

Data-based Decision Making: Understanding, Assessing, and Using Data

Office of HIV Planning

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Understanding Data Types and Sources

Importance of Data in RWHAP Planning

Terms and Definitions

Data Types and Sources

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
- Some experts prefer the term “data-informed” decision making, since decisions are based on multiple factors

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:**
 - 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

PC Task	Role of Data in Implementing PC Tasks
Needs Assessment	Collection and analysis of information about PLWH service needs, barriers, and gaps – a major source of data for decision making
Integrated/ Comprehensive Planning	Development of plan goals, objectives & strategies all based on data of many types and sources
PSRA including Directives	Decisions about priorities, resource allocation, directives, and reallocations all expected to be data-based
System of Care	Many types of data needed to identify and address system of care weaknesses/gaps and improve services
Assessment of the Administrative Mechanism	Data from recipient & subrecipients used to assess whether funds are getting to the community on a timely basis to support services

Importance of Data

- **Data from multiple sources are needed to:**
 - Provide an understanding of diverse service needs of PLWH
 - Highlight service barriers and gaps
 - Help identify service models with positive clinical outcomes for all PLWH or particular subgroups
 - Help ensure best use of limited resources
 - Contribute to fair and objective decisions
- **Without access to adequate data from multiple sources,** decisions are often based on personal experience or “impassioned pleas”

Terms and Definitions

Epidemiologic Terms

HIV Care Continuum

Unmet Need

Assessing Service Needs and Gaps

Quantitative vs. Qualitative Data

Epidemiologic Terms:

Incidence (New Cases)

- **Incidence:** The number of new cases of a disease in a population during a defined period of time – such as the number of new HIV cases in your EMA reported during 2018
- **Incidence rate:** The frequency of new cases of a disease that occur per unit of population during a defined period of time – such as the rate of new HIV cases per 100,000 population in your EMA in 2018

Epidemiologic Terms:

Prevalence (Total Cases)

- **Prevalence:** The *total number* of people in a defined population diagnosed with a specific disease or condition at a given time—such as the total number of people diagnosed with HIV in your EMA or TGA as of December 31, 2018
 - Can refer to all cases diagnosed from the beginning of the epidemic
 - More often “total living cases”: the number of people diagnosed and living with the disease
- **Prevalence rate:** The total or cumulative number of cases of a disease per unit of population as of a defined date—such as the rate of HIV cases per 100,000 population diagnosed in your EMA or TGA as of December 31, 2018

Other Common Epi Terms

- **Sample:** A group of people selected from a total population with the expectation that studying this group will provide important information about the total population
- **Percentage:** A proportion of the whole in which the whole is 100
*Example: 15 of 60 new cases of HIV were among women
15 divided by 60 = .25 and .25 x 100 = 25%*
- **Trends:** Long-term movement of change in frequency, such as 5-year trends in HIV incidence among youth

Other HIV-related Epi Terms

- **Risk factor:** A behavior, condition, or other factor that increases the likelihood of HIV infection
- **Transmission category:** The risk factor most likely to have resulted in HIV transmission
- **Stage 3 HIV infection:** AIDS – CD4 count falls below 200; immune system badly damaged and can no longer fight off serious illnesses (“opportunistic infections”)
- **Late testers:** Individuals who have stage 3 HIV infection (AIDS) when first diagnosed or within 12 months after

HIV Care Continuum

- **Definition:** A model of HIV medical care that shows “the series of steps from the time a person receives a diagnosis of HIV through the successful treatment of their infection with HIV medications”*
- **Data:** Percent of individuals with HIV who are engaged at each step
- **Terminology:** Sometimes referred to as the “HIV treatment cascade” or Gardner cascade (developed by Dr. Edward Gardner and colleagues in 2011)

* CDC, “Understanding the HIV Care Continuum,” July 2017



**Diagnosed
with HIV**



**Linked to
Care**



**Engaged or
Retained in
Care**



**Achieved
Viral
Suppression**

Steps in the HIV Care Continuum

1. **Diagnosed with HIV:** received a positive HIV test that was reported to the CDC
2. **Linked to care:** visited an HIV-related health care provider
3. **Received or retained in care:** received medical care for HIV infection
4. **Virally suppressed:** have a very low level of HIV in their blood

