Engagement in Medical Care Among People Living with HIV in Rhode Island, 2019–2024

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BACKGROUND

As part of the Paris Declaration on Fast-Track Cities Ending the HIV Epidemic, Rhode Island is committed to achieving the 95-95-95 goal which outlines the following targets: 95% of people living with HIV know their status, 95% of those diagnosed with HIV are receiving treatment, and 95% of HIV cases on treatment have achieved viral suppression.[1] This ambitious goal was set with the intention of ending the HIV epidemic by 2030 and builds off the previously outlined 90-90-90 goal established in 2014 by UNAIDS.[2] HIV treatment significantly improves the overall health outcomes for people living with HIV (PLWH) and generates substantial population-level benefits by disrupting HIV transmission. PLWH who achieve and maintain an undetectable viral load by consistently taking their antiretroviral therapy (ART) cannot transmit HIV to their needle-sharing or sexual partners. Due to this, ensuring individuals diagnosed with HIV are linked to and retained in medical care is instrumental in reducing HIV transmission.

Nationally, among approximately 1.1 million PLWH at the end of 2023, 76% had received HIV treatment, 55% were retained in medical care, and 67% had achieved viral suppression.[3] Rhode Island is currently surpassing these national averages due to its multifaceted approach to engagement and retention in care for PLWH. In Rhode Island, it has previously been estimated that 93% of PLWH know their status, 76% of those that know their status are engaged in care, and 93% of those engaged in care have achieved viral suppression.[4] The high rates of viral suppression among HIV cases engaged with medical care highlight the importance of sustained engagement and suggest that focused efforts on increasing the number of cases linked to care could result in meaningful reductions of HIV transmission in the state.

The Rhode Island Department of Health (RIDOH) conducts three major activities focused on engagement in care: (1) attempting to outreach and link all newly diagnosed cases of HIV in RI to medical care, (2) operating a return-to-care provider referral system that supports HIV medical and non-medical providers in locating and re-engaging cases who have fallen out of care, and (3) using surveillance-based methods to identify PLWH who are potentially not in care. RIDOH also has field staff available to minimize barriers in retention to care, such as scheduling assistance and transportation to appointments for PLWH. Additionally, the work being done by medical providers and AIDS service organizations in RI who conduct case management activities to ensure their patients and clients are engaged in care plays a large role in the high levels of engagement we observe in the state.

The purpose of this paper is to provide a comprehensive snapshot of PLWH who have fallen out of medical care in RI between 2019–2024 and to describe yearly trends in engagement in care of HIV cases.

METHODS

Data were reviewed from the HIV Surveillance database eHARS (Enhanced HIV/AIDS Reporting System) of PLWH and residing in Rhode Island between 2019–2024. Descriptive characteristics including sex at birth, age, race and ethnicity, risk, country of birth, and place of diagnosis were examined. Some demographic categories were collapsed due to RIDOH's small numbers policy which prohibits counts of <5 to be published. Prevalence estimates were generated using surveillance and CD4 data for persons aged ≥13 years old at diagnosis.

PLWH who resided in RI during the specified year were considered to be not in care (NIC) if: (1) they were presumed to be alive when the datasets were updated and exported from eHARS, (2) they have no reported CD4 count or percent, HIV viral load, or HIV-1 genotype test results in eHARS based on a specimen collected during the specified year, and (3) they have no other evidence of receipt of HIV medical care during the specified year. HIV cases who appeared to be out of care for 10 or more years were excluded from this analysis based on the assumption that they moved outside the state or are deceased. It typically takes eight to ten years for HIV to progress to stage three disease (AIDS) and the life expectancy for individuals diagnosed with AIDS who are not on ART is one to three years.[5] Case counts of individuals not in care were further divided into two categories: chronically not in care and newly not in care. Chronically not in care was defined as PLWH who were not in care for two or more consecutive years. Newly not in care was defined as PLWH who were engaged in care in the previous year and had fallen out of care during the specified year. All analyses were performed using SAS (version 9.4).

