



OCS

OHTN COHORT STUDY

OCS QUICK FACTS

Quality of Life for People Living with HIV (PLWH) in Ontario

Quality of life (QoL) is an important indicator for HIV treatment, care and support. The OCS uses the *PozQoL* tool that was developed specifically to measure different domains of QoL for people living with HIV.

The 2,258 OCS participants who completed the questionnaire in 2022 identified the following issues:

Health concerns domain

- 52% worry about their health
- 51% fear the health effects of HIV with aging
- 45% worry about the impact of HIV on their health

Social domain

- 63% feel HIV does not limit/slightly limits personal relationships
- 68% feel a sense of belonging with people around
- 53% fear being rejected if people know their HIV status

Functional domain

- 73% indicated HIV does not prevent/slightly prevents them from doing as much as they'd like
- 70% said that having HIV does not limit/slightly limits opportunities
- 20% said managing HIV wears them out

Psychological domain

- 85% enjoy life
- 89% feel good about themselves
- 82% feel in control of their life
- 84% feel optimistic about their future

Despite people living with HIV in Ontario have relatively high scores for QoL, they need more support to ensure they feel confident about their health and are able to live free of stigma.

OCS Cohort Profile Characteristics

As of December 2022, the OCS had a total of 5,388 active participants, including those who are no longer active at sites but contribute to ongoing viral load data. To better understand the characteristics of our cohort and plan strategic recruitment for future years, we analysed active participant data.

Of the 452 new participants enrolled in the OCS over the past 24 months, 72% were male and 25% female. In terms of time since HIV diagnosis:

- 4% were within less than 1 year of diagnosis
- 33% were within 1 to 5 years
- 18% were within 6 to 10 years
- 39% were diagnosed more than 11 years ago.

In terms of the populations most affected by HIV, the cohort is representative:

- 59% are gay, bisexual or other men who have sex with men
- 20% are African, Caribbean or Black
- 4% are Indigenous
- 7% people who inject drugs.

Although there are OCS clinics in the province, 70% of OCS participants reside in Toronto while 19% reside in the South West, and 10% in the South East. Compared to the Public Health Ontario Laboratories (PHO) data on people living with HIV in the province, the OCS slightly overrepresents Toronto. Otherwise, the OCS is overall fairly