Quick Reference Handout 10.1: PC/PB Guide to Data Types and Sources

HIV SURVEILLANCE AND RELATED DATA

Epidemiologic (Epi) Profile

Source and Frequency

Who Provides the Data and How Often

- State or local surveillance staff—prepared annually
- Epi profile for the EMA/TGA may be included in an annual state profile or prepared separately

Typical Content

What Kinds of Data/Information are Included

A description of the distribution of HIV in various populations in the EMA or TGA in terms of sociodemographic, geographic, behavioral, and clinical characteristics:

- Characteristics of the general population, persons newly diagnosed with HIV infection, persons living with HIV disease, and persons at risk for HIV
- Trends in the epidemic

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PB understand the epidemic and identify trends that will affect service needs overall and for particular PLWH groups
- Changes over time help in understanding impact of prevention and care services

For More Information

- CDC and HRSA agreed some years ago on guidelines for a joint epi profile for HIV prevention and care based on calendar year data. Integrated Guidance last updated in August 2014 and available at: www.cdc.gov/hiv/pdf/guidelines_developing_epidemiologic_profiles.pdf

HIV SURVEILLANCE AND RELATED DATA

HIV Care Continuum

Source and Frequency

Who Provides the Data and How Often

- Continuum for all PLWH in the service area is usually prepared by state or local surveillance staff
- The recipient is often involved in preparation of continuums for RWHAP clients since they require use of client data
- Provided at least annually; some jurisdictions prepare them more frequently

Typical Content

What Kinds of Data/Information are Included

- A model of HIV medical care that shows the steps or stages of HIV care that PLWH go through and the percent of PLWH in each stage as of a specific date
- May begin with the estimated total number of people living with HIV (including those unaware of their status) or with the number diagnosed and living with HIV
- Typical stages in the continuum include:
  1. Being diagnosed with HIV
  2. Being linked to care
  3. Engagement and retention in care (based on doctor visits and/or laboratory tests), and viral suppression (a very low level of HIV in the body)
- Sometimes being prescribed antiretroviral therapy (ART) is included as a stage/step prior to viral suppression
- PC/PB often receives both a continuum for all PLWH, and a separate continuum for RWHAP clients, often with multiple break-downs by subpopulation

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PBs understand strengths and weaknesses in the system of care and identify need for additional attention to particular steps (e.g., linkage to care, retention in care, viral suppression)
- Population-specific continuums are very helpful in identifying HIV-related health disparities so that the PC/PB can strengthen service models at a particular stage in the continuum for a particular population to address late linkage, poor retention, or a lower rate of viral suppression

For More Information

- "Understanding the HIV Care Continuum," (including the national continuum) available at: www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf

HIV SURVEILLANCE AND RELATED DATA

HIV Tests and Diagnoses

Source and Frequency

Who Provides the Data and How Often

- State or local surveillance unit and State and/or local HIV prevention unit—usually provided to the PC/PB annually, but may be available more frequently

Typical Content

What Kinds of Data/Information are Included

- Includes data on:
  - *Number of people who receive HIV tests*
  - *Number and percent testing positive and their characteristics*
  - *Number referred to needed services*
- RWHAP Part A programs required to implement a strategy for the Early Identification of Individuals with HIV/AIDS (EIIHA), which involves identifying key target populations, locating individuals with HIV who do not know their HIV status, informing them of their status through testing, and helping link them to medical care and support services—so data are reported on these populations

Typical Use

How PC/PBs Use this Data for Decision Making

- Provides data needed to predict future demand for care and the need to fund services like Outreach and Early Intervention Services (EIS), which help get people tested, and linked to care

For More Information

- For a description and implementation guidance for EIS and Outreach services, see Policy Clarification Notice (PCN) 16-02 available at: hab.hrsa.gov/sites/default/files/hab/program-grants-management/ServiceCategoryPCN_16-02Final.pdf
- CDC recommendations and other information about HIV testing are summarized at: www.cdc.gov/hiv/testing/index.html

HIV SURVEILLANCE AND RELATED DATA

Estimate of Unmet Need

Source and Frequency

Who Provides the Data and How Often

- State or local surveillance unit usually provides the estimate and often provides data on the characteristics of PLWH who are out of care, generally using primarily surveillance data—depending on federal requirements—usually prepared or updated annually for inclusion in the annual RWHAP Part A application
- Assessment of unmet need done by the PC/PB as part of its assessment of service needs and barriers

