## **Instruction Manual for the Client Demonstration Project**

OMB # 0915-0275 Through 12/31/2004

HIV/AIDS Bureau Office of Science and Epidemiology Health Resources and Services Administration 5600 Fishers Lane, Room 7-90 Rockville, MD 20857

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#### **CDP PROVIDER- AND CLIENT-LEVEL FORMS**

A data file consisting of all the information contained in the Client Demonstration Project (CDP) forms shall be submitted by all grantees and contractors/sub-contractors who are recipients of Title III and/or Title IV funding. There are two separate forms, a Provider-Level form and a Client-Level form. Likewise, two data files shall be submitted to the HIV/AIDS Bureau (HAB), one consisting of all provider-level data elements and a client-level file consisting of all unduplicated client records.

Grantees are required to submit the Provider-Level data quarterly, along with the Client-Level data. Much of the information is static, needing only to be filled out once a year. Some of the information should only be filled out at the end of the year, including HIV Counseling Information and Title III Funding Information.

The Client-Level form is completed, for each client. Data for the client-level form is submitted to HAB on a quarterly basis. Each submission is cumulative, so in April, only one quarter of data is submitted. In July, an updated file is sent that includes information and updates from January-June. The submission process continues so in October, the file includes information from January - September, and at the end of January, the file containing all information for the entire previous year is submitted. Many items only need to be updated once a year. (For instance, if a woman has a pap smear in February, her record is updated to yes, pap smear, and that question remains a yes, for the rest of the year.) There are a limited number of variables including the following: service visits, referrals, CD4 counts, and viral load results that must be answered and updated each quarter. As mentioned above, it is expected that the remaining data elements are filled out as the information is obtained or changes throughout the year. Data are collected on a quarterly basis so that any data quality problems can be quickly identified and corrected before the end of the year.

#### **Reporting Periods**

The reporting periods for the Client-Level data include the following:

- ✤ Quarter 1 January 1 through March 31;
- ✤ Quarter 2 April 1 through June 30;

- Quarter 3 July 1 through September 30; and
- ✤ Quarter 4 October 1 through December 31.

#### Grantees are required to submit their data to HAB/HRSA one month after the end of the quarter, for the preceding quarter.

Data submission are expected to arrive at HRSA by the following dates:

- Quarter 1 April  $30^{\text{th}}$
- Quarter 2 July  $30^{\text{th}}$
- Quarter 3 October  $30^{\text{th}}$
- ✤ Quarter 4 January 30<sup>th</sup>

#### **GENERAL INSTRUCTIONS**

While completing the CDP forms, keep in mind the following:

- For close-ended questions (i.e. where checkboxes are provided for your response), provide only *one* response, unless instructed otherwise.
- All close-ended questions require a response, unless a skip is invoked during a series of questions.
- Leave open-ended questions (e.g. dates, counts etc.) blank if the information is not available, unless instructed to fill in a "zero."
- Before submitting data to HRSA, remember to update all questions, as necessary, and to answer all quarterly variables.

#### **PROVIDER-LEVEL FORM**

#### 1. Provider name

Give the name of the agency/service provider for whom this data report is being completed.

*Provider agency/service provider* is the agency that provides direct services to clients (and their families) that are funded by the Ryan White CARE Act. Services may be funded through one or more Federal Ryan White CARE Act grants or through subcontract(s) with official Ryan White CARE Act grantees. A provider may also be a grantee, such as in Titles III and IV.

Questions 2 through 3e refer to the provider agency listed in Question 1.

#### 2. Provider address

#### a. Street

Enter the street address of the provider listed in Question 1 (where service is provided).

#### b. City

Enter the city of the provider listed in Question 1.

#### c. State

Enter the state of the provider listed in Question 1.

#### d. ZIP code

Enter the five-digit ZIP code of the provider listed in Question 1.

#### e. Provider ID #

Report the unique 4-digit provider ID number.

#### f. Taxpayer ID #

Give the unique 9-digit taxpayer ID number of the provider agency. This number has been given to the agency by the Internal Revenue Service and is a taxpayer identifying number issued to an organization or agency, upon application, for use in connection with filing requirements.

#### 3. Contact information

#### a. Name

Enter the name of the contact person at the provider agency listed in Question 1 who is responsible for completing the data in this report.

#### b. Title

Enter the title of the person listed in Question 3a.

#### c. Phone number

Enter the telephone number, including the area code, of the person listed in Question 3a.

#### d. Fax number

Enter the fax number, including the area code, of the person listed in Question 3a.

#### e. Email address

Enter the email address of the person listed in Question 3a.

#### 4. Person completing this form

#### a. Name

Enter the name of the person at the agency (as defined in Question 1) who is completing this form.

#### b. Phone number

Enter the telephone number, including the area code, of the person listed in Question 4a.

#### c. Email address

Enter the email address of the person listed in Question 4a.

#### 5. Calendar Year for Reporting

Enter the start and end dates of the reporting period for the provider agency. The dates should be January 1-December 31<sup>st</sup> of the current year, unless the agency began receiving CARE Act funding after January 1.

#### 6. Reporting scope

Indicate the reporting scope for the collection of the data in this report using the predetermined response codes listed below. Select only one response code.

*Reporting Scope 1:* ALL clients receiving a service ELIGIBLE for Title I, II, III, or IV funding.

*Explanation:* Reporting scope for providers reporting ELIGIBLE services. Data are based on all services that are eligible for funding from Ryan White Title I, II, III, or IV.

Under the ELIGIBLE reporting scope, clients receiving any service eligible for Ryan White Title I, II, III, or IV funding are included in the report even if the service was not paid for with Ryan White Title I, II, III, or IV funds. <u>This</u> reporting scope is preferred by HRSA.

*Reporting Scope 2:* ONLY clients receiving a Title I, II, III, or IV FUNDED service.

*Explanation:* Reporting scope for providers reporting FUNDED clients. Data are based on clients for whom services are paid for by Ryan White Title I, II, III, or IV funding.

Under the FUNDED scope, only clients receiving services paid for exclusively with Ryan White Title I, II, III, or IV funds are included in the report. Typically, this is a subset of the eligible reporting scope. Providers using the funded-only reporting scope must:

- Have an adequate mechanism for tracking clients and services by funding stream;
- Have secured prior approval from their grantee in consultation with HRSA; and
- Report actual numbers of clients and services.

#### 7. Provider type

Using the provider types listed below, select the type of provider that best describes the agency completing this data report. *Select only one choice.* 

#### **Provider types:**

*Hospital or university-based clinic* includes ambulatory/outpatient care departments or clinics, emergency rooms, rehabilitation facilities (physical, occupational, speech), hospice programs, substance abuse treatment programs, STD clinics, AIDS clinics, and inpatient case management service programs.

*Publicly funded community health center* includes community health centers, migrant health centers, rural health centers, and homeless health centers.

### *Publicly funded community mental health center* is self-explanatory.

*Other community-based service organization (CBO)* includes non-hospital-based organizations, AIDS service and volunteer organizations, private nonprofit social service and mental health organizations, hospice programs (home and residential), home health care agencies, rehabilitation programs, substance abuse treatment programs, case management agencies, and mental health care providers.

*Health department* includes State or local health departments.

- Substance abuse treatment center is an agency that focuses on the delivery of substance abuse treatment services.
- *Solo/group private medical practice* includes all health and health-related private practitioners and practice groups.
- Agency reporting for multiple fee-for-service providers is an agency that reports data for more than one fee-for-service provider (e.g., State operating a reimbursement pool).
- *PLWHA coalition* includes organizations of People Living with HIV/AIDS that provide support services to individuals and families affected by HIV and AIDS.
- *VA facility* is a facility funded through the Veterans Administration.
- *Other facility* includes facilities other than those listed above.

8. Did you receive funding under Section 330 of Public Health Service Act (funds community health centers, migrant health centers, and health care for the homeless) during this reporting period?

Indicate whether you received funding under Section 330 of the Public Health Service Act (PHSA) during the reporting period. Section 330 is a section of the PHSA that funds community health centers, migrant health centers, and health care for the homeless programs. *Provide a response to this question only if you have identified the provider type in #7 as "Publicly funded community health center."* 

Section 330 of PHSA supports the development and operation of community health centers, migrant health centers, and health care for the homeless that provide preventive and primary health care services, supplemental health and support services, and environmental health services to medically underserved areas/populations.

#### 9. Ownership status

Using the categories defined below, check the box next to the description that best describes the provider's status of incorporation.

#### **Types of ownership status:**

*Public/local* means that the organization is funded by a local government entity and is operated by local government employees. Local health departments are examples of local publicly owned organizations.

*Public/state* means that the organization is funded by a State government entity and is operated by State government employees. A State health department is an example of a State publicly owned organization.

*Public/Federal* means that the organization is funded by the Federal government and is operated by Federal government employees. A Federal agency is an example of a Federal publicly owned organization.

*Private, nonprofit (not faith-based)* means that the organization is owned and operated by a private, not-for-profit, non-religious-based entity, such as a nonprofit health clinic.

*Private, for-profit* means that the organization is owned and operated by a private entity, even though the organization may receive government funding. A privately owned hospital is an example of a private, for-profit organization.

*Unincorporated* means that an agency is not incorporated.

*Faith-based organization* means that the organization is owned and operated by a religiously affiliated entity, such as a Catholic hospital.

*Other* means an agency is owned by someone other than those listed above.

#### 10. Source of Ryan White CARE Act funding

Check the provider agency's source(s) of funding under Ryan White CARE Act Titles I, II, III, or IV. *Check all that apply*.

This item includes funding that is received directly from the Federal government (grantee), through a subcontract with a CARE Act grantee (service provider), or through Title II funding to a Consortium.

*Title I* is the part of the Ryan White CARE Act that provides direct financial assistance to designated EMAs that have been the most severely affected by the HIV epidemic. The purpose of these funds is to deliver or enhance HIV-related (1) outpatient and ambulatory health and support services, including case management and comprehensive treatment services for individuals with HIV disease and families; and (2) inpatient case management services that prevent unnecessary hospitalization or that expedite discharge, when medically appropriate, from inpatient facilities.

*Title II* is the part of the Ryan White CARE Act that authorizes the distribution of Federal funds to States and Territories to improve the quality, availability, and organization of health care and support services for individuals with HIV disease and their families. The CARE Act emphasizes that such care and support be part of a continuum of care in which all the needs of individuals with HIV disease and their families are coordinated. The funds are distributed among States and Territories based, in part, on the number of AIDS cases in each State (or Territory) as a proportion of the number of AIDS cases reported in the entire United States.

*Title III* is the part of the Ryan White CARE Act that provides support for early intervention services, including preventive, diagnostic, and therapeutic services for HIV/AIDS clients. This specifically includes a continuum of comprehensive primary health care, referrals for specialty care, counseling and testing, outreach, and case management and eligibility assistance.

