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COHORT PROFILE

Cohort profile update: the Johns Hopkins HIV clinical cohort, 1989–2023

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Abstract
The Johns Hopkins HIV Clinical Cohort, established in 1989, links comprehensive, longitudinal clinical data for adults with HIV receiving care in the Johns Hopkins John G. Bartlett Specialty Practice in Baltimore, Maryland, USA, to aid in understanding HIV care and treatment outcomes. Data include demographics, laboratory results, inpatient and outpatient visit information and clinical diagnoses, and prescribed and dispensed medications abstracted from medical records. A subset of patients separately consents to self-report patient-centric outcomes on standardized instruments approximately every 6 months, and another subset separately consents to contribute plasma and peripheral blood mononuclear cells to a linked specimen repository approximately annually. The cohort has cumulatively enrolled over 8000 people, with just under 2000 on average attending ≥ 1 HIV primary care visit in any given year. The cohort reflects the HIV epidemic in Baltimore: in 2021, median age was 57, 64% of participants were male, 77% were non-Hispanic Black, and 37% acquired HIV through injection drug use. This update to the cohort profile of the Johns Hopkins HIV Clinical Cohort illustrates both how the population of people with HIV in Baltimore, Maryland, USA has changed over three decades, and we have adapted data collection procedures over three decades to ensure this long-running cohort remains responsive to patient characteristics and research gaps in the provision of care to people with HIV and substance use.

Keywords Clinical cohort · HIV · Retention in care · Substance use

Study setting

The Johns Hopkins John G. Bartlett Specialty Practice provides comprehensive clinical care for patients with human immunodeficiency virus (HIV) and other infectious diseases. The practice serves a population that principally resides in Baltimore City, a geographic focus region for the federal ending the HIV Epidemic initiative in the United States [1, 2]. The clinic demographics match the demographics of people with HIV (PWH) in Baltimore, Maryland which differ from the demographics of PWH in other regions of the United States [3, 4]. The clinical practice opened in 1984 and has evolved over the past nearly four decades to meet the changing needs of the clinic population including: providing on-site pharmacy services with clinical pharmacists trained in HIV care, laboratory, case management, social work, and patient navigation services; providing high-volume specialty care such as gynecologic and psychiatric services; supporting on-site nephrology, gastrointestinal, and geriatric services; incorporating hepatitis C virus testing and treatment with direct acting antiretrovirals; and providing comprehensive substance use disorder treatment, including buprenorphine and peer-delivered Recovery Support Services. The substance use treatment program, established in 2008, provides low-threshold care guided by key principles of same-day substance use disorder treatment initiation (including buprenorphine/naloxone for patients with opioid use disorder), coupled with substance use counseling and mental health services, a harm reduction approach, flexibility, and easy availability of treatment [5]. This integrated model was one of the first to offer office-based treatment for opioid use disorder in an urban HIV clinic setting instead of out-of-clinic referral for such a treatment. Moreover, the practice provides care for patients regardless of insurance status. Clinic-based social workers facilitate appropriate referral

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to public resources and financial assistance programs for necessary clinical services, such that the barriers to necessary clinical care are attenuated, despite a high prevalence of socioeconomic barriers in the patient population.

Data collection

The Johns Hopkins HIV Clinical Cohort (JHHCC) was established in 1989 to aid in understanding and quantifying care and treatment outcomes for people with HIV engaged in HIV clinical care [6]. Since its inception, the cohort has been principally supported by the National Institutes of Health, with additional support from the state of Maryland, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Food and Drug Administration and some commercial entities. As our clinic has adapted its service-delivery model over time to meet the changing clinical needs of our patients, our cohort has adapted our data collection procedures to meet the changing research needs of the field.

At its core, the JHHCC links comprehensive and longitudinal clinical data for PWH receiving care in the Johns Hopkins John G. Bartlett Specialty Practice who provided written informed consent to share their data. In contrast to the interval cohorts of PWH that had been established–namely the Multicenter AIDS Cohort [7] and the AIDS Linked to the IntraVenous Experience [8] studies–the JHHCC is a clinical cohort [9]. Instead of requiring participants to attend specific study visits for data collection, we leverage data generated as part of routine clinical care. This allows for detailed description and evaluation of real-world practice patterns and outcomes beyond a distinct set of regimented observations and outcomes. For example, we have been able to report on frequency of missed clinic visits, time-updated viral load measurements, hepatitis C virus micro-elimination, and use of telemedicine during the COVID-19 pandemic [10–13]. In contrast to many other clinical cohorts, we have supplemented medical health records data with medical record review and adjudication of key clinical outcomes, self-reported patient-centric outcomes, and a specimen repository.

Historically, clinical data were abstracted from paper-based medical records. However, the number and variety of data elements included in our data has expanded dramatically with the advent of electronic medical records, electronic transfers of medical data, and health information exchanges. Demographics, laboratory results, inpatient and outpatient visit information and clinical diagnoses, and prescribed and dispensed medications are abstracted and extracted from medical records across the Johns Hopkins Health System (JHHS). Demographic information is reported by patients at clinical encounters in the JHHS and recorded in the medical record. Laboratory results include all those tests that are performed at JHHS laboratories and the two largest commercial laboratories in the region: Quest Diagnostics and LabCorp. A key set of diagnoses were abstracted from the medical records in the early years of the cohort. Abstraction occurred every 6 months according to standardized protocols and into structured databases. Because data were abstracted, we were able to capture diagnoses that were not tied to billing codes. Around 2011, we began extracting diagnostic information based on the International Classification of Diseases, Ninth Revision (ICD-9) codes, from clinical billing files: usually there was only a single diagnosis code associated with a visit (AIDS). With the introduction of our electronic health record system in 2013–2014, diagnosis codes became more granular due to their requirement to support orders for laboratory or imaging tests, medications, or clinical encounters. (Although the electronic health record was instituted in 2013–2014, different clinics throughout the JHHS adopted it at different times and so the availability of diagnoses increased over a period of many months.) Starting 2015, ICD-10 codes were used to record diagnoses. Information on inpatient care, including the hospital admission and discharge dates, and all recorded inpatient diagnoses, are extracted from the electronic health record. Since 2014, all scheduled visits in the JHHS–including HIV clinic visits, mental health and substance use treatment visits, and other specialty visits–are extracted from the electronic health record, along with the appointment status (attended, missed, cancelled, or rescheduled). Finally, we collect information on medications prescribed by Johns Hopkins clinicians as part of patient care and medications that patients self-report to their clinicians and that have been added to patients' medication list. Upon enrollment into the cohort, patients' full history of antiretroviral therapy (ART) is also abstracted from clinical notes into the medication file. Prescription data are complemented by medication dispensing data from the JHHS pharmacy and other commercial laboratories across the region. Deaths are ascertained for all patients regardless of their continued engagement in clinical care from clinic sources (including reviews of data in the Maryland Health Information Exchange available through Care Everywhere [14] and reports from next-of-kin) and regular links with the Social Security Death Index and National Death Index.

