

HIV Prevention Indicators



What are national health indicators and why do they matter?

An indicator can serve as a shortcut to understanding what is happening with an epidemic—by choosing a few key data points, we can, at a glance, have a general sense of what might be going on with a disease. Choosing the wrong indicators may misrepresent what is actually happening and can have consequences when communities and key stakeholders incorrectly invest limited time and resources.

Where do indicators come from?

Typically, national indicators come from government-led efforts to monitor what is going on with a disease or condition.

Given government involvement in establishing many national indicators, it is important to know that political considerations can influence decisions. With HIV, stigma and moralizing can also influence which indicators to promote. **That is why well-informed community involvement in indicator development is essential.**

What are the indicators we use for HIV prevention in the United States?

Deciding on a finite set of indicators for any health-related issue is a complicated process. The benefit of limiting the number of indicators is that it makes assessing the state of our prevention efforts more manageable. The drawback is that there may be gaps in what we are monitoring, and any misrepresentation in the data can have consequences.

Basic definition of health indicators

A measurable characteristic that describes:

- ▶ The health of a population (e.g., life expectancy, mortality, disease incidence, etc.).
- ▶ Determinants of health (e.g., health behaviors, health risk factors, physical environments, and socioeconomic environments).
- ▶ Health care access, cost, quality, and use. Depending on the measure, a health indicator may be defined for a specific population, place, or geographic area. (https://www.cdc.gov/nchs/ppt/nchs2012/li-18_churchill.pdf)

Source: CDC

Some of the most notable and widely visible indicators for HIV prevention for HIV-negative individuals are available in Goals 1 and 3 of the National HIV/AIDS Strategy (NHAS). The indicators are chosen and promoted through the White House's Office of National HIV/AIDS Policy (ONAP) and supported through information obtained by the CDC. [Note: ONAP still exists at the time of this publication, but the new presidential administration is not obligated to keep it.]

The following list of NHAS goals and indicators focus on key aspects of HIV prevention in the US. Let's look at where these indicators come from, and where they might be improved.

TAG

Treatment Action Group

NHAS Goal 1: Reducing new HIV infections

- ▶ **Indicator 1: Increase the percentage of people living with HIV who know their serostatus to be at least 90%**
- ▶ **Data source for indicator:** National HIV Surveillance System
- ▶ **Considerations:** This indicator re-establishes the central importance of increased testing in all HIV prevention efforts. The target seems generally straightforward, though TAG has previously suggested that this indicator should also emphasize diagnosing people as soon as possible after infection. There is no denying that testing is the bedrock of all our work in HIV prevention.
- ▶ **Indicator 2: Reduce the number of new diagnoses by at least 25%**
- ▶ **Data source for indicator:** National HIV Surveillance System
- ▶ **Considerations:** Advocates have questioned whether this is the right measure for new infections (see more in the text box on New Diagnoses vs. Incidence). Some advocates would argue that this

could be more ambitious; in 2015 TAG suggested that a 45% reduction would be more in line with national ambitions to end HIV as an epidemic.

