



## PrEP Data – FAQs

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

**Pre-exposure prophylaxis (PrEP)** is when people at high 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 2016. These individuals are referred to as "PrEP users". 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 has increased by 880 percent since 2012, an average 73 percent increase year over year from 2012 to 2016.**

- In 2016, there were 77,120 PrEP users in the U.S., up from 8,768 PrEP users in 2012.

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

- 93 percent of all PrEP users in 2016 were male, which is about 14 times higher than the number of female PrEP users. Men accounted for 81 percent of all new HIV diagnoses in 2016.
- In 2016, 64 percent of all PrEP users were 25- to 44-years old. This age group represented more than half (54 percent) of all new HIV diagnoses during the same period.

**Nearly 50% of PrEP users in 2016 were located in just five states: New York, California, Florida, Texas, and Illinois.**

- When looking at the rate of PrEP use—the number of people in a state using PrEP per 100,000 population—the five states with the highest rates in 2016 were New York, Massachusetts, Rhode Island, Washington, and Illinois.
- In 2016, the Northeast region of the U.S. had approximately twice the rate of PrEP use (47.4 PrEP users per 100,000 population) compared to the West (28.1 PrEP users per 100,000 population).

population), the South (22.6 PrEP users per 100,000 population), and the Midwest (23.5 PrEP users per 100,000 population) regions.

**The South is the region with 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 percent (23,091 persons) of all PrEP users in 2016. The region represented more than half (52 percent) of all new HIV diagnoses in 2016.

**4. Why were these data released on AIDSVu?**

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](#). By releasing the first-ever state-level data and interactive maps on PrEP users across the U.S., 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. What other PrEP-related resources does AIDSVu have?**

In addition to the release of the PrEP data and maps, AIDSVu has also launched a new page—[Deeper Look: PrEP](#)—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 guest blogs and will be 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 is also an inaugural user of 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 is led by Dr. Aaron Siegler at Emory University's Rollins School of Public Health. The development and maintenance of the PrEP Locator is funded by the M•A•C AIDS Fund.

**6. What is the source of the PrEP data?**

Data on PrEP users displayed on AIDSVu were obtained from Source Healthcare Analytics, LLC (SHA) with the support of Gilead Sciences, Inc., and compiled by researchers at the Rollins School of Public Health at Emory University. SHA provided Gilead with national, electronic, patient-level prescription data from an overall sample that represents over 54,000 pharmacies, 1,500 hospitals, 800 outpatient facilities, and 80,000 physician practices. This is an open sample of commercially available data, which excludes entities that do not make their data available, such as closed healthcare systems. All patient-level prescription data were de-identified and linked to confirmatory data from a de-identified medical insurance claims database. Gilead then utilized a validated algorithm<sup>1</sup> 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. Through a data

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<sup>1</sup> 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.



sharing agreement between SHA, Gilead, and Emory University, Gilead shared aggregate datasets at the state- and ZIP3-level with Emory. Emory then applied data suppression rules and developed the publicly available maps and data sets for AIDSVu. Please see the [Data Methods](#) page for additional information.

## 7. What are the limitations of the PrEP data?

There is currently no single data source that includes data on all unique users of PrEP across the U.S. Source Healthcare Analytics (SHA) collects data from over 54,000 pharmacies, 1,500 hospitals, 800 outpatient facilities, and 80,000 physician practices across the U.S. SHA's dataset contains prescription, medical, and hospital claims data for all payment types, including commercial plans, Medicare Part D, cash, assistance programs, and Medicaid. From this overall sample, AIDSVu presents a subset of data comprising prescriptions for TDF/FTC for PrEP.

SHA's dataset is an open sample of commercially available data, which excludes entities that do not make their data available, such as closed healthcare systems. As a result, the data displayed on AIDSVu underestimates the total number of PrEP users in the U.S.

Medical procedure and diagnosis code data were not available for 28% of the SHA records. These procedure and diagnosis codes are required to determine whether an individual TDF/FTC prescription was made for PrEP, for treatment of HIV or Hepatitis B infection, or was used for post-exposure prophylaxis (PEP). These 28% of records were assumed to not represent TDF/FTC prescriptions for PrEP, although some proportion of these records were likely, in reality, PrEP prescriptions. This is a further source of underestimation of PrEP users.

Data are derived from prescriptions to unique people; however, those who fill a prescription may not use it. Additionally, the overall total population may be fewer than the sum of age group total population for a given year because people may be counted twice if they switch age groups within a certain year (i.e. if a person turns 35 in 2016 then the person is counted in both the 25-34 and 35-44 age groups in 2016).

## 8. Who is Source Healthcare Analytics, LLC?

Source Healthcare Analytics, LLC 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](http://www.symphonyhealth.com).

## 9. Why do the PrEP data not include race/ethnicity?

State-level PrEP data by race/ethnicity are currently not available in the dataset from Source Healthcare Analytics. AIDSVu recognizes the significance of these data in helping to better understand and highlight racial/ethnic disparities in PrEP access and uptake. AIDSVu will explore the possibility of obtaining and mapping PrEP data by race/ethnicity in the future.

[A poster presentation by Mera et al.](#) in July 2017 at the 9<sup>th</sup> International AIDS Society Conference on HIV Science (IAS) included data on the [race/ethnicity of individuals in the U.S. who started PrEP](#) from January 2012 through September 2016. Since data on race/ethnicity are not routinely included in pharmacy records, the data presented by Mera et al. represented about 40% of unique individuals who started PrEP during that time period. The analysis revealed that 73 percent of

people that started PrEP from January 2012 through September 2016 were white, 13 percent were Hispanic/Latino, 10 percent were African American, and 4 percent were Asian.

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

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. TDF/FTC is the only medicine currently approved by the U.S. Food and Drug Administration (FDA) for PrEP use. On AIDSVu, these individuals are referred to as “PrEP users”. These data are raw—not projected—and are subject to the limitations of the dataset as described above and on the Data Methods page; therefore, these data underestimate the total number of PrEP users in the U.S.

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 used estimates from multiple data sources to project for the total number of unique persons using TDF/FTC for PrEP in the U.S. at a given point in time. This method, however, does not provide state-level estimates. 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”.

## **11. How often will new PrEP data be released?**

AIDSVu plans to release updated PrEP maps and data on an annual basis and intends to release PrEP data from 2017 as soon as they are available. Moving forward, AIDSVu will explore the feasibility of providing more frequent data updates, as well as mapping data at finer geographic levels. You can [sign up](#) on the AIDSVu website to receive email notifications when new features or data are added to the site.