Since 2001, patients have been invited to participate in a survey using standardized survey instruments in domains including mental health symptoms (depression, anxiety, post-traumatic stress disorder), substance use (alcohol, tobacco, cannabis, and other substances), sexual transmission risk behaviors, medication adherence, quality of life, patient-provider trust and HIV stigma. Consent to participate in this survey is separate from consent to share medical records. The survey is self-administered on a dedicated desktop or tablet in English (there is a Spanish version, but we have not had sufficient demand to implement it previously). Study staff provide instructions on how to complete the survey and can assist the participant in survey completion, if needed. Surveys are administered approximately every six months in conjunction with a clinical visit. In 2013, the survey questions underwent significant revisions to harmonize core data elements with other patient reported outcome (PRO)

surveys from other clinical cohorts participating in the Center for AIDS Research (CFAR) Network of Integrated Clinical Systems (CNICS) [15, 16]. However, there is capacity to include or retain site-specific questions at the sole discretion of the JHHCC. For example, in December 2023, we expanded questions on illicit drug use in response to the local drug market, adding specific questions about use of xylazine ("Tranq") [17] and use of fentanyl test strips, and we added questions on Social Determinants of Health. An abbreviated list of key JHHCC PRO data elements appears in Appendix 1. From 2007 to September 2023, we had collected 22,663 PRO surveys from 2,831 unique patients; this represents 64% of patients in the cohort with ≥ 1 attended HIV clinic visit during the same time. Median number of surveys per patient was 6 (IQR: 2, 12). Median months between consecutive PRO surveys was 7.4 (IQR: 5.7, 12.7).

Since its inception, a unique feature of the JHHCC, in contrast to many other clinical cohorts of PWH, is the high prevalence of substance use among our participants. To capture this important risk factor for poor HIV care outcomes, trained medical record abstractors review the medical record including clinic notes, problem lists, and laboratory-based toxicology reports for all contiguous 6-month periods that patients are in care and indicate any tobacco, alcohol, cocaine, and heroin use. We triangulated data from the medical record abstraction and self-report and estimated the medical record abstraction has sensitivity/specificity of around 75%/90% for tobacco, 42%/86% for any alcohol use, 29%/93% for hazardous alcohol use, 67%/98% for cocaine, and 66%/99% for heroin use [18]. Although still low, the sensitivity for identifying cocaine and heroin use with medical record abstraction is higher than the sensitivity based on self-report.

Since June 2001, we have also managed a linked specimen repository for a subset of our cohort. Patients who provide separate consent to participate in the repository contribute plasma and peripheral blood mononuclear cells (PBMCs) samples to the repository approximately annually. As of September 2023, there were 25,433 unique specimens drawn on 10,260 unique visits from 2233 unique patients; this represents 40% of patients in the cohort with ≥ 1 attended HIV clinic visit from 2001 to 2023. The median number of specimens per patient was 8 (IQR: 3, 16). Over 2000 specimens have been used to support a broad range of studies supporting cure research, development of new HIV assays, cardiovascular and other comorbidity research, and research in a number of domains. Table 2 (Appendix 1) shows patient demographics for patients who have consented to participate in the self-interview, specimen repository, both, or neither (only consented to share their medical records). While all patients who are prospectively enrolled are invited to participate in all three studies, because the self-interviews and specimen repository started later (and thus patients who had already enrolled in the parent cohort had to be re-approached for participation in the sub-studies), and because of patient preference for participation, there are minor differences in the demographics of patients in each sample.

Since 2007, we have participated in clinical validation of selected clinical outcomes: cancer, end-stage renal disease, end-stage liver disease, myocardial infarction, stroke, atrial fibrillation and venous thromboembolism. This was done retrospectively and is updated prospectively every few years. Presumptive instances of each of these outcomes are identified and a panel of trained clinicians reviews details of the patients' medical records to classify presumptive cases as confirmed or to rule them out. Confirmed myocardial infarctions are further classified into type I (attributable to an acute atherothrombotic coronary event) or type II (secondary to myocardial oxygen supply and demand imbalance in the setting of acute illness, such as sepsis or acute substance intoxication) [19–21].

Finally, in 2023–2024, we geocoded participant addresses going back to 2014 to the census block group level and are in the process of merging data into our cohort on area-level indicators of social determinants of health, including exposure to violence and levels of economic investment. A map of the distribution of our patients' most recent addresses appears in Fig. 1.

Methods for cohort summary

Below, we describe the demographics and select clinical features of the cohort over time. We summarize the characteristics of the cohort for four years (at seven-year intervals) from 2001 to 2022 (the last full year for which data were available; data are updated quarterly and usually available 3–5 months after the end of each quarter). We report on the number engaged in care in each year, which we defined as having attended ≥ 1 HIV clinic visit in the calendar year. We also report on losses to follow-up two different ways: in Fig. 2, we defined loss to clinic as 18 months from the last attended HIV clinic visit for each patient; in Table 1 we defined loss to clinic as having no attended HIV clinic visits in a calendar year after attending ≥ 1 visit in the prior year. Interpreting "loss to clinic" in this cohort is challenging, as it might indicate patients have transferred care elsewhere, dropped out of HIV care, or (increasingly, with improvements in ART and longer duration of HIV infection) be in good enough health that their clinician has reduced their scheduled visit frequency [11, 22]. This is a clinical cohort that does not have dedicated resources for encouraging retention; patients are free to transfer their HIV care to another clinic for any reason. Whether patients transfer care elsewhere or drop out of HIV care entirely, they are always welcome to reengage in care in the Bartlett Clinic and re-enter the cohort. In Table 1, some patients classified as lost to care in one year may be included as engaged in care in a subsequent year. In Fig. 2, patients' follow-up lines are not interrupted during periods where they are temporarily out of care or in care at another clinic. A full treatment of the issues with measuring retention or engagement in HIV care is beyond the scope of this

cohort profile [11, 22–24]. The definition of loss to follow-up that should be applied to the cohort to generate an analytic data set depends on the research question [25].

