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

Literature Review:
Barriers and Facilitators of People with HIV Who Are Out of HIV Care and Implications for a National Learning Collaborative

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Prepared by: Britanie Carlozzi, Shakeila Lewis-Chery, Tarik Itum, Marcky Antonio, Raihana Rahman, T'Oluwanimi Ademola-Thomas, and Clemens Steinbock

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Table of Contents

A. Introduction

The Ryan White HIV/AIDS Program (RWHAP) provides critical healthcare and support services to over half a million individuals with HIV in the United States, accounting for more than half of the country's diagnosed HIV population.[1] Despite this extensive federal support, only 74% of people with diagnosed HIV have received HIV care, and retention in care stood at just 50% in 2018.[2]

Over the past decade, the National HIV/AIDS Strategy has guided HIV care across the United States. The 2022-2025 National HIV/AIDS Strategy has four main goals in order to reduce new HIV transmissions in the United States by 75% by 2025 and by 90% by 2030: (1) Prevent new HIV infections; (2) Improve HIV-related health outcomes of people with HIV; (3) Reduce HIV related disparities and health inequities; and (4) Achieve integrated, coordinated efforts that address the HIV epidemic among all partners and interested parties.[3]

Success along the HIV care continuum requires timely diagnosis, prompt linkage to care, consistent ongoing medical treatment, and effective viral suppression to manage infection and to improve health outcomes.[4] A crucial aspect of ending the HIV epidemic involves identifying and addressing gaps in care, particularly focusing on individuals with HIV who are out of care. Re-engaging these individuals is essential, as it ensures they receive the necessary access to achieve and maintain viral suppression, leading to closing gaps along the care continuum. This approach not only enhances individual health but also contributes to broader public health goals by reducing the incidence of HIV and advancing efforts to end the epidemic.[5]

Focusing on individuals who are out of care is vital because they face a higher risk of health outcomes, such as uncontrolled viral loads and increased susceptibility to opportunistic infections.[6] Their disengagement from care also heightens the risk of HIV transmissions to others. By re-engaging these individuals, healthcare systems can improve their quality of life, mitigate the overall impact of the epidemic.[7] Prioritizing this group is key to advancing public health strategies and achieving the ambitious goals set forth in the National HIV/AIDS Strategy.[8]

There are multifaceted barriers to retention in HIV care, each contributing to the complex challenges of maintaining consistent treatment.[9] Demographic factors, such as race, ethnicity, and age, can influence access to and engagement in healthcare services. Social determinants of health (SDOH), such as financial constraints, lack of insurance, housing instability, and food insecurity can severely impact an individual's ability to maintain regular care. Co-occurring conditions, including mental health challenges, substance use disorders, and other factors, such as lack of access to a regular HIV care provider, and mistrust or dissatisfaction with previous healthcare experiences, further complicate routine access to care.[10,11] Individuals living in rural or underserved areas may face additional difficulties accessing specialized HIV care and support services.[12]

Addressing these multifaceted barriers requires a comprehensive approach that considers and integrates various factors to improve retention and ensure that individuals with HIV receive the continuous care they need.[13] By understanding and tackling these obstacles, healthcare systems can develop targeted strategies to enhance care delivery, reduce disparities, and improve health outcomes for all individuals with HIV.

The goal of this literature review is to inform the Center for Quality Improvement & Innovation (CQII)'s planning team, comprised of CQII staff, faculty, and individuals with lived experience, to plan, implement, and evaluate an upcoming national quality improvement (QI) learning collaborative. This literature review will: (1) provide a comprehensive background on the importance of this national public health priority by reviewing national strategies, federal guidelines, and data sources; (2) outline general guidance on the literature review process, including the sources and search terms used; (3) offer definitions of key terms, such as retention in care, viral suppression, and linkage to care; (4) explore characteristics of HIV-diagnosed clients not in care, including their demographics, barriers, and facilitators; and (5) propose implications for the upcoming CQII collaborative, including suggested definitions, indicators, team selection, and implementation strategies. Finally, an appendix will provide an annotated bibliography to support the review's findings.

B. General Literature Review Guidance

This literature review was conducted over a 6-month period (February 2024-August 2024) and was contributed to by the following individuals: Clemens Steinbock; Britanie Carlozzi; Shakeila Lewis-Chery; Tarik Itum; Marcky Antonio; Raihana Rahman; and T'Oluwanimi Ademola-Thomas. Process steps included: defining the research questions and objectives, developing a protocol with inclusion and exclusion criteria, conducting a comprehensive literature search, assessing and selecting relevant studies, and synthesizing findings.

The following types of studies were considered for this review: primary research data from prospective cohort studies, cross sectional surveys, case-control studies and meta-analysis; intervention studies including randomized controlled trials, clinical trials, pre and post intervention studies and meta-analysis; and observational studies including case reports, qualitative studies and small observational studies. Studies included in this review were those that were published between 2010-2024 and involved published patient data from the United States.

The search was conducted in PubMed using the following terms: out of HIV care; barriers to HIV care; facilitators to HIV care; linkage to HIV care; retention in HIV care; newly diagnosed HIV; patient acceptance of HIV diagnosis and HIV care; time to HIV treatment; test and treat; coping with HIV diagnosis; best practices for transitioning into HIV care; transition to HIV care; same day HIV treatment; data to care; SDOH and HIV care; access to HIV care; and demographics and HIV care.

C. Out of Care - A National Priority

1. National HIV/AIDS Strategy

The National HIV/AIDS Strategy (NHAS) for the United States 2022–2025 is a comprehensive framework designed to guide the nation's response to the HIV epidemic with the aim of ending the epidemic by 2030.[14] The strategy focuses on four key goals:

a) **Prevent New HIV Infections**: This goal emphasizes increasing access to and use of HIV prevention services, including pre-exposure prophylaxis (PrEP) and harm reduction programs, to reduce the incidence of new HIV infections.
b) **Improve HIV-Related Health Outcomes for People with HIV**: This strategy aims to enhance the quality of care for individuals with HIV by improving access to medical care, achieving viral suppression, and addressing health disparities.
c) **Reduce HIV-Related Disparities and Health Inequities**: This goal focuses on addressing the social determinants of health and systemic inequities that disproportionately affect certain populations, including racial and ethnic minorities, LGBTQ+ individuals, and people living in poverty.

d) **Achieve Integrated, Coordinated Efforts**: This strategy promotes collaboration among federal, state, and local entities, as well as community-based organizations, to create a unified and effective response to the HIV epidemic.

The NHAS emphasizes the critical need to support individuals who are not linked to care or fall out of care and cited that in 2019 only 58% of people with diagnosed HIV were retained in care, and 81% were linked to care within a month. Additionally, 23% of those not receiving care accounted for 43% of new infections, highlighting the serious impact of falling out of care on both community and national health.[14]

To address these identified needs, the NHAS outlines the following strategies to prevent and manage care disengagement, relevant to the upcoming CQII collaborative:

- Goal 2: Improve HIV-Related Health Outcomes of People with HIV
    - 2.1 Link people to care immediately after diagnosis and provide low-barrier access to HIV treatment
        - 2.1.1 Provide same-day or rapid (within 7 days) start of antiretroviral therapy for persons who are able to take it; increase linkage to HIV health care within 30 days for all persons who test positive for HIV
    - 2.2 Identify, engage, or reengage people with HIV who are not in care or not virally suppressed
        - 2.2.1 Expand uptake of data-to-care models using data sharing agreements, integration and use of surveillance, clinical services, pharmacy, and social/support services data to identify and engage people not in care or not virally suppressed
        - 2.2.2 Identify and address barriers for people who have never engaged in care or who have fallen out of care
    - 2.3 Increase retention in care and adherence to HIV treatment to achieve and maintain long-term viral suppression and provide integrative HIV services for HIV-associated comorbidities, coinfections, and complications, including STIs
        - 2.3.2 Develop and implement effective, evidence-based, or evidence-informed interventions and supportive services that improve retention in care
        - 2.3.3 Expand implementation research to successfully adapt effective evidence-based interventions, such as HIV telehealth, patient and peer navigators, accessible pharmacy services, community health workers, and others, to local environments to facilitate uptake and retention to priority populations

The NHAS stipulates the following indicators to achieve the following targets to be achieved by 2025:

- Indicator 5: Increase linkage to care within 1 month of diagnosis to 95% from a 2017 baseline of 77.8%
- Indicator 6: Increase viral suppression among people with diagnosed HIV to 95% from a 2017 baseline of 63.1%

Linkage to care and rapid initiation of antiretroviral therapy after HIV diagnosis is a key pillar of reaching the aims of this public health priority.[15] These goals and indicators highlight the NHAS's commitment to addressing retention as a national priority to end the HIV epidemic.

2. HRSA Ending the HIV Epidemic (EHE) and RWHAP Services Report (RSR)

The HRSA HIV/AIDS Bureau's RWHAP Ending the HIV Epidemic (EHE) in the U.S. Initiative Data Report 2022 provides a comprehensive overview of the initiative's performance and impact in supporting individuals with HIV across the United States.[16] Throughout the Fiscal Year 2020, EHE efforts were particularly focused on linking individuals who were newly diagnosed and out of care to care, and to support those who faced barriers to staying in care.

