HIV Care Continuum

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AETC AIDS Education & Training Center Program New England

HIV Care Continuum

This educational packet is a curated compilation of resources on the HIV care continuum.

The contents of this packet are listed below:

- HIV Care Continuum (HIV.gov)
- Understanding the HIV Care Continuum (CDC)
- Overall U.S. HIV Care Continuum (CDC)
- HIV Care Continuum by Race/Ethnicity (CDC)
- HIV Care Continuum by Age (CDC)
- HIV Care Continuum Among Women (CDC)
- HIV Care Continuum Among Men (CDC)
- HIV Care Continuum Among Transgender People (CDC)

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HIV Care Continuum

hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum

What Is the HIV Care Continuum?

The HIV care continuum is a public health model that outlines the steps or stages that people with HIV go through from diagnosis to achieving and maintaining viral suppression (a very low or undetectable amount of HIV in the blood) through care and treatment with HIV medicine called antiretroviral therapy or ART.

The steps are:

- diagnosis of HIV infection
- linkage to HIV medical care
- receipt of HIV medical care
- retention in medical care
- achievement and maintenance of viral suppression

Viral suppression is defined as having less than 200 copies of HIV per milliliter of blood by consistently taking HIV medicine. HIV medicine can also make the viral load so low that it doesn't show up in a standard lab test. This is called having an undetectable viral load.

Reaching and maintaining HIV viral suppression or an undetectable viral load is a primary goal of HIV treatment. Treatment with HIV medicine is recommended for all people with HIV, regardless of how long they've had the virus or how healthy they are.

Why Is the HIV Care Continuum Important?

The HIV care continuum is useful both as an **individual-level** tool to assess care outcomes, as well as a **population-level** framework to analyze the proportion of people with HIV in a given community who are engaged in each successive step. This helps policymakers and

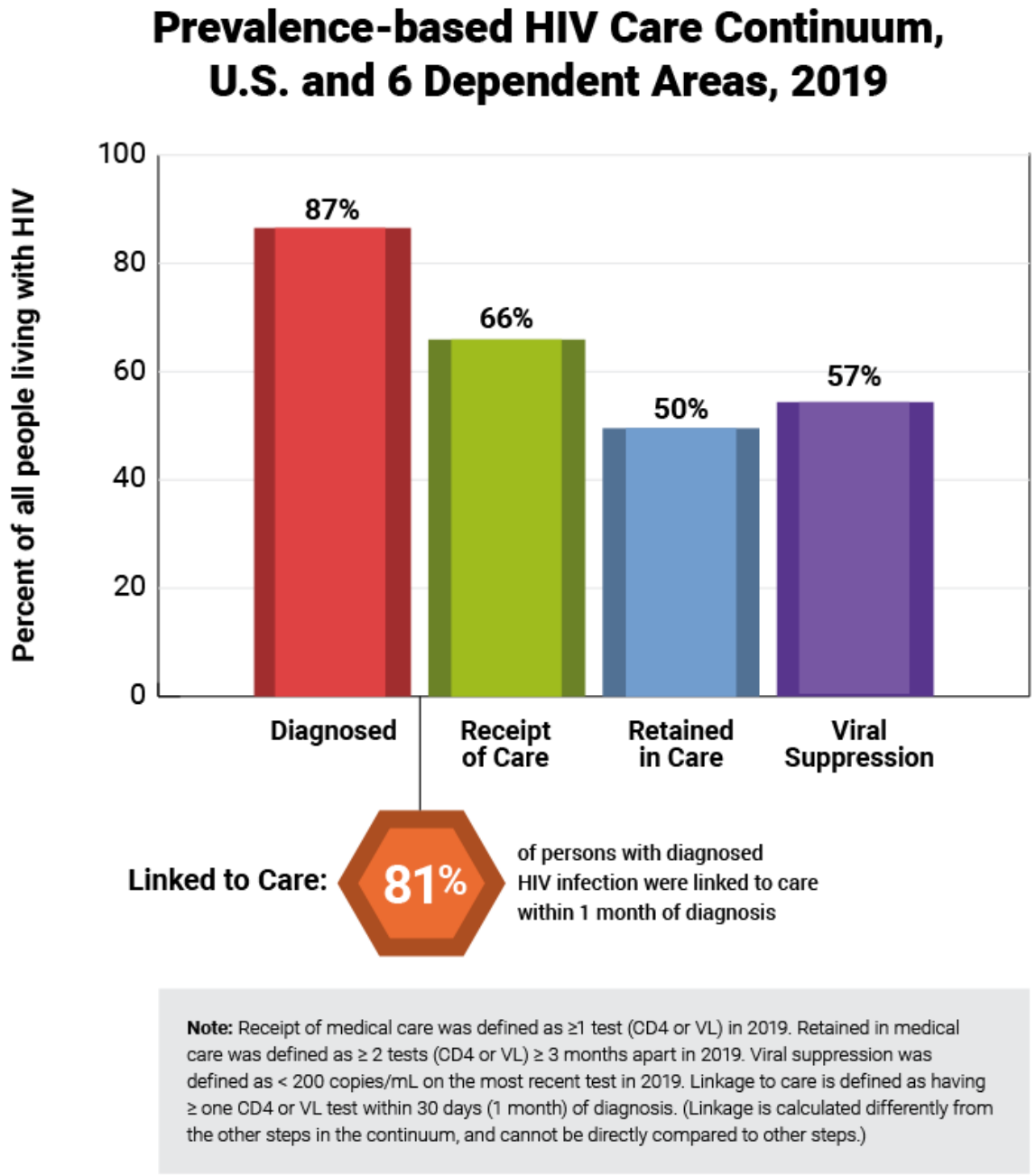
service providers better pinpoint where gaps in services might exist and develop strategies to better support people with HIV to achieve the treatment goal of viral suppression.

