Using Data for Decision Making: Part 1

May 23, 2019

2:00 PM - 3:30 PM ET

Molly Tasso (Planning CHATT)

Jesse Carter (Planner, HIV/STD Prevention and Care Branch, Texas Department of State Health Services)

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Community HIV/AIDS Technical Assistance & Training

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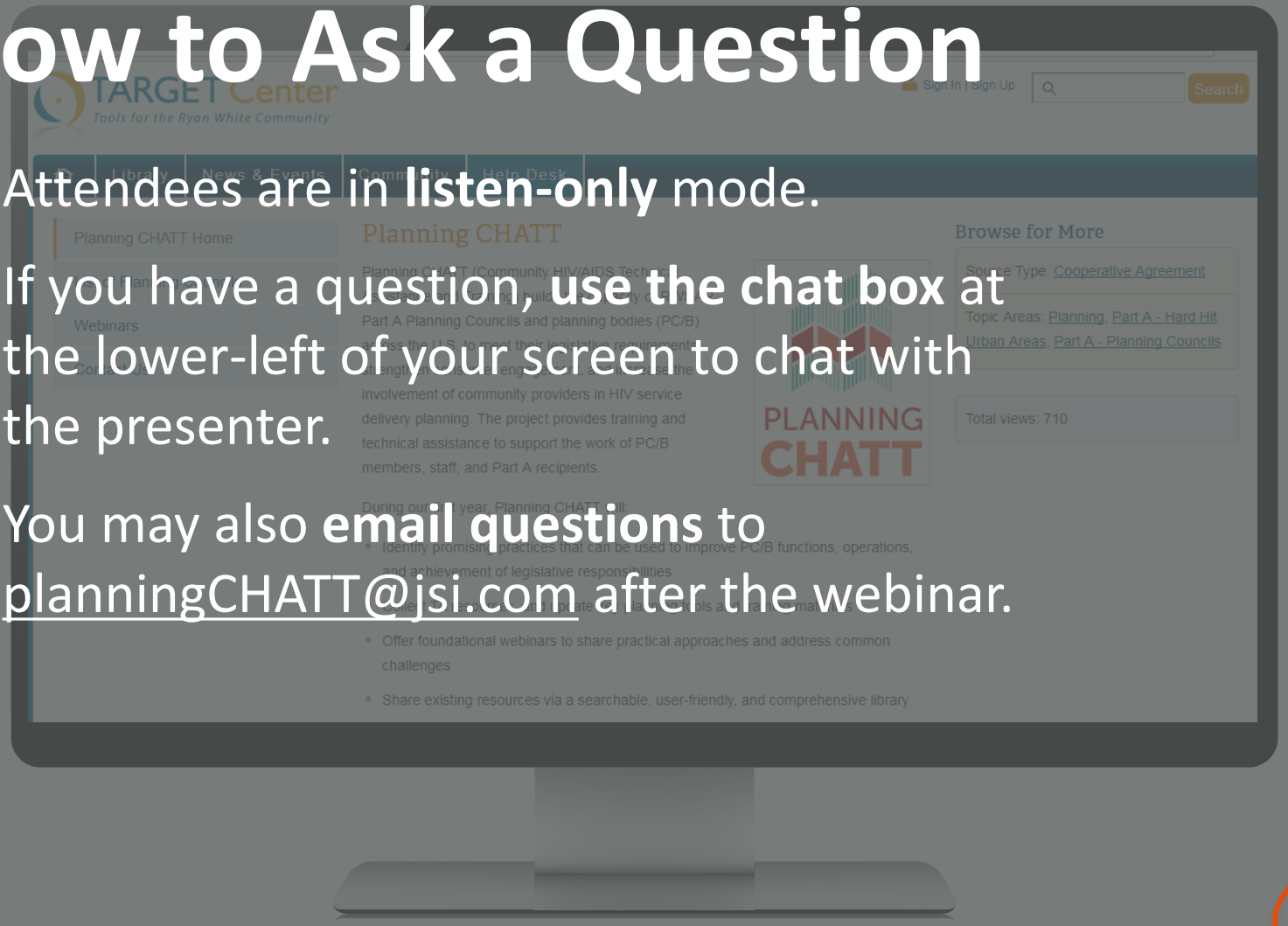
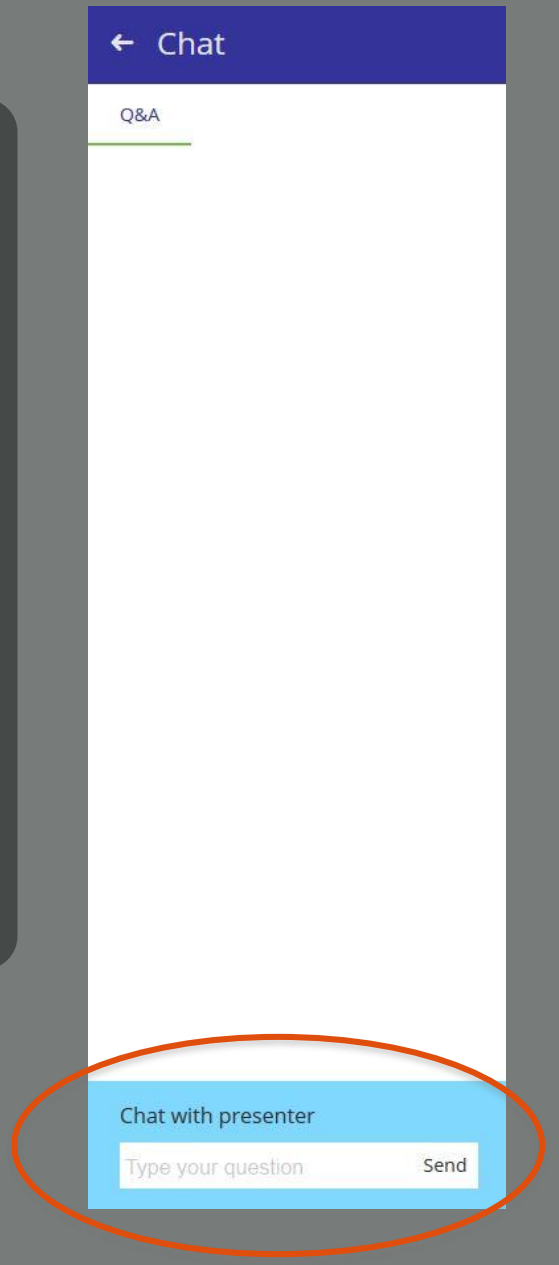
How to Ask a Question

- Attendees are in **listen-only** mode.
- If you have a question, **use the chat box** at the lower-left of your screen to chat with the presenter.
- You may also **email questions** to planningCHATT@jsi.com after the webinar.





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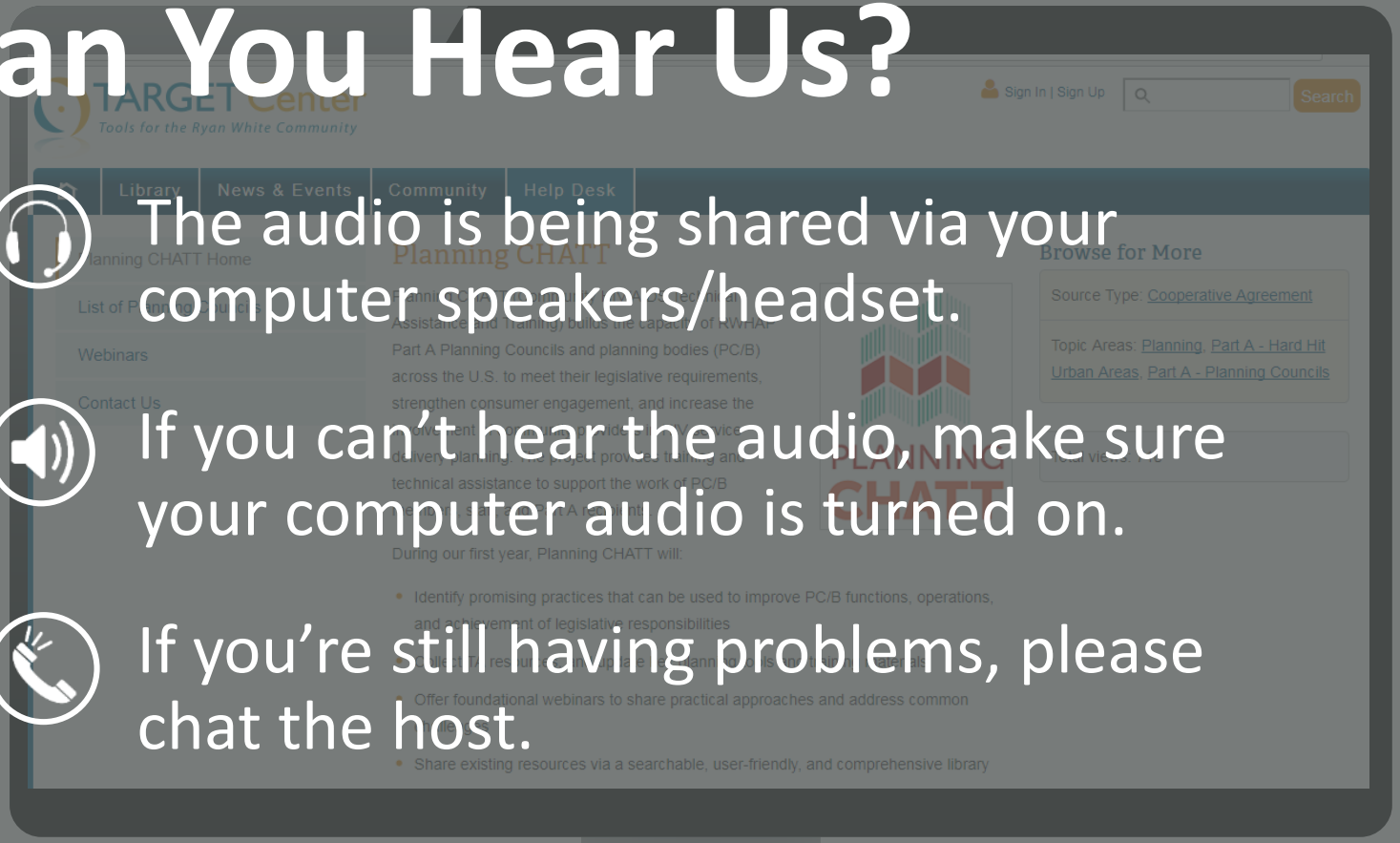

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Agenda

1. Importance of Data in RWHAP Planning
2. Types and Sources of Data Commonly Used for RWHAP Planning
3. Addressing Gaps in Data
4. Assessing Data Quality and Usefulness
5. Importance of Using Multiple Data Sources for Decision Making
6. Resources
7. Questions and answers

Objectives

By the end of the webinar, you will be able to:

- Articulate the benefits of using data for HIV planning and decision making.
- Define important data-related terminology.
- Identify and describe types of data PC/PBs use for HIV planning and decision making.
- Assess quality and comprehensiveness of data.

