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Working together: Allies in researching gender and combination antiretroviral therapy treatment change

Claudette Cardinal[1], Carly Marshall[1], Alison R. McClean[1], Niloufar Aran[1], Katherine W. Kooij[1], Jason Trigg[1], Erin Ding[1], Kate Salters[1,2], Robert S. Hogg[1,2] on behalf of the CANOC Collaboration†

1. British Columbia Centre for Excellence in HIV/AIDS, Vancouver BC, Canada
2. Simon Fraser University, Burnaby BC, Canada

ABSTRACT

This is a story of working together collaboratively, and as reflexive colleagues, to answer the research question: Do men, women and transgender individuals in Canada experience the same number of combination antiretroviral therapy (cART) treatment changes? It was a long and winding journey, with bumps along the way, as together we developed a meaningful approach to using data from the Canadian HIV Observational Cohort (CANOC). Reciprocal learning and continued growth were at the heart of this project. Claudette first asked the question based on personal experiences and conversations with peers and the team worked collaboratively and flexibly to address her research objectives and conduct the analysis. Claudette, an Indigenous Elder, would offer a blessing and land acknowledgement to start us off in a good way for our regular check ins and meetings. A total of 10,555 people living with HIV in CANOC were included in the study (8,728 men, 1,771 women and 56 transgender) from five provinces in Canada. Women and transgender individuals experienced a higher crude number of cART regimen changes (1.95 and 2.09 mean changes, respectively) compared to men (1.63 mean changes). Women and transgender individuals also had a higher rate of change (0.26 and 0.27 mean changes/person year (PY) follow up, respectively) compared to men (0.22 mean changes/PY follow up). The risk of experiencing a cART change was significantly higher for women (adjusted incidence rate ratio (aIRR) 1.21 (95% confidence interval (CI) 1.16-1.25) and transgender individuals (aIRR 1.23 (95%CI 1.03-1.48), compared to men after adjusting for significant variables. This is our story of combining living experience of HIV with traditional epidemiological methods.

Keywords Peer research; gender; treatment change; antiretroviral therapy

Corresponding author: Robert Hogg, PhD
Email: bobhogg@bccfe.ca
Phone: (778) 875-5583

ACKNOWLEDGEMENTS

We acknowledge that we live, work, play, and explore on the lands of the Squamish, Tsleil-Waututh, and Musqueam. We thank all of the participants who contributed their data and made this work possible. We would also like to acknowledge Elder Sheila Nyman who was an instrumental guide and mentor during Claudette's first year term as a CANOC Community Investigator. Finally, thank you to the Building More Bridges team for their insight in

reviewing our paper and approving our choice to submit to the Journal of Indigenous HIV Research.

We would also like to acknowledge all of CANOC's affiliated researchers: Principal Investigator: Robert Hogg (British Columbia Centre for Excellence in HIV/AIDS; Simon Fraser University); Site Principal Investigators: Zabrina Brumme (British Columbia Centre for Excellence in HIV/AIDS), Ann N. Burchell (Ontario HIV Treatment Network (OHTN); University of Toronto; OHTN Cohort Study (OCS)], Curtis Cooper (University of Ottawa; OCS), Deborah Kelly (Memorial University of Newfoundland), Abigail Kroch (Ontario HIV Treatment Network; University of Toronto), Marina Klein (Montreal Chest Institute Immunodeficiency Service Cohort; McGill University), Mona Loutfy (University of Toronto; Maple Leaf Medical Clinic; OCS), Nima Machouf (Clinique Medicale l'Actuel; Universite de Montreal), Julio Montaner (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), Kate Salters (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), Rejean Thomas (Clinique Médicale l'Actuel), Stephen Sanche (University of Saskatchewan), Sharon Walmsley (University Health Network; University of Toronto); Alexander Wong (University of Saskatchewan); Co-Principal Investigators: Tony Antoniou (St Michael's Hospital; University of Toronto; Institute for Clinical Evaluative Sciences), Ahmed Bayoumi (St Michael's Hospital; University of Toronto), Mark Hull (British Columbia Centre for Excellence in HIV/AIDS), Bohdan Nosyk (British Columbia Centre for Excellence in HIV/AIDS; Simon Fraser University); Co-Investigators: Angela Cescon (Northern Ontario School of Medicine), Michelle Cotterchio (Cancer Care Ontario; University of Toronto), Charlie Goldsmith (Simon Fraser University), Silvia Guillemi (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), P. Richard Harrigan (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), Marianne Harris (St Paul's Hospital), Sean Hosein (Community AIDS Treatment Information Exchange (CATIE)), Sharon Johnston (Bruyere Research Institute; University of Ottawa), Claire Kendall (Bruyere Research Institute; University of Ottawa), Clare Liddy (Bruyere Research Institute; University of Ottawa), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), David Moore (British Columbia Centre for Excellence in HIV/AIDS; University of British Columbia), Alexis Palmer (British Columbia Centre for Excellence in HIV/AIDS; Simon Fraser University), Sophie Patterson (British Columbia Centre for Excellence in HIV/AIDS; Simon Fraser University), Peter Phillips (British Columbia Centre for Excellence in HIV/ AIDS; University of British Columbia), Anita Rachlis (University of Toronto; OCS), Sean B. Rourke (University of Toronto; OCS), Janet Raboud (University of Toronto; University Health Network; OCS), Hasina Samji (British Columbia Centre for Excellence in HIV/AIDS), Marek Smieja (McMaster University), Benoit Trottier (Clinique Medicale l'Actuel, Universite de Montreal), Chris Tsoukas (McGill University), Mark Wainberg (McGill University; Lady Davis Institute for Medical Research), Collaborators: Chris Archibald (Public Health Agency of Canada Centre for Communicable Diseases and Infection Control), Margaret Kisikaw Piyesis (Canadian Aboriginal AIDS Network), Monique Doolittle-Romas (Canadian AIDS Society), Laurie Edmiston (Canadian Treatment Action Council), Sandra Gardner (OHTN; University of Toronto; OCS), Brian Huskins (Canadian Treatment Action Council), Jerry Lawless (University of Waterloo), Douglas Lee (University Health Network; University of Toronto; Institute for Clinical Evaluative Sciences (ICES)), Renee Masching (Canadian Aboriginal AIDS Network), Stephen Tattle (Canadian Working Group on HIV & Rehabilitation), Alireza Zahirieh (Sunnybrook Health Sciences Centre); Analysts and Staff: Claire Allen (Regina General Hospital), Nic Bacani (British Columbia Centre for Excellence in HIV/AIDS), Stryker Calvez (Saskatoon HIV/AIDS

Research Endeavour (SHARE)), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Jason Chia (British Columbia Centre for Excellence in HIV/AIDS), Daniel Corsi (The Ottawa Hospital Immunodeficiency Clinic; Ottawa Hospital Research Institute), Erin Ding (British Columbia Centre for Excellence in HIV/AIDS), Louise Gilbert (Immune Deficiency Treatment Centre), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Lucia Light (OHTN), David Mackie (The Ottawa Hospital), Costa Pexos (McGill University), Paul Sereda (British Columbia Centre for Excellence in HIV/AIDS), Susan Shurgold (British Columbia Centre for Excellence in HIV/AIDS), Leah Szadkowski (University Health Network), Chrissi Galanakis (Clinique Medicale L'Actuel), Jason Trigg (British Columbia Centre for Excellence in HIV/AIDS), Monica Ye (British Columbia Centre for Excellence in HIV/AIDS), Benita Yip (British Columbia Centre for Excellence in HIV/AIDS), Jaime Younger (University Health Network), and Julia Zhu (British Columbia Centre for Excellence in HIV/AIDS).

