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## Cohort Profile Update: Reflecting back and looking ahead: Updating the Comparative Outcomes and Service Utilization Trends (COAST) Study to include 28 years of linked data from people with and without HIV in British Columbia, Canada

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### Abstract

#### Introduction

The Comparative Outcomes and Service Utilization Trends (COAST) study compares health outcomes among People With HIV (PWH) and People Without HIV (PWoH) in British Columbia (BC), Canada. The cohort was recently updated to include persons diagnosed with HIV after March 31, 2013, and expanded to broaden research applications.

#### Methods

COAST includes PWH and a 10% random sample of the general population without HIV, all aged  $\geq 19$ . Our study links an HIV registry to healthcare practitioner billing, hospital and emergency department attendance data, prescription drug dispensations, and a cancer registry. Our cohort update included new sampling strategies, adding data on emergency department visits not previously captured, and extending our follow-up period to 28 years (from 1992 to 2020). COAST now includes 17,119 PWH and 615,264 PWoH.

#### Findings to date

COAST has contributed to our understanding of combination antiretroviral therapy (ART) use, health service utilization, chronic diseases, mental health and substance use disorders, and mortality among PWH in BC. Key findings include earlier age at diagnosis of certain chronic conditions, a higher incidence of mood disorders among PWH, and noteworthy shifts in causes of death among PWH on ART. The updated cohort will provide insights into the changing nature of the population living with HIV in BC and serves as a novel foundation for further research.

#### Future plans

To explore and extend knowledge of the evolving trends among people living and aging with HIV in BC, regular data linkage updates and the inclusion of additional datasets are scheduled every two years.

#### Keywords

HIV research; longitudinal cohort studies; healthcare use; administrative data; data linkage; public health; ageing; HIV; population health

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## Introduction

### Purpose of COAST

The introduction of combination antiretroviral therapy (ART) has resulted in substantial declines in the incidence and severity of HIV-related complications [1, 2]. The life expectancy of People With HIV (PWH) who begin ART with maintained immune function is nearing that of the general population [3]. However, various subpopulations – including PWH starting ART at lower CD4 counts, PWH who acquired HIV via injection drug use, and PWH from racialized communities – often experience poorer outcomes [4]. Despite recent improvements in HIV treatment and care, health outcomes among PWH remain poorer than People Without HIV (PWoH) [5].

The Comparative Outcomes and Service Utilization Trends (COAST) study in British Columbia (BC), Canada, was developed by the BC Centre for Excellence in HIV/AIDS (BC-CfE) to examine and compare health outcomes and healthcare utilization among people aged 19 and older with and without HIV. COAST includes data on virtually all known people with HIV and a 10% random sample of the BC population without HIV [6]. The study is based on a linkage between an HIV registry and administrative health databases including data on healthcare practitioner billing, a cancer registry, hospital and emergency department attendance data, prescription drug dispensations, and mental health data. Due to its breadth and data capture, COAST is uniquely positioned to examine the complex interaction between HIV, concurrent conditions, and social determinants of health in a setting of publicly-funded healthcare and free ART for treatment and prevention for all.

### Key findings and contributions of COAST

During the initial follow-up period of COAST (April 1, 1996, to March 31, 2013), a significant reduction in mortality and a remarkable shift in the cause of death from HIV-related to non-HIV-related was observed among PWH [7]. We also noted a higher prevalence and lower age at diagnosis of eight chronic age-related conditions in PWH compared to age-sex matched controls without HIV [8]. Work by Nanditha et al. (2022) underscored the importance of using appropriately defined and consistent lookback windows (search periods within which people's healthcare records are queried relative to a date of interest) when querying administrative health data to assess the prevalence and incidence of chronic diseases [9]. Previous COAST studies also identified sex differences in health outcomes among PWH: a study by Closson et al. (2020) found that HIV-positive status was associated with a higher rate of mood disorder diagnosis among males but not among females [10]. Another study found a lower life expectancy and time spent in a healthy state among females with HIV compared to males with and both sexes without HIV [11]. Access to province-wide data also allowed for comparisons across geographic regions, finding significant differences in morbidity and mortality by region [5], and poorer health outcomes for PWH in rural areas compared to urban PWH residents [12].

### Rationale for expansion and update of COAST

The original COAST study linked data from the BC-CfE HIV Drug Treatment Program (DTP) with several Population Data BC data holdings from 1996 to 2013, as detailed elsewhere [6]. In the intervening decade, many factors have affected the care patterns and health trajectories of PWH. Importantly, between 2012 and 2015, the International Antiviral Society and BC-CfE revised their guidelines to recommend initiating HIV treatment for PWH regardless of CD4 count [13, 14]. Additionally, new HIV medications including second-line integrase strand transfer inhibitors received approval in Canada between 2012 and 2013 [15, 16], and have since emerged as first-line ART options [17, 18]. In BC, in an effort to expand HIV testing and treatment, the BC-CfE launched the Seek and Treat for Optimal Prevention of HIV/AIDS (STOP HIV/AIDS) program in 2010 [19]. This initiative led to new HIV diagnoses, an increased proportion of people on ART, and a change in the demographic profile of PWH in the years that followed [20].

Simultaneously, BC has been home to one of the most devastating illicit drug use crises in the world [21], disproportionately affecting PWH in terms of drug use disorders and overdose mortality [22–24]. This crisis has prompted the development of new strategies to mitigate harms of drug use and expand care to those living with continued substance use disorders which, in turn, may have differential effects on health outcomes and utilization patterns of PWH.

Thirdly, we developed novel techniques affecting the completeness of our cohort makeup. We modified the algorithm for identifying PWH who were never enrolled in the DTP to reflect recent work by Emerson et al. (2023) [25]. The new algorithm has allowed for an updated identification of PWH, validated in the modern era. In addition, we expanded the follow-up to include PWH identified between April 1, 2013, and March 31, 2020, and captured an additional four years of data at the front end (from 1992 to 1996). We also refined the strategy for sampling people without HIV in our study by initially sampling 10% of the total BC population in 1992, followed by 10% of eligible people in each year of follow-up and then 10% of eligible people who turned 19 during each year of follow up. We also included the specific year of sampling for each individual, a detail that was not part of the original protocol.

Lastly, advancements in accessing the province's health data have allowed us to integrate more robust data on emergency department use into our already extensive collection of administrative data, which strengthens the depth and comprehensiveness of our research, providing a strong basis for various analyses.

### Future plans for expanded COAST

The updated cohort will provide the foundation for an important HIV research program focused on examining healthcare use and outcomes among PWH. The extended follow-up will allow for a more complete examination of trends in incidence and treatment of HIV and other comorbidities detailing the socio-demographic makeup of the province's population living with HIV to better serve this population.

In addition, the extended follow-up will help understand the distribution and effects of concurrent diseases of aging and drug use disorders, which has already led to the development of a new embedded cohort studies.

## Updated cohort description

### Data linkage and datasets

The BC-CfE's DTP, funded by the BC Ministry of Health (MoH), offers HIV treatment and prevention (pre-exposure prophylaxis: PrEP, post-exposure prophylaxis: PEP) in the form of ART to medically eligible people at no cost to the individual [26]. Although the DTP includes subprograms for both HIV treatment and preventive therapies, our study only includes data from the HIV treatment program. Therefore, individuals on PrEP or PEP are automatically excluded, and the term "DTP" in this paper specifically refers to the HIV Treatment program. The DTP registry includes data on ART and clinical disease markers for all PWH accessing HIV care in BC. This registry was linked to administrative health data held at Population Data BC, a multidisciplinary institution which houses individual-level, de-identified, longitudinal data on all BC residents [27].