Supporting people with HIV to move through the steps of the continuum to achieve and maintain viral suppression or an undetectable viral load is critically important. Research shows that people with HIV who get and keep an undetectable viral load can **live long and healthy lives** and **will not transmit HIV to their HIV-negative partners through sex**. This is sometimes called "Undetectable = Untransmittable" or U=U.

For individuals with HIV to gain these benefits, they need to be aware that they have HIV, be connected to and engaged in regular HIV care, and receive and adhere to treatment with HIV medicine. However, there are obstacles that can contribute to poor engagement in HIV care and treatment, substantially limiting the effectiveness of efforts to improve health outcomes for those with HIV and reduce new HIV transmissions.

Knowing where the gaps are most pronounced and for what populations is vital to knowing how, where, and when to intervene to break the cycle of HIV transmission in the United States and improve health outcomes for people with HIV.

What Does the HIV Care Continuum Show?



CDC, Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. HIV Surveillance Supplemental Report 2021; 26(No. 2). Published May 2021.

Prevalence-based continuum. This HIV care continuum chart is based on the prevalence of HIV in the U.S. in 2019. Published in May 2021, this is the latest available prevalence-based HIV care continuum data from CDC. *Prevalence* describes the number of people with HIV at a given time, regardless of when they acquired HIV or whether they have received a diagnosis. (Some people may have HIV but not know it). Prevalence data is useful for planning and resource allocation, as it reflects the number of people—diagnosed and undiagnosed—who currently need HIV testing, care, and treatment services. Prevalence rates

are also useful for comparing HIV disease between populations and for monitoring trends over time. (Read more about the prevalence-based approach to monitoring the HIV care continuum and how it is used.)

According to CDC, an estimated 1.2 million people aged 13 and older had HIV in the United States at the end of 2019. Of those 1.2 million people:

- **Diagnosis**—An estimated **87% were diagnosed**. That means that 13% of people with HIV (nearly 1 in 7) did not know they had HIV and were therefore not accessing the care and treatment they need to stay healthy and prevent transmitting the virus to their partners.
- **Receipt of Care**—Approximately **66% had received HIV medical care**. CDC measures receipt of care as the percentage of persons with diagnosed HIV who had at least one CD4 or viral load test run by a health care professional in a given year. Once in medical care, people can start HIV medicine to help them stay healthy and protect their partners. Initiating ART is recommended for all people with diagnosed HIV.
- **Retention in Care**—Approximately **50% were retained in care**. CDC measures retention in care as the percentage of persons with diagnosed HIV who had two or more CD4 or viral load tests, performed at least three months apart. People with HIV who have ongoing, regularly scheduled medical care have been shown to have better health outcomes and increased safer sexual behaviors.
- **Viral Suppression**—An estimated **57% had achieved viral suppression**. CDC measures viral suppression as a viral load test result of <200 copies/mL at the most recent viral load test during measurement year.
- **Linkage to care—**According to CDC, of those who received an HIV diagnosis in 2019, **81% were linked to care** within one month. This figure is calculated differently from other steps in the continuum, so it cannot be directly compared. CDC defines linkage as having one or more documented CD4 or viral load tests within 30 days (1 month) of HIV diagnosis. The denominator is limited to the number of people receiving an HIV diagnosis *in a given year*, rather than the total number of people with HIV that is used in the calculations for the other continuum steps. Rapid linkage to care is important because it can shorten the time to viral suppression, which helps people stay healthy and prevents sexual transmission of the virus.