Typical Content

What Kinds of Data/Information are Included

- Estimate of the number of people living with HIV in the service area who know they are HIV-positive but are not receiving HIV-related medical care
- Often provided with the estimate is a description of characteristics of people who are out of care—usually race/ethnicity, age, sex, risk factor, place of residence within the EMA or TGA, year of first diagnosis, and sometimes date of most recent laboratory test

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PB understand how many PLWH are out of care and what PLWH subpopulations are most likely to be out of care, and to explore ways to find such PLWH, link or relink them to care, and improve retention and viral suppression

For More Information

- Requirements for estimating unmet need are updated in each annual RWHAP Part A Notice of Funding Opportunity (NOFO), which is available from the recipient and online
- Part A Manual provides guidance on unmet need in Section XI, Chapter 3: Needs Assessment; available at: hab.hrsa.gov/sites/default/files/hab/Global/happartamanual2013.pdf

NEEDS ASSESSMENT FINDINGS

Service Needs

Source and Frequency
Who Provides the Data and How Often

- PC/PB—usually gathered with involvement of PC/PB support staff and consultants as well as PC/PB members
- PC/PBs often develop a multi-year needs assessment plan with different components implemented each year

Typical Content
What Kinds of Data/Information are Included

- Information about the number, characteristics, and service needs and barriers of people living with HIV, both in and out of care—typically includes both:
  - Quantitative data on service needs, ability to obtain needed services, and service barriers. This quantitative data is collected through surveys or structured interviews with PLWH, including consumers and PLWH who are out of care or receive services through other sources, and other stakeholders.
  - Qualitative or mixed data that provide in-depth perspectives on issues such as service experiences, services, barriers to care, and factors that encourage linkage, treatment adherence, and retention in care. This qualitative data is based on discussions at focus groups, town hall meetings, key informant interviews and discussion sessions.
- A special study is usually required to learn about service barriers and gaps for PLWH who are out of care.

Typical Use
How PC/PBs Use this Data for Decision Making

Provides information needed for decision making for most PC/PB roles, especially for:

- Priority setting and resource allocations (PSRA) including development of directives
- Improving service access, quality, and outcomes overall and for specific populations

For More Information

- May 2018 webinar "Conducting RWHAP Part A Planning Council/Planning Body Needs Assessments"—available at: www.targetHIV.org/planning-chatt/needs-assessments-webinar_may2018
- Training Guide for RWHAP Planning Councils/Planning Bodies, Module 4: Needs Assessment. 2019. Available at: www.targetHIV.org/planning-chatt/module4

NEEDS ASSESSMENT FINDINGS

Service System

Source and Frequency
Who Provides the Data and How Often

- PC/PB—usually gathered with involvement of PC/PB support staff and consultants as well as PC/PB members
- PC/PBs often develop a multi-year needs assessment plan with different components implemented each year

Typical Content
What Kinds of Data/Information are Included

Provider resources available to meet the needs of PLWH, including:

- An inventory of HIV-related core medical and support services, both RWHAP and non-RWHAP funded, providing basic information such as location, services provided, and number of slots
- A profile of provider capacity and capability, including service availability (e.g., available "slots" by service category,) accessibility (e.g., office hours, public transportation), and appropriateness (e.g., language services, training to work with specific subpopulations, cultural competence)

Typical Use
How PC/PBs Use this Data for Decision Making

Provides information needed for decision making for most PC/PB roles, especially for:

- Priority setting and resource allocations (PSRA) including development of directives
- Improving service access, quality, and outcomes overall and for specific populations

For More Information

- May 2018 webinar "Conducting RWHAP Part A Planning Council/Planning Body Needs Assessments"—available at: www.targetHIV.org/planning-chatt/needs-assessments-webinar_may2018
- Training Guide for RWHAP Planning Councils/Planning Bodies, Module 4: Needs Assessment. 2019. Available at: www.targetHIV.org/planning-chatt/module4

NEEDS ASSESSMENT FINDINGS

Service Gaps

Source and Frequency
Who Provides the Data and How Often

- PC/PB—usually gathered with involvement of PC/PB support staff and consultants as well as PC/PB members
- PC/PBs often develop a multi-year needs assessment plan with different components implemented each year

Typical Content
What Kinds of Data/Information are Included

- Linking of PLWH and provider data to identify types of services that are not sufficiently available, accessible, or appropriate to meet the identified needs of PLWH overall or specific populations, in the EMA/TGA