*Title IV* is the part of the Ryan White CARE Act that supports coordinated services and access to research for children, youth, and women with HIV disease and their affected family members.

*Title IV Adolescent Initiative* is part of the Title IV program aimed at identifying adolescents who are HIV positive and enrolling them in care.

### 11. Indicate the amount of funding received during this reporting period for ALL the following categories:

Indicate the total dollar amount received by the provider agency during the reporting period. *If no funds were received, report "zero" in the space provided.* 

#### a. Title I

Indicate the total dollar amount of Title I (EMA) funds received by the provider agency during the reporting period. This amount does not necessarily reflect how much of the Title I funds were expended by your organization.

#### b. Title II

Indicate the total dollar amount of Title II (State/Consortium) funds received during the reporting period. This amount does not necessarily reflect how much of the Title II funds were expended by your organization.

#### c. Title III

Indicate the total dollar amount of Title III funds received during the reporting period. This amount does not necessarily reflect how much of the Title III funds were expended by your organization.

#### d. Title IV

Indicate the total dollar amount of Title IV funds received during the reporting period. This amount does not necessarily reflect how much of the Title IV funds were expended by your organization.

### 12. Indicate the amount of Title I, II, III, or IV Ryan White CARE Act funds EXPENDED on oral health care:

Indicate the total dollar amount expended on oral health care by the provider agency during the reporting period. Unlike the previous question, only the funds actually spent on oral health care should be recorded here. *If no funds were expended, report "zero" in the space.* 

### 13. During this reporting period, did you provide the grantee with support in any of the following areas?

For each of the six services listed, indicate whether the service was provided to the grantee of record by the provider agency by checking "Yes" or "No."

*Planning or evaluation* is the systematic (orderly) collection of information about the characteristics, activities, and outcomes of services or programs to assess the extent to which objectives have been achieved, identify needed improvements, and/or make decisions about future programming.

Administrative or technical support is the provision of qualitative and responsive "support services" to an organization. Services may include human resources, financial management and administrative services (e.g., property management, warehousing, printing/ publications, libraries, claims, medical supplies, and conference/training facilities).

*Fiscal intermediary services* include reimbursements received or collected on behalf of health care professionals for services rendered or other related fiduciary services pursuant to health care professional contracts.

*Technical assistance* or TA is the identification of need for and delivery of practical program and technical support to the CARE Act community. TA should assist grantees, planning bodies, and affected communities in designing, implementing, and evaluating CARE Act-supported planning and primary care service delivery systems.

*Capacity development* is a set of core competencies that contribute to an organization's ability to develop effective HIV health care services, including the quality, quantity, and cost effectiveness of such services. These competencies also sustain the infrastructure and resource base necessary to develop and support these services. Core competencies include: management of program finances; conducting effective HIV service delivery, including quality assurance; personnel management and board development; resource development, including preparation of grant applications to obtain resources and purchase of supplies/equipment; conducting service evaluation; and cultural competency development.

Quality management is a continuous process to improve the degree to which a health or social service meets or exceeds established professional standards and user expectations. The purpose of a quality management program is to ensure that (a) services adhere to PHS guidelines and established clinical practice; (b) program improvements include supportive services; (c) supportive services are linked to access and adherence to medical care; and (d) demographic, clinical and utilization data are used to evaluate and address characteristics of the local epidemic. It is a systematic process with identified leadership, accountability, and dedicated resources, and uses data and measurable outcomes to determine progress toward relevant, evidence-based benchmarks. It also focuses on linkages, efficiencies, and provider and clie nt expectations in addressing outcome improvement. This is a continuous process that is adaptive to change and that fits within the framework of other programmatic quality assurance and quality improvement (QI) activities (e.g., JCAHO, Medicaid, and other HRSA programs). Data collected are used to feed back into the process to assure that goals are accomplished and are concurrent with improved outcomes.

#### 14. Did you administer an AIDS Drug Assistance Program (ADAP) or local pharmaceutical assistance program that provides HIV/AIDS medication to clients during this reporting period?

Indicate whether the provider agency administered an ADAP or APA program during the reporting period. *If your response is "No" skip to Question #13.* 

ADAP is typically a centrally administered program operated at the State level that receives both Ryan White CARE Act Title II ADAP-earmarked and Title II base funds. Other AIDS pharmaceutical assistance programs typically operate at the local EMA or consortia level Funds for these programs may come from a variety of sources that are not federally earmarked for AIDS medications. These may include Title I and private sources.

ADAP, AIDS Drug Assistance Program, is a Stateadministered program authorized under Title II of the CARE Act that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid.

APA, AIDS pharmaceutical assistance program is a local pharmacy assistance program implemented by a Title I EMA or Title II State. The Title II grantee consortium or Title I planning council contracts with one or more organizations to provide HIV/AIDS medications to clients. These organizations may or may not provide other services (e.g., primary care, case management) to the patients or clients that they serve through a Ryan White (or other funding sources) contract with their grantee.

Programs are considered a local APA if they provide HIV/AIDS medications to clients and meet *all* of the criteria listed below:

- Have a client enrollment process;
- Have uniform benefits for all enrolled clients;
- Have a record system for distributed medications; and
- Have a drug distribution system.

Programs are *not* local APAs if they dispense medications in one of the following situations:

- Medications are dispensed to a client as a result or as a component of a primary medical visit;
- Medications are dispensed to a client on an emergency basis (an emergency basis is defined as a single occurrence of short duration); or
- Money or cash vouchers are given to a client to procure medications.

#### a. Type of program administered

If your agency administers an ADAP or other APA program, specify the program type:

- State ADAP or
- Local pharmaceutical assistance program.

### 15. Did you provide a Health Insurance Program (HIP) during this reporting period?

Indicate whether your agency provided health insurance through HIP (with Ryan White CARE Act funds) during the reporting period.

*HIP* is a program that makes premium payments, copayments, deductibles, or risk pool payments on behalf of a client to keep his or her private health insurance active.

## 16. Indicate which of the following populations were especially targeted for outreach or services during this reporting period.

Check the box next to each population group that the program specially targeted (set as a goal to achieve and directly allocated funds to support) for outreach efforts or service delivery in the reporting period. The program caseload of clients who are HIV positive may not be entirely representative of the target populations indicated. *Check all boxes that apply to your agency. If other populations that are not listed here were targeted, check "Other.*"

*Target population* is a population to be reached through some action or intervention; may refer to groups with specific demographic or geographic characteristics.

#### If other specify

Report other type of population group, if "Other" was selected as a response in the preceding question.

### 17. Which of the following categories describes your agency? An agency in which ...

Check *ALL* categories that describe your agency.

"Other" may be chosen only if none of the other categories describe your agency.

### 18. Total paid staff, in FTEs, funded by any Title of the CARE Act:

Report the number of paid staff, in full-time equivalencies (FTEs), that were funded by the CARE Act during this reporting period. *Enter a "zero" if there are no paid staff to report.* 

#### How to calculate FTEs:

*Step One:* Count each staff member who works fulltime (at least 35–40 hours per week) on HIV/AIDS care as one FTE. Full-time employees who regularly work overtime should not be counted as more than one FTE.

If a percentage of each staff member's time is being funded by Titles I, II, III, and/or IV, you can simply add the percentages to calculate the total. For example: Physician .50 FTE, Nurse Practitioner 1.0 FTE, Dentist .20 FTE, Case Manager .75 FTE, C&T 1.0 FTE = 3.45 FTEs.

*Step Two:* Identify the staff members who do not work full-time on HIV/AIDS care (e.g., part-time employees or full-time employees who spend only a portion of their time in HIV/AIDS care), and sum the weekly hours they spend in HIV/AIDS care. Divide this number by your agency's definition of full-time (e.g., 40 hours per week).

*Step Three:* Add the FTEs calculated in steps one and two. This sum is the number of FTEs you should report.

#### **19.** Total volunteer staff, in FTEs, dedicated to HIV care:

Report the total number of volunteer staff (at all sites within your overall program) in full-time equivalent positions dedicated to HIV care during the reporting period. To calculate FTEs, follow the method of calculation indicated in Question #16. *Enter a "zero" if there are no volunteer staff to report.* 

#### 20. Was HIV counseling and testing provided as part of your program during this reporting period?

Indicate whether HIV counseling and testing were provided as part of your outpatient system of care during the reporting period, either in your facility or by procuring or subsidizing the services provided by other programs. *If your response is "No" skip to Question #30* 

### 21. Did your agency provide HIV testing to infants (24 months or younger) during this reporting period?

Indicate whether you provide HIV testing to infants during this reporting period. *If your response is "No" skip to Question #22.* 

Infants are 24 months of age or younger.

a. Indicate the total number of infants tested during this reporting period.

### b. Indicate the total number of infants tested during this reporting period who were HIV positive.

### 22. Were Ryan White CARE Act funds used to support HIV counseling and testing services?

Indicate whether CARE Act funds were used to support HIV counseling and testing services during the reporting period, regardless of where these services were provided (that is, at your outpatient facility or at another site within your program). *Skip to question 30, if you selected reporting scope 2 for question 6 and do not wish to continue with this section.* 

### 23. How many individuals received HIV pretest counseling during this reporting period?

Indicate the number of individuals who received either confidential or anonymous HIV pretest counseling (counseling before testing for HIV antibodies) by a person qualified to provide such counseling, during the reporting period.

*Confidential* means information such as name, sex, age, etc., is collected on the client, and the client is reassured that no identifying information will be shared or passed on to anyone.

*Anonymous* means no identifying information is collected from the client.

## 24. Of the individuals who received HIV pretest counseling (See #22), how many were tested for HIV antibodies during this reporting period?

Indicate the number of individuals who were tested for HIV antibodies. This item may be a subset of Question #22.

#### 25. Of the individuals who received HIV pretest counseling and were tested for HIV antibodies during this reporting period (See #23), how many had a positive test result during this reporting period?

Indicate the number of individuals who tested positive for HIV antibodies during the reporting period. This item is a subset of Question #23 above.

#### 26. Of the individuals who received HIV pretest counseling and were tested for HIV antibodies during this reporting period (See #24), how many received HIV post-test counseling during this reporting period, regardless of test results?

Indicate the number of individuals who, after being tested for HIV antibodies, returned for HIV posttest counseling from a person qualified to provide such counseling, during the reporting period, regardless of their test results. This includes every person tested for HIV, whether the test result was positive, negative, or indeterminate. This item may be a subset of all clients tested for HIV in Question #23 above.

#### 27. Of the individuals who tested positive (See #25), how many did NOT return for HIV post-test counseling, during this reporting period?