Diagnosis-based continuum. Different analyses present the steps or stages of the HIV care continuum in different ways. For example, CDC also offers a *diagnosis-based continuum*, which shows each step as a percentage of the number of people with *diagnosed* HIV. According to CDC data published in 2022, of the 944,247 people ages 13 and older with *diagnosed* HIV in the U.S. during 2020, 74% had received some HIV medical care, 51% were retained in care, and 65% were virally suppressed. In addition, among the 28,422 individuals who received an HIV diagnosis in 2020 in the 46 jurisdictions with complete reporting of laboratory data to CDC, 82% were linked to medical care within one month of diagnosis. **(CDC cautions that data for 2020 should be interpreted with caution due to the**

impact of COVID-19 on access to HIV testing, care-related services, and case surveillance activities in states and local jurisdictions.) (Read about the diagnosis-based approach to monitoring the HIV care continuum.)

How Is the HIV Care Continuum Being Used?

Federal, state, and local health departments, community-based organizations, health care providers, and people with HIV continue to use the HIV care continuum to measure progress toward HIV goals as well as to pinpoint where gaps in services may exist in connecting individuals with HIV to sustained, quality care and treatment. Knowing where drop-offs are most pronounced and for which populations helps policymakers, public health officials, and health care providers implement system improvements to support all persons with HIV so they are able to successfully navigate the continuum and achieve and maintain viral suppression.

Understanding the HIV Care Continuum

Overview

Recent scientific advances have shown that antiretroviral therapy (ART) not only preserves the health, quality of life, and life expectancy of people living with HIV, but people living with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load have effectively no risk of transmitting HIV to their HIV-negative sexual partners.

These developments have transformed the nation's approach to HIV prevention. By ensuring that everyone with HIV is aware of their infection, receives the treatment they need, and achieves sustained viral suppression, we can sharply reduce new infections in the United States.

This vision is a core focus of CDC's high-impact HIV prevention strategy, which aims to achieve the greatest possible reductions in HIV infections by making sure that resources go to the regions, populations, and prevention strategies where they will have the greatest impact.

To help gauge progress towards national goals (see sidebar) and direct HIV prevention resources most effectively, CDC tracks the "HIV care continuum." The continuum is the series of steps from the time a person receives a diagnosis of HIV through the successful treatment of their infection with HIV medications. This fact sheet explains the various approaches and data used to develop the HIV care continuum, how it is used to improve outcomes for people living with HIV in the United States, and how it helps guide the nation's response to HIV.

National HIV/AIDS Strategy, 2020 Objectives on HIV Diagnosis and Care

At the national level several specific goals related to early HIV diagnosis and effective care include:

- 90% — Increasing the number of HIV-positive **individuals aware of their status** to 90%.
- 85% — Increasing the proportion of **persons with newly diagnosed HIV who are linked to care** within one month to 85%.
- 80% — Increasing the proportion **of HIV-diagnosed individuals whose virus is effectively suppressed to 80%,** with an emphasis on youth and persons who inject drugs.

What is the HIV Care Continuum?

The ultimate goal of HIV treatment is to achieve viral suppression, which means the amount of HIV in the body is very low or undetectable. This is important for people with HIV to stay healthy, have improved quality of life, and live longer. People living with HIV who maintain viral suppression have effectively no risk of passing HIV to others.

The HIV care continuum consists of several steps required to achieve viral suppression. Specifically, CDC tracks:

Diagnosed

received a diagnosis of HIV

Linked to care*

visited an HIV heath care provider within 1 month (30 days) after learning they were HIV positive

Received** or were retained in care***

received medical care for HIV infection

Viral suppression

their HIV "viral load" – the amount of HIV in the blood – was at a very low level.

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Division of HIV/AIDS Prevention

* Linked to care is calculated differently from other steps in the continuum, and cannot be directly compared to other steps. See Table 1 on page 5 for details.