*Sometimes included in the continuum of a RWHAP program prior to Virally Suppressed: **Prescribed antiretroviral therapy (ART)***

“Unmet Need” or “Not in Care” Definition

- **Unmet need** refers to individuals with HIV in a jurisdiction who are *aware* of their HIV status and are *not in care* – people who have been diagnosed with HIV but are not receiving HIV-related medical care
- **Estimate of unmet need:** Number and percent of all diagnosed PLWH who are not in care

HIV-Positive Unaware Individuals

- **HIV-positive/unaware:** Individuals with HIV who are unaware of their status—they have not received an HIV diagnosis—because they have never been tested, or did not receive their test results
- **The Early Identification of Individuals with HIV/AIDS (EIIHA) Initiative** helps to:
 - Identify individuals with HIV who do not know their status
 - Make them aware who are unaware of their status and enable them to use health and support services
 - Reduce barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities [§2603(b)(2)(A)]

Data-Related Concepts in Assessing Service Needs and Gaps

- **Geographic disparities:** Differences in access to needed services based on where an individual lives
- **Availability of services:** Level or number of available “slots” within a service category in a specified geographic area, and whether there are waiting lists
- **Accessibility of services:** Extent to which services in a particular geographic area can be obtained conveniently by PLWH who need them, based on factors like access to public transportation, parking, service hours, and disability access
- **Appropriateness of services:** Extent to which services meet the needs of various PLWH subpopulations, in terms of languages spoken, service models, and cultural competence with regard to race/ethnicity, sexual orientation and identity

Quantitative and Qualitative 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

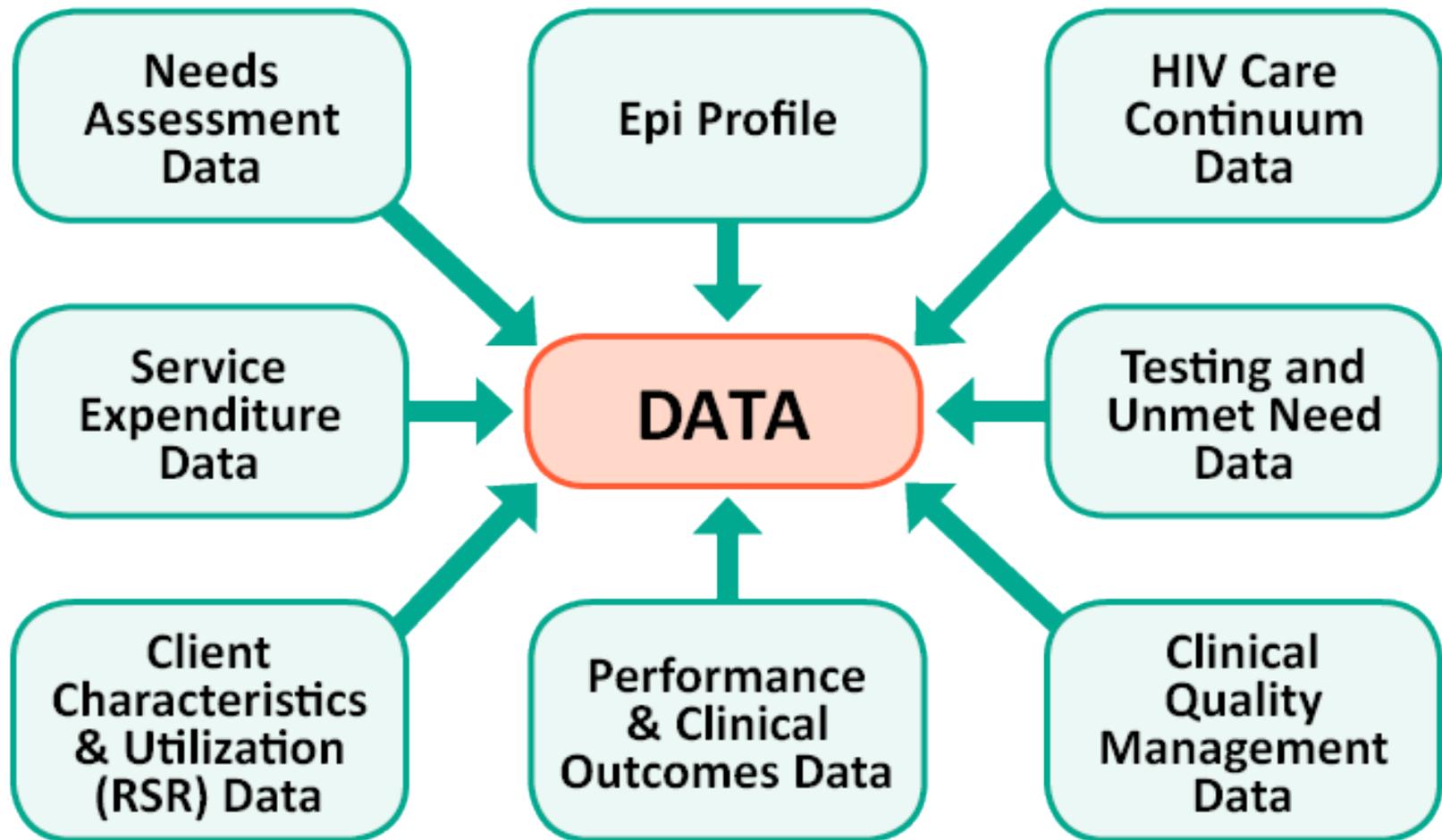
Measures of “Central Tendency” (Averages)

