIDS Bureau

Using Data to Measure Public Health Performance:

A Guide for Ryan White HIV/AIDS Program Grantees



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PURPOSE of the MONOGRAPH

This monograph is designed to inform Ryan White HIV/AIDS Program grantees and their service providers and consumers about why data are gathered, what legal authority the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has to collect data, what types of data are gathered, how the data are used by HRSA/HAB and their grantees, and what questions the data address.

Grantees and providers funded by Parts A, B, C, or D of the Ryan White HIV/AIDS Program have a core set of data collection and reporting requirements that focus on outcomes, performance monitoring, and other program requirements. The program Parts also have additional data collection and reporting requirements that reflect their unique roles and responsibilities. Part F–funded programs, for example, have different data collection and reporting requirements that reflect their unique programmatic aims.

Overarching HRSA/HAB data collection and reporting requirements focus on meeting congressional and other administrative reporting requirements, describing clients and funded agencies, monitoring the services provided, documenting the impact of funds on communities at large and specific population groups, evaluating the quality and performance of funded programs, and monitoring how funded agencies use Ryan White HIV/AIDS Program funds and their adherence to HRSA/HAB grant requirements.

HRSA/HAB relies on grantees and providers to gather and report most data collected. Data take several forms, including program performance and administrative information, financial indicators of the need for services, utilization and quality of services; and demographic, clinical, and psychosocial characteristics of those served. Given their role in producing timely and accurate data, grantees and providers must be aware of HAB's data requirements and their uses of the data. It is also essential that grantees and providers understand how they can use their own data to support their planning, resource allocation, fiscal and program monitoring, and quality and performance assessment.

ORGANIZATION of the MONOGRAPH

This monograph focuses on HRSA/HAB's key data reporting requirements, the Parts or other grantees that must meet those requirements, the time periods that the reports cover, and major data domains addressed by the reports. The monograph also summarizes the ways in which HRSA/HAB staff synthesize data, the types of routine and ad hoc reports generated by HRSA/HAB, and key reports that illustrate HRSA/HAB's use of data. Links to examples of those reports, as well as links to other Web-based resources, are offered in later sections. Finally, the monograph provides a list of acronyms and terms to assist the reader.

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I. Program Overview

The Ryan White HIV/AIDS Program is a Federal program that funds HIV-related medical care and essential support services as well as technical assistance (TA), clinical training, and research on innovative models of care. The program works with cities, States, and community-based organizations (CBOs) to meet the needs of communities and populations affected by HIV/AIDS. The program reaches more than half a million people a year who have insufficient health care coverage or financial resources to meet their HIV clinical and supportive needs and thereby fills in gaps in care not covered by other sources. The services provided by the Ryan White HIV/AIDS Program relate to 4 of the 10 Leading Health Indicators for Healthy People 2010: Access to Health Care, Mental Health, Responsible Sexual Behavior, and Substance Abuse.

The Ryan White HIV/AIDS Program is administered by HRSA/HAB. The program is authorized by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law (P. L.) 111–87). The legislation was first enacted in 1990 as the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and was amended and reauthorized in 1996, 2000, and 2006.

Ryan White HIV/AIDS Program funds are awarded to agencies located around the United States that deliver care to eligible individuals under funding categories called Parts. These Parts, which are designated A through F, target funds to State and local entities and together create a comprehensive funding structure. Each Part is described in more detail below.

PART A

Part A provides emergency assistance to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)—population centers most severely affected by the epidemic. EMA eligibility requires an area to report more than 2,000 AIDS cases in the most recent 5 years and to have a population of at least 50,000. To be eligible as a TGA, an area must have at least 1,000 reported but fewer than 2,000 new AIDS cases in the most recent 5 years.

As of the 2009 reauthorization, 22 EMAs and 34 TGAs receive Part A funds. EMAs and TGAs range from a single city or county to a combination of more than 26 political entities; some span more than one State. EMA and TGA geographic boundaries are based on the U.S. Census. Grants are awarded to the chief elected official of the city or county that provides health care services to the greatest number of people living with AIDS in the EMA/TGA. In Denver, Colorado, for example, the awardee is the Mayor's Office of HIV Resources.

Part A funds may be used to provide a continuum of care for people living with HIV disease. At least 75 percent of the award must be used for core medical services, and 25 percent for support services. Core services are limited to outpatient and ambulatory services; AIDS Drug Assistance Program (ADAP) treatment in accordance with section 2616 of the Public Health Service (PHS) Act; AIDS pharmaceutical assistance;[1] oral health; early intervention; health insurance premium and cost-sharing assistance for people with low income; home health care; medical nutrition therapy;

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[1] Refers to local pharmacy assistance programs that provide HIV medications. Pharmaceutical assistance programs are not paid for with Part B "earmarked" ADAP funds and may be implemented through Part A grant funds and/or Part B base award funds.

hospice services; home- and community-based health services; mental health services; substance abuse outpatient care; and medical case management, including treatment adherence services. Support services must be linked to medical outcomes and may include outreach, medical transportation, linguistic services, respite care for people caring for HIV/AIDS patients, referrals for health care and other support services, case management, and substance abuse residential services.

EMA and TGA Planning Councils set priorities and allocate funds for services on the basis of the size, demographics, and needs of the HIV-infected population. Planning Councils are required to develop a comprehensive plan for the provision of services that includes strategies for identifying people who are not in care and strategies for coordinating services to be funded.

PART B

Part B provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and U.S. Pacific Territories and associated jurisdictions. Part B grants include a base grant, the ADAP award, ADAP supplemental grants, and supplemental grants to States with “emerging communities,” defined as jurisdictions reporting between 500 and 999 cumulative AIDS cases over the most recent 5 years. Funds are distributed via formula and other criteria. Part B grants are also required to meet the same 75:25 ratio for core medical services and support services, as defined above.

Part B base grants are awarded to States and Territories using a formula based on reported living cases of HIV/AIDS. States with more than 1 percent of the total HIV/AIDS cases reported in the United States during the previous 2 years must provide matching funds with their own resources using a formula outlined in legislation. Additional Part B funds are earmarked for State ADAPs, which primarily provide medications, although treatment adherence services are also funded. Five percent of the ADAP earmark is reserved for grants to States and Territories that have severe medication assistance needs. A supplemental, competitive program based on demonstrated need is available to States and Territories.

PART C

The Part C Early Intervention Services (EIS) Program funds comprehensive primary health care in an outpatient setting for people living with HIV disease. Funding recipients include Federally Qualified Health Centers under section 1905(1)(2)(B) of the Social Security Act; grantees under section 1001 (regarding family planning other than States); comprehensive hemophilia diagnostic and treatment centers; rural health clinics; health facilities operated by or pursuant to a contract with the Indian Health Services; CBOs, hospitals, or other health facilities that provide early intervention services to people infected with HIV/AIDS through intravenous drug use; and nonprofit private entities that provide comprehensive primary care services to populations at risk for HIV/AIDS, including faith-based organizations and CBOs.

The Part C program divides allowable costs among five Part C cost categories: EIS, core medical services, support services, clinical quality management (CQM), and administration. EIS costs are associated with the direct provision of medical care and make up at least 50 percent of a grantee budget. Services may include primary care, oral health care, outpatient mental health and substance abuse treatment, specialty and subspecialty care, referrals for health and support services, laboratory, x-ray, and other diagnostic tests; medical and dental equipment and supplies; medical case management; electronic medical records; patient education and adherence monitoring in conjunction with medical care; transportation for clinical providers to offer care; periodic medical evaluations; and other clinical and diagnostic services regarding HIV/AIDS.

PART D

Part D grantees provide family-centered services involving outpatient or ambulatory care (directly or through contracts) for women, infants, children, and youth with HIV/AIDS. Grantees are expected to provide primary medical care, treatment, and support services to improve access to health care. Part D funds primary and specialty medical care unless funds are available from other sources, support services, logistical support, and coordination. In addition, grantees are required to educate clients about research and research opportunities and inform all clients about the benefits of participation and how to enroll in research.

PART F: SPNS

The Special Projects of National Significance (SPNS) Program advances knowledge and skills in the delivery of health and support services to underserved populations diagnosed with HIV infection. SPNS grants fund innovative models of care and support the development of effective delivery systems for HIV care. The SPNS Program provides mechanisms to quickly respond to emerging needs of people receiving assistance under this Part; fund special programs to develop a standard electronic client information data system to improve the ability of grantees to report client-level data; advance knowledge and skills in the delivery of health and support services to people with HIV who are underserved by promoting the dissemination and replication of effective models of HIV care; and support, assess, and evaluate the effectiveness of innovative program design.

The SPNS Program is an integral link to all Ryan White HIV/AIDS Program Parts: It provides opportunities to develop new services while assessing the effectiveness of models of care. To meet SPNS goals, funded organizations must contain a strong evaluation component and disseminate information necessary for effective replication. As grantees develop innovative services, the SPNS Program provides the funding and expertise for grantees to evaluate innovations and disseminate findings to the HIV community.

PART F: THE AETC PROGRAM

The AIDS Education and Training Centers (AETC) Program supports a network of 11 regional centers (and more than 130 local associated sites) that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV/AIDS (PLWHA). AETCs serve all 50 States, the District of Columbia, the Virgin Islands, Puerto Rico, and U.S. Pacific jurisdictions. The AETC Program increases the number of health care providers who are effectively educated to counsel, diagnose, treat, and medically manage people with HIV disease and to help prevent high-risk behaviors that lead to HIV transmission. The AETC Program teaches health care professionals to serve as HIV resources in their communities. The goal is to reduce disparities in health outcomes and increase the number of providers in underserved areas.

Training is targeted to providers who serve minority populations, the homeless, rural communities, incarcerated populations, and Ryan White HIV/AIDS Program–funded sites. AETCs focus on training primary health care clinicians (i.e., physicians, physician assistants, nurses, nurse practitioners, dentists, pharmacists) and training activities are based on assessed local needs. Emphasis is placed on interactive, hands-on training and clinical consultation to assist providers with complex issues, including those related to the management of highly active antiretroviral therapy (HAART). AETCs collaborate with other Ryan White HIV/AIDS Program–funded organizations, area health education centers, HIV/AIDS CBOs, and medical and health professional organizations.

PART F: DENTAL PROGRAMS

All grant programs of the Ryan White HIV/AIDS Treatment Extension Act of 2009 can support the provision of oral health services. Two Part F programs, however, specifically focus on funding oral health care for people living with HIV: the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnership Program (CBDPP). The DRP assists institutions with accredited dental or dental hygiene education programs by defraying their unreimbursed costs associated with providing oral health care to people with HIV. Institutions that participate in the DRP report that unreimbursed costs of care continue to rise.

The CBDPP was first funded in fiscal year (FY) 2002 to increase access to oral health care services for HIV-positive individuals while providing education and clinical training for dental care providers, especially those in community-based settings. To achieve its goals, the CBDPP works through multipartner collaborations among dental and dental hygiene education programs and community-based dentists and dental clinics. Community-based program partners and consumers help design programs and assess their impact. Important program components include the following activities: increasing access to oral health care for people with HIV; providing dental and dental hygiene students and postdoctoral dental residents with training in the management of oral health care for people with HIV; and supporting the training of the next generations of oral health care providers to enable them to manage the oral health needs of people with HIV.

PART F: MINORITY AIDS INITIATIVE

Minority AIDS Initiative (MAI) grants provide funding to evaluate and address the disproportionate impact of HIV/AIDS on African-Americans and other minority populations. The Ryan White HIV/AIDS Treatment Modernization Act of 2006 codified the MAI as part of the Ryan White HIV/AIDS Program in the PHS under Title XXVI.

MAI funds are distributed through the grant mechanism previously established under the CARE Act. Through Parts A and B, EMAs/TGAs and States compete for funding to enable them to better address disparities in access, treatment, care, and health outcomes. MAI funds for Parts C, D, and F continue to be awarded at the same time as programs receive their other Ryan White HIV/AIDS Program funds.

SUMMARY

The Ryan White HIV/AIDS Program serves people who have insufficient health care coverage or financial resources for coping with HIV disease. It does so in part by filling gaps in care not covered by other funding sources. The majority of Ryan White HIV/AIDS Program funds support medical care and essential support services, although some monies are used to fund technical assistance, clinical training, and research.

Ryan White HIV/AIDS Program Parts vary widely in scope, responsibilities, grantee organizational size and focus, geographic service area, budget size, and number of clients. In addition to addressing medical care and support service needs, the Ryan White HIV/AIDS Program funds and evaluates innovative models of care; supports the development of effective delivery systems for HIV care; and conducts targeted, multidisciplinary education and training programs for health care providers treating people living with HIV/AIDS.

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2. Why HRSA/HAB Collects Data

HRSA/HAB is responsible for the administration of more than $2 billion in Federal funds. The Bureau is accountable to Congress, the Office of the President, the public, and people living with HIV/AIDS.

HRSA/HAB must ensure that Ryan White HIV/AIDS Program funds are used effectively, as intended by the Ryan White HIV/AIDS Treatment Extension Act of 2009, and supplement but do not replace other funds for HIV care. HRSA/HAB is responsible for meeting congressional reporting requirements set out in the authorizing legislation. The Bureau must describe the use of Ryan White HIV/AIDS Program funds to ensure access to HIV treatment and care; address geographic, racial, and ethnic disparities; and improve the quality of care and clinical outcomes for people living with HIV disease. HRSA/HAB also has an ongoing responsibility to document how these Federal funds are used; describe the organizations and geographic areas that receive those funds; and assess the impact of funds on consumers, systems of care, and funded providers.

To summarize, HRSA/HAB collects data for the following reasons:

- To meet Federal reporting requirements established by Congress through statute
- To respond to congressional, HHS, and other inquiries
- To assess the quality of services funded by the Ryan White HIV/AIDS Program
- To appraise the performance of HRSA/HAB grantees and their providers
- To evaluate the impact of the Program-funded services and policies
- To meet Federal grants management requirements.

LEGISLATIVE AUTHORITY to COLLECT and REPORT DATA

Public Health Service Act

Since the inception of the PHS Act, HHS has exercised its public health authority to fulfill its mission to protect the Nation's health. HRSA's public health authority has been used to govern how health care services are made available and accessible to underserved and vulnerable populations. Domestically, Title XXVI of the PHS Act provided increased HIV health care services, including case management for infected, economically disadvantaged, and uninsured persons with a special emphasis on HIV/AIDS-infected and -affected women, infants, children, and youth. Authority under the PHS Act has given HHS the right to make grants available to eligible entities that render services outlined in Parts A, B, C, D, and F of the Ryan White HIV/AIDS Treatment Extension Act of 2009. The HHS Secretary, acting through HRSA/HAB, has awarded grants to EMAs and TGAs to provide core medical and support services to people with HIV/AIDS.

Office of Management and Budget

The Office of Management and Budget (OMB) requires the submission of client-level data from recipients of Ryan White HIV/AIDS Program funds, and it has made doing so a requirement for approval of information-collection activities. Also, client-level data is needed to respond to OMB's Performance and Assessment Rating Tool (PART) reviews, which OMB uses for strategic planning and to assess program performance. Client-level data for PART reviews does not include any personally identifiable health information. Because the discussion that follows concerns HRSA's authority and responsibility to collect and receive protected health information (PHI), it must be noted that no restrictions have been imposed on the use or disclosure of deidentified health information to the HHS public health authority.

Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act (HIPAA; P. L. 104–191) Privacy Rule recognizes the need for public health authorities and others responsible for public health safety to have access to PHI to fulfill their public health mission. Thus, the privacy rule permits covered entities to disclose PHI to the public health authority without authorization for specified public health purposes. The privacy rule recognizes that public health reports made by covered entities are an important means of identifying threats to the health and safety of the public at large as well as individuals (see 45 Code of Federal Regulations (CFR) 164.512(b)).

With respect to general public health activities, the privacy rule permits covered entities to disclose PHI, without authorization, to public health authorities who are legally authorized to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This disclosure includes the reporting of a disease or injury and conducting public health surveillance, investigations, or interventions (see 45 Code of Federal Regulations (CFR) 164.512(b)(1)(i)).

