
HRSA Ryan White HIV/AIDS Program Center for Quality Improvement & Innovation



Consumer Webinar

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Presenter



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Director Consumer Affairs

Ground Rules for Webinar Participation

- Actively participate and use the chat function to interact during the presentation(s)
- Please do not put us on hold
- Mute your line if you are not speaking
- The webinar will be recorded so that anyone who missed can replay it before the next webinar.

Webinar Learning Objectives

- Introduce data definition
- Explain objectivity of quantitative data and subjectivity of qualitative data
- Introduce data terms and concepts of percentage, r and average
- Identify a health disparity



Who said?

“In God We Trust, All Others Must Bring Data.”

Edward Deming

<https://deming.org/deming/the-deming-philosophy>



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Key Data Terms

What are Data?

- Data (n) (plural): Facts or information used usually to calculate, analyze, or plan something



Source: <http://www.merriam-webster.com/dictionary/data> accessed on 04/05/14

Data: Cultural Competency

- Data are the voice of the system . . .
- If you want to learn more about a system, ask questions about the data it generates



Types of Data

Quantitative Data (Things you can measure or count like numbers)

- How many jelly beans do you see?



- What are some ways to count the jelly beans?

Types of Data

Qualitative Data (Things that cannot be easily measured, but can be described)

- **What are some ways to describe the Jelly Beans?**
- **Do we all agree on the ways to describe Jelly Beans?**



Introduction to Data as an Assessment Tool

Data Terms: Percent

- Percent

- One part in a hundred

*“If the report states that **80** out of **100** patients achieved viral load suppression.”*

- A percentage or portion

“What percent of our patients have not achieved viral load suppression?”

20%

Data Set

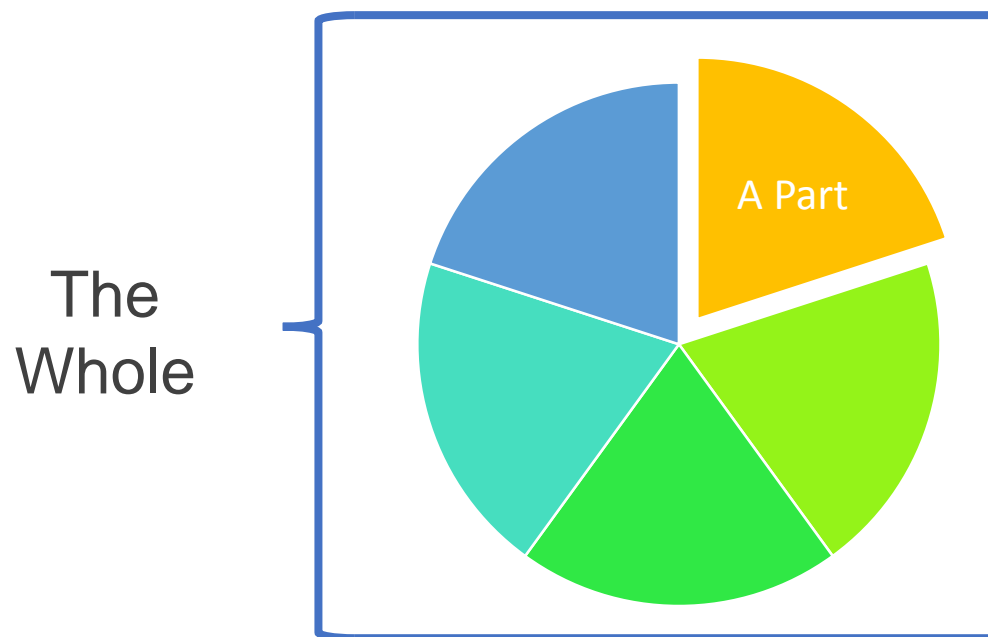
Performance Measure	Total	
	Numerator	Denominator
Medical Visits	7542	8769
Viral Load Monitoring	6122	7653
Viral Suppression	5681	6634
PCP Prophylaxis	1303	1430
Syphilis Screening	6695	8974
Oral Exam	2147	8924

Question

What percentage of patients achieved viral suppression?



A percent is just a part of the whole



Do we have to do math?



Adapted from: *NQC Training of Consumers on Quality: Facilitator Manual to Build Capacity of People Living with HIV to Actively Participate in Quality Improvement Activities (2014)*. Developed by the New York State Department of Health AIDS Institute National Quality Center. Funded through a cooperative agreement with the Health Resources and Services Administration HIV/AIDS Bureau.