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Community HIV/AIDS
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Community HIV/AIDS Technical Assistance and Training (Planning CHATT) Project

- Planning CHATT builds the capacity of Ryan White HIV/AIDS Program (RWHAP) Part A planning councils/planning bodies and planning bodies (PC/PB) across the U.S.
- Our goal is to help PC/PB to meet legislative requirements, strengthen consumer engagement, and increase the involvement of community providers in HIV service delivery planning.

Webinar Presenters

- **Molly Tasso**

  Planning CHATT

- **Jesse Carter**

  Planner, HIV/STD Prevention and Care Branch
  Texas Department of State Health Services

Importance of Data in RWHAP Planning

"Without data, all anyone has are opinions. Data elevates the probability that you'll make the right decision."

– W. Edwards Deming

What is Data-based Decision Making?

- **Definition:** Decision making that is guided and supported by documented information – data – rather than based primarily or solely on personal experience, observation, anecdotes, or intuition/insight
- Data used by PC/PBs should include:
  - *Quantitative and/or qualitative information obtained and reviewed systematically using sound methods*
  - *Information from multiple sources, gathered using several different approaches*
- Some experts prefer the term “data-informed” decision making, since decisions are based on multiple factors

Qualitative v. Quantitative Data

- **Quantitative data:** Information that can be expressed in numbers, counted, or compared on a scale – such as epi data or PLWH survey data
- **Qualitative data:** Information that cannot easily be measured or expressed in numbers – such as narrative data from a focus group, consumer town hall meeting, open-ended interview, or direct observations
  - *Usually described in terms of common themes and patterns of response*
  - *Often complement and help explain quantitative data*

Poll

Why is it important to use data for HIV planning?
(select all that apply)

- ❑ Helps establish, support, and improve systems of care.
- ❑ Data guide important HIV planning processes.
- ❑ Helps make accurate and appropriate planning decisions.
- ❑ Helps avoid decision making based on ‘impassioned pleas’.
- ❑ All of the above

Importance of Data

- **Data-based decision making is essential** to establishing, supporting, and improving a system of quality care
- **Data guide the entire planning process** – essential for all PC/PB roles:
  - Understanding service needs, barriers, and gaps in your service area – overall and for PLWH subpopulations
  - Making sound decisions about use of available funds
  - Targeting funds to particular service models, geographic areas, and PLWH subpopulations
  - Improving care for disproportionately affected groups

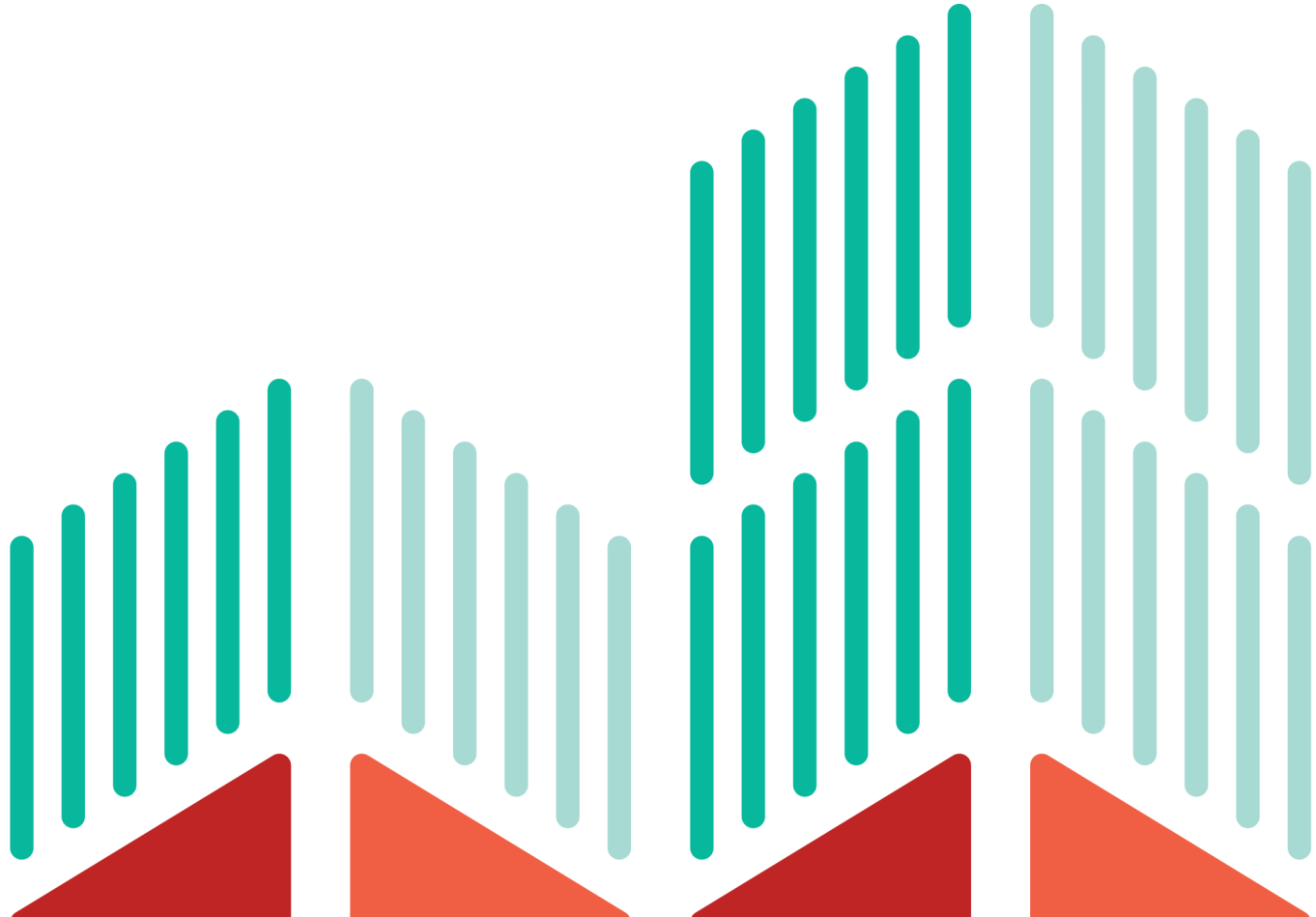
Challenges of Using Data

- Everyone uses data in daily life, but people new to community planning may have limited experience in use of data for planning decisions
- Most PC/PB members need training on HIV-related data terms, data sources, and how to assess and use data
- Data are not always presented in user-friendly formats
- Full discussion and review of new data and analyses require time and effort

Discussion

What are some of your PC/PB’s challenges in using data for HIV planning? Chat in answer.

How PC/PBs Use Data to Illuminate and Address Disparities



Four Common Types of Disparities Addressed Through HIV Planning

- Unmet need
- Service gaps
- Availability of services
- Geographic disparities

Unmet Need

- **What it is:** Refers to individuals with HIV in a jurisdiction who know their status but are not receiving HIV-related medical care
- **How it's measured:** Estimate based on a HRSA/HAB Unmet Need Framework, now being updated – basic approach:
  - *Determine the number of PLWH in the jurisdiction through surveillance data*
  - *Subtract the number who are "in care" based on measures like viral load or CD4 count – the rest are assumed to be out of care and have unmet need.*
- **How it can be addressed with HIV planning:** Provide funding for service categories and help develop strategies that link PLWH to care immediately after diagnosis and for find, relink, and retain in care those who dropped out

Service Gaps

- **What it is:** The identified unfulfilled need for HIV- related services other than primary medical care among individuals who know their HIV status and live in a specified geographic area.
  - *This term is used to avoid confusion with the HAB definition of "unmet need" as referring to primary medical care.*
- **How it's measured:** Through needs assessment & recipient data
  - *A PLWH survey asking what services they needed but didn't receive*
  - *Recipient identification of services with waiting lists or appointment delays*
- **How it can be addressed with HIV planning:** Provide funding or directives designed to make needed services more available

