AIDSVu

PrEP Data – FAQs

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1. What is Pre-Exposure Prophylaxis (PrEP)?

Pre-exposure prophylaxis (PrEP) is when people at risk for HIV take HIV medicine daily to lower their chances of getting infected with HIV. When taken every day, PrEP can provide a high level of protection against HIV and is even more effective when it is combined with condoms and other prevention methods. When someone is exposed to HIV, PrEP can help prevent the virus from establishing a permanent infection in the body. The U.S. Food and Drug Administration (FDA) approved the HIV medicine tenofovir [TDF]/emtricitabine [FTC] (TDF/FTC) for daily use as PrEP in 2012. Visit CDC's "PrEP" page to learn more.

- **Pre** = Before
- **Exposure** = Coming into contact with HIV
- **Prophylaxis** = Treatment to prevent an infection from happening

2. What data do the AIDSVu PrEP maps visualize?

AIDSVu data represent the number of people who had at least one day of prescribed TDF/FTC for PrEP in a calendar year from 2012 to 2017. These individuals are referred to as "PrEP users". AIDSVu's PrEP data represents a conservative, or minimum, number of PrEP users in each state in the U.S. by year. The actual number of PrEP users is higher.

The PrEP data are presented at the state-level and can be viewed as number of PrEP users and rate of PrEP use, expressed as the number of PrEP users per 100,000 people in the population. The PrEP data can be broken down by age (year of birth, displayed as 24 and under, 25 to 34, 35 to 44, 45 to 54, 55+) and sex (sex at birth, displayed as male or female). Data on PrEP use can be viewed alongside social determinants of health, such as poverty, high school education, median household income, income inequality, and people without health insurance.

Please see the Data Methods page for additional information.

3. What do the PrEP data reveal?

The number of PrEP users increased by 29% from 2016 to 2017, continuing a trend of consistent growth in PrEP use since 2012.

- The rate of PrEP use increased from 3.3 PrEP users per 100,000 population in 2012 to 36.7 PrEP users per 100,000 population in 2017, a 56% average annual increase from 2012 to 2017.
- In 2017, there were at least 100,282 PrEP users in the U.S. The PrEP data displayed on AIDSVu represent a conservative, or minimum, number of PrEP users in the U.S. by year.

Men and 25- to 44-year olds were more likely to be PrEP users.

- 94% of all PrEP users in 2017 were male, which is about 16 times higher than the number of female PrEP users. Men accounted for 81% of all new HIV diagnoses in 2016.
- From 2012 to 2017, there was a 68% average annual increase in the rate of PrEP use among males compared to a 5% annual increase in the rate of PrEP use among females.
- In 2017, 63% of all PrEP users were 25- to 44-years old. This age group represented more than half (54%) of all new HIV diagnoses in 2016.

The top five states[1] with the highest rates of PrEP use in 2017 were Washington, D.C., New York, Massachusetts, Rhode Island, and Washington.

- In 2017, the Northeast region of the U.S. had approximately twice the rate of PrEP use (61.9 PrEP users per 100,000 population) compared to the West (35.6 PrEP users per 100,000 population), the South (29.4 PrEP users per 100,000 population), and the Midwest (29.9 PrEP users per 100,000 population) regions.

- Nearly 50% of PrEP users in 2017 were located in just five states: New York, California, Florida, Texas, and Illinois. These states account for 37% of the U.S. population and represented 46% of all people newly diagnosed with HIV in 2016.

The South has the highest number of new HIV diagnoses in the U.S. but has disproportionately fewer people using PrEP.

- The Southern U.S. accounted for only 30% of all PrEP users in 2017 but the region represented more than half (52%) of all new HIV diagnoses in 2016.

The PrEP-to-Need Ratio (PnR)—the ratio of the number of PrEP users to the number of people newly diagnosed with HIV—serves as a measurement for whether PrEP use appropriately reflects the need for HIV prevention in a geographic region or demographic subgroup.

- Overall, the annual PnR increased from 0.2 in 2012 to 2.5 in 2017. In other words, in 2017, for every one person newly diagnosed with HIV, there were 2.5 HIV-negative persons using PrEP.

- In 2017, the PnR for women (0.8) was less than a third of the PnR for men (2.9), indicating an inequity in PrEP use for women relative to their need.

- The Southern U.S. represented half of new HIV diagnoses in 2016 (52%) but had the lowest PnR (1.5) in 2017 among all regions. In contrast, the Northeast region had the highest PnR (4.7) in 2017.

- While the annual PnR increased for all age groups from 2012 to 2017, those aged 24 years and younger had the lowest PnR (1.5) and those aged 35 to 44 years had the highest PnR (3.1).

To learn more about key trends in the use of PrEP from 2012 to 2017, please see Sullivan et al.'s recent article in *Annals of Epidemiology* titled "Trends in the use of oral emtricitabine/tenofovir disoproxil fumarate for pre-exposure prophylaxis against HIV infection, United States, 2012-2017."

[1] For the purposes of this analysis, Washington, D.C. is treated as a state.