Funding details: CANOC is funded by the Canadian Institutes of Health Research (CIHR) through a Centres Grant (CIHR#02684); two Operating Grants (CIHR#134047, CIHR#136882); a Foundation Grant (CIHR#143342); in collaboration with the CIHR Canadian HIV Trials Network (CTN#242). The funders had no role in study design, data collection, analysis, interpretation, and decision to publish.

Disclosures: CC, CM, ARM, NA, KWK, JT, ED, KS, and RSH have no conflicts to disclose.

INTRODUCTION

Historically there has been little recognition of Indigenous ownership, perspectives, knowledge or methodology and leadership in research involving Indigenous peoples in Canada. However, in the last decade, there has been more emphasis of and support for using Indigenous methodologies to ensure research agendas are community driven, and to help gain and build trust between academic researchers and communities with lived and living experience (Christopher, Watts, McCormick, & Young, 2008; Hyett, Marjerrison, & Gabel, 2018). Community-based participatory research methods aim to create more equitable and collaborative environments where those who are affected by the research are actively involved throughout the research process from the development of relevant research questions to the dissemination of findings in an accessible and meaningful way back to the community (Wallerstein & Duran, 2010). The First Nations principles of Ownership, Control, Access and Possession[1] (OCAP®) for example, are guidelines that "respects a community to make its own decisions regarding why, how and by whom information is collected, used or shared" (First Nations Governance Centre, 2018).

In the current study, Claudette, an Indigenous Community Investigator within the Canadian HIV Observational Cohort (CANOC), collaborated with a team of academic researchers to answer her question that developed from her own living experience. The findings will be brought back to the community through traditional storytelling and knowledge sharing.

[1] OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). Please see their website for more information and a full definition of OCAP®.

Claudette has a deep-rooted history of involvement in HIV research, advocacy, and community-based projects with special attention to Indigenous, aging, gender, and mental health projects. Although she has enjoyed many successes this year, including being awarded multiple national and international scholarships and presentations, the road to get here has not always been easy.

Claudette's herstory

We will be using the term herstory instead of history as an Elder once taught me that all stories are real and true and that there are as many personal titles for stories as there are genders. As I reflect on my early experiences with research, my herstory with research comes to mind. I remember being recruited by a clinical trial in early 2019; I left with all the forms signed and an appointment. Still, I was contemplating if I was going to go through with this study, it was just not sitting right with me. I remember having a conversation with a peer who was involved in the same clinical trial and I expressed to him I was worried about my upcoming appointment. He shared his experience and explained that he had not felt the same since having the procedure done. I had doubts about the research and how invasive it was, so I went home and found the forms, called the number to cancel and withdrew my name from the clinical trial.

When I first heard of CANOC's Community Investigator program in 2015 and its recruitment of peers from across Canada, I was unsure if the opportunity was the right fit for me. Research seemed like something for the '*sciencey'* academic types, however I wanted to be involved. My peers and I have long felt we were being held hostage by power differentials between ourselves and care providers, and I knew that being involved in research could help mitigate this. I applied to the Community Investigator program; my application, however, was rejected. Around the same time, I experienced the traumatic loss of my daughter. I felt things slipping a bit.

I remained dedicated to research and advocacy and continued to attend conferences and community events. I attended school for social work and reapplied to the Community Investigator program in 2017. My application was successful this time and obtaining this role led to the close relationship between myself, the CANOC team, and the BC Centre for Excellence in HIV/AIDS (BC-CfE).

I bring a great deal of living experience—25+ years—to the work I do. After several encounters in the healthcare system where I did not feel fully informed about my options or given a chance to voice my concerns, the healthcare system must prove to me that procedures are necessary. For example, they wanted to take out my gallbladder or spleen, yet provided no reason. I understand now that it takes all the members of the healthcare team clearly explaining why they need to do the procedure in order to achieve informed consent.

I remember my journey with combined antiretroviral therapy (cART). From 1995-1998, my first regimen consisted of lamivudine (3TC), stavudine (D4T), zidovudine (AZT). The side effects if taken later in the day (i.e., 11 am versus 8 am) included dizziness, feeling like I'm off balance, ringing in ears, and nausea. I avoided taking medication or I used alcohol to combat side effects in the early years. I took 3TC and D4T (Zerit) from 1998-2000. From 2003-2005, I took a drug holiday because of the side effects and other life circumstances. Later, I developed resistance to 3TC while I was going on and off the medication and not properly taking it. In 2006, I was switched to a 5-pill combination including one that looked

like an ostrich egg (tenofovir disoproxil fumarate or TDF), atazanavir, the stinky one (ritonavir), emtricitabine, and lamivudine. I then had to go for liposuction and my surgeon confirmed that the ritonavir had caused my Buffalo Hump—a side effect of some HIV medication. I started metformin to lessen the fat accumulation and suffered more menstrual bleeding. The endocrinologist switched me to human growth hormone, and I suffered finger tingling, and what felt like superwoman strength for the 6 years I was taking it. I was later given a combined pill of emtricitabine/TDF (Truvada) and atazanavir. I switched to Stribild (elvitegravir, cobicistat, emtricitabine, TDF) in 2016, and later advocated to receive tenofovir alafenamide (TAF) in place of TDF. Most recently, I heard that Genvoya (elvitegravir, cobicistat, emtricitabine, and TAF) had fewer side effects, specifically for women, and tried to switch over. I have been on Genvoya ever since.

Over the years, I would ask my doctors what the specific side effects for women were for the medications. No one gave me a straight answer, and they only ever provided me a list of general side effects. When I spoke to my peers and heard their experiences and from what I experienced myself, I noticed that side effects differ based on gender. I now know that much of clinical trials have male-dominant patient pools, and the side effects documented may therefore be specific to the male gender. As I age on these medications, I cannot not tell if the sweating and anxiety are from natural menopause or are side effects of Genvoya. Throughout my years, I have experienced many, many regimen switches.