Indicate the number of individuals who had a positive HIV-antibody test result and did not return for HIV posttest counseling, during the reporting period. This may be a subset of the number of individuals who tested positive for HIV antibodies given in Question #24 above.

#### 28. Of the individuals who tested for HIV antibodies and had a positive test result (See #25), how many became new patients at your clinic during this reporting period?

Indicate the number of individuals who tested for HIV antibodies and had a positive test result, and became new patients during this reporting period. The number here should be equal to or less than the number in Question #25 above.

### 29. Did your program offer partner notification services during this reporting period?

Indicate if you offered partner notification services during the reporting period. If partner notification was offered through referral to another organization, or it is not offered, indicate by "No." This includes notification of both sex partners and injection drug use partners. *If your response is "No" skip to Question #30.* 

*Partner notification* is when a physician in your program notifies the partner of a client of possible exposure to HIV. It is not the number of individuals who tested positive for HIV antibodies and offered partners' names for notification, nor is it the number of individuals who came to your program because of a referral by a partner notification service.

### a. Indicate the number of at-risk partners notified during this reporting period:

Indicate the number of at-risk partners who were directly contacted by a provider to discuss their possible exposure to HIV. Do not count the number of clients counseled on disclosure issues. Do not count number of clients who were referred to an agency that provided partner notification services.

### 30. Cost and revenue of primary care and other program during this reporting period:

Your response to each of the following items will indicate the cost of or revenue for providing "Primary care" and "Other program services" as defined below. *If Title III money was not used to support a particular service, the response for that service should be a " zero." Do not leave any line blank.* 

*Primary health care* is any preventive, diagnostic, or therapeutic health service received on an outpatient basis by a patient who is HIV positive. Examples include medical, subspecialty care, dental, nutrition, mental health or substance abuse treatment, and pharmacy services; radiology, laboratory, and other tests used for diagnosis and treatment planning; HIV counseling and testing; and the cost of making and tracking referrals for medical care.

*Other program services*, for Title III reporting purposes, refers to optional services that are eligible for Title III funds. Examples include case management, eligibility assistance, social work, outreach, CME, etc. Check the line-item budget on your last approved application for clarity. Do NOT include any administrative costs, expenditures or revenues. If you are providing a Title III eligible service that is *fundable*, include it, even if it is not being *funded* under your grant.

#### a. Total cost of providing service

Indicate the total cost (personnel, supplies, rent, etc.) to the EIS Program of providing each category of early intervention service, during the reporting period. Each dollar figure should be representative of the amount of money it takes to provide the service as part of the EIS Program.

These amounts are independent of funding sources and will give some indication of the cost for providing HIV-related care.

#### b. Title III grant funds expended

Indicate the amount of the Title III funds expended to support each category of service during the reporting period. This is the amount of Title III monies used to cover part of the total cost of providing each service.

#### c. Direct collections from patients

Indicate the amount of money collected directly from clients as payment for services provided during the reporting period. This would include any out-of pocket payment from clients such as co-payments, deductibles, nominal per-visit fees, etc. This is the amount of money received from patients that is used to cover part of the total cost of providing each service.

### d. Reimbursements received from third party payer(s)

Indicate the amount of reimbursements received from third-party payers (public and private) as payment for services provided during the reporting period. This includes reimbursements from Medicaid, private insurance, VA benefits, etc. This is the amount of money that is used from third-party payers to cover part of the cost of providing each service.

#### e. All other sources of income

Indicate the amount of other sources of income or revenue (other than Ryan White CARE Act Title III, direct collections from patients, and reimbursements received from third-party payers that were used during the reporting period to support services in your EIS program. This is the amount of money that was used from other sources of income to cover part of the cost of providing each service. Other sources may be from city, county, or State agencies; academic institutions, foundations, and corporations; and fundraising activities, bequests, and donations. Any other Ryan White CARE Act funding, such as Title I, Title II, or Title IV, and any other Federal agency funding (CDC, SAMHSA, BPHC, etc.) used to support any category of service should also be included here.

#### 31. Were services available through your Early Intervention Services (EIS) program provided at more than one site during this reporting period?

Record whether the grantee organization provided Early Intervention Services, that is, Title III-eligible services, at more than one site during the reporting period. *If your response is "No" skip to Question* #32.

### a. If yes, how many sites provided EIS services during this reporting period?

Indicate the number of sites at which EIS were provided during the reporting period.

## 32. Please indicate which of the following primary care services were made available to your clients who were HIV positive during this reporting period.

Check whether each health service was available to patients who are HIV positive, within the EIS program or through referral to providers outside of the EIS program, during the reporting period. *Yes, within the EIS program* is a program that encompasses the care supported by the Title III legislation and is made available by the grantee organization and its subcontractors. Subcontractors render care to clients referred to them by the grantee organization and are reimbursed for their services or otherwise have a remunerative relationship with the grantee for the referred service.

*Yes, through referral (Outside the EIS Program)* is a referral made to a provider that (1) is not part of the grantee organization; (2) does not have a contractual relationship with the grantee; and (3) does not receive reimbursement from the Title III grantee or its parent organization.

It is not necessary to indicate how many patients received each service or how many patient visits were made to obtain each service. All the services you have indicated may not have been utilized during the reporting period. However, the services you have indicated should have been available if a patient had required them within the EIS program or through referral. If services other than those listed below were available, check "other." See list below for a description of services.

#### **Description of services:**

Ambulatory/outpatient medical care is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting. This includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to, and provision of, specialty care (includes all medical subspecialties). Primary Medical Care for the Treatment of HIV Infection includes the provision of care that is consistent with the Public Health Service's Health Service guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.

Dermatology refers to care related to the skin.

Dispensing of pharmaceuticals is the provision of

prescription drugs to prolong life or prevent the deterioration of health.

*Gastroenterology* refers to care related to the stomach and intestines.

*Mental health services* are psychological and psychiatric treatment and counseling services, to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.

*Neurology* refers to care related to the nervous system.

*Nutritional counseling* is services provided by a licensed/registered dietitian outside of a primary care visit. Nutritional counseling provided by other than a licensed/registered dietitian should be recorded under "Psychosocial support services."

*Obstetrics/gynecology services* refer to care related to the female reproductive organs, including pregnancy.

*Optometry/ophthalmology* refers to care related to the eye.

*Oral health care* refers to care related to teeth and gums including diagnostic, preventive, and therapeutic services that are provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries as well as other trained primary care providers.

*Rehabilitation services* include services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.

*Substance abuse services* include the provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) provided in an outpatient setting rendered by a physician or under the supervision of a physician, or by other qualified personnel. *Other services* are other Title III-eligible, primary care services not listed above.

# 33. How many unduplicated patients who are HIV positive were referred outside the EIS program for any health service that was not available within the EIS program during the reporting period?

Indicate the total number of individuals who were referred outside the EIS program for any health service that was not available within the EIS program during the reporting period.

**Provider - level Form is Complete. Proceed to the Client - level form.** 

#### **CLIENT-LEVEL FORM**

#### 1. What is client's URN?

Report the Unique Record Number (URN) for the client. The URN is the 9-digit encrypted record number following HRSA's URN specifications that distinguishes the client from all other clients and that is the same for the client for all quarterly submissions and provider settings, if applicable.

#### 2. What is client's ZIP code?

Report the client's 5-digit ZIP code. If the ZIP code is unknown report 99999. If the client is homeless, report the ZIP code where the client usually spends the night or the ZIP code of the agency.

#### 3. What is the provider ID number?

Report the unique 4-digit provider ID number. This should be the same number that is provided for question 2e on the provider-level form so that the client record can be linked to the provider data file.

### 4. Is the client a "new" client during this reporting period?

Report whether the client is "new" during the reporting period.

*New client* is a person who received services from a provider for the first time ever during this reporting period. Individuals who return for care after an extended absence are not considered to be new unless past records of their care are not available.

#### 5. What is the client's gender?

Report the gender of the client.

*Transgender* means exhibiting the appearance and behavioral characteristics of the opposite sex, and is based on self-report by the client.

#### 6. What is the client's year of birth?

Report the 4-digit code for client's year of birth. Enter 9999 if year of birth is unknown.

### a. If year of birth is unknown, what is the client's estimated age?

Report the client's estimated age, if year of birth is not known. *Client's estimated age must be reported if year of birth is unknown*.

#### 7. Is the client of Hispanic or Latino/a ethnicity?

Report the client's Hispanic or Latino/a ethnicity, based on their self-report.

*Hispanic or Latino/a* is a person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.

#### 8. What is the client's race?

Report the client's racial group, based on the selfreport of the client. All individuals who identify themselves with more than one race should be reported as such. *Check all that apply*.

*White* is a person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

*Black or African American* is a person having origins in any of the black racial groups of Africa.

*Asian* is a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

*Native Hawaiian/Pacific Islander* is a person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

*American Indian or Alaskan Native* is a person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

*Unknown/unreported* is a person who does not identify with one of the racial categories listed above.

#### 9. What is the client's income?

Report the client's income category, based on the Federal poverty line, at the end of the reporting period, or the most recent data available within the reporting period. Income is defined in ranges relative to the Federal poverty guidelines. Poverty guidelines may be accessed at: <u>http://aspe.hhs.gov/poverty/</u>

*Equal to or below the Federal poverty line* means that the client's annual household income is the same as or below the Federal poverty line.

*Within 101–200% of the Federal poverty line* means that the client's income is equal to or no more than double the Federal poverty line.

*Within 201–300% of the Federal poverty line* means that the client's income is double or no more than triple the Federal poverty line.

*More than 300% of the Federal poverty line* means that the client's income is triple or more above the Federal poverty line.

*Unknown/unreported* means that the client's income is unknown or was not reported.

#### 10. What is the client's housing/living arrangement?

Record the client's regular place of residence at the end of the reporting period, or most recent data available, using the categories defined below.

#### Housing/living arrangements:

*Permanently housed* includes apartments, houses, foster homes, long-term residences, and boarding homes, as long as they are not time limited.

*Non-permanently housed* includes homeless, as well as transient or transitional housing. Homeless includes shelters, vehicles, the streets, or other places not intended as a regular accommodation for living. Transitional housing includes any stable but temporary living arrangement, regardless of whether or not it is part of a formal program.

*Institution* includes residential, health care, and correctional facilities. Residential facility includes supervised group homes and extended treatment programs for alcohol and other drug abuse or for mental illness. Health care facility includes hospitals, nursing homes and hospices. Correctional facility includes jails, prisons, and correctional halfway houses.

*Other* means other housing/living arrangements not listed above.

*Unknown/unreported* means housing/living arrangements were not reported.

#### 11. What is the client's HIV/AIDS status?

Report the client's HIV/AIDS status at the end of the reporting period.

