

OHTN Cohort Study (OCS) Quarterly Update

July 2021

OCS Productivity during COVID

Despite the challenges of the pandemic, the OCS has continued to engage participants and be productive. In the first quarter of this year is equivalent to pre-pandemic times, OCS data collectors completed a total of 622 interviews, 458 chart reviews, and 54 new consents. We thank them for their dedication to participants and the success of the study during these unpredictable times.

Making the OCS More Representative

To ensure the OCS represents all Ontarians living with HIV, we have recruited new clinics that represent underrepresented populations and regions of the province. To overcome language barriers, we now offer Spanish and French surveys to participants across all OCS sites.

Governance Committee Recruitment

The OCS Governance Committee evaluates each OCS project proposal for its relevance to the community and the ethics of the intended data use. The Committee specifically recruits people who represent the priority populations for HIV prevention in Ontario. In an effort to best reflect the communities we serve, the OCS is currently seeking individuals who identify as African, Caribbean and Black men and/or Gay, Bisexual and other Men who have sex with Men. Interested parties should inquire by **August 15, 2021**. More information can be found at <http://ohtncohortstudy.ca/ocs-governance-committee-recruitment>.

Setting Research Priorities

Between June and August each year, we review the OCS questionnaire to ensure the questions are relevant and reflect current research interests. We send an annual survey to our partners to solicit new research ideas. This year's priorities include: experience of hope, vocational rehabilitation, and treatment uptake.

Supporting Sub-studies

Each year, the OCS receives requests from external researchers who want to engage OCS participants in sub-studies that have been approved by the OCS Governance Committee. The OCS has now made it easier

OCS Quick Facts

COVID-19 infections:

May 2020–Jun 2021

37% of participants tested for COVID-19

8% of participants tested positive

COVID-19 vaccine uptake:

As of June 30th:

89% of participants received or are willing to take the COVID-19 vaccine.

Of participants who received vaccine:

78% received one dose

22% received two doses.



to recruit OCS participants to these sub-studies, and reduced the burden on participants by making it possible to share some data. The OCS Data Administration Portal creates a unique sub-study ID for each participant which is linked to an external survey. The sub-study coordinator consents the participant and collects the data, which is held by the sub-study. At some point during the research, the list of IDs is shared with the OCS, which will provide a data cut based on the approved study protocol.

This new feature has been piloted with two implementation science sub-studies now underway in collaboration with Maple Leaf Medical Center. Both studies are designed to give OCS participants access to resources to support their health and wellbeing:

- Ta Vie en Santé, led by Dr. José Coté at the University of Montreal, offers an online smoking cessation program for people living with HIV
- an intervention study, led by Dr. Kelly O'Brien, offers virtual physical activity exercises and training for study participants.

We congratulate Dr. Ann Burchell, who has received CIHR funding to examine COVID seroprevalence among people living with HIV. Dr. Burchell's sub-study will recruit OCS participants to provide dried blood spot (DBS) samples, which will be assessed for COVID antibodies.

Improving Data Linkages

The OCS team recently developed a new software application to facilitate data linkages with Public Health Ontario and the Institute for Clinical Evaluative Sciences (ICES). The application was tested and implemented with both partners and linkages are complete. The 2017 OCS data release is now available at ICES for research studies. Two studies have already been approved by the OCS Governance Committee to work with this data to examine: cancer burden (A. Burchell) and resistance testing (L. Mbuagbaw). Updated data linkages will begin in 2022. To work with OCS/ICES linked data, a submission should be made to the OCS before applying at ICES for access.

Respecting Indigenous Data Sovereignty

The impact of colonization, residential schools, the 60's scoop, along with individual and systemic racism continue to drive health outcomes, including HIV, for Indigenous Peoples in Ontario. The OCS is committed to supporting proper, respectful research that acknowledges and complies with the sovereignty of Indigenous Peoples. To do that, we must implement specific data governance strategies specific to Indigenous participant data and research studies. In collaboration with Sean Hillier, an Indigenous scholar at York University, the OCS held three consultations with Indigenous stakeholders to develop a new model of governance. In this model, a committee of Indigenous community members will review any research proposals that plan to use Indigenous data as well as any research results that impact Indigenous Peoples. We anticipate the committee will hold its first meeting soon, and we welcome new proposals for research that has the potential to enhance care and health for Indigenous individuals living with HIV, their communities, and nations.





Sharing OCS Findings: CAHR 2021

The OCS study was well represented at the Canadian Association for HIV Research conference this year. Thanks to the work of all our colleagues, analysts, and community members, the study provided foundational research for two poster presentations and four oral presentations: <https://www.youtube.com/user/CAHRACRV>

Check out the following oral abstract presentations:

[W. Oakes Prevalence of Self Reported COVID Infection, Household Exposure and Frontline Work among People Living with HIV During the COVID-19 Pandemic](#)

[T. Bekele Increased Economic Hardship due to the COVID 19 Pandemic among Participants of the OCS](#)

[K. Cronin Loneliness and Elevated Prevalence of Depression during COVID 19 Pandemic among People living with HIV](#)

[E. Winkler Impact of the COVID 19 Pandemic on Deferral of Health Care and Mental Health Services](#)

The **Ontario HIV Treatment Network Cohort Study (OCS)** is an ongoing research study that collects clinical, social and behavioural information about people living with HIV (PHA) in Ontario. Participation in the study is voluntary, and all personally identifying information of study participants is removed to ensure confidentiality. The OCS was established to improve our understanding of HIV and inform HIV prevention, care and treatment strategies for people living with HIV and groups at risk of HIV infection. For more information about the OCS, please visit www.ohtn.cohortstudy.ca or email ocs@ohtn.on.ca.