The majority of the datasets used here were the most recent versions of the datasets used in the original study. Additionally, we included data from the National Ambulatory Care Reporting System (NACRS) [28], which collects data on emergency department usage, primarily unscheduled emergency department visits. For BC, this dataset is available from 2012 onwards [29]. While not all eligible facilities in BC report to NACRS, higher-volume facilities, which contribute the majority of data, do submit reports. Although indication of emergency department use in BC can be partly captured via other available sources in COAST, the addition of NACRS provided two advantages: the NACRS dataset increased our capture of emergency department use among PWH by approximately 10%, and provided specific, detailed information on triage, nature of discharge, mode of arrival and presenting complaint (information unavailable from the other sources of emergency department-based health care use).

The various datasets included in our study are managed and governed by Data Stewards, who are representatives from the organizations whose data are housed at Population Data BC. Access to data provided by the Data Stewards is subject to approval but can be requested for research projects through the Data Stewards or their designated service providers. The following datasets were used in this study: DTP data; Consolidation file; Discharge Abstract Database(DAD); Medical Services Plan (MSP); PharmaCare; PharmaNet; NACRS; Mental Health Services, BC Cancer Registry [30], and Vital Statistics deaths [31] (Supplementary Table 1). Further information regarding these datasets can be obtained by visiting the Population Data BC project webpage [https://my.popdata.bc.ca/project\\_listings/18-223/collection\\_approval\\_dates](https://my.popdata.bc.ca/project_listings/18-223/collection_approval_dates). All inferences, opinions, and conclusions drawn in this publication are those of the author(s), and do not reflect the opinions or policies of the Data Steward(s).

### Persons With HIV cohort update

Individuals with HIV were identified through four possible indicators, two from the DTP and two from outside the DTP, namely (1) a detectable viral load for HIV, (2) an ART dispensation for treatment, (3) an HIV/AIDS-related death, and/or (4) meeting the criteria of an HIV case-finding algorithm applied to healthcare records (Figure 1). The majority of PWH were identified via information held in the DTP, specifically a detectable viral load for HIV or an ART dispensation. Among the PWH identified by having a recorded detectable plasma viral load for HIV, we excluded individuals who had only one viral load measurement and, additionally, either (1) had no linked administrative health data, or (2) had less than 30 days of follow-up with known HIV risk information in the DTP registry (Figure 2). The majority (89%) of the excluded PWH had no linked administrative datasets, indicating no verifiable engagement with healthcare services in BC. Including these individuals would inflate our denominator without contributing meaningful follow-up data. By excluding them, we ensure a more accurate cohort that better reflects the true population of PWH actively engaged in BC's healthcare system. Furthermore, the absence of follow-up time in these datasets may suggest limited time spent in BC.

To identify PWH through the HIV/AIDS-related mortality indicator, we queried all cause of death fields in the mortality dataset during the observation period. Specifically, we searched for International Classification of Diseases [ICD]-9/-9-CM codes beginning with 042, 043, 044, 795.8, 795.71, V08 as well as ICD-10/10-CA codes beginning with B24, Z21, R75, O98.7 (although only ICD-9 and ICD-10 diagnostic codes should appear in death records, for completeness, we queried diagnostic codes from all ICD-9 and ICD-10 versions).

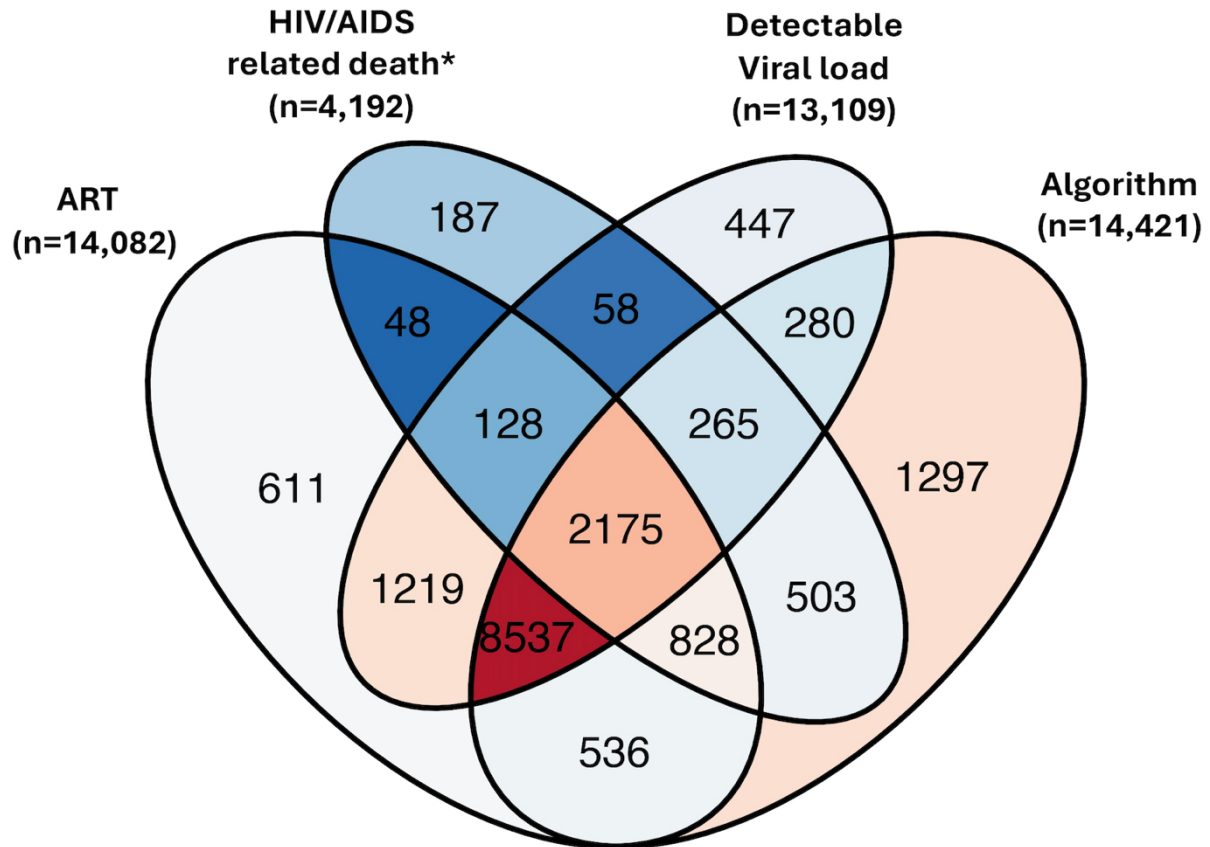
For individuals with HIV identified through healthcare contact, we queried a pool of all persons in BC with any HIV-related healthcare use, based on HIV-related ICD diagnostic codes. Persons from this pool who had not been identified as having HIV through the DTP or death records were classified as having HIV if they met a specific pattern of HIV-related healthcare use. Specifically, such individuals were classified as having HIV if they recorded at least: (a) five HIV-related healthcare practitioner encounters within a 12-month period, (b) two HIV-related hospitalizations within a 12-month period, or (c) one hospitalization with HIV as the most responsible diagnosis. This HIV case-finding algorithm has been validated against HIV test results in BC using data from 1996 to 2020, exhibiting 99.89% specificity and 82.21% sensitivity, and is described in more detail elsewhere [25].