** Receipt of medical care was defined as ≥1 test (CD4 or viral load [VL]) in 2016.

*** Retained in continuous medical care was defined as ≥2 tests (CD4 or VL) ≥3 months apart in 2016. Viral suppression was defined as <200 copies/mL on the most recent VL test in 2016. See Table 1 on page 5 for details.

Two Ways to Monitor the Continuum

CDC currently uses two different approaches to monitor the HIV care continuum. The two approaches are used for different purposes, and both are essential to monitor the nation's progress and identify key HIV prevention and care needs.

The major difference between the two approaches is that they have **different denominators.** That is, they measure progress among different groups of people living with HIV:

The prevalence-based HIV care continuum describes the number of people who are at each step of the continuum as a percentage of the ***total* number of people living with HIV** (known as HIV prevalence). Prevalence includes both people whose infection has been diagnosed and those who are infected but don't know it.

This approach allows us to monitor elements of the care continuum by measuring the care outcomes among all Americans living with HIV. It can also monitor outcomes for broad populations, such as African Americans or men who have sex with men (MSM). However, because of certain statistical limitations, this approach does not allow more segmented analyses within those populations, such as young black MSM. See Figure 1 for the 2016 prevalence-based HIV care continuum.

The diagnosis-based HIV care continuum shows each step as a percentage of **the number of people living with diagnosed HIV.**

This approach gives us more detailed information about persons who are living with diagnosed HIV and provides a way to look at the continuum within subgroups of affected populations, for example young black MSM. For the 2016 diagnosis-based continuum, see Figure 2.

The difference is in the denominators • All people living with HIV (includes persons with diagnosed and undiagnosed infection) is used as the denominator for the prevalence-based continuum. People living with ***diagnosed*** HIV is the denominator used for the diagnosis-based continuum.

Figure 1: Prevalence-based HIV Care Continuum, 2016

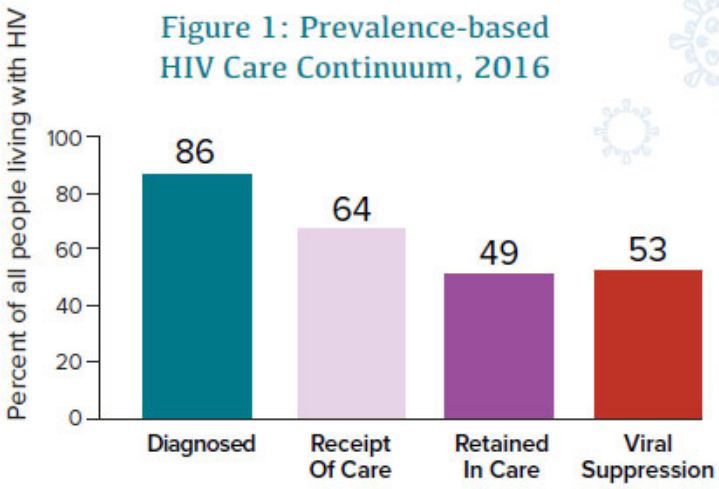
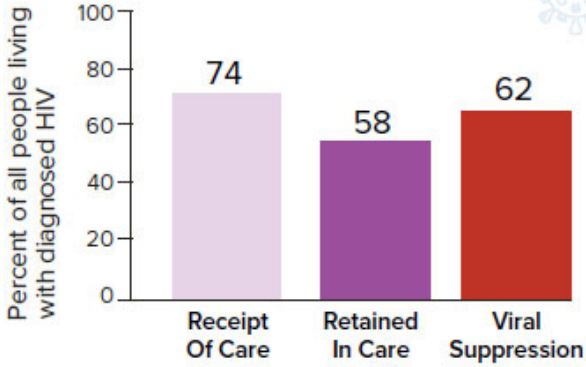
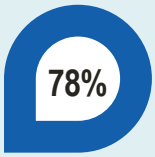


Figure 2:Diagnosis-based HIV Care Continuum, 2016



Linked to Care



- In 2017, 78% of persons receiving a diagnosis of HIV were linked to care within 1 month.
- Defined as linked to care within 1 month of HIV diagnosis.
  - Denominator is persons receiving a diagnosis of HIV in a measurement year
  - Numerator is the number of persons who were linked to care within 1 month.
- Because it has a different denominator, it cannot be directly compared to other steps in the continuum.