4. Why were these data released on AIDSVu, and why does data on PrEP use matter?

It is said that things that are not measured do not change. AIDSVu's mission is to make HIV-related data widely available, easily accessible, and locally relevant to inform public health decision making. Increasing the use of PrEP is a core component of Getting to Zero campaigns in cities and states across the U.S. and is one of four key focus areas in the National HIV/AIDS Strategy. AIDSVu's state-level PrEP data help health departments, elected officials, medical professionals, and community leaders better understand and visualize trends in PrEP use over time, so they can develop programs and policies to increase PrEP awareness and access where it is needed most. By releasing the first-ever state-level data and interactive maps on PrEP users across the U.S., and adding new PrEP data each year, AIDSVu is continuing its commitment to provide public health officials, policymakers, healthcare professionals, researchers, and community leaders with a more comprehensive view of the HIV epidemic at the local, state, and national levels.

5. How can the PrEP data be utilized on AIDSVu?

State-level PrEP data on AIDSVu can be viewed alongside social determinants of health and other HIV data, such as new diagnoses, prevalence, and mortality. Additionally, AIDSVu provides downloadable PrEP datasets at the state- and ZIP3-level for researchers and health departments to utilize in their own analyses. Check the AIDSVu blog for recent examples of PrEP data utilization.

AIDSVu also features a PrEP Locator, a national directory of providers of PrEP in the U.S. developed by Emory University's Rollins School of Public Health with support from M•A•C AIDS Fund. The PrEP Locator is now managed by CDC's National Prevention Information Network (NPIN). PrEP provider locations can be overlaid on top of AIDSVu's PrEP use maps.

6. What other PrEP-related resources does AIDSVu have?

In addition to the PrEP data and maps, AIDSVu also features a Deeper Look: PrEP page, which is dedicated to promoting public awareness about PrEP, visualizing key facts about PrEP, and advancing education around PrEP. The page features insights from the data, infographics, and blogs by HIV experts and is updated on an ongoing basis. Additionally, AIDSVu provides downloadable PrEP maps and datasets at the state-level and PrEP datasets at the ZIP3-level for researchers and health departments to utilize in their own analyses. ZIP3 refers to the three-digit ZIP code prefix assigned by the U.S. Postal Service; there are approximately 930 ZIP3's in the U.S.

AIDSVu also features a PrEP Locator, a national directory of public and private practice providers of PrEP across the U.S. AIDSVu users can find local PrEP providers near them with this valuable tool. The PrEP Locator project was developed by Emory University's Rollins School of Public Health with support from M•A•C AIDS Fund. The PrEP Locator is now managed by CDC's National Prevention Information Network (NPIN).

7. What is the source of the PrEP data?

The release of the PrEP data on AIDSVu was made possible through a unique data sharing agreement that allowed this proprietary data to be shared publicly for the first time. The data were obtained from Symphony Health with the support of Gilead Sciences, Inc., and compiled by researchers at the Rollins School of Public Health at Emory University.

Symphony Health provided Gilead with national, electronic, patient-level prescription data from an overall sample that represents more than 54,000 pharmacies, 1,500 hospitals, 800 outpatient facilities, and 80,000 physician practices across the U.S. This is an open sample of commercially available data, which excludes entities that do not make their data available to Symphony Health, such as closed healthcare systems. The dataset contains prescription, medical, and hospital claims data for all payment types, including commercial plans, Medicare Part D, cash, assistance programs, and Medicaid.

All patient-level prescription data were de-identified and linked to confirmatory data from a de-identified medical insurance claims database. Gilead utilized a validated algorithm[2] to exclude prescriptions for TDF/FTC that were made for other known indications, such as HIV treatment, post-exposure prophylaxis, and chronic hepatitis B management. Gilead then shared aggregate datasets at the state- and ZIP3-level with Emory. Finally, Emory applied data suppression rules and developed the publicly available maps and data sets for AIDSVu.

Please see the Data Methods page for additional information.

8. Who is Symphony Health?

Symphony Health is a leading provider of high-value data, analytics, technology solutions, and actionable insights for healthcare and life sciences manufacturers, payers, and providers. For more information, visit www.symphonyhealth.com.

9. What are the limitations of the PrEP data?

The U.S. healthcare system is very fragmented, and that fragmentation carries over to the way that data is collected and shared across the healthcare system. There are a large number of public and private healthcare data collection systems in the U.S.; however, data do not flow among these entities in a cohesive or standardized way. Due to this fact, there is currently no single entity or data source that collects data on all users of PrEP across the U.S.

[2] MacCannell T, Verma S, Shvachko V, Rawlings K, Mera R. Validation of a Truvada for PrEP Algorithm using an Electronic Medical Record. 8th IAS Conference on HIV Pathogenesis, Treatment & Prevention. Vancouver Canada July 2015.

AIDSVu's PrEP data represents a conservative, or minimum, number of PrEP users in each state in the U.S. by year. The actual number of PrEP users is higher. There are several key reasons for this:

1) AIDSVu's PrEP dataset is derived from a single data source: Symphony Health. Symphony Health collects data from over 54,000 pharmacies, 1,500 hospitals, 800 outpatient facilities, and 80,000 physician practices across the U.S. However, the dataset does not contain all sources of TDF/FTC prescriptions in the U.S. For example, closed healthcare systems do not share their data with Symphony Health. Additionally, other entities may choose not to share their data with Symphony Health for their own reasons.