- **Mean:** the numerical average – the sum of values divided by the total number of values
- **Median:** the middle value in a data set, with about half the values higher and half lower
- **Mode:** the most commonly occurring value

Example: For values 10, 7, 5, 8, and 5:

- **Sum** is $10+7+5+8+5=35$ and **total number of values** is 5
- **Mean** is $35\div 5=7$
- **Median** is 7 [10, 8, **7**, 5, 5]
- **Mode** is 5 [it occurs twice]

Types of Data Needed for RWHAP Planning



Note: Some data types overlap

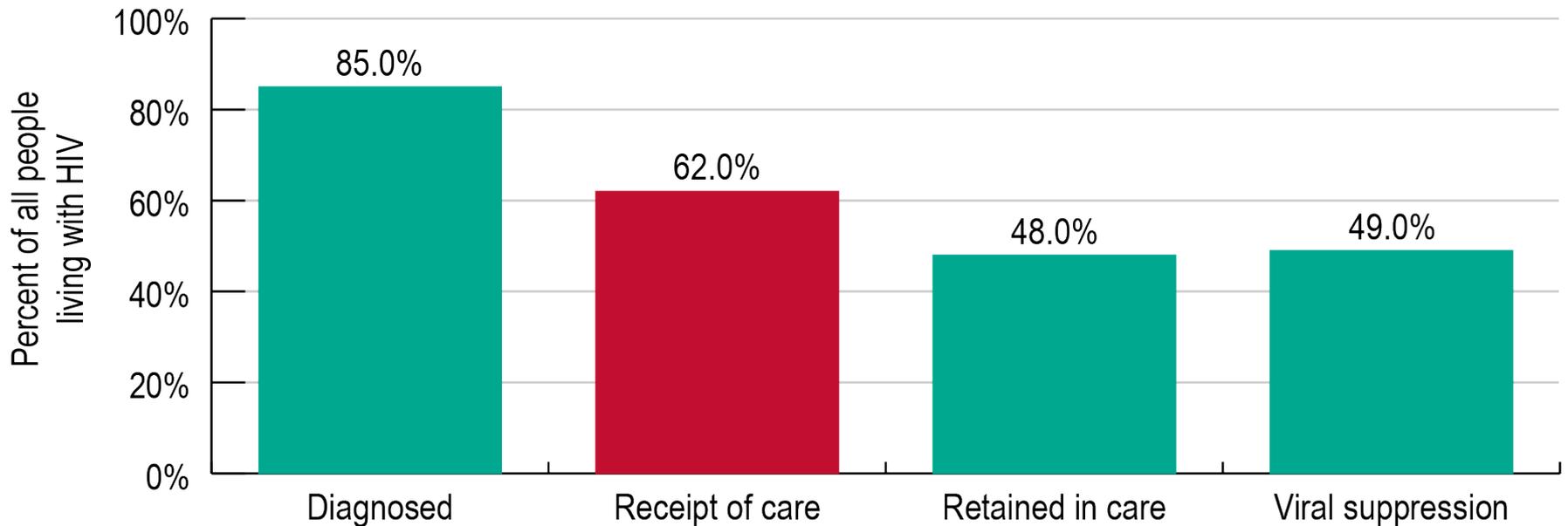
Epidemiologic Profile

- **Source:** State or local HIV surveillance staff, from eHARS (enhanced HIV/AIDS Reporting System) data
- **Frequency:** 1-2 years
- **Content:** The 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