Generally, "covered entities" (e.g., some health care providers, health plans, and health care clearing houses) are required to reasonably limit the PHI disclosed for public health purposes to the minimum amount necessary to accomplish the public health purpose. Covered entities, however, are not required to make a "minimum necessary" determination for disclosures by a health care provider for treatment purposes; disclosure to the individual who is the subject of the health information or if the subject of the information has given authorization; disclosures to comply with HIPPA or other laws; or disclosure to HHS when information is required under the Privacy Rule for enforcement purposes (see 45 CFR 164.502(b)). Moreover, the privacy rule stipulates that in making disclosures to a public health authority, covered entities may reasonably rely on the judgment of the party requesting information to stipulate the minimum amount of information needed.

According to HRSA's resource guide *Protecting Health Information Privacy and Complying with Federal Regulations* (April 2004), HHS is not subject to the privacy rule because it does not meet the rule's definition of a covered entity,[2] but it remains subject to the Federal Privacy Act. HRSA/HAB's grantees, however, meet the definition of a covered entity under the privacy rule. As discussed earlier, a covered entity may disclose PHI without the patient's authorization to authorities authorized by law to collect or receive such information.

HRSA/HAB is required to monitor and assess its grants by conducting evaluation activities in accordance with Section 241 of the PHS Act and the OMB Uniform Administrative Requirements for grants. Disclosure of PHI by covered entities to HRSA/HAB for this purpose is permitted under the health oversight exception (45 CFR 164.512(d)). In other circumstances, HRSA/HAB is authorized by law to collect information for monitoring trends in the HIV epidemic, such as demographic data in applications for funding under the Ryan White HIV/AIDS Program. (See references at the end of this document to the following sections of the PHS Act: 2605(b), 2613(c)[(E)], 2617(b)(2), and 2664(a)(2).) The public health activity exception found in 45 CFR 164.512(b) also permits disclosure of PHI to HRSA/HAB for this purpose by grantees that are covered entities.

Ryan White HIV/AIDS Treatment Extension Act of 2009

The collection and submission of data for the Ryan White HIV/AIDS Program is a public health activ-

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[2] To learn more about which organizations qualify as "covered entities" and to access resources available to them, visit www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html.

ity that is consistent with provisions of the Ryan White HIV/AIDS Treatment Extension Act of 2009 and enabling directives, rules, and guidelines governing the use of Federal monies. The Ryan White HIV/AIDS Program requires the submission of annual reports by the HHS Secretary to the appropriate committees of Congress. Client-level data is one requirement for the Secretarial submission. Its use eliminates duplication of individual records. Grantees and service providers receiving Ryan White HIV/AIDS Program funds complete the Ryan White HIV/AIDS Program Services Report (RSR) detailing information on all the clients served during the course of the calendar year.

The Ryan White HIV/AIDS Treatment Extension Act of 2009 contains implicit HRSA/HAB authority to collect client-level data and information. The law stipulates that EMA/TGA applicants shall submit an application that includes information required under Section 2603(b), information concerning the expected expenditures, and how those expenditures will improve overall client outcomes as described under the State plan under Section 2617(b) and through the additional outcomes measures as identified by the EMA or TGA Planning Council under Section 2602(b).

Section 2603 maintained provisions for States and jurisdictions reporting code-based data rather than client-level, or name-based, data to HRSA/HAB. One such provision includes a 5 percent penalty against their count of living HIV cases and a 5 percent cap on increases in the HIV case count because code-based data are believed to be less accurate and include more duplicated counts than do client-level data. In FY 2012, the 5 percent penalty increases to 6 percent, and by FY 2013, code-based protections will be eliminated because all States and jurisdictions will be required to have transitioned to a name-based system.

P. L. 111–87, Section 2617(b), states that State applications for Part B funds shall contain a determination of the size and demographics of the population with HIV/AIDS in the State.

Part A supplemental grant funding criteria include demonstrated success in identifying undiagnosed HIV-positive persons and engaging and retaining them in appropriate care.

State HIV Care Consortia shall make available to the Secretary of HHS data and information on the program that may be required to perform an independent evaluation. Part C applicants are to submit to the Secretary a report providing:

- The number of people to whom the applicant provides EIS pursuant to the grant;
- Epidemiologic and demographic data on the population of such individuals; and
- The extent to which the costs of HIV-related health care for such individuals are paid by third-party payors.

Part C applicants also agree to submit information regarding funds expended in accordance with this title and shall include necessary client-level data to complete unmet need calculations.

APPRAISE PROGRAM PERFORMANCE

As a Federal agency, the Government Performance and Results Act of 1993 (GPRA) requires HRSA/HAB to develop strategic plans with long-term, outcome-oriented goals and objectives; annual goals linked to achieving long-term goals; and annual reports on results. GPRA was intended to address several broad purposes, including strengthening the confidence of the American people in their government; improving Federal program effectiveness, accountability, and service delivery; and enhancing congressional decision making by providing more objective information on program performance. GPRA also requires executive agencies to prepare annual performance plans that articulate goals for the upcoming fiscal year that are aligned with long-term strategic goals. Plans must include results-oriented annual goals linked to program activities as well as indicators to measure performance against the results-oriented goals. Since FY 1999, Federal agencies have issued performance plans annually to correspond with congressional budget submissions.

Finally, GPRA requires agencies to measure performance toward the achievement of the goals in their annual performance plan and report annually on their progress in program performance reports. If a goal is unmet, the report must provide an explanation and present the actions needed to meet any unmet goals in the future. These reports provide important information to agency managers, policymakers, and the public on what each agency accomplished with the resources it was given. Federal agencies have issued annual performance reports since FY 2000.

HRSA prepares an annual performance report that summarizes its plan, performance measures, and summary performance data for HRSA/HAB and the various agencies in HRSA. (See www.hrsa.gov/about/annualperformance08/.) The Ryan White HIV/AIDS Program's performance measures are tied to HRSA's overall goals, which serve as the Program's performance management framework. The measures allow the Program to track progress in reaching those goals. (Visit www.hrsa.gov/about/budgetjustification/performanceappendix11.pdf.)

ASSESS the IMPACT of FUNDED SERVICES

HRSA/HAB monitors and describes the use of Ryan White Program funds to ensure access to treatment and care, address health disparities, and improve the quality of care and clinical outcomes. Data regarding services provided, funding, and client demographic and medical processes and outcomes are required for Part C– and Part D–funded grantees and providers. Health Insurance Programs (HIPs) are also required to submit aggregate data on the demographic characteristics of clients served; expenditures for premiums, deductibles, and co-payments; sources and amount of Ryan White HIV/AIDS Program funds used by the HIP; and program income from other sources. State agencies and other entities use Ryan White HIV/AIDS Program funds (except funds from ADAP) to pay for or supplement client health insurance.

Until recently, HRSA/HAB data reports summarized the clients served in the aggregate. The reports did not provide unduplicated counts of clients served, thereby hampering HRSA/HAB's ability to achieve its oversight and evaluation responsibilities. In 2006, Congress directed HRSA/HAB to gather and report client-level data from grantees and their providers and as of January 2009 Ryan White HIV/AIDS Program grantees and some of their service providers were required to begin gathering and reporting client-level data through the RSR (see Section 2.1.4), which requires client-level data to be submitted twice annually. The data submitted are similar in content to those in the Ryan White HIV/AIDS Program Annual Data Report (RDR), although client-level data rather than aggregate data are submitted in the RSR. Additionally, grantee and provider reports that gather organizational and funding data are required. RSR data gathered over time will ultimately give HRSA/HAB staff the ability to compute trends in the number of clients served, services provided, and clinical processes and outcomes. Clients' longitudinal service utilization can be analyzed to assess differences related to geographic, sociodemographic, or clinical factors.

HRSA/HAB requires its grantees and their providers to complete several annual reports. The RDR must be completed by grantees and their providers receiving funds from Parts A, B, C, or D. It gathers data regarding their organizational characteristics; sources and amounts of Ryan White HIV/AIDS Program funds; aggregate client demographic and clinical characteristics; the number of clients served and units of service provided for each service category; and medical processes and outcome measurement data.

RSR data give HRSA/HAB the opportunity to describe the distribution of Ryan White HIV / AIDS Program funds. The RDR will be discontinued when HRSA/HAB is confident that grantees and their providers can provide accurate, timely, and complete RSR data. Until that time, grantees and their providers will be required to submit both the RDR and the RSR.

HRSA/HAB monitors the impact of ADAPs in expanding access to HIV treatments to ensure that geographic and other disparities are reduced and funds are used efficiently. Part B grantees submit the ADAP Quarterly Data Report and also submit an annual report with the first quarterly report of the fiscal year (i.e., July 31). The ADAP report gathers aggregate data regarding the number and characteristics of clients served, funds received and expenditures, drug pricing for medications purchased, and the number of clients receiving specific types of medications. The ADAP Annual Data Report also requires grantees to submit the amount of ADAP funds received and expended for that grant year, a list of the medications in the ADAP formulary, the criteria and process used to determine ADAP financial and clinical eligibility, and cost-saving strategies. Eventually, HRSA/HAB plans to collect ADAP reporting data in a manner that complements data collected through the RSR.

HRSA/HAB monitors the services provided by and the impact of focused oral health services programs through annual reports that are required by grant guidance. The Dental Services Report is submitted annually by oral health programs funded by the Part F CBDPP and/or the DRP. This report gathers aggregate data from grantees on the number and characteristics of clients served, the number and type of visits by service type, the location at which oral health patients receive their primary medical care, sources and amount of Ryan White HIV/AIDS Program and other funds received, and staffing and training of dental students and other trainees. DRP grantees also are asked to describe how these funds are used and provide data on unreimbursed costs. In addition, DRP grantees must submit a narrative summarizing the site(s) in which services are provided, working relationships with other Ryan White HIV/AIDS Program grantees, outreach activities, and the capabilities of the grantee to educate trainees in providing oral health care for patients with HIV.

HRSA/HAB assesses the impact of the Part A MAI using the annual Part A MAI Report. Part A grantees must submit an MAI Annual Plan and an MAI Annual Report. The report gathers aggregate data about the amount of MAI funds allocated and spent, the racial and ethnic communities served, and the characteristics of MAI-funded services.

HAB requires AETC data to evaluate the extent to which targeted, multidisciplinary education and training programs meet the needs of health care providers treating people living with HIV. To address HRSA/HAB's data requirements, AETCs submit annual program reports as well as data reports that summarize individual training sessions.

MONITOR USE of HRSA/HAB FUNDS and ADHERENCE to GRANT REQUIREMENTS

HAB requires ongoing fiscal and program data to ensure the ongoing accountability of grantees and their providers and ensure their adherence to statutory requirements and program guidance. To fulfill those requirements, grantees of Parts A, B, C, and D are required through their Notice of Grant Award to submit to HRSA/HAB quarterly and annual progress reports. These reports summarize grantees' major accomplishments, factors that facilitated or hindered program implementation, and other information. The data help HRSA/HAB Project Officers conduct ongoing monitoring of grantees, address barriers to programmatic implementation, and identify TA needs.

Monitoring of grantee expenditures is an important responsibility of HRSA/HAB. HRSA grants management staff and HRSA/HAB Project Officers monitor expenditures through the Federal Financial Report (FFR). The FFR requires grantees to report the amount of funds expended in the grant year, grant income, unobligated (or unspent) funds, and related data. Allocation and Expenditure (A&E) Reports required of Parts A, B, C, and D grantees inform HRSA/HAB Project Officers about the planned and actual expenditure of funds for direct services and non-service activities. HRSA/HAB uses the data reported by the grantees to ensure that Part A and Part B grantees meet the requirement of the Ryan White HIV/AIDS Treatment Extension Act of 2009 that at least 75 percent of direct service funds be allocated to core services.

DEMONSTRATE NEED

As discussed earlier, applicants for Ryan White HIV/AIDS Program funds must demonstrate the need for those funds. Grant guidance specifies the data to be included in grant applications. Each Program Part has different grant guidance requirements, which are based on statutory requirements and programmatic responsibilities. Cross-Part requirements include an itemized budget by Program service category, a summary of the need for Ryan White HIV/AIDS Program funds in the applicant's targeted service area, planned activities, the methods used to assess the performance of funded services, and a description of the applicant's quality management (QM) program.

Additional information to be submitted varies depending on the Part and whether the applicant is applying for new or continuing funding. The data submitted in grant applications are used to evaluate the need for requested funds, set award amounts, assess the extent to which grantees adhere to Federal grant and HRSA/HAB program requirements, and form the basis for future performance and quality monitoring.

SUMMARY

- HRSA/HAB collects data to meet Federal reporting requirements established by Congress; respond to congressional, HHS, and other inquiries; assess the quality of services funded by the Ryan White HIV/AIDS Program; appraise the performance of HRSA/HAB grantees and their providers; evaluate the impact of Program-funded services and policies; and fulfill Federal grant management requirements.
- The PHS Act gives HHS the right to make grants available to eligible entities that render services outlined in the Ryan White HIV/AIDS Treatment Extension Act of 2009. The HHS Secretary, acting through HRSA/HAB, awards grants to EMAs and TGAs to provide core medical and support services to people with HIV/AIDS.
- The collection and submission of data for the Ryan White HIV/AIDS Program is a public health activity and is consistent with provisions of the Ryan White HIV/AIDS Treatment Extension Act of 2009 and enabling directives, rules, and guidelines governing the use of Federal funds. The Ryan White HIV/AIDS Program requires the submission of annual reports by the HHS Secretary to Congress. Unduplicated client-level data are required for the Secretarial submission.
- The HIPAA Privacy Rule recognizes the need for public health authorities and others responsible for ensuring public health safety to have access to PHI to carry out their public health mission. The rule permits covered entities to disclose PHI to the public health authority without authorization for specified public health purposes. It also permits covered entities to disclose PHI, without authorization, to public health authorities who are authorized to receive such reports to prevent or control disease, injury, or disability.
- HRSA/HAB also requires data to demonstrate the need for funding requests; monitor use of HRSA/HAB funds; ensure adherence to grant requirements; assess the impact of services funded by the Ryan White HIV/AIDS Program; and appraise the performance of funded programs.

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3. Types of Data Collected and Reporting Mechanisms

This chapter provides an overview of the data reporting forms that HRSA/HAB routinely gathers. It describes the purpose of each form or other data collection activity, the grantees or other entities required to complete the reports, the reporting periods, the forms used and where they are found on the HRSA/HAB Web site, a summary of the data collected, and methods used by grantees or other reporting entities to submit their reports. Table 3.1 lists the HRSA/HAB reports, the Ryan White HIV/AIDS Program Parts required to submit the reports, units of analysis, and reporting periods.

TABLE 3.1. OVERVIEW of HRSA/HAB DATA REPORTS

Report	Ryan White HIV/AIDS Program Part	Units of Analysis	Reporting Period
Ryan White HIV/AIDS Program Services Report (RSR)	A, B, C, D, and F	Grantee, provider, and client-level data	Annual
Ryan White HIV/AIDS Program Data Report (RDR)	A, B, C, D, and F	Aggregate client data	Annual
AIDS Drug Assistance Program (ADAP) Quarterly and Annual Reports	B	ADAP program and aggregate client data	Quarterly and annual
Part A Minority AIDS Initiative (MAI) Report	A	MAI program and aggregate client data	Annual
Community-Based Dental Partnership Program (CBDPP) and Dental Reimbursement Program (DRP) Dental Services Report	F	CBDPP grantee and DRP applicant pre- and postdoctoral dental education programs and dental hygiene education programs	Annual
AIDS Education and Training Center (AETC) Event Record and Participant Information Form	F	AETC regional centers, local associated sites, and National centers	Training event
Federal Financial Report (FFR)	A, B, C, D, and F	Grantee	Annual
Allocation and Expenditure (A&E) Reports	A and B (C and D reporting began in 2009)	Grantee	Annual

RYAN WHITE HIV/AIDS PROGRAM SERVICES REPORT

Report Purpose

All Program Parts of the Ryan White HIV/AIDS Program specify HRSA/HAB responsibilities in the administration of grant funds, allocation of funds, evaluation of programs for the population served, and improvement of the quality of care. Accurate records of the providers receiving Ryan White HIV/AIDS Program funding, the services provided, and the clients served continue to be critical to the implementation of the legislation and thus are necessary for HRSA/HAB to fulfill its responsibilities.