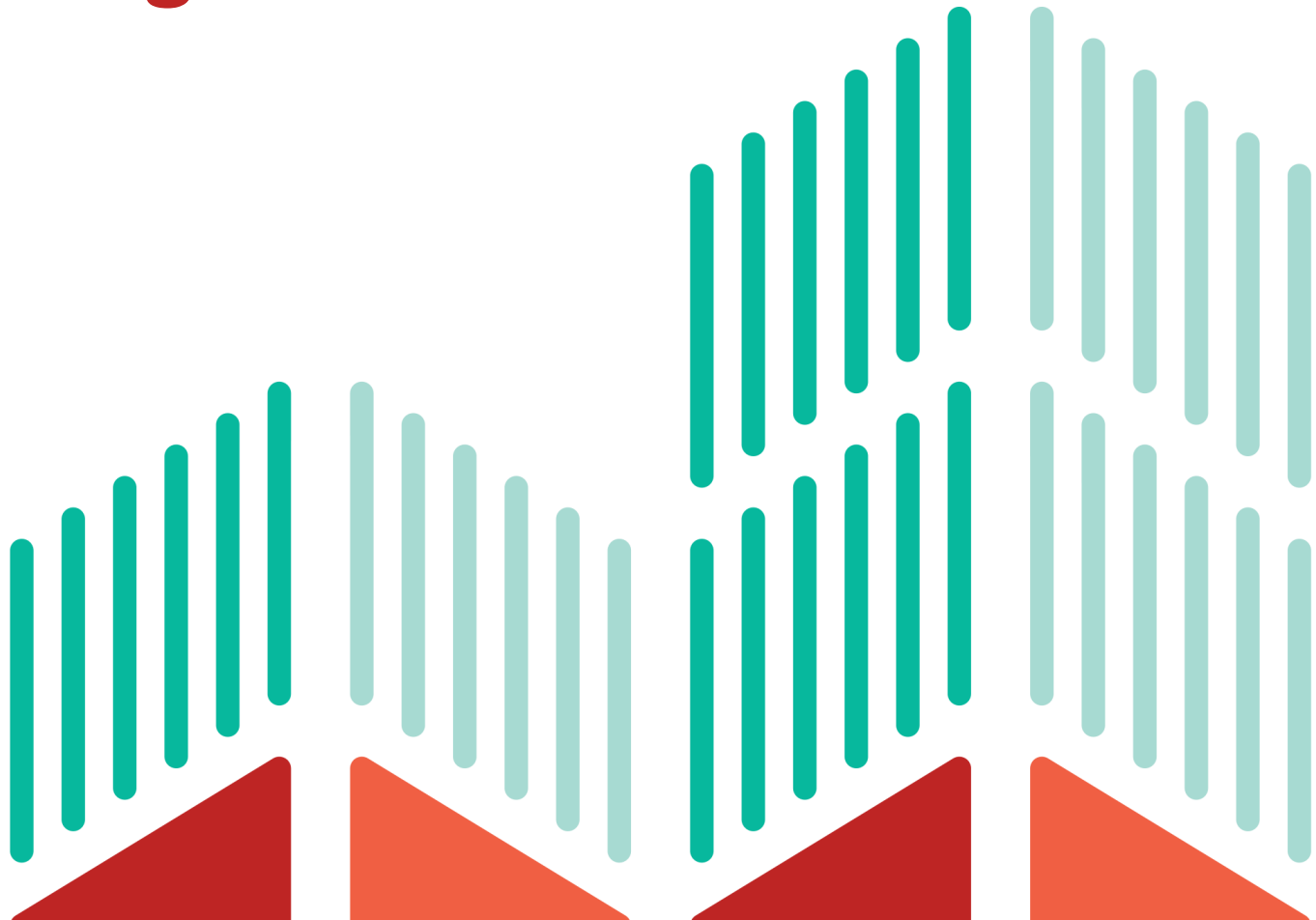
Availability of Services

- **What it is:** Level or number of available “slots” within a service category in a specified geographic area, and whether there are waiting lists
- **How it’s measured:** As part of a Resource Inventory or Profile of Provider Capacity and Capability, asking providers (Part A and non-Part A) how many service slots they have for each HIV service, and whether they have more demand than slots
- **How it can be addressed with HIV planning:** Increase funding for service categories with insufficient slots or explore refined service models

Geographic Disparities

- **What it is:** Differences in access to needed services based on where an individual lives
- **How it's measured:** By comparing the number (or capacity) of service providers offering needed services across geographic areas in the EMA or TGA in an accessible way
- **How it can be addressed with HIV planning:** EMAs and TGAs can use this information, found in the needs assessment, to better understand and address geographic disparities and inequities in access to care.

Types and Sources of Data Commonly Used for RWHAP Planning



Poll

Which of these five data sources are you **MOST comfortable** working with (select one)?

- ❑ Epidemiologic Profile Data
- ❑ Care Continuum Data
- ❑ Needs Assessment Data
- ❑ Resource Inventory
- ❑ Service Expenditure and Cost Data
- ❑ Client Characteristics & Service Utilization Data

Poll

Which of these five data sources are you **LEAST comfortable** working with (select one)?

- ❑ Epidemiologic Profile Data
- ❑ Care Continuum Data
- ❑ Needs Assessment Data
- ❑ Resource Inventory
- ❑ Service Expenditure and Cost Data
- ❑ Client Characteristics & Service Utilization Data

Epidemiologic Profile

What it is and what it shows:

- A document that describes the burden of HIV on the population of an area including distribution of HIV in various populations in an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics
- Includes characteristics of the general population, persons newly diagnosed with HIV infection, persons living with HIV disease, persons at risk for HIV
- Trends in the epidemic

Where it comes from:

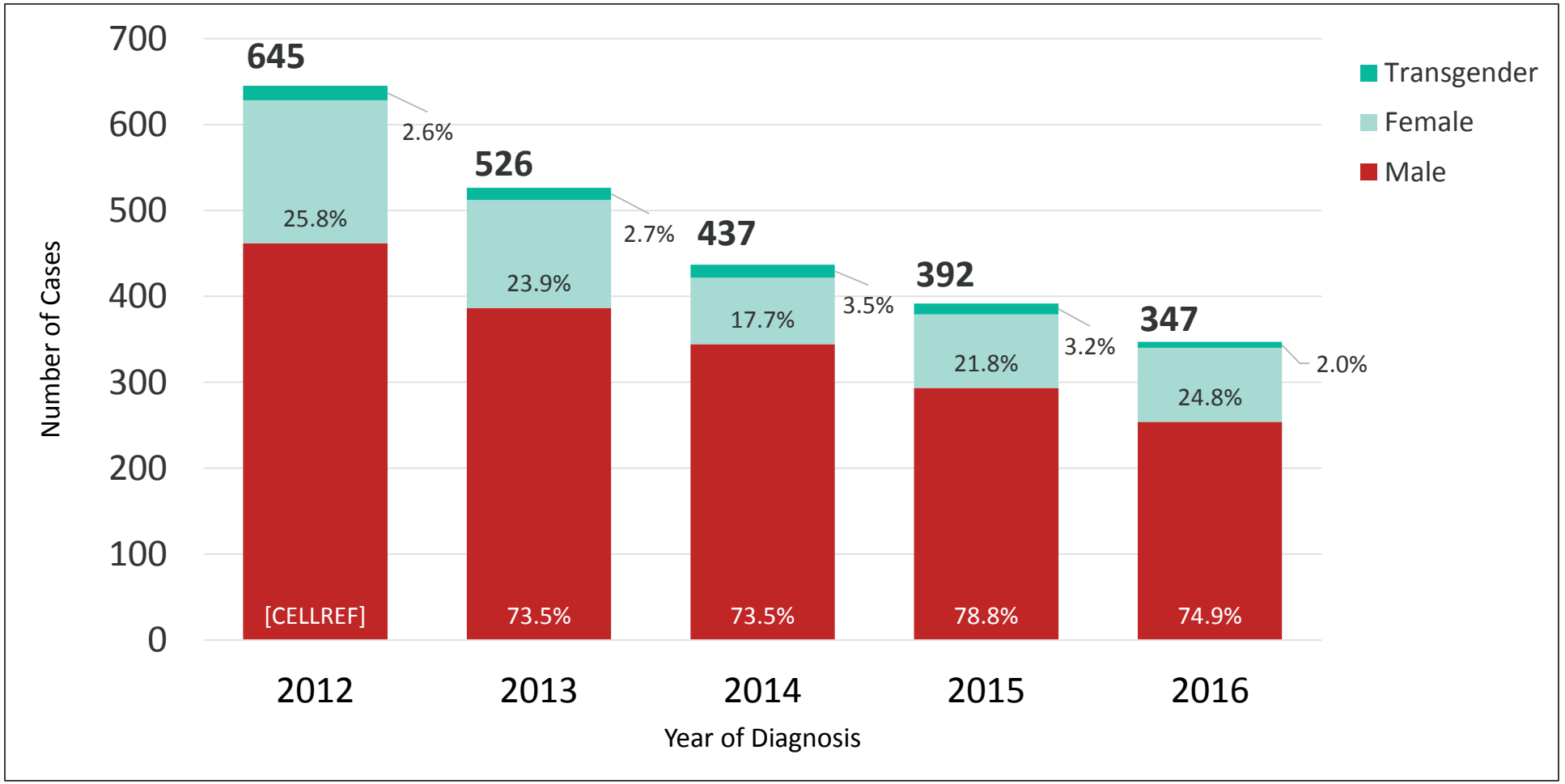
- Provided by state or local HIV surveillance staff, from eHARS (enhanced HIV/AIDS Reporting System) data
- Usually based on a calendar year

Epidemiologic Profile, continued

How it's used:

- Provides an overall picture of HIV in the service area
- Helps in identifying subpopulations and geographic areas with increasing rates of HIV
  - *Enables recipient and PC/PB to develop or refine services to ensure appropriate care for emerging groups*
  - *For an integrated prevention and care PC/PB, helps in identifying populations for primary prevention, testing, and prevention for HIV-positive individuals*
- Helps in identifying populations for focused special attention in assessment of PLWH service needs and barriers

Sample Epi Profile Chart:
Newly Diagnosed HIV Cases by Year and Gender Identity



Source: Annual Epidemiology and Surveillance Report: Data through 2016, Washington, DC

HIV Care Continuum Data

What it is and what it shows:

- Model that outlines the stages of HIV medical care that people living with HIV go through from initial diagnosis to achieving the goal of viral suppression and shows the proportion of individuals living with HIV who are engaged at each stage.
- Two kinds of care continuums: Prevalence based and diagnosis based