- **Use:** Helps PC understand the epidemic and implications for service needs and priorities

HIV Care Continuum

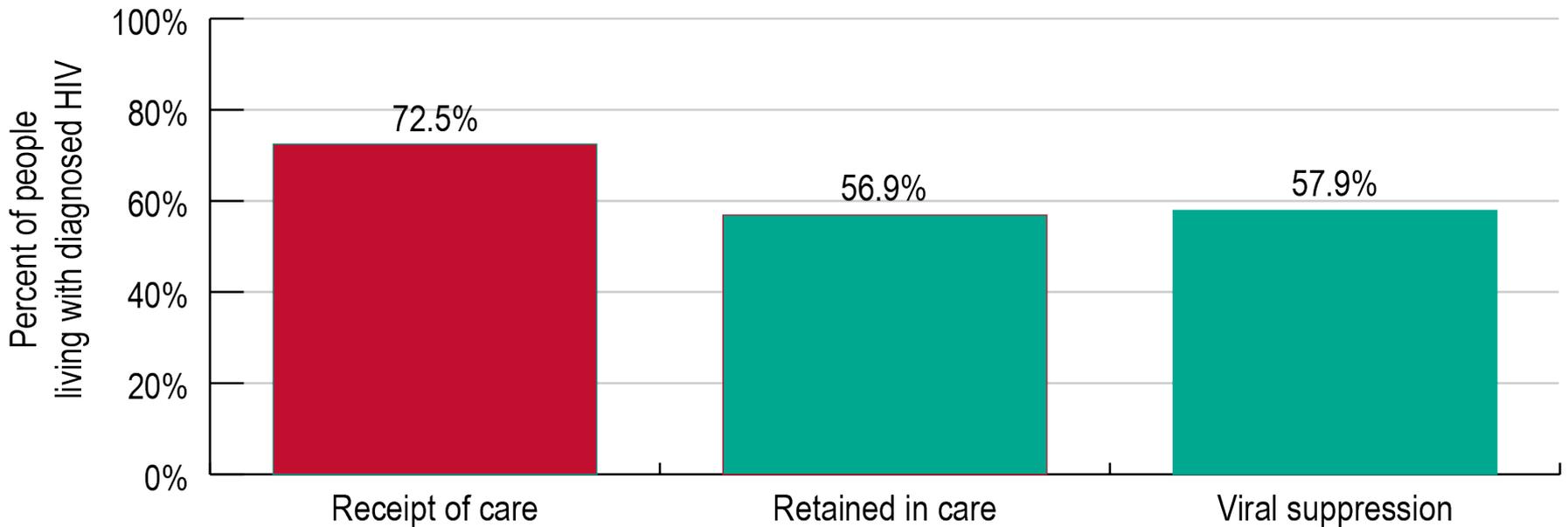
- **Source:** State or local HIV surveillance staff
- **Frequency:** varies
- **Content:** Often 2 different continuums
 - All PLWH in the service area
 - RWHAP clients, often with multiple breakdowns to show both all RWHAP clients and various subpopulations
- **Use:** Helps PC understand strengths and weaknesses in system of care and identify need for additional attention to particular steps (such as retention in care) 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 whose infection has been diagnosed and those who are infected but don't know it