In the PWH cohort, baseline was defined as the latest of the date of the participant's 19th birthday, the date of first HIV-related record, or April 1, 1992.

### Random sample of people without HIV cohort

The random sample of PWoH (comparison cohort) was updated using the Consolidation File from Population Data BC, which contains demographic information and location of residence for all eligible individuals who receive healthcare services in BC [32]. The data update was conducted in three phases.

Figure 1: Distribution of PWH by possible identification methods in our cohort



\*Includes all PWH who died during follow up with an HIV/AIDS related ICD code in their death record. Total number of PWH in Table 1 can be derived from this figure by:

- (1) adding all numbers in sections “ART” and “Detectable Viral load” to get PWH identified through BC-CfE’s DTP.
- (2) adding numbers in sections “HIV/AIDS related death” and “Algorithm” except those intersecting with “ART” and “Detectable Viral Load” to get PWH identified through administrative data.

First, we randomly selected 10% of all adults who were 19 years or older with active MSP registration or billing information in the first year of follow-up (April 1, 1992). MSP is the public health insurance for all eligible BC residents, and it covers medically required services provided by health professionals in the province [33]. This sample constituted the cohort we followed over time. Next, we randomly selected 10% of new MSP registrations who met the age criterion for each subsequent year of follow-up. In the final phase, we randomly selected 10% of individuals with a current/ongoing MSP registration who turned 19 that year for each subsequent year of follow-up. We then excluded confirmed PWH and potential PWH (i.e., those with HIV-related MSP, Discharge Abstract Database, or PharmaNet records who did not meet the algorithm criteria) from this cohort to include only people without any HIV-related health records. This strategy was necessary to ensure that our sample was representative of BC’s adult population without HIV for each year of follow-up (Figure 3).

For participants in the random sample cohort, the baseline date was the latter of their 19<sup>th</sup> birthday, the first date registered in the MSP dataset or April 1, 1992. Loss to follow-up in both cohorts was defined as an inactive MSP registration

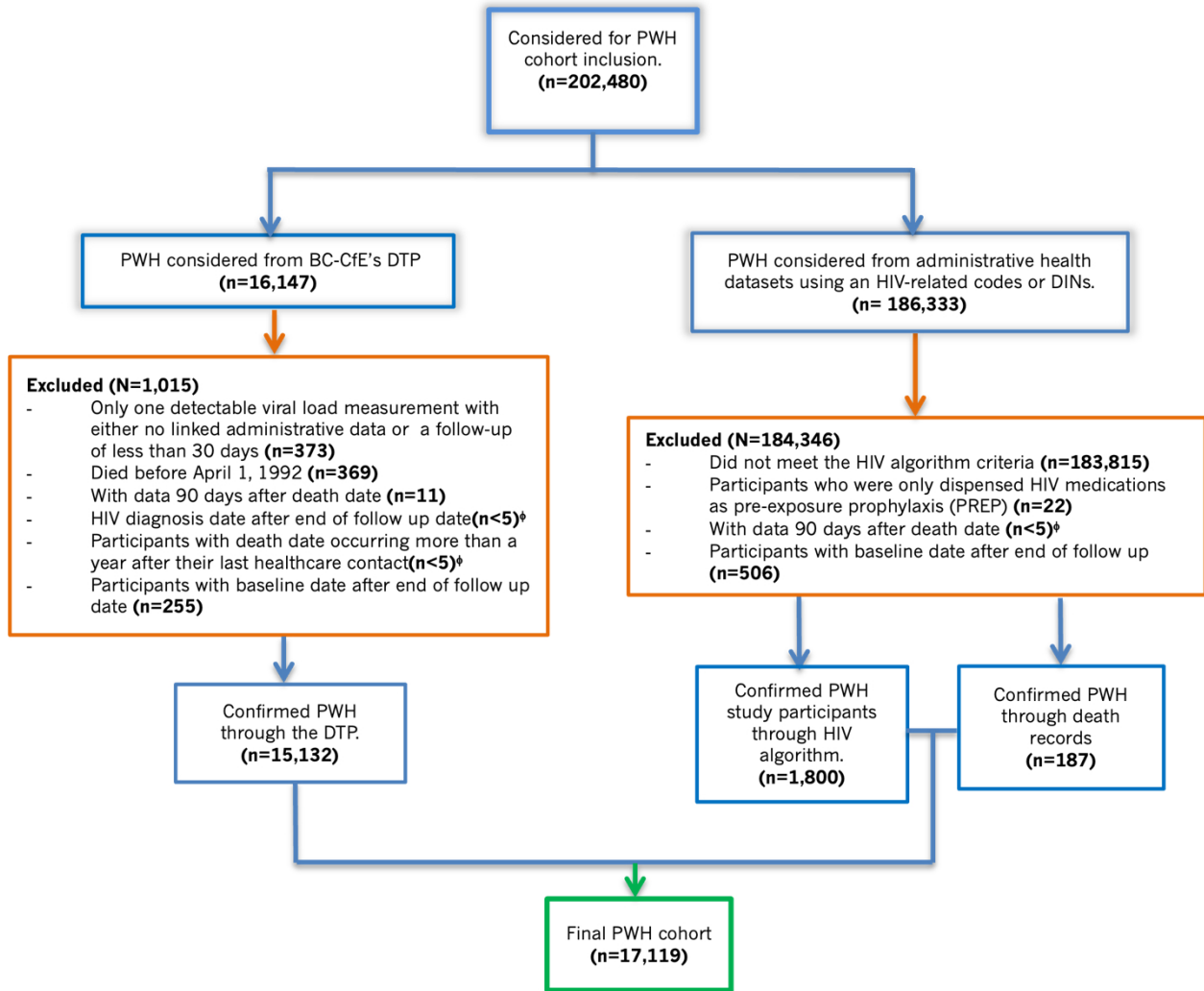
or no healthcare contact within 18 months of the study end date (March 31, 2020). These individuals were censored at the date of their last healthcare contact. Since our study included linked mortality data from the BC Vital Statistics agency, we censored participants who died during follow-up using their death date.

## Other linked cohorts

In addition to the PWH and random sample cohorts, our updated study includes several project-specific cohorts. The Gay, Bisexual, and Other Men who have sex with Men (GBMSM) cohort includes GBMSM living with and without HIV in Metro Vancouver (specifically the cities of North Vancouver, Vancouver, Richmond, New Westminster, Surrey, Delta, Burnaby, Port Moody and Port Coquitlam, together representing about 50% of BC’s total population). GBMSM status was self-reported through a cross sectional survey conducted as part of the Momentum health study [34, 35]. This survey was then linked to the administrative health datasets in COAST to create the GBMSM cohort. The primary objective of this cohort is to examine the disparities in health outcomes, such as substance use-related disorders,



Figure 2: Creation of the People With HIV cohort in the updated study



**Abbreviations:** DINs Drug Identification Numbers; DTP Drug Treatment Program; PWH People With HIV.

<sup>φ</sup>Values below 5 were reported as <5 due to data privacy.

hospitalizations and mortality between GBMSM and the general male population as well as GBMSM with and without HIV.

We have partnered with the Neurology Department of the University of British Columbia to create the COAST-Multiple Sclerosis (MS) cohort. This cohort combines COAST datasets with data from BC Multiple Sclerosis to examine the risk of multiple sclerosis among PWH and PWoH, and assess how ART exposure modifies this risk [36]. Lastly, we are also developing a case-finding algorithm to construct a hepatitis C virus (HCV) cohort. This cohort will consist of individuals ever infected with HCV, with the aim of monitoring the incidence and outcomes related to HIV/HCV co-infection among BC residents over time.