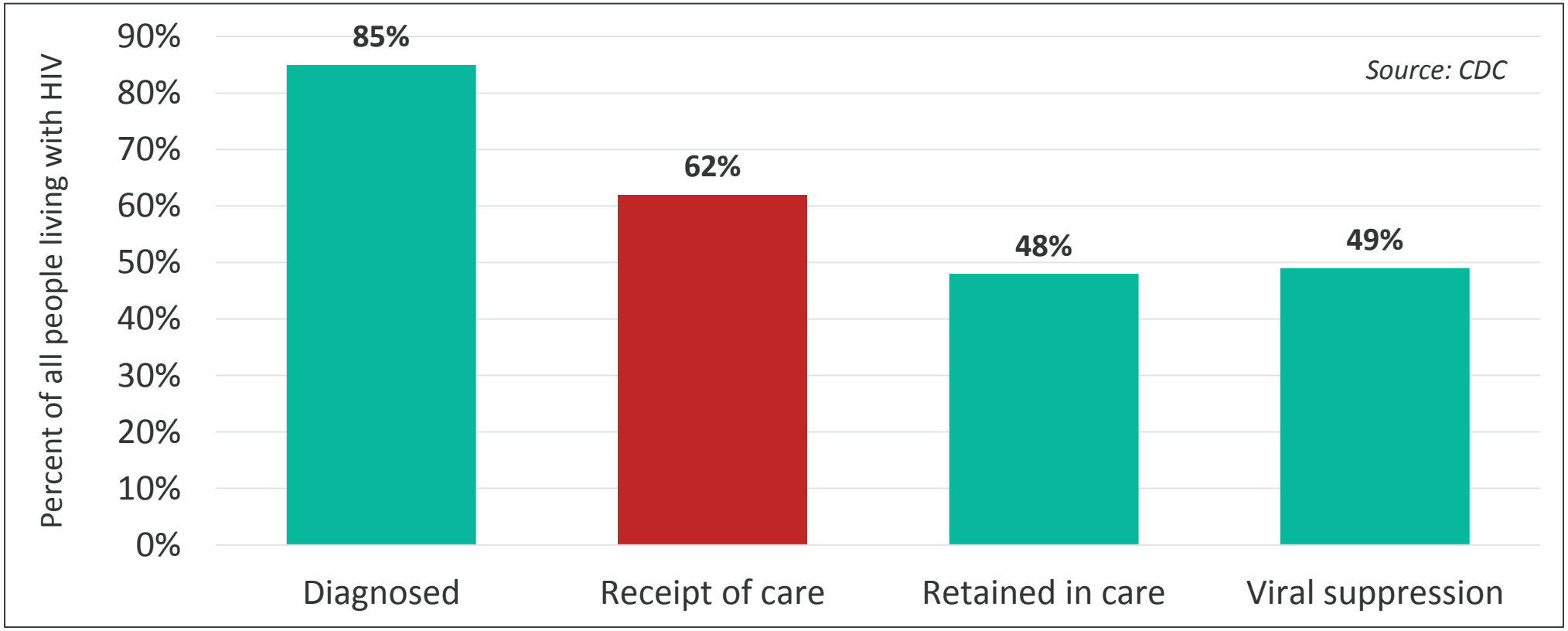
Where it comes from:

- Data provided by state or local HIV surveillance staff
- Provided at least annually; sometimes more often

How it's used:

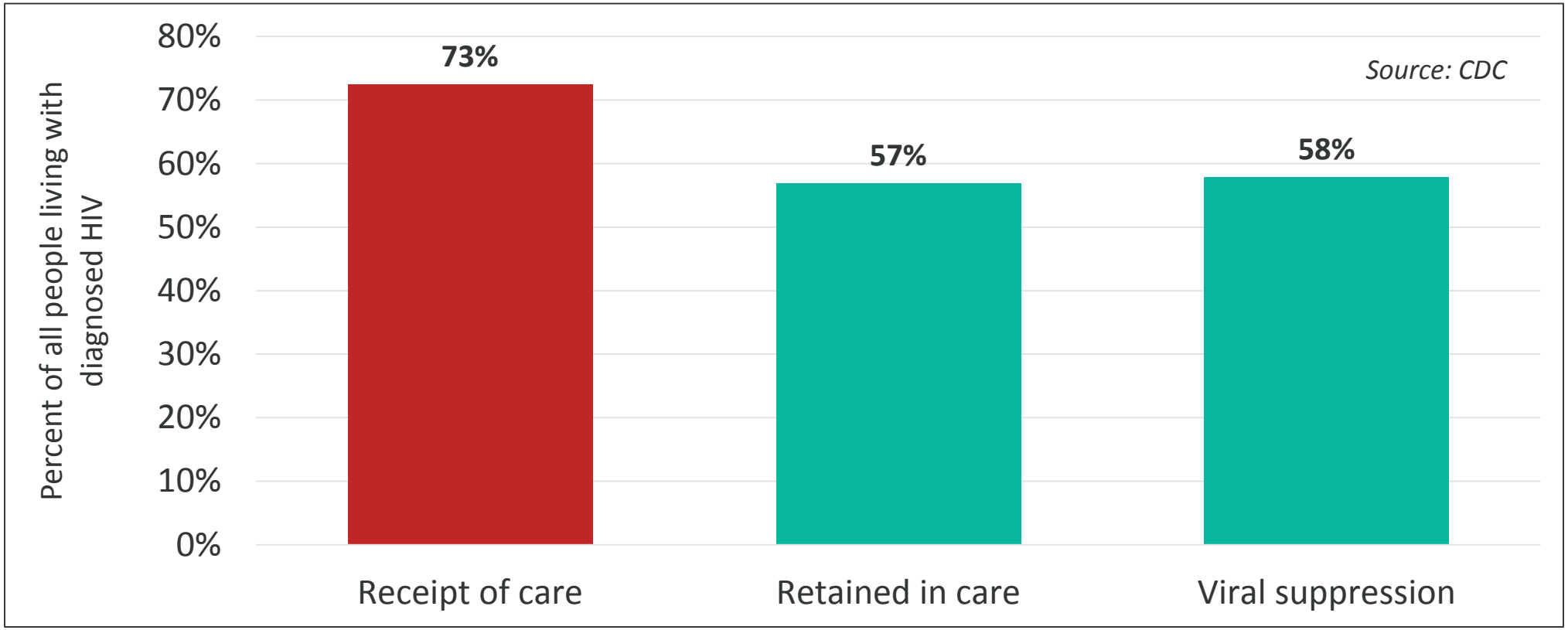
- Helps PC/PB understand strengths and weaknesses in system of care and identify need for additional attention to particular steps (e.g., linkage, retention, viral suppression) and PLWH subpopulations.

Prevalence-based HIV Care Continuum, U.S., 2014



This is called the *prevalence-based* HIV care continuum because it shows each step as a percentage of the total number of people living with HIV, including people who have been diagnosed and aware they are living with HIV and those who have not been diagnosed and don't know they are living with HIV.

Diagnosis-Based HIV Care Continuum, U.S., 2014



This is called the *diagnosis-based* HIV care continuum because it shows each step as a percentage of people living with diagnosed HIV.

Discussion

Which of type of HIV care continuum do you think is most useful for your PC/PB – prevalence-based or diagnosis-based?
Tell us which one and why in the chat box.

Needs Assessment Data

What it is and what it shows:

- Number, characteristics, service needs and barriers of PLWH, both in and out of care
- Provider resources available to meet those needs
- Service gaps, overall and for various PLWH subpopulations

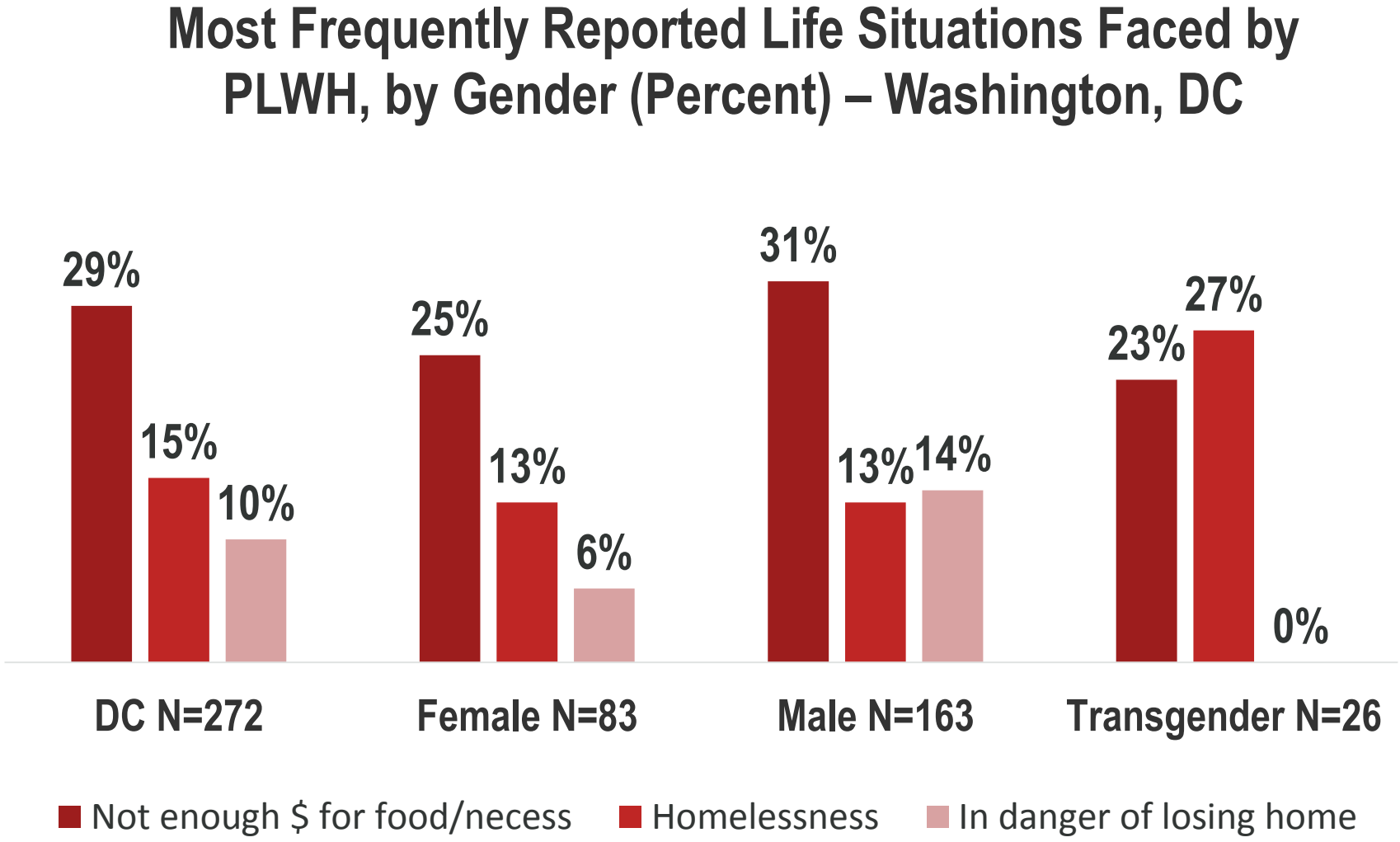
Where it comes from:

- Data from needs assessment activities conducted by PC/PB, including staff and/or consultants
- Usually a multi-year cycle, with some new data collected each year

How it's used:

- Set priorities, allocate resources, develop directives, and improve service access and quality, overall and for specific populations

Sample Needs Assessment Data: PLWH Survey



- The most frequently reported life situation PLWH said they dealt with over the past 12 months was not having money for food and other necessities
- Male PLWH were the most likely to report not having enough money for food and other necessities and being in danger of losing their home
- Transgender PLWH were the most likely to report homelessness

Resource Inventory Data

What it is and what it shows:

- A regularly updated, comprehensive listing and description of HIV-related services available to PLWH in the EMA or TGA, regardless of funding source
- Provides information on types of services provided, location and hours, number of clients served, and funding sources – often in chart form
- Often includes information on levels of funding from non-Part A sources

Where it comes from:

- Usually developed as part of the Needs Assessment, under PC/PB supervision

How it's used:

- Used in integrated/comprehensive plan development and during the PSRA process
- Often used to develop Resource Guide for service providers and clients

Example of resource inventory

Provider Name	Location/ Service Area	Funding Sources	Core Medical Services and # of Slots	Support Services and # of Slots
Jefferson Clinic	MidCity – Serves entire TGA	Part A, Part C plus private funds – $3.7 million	• OAHS - 240 • MCM – 200 • Mental Health – 100 • Med Nutr Ther – 75	• Transportation – 50% of clients • Outreach – 120
Wellington Community Health Center	North End – targets Wards 2 and 3	Part A, Part B – $3.2 million; State Mental Health - $700K	• OAHS – 150 • MCM – 200 • Oral Health – 300 • Mental Health – 100	• Transportation – 30% of clients • Food Pantry – 300
Women Helping Women	South Side – targets women in central city	Part A, Part D, State Substance Abuse Funds – $1.3 million	• Outpatient Substance Abuse – 78 • Mental Health - 56 • MCM – 50	• Transportation – 70 • NMCM – 55

Service Expenditure and Cost Data

What it is and what it shows:

- Projected and actual expenditures by service category, plus:
  - Costs for one unit of service, such as 1 case management visit lasting 30 minutes
  - Cost to serve one client for a year

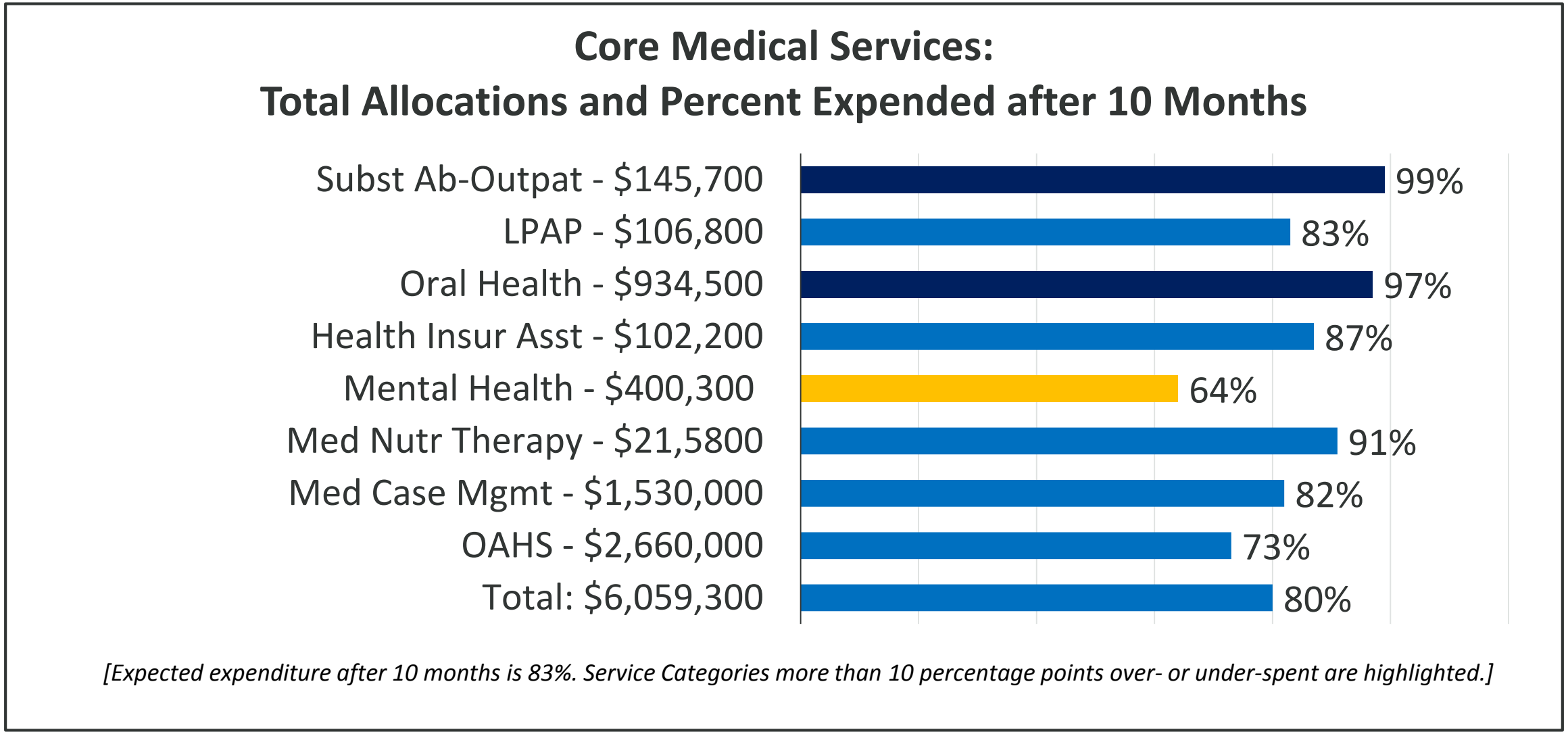
Where it comes from:

- Recipient or administrative agency
- Expenditures usually provided monthly, with an annual summary

How it's used:

- Helps PC/PB make funding decisions, adjusting allocations based on actual use of funds and determining costs to serve additional clients

Sample TGA Expenditures Summary for Core Medical Services



[Expected expenditure after 10 months is 83%. Service Categories more than 10 percentage points over- or under-spent are highlighted.]

Client Characteristics and Service Utilization Data

What it is and what it shows:

- Information about the use of RWHAP Part A services, including the number and characteristics of clients, overall and by service category, and the amount or units of service provided