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

Needs Assessment Data

- **Source:** Collected by PC, including staff and/or consultants
- **Frequency:** Usually a multi-year cycle, with some new data each year
- **Content:**
 - 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
- **Use:** Helps PC to set priorities, allocate resources, develop directives, and improve service access and quality, overall and for specific populations

Service Expenditure and Cost Data

- **Source:** Recipient (AACO)
- **Frequency:** Expenditures usually provided quarterly, with an annual summary
- **Content:** Projected and actual expenditures by service category
- **Use:** Helps PC make funding decisions, adjust allocations based on actual use of funds and determine costs to serve additional clients

Client Characteristics and Service Utilization Data

- **Source:** Recipient (AACO), usually gathered through its client-level data system and included in the RWHAP Services Report (RSR)
- **Frequency:** Annual
- **Content:** 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
- **Use:** Help PC understand demand for specific services and identify differences in use of services by various PLWH groups

HIV Tests and Diagnoses Data

- **Source:** State/local surveillance and HIV prevention unit staff, as reported by testing sites
- **Frequency:** Ongoing; reported at least annually
- **Content:**
 - Number of people who receive HIV tests
 - Number and percent testing positive and their characteristics
 - Number referred to needed services (care or prevention)
- **Use:** Helps PC predict future demand for care and the need to fund services like Outreach and Early Intervention Services (EIS), which help get people identified, tested, and linked to care if HIV-positive

Unmet Need Data (Estimate and Assessment)

- **Source:** State or surveillance staff provide estimate; PC/PB may assess unmet need as part of its needs assessment
- **Frequency:** Usually updated/reported annually
- **Content:**
 - Estimate of the number of PLWH in the service area who know they are HIV-positive but are not receiving HIV-related medical care
 - Assessment of the characteristics, service barriers and gaps of PLWH with unmet need
- **Use:** Helps PC to understand how many PLWH are out of care and consider ways to find such PLWH, link or relink them to care, and improve retention

Clinical Quality Management (CQM) Data

- **Source:** Recipient (AACO), based on a CQM program of coordinated activities carried out by recipient and subrecipients (service providers)
- **Frequency:** Ongoing; data shared with PC at least annually
- **Content:** Data on client care, health outcomes, and client satisfaction, including results of quality improvement activities
- **Use:** Helps PC identify need for changes in program models or funding to help improve service quality and outcomes

Recipient Monitoring Data

- **Source:** Recipient (AACO), based on monitoring of subrecipients, including an annual monitoring visit
- **Frequency:** Ongoing; data shared with PC at least annually
- **Content:** Information on extent to which subrecipients are meeting requirements, including service standards, for their service categories
- **Use:** Helps PC identify need for changes in program models or funding to improve service quality and outcomes, and possible need to refine service standards

Performance Measures and Clinical Outcomes Data

- **Source:** Usually provided by the recipient, based on various data sources (e.g., HIV care continuum, client-level database, CQM data, monitoring data)
- **Frequency:** At least annually
- **Content:** Percent of all PLWH or RWHAP clients that meet a particular measure or standard, usually chosen from the HRSA Performance Measure Portfolio. May relate to:
 - A process, such as development of a case management care plan or a mental health assessment
 - A clinical outcome, such as viral suppression
- **Use:** Helps PC identify service strengths and weaknesses and develop directives, improve models of care, and/or revise service standards to improve care

Data from Other Programs

- **Sources:** Many, including other federal agencies and programs such as CDC HIV prevention funding, Housing Opportunities for Persons With AIDS (HOPWA), Medicaid and Medicare, Substance Abuse and Mental Health Services Administration programs, state and local agencies
- **Frequency:** Usually annual, prior to PSRA
- **Content:** Most often number of clients in the program who are PLWH and their characteristics, services provided to them, and costs overall and/or by type of service
- **Use:** Helps PC determine the level and sources of other funding for HIV services and avoid duplication of effort