RESULTS

Between January 2019–December 2024, 1,418 unique PLWH were identified as out of care in RI at some point during the six-year timeframe. The majority of individuals who had fallen out of care were male (76.3%) and most identified as non-Hispanic White (43.3%) followed by Hispanic (27.9%) and non-Hispanic Black (25.5%). Middle-aged PLWH compromised the bulk of those not in care with the 55–64 age group (27.9%) being the most common, followed by the 45–54 (24.5%) and 35–44 age groups (20.1%), respectively. Smaller percentages of young (13–34 years) and elderly (65+ years) PLWH were observed in those who had fallen out of care. The most common risk groups were men who have sex with men (MSM) (45.2%) and heterosexual contact (23.0%). This corresponds with overall risk breakdowns in people diagnosed with HIV in RI where injection drug use (IDU) remains low.[4] More than half of PLWH who were not in care were US-born (59.2%); however, there were a notable number of foreign-born cases not in care as well (27.4%). As expected, many of those not in care were PLWH who had been diagnosed in RI (53.3%), followed by those who had been diagnosed in another US state (28.2%). [**Table 1**]

When excluding cases who have no evidence of residing in RI for 10 or more years, the percent of PLWH who engaged in medical care has been stable between 2019–2024 at approximately 81% or greater, except in 2021 when we saw a decline to 77% engaged in care. The number of PLWH who were chronically not in care has continued to rise over this 6-year timeframe. In addition, out of all PLWH in RI, the percent who fell out of care each year has remained low at 7% between 2019–2024, except in 2020 and 2021 where we saw an increase. This provides evidence that RI has achieved consistently high levels of engagement in care and successfully retains approximately 93% of HIV cases in care every year, with the pandemic years being the exception. **[Figure 1]**

Those not in care were further categorized into chronically not in care and newly not in care to better understand

Table 1. Sociodemographic Characteristics Among PLWH Identified as Not in Care in RI, 2019–2024

Characteristic	Not in Care N=1,418
Sex at Birth	
Male	1,082 (76.3%)
Female	334 (23.6%)
Race/Ethnicity	
Not Hispanic, White	614 (43.3%)
Not Hispanic, Black/African American	362 (25.5%)
Hispanic, any race	396 (27.9%)
Not Hispanic, Other	26 (1.8%)
Age Groups	
13–24	27 (2.0%)
25–34	192 (13.5%)
35–44	285 (20.1%)
45–54	347 (24.5%)
55–64	396 (27.9%)
65+	166 (11.7%)
Risk Factors	
MSM	641 (45.2%)
IDU	178 (12.6%)
MSM & IDU	80 (5.6%)
Heterosexual/Presumed Heterosexual	326 (23.0%)
Perinatal	14 (1.0%)
Country of Birth	
US	840 (59.2%)
Foreign-born	389 (27.4%)
Place of Diagnosis	
RI	756 (53.3%)
Other US State	400 (28.2%)
Other Country	83 (5.9%)