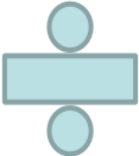
STEP ONE

Patients Who **Were**
Virally Suppressed

Patients Who
Should Have Been
Virally Suppressed

N = Number

Numerator



Denominator



N

5681

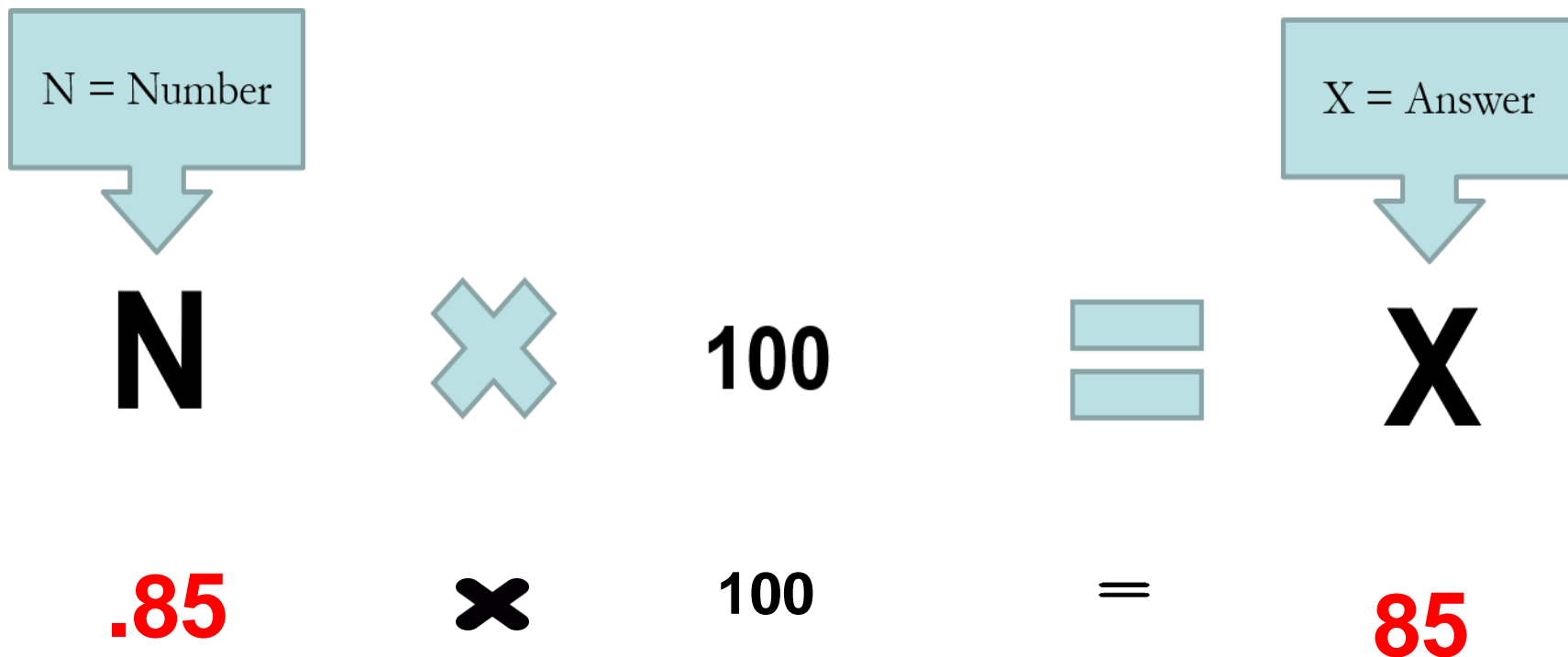


6684



.8499

STEP TWO



ANSWER

X



Percentage

85



85%

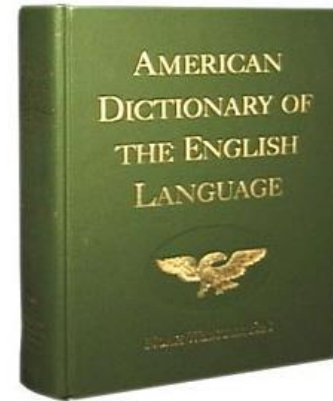
Answer

- After dividing 5681 by 6634 and then multiplying by 100 you get the answer or percentage
- What is the total patient population achieved viral suppression in the measurement period

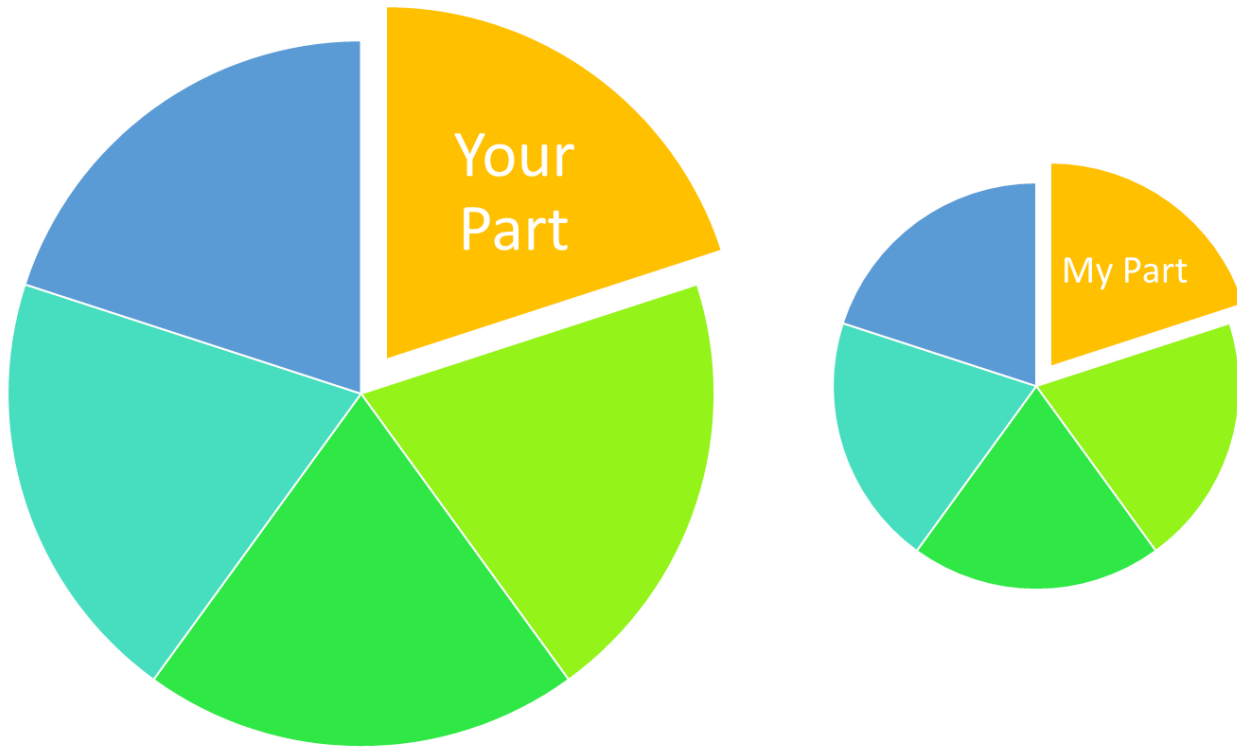
85%

Data Terms: Rate

- Rate
 - A quantity measured with respect to another measured quantity
 - *a rate of speed of 60 miles an hour.*
 - A measure of a part with respect to a whole; a proportion
 - *the mortality rate; a tax rate*



Rate



When and Why Do We Calculate Rates?