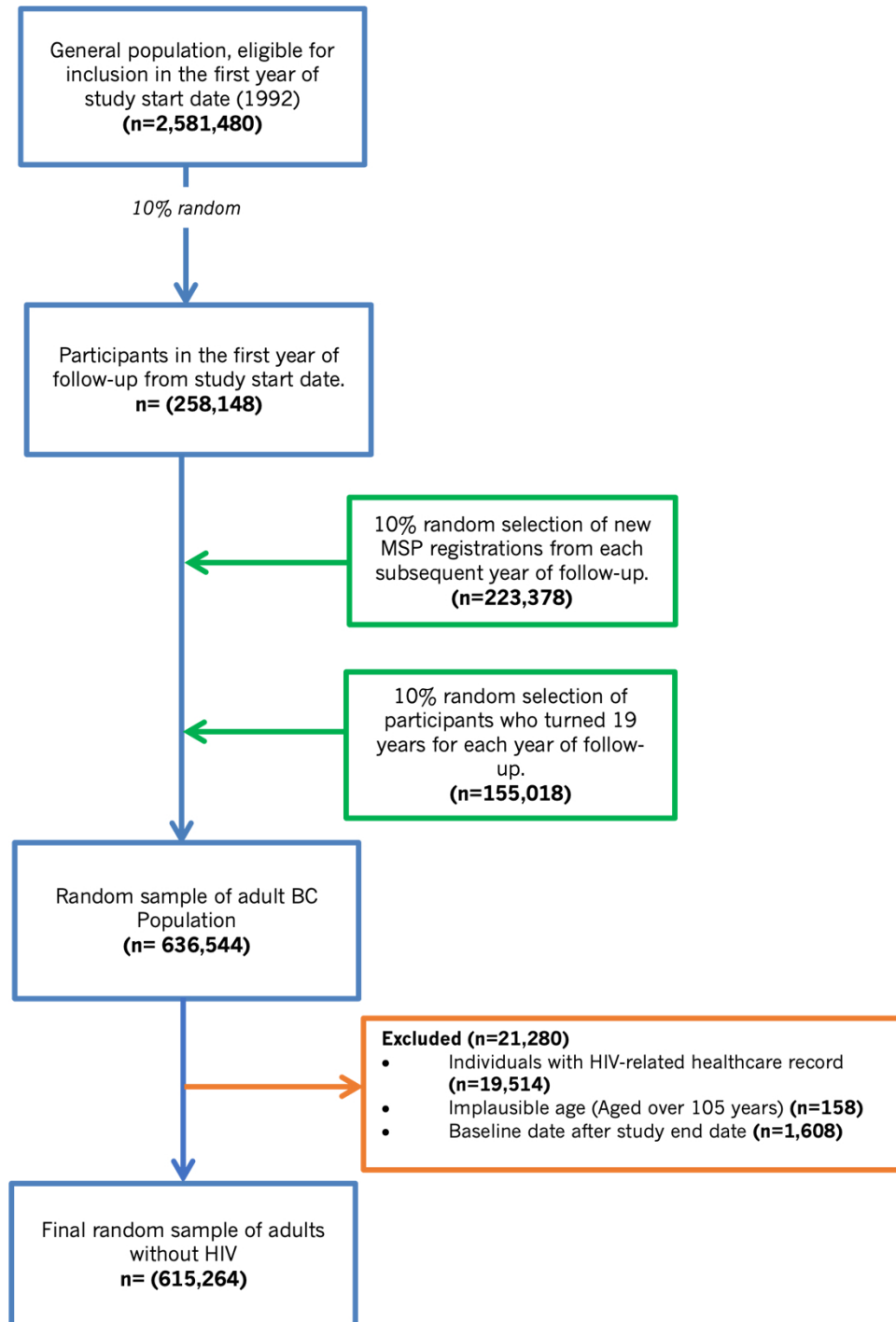
## Patient and public involvement in COAST

The active involvement of PWH has always been crucial in HIV research. However, the growing preference for big data in recent times has limited their involvement. The COAST team has actively built in community engagement in our studies to varying degrees (Supplementary Table 2).

In particular, our team has created a community advisory board, which includes people who self-identify as women, transgender, Indigenous, people who use substances and peers from diverse communities. The advisory board acts as a consultative body to provide insight into healthcare utilization and health outcomes of people living with and without HIV. Their input will contribute to developing culturally appropriate research questions and ensuring that the needs of PWH are prioritized when conducting any study using the COAST data.

Our team is further demonstrating support for patient and public involvement by encouraging adults living with HIV to lead some of our ongoing projects with support from the COAST team [37–39]. An example of such a project is our study examining the incidence of acute index and recurrent cardiovascular events among People with and without HIV, where a group of peer researchers on our team conceptualized and developed the research question and study objectives [39]. Finally, we have begun integrating qualitative aspects into some of our ongoing studies. This initiative involves organizing focus group discussions and in-depth interviews to capture participants' perspectives, thereby adding richness and depth of understanding to our quantitative research [40].

Figure 3: Creation of the random sample without HIV cohort in the updated study



## Initial findings

The updated COAST study includes a total of 632,383 participants, of whom 17,119 were living with HIV, with 1,987 of these cases identified through administrative data (HIV algorithm and mortality dataset). The percentage of males among PWH identified through administrative data, those identified through the DTP, and the random sample cohort were 78%, 83% and 51%, respectively. At baseline, PWH identified through administrative data were older (Median = 40 years; [Q1-Q3] = [32–49]) compared to those identified through the DTP (Median = 37 years; [31–44]) and the random sample cohort (Median = 31 years; [19–46]).

Among these three groups, the random sample cohort had the longest follow-up period (Median = 167 months; [58–320]) (Table 1).

Almost half of the PWH entered our cohort between 1992 and 2002, for those identified through administrative data (47%) and those through the DTP (46%). In terms of ART use, 93% of PWH from the DTP were on ART at some point during the study. The median nadir CD4 count ever for PWH from administrative data and those from the DTP were 30 cells/mm<sup>3</sup> ([Q1-Q3]: 10–175) and 150 cells/mm<sup>3</sup> ([Q1-Q3]: 40–300) respectively. The proportion of people with HIV/hepatitis C virus co-infection ever in the DTP-identified PWH, based on the available data was found to

Table 1: Descriptive characteristics of participants in the updated COAST study based on first available data