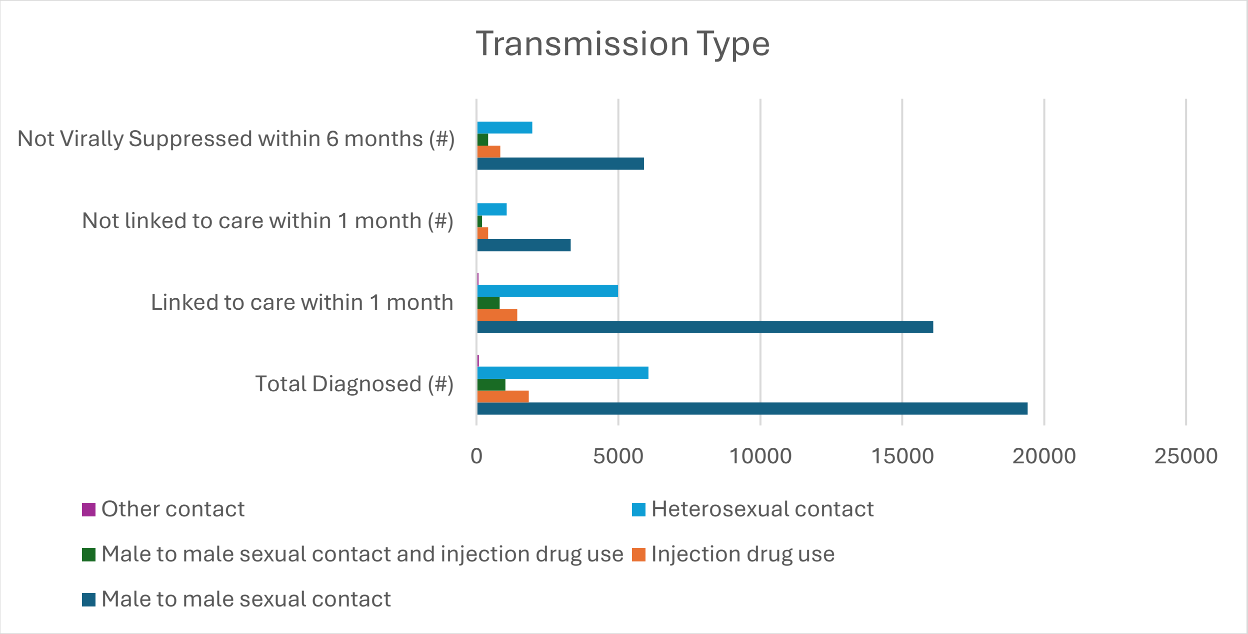
In 2022, EHE-funded providers served 22,001 clients new to care and 19,204 clients estimated to be re-engaged in care. This is nearly double the number of new clients served in 2020, when EHE-funded providers served 11,792 clients new to care and 7,085 clients estimated to be re-engaged in care.[16]

The RWHAP Services Report (RSR) is an annual report published by HRSA that provides detailed data on the services provided by the RWHAP.[17] During calendar years 2020, 2021, and 2022, the RSR highlighted two populations: (1) clients new to care; and (2) clients estimated to be re-engaged. In 2020, 18.2% of patients reported in the RSR were not linked to HIV medical care, and 34.6% did not have viral suppression within 6 months of diagnosis.[18] These findings emphasize the critical importance of studying the out of care population, and highlights RWHAP 's commitment to addressing and mitigating the factors that contribute to care disengagement.

3. Centers of Disease Control (CDC) Data

The CDC released the HIV Surveillance Supplemental Report in 2022 that includes the rates of those with HIV who are linked, not linked, virally suppressed, and not virally suppressed with various characteristics including gender, age at diagnosis, race/ethnicity, state of residence, population area of residence, and region of residence.[18] The national dataset includes information on populations that, according to the NHAS, are disproportionately impacted by HIV and should be prioritized when implementing interventions to improve access to and quality of HIV care.

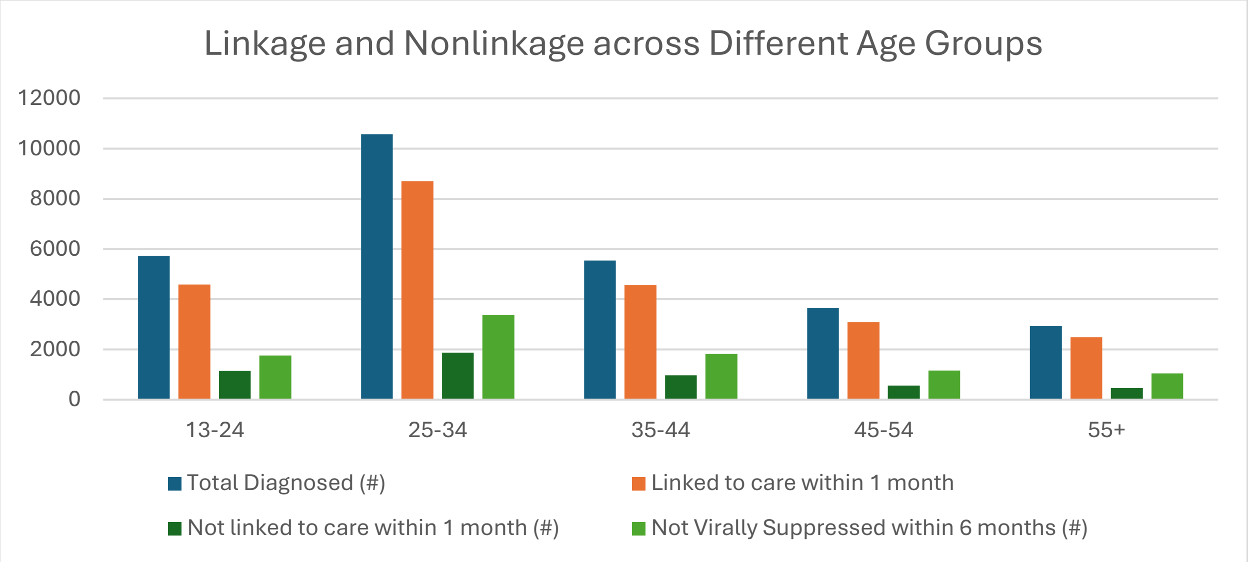
Figure 1: 2022 HIV Surveillance Supplemental Report: Linkage to Care and Viral Suppression by Transmission Category[18]



Among those diagnosed through male-to-male sexual contact, 83% were linked to care within one month, but 31% were not virally suppressed within six months. Injection drug users had a lower linkage rate at

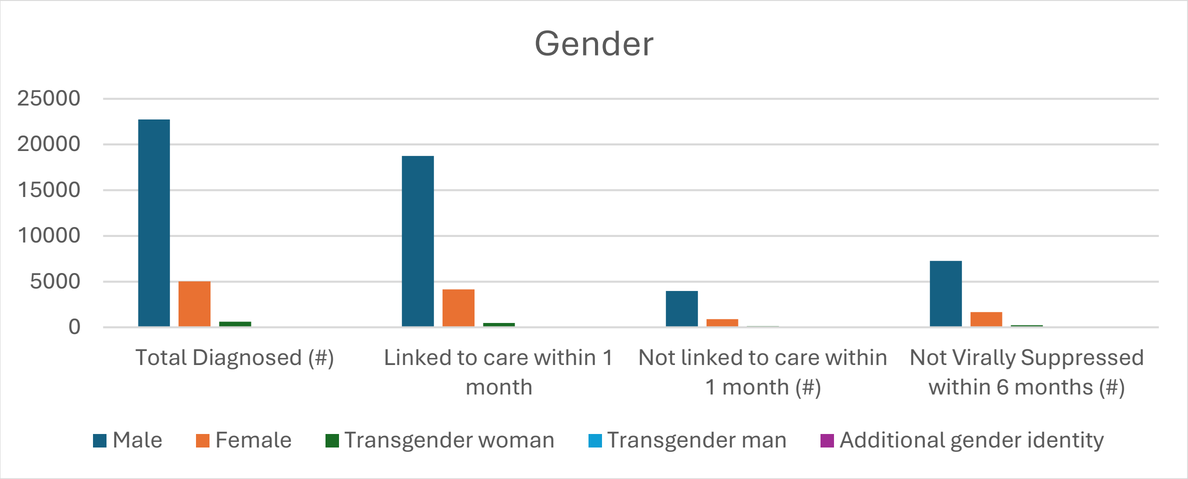
78% and a higher proportion not virally suppressed (46%), while heterosexual contacts had an 82% linkage rate and 32% were not virally suppressed.[18]

Figure 2: 2022 HIV Surveillance Supplemental Report: Linkage to Care and Viral Suppression by Age[18]



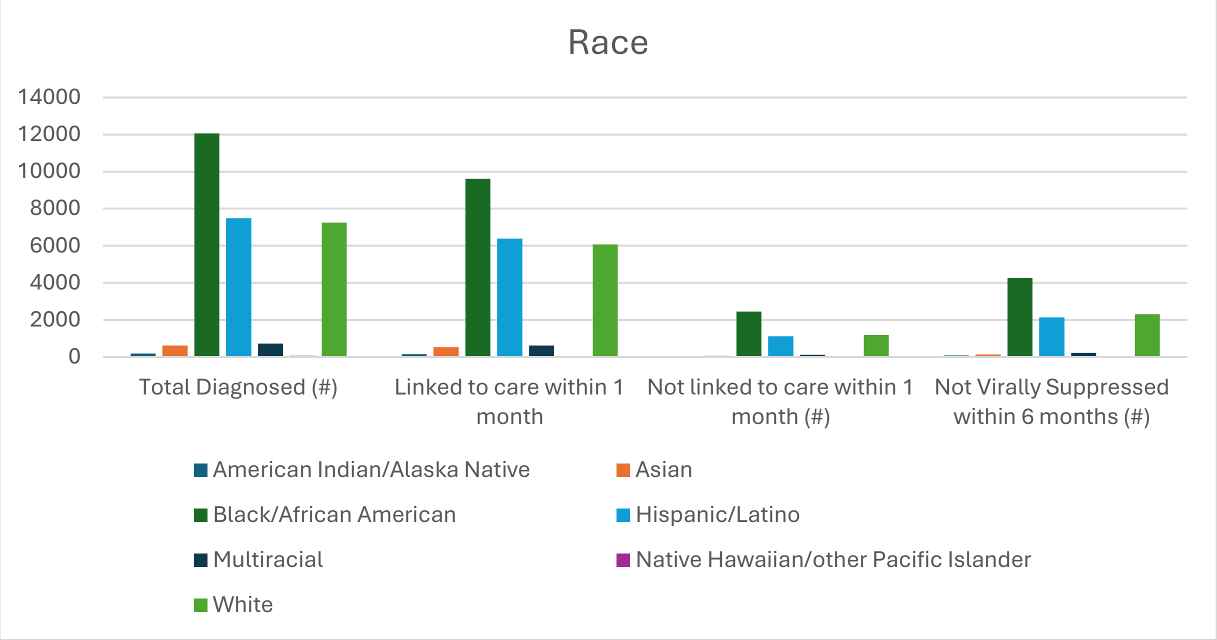
Data on HIV diagnoses across different age groups indicate that individuals aged 13-24 had the highest proportion not linked to care within one month (20%) and the highest number not virally suppressed (31%). In contrast, individuals aged 55 and above were more likely to be linked to care within 1 month (84.4%) compared to younger groups (72.0%), but they have a higher rate of not being virally suppressed within 6 months (35.3%) compared to other age groups (33.2%).[18]

Figure 3: 2022 HIV Surveillance Supplemental Report: Linkage to Care and Viral Suppression by Gender Identity[18]



Males had the highest number of diagnoses and the highest number not linked to care within one month (17%). Transgender women had a lower linkage rate compared to females and a higher proportion not virally suppressed (36%), transgender men and those with additional gender identities had relatively low numbers overall and comparable linkage and suppression rates.[18]

Figure 4: 2022 HIV Surveillance Supplemental Report: Linkage to Care and Viral Suppression by Race/Ethnicity[18]



Black/African American individuals had the highest number of diagnoses and the highest number not linked to care within one month (20%), along with a significant proportion not virally suppressed (35%). Hispanic/Latino and White individuals also had notable rates of not being virally suppressed, but the overall linkage to care was higher compared to Black/African American individuals.