I have a problem. . .

- A lot of people living with HIV
- **A medium size urban center**
- **A higher percentage of the population living with HIV**
- A huge impact on my city
- A need to accurately compare my problem to yours

You have a problem. . .

- A lot of people living with HIV
- **A metropolis or large city**
- **More actual persons living with HIV**
- A huge impact on my city
- A need to accurately compare my problem to yours

Sample Data Set

CITY	AIDS Cases Reported	Population estimate
Los Angeles, CA	24,727	12,692,603
Baltimore, MD	10,301	2,669,702
Dallas, TX	7,993	6,156,652
San Juan, PR	7,858	2,559,753

Question

What is the rate of AIDS in each of these cities?



Calculating Rates

Step One:

Divide **AIDS Cases Reported** by the **Population Estimate** which will give us a **Number**

Step Two:

Multiply the **Number** by 100,000 to get the **Rate**



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Why Do We Multiply By 100,000?

- **To Compare**
 - Not all cities have the same population so we standardize the population so we can compare.
- **To Simplify**
 - Such small numbers comparatively that you would end up with .05 of a person . . . How do we plan for that?

Example: Calculating Rate for LA

Step 1

$$\begin{array}{l} \text{Los Angeles, CA} \quad \text{AIDS Cases Reported} \quad \div \quad \text{Population Estimate} \quad = \quad \text{Number} \\ \\ 24,727 \quad \div \quad 12,692,603 \quad = \quad .001948 \end{array}$$

Step 2

$$\text{Number} \quad \times \quad 100,000 \quad = \quad \text{Answer}$$

$$.001948 \quad \times \quad 100,000 \quad = \quad 194.81$$

Question

What city has the highest AIDS rate per 100,000 people?



Answers

If the city had 100,000 people this is how many would have AIDS

Rank by AIDS Rate (if city had 100,000 people)

CITY	Rate
Los Angeles, CA	
Baltimore, MD	
Dallas, TX	
San Juan, PR	

RANK
1. 194.81
2. 385.85
3. 129.83
4. 306.98



Data Set: Client Satisfaction rating on Scale of 1-10

- What if I told you that Kehmisha, Tulivia, Roselia, and Keema were all long term patients of the clinic?
- What if I told you that Jasmine, Ariana, and Esmeralda were all newly enrolled patients?

Respondent Names	Rating
Kehmisha	9
Michele	6
Tulivia	9
Jasmine	1
Mary	5
Roselia	9
Jane	7
Esmeralda	1
Keema	9
Ariana	1

Add and then divide

RATING

9

6

9

1

5

9

7

1

9

1

Data Terms: Average

- Add each of the numbers and divide by the total number of numbers
- There are ten numbers, therefore 10 is the total number of numbers
- Add numbers together and divide by 10
 - a) $9 + 6 + 9 + 1 + 5 + 9 + 7 + 1 + 9 + 1 = 57$
 - b) $57 / 10 = 5.7$
- **5.7** is your Average

Playing with Data Sets

- What if the data set was national race/ethnicity data?

Race	AIDS	RATE
White	?	?
Black	?	?
Hispanic	?	?
Pacific Islander	?	?
Native American	?	?

- What if the data set was broken down by gender?

Gender	Viral Suppression	Percent
Male	?	?
Female	?	?
Transgender	?	?

Data Limitations

- Things to consider . . .
 - If you want it, you have to go get it
 - By the time you got it, its old
 - There is a lot of it
 - It has to be interpreted and analyzed
 - Appears to be, May indicate, Could mean
 - It can be manipulated (massaging data)
 - It's always changing

Don't let the perfect be the enemy of the good!

What is an example of a data set with limitations?



