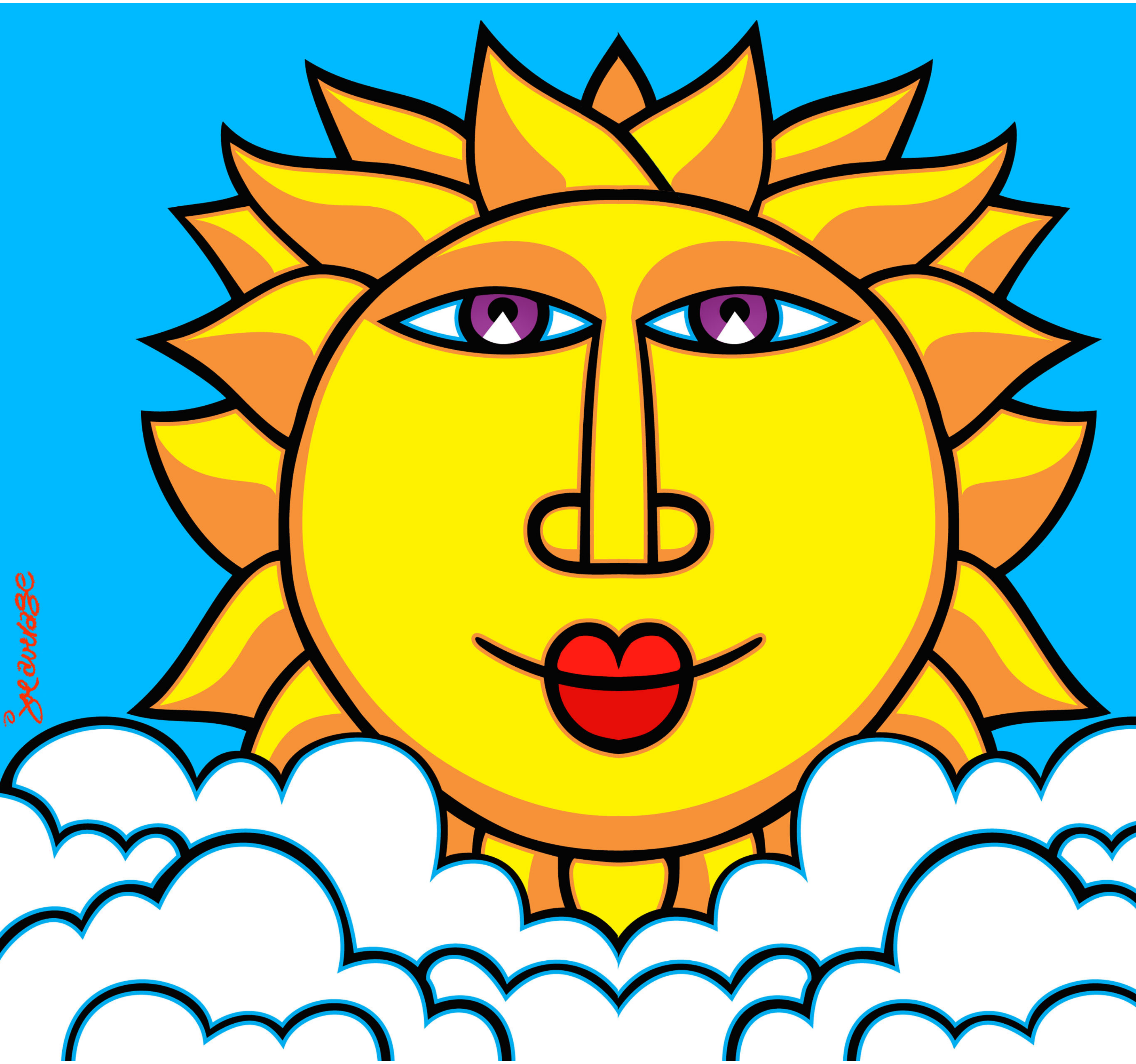
Eng/aging and HIV

Knowledge Exchange Between Administrative Data Researchers, Older Adults Living with HIV and Stakeholders in British Columbia