*HIV positive, not AIDS* means the client has tested positive for and been diagnosed with HIV, but has not advanced to AIDS.

*HIV positive, AIDS status unknown* means the client has tested positive for and been diagnosed with HIV.

It is unknown whether or not the client has advanced to AIDS.

*CDC-defined AIDS* means the client has advanced to and been diagnosed with CDC-defined AIDS.

*HIV negative (affected clients only)* means the client is HIV-negative and is an affected friend or family member of an individual who is HIV positive.

*Unknown/unreported* means the HIV/AIDS status of the client is unknown and not documented.

**NOTE**: Once a client has been diagnosed with AIDS, they are always counted in the CDC-defined AIDS category regardless of disease indicators (i.e., CD4 counts).

#### 12. What is the clients' vital/enrollment status?

Report the client's vital/enrollment status at the end of the reporting period.

*Active* is a client whose status is active during any part of this reporting period.

*Deceased* means that the client died sometime during this reporting period.

*Inactive* means that the status of the client is inactive (as defined by your agency), which includes many possible reasons (e.g., client moved or is lost to follow-up).

*Unknown/unreported* means the vital/enrollment status is unknown or not reported.

#### 13. What is the client's source of medical insurance?

Enter the client's primary source of medical insurance for HIV-related care. Select only one form of insurance for each client. Report the medical insurance that provides the most reimbursement if a client has more than one source of insurance.

*Private* means health insurance plans such as BlueCross/BlueShield, Kaiser Permanente, Aetna, etc.

*Medicare* is a health insurance program for people 65 years of age and older, some disabled people under 65 years of age, and people with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant).

*Medicaid* is a jointly funded, Federal-State health insurance program for certain low-income and needy people.

*Other public* means other Federal, State, and/or local government programs providing a broad asset of benefits for eligible individuals. Examples include State-funded insurance plans, military health care (CHAMPUS), State Children's Insurance Program (SCHIP), Indian Health Services, and Veterans Health Administration.

*No insurance* means either the client has no insurance to cover the cost of services, or self-pay.

*Other* means client has an insurance type other than those listed above.

*Unknown/unreported* means the primary source of medical insurance is unknown and not documented.

#### a. If "Other", describe"

Report other source of medical insurance if "Other" was selected as a response in the preceding question.

### 14. What is client's primary risk factor for HIV infection?

Report the client's risk factors for HIV infection. Persons with more than one reported mode of exposure to HIV are counted in the exposure category listed first in the hierarchy, except for persons with a history of both homosexual/bisexual contact and injection drug use. They are counted in a separate category. *Check only one response*.

*Male who have sex with male(s) (MSM)* cases include men who report sexual contact with other men (i.e., homosexual contact) and men who report sexual contact with both men and women (i.e., bisexual contact).

*Injection drug user (IDU)* cases include persons who report use of drugs intravenously or through skin-popping.

Male who has sex with male(s) and injection drug users (MSM and IDU) cases include men who report sexual contact with men and use of drugs intravenously or through skin-popping.

*Hemophilia/coagulation disorder* cases include individuals with delayed clotting of the blood.

Heterosexual contact cases are persons who report specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user). *Receipt of transfusion of blood, blood components, or tissue* are cases which transmission by blood , blood components, or tissue transfusion.

Mother with/at risk for HIV infection (perinatal transmission) cases include transmission of disease from mother to child during pregnancy. This category is exclusively for infants and children infected by mothers who are HIV positive or at risk.

*Other* means the individual's exposure is known, but not listed above.

*Undetermined/unknown, risk not reported* means the individual's exposure is unknown or not reported for data collection.

## 15. Does the client have a self-reported or documented history of substance abuse or dependency problems (including injection drugs, alcohol)?

Indicate whether or not the client has a history of substance abuse and/or dependency problems using the predetermined response codes. This data element can be answered by the client or through information retrieved from medical records. Medical record documentation can include a formal diagnosis, but can also include information from case notes as assessed by a case manager or caseworker. Substances include injection drugs, marijuana, alcohol, and any other illicit drugs. This data element should be answered in conjunction with Item #15a. Select only one response.

*No History* means that the client does not have a history of substance abuse/dependency problems.

Active history is defined as the client having a substance abuse/dependency problem, which was present during the current calendar year.

*Not active history* is defined as the client having a substance abuse/dependency problem, but it has not been present during the current calendar year.

*Unknown* means that it is unknown and not documented whether the patient has a history of substance abuse/dependency problems.

### a. What is the client's current substance abuse treatment or counseling status?

Indicate the treatment and/or counseling status of the patient during the current calendar year in regards to substance abuse and dependency problems using the predetermined response codes. This data element should be answered in conjunction with Item #15.

Select only one response. Please note that if the answer to Item #15 is "no," skip to item #16.

*In treatment with in-house primary care provider* means that the treatment is being provided on site by the primary physician.

In treatment with a trained substance abuse counselor means that individual or group treatment is being provided on or off site by a trained substance abuse counselor.

*No active treatment* means that no treatment is being provided to the client.

Other includes any other treatment not listed above.

*Unknown/unreported* means the individual's treatment status is unknown.

### 16. Does the client have a self-reported or documented history of a mental health condition?

Indicate whether or not the client has a history of a mental health condition(s) using the predetermined response codes. This data element can be answered by the client or through information retrieved from medical records. Medical record documentation can include a formal diagnosis, but can also include information from case notes as assessed by a case manager or caseworker. Mental health conditions include depression, psychosomatic disorders, psychosocial disorders, and all other listed conditions in the DSM-IV. This data element should be answered in conjunction with Item #16a. Select only one response.

*No history* means that client does not have a history of a mental health condition.

Active history is defined as the client having a mental health condition, which was present during the current calendar year.

*Not active history* is defined as the client having a mental health condition but it has not been present during the current calendar year.

*Unknown* means that it is unknown and not documented whether the patient has a history of a mental health condition.

### a. What is the client's current mental health treatment or counseling status?

Indicate the treatment and/or counseling status of the patient during the current calendar year, in regards to

mental health conditions using the predetermined

response codes. This data element should be answered in conjunction with Item #16. Select only one response. Please note that if the answer to Item #16 is "no," skip to item #17.

*In treatment with in-house primary care provider* means that the treatment is being provided on site by the primary care provider.

In treatment with psychiatrist or mental health professional means that individual or group treatment is being provided on or off-site by a psychiatrist or mental health professional.

*No active treatment* means that no treatment is being provided to the client.

Other includes any other treatment not listed above.

*Unknown/unreported* means the individual's treatment status is unknown.

#### 17. Total number of visits received for each service:

For all services that the client has received, enter the total number of visits made by those clients during the reporting period. Only record service visits that were provided within your organization. Do not record referrals here. *If the client received no visits in a service category, record the total number of visits as zero.* 

**NOTE**: A client may only have one visit for each service category per day. For a residential substance abuse treatment center, each day in a residential facility equals one visit. For example, if a client spends 20 days in a residential facility, this counts as 20 visits.

#### Service categories:

a. *Ambulatory/outpatient medical care* is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting. This includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral

to and provision of specialty care (includes all medical subspecialties).

- b. *Mental health services* are psychological and psychiatric treatment and counseling services to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.
- C. *Oral health care* includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.
- d. *Substance abuse services-Outpatient* are the provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) provided in an outpatient setting rendered by a physician or under the supervision of a physician, or by other qualified personnel.
- e. *Substance abuse services-Residential* are the provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) provided in an inpatient health service setting (short-term).
- f. *Rehabilitation services* include services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.
- g. *Home health: para-professional care* is the provision of services by a homemaker, home health aide, personal caretaker, or attendant caretaker. This definition also includes non-medical, non-nursing assistance with cooking and cleaning activities to help clients with disabilities remain in their homes.
- h. *Home health: professional care* is the provision of services in the home by licensed health care workers such as nurses.

- i. *Home health: specialized care* is the provision of services that include intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other high-tech therapies.
- j. Case management services are a range of clientcentered services that link clients with health care, psychosocial, and other services. Ensures timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Also includes inpatient case management services that prevent unnecessary hospitalization or that expedite discharge from an inpatient facility. Key activities include: (1) initial assessment of service needs, (2) development of a comprehensive, individualized service plan, (3) coordination of services required to implement the plan, (4) client monitoring to assess the efficacy of the plan, and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services. This includes any type of case management (e.g., face-to-face or via telephone).
- k. *Buddy/companion service* is an activity provided by volunteers/peers to assist the client in performing household or personal tasks and providing mental and socia l support to combat the negative effects of loneliness and isolation.
- 1. *Child care services* are the provision of care for the children of clients who are HIV positive while the clients are attending medical or other appointments or attending Title -related meetings, groups, or training. **NOTE**: This does not include childcare while client is at work.
- m. Child welfare services are the provision of family preservation/unification, foster care, parenting education, and other child welfare services. Services designed to prevent the break-up of a family and to reunite family members. Foster care assistance to place children under the age of 21 years, whose parents are unable to care for them, in temporary or permanent homes and to sponsor programs for foster families. Other services related to juvenile court proceedings, liaison to child protective services,

involvement with child abuse and neglect investigations and proceedings, or actions to terminate parents' rights. Presentation or distribution of information to biological, foster, and adoptive parents, future parents, and/or caretakers of children who are HIV positive about risks and complications, caregiving needs, and developmental and emotional needs of children.

- Client advocacy is the provision of advice and assistance obtaining medical, social, community, legal, financial, and other needed services. Advocacy does not involve coordination and follow -up on medical treatments, as case management does.
- O. *Day or respite care for adults* is the provision of community or home-based, non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client.
- p. Developmental assessment/early intervention *services* are the provision of professional early interventions by physicians, developmental psychologists, educators, and others in the psychosocial and intellectual development of infants and children. Involves assessment of an infant's or child's developmental status and needs in relation to the involvement with the education system, including assessment of educational early intervention services. Includes comprehensive assessment of infants and children taking into account the effects of chronic conditions associated with HIV, drug exposure, and other factors. Provision of information about access to Head Start services, appropriate educational settings for HIV-affected clients, and education/assistance to schools.
- q. *Early intervention services for Titles I and II* are counseling, testing, and referral services to PLWHA who know their status but are not in primary medical care, or who are recently diagnosed and are not in primary medical care for the purpose of facilitating access to HIV-related health services.
- r. *Emergency financial assistance* is the provision of short-term payments to agencies, or establishment of voucher programs to assist with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and

food stamps), and medication when other resources are not available.