See Table 1 on page 4 for additional details

Different Approaches for Different Needs

CDC's current approaches draw on the best data available.

It is **important to know how the continuum will be used.** Some uses of the **prevalence-based continuum** include:

- Monitoring testing efforts in the U.S. and demonstrating the importance of diagnosing HIV infections to achieve viral suppression
- Monitoring how the U.S. is doing among **all** persons living with HIV
- Comparing U.S. data to other countries who monitor the continuum among all persons living with HIV

Some uses of the **diagnosis-based continuum** include:

- Monitoring U.S. progress in comparison to national 2020 goals
- Monitoring U.S. progress in comparison to the UNAIDS 90-90-90 goals
- Monitoring disparities by examining data among sub-groups of the population
- Monitoring data at a local level to understand local progress and identify additional action steps to meet national level goals

Ways of presenting the continuum also will continue to evolve over time, as better and more complete data become available.

How CDC Develops the Continuum

The data for both the prevalence- and diagnosis-based continua of care approaches come from:

The National HIV Surveillance System (NHSS), which provides a range of information on people who have diagnosed HIV or have died with HIV. Data are from every U.S. state and territory and the District of Columbia and include sex, race/ethnicity, route of transmission, and age. The data are reported to CDC by state and local health departments. This is the source of data for both the prevalence and diagnosis denominators. Data from the states and D.C. that have complete laboratory reporting are used to calculate some measures of the continuum.

For more information, details on the two continuum approaches are found in Table 1 below. Some of these indicators are also used to monitor progress toward the national goals. For more information on national indicators, please see https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-national-hiv-care-outcomes.pdf.

What is CDC doing to improve the outcomes at every step of the HIV Care Continuum?

CDC is undertaking many initiatives including:

- **Directly funding health departments to implement a comprehensive HIV surveillance and prevention program** – to prevent new HIV infections and achieve viral suppression among persons living with HIV. The integrated approach promotes and supports improving health outcomes for persons living with HIV through achieving and sustaining viral suppression, and reducing health-related disparities by using quality, timely, and complete surveillance and program data to guide HIV prevention efforts. Priority activities include HIV testing; linkage to, re-engagement in, and retention in care and support for achieving viral suppression; support for pre-exposure prophylaxis (PrEP); community-level HIV prevention activities; and HIV transmission cluster investigations and outbreak response efforts.
- **Directly funding community-based organizations (CBOs)** – to increase HIV testing, improve linkages to care and support improvement of viral suppression for persons living with HIV, and improve linkages to PrEP and other prevention services for persons who are at risk for HIV.
- **Providing technical assistance** – to help health departments and CBOs develop the tools and skills to successfully implement effective HIV prevention activities for people living with HIV in their communities.
- **Improving surveillance capability and technology** – to assist states in outbreak response and improving completeness of laboratory data that are needed to assess many of the steps in the HIV care continuum and the selected national HIV care outcomes.
- **Researching new approaches** – to include studies of clinical, behavioral and structural interventions to help people with HIV stay in care, get back in care if they fall out of care, and adhere to their medications.
- **Developing guidelines** – to assist health care providers with HIV testing, care, treatment, and prevention.
- **Launching educational campaigns and an HIV Risk Reduction Tool** – to implement social marketing campaigns and provide educational resources; to help health care providers, at-risk populations, people with HIV, and the general public to reduce HIV stigma; increase HIV testing, prevention, and treatment; and understand risks for getting or transmitting HIV.