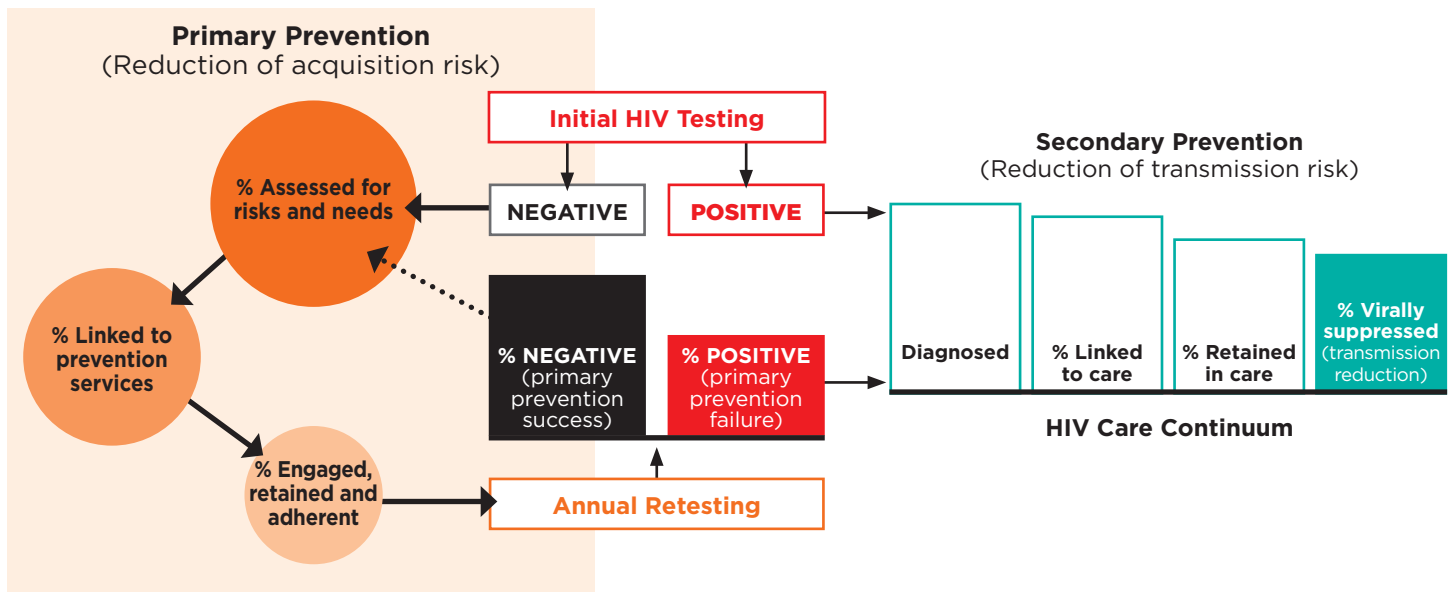
- ▶ **Indicator 3: Reduce the percentage of young gay and bisexual men who have engaged in high-risk behaviors by at least 10%**
- ▶ **Data source for indicator:** Youth Risk Behavioral Surveillance System
- ▶ **Considerations:** This is the only indicator that directly looks at the success of an HIV prevention intervention that is inclusive of HIV-negative individuals. In choosing an HIV-prevention indicator for HIV-negative individuals, many interventions could have been chosen, such as access to/knowledge of post-exposure prophylaxis (PEP), comprehensive sexual education, syringe access programs, knowledgeable healthcare providers, etc. The decision to focus on high-risk behaviors (number of sexual partners, condom usage, and intravenous drug use) for one key population is very limited. Given the complicated and inconclusive evidence base for behavioral interventions, it is peculiar that this particular HIV-prevention strategy was singled out as an indicator

New diagnoses vs. incidence

New diagnoses: The number of people who received a (confirmed) HIV-positive diagnosis in a given period of time (usually a year). This is NOT a measure of how many people were newly infected—it is a measure of how many people were tested and received an HIV-positive diagnosis in that time period. Because people can go years without knowing they have HIV, the people getting the diagnosis may have been infected at any time. As an indicator, the number of new diagnoses is always influenced by two major factors: 1. The number of new infections in a community, and 2. How well we're doing with testing a community and finding those infections. What this means is that a rise or fall in new diagnoses might be showing an actual increase or decrease in new infections, or it might be measuring a new increase or decrease in testing. It's an imperfect measure that should always be considered along with testing rates.

Incidence: This is an *estimate* of the number of people who became newly infected in a given time period (usually a year), and can be complicated to determine accurately. A well-done incidence estimate is greatly preferred over “new diagnoses” for determining how many people are newly infected in a year. Unlike new diagnoses, incidence is less likely to be biased by testing rates, meaning we have a better idea of how many people are actually getting HIV and, by extension, how well we're doing with our HIV prevention efforts. However, incidence estimates can be expensive (to be done well, they generally require the collection of additional lab tests to determine the time of infection) and may take a while to calculate. Because of this, the NHAS switched to new diagnoses in the most recent update. New CDC estimates released in 2017 indicate that we may be seeing a return to incidence, although the estimates use a new methodology that is still being worked out and debated.

An integrated primary and secondary HIV prevention continuum: Conceptual framework



Recently, TAG has been involved in developing a conceptual framework illustrating the interplay between processes to halt both the acquisition and transmission of HIV. The primary HIV prevention cycle, left, begins with HIV testing. Risk and needs assessments, linkage to services, engagement in risk-reduction prevention interventions and HIV testing are repeated for as long as an individual remains at risk for HIV acquisition. Each component contains a suggested measure, or indicator, that could be used to help assess how well we are preventing or treating new infections on a local, state, or national level. Read more about each metric in the table on page 4.