Typical Use
How PC/PBs Use this Data for Decision Making

Provides information needed for decision making for most PC/PB roles, especially for:

- Priority setting and resource allocations (PSRA) including development of directives
- Improving service access, quality, and outcomes overall and for specific populations

For More Information

- May 2018 webinar "Conducting RWHAP Part A Planning Council/Planning Body Needs Assessments"—available at: www.targetHIV.org/planning-chatt/needs-assessments-webinar_may2018
- Training Guide for RWHAP Planning Councils/Planning Bodies, Module 4: Needs Assessment. 2019. Available at: www.targetHIV.org/planning-chatt/module4

RWHAP SERVICES REPORT (RSR)

Client Characteristics and Service Utilization

Source and Frequency

Who Provides the Data and How Often

- Recipient, based on data entered into client-level data system by subrecipients—data reported for the RWHAP Services Report (RSR), which includes calendar-year data, and is submitted to HRSA/HAB each year in March

Typical Content

What Kinds of Data/Information are Included

- Data on the characteristics of RWHAP clients, including demographics, HIV clinical information, HIV medical and support services received
- Data on the number and characteristics of RWHAP Part A clients overall and by service category
- Data on the level of services provided overall and by service category, including units of service provided

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PBs understand demand for specific services and identify differences in use of services by various PLWH groups

For More Information

- For information on the contents and uses of the RSR, see the description at: hab.hrsa.gov/program-grants-management/ryan-white-hivaids-program-services-report-rsr
- For national and state-level reports developed from the RSR covering all RWHAP Parts, see "Data Reports and Slide Decks," including annual client-level data reports, at: hab.hrsa.gov/data/data-reports

OTHER DATA FROM THE RECIPIENT

Service Expenditure and Cost Data

Source and Frequency

Who Provides the Data and How Often

- Recipient—from its internal financial management staff/system—usually includes monthly and annual reports

Typical Content

What Kinds of Data/Information are Included

- Projected (allocated and contracted) and actual expenditures for each Part A-funded service category: all core medical services, all support services, and all services, year-to-date
- Proportion of funds spent to date and whether expenditures are at, below, or above projections (for example: after 6 months, would expect 50% of funds to have been spent)
- Costs for one unit of service (for example: one 15-minute visit with a clinician or one 30-minute meeting with a medical case manager), often provided annually
- Annual cost to serve one client by service category calculated at the end of the year

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PB determine the need for reallocations across service categories during the program year
- Helps PC/PB make funding decisions as part of priority setting and resource allocation, adjust future allocations based on actual use of funds and estimate the costs of serving additional clients—for example:
  - Review of service categories that end the year over- or under-expended helps the PC/PB determine the level of demand for a particular service and whether it may need more or less funding in the future
  - Per client costs can be used in projecting funds required for increasing service levels

OTHER DATA FROM THE RECIPIENT

Clinical Quality Management (CQM) Findings

Source and Frequency

Who Provides the Data and How Often

- Recipient—data obtained through the CQM program by subrecipients working with the recipient. Performance measurement occurs at least quarterly, with summary data reported to the PC/PB at least annually.

Typical Content

What Kinds of Data/Information are Included

- Information on patient care, health outcomes, and patient satisfaction
- Data on performance measures by provider and within and across service categories (for example: what percent of outpatient ambulatory health services clients received a mental health screening; what percent of female clients received an annual pap smear); includes data showing disparities across different target populations
- Data on client HIV viral suppression and other health outcomes
- Data from quality improvement programs documenting changes made to improve services

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PBs identify program strengths and weaknesses and possible need for changes in service models or funding to improve service quality and outcomes

For More Information

- For HRSA/HAB guidance on CQM, see Policy Clarification Notice 15-02 on Clinical Quality Management, available at: hab.hrsa.gov/sites/default/files/hab/Global/clinicalqualitymanagementpcn.pdf

OTHER DATA FROM THE RECIPIENT

Performance and Clinical Outcomes

Source and Frequency

Who Provides the Data and How Often

- Recipient—data obtained through the CQM program by subrecipients working with the recipient. Performance measurement occurs at least quarterly, with summary data reported to the PC/PB at least annually.