We report on key HIV clinical outcomes that are part of the HIV care continuum and targets of the National HIV/AIDS Strategy [26]. Specifically, we report on the proportion of people retained in care, defined as attending ≥ 2 clinic visits > 90 days apart, excluding people from the denominator who were newly enrolled in care or who died prior to the end of the calendar year in question. ART use was defined as having an active prescription for ≥ 3 antiretrovirals or an approved 2-drug regimen for ≥ 1 day during the calendar year. Viral suppression was defined as having the last viral load in the calendar year ≤ 400 copies/mL, excluding people from the denominator who did not have a viral load test in the year. Because patients with inconsistent ART adherence may gain and lose viral suppression over the course of a year, we also report on durable viral suppression defined as having all viral load measurements during the calendar year ≤ 400 copies/mL [12].

Finally, we report on indicators of mental health symptoms and substance use, and mental health and substance use disorders. From the diagnosis file, we included the following ICD-9 and ICD-10 codes for: depression (296.2-296.3, F32.0-F32.3, F32.9, F33.0-F33.3, F33.8, F33.9); anxiety (300.00, 300.02, F41.1, F41.9), alcohol use disorder (303, 305.0, F10.1-F10.2, V11.3), cocaine use disorder (304.2, 305.6, F14.1-F14.2), and opioid use disorder (304.0, 304.7, 305.5, F11.1-F11.2). From the self-interviews, we defined moderate-to-severe depressive symptoms based on a score ≥ 10 on the patient health questionnaire-8 (PHQ-8), which has sensitivity of 88% and specificity of 88% for major depressive disorder [27, 28]. We defined anxiety based on a score ≥ 10 on the generalized anxiety disorder (GAD-7), which has sensitivity of 89% and specificity of 82% for generalized anxiety disorder [29]. We defined unhealthy alcohol use based on a score on the Alcohol Use Disorders Identification Test-Consumption questions (AUDIT-C) ≥ 3 for women and ≥ 4 for men (based on sex at birth), which has sensitivity of 73–91% and specificity of 70–91% for heavy drinking [30, 31]. Recent cocaine and non-prescribed opioid use were defined as endorsing using the drug in the past 3 months in any form or route (e.g., non-prescribed opioid use included taking prescription opioids not prescribed to the individual or not as prescribed, heroin, and fentanyl) on the alcohol, smoking, and substance involvement screening test (ASSIST) [32, 33]. The medical record review is specific to heroin as opposed to any non-prescription opioid, but it is likely that information in the medical record is not similarly specific (e.g., a clinical note might generically state that the patient is using "opioids" and the medical record review would pick that up, but if the note specifically identifies a patient is using fentanyl, the medical record review should not pick that up). We are in the process of adding a new flag for other opioids to the medical record review form.

Figure 1 was created with the ggplot2 package in the tidyverse in R [34, 35]. SAS version 9.4 (Cary, NC) was used to generate all other tables and figures.

Cohort demographics and engagement in care over time

Characteristics of the JHHCC for 2001, 2008, 2015, and 2022 appear in Table 1. Characteristics of the JHHCC for all years from 1998 to 2022 are given in Table 3 (Appendix 1). The size of the cohort in any given year, defined as the number attending ≥ 1 HIV primary care visit, is typically just under 2000 patients. The largest number of active patients was 2159 in 2017. While the number of new patients enrolled into the cohort over time appears to have declined, this is mainly a result of a larger trend of declining rates of new HIV infections in Baltimore, the United States, and globally [3, 36], which means fewer people enrolling into the clinic with new infections. There were 1874 active patients in 2022, representing 19% of the number of PWH reported to be living in Baltimore City in 2021 (although 45% of our patients in 2022 resided outside the city; Fig. 1). The majority of PWH in our cohort were ≥ 50 years (median age was 57, IQR: 47, 64), male (64%, relative to 67% of PWH in Baltimore City), and non-Hispanic Black (77%, relative to 83% of PWH in Baltimore City) [3]. The median age increased from 41 years in 2001, consistent with the shifting demographics of PWH nationally [37]. The proportion of the cohort that is male decreased slightly from 68% in 2001, while the proportion of the cohort that is Black increased slightly from 74%. The proportion who acquired HIV through prior injection drug use decreased from 37% in 2001 to 22% in 2022.

Figure 2 shows enrollment and engagement in the cohort over time, January 1998-September 2023, where green dots show deaths and blue dots show "loss to clinic"–defined as the first gap in HIV primary care visits lasting ≥ 18 months (a more lenient definition of loss to clinic than we used in Table 1 to account for the "churn" in and out of engagement in care that is a feature of the HIV care continuum [23]). Every year, on average 9% of patients do not attend an HIV clinic visit (Table 1). However, over half of the time, patients have some sort of additional engagement during this gap or follow-up after this gap: 17% of patients had a viral load measurement in the year in which they did not attend a clinical visit, 66% of which were ≤ 400 copies/mL; 45% of the time, patients returned for a follow-up clinic visit after having a gap of ≥ 12 months in clinic visits; and 48% of the time, patients had a follow-up viral load measurement after having a gap of ≥ 12 months in clinic visits, 51% of which were ≤ 400 copies/mL.