Sum Up

- RWHAP Part A planning is data-based
- PCs need to become familiar with:
 - Data-related terms
 - Various types of data reports and summaries used in decision making about priorities, allocations, directives, and service models
- Each type of data provides important information about some aspect of service needs, barriers, gaps, system of care, and service quality and outcomes
- Data now more detailed and useful for directing funds and tailoring services to meet diverse PLWH needs
- PCs need to arrange timely access to needed data

Assessing Data Quality and Usefulness

Data Myths and Realities

- *Consumers don't understand data*
 - Many people are uncomfortable using data: more people are *innumerate* than *illiterate*
 - People often think they won't understand HIV-related data and charts because they don't use them every day
- *It takes a Ph.D. to understand RWHAP data*
 - People can learn to understand and use data
 - Moderate training is sufficient to understand most RWHAP data if it is well presented
- *Data will give you the answer*
 - Data can be spun to give you many different answers
 - Data vary greatly in quality and need to be assessed

Assessing Data Quality

PC 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 Support Staff, Consultants, & Recipient Staff:

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

Critical Factors for Reviewing or “Weighing” Data

1. Number of respondents/Size of study
2. Representativeness/Sampling
3. Content/Questions
4. Quality Control

Numbers and Representativeness: Who Was Included in the Survey or Study?

- **Numbers:** Numbers of people or sample size – more weight to data from larger numbers of people
- **Representativeness:** More confidence in data when the individuals sampled were chosen to represent the entire HIV population, subpopulation, or the targeted portion of the community – through:
 - **Probability sampling**
 - **Purposive or representative sampling**

Numbers and Representativeness: Who Was Included in the Survey or Study?

- **Probability sampling:** Using a random sampling method where each member of the population has an equal probability of being included, so that findings can be assumed to reflect the entire population from which the sample was drawn
- **Purposive or representative sampling:** Selecting people for the study so that they mirror the HIV population in your EMA or the subpopulation you are targeting

Content/Questions and Quality Control

- **Content/Questions:** Look at whether the questions asked were clear and understandable, so that they were likely to generate reliable data that really measure what they were supposed to be measuring
- **Quality control:** Look for evidence that the data were collected using appropriate methods and by appropriately trained individuals
 - Data collection process carefully managed/monitored and agreed-upon methods implemented
 - Data reviewed for completeness, nonduplication, and data entry where relevant

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 by trained individuals?
- Was there “quality control” to be sure the stated data gathering and analysis process was followed?

Terms for Key Measures of Data Quality: Reliability and Validity

- **Reliability** involves consistency and “repeatability” of findings
 - you would get the same results if:
 - You did the study a second time
 - You asked the same person the same question again
- **Validity** involves the credibility or “believability” of your findings – they truly represent the phenomenon you are trying to measure
 - The tools used measured what they were supposed to measure (*internal validity*)
 - The results can be “generalized” or assumed to apply to people beyond the sample in the study (*external validity*)

Source: “Introduction: Reliability and Validity,” UC Davis, <http://psc.dss.ucdavis.edu/sommerb/sommerdemo/intro/validity.htm>

Sound Data Use Practices for the PC

- Provide data presentations and discussions throughout the year, using consistent formats and terminology
- *Always* allow for discussion during or immediately after data are presented
- *Always* do some training along with the presentation
- Develop and consistently follow a process to weigh, summarize, compare, and use data to reach decisions
- Give organized opportunities for individual and research-based data to be presented before decision making
- Have a policy and process to manage conflict of interest
- Empower all members to use and help enforce a commitment to data-based decision making

Sound Data-Use Practices for PC Members and Committee Members

- Become familiar with all the data types and sources
- Review both quantitative and qualitative data
- Look for appropriate and timely data to answer specific questions
- Begin by looking for the main findings—but don't stop there
- Always look at the data for subpopulations
- Ask the right questions to assess data quality
- Identify data gaps
- Triangulate—and give most weight to the “best” data

Using Quantitative and Qualitative Data

- Use quantitative data to identify issues
- Use qualitative information to understand the issues better
Example:
 - **Using quantitative data:** Client utilization and characteristics data show that Latinas were much less likely to use mental health services last year than in prior years
 - **Using qualitative data:** A Latina focus group indicates that two bilingual clinical social workers left their jobs about a year ago and were replaced by staff who do not speak Spanish – and sometimes no interpreter is available