Horn T, Sherwood J, Remien RH, Nash D, Auerbach JD, et al. Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model. *J Int AIDS Soc.* 2016 Nov 17;19(1):21263. doi: 10.7448/IAS.19.1.21263.

rather than other more proven tools (PEP, syringe access, comprehensive sexual education, structural-level interventions, etc.). Also, the power dynamics of having the US government call for surveillance and modification of sexual behaviors within a small group of youth who are stigmatized for their sexuality should be considered when assessing the value of this approach. We argue that this indicator should be discontinued and replaced entirely with the new developmental PrEP indicator and perhaps an indicator on comprehensive sexual education in schools based upon CDC school surveillance.

- ▶ **Data source for indicator:** National HIV Surveillance System
- ▶ **Considerations:** Reducing disparities in priority populations is a social justice imperative in HIV prevention. Advocates have noted, however, that this list is missing at least two essential groups: transgender men and women. Growing disparities in Latino populations compared to white communities also should be considered here. Additionally, by relying on new diagnoses as the data source, this indicator (just as with indicator 2) opens itself up to being more biased by differing testing rates within different communities.

NHAS Goal 3: Reducing HIV-related disparities and health inequities

- ▶ **Indicator 9: Reduce disparities in the rate of new diagnoses by at least 15% in the following groups: gay and bisexual men, young African-American gay and bisexual men, African-American women, and persons living in the southern United States.**

Step	HIV Testing and Retesting	Risk and Needs Assessment	Linkage to Prevention Services	Engagement, Retention, and Adherence
Elements and Metrics	Testing through: community health centers; physician offices; hospital-based inpatient and ambulatory care clinics; emergency departments; CBO/ASO; home/self-testing; harm reduction and substance use programs; mobile/venue-based units.	STI screening; pregnancy and family planning; mental health and substance abuse; trauma and violence; insurance coverage; primary care engagement; housing and employment status; and sexual health screenings	Documented linkage to: health insurance, including ACA/health insurance navigation; primary care provider or community-based PrEP or PEP providers; syringe exchange and other harm reduction programs; and/or DIS/public health departments	Engagement (number/type of visits); client-provider relationship; intervention adherence (e.g., uptake and continued utilization of PrEP and PEP)
Data Sources	NHM&E; health departments; community clinics; labs (public and private); ACA plans; CMS and state Medicaid databases; Veterans Administration health centers; prisons and jails; Bureau of Primary Health Care/HRSA; OB-GYN; emergency rooms	ICD 9 & 10; CBO programmatic and client data; Healthy People 2020.	NHM&E; additional data sources needed	NHM&E, BRFSS, YRBS, NHBS, NSFG, PRAMS, CMS, and MMP hospital discharge data; data brokers; Medicaid registries; and CBO program data, including housing and supportive services.

In contrast to the relatively straightforward data elements used to assess outcomes along the HIV care continuum, the metrics required to populate a primary HIV prevention continuum involving different systems of service delivery, interventions, and outcome measures are incredibly complex and often without adequate or complete population-based data sources. Here we highlight some potential elements, metrics and data sources for the primary HIV prevention cycle.

Abbreviations	BRFSS, Behavioral Risk Factor Surveillance System	DIS, Disease Intervention Specialists	NHBS, National HIV Behavioral Surveillance	PEP, post-exposure prophylaxis	STI, sexually transmitted infection(s)
ACA, the Patient Protection and Affordable Care Act	CBO, community-based organization	HRSA, Health Resources and Services Administration	NHM&E, National HIV Prevention Monitoring and Evaluation	PRAMS, Pregnancy Risk Assessment Monitoring System	YRBS, Youth Risk Behavior Surveillance System
ASO, AIDS service organization	CMS, the Centers for Medicare & Medicaid Services	MMP, Medical Monitoring Project	NSFG, National Survey of Family Growth	PrEP, pre-exposure prophylaxis	

Horn T, Sherwood J, Remien RH, Nash D, Auerbach JD, et al. Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model. *J Int AIDS Soc.* 2016 Nov 17;19(1):21263. doi: 10.7448/IAS.19.1.21263.