With gratitude to Joe Average for letting us reproduce this image to this project
https://www.joeaverage.ca/

BRITISH COLUMBIA
CENTRE *for* EXCELLENCE
in HIV/AIDS

COAST

Acknowledging

We respectfully acknowledge the unceded Traditional Ancestral Territories, lands and waters of the Coast Salish peoples. We honour the xʷməθkʷəy̓əm (Musqueam̱), Sḵwx̱wú7mesh Úxwumixw (Squamish), səl̓ilw̓ətaʔɬ (Tsleil-Waututh), q̓íc̓əy̓ (Katzie), kʷikʷəƛ̓əm (Kwikwetlem), Qw’o:ntl’an (Qayqayt), q’ʷa:n̓ƛ̓’ən̓ (Kwantlen), Semiahmoo, and sc̓əwaθən məsteyəx (Tsawwassen) whose lands on which we live, work, play and learn.

Contents:

Mitacs

vancouver foundation

MICHAEL SMITH FOUNDATION FOR HEALTH RESEARCH
Discover. Connect. Engage.

SFU CERi
COMMUNITY-ENGAGED RESEARCH

What is COAST?

Our Eng/aging and HIV research project engages with a study called The Comparative Outcomes And Service Utilization Trends (COAST) Study. COAST assembles **administrative health data**—that is, data that is generated at every encounter with the health care system for administrative or billing purposes—and other kinds of data collected from all known people living with HIV in B.C. over 19 years of age and a 10% random sample of the entire B.C. adult population. The number of participants is a rough estimate right now because the data is so new, but the total number of people living with HIV >19 in BC is estimated at 15,624 and the 10% random sample of B.C. adults is estimated at 626,687.

COAST has two major aims:

1. To evaluate (changes in) health status related to HIV treatment and health care services use among adults living with HIV.
2. To assess how these (changes in) health status differ from those observed in a random sample of the general BC population.

To achieve these aims, COAST pulls together different kinds of data from 17 separate sources.