Previously, HRSA/HAB required that all Ryan White HIV/AIDS Program–funded grantees and their contracted service providers report aggregate data annually using the RDR. However, aggregate data are limited in two ways:

- Aggregate data lack client identifiers and cannot be merged and unduplicated across service providers within a given geographic area. As a result, grantees and HRSA/HAB cannot obtain accurate counts of the number of people the Ryan White HIV/AIDS Program serves.
- Aggregate data cannot be analyzed in the detail required to assess quality of care, or to account sufficiently for the use of Ryan White HIV/AIDS Program funds.

To address these deficiencies, in 2009 Ryan White HIV/AIDS Program grantees and service providers began using a new biannual data reporting system, the RSR, to report information to HRSA/HAB on their programs and the clients they serve. HRSA/HAB expects all grantees and providers to submit RDRs during the transition to client-level reporting.

HAB's goal is to build a client-level data reporting system that provides data on the characteristics of the funded grantees, their service providers, and the clients served with program funds. The data submitted to HRSA/HAB will be used to monitor the outcomes achieved on behalf of HIV/AIDS clients and their affected families receiving care and treatment through Ryan White HIV/AIDS Program grantees and providers. Data also will help address the disproportionate impact of HIV in communities of color by assessing organizational capacity and service utilization in minority communities; describe the use of Ryan White HIV/AIDS Program funds; and address the needs and concerns of the U.S. Congress and the HHS Secretary concerning the HIV/AIDS epidemic and the Ryan White HIV/AIDS Program.

Required Reporting Entities

The RSR includes three components: the Grantee Report, the Service Provider Report, and the Client Report.

- The Grantee Report collects basic information about the grantee organization and the service provider contracts that it funded during the reporting period. This report is completed by all Part A, Part B, Part C, Part D (including the Adolescent Initiative), and Part F (MAI) grantees. The grantee of record is the official Ryan White HIV/AIDS Program grantee that receives Federal funding directly from HRSA.
- The Service Provider Report collects basic information about both the service provider agency and the services it delivered under each of its Ryan White HIV/AIDS Program contracts. This report is completed by all (1) service providers directly serving clients and their affected family members; and (2) grantees of record (e.g., agencies that provide administrative and technical services). Service providers may be directly funded through one or more Parts, through subcontracts with one or more grantees, or through subcontracts with a grantee's fiscal intermediary (an administrative agent of the grantee). A service organization that has a contract with Ryan White HIV/AIDS Program grantees

is considered a first-line provider. First-line providers are required to complete the Provider Report.

- The Client Report (client-level data) collects one record for each Ryan White HIV/AIDS Program client served. Each record includes the encrypted, unique client identifier (UCI)[3] and basic demographic data. A client's record may also include HIV clinical information and data about the HIV-related medical care and support services received at the service provider. For the 2009 RSR, grantees and first-line providers of outpatient or ambulatory medical care services or case management services (medical or nonmedical) are required to submit a Client Report.

  A service organization that enters into a contract with a first-line provider is considered a second-line provider. The grantee has discretion as to how to submit data on clients served by a second-line provider. The data may be submitted by the first-line provider as directed by the grantee or by the second-line provider as directed by the grantee and the first-line provider. If the second-line provider is directed to report its own client data, it must also complete a Provider Report, and the grantee must include the second-line provider in the Grantee Report.[4]

Reporting Period

The reporting year is a calendar year. In 2009, Ryan White HIV/AIDS Program grantees must submit data twice per year, as required by HRSA/HAB. Grantees will submit two RSRs for each reporting (calendar) year:

- An interim report for the period January 1 through June 30; and
- An annual report for the period January 1 through December 31.

The timeline for 2009 RSR reporting is available online at http://hab.hrsa.gov/manage/cldtimeline.htm. The final submission deadline is April 26, 2010. Reporting requirements and timeline will be updated in subsequent reporting cycle.

Reporting Form

The Grantee and Provider Reports, along with the instructions for the Client Report, are available at: http://hab.hrsa.gov/manage/CLD.htm.

Summary of Data Collected

Grantee Report. The Grantee Report collects grantee contact information; assesses the status of the grantee's CQM program for assessing HIV health services; and lists the names and addresses of providers funded by the grantee, the start and end dates of contracts with providers, the amounts of the contracts, and the service categories funded. Providers cannot submit their reports for grantee review until their grantee(s) have certified their Grantee Reports in the RSR.

Provider Report. All agencies that provide direct client services must complete one Service Provider Report online. Multiply funded providers must include information from all program Parts under which the agency is funded in their Service Provider Report. The report includes contact information, provider organizational characteristics, whether funds are received under Section 330 of the PHS (e.g., community health centers, migrant health centers, or health care for the homeless sites), ownership status, the status of the agency's clinical management program for assessing HIV health services, and whether Ryan White HIV/AIDS Program funds are expended on oral health

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[3] The encrypted, unique client identifier ensures the privacy and security of clients' health care information yet provides the benefit of linking reports on the same client from multiple providers. To learn more, visit: www.careacttarget.org/library/media/datacollection/UCIandYou.pdf.

[4] Additional information on RSR Provider and Client Report requirements is located in the RSR Instruction Manual, available at http://hab.hrsa.gov/manage/CLD.htm.

services. The Report also includes a list of grantees and contact information for each grant in which the provider is funded. The provider verifies whether it is contracted to provide administrative and technical, core medical, support, or HIV counseling and testing services. The provider also reports the number of paid staff funded by the Program. If the agency was contracted to provide HIV counseling and testing during the reporting period, it must report the number of people tested for HIV, the number of people who tested positive, the number of people who received posttest counseling, and the number referred to HIV medical care. The provider must also report the number of people who tested negative and the number in that group who received posttest counseling.

Client Report. The Client Report is a deidentified collection of client-level information without personally identifying information. The Client Report is linkable to Provider Reports through a unique provider organization identifier assigned through the RDR or RSR. Client records are linked using a UCI generated by the HRSA/HAB UCI generation utilities. Client records include the date of the first service visit at the provider's agency, birth year, race, ethnicity, gender, transgender status, Federal Poverty Level (FPL) status, housing status, health insurance, and first three digits of the ZIP code at the end of the reporting period. HIV clinical and transmission factor data collected in the report include HIV/AIDS status; year of client's AIDS diagnosis; HIV/AIDS risk factor; vital enrollment status at the end of the reporting period; and the date of the client's death, if applicable. The Client Report also collects data on the number of visits in the reporting quarter for each core medical service. The report assesses whether the client received AIDS Pharmaceutical Assistance (APA) program, HIP, or support services in each reporting quarter.

For clients receiving outpatient or ambulatory medical care, the report collects the following information for the reporting period:

- Whether the client received risk reduction screening or counseling
- The date of the client's first ambulatory care service at the provider agency
- All dates of the client's outpatient or ambulatory care visits in the provider's HIV care setting with a clinical provider
- CD4 counts and viral loads and their dates
- Whether the client was prescribed *pneumocystis carinii* pneumonia (PCP) prophylaxis
- Whether the client was prescribed HAART
- Whether the client has been screened for tuberculosis (TB) since HIV diagnosis
- Whether the client was screened for syphilis in the reporting period or since HIV/AIDS diagnosis
- Whether the client was screened for hepatitis B in the reporting period or since HIV/AIDS diagnosis
- Whether the client was screened for hepatitis C in the reporting period or since HIV/AIDS diagnosis
- Whether the client was screened for substance abuse or mental health.

For women, the Report identifies whether the client received a Pap smear or was pregnant in the reporting period. If she was pregnant, the Report identifies in which trimester she received prenatal care and was prescribed ARV therapy.

Report Submission Method

Grantee Report. HRSA requires grantees to submit postaward reports, including the RSR, online using the Electronic Handbook (EHB).

Service Provider Report. Service providers complete this report online. Service providers that also are grantees of record (i.e., that receive funding directly from HRSA/HAB) access and submit this report online through the EHB. All other service providers access and submit the RSR through the RSR system at: https://performance.hrsa.gov/hab/RegLoginApp/Admin/Login.aspx.

Client Report (client-level data). Service providers submit this report as an electronic upload file using a standard Extensible Markup Language (XML) format from within the Provider Report.

RYAN WHITE HIV/AIDS PROGRAM DATA REPORT (Instrument Retired: Jan. 2011)

Report Purpose

Service providers funded by the Ryan White HIV/AIDS Program must complete the RDR detailing aggregate information on all the clients they served during the calendar year. In the future, the RDR will be phased out, and grantees will report to HRSA/HAB using the RSR.

Required Reporting Entities

The RDR should be completed by all Ryan White HIV/AIDS Program Part A, Part B, Part C, Part D (including the Adolescent Initiative), and Part F (MAI) grantees, service providers, and consortia (Part B). Ryan White HIV/AIDS Program grantees receive Federal funding directly from HRSA/HAB. A grantee agency may be the same as the provider agency, or it may be the agency through which the provider agency is subcontracted. The service provider is the agency that provides direct services to clients and their families and is funded by the Ryan White HIV/AIDS Program. Services may be directly funded by one or more Parts of the Ryan White HIV/AIDS Program or through subcontract(s) with official Ryan White HIV/AIDS Program grantees of record. A grantee or provider must complete only the organizational section of the report if the only services provided during the reporting period are (1) planning or evaluation, (2) administrative or technical support, (3) fiscal intermediary services, (4) TA, (5) capacity development, or (6) QM.

Providers funded under more than one Part complete the RDR only once, including information from all Parts under which they are funded. Providers should report data on all clients who received services eligible for Parts A, B, C, D (including Adolescent Initiative funding), or Part F (MAI), regardless of the actual funding source used to pay for those services. Grantees and providers that choose to report only on the subset of clients who received funded services from any Part of the Ryan White HIV/AIDS Program must have special permission.

Reporting Period

RDRs must be submitted by mid-March for the preceding calendar year.

Reporting Form

The reporting form is available at: http://hab.hrsa.gov/rdr/#a.

Summary of Data Collected

The RDR is divided into seven sections, as shown in Table 3.2 (page 16). Not all grantees and providers are required to respond to each section. Some sections are specific to Parts C and D. Only programs administering a Health Insurance Program (HIP) should complete Section 7.

Section 1. Section 1 gathers information about the grantee or provider completing the RDR, organizational information, sources and amounts of Ryan White HIV/AIDS Program funding, whether the agency administers an ADAP or local APA program, whether the agency provides HIP, the populations especially targeted for outreach or services, total paid and volunteer staff, and the types of services provided to grantees.

Section 2. Section 2 collects aggregated client information, including the number of unduplicated clients served and their HIV serostatus; vital and enrollment status; and demographic, economic, housing, and medical insurance data.

Section 3. Section 3 summarizes the types of services offered by service category. For core medical service categories, grantees and providers report the total number of unduplicated clients served and the total number of visits during the reporting period. For support service categories, grantees and providers report which services were offered and the total number of unduplicated HIV-positive and -affected clients served.

TABLE 3.2. RYAN WHITE HIV/AIDS PROGRAM DATA REPORT (RDR)

RDR Section		Part A	Part B	Part C	Part D	Part F(MAI)
1	Service provider information	✓	✓	✓	✓	✓
2	Client information	✓	✓	✓	✓	✓
3	Service information	✓	✓	✓	✓	✓
4	HIV counseling and testing	✓	✓	✓	✓	✓
5	Medical information	✓	✓	✓	✓	✓
6	Demographic tables/part-specific data for Parts C and D					
6.1	Part C information			✓		
6.2	Part D information				✓	
7	Health Insurance Program information	✓	✓	✓		✓

Section 4. Section 4 describes HIV counseling and testing provided by grantees and providers as part of their program and whether that service was supported by Ryan White HIV/AIDS Program funds during the reporting period. Data reported include the number of clients receiving pre- and posttest counseling, number of clients tested, number of clients receiving HIV posttest confidential or anonymous counseling, number of clients receiving a positive test result, whether the program participated in partner notification, and number of at-risk partners who were notified.

Section 5. Section 5 focuses on information from medical services providers for HIV-positive or -indeterminate clients with at least one outpatient or ambulatory medical care visit in the reporting period. Data gathered include client demographics, mode of exposure to HIV, number of clients served, number of clients receiving TB testing and treatment, number of clients receiving sexually transmitted infection testing and treatment, hepatitis C screening and testing and treatment, number of clients newly diagnosed with AIDS, number of clients receiving pelvic exams and cervical Pap tests, number of pregnant HIV-positive clients and the month in which they entered prenatal care, and the type of QM program used by medical providers.

Section 6. Section 6 is completed by Part C and D grantees and providers. Section 6.1 summarizes the demographic, HIV exposure category, and clinical characteristics of HIV-positive or -indeterminate clients who received at least one primary health care service in the period for Part C grantees and service providers. Additionally, Part C grantees and providers report the cost and revenue of primary health care and other programs during the reporting period, the number of sites providing EIS, and the types of primary health services made available to HIV-positive and -indeterminate clients (e.g., outpatient or ambulatory medical care, specialty medical services, dispensing of pharmaceuticals, oral health care, substance abuse services). The number of unduplicated HIV-positive clients referred for services outside the EIS program also is reported, as is the vital status of clients at the end of the reporting period. Section 6.2 summarizes the demographics; HIV exposure category; and clinical characteristics of HIV-positive, -indeterminate, or -affected family members as well as the number of clients served in the reporting period.

Section 7. Section 7 is completed by State agencies and other entities that use Ryan White HIV/AIDS Program funds (except for ADAP) to pay for or supplement clients' health insurance. HIP data collected include total number of unduplicated clients, number of new clients served, client demographic characteristics, and total expenditures. Sources and total amount of HIP funds expended are reported for the Ryan White HIV/AIDS Program (e.g., Part A, Part B, Part C) and other funding sources (e.g., Federal Section 330, State and local, and client payments). Section 7 also collects HIP annual expenditures and unduplicated clients enrolled in high-risk insurance pools, Medicare supplements, and other health insurance. Cost, unduplicated clients, and total client months of enrollment are reported separately (by premiums, deductibles, and copayments) for health insurance program-based HIP expenditures.

Report Submission Method

Grantees and providers submit RDRs through the EHB.

Note on Discontinuation

HRSA/HAB expects the RDR to be obsolete on or before 2012. The delay in discontinuing the RDR is related to the time likely to be required to improve the quality of RSR data submitted by HRSA/HAB grantees and providers. Expansion of the types of providers required to complete the RSR also will also need to be completed. While the HRSA/HAB grantees improve their capability to submit high-quality RSR data, HRSA/HAB must rely on the data found in the RDR to respond to questions from Congress and the Office of the President.

AIDS DRUG ASSISTANCE PROGRAM QUARTERLY and ANNUAL REPORTS

Report Purpose

The ADAP Quarterly Report (AQR) is a condition of the Part B grant award and is used to monitor quarterly trends in ADAP funding and expenditures, enrollment in ADAP medication and health insurance assistance, access to medications, and cost-saving strategies. The Annual Report aggregates data from the AQRs. Also, Section 2618(a)(2)(F)(ii) of the PHS Act states that 5 percent of the ADAP appropriation will be reserved as supplemental funding to purchase medications for States and Territories with demonstrated severe need. This funding is available to States and Territories on the basis of (1) a financial requirement of <200 percent FPL; (2) limited formulary compositions for all core classes of ARV medications; (3) waiting list, capped enrollment, or expenditures; and (4) an unanticipated increase in eligible clients with HIV/AIDS. HRSA/HAB determines whether States and Territories are eligible to apply for the ADAP supplemental award on the basis of the data they submit in the AQR.