NHAS indicators in development

The 2016 progress report for the updated 2020 NHAS also included three new developmental indicators specific to three additional topics:

PrEP

- ▶ **Goal: Increase use of pre-exposure prophylaxis by 500%**
- ▶ **Data source for indicator:** Data licensed from MarketScan Commercial Claims and Encounter Database and analyzed by the CDC
- ▶ **Considerations:** As an indicator in development, this is a step in the right direction, but there is much room for growth. The data source only looks at about 100 large employer-sponsored health insurance plans nationwide, meaning that it is not nationally representative. By only collecting information on employed individuals, we likely

will not be monitoring the situation with more marginalized individuals who are more likely to get PrEP through Medicaid, Gilead’s medication assistance program, and state PrEP assistance plans. The MarketScan data also do not collect information on risk behaviors, meaning that we will not know how uptake is progressing for a number of key populations. Considering that the baseline year of 2014 only had 9,375 individuals on PrEP, while the CDC estimates that around 1.2 million Americans are in need of PrEP, the target of 56,250 individuals on PrEP by 2020 seems a woefully unambitious first target. Advocates will need to push for better quality PrEP uptake data to be made available and for targets that better reflect the urgency of the situation. Also, while this indicator is meant to monitor the end result of our PrEP efforts, we may, again, be better served by additional indicators that assess progress on social and structural barriers to PrEP, such as healthcare provider knowledge and access to healthcare coverage.

Transgender populations

- ▶ **Goal: Increase viral suppression among transgender women in HIV medical care to 90%**
- ▶ **Data source for indicator:** Ryan White HIV/AIDS Program Services Report (RSR)
- ▶ **Considerations:** Again, while this is a step in the right direction after decades of zero to minimal commitment to addressing transgender invisibility in data, there is much room for growth. While the RSR provides data that are already available and more reliable than other sources, not all HIV-positive transgender women receive Ryan White (federal) funding for their HIV care, so this indicator is not nationally representative. Also, the indicator only looks at transgender women who received at least one outpatient healthcare visit from a Ryan White HIV/AIDS provider and had at least one viral load test during the measurement year, meaning that it does not look at transgender women who have fallen out of care—a potentially significant limitation. The indicator does not look at transgender men due to the small number of transgender men in RSR data, and the indicator completely focuses on HIV-positive individuals, leaving vulnerable HIV-negative transgender individuals out of the equation. While NHSS data now include a way to capture transgender identity,

the quality of that data is still being assessed. According to ONAP, as of December 2016, the Department of Health and Human Services has plans to develop an issue brief outlining strategy and implementation plans to add sexual orientation and gender identity questions to national surveys, administrative data systems, and electronic health records, so it will be important for advocates to closely monitor that situation, ensure that the brief is still released, and that the plan is implemented.

Stigma

- ▶ **Goal: Reduce HIV stigma by 25%**
- ▶ **Data source for indicator:** Medical Monitoring Project (MMP)
- ▶ **Considerations:** This measure is captured using a scale that can be accessed publicly at this link (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2001277/>). Again, this is a step in the right direction, but as an indicator in development there is much room for growth. Measuring stigma is always challenging and reducing it to one indicator excludes a number of important perspectives. In this case, ONAP has decided to focus on four kinds of stigma perceived by people living with HIV:

Revised stigma scale: Items of subscales

Items (number from original scale)	Subscale	Alpha	Correlation with original subscale
24. I have been hurt by how people reacted to learning I have HIV. 35. I have stopped socializing with some people because of their reactions of my having HIV. 36. I have lost friends by telling them I have HIV.	Personalized stigma	.75	.90, p<.01
17. I am very careful who I tell that I have HIV. 25. I worry that people who know I have HIV will tell others.	Disclosure	.73	.74, p<.01
7. I feel that I am not as good a person as others because I have HIV. 12. Having HIV makes me feel unclean. 15. Having HIV makes me feel that I'm a bad person.	Negative self-image	.84	.85, p<.01
14. Most people think that a person with HIV is disgusting. 16. Most people with HIV are rejected when others find out.	Public attitudes	.72	.71, p<.01

Wright K, Naar-King S, Lam P, Templin T, Frey M. Stigma scale revised: reliability and validity of a brief measure of stigma for HIV+ youth. *J Adolesc Health*. 2007 Jan;40(1):96-8. Table 1, Revised stigma scale: items of subscales. Reprinted with permission from Elsevier.

personalized stigma, disclosure, negative self-image, and public attitudes. One thing to note is that none of this looks at the stigma experienced by HIV-negative people who are highly vulnerable to infection and what they might experience in trying to access comprehensive prevention tools. Also, by looking at people living with HIV exclusively and not external groups of interest (i.e., healthcare providers), we are not emphasizing the need for other community members to make changes in how they think of or treat people living with HIV, instead we are emphasizing the need to change the *perceptions* of stigma that people living with HIV have. This indicator of stigma would likely have more impact if it widened the scope to focus on the needs of HIV-negative individuals and looked more at stigmatizing attitudes held by healthcare providers and broader American society.