Figure 1. Percent of PLWH in Rhode Island Engaged in Medical Care, 2019–2024

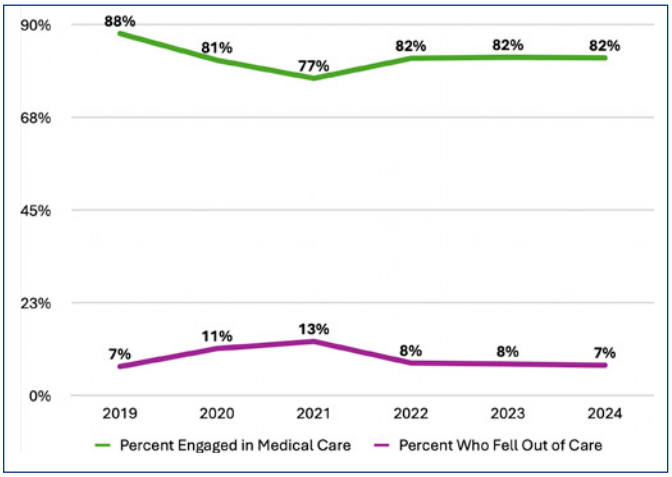
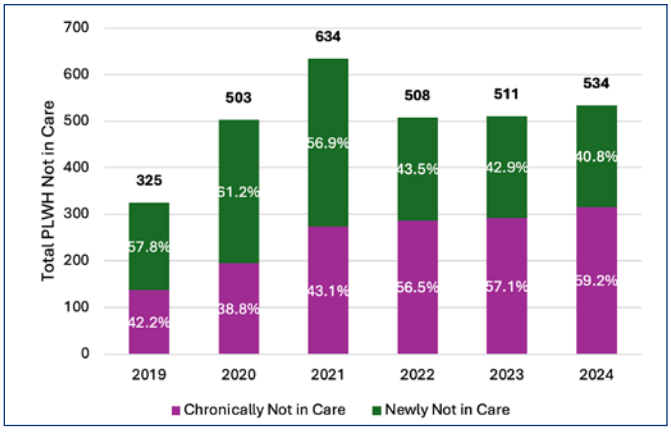


Figure 2. PLWH Not in Care in Rhode Island, 2019–2024



if previous engagement in care estimates in RI were being impacted by individuals repeatedly not in care year after year. In 2019, 42.2% of not in care cases were chronically not in care compared to 59.2% in 2024. Further analysis is required to determine if this is due to cases who we couldn't verify moved out of RI, inflating the chronically not in care counts or if PLWH who fall out of care aren't being successfully re-engaged. [**Figure 2**]

DISCUSSION

Two major activities in RI that can contribute to the engagement in care estimates include locating and re-engaging individuals referred in our return-to-care (RTC) program and investigating cases identified as not in care (NIC) through our surveillance-based methods to verify if they have moved out of state or are deceased. In 2020, our RTC program and NIC investigations were put on pause due staffing capacity during the COVID-19 pandemic. We resumed our RTC program in July 2022; however, NIC investigations have remained paused through 2024. The slight decline in engagement in care in 2021 may be explained by additional barriers to care introduced during the COVID-19 pandemic and the pause of both RIDOH's RTC program and NIC investigations. Given that 2019 had the highest percent of cases engaged in care and smallest count of individuals chronically not in care, it is possible that NIC investigations generated a more accurate number of those truly not in care in RI.

Previous engagement in care estimates for RI were measured with no exclusion of individuals who have been out of care for extended amounts of time, often including PLWH who have been out of care for up to 35 years. Thus, previous engagement in care estimates for RI have been underestimating the level of engagement in care of PLWH in the state. There are many limitations with assessing individuals not in care based on receipt of laboratory documents as a proxy for care. State health departments conduct routine interstate duplicate review twice a year to identify PLWH who have moved outside their jurisdiction, ensuring prevalence estimates are accurate. However, individuals who have moved out of the country will continue to be identified as not in care because there is no way to verify that they are no longer in the US. Additionally, PLWH who move out of state while they are undetectable and remain undetectable may not be identified in other state health department's surveillance databases as a case, making it appear that the individual is out of care in RI. Lastly, individuals who have attended medical appointments but did not get lab work done will also appear as not in care when they have engaged with their medical provider. Therefore, even with the exclusion criteria applied to engagement in care estimates presented in this paper, it is highly probable that engagement in care among PLWH in RI is even higher.

Recently, both Massachusetts and Connecticut have described trends in engagement in care in their jurisdictions, reporting differences by age, race/ethnicity, and risk.[6-8] Further analysis and statistical modeling are required to come to any conclusions about factors associated with engagement in care in RI. This analysis was conducted to broaden our understanding of populations successfully engaged in care in RI and importantly, populations not engaged in care. The results of this paper will be used to improve RIDOH's activities designed to engage or re-engage people in care. Additional analysis will be performed to understand the impact of the RTC program on engagement in care in subsequent publications.

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