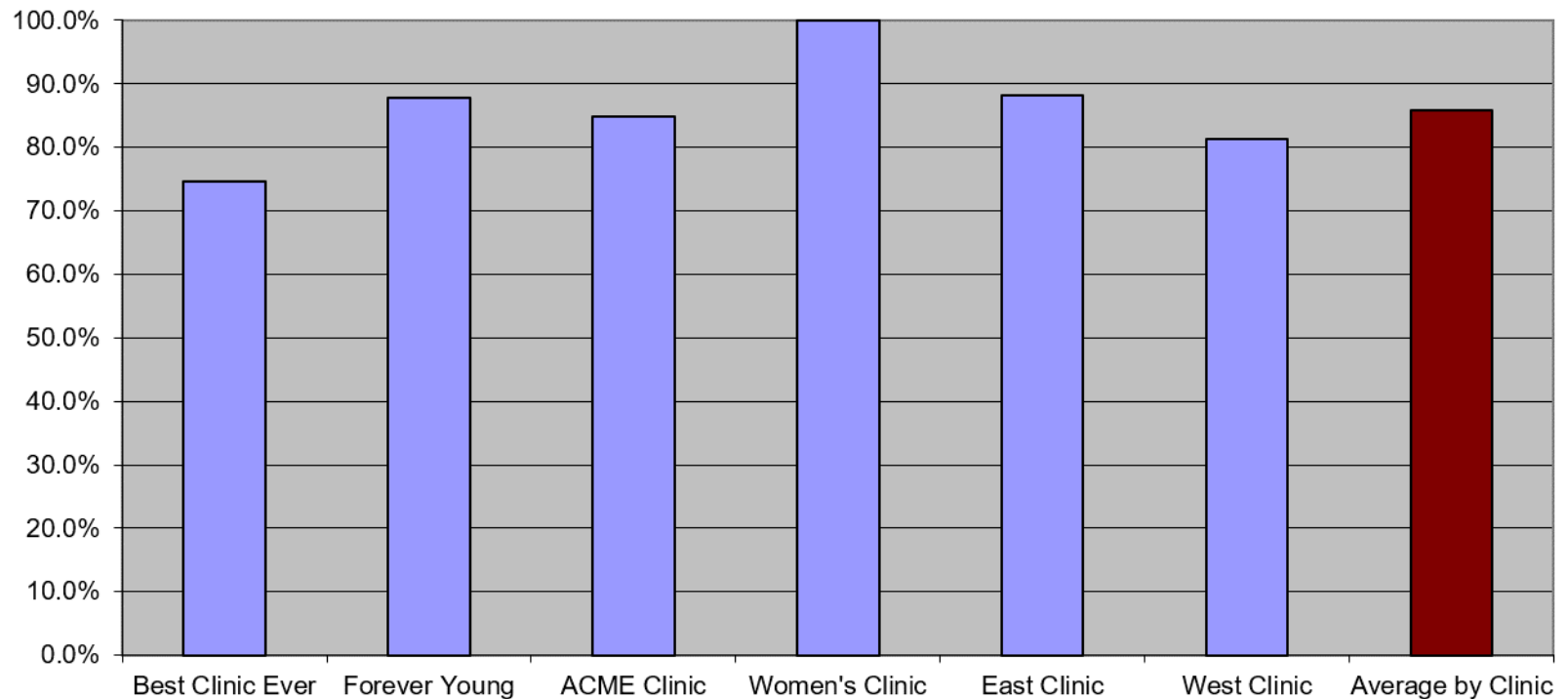
What Are The Data Telling Us?

Examples of Data Sets



What Are the Data Telling Us?

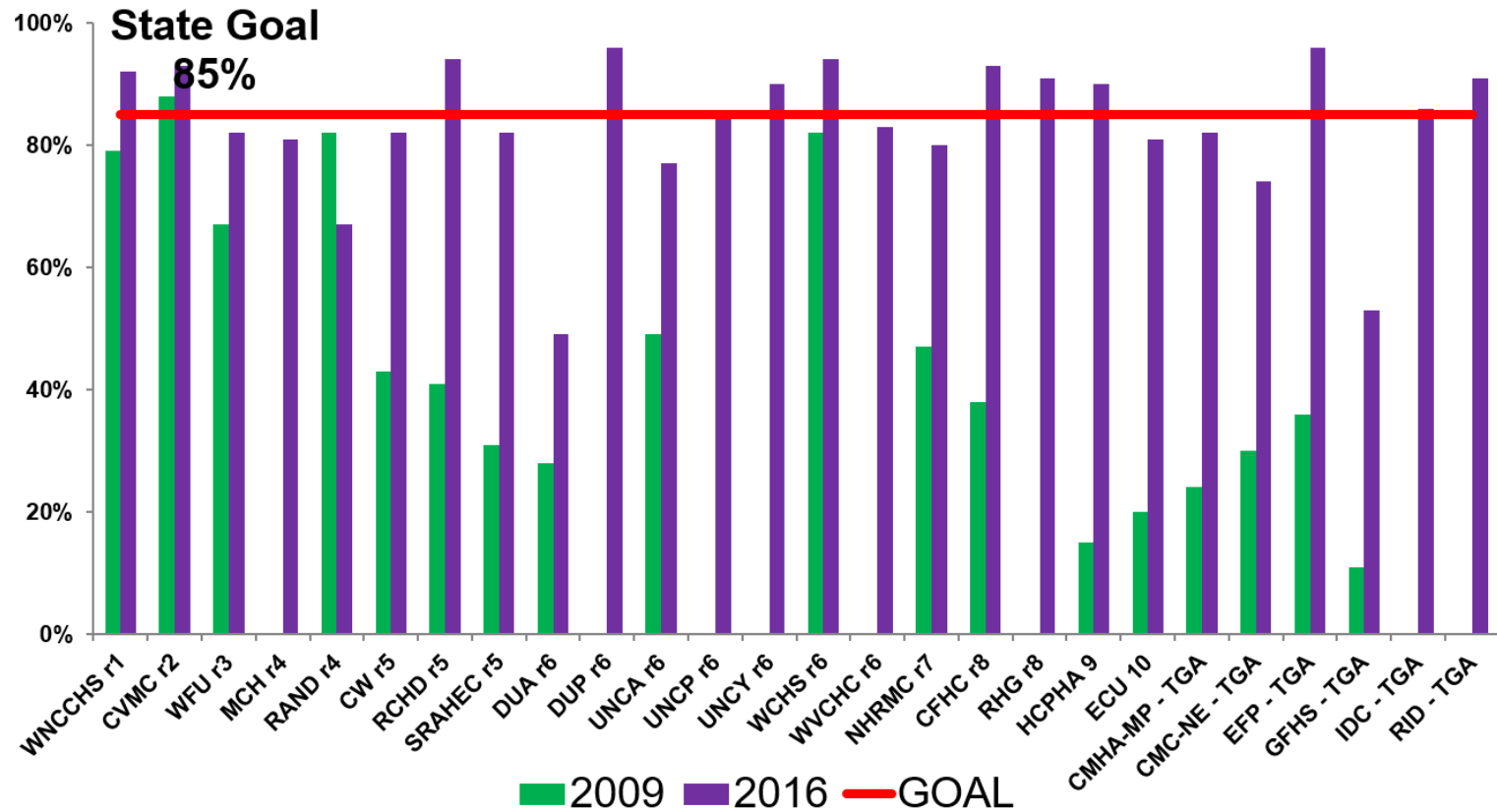
Quality Indicator Data Report (April 2012)
Indicator: Medical Visits