Reflective of changing ART treatment recommendations and patterns of care seeking following the COVID-19 pandemic, the proportion of people prescribed ART increased from 69% in 2001 to 99% in 2022, while the proportion of people retained in care–defined as attending ≥ 2 HIV primary care visits ≥ 90

Table 1 Characteristics (number (%) unless otherwise specified) of patients in care in the Johns Hopkins HIV Clinical Cohort for select years

	2001	2008	2015	2022
Engaged in care[a]	1441	1687	1789	1874
Newly enrolled	392	263	121	40
Lost to care[b,c]	119 (11)	165 (11)	159 (9)	186 (10)
Deaths[d]	59	35	22	27
Patient demographics				
Male sex	985 (68)	1114 (66)	1148 (64)	1199 (64)
Age, years–median (IQR)	41 (35, 46)	46 (40, 52)	52 (44, 58)	57 (47, 64)
Black race	1060 (74)	1239 (73)	1358 (76)	1444 (77)
HIV acquisition risk group				
Injection drug use	540 (37)	515 (31)	445 (25)	406 (22)
Men who have sex with men	414 (29)	480 (28)	515 (29)	640 (34)
Heterosexual contact	719 (50)	918 (54)	1004 (56)	978 (52)
Years since enrollment – median (IQR)	1.9 (0.9, 3.5)	5.7 (1.7, 8.7)	8.5 (4.6, 14.3)	11.7 (6.5, 19.2)
HIV clinical outcomes				
Retained in care[e,c]	814 (81)	1172 (84)	1368 (83)	1352 (75)
Prescribed ART[f]	999 (69)	1468 (87)	1720 (96)	1859 (99)
Virally suppressed[g,c]	615 (45)	1235 (74)	1406 (89)	1031 (90)
Durable viral load suppression[h,c]	378 (28)	937 (56)	1230 (78)	948 (83)
Clinical diagnoses within past 2 years				
Depression	251 (17)	287 (17)	713 (40)	435 (23)
Anxiety	34 (2)	30 (2)	250 (14)	190 (10)
Alcohol use disorder	130 (9)	135 (8)	254 (14)	128 (7)
Cocaine use disorder	177 (12)	176 (10)	194 (11)	111 (6)
Opioid use disorder	207 (14)	195 (12)	265 (15)	208 (11)
Self-reported outcomes, N (%)[i,c]				
PHQ-8 ≥ 10		21 (2)	155 (13)	171 (17)
GAD-7 ≥ 10			93 (8)	113 (11)
AUDIT-C ≥ 3 for women, ≥ 4 for men		170 (20)	240 (21)	228 (22)
Recent cocaine use		38 (4)	77 (7)	143 (14)
Recent non-prescribed opioid use		62 (7)	159 (14)	105 (11)
Medical record review, recent				
Hazardous alcohol use	235 (17)	222 (13)	247 (14)	161 (11)
Cocaine use	322 (23)	262 (16)	181 (10)	115 (8)
Heroin use	311 (23)	179 (11)	124 (7)	73 (5)

[a]Defined as attending ≥ 1 HIV primary care visit in the calendar year

[b]Defined as not attending any HIV primary care visits in the calendar year after attending ≥ 1 HIV primary care visit in the prior year; denominator for proportion is number attending ≥ 1 HIV primary care visit in the prior year

[c]Not a proportion of those Engaged in care (first row of Table 1)

[d]Not restricted to patients who were engaged in care

[e]Attended ≥ 2 clinic visits ≥ 90 days apart; denominator excludes people newly enrolled in care in the calendar year and people who die prior to the end of the calendar year

[f]ART defined as being on a 3-drug regimen or an approved 2-drug regimen

[g]Last HIV viral load in the calendar year ≤ 400 copies/mL (based on limit of detection for HIV RNA quantification tests at the start of the study period); proportion excludes patients who are missing an HIV viral load value

[h]All HIV viral load measurements in the calendar year ≤ 400 copies/mL; proportion excludes patients who are missing an HIV viral load value

[i]On any PRO in calendar year or year prior; proportion calculated out of people with ≥ 1 PRO in calendar year or year prior