- S. Food bank/home-delivered meals is the provision of actual food, meals, or nutritional supplements. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item.
- t. *Health education/risk reduction* is the provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information, including information dissemination about medical and psychosocial support services and counseling, to help clients with HIV improve their health status.
- Housing and housing-related services are the u. provision of short-term assistance to support temporary or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related services may be housing in medical treatment programs for chronically ill clients (e.g., assisted living facilities), specialized short-term housing, transitional housing, and non-specialized housing for clients who are HIV affected. Category includes access to short-term emergency housing for homeless people. This also includes assessment, search, placement, and the fees associated with them. **NOTE**: If housing services include other service categories (e.g., meals, case management, etc.) these services should also be reported in the appropriate service categories.
- V. Legal services are the provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders, wills, trusts, bankruptcy proceedings, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the CARE Act. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.
- W. *Nutritional counseling* is provided by a licensed registered dietitian outside of a primary care visit. Nutritional counseling provided by other

than a licensed/registered dietitian should be recorded under "Psychosocial support services."

- **x**. *Outreach* services include programs that have as their principal purpose identification of people with HIV disease so that they may become aware of, and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.
- y. *Permanency planning* is the provision of services to help clients or families make decisions about placement and care of minor children after the parents/caregivers are deceased or are no longer able to care for them.
- Z. Psychosocial support services are the provision of support and counseling activities, including alternative services (e.g., visualization, massage, art, music, and play), child abuse and neglect counseling, HIV support groups, pastoral care, recreational outings, caregiver support, and bereavement counseling. Includes other services not included in mental health, substance abuse, or nutritional counseling that are provided to clients, family and household members, and/or other caregivers and focused on HIV-related problems.
- aa. *Referral for health care/supportive services* is the act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made formally from one clinical provider to another, within the case management system by professional case managers, informally through support staff, or as part of an outreach program.
- ab. *Referral to clinical research* is the provision of education about and linkages to clinical research services through academic research institutions or other research service providers. Clinical

research are studies in which new treatments drugs, diagnostics, procedures, vaccines, and other therapies—are tested in people to see if they are safe and effective. All institutions that conduct or support biomedical research involving people must, by Federal regulation, have an institutional review board (IRB) that initially approves and periodically reviews the research.

- ac. *Residential or in-home hospice care* means room, board, nursing care, counseling, physician services, and palliative therapeutics provided to patients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal patients.
- ad. *Transportation services* include conveyance services provided, directly or through voucher, to a client so that he or she may access health care or support services.
- ae. *Treatment adherence services* are the provision of counseling or special programs to ensure readiness for, and adherence to, complex HIV/AIDS treatments.
- af. *Other services* are other services not listed above.

#### 18. Please indicate the client's dates of the following:

Report the following dates for the patient. The purpose of the following two questions is to determine how long it takes for a patient to enter primary medical care after their initial HIV diagnosis.

#### a. Initial HIV diagnosis:

Report the date of the patient's initial HIV diagnosis, regardless of whether the diagnosis occurred at your agency. Client's self-report can be used here.

#### b. Entry into HIV primary medical care

Report the date of the patient's initial entry into HIV primary medical care, regardless of whether the patient first entered HIV care at your agency. Client's self-report can be used here.

## 19. If client was new, did client enter HIV primary medical care as a result of counseling and testing services?

New is defined here as "New to HIV Primary Medical Care". Thus, if the date in q. 18b is the current calendar year, this question should be answered. Report if the patient entered HIV primary medical care as a result of counseling and testing services. *If the patient is not "New" please respond as "Not applicable."* 

For all questions in the medical section (Questions 20-40), except 28 and 29 (which are quarterly), the time period is anytime throughout the current calendar year (January 1 – December 31). All questions should be answered the first quarter and then updated as necessary throughout the rest of the year.

## 20. Was a screening/evaluation for HIV transmission risk behaviors conducted as part of the client's medical care?

Indicate if the patient received a screening and/or an evaluation for HIV transmission risk behaviors this year. The screening/evaluation must be done by a physician for example an MD, NP, or PA. With CDC's and HRSA's new emphasis on prevention with positives, this question is meant to determine whether the patient has been evaluated (and if necessary has received or been referred for on-going prevention counseling) for current sexual and drugusing behaviors that may be putting others at risk of contracting HIV. For more information about CDC's new prevention guidelines go to

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5 215a1.htm

### 21. Was partner notification counse ling included as part of the client's medical care?

Report if partner notification counseling was included as part of a patient's routine care this year. Title III agencies are required by law to counsel patients regarding partner notification. The purpose of this question is to determine the extent to which partner notification counseling is being done by Title III and IV agencies either on site by the primary care provider or through referrals to another agency.

For Questions #22, #23, #24, #27, #28, #31, and #39 if the client's response to a screening/testing question is "No" or "Unknown/unreported" skip to the next question. Similarly, if the client's response

### to the screening/testing result is "Negative" or "Unknown/unreported" skip to the next question.

#### 22. Has the client received a TB skin test?

Report if the patient received a TB skin test at any time this year. If the patient was diagnosed with TB in the past, making a skin test unnecessary, choose "No, not medically indicated."

#### a. What was the result of the TB skin test?

Report the result of the patient's TB skin test.

### b. Did the client receive treatment due to a positive TB skin test?

For patients who tested positive on their TB skin test, indicate whether or not the patient is currently receiving treatment and/or prophylaxis or whether treatment occurred in the past. TB treatment or prophylaxis includes different options, depending on possible drug interactions and resistance issues. Please follow the USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus. This document can be found at http://www.aidsinfo.nih.gov/guidelines/.

#### 23. Did the client receive screening/testing for syphilis?

Report if the patient received any screening/testing services for syphilis this year. With the increase in syphilis occurring in homosexual populations across the country, it is important to screen (and treat if necessary) at-risk patients for syphilis. For more information go to

http://www.aidsinfo.nih.gov/guidelines/ .

### a. What was the result of the syphilis screening test?

Report the result of the patient's syphilis screening test.

#### b. Did the client receive treatment for syphilis?

Report if the patient received any treatment services for syphilis at any time this quarter or at any time previously.

### c. Was the Health Department contacted about the positive syphilis test?

Report if the patient's positive syphilis test was reported to the Health Department. All positive tests are required by law to be reported to the Health Department.

## 24. Did the client receive screening/testing for any treatable sexually transmitted infection (STI) other than syphilis and HIV?

Report if the patient received any screening/testing services for any other treatable Sexually Transmitted Infection (STI) this year. HIV+ individuals who have an STI are more likely to spread HIV than those without an STI, so it is essential that patients at risk of contracting STIs be screened and treated if necessary. More information can be found at http://www.aidsinfo.nih.gov/guidelines/.

### a. What was the result of the STI (other than syphilis and HIV) screening test?

Report the result of the patient's STI screening test.

b. Did the client receive treatment for an STI (other than syphilis and HIV)?

Report if the patient received any treatment services for an STI (other than syphilis and HIV) at any time this year.

## 25. If the client is anti-HAV negative AND at increased risk for HAV infection, did the client receive hepatitis A vaccine (Havrix, Vaqta)?

Report if the patient received a hepatitis A vaccine at any time this year. IDUs, MSMs, and those with chronic liver disease including chronic HBV and HCV infection are all at increased risk for HAV infection. For more information go to CDC's webpage:

http://www.cdc.gov/ncidod/diseases/hepatitis/index.h tm

## 26. If the client is anti-HBV negative AND at increased risk for HBV infection, did the client receive hepatitis B vaccine (Engerix-B, Recombivax)?

Report if the patient received a hepatitis B vaccine at any time this year. Sexually active MSMs and Heterosexuals, IDUs, household members of those with chronic HBV infection, and Hemophiliacs are all at increased risk for HBV infection. For more information go to CDC's webpage: http://www.cdc.gov/ncidod/diseases/hepatitis/index.h

tm Has the client received scre

### 27. Has the client received screening/testing for hepatitis C?

Report if the patient received any screening/testing services for hepatitis C this year.

### a. What was the result of the hepatitis C screening test?

Report the result of the patient's hepatitis C screening test.

### b. Was the client referred for evaluation/treatment for hepatitis C?

Report if the patient received any evaluation/ treatment services for hepatitis C at any time this year.

### 28. Enter the most recent CD4+ T-lymphocyte count (cells/μL) test result for each quarter.

Report the CD4+ count for the corresponding quarters: January through March (quarter 1); April through June (quarter 2); July through September (quarter 3); and October through December (quarter 4). *If the CD4+ count is unknown, record a "0"for each corresponding quarter.* 

### 29. What is the client's lowest ever CD4+ T-lymphocyte count (cells/ mL) test result?

Report the patient's lowest ever CD4+ count and the corresponding date. Patient's self-report can be used here. *If the count is not available, record a "0." If the date is not available, leave the field blank.* 

#### 30. What was the client's CD4+ T-lymphocyte count (cells/µL) test result when the client first entered HIV primary medical care?

Report the patient's lowest CD4+ count and the corresponding date, when the patient first received care for their HIV disease. Patient's self-report can be used here. *If the count is not available, record a* "-9." *If the date is not available, leave the field blank.* 

### 31. Enter the most recent Viral load (copies) test results per quarter.

Report the viral load test result for the patient for the corresponding quarters: January through March (quarter 1); April through June (quarter 2); July through September (quarter 3); and October through December (quarter 4). *If the viral load results are unknown, record a "-9" for each corresponding quarter. If the viral load results are undetectable record a "0".* 

### 32. Which of the following best describes the client's antiretroviral therapy?

Enter the antiretroviral therapy that best describes the patient's current therapy. For more information about the recommended guidelines for antiretroviral therapy go to http://www.aidsinfo.nih.gov/document/data/guideline s\_html\_lib/html\_adult\_02-04-02.html

*None* means that the patient has not been evaluated and no action has been taken regarding antiretroviral therapy.

*None, not medically indicated* means that the patient has been evaluated but no action is necessary because of the patient's health.

*None, patient refused* means that the patient was evaluated and determined to need antiretroviral therapy but the patient refused the therapy.

*None, patient not ready* means that the patient was evaluated, and it was determined that the patient was not ready to receive antiretroviral therapy

*HAART, 1<sup>st</sup> Regimen* (Highly Active Antiretroviral Therapy) means that the patient was antiretroviralnaïve before beginning treatment and this is the patient's first HAART regimen. HAART is generally described as one protease inhibitor AND two nucleoside analogue reverse transcriptase inhibitors (NRTIs).

HAART, More than 1<sup>st</sup> Regimen means that the patient has failed one or more regimens of HAART, but is continuing HAART treatment.

*Other* means that the patient is receiving mono, dual, or other combination antiretroviral therapy that does not meet the definition of HAART.

*Unknown/unreported* means the individual's therapy is unknown.

#### 33. Did the client receive a pelvic exam?

Report if the patient received a pelvic exam at any time between January and December. *If the patient is male, skip to Question #35.* 

#### 34. Did the client receive a vaginal Pap smear?

Report if the patient received a vaginal Pap smear at any time between January and December.