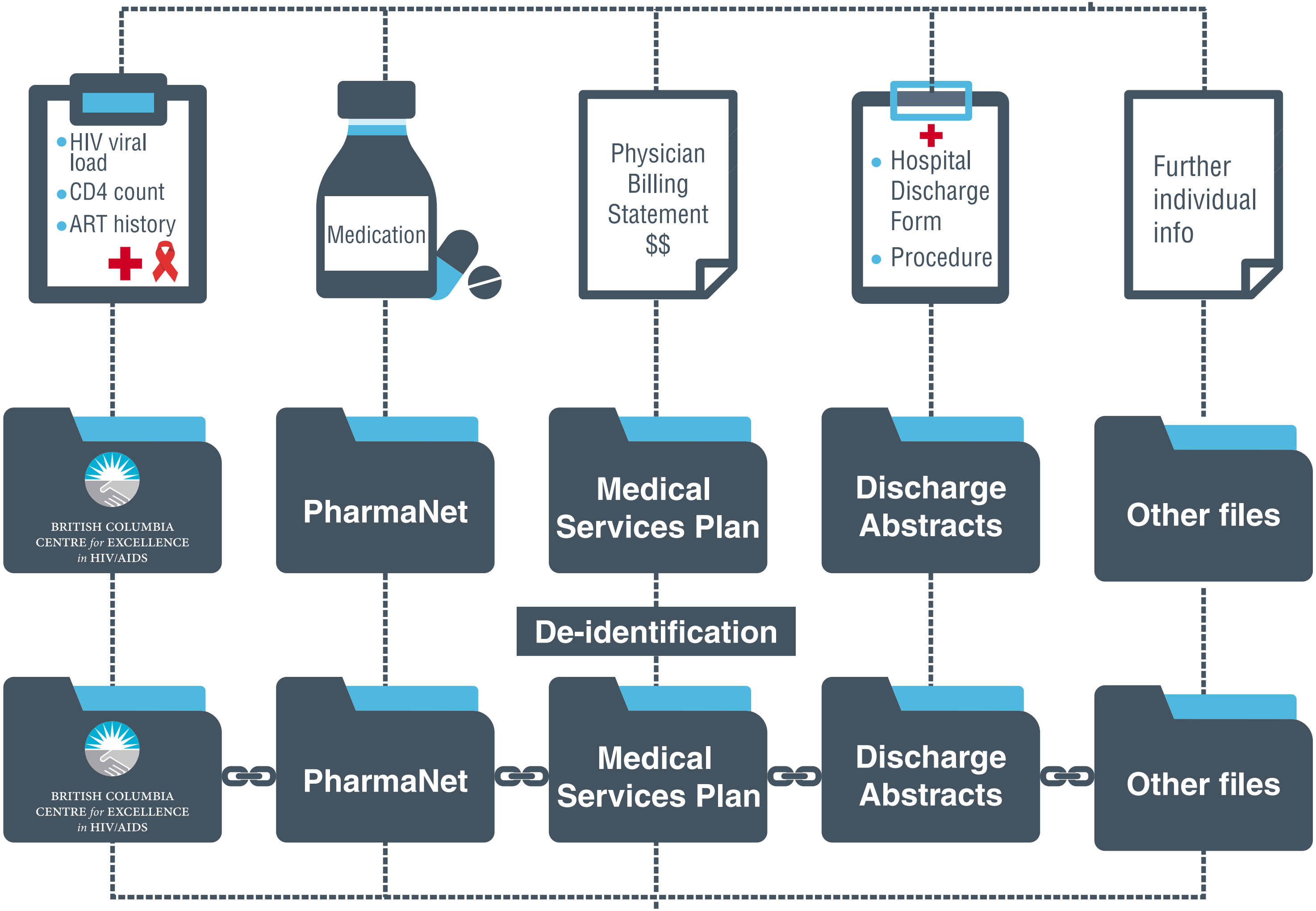
The majority of COAST data is administrative health data. When an individual interacts with the B.C. health care system, their information is collected largely for billing purposes. For example, following one's visit with their physician, the physician (or physician's assistant) will enter a code assigned to the particular diagnosis, symptom, or procedure related to one's visit into an individual's file in the computer system, e.g. HIV-related code, routine clinical visit code. Each code has a billing or payment cost associated with it. Depending on the system in place, many outpatient physicians, for example, get paid based on which codes they submit. Other individual data like prescription drug information and hospital discharge information, for example, is also collected.

For a full description of the 17 sources and types of data assembled in COAST, see our virtual project folder in SFU Vault.

Individuals' information gathered at each source is called a **data set**. Data sets from each source are shared and combined to create **linked data**: COAST links records belonging to the same individual across these various sources and over time (1992-2020).

When linked data are used for research purposes like in COAST, they are **de-identified** to reduce the chance that they could be traced back to any specific individual.[1]

How COAST data comes together:



- HIV viral load
- CD4 count
- ART history

Medication

Physician Billing Statement $$

- Hospital Discharge Form
- Procedure

Further individual info

BRITISH COLUMBIA CENTRE *for* EXCELLENCE *in* HIV/AIDS

PharmaNet

Medical Services Plan

Discharge Abstracts

Other files

De-identification

BRITISH COLUMBIA CENTRE *for* EXCELLENCE *in* HIV/AIDS

PharmaNet

Medical Services Plan

Discharge Abstracts

Other files

New linked data set

COAST

Research Team

What can we know from COAST

The data from each source can be combined to provide a broad range of information--clinical, social, economic, and ecological factors--associated with the health of British Columbians and more specifically, people living with HIV in B.C. This can advance our understanding of the complexity of living with HIV. The potential scope of COAST includes:

HIV cascade of care:

HIV treatment, viral suppression

Healthcare utilization and resources:

healthcare costs, hospital admissions

Health outcomes:

mortality rates, life expectancy, injuries

Aging and comorbidities:

cancers, cardiovascular diseases, chronic respiratory diseases, liver diseases, renal diseases

Mental health:

mood disorders, schizophrenia

What kinds of research questions can be asked

The following are examples of research questions using COAST:

Example 1:

What did we ask?

What are the main causes of death among people living with and without HIV from 1996-2012? Have causes of death changed over time?

What traits did we look at?

Age, sex, and whether people had ever been on HIV treatment.