Table 1: Calculating the Continuum: Step by Step

Continuum Step	
Diagnosed	Measures the percentage of the total number of people living with HIV whose infection has been diagnosed. The denominator for this continuum step is HIV prevalence, which is the total number of people living with HIV (includes both those with diagnosed infection and those with undiagnosed infection). HIV prevalence is estimated through statistical modeling using National HIV Surveillance System (NHSS) data from all U.S. states and the District of Columbia (DC).
Receipt of Care	NHSS data from states and DC with complete reporting of CD4 and viral load test results are used to estimate "receipt of care" and "retained in care." Receipt of care is measured as the percentage of persons with diagnosed HIV who had at least one CD4 or viral load test. The denominator for the prevalence-based continuum is all persons living with HIV (HIV prevalence). The denominator for the diagnosis-based continuum is all persons living with diagnosed HIV (diagnosed prevalence*).
Retained in Care	NHSS data from states and DC with complete reporting of CD4 and viral load test results are used to estimate "receipt of care" and "retained in care." Retained in care is measured as the percentage of persons with diagnosed HIV who had two or more CD4 or viral load tests, performed at least three months apart. The denominator for the prevalence-based continuum is all persons living with HIV (HIV prevalence). The denominator for the diagnosis-based continuum is all persons living with diagnosed HIV (diagnosed prevalence*).
Viral Suppression	NHSS data from states and D.C. that have complete laboratory reporting are used to determine viral suppression. Viral suppression is measured as a viral load test result of <200 copies/mL at the most recent viral load test during measurement year. The denominator for the prevalence-based continuum is all persons living with HIV (HIV prevalence). The denominator for the diagnosis-based continuum is all persons living with diagnosed HIV (diagnosed prevalence*).
Linked to Care	NHSS data from states and DC with complete reporting of CD4 and viral load test results are used to determine "linked to care." Linked to care measures the percentage of people *receiving a diagnosis of HIV in a given calendar year* who had one or more documented CD4 or viral load tests *within 30 days (1 month) of diagnosis.* Because this measure is limited to people with HIV diagnosed in a single year, it cannot be directly compared to other steps in the continuum. This means that the denominator for linkage to care is ***different*** from the denominators used to calculate the other steps in the continuum. It is also important to note that an individual who enters care more than 30 days after diagnosis may still be included in subsequent steps of the continuum, but would not be counted as "linked to care."

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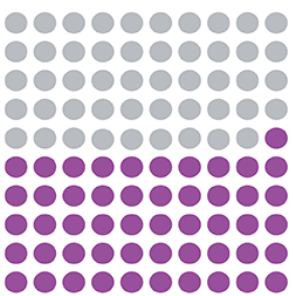
*Diagnosed prevalence is defined as the number of persons with HIV diagnosed through the end of 1 year and are living through the end of the next year (e.g. diagnosed prevalence for 2016 is defined as persons receiving a diagnosis of HIV by end of 2015 and living through the end of 2016).

HIV Care Among People with Diagnosed HIV in 45 States and the District of Columbia*

For every 100 people overall with diagnosed HIV:

74 received some HIV care†



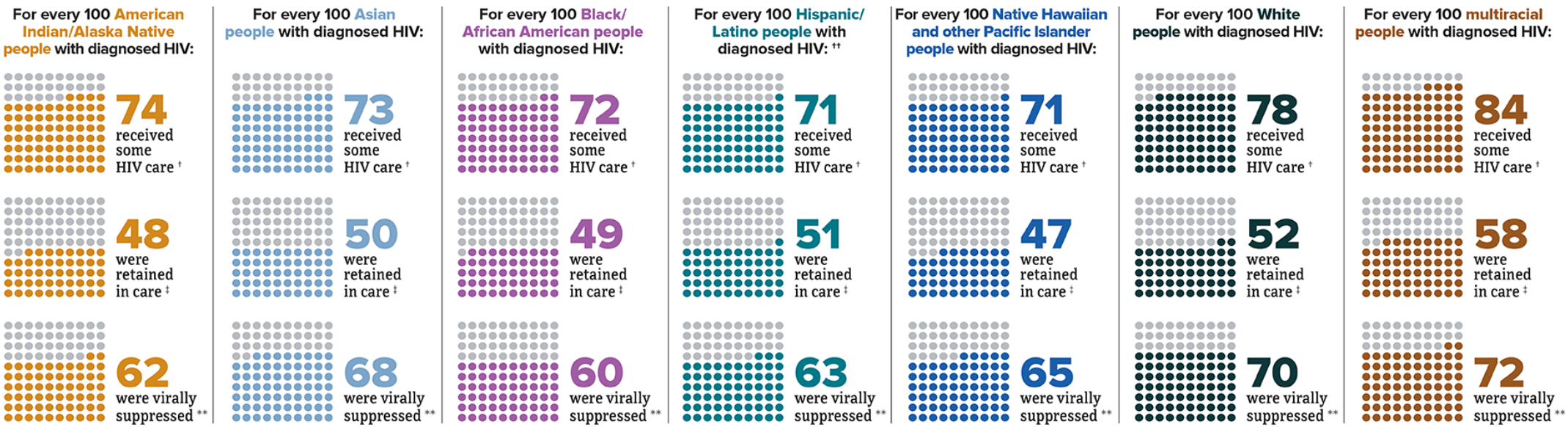
51 were retained in care ‡

65 were virally suppressed **

Data for 2020 should be interpreted with caution due to the impact of the COVID-19 pandemic. For more information, view the report commentary section.
Data from 45 states and the District of Columbia with complete reporting of laboratory data to CDC.
* Among people aged 13 and older.
† At least 1 viral load or CD4 test.
‡ Had 2 viral load or CD4 tests at least 3 months apart in a year.
** Based on most recent viral load test.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2020. *HIV Surveillance Supplemental Report*, 2022; 27(3).