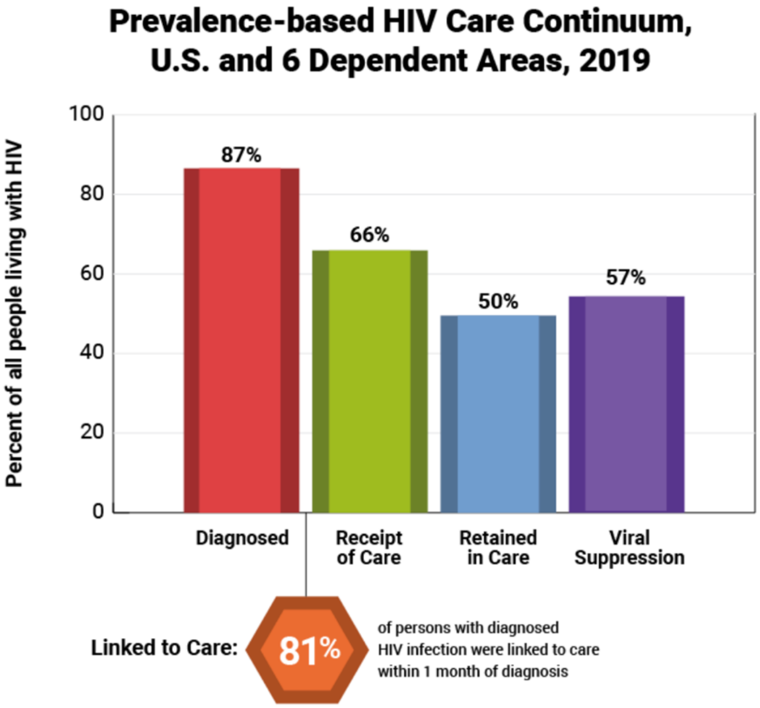
4. HIV Care Continuum/Diagnosis-Based Continuum

The HIV Care Continuum is a model that outlines the stages of care that individuals with HIV should progress through to achieve optimal health outcomes and prevent the spread of the virus.[19] It is used to monitor and improve the effectiveness of HIV care and treatment services.

The continuum includes the following stages:

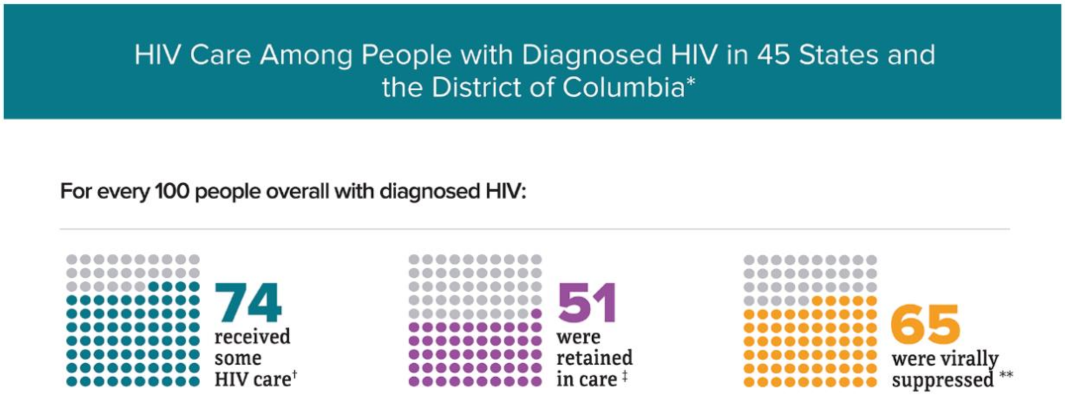
a) **Diagnosed**: Receiving a diagnosis of HIV
b) **Linked to Care**: Visiting an HIV healthcare provider within 30 days of diagnosis
c) **Received Care**: Ongoing medical care for HIV infection
d) **Viral Suppression**: Achieving a very low or undetectable viral load

Figure 5: Prevalence-based HIV Care Continuum[19]



The Diagnosis-based Continuum is a framework specifically designed to track and address the care and treatment journey of individuals diagnosed with HIV.[20] It focuses on the various stages and transitions that occur once an individual receives a positive HIV diagnosis.

Figure 6: Diagnosis-based HIV Care Contintuum[19]



5. <u>Geographic Disparities</u>

According to the NHAS, the HIV epidemic disproportionately impacts those individuals living in the South and rural areas. In 2019, it was estimated that more than one-half of new HIV infections occurred in the South.[14] The CDC national data relate this disparity to rates of non-linkage to HIV care. Tennessee, Indiana, West Virginia, and Mississippi, and other Southern states have some of highest non-linkage to care rates across the country (*Figure 5*). This geographic trend in the South further demonstrates the national impact of non-linkage, which can cause people with HIV to fall out of care.

Figure 7: Choropleth Map of the Continental United States illustrating areas where individuals were not linked to HIV care in 2022.[18]

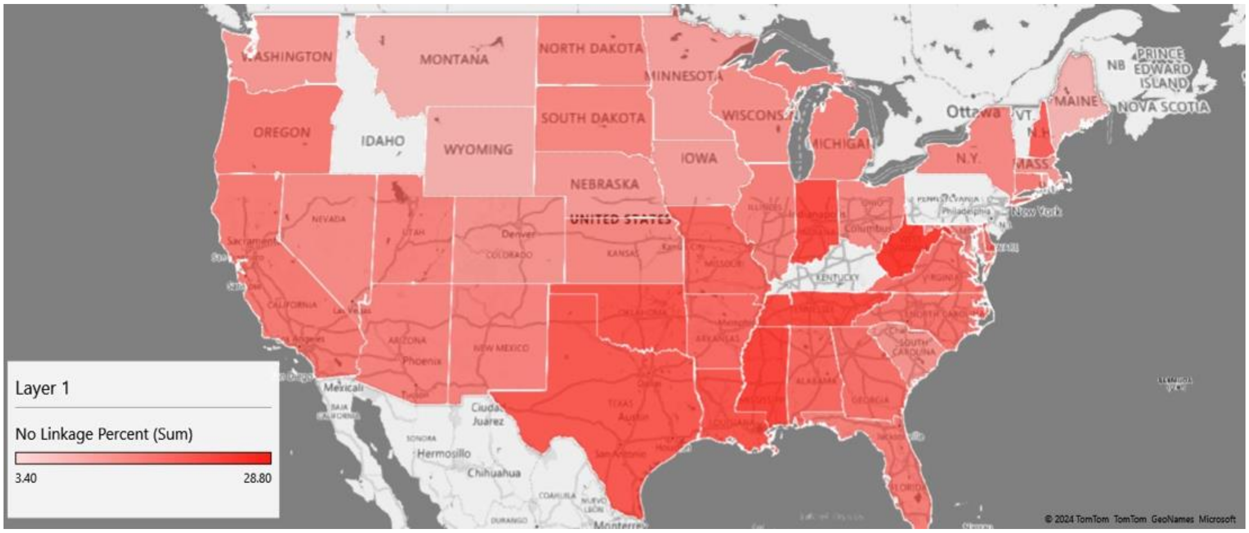
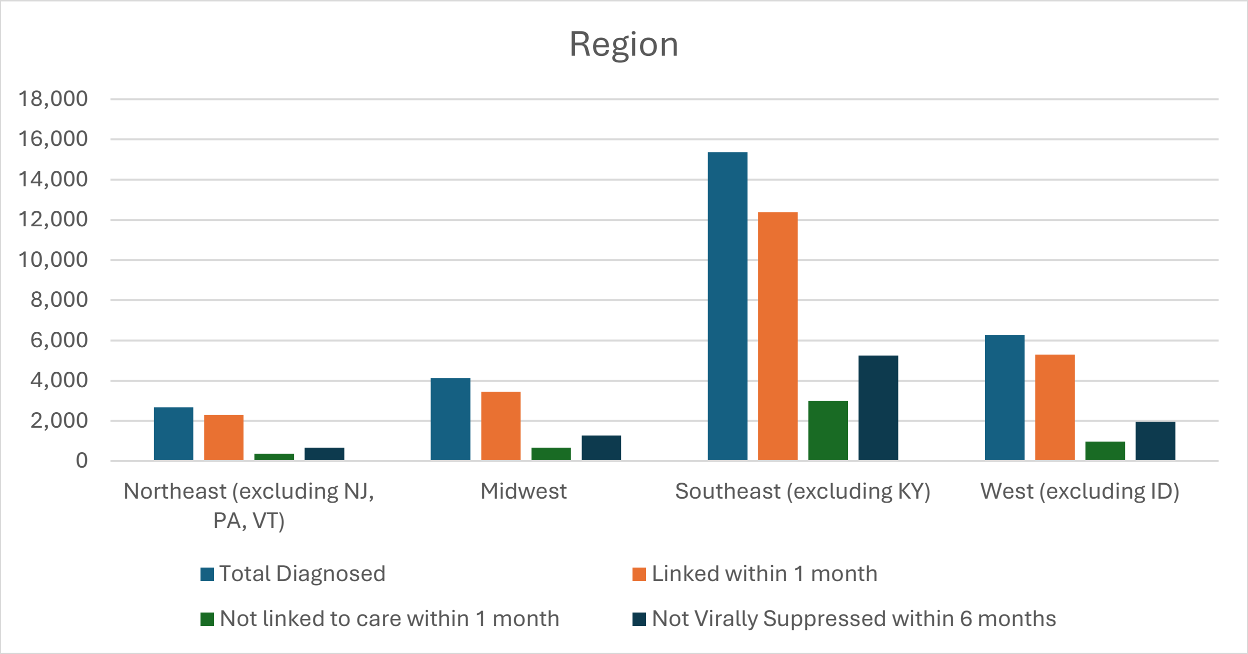


Figure 8: 2022 HIV Surveillance Supplemental Report: Linkage to Care and Viral Suppression by Geographic Region[18]



The Southeast had the highest number of diagnoses, and the greatest number not linked to care within one month (19%), as well as the highest proportion not virally suppressed (34%). The Midwest and West regions had lower proportions of individuals not linked to care, but the Midwest had the highest rate of not being virally suppressed (31%).