What did we find?

- Despite the remarkable decline in death from HIV-related causes, HIV/AIDS is still the leading cause of death among people living with HIV

- The second major cause of death is cancers. This is also the leading cause of death among HIV-negative individuals.

- People living with HIV remain at a higher risk of death compared to those living without HIV.

What does this mean?

- We need more research about mortality causes and rates to better prevent and manage illness and death.

- Prevention and management of cancers and heart conditions is key to improving lifespan among both people living with and without HIV.

For full details see: Oghenowede,E. et al. (2017). 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 Infectious Diseases,* 17:174

Example 2:

What did we ask?

How many adults living with HIV on treatment were newly ill with more than one long-term illness from 2000-2012? Have trends changed over time?

What traits did we look at?

Age, sex, ethnicity, sexual orientation, injection drug use.

What did we find?

- The number of people who got high blood pressure greatly increased (nearly doubled) from 2000 to 2012

- People over 50 years old got long-term illnesses much more than younger folks

- The number of people who got kidney disease and liver disease decreased

- The number of people who got diseases of the heart and blood vessels, diabetes, and asthma/lung diseases stayed roughly the same.

What does this mean?

- These trends are somewhat reassuring for an aging population of people living with HIV.

- However, the high number of people living with HIV who had more than one long-term illness means we need to make more efforts to ensure healthy aging among people living with HIV.

For full details see: Gali, B. et al. (2019). Incidence of Select Chronic Comorbidities among a Population-based Cohort of HIV-Positive Individuals Receiving Highly Active Antiretroviral Therapy. *Current Medical Research and Opinion*, 35(11): 1955-1963.

Why COAST is exciting!

COAST is one of the world's largest and most robust datasets of people living with HIV in comparison to the general population. This is due to B.C.'s universal, publicly-funded health care system and universal access to HIV treatment in B.C. Unlike many other countries and Canadian provinces, in B.C. people living with HIV have access to HIV treatment at no cost and all eligible residents have access to health care services and medication through B.C.'s publicly-funded healthcare system. This means there is a uniquely large, diverse population using the B.C. health care system, including HIV treatment, that COAST can keep track of over a long period of time.

COAST is an opportunity to generate useful evidence about living with HIV over time with the potential to produce changes that have a positive impact on health.

Community experts bring COAST research "home"

~ Greater Involvement of People Living with HIV

Since the 1980s, HIV/AIDS community groups have engaged with science to ensure that research is done with them instead of simply about them,[2] yet is is rare for communities to engage with administrative data studies like COAST.[3] Our collaborative project embraces how to embody the "nothing about us without us" principle in administrative data studies to ensure ongoing authentic engagement across all HIV research.

The numeric data COAST generates is highly valuable, but its full potential can only be gained through the guidance of people who actually live the reality of aging with HIV every day.This project aims to engage older adults living with HIV, care providers, and other researchers in COAST to ensure COAST's research is ethical, valid, and meaningful to people living with HIV in all their diversity--deepening our understanding of issues related to aging and HIV. This project hopes to mobilize knowledge about aging with HIV to improve health services and health outcomes for people living with HIV.

People living with HIV are experts in their field and community and can teach researchers and academics as well as learn from them. In this spirit of reciprocity, we are "bridging capacity" or bridging our worlds of expertise.[4]

Community-based research like ours is not often done with administrative data. We have the potential to significantly contribute to research on aging and HIV and we're breaking new ground in the way that we do this—by bringing the data back to the people it is about: people living with HIV and British Columbians.

~ Aging and HIV

To an unprecedented degree in the history of HIV/AIDS, people living with HIV are aging largely owing to the success of HIV treatment. In North America, over 50% of people living with HIV are now over the age of fifty.[5,6] Two decades ago, only 10% of people living with HIV were over the age of fifty in B.C.[7] In many regions, HIV is no longer deemed a fatal diagnosis; rather, it is increasingly regarded as a chronic illness.[8,9,10] Individuals on treatment are living to similar ages as the general population.[11]

In tandem with the increase of people aging with HIV, research on this topic is only just emerging. Because COAST is able to track people's health and health service use over a long period of time, it has the potential to tell us about people's health as they age. Our council is poised to contextualize COAST's numeric data and significantly contribute to knowledge about HIV and aging, which is not yet well understood. We can identify where and how to focus efforts to improve well-being.