Additional indicators needed

Indicators for process, not just outcomes: there may be room for more indicators that help us monitor gaps in HIV-prevention efforts. An increase in new diagnoses, for example, does not specify which of our national efforts might be failing. There may be other indicators, such as provider willingness to prescribe PrEP, healthcare coverage, etc., that might be more useful in fixing broken systems that could be explored (see text box on “New Directions for Indicators”).

A few data advocacy tips

When advocating for better local, state, and national HIV prevention indicators and surveillance, we typically need to be comfortable asking questions and making comments about data. Here are a few tips to keep in mind:

Numbers are political

As with any political process, it is important that HIV-prevention advocates monitor government surveillance and indicator discussions to ensure that the decisions being made reflect the best interests of affected communities.

New directions for indicators

Moving away from/improving behavioral indicators?: Indicators looking at sexual behaviors and intravenous drug use (such as indicator 3 in NHAS) are very common in HIV prevention. However, the validity of these types of indicators is questionable. Oftentimes, behavioral indicators are based on data sources that are self-reported only. Considering how sensitive and stigmatized these topics are, such self-reported data are often very biased—people may not feel safe to answer honestly. Government intentions to modify sexual behaviors within minority groups that are already stigmatized because of their sexuality brings up questions: should powerful government officials try to alter sexual practices in disenfranchised communities, especially given the shaky evidence base for behavioral interventions?

Incorporating biomedical prevention: For sexual transmission, nothing has been proven to be more effective in the real world for HIV-negative individuals than PrEP. Also, PEP is the only prevention intervention that can keep an individual negative AFTER a possible exposure. We don't have great indicators nationally for PrEP and PEP yet, which is a huge gap, given their importance in HIV prevention.

Structural and Social Determinants of Health: Prevention indicators in the United States have a tendency to focus on individual knowledge and behaviors, but many who are involved in public health believe that they need to better reflect context. Social and structural factors such as stigma, access to healthcare, discriminatory laws and policies, poverty, etc., may be better factors to consider when exploring why prevention efforts fail. Modernizing indicators to better look at context in addition to individual-level factors would be a step in the right direction.

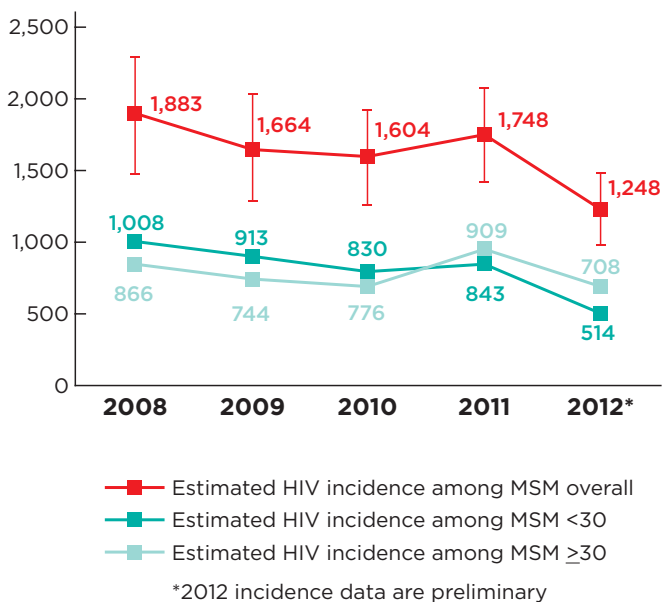
You really are smart enough to speak up and ask questions

Don't let alphabet soup intimidate you. MDs, MPHs, and PhDs all have a lot of education (and a lot of privilege), but they are not the only experts in the room. If something doesn't seem right to you, be empowered to speak up and ask questions.