Required Reporting Entities

Part B grantees must complete the AQR form.

Reporting Period

The AQR is due on the last business day of the month following the end of the quarter. The Annual Report is submitted with the first quarterly report of the fiscal year, which is due on July 31 of each year.

Reporting Form

The form and instructions for completing the ADAP Quarterly and Annual Reports are available at http://hab.hrsa.gov/tools.htm#RDR.

Summary of Data Collected

The AQR collects data on the grantee, client demographic and financial characteristics, enrollment counts, use of HAART by clients, coverage limits (e.g., enrollment caps, waiting list, capped expenditures, and drug-specific enrollment caps), changes in the program's eligibility criteria in the quarter, ADAP funding received, expenditures, and drug pricing. Client data include clients receiving one or more drugs and clients receiving insurance services (e.g., premiums, copayments, or deductibles). The Annual Report collects annual summary data for the fiscal year. Data collected include ADAP funding, a list of all medications in the ADAP formulary, annual ADAP cost per client, ADAP financial eligibility, frequency of client recertification, clinical eligibility criteria for enrolling in ADAP, and cost-saving strategies.

Report Submission Method

Grantees submit reports through the EHB.

PART A MAI REPORT

Report Purpose

Part A grantees receiving MAI funds must submit two components of the MAI Report annually: (1) the Part A MAI Annual Plan for the use of these funds, and (2) the year-end Part A MAI Annual Report documenting program outcomes. Each Part A MAI Report has two parts: (1) Web forms for standardized quantitative and qualitative information and (2) an accompanying narrative providing background information to explain the data submitted and a summary of program accomplishments, challenges, and lessons learned.

Required Reporting Entities

Part A grantees receiving MAI funds must file a report.

Reporting Period

The MAI Report is due 90 to 120 days after the budget period start and end dates.

Reporting Form

The form is available at http://hab.hrsa.gov/tools.htm.

Summary of Data Collected

The purpose of the Web forms is to collect standardized quantitative and qualitative information on how the funds were spent, the number of service units provided, the total number of clients served; the total numbers of women, infants, children, and youth served; and up to three client-level health outcomes achieved for each service or activity provided to each ethnic or racial community. The MAI Narrative is a 2- to 4-page document in which grantees provide (1) background information needed to explain the data included in the Web forms; (2) a summary of program achievements in relation to planned goals and objectives, including client-level health outcomes and capacity development or TA activities; and (3) challenges and lessons learned in providing MAI-funded services.

Report Submission Method

Grantees submit reports through the EHB.

DENTAL SERVICES REPORTS

Report Purpose

The Dental Services Report is used by two different programs under the Ryan White HIV/AIDS Treatment Extension Act of 2009: the CBDPP and the DRP. The Dental Services Report is designed to collect data from accredited pre- and postdoctoral dental education programs and dental hygiene education programs on oral health services provided to HIV-positive patients. Institutions applying for DRP funding may submit a completed Dental Services Report annually to receive assistance with unreimbursed costs of care incurred in providing direct oral health services. CBDPP grant recipients use the Dental Services Report to submit annual program data as a condition of their grant awards.

Required Reporting Entities

CBDPP and DRP grantees are required to submit a completed data report annually reflecting aggregate data from all CBDPP members and sites.

Reporting Period

The report is due 6 months after the end of each calendar year.

Reporting Form

The report is available at http://hab.hrsa.gov/tools.htm#Dental.

Summary of Data Collected

The Dental Services Report collects institutional and program contact information; the number of patients served by the program (if the institution is using the form to submit CBDPP data or apply for DRP funds); patient demographic, financial, and clinical data; the number and type of oral health services provided; funding and payment coverage; and staffing and training. For DRP funding applicants, additional information is reported about DRP fund use, unreimbursed costs, and methods used to calculate unreimbursed funds. DRP applicants also must provide a narrative report about the applicant's site, working relationship with other Ryan White HIV/AIDS Program–funded agencies, involvement in the Statewide Coordinated Statement of Need (SCSN), outreach activities to HIV-positive persons, and the program's special strengths or unique characteristics.

Report Submission Method

DRP grantees must submit their Dental Services Report using two methods: (1) They must upload a PDF of their report to grants.gov, and (2) they must e-mail their data file to WRMA/CSR, a HRSA information technology contractor.

AIDS EDUCATION and TRAINING CENTER REPORTS

Event Record

Purpose of the Report. The Event Record (ER)collects summary information about the events undertaken by AETCs. AETCs support a network of 11 regional centers (and more than 130 local associated sites) that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV/AIDS. Several national, cross-cutting AETC components support and complement the regional training centers. The ER summarizes events sponsored by regional centers and local associated sites as well as events sponsored by the AETC National Resource Center, the National Minority AETC, the AETC National Evaluation Center, and the National HIV/AIDS Clinicians' Consultation Center.

Required Reporting Entities. AETC regional centers, local associated sites, and national centers complete the ER.

Reporting Period. The day of the event is the reporting period.

Reporting Form. The ER is completed by the AETC regional centers, local associated sites, and national centers at the completion of the event.

Summary of Data Collected. The ER collects information on topics covered in the event, the organizations that helped with the event, the number of participants, and the length and type of event (e.g., didactic presentation, skill building, clinical training, group or individual clinical consultation, TA). The ER assesses methods or technologies used in the event (e.g., chart/case review, clinical preceptorship, computer-based, conference call, lecture/worship, role play, self-study, telemedicine). Also, the ER collects information as to whether the event was funded by the American Indian/Alaska Native Initiative, Border Health Initiative, or MAI.

Report Submission Method. The reports are submitted by AETC grantees and local associated sites through the EHB.

Participant Information Form

Report Purpose. The Participant Information Form (PIF) summarizes information regarding health care professionals and other participants of AETC-sponsored events.

Required Reporting Entities. Participants complete the PIF at the end of the event.

Reporting Period. The day of the event is the reporting period.

Reporting Form. The PIF is completed by participants at the end of the training event and then gathered by the AETC regional centers, local associated sites, and national centers

Summary of Data Collected. The PIF collects data on participants' profession or discipline, primary functional role, principal employment setting, funding of employment setting, demographic characteristics, whether the participant provides services directly to HIV-positive clients, number of years in which the participant has provided direct services to HIV-positive clients, and the number and demographic characteristics of HIV-positive patients served in the past year.

Report Submission Method. The reports are submitted by grantees and local associated sites through the EHB.

FEDERAL FINANCIAL REPORT

Report Purpose. The FFR is an annual report of expenditures, including unobligated balances.

Required Reporting Entities. All HRSA/HAB grantees.

Reporting Period. A FFR is required within 90 days of the end of each budget period.

Reporting Form. Grantees must use Standard Form (SF) 425, available at www.whitehouse.gov/omb/assets/grants_forms/ff_report_fill.pdf.

Summary of Data Collected. The FFR replaces the Payment Management System 272 and the Federal Status Report SF 269 forms. Data include grantee name and address, employer identification number, grant period, and reporting period. Detailed information about grant transactions is required, including total outlays, refunds or rebates, program income (third party or in-kind contributions), cost share, Federal and grantee share of net outlays, unobligated balance of Federal funds, and indirect expenses.

Report Submission Method. HRSA/HAB requires grantees to submit postaward reports online using the EHB; see https://grants.hrsa.gov/webexternal.

ALLOCATION and EXPENDITURE REPORTS

Report Purpose. Ryan White HIV/AIDS Program grantees must submit two reports annually to HRSA/HAB describing (1) how grant funds were allocated and (2) how the funds were spent.

Required Reporting Entities. Parts A, B, C, and D.

Reporting Period. Grantees must submit A&E reports electronically using Microsoft Excel templates provided by HRSA/HAB in the EHB no later than the due dates in Table 3.3 (page 21).

Reporting Form. Report templates are created in Excel. After opening the file, it is saved using a name that identifies the reporting organization, the fiscal year, and the report name. This file naming convention helps HRSA/HAB distinguish and track grantee report submissions.

Summary of Data Collected. Allocation report data include grantee contact information, amount of total grant award, and the amount of the award allocated for each service category. Expenditure report data include grantee contact information, the amount of the total award and approved carryover expended, and the amount of the award expended for each service category.

Report Submission Method. The reports are submitted by grantees through the EHB.

SUMMARY

- HRSA/HAB grantees and their providers are required to gather and electronically submit data using standardized reports that address the requirements of the Ryan White HIV/AIDS Treatment Extension Act of 2009 and grant guidance. The reports are generally submitted through the EHB to ensure complete, accurate, consistent, and timely data.
- The RSR must be submitted by Part A, B, C, and D grantees in 6-month reporting cycles. Grantee, Provider, and Client Reports gather data needed for fiscal accountability;

TABLE 3.3. DUE DATES for PROGRAM ALLOCATIONS and PROGRAM EXPENDITURE REPORTS

Report	Grant	Due Date
Allocation Report	Part A	90 days after the Part A budget period start date
	Part A MAI	60 days after the Part A MAI grant budget period start date
	Part B	90 days after the Part B budget period start date
	Part B MAI	60 days after the Part B MAI grant budget period start date
	Part C	60 days after grant is awarded
	Part D	60 days after the grant is awarded
Expenditure Report	Part A	150 days after the Part A grant budget end date
	Part A MAI	60 days after the Part A MAI grant budget period end date
	Part B	150 days after the Part B grant budget end date
	Part B MAI	60 days after the Part B MAI grant budget period end date
	Part C	90 days after budget period ends
	Part D	90 days after budget period ends

data for evaluating performance, outcomes, quality, resource allocation, and needs assessment; and data for financing, organizing, and delivering services. Longitudinal client-level data are collected, enhancing the capacity of HRSA/HAB to determine the number of clients served over time, the services they receive, the quality of services provided, and the impact of Ryan White HIV/AIDS Program funds on geographic and socio-demographic subpopulations.

- The RDR collects annual cross-sectional data from grantees and providers. Because the RDR client data do not provide unduplicated counts, HRSA/HAB expects the RDR to be obsolete in or before 2012. The delay in discontinuing the RDR is related to the period likely to be required for improvement of the quality of RSR data submitted by HRSA/HAB grantees and providers. While the HRSA/HAB grantees improve their capability to submit high-quality RSR data, HRSA/HAB must rely on the data found in the RDR to respond to questions from Congress and the Office of the President.
- The ADAP Quarterly and Annual Reports collect data regarding unique aspects of the Part B ADAP. The reports gather data on ADAP expenditures, benefits, and enrollment and on cost-saving strategies such as coverage limits, waiting lists, capped expenditures, and drug-specific enrollment caps. Data are also reported on health insurance premium, co-payment, and deductible expenditures as

well as on the number of people receiving those benefits.

- Part A grantees receiving MAI funds must submit an Annual Plan for the use of the funds as well as the year-end Part A MAI Annual Report, which documents program outcomes. The report gathers standardized quantitative and qualitative data, and an accompanying narrative provides background information to explain the data submitted and includes a summary of program accomplishments, challenges, and lessons learned.
- The Dental Services Report collects data about the organizational settings receiving Part F dental services funds, cross-sectional service utilization and client count data, financial information, staffing, and training. For DRP funding applicants, additional information is reported about the use of DRP funds, unreimbursed costs, and methods used to calculate unreimbursed funds.
- AETC reports focus on the unique training responsibilities of AETCs. Cross-sectional data are gathered about the training events offered and the participants of those events.
- Grantees submit two financial reports to HRSA/HAB. The FFR is an annual report of expenditures including unobligated balances. The A&E Reports are submitted by grantees at the beginning of the grant period (i.e., explaining how funds were allocated) and end of the grant period (i.e., explaining how funds were spent).

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4. How HRSA/HAB Uses the Data It Collects

OVERVIEW of ROUTINE SUMMARY REPORTS

HRSA/HAB synthesizes data collected from the reporting systems described in Chapter 3 to prepare reports and disseminate them through the HRSA/HAB Web site. HRSA/HAB publishes a biennial Ryan White HIV/AIDS Program progress report, an annual data summary in alternating years, biennial State profiles, annual grantee A&E reports, and an annual AETC annual report. HRSA/HAB also produces an annual report to Congress.

Progress Report

The biennial Ryan White HIV/AIDS Program Progress Report documents the successes and challenges of the Ryan White HIV/AIDS Program from a public health perspective. The report includes information about the evolving epidemic; data on client demographics, programs, and services; and individual stories of Ryan White clients whose lives have been affected by the disease and improved by Program services. The 2008 Ryan White HIV/AIDS Program Progress Report, *The Power of Connections,* synthesizes information about featured Ryan White HIV/AIDS Program–funded providers, describes the Parts and their funding levels, identifies Program accomplishments, summarizes key changes in the Program, and discusses environmental challenges facing the Ryan White community. It also summarizes Program expenditures by service category. RDR client demographic data summaries include gender, age group, race/ethnicity, health insurance, household income, and housing arrangements. RDR organizational data describing the types of providers funded by the Ryan White HIV/AIDS Program are also integrated into the report. AETC training data are used to summarize the most common professions participating in AETC events.

The 2008 Progress Report identified several key challenges, including the likely increase in demand for services associated with new HIV testing guidelines, the aging of people living with AIDS, retention of patients in care, the HIV workforce shortage, changes in the Medicaid program resulting from the Deficit Reduction Act, fiscal viability of programs funded by the Ryan White HIV/AIDS Program, the need for client-level data, and reauthorization of the Ryan White HIV/AIDS Treatment Modernization Act of 2006. The Progress Reports published in 2002, 2004, 2006, and 2008 are available at http://hab.hrsa.gov/publications/progressreports.htm. The next Progress Report will be produced in August 2010.

Annual Data Summary

The biennial Annual Data Summary synthesizes data collected by the RDR and the quarterly and annual ADAP reports to provide a comprehensive summary of how Ryan White HIV/AIDS Program funds are used to deliver health care services to individuals and families living with or affected by HIV. Unlike the Ryan White HIV/AIDS Program Progress Report, the Annual Data Summary provides a quantitative summary of Program activities, including an overview of (1) the characteristics of provider organizations; (2) the number and characteristics of clients served; and (3) the types of services provided, number of clients receiving these services, and number of client visits by type of service. Provider information summarizes the types of providers participating in the Ryan White HIV/AIDS Program, their ownership status, the Parts that fund them, and staffing by employees and volunteers. Client information summarizes the distribution of clients by gender, race/ethnicity, age group, household income, housing arrangements, HIV/AIDS status, and medical insurance.

Tabular data are provided that separately report these characteristics for HIV-positive and -affected clients. The number of clients served and the total visits per HIV-positive client are summarized by service category.

The report also summarizes the following data:

- Number of providers serving clients in health care services and case management
- Average (mean), median, and range (from lowest to highest) of visits to these providers.
- Frequency of HIV-positive and -affected clients receiving support services by support service categories
- Number of Ryan White HIV/AIDS Program providers offering HIV counseling and testing, whether Program funds were specifically used for this service, whether the providers offer partner notification, and the number of infants tested.

The report summarizes ADAP expenditures for pharmaceuticals, dispensing and administrative costs, health insurance coverage, and adherence and access activities funded under the ADAP Flexibility Policy. It also summarizes the demographic characteristics of ADAP clients.

The Annual Data Summary reports are available at http://hab.hrsa.gov/reports/data2a.htm.

State and Territory Profiles

HAB publishes biannual Ryan White HIV/AIDS Program State Profiles summarizing facts about each State and Territory population, the HIV/AIDS epidemic in each State and Territory, and Program funding. These State profiles can be used for local HIV planning and needs assessments as well as to compare States. Each State profile summarizes the State or Territory's population size, economic status, and rate of public and commercial insurance enrollment. The profiles also report the amount and sources of Ryan White funding, characteristics of funded providers, and the types of services funded. The profiles also summarize the demographic characteristics of clients served in core services, support services, and the State's ADAP.

Similar data, summarized for the United States, individual States, and Territories, are found on the TARGET Center Web site. The TARGET site provides an interactive map that can be used to select individual State or Territory profiles. A list of Ryan White HIV/AIDS Program grantees also can be selected. State and Territory profiles are located at http://careacttarget.org/community.asp.