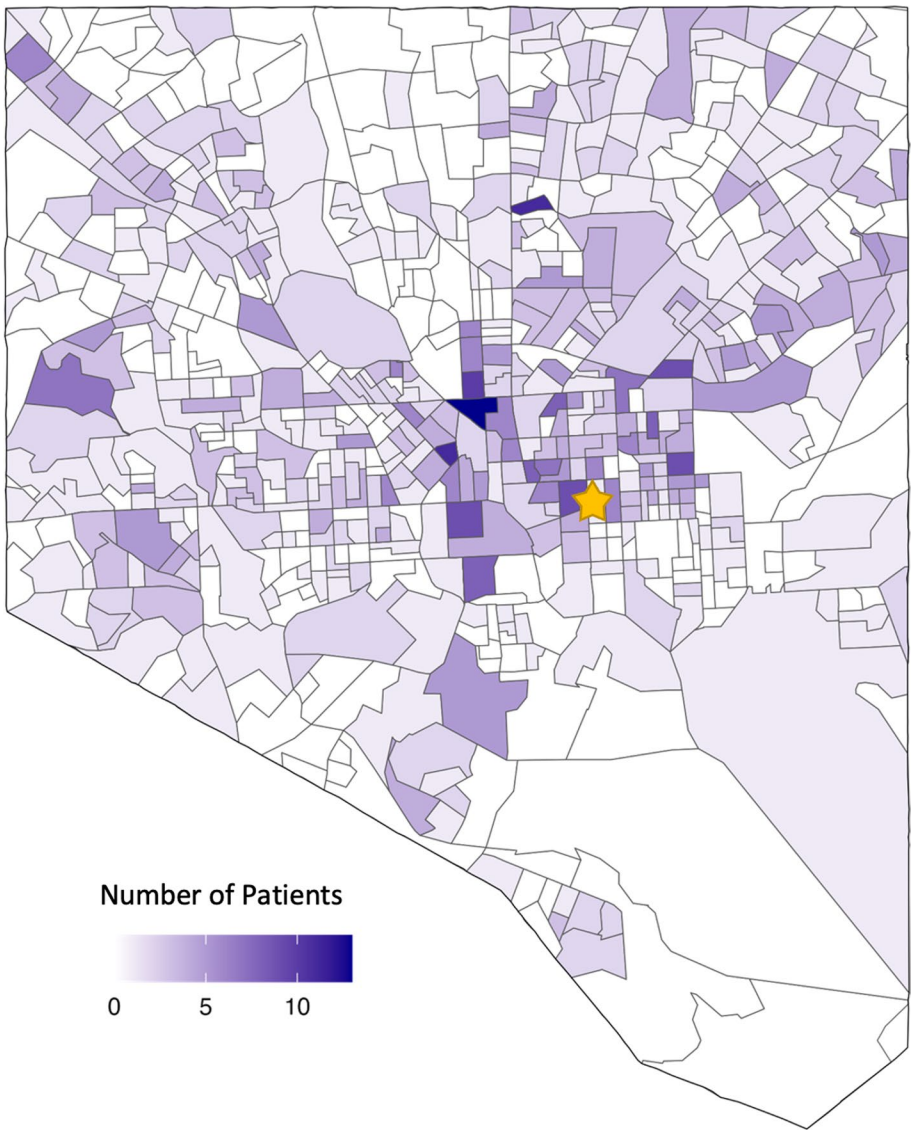

Fig. 1 Location of the John G. Bartlett Specialty Practice and geospatial distribution of the residential addresses of Johns Hopkins HIV Clinical Cohort patients living in Baltimore City, 2022[a]. [a]Last known address of 1,030 patients who attended at least one HIV primary care visit in 2022, geocoded to 2010 U.S. Census block groups in Baltimore City. An additional 842 patients (45%) lived outside of Baltimore City, including 268 (14%) in Baltimore County, 277 (15%) in another county in Maryland, and 54 (3%) in another U.S. state or Washington, DC; address data could not be geocoded for 245 patients (13%)

days apart [38]–decreased from 81 to 84% in 2001–2015 to 75% in 2022. Figure 3 shows the number of patients enrolled in the cohort who were prescribed "highly active" ART over time from 1998 to September 2023 as a series of stacked curves with separate curves for antiretroviral regimen class. Major shifts to integrase inhibitors are visible starting around 2016. The proportion of people with viral suppression increased from 45% in 2001 to 90% in 2022 (Table 1) [12].

Substance use and mental health

Systemic racism has fostered high levels of racial residential segregation, concentrated poverty, and syndemic conditions of HIV, substance use, and mental health disorders in Baltimore, Maryland [39–41]. Substance use and mental health symptoms are associated with poor clinical outcomes among people living with HIV [42–44]. Table 1 includes the prevalence of depression, anxiety, and substance use over time, based on clinical diagnoses and based on PROs in each year: PHQ-8 (depression) score ≥ 10; GAD-7 score ≥ 10; AUDIT-C ≥ 3 for women or ≥ 4 for men; and any cocaine or non-prescribed opioid use in the 3 months before the self-interview. The prevalence of depression and anxiety have increased over time. These increases may be attributable to multiple factors in addition to, or aside from, a true increase in the prevalence of mental health disorders, mainly related to improved data capture and increased recognition of these disorders. There are increases in 2011 when we started extracting diagnoses from the clinical billing files, and through 2013–2014 during the transition to our electronic health record system. Additionally, the introduction of ICD-10 codes in 2016 may have provided more opportunity for the capture of depressive episodes, although this transition in coding systems likely had minimal impact [45]. Over time, the clinic has continued to adapt their clinical focus to identify and treat the spectrum

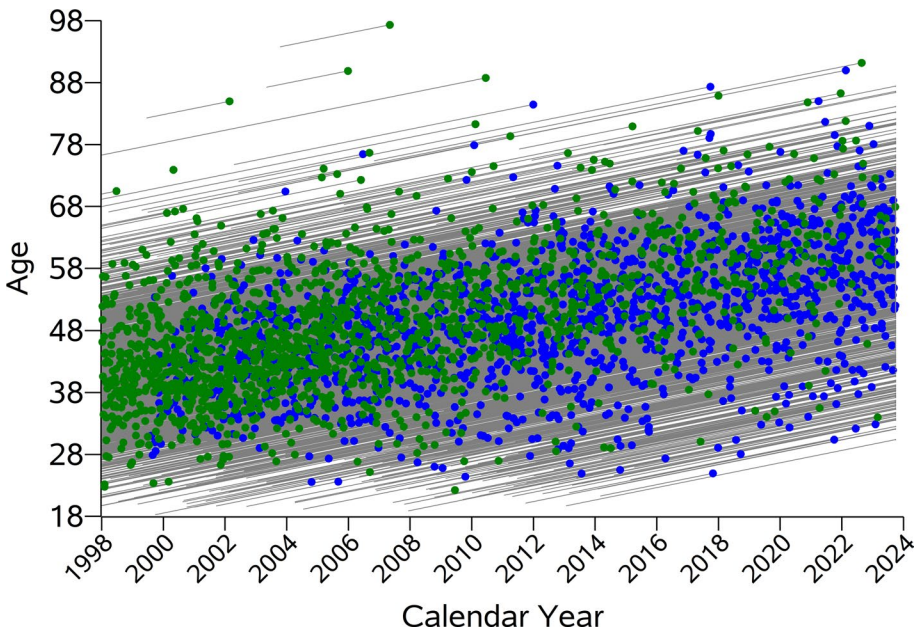

Fig. 2 Engagement in the Johns Hopkins HIV Clinical Cohort over time, by age and calendar year, 1998–2024. Gray lines represent time spent in care in the HIV clinic from first visit until death (green dots) or loss to follow-up (18 months from the last attended clinic visit; blue dots)

of comorbid conditions that predominate in our patient population including, and especially, mental health and substance use disorders; this especially accelerated with increased funding for our co-located psychiatry service in 2015 which expanded capacity to evaluate, diagnose, and treat patients.

Prevalence of unhealthy alcohol use has remained steady at just over 20% of patients, while prevalence of cocaine and opioid use declined in the medical record but increased based on self-report. As noted above, the medical record review was designed to capture heroin use while the self-report includes any non-prescribed opioid use, and has thus been more responsive to the evolution of the opioid epidemic with shifts to synthetic opioids [46]. Even historically, however, there is not good overlap in patients identified as having recent substance use by the medical record review and the self-report [18]–this could be because patients may be more or less likely to disclose substance use on a tablet-based survey versus in a face-to-face conversation with their physician [47–49]. Finally, there are likely temporal trends in the degree to which and what types of substance use are prioritized when providing HIV clinical care.

There are varying degrees of concordance between prevalence of past-2-year diagnoses of depression, anxiety, and substance use disorders and the prevalence of past-2-week depressive or anxiety symptoms and past-3-month substance use.