Variable	PWH identified through administrative data	PWH identified through BC-CfE's DTP	Random sample without HIV
	(N = 1,987)	(N = 15,132)	(N = 615,264)
	n (%)	n (%)	n (%)
<b>Sex<sup>β</sup></b>			
Female	426-430** (21)	2,534-2,540** (17)	300,955 (49)
Male	1,558 (78)	12,597 (83)	313,877 (51)
Unknown	<5 <sup>φ</sup>	<5 <sup>φ</sup>	432
<b>Neighbourhood block level Income Quintile</b>			
Q1-Lowest Income Quintile	402 (41)	4,772 (38)	127,493 (22)
Q2	197 (20)	2,662 (21)	116,777 (20)
Q3	159 (16)	2,170 (17)	111,810 (20)
Q4	112 (11)	1,602 (13)	108,489 (19)
Q5	106 (11)	1,391 (11)	106,527 (19)
Missing <sup>χ</sup>	1,011	2,535	44,168
<b>Geographical Location</b>			
Large Urban areas	581 (80)	10,609 (84)	376,813 (68)
Small Urban areas	96 (13)	1,315 (10)	110,821 (20)
Rural areas	50-60** (7)	675-680** (5)	68,086 (12)
Territories	<5 <sup>φ</sup>	<5 <sup>φ</sup>	25(0)
Missing <sup>χ</sup>	1,259	2,532	59,519
<b>Health Authority</b>			
Interior	120 (9)	805 (6)	91,195 (15)
Fraser	288 (21)	2,929 (21)	193,544 (33)
Vancouver Coastal	781 (56)	8,114 (58)	177,630 (30)
Vancouver Island	150 (11)	1,567 (11)	92,085 (16)
Northern	46 (3)	483 (3)	36,701 (6)
Missing	602	1,234	24,109
<b>Ever been on ART</b>	NA		NA
Yes		14,082 (93)	
No		1,050 (7)	
<b>Hepatitis C</b>			
Ever had Hepatitis C	NA	4,314 (37)	NA
Never had Hepatitis C		7,215 (63)	
Unknown		3,603	
<b>Substance use disorder (SUD)<sup>δ</sup></b>			
Ever had SUD	904 (45)	6,456 (43)	40,160 (7)
Never had SUD	1,083 (55)	8,676 (57)	575,104 (93)
<b>Calendar period of HIV diagnosis</b>			NA
pre-1992	245 (12)	1,282 (8)	
1992-2002	932 (47)	6,902 (46)	
2003-2013	569 (29)	4,810 (32)	
>2013	241 (12)	2,138 (14)	
<b>Lost to follow-up</b>			
Yes	544 (27)	1,730 (11)	126,988 (21)
No (alive)	442 (22)	8,534 (56)	406,575 (66)
No (died)	1,001 (50)	4,868 (32)	81,701 (13)
<b>Alive as of March 2020</b>			
Yes	442 (31)	8,534 (64)	406,575 (83)
No	1,001(69)	4,868 (36)	81,701 (17)

Continued

Table 1: Continued

Variable	PWH identified through administrative data	PWH identified through BC-CfE's DTP	Random sample without HIV
	(N = 1,987)	(N = 15,132)	(N = 615,264)
	n (%)	n (%)	n (%)
<b>Died during follow-up</b>			
Yes	1,001 (50)	4,868 (32)	81,701 (13)
No	986 (50)	10,264 (68)	533,563 (87)
<b>Participant age as of the COAST baseline date</b>	40 (32–49)	37 (31–44)	31 (19–46)
<b>Nadir CD4 count (cells/mm<sup>3</sup>)</b>	30 (10–175)	150 (40–300)	NA
<b>Follow-up time (months)</b>	23 (4–87)	112 (42–207)	167 (57–320)

**Note:** Missing values were excluded from the calculation of proportions.

<sup>β</sup>Sex value was based on what appeared on an individual's healthcare card. As such, we are unable to distinguish between biological sex and gender identity.

<sup>χ</sup>The significant number of missing data for neighbourhood block level income and geographical location was because the earliest year of this geographic boundary (dissemination area, formerly 'enumeration area') available for this data linkage was 1994. As such, participants who entered the cohort prior to 1994 were more likely to have some incomplete geography-based demographic information.

<sup>φ</sup>Values below 5 were reported as <5 due to data privacy.

<sup>\*\*</sup>Small cell counts (<5) were protected by displaying a range for the next smallest number due to data privacy.

<sup>δ</sup>Using the 2023 version of the BC Ministry of Health case definitions, substance use disorder was defined as one or more hospitalization with an SUD diagnostic code OR two or more healthcare practitioner visits with an SUD diagnostic code within a year [41].

be 37%. We did not have information on hepatitis C infection for PWH identified through administrative data and among PWoH. Overall, we noticed a markedly higher prevalence of substance use disorder (SUD) among the PWH, whether from administrative data (45%) or from the DTP (43%), compared to PWoH (7%). While 32% of the PWH identified through DTP died during follow-up, the rate was higher among those identified through administrative data (50%) but lower for the random sample cohort (13%).

### Cohort composition over time

As shown in figure 4, the population living with HIV has changed considerably over the last 28 years, which is reflected in a shift in demographic characteristics of the COAST cohort. The increasing availability of ART and associated public health efforts manifested in an increase in the proportion of PWH with CD4 cell counts  $\geq 200$  cells/mm<sup>3</sup> over time and an ageing PWH population with the proportion of those who are 60 years and above increasing from 4% in 1992 to 26% in 2020. Furthermore, the proportion of females and those living in less affluent neighbourhood block areas increased over time, along with the proportion of PWH with an indication of SUD, which tripled between 1992 (9%) and 2020 (28%). The proportion of participants with mood and anxiety disorder also increased from 27% to 36% between 1992 and 2020.

The distribution of PWH across different geographical areas in our cohort showed a small shift over time. The proportion living in large urban areas decreased from 87% in 1992 to 82% in 2020, while the proportion living in small urban areas increased from 6% to 11%. The population living

in rural areas (around 7%) remained the same (Supplementary Table 3).