Allocation and Expenditure Reports

A&E reports submitted by Ryan White HIV/AIDS Program grantees are consolidated in a single site on the HRSA/HAB Web site along with a report summarizing allocations and expenditures for each Part. Part A grantee allocation reports are posted for FY 1999 to 2003. Part A A&E reports are posted for 2004 to 2008. Part B grantee A&E reports are posted for 2004 to 2007. As of 2009, Part C and D grantees will also be required to submit these reports. A&E reports are available in PDF and Excel versions at http://hab.hrsa.gov/reports/data2b.htm#2.

The A&E reports are used by HRSA/HAB Project Officers to ensure that grantees use Ryan White HIV/AIDS Program funds as required by the Ryan White HIV/AIDS Treatment Extension Act of 2009, including the required allocation of 75 percent of funds for core medical services. The reports also inform the Project Officers about the funding priorities within core medical and social support service categories set by the grantee. Finally, the data are used to compare grantees allocations and expenditures, compute trends over time, and assess the impact of the shift in emphasis to core medical services.

AETC Annual Report

The AETC Annual Report summarizes the mission of the program; offers an overview of the AETC Training Network; and highlights the network's accomplishments, including those associated with MAI-funded initiatives focusing on training providers to serve racial and ethnic minorities. The report also summarizes information about trainee demographic characteristics, professions or disciplines, and principal employment settings. Detailed information is provided about AETC training activities, including the number of activities and events, number of training hours, number of trainees, and training topics. AETC Annual Reports are located at http://hab.hrsa.gov/reports/data2a.htm.

SUMMARY

- HRSA/HAB produces reports annually that summarize the accomplishments of the Ryan White HIV/AIDS Program, summarize the agencies participating in the program, and describe the clients served. These reports are prepared to address congressional requirements and to inform the HIV/AIDS community about the Program's impact.
- Data reported to HRSA/HAB form the basis for addressing ongoing inquiries by Congress, State and local policymakers, HIV/AIDS advocates, and others. The data also form the basis for policy studies delving into timely topics associated with HIV care and treatment.
- In addition to the reports produced by HRSA/HAB, grants management staff and Project Officers use data gathered by HRSA/HAB for their ongoing fiscal and programmatic monitoring requirements. These reports help staff understand the unique challenges encountered by grantees and providers as well as their accomplishments and impact.

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5. How Grantees Can Use Required Data

This chapter summarizes how HRSA/HAB grantees can use data to fulfill their responsibilities. The scope and complexity of those responsibilities vary by Ryan White HIV/AIDS Program Part and the size of grantee's service area (e.g., State, EMA, city, neighborhood). Variability also is associated with the size and scope of the HIV epidemic in the service area, the amount of funds awarded to the grantee, number of Parts funded, number of clients served, number of providers, mix of services funded, and interventions undertaken. This chapter offers examples of specific constructs, data elements that can be used to measure those constructs, and ways data reported to HRSA/HAB can be used by grantees to fulfill their responsibilities.

RESPONSIBILITIES of GRANTEES THAT CAN BE ASSISTED by DATA

Figure 5.1 summarizes common responsibilities of Part A, B, C, and D grantees. (Grantees may have other responsibilities that require data as well.)

FIGURE 5.1. COMMON GRANTEE RESPONSIBILITIES THAT REQUIRE DATA

Achieving Health Outcomes

- Improving health outcomes through core and support services

Clinical Quality Management and Performance Assessment

- Provider adherence to established clinical practice standards, protocols, and HHS guidelines
- Developing and testing new processes or program strategies to achieve improvement at client, administrative, program, or system levels
- Achieving clinical goals and outcomes
- Frontline worker productivity

Resource Allocation

- Priority setting
- Timely and complete disbursement of funds

Financing, Organizing, and Delivering Services

- Implementing a coordinated, comprehensive system of care
- Ensuring available, accessible, and culturally competent services
- Identifying, engaging, and retaining clients
- Understanding the characteristics of clients engaged and not engaged in the care system
- Monitoring service utilization patterns and service mix
- Managing utilization, enrollment, eligibility, formulary, waiting lists, and capped benefits
- Ensuring that the Ryan White HIV/AIDS Program is payor of last resort, third-party reimbursement, and program income
- Addressing the unique needs of "special populations"
- Coordinating funders and benefits
- Purchasing, contracting, fiscal and program monitoring, cost assessment, and expenditure forecasting
- Evaluating achievement of program objectives

Training

- Assessing and addressing training needs
- Evaluating training

Needs Assessment

- HIV seroprevalence and surrogate markers
- Social context of HIV/AIDS
- Target populations and their unique needs
- HIV service delivery and financing system
- Barriers or facilitators to care
- Documenting demand for care
- Unmet need for care

MEASURING QUALITY and PERFORMANCE

Part A and B grantees are required to evaluate program "effectiveness." Although legislative language on evaluation is more limited for Parts C and D, program guidance requires evaluation. Specific evaluation requirements include the following:

- Each Part A Planning Council shall establish priorities for allocating funds on the basis of factors including the "demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available. Each Council may, at its discretion, "assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs."
- Each Part B consortium is required to submit to the State an application that

  (D) demonstrates that the consortium has created a mechanism to evaluate periodically—(i) the success of the consortium in responding to identified needs; (ii) the cost-effectiveness of the mechanisms employed by the consortium to deliver comprehensive care; and (E) demonstrates that the consortium will report to the State the results of the evaluations described in subparagraph (D) and shall make available to the State or the Secretary, on request, such data and information on the program methodology that may be required to perform an independent evaluation.

- Part C programs may spend no more than "7.5 percent, including planning and evaluation of the grant for administrative expenses with respect to the grant" (§ 2664(g)(3)).
- Each Part D program is required by the Secretary to "directly or through contracts with public and private entities, provide for evaluations of programs carried out pursuant to subsection (a)" (§ 2671(h)(2)).

The Ryan White HIV/AIDS Treatment Extension Act of 2009 requires that QM programs be established by all programs. QM, as defined by HRSA/HAB, seeks to enhance the quality of HIV care provided and increase access to services by measuring how health and social services meet established professional standards and user expectations. All parts of the Ryan White HIV/AIDS Program are required to undertake the QM activities outlined below:

- Grantees under all four Parts must

  establish a QM program to assess the extent to which HIV health services provided to patients under the grant are consistent with the most recent PHS guidelines for the treatment of HIV disease and related opportunistic infections (OIs) and, as applicable, to develop strategies for ensuring that such services are consistent with the guidelines for improvement in the access to and quality of HIV health services.

- Part A and Part B grantees may allocate up to the lesser of 5 percent of the total grant amount or $3 million for QM activities. Funding limits are not specified for Part C and Part D. Guidance from HRSA/HAB indicates that QM programs are intended to help grantees evaluate and improve the quality of primary care and health-related supportive services provided under the Ryan White HIV/AIDS Treatment Extension Act of 2009. To meet the purpose of continuously improving systems of care for individuals and populations, HRSA/HAB expects evaluations of quality of care to consider the quality of service inputs (e.g., staffing, resources), service delivery process, and service outcomes.

The HRSA/HAB *HIV/AIDS Core Clinical Performance Measures for Adults and Adolescents* are a set of indicators for use in monitoring the quality of care provided. The measures can be used as defined or can be further modified by a grantee to meet that entity's individual needs. Grantees

FIGURE 5.2. HRSA/HAB PERFORMANCE MEASURES

Group 1 Measures
- ARV therapy for pregnant women
- CD4 T-cell count
- HAART
- Medical visits
- PCP prophylaxis

Group 2 Measures
- Adherence assessment and counseling
- Cervical cancer screening
- Hepatitis B vaccination
- Hepatitis C screening
- HIV risk counseling
- Lipid screening
- Oral exam
- Syphilis screening
- Tuberculosis screening

Group 3 Measures
- Chlamydia screening
- Gonorrhea screening
- Hepatitis B screening
- Hepatitis/HIV alcohol counseling
- Influenza vaccination
- *Mycobacterium avium* complex prophylaxis
- Mental health screening
- Pneumococcal vaccination
- Substance use screening
- Tobacco cessation counseling
- Toxoplasma screening

should select measures that are most important to their agencies and the populations they serve. Note, however, that several measures are incorporated into the RSR Client Report.

HRSA/HAB Core Clinical Performance Measures fall into three groups. Each measure can be used by all programs funded by the Ryan White HIV/AIDS Program at the provider or system level.

1. Group 1 measures provide an excellent start and can serve as a foundation on which to build, especially if a clinical program has no performance measures. These measures are incorporated into the RSR.
2. Group 2 measures are important measures for a robust clinical QM program and should be seriously considered.
3. Group 3 measures represent areas of care that are considered “best practice,” but may lack written clinical guidelines or rely on data that are difficult to collect.

Grantees are encouraged to include the core clinical performance measures in their QM plans. Although data are not required to be submitted to HRSA/HAB (except for those measures incorporated in the RSR Client Report), grantees are strongly encouraged to track and trend data on these measures to monitor the quality of care provided. Figure 5.2 (above) outlines group measures.

On the basis of input from key stakeholders, HRSA/HAB also released sets of performance measures in the following areas:

- *Medical case management*. The Medical Case Management Measures target all clients, regardless of age, and focus on two key issues: care plans and medical visits. Medical case management programs are encouraged to utilize the core clinical performance measures as appropriate.
- *Oral health*. The Oral Health Performance Measures target all clients. The measures are intended for use by programs providing direct oral health services and include dental and medical history, dental treatment plan, oral health education, periodontal screening or examination, and phase I treatment plan completion.
- *ADAP programs*. The AIDS Drug Assistance Program measures are intended for use by the ADAP. Four measures are included and target all clients, regardless of age: application determination, eligibility recertification, formulary, and inappropriate antiretroviral regimen.

These measures, similar to the Core Clinical Performance Measures, can be modified to meet grantees' programmatic objectives. (See http://hab.hrsa.gov/special/habmeasures.htm#performance2.)

Each performance measure specifies how to calculate the numerator and denominator, patient exclusions, and data elements required to compute the measure; suggested data sources; national goals, targets, or benchmarks for use by grantees for comparison; outcome measures that might be used by grantees; the basis for selection of the measure, if the measure is an OPR measure; and the national guideline addressed by the measure. HRSA/HAB posts the measures on its Web site at http://hab.hrsa.gov/special/habmeasures.htm.

A reference guide, *HRSA/HAB HIV Core Clinical Performance Measures for Adults & Adolescents: Companion Guide*, has been developed to assist grantees in the use and implementation of the core clinical performance measures. Frequently asked questions are answered at http://hab.hrsa.gov/special/habmeasures.htm#performance3.

Figure 5.3 shows how a grantee might apply a Group 1 measure to assess provider performance.

FIGURE 5.3. APPLYING CORE CLINICAL PERFORMANCE MEASURES: CASE EXAMPLE

A Part B grantee wants to assess the performance of its 13 clinical providers in delivering outpatient and ambulatory medical care to non-Hispanic Black or African-American, Non-Hispanic White, and Hispanic clients. The grantee applies the HRSA/HAB Group 1 measure "Medical Visits" to assess performance. Grantee staff used a client-level data system that was developed to meet HRSA/HAB's RSR reporting requirement to conduct the analysis. Using specifications from the RSR Client Report cited below, the formula for the medical visit rate is as follows:

$$\textit{Percentage of clients with HIV infection who had two or more medical visits in an HIV care setting in the measurement year} = \frac{\textit{Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges (i.e., physician, physician assistance, nurse practitioner) in an HIV care setting 2 or more times at least 3 months apart during the measurement year (ClientReportServiceVisits; ID 16-25)}}{\textit{Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year (ClientReportServiceVisits; ID 16-25)} - \textit{Patients newly enrolled in care during the past 6 months of the year (Enrollment StatusID; ID 2)}}$$

The Part B grantee computed the percentage of clients with HIV infection who had two or more medical visits in an HIV care setting in the measurement year. Three sets of rates were computed for non-Hispanic Whites, non-Hispanic Blacks, and Hispanics for the 13 Part B–funded clinics in the State. Each clinic was assigned a random number, and the results were presented in the Part A Clinical Quality Network. The clinics were told which random number they were assigned so that their rates were available to them.

The network concluded that some clinics had relatively low visit rates among Non-Hispanic Blacks and Hispanics. Those clinics agreed to conduct a quality improvement project (QIP) to identify and overcome barriers to medical visits. Several other clinics reported that they were concerned that although race and ethnicity were not associated with lower visit rates, they wanted to increase the number of visits generally among all groups. They also agreed to undertake a QIP. Seven months later, the clinics met again. Updated analyses found that visit rates had increased significantly for all but two clinics during the previous 6-month QIP period. The grantee continued to work with the two clinics to identify structural barriers that were contributing to disparities in visit rates.

Source: Science Applications International Corporation, HRSA. *Ryan White services report (RSR) data dictionary and XML schema implementation guide for the client-level data report: version 2.1*. October 13, 2009. Available at: www.careacttarget.org/library/RSR_Client-Level_Data_Dictionary_010610.pdf. Accessed January 4, 2010.

MEASURING OUTCOMES

Many factors contribute to the need for outcomes evaluation among Ryan White HIV/AIDS Program grantees and their providers. Client-level outcomes data are available through the RSR. Grantees and planning bodies need outcomes evaluation data to support their work at the State and local levels. Both grantees and lead agencies need outcome measures to include in requests for proposals and provider contracts so they can document results. Planning bodies need outcomes data as input to planning and priority setting. States and municipalities often require documentation that programs are making a difference, whether they are supported solely by the Ryan White HIV/AIDS Treatment Extension Act of 2009 or by a combination of public and other funding sources. Providers must document program outcomes as they seek public and private funds and as they work to improve and coordinate services.

HIV/AIDS care is now based largely on a medical service delivery model designed to reduce morbidity and mortality. Determining the effectiveness of Ryan White HIV/AIDS Program services therefore requires understanding whether such services help clients access care and achieve improved health status. As a result, outcomes evaluation for almost any Ryan White HIV/AIDS Program–supported service category, from case management to transportation, needs to include an indication of whether program participation can demonstrate linkages to primary care—which, in turn, contributes to improved clinical outcomes. Most providers lack access to data on client health status, but they can document their ability to link clients to outpatient or ambulatory medical care (e.g., helping them engage in care, keep appointments, adhere to medications).

Ryan White HIV/AIDS Program grantees, especially Part A and Part B grantees, typically help support a system of HIV/AIDS services. Grantees and planning bodies want evaluation data that can guide decision making about program priorities and resource allocation. Ideally, that means understanding the outcomes associated not just with one category of services (e.g., primary medical care or medical case management) but with a combination of core medical and support services—or an entire system of care.

Table 5.1 (page 31) offers examples of various measures that grantees may use to assess outcomes. For more information, see *Outcomes Evaluation: Technical Assistance Guide*, available at http://hab.hrsa.gov/tools/outcomes.htm.

RESOURCE ALLOCATION

The resource allocation process requires data in order to set priorities and track the timely and complete expenditure of Ryan White HIV/AIDS Program funds, as required by the Ryan White HIV/AIDS Treatment Extension Act of 2009 and grant guidance. Grantees determine resource allocations through the findings of needs assessments; previous expenditure history; and input from Planning Councils, care consortia, and people living with HIV/AIDS.

Tracking allocations and expenditures and ensuring the timely disbursement of funds are important responsibilities of grantees. These activities can be greatly enhanced by timely and accurate expenditure data from grantees' accounting systems and from invoices and related materials submitted by their providers. These data are summarized in A&E reports and are used in grant applications, progress reports, and FFRs.

Trend analysis is an important tool to help grantees track historic expenditures and plan future allocations and expenditures. Forecasting can help estimate funds needed to meet demand for services, unobligated and expended funds, current and future program income, and unobligated funds carried over to the next grant period. Figure 5.4 (p. 32) shows how a Part B grantee can use data to forecast expenditures and improve efficiency.