Talking to my Indigenous peers and peers of diverse backgrounds, there are side effects specific to us. For example, being an Indigenous woman, I am lactose intolerant and some of the binding agents used in pills are lactose-based. There may be differences in the prevalence of lactose intolerance by ethnicity (Hammer, Högenauer, Friedman, & Grover, 2020), and Indigenous peoples and people of colour may therefore have side effects that are not "normal" according to previous studies. Through conversations with peers and my own experiences living with HIV, I developed the first research question I intended to explore with CANOC: **Do men, women and transgender individuals experience the same number of antiretroviral therapy treatment changes?**

LITERATURE

When cART is initiated early and properly adhered to without treatment interruptions, HIV viral replication is suppressed which allows for an immune response resulting in a dramatic decrease of HIV viral load (VL) and an increase in the number of CD4 T-lymphocyte cells (Grabar, 2000). However, these outcomes rely on early initiation of cART, continual adherence and lack of treatment disruptions because nonadherence and treatment interruptions are associated with failure to suppress viral load (Li et al., 2005; McNabb et al., 2001), decreased survival (Barrón et al., 2004; Losina et al., 2009) and the development of antiretroviral resistance (Sethi, Celentano, Gange, Moore, & Gallant, 2003).

Previous research has shown that there are important gender differences in the risk of experiencing treatment discontinuation or regimen changes, and have identified female gender as a risk factor for treatment interruptions (Hughes, Mattson, Scheer, Beer, & Skarbinski, 2014; Moore et al., 2010), poor adherence (Puskas et al., 2011; Tapp et al., 2011), and failure to achieve virologic suppression (Geretti et al., 2008). Additionally, women are at a higher risk of experiencing adverse drug reactions (Hoffmann et al., 2017; Prosperi et al.,

2012) and there is some evidence of sex-related differences in cART toxicity (M Floridia, Giuliano, Palmisano, & Vella, 2008).

Indigenous ethnicity has also been identified as a risk factor for treatment interruptions (Samji, Chen, Salters, Montaner, & Hogg, 2014). Furthermore, in a comparison of Indigenous vs non-Indigenous participants in CANOC, Indigenous participants were less likely to achieve viral suppression, and had a shorter time to treatment interruption (Benoit et al., 2017; Jaworsky et al., 2018).

Using data from the CANOC collaboration of individuals on cART in Canada, our aim was to investigate whether the rate of cART changes differs by gender and if the risk of experiencing a regimen change is higher among women and transgender individuals compared to men. Additionally, we also wanted to investigate if the rate of cART changes differs by gender among Indigenous participants and if the risk of experiencing a regimen change is higher among Indigenous women and transgender individuals compared to Indigenous men. Finally, we investigated other sociodemographic factors and clinical characteristics which are associated with a higher risk of experiencing cART regimen changes.

METHODS

Early Learning

To answer my question, I had to navigate working with the analysts, statisticians, and research staff. It was a challenge working from home, feeling disconnected from the BC-CfE, and forming relationships with new staff members over time. Sometimes it was hard to understand the data and technical jargon, the delays, and the shifting roles of individuals at the BC-CfE, however, we were all learning together.

Gaining Momentum

Working together as a team, we learned how to communicate with and listen to each other. We became allies who appreciated and valued the unique strengths each member brought to the team. It was all worth it when the results came back, and I had the “Aha!” moment. My living experience led me to this question, and seeing the results align with that living experience was liberating. I am excited to share my experience and bring the results of my study back to the community in my own way of traditional storytelling and knowledge sharing. Leading research has been a part of healing and a welcome distraction. I find focus in leading and contributing to research and hope my story will help others navigate the research world.

CANOC Study

This retrospective observational study was conducted using data from CANOC, a collaboration of clinical cohorts from research centres, universities, and clinics across Canada of treatment naïve PLWH initiating cART between January 1, 2000 and December 31, 2016 (Palmer et al., 2011). At the time of the study, there were 11 cohorts from the provinces of BC, Saskatchewan, Ontario, Québec and Newfoundland and Labrador. The cohorts included

individuals from all transmission categories and various models of care. More details and specific inclusion criteria has been described previously (Palmer et al., 2011).

For this study, we included those with a known gender (self-reported) and at least 18 months follow up time (n=10,555). Additionally, eligible participants had to have at least one plasma viral load result within 1 year of initiating cART and at least 2 consecutive VL results post-initiation at least 30 days apart to assess suppression. Finally, participants who achieved suppression had to have at least one VL result within one year of suppressing and at least 2 consecutive VL results post-suppression at least 30 days apart, to assess rebound within one year of suppression.

Additionally, we performed a sub analysis comparing men, women and transgender individuals, stratified by Indigenous versus non-Indigenous ethnicity (n=802). Inclusion in this sub-analysis required known ethnicity data, in addition to the above inclusion criteria.

Outcomes

The primary outcome of interest was a cART regimen change, defined as either any drug change or a third drug class change. Changes between brands, including generics, were not counted. To reduce the impact of data artifacts created by overlapping prescriptions, the minimum duration of a cART regimen was set to 30 days and the minimum regimen size was set to three drugs. For our outcome, the primary covariate was gender. Due to the clinic-based setting of CANOC, we are unsure how gender is reported in each clinic. Gender may be self-reported or may default to sex if no gender is indicated.

Statistical Methods

Demographic and clinical characteristics were summarized overall and stratified by gender (men, woman, or transgender), and among Indigenous participants stratified by gender. Frequencies and proportions were used to describe categorical variables (ex. men, women, transgender) and medians (Quartile 2) and interquartile range (Quartile 1 [Q1] – Quartile 3 [Q3]) were used to describe continuous variables (ex. age).

To evaluate if women living with HIV experience more frequent cART regimen changes than men, the mean number of changes per participant was calculated, as well as the rate of change using the mean number of changes by gender over person years of follow up. The association of clinical and social demographic covariates and the incidence (new incidences) of cART changes was estimated using a Poisson regression (Legler & Roback, 2019). Kaplan-Meier curves were used to assess time to first cART regimen changes by gender (Rich et al., 2010).

Univariate and multivariate (multiple covariates) Poisson regression models were used to examine the incidence of cART changes during follow up and the relative risk in women and transgender individuals compared to men. The multivariate explanatory model was adjusted for era of cART initiation, first line regimen categorized by third drug, province, rural or urban location, ever coinfected with hepatitis C, suppression and rebound, gender, nadir CD4 (lowest CD4 count) (per 100 cells/ mm^3) and baseline VL (log10 copies/mL). Explanatory variables were selected based on prior knowledge and model selection was done by a modified backward technique based on Akaike's Information Criterion (AIC) and Type III p-value which finds the best fit mode with significant variables.

Knowledge dissemination

Not only does the CANOC community investigator program work to engage community members in collaborative research initiatives, facilitating opportunities for knowledge translation and exchange activities to make research findings more readily available to community organizations and individuals living with HIV is also highly important. Monthly webinars are hosted that focus on presentation and research skills, after which community investigators are encouraged to present their work and involvement in the program to other members of the program who work across Canada. In preparing this manuscript, our team needed to learn to work together and learn from each other to ensure our findings are understandable and accessible to those who are affected by this work.

Our abstract was accepted for an ancillary event called "The Stats Talk Back" at the Canadian Association for HIV Research (CAHR) 2020 conference, however due to the coronavirus 2019 (COVID-19) pandemic, the event did not take place. We now plan to host this event in 2021 and aim to bring the findings of the current study back to the community, as well as to facilitate conversations around medication side effects in an informal setting to allow event attendees to engage and learn. By including a rotating seat for clinicians, HIV medical professionals as well as individuals with personal experience of treatment side effects who feel comfortable sharing, we hope this event will be a safe space for meaningful dialogue, learning and sharing.