#### 35. Did the client receive a rectal Pap smear?

Report if the patient received a rectal Pap smear at any time between January and December. This is not yet a USPHS Recommended Standard of Care for HIV disease and is not officially endorsed by HAB as a standard of care. However, during consultation with primary care providers, HAB was informed that this was an important test to track, so this question was added to the data instrument.

### 36. Was the client diagnosed with any of the following AIDS-defining conditions?

Using the CDC AIDS-defining conditions, indicate whether or not the patient was diagnosed with each condition at any time using the predetermined response codes. Select all responses that are applicable.

### 37. Has the client received Pneumocystis carinii pneumonia (PCP) prophylaxis?

Indicate whether or not the patient received PCP prophylaxis this year using the predetermined response codes. Treatment guidelines state that patients with a CD4+ T-lymphocyte count of <200/uL or a history of oropharyngeal candidiasis should receive PCP prophylaxis. Please refer to the USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus developed by the U.S. Public Health Service and the Infectious Diseases Society of America. This document can be found at <u>http://www.aidsinfo.nih.gov/guidelines/</u>. Select only one response. Based on the response of question 28, this should be evaluated quarterly.

#### 38. Has the client received a pneumococcal vaccine?

Indicate whether or not the patient received pneumococcal vaccine this year. Treatment guidelines state that adults and adolescents who have a CD4+ T-lymphocyte count of greater than or equal to 200 cells/ $\mu$ L should be administered a single dose of 23-valent polysaccharide pneumococcal vaccine if they have not received this vaccine during the previous five years. This document can be found at <u>http://www.aidsinfo.nih.gov/guidelines/</u>. Select only one response.

#### 39. Was the client pregnant this year?

Indicate whether the patient was pregnant at any time between January and December. *If the response is "No" or "Unknown/unreported" or if the patient is male, skip to Question #41.* 

#### a. During what trimester did the client <u>enter</u> prenatal care?

Indicate whether the patient entered care during the  $1^{st}$ ,  $2^{nd}$ , or  $3^{rd}$  trimester of pregnancy or whether delivery marked the patient's entry into care.

### b. Did the client receive antiretroviral medications to prevent maternal to child transmission of HIV?

Indicate whether the patient received antiretroviral medications during pregnancy for the purpose of preventing maternal to child transmission of HIV. Recommended treatment guidelines state that to prevent perinatal transmission, ZDV chemoprophylaxis should be incorporated into the antiretroviral regimen. For more information go to <u>http://www.aidsinfo.nih.gov/guidelines/</u> Select only one response.

#### c. Did the client deliver any children this year?

Indicate whether the patient delivered any children at any time between January and December.

### 40. How many children were delivered to this client this year?

Indicate the total number of children delivered (live births) between January and December to patients who were HIV positive.

#### a. Were any of the children HIV-positive?

Report if any of the children delivered were HIVpositive. *If the response is "No" or "Unknown/unreported" skip to Question #41.* 

#### b. If yes, how many children delivered were HIVpositive?

Of the total number of children delivered, enter the number who tested HIV positive at any time between January and December.

#### 41. Was this client referred outside the Early Intervention Services (EIS) program (Title III) and/or your network (Title IV) for any service that was unavailable within your program or network?

Report whether the patient was referred outside of the program or network for any service that was unavailable within the program or network this year.

### 42. Indicate the type of outside referral as well as whether the client received the service.

For all services, record that the patient was referred and whether the patient received the service. If the response for the Patient Referred field is "No" or "Unknown/unreported," leave the Patient Received Services field blank.

#### GLOSSARY OF RYAN WHITE CARE ACT TERMS

| ADAP  | AIDS Drug Assistance Program—A State-administered program authorized under Title II of the CARE Act that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid.  |
|---|--|
| ADAP Flexibility<br>Policy                                    | HIV/AIDS Bureau's (HAB) Policy Notice 00-02 provides grantees greater flexibility in the use of ADAP funds and permits expenditures 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. Please note that grantees <i>must</i> request in writing to use ADAP dollars for services other than medications.   |
| Affected client   | A family member or partner of an infected client who receives at least one Ryan White CARE Act supportive or case management service during the reporting period.  |
| Agency reporting for<br>multiple fee-for-<br>service provider | An agency that reports data for more than one fee-for-service provider.  |
| 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.  |
| AIDS  | Acquired immune deficiency syndrome—A disease caused by the human immunodeficiency virus.  |
| Ambulatory/<br>outpatient medical<br>care                     | The provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting. This includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). Primary Medical Care for the Treatment of HIV Infection includes the provision of care that is consistent with the Public Health Service's Health Service guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies. |
| American Indian or<br>Alaskan Native                          | A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.   |
| Antiretroviral  | A substance that fights against a retrovirus, such as HIV. (See Retrovirus)  |
| ΑΡΑ   | <i>AIDS pharmaceutical assistance</i> —A local pharmacy assistance program implemented by a Title I EMA or Title II state. The Title II Grantee, consortium or Title I Planning Council contracts with one or more organizations to provide medications to clients. These organizations may or may not provide other services (e.g., primary care, case management) to the patients or clients that they serve through a Ryan White (or other funding sources) contract with their grantee.  |
| Asian   | A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.   |
| Black or African<br>American                                  | A person having origins in any of the black racial groups of Africa.   |
| Buddy/companion<br>service                                    | An activity provided by volunteers/peers to assist the client in performing household or personal tasks, and providing mental and social support to combat the negative effects of loneliness and isolation.   |

| CARE Act                    | <i>Ryan White Comprehensive AIDS Resources Emergency Act</i> —The Federal legislation created to address the health care and service needs of people living with HIV/AIDS (PLWHA) disease and their families in the United States and its Territories. The CARE Act was enacted in 1990 (Pub. L. 101-381), reauthorized in 1996 as the Ryan White CARE Act Amendments of 1996, and reauthorized again in 2000 as the Ryan White CARE Act Amendments of 2000.  |
|-----------------------------|---|
| Case management<br>services | A range of client-centered services that link clients with health care, psychosocial, and other services. Ensures timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Also includes inpatient case management services that prevent unnecessary hospitalization or that expedite discharge from inpatient facility. Key activities include: (1) initial assessment of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan, and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services.   |
| CDC                         | <i>Centers for Disease Control and Prevention</i> —The DHHS agency that administers HIV/AIDS prevention programs, including the HIV Prevention Community Planning process, among other programs. The CDC is responsible for monitoring and reporting infectious diseases, administers AIDS surveillance grants, and publishes epidemiologic reports such as the HIV/AIDS Surveillance Report.   |
| CD4 or CD4+ cells           | Also known as "helper" T-cells, these cells are responsible for coordinating much of the immune response. HIV's preferred targets are cells that have a docking molecule called "cluster designation 4" (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4 levels appear to be the best indicator for developing opportunistic infections.   |
| CD4 cell count              | The number of T-helper lymphocytes per cubic millimeter of blood. The CD4 count is a good predictor of immunity. As CD4 cell count declines, the risk of developing opportunistic infections increases. The normal range for CD4 cell counts is 500 to 1500 per cubic millimeter of blood. CD4 counts should be rechecked at least every 6 to 12 months if CD4 counts are greater than 500/mm <sup>3</sup> . If the count is lower, testing every 3 months is advised. A CD4 count of 200 or less indicates AIDS.   |
| CEO                         | <i>Chief Elected Official</i> —The official recipient of Title I CARE Act funds within the EMA, usually a city mayor, county executive, or chair of the county board of supervisors. The CEO is ultimately responsible for administering all aspects of the CARE Act in the EMA and ensuring that all legal requirements are met. In EMAs with more than one political jurisdiction, the recipient of Title I CARE Act funds is the CEO of the city or urban county that administers the public health agency that provides outpatient and ambulatory services to the greatest number of people with AIDS in the EMA.   |
| Child care services         | The provision of care for the children of clients who are HIV positive while the clients are attending medical or other appointments or attending Title-related meetings, groups, or training. This does not include child care while the client is at work.  |
| Child welfare<br>services   | The provision of family preservation/unification, foster care, parenting education, and other child welfare services. Services designed to prevent the break-up of a family and to reunite family members. Foster care assistance to place children under the age of 21 years, whose parents are unable to care for them, in temporary or permanent homes, and to sponsor programs for foster families. Includes other services related to juvenile court proceedings, liaison to child protective services, involvement with child abuse and neglect investigations and proceedings, or actions to terminate parents' rights. Involves presentation or distribution of information to biological, foster, and adoptive parents, future parents, and/or caretakers of children who are HIV positive about risks and complications, caregiving needs, and developmental and emotional needs of children. |

| Client  | See infected client or affected client.   |
|---|---|
| Client advocacy                                       | The provision of advice and assistance obtaining medical, social, community, legal, financial, and other needed services. Advocacy does not involve coordination and follow-up on medical treatments, as case management does.  |
| Combination therapy                                   | Two or more drugs or treatments used together to achieve optimum results against HIV infection and/or AIDS. For more information on treatment guidelines, visit <u>http://hivatis.org/trtgdlns.html</u>   |
| Co-morbidity  | A disease or condition, such as mental illness or substance abuse, co-existing with HIV disease.  |
| Consortium/HIV Care<br>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 Title II grant assistance to plan, develop, and deliver (directly or through agreement with others) comprehensive outpatient health and support services for individuals with HIV disease. Agencies comprising the consortium are required to have a record of service to populations and sub-populations with HIV.   |
| Continuum of care                                     | An approach that helps communities plan for, and provide, a full range of emergency and long-<br>term service resources to address the various needs of PLWHA.  |
| Day or respite care for adults                        | Community or home-based, nonmedical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of an adult client.  |
| DCBP  | <i>Division of Community Based Programs</i> —The division within HRSA's HIV/AIDS Bureau that is responsible for administering Title III, Title IV, and the HIV/AIDS Dental Reimbursement Program.   |
| Developmental   | The provision of professional early intervention by physicians, developmental psychologists,  |
| assessment/early<br>intervention services             | educators, and others in the psychosocial and intellectual development of infants and children.<br>Involves assessment of an infant's or child's developmental status and needs in relation to the<br>involvement with the education system, including assessment of educational early intervention<br>services. Includes comprehensive assessment of infants and children taking into account the<br>effects of chronic conditions associated with HIV, drug exposure, and other factors. Provides<br>information about access to Head Start services, appropriate educational setting for HIV-affected<br>clients, and education/assistance to schools. |
| Dispensing of pharmaceuticals                         | The provision of prescription drugs to prolong life or prevent deterioration of health.   |
| DSS   | <i>Division of Service Systems</i> —The division within HRSA's HIV/AIDS Bureau that is responsible for administering Title I and Title II (including the AIDS Drug Assistance Program, ADAP).   |
| DTTA  | <i>Division of Training and Technical Assistance</i> —The division within HRSA's HIV/AIDS Bureau that is responsible for administering the AIDS Education and Training Centers (AETC) Program and technical assistance and training activities of the HIV/AIDS Bureau.  |
| Early intervention                                    | See HIV/EIS (HIV Early Intervention Services/Primary Care)  |
| Early intervention<br>services for Titles I<br>and II | A combination of services that include outreach, HIV counseling and testing, referral, and the provision of outpatient medical care and supportive services designed and coordinated to bring individuals with HIV disease into the local HIV continuum of care.  |
| Eligibility criteria                                  | The standards set by a State ADAP, usually through an advisory committee, to determine who receives access to ADAP services. Financial eligibility is usually determined as a percentage of Federal Poverty Level (FPL), such as 200% FPL. Medical eligibility is most often a positive HIV diagnosis. Eligibility criteria vary among ADAPs.   |