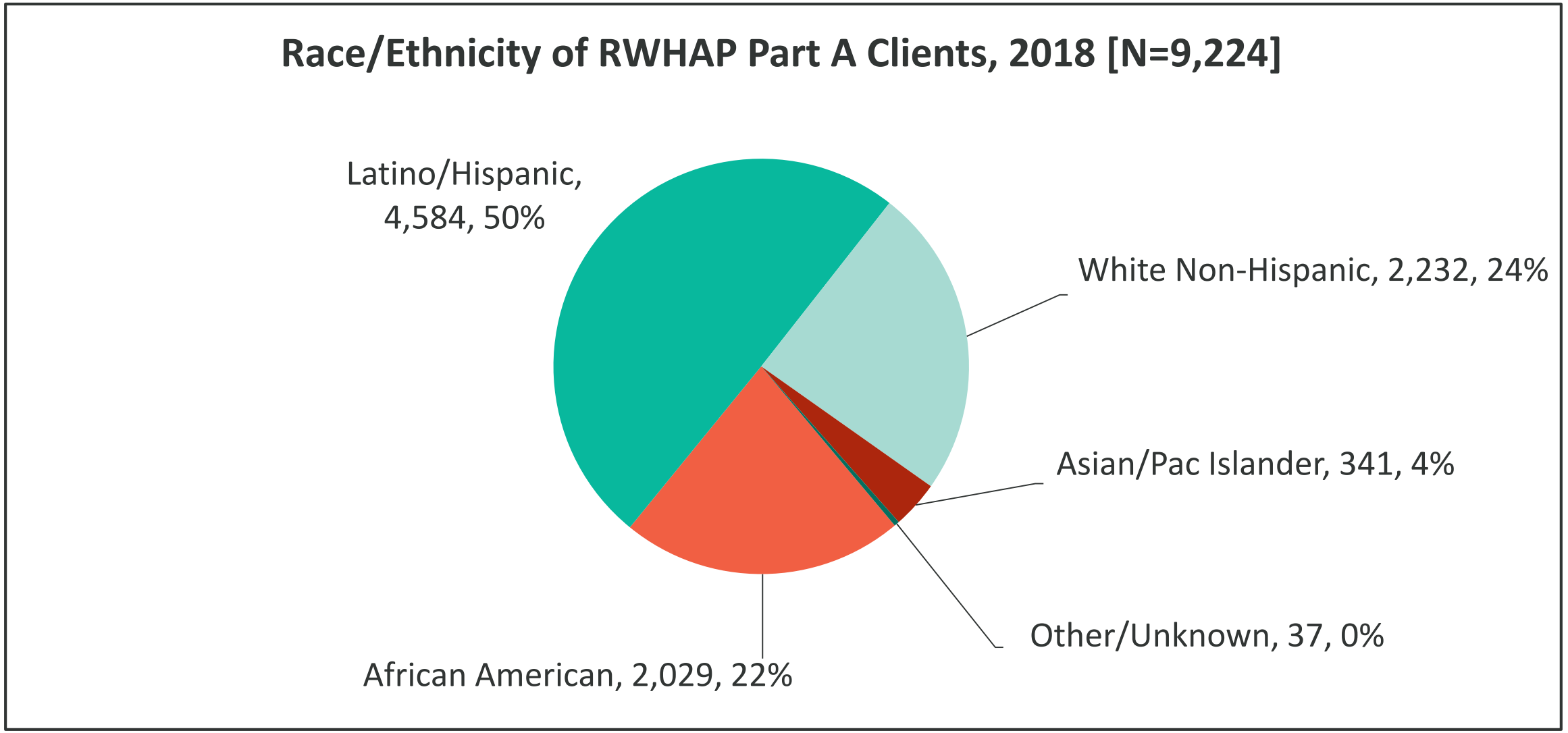
Where it comes from:

- Recipient, usually gathered through its client-level data system and included in the RWHAP Services Report (RSR)
- Provided annually

How it's used:

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

Sample SW EMA Client Data

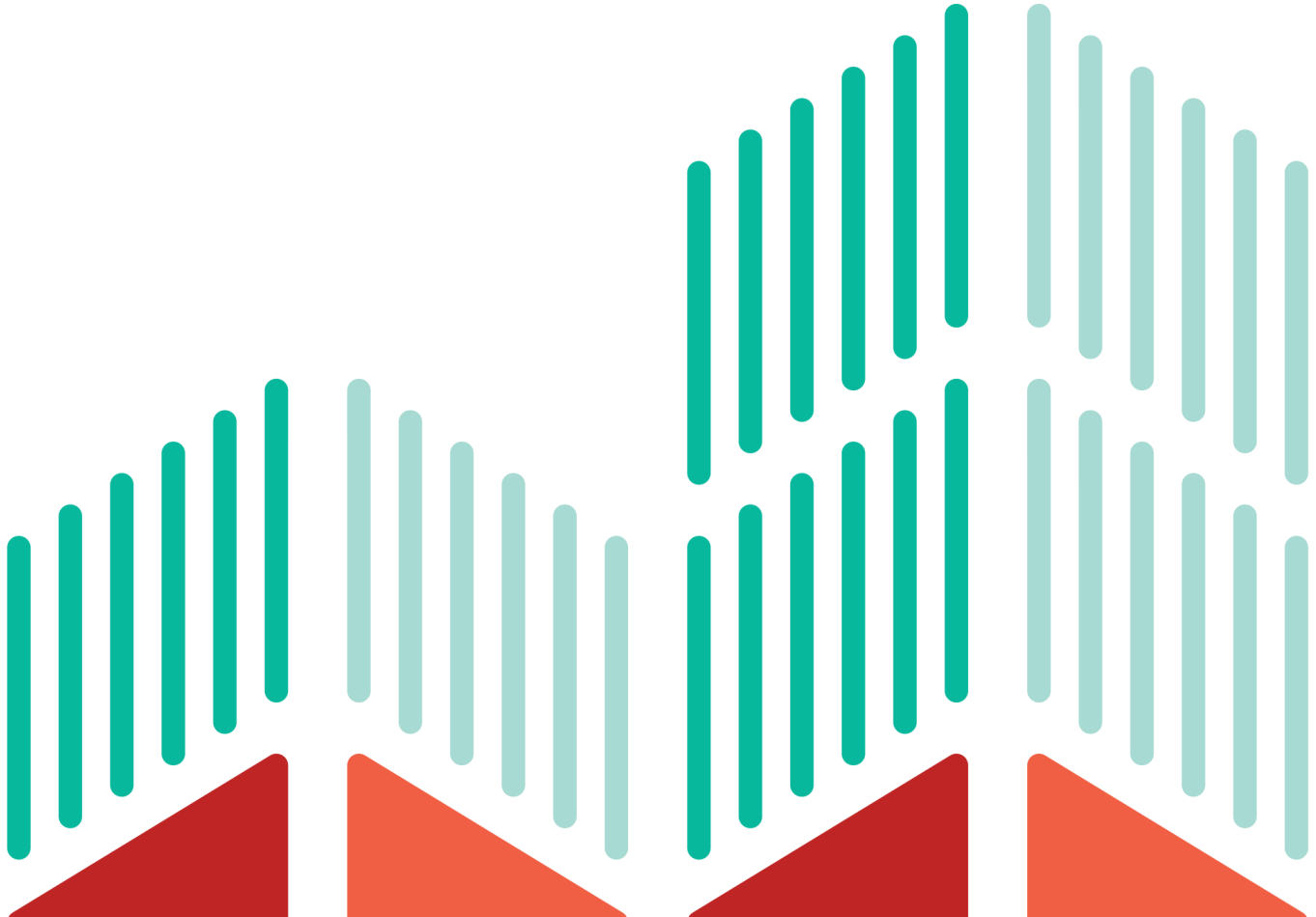


Poll

What other types of data do you use for HIV planning? Select all that apply.

- ❑ HIV tests and diagnoses
- ❑ Unmet need data (estimate and assessment)
- ❑ Clinical Quality Management (CQM) data
- ❑ Recipient monitoring data
- ❑ Performance measures and clinical outcomes data
- ❑ Other? Chat it in.

Addressing Gaps in Data



Dealing with Data Gaps

- No PC/PB has all the data needed for decision making
- Data gaps often caused by:
  - Limited resources
  - Limited needs assessment and data analysis skills and experience on the part of PC/PB and/or recipient staff
  - Lack of agreements with state surveillance staff to provide newer types of data
  - Limited time for data gathering or analysis, given other responsibilities
  - Lack of agreement between PC/PB and recipient regarding data needs and how best to meet them

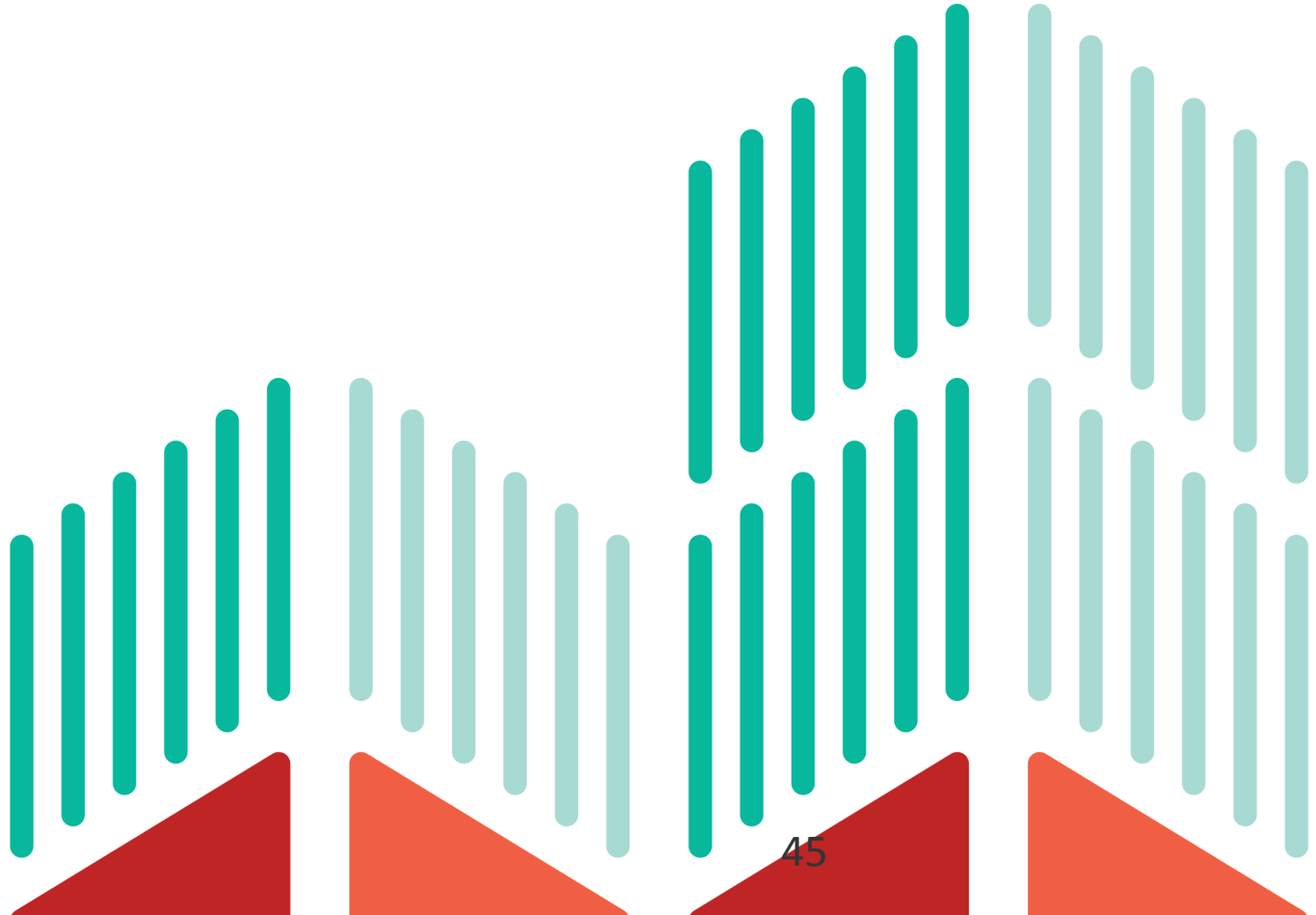
Addressing Data Gaps

- Become familiar with the various types of data that *should* be available to the PC/PB based on sound practice and HRSA/HAB guidance
- Incorporate data sharing agreements into your Memorandum of Understanding (MOU), including:
  - What data the recipient will provide
  - In what formats
  - On what schedule
- Explore what data needs can be met by the PC/PB, PCS, or consultants through needs assessment, town halls, roundtables, or other approaches

Addressing Data Gaps, cont.