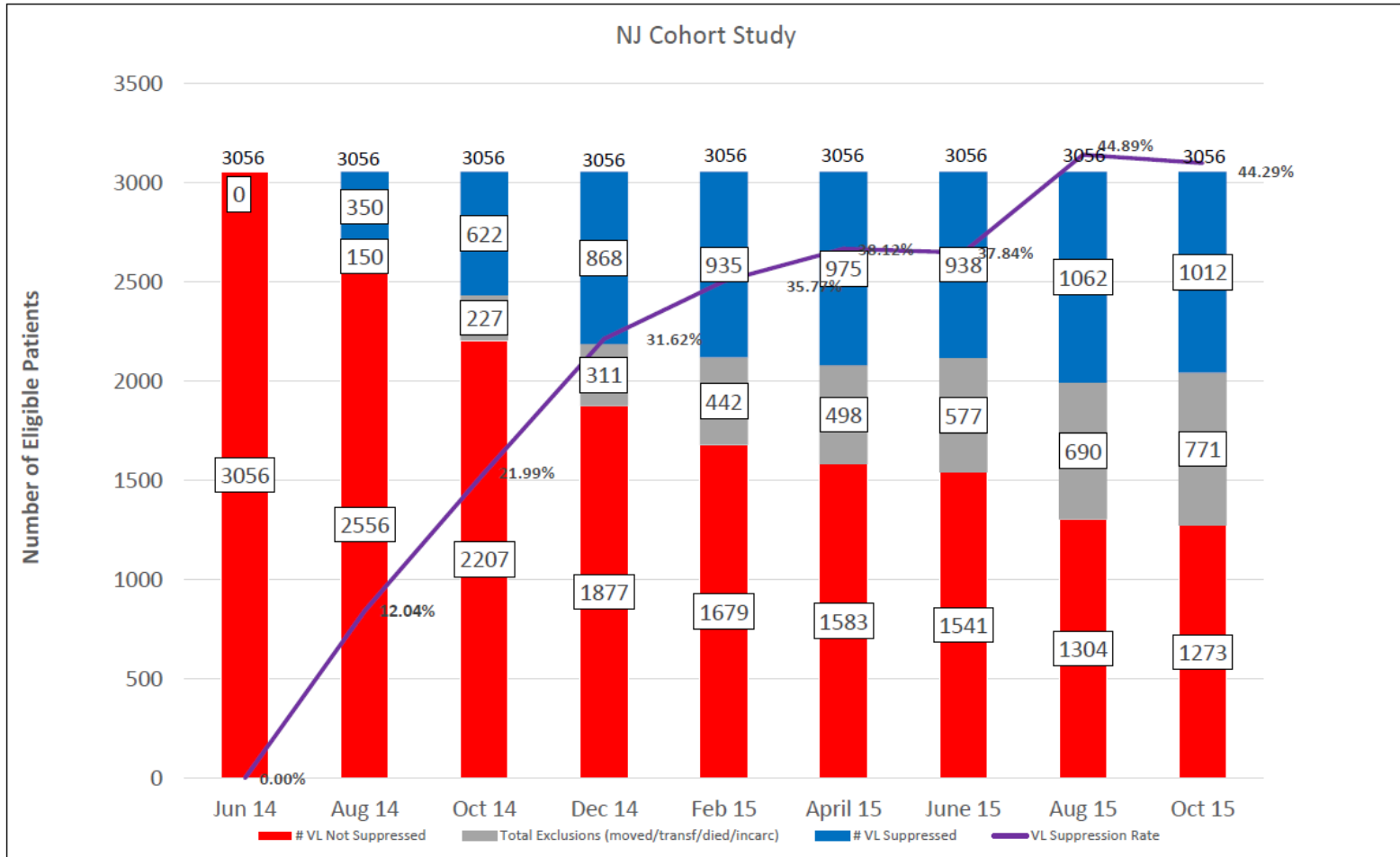
What Are the Data Telling Us?

HAB 13 – SYPHILIS SCREENING

10/2008 -9/2009 and 10/2015 – 9/2016, State goal = 85%



What Are the Data Telling Us?



The HIV Care Continuum

- The HIV Care Continuum is one way to look at a series of measures for HIV care
- The HIV Care Continuum helps to “frame” our efforts by thinking about engagement to care in measurable steps
- States, regions, cities, and clinics all have the ability to build their own continuums by shaping the way they measure care and collect data
- Patient experience can help inform improvements

HIV Care Continuum

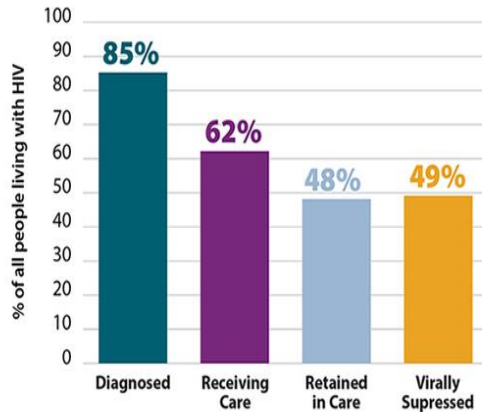


<https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum>

HIV Care Continuum

HIV Care Continuum, United States, 2014

An estimated 1.1 million people are living with HIV in the United States.



★ ★ ★ **HIV** *in the* **United States** ★ ★ ★

Not all people with HIV are getting the care they need.

1.1 million people living with HIV in the US in 2015

85%

diagnosed

62%

received care

48%

retained in care*

49%

virally suppressed**

* Had 2 tests at least 3 months apart to measure level of virus in the body. ** Virus at low enough level to stay healthy and reduce transmission risk. Based on most recent test. Based on the most recent data available in April 2018.

Get Tested. Get in Care. Stay in Care.