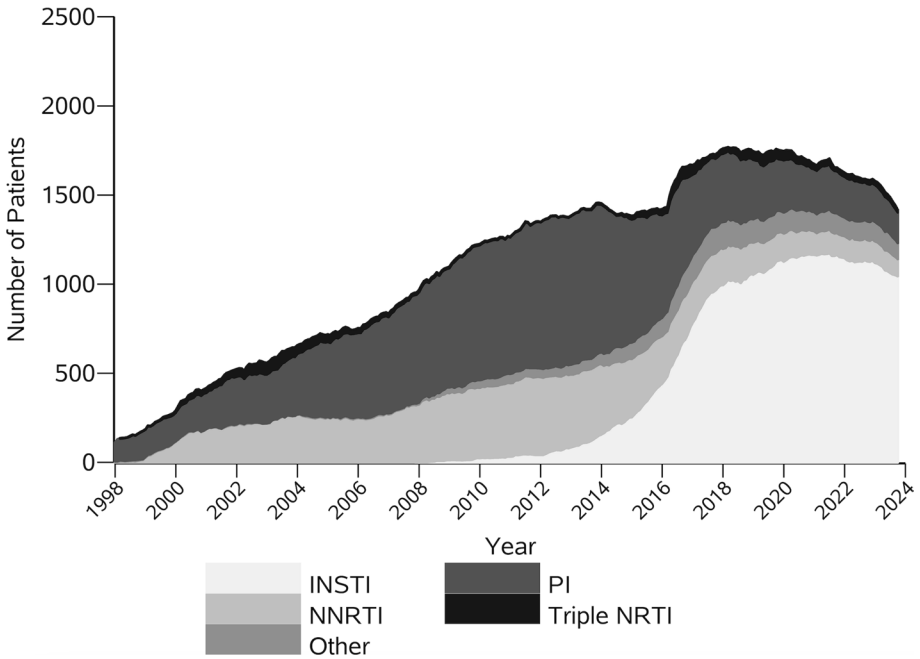

Fig. 3 Stacked number of patients on ART by regimen class, Johns Hopkins HIV Clinical Cohort, January 1998-September 2023.* Abbreviations: INSTI, integrase strand transfer inhibitor; NNRTI, non-nucleoside reverse transcriptase inhibitor; NRTI, nucleoside reverse transcriptase inhibitor; PI, protease inhibitor

While we might expect some correlation because, for example, we would hope that a depressive episode that results in a positive screen on the PHQ-8 would be diagnosed, there are other reasons that these variables would not correlate including: different look-back periods; they measure different constructs (e.g., depressive symptoms is not a perfect proxy for a clinical illness and a clinical diagnosis of depression may be made to support ongoing, successful depression treatment in a patient without depressive symptoms); there are different sources of measurement error influencing the different variables (e.g., a patient with bipolar disorder may screen positive on the PHQ-8 while having a depressive episode, but should not receive a diagnosis of depression).

Collaboration and data sharing

A goal of the JHHCC is to encourage collaboration. The JHHCC has contributed data to multiple cohort collaborations over its tenure [15, 50–52]. We also collaborate with internal and external researchers on projects that use only JHHCC data. To conduct a study with JHHCC data, we request that collaborators complete a Research Design Concept Sheet that includes a short background narrative to contextualize the proposed project; specific aims; definition of the study population with inclusion and exclusion criteria; requested covariates; and analytic plan. JHHCC team members are available to assist with the completion of the Concept Sheet. Outside investigators are required to complete a Data Use Agreement to receive data for approved Concept Sheets. To date, over 600 publications have been produced using data from the JHHCC, involving over 280 investigators, the majority of whom have been early-stage investigators.

Conclusions

The JHHCC is a unique resource for understanding and quantifying care patterns and treatment outcomes for PWH engaged in routine clinical care over the past three decades. It is unique in the breadth and depth of data elements available, and in the demographics of our patient population. Finally, it is distinct in the high prevalence of substance use and mental health symptoms and disorders that represent a high-priority area of intervention for improving outcomes for PWH.

Appendix 1: Abbreviated list of key JHHCC PRO data elements

Domain
ART adherence
Substance use, including tobacco/cigarette use history (Modified ASSIST)
Alcohol use (US-AUDIT, AUDIT-C, MINI)
Receipt of drug or alcohol treatment (including type)
Depressive symptoms (PHQ-8)
Panic symptoms (PHQ-PD)
Anxiety symptoms (GAD-7)
HIV Stigma
Sexual risk behaviors (PROMIS; number, gender, and HIV status of partners, condom use, etc.)
Intimate partner violence
Gender identity and sexual orientation
Physical activity
Quality of life (EuroQOL)
HIV symptom index
Provider satisfaction
Index of engagement in care
COVID-19 impact (limited duration: February-September 2021)
Falls
Housing stability, other social determinants of health

See Appendix Tables 2 and 3.

Table 2 Patient demographics (number (percent) unless otherwise specified) according to data they have consented to provide, restricted to patients with any follow-up after 2001 when Self-interview and Specimen collection began

	Self-interview & specimens & medical record	Self-interview & medical record	Specimens & medical record	Medical record only
N	1845	821	209	2661
Male sex	1202 (65)	523 (64)	135 (65)	1819 (68)
Age at enrollment, years–median (IQR)	43 (35, 51)	43 (33, 51)	39 (34, 46)	39 (33, 46)
Black race	1546 (84)	607 (74)	167 (80)	1874 (70)
HIV acquisition risk group				
Injection drug use	633 (34)	218 (27)	85 (41)	813 (31)
Men who have sex with men	461 (25)	252 (31)	60 (29)	914 (34)
Heterosexual contact	1026 (56)	435 (53)	98 (47)	1269 (48)
Year of enrollment–median (IQR)	2007 ('02,'15)	2010 ('06,'14)	2003 ('99,'11)	2002 ('99,'10)

Table 3 Characteristics (number (%) unless otherwise specified) of patients in care in the Johns Hopkins HIV Clinical Cohort for all years