D. Characteristics of Patients Not in HIV Care

1. Patient Characteristics

Individuals who are diagnosed with HIV but not engaged in HIV care pose significant challenges to both their own health and public health efforts of ending the HIV epidemic. According to a report published by the CDC, an estimated 43% of HIV transmissions originate from individuals diagnosed and aware of their status but not engaged in care, despite this demographic only accounting for 23% of people with HIV.[21] In light of these findings, researchers aim to understand the factors that prevent people with HIV from being linked to care, as well as identify the specific characteristics of people with HIV affected by these factors.

a) Demographics
The demographics of people with HIV who are out of HIV care differ from those of their counterparts who are engaged in HIV care. In terms of race and ethnicity, those who are out of care have an increased likelihood of being Black (50% out of care v. 39% in care), and a decreased likelihood of being Hispanic/Latino (16% out of care v. 24% in care) or White (26% out of care v. 30% in care). Additionally, out of care individuals are more likely to be younger when considering the following age groups: 18-29 (12% v. 8%) and 30-39 (20% v. 16%).[22]

b) Health Coverage and Ryan White Support
Individuals with HIV who were out of HIV care are more likely to be uninsured (14% out of care v. 10% in care), less likely to have private insurance (29% out of care v. 35% in care), and less likely to receive Ryan White support (39% out of care v. 50% in care).[22]

c) Access and Barriers to Care
People with HIV who were out of care have an increased likelihood of not having a regular HIV provider (16% out of care v. 4% in care) and are more likely to report being "very or somewhat" dissatisfied with prior HIV care they received within the last 12 months (8% out of care v. 3% in care). People with HIV who are out of care are also more likely to identify with various barriers to care, such as financial constraints or a lack of insurance (27% out of care v. 12% in care), mental health problems (24% out of care v. 12% in care), and difficulty in physically accessing a doctor's office (18% out of care v. 8% in care).[22]

d) Unmet Ancillary Needs
In considering ancillary services, 56% of people with HIV who are out of care had at least one unmet need versus 43% of their in-care counterparts. These needs were assessed through three dimensions: clinical support services (24% out of care v. 14% in care), non-HIV medical/behavioral services (35% out of care v. 27% in care), and substance use services (34% out of care v. 22% in care). Within substance use services, out of care individuals reported higher rates of facing housing instability (32% out of care v. 18% in care) and food insecurity (27% out of care v. 18% in care) within the prior 12 months.[22]

2. Barriers for Retention to Care

a) Stigma, Discrimination, and Provider Trust
Stigma and discrimination within healthcare systems are significant barriers to retention in care. Patients who fear being judged or mistreated due to their HIV status may avoid seeking care, ultimately withdraw from treatment. [23] Similarly, perceived stigma or anticipatory shaming due to decreased health literacy

(i.e., lack of knowledge on HIV) serve as barriers to seeking or continuing care.[23] Moreover, provider shortcomings, such as having a poor relationship with their patients and not providing enough information about the importance of HIV care, may similarly prevent patients from remaining in care.[24] A study discovered that patients who received testing because of a requirement (e.g., for military, jail entry, study protocol, immigration purposes) are less likely to schedule follow-up appointments, because they may have had providers who were not actively involved in referral and linkage processes.[25]

b) Mental Health

Mental health challenges, such as depression and anxiety, are prevalent among individuals with HIV, which ultimately hinder ongoing retention in care. When left unaddressed, these challenges may lead to missed appointments and low treatment adherence, ultimately defining a patient as "out of care."[26] This difference is directly seen when comparing those in care versus those out of care. Unmet ancillary care needs, specifically those requiring non-HIV biopsychosocial services, tend to be out of care at a rate higher than their counterparts.[22]

c) Substance Use

Individuals engaging in substance use may detriment their HIV care, ultimately leading to non-retention through several factors: lack of adherence, lack of healthcare engagement, socioeconomic and mental health implications. By engaging in drug use, individuals can impede adherence to prescribed ART regimens, either missing or inconsistently taking doses, hindering efforts to achieve viral suppression. Drug use may also result in drug-related emergencies, which impede HIV-related medical visits. Additionally, the intersections of drug use, socioeconomic status, and mental health are robust and well-documented, with drug use yielding harmful effects across both socioeconomic status and mental health.[27]

d) Socioeconomic Factors

There is a significant correlation between SDOH, such as lower household income, lack of healthcare insurance, or poor retention in care.[28,29,30] The cost of HIV care and treatment is a significant financial burden, and patients without the necessary means to cover the costs may prioritize basic needs over their healthcare costs. Other SDOH barriers include housing instability, lack of adequate transportation, and lower education levels.[25,31,32] Interventions exist that can provide assistance with these issues; for example, transportation vouchers and housing support can help facilitate retention.[33]

e) Health Care System Challenges

Fragmentation within the healthcare system, such as a lack of coordination between services and long wait times, poses significant challenges to retaining individuals in HIV care. Patients may become frustrated while navigating a complex healthcare system, leading to disengagement from care.[34] Streamlining care processes and improving coordination between providers are necessary in overcoming these barriers.[35]

Testing location may also hinder or facilitate HIV care. Those who are tested for HIV at non-healthcare sites, especially correctional facilities, are less likely to be retained in care than those who are tested at healthcare sites.[28,36] Healthcare facilities with greater access to referral and linkage resources, or in-house HIV care units, are better able to keep persons diagnosed with HIV in care. Additionally, clinicians must ensure that they identify individuals with HIV who have comorbidities and refer them to the appropriate provider for HIV care follow-up. This strategy would improve retention in care through care coordination, case management, and colocation of medical and mental health/substance use treatment programs.[25,29] Even among healthcare sites, the setting in which individuals are diagnosed impacts retention. Individuals diagnosed in hospital wards and emergency departments have lower linkage to care rates than those diagnosed in primary care clinics, as they are less likely to fully understand their post discharge treatment plan. This lack of understanding impacts their ability to understand discharge instructions, including creating and attending follow-up appointments.[29]

3. Facilitators for Retention to Care

a. Psychosocial Support
Interventions including peer support groups, counseling, and mental health services, can significantly enhance retention in HIV care by addressing emotional and psychological challenges faced by individuals with HIV.[26] Said interventions may additionally address stigma and isolation that hinder engagement in care, ultimately improving retention rates.

b. Health Literacy
Health literacy, in general and regarding HIV, is essential for patients to engage in continuous care. Educational programs that provide knowledge on HIV, treatment regimens, and the consequences of not maintaining viral suppression, are critical for improving retention.[37] Ultimately, patients who are better informed are more likely to stay retained in care and adhere to treatment protocols.

c. Integrated Care Model
Integrating services, such as mental health care, substance use treatment, and social support services within HIV care settings facilitates retention by addressing the complex needs of patients.[35] Integrated care models reduce the burden of navigating multiple systems, allowing patients to access comprehensive care, address other healthcare needs, and remain in HIV care.

E. Implications for the CQII Care Collaborative

CQII has a rich history of implementing national learning collaboratives. In the previous *create+equity Collaborative* (Jan 2021 to Jun 2022), CQII engaged 84 recipients to focus on viral suppression among high-risk patient populations, those with housing, substance use, and mental health needs. Based on data from ~60,000 patients, the viral suppression rate significantly increased for these patient groups in comparison to other patients seen by the same sites. The CQII *Impact Now Collaborative* (Jan 2023 to Jun 2024) targeted recipients/subrecipients that have the potential to make the highest national impact by raising their viral suppression rates to the national mean and beyond. The overall viral suppression rate across 23 sites participating in this collaborative increased from 84.7% at baseline (March 2023) to 87.74% in June 2024 increasing the number of people with HIV who are virally suppressed by 3.1% [the final evaluation report has been submitted to HRSA for review and approval].

The CQII Care (Connecting And Re-engaging Everyone) Collaborative (a working title as of Sep 2024) aims to address critical challenges and gaps in HIV care among people with HIV. This collaborative will focus on five key areas to improve health outcomes and reduce HIV transmission rates:

1. **Linkage to Care:** The upcoming CQII collaborative seeks to improve the percentage of newly diagnosed individuals who are linked to HIV care within one month of diagnosis. Currently, 19% of people with diagnosed HIV are not linked to care within this crucial timeframe.[14] The 2022 RSR data highlight that certain populations, such as younger clients (aged 13-24) and transgender individuals, have lower rates of timely linkage to care. Specifically, only 76.2% of young clients were linked to care within 30 days, compared to 80.5% overall. The collaborative will focus on improving linkage rates of these groups to ensure they receive timely access to HIV care and begin ARV treatment as early as possible. Research shows the sooner an individual is linked to care the better their adherence and retention rates.[38]

2. **Retention in Care:** National improvement goals aim to have 95% of people with HIV retained in care. The currently estimated national rate suggests that only 57% of people with HIV are retained in care.[18] Retention in care remains a challenge, particularly among certain racial and ethnic groups.[10] According to the 2022 RSR, Black/African American clients ages 20-39 and younger clients aged 13-24 have lower retention rates, with only 71.1% of Black/African American clients and 66.7% of young clients retained in care, compared to 74.5% overall. Retention in care can be predictor for ART adherence and viral suppression.[2,18]
3. **Viral Suppression:** The collaborative emphasizes the importance of increasing the percentage of individuals who achieve viral suppression, a key indicator of successful HIV treatment. While achieving viral suppression is critical, disparities continue to exist, the 2022 RSR data show that while 89.7% of overall RWHAP clients achieved viral suppression, lower rates were observed among Black/African American clients (87.1%) and younger clients aged 13-24 (80.1%). The collaborative aims to improve viral suppression rates in these populations. Viral suppression not only improves the health of the individual but also significantly reduces the risk of HIV transmissions to others.[39]
4. **Quality Improvement (QI) Capacity:** The collaborative is committed to strengthening the organizational capacity for quality improvement among participating sites that meet clinical quality management expectations, as assessed through a standardized tool. This tool includes the following dimensions: Quality Infrastructure (Program Leadership, Quality Management Committee, Staff Engagement in Quality Improvement, Engagement of People with HIV); Performance Measurement (Performance Measurement, Performance Data Findings Are Used for Quality Improvement: and Quality Improvement Activities (QI Project Implementation, QI Project Outcomes). By increasing the percentage of participating sites that meet the quality management expectations the collaborative aims to enhance their ability to meet external funding requirements as outlined by the HRSA HIV/AIDS Bureau in the Policy Clarification Notice 15-02.[43]
5. **Patient Engagement:** Recognizing the importance of involving people with HIV as equal partners in site-specific improvement efforts, the collaborative strives to increase the number of participating sites that routinely engage persons with HIV in their improvement projects. Engaging patients in the improvement process enhances the relevance and effectiveness of interventions, fostering a more patient-centered approach.