Finally, Claudette was accepted to present the findings from the analysis comparing Indigenous women to Indigenous men at the International AIDS Society Indigenous pre-conference titled Weaving Indigenous Stories, Experience and Resilience (WISER), in July 2020. (link to presentation [start at 1:01]: (https://www.youtube.com/watch?v=euhx1G2RVQk&list=PL3DUDfltV5H3F4JUtVXdB0Y7BrDjyEwRQ&index=8&t=4296s).

RESULTS

Study Population

Of the 13,040 individuals in the CANOC study, 2485 were excluded due to insufficient follow-up time (2008) or insufficient gender (6) or viral load data (471) (Figure 1). This left a total of 10,555 participants included in the study, of which 8728 (82.7%) were men, 1771 (16.8%) were women and 56 (0.5%) were transgender. Demographic and clinical characteristics overall, stratified by gender, are presented in Table 1. Most of the participants were from BC (46.5%), with fewer from Ontario and Quebec (29.0% and 21.3%, respectively). The median duration of time living with HIV was 9 years (Q1-Q3: 5-13 years) overall, and 9 years (Q1-Q3: 5-13 years) for men, 8 years (Q1-Q3: 5-12 years) for women and 7 years (Q1-Q3: 5-11 years) for transgender individuals. Median age at cART initiation was 40 years (Q1-Q3: 33-47 years) overall. Among the participants, 27.3% experienced zero cART regimen changes, 29.3% experienced one change, and 18.8% experienced two changes. The maximum number of cART regimen changes was 17.

The sub analysis compared men, women, and transgender individuals, stratified by Indigenous and non-Indigenous ethnicity. Of the 13,040 individuals in CANOC, a total of 7461 participants with ethnicity information available were included. Our analysis included

802 (10.7%) Indigenous and 6659 (89.3%) non-Indigenous participants. Of the Indigenous individuals, 441 (55.0%) were men, 348 (43.4%) were women and 13 (1.6%) were transgender. Most of the Indigenous participants were from BC (69.6%). The median duration of time living with HIV was 5 years (Q1-Q3: 4-8 years) overall, and median age at cART initiation was 38 years (Q1-Q3: 31-44 years) overall. Among the Indigenous participants, 27.2% experienced zero cART regimen changes; however, 28.3% experienced one change and 19.0% experienced two changes.

cART regimen changes by gender

Both women and transgender individuals experienced a higher mean number of cART regimen changes per participant compared to men (1.95 and 2.09 versus 1.63 mean changes, respectively). Women and transgender individuals also experienced a higher rate of change compared to men (0.26 and 0.27 versus 0.22 mean changes per person year (PY) follow up, respectively) (Table 2). The time to first cART regimen change was significantly different between women, transgender individuals and men (p=0.0001) (Figure 2).

In the univariable Poisson regression model, women had a higher risk of experiencing a cART regimen change compared to men (incident rate ratio (IRR) 1.21 (95% confidence interval (CI) 1.16-1.25) (Table 3). Similarly, transgender individuals had a significantly higher risk of experiencing a cART change compared to men (IRR 1.23 (95% CI 1.03-1.48)). After adjusting for era of cART initiation, first line regimen (categorized by third drug), Province, location participants reside in, ever coinfected with hepatitis C, suppression and rebound, nadir CD4 and baseline VL, the risk of women experiencing a cART regimen change remained significantly higher compared to men (aIRR 1.13 (95% CI 1.08-1.18)) (Table 3).

cART changes of Indigenous participants by gender

Indigenous women experienced a higher crude number of cART regimen changes per participant compared to Indigenous men (1.96 and 1.55 mean changes, respectively). Women also experienced a higher rate of change compared to men (0.28 and 0.24 mean changes per person year (PY) follow up, respectively) (Table 4). Indigenous transgender individuals experienced a higher crude number of cART regimen changes per participant compared to men (1.62 and 1.55 mean changes), however they experienced a lower rate of change compared to men (0.20 and 0.24 mean changes per PY follow up, respectively) (Table 4). The time to first cART regimen change was significantly different between Indigenous women, transgender individuals and men (p=0.027) (Figure 3).

In the univariable Poisson regression model, Indigenous women had a higher risk of experiencing a cART regimen change compared to Indigenous men (IRR 1.19 (95% CI 1.07-1.32) (Table 5). Indigenous transgender individuals did not have a statistically significant risk of experiencing a cART regimen change compared to Indigenous men (IRR 0.85 (95% CI 0.55-1.31)). After adjusting for era of cART initiation, first line regimen (categorized by third drug), Province, location participants reside in, ever coinfected with hepatitis C, country of birth, baseline CD4, suppression and rebound, age at first cART initiation and baseline VL, the risk of Indigenous women experiencing a cART regimen change remained significantly higher compared to Indigenous men (aIRR 1.13 (95% CI 1.01-1.28)) (Table 5).

Other factors associated with cART regimen changes

In the univariable Poisson regression model, the risk of experiencing a cART regimen change was significantly higher if VL suppression was not achieved, compared to those who achieved VL suppression within 12 months of cART initiation and did not rebound in the following 12 months (IRR 1.37 (95% CI 1.28-1.46)). After adjusting in the multivariable model, the risk remained significantly higher (aIRR 1.30 (95% CI 1.23-1.40)).

Additionally, the risk of experiencing cART changes was significantly higher for individuals with a higher baseline VL compared to those with a lower baseline VL (IRR 1.11 (95% CI 1.08-1.14)) and remained significantly higher in the multivariable model (aIRR 1.08 (95% CI 1.05-1.12)).

Compared to individuals on non-nucleoside reverse transcriptase inhibitor (NNRTI) first line regimens, the risk of experiencing cART changes was significantly higher among individuals with protease inhibitor (PI) first line regimens (IRR 1.27 (95% CI 1.23-1.31)). The risk remained significantly higher in the multivariable model (aIRR 1.21 (95% CI 1.17-1.25)).

DISCUSSION

The overarching goal of the CANOC community investigator program is to "improve treatment quality, health outcomes and engagement with care for individuals living with HIV in Canada" (BC Centre for Excellence in HIV/AIDS, n.d.). The program takes a participatory action approach by involving community members in the research process and ensuring the research reflects what the community wants to see changed or feels is a gap from their own personal experiences. Additionally, the program aims to ensure research findings are more available to community organizations and individuals living with HIV by facilitating knowledge translation activities that allow for capacity building and reciprocal learning between the community investigators and scholars (BC Centre for Excellence in HIV/AIDS, n.d.).