	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Engaged in care[a]	743	904	1187	1441	1490	1520	1539	1489	1502	1584	1687	1785
Newly enrolled	368	321	401	392	257	236	175	131	159	249	263	227
Lost to care[b,c]	86 (19)	135 (20)	111 (14)	119 (11)	166 (13)	192 (14)	161 (12)	165 (12)	160 (12)	180 (13)	165 (11)	132 (8)
Deaths[d]	30	40	55	59	53	53	55	54	43	45	35	36
Patient demographics												
Male sex	506 (68)	620 (69)	806 (68)	985 (68)	1000 (67)	1002 (66)	1020 (66)	982 (66)	996 (66)	1046 (66)	1114 (66)	1165 (65)
Age, years–median (IQR)	39 (34, 44)	39 (35, 45)	40 (35, 45)	41 (35, 46)	42 (36, 47)	42 (37, 48)	43 (38, 49)	44 (39, 50)	45 (39, 51)	46 (40, 51)	46 (40, 52)	47 (40, 53)
Black race	575 (77)	673 (74)	895 (75)	1060 (74)	1097 (74)	1112 (73)	1127 (73)	1090 (73)	1088 (72)	1161 (73)	1239 (73)	1332 (75)
HIV acquisition risk group												
Injection drug use	339 (46)	373 (41)	472 (40)	540 (37)	542 (36)	528 (35)	529 (34)	481 (32)	462 (31)	474 (30)	515 (31)	530 (30)
Men who have sex with men	209 (28)	275 (30)	349 (29)	414 (29)	427 (29)	426 (28)	426 (28)	431 (29)	434 (29)	460 (29)	480 (28)	486 (27)
Heterosexual contact	354 (48)	440 (49)	593 (50)	719 (50)	761 (51)	794 (52)	806 (52)	772 (52)	784 (52)	843 (53)	918 (54)	992 (56)
Years since enrollment–median (IQR)	1.0 (0.6, 1.5)	1.4 (0.7, 2.2)	1.7 (0.7, 2.9)	1.9 (0.9, 3.5)	2.6 (1.3, 4.3)	3.2 (1.7, 5.1)	3.9 (2.1, 5.9)	4.6 (2.7, 6.8)	5.2 (2.9, 7.5)	5.6 (2.1, 8.1)	5.7 (1.7, 8.7)	5.9 (2.0, 9.3)
HIV clinical outcomes												
Retained in care[e,c]	275 (77)	441 (80)	597 (80)	814 (81)	956 (81)	1013 (82)	1098 (83)	1056 (81)	1033 (79)	1054 (81)	1172 (84)	1313 (86)
Prescribed ART[f]	457 (62)	610 (67)	822 (69)	999 (69)	1021 (69)	1081 (71)	1145 (74)	1158 (78)	1207 (80)	1327 (84)	1468 (87)	1589 (89)
Virally suppressed[g,c]	221 (31)	335 (39)	494 (44)	615 (45)	637 (45)	683 (47)	796 (53)	865 (60)	941 (64)	1055 (68)	1235 (74)	1378 (79)
Durable viral load suppression[h,c]	101 (14)	186 (22)	310 (27)	378 (28)	428 (30)	440 (30)	532 (36)	627 (43)	683 (47)	787 (51)	937 (56)	1098 (63)
Clinical diagnoses within past 2 years												
Depression	207 (28)	206 (23)	224 (19)	251 (17)	244 (16)	249 (16)	235 (15)	208 (14)	210 (14)	252 (16)	287 (17)	344 (19)
Anxiety	12 (2)	23 (3)	33 (3)	34 (2)	36 (2)	29 (2)	19 (1)	13 (1)	16 (1)	18 (1)	30 (2)	51 (3)
Alcohol use disorder	72 (10)	87 (10)	116 (10)	130 (9)	137 (9)	127 (8)	143 (9)	122 (8)	106 (7)	112 (7)	135 (8)	171 (10)
Cocaine use disorder	126 (17)	118 (13)	154 (13)	177 (12)	180 (12)	196 (13)	199 (13)	168 (11)	155 (10)	151 (10)	176 (10)	181 (10)
Opioid use disorder	162 (22)	167 (18)	211 (18)	207 (14)	216 (14)	224 (15)	208 (14)	188 (13)	175 (12)	175 (11)	195 (12)	218 (12)
Self-reported outcomes, N (%)[i,c]												
Unique patients with ≥ 1 self-interview										573	855	939
PHQ-8 ≥ 10										13 (2)	21 (2)	22 (2)
GAD-7 ≥ 10												
AUDIT-C ≥ 3 for women, ≥ 4 for men										111 (19)	170 (20)	178 (19)
Recent cocaine use										27 (5)	38 (4)	39 (4)
Recent non-prescribed opioid use										46 (8)	62 (7)	60 (6)
Medical record review, recent												
Hazardous alcohol use	151 (21)	191 (22)	234 (20)	235 (17)	238 (16)	233 (16)	191 (13)	186 (13)	199 (13)	218 (14)	222 (13)	246 (14)
Cocaine use	228 (31)	222 (25)	298 (26)	322 (23)	315 (22)	312 (21)	272 (18)	261 (18)	251 (17)	267 (17)	262 (16)	257 (14)
Heroin use	209 (29)	226 (26)	301 (26)	311 (23)	293 (20)	259 (17)	232 (15)	198 (14)	172 (12)	166 (11)	179 (11)	185 (10)

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Engaged in care[a]	1854	1890	1885	1670	1791	1789	2131	2159	2119	2081	2022	1963	1874
Newly enrolled	195	207	146	101	124	121	436	149	114	115	59	66	40

Table 3 (continued)