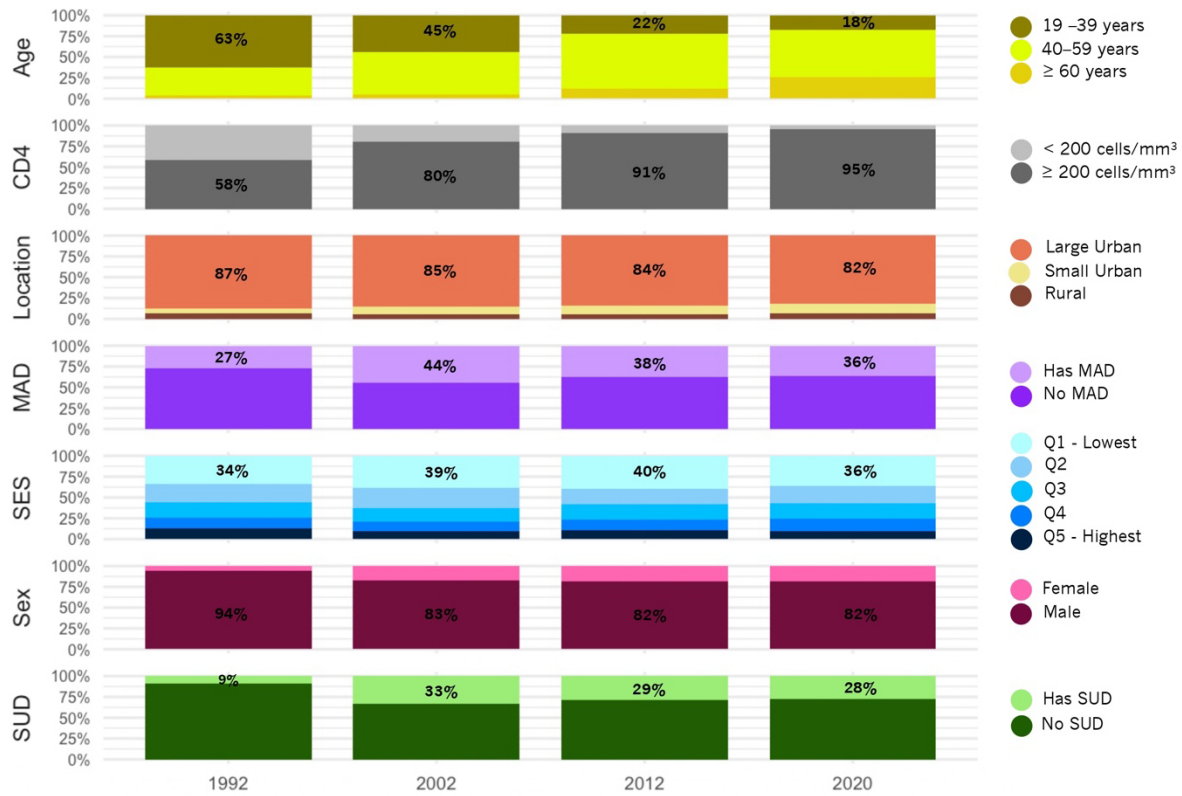
### Discussion

Our study update extends the follow-up period such that almost three decades of data are now available (1992–2020). It also includes a new data source, providing dedicated information on emergency department use, and implements new sampling strategies for creating our comparative cohort and identifying PWH who never enrolled in the DTP or had an HIV/AIDS-related death. Additionally, we have created GBMSM and MS cohorts to analyze differences in health service utilization within these specific populations. Due to the almost complete capture of known PWH in BC and the comprehensive nature of our population-based linkage study, we are able to explore a wide variety of health outcomes among PWH in comparison to people without HIV in BC. To date, COAST remains the only Canadian cohort that links comprehensive data on ART use with administrative health data to capture healthcare utilization, with a focus on people with and without HIV.

The extension of the follow-up period makes examining the long-term effects of modifications to HIV treatment guidelines implemented after 2013, including those on newly available ART, possible. For instance, while some earlier antiretroviral medications were associated with an increased risk of developing cardiovascular disease, [43–45] this risk is not fully understood in newer classes of ARTs, such as integrase inhibitors. Therefore, this data update allows



Figure 4: Cohort composition over time



#### Abbreviations.

**MAD**, Mood and Anxiety Disorder; **SES**, Socioeconomic Status (Neighbourhood block level income quintiles were used as proxy for socioeconomic status); **SUD**, Substance Use Disorder.

#### Note:

- Calculations are based on those alive at the beginning of each period
- Missing values were excluded from the calculation of the proportions.
- Total number of PWH at each time point: 1992 (n = 1,663); 2002 (n = 5,787); 2012 (n = 8,138); 2020 (n = 8,706).
- Location was determined using the statistical area classification developed by Statistics Canada [42].
- Using the 2023 version of the BC Ministry of Health case definitions [41]:
  - cases of substance use disorder were defined as one or more hospitalization with SUD diagnostic code OR two or more healthcare practitioner visits with SUD diagnostic code.
  - cases of mood and anxiety disorder were defined as one or more hospitalization with mood and anxiety disorder diagnostic code OR two or more healthcare practitioner visits with mood and anxiety disorder diagnostic code.

for long-term follow-up of individuals exposed to these medications, potentially informing future guidelines related to prescribing these medications.

Another key aspect of our updated study is our capacity to investigate the intersection of the HIV epidemic and the ongoing drug toxicity overdose crisis. The addition of the NACRS dataset has significantly enhanced our ability to capture crucial details associated with overdose events treated in the emergency setting. Ongoing efforts to secure access to ambulance data will further enable us to explore overdose incidents that do not result in emergency department or hospital admissions. Using administrative datasets, the COAST study acknowledges the significance of patient and other stakeholder involvement in research. We have developed

a framework to actively involve the community in all aspects of COAST-related research. This framework includes creating a community advisory board, encouraging peer researchers to lead projects, and organizing focus group discussions to gather participant perspectives [38–40].

While our study has several notable strengths, it is important to acknowledge its limitations. First, our study is unable to account for healthcare encounters that occurred outside of BC. The COAST study is also limited by the lack of important demographic information such as ethnicity, gender identity, and sexual orientation for the comparison cohort. Lastly, incomplete coding and coding errors exist within administrative data, which allows for the possibility of misclassification bias in any epidemiologic research that uses

such data [46]. As always, associations identified in analyses using this type of data should be interpreted with caution since it is not possible to rule out the influence of unmeasured confounders.

## Ongoing studies, planned updates & contributions to HIV care

Since the creation of the original cohort, we have had over 30 publications covering key areas such as health service utilization, mortality, chronic comorbidities, ART use, substance use and mental health disorders. The data update has allowed us to expand our focus to include studies on the new classes of ARTs and emergency department use, in addition to the abovementioned areas. Due to our study population's dynamic nature, we plan to update our cohort by further extending our follow up period and potentially adding new datasets every two years to continue monitoring patterns in health outcomes among cohort participants.

As we expand our research focus, it is important to highlight how findings from our studies play a crucial role in shaping HIV treatment guidelines and policy recommendations. In particular, findings from the COAST study could contribute to updates in BC's HIV treatment guidelines, developed by the BC-CfE. Additionally, various community partners could use findings from our study to support advocacy efforts aimed at improving HIV care. Lastly, the disparities in health outcomes between people with and without HIV can serve as valuable information for government institutions to ensure the development of tailored healthcare policies for PWH.

## Collaboration

COAST has led to notable and highly productive collaborations, including the Canadian HIV Observational Cohort (CANOC) studies [47], the Momentum health study [34] and the Longitudinal Investigation into Supportive and Ancillary Health Services (LISA) study [48].

The COAST team welcomes potential collaboration with other researchers on key topics related to HIV/AIDS. However, it should be noted that BC-CfE is the only authorized institution to conduct analysis on COAST data due to ethical considerations and research agreements. Interested researchers should contact the Principal Investigator at rhogg@sfu.ca with their research proposal.

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## Author contributions

RSH designed the study, with input from all co-authors. PS, JT, JL were responsible for data curation. ED conducted

the formal analysis. PS, JT, SDE, JL and ED had access to the data. RSH acquired funding for the study. MOB was responsible for data visualization. MOB, KWK and RSH, wrote the first draft. All authors contributed to interpreting the results and critically revising the draft, and all agreed on the final version. MOB and RSH are responsible for the decision to submit for publication.

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## Conflicts of Interests

All authors have no conflicts of interest to declare.

## Ethics approval

The COAST study has received approval from the University of British Columbia/Providence Health Care Research Ethics Board and Simon Fraser University Office of Research Ethics (#H22-02875). The study complies with the BC Freedom of Information and Protection of Privacy Act (FIPPA) and did not require informed consent as it is conducted retrospectively for research and statistical purposes only using anonymized data.

## Data availability statement

The data used for this study are not publicly available. For further information on the data and materials used in our study, please contact the corresponding author.