Here we present one example of how this program creates opportunities for working together, learning from each other and ultimately ensuring our research findings are relevant and available to the communities we serve. There is growing support for and emphasis of the importance of using community based participatory action and strength-based research methodologies to include Indigenous peoples in research processes (Cargo & Mercer, 2008; Hyett et al., 2018). Dr. Caxaj demonstrates the great potential of creating community driven, ethically sound research processes by using participatory action and storytelling approaches together that foster relationships, transparent knowledge exchange and flexibility (Caxaj, 2015). Claudette, an Indigenous CANOC community investigator, experienced treatment changes herself and heard stories of others experiencing the same thing which led her to ask the question of whether the rate of cART regimen changes differs by gender. Through traditional storytelling and with her own way of knowledge sharing, Claudette will host an event to share our findings with the community and bring a voice and a name to the individuals who make up the statistics.

Our findings corroborated Claudette's experience and suggest that women and transgender individuals experience a significantly higher rate of cART treatment changes compared to men in Canada, overall as well as within the subpopulation of Indigenous individuals. Our

findings also support the findings of several other studies conducted in smaller samples and subpopulations in the United states and Canada (Hughes et al., 2014; Jaworsky et al., 2018; Moore et al., 2010; Touloumi et al., 2006).

One possible explanation for our findings could be that women experience more frequent and severe adverse reactions to ART (Ofotokun & Pomeroy, 2003). Women are more likely to experience side effects such as lactic acidosis while on nucleoside reverse transcriptase inhibitors, rashes while on non-nucleoside reverse transcriptase inhibitors, and gastro-intestinal intolerance, lipodystrophy, metabolic disorders and hypertension while on protease inhibitors compared to men (Ofotokun & Pomeroy, 2003). Experiencing side effects has been found to be a main contributor to why PLWH experience treatment changes (Prosperi et al., 2012; Swiss HIV Cohort study et al., 2010), thus if women are experiencing more adverse side effects it may partly explain why they experience more treatment changes. While it is not entirely clear why women experience more side effects to cART compared to men, differences in body weight and composition, as well as hormonal differences in women and their effect on drug metabolism have been suggested (M Floridia et al., 2008; Ofotokun & Pomeroy, 2003). Despite these differences between men and women which may influence drug response, tolerability and toxicity, many of the HIV clinical trials evaluating the efficacy and tolerability of cART have included mostly men. One systematic review looking at the participation of women in ART clinical trials published between 1994 and 2011 found the median female participation was 19.2% (0-94.2%) in 387 trials. Additionally, despite both men and women being eligible to participate, 11(2.8%) of the trials enrolled only men (Curno et al., 2016). Since the dosage of cART is the same regardless of gender or body weight, this may help to explain why women are more likely to experience more frequent side effects to cART, and thus more treatment changes compared to men.

Another possible explanation for our finding that women experience a higher rate of cART regimen change compared to men could be a result of pregnancy. A study in Italy showed that women who unexpectedly became pregnant experienced more regimen changes to switch to a regimen that was safer for both the mother and the developing foetus (Marco Floridia et al., 2006). While in the current study we do not have data on pregnancy, it is plausible that we may see a higher rate of change among women of a reproductive age compared to those outside of the reproductive age group.

A possible explanation for our finding that transgender individuals experience a higher rate of cART regimen change compared to men could be a result of interactions between cART and hormone treatment which may have an impact on side effects (Sevelius, Carrico, & Johnson, 2010). Additionally, the differences we saw may be influenced by the high priority transgender individuals place on transition-related care, including hormone therapy, over their HIV-related care (Kammerer, Mason, Connors, & Durkee, 2001).

In addition, there was a higher proportion of men (80%) compared to women (66%) and transgender individuals (59%) who achieved viral suppression and remained virally suppressed (did not experience viral rebound within 12 months of suppression). One of the most common reasons for a physician to recommend a cART regimen change is due to virologic failure (Kempf et al., 2009). Thus, another possible reason to explain the higher rate of cART regimen changes could be that women and transgender individuals were more likely to not achieve viral suppression and were also more likely to experience VL rebound within 12 months of viral suppression compared to men.

While physiological differences may partly explain the difference we saw in the number and rate of cART regimen changes between women, transgender individuals and men, other demographic and psychosocial factors also have an impact on ability to access, adhere to or remain on cART. Financial hardship, unemployment, and unstable housing, all indicators of lower socioeconomic status, have been shown to be strongly associated with cART non-adherence in a setting of universal access to health care (Burch et al., 2016). These factors may also influence the rate of treatment changes and may differentially impact women and Indigenous women compared to men.

The CANOC community investigator program supported Claudette to develop her research question, identify the important components of the work she does, and share her work in multiple ways that ensures her findings are shared with the community in a way that is meaningful to her. From her living experience, she knows how important this research question is to many PLWH and she is very happy to be able to share these important findings.

Strengths and limitations

A considerable strength of this study was that the entire research process—from identifying the question, to bringing findings back to the community—was led by an Indigenous elder. Claudette helped the team honour the sentiment of "nothing about us without us." However, the journey wasn't always so easy. Our team members have different education, work and life experience so it was not always clear how to effectively and efficiently collaborate together. Additionally, COVID-19 impacted everyone differently and we had to adjust to working and collaborating remotely. We learned the importance of being patient with each other and meeting people where they are at. Listening to each other's stories and taking the time to get to know each other helped us identify each other's strengths and enabled us to work cohesively as a team, as outlined in the teachings of the beaver:

> "In building a dream, teamwork is necessary. To accomplish a goal with others involves working with the group mind.
>
> Group mind constitutes harmony of the highest order, without individual egos getting in the way.
>
> Each partner in the project honours the talents and abilities of the others, and know how to complete the piece of the puzzle that belongs to them.
>
> In working well with others, a sense of community is achieved and unity ensues." (Sams & Carson, 1988)

In terms of limitations, CANOC enrols participants who are linked to and retained in care as it is a clinic-based cohort. As such, women and Indigenous peoples living with HIV may be missed by the cohort as they are less likely to be linked to care and on cART. This may have led to an underestimation of the risk of experiencing cART regimen changes among women and Indigenous peoples. Additionally, data from BC is population based, and captures all individuals on cART in the province, from a variety of health care settings. In other provinces, CANOC cohorts are clinic based and may not include a fully representative sample of PLWH who access care outside of specialized HIV or infectious disease clinics. Finally, because CANOC is comprised of linked cohorts across Canada, gender data may be recorded and collected differently by province and by clinic.

CONCLUSION

Our findings demonstrate the importance of recognizing all ways of knowing. Awareness, connectedness, and growth gave us the strength to create this work of research. Empowering the community and honouring the 'nothing about us without us' approach created an amazing collaborative environment which unified our team. Our findings show that women and transgender individuals within the context of the publicly funded Canadian health care system experience a higher rate of change and are more likely to experience cART regimen changes compared to men. Remaining on cART and adhering with minimal or no treatment interruptions is critical to HIV prognosis and outcomes. Given that the rate of HIV diagnoses in Canadian women is rising, targeted interventions and better communication between health care providers and women should be implemented.