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Lost to care[b,c]	141 (8)	171 (10)	189 (10)	339 (19)	173 (11)	159 (9)	146 (8)	146 (7)	184 (9)	188 (9)	166 (8)	174 (9)	186 (10)
Deaths[d]	37	26	39	27	30 (2)	22 (1)	35 (2)	29 (1)	43 (2)	35 (2)	31 (2)	42 (2)	27
Patient demographics													
Male sex	1206 (65)	1224 (65)	1221 (65)	1079 (65)	1152 (64)	1148 (64)	1370 (64)	1391 (64)	1353 (64)	1321 (63)	1290 (64)	1246 (63)	1199 (64)
Age, years–median (IQR)	48 (41, 54)	49 (42, 54)	49 (42, 55)	50 (43, 56)	51 (44, 57)	52 (44, 58)	53 (46, 59)	54 (46, 60)	55 (46, 61)	55 (47, 62)	56 (47, 62)	57 (47, 63)	57 (47, 64)
Black race	1391 (75)	1420 (75)	1435 (76)	1315 (79)	1363 (76)	1358 (76)	1614 (76)	1637 (76)	1609 (76)	1609 (77)	1548 (77)	1514 (77)	1444 (77)
HIV acquisition risk group													
Injection drug use	550 (30)	534 (28)	520 (28)	474 (28)	477 (27)	445 (25)	567 (27)	565 (26)	516 (24)	488 (23)	453 (22)	426 (22)	406 (22)
Men who have sex with men	524 (28)	535 (28)	526 (28)	448 (27)	518 (29)	515 (29)	623 (29)	656 (30)	659 (31)	657 (32)	654 (32)	640 (33)	640 (34)
Heterosexual contact	1017 (55)	1038 (55)	1050 (56)	943 (56)	998 (56)	1004 (56)	1151 (54)	1149 (53)	1123 (53)	1097 (53)	1067 (53)	1038 (53)	978 (52)
Years since enrollment–median (IQR)	6.1 (2.3, 10.0)	6.1 (2.7, 10.9)	6.6 (3.2, 11.6)	6.9 (3.6, 12.3)	7.9 (4.4, 13.3)	8.5 (4.6, 14.3)	8.0 (1.9, 14.3)	8.4 (1.9, 15.1)	9.1 (2.7, 15.7)	9.5 (3.6, 16.4)	10.4 (4.6, 17.4)	10.9 (5.5, 18.5)	11.7 (6.5, 19.2)
HIV clinical outcomes													
Retained in care[e,c]	1353 (83)	1353 (82)	1370 (80)	1137 (74)	1301 (79)	1368 (83)	1343 (81)	1635 (83)	1555 (79)	1536 (80)	1461 (76)	1371 (74)	1352 (75)
Prescribed ART[f]	1680 (91)	1760 (93)	1788 (95)	1609 (96)	1737 (97)	1720 (96)	2076 (97)	2099 (97)	2091 (99)	2050 (99)	2006 (99)	1940 (99)	1859 (99)
Virally suppressed[g,c]	1465 (81)	1525 (84)	1514 (84)	1319 (85)	1405 (89)	1406 (89)	1883 (91)	1898 (92)	1893 (93)	1877 (94)	1641 (95)	1674 (93)	1031 (90)
Durable viral load suppression[h,c]	1207 (67)	1278 (71)	1310 (73)	1171 (75)	1226 (77)	1230 (78)	1671 (81)	1691 (82)	1705 (84)	1704 (86)	1554 (90)	1573 (88)	948 (83)
Clinical diagnoses within past 2 years													
Depression	359 (19)	501 (27)	519 (28)	523 (31)	639 (36)	713 (40)	902 (42)	820 (38)	683 (32)	672 (32)	609 (30)	552 (28)	435 (23)
Anxiety	87 (5)	154 (8)	196 (10)	199 (12)	223 (12)	250 (14)	312 (15)	282 (13)	213 (10)	218 (10)	233 (12)	236 (12)	190 (10)
Alcohol use disorder	221 (12)	287 (15)	317 (17)	282 (17)	256 (14)	254 (14)	241 (11)	212 (10)	156 (7)	168 (8)	150 (7)	158 (8)	128 (7)
Cocaine use disorder	212 (11)	244 (13)	248 (13)	232 (14)	215 (12)	194 (11)	213 (10)	195 (9)	131 (6)	137 (7)	137 (7)	137 (7)	111 (6)
Opioid use disorder	242 (13)	297 (16)	330 (18)	310 (19)	278 (16)	265 (15)	294 (14)	291 (13)	269 (13)	270 (13)	253 (13)	243 (12)	208 (11)
Self-reported outcomes, N (%)[i,c]													
Unique patients with ≥ 1 self-interview	1093	1135	1090	919	1005	1149	1419	1330	1206	1164	1111	1027	1031
PHQ-8 ≥ 10	70 (6)	125 (11)	91 (8)	52 (6)	88 (9)	155 (13)	267 (19)	270 (20)	228 (19)	213 (18)	203 (18)	164 (16)	171 (17)
GAD-7 ≥ 10				12 (4)	50 (5)	93 (8)	139 (10)	125 (10)	101 (9)	110 (10)	122 (11)	107 (11)	113 (11)
AUDIT-C ≥ 3 for women, ≥ 4 for men	219 (20)	264 (23)	257 (24)	187 (20)	187 (19)	240 (21)	325 (23)	320 (24)	281 (23)	269 (23)	243 (22)	205 (20)	228 (22)
Recent cocaine use	60 (5)	88 (8)	88 (8)	61 (7)	68 (7)	77 (7)	143 (10)	201 (15)	191 (16)	169 (15)	157 (14)	137 (13)	143 (14)
Recent non-prescribed opioid use	68 (6)	66 (6)	49 (4)	56 (6)	133 (13)	159 (14)	190 (13)	170 (13)	111 (9)	103 (9)	105 (10)	104 (10)	105 (11)
Medical record review, recent													
Hazardous alcohol use	271 (15)	289 (15)	306 (16)	255 (15)	266 (15)	247 (14)	292 (14)	282 (13)	307 (15)	324 (16)	288 (15)	242 (13)	161 (11)
Cocaine use	243 (13)	245 (13)	214 (11)	181 (11)	215 (12)	181 (10)	229 (11)	243 (12)	231 (11)	221 (11)	175 (9)	162 (9)	115 (8)
Heroin use	145 (8)	153 (8)	121 (6)	107 (6)	132 (7)	124 (7)	148 (7)	159 (8)	148 (7)	140 (7)	122 (6)	108 (6)	73 (5)

[a]Defined as attending ≥ 1 HIV primary care visit in the calendar year

[b]Defined as not attending any HIV primary care visits in the calendar year after attending ≥ 1 HIV primary care visit in the prior year; denominator for proportion is number attending ≥ 1 HIV primary care visit in the prior year

[c]Not a proportion of those Engaged in care (first row of Table 1)

[d]Not restricted to patients who were engaged in care

[e]Attended ≥ 2 clinic visits ≥ 90 days apart; denominator excludes people newly enrolled in care in the calendar year and people who die prior to the end of the calendar year

[f]ART defined as being on a 3-drug regimen or an approved 2-drug regimen

[g]Last HIV viral load in the calendar year ≤ 400 copies/mL (based on limit of detection for HIV RNA quantification tests at the start of the study period); proportion excludes patients who are missing an HIV viral load value

[h]All HIV viral load measurements in the calendar year ≤ 400 copies/mL; proportion excludes patients who are missing an HIV viral load value

[i]On any PRO in calendar year or year prior; proportion calculated out of people with ≥ 1 PRO in calendar year or year prior

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Declarations

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