Differences in HIV Care Among People with Diagnosed HIV by Race/Ethnicity*

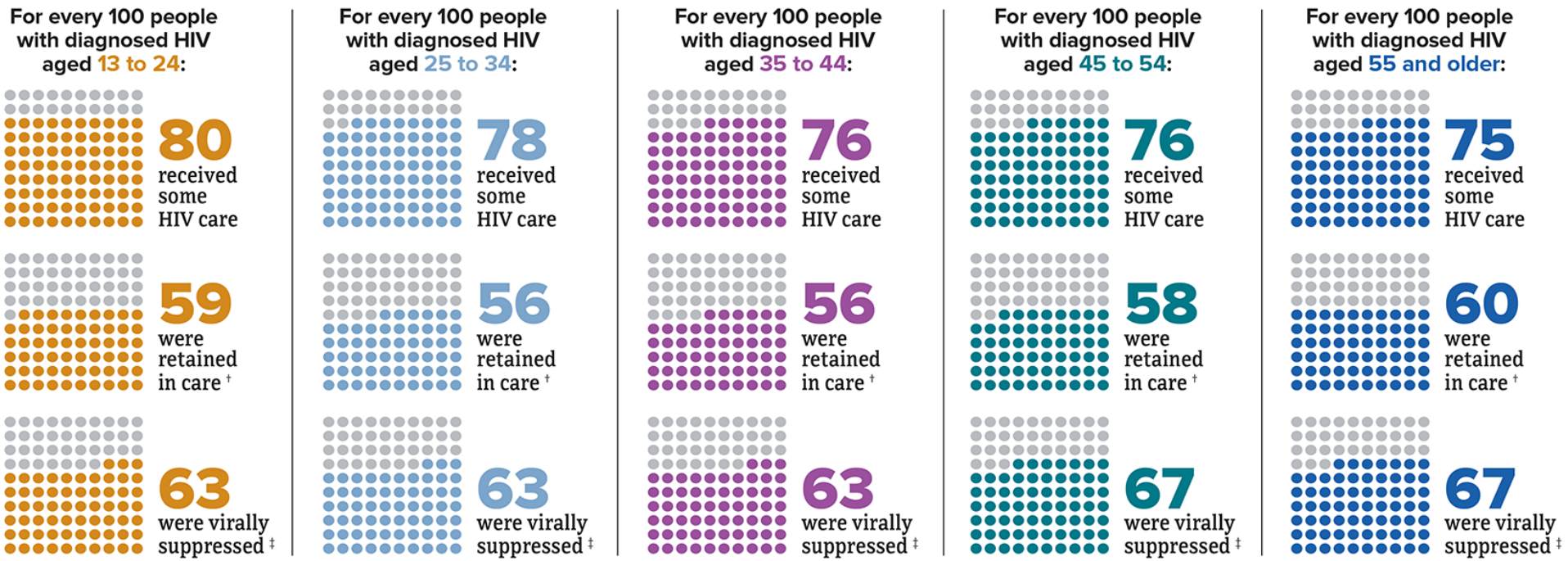


Data for 2020 should be interpreted with caution due to the impact of the COVID-19 pandemic. For more information, view the report commentary section.
Data from 45 states and the District of Columbia with complete reporting of laboratory data to CDC.

* Among people aged 13 and older.
† At least 1 viral load or CD4 test.
‡ Had 2 viral load or CD4 tests at least 3 months apart in a year.
** Based on most recent viral load test.
†† Hispanic/Latino people can be of any race.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2020. *HIV Surveillance Supplemental Report*, 2022; 27(3).

People with Diagnosed HIV in 44 States and the District of Columbia by Age, 2019*



For comparison, for every **100 people overall** with diagnosed HIV, **76 received some care, 58 were retained in care**, and **66 were virally suppressed.**

* Data not available for children aged 12 and under.
† Had 2 viral load or CD4 tests at least 3 months apart in a year.
‡ Based on most recent viral load test.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report* 2021;26(2).