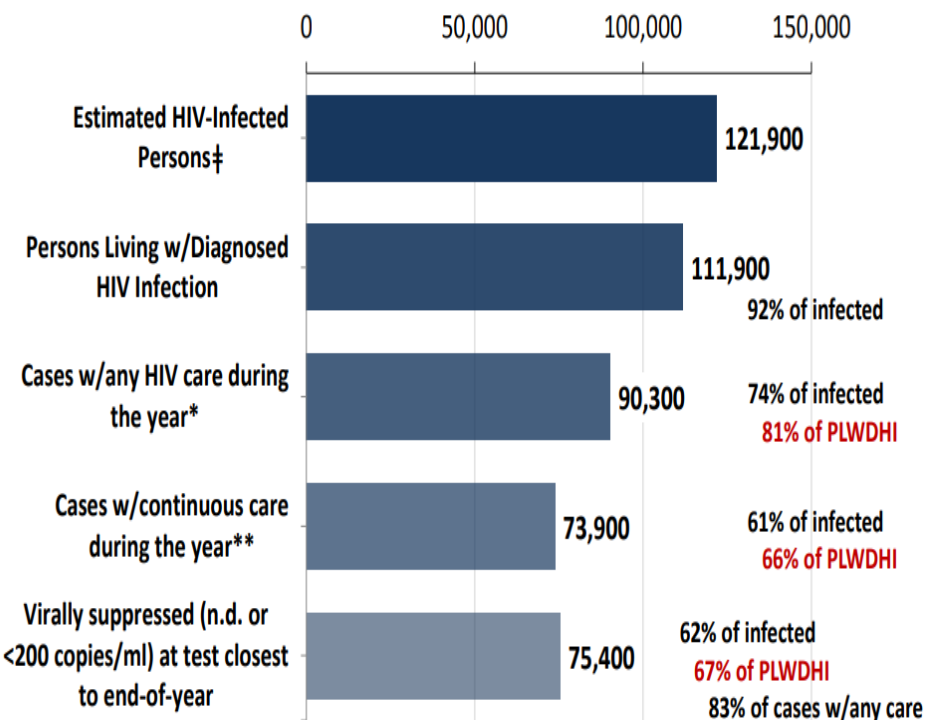
Be Healthy.

<https://www.cdc.gov/nchhstp/newsroom/2017/HIV-Continuum-of-Care.html#Graphics>

New York State Cascade of Care Continuum

New York State Cascade of HIV Care, 2015

Persons Residing in NYS† at End of 2015



†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.

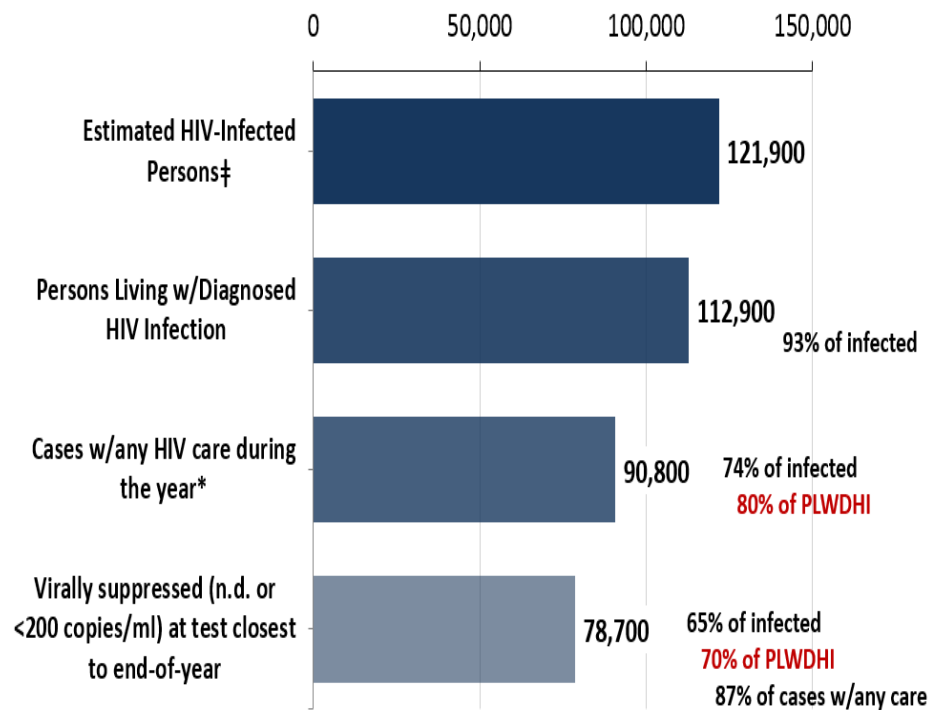
‡ Estimated unknown 6.7% for NYC and 13% Rest of State

*Any VL, CD4, genotype test during the year; ** At least 2 tests, at least 91 days apart



New York State Cascade of HIV Care, 2016

Persons Residing in NYS† at End of 2016



†Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.

‡ Estimated unknown 5.0% for NYC and 15% Rest of State

*Any VL, CD4, genotype test during the year.



Health Disparity and Health Equity Definitions

- Health Disparity – systematic difference in health between social groups
- Health Equity - the absence of disparities or avoidable differences among social groups

Adapted from: HEALTH RESOURCES AND SERVICES ADMINISTRATION, OFFICE OF HEALTH EQUITY. HEALTH EQUITY REPORT 2017. ROCKVILLE, MARYLAND: U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES; 2018.

Overview:

The end+disparities ECHO Collaborative is about improvement of care for people living with HIV, not performance measurement. However, measurement plays an important role throughout the initiative. Collaborative participants are expected to submit their performance data, using standardized measurement definitions, every other month using the online end+disparities database. Always remember that measurement should be designed to accelerate improvement, not slow it down.