TABLES AND FIGURES

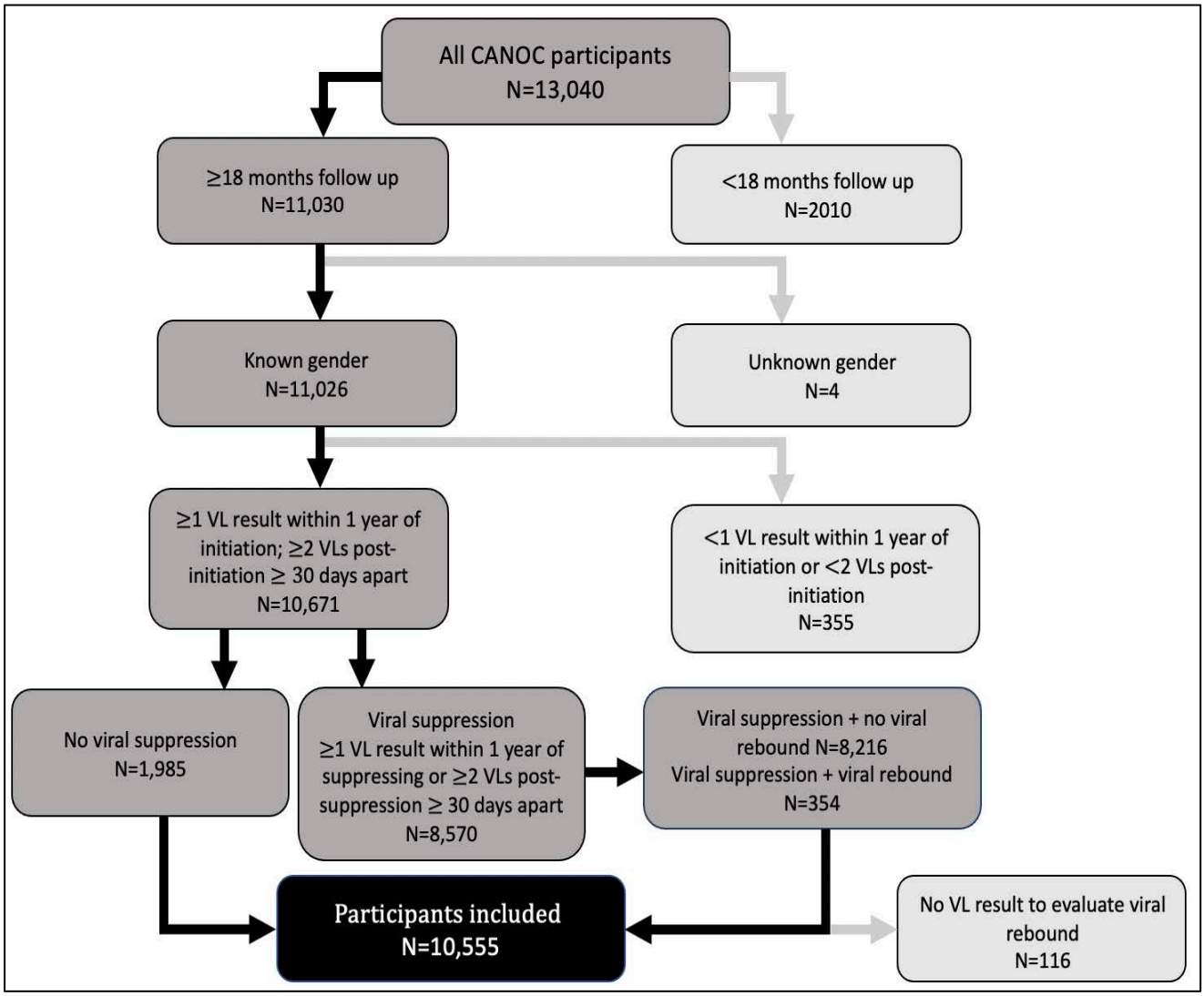

Figure 1. Flow chart of participants included in the study from the entire CANOC collaboration.

Table 1. Demographic and baseline clinical characteristics by gender and overall

Variable	Overall (N=10,555) N (%) or median (Q1-Q3)	Men (N=8728) N (%) or median (Q1-Q3)	Women (N=1771) N (%) or median (Q1-Q3)	Transgender (N=56) N (%) or median (Q1-Q3)
Any cART changes since cART initiation				
Yes	7677 (72.7)	6298 (72.2)	1338 (75.6)	41 (73.2)
No	2878 (27.3)	2430 (27.8)	433 (24.4)	15 (26.8)
Number of cART changes since initiation				
0 (No changes)	2878 (27.3)	2430 (27.8)	433 (24.4)	15 (26.8)
1	3088 (29.3)	2627 (30.1)	449 (25.4)	12 (21.4)
2	1987 (18.8)	1632 (18.7)	343 (19.4)	12 (21.4)
3	1237 (11.7)	993 (11.4)	237 (13.4)	7 (12.5)
>3	1365 (12.9)	1046 (9.9)	309 (2.9)	10 (0.1)
Age at first cART initiation (years)	40 (33.0-47.0)	40 (33.0-47.0)	36 (30.0-44.0)	37 (30.5-41.5)
Province				
BC	4907 (46.5)	3946 (45.2)	923 (52.1)	38 (67.9)
Saskatchewan	272 (2.6)	161 (1.8)	111 (6.3)	<5
Ontario	3058 (29.0)	2510 (28.8)	530 (29.9)	18 (32.1)
Quebec	2245 (21.3)	2048 (23.5)	197 (11.1)	<5
Newfoundland	73 (0.7)	63 (0.7)	10 (0.6)	<5
Born in Canada				
Yes	2164 (20.5)	1810 (20.7)	342 (19.3)	12 (21.4)
No	1389 (13.2)	987 (11.3)	394 (22.2)	8 (14.3)
Unknown	7002 (66.3)	5931 (68.0)	1035 (58.4)	36 (64.3)
Location participant resides in				
Urban	9447 (89.5)	7858 (90.0)	1538 (86.8)	51 (91.1)
Rural	544 (5.2)	444 (5.1)	96 (5.4)	<5
Unknown	564 (5.3)	426 (4.9)	137 (7.7)	<5
Era of cART initiation				
2000-2003	1896 (18.0)	1528 (17.5)	347 (19.6)	21 (37.5)
2004-2007	2485 (23.5)	2046 (23.4)	429 (24.2)	10 (17.9)