## References

1. Hogg RS, Heath KV, Yip B, Craib KJ, O'Shaughnessy MV, Schechter MT, et al. Improved survival among HIV-infected individuals following initiation of antiretroviral therapy. *JAMA*. 1998 Feb 11;279(6):450–4. <https://doi.org/10.1001/jama.279.6.450>
2. Lima VD, Harrigan R, Bangsberg DR, Hogg RS, Gross R, Yip B, et al. The Combined Effect of Modern Highly Active Antiretroviral Therapy Regimens and Adherence on Mortality Over Time. *J Acquir*

- Immune Defic Syndr 1999. 2009 Apr 4;50(5):529. <https://doi.org/10.1097/QAI.0b013e31819675e9>
3. Trickey A, Sabin CA, Burkholder G, Crane H, Monforte A d'Arminio, Egger M, et al. Life expectancy after 2015 of adults with HIV on long-term antiretroviral therapy in Europe and North America: a collaborative analysis of cohort studies. *Lancet HIV*. 2023 May;10(5):e295–307. [https://doi.org/10.1016/S2352-3018\(23\)00028-0](https://doi.org/10.1016/S2352-3018(23)00028-0)
4. Samji H, Cescon A, Hogg RS, Modur SP, Althoff KN, Buchacz K, et al. Closing the Gap: Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada. *PLoS ONE*. 2013 Dec 18;8(12):e81355. <https://doi.org/10.1371/journal.pone.0081355>
5. Nanditha NGA, Zheng G, Tafessu HM, McLinden T, Bratu A, Kopec J, et al. Disparities in multimorbidity and mortality among people living with and without HIV across British Columbia's health regions: a population-based cohort study. *Can J Public Health Rev Can Santé Publique*. 2021 Aug 30;112(6):1030–41. <https://doi.org/10.17269/s41997-021-00525-4>
6. Eyawo O, Hull MW, Salters K, Samji H, Cescon A, Sereda P, et al. Cohort profile: the Comparative Outcomes And Service Utilization Trends (COAST) Study among people living with and without HIV in British Columbia, Canada. *BMJ Open*. 2018 Jan 1;8(1):e019115. <https://doi.org/10.1136/bmjopen-2017-019115>
7. Eyawo O, Franco-Villalobos C, Hull MW, Nohpal A, Samji H, Sereda P, et al. Changes in mortality rates and causes of death in a population-based cohort of persons living with and without HIV from 1996 to 2012. *BMC Infect Dis*. 2017 Feb 27;17(1):174. <https://doi.org/10.1186/s12879-017-2254-7>
8. Nanditha NGA, Paiero A, Tafessu HM, St-Jean M, McLinden T, Justice AC, et al. Excess burden of age-associated comorbidities among people living with HIV in British Columbia, Canada: a population-based cohort study. *BMJ Open*. 2021 Jan 1;11(1):e041734. <https://doi.org/10.1136/bmjopen-2020-041734>
9. Nanditha NGA, Dong X, McLinden T, Sereda P, Kopec J, Hogg RS, et al. The impact of lookback windows on the prevalence and incidence of chronic diseases among people living with HIV: an exploration in administrative health data in Canada. *BMC Med Res Methodol*. 2022 Jan 6;22(1):1. <https://doi.org/10.1186/s12874-021-01448-x>
10. Closson K, Osborne C, Smith DM, Kesselring S, Eyawo O, Card K, et al. Correction to: Factors Associated with Mood Disorder Diagnosis Among a Population Based Cohort of Men and Women Living With and Without HIV in British Columbia Between 1998 and 2012. *AIDS Behav*. 2020 Jan;24(1):345–55. <https://doi.org/10.1007/s10461-019-02693-4>
11. Hogg RS, Eyawo O, Collins AB, Zhang W, Jabbari S, Hull MW, et al. Health-adjusted life expectancy in HIV-positive and HIV-negative men and women in British Columbia, Canada: a population-based observational cohort study. *Lancet HIV*. 2017 Jun 1;4(6):e270–6. [https://doi.org/10.1016/S2352-3018\(17\)30029-2](https://doi.org/10.1016/S2352-3018(17)30029-2)
12. Jaworsky D, Loutfy M, Lu M, Ye M, Bratu A, Sereda P, et al. Influence of the definition of rurality on geographic differences in HIV outcomes in British Columbia: a retrospective cohort analysis. *Can Med Assoc Open Access J*. 2020 Oct 1;8(4):E643–50. <https://doi.org/10.9778/cmajo.20200066>
13. Thompson MA, Aberg JA, Hoy JF, Telenti A, Benson C, Cahn P, et al. Antiretroviral Treatment of Adult HIV Infection: 2012 Recommendations of the International Antiviral Society–USA Panel. *JAMA*. 2012 Jul 25;308(4):387–402. <https://doi.org/10.1001/jama.2012.7961>
14. Montaner PJ, Guillemi S, Harris M. Therapeutic Guidelines for Antiretroviral (ARV) Treatment of Adult HIV Infection. 2015;
15. Details for: TIVICAY [Internet]. [cited 2023 Nov 22]. Available from: <https://dhpp.hpfb-dgpsa.ca/dhpp/resource/89957>
16. accm. Stribild (the Quad) approved in Canada (from CATIE) [Internet]. accmontreal.org. 2012 [cited 2023 Nov 22]. Available from: <https://accmontreal.org/stribild-the-quad-approved-in-canada/>
17. Patel DA, Snedecor SJ, Tang WY, Sudharshan L, Lim JW, Cuffe R, et al. 48-Week Efficacy and Safety of Dolutegravir Relative to Commonly Used Third Agents in Treatment-Naive HIV-1-Infected Patients: A Systematic Review and Network Meta-Analysis. *PLOS ONE*. 2014 Sep 4;9(9):e105653. <https://doi.org/10.1371/journal.pone.0105653>
18. Ji H, Patterson A, Taylor T, Rank C, Halverson J, Capina R, et al. Prevalence of Primary Drug Resistance Against HIV-1 Integrase Inhibitors in Canada. *J Acquir Immune Defic Syndr* 1999. 2018 May 1;78(1):e1–3. <https://doi.org/10.1097/QAI.0000000000001649>
19. Nanditha NGA, Dong X, Tafessu HM, Wang L, Lu M, Barrios R, et al. A province-wide HIV initiative to accelerate initiation of treatment-as-prevention and virologic suppression in British Columbia, Canada: a population-based cohort study. *Can Med Assoc Open Access J*. 2022 Jan 1;10(1):E27–34. <https://doi.org/10.9778/cmajo.20210093>
20. Data & Monitoring – STOP HIV/AIDS [Internet]. [cited 2024 Jul 11]. Available from: <https://stophiv aids.ca/data-monitoring/>
21. Health. Provincial health officer declares public health emergency | BC Gov News [Internet]. 2016 [cited 2023 Nov 5]. Available from: <https://news.gov.bc.ca/releases/2016HLTH0026-000568>