Key Findings:

There is a clear trend toward higher viral suppression rates reported by numerous community partners in their sub-populations . The collaborative measures vulnerable sub-populations of RWHAP patients as follows: B/AA/L women = 84.1%, MSM of color = 81.7%, Transgender = 80.5%, and Youth = 75%.

Indicator Definitions:

Total Caseload	Percentage of patients, of all ages, with a diagnosis of HIV with an HIV viral load less than 200 copies/ml at last HIV viral load test during the 12-month measurement year (National Quality Forum #: 2082)
Youth	Percentage of youth clients age 13-24, with a diagnosis of HIV with an HIV viral load less than 200 copies/ml at last HIV viral load test in the 12-month measurement period
Transgender	Percentage of transgender clients, of all ages, with a diagnosis of HIV with an HIV viral load less than 200 copies/ml at last HIV viral load test in the 12-month measurement period
Black/African American and Latina Women	Percentage of Black/African American and Latina Women, of all ages, with HIV infection whose last viral load in the 12-month measurement period is less than 200 copies/ml
MSM of Color	Percentage of men, of all ages, who have sex with men (MSM) clients of color with HIV infection (including MSM of Color who use injection drugs) whose last viral load in the 12-month measurement period is less than 200 copies/ml

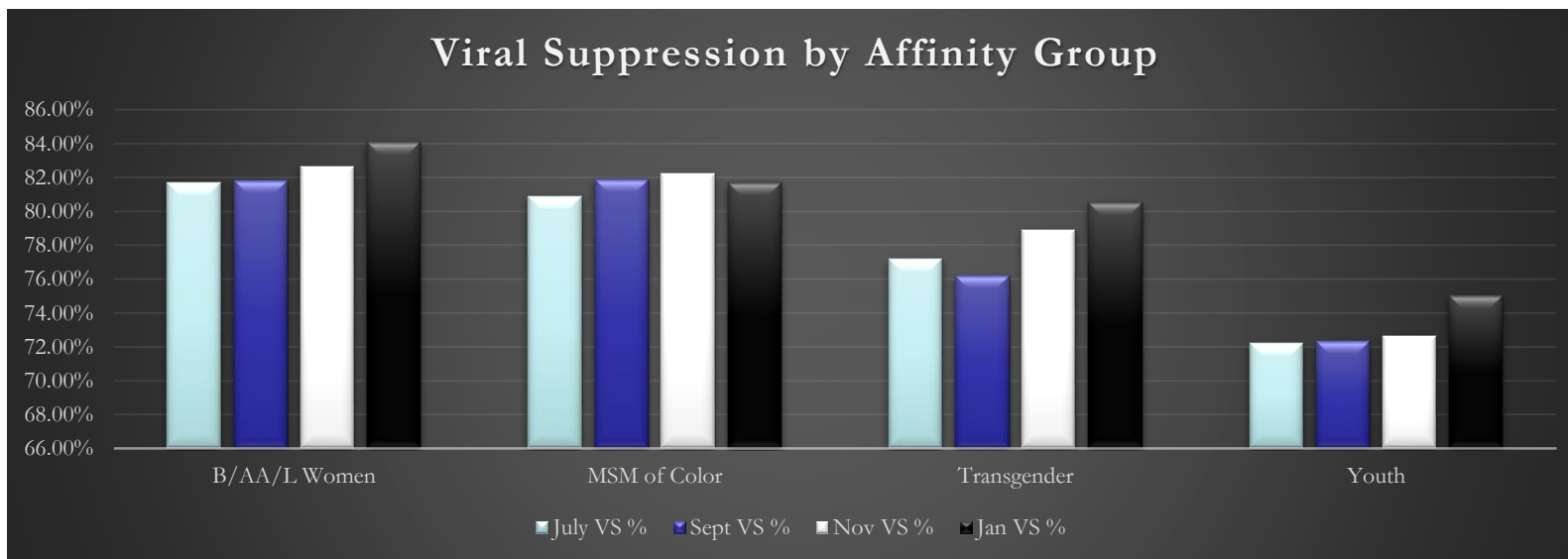
Data Limitations:

- All data are self-reported by Collaborative participants.
- Each submission may represent a single agency or an aggregated score of multiple agencies.
- Each reporting cycle represents a snapshot of cross-sectional submissions; this is not a cohort study; the viral suppression rates of individual patients are not followed over time.
- Larger collaborative participants have a greater impact on the overall viral suppression mean value than smaller participants with fewer patients.

The end+disparities ECHO Collaborative is a national initiative to reduce disparities in four disproportionately affected HIV subpopulations: MSM of Color, Black/African American/Latina Women, Transgender People, and Youth. The 18-month collaborative aims to increase viral suppression in these four key HIV subpopulations and increase local quality improvement capacities. The initiative is managed by the HRSA Ryan White HIV/AIDS Program Center for Quality Improvement & Innovation (CQII), developed using the Project Extension for Community Health Outcomes (ECHO) model, and is supported by the HRSA HIV/AIDS Bureau.



end+disparities ECHO Collaborative: January 2019 Benchmark Report



Affinity Group	July Den	July Num	July VS %	Sept Den	Sept Num	Sept VS %	Nov Den	Nov Num	Nov VS %	Jan Den	Jan Num	Jan VS %
B/AA/L Women	10,071	8227	81.70%	9799	8015	81.80%	8920	7369	82.60%	8497	7149	84.10%
MSM of Color	14,992	12,124	80.90%	12593	10309	81.90%	11493	9450	82.20%	11986	9791	81.70%
Transgender	632	488	77.20%	606	462	76.20%	541	427	78.90%	549	442	80.50%
Youth	3625	2616	72.20%	3240	2342	72.30%	2836	2058	72.60%	2917	2187	75%