1. Definitions - For the purposes of this collaborative, the following definitions are considered:

- **Retention in Care** refers to a patient, regardless of age, with a diagnosis of HIV attending at least two [1] medical encounters [2], spaced at least 90 days apart, within a 12-month rolling measurement period. If a patient does not meet this, they are considered **Out of Care.**[40]
  - **Patient Exclusions:** Patients who expired during the measurement year; patients who became incarcerated during the measurement year; patients who relocated or transferred their HIV care with documentation in the medical record [3].
  - **Notes:** [1] At least one of the two HIV medical care encounters needs to be a medical visit with a provider with prescribing privileges. [2] An HIV medical care encounter is a medical visit with a provider with prescribing privileges or an HIV viral load test. [3] The following exclusions are not included in the current HRSA retention indicator definition: patients who became incarcerated during the measurement year.

- **Linkage to Care** refers to a patient who has an HIV medical care encounter within 30 days of the HIV diagnosis within a 12-month rolling measurement period.[41] [4]
  - **Patient Exclusions:** None.

  - **Notes:** [4] An HIV medical care encounter is a medical visit with a provider with prescribing privileges or an HIV viral load or CD4 test.
  - **Best Practice:** While the linkage to care measure allows for a 30-day window, the patient should ideally be linked to care, and ARV treatment is initiated on the same day.

- **Viral Suppression** refers to the percentage of patients, regardless of age, with a diagnosis of HIV with an HIV viral load less than 200 copies/ml at last HIV viral load test during the measurement year.[42]
  - **Patient Exclusions:** Patients who expired during the measurement year; patients who became incarcerated during the measurement year; patients who relocated or transferred their HIV care with documentation in the medical record.

F. Appendix: Abstracts of Selected Articles in the Peer-Reviewed Literature

Anderson, A. N., et al. (2020). "Disparities in Retention in Care Among Adults Living with HIV/AIDS: A Systematic Review." AIDS Behav 24(4): 985-997.

As national HIV prevention goals aim to increase the proportion of persons with HIV, determining existing disparities in retention in care will allow for targeted intervention. The purpose of this systematic review was to identify existing disparities in retention in care. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) 2015 guided this systematic review. Electronic databases, including PubMed/MEDLINE, CINAHL, Sociological Collection, PsychInfo, and Cab Direct/Global Health, were systematically searched and twenty studies were included. This review identified disparities in retention in care that have been documented by race, gender, age, HIV exposure, incarceration history, place of birth, and U.S. geographic location. Research is necessary to further identify existing disparities in retention in care and to better understand determinants of health disparities. Additionally, interventions must be tailored to meet the needs of health disparate populations and should be assessed to determine their effectiveness in reducing health disparities.

Bamford, L. P., et al. (2010). "Factors associated with delayed entry into primary HIV medical care after HIV diagnosis." AIDS 24(6): 928-930.

The aim of the study was to assess the median time between HIV diagnosis and entry into primary HIV medical care in a large urban area and to assess the potential individual, diagnosing facility, and community level factors influencing entry into care. One thousand two hundred and sixty-six individuals diagnosed with HIV in Philadelphia between 1 July 2005 and 30 June 2006 were followed until entry into care through 15 June 2007. Time to entry into care was calculated as a survival time variable and was defined as the time in months between the date of HIV diagnosis and the date more than 3 weeks after diagnosis when a CD4 cell count or percentage and/or HIV viral load were obtained. The median time to entry into care for all individuals was 8 months, with a range of 1-26 months. Factors associated with delayed entry into care included age more than 40 years [hazard ratio (HR) = 0.85; 95% confidence interval (CI) = 0.75-0.97] and diagnosis as an inpatient in the hospital (HR = 0.37; 95% CI = 0.37-0.57). Factors associated with earlier entry into care included Hispanic ethnicity (HR = 1.39; 95% CI = 1.05-1.84), male sex with men as HIV transmission risk factor (HR = 1.27; 95% CI = 1.03-1.56), and residence in a census tract with a high poverty rate (HR = 1.68; 95% CI = 1.22-2.30). Individuals newly diagnosed with HIV in Philadelphia demonstrated marked delays in accessing care highlighting the tremendous need for interventions to improve overall linkage. These interventions should especially be targeted at those aged more than 40 years and those diagnosed in the hospital.

Batchelder, A. W., et al. (2020). "A novel technology-enhanced internalized stigma and shame intervention for HIV-positive persons with substance use disorders." Cogn Behav Pract 27(1): 55-69.

Internalized stigma, shame, and other negative self-conscious emotions are inadequately addressed barriers to HIV-related self-care, particularly among people actively using substances. Innovative approaches are needed to optimize ART adherence as well as engagement in HIV care among people living with HIV and substance use disorders. Based on qualitative feedback from providers and patients, The study iteratively developed and conducted a proof-of-concept study of a relatively brief transdiagnostic emotion regulation intervention designed to improve ART adherence care by addressing behavioral and psychological barriers, including internalized stigma and shame, among people living with HIV and active substance use disorders. The final intervention included 5 individual sessions focused on metacognitive awareness of emotions and thoughts, cognitive reframing of dysfunctional thoughts about the self-using concepts such as self-compassion and identifying and reaching the participants' personalized HIV-self-care goal(s). All participants received daily texts querying current emotion and weekly texts querying ART adherence and substance use. To extend the effects of the intervention, the authors developed a personalized bi-directional text component through which participants received their personalized compassionate self-statements, informed by the intervention content, in response to their answers to emotion queries for 8 weeks after the 5 sessions. The texts modeled using compassionate self-statements as a form of cognitive reframing, consistent with cognitive restructuring of distorted core beliefs. The authors consented 10 participants living with HIV and problematic substance use in the proof-of-concept pilot. Of the 8 participants who completed all intervention sessions, participants replied to 70% of all text messages sent. All 8 reported strong acceptability of the intervention content. This emotion-focused, technology-enhanced intervention demonstrated proof-of-concept, in that this patient population would participate in this intervention. A larger randomized controlled pilot is needed to determine feasibility and acceptability among people living with HIV and substance use disorders, a hard-to-reach and underserved population.

Bauermeister, J. A., et al. (2021). "Approaches to Promoting Linkage to and Retention in HIV Care in the United States: a Scoping Review." Curr HIV/AIDS Rep 18(4): 339-350.

Linkage to and retention in HIV care, as conceptualized in the HIV care continuum, remain critical steps towards achieving and maintaining viral suppression. The authors evaluated recently published (Jan 2018-Nov 2020) peer-reviewed clinical trials of linkage to and retention in care outcomes in the United States. The study identified 12 trials evaluating linkage to and retention in care outcomes in the United States. Most trials did not adhere to standardized definitions or metrics for linkage to or retention in HIV care, hindering comparisons between studies. Four interventions indicated improvements on linkage to or retention in HIV care at follow-up, relying on behavioral incentives and/or case management as key intervention strategies. The authors recommend the adoption standardize metrics across linkage and retention trials, and the future use of implementation science frameworks to identify implementation facilitators and barriers, and evaluate key strategies associated with improvements in linkage to and retention in care.

Bouabida, K., et al. (2023). "Challenges and barriers to HIV care engagement and care cascade: viewpoint." Front Reprod Health 5: 1201087.

Patients with HIV are subject to long-term management and a complex care process. Patients with HIV are clinically, socially, and emotionally vulnerable, face many challenges, and are often stigmatized. Healthcare providers should engage them with diligence in the HIV care cascade process. In this paper, the authors discuss from our viewpoint certain social and public health barriers and challenges that should be considered by healthcare providers to better engage patients in the HIV care cascade process and maximize its outcomes.

Brawner, B. M., et al. (2017). "Place Still Matters: Racial/Ethnic and Geographic Disparities in HIV Transmission and Disease Burden." J Urban Health 94(5): 716-729.

Neighborhood-level structural interventions are needed to address HIV/AIDS in highly affected areas. To develop these interventions, the authors need a better understanding of contextual factors that drive the pandemic. The authors used multinomial logistic regression models to examine the relationship between census tract of current residence and mode of HIV transmission among HIV-positive cases. Compared to the predominantly white high HIV prevalence tract, both the predominantly black high and low HIV prevalence tracts had greater odds of transmission via injection drug use and heterosexual contact than male-to-male sexual contact. After adjusting for current age, gender, race/ethnicity, insurance status, and most recently recorded CD4 count, there was no statistically significant difference in mode of HIV transmission by census tract. However, heterosexual transmission and injection drug use remain key concerns for underserved populations. Blacks were seven times more likely than whites to have heterosexual versus male-to-male sexual contact. Those who had Medicaid or were uninsured (versus private insurance) were 23 and 14 times more likely, respectively, to have injection drug use than male-to-male sexual contact and 10 times more likely to have heterosexual contact than male-to-male sexual contact. These findings can inform larger studies for the development of neighborhood-level structural interventions.

Dasgupta, S., et al. (2020). "Systematic monitoring of retention in care in U.S.-based HIV care facilities." AIDS Care 32(1): 113-118.

National guidelines recommend that HIV providers systematically monitor retention in care to identify and re-engage persons sub optimally in care. The authors described (1) U.S.-based outpatient HIV care facilities that systematically monitor retention in care, and (2) characteristics of patients attending facilities that monitored retention in care. The authors used data collected during 6/2014-5/2015 from the Medical Monitoring Project, an annual, cross-sectional survey that produces nationally representative estimates of characteristics of HIV-positive persons in medical care. The authors described systematic monitoring of retention in care among facilities and patients attending facilities providing this service using weighted percentages and 95% confidence intervals and used Rao-Scott chi-square tests ($p < .05$) to assess differences by selected characteristics. Overall, 67% of facilities systematically monitored retention in care, and 81% of patients attended these facilities. Federally qualified health centers, community-based organizations, health departments, non-private practices, and Ryan White HIV/AIDS Program (RWHAP)-funded facilities were more likely to systematically monitor retention in care. Persons living in poverty, and those who were homeless or incarcerated, or injected drugs were more likely to attend facilities with this service. Although systematic monitoring of retention in care is accessible for many patients, improvements at other, non-RWHAP-funded facilities may help in reaching national prevention goals.