What is your role in the project?

Aging and HIV: Data query and analysis

You are a member of the research council that will guide our research about aging and HIV. As a Council, we will meet regularly via virtual meetings (until further notice) and electronic communications to co-develop and carry out our research plan. This will include sharing our experiences, knowledge, and interests about aging with HIV, particularly honouring the perspectives of council members who are older adults living with HIV. Together we will translate these into one to two research questions that can be answered with the COAST data (administrative data can be limited).

We will complete and submit one to two “data analysis request” forms based on our research questions. COAST analysts and statisticians will calculate and analyze the data, which they will present to us in numeric form. We will interpret this data – that is, try to understand and explain what these numbers reveal about aging with HIV. Our insight and experiences will inform and enrich this data.

We will develop and carry out a plan to disseminate and mobilize our findings (e.g. publications, presentations, community forum).

Community Engagement in COAST: Structured Reflexivity

As we conduct this research, we will critically reflect on and analyze our process in real time. Why? Community engagement in administrative data research is not common; therefore, our research process will itself serve as research regarding the effectiveness and challenges of this particular kind of project. What is valuable about our project? What are the challenges? What could we have done better? How did we feel about being a part of it? From our experience, what can we teach others who wish to do community-based research using administrative data?

In meetings we can share our thoughts and feelings about the project and through this process, we will be able to develop evaluation strategies together.

Collaborative and emergent research

As a council, members will actively shape the research. The project will therefore be **emergent**; that is, it will evolve through continual mutual learning amongst the council through back and forth exchange. Hence, the term, **“knowledge exchange”** in the project title (as an aside, the title is up for change based on council consensus). Knowledge exchange represents what we are doing as a council—coming together to co-plan, produce, and mobilize knowledge we create together by sharing and learning from one another.

First steps

Our council is coming together for initial meetings. During these meetings we will: do introductions; develop ground rules to establish a safer atmosphere that promotes active listening and open dialogue; start to learn about COAST and administrative health data (i.e. through presentation(s)); start to learn about the field of knowledge exchange (i.e. through presentation(s)); and develop a research plan and schedule.

You can read all COAST research findings to date in our virtual project folder in SFU Vault.

Glossary of Terms

Administrative health data: Data collected in the course of providing and/or paying for health services.

Data set: a collection of data that has been gathered using the same criteria.

De-identified data: Data where the personal identifiers of the individuals have been removed with the intent of minimizing the chance of re-identification.

Emergent research: Research that evolves over the course of a project in response to learning new ideas, concepts, or findings. It is a flexible approach that allows for ongoing changes as appropriate to project developments.

Knowledge exchange: Collaborative research design, inquiry, analysis, and mobilization of knowledge between researchers, research users, and decision makers (not mutually exclusive categories) through mutual learning and interaction. The goal is to apply knowledge gained to improve the health and quality of life of older adults living with HIV.

Linked data: a collection of data, usually for research purposes, that combines two or more differences sources.

Council Directory

Andreea Bratu
COAST Research Coordinator, BC
Centre for Excellence in HIV/AIDS,
PhD Student, UBC
abratu@bccfe.ca

Antonio Marante
Peer Research Associate,
BC Centre for Excellence in HIV/AIDS
amarante@bccfe.ca

Carly Marshall
COAST Research Coordinator
BC Centre for Excellence in HIV/
AIDS (2020-2022)

Kathleen Inglis
Social Scientist/Researcher,
University of Victoria
klinglis@sfu.ca | 604-836-5012

Neora Pick
Clinical Professor, Division of Infectious Diseases,
UBC; Medical Director, Oak Tree Clinic.
npick@cw.bc.ca

Niloufar Aran
MSc Student, SFU; Research Coordinator, CANOC Study, BC
Centre for Excellence in HIV/AIDS
naran@bccfe.ca