end+disparities ECHO Collaborative: January 2019 Benchmark Report

Data Cycle 4:
Jan., 2019

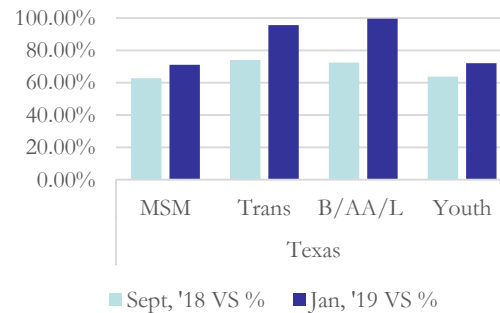
Review Period:
Nov 1, 2017 –
Oct 31, 2018

of Submissions:
97

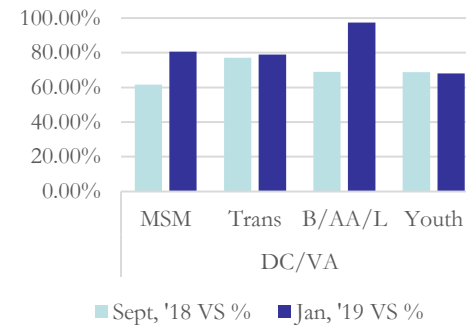
of Patients:
120,929

**Total Case Load
Viral Suppression
Average:**
83.9%

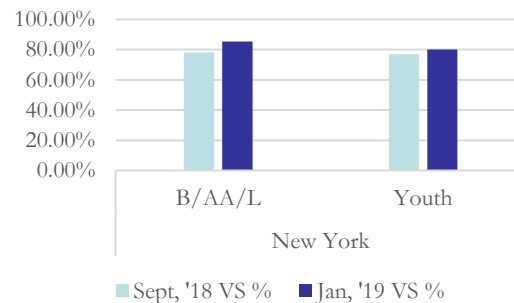
Texas RG VS by Affinity Group



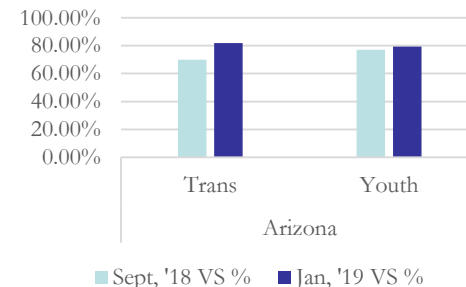
DC/VA RG VS by Affinity Group



New York RG VS by Affinity Group

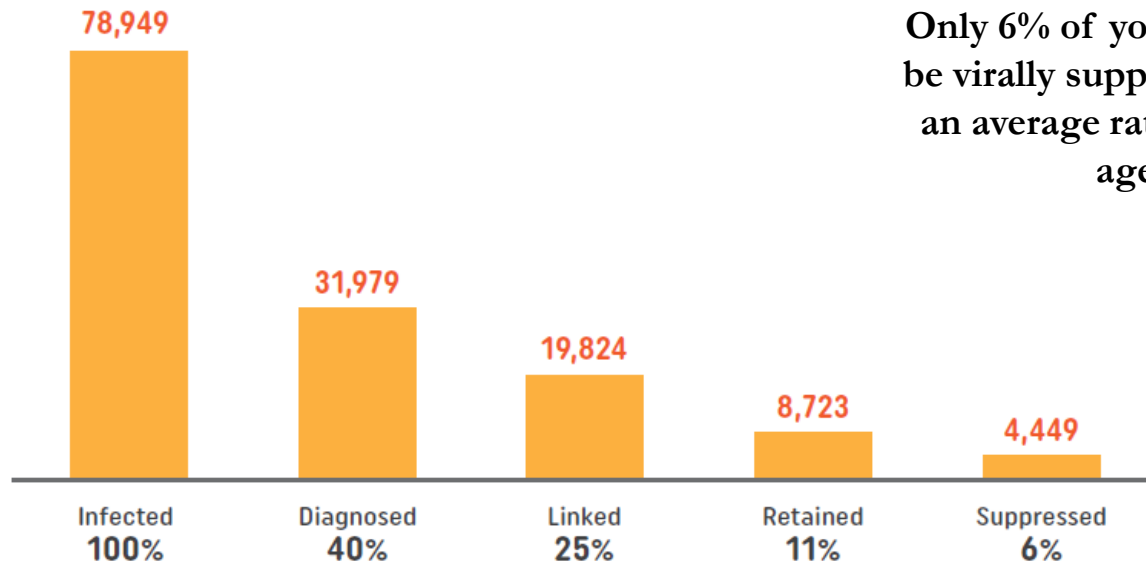


Arizona RG VS by Affinity Group



Disparity: Youth Aged 13-24

HIV Care Continuum in HIV-infected Youth in the United States



Only 6% of youth are estimated to be virally suppressed, compared to an average rate of 30% across all age groups.

Trivia Question.....Who said?

“Conducting data analysis is like drinking a fine wine. It is important to swirl and sniff the wine, to unpack the complex bouquet and to appreciate the experience. Gulping the wine doesn’t work.”

Daniel B. Wright



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Useful Resources

United States Agency for International Development:

- <https://www.usaid.gov/what-we-do/global-health/hiv-and-aids/technical-areas/strategic-information/hiv-aids-data-us>

Health Resources Services Administration

HIV/AIDS Bureau (HAB): <https://hab.hrsa.gov/data>

Centers for Disease Control and Prevention: <https://www.cdc.gov/DataStatistics/>

Center for Quality Improvement & Innovation

- <https://targethiv.org/category/source/center-quality-improvement-and-innovation-cqii>

Quality Academy: <https://targethiv.org/searches/quality%20academy>

Consumer Academy: <https://targethiv.org/searches/consumer%20academy>

Training of Consumers on Quality Facilitators Guide:

<https://targethiv.org/sites/default/files/file-upload/resources/NQC%20TCQ%20Guide%20Final.pdf>



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Thank You!

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