2008-2011	3650 (34.6)	3050 (34.9)	587 (33.1)	13 (23.2)
2012-2016	2524 (23.9)	2104 (24.1)	408 (23.0)	12 (21.4)
First line regimen categorized by third drug				
NNRTI	4475 (42.4)	3810 (43.7)	648 (36.6)	17 (30.4)
PI	4725 (45.8)	3728 (42.7)	970 (54.8)	27 (48.2)
IIN	928 (8.8)	822 (9.4)	100 (5.6)	6 (10.7)
Other	427 (4.1)	368 (4.2)	53 (3.0)	6 (10.7)
Ever coinfected with Hepatitis C				
Yes	2581 (24.5)	1857 (21.3)	703 (39.7)	20-25
No	7591 (71.9)	6602 (75.6)	956 (54.0)	33 (58.9)
Unknown	383 (3.6)	269 (3.1)	112 (6.3)	<5
Duration of time living with HIV (years)	9 (5.0-13.0)	9 (5.0-13.0)	8 (5.0-12.0)	7 (5.0-11.0)
Baseline VL (Log10 copies/mL)	4.9 (4.4-5.0)	4.9 (4.4-5.0)	4.6 (4.1-5.0)	4.9 (4.3-5.0)
Baseline CD4 (cells/mm^3)				
< 200	4047 (38.3)	3282 (37.6)	734 (41.4)	31 (55.4)
>= 200	6508 (61.7)	5446 (62.4)	1037 (58.6)	25 (44.6)
Nadir CD4 (cells/mm^3)	202 (90.0-320.0)	210 (100.0-329.0)	170 (70.0-282.0)	120 (30.0-265.0)
Suppression and rebound				
VL suppressed within 12 months and no rebound within 12 months after it	8216 (77.8)	7015 (80.4)	1168 (66.0)	33 (58.9)
VL rebound within 12 months after suppressing within 12 months	354 (3.4)	229 (2.6)	121 (6.8)	<5 (7.1)
Did not achieve VL suppression within 12 months	1985 (18.8)	1484 (17.0)	482 (27.2)	15-20

cART=combined Antiretroviral therapy; BC=British Columbia; NNRTI=Non-Nucleoside Reverse Transcriptase Inhibitor; PI=Protease Inhibitor; INI=Integrase Inhibitors; VL=viral load

Table 2. Total and mean number of cART changes and rate of cART changes by gender.

	All participants	Men	Women	Transgender
N	10555	8728	1771	56
Total number of changes	17839	14270	3452	117
Mean number of changes per participant	1.69	1.63	1.95	2.09
p value*	-	-	<0.0001	0.011
Person years of follow up	78807.91	65285.56	13087.29	435.06
Rate of change per person year	0.23	0.22	0.26	0.27
p value*	-	-	<0.0001	0.031

cART=combination antiretroviral therapy

**comparing between men and women and men and transgender individuals*

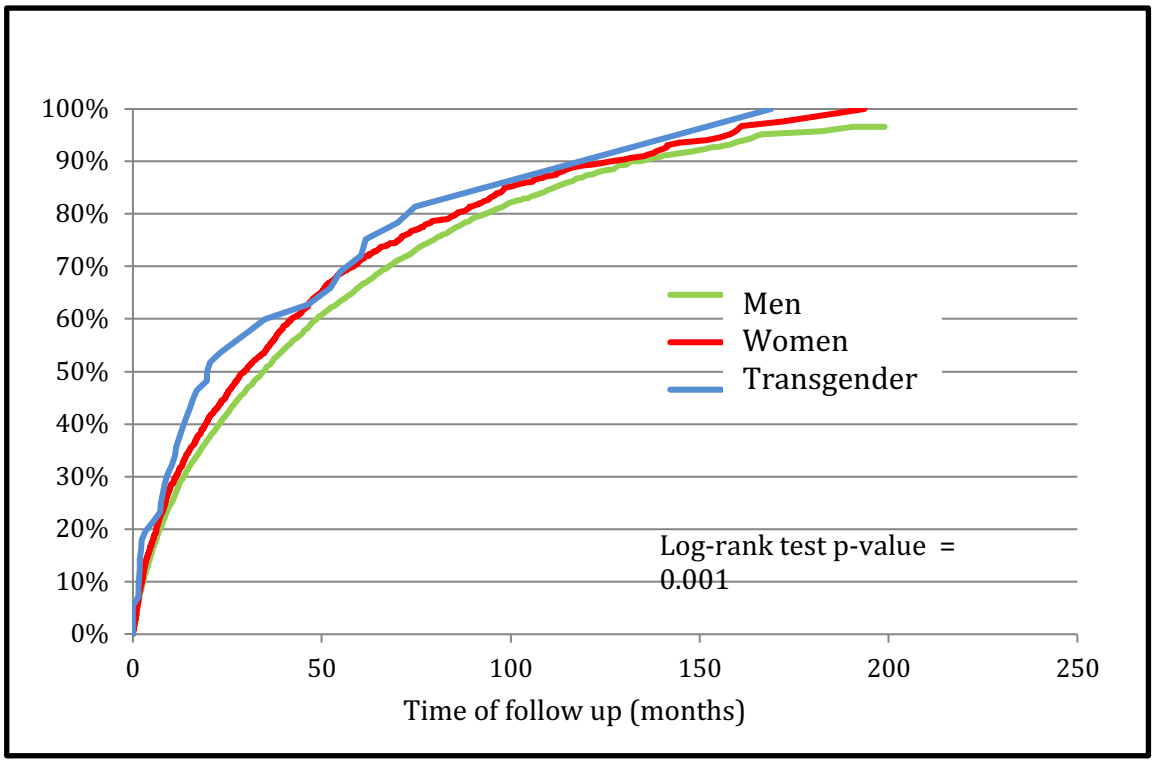

Figure 2. Probability of cART regimen changes by gender. Kaplan Meier curve of time to first combined antiretroviral therapy (cART) regimen change by gender.

Table 3. Univariable and multivariable cART regimen changes using Poisson regression model (n=10,555)

Variable	Unadjusted	Adjusted
	IRR (95% CI)	IRR (95% CI)
Gender		
Men	ref	ref
Women	1.21(1.16, 1.25)	1.13(1.08, 1.18)
Transgender	1.23(1.03, 1.48)	1.08(0.89, 1.3)
Age at first cART initiation (per 20 years)	0.96(0.94, 0.99)	-
Province		
BC	ref	ref
Saskatchewan	1.07(0.95, 1.2)	1.01(0.88, 1.17)
Ontario	0.98(0.94, 1.01)	1.04(1, 1.08)
Quebec	0.97(0.93, 1)	1.06(1.01, 1.1)
Newfoundland	1.05(0.87, 1.27)	1.05(0.87, 1.28)
Country of birth is Canada		
Yes (Canada born)	ref	-
No	0.95(0.9, 1)	-
Unknown	0.95(0.92, 0.99)	-
Location participant resides in		
Urban	ref	ref
Rural	0.95(0.89, 1.02)	0.94(0.88, 1.01)
Era of cART initiation		
2000-2003	ref	ref
2004-2007	0.95(0.91, 0.99)	0.97(0.93, 1.01)
2008-2011	0.82(0.79, 0.85)	0.93(0.89, 0.97)
2012-2016	1.05(0.99, 1.1)	1.26(1.19, 1.34)
First line regimen categorized by 3rd drug		
NNRTI	ref	ref
PI	1.27(1.23, 1.31)	1.21(1.17, 1.25)
IIN (integrase)	0.96(0.88, 1.05)	0.9(0.82, 0.99)
Other	1.5(1.41, 1.6)	1.41(1.31, 1.5)
Ever coinfected with Hepatitis C		
Yes	ref	ref
No	0.89(0.86, 0.92)	0.96(0.92, 0.99)
Baseline VL (Log10 copies/mL)	1.11(1.08, 1.14)	1.08(1.05, 1.12)
Baseline CD4 (cells/mm^3)		