Women with Diagnosed HIV in 44 States and the District of Columbia, 2019*

Compared to all people with diagnosed HIV, women have lower viral suppression rates. **For every 100 women with diagnosed HIV in 2019:**

76 received some HIV care

58 were retained in care †

64 were virally suppressed ‡

For comparison, for every **100 people overall** with diagnosed HIV, **76 received some care**, **58 were retained in care**, and **66 were virally suppressed**.

* Based on sex assigned at birth.
† Had 2 viral load or CD4 tests at least 3 months apart in a year.
‡ Based on most recent viral load test.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report.* 2021;26(2).

Adult and Adolescent Men with HIV in the 50 States and District of Columbia

At the end of 2018, an estimated **1.2 MILLION AMERICANS** had HIV. Of those, 912,100 were men.

6 in 7
men knew they had the virus.

It is important for men to know their HIV status so they can take medicine to treat HIV if they have the virus. Taking HIV medicine every day can make the viral load undetectable. People who get and keep an undetectable viral load (or stay virally suppressed) can live a long and healthy life. They also have effectively no risk of transmitting HIV to HIV-negative sex partners.

When compared to people overall with HIV, men have the same viral suppression rates. But more work is needed to increase these rates. In 2018, for every **100 men with HIV**:

65 received some HIV care

49 were retained in care *

56 were virally suppressed †

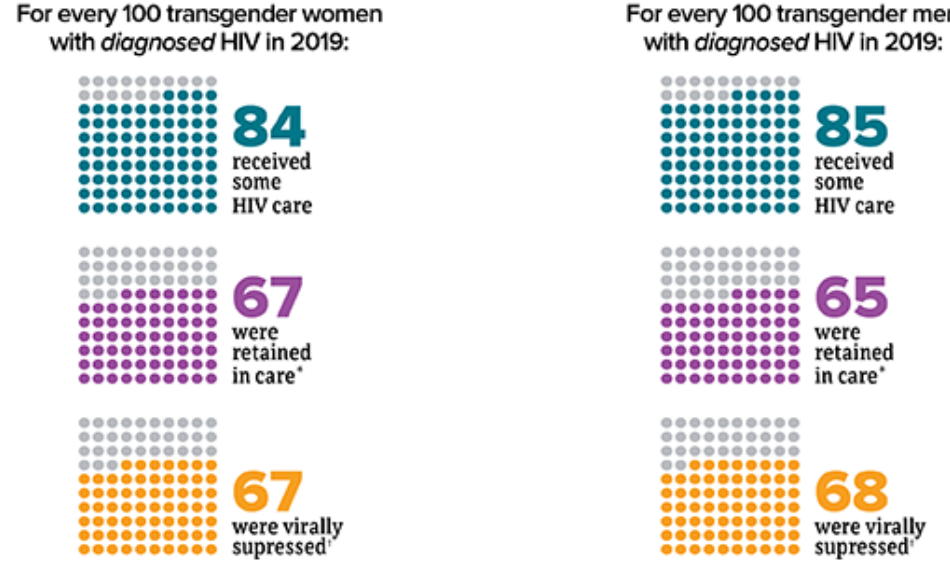
For comparison, for every **100 people overall** with HIV,
65 received some HIV care, **50 were retained in care**, and **56 were virally suppressed**.

*Had 2 viral load or CD4 tests at least 3 months apart in a year.
†Based on most recent viral load test.

Source: CDC. Estimated HIV incidence and prevalence in the United States, 2014–2018. *HIV Surveillance Supplemental Report.* 2019;25(1).
Source: CDC. Selected national HIV prevention and care outcomes (slides).

Transgender People with Diagnosed HIV in 44 States and the District of Columbia, 2019

Compared to all people with *diagnosed* HIV in 2019, transgender women have about the same viral suppression rates, and transgender men have higher viral suppression rates. More work is needed to increase these rates.



For comparison, for every **100 people overall** with diagnosed HIV, **76 received some care**, **58 were retained in care**, and **66 were virally suppressed**.

* Had 2 viral load or CD4 tests at least 3 months apart in a year.
† Had less than 200 copies of HIV per milliliter of blood on most recent viral load test.

Source: Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 Dependent Areas, 2019, *HIV Surveillance Special Report* 2021; 26(2).