| EMA                                | <i>Eligible Metropolitan Area</i> —The geographic area eligible to receive Title I CARE Act funds. The boundaries of the eligible metropolitan area are defined by the Census Bureau. Eligibility is determined by AIDS cases reported to the Centers for Disease Control and Prevention (CDC). Some EMAs include just one city and others are composed of several cities and/or counties. Some EMAs extend over more than one State.  |
|------------------------------------|--|
| Emergency financial assistance     | The provision of short-term payment for essential utilities and for medication assistance when other resources are not available.  |
| Epidemic                           | A disease that occurs clearly in excess of normal expectation and spreads rapidly through a demographic segment of the human population. Epidemic diseases can be spread from person to person or from a contaminated source such as food or water.  |
| Exposure category                  | See risk factor.   |
| Faith-based organization           | An organization that is owned and operated by a religiously affiliated entity, such as a Catholic hospital.  |
| Family centered                    | A model in which systems of care under Ryan White Title IV are designed to address the needs of PLWHA and affected family members as a unit, by providing or arranging for a full range of services. The family structures may range from the traditional, biological family unit to non-traditional family units with partners, significant others, and unrelated caregivers.   |
| Family members                     | Includes children, partners, biological parents, adoptive parents, foster parents, grandparents, other caregivers, and siblings (who may or may not be living with HIV).   |
| Food bank/home-<br>delivered meals | The provision of actual food, meals, or nutritional supplements. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item.  |
| FTEs                               | <i>Full-time equivalent</i> —A standard measurement of full-time staff (either paid or volunteer), which is based on a 35 to 40 hour work week. It is calculated by taking the sum of all hours worked by staff in the EIS Program and dividing by 35 to 40, depending on how your organization defines full-time employment. For example, 2 staff members who work 20 hours each per week represent 1 FTE, assuming full-time employment is defined as 40 hours per week.   |
| Grantee of record                  | The official Ryan White CARE Act grantee that receives Federal funding directly from the Federal government (HRSA). This agency may be the same as the provider agency, or may be the agency through which the provider agency is subcontracted.   |
| HAART                              | <i>Highly active antiretroviral therapy</i> —An aggressive anti-HIV treatment usually including a combination of three or more drugs with activity against HIV whose purpose is to reduce viral load to undetectable levels.   |
| НАВ                                | <i>HIV/AIDS Bureau</i> — The bureau within the Health Resources and Services Administration (HRSA) of the DHHS that is responsible for administering the Ryan White CARE Act. Within HAB, the Division of Service Systems administers Title I, Title II, and the AIDS Drug Assistance Program (ADAP); the Division of Community Based Programs administers Title III, Title IV, and the HIV/AIDS Dental Reimbursement Program; and the Division of Training and Technical Assistance administers the AIDS Education and Training Centers (AETC) Program. The Bureau's Office of Science and Epidemiology administers the Special Projects of National Significance (SPNS) Program. |
| Health education/risk reduction    | The provision of services that educate clients with HIV about HIV transmission and how to reduce<br>the risk of HIV transmission. It includes the provision of information about medical and<br>psychosocial support services and counseling, to help clients with HIV improve their health status.  |
| High-risk insurance<br>pool        | A State health insurance program that provides coverage for individuals who are denied coverage due to a pre-existing condition or who have health conditions that would normally prevent them from purchasing coverage in the private market.   |

| HIP                                       | <i>Health Insurance Program</i> —A program authorized and primarily funded under Title II of the CARE Act that makes premium payments, co-payments, deductibles, or risk pool payments on behalf of a client to maintain his/her health insurance coverage.   |
|---|---|
| Home health: para-<br>professional care   | The provision of services by a homemaker, home health aide, personal caretaker, or attendant caretaker. This definition also includes non-medical, non-nursing assistance with cooking and cleaning activities to help disabled clients remain in their homes.  |
| Home health: professional care            | The provision of services in the home by licensed health care workers such as nurses.   |
| Home health:<br>specialized care          | The provision of services that include intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other high-tech therapies.  |
| Housing or housing-<br>related services   | The provision of short-term assistance to support temporary or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related services may be housing in medical treatment programs for chronically ill clients (e.g., assisted living facilities), specialized short-term housing, transitional housing, and non-specialized housing for HIV-affected clients. Category includes access to short-term emergency housing for homeless people. This also includes assessment, search, placement, and the fees associated with them.  |
| Hispanic or Latino/a                      | A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.  |
| HIV/AIDS status                           | The outcome of the client's HIV test result, which includes: (1) HIV-positive not AIDS—client tested positive for and being diagnosed with HIV, but has not advanced to AIDS; (2) HIV-positive AIDS status unknown—client tested positive for and been diagnosed with HIV, but it is unknown whether or not the client has advanced to AIDS; (3) CDC-defined AIDS—client has advanced to and been diagnosed with CDC-defined AIDS; (4) HIV-negative (affected)—client is HIV-negative and is an affected individual of an HIV-positive friend or family member; and (5) unknown—HIV/AIDS status of the client is unknown and not documented.  |
| HIV counseling and testing                | The delivery of HIV counseling to an individual. Counseling includes pretest and posttest counseling activities (e.g., offering the individual the HIV antibody test, as appropriate; services discussing the benefits of testing, including the medical benefits of diagnosing HIV disease in the early stages and of receiving early intervention primary care; reviewing the provisions of laws relating to confidentiality, including information regarding any disclosures that may be authorized under applicable law, and information regarding the availability of anonymous counseling and testing; and discussing the significance of the results, including the potential for developing HIV disease). Testing refers to antibody tests administered by health professionals to ascertain and confirm the presence of HIV infection (includes ELISA and Western Blot). |
|   | Counseling and testing <u>does not</u> include tests to measure the extent of the deficiency in the immune system because these tests are considered to be fundamental components of comprehensive primary care. This service category excludes mental health counseling/therapy, substance abuse counseling/treatment, and psychosocial support services. These services are listed separately.  |
| HIV disease                               | Any signs, symptoms, or other adverse health effects due to the human immunodeficiency virus.   |
| HIV/EIS                                   | <i>HIV Early Intervention Services/Primary Care</i> —A program that encompasses the care supported by the Title III legislation and is made available by the grantee organization and its subcontractors. Subcontractors render care to clients referred to them by the grantee organization, and are reimbursed for their services, or otherwise have a remunerative relationship with the grantee for the referred service.   |
| Hospital or<br>university-based<br>clinic | Includes ambulatory/outpatient care departments or clinics, emergency rooms, rehabilitation facilities (physical, occupational, speech), hospice programs, substance abuse treatment programs, STD clinics, AIDS clinics, and inpatient case management service programs.   |

| HRSA   | <i>Health Resources and Services Administration</i> —The DHHS agency that is responsible for directing national health programs that improve the Nation's health by assuring equitable access to comprehensive, quality health care for all. HRSA works to improve and extend life for people living with HIV/AIDS, provide primary health care to medically underserved people, serve women and children through State programs, and train a health workforce that is both diverse and motivated to work in underserved communities. HRSA is also responsible for administering the Ryan White CARE Act. |
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| IDU  | Injection drug user   |
| Infected client                                | An individual who is HIV positive who receives at least one Ryan White CARE Act-eligible service during the reporting period.   |
| Lead agency                                    | The agency responsible for contract administration; also called a fiscal agent. An incorporated consortium sometimes serves as the lead agency.   |
| Legal services                                 | The provision of services to individuals with respect to powers of attorney, do not resuscitate orders, wills, trusts, bankruptcy proceedings, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under CARE Act. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.   |
| Local, county or<br>State health<br>department | Publicly funded health department administered by a local, county, or State government.   |
| Manufacturers'<br>rebates                      | Dollars received from drug manufacturers, which represent a percentage of the cost of the drug.   |
| Medicaid                                       | A jointly funded, Federal-State health insurance program for certain low-income and needy people.   |
| Medicare                                       | A health insurance program for people 65 years of age and older, some disabled people under 65 years of age, and people with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant).  |
| Mental health<br>services                      | Psychological and psychiatric treatment and counseling services, for individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.   |
| More than one race                             | A person who identifies with more than one racial category.   |
| Native Hawaiian or<br>Other Pacific Islander   | A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.  |
| NDC  | <i>National Drug Code</i> —The identifying drug number maintained by the FDA. For purposes of the Section 340B Drug Discount Program, the NDC number is used including labeler code (which is assigned by the FDA and identifies the establishment), product code (which identifies the specified product or formation), and package size code when reporting requested information.  |
| New clients                                    | Persons who received services from a provider for the first time ever during this reporting period.<br>Individuals who returned for care after an extended absence are not considered to be new unless past records of their care are not available.  |
| Non-permanent                                  | Includes persons who are homeless, as well as transient or in transitional housing. Homeless includes shelters, vehicles, the streets, or other places not intended as a regular accommodation for sleeping. Transitional housing includes any stable but temporary living arrangement, regardless of whether or not it is part of a formal program.  |
| Nutritional counseling                         | Services provided by a licensed registered dietitian outside of a primary care visit. Nutritional counseling provided by other than a licensed/registered dietitian should be recorded under "Psychosocial support services."   |