22. Bing EG, Burnam MA, Longshore D, Fleishman JA, Sherbourne CD, London AS, et al. Psychiatric Disorders and Drug Use Among Human Immunodeficiency Virus–Infected Adults in the United States. *Arch Gen Psychiatry*. 2001 Aug 1;58(8):721–8. <https://doi.org/10.1001/archpsyc.58.8.721>
23. Green TC, McGowan SK, Yokell MA, Pouget ER, Rich JD. HIV infection and risk of overdose: a systematic review and meta-analysis. *AIDS Lond Engl*. 2012 Feb 20;26(4):403–17. <https://doi.org/10.1097/QAD.0b013e32834f19b6>
24. Salters KA, Parent S, Nicholson V, Wang L, Sereda P, Pakhomova TE, et al. The opioid crisis is driving mortality among under-served people living with HIV in British Columbia, Canada. *BMC Public Health*. 2021 Apr 8;21(1):680. <https://doi.org/10.1186/s12889-021-10714-y>
25. Emerson SD, McLinden T, Sereda P, Lima VD, Hogg RS, Kooij KW, et al. Identification of people with low prevalence diseases in administrative healthcare records: A case study of HIV in British Columbia, Canada. *PLOS ONE*. 2023 Aug 31;18(8):e0290777. <https://doi.org/10.1371/journal.pone.0290777>
26. Drug Treatment Program | BC Centre for Excellence in HIV/AIDS [Internet]. [cited 2023 Jun 26]. Available from: <https://www.bccfe.ca/drug-treatment-program>.
27. About PopData | Population Data BC [Internet]. [cited 2023 Jun 25]. Available from: <https://www.popdata.bc.ca/about>.
28. Canadian Institute for Health Information (2022): National Ambulatory Care Reporting System. V2. Population Data BC [publisher]. Data Extract. MOH (2020).
29. Peterson S, Wickham M, Lavergne R, Beaumier J, Ahuja M, Mooney D, et al. Methods to comprehensively identify emergency department visits using administrative data in British Columbia.
30. BC Cancer (2020): BC Cancer Registry Data. V2. Population Data BC. Data Extract. BC Cancer (2020).
31. British Columbia Ministry of Health [creator](2021): Vital Events Deaths. V2. Population Data BC [publisher]. Data Extract. MOH(2020).
32. Central Demographics File (MSP Registration and Premium Billings, Client Roster and Census Geodata)/Consolidation file (MSP registration and premium billing) data set | Population Data BC [Internet]. [cited 2023 Jun 26]. Available from: [https://www.popdata.bc.ca/data/demographic/consolidation\\_file](https://www.popdata.bc.ca/data/demographic/consolidation_file).
33. Health M of. Medical Services Plan - Province of British Columbia [Internet]. Province of British Columbia; [cited 2023 Jun 25]. Available from: <https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/msp>.
34. Momentum | BC Centre for Excellence in HIV/AIDS [Internet]. [cited 2023 Jun 26]. Available from: <https://bccfe.ca/research/momentum/publications>.
35. Moore DM, Cui Z, Lachowsky N, Raymond HF, Roth E, Rich A, et al. HIV community viral load and factors associated with elevated viremia among a community-based sample of men who have sex with men (MSM) in Vancouver, Canada. *J Acquir Immune Defic Syndr* 1999. 2016 May 1;72(1):87–95. <https://doi.org/10.1097/QAI.0000000000000934>.
36. McKay KA, Wijnands JMA, Manouchehrinia A, Zhu F, Sereda P, Li J, et al. Risk of Multiple Sclerosis in People Living with HIV: An International Cohort Study. *Ann Neurol* [Internet]. [cited 2024 Jan 28];n/a(n/a). Available from: <https://doi.org/https://onlinelibrary.wiley.com/doi/abs/10.1002/ana.26840>. <https://doi.org/10.1002/ana.26840>
37. Nicholson V, Bratu A, McClean AR, Jawanda S, Aran N, Hillstrom K, et al. Indigenizing our Research: Indigenous Community Leadership in HIV Epidemiology Research. *Int J Popul Data Sci* [Internet]. 2021 May 20 [cited 2023 Sep 20];6(1). Available from: <https://ijpds.org/article/view/1386>. <https://doi.org/10.23889/ijpds.v6i1.1386>.
38. Inglis, Nicholson, Valerie, Campbell, Wayne, Frank, Peggy, Lambert Sandy, Magagula, Patience, et al. HIV Research in the Age of Big Data: Developing a Framework for Community-Led Big Data Research through the Eng/aging Project. In London, ON, Canada; 2024. p. 335. Available from: [https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract\\_Book-with-cover.pdf](https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract_Book-with-cover.pdf).
39. Muirhead, Campbell Wayne, Inglis Kathleen, Nicholson Valerie, Budu Michael, Frank Peggy, et al. Incidence and Recurrence Rates of Cardiovascular Disease (CVD) Events Among People Living With and Without HIV in British Columbia: A Community-led Study with The Eng/aging Project. In London, ON, Canada; 2024. p. 274. Available from: [https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract\\_Book-with-cover.pdf](https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract_Book-with-cover.pdf).
40. Gill, K.N, Lambert Sandy, Parashar Surita, Cardinal Hazel, Inglis Kathleen, Gregg Delilah, et al. Documenting the Process and Impact of Community Academic Collaborations within a Project Focused on the Health Impacts of Nonfatal Overdoses Among People Living with and without HIV. In London, ON, Canada; 2024. p. 328. Available from: [https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract\\_Book-with-cover.pdf](https://www.cahr-acrv.ca/wp-content/uploads/2024/04/Abstract_Book-with-cover.pdf).
41. Chronic Disease Dashboard [Internet]. [cited 2024 Jul 16]. Available from: <http://www.bccdc.ca/health-professionals/data-reports/chronic-disease-dashboard#Case-definitions>.



42. Government of Canada SC. Statistical Area Classification by Province and Territory - Variant of SGC 2016 [Internet]. 2016 [cited 2024 Dec 2]. Available from: [https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getCET\\_Page&VD=317043&Item=318531](https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getCET_Page&VD=317043&Item=318531).
43. Bavinger C, Bendavid E, Niehaus K, Olshen RA, Olkin I, Sundaram V, et al. Risk of Cardiovascular Disease from Antiretroviral Therapy for HIV: A Systematic Review. PLOS ONE. 2013 Mar 26;8(3):e59551. <https://doi.org/10.1371/journal.pone.0059551>
44. Eyawo O, Brockman G, Goldsmith CH, Hull MW, Lear SA, Bennett M, et al. Risk of myocardial infarction among people living with HIV: an updated systematic review and meta-analysis. BMJ Open. 2019 Sep 1;9(9):e025874. <https://doi.org/10.1136/bmjopen-2018-025874>
45. Hemkens LG, Bucher HC. HIV infection and cardiovascular disease. Eur Heart J. 2014 Jun 1;35(21):1373–81. <https://doi.org/10.1093/eurheartj/ehf528>
46. Emerson SD, McLinden T, Sereda P, Yonkman AM, Trigg J, Peterson S, et al. Secondary use of routinely collected administrative health data for epidemiologic research: Answering research questions using data collected for a different purpose. Int J Popul Data Sci [Internet]. 2024 Nov 19 [cited 2024 Dec 5];9(1). Available from: <https://ijpds.org/article/view/2407.10.23889/ijpds.v9i1.2407>.
47. Palmer AK, Klein MB, Raboud J, Cooper C, Hosein S, Loutfy M, et al. Cohort profile: the Canadian Observational Cohort collaboration. Int J Epidemiol. 2011 Feb;40(1):25–32. <https://doi.org/10.1093/ije/dyp393>
48. Duncan KC, Salters K, Forrest JI, Palmer AK, Wang H, O'Brien N, et al. Cohort Profile: Longitudinal Investigations into Supportive and Ancillary health services. Int J Epidemiol. 2013 Aug 1;42(4):947–55. <https://doi.org/10.1093/ije/dys035>

## Abbreviations

ART:	Antiretroviral Therapy
BC:	British Columbia
BCCfE:	BC Centre for Excellence in HIV/AIDS
CANOC:	Canadian Observational Cohort
COAST:	Comparative Outcomes and Service Utilization Trends
DTP:	Drug Treatment Program
GBMSM:	Gay, Bisexual, and Other Men who have sex with Men
HCV:	Hepatitis C Virus
ICD:	International Classification of Diseases
LISA:	Longitudinal Investigations into Supportive and Ancillary health services
MAD:	Mood and Anxiety Disorder
MS:	Multiple Sclerosis
MSP:	Medical Services Plan
NACRS:	National Ambulatory Care Reporting System
PEP:	Post Exposure Prophylaxis
PRpP:	Pre-Exposure Prophylaxis
PWH:	People with HIV
PWoH:	People without HIV
SES:	Socioeconomic Status
STOP	Seek and Treat for Optimal Prevention of
HIV/AIDS:	HIV/AIDS
SUD:	Substance Use Disorder