Data Gaps

- No PC has all the data needed for decision making
- Data gaps are often caused by:
 - Limited resources
 - Limited needs assessment and data analysis skills and experience on the part of PC 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 and recipient regarding data needs and how best to meet them

Sum-Up

- Data-based decision making is the foundation for effective planning by PCs
- The PC and recipient share responsibility for ensuring the availability of needed data
- PC members should be prepared to act as both advocates and planners – always as good users of data
- All PC staff and committee members share responsibility for ongoing, informed use of data for decision making
- Decisions should always consider both the needs of all PLWH and the needs of populations facing HIV-related disparities in service access and outcomes

Let's Practice!

Newly Diagnosed HIV

TABLE 3
By Race/Ethnicity | 2018

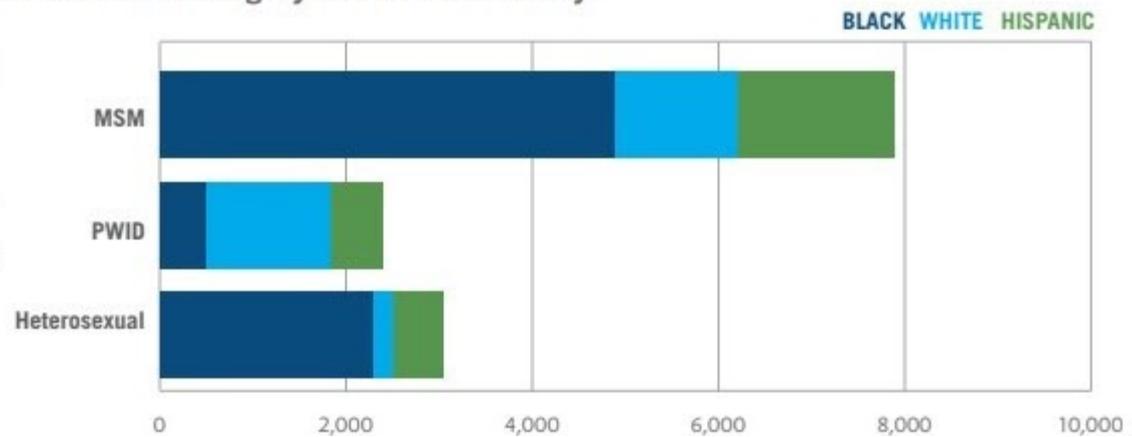
Racial/ethnic health disparities persist and mirror disparities observed across the nation.