Dombrowski, J. C., et al. (2019). "HIV Care for Patients With Complex Needs: A Controlled Evaluation of a Walk-In, Incentivized Care Model." Open Forum Infect Dis 6(7): ofz294.

New approaches are needed to provide care to persons with HIV who do not engage in conventionally organized HIV clinics. The Max Clinic in Seattle, Washington, is a walk-in, incentivized HIV care model located in a public health STD clinic that provides care in collaboration with a comprehensive HIV primary care clinic (the Madison Clinic). The authors compared outcomes in the first 50 patients enrolled in Max Clinic and 100 randomly selected matched Madison Clinic control patients; patients in both groups were virally unsuppressed (viral load [VL] >200 copies/mL) at baseline. The primary outcome was any VL indicating viral suppression (>/=1 VL <200 copies/mL) during the 12 months postbaseline. Secondary outcomes were continuous viral suppression (>/=2 consecutive suppressed VLs >/=60 days apart) and engagement in care (>/=2 medical visits >/=60 days apart). The authors compared outcomes in the 12 months pre- and postbaseline and used generalized estimating equations to compare changes in Max vs control patients, adjusting for unstable housing, substance use, and psychiatric disorders. RESULTS: Viral suppression improved in both groups pre-to-post (20% to 82% Max patients; $P < .001$; and 51% to 65% controls; $P = .04$), with a larger improvement in Max patients (adjusted relative risk ratio [aRRR], 3.2; 95% confidence interval [CI], 1.8-5.9). Continuous viral suppression and engagement in care increased in both groups but did not differ significantly (continuous viral suppression: aRRR, 1.5; 95% CI, 0.5-5.2; engagement: aRRR, 1.3; 95% CI, 0.9-1.9). The Max Clinic improved viral suppression among patients with complex medical and social needs.

Dombrowski, J. C., et al. (2015). "Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program." AIDS Patient Care STDS 29(5): 279-287.

Improving patient retention in HIV care and use of antiretroviral therapy (ART) are key steps to improving the HIV care continuum in the US. However, contemporary quantitative data on barriers to care and treatment from population-based samples of persons poorly engaged in care are sparse. The authors analyzed the prevalence of barriers to clinic visits, ART initiation, and ART continuation reported by 247 participants in a public health HIV care relinkage program in King County, WA. The authors identified participants using HIV surveillance data (N=188) and referrals from HIV/STD clinics and partner services (N=59). Participants most commonly reported insurance (50%), practical (26-34%), and financial (30%) barriers to care, despite residing in a state with essentially universal access to HIV care. Perceived lack of need for medical care was uncommon (<20%), but many participants (58%) endorsed a perceived lack of need for medication as a reason for not initiating ART. Depression and substance abuse were both highly prevalent (69% and 54%, respectively), and methamphetamine was the most commonly abused substance. Barriers to HIV care and treatment may be amenable to intervention by health department outreach in coordination with existing HIV medical and support services.

Fauci, A. S., et al. (2019). "Ending the HIV Epidemic: A Plan for the United States." JAMA 321(9): 844-845.

In his 2019 State of the Union Address, President Donald J. Trump outlined a bold initiative to end the HIV epidemic in the United States within 10 years. Despite significant progress in HIV treatment and prevention, the epidemic remains a severe public health issue, particularly affecting marginalized communities. The proposed strategy aims to reduce new HIV infections by 75% within 5 years and 90% within 10 years, focusing on hotspots and leveraging advances in biomedical research and treatment. This initiative will involve a coordinated effort among federal agencies, local health departments, and community organizations to expand access to diagnosis, treatment, and preventive services.

Gillot, M., et al. (2022). "Linkage to HIV Medical Care and Social Determinants of Health Among Adults With Diagnosed HIV Infection in 41 States and the District of Columbia, 2017." Public Health Rep 137(5): 888-900.

To reduce the number of new HIV infections and improve HIV health care outcomes, the social conditions in which people live and work should be assessed. The objective of this study was to describe linkage to HIV medical care by selected demographic characteristics and social determinants of health (SDH) among US adults with HIV at the county level. The authors used National HIV Surveillance System data from 42 US jurisdictions and data from the American Community Survey to describe differences in linkage to HIV medical care among adults aged >/=18 with HIV infection diagnosed in 2017. The authors categorized SDH variables into higher or lower levels of poverty (where <13% or >/=13% of the population lived below the federal poverty level), education (where <13% or >/=13% of the population had <high school diploma), and health insurance coverage (where <12% or >/=12% of the population lacked health insurance). The authors calculated prevalence ratios (PRs) and 95% CIs. Of 33 204 adults with HIV infection diagnosed in 2017, 78.4% were linked to HIV medical care </=1 month after diagnosis. Overall, rates of linkage to care were significantly lower among men and women living in counties with higher versus lower poverty (PR = 0.96; 95% CI, 0.94-0.97), with lower versus higher health insurance coverage (PR = 0.93; 95% CI, 0.92-0.94), and with lower versus higher education levels (PR = 0.97; 95% CI, 0.96-0.98). Increasing health insurance coverage and addressing economic and educational disparities would likely lead to better HIV care outcomes in these areas.

Li, Z., et al. (2019). "Vital Signs: HIV Transmission Along the Continuum of Care - United States, 2016." MMWR Morb Mortal Wkly Rep 68(11): 267-272.

In 2016, an estimated 1.1 million persons had human immunodeficiency virus (HIV) infection in the United States; 38,700 were new infections. Knowledge of HIV infection status, behavior change, and antiretroviral therapy (ART) all prevent HIV transmission. Persons who achieve and maintain viral suppression (achieved by most persons within 6 months of starting ART) can live long, healthy lives and pose effectively no risk of HIV transmission to their sexual partners. A model was used to estimate transmission rates in 2016 along the HIV continuum of care. Data for sexual and needle-sharing behaviors were obtained from National HIV Behavioral Surveillance. Estimated HIV prevalence, incidence, receipt of care, and viral suppression were obtained from National HIV Surveillance System data. RESULTS: Overall, the HIV transmission rate was 3.5 per 100 person-years in 2016. Along the HIV continuum of care, the transmission rates from persons who were 1) acutely infected and unaware of their infection, 2) non-acutely infected and unaware, 3) aware of HIV infection but not in care, 4) receiving HIV care but not virally suppressed, and 5) taking ART and virally suppressed were 16.1, 8.4, 6.6, 6.1, and 0 per 100 person-years, respectively. The percentages of all transmissions generated by each group were 4.0%, 33.6%, 42.6%, 19.8%, and 0%, respectively. Approximately 80% of new HIV transmissions are from persons who do not know they have HIV infection or are not receiving regular care. Going forward, increasing the percentage of persons with HIV infection who have achieved viral suppression and do not transmit HIV will be critical for ending the HIV epidemic in the United States.

Mgbako, O., et al. (2022). "A Systematic Review of Factors Critical for HIV Health Literacy, ART Adherence and Retention in Care in the U.S. for Racial and Ethnic Minorities." AIDS Behav 26(11): 3480-3493.

Despite advances in ART, the HIV epidemic persists in the U.S., with inadequate adherence to treatment and care a major barrier to ending the epidemic. Health literacy is a critical factor in maximizing ART adherence and healthcare utilization, especially among vulnerable populations, including racial and ethnic minorities. This U.S-based systematic review examines psychosocial variables influencing health literacy among persons with HIV, with a focus on racial and ethnic minorities. Although findings are limited, some studies showed that HIV-related stigma, self-efficacy, and patient trust in providers mediate the relationship between health literacy and both ART adherence and HIV care retention. To inform effective, equitable health literacy interventions to promote adherence to HIV treatment and care, further research is needed to understand the factors driving the relationship between health literacy and HIV outcomes. Such work may broaden our understanding of health literacy in the context of racial equity.

Mugavero, M. J., et al. (2010). "From access to engagement: measuring retention in outpatient HIV clinical care." AIDS Patient Care STDS 24(10): 607-613.

Engagement in HIV care is increasingly recognized as a crucial step in maximizing individual patient outcomes. The recently updated HIV Medicine Association primary HIV care guidelines include a new recommendation highlighting the importance of extending adherence beyond antiretroviral medications to include adherence to clinical care. Beyond individual health, emphasis on a "test and treat" approach to HIV prevention highlights the public health importance of engagement in clinical care as an essential intermediary between the putative benefits of universal HIV testing ("test") followed by ubiquitous antiretroviral treatment ("treat"). One challenge to administrators, researchers and clinicians who want to systematically evaluate HIV clinical engagement is deciding on how to measure retention in care. Measuring retention is complex as this process includes multiple clinic visits (repeated measures) occurring longitudinally over time. This article provides a synthesis of five commonly used measures of retention in HIV care, highlighting their methodological and conceptual strengths and limitations, and suggesting situations where certain measures may be preferred over others. The five measures are missed visits, appointment adherence, visit constancy, gaps in care, and the Human

Resources and Services Administration HIV/AIDS Bureau performance measure for retention in HIV care. As has been noted for antiretroviral medication adherence, there is no gold standard to measure retention in care, and consideration of the advantages and limitations of each measure, particularly in the context of the desired application, should guide selection of a retention measure.

Padilla, M., et al. (2022). "The Boundary of HIV Care: Barriers and Facilitators to Care Engagement Among People with HIV in the United States." AIDS Patient Care STDS 36(8): 321-331.

Treating people with HIV quickly and effectively to achieve viral suppression is a key strategy for Ending the HIV Epidemic. Understanding barriers and facilitators to HIV care engagement could improve outcomes among people with HIV and reduce HIV infections. The authors sampled people with HIV who participated in the Medical Monitoring Project from June 2018 to May 2019 and were not engaged in HIV care to participate in 60-min semi structured telephone interviews on barriers and facilitators to HIV care engagement. The authors used applied thematic analysis and placed codes into themes based on their frequency and salience. Participants reported various intrapersonal, health system, and structural barriers to care. The authors conceptualize the boundary of care as the space between the stages of the HIV care continuum, where people with HIV may find themselves when they lack intrapersonal, health system, and structural support. Research and interventions tackling these barriers are needed to improve outcomes among people with HIV and reduce HIV infections.