- Maximize use of existing data through improved analysis
- Make a chart showing needed data types, content, use, and current or potential sources
- Develop a plan to fill remaining gaps
  - Explore what PC/PB members, service providers, or other stakeholders can provide
  - Seek help from area universities

Assessing Data Quality & Usefulness



Not All Data are Created Equal!

There are multiple ways data can be ‘of poor quality’

- Outdated
  - Example: Care continuum developed using data from 10 years prior
- Incomplete
  - Example: Service expenditure data with several service categories missing
- Unclear
  - Example: Resource inventory data does not specify RWHAP funding source for services (e.g. RWHAP Part A, Part B, Part C, etc.).

Bottom line:
Data quality is important!

Assessing Data

PC/PB member roles:

- Review data from multiple sources
- Ask questions about how data were gathered, tabulated, and analyzed
- Compare and weigh data from different sources and studies
- Decide how much confidence to place in the data
- Give the greatest weight in decision making to the “best data”

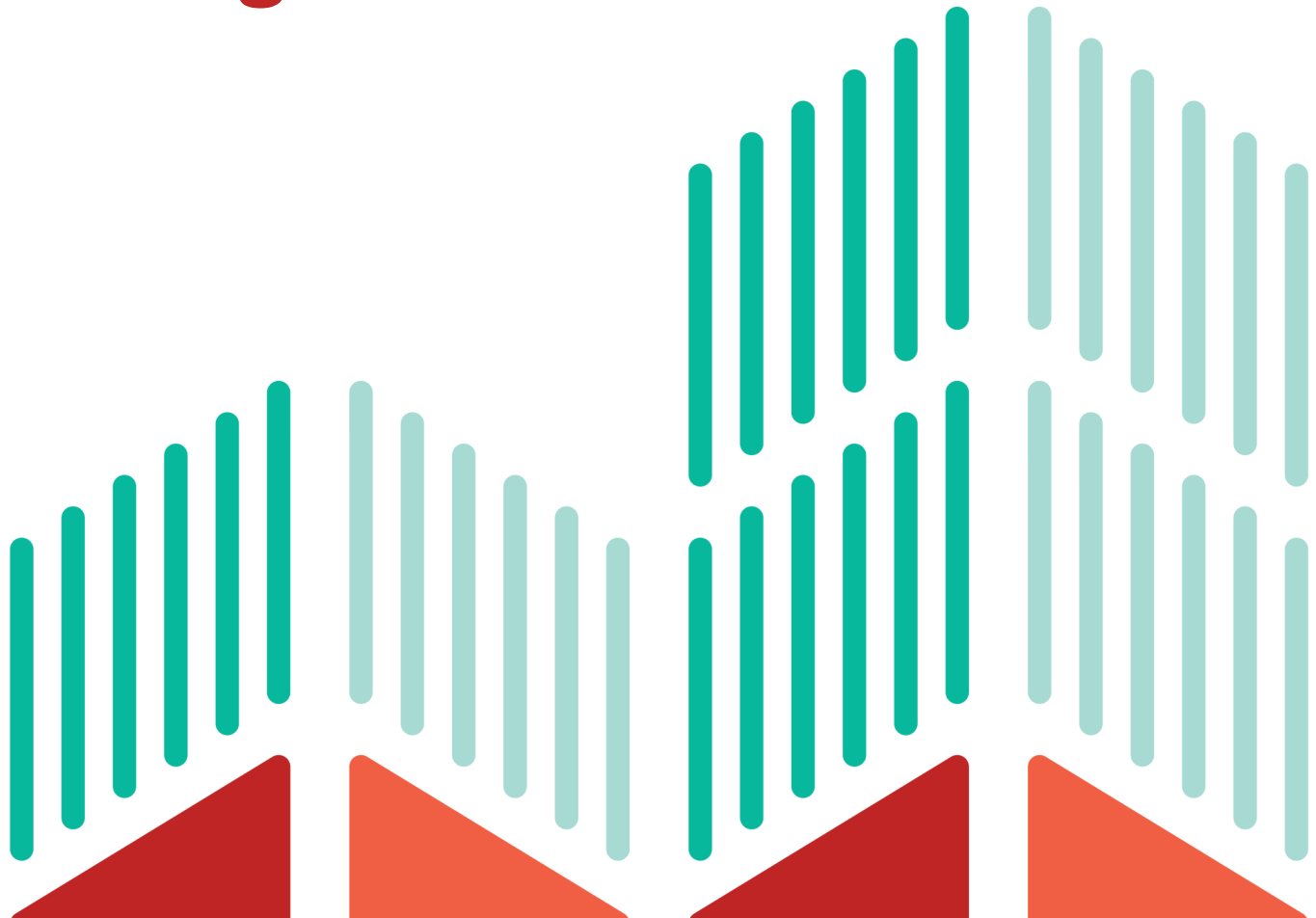
PC/PB Support Staff, Consultants, and Recipient Staff roles:

- Provide/present data from various sources
- Understand and share information on data quality and limitations

Helpful Questions to Ask in Assessing and Interpreting Surveys and Studies

- Who was responsible for the study?
- Were knowledgeable consumers and other PLWH involved in design?
- Does the “tool” use good questions? Are they clear and understandable? Do they seem likely to generate reliable data that really measure what the study is supposed to be measuring? Was the tool pre-tested?
- What was the sample size? Is it representative?
- What evidence is there that the data were collected using appropriate methods and trained individuals?
- Was there “quality control” to be sure the stated data gathering and analysis process was followed?

Importance of Using Multiple Data Sources for Decision Making



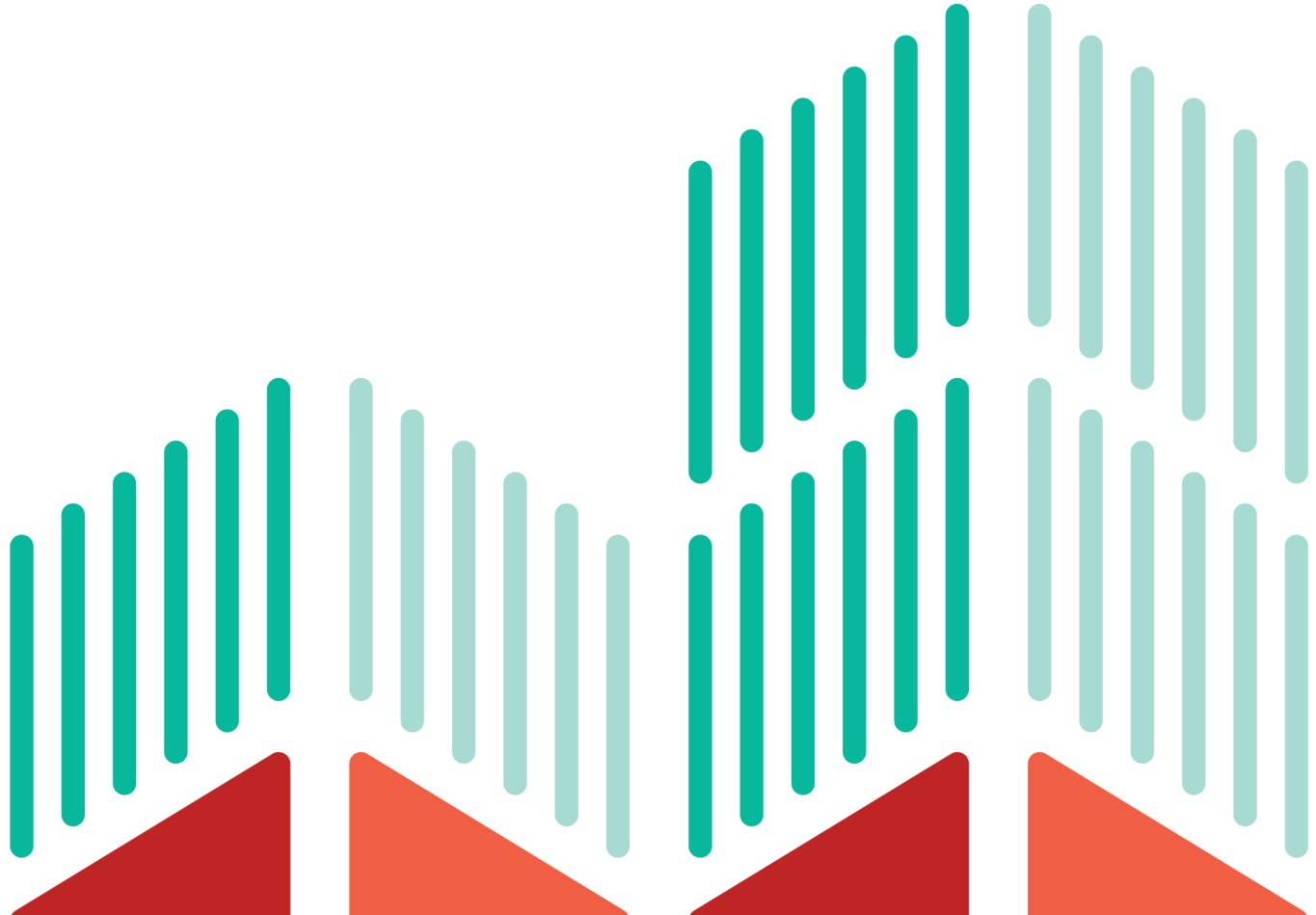
Data Triangulation

- A PC/PB can have additional confidence in findings found in more than one needs assessment activity, study, or data set, and can use multiple methods to increase understanding of a topic or issue – that process is called triangulation.
- Bottom line: Review more than one data source when available.