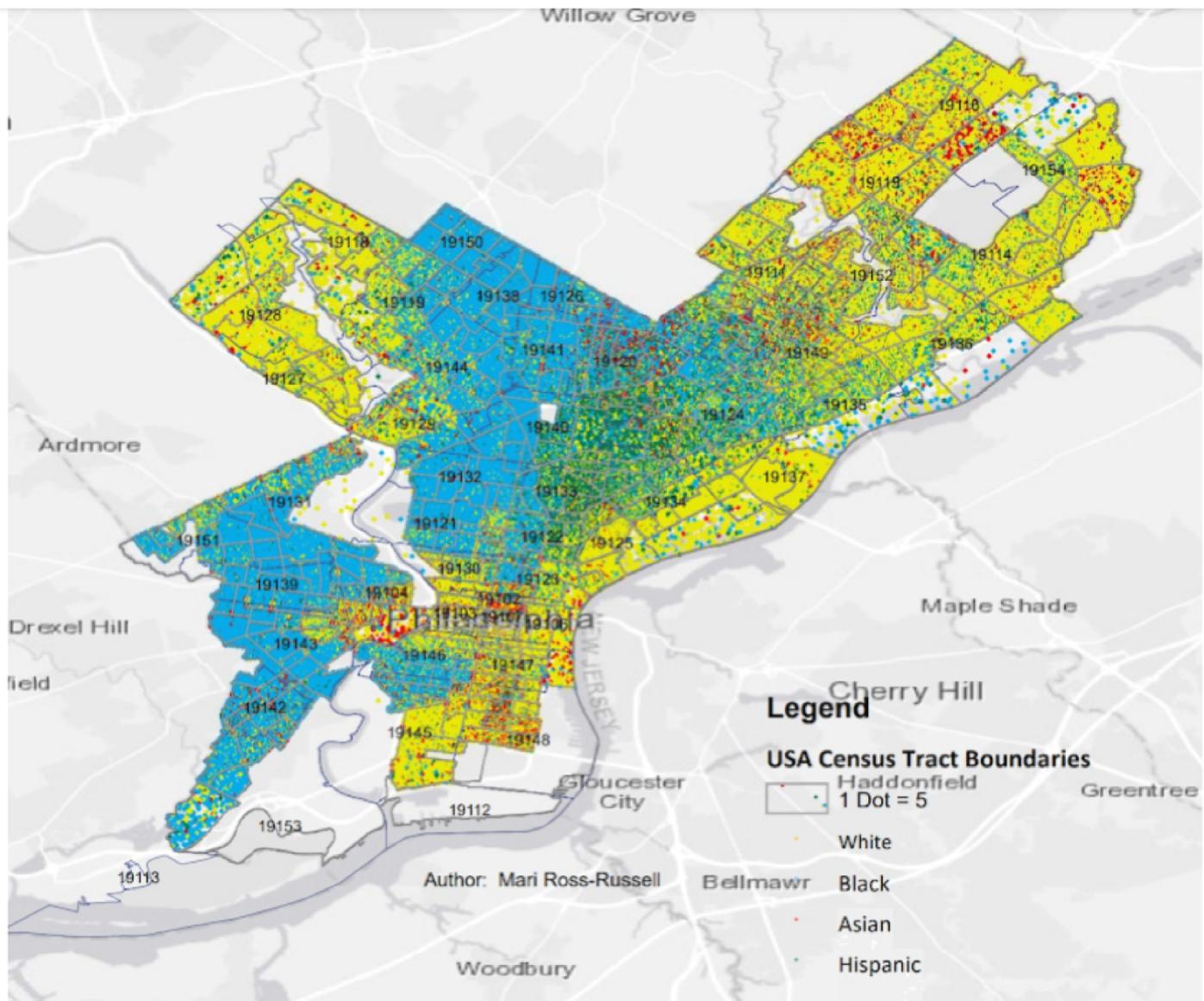
	BLACK		HISPANIC		WHITE	
	N	%	N	%	N	%
Total	246	100.0 %	85	100.0 %	78	100.0 %
Sex at Birth						
Female	59	23.9 %	22	25.8 %	16	20.5 %
Male	187	76.0 %	63	74.1 %	62	79.4 %
Age Category						
13-19	12	4.8 %	8	9.4 %	0	0.0 %
20-24	60	24.3 %	17	20.0 %	8	10.2 %
25-29	45	18.2 %	9	10.5 %	18	23.0 %
30-39	63	25.6 %	26	30.5 %	27	34.6 %
40-49	23	9.3 %	12	14.1 %	11	14.1 %
50+	43	17.4 %	13	15.2 %	14	17.9 %
Transmission Risk						
MSM	122	49.5 %	42	49.4 %	33	42.3 %
PWID	12	4.8 %	14	16.4 %	34	43.5 %
MSM/PWID	*	*	*	*	*	*
Heterosexual	57	23.1 %	14	16.4 %	*	*
No Reported Risk	52	21.1 %	14	16.4 %	*	*

FIGURE 1

PrEP Indication by Transmission Category and Race/Ethnicity¹

¹ Methods based on Smith, D.K., Handel, M.V., & Grey, J. (2018). Estimates of adults with indications for HIV pre-exposure prophylaxis by jurisdiction, transmission risk group, and race/ethnicity, United States 2015. *Annals of Epidemiology*.





Census tracts are population density based, the larger the population the smaller the geographic area. Generally, the population within a census tract is from 2,500 to 8,000. Based on the United States