| OI  | <i>Opportunistic infection</i> —An infection or cancer that occurs in persons with weak immune systems due to AIDS, cancer, or immunosuppressive drugs such as corticosteroids or chemotherapy. Karposi's Sarcoma (KS), pneumocystis pneumonia (PCP), toxoplasmosis, and cytomegalovirus are all examples of opportunistic infections.  |
|---|---|
| ОМВ   | <i>Office of Management and Budget</i> —The office within the executive branch of the Federal government, which prepares the President's annual budget, develops the Federal government's fiscal program, oversees administration of the budget, and reviews government regulations.  |
| Oral health care                                  | Includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.  |
| OSE   | <i>Office of Science and Epidemiology</i> —The office within HRSA's HIV/AIDS Bureau that administers the SPNS Program, HIV/AIDS evaluation studies including the CDP, and the CARE Act Data Report.   |
| Other community-<br>based service<br>organization | Includes non-hospital-based organizations, AIDS service and volunteer organizations, private non-<br>profit social service and mental health organizations, hospice programs (home and residential),<br>home health care agencies, rehabilitation programs, substance abuse treatment programs, case<br>management agencies, and mental health care providers.  |
| Outreach services                                 | Include programs which have as their principal purpose identification of people with HIV disease<br>so that they may become aware of, and may be enrolled in, care and treatment services (i.e., case<br>finding), not HIV counseling and testing nor HIV prevention education. Outreach programs must<br>be planned and delivered in coordination with local HIV prevention outreach programs to avoid<br>duplication of effort; be targeted to populations known through local epidemiologic data to be at<br>disproportionate risk for HIV infection; be conducted at times and in places where there is a high<br>probability that HIV-infected individuals will be reached; and be designed with quantified program<br>reporting that will accommodate local effectiveness evaluation. |
| Outside the EIS<br>Program                        | A referral made to a provider that (1) is not part of the grantee organization; (2) does not have a contractual relationship with the grantee; and (3) does not receive reimbursement from the Title III grantee or its parent organization.  |
| Patients  | All individuals with HIV infection who received at least one primary health care service during the reporting period.   |
| Permanency<br>planning                            | The provision of services to help clients or families make decisions about placement and care of minor children after the parents/caregivers are deceased or are no longer able to care for them.   |
| Permanent housing                                 | Includes apartments, houses, foster homes, long-term residences, and boarding homes, as long as they are not time limited.  |
| PHSA  | Public Health Service Act.  |
| PLWHA   | People living with HIV/AIDS.  |
| PLWHA coalition                                   | Organizations of people living with HIV/AIDS that provide support services to individuals and families affected by HIV and AIDS.  |
| Primary health care service                       | Any preventive, diagnostic, or therapeutic health service received on an outpatient basis by a patient who is HIV positive. Examples include medical, subspecialty care, dental, nutrition, mental health or substance abuse treatment, and pharmacy services; radiology, laboratory, and other tests used for diagnosis and treatment planning; and counseling and testing.  |
| Private health insurance                          | Health insurance plans such as Blue Cross/Shield, Kaiser Permanente, Aetna, etc.  |
| Private, for-profit<br>ownership                  | The organization is owned and operated by a private entity, even though the organization may receive government funding. A privately owned hospital is an example of a private, for-profit organization.  |

| Private, nonprofit<br>(not faith-based)            | The organization is owned and operated by a private, not-for-profit, non-religious-based entity, such as a non-profit health clinic.  |
|--|---|
| Prophylaxis  | Treatment to prevent the onset of a particular disease (primary prophylaxis) or recurrence of symptoms in an existing infection that has been brought under control (secondary prophylaxis).  |
| Provider agency/<br>serviœ provider                | The agency that provides direct services to clients (and their families) that are funded by the Ryan White CARE Act. Services may be funded through one or more Federal Ryan White CARE Act grants, or through subcontract(s) with official Ryan White CARE Act grantees. A provider may also be a grantee such as in Titles III and IV.  |
| Psychosocial<br>support services                   | The provision of support and counseling activities, including alternative services (e.g., visualization, massage, art, music, play, and other rehabilitation therapies), child abuse and neglect counseling, HIV support groups, pastoral care, recreational outings, caregiver support, and bereavement counseling. Includes other services not included in mental health, substance abuse, or nutritional counseling that are provided to clients, family and household members, and/or other caregivers and focused on HIV-related problems.   |
| Public/Federal<br>ownership                        | The organization is funded by the Federal government and is operated by Federal government employees. A Federal agency is an example of a publicly owned organization.  |
| Public/local<br>ownership                          | The organization is funded by a local government entity and is operated by local government employees. Local health departments are examples of publicly owned organizations.   |
| Public/State<br>ownership                          | The organization is funded by a State government entity and is operated by State government employees. A State health department is an example of a publicly owned organization.  |
| Publicly funded<br>community health<br>center      | Includes community health centers, migrant health centers, rural health centers, and homeless health centers.   |
| Referral for health<br>care/supportive<br>services | The act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made formally from one clinical provider to another, within the case management system by professional case managers, informally through support staff, or as part of an outreach program.   |
| Referral to clinical research                      | The provision of education about and linkages to clinical research services through academic research institutions or other research service providers. Clinical research involves studies in which new treatments—drugs, diagnostics, procedures, vaccines, and other therapies—are tested in people to see if they are safe and effective. All institutions that conduct or support biomedical research involving people must, by Federal regulation, have an IRB that initially approves and periodically reviews the research.  |
| Referrals for health services                      | The act of directing a patient who is HIV positive to a health service not available within an EIS program. For the purposes of Title III data reporting, the process of making a referral is independent of the health service provided, and does not require evidence that the patient actually received the service for which he or she was referred. However, if the service that the patient is being referred for is paid for by the EIS program, then the cost of providing referral services should be reported. Title III funds can be used to pay for the costs associated with making the referral, as well as to pay for the services for which the patient services provided outside of the EIS Program. Case management and other referrals for social or support services should not be reported in the Referrals Section, nor should they be factored into the cost of providing referral services. Examples of health services for which patients may be referred outside of the EIS Program include primary health care or specialty health services, any diagnostic health services such as radiology, lab tests, mental health evaluations, biopsies, and so forth. |

| Rehabilitation<br>services                           | Services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.  |
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| Reporting period                                     | A calendar year, January 1 through December 31 of the reporting year. The reporting period may be shorter than a year if a provider agency did not receive CARE Act Title funding for an entire calendar year.  |
| Residential or in-<br>home hospice care              | Room, board, nursing care, counseling, physician services, and palliative therapeutics provided to patients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal patients.  |
| Retrovirus   | A type of virus that, when not infecting a cell, stores its genetic information on a single-stranded RNA molecule instead of the more usual double-stranded DNA. HIV is an example of a retrovirus. After a retrovirus penetrates a cell, it constructs a DNA version of its genes using a special enzyme, reverse transcriptase. This DNA then becomes part of the cell's genetic material.  |
| Risk factor or risk<br>behavior/exposure<br>category | Behavior or other factor that places a person at risk for disease. For HIV/AIDS, this includes such factors as male-to-male sexual contact, injection drug use, and commercial sex work.  |
| Section 330 of PHSA                                  | Supports the development and operation of community health centers that provide preventive and primary health care services, supplemental health and support services, and environmental health services to medically underserved areas/populations.  |
| Self-pay   | Client paid for the majority of his or her own care.  |
| Solo/group private medical practice                  | Includes all health and health-related private non-profit practitioners and practice groups.  |
| SPNS   | <i>Special Projects of National Significance</i> —A health services demonstration, research, and evaluation program funded under Part F of the CARE Act. SPNS projects are awarded competitively.   |
| STI  | Sexually transmitted infection— Infections spread by the transfer of organisms from person to person during sexual contact.   |
| Substance abuse treatment center                     | An agency that focuses on the delivery of substance abuse treatment services.   |
| Substance abuse services-outpatient                  | The provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal or illegal drugs) provided in outpatient setting rendered by a physician or under the supervision of a physician, or other qualified personnel.   |
| Substance abuse services-residential                 | The provision of treatment to address substance abuse (including alcohol and/or legal and illegal drugs) problems provided in an inpatient health service setting (short term).   |
| Target population                                    | A population to be reached through some action or intervention; may refer to groups with specific demographic or geographic characteristics.  |
| TB skin test (PPD<br>Mantoux)                        | The abbreviation for purified protein derivative, a substance used in intradermal testing for tuberculosis.   |
| Title I  | The part of the Ryan White CARE Act that provides direct financial assistance to designated<br>Eligible Metropolitan Area (EMAs) that have been the most severely affected by the HIV<br>epidemic. The purpose of these funds is to deliver or enhance HIV-related: (1) outpatient and<br>ambulatory health and support services, including case management and comprehensive treatment<br>services for individuals and families with HIV disease; and (2) inpatient case management services<br>that prevent unnecessary hospitalization or that expedite discharge, when medically appropriate,<br>from inpatient facilities. |

| Title II                      | The part of the Ryan White CARE Act that authorizes the distribution of Federal funds to States<br>and Territories to improve the quality, availability, and organization of health care and support<br>services for individuals with HIV disease and their families. The CARE Act emphasizes that such<br>care and support is part of a continuum of care in which all the needs of individuals with HIV<br>disease and their families are coordinated. The funds are distributed among States and Territories<br>based, in part, on the number of AIDS cases in each State (or Territory) as a proportion of the<br>number of AIDS cases reported in the entire United States. |
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| Title III                     | The part of the Ryan White CARE Act that provides support for early intervention services, including preventive, diagnostic, and therapeutic services for HIV/AIDS clients. This particularly includes a continuum of comprehensive primary health care, referrals for specialty care, counseling and testing, outreach, case management, and eligibility assistance.  |
| Title IV                      | The part of the Ryan White CARE Act that supports coordinated services and access to research for children, youth, and women with HIV disease and their affected family members.   |
| Transmission<br>category      | A grouping of disease exposure and infection routes. In relation to HIV disease, exposure groupings include injection drug use, men who have sex with men, heterosexual contact, perinatal transmission, etc.  |
| Transportation services       | Conveyance services provided, directly or through voucher, to a client so that he or she may access health care or support services.   |
| Treatment adherence services  | Provision of counseling or special programs to ensure readiness for, and adherence to, complex HIV/AIDS treatments.  |
| Unduplicated client count     | An accounting of clients in which a single individual is counted only once. For providers with multiple sites, a client is only counted once, even if he or she receives services at more than one of the provider's sites.  |
| Unique record<br>number (URN) | Nine-digit encrypted record number following HRSA's URN specifications that distinguishes the client from all other clients and that is the same for the client across all provider settings. The URN is constructed using the first letter of the first name, the third letter of the first name (if blank use middle initial, if no middle initial use '9'), first letter of the last name, third letter of the last name (if blank, use '9'), month of birth, day of birth, and gender code. This string is then encrypted using a HRSA-supplied algorithm that can be incorporated into the provider's data collection system.   |
| VA facility                   | Any facility funded through the Veterans Administration.   |
| Viral load test               | A test that measures the quantity of HIV RNA in the blood. Results are expressed as the number of copies per milliliter of blood plasma. This test is employed as a predictor of disease progression.  |
| White                         | A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.  |