Typical Content

What Kinds of Data/Information are Included

- Data used to monitor and improve the quality of care across the EMA/TGA and within service provider organizations, usually based on the percent of clients that meet the goal or service standard
- Measures may relate to a process (such as frequency of medical visits or development of a case management care plan) or clinical outcome (such as viral suppression)

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PBs make funding decisions and identify needed changes in service standards or models of care

For More Information

- HRSA/HAB has developed a performance measure portfolio focusing on "critical areas of HIV care and treatment" and aligned with the steps along the HIV care continuum; recipients use this portfolio to choose performance measures. Available at: hab.hrsa.gov/clinical-quality-management/performance-measure-portfolio

DATA FROM OTHER PROGRAMS

Centers for Disease Control and Prevention HIV Prevention

Source and Frequency
Who Provides the Data and How Often

- State and local agencies responsible for HIV prevention; often in the same local government unit as RWHAP

Typical Content
What Kinds of Data/Information are Included

- Data on funds for services such as HIV education, testing, linkage to care/partner notification, and prevention including prevention for positives

Typical Use
How PC/PBs Use this Data for Decision Making

- Supports coordination of funding and services, especially in such service areas as Outreach, Early Intervention Services, and Health Education/Risk Reduction

For More Information

- See the 2018 Fact Sheet on "Integrated HIV Surveillance and Prevention Funding for Health Departments," at: www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/cdc-hiv-ps18-1802-factsheet.pdf

Medicaid

Source and Frequency
Who Provides the Data and How Often

- State Medicaid agency, usually provided annually or upon request

Typical Content
What Kinds of Data/Information are Included

- Data on Medicaid expenditures for PLWH in the service area, services provided, and number and characteristics of PLWH clients; includes total expenditures and expenditures by type of service, or for core medical versus support services

Typical Use
How PC/PBs Use this Data for Decision Making

- Helps PC/PBs determine the level and sources of other funding for HIV services and avoid duplication of effort

For More Information

- Medicaid programs are run by the states and very considerably in services provided; nationally, Medicaid is the largest single source of coverage for PLWH; for a summary of its importance, see the one-page Fact Sheet, "Medicaid's Role for Individuals with HIV," prepared by the Kaiser Family Foundation, at: files.kff.org/attachment/Infographic-Medicaids-Role-for-Individuals-with-HIV

DATA FROM OTHER PROGRAMS

Housing Opportunities for Persons With AIDS (HOPWA)

Source and Frequency
Who Provides the Data and How Often

- Department of Housing and Urban Development (HUD) and regional or local recipients or subrecipients, usually obtained annually

Typical Content
What Kinds of Data/Information are Included

- Data on number of PLWH receiving housing assistance through HOPWA, type of assistance received, client characteristics, and waiting lists

Typical Use
How PC/PBs Use this Data for Decision Making

- Helps PC/PBs determine the level and sources of other funding for HIV services and avoid duplication of effort

For More Information

- See the HUD website, HIV/AIDS Housing, at: www.hud.gov/program_offices/comm_planning/aidshousing

Substance Abuse and Mental Health Services

Source and Frequency
Who Provides the Data and How Often

- Substance Abuse and Mental Health Services Administration (SAMHSA) and state and/or local recipients and subrecipients, usually obtained annually

Typical Content
What Kinds of Data/Information are Included

- Funding awarded for mental health services and for substance abuse services that target PLWH, including number of agencies/programs funded, number of PLWH served through such programs, types of services, and sometimes client characteristics

Typical Use
How PC/PBs Use this Data for Decision Making

- Helps PC/PBs determine the level and sources of other funding for HIV services and avoid duplication of effort

For More Information

- Description and links to SAMHSA's behavioral health (mental health and substance use disorder) services. Available at: www.samhsa.gov/programs

DATA FROM OTHER PROGRAMS

State and Local HIV Funding

Source and Frequency

Who Provides the Data and How Often

- State HIV agency; city or county HIV agency — both usually a part of the Department of Health

Typical Content

What Kinds of Data/Information are Included

- Amount of funding awarded for HIV services, overall and by type of service, number of funded agencies, number of PLWH served, and characteristics of clients if available

Typical Use

How PC/PBs Use this Data for Decision Making

- Helps PC/PBs determine the level and sources of other funding for HIV services and avoid duplication of effort

For More Information

- Non-RWHAP state HIV funding comes from various sources, especially drug rebates from the 340(b) Drug Discount Program
- State and local governments may provide general revenues or earmarked funds for HIV prevention and care