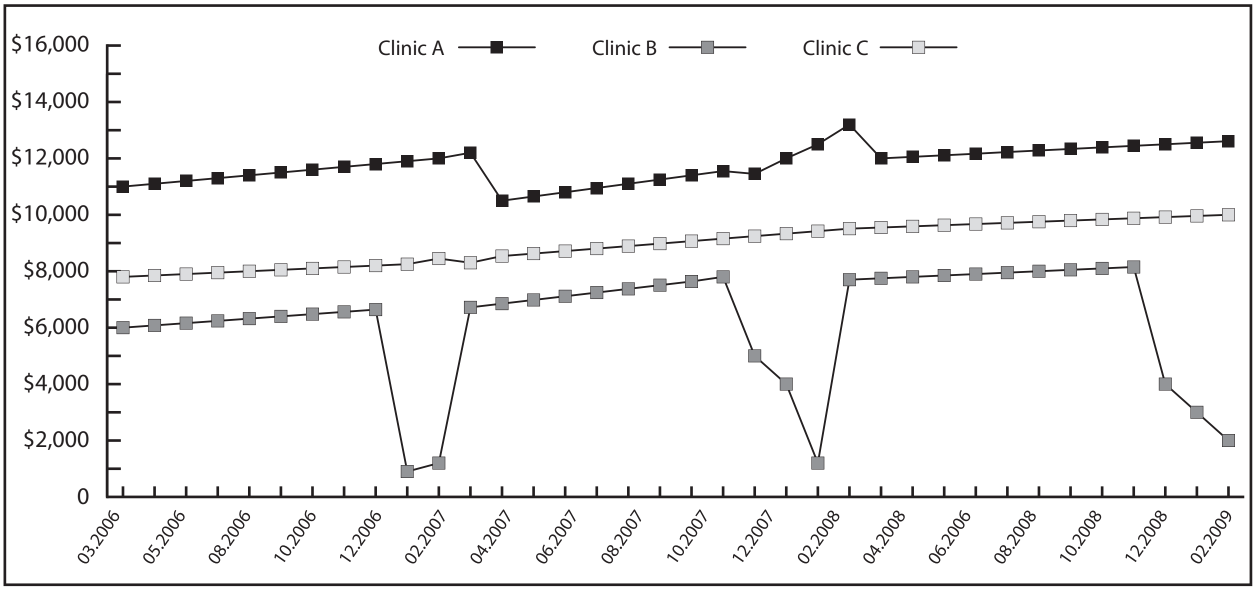
TABLE 5.1. EXAMPLES of CLIENT- and PROGRAM-LEVEL OUTCOME MEASURES, DATA ELEMENTS, and RSR CLIENT REPORT VARIABLE NAMES

Measure	Program-Level Outcome	Client-Level Outcomes	Data Elements	RSR Client Report Variable Names
Morbidity and Mortality Outcomes and Indicators				
Slowing and prevention of disease progression	Disease progression among Ryan White HIV/AIDS Program clients is slowed or prevented over time.	Improved or maintained average CD4 counts and viral loads for clients as measured over a specified period	Changes in CD4 counts and viral loads for individual clients over a specified period.	ClientReportCd4Test, Count, ServiceData ClientReportViralLoad-Test, Count, ServiceDate
Reduced mortality rates	Mortality rates among clients served by Ryan White HIV/AIDS Program providers are reduced over time.	Change in the percentage of clients dying from AIDS or other HIV-related conditions over a specified period	Number and percentage of deaths from AIDS or other HIV-related conditions during specified time periods	EnrollmentStatusID, DeathDate
Service Outcomes and Indicators				
Increased number of clients using outpatient/ambulatory medical care	Number of clients using outpatient/ambulatory medical care increases over time.	Change in the number of clients who used outpatient/ambulatory medical care over a specified period	Change in the number of clients who used outpatient/ambulatory medical care after a specified time period	ClientReportService-Visits, QuarterID, ServiceID
Increased number of clients maintaining use of outpatient/ambulatory medical care	Number of clients maintaining their use of outpatient/ambulatory medical care over time.	Change in the number of clients who maintained their use of outpatient/ ambulatory medical care after a specified period	Number and percentage of HIV-positive clients who maintained their use of outpatient/ambulatory medical care in specified time periods	ClientReportService-Visits, QuarterID, ServiceID
Increase in the number of clients who obtained support services	Number of clients accessing support services increases over time.	Change in the number of HIV-positive clients who obtain support services over a specified period	Increased number of clients using support services	ClientReportService-Delivered, QuarterID, ServiceID, DeliveredID
Increased number of clients prescribed HAART	Number of clients prescribed HAART increases over time.	Change in the number of clients who are prescribed HAART after a specified period	Increased number of clients prescribed HAART	PrescribedHaartID
Increased number of clients screened for syphilis	Number of clients screened for syphilis increases over time.	Change in the number of clients screened for syphilis after a specified period	Increased number of clients screened for syphilis	ScreenedSyphilisID
Increased number of pregnant women prescribed ARV medication before delivery	Number of pregnant women clients prescribed ARVs increases over time.	Change in the number of pregnant women who are prescribed ARVs in the first through third trimester over a specified time	Increased number of women clients prescribed ARVs prior to delivery	GenderID, PregnantID, PrenatalCareID, PrescribedArv MedicationID

FIGURE 5.4. USING SPENDING HISTORY to FORECAST EXPENDITURES: CASE EXAMPLE

A Part B grantee has fee-for-service reimbursement contracts with three clinics to provide outpatient/ambulatory medical care. Clinics are reimbursed $35 per 15-minute unit of service. A new Part B contract manager is hired, and she uses the calculations presented in Figure 5.4 to become more familiar with the spending history of the clinics.

Monthly Part B Fee-for-Service Expenditures Submitted by Three Clinics for the Grant



Years 2006 to 2008

Clinic A tends to have somewhat decreased expenditures in November and December of each year and then sharply increased expenditures in February and March. The contract manager discusses the expenditure history with Clinic A staff and learns that they do not schedule clinic appointments for 1 week in November and 2 weeks in December because of vacations for staff who are university employees. She also learns that the clinic then books as many clinic visits as possible late in the fiscal year to make up for the lost revenue.

The contract manager also reviews the expenditure history of Clinic B, and then interviews the staff. The staff reports that they have steadily increased staff and clinic appointments during the 3 years of Part B funding.

In reviewing the expenditure history of Clinic C, the contract manager finds that the clinic has few visits at the end of the fiscal year. Clinic C staff report that they have had steady increases in visits over the 3 fiscal years but run out of Part B funds toward the end of the grant year and cannot exceed their contracted annual allocation. Clinic C staff report that they have to refer patients to one of the other clinics during this period, affecting continuity of care and attrition of patients to the other clinics.

In response to her findings, the contract manager schedules TA meetings with Clinics A and C to discuss ways to redesign their scheduling and expenditures.

FINANCING, ORGANIZING, and DELIVERING SERVICES

Table 5.2 (page 33) summarizes the responsibilities of HRSA/HAB grantees for financing, organizing, and delivering services, as outlined in the Ryan White HIV/AIDS Treatment Extension Act of 2009 and grant guidance. Grantees may have added responsibilities for which data are needed.

ASSESSING NEED for HIV/AIDS SERVICES

Part A, B, C, and D grantees are responsible for assessing the need for services among their service population, so that they can address those needs through Ryan White HIV/AIDS Program and other funds. Needs assessment responsibilities are summarized in the Ryan White HIV/AIDS Treatment Extension Act of 2009 and grant guidance,

TABLE 5.2. TYPES and SOURCES of DATA USED in FINANCING, ORGANIZING, and DELIVERING SERVICES

Responsibility	Examples of Data	HRSA/HAB Data Sources
Implementing a coordinated, comprehensive system of care	Services offered; interventions or treatment modalities used by providers; inter- and intra-agency referral patterns; client flow from identification, linkage, engagement, and retention in care; capacity of service providers; types of personnel and full-time equivalents	RDR, RSR (Provider Report and Client Reports), MAI Report, grant applications
Ensuring available, accessible, and culturally competent services	Eligibility determination criteria, service mix, interventions modalities used, geographic and organizational location of services, transportation to providers, parking at provider, staff cultural and linguistic competencies, telephone and reception procedures, appointment scheduling process, kept or broken appointment rates, wait time for appointments, wait time at provider, client flow in provider's facility, capacity of provider to serve current and future client demand	
Understanding characteristics of clients engaged and not engaged in the care system	Client service utilization rates; service mix; sequencing of services used over time; kept or broken appointment rates; HIV care dropout rates; factors associated with retention in HIV care; client demographic, clinical, financial, psychosocial, and other characteristics	
Identifying, engaging, and retaining clients	Interventions to identify, link, engage, and retain clients in care; sequencing of service use; use of multiple service providers; number of days between medical visits; number of clients dropping out of care; service utilization patterns over time	RSR, MAI Report, CBDPP and DRP Dental Services Report, grant applications
Describing service utilization patterns and service mix	Funded service categories, number of units of service used over time, service mix, sequencing of services over time, period between services used	
ADAP and HIP utilization management, enrollment, eligibility, formulary, waiting lists, capped benefits	Eligibility determination criteria; formulary; policies regarding capped benefits, waiting lists, and enrollment; medication utilization rates; mix of medications used over time; types of insurance continuation benefits used (e.g., co-pay, deductible)	ADAP Quarterly and Annual Report
Ensuring that the Ryan White HIV/AIDS Program is payor of last resort, third-party reimbursement, tracking program income	Client health insurance enrollment, amount of third-party reimbursement, amount of program income	Grant application, FFR, A&E Reports
Addressing the unique needs of "special populations"	Cultural and linguistic characteristics; rates of homelessness or unstable housing; comorbid chronic health conditions; addiction, mental illness, and other social characteristics; geographic location	RSR, MAI Report grant applications
Coordinating funders and benefits	Service gaps; perceptions of grantees, other funders, and providers regarding coordination; participation in planning and fund raising activities	Grant applications
Purchasing, contracting, fiscal and program monitoring, cost assessment, and expenditure forecasting	Amount of funds obligated and expended, contract requirements, contractor performance based on contract requirements, draw-down rates of providers, extent to which services provided meet contract requirements, amount of expenditures	Financial Status Report, grant applications
Evaluating achievement of program objectives	Types of services and interventions provided, frequency of those inputs, utilization patterns, outcomes resulting from the service or intervention	RSR, RDR, ADAP Quarterly and Annual Report, AETC Reports

Note: Several primary sources are used to gather data for the RDR and RSR. These sources include client intake forms, grantee fee-for-service claims, electronic health records, and chart abstraction.

which identify needs assessment components, including use of HIV seroprevalence and surrogate markers to estimate current and future demand for HIV services; the social context of HIV/AIDS, such as HIV risk behaviors, that help describe populations needing services and their unique requirements; the current HIV service delivery and financing system; barriers to care; demand for care on the basis of the number of people living with HIV/AIDS who do not have health insurance or other resources to pay for care; and estimated unmet need on the basis of the size of the population aware that they are living with HIV/AIDS but are not in care.

Ryan White HIV/AIDS Program grantees use many data sources to conduct needs assessment. Table 5.3 (page 35) summarizes the types of data and their sources. Several factors contribute to the sources used:

- HIV/AIDS epidemiologic profiles address the scope of the HIV/AIDS epidemic, document unmet need, and demonstrate the disproportionate impact of HIV/AIDS on vulnerable populations. Availability of timely, detailed epidemiologic data is vital.
- In some jurisdictions, HIV name-based reporting is relatively recent, so 3 or more years of HIV incidence and prevalence data may not be available to compute trends in new HIV living cases that have not transitioned to AIDS.
- Information regarding the components of the HIV service delivery and financing systems may vary. Data regarding HIV/AIDS-related hospitalization rates, emergency department admissions, and public or commercial insurance expenditures may be unavailable or untimely because of the time required to gather and report data.
- Other factors contributing to the use of data include the availability of detailed survey or other data that can be used to describe the demographic, economic, health insurance coverage, and geographic characteristics of living HIV/AIDS cases. In some jurisdictions, government or other sponsors have supported the cost of those surveys. In other jurisdictions, Ryan White HIV/AIDS Program grantees have sponsored surveys.
- Knowledge of secondary data sources and the ability among grantee staff to synthesize data from several sources also contribute to the varied use of data.
- The size of the service area to be addressed by the needs assessment contributes to the approach taken by grantees. For example, urban areas in a State may have detailed data available for needs assessment, but rural areas may have minimal data.

Several HRSA/HAB resources are available to assist grantees with assessing need. Grantees are encouraged to use the HRSA/CDC Integrated Guidelines (available at www.cdc.gov/hiv/epi_guidelines.htm) as a tool for developing and reporting epidemiologic profile data. Also available is a framework summarizing data inputs and methods for computing unmet need (see http://hab.hrsa.gov/tools/unmetneed).

SUMMARY

- HRSA/HAB grantees use data to address responsibilities including achieving health outcomes; clinical QM and performance assessment; resource allocation; financing, organizing, and delivering services; training; and needs assessment.
- The types of data needed by grantees vary by Part, size of the service area, size and scope of the HIV epidemic addressed by the grantee, amount of funds allocated to the grantee, number of clients served, number of providers, service mix, and interventions undertaken.
- Reports required by HRSA/HAB can be used to address many grantee responsibilities. The

availability of RSR client-level data submitted to HAB, if also used by grantee, may greatly improve through the RSR to meet administrative, programmatic, QM, planning, resource allocation, and other responsibilities.

- The *HRSA/HAB HIV/AIDS Core Clinical Performance Measures for Adults and Adolescents* can be used to monitor the quality of care provided by Program grantees or their contracted providers. Several of the measures are incorporated into the RSR Client Report. Grantees should select measures that are most important to their agencies and the populations they serve. Some HRSA/HAB Group 1 performance measures are included in the RSR.

TABLE 5.3. TYPES and SOURCES of HRSA/HAB DATA SOURCES USED in HIV NEEDS ASSESSMENTS

Responsibility	Examples of Data	HRSA/HAB Data Sources
HIV seroprevalence and surrogate markers	HIV/AIDS incidence and prevalence, CD4 and viral load, resistance, geographic distribution, demographic characteristics, year of HIV and AIDS diagnosis, and HIV risk behaviors	RDR, RSR Client Report, MAI Report
Social context of HIV/AIDS	Demographic characteristics of HIV/AIDS cases, social and economic characteristics, health insurance coverage	RDR, RSR Client Report, MAI Report
Target populations and their unique needs	Rates of homelessness, unstable housing, addiction, mental illness, and other social characteristics; income and other economic characteristics; type of health insurance coverage and scope of benefits; family characteristics	RDR, RSR Client Report, MAI Report
HIV service delivery and financing system	Inventory of providers delivering HIV services, types and amounts of Ryan White HIV/AIDS Program and other funds, eligibility criteria for health insurance, eligibility criteria for disability income programs, mix of services available, HIV-related inpatient admissions and emergency room visits	RDR, RSR Provider Report, ADAP Quarterly and Annual Reports
Barriers or facilitators to care	Eligibility determination process, capacity to serve more clients, travel time to HIV providers, parking, transportation, hours of operation, wait time for appointments, wait time at provider site, culturally or linguistically competent clinicians and other workers, availability of services, use of personnel to facilitate navigation of the care continuum	RDR, RSR Client Report
Documenting demand for care	Service utilization rates, frequency of visits or other units of service, mix of services used	RDR, RSR (Client Report), MAI Report, ADAP Quarterly and Annual Report, CBDPP and DRP Dental Services Report
Unmet need for care	HIV seroprevalence rates, AIDS rates, enrollment in health insurance or other insurance coverage, rates of HIV-positive jail and prison inmates	RDR, RSR (Client Report)

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6. Conclusion

HRSA/HAB collects data to adhere to Federal reporting requirements and to ensure accountability and delivery of high-quality clinical and support services. Quality data improve health utilization, enable program evaluation, ensure grantee effectiveness and, ultimately, improve the health and well-being of people living with HIV/AIDS. These data, along with the results of administrative decision making, permit HRSA/HAB to fulfill the core public health functions of assessment, policy development, and assurance for delivering care and treatment services to those people living with HIV/AIDS in the United States.