A little data literacy

Having some basic knowledge of statistics and epidemiology can significantly improve your contribution to discussions on surveillance and national indicators. Whenever we can't get total, census-level data on an indicator, we will use statistical modeling to estimate the true value based upon what information we do have. Modeling can be extremely complicated, but there are a few simple things you can keep in mind when you're looking at any estimate:

Follow the bars: When we make estimates in statistics, there is always some uncertainty with our results. We account for this with confidence intervals (CIs); a range of values within which the actual value is likely to fall. CIs tend to be graphically represented with error bars extending from a data point (see graph



The importance of confidence intervals: The red line in the graph represents incidence ESTIMATES for all MSM in New York City. The error bars for each data point show the CI for that estimate. Just glancing at the graph, we might assume that new infections are going down. But because most of the error bars overlap across all years, we don't actually know if infections are going down or just staying the same.

More on those national data sources

The CDC is in charge of collecting much of the data we use for these national indicators. Some useful HIV prevention surveillance provided by the CDC:

National HIV Surveillance System (NHSS):

The CDC's National HIV Surveillance System is the primary source for monitoring HIV trends in the United States. The CDC funds and assists state and local health departments to collect the information. Health departments report de-identified data to the CDC so that information from around the country can be analyzed to determine who is being affected and why. <http://www.cdc.gov/hiv/statistics/index.html>

National HIV Behavioral Surveillance (NHBS):

As of 2016, **22 jurisdictions** with a high AIDS prevalence are funded to conduct NHBS. Trained interviewers in all NHBS jurisdictions use a standardized anonymous questionnaire to collect information on HIV-related risk behaviors, HIV testing, and use of HIV-prevention services. HIV testing is also offered to all participants. <http://www.cdc.gov/hiv/statistics/systems/nhbs/>

Youth Risk Behavior Surveillance System (YRBSS):

YRBSS monitors six types of health-risk behaviors that contribute to the leading causes of death and disability among youth and adults, including sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection. <http://www.cdc.gov/healthyouth/data/yrbs/index.htm>

at left) and numerically written using parentheses to show the upper and lower bounds of likely values. For example, let's say that we come up with an estimate of 100 new infections for incidence in a certain population in the past year, and we're 95% sure that the true value is between 50 and 150 new infections. We might write that confidence interval as: *95% CI: 50-150*. If you're looking at an estimate (such as incidence, prevalence, or treatment effect)

and don't see a confidence interval, that is an important limitation of the reported analysis. CIs are important in determining trends. Let's say that we are trying to see if there is a real change in incidence from year to year (which, again, is an ESTIMATE). A downward slope might look very optimistic. But the error bars or CI values might provide additional information. If the error bars for one estimate overlap with the preceding estimate or estimates, there may not actually be any differences between the estimates—the real value may be toward the high end of the CI one year and toward the low end of the CI the following year, meaning there's a chance that there was no improvement.

Not statistically significant: If an estimate is not statistically significant, then there is very little, if anything, that you can conclude from it. It means that the findings might be real or they might be due to chance. How do we know if something is statistically significant? When we come up with an estimate, we also calculate a p-value—which is a measure of statistical significance that lies between the values of zero and one. The closer to zero the p-value is (i.e., 0.0001) the MORE significant the findings. The closer to 1 the p-value is (i.e., 0.99999), the LESS significant the findings. What is considered “significant” depends on other decisions and