Triangulation of Data

- The process of comparing data on the same topic from 2 or more sources or research studies to:
  - See whether they report similar findings – “cross check” or “cross-validate” the data
  - Increase understanding of the topic
- PC/PB can have greater confidence in findings that are reported from several different studies or sources, or obtained through different methods

Resources



Compendium of Materials
for Planning Council Support Staff

www.targetHIV.org/planning-chatt/pcs-compendium

- Quick Definitions and Descriptions for Data-related Terms and Concepts Used by RWHAP Planning Bodies
- Understanding and Using Data: Model Planning Council Training Session

TRAINING GUIDE

for Ryan White HIV/AIDS Program Part A Planning Councils/Planning Bodies

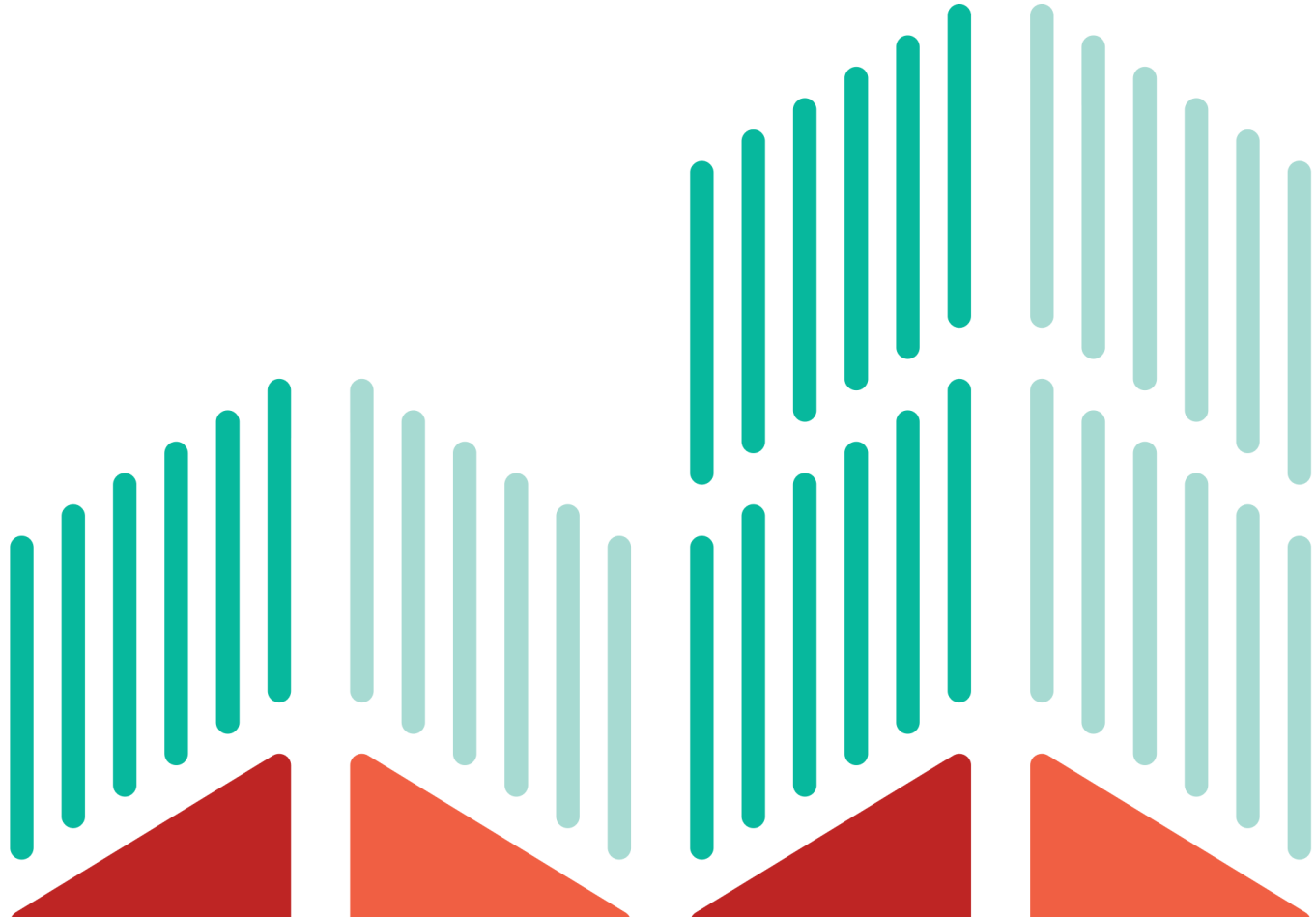
A Member's First Planning Cycle

www.targetHIV.org/planning-chatt/training-guide

Data-specific Training Guide Modules

- Module 4: Needs Assessment
- Module 5: PSRA
- Module 7: Maintaining and Improving a System of Care
- **Coming soon!**
  Module 10: Data-based Decision Making: Understanding, Assessing, and Using Data

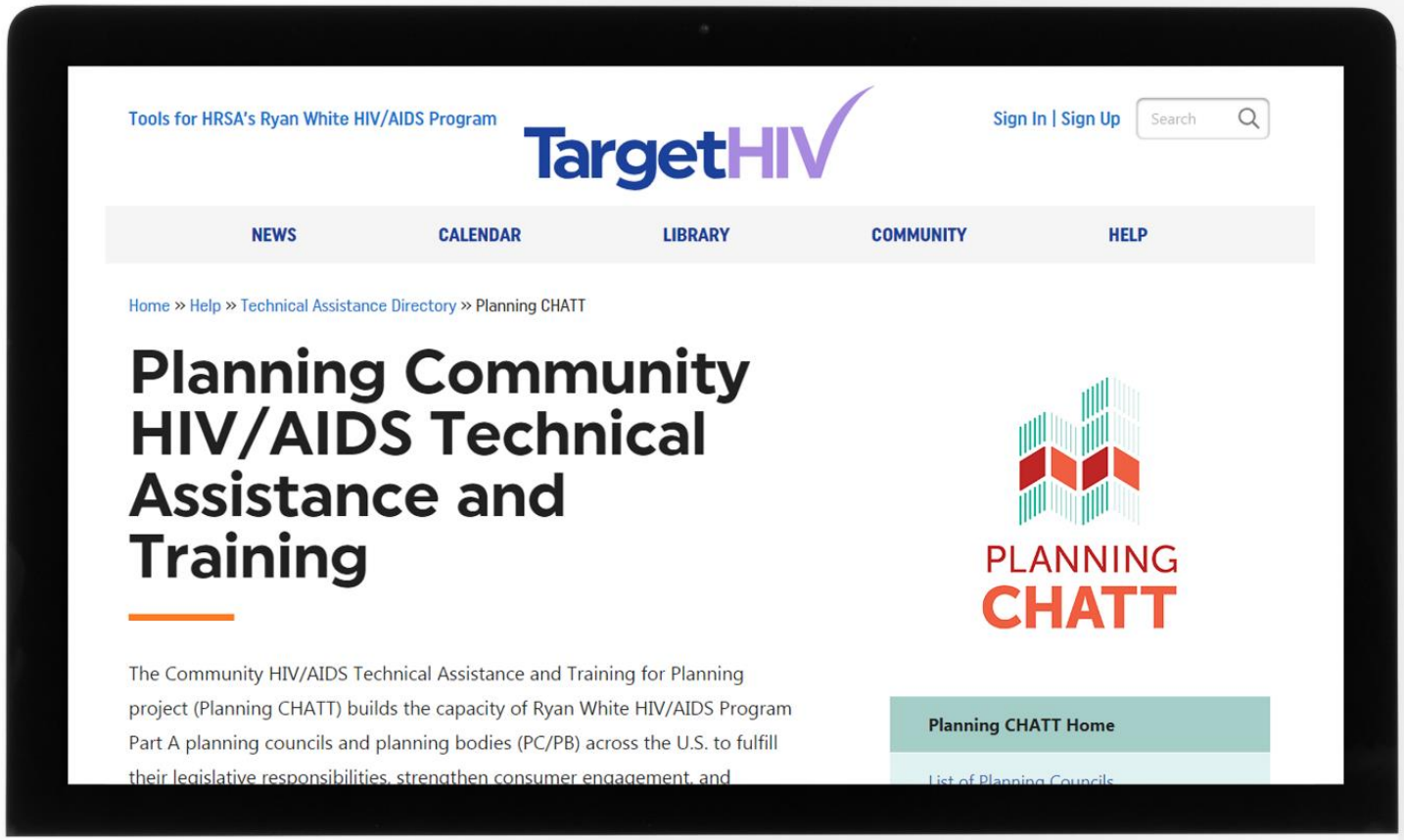
Questions & Answers



Coming soon!

Using Data for Decision Making Part 2

- May 30, 2019
- 2:00-3:30 pm ET/11:00 am -12:30 pm PT



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