Data collection allows HRSA/HAB to monitor and describe the use of funds and ensure provider adherence to grante requirements. It enables HRSA/HAB to assess the impact of services in terms of breadth, reach, and health outcomes. In the process, the data are used to communicate with public health authorities regarding which program components and providers are having the greatest impact and where improvements can be made.

Ryan White HIV/AIDS Program data are used across public health practice to deal with clinical and support service issues, improve education, identify—and reduce—risk factors and health disparities, and share best practices to ensure an ever-more strategic and successful approach to treating people living with HIV/AIDS. By improving data collection, the Program can better track performance measure guidelines, address severity of need, and report back to Congress—and the American public—the Program's health results and effectiveness in meeting its charge.

The Ryan White HIV/AIDS Program has been delivering care for more than 20 years. Over that time, improving care and treatment services has meant reporting the Program's public health results so that funding dollars can be efficiently used and services can be effectively targeted.

The Ryan White HIV/AIDS Program is the largest HIV/AIDS-specific program in the United States. Improved data collection ensures that HRSA/HAB can continue this legacy as a public health provider. Implementing data tracking services and producing data reports assist in continued advances and improvements in Program efforts to address HIV. And improving Program efficacy ensures that the continuum of care that exists today for so many people living with HIV/AIDS not only will be here tomorrow but will be better and stronger than ever.

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Acronyms and Glossary

ACRONYMS

A&E	Allocation and Expenditure Report
ADAP	AIDS Drug Assistance Program
AETC	AIDS Education and Training Center
AIDS	Acquired immunodeficiency syndrome
APA	AIDS Pharmaceutical Assistance Program
AQR	ADAP Quarterly Report
CARE	Comprehensive AIDS Resources Emergency Act
CBDPP	Community-Based Dental Partnership Program
CBO	Community-Based Organization
CFR	Code of Federal Regulations
CQM	Clinical Quality Management
DRP	Dental Reimbursement Program
EHB	Electronic handbook
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
ER	Event Record
FFR	Federal Financial Report
FPL	Federal Poverty Level
FY	Fiscal year
GPRA	Government Performance and Results Act
HAART	Highly active antiretroviral therapy
HAB	HIV/AIDS Bureau
HHS	Department of Health and Human Services
HIP	Health Insurance Program
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human immunodeficiency virus
HRSA	Health Resources and Services Administration
MAI	Minority AIDS Initiative
OMB	Office of Management and Budget
PART	Performance and Assessment Rating Tool
PCP	Pneumocystis carinii pneumonia
PHI	Protected health information
PHS	Public Health Service
PIF	Participant information form
PLWHA	Person living with HIV/AIDS
PL	Public Law
QIP	Quality improvement project
QM	Quality Management
RDR	Ryan White HIV/AIDS Program Annual Data Report
RSR	Ryan White HIV/AIDS Program Services Report
SCSN	Statewide Coordinated Statement of Need
SPNS	Special Project of National Significance
TA	Technical assistance
TB	Tuberculosis
TGA	Transitional Grant Area
UCI	Unique client identifier
XML	Extensible Markup Language

GLOSSARY

Term	Definition	Source*
Access	The ability to obtain appropriate health care services. Barriers to access can be financial (insufficient monetary resources), geographic (distance to providers), organizational (lack of available providers), or sociological (e.g., discrimination, language barriers). Efforts to improve access often focus on providing/improving health coverage.	AcademyHealth, Health Services Research Methods Web site.
ADAP earmark	The amount of Federal Ryan White HIV/AIDS Program, Part B funds specifically designated by Congress through the annual appropriations process to ADAP for the Federal fiscal year.	NASTAD, *ADAP Glossary: Definitions and Acronyms*.
ADAP flexibility policy	Policy providing grantees greater flexibility in the use of ADAP funds and permitting expenditures of up to 50 percent of ADAP funds for services that improve access to medications, increase adherence to medication regimens, and help clients monitor their progress in taking HIV-related medications. Grantees must submit to HRSA a written request to use ADAP dollars for services other than medications.	NASTAD, *ADAP Glossary: Definitions and Acronyms*.
Administrative data	Computerized records that are gathered for an administrative purpose but contain information that can be used for other purposes.	Billings, *Using Administrative Data To Monitor Access, Identify Disparities, and Assess Performance of the Safety Net*.
Affected family member	A family member or partner of an infected client who receives at least one Ryan White HIV/AIDS Program support service during the reporting period.	HRSA, 2009 Ryan White Data Report Instruction Manual.
Aggregate data	Combined data, composed of multiple elements, often from multiple sources. For example, combining demographic data about clients from all primary care providers in a service area generates aggregate data about client characteristics.	HRSA, 2009 Ryan White Data Report Instruction Manual.
Benchmarking	The process of setting organizational goals and measures in comparison to those of other organizations or products. Most often, comparison is made to products, services, and practices recognized as leaders in the field or industry. The benchmarking process is a quality assurance effort designed to identify best practices that will lead to improvements in products and services.	AcademyHealth, Health Services Research Methods Web site.
Capped enrollment	A limit on the maximum number of people who can be enrolled in an ADAP at any given time.	ADAP Quarterly Report.
Capacity	The amount of services a provider can deliver (i.e., the number of service units and the estimated number of clients who can be served).	Centers for Disease Control and Prevention (CDC) and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Client Report	The RSR Client Report (client-level data) collects one record for each Ryan White HIV/AIDS Program client served. Each record includes the client's encrypted unique identifier and basic demographic data. A client's record may also include HIV clinical information and data about the HIV-care medical and support services received at the service provider. This report is completed by all service providers that deliver and/or pay for direct client services with Ryan White HIV/AIDS Program funds.	HRSA, *Ryan White HIV/AIDS Program Services Report Instructional Manual v2.1*. (RSR Instruction Manual 2.1)

*Complete references are provided in the reference list.

GLOSSARY (cont'd)

Term	Definition	Source
Comprehensive planning	A process to determine how HIV services will be organized and delivered. Comprehensive planning requires Planning Councils and consortia to answer the following questions: (1) Where are we now? (2) Where should we be going? (3) How will we get there? (4) How will we monitor our progress?	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Confidential information	Client information, such as name, gender, age, and HIV status, whose unauthorized disclosure could cause the client unwelcome exposure, discrimination, or abuse.	HRSA, *RSR Instruction Manual v2.1*.
Consortium/ HIV Care Consortium	An association of one or more public and one or more nonprofit private, health care, and support service providers, people with HIV/AIDS, and community-based organizations operating within areas determined by the State to be most affected by HIV disease. The consortium agrees to use Part B grant assistance to plan, develop, and deliver (directly or through agreement with others) comprehensive outpatient health and support services for people with HIV disease. Agencies constituting the consortium are required to have a record of service to populations and subpopulations with HIV/AIDS.	HRSA, *RSR Instruction Manual v2.1*.
Continuum of care	An approach that helps communities plan for and provide a full range of emergency and long-term service resources to address the various needs of PLWHA.	HRSA, *RSR Instruction Manual v2.1*.
Core medical services	A set of essential, direct health care services provided to people living with HIV/AIDS, as first defined in the Ryan White HIV/AIDS Treatment Modernization Act of 2006.	HRSA, *RSR Instruction Manual v2.1*.
Data	Factual information (such as measurements or statistics) used as a basis for reasoning, discussion, or calculation	National Institutes of Health, Medline Plus.
Data collection	Systematic gathering of data for a particular purpose from various sources, including questionnaires, interviews, observation, existing records, and electronic devices. The process is usually preliminary to statistical data analysis.	University of Chicago Library, *Health Statistics: Glossary of Statistical Terms*.
Demographic data	Statistical characteristics of human populations. Commonly used demographics include race, age, income, disabilities, mobility (e.g., travel time to work, number of vehicles available), educational attainment, and employment status.	Merriam-Webster Online.
Disparities	Persistent gaps between the health status of minorities and non-minorities in the United States.	HHS National Partnership for Action to End Health Disparities.
Effectiveness	The effect of a treatment in a "real" clinical practice setting. Effects or outcomes may be measured in terms of quality-adjusted life years, cases of disease (symptoms) prevented, or years of life saved.	AcademyHealth, Health Services Research Methods Web site.
Eligible Metropolitan Area (EMA)	The geographic area eligible to receive Part A Ryan White HIV/AIDS Program funds. The boundaries of the EMA/TGA are defined by the Census Bureau. Eligibility is determined by AIDS cases reported to the CDC. Some EMAs include just one city, and others are composed of several cities and/or counties. Some EMAs extend across more than one State.	HRSA, *RSR Instruction Manual v2.1*.

GLOSSARY (cont'd)

Term	**Definition**	**Source**
Emerging communities	Jurisdictions reporting between 500 and 999 cumulative reported living AIDS cases over the most recent 5 years.	HRSA, *Part B: Grants to States and Territories*.
Epidemiologic profile	A document that describes the HIV/AIDS epidemic in various populations and identifies characteristics of both HIV-positive and HIV-negative persons in defined geographic areas. It is composed of information gathered to describe the effects of HIV/AIDS on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. The epidemiologic profile serves as the scientific basis from which HIV prevention and care needs are identified and prioritized for a jurisdiction.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Epidemiology	The study of the distribution and determinants of health-related States or events in specified populations and the application of this study to the control of health problems.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Estimate	A value generated when precise data are not available. An estimate may be made on the basis of available data and an understanding of how the data can be generalized to larger populations. In some instances, national or State data may be statistically adjusted to estimate local conditions. Good estimates are accompanied by statistical estimates of error (a confidence interval), which describe the limitations of the estimate.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Expenditure cap	The maximum amount of dollars that can be spent by an ADAP, usually per client.	ADAP Quarterly Report.
Federal Poverty Level	The amount of income determined by HHS to provide a bare minimum for food, clothing, transportation, shelter, and other necessities. FPL is reported annually and varies according to family size. Public assistance programs usually define income limits in relation to the FPL.	AcademyHealth, Health Services Research Methods Web site.
Formulary	A drug list that establishes the number of drugs available within a therapeutic class for purposes of drug purchasing, dispensing, and reimbursement.	NASTAD, *ADAP Glossary: Definitions and Acronyms.*
Gender	The socially and psychologically constructed, understood, and interpreted set of characteristics that describe the current self-reported sexual identity of a person. Gender categories include male (a person with strong and persistent identification with the male sex), female (a person with strong and persistent identification with the female sex), and transgender (a person whose gender identity is not congruent with his or her biological sex, regardless of the status of surgical and hormonal sex reassignment processes). "Transgender" refers to a continuum of gender expressions, identities, and roles that expand the current dominant cultural values of what it means to be male or female.	HRSA, *RSR Instruction Manual v2.1.*
Geographic information systems	Integrated hardware, software, and data for capturing, managing, analyzing, and displaying all forms of geographically referenced information.	ESRI, *Guide to Geographic Information Systems*.

GLOSSARY (cont'd)

Term	Definition	Source
Grantee of record	The grantee of record is the official Ryan White HIV/AIDS Program grantee that receives Federal funding directly from HRSA. This agency may be the same provider agency or may be the agency that contracts with other agencies to provide Program services.	HRSA, *RSR Instruction Manual v2.1*.
Grantee Report	The collection of basic information about the grantee organization and the service provider contracts that it funded during the reporting period. It is completed by all Ryan White HIV/AIDS Program Part A, Part B, Part C, Part D (including the Adolescent Initiative), and Part F (MAI) grantees.	HRSA, *RSR Instruction Manual v2.1*.
Health insurance program	A program of financial assistance for eligible people living with HIV to enable them to maintain continuity of health insurance or to receive medical benefits under a health insurance program. It includes premium payments, risk pools, co-payments, and deductibles.	HRSA, *RSR Instruction Manual v2.1*.
High-risk insurance pool	A State health insurance program that provides coverage for people who are denied coverage as a result of a preexisting condition or who have health conditions that would normally prevent them from purchasing coverage in the private market.	HRSA, *RSR Instruction Manual v2.1*.
Highly active anti-retroviral therapy	An aggressive anti-HIV treatment that involves a combination of three or more drugs whose purpose is to reduce HIV viral load to undetectable levels.	HRSA, *RSR Instruction Manual v2.1*.
Hispanic	A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be synonymous with "Hispanic or Latino."	HRSA, *RSR Instruction Manual v2.1*.
HIV risk factor or risk behavior/ exposure category	Behavior or another factor that places a person at risk for disease. For HIV/ AIDS, risk factors include male-to-male sexual contact, injection drug use, and commercial sex work.	HRSA, *RSR Instruction Manual v2.1*.
Longitudinal data	A data set is longitudinal if it tracks the same type of information on the same subjects at multiple points in time.	National Center for Analysis of Longitudinal Data in Education Research.
Mean	A measure of central tendency in a set of data commonly referred as the "average." The arithmetic mean is derived by summing all values then dividing by the number of observations.	AcademyHealth, Health Services Research Methods Web site.
Median	The value halfway through an ordered data set, below which 50 percent of the scores fall; a good measure of central tendency that works well with skewed (non-normal) data.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.

GLOSSARY (cont'd)

Term	Definition	Source
Needs assessment	The process of gathering and analyzing information from a variety of sources to determine the current status and the unmet needs for HIV prevention or care among a defined population or in a geographic area.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Outcome	A change in individuals, populations, or organizations attributed to (or associated with) independent variables not predetermined by the investigator.	AcademyHealth, Health Services Research Methods Web site.
Output	Measures of the direct products or volume of program operations, such as the number of service units that a program delivers; primary care examples include the number of clients served, CD4 and viral load tests completed, and specialty care consultations provided.	HRSA, *Outcomes Evaluation Technical Assistance Guide*.
Performance measures	Methods or instruments to estimate or monitor the extent to which the actions of a health care practitioner or provider conform to practice guidelines, medical review criteria, or standards of quality.	AcademyHealth, Health Services Research Methods Web site.
Planning Council	Takes the lead in conducting many of its legislated responsibilities and shares duties with the grantee in some areas. Planning Councils are responsible for establishing operations to make planning tasks function smoothly, assessing the EMA's/TGA's HIV/AIDS service needs and gaps, establishing priorities for the allocation of funds, and developing a comprehensive plan for the organization and delivery of HIV services that is compatible with existing State and local plans.	HRSA, *Ryan White Part A: Planning Council Primer.*
Program income	Program income is gross income earned by a recipient, subrecipient, or a contractor under a grant that is directly generated by the grant-supported activity or earned as a result of the award. Program income includes income from fees for services performed (e.g., direct payment, or reimbursements received from Medicaid, Medicare, and third-party insurance) and income a recipient or subrecipient earns as the result of a benefit made possible by receipt of a grant or grant funds (e.g., income as a result of drug sales when a recipient is eligible to buy the drugs because it has received a Federal grant).	HIV Emergency Relief Project Grants Part A.
Provider type	Provider types include hospital or university-based clinics, publicly funded community health center, publicly funded community mental health center, other CBO, health department, substance abuse treatment center, solo/group private medical practice, agency reporting for multiple fee-for-service providers (e.g., State operating a reimbursement pool), person living with HIV/AIDS coalition, or a facility funded through the U.S. Department of Veterans Affairs. Grantees are asked to select the provider type that best describes their agency; if a grantee selects "other facility," it must provide a description.	HRSA, *RSR Instruction Manual v2.1*.
Psychosocial support services	The provision of support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. Includes nutrition counseling provided by a nonregistered dietitian but excludes the provision of nutritional supplements.	HRSA, *2009 Ryan White Data Report Instruction Manual*.