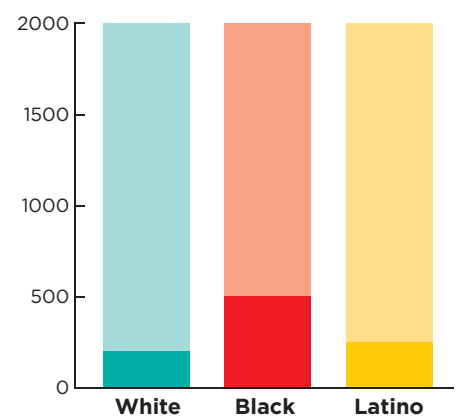
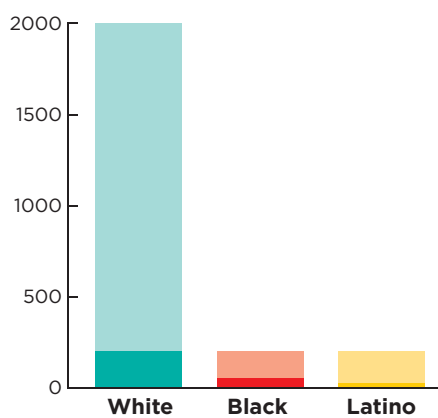
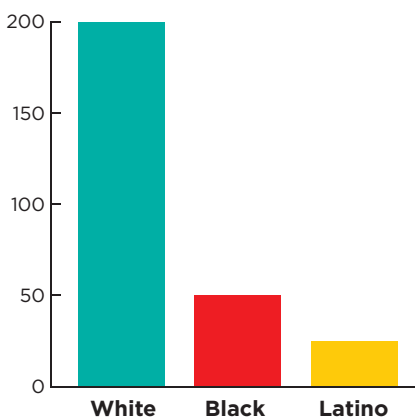
circumstances with the research, but just remember that if you see a larger p-value (typically 0.05 and higher), it likely isn't statistically significant.

Trends and time points: When assessing progress in HIV prevention, it's important to look at the short-term and long-term trends—a single time point only tells us so much. If the numbers have gone up or down in the past few years, that can give you some idea of how things are going. Also, remember that it's easy to select one particular “snapshot” that makes things look worse or better than they are. For example, perhaps you see that incidence is down 5% in the past 5 years—you might conclude that things are great. However, if you widen the lens and see that incidence has gone up 20% in the past 10 years overall, then we might reach a different conclusion.

Absolute number vs. rates: Rates are very important in order to understand disparities in different groups. Let's look at an example. Let's say that we have the following numbers of new infections broken down by race for an imaginary population:

White: 200, African American: 50, Latino: 25

Looking at the absolute number would make it seem like the real concern is in the White community. But what if we look at the rate?



Graph 1: Looking at the absolute number of new infections, we might assume that White people are most affected.

Graph 2: What if we look at these absolute numbers in the context of the overall population? Here the darker color in each bar shows the number of new infections, and the lighter color represents the total population. While there are more infections in White people, they also greatly outnumber Black and Latino community members overall.

Graph 3: Rates are important: they allow us to directly compare across populations of different sizes. Here we imagine what the graph would look like if there were equal numbers of White, Black, and Latino community members, but with the same proportion of new HIV infections from Graph 2. You can now clearly see that Black and Latino community members are disproportionately affected.

White: 200/2000, African American: 50/200, Latino: 25/200

By looking at the rate within the larger racial group in this hypothetical scenario, we see that HIV is actually a larger problem in the African-American community. We also see that, even though there was a small absolute number of the Latino population with HIV, it is actually slightly more affected than the White community.

Missing/hidden populations

► **Remember to look at subpopulations:** When we're looking at absolute numbers or rates for a large(r) group, it's important to think about what small subsets might be hidden within that data. For example, let's say that we're shown a graph for men who have sex with men (MSM) showing what looks like a decline in incidence (new infections). Our first reaction is likely to be positive—but what if we ask them to further break it down by race? Perhaps we see that there is a large decline in incidence for white MSM that is covering up an increase in MSM of color. By not breaking it down into smaller groups, it's possible to hide disappointing results within those subsets.

► **Miscategorized/misgendered/transgender populations:** Miscategorizing is a problem that can happen quite often in data collection. Someone may be marked as a “high-risk heterosexual” when they're actually a man who has sex with men. Or someone may be marked as Latino when they're actually Native American. One frustrating case of this is the invisibility of transgender men and women. In some cases there are robust efforts to stop miscategorizing, but the US government has shamefully ignored and neglected the transgender population for decades. By not formalizing accurate data collection for gender identity until recently, and with no actual implementation plan for rapid improvement of transgender data, transgender men and women continue to be miscategorized/misgendered and placed into other categories. In the case of transgender women, they are generally added into the MSM category.

► **Uncounted/undocumented populations:** When looking at surveillance and indicators, it's also important to remember who isn't being counted. For example, depending on how the data are being collected, we may have numbers for Latino populations that miss undocumented communities. This may not be a deliberate exclusion, but simply a challenge of accessing populations. In other cases, such as with sex workers, we may specifically decide to not collect data on potentially vulnerable populations due to stigma and discrimination.

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EMAIL jeremiah.johnson@treatmentactiongroup.org

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