< 200	ref	-
>= 200	0.89(0.86, 0.92)	-
Nadir CD4 (per 100 cells/mm^3)	0.94(0.93, 0.95)	0.97(0.96, 0.98)
Suppression and rebound		
VL suppressed within 12 months and no rebound within 12 months after it	ref	ref
VL rebound within 12 months after suppressing within 12 months	1.37(1.28, 1.46)	1.3(1.21, 1.4)
Did not achieve VL suppression within 12 months	1.43(1.38, 1.48)	1.33(1.28, 1.38)

IRR=Incidence rate ratio; 95% CI=95% Confidence interval; cART=combined antiretroviral therapy; BC=British Columbia; NNRTI=Non-Nucleoside Reverse Transcriptase Inhibitor; PI=Protease Inhibitor; INI=Integrase Inhibitors; VL=viral load

Table 4. Total and mean number of cART regimen changes and rate of cART regimen change by gender among Indigenous participants

	All participants	**Men**	**Women**	**Transgender**
N	802	441	348	13
Total number of changes	1385	682	682	21
Mean number of changes per participant	1.73	1.55	1.96	1.62
Person years of follow up	5434.12	2896.94	2432.19	104.99
Rate of change per person year	0.25	0.24	0.28	0.20

cART= combined antiretroviral therapy

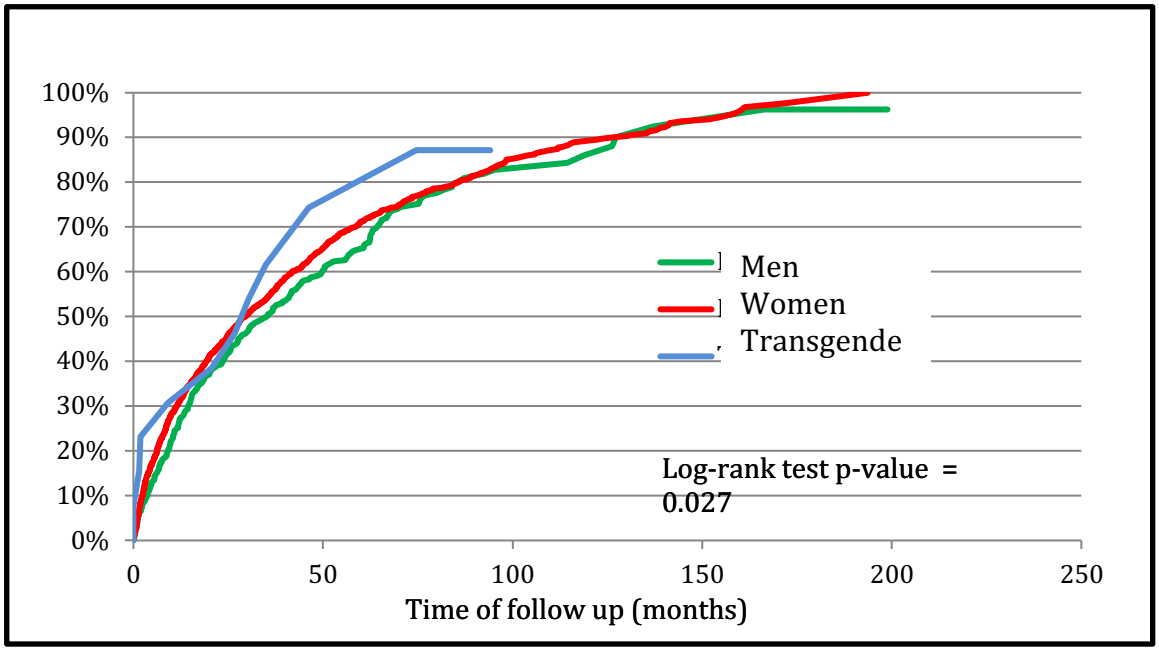

Figure 3. Probability of cART regimen changes by gender among Indigenous participants. Kaplan Meier curve of time to first combined antiretroviral therapy (cART) regimen change by gender among Indigenous participants.

Table 5: Univariable and multivariable cART regimen changes among Indigenous participants using Poisson regression model (n=802)

	Unadjusted	Adjusted
Variable	**IRR (95% CI)**	**IRR (95% CI)**
Gender		
Men	ref	ref
Women	1.19(1.07, 1.32)	1.13(1.01, 1.28)
Transgender	0.85(0.55, 1.31)	0.89(0.57, 1.39)
Province		
BC	ref	ref
Saskatchewan	1.04(0.89, 1.21)	1.01(0.81, 1.27)
Ontario	0.85(0.71, 1.02)	0.94(0.78, 1.14)
Quebec	1.14(0.66, 1.97)	1.15(0.66, 2.01)
Country of birth is Canada		
Yes (Canada born)	ref	ref
No	0.95(0.6, 1.5)	0.97(0.61, 1.55)
Unknown	0.86(0.78, 0.96)	0.92(0.8, 1.05)

Location participant resides in		
Urban	ref	ref
Rural	1.16(0.98, 1.36)	1.18(0.98, 1.41)
Era of cART initiation		
2000-2003	ref	ref
2004-2007	0.98(0.85, 1.13)	1(0.86, 1.17)
2008-2011	0.8(0.7, 0.92)	0.88(0.75, 1.04)
2012-2016	1.01(0.86, 1.2)	1.18(0.95, 1.47)
First line regimen categorized by 3rd drug		
NNRTI	ref	ref
PI	1.06(0.95, 1.18)	1.05(0.93, 1.19)
IIN (integrase)	0.83(0.55, 1.26)	0.84(0.52, 1.37)
Other	1.16(0.87, 1.56)	1.04(0.76, 1.43)
Ever coinfected with Hepatitis C		
Yes	ref	ref
No	0.86(0.75, 0.98)	0.96(0.83, 1.11)
Baseline CD4 (cells/mm^3)		
< 200	ref	ref
>= 200	0.84(0.76, 0.94)	1.33(1.05, 1.67)
Suppression and rebound		
VL suppressed within 12 months and no rebound within 12 months after it	ref	ref
VL rebound within 12 months after suppressing within 12 months	1.38(1.13, 1.69)	1.33(1.05, 1.67)
Did not achieve VL suppression within 12 months	1.54(1.38, 1.72)	1.48(1.31, 1.68)
Age at first cART initiation (per 20 years)	0.91(0.81, 1.02)	1.07(0.93, 1.22)
Baseline VL (Log10 copies/mL)	1.10(1, 1.21)	1.11(0.99, 1.24)

IRR=Incidence rate ratio; 95% CI=95% Confidence interval; cART=combined antiretroviral therapy; BC=British Columbia; NNRTI=Non-Nucleoside Reverse Transcriptase Inhibitor; PI=Protease Inhibitor; INI=Integrase Inhibitors; VL=viral load

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