Przybyla, S., et al. (2022). "Substance Use and Adherence to Antiretroviral Therapy among People Living with HIV in the United States." Trop Med Infect Dis 7(11).

People with HIV report substance use at higher rates than HIV-uninfected individuals. The potential negative impact of single and polysubstance use on HIV treatment among diverse samples of people with HIV is underexplored. People with HIV were recruited from the Center for Positive Living at the Montefiore Medical Center (Bronx, NY, USA) from May 2017-April 2018 and completed a cross-sectional survey with measures of substance use, ART use, and ART adherence. The overall sample included 237 people with HIV (54.1% Black, 42.2% female, median age 53 years). Approximately half of the sample reported any current substance use with 23.1% reporting single substance use and 21.4% reporting polysubstance use. Polysubstance use was more prevalent among those with current cigarette smoking relative to those with no current smoking and among females relative to males. Alcohol and cannabis were the most commonly reported polysubstance combination; however, a sizeable proportion of people with HIV reported other two, three, and four-substance groupings. Single and polysubstance use were associated with lower ART adherence. A thorough understanding of substance use patterns and related adherence challenges may aid with targeted public health interventions to improve HIV care cascade goals, including the integration of substance use prevention into HIV treatment and care settings.

Remien, R. H., et al. (2019). "Mental health and HIV/AIDS: the need for an integrated response." AIDS 33(9): 1411-1420.

Tremendous biomedical advancements in HIV prevention and treatment have led to aspirational efforts to end the HIV epidemic. However, this goal will not be achieved without addressing the significant mental health and substance use problems among people living with HIV (people with HIV) and people vulnerable to acquiring HIV. These problems exacerbate the many social and economic barriers to accessing adequate and sustained healthcare and are among the most challenging barriers to achieving the end of the HIV epidemic. Rates of mental health problems are higher among both people vulnerable to acquiring HIV and people with HIV, compared with the general population. Mental health impairments increase risk for HIV acquisition and for negative health outcomes among people with HIV at each step in the HIV care continuum. The authors have the necessary screening tools and efficacious treatments to treat mental health problems among people living with and at risk for HIV. However, the authors need to prioritize mental health treatment with appropriate resources to address the current mental health screening and treatment gaps. Integration of mental health screening and care into all HIV testing and treatment settings would not only strengthen HIV prevention and care outcomes, but it would additionally improve global access to mental healthcare.

Robertson, M., et al. (2016). "Delayed entry into HIV medical care in a nationally representative sample of HIV-infected adults receiving medical care in the USA." AIDS Care 28(3): 325-333.

Before widespread ART, an estimated 17% of people delayed HIV care. The authors report national estimates of the prevalence and factors associated with delayed care entry in the contemporary ART era. The authors used Medical Monitoring Project data collected from June 2009 through May 2011 for 1425 persons diagnosed with HIV from May 2004 to April 2009 who initiated care within 12 months. The authors defined delayed care as entry >three months from diagnosis. Adjusted prevalence ratios (aPRs) were calculated to identify risk factors associated with delayed care. In this nationally representative sample of HIV-infected adults receiving medical care, 7.0% (95% confidence interval [CI]: 5.3-8.8) delayed care after diagnosis. Black race was associated with a lower likelihood of delay than white race (aPR 0.38). Men who have sex with women versus women who have sex with men (aPR 1.86) and persons required to take an HIV test versus recommended by a provider (aPR 2.52) were more likely to delay. Among those who delayed 48% reported a personal factor as the primary reason. Among persons initially diagnosed with HIV (non-AIDS), those who delayed care were twice as likely (aPR 2.08) to develop AIDS as of May 2011. Compared to the pre-ART era, there was a nearly 60% reduction in delayed care entry. Although relatively few HIV patients delayed care entry, certain groups may have an increased risk. Focus on linkage to care among persons who are required to take an HIV test may further reduce delayed care entry.

Song, W. and M. S. Mulatu (2023). "Factors Associated With Rapid Linkage to HIV Medical Care Among Persons Newly Diagnosed With HIV Infection in the United States, 2019 to 2020." Sex Transm Dis 50(7): 439-445.

Rapid linkage to HIV medical care, ideally within 7 days of a person's diagnosis with HIV infection, is a vital strategy of the Ending the HIV Epidemic initiative in the United States. The authors analyzed HIV testing data to evaluate the prevalence of and factors associated with rapid linkage to HIV medical care. The publication used HIV testing data reported by Centers for Disease Control and Prevention-funded 60 state and local health departments and 29 community-based organizations from 2019 to 2020. Variables analyzed include rapid linkage to HIV medical care (within 7 days of diagnosis), demographic/population characteristics, geographic region, test site type, and test year. Multivariable Poisson regression analysis was conducted to evaluate the characteristics associated with rapid linkage to HIV medical care. A total of 3,678,070 HIV tests were conducted, and 11,337 persons were newly diagnosed with HIV infection. Only 4710 persons (41.5%) received rapid linkage to HIV medical care, which was more likely among men who have sex with men or persons who were diagnosed in Phase I Ending the HIV Epidemic jurisdictions and less likely among persons diagnosed in sexually transmitted disease clinics or the South region. Less than one-half of persons newly diagnosed with HIV infection in Centers for Disease Control and Prevention-funded HIV testing programs were linked to HIV medical care within 7 days of diagnosis. Rapid linkage to care varied significantly by population characteristics and setting. Identifying and removing potential individual, social, or structural barriers to rapid linkage to care can help improve HIV-related health equity and contribute to the national goal of ending the HIV epidemic.

Yehia, B. R., et al. (2015). "Location of HIV diagnosis impacts linkage to medical care." J Acquir Immune Defic Syndr 68(3): 304-309.

The study evaluated 1359 adults newly diagnosed with HIV in Philadelphia in 2010-2011 to determine if diagnosis site (medical clinic, inpatient setting, counseling and testing center (CTC), and correctional facility) impacted time to linkage to care (difference between date of diagnosis and first CD4/viral load). A total of 1093 patients (80%) linked to care: 86% diagnosed in medical clinics, 75% in inpatient settings, 62% in CTCs, and 44% in correctional facilities. Adjusting for other factors, diagnosis in inpatient settings, CTCs, and correctional facilities resulted in a 33% (adjusted hazard ratio = 0.77; 95% confidence interval: 0.64 to 0.92), 46% (0.56; 0.42-0.72), and 75% (0.25; 0.18-0.35) decrease in the probability of linkage compared with medical clinics, respectively.

Zang, X., et al. (2020). "Prioritizing Additional Data Collection to Reduce Decision Uncertainty in the HIV/AIDS Response in 6 US Cities: A Value of Information Analysis." Value Health 23(12): 1534-1542.

The ambitious goals of the Ending the HIV Epidemic initiative require a targeted, context-specific public health response. Model-based economic evaluation provides useful guidance for decision making while characterizing decision uncertainty. The publication aims to quantify the value of eliminating uncertainty about different parameters in selecting combination implementation strategies to reduce the public health burden of HIV/AIDS in 6 U.S. cities and identify future data collection priorities. The publication used a dynamic compartmental HIV transmission model developed for 6 US cities to evaluate the cost-effectiveness of a range of combination implementation strategies. Using a metamodeling approach with nonparametric and deep learning methods, the authors calculated the expected value of perfect information, representing the maximum value of further research to eliminate decision uncertainty, and the expected value of partial perfect information for key groups of parameters that would be collected in practice. The population expected value of perfect information ranged from $59 683 (Miami) to $54 108 679 (Los Angeles). The rank ordering of expected value of partial perfect information on key groups of parameters were largely consistent across cities and highest for parameters pertaining to HIV risk behaviors, probability of HIV transmission, health service engagement, HIV-related mortality, health utility weights, and healthcare costs. Los Angeles was an exception, where parameters on retention in pre-exposure prophylaxis ranked highest in contributing to decision uncertainty. Funding additional data collection on HIV/AIDS may be warranted in Baltimore, Los Angeles, and New York City. Value of information analysis should be embedded into decision-making processes on funding future research and public health intervention.

Zanoni, B. C. and K. H. Mayer (2014). "The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities." AIDS Patient Care STDS 28(3): 128-135.

Little is known about how adolescents and young adults contribute to the declines in the cascade of care from HIV-1 diagnosis to viral suppression. The publication reviewed published literature from the Unites States reporting primary data for youth (13-29 years of age) at each stage of the HIV cascade of care. Approximately 41% of HIV-infected youth in the United States are aware of their diagnosis, while only 62% of those diagnosed engage medical care within 12 months of diagnosis. Of the youth who initiate antiretroviral therapy, only 54% achieve viral suppression and a further 57% are not retained in care. The publication estimates less than 6% of HIV-infected youth in the United States remain virally suppressed. The authors explore the cascade of care from HIV diagnosis through viral suppression for HIV-infected adolescents and young adults in the United States to highlight areas for improvement in the poor engagement of the infected youth population.