Patience Magagula

Executive Director,
Afro-Canadian Positive Network of BC
Peer Research Associate, BC Centre for Excellence in HIV/AIDS.
patience.acpnet@gmail.com
pmagagula@bccfe.ca

Robert Hogg

Senior Research Scientist, BC Centre for Excellence in HIV/AIDS; Distinguished Professor, Associate Dean, Research, Faculty of Health Sciences, SFU.
robert_hogg@sfu.ca

Silvia Guillemi

Clinical Professor Department of Family Medicine, UBC, Clinical Advisor BC Centre for Excellence in HIV/AIDS
sguillemi@bccfe.ca

Valerie Nicholson

Peer Indigenous Research Associate, BC Centre for Excellence in HIV/AIDS; Peer Navigator, AIDS Vancouver.
vnicholson@bccfe.ca

Wayne Campbell

Community Programs Coordinator, AIDS Vancouver
WayneC@aidsvancouver.org

Endnotes

[1] Teng, J., Bentley, C., Burgess, M., O'Doherty, K., and McGrail, K. for the BC Data Deliberation research team (2019). Research Data Use in a Digital Society: A Deliberative Public Engagement. https://www.popdata.bc.ca/sites/default/files/documents/projects/Public_Engagement/Public%20Deliberation%20Event%202019%20Booklet%20FINAL.pdf

[2] Epstein, Steven. (1996). Impure Science: AIDS, Activism, and the Politics of Knowledge. Berkeley: University of California Press.

[3] While community engagement in administrative data-driven research is rare, pioneering work in this area includes the Building Bridges and Building More Bridges projects. These projects, co-led by Indigenous peoples and allied stakeholders, use Indigenous methodologies and community-based participatory research principles to conduct HIV research using a large Canadian administrative dataset called CANOC.

[4] AHA Centre (2018). Capacity Bridging. Retrieved from http://www.ahacentre.ca/uploads/9/6/4/2/96422574/capacity_bridging_-_finaljune_2018.pdf

[5] CDC (2018). HIV among people aged 50 and older. Retrieved from https://www.cdc.gov/hiv/group/age/olderamericans/index.html

[6] CIHR Canadian HIV Trials Network (2018). HIV, aging, and the CTN. Retrieved from https://www.hivnet.ubc.ca/knowledge-center/hiv-aging/

[7] Koehn, K., Burgess, H., Enjetti, A., Lyndon, S., Cardinal, C., Ranville, F., Nicholson, V., Marziali, M., Salters, K., Parashar, S. (2019). The BC Home and Community Care System and Older Adults living with HIV. http://bccfe.ca/sites/default/files/uploads/publications/centredocs/envscan_may2019_final.pdf

[8] Mills, E.J., Bakanda, C., Birungi, J., Chan, K. Ford, N., Cooper, C.L., Nachega, J.B., Dybul, M., and Hogg, R.A. (2011). Life Expectancy of Persons Receiving Combination Antiretroviral Therapy in Low-Income Countries: A Cohort Analysis From Uganda. *Annals of Internal Medicine*, 155: 209-216.

[9] Matic, S., Lazarus, J.V., & Donoghoe, M.C. (Eds.) (2006). HIV/AIDS in Europe: Moving from death sentence to chronic disease management. World Health Organization. Retrieved from https://www.euro.who.int/__data/assets/pdf_file/0010/78562/E87777.pdf

[10] Samji, H., Cescon, A., , Hogg, R.S., Modur, S.P., Althoff, K.N., Buchacz, K., Burchell, A.N., Cohen, M., Gebo, K.A., Gill, M.J., Justice, A., Kirk, G., Klein,M.B., Korthuis, P.T., Martin, J., Napravnik, S., Rourke, S., B., Sterling, T.R., Silverberg, M.J., Deeks, S., Jacobson, L.P., Bosch, R.J., Kitahata, M.M., Goedert, J.J., Moore, R., & Gange, S.J. for The North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) of IeDEA. Closing the gap: Increases in life expectancy among treated HIV-positive individuals in the United States and Canada. PLoS One, 8(12): e81355.

[11] Deeks, S.G., Lewin, S.R., Havlir, D.V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet*, 382(9903), 1525–1533.

COAST