GLOSSARY (cont'd)

Term	Definition	Source
Qualitative data	Information from sources such as narrative behavior studies, focus group interviews, open-ended interviews, direct observations, ethnographic studies, and documents. Findings from these sources are usually described in terms of common themes and patterns of response rather than by numeric or statistical analysis. Qualitative data often complement and help explain quantitative data.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Quality	The degree to which a health or social service meets or exceeds established professional standards and user expectations. Evaluations of the quality of care must consider the quality of inputs, service delivery process, and outcomes, to continuously improve systems of care for individuals and populations.	HAB program guidance.
Quantitative data	Numeric information (e.g., numbers, rates, percentages).	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Race	Defined according to the OMB reporting standards for race and ethnicity. OMB's *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* provides a minimum standard for maintaining, collecting, and presenting data on race and ethnicity for all Federal reporting purposes. HAB is required to use the OMB reporting standards. The standards were developed to provide a common language for uniformity and comparability in the collection and use of data on race and ethnicity by Federal agencies. The standards have five categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There are two categories for data on ethnicity: "Hispanic or Latino," and "Not Hispanic or Latino." The racial category descriptions, defined in October 1997, are required for all Federal reporting.	HRSA, *RSR Instruction Manual v2.1*.
Range	The largest and smallest values in a data set.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Rate	A measure of the frequency of an event or a disease compared with the number or persons at risk for the event or disease.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.

GLOSSARY (cont'd)

Term	Definition	Source
Reporting scope	For the RDR, Scope 01 is the reporting scope for providers reporting eligible services. Under the ELIGIBLE reporting scope, clients receiving any service eligible for Ryan White Parts A, B, C, D, or F (MAI) funding are included in the report even if the service was not paid for with Ryan White Parts A, B, C, D, or F (MAI) funds. This reporting scope is preferred by HRSA. Scope 02 is the reporting scope for providers reporting funded clients. Under the FUNDED scope, only clients receiving services paid for exclusively with Ryan White A, B, C, D, or F (MAI) funds are included in the report. Providers using the funded-only reporting scope must have an adequate mechanism for tracking clients and services by funding stream and have secured prior approval from their grantee in consultation with HRSA.	HRSA, *2009 Ryan White Data Report Instruction Manual.*
Service gap	The identified unfulfilled need for HIV/AIDS-related services other than primary medical care among people who know their HIV status in a specified geographic area—a term used to avoid confusion with the HAB definition of "unmet need" as referring specifically to primary medical care.	HRSA, *Using Data, Assessing Needs: Quick Definitions and Descriptions for Data-Related Terms and Concepts Used by Ryan White Part A Planning Councils*.
Service provider	The agency that provides direct services to clients and their families and/or grantees of record (e.g., agencies that provide administrative and technical services). Service providers may be directly funded through one or more program Parts, through subcontract(s) with one or more grantee; or through subcontract(s) with a grantee's fiscal intermediary (an administrative agent of the grantee).	HRSA, *RSR Instruction Manual v2.1*.
Service Provider Report	The RSR Service Provider Report collects basic information about both the service provider agency and the services it delivered under each of its Ryan White HIV/AIDS Program contracts. This report is completed by all Ryan White HIV/AIDS Program (1) service providers directly serving clients and their affected family members, and (2) grantees of record (e.g., agencies that provide administrative and technical services). Service providers may be directly funded through one or more Parts through subcontracts with one or more grantees or through subcontracts with a grantee's fiscal intermediary (an administrative agent of the grantee).	HRSA, *RSR Instruction Manual v2.1*.
Small-area analysis	Method of analyzing the variation in utilization of health care in small geographic or demographic areas. It is often used to study, for example, the usage rates for a given service or procedure in several small areas, documenting the variation among them. By comparing high- and low-utilization areas, the analysis attempts to determine patterns and identify variables that are associated with and contribute to the variation.	University of Chicago, Health *Statistics Glossary of Statistical Terms*.
Sociodemographic factors	Background information about the population of interest (e.g., age, sex, race, educational status, income, geographic location). These factors are often thought of as explanatory because they help researchers make sense of the results of analyses.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.

GLOSSARY (cont'd)

Term	Definition	Source
Socioeconomic status	A measure of social and economic factors that helps describe a person's standing in society (e.g., income level in relation to the FPL, educational achievement, neighborhood of residence, home ownership).	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Statewide Coordinated Statement of Need (SCSN)	Provides a collaborative mechanism to identify and address significant care issues related to the needs of people living with HIV/AIDS, and to maximize coordination, integration, and effective linkages across the Ryan White HIV/AIDS Program Parts. In addition, the SCSN process is expected to result in a document that reflects the input and approval of all Ryan White HIV/AIDS Program Parts. The State Part B program is responsible for coordinating the SCSN, but all Parts and grantees are expected to participate.	HRSA, *Ryan White HIV/AIDS Program Part A Manual*.
Support Services	Support services are a set of services needed to achieve medical outcomes that affect the HIV-related clinical status of a person living with HIV/AIDS.	HRSA, *RSR Instruction Manual v2.1*.
Target	Measurable objectives stating the desired level of outcome achievement for a program (e.g.,"to have a perinatal transmission rate below X percent for women receiving ARV prophylaxis to prevent perinatal transmission").	HRSA, *Outcomes Evaluation Technical Assistance Guide*.
Transitional Grant Area (TGA)	Metropolitan areas with between 1,000 and 1,999 new cases of AIDS reported in the past 5 years and at least 1,500 cumulative living cases of AIDS as of the most recent calendar year. There are 34 TGAs.	HRSA, Ryan White Part A: Planning Council Primer.
Trend	A long-term movement or change may be presented as a line graph.	CDC and HRSA, *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning*.
Unique client identifier	A unique alphanumeric code that distinguishes one Ryan White client from all others and is the same for the client across all provider settings.	HRSA, *RSR Instruction Manual v2.1*.
Unmet need	Unmet need is the need for HIV-related health services by people with HIV who are aware of their HIV status and are not receiving regular primary health care.	Kahn, Janney, and Franks, *A Practical Guide to Measuring Unmet Need for HIV-Related Primary Medical Care*.
Waiting list	A list of people who are not receiving services but who will be served as openings become available. Waiting lists may be needed for several reasons, such as limited funding or a limit on the number of people already being served.	ADAP Quarterly Report.

References

Academy Health. *Health services research (HSR) methods*. n.d. Available at: www.hsrmethods.org/. Accessed March 12, 2010.

Billings J. *Using administrative data to monitor access, identify disparities, and assess performance of the safety net*. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality; n.d. Available at: www.ahrq.gov/data/safetynet/billings.htm. Accessed March 1, 2010.

Centers for Disease Control and Prevention and Health Resources and Services Administration. *Integrated guidelines for developing epidemiologic profiles: HIV Prevention and Ryan White CARE Act community planning*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2004. Available at: www.cdc.gov/hiv/topics/surveillance/resources/guidelines/epi-guideline/pdf/epi_guidelines.pdf. Accessed March 1, 2010.

ESRI. *The guide to geographic information systems*. What is GIS? n.d. Available at: www.gis.com/content/what-gis. Accessed March 1, 2010.

Government Performance Results Act of 1993. P. L. 103–62. Available at: www.whitehouse.gov/omb/mgmt-gpra_gplaw2m/#h1. Accessed February 25, 2010.

Health Insurance Portability and Accountability Act of 1996. P. L. 104–191. Available at: www.cms.hhs.gov/HIPAAGenInfo/Downloads/HIPAALaw.pdf. Accessed February 25, 2010.

Health Resources and Services Administration. *2008 State and Territory profiles*. 2009. Available at: http://hab.hrsa.gov/stateprofiles/. Accessed February 25, 2010.

Health Resources and Services Administration. *A living history. Funding levels: then and now*. n.d. Available at: www.hab.hrsa.gov/livinghistory/legislation/funding.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *AIDS Drug Assistance Program quarterly data report.* n.d. OMB No. 0915–0294. Available at: ftp://ftp.hrsa.gov/hab/2007%20ADAP%20PaperForm_Final%20_Feb%2022_08_.pdf.

Health Resources and Services Administration. *AIDS Education and Training Centers participant information form*. n.d. Available at: www.uic.edu/depts/matec/vsic/PIF01.PDF. Accessed February 25, 2010.

Health Resources and Services Administration. *Appendix A: HRSA grant application user guide*. Rockville, MD: Author; 2009. Available at: www.hrsa.gov/grants/Docs/UserGuide.pdf. Accessed March 1, 2010.

Health Resources and Services Administration. *HAB HIV core clinical performance measures for adults and adolescents: companion guide*. 2009. Available at: ftp://ftp.hrsa.gov/hab/habPMsGuide09.pdf. Accessed March 1, 2010.

Health Resources and Services Administration. *HAB performance measures*. n.d. Available at: http://hab.hrsa.gov/special/habmeasures.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *HIV/AIDS programs: program data. Services delivered and clients served*. n.d. Available at: http://hab.hrsa.gov/reports/data2a.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *HIV/AIDS programs: reporting requirements. Online data entry, forms, instruction, and technical assistance*. 2009. Available at: http://hab.hrsa.gov/tools.htm#RDR. Accessed February 25, 2010. [Includes information and links about the ADAP quarterly data report; the A&E, Dental Services, and Part A MAI reports; the RSR; the ADAP annual report; and the RDR.]

Health Resources and Services Administration. *HIV Early Intervention Services Program: competing continuation and new proposals for existing geographic service areas, program guidance*. 2010.

Health Resources and Services Administration. HIV Emergency Relief Project Grants Part A. HRSA Announcement No. HRSA–09–184. Available at: https://grants.hrsa.gov/webExternal/FundingOppDetails.asp?FundingCycleId=06D8FDFA-07EE-40AE-A5C3-913EDC1FA902&ViewMode=EU&GoBack=&PrintMode=Y&OnlineAvailabilityFlag=&pageNumber=&version=&NC=&Popup=. Accessed March 12, 2010.

Health Resources and Services Administration. *HRSA electronic handbook for applicants/grantee. Registration*. n.d. Available at: https://grants.hrsa.gov/webexternal/Registration.asp. Accessed March 1, 2010.

Health Resources and Services Administration. *Instructions for completing the 2009 Ryan White HIV/AIDS Program Annual Data Report*. Rockville, MD: HIV/AIDS Bureau, Division of Science and Policy, Health Resources and Services Administration; 2010. Available at: http://hab.hrsa.gov/rdr/2009RDRinstructions.pdf . Accessed March 1, 2010.

Health Resources and Services Administration. *Online performance appendix: fiscal year 2011*. 2010. Available at: www.hrsa.gov/about/budgetjustification/performanceappendix11.pdf. Accessed April 1, 2010.

Health Resources and Services Administration. *Outcomes evaluation technical assistance guide. Primary medical care outcomes: Titles I and II of the Ryan White CARE Act*. Rockville, MD: Author; 1999. Available at: http://hab.hrsa.gov/tools/outcomes.htm. Accessed March 1, 2010.

Health Resources and Services Administration. *Part B. States and territories*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/partb.htm. Accessed May 14, 2010.

Health Resources and Services Administration. *The power of connections: 2008 Ryan White HIV/AIDS Program progress report*. Rockville, MD: Author; 2008. Available at: http://hab.hrsa.gov/publications/progressreport08/2008ProgressReport.pdf. Accessed February 25, 2010.

Health Resources and Services Administration. *Protecting health information privacy and complying with Federal regulations. A resource guide for HIV services providers and the Health Resources and Services Administration's HIV/AIDS Bureau Staff*. Rockville, MD: Author; 2004. Available at: ftp://ftp.hrsa.gov/hab/hipaa04.pdf. Accessed February 25, 2010.

Health Resources and Services Administration. *Ryan White HIV/AIDS Program Part A manual*. Available at: http://hab.hrsa.gov/tools/parta/parta/ptAsec3chap2.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The Ryan White HIV/AIDS Program services report (RSR)*. 2009. Available at: http://hab.hrsa.gov/manage/CLD.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *Ryan White HIV/AIDS Program services report instructional manual version 2.1*. Rockville, MD: Author; n.d. Available at: http://hab.hrsa.gov/manage/RSRInstructionManual.pdf. Accessed March 1, 2010.

Health Resources and Services Administration. *Ryan White Part A: Planning Council primer*. Rockville, MD: Author; 2008. Available at: http://hab.hrsa.gov/tools/pcprimer2008.pdf. Accessed March 1, 2010.

Health Resources and Services Administration. *Ryan White Services Report data dictionary and XML schema implementation guide for the Client-Level Data Report, version 2.1*. Rockville, MD: Author; 2009. Available at: https://performance.hrsa.gov/hab/CLDXMLSchema/RSR%20Client-Level%20Data%20Dictionary.pdf. Accessed March 1, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program client level data*. n.d. Available at: http://hab.hrsa.gov/manage/CLD.htm. Accessed March 1, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Minority AIDS Initiative*. n.d. Available at: http://hab.hrsa.gov/treatmentmodernization/minority.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part A—grants to emerging metropolitan and transitional grant areas*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/parta.htm#1. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part B—grants to states and territories*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/partb.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part C—early intervention services*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/partc.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part D—services for women, infants, children, youth and their families*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/partd.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part F—dental programs*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/dental.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. Part F—education and training centers*. 2008. Available at: http://hab.hrsa.gov/treatmentmodernization/educating.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *The HIV/AIDS Program: Ryan White Parts A–F. SPNS—Special Projects of National Significance (Part F).* n.d. Available at: http://hab.hrsa.gov/treatmentmodernization/spns.htm. Accessed February 25, 2010.

Health Resources and Services Administration. *Using data, assessing needs: quick definitions and descriptions for data-related terms and concepts used by Ryan White Part A Planning Councils*. Rockville, MD: U.S. Department of Health and Human Services; 2007.

Kahn JG, Janney J, Franks PE. *A practical guide to measuring unmet need for HIV-related primary medical care: using the unmet need framework*. San Francisco: University of California Institute for Health Policy Studies; 2003. Available at: ftp://ftp.hrsa.gov/hab/unmetneedpracticalguide.pdf. Accessed March 1, 2010.

National Alliance of State and Territorial AIDS Directors. *ADAP glossary: definitions and acronyms*. Washington, DC: National Alliance of State and Territorial AIDS Directors; 2007. Available at: www.nastad.org/Docs/Public/Resource/2007918_ADAP%20Glossary_Final_Sept_2007.pdf. Accessed March 1, 2010.

National Center for Analysis of Longitudinal Data in Education Research. *What are longitudinal data?* Available at: www.caldercenter.org/. Accessed March 12, 2010.

National Institutes of Health. *Medline Plus*. Available at: www.caldercenter.org/longdata.cfm. Accessed March 12, 2010.

Public Health Service Act of 1994. 42 U.S.C. § 201 *et seq*. Available at: www.law.cornell.edu/uscode/html/uscode42/usc_sup_01_42_10_6A.html. Accessed February 25, 2010.

Ryan White HIV/AIDS Treatment Extension Act of 2009. P. L. 111–87. Available at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_public_laws&docid=f:publ087.111.pdf. Accessed February 25, 2010.

Ryan White HIV/AIDS Treatment Modernization Act of 2006. P. L. 109–41. Available at: ftp://ftp.hrsa.gov/hab/reauth06.pdf. Accessed February 25, 2010.

Social Security Administration. *Compilation of the Social Security laws*. 2010. Available at: www.socialsecurity.gov/OP_Home/ssact/ssact.htm. Accessed February 25, 2010.

University of Chicago Library. *Health statistics: glossary of statistical terms*. n.d. Available at: www.lib.uchicago.edu/e/su/med/healthstat/statglossary.html. Accessed March 12, 2010.

U.S. Department of Health and Human Services. *Health Insurance Portability and Accountability Act privacy rule: minimum necessary*. 45 CFR 164.502(b), 164.514(d). April 4, 2003. Available at: www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/minimumnecessary.pdf. Accessed February 25, 2010.

U.S. Department of Health and Human Services, National Partnership for Action to End Health Disparities. *Health disparities: What are health disparities?* 2010. Available at: http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=13. Accessed March 12, 2010.

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For more information
The Ryan White HIV/AIDS Program is administered by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau.

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