G. Citations

1. Health Resources and Services Administration. (2023). *Ryan White HIV/AIDS program annual client-level data report: 2022*. U.S. Department of Health and Human Services. https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2022.pdf
2. Padilla, M., Carter, B., Gutierrez, M., & Fagan, J. (2022). The Boundary of HIV Care: Barriers and Facilitators to Care Engagement Among People with HIV in the United States. *AIDS patient care and STDs*, *36*(8), 321–331. https://doi.org/10.1089/apc.2022.0062
3. The White House. (2021). *National HIV/AIDS strategy for the United States: Updated to 2025*. https://www.whitehouse.gov/wp-content/uploads/2021/11/National-HIV-AIDS-Strategy.pdf
4. U.S. Department of Health and Human Services. (n.d.). *HIV care continuum.* HIV.gov. https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum
5. Centers for Disease Control and Prevention. (n.d.). *HIV care continuum.* https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf
6. Dombrowski, J. C., Galagan, S. R., Ramchandani, M., Dhanireddy, S., Harrington, R. D., Moore, A., Hara, K., Eastment, M., & Golden, M. R. (2019). HIV Care for Patients With Complex Needs: A Controlled Evaluation of a Walk-In, Incentivized Care Model. *Open forum infectious diseases*, *6*(7), ofz294. https://doi.org/10.1093/ofid/ofz294
7. Bouabida, K., Chaves, B. G., & Anane, E. (2023). Challenges and barriers to HIV care engagement and care cascade: viewpoint. *Frontiers in reproductive health*, *5*, 1201087. https://doi.org/10.3389/frph.2023.1201087
8. Zang, X., Jalal, H., Krebs, E., Pandya, A., Zhou, H., Enns, B., & Nosyk, B. (2020). Prioritizing Additional Data Collection to Reduce Decision Uncertainty in the HIV/AIDS Response in 6 US Cities: A Value of Information Analysis. *Value in health: the journal of the International Society for Pharmacoeconomics and Outcomes Research*, *23*(12), 1534–1542. https://doi.org/10.1016/j.jval.2020.06.013
9. Mgbako, O., Conard, R., Mellins, C. A., Dacus, J. D., & Remien, R. H. (2022). A Systematic Review of Factors Critical for HIV Health Literacy, ART Adherence and Retention in Care in the U.S. for Racial and Ethnic Minorities. *AIDS and behavior*, *26*(11), 3480–3493. https://doi.org/10.1007/s10461-022-03680-y
10. Anderson, A. N., Higgins, C. M., Haardörfer, R., Holstad, M. M., Nguyen, M. L. T., & Waldrop-Valverde, D. (2020). Disparities in Retention in Care Among Adults Living with HIV/AIDS: A Systematic Review. *AIDS and behavior*, *24*(4), 985–997. https://doi.org/10.1007/s10461-019-02679-2
11. Dasgupta, S., Weiser, J., Craw, J., Tie, Y., & Beer, L. (2020). Systematic monitoring of retention in care in U.S.-based HIV care facilities. *AIDS care*, *32*(1), 113–118. https://doi.org/10.1080/09540121.2019.1619660
12. Centers for Disease Control and Prevention. (n.d.). *HIV data & research: Facts and statistics*. Centers for Disease Control and Prevention. https://www.cdc.gov/hiv/data-research/facts-stats/index.html
13. Brawner, B. M., Guthrie, B., Stevens, R., Taylor, L., Eberhart, M., & Schensul, J. J. (2017). Place Still Matters: Racial/Ethnic and Geographic Disparities in HIV Transmission and Disease Burden. *Journal of urban health: bulletin of the New York Academy of Medicine*, *94*(5), 716–729. https://doi.org/10.1007/s11524-017-0198-2
14. The White House. (2021). *National HIV/AIDS Strategy: Update to the 2020-2025.* https://www.whitehouse.gov/wp-content/uploads/2021/11/National-HIV-AIDS-Strategy.pdf
15. Fauci, A. S., Redfield, R. R., Sigounas, G., Weahkee, M. D., & Giroir, B. P. (2019). Ending the HIV epidemic: A plan for the United States. *JAMA, 321*(9), 844–845. https://doi.org/10.1001/jama.2019.1343

16. Health Resources and Services Administration. (2022). *Ending the HIV epidemic: HRSA data report 2022*. https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/hrsa-ehe-data-report-2022.pdf
17. Health Resources and Services Administration. (2022). *Ryan White HIV/AIDS program annual client-level data report 2022*. https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2022.pdf
18. Centers for Disease Control and Prevention. (2023, August 21). *CDC publishes new HIV surveillance reports*. Centers for Disease Control and Prevention. https://www.cdc.gov/nchhstp/director-letters/cdc-publishes-new-hiv-surveillance-reports.html
19. HIV.gov. (n.d.). *HIV/AIDS care continuum*. U.S. Department of Health and Human Services. https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum
20. Centers for Disease Control and Prevention. (n.d.). *HIV care continuum*. https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf
21. Li Z, Purcell DW, Sansom SL, Hayes D, Hall HI. Vital Signs: HIV Transmission Along the Continuum of Care — United States, 2016. MMWR Morb Mortal Wkly Rep 2019;68:267–272. DOI: http://dx.doi.org/10.15585/mmwr.mm6811e1
22. Kaiser Family Foundation. (2024). *What do we know about people with HIV who are not engaged in regular HIV care?* Retrieved from https://www.kff.org/hivaids/issue-brief/what-do-we-know-about-people-with-hiv-who-are-not-engaged-in-regular-hiv-care/
23. Mgbako, O., Conard, R., Mellins, C. A., Dacus, J. D., & Remien, R. H. (2022). A Systematic Review of Factors Critical for HIV Health Literacy, ART Adherence and Retention in Care in the U.S. for Racial and Ethnic Minorities. *AIDS and behavior*, *26*(11), 3480–3493. https://doi.org/10.1007/s10461-022-03680-y
24. Dombrowski, J. C., Simoni, J. M., Katz, D. A., et al. (2015). Barriers to HIV care and treatment among participants in a public health HIV care re-linkage program. *AIDS Patient Care and STDs, 29*(6), 279–287. https://doi.org/10.1089/apc.2014.0286
25. Robertson, M., et al. (2016). Delayed entry into HIV medical care in a nationally representative sample of HIV-infected adults receiving medical care in the USA. *AIDS Care, 28*(3), 325–333. https://doi.org/10.1080/09540121.2015.1091172
26. Remien, R. H., Stirratt, M. J., Nguyen, N., Robbins, R. N., Pala, A. N., & Mellins, C. A. (2019). Mental health and HIV/AIDS: The need for an integrated response. *AIDS, 33*(9), 1411-1420. https://doi.org/10.1097/QAD.0000000000002227
27. Przybyla, S., Ashare, R. L., Cioffi, L., Plotnik, I., Shuter, J., Seng, E. K., & Weinberger, A. H. (2022). Substance Use and Adherence to Antiretroviral Therapy among People Living with HIV in the United States. *Tropical medicine and infectious disease*, *7*(11), 349. https://doi.org/10.3390/tropicalmed7110349
28. Bamford, L. P., Ehrenkranz, P. D., Eberhart, M. G., et al. (2010). Factors associated with delayed entry into primary HIV medical care after HIV diagnosis. *AIDS, 24*(6), 928–930. https://doi.org/10.1097/QAD.0b013e328336b81d
29. Yehia, B. R., Ketner, E., Momplaisir, F., Stephens-Shields, A. J., Dowshen, N., Eberhart, M. G., & Brady, K. A. (2015). Location of HIV diagnosis impacts linkage to medical care. *JAIDS: Journal of Acquired Immune Deficiency Syndromes, 68*(3), 304–309. https://doi.org/10.1097/QAI.0000000000000459
30. Dombrowski, J. C., Simoni, J. M., Katz, D. A., et al. (2015). Barriers to HIV care and treatment among participants in a public health HIV care re-linkage program. *AIDS Patient Care and STDs, 29*(6), 279–287. https://doi.org/10.1089/apc.2014.0286
31. Gillot, M., et al. (2022). Linkage to HIV medical care and social determinants of health among adults with diagnosed HIV infection in 41 states and the District of Columbia, 2017. *Public Health Reports, 137*(5), 888–900. https://doi.org/10.1177/00333549221121537

32. Zanoni, B. C., & Mayer, K. H. (2014). The adolescent and young adult HIV cascade of care in the United States: Exaggerated health disparities. *AIDS Patient Care and STDs, 28*(3), 128–135. https://doi.org/10.1089/apc.2013.0345
33. Paschen-Wolff, M. M., Scheidell, J. D., Ford, H., Zahler, K., & Parsons, J. T. (2020). A systematic review of factors critical for HIV health literacy, ART adherence, and retention. *AIDS and Behavior, 24*(8), 2145-2165. https://doi.org/10.1007/s10461-020-02845-x
34. Eaton, E. F., Westfall, A. O., McCormick, L., Phillips, E., & Chatham, A. (2019). Approaches to promoting linkage to and retention in HIV care in the United States. *Current HIV/AIDS Reports, 16*(1), 25-37. https://doi.org/10.1007/s11904-019-00433-3
35. Mugavero, M. J., Davila, J. A., Nevin, C. R., & Giordano, T. P. (2013). From access to engagement: Measuring retention in outpatient HIV clinical care. *AIDS Patient Care and STDs, 24*(10), 607-613. https://doi.org/10.1089/apc.2010.0086
36. Song, W., & Mulatu, M. S. (2023). Factors associated with rapid linkage to HIV medical care among persons newly diagnosed with HIV infection in the United States, 2019 to 2020. *Sexually Transmitted Diseases, 50*(7), 439–445. https://doi.org/10.1097/OLQ.0000000000001486
37. Batchelder, A. W., Moskowitz, J. T., Jain, J., Cohn, M., Earle, M. A., & Carrico, A. W. (2020). A novel technology-enhanced internalized stigma and shame intervention for HIV-positive persons with substance use disorders. *Cognitive and behavioral practice*, *27*(1), 55–69. https://doi.org/10.1016/j.cbpra.2019.03.001
38. Bauermeister, J. A., Bonett, S., Rosengren, A. L., Choi, S. K., & Watson, D. (2021). Approaches to Promoting Linkage to and Retention in HIV Care in the United States: a Scoping Review. *Current HIV/AIDS reports*, *18*(4), 339–350. https://doi.org/10.1007/s11904-021-00557-y
39. Dawson, L., & Kuo, T. (2019). *Behavioral health and HIV service utilization among people living with HIV in the United States*. *AIDS and Behavior*, *23*(12), 3385-3395. https://doi.org/10.1007/s10461-019-02679-2
40. Health Resources and Services Administration. (n.d.). *Annual Retention in Care*. Ryan White HIV/AIDS Program. https://ryanwhite.hrsa.gov/grants/performance-measure-portfolio/core-measures/annual-retention-in care
41. U.S. Department of Health and Human Services. (2023). *Guidelines for the use of antiretroviral agents in adults and adolescents with HIV*. https://clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/adult-adolescent-arv/guidelines-adult-adolescent-arv.pdf
42. Health Resources and Services Administration. (n.d.). *Viral Load Suppression*. Ryan White HIV/AIDS Program. https://ryanwhite.hrsa.gov/grants/performance-measure-portfolio/core-measures/hiv-viral-load-suppression
43. Health Resources and Services Administration. (2015). PCN 15-02: Clarification on the use of clinical quality measures (CQMs) in the Ryan White HIV/AIDS Program. U.S. Department of Health and Human Services. https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/pcn-15-02-cqm.pdf