2) AIDSVu's PrEP dataset also excludes TDF/FTC prescriptions that do not have sufficient medical procedure or diagnosis codes to confirm that the prescription was for PrEP and not for any other use, such as HIV treatment, chronic Hepatitis B treatment, or post-exposure prophylaxis. Due to the stringent criteria used to identify PrEP users, roughly 28% of patient records were removed from the AIDSVu dataset altogether because they did not have sufficient medical procedure and diagnosis code data available to confirm their use of TDF/FTC for PrEP, although some proportion of these records were likely, in reality, PrEP prescriptions.

3) AIDSVu's PrEP dataset presents "raw" data, or in other words, data that have not been adjusted or projected in any way to account for known sources of undercounting or missing data.

Analyses of AIDSVu's 2012-2017 PrEP data were recently published in Sullivan et al.'s article in *Annals of Epidemiology* titled "Trends in the use of oral emtricitabine/tenofovir disoproxil fumarate for pre-exposure prophylaxis against HIV infection, United States, 2012-2017." In this paper, the researchers conducted a sensitivity analysis for the number of national PrEP users in 2017. The sensitivity analysis is a useful attempt to better understand the extent of undercounting in the AIDSVu PrEP dataset. The researchers varied plausible ranges of values for (1) the proportion of TDF/FTC prescriptions that are not captured in the Symphony Health database, and (2) the proportion of unclassified TDF/FTC monotherapy in the Symphony Health database that is used for PrEP. The sensitivity analysis estimated that the number of individuals using PrEP in 2017 ranged from 100,282 to 205,167, with a best estimate of 172,479.

10. What can the PrEP data on AIDSVu be used for?

The PrEP datasets on AIDSVu provide consistent, comparable, replicable numbers of annual PrEP users by state with known limitations that are described to the best extent possible. These data are well suited to be used for public health research and planning purposes. For example, these data can be used to:

- Monitor progress, trends, and disparities in PrEP use at the state-level and among specific age groups or sexes;
- Compare PrEP use among states and regions;
- Support research to investigate questions related to PrEP awareness, access, and use; and

- Inform public health planning.

11. Why do the PrEP data on AIDSVu not include race/ethnicity?

AIDSVu recognizes the significance of better understanding and highlighting trends in racial/ethnic disparities in PrEP use. As a result, AIDSVu is actively working to publicly release PrEP use data by race/ethnicity at the state-level from Symphony Health in 2019.

In October 2018, CDC published an MMWR article on people prescribed PrEP in the U.S. from 2014 to 2016 and their demographic characteristics, including race/ethnicity. The researchers analyzed data from the IQVIA database—a different data source than that presented on AIDSVu—which represents approximately 92% of all prescriptions dispensed from retail pharmacies and 60%–86% dispensed from mail order outlets in the United States. Only 42% of PrEP users identified in the IQVIA database had race/ethnicity information available. The researchers found that among PrEP users with available race/ethnicity data: 68.7% were white, 11.2% were Black, 13.1% were Hispanic, and 4.5% were Asian. When stratified by sex, among female PrEP users with available race/ethnicity data: 48.3% were white, 25.9% were Black, and 17.5% were Hispanic.

12. How are these data different from other data on PrEP that have been shared publicly?

AIDSVu's PrEP data are not intended to be compared to any other publicly available data on PrEP use due to the significant differences in data sources and methodologies. Data displayed on AIDSVu represent the number of unique persons, by state, who had at least one day in a calendar year of prescribed TDF/FTC for PrEP. On AIDSVu, these individuals are referred to as "PrEP users".

The dataset presents "raw" data, or in other words, data that have not been adjusted or projected in any way to account for known sources of undercounting or missing data. The data are subject to the limitations of the dataset as described above and on the Data Methods page; therefore, AIDSVu's PrEP data is a conservative, or minimum, number of PrEP users in each state in the U.S. by year.

There is currently no single data source that includes data on all unique users of PrEP across the U.S. Other publicly shared data on PrEP use have derived estimates from different data sources or from multiple data sources. Additionally, data has also been shared publicly on the cumulative number of unique persons who have initiated TDF/FTC for PrEP since 2012, also referred to as "PrEP starts".

13. How often will new PrEP data be released?

AIDSVu continually strives to increase the granularity of its publicly-available data to support more-informed local public health decision making. To that end, AIDSVu plans to release updated PrEP maps and data on an annual basis. And in early 2019, AIDSVu intends to release county-level estimates of PrEP use from 2012 to 2017.

Additionally, AIDSVu has also made substantial progress on releasing PrEP use data by race/ethnicity at the state-level from Symphony Health, and is working to release these data publicly in 2019. AIDSVu recognizes the significance of these data in helping to better understand and highlight racial/ethnic disparities in PrEP awareness, access, and use.

You can sign up on the AIDSVu website to receive email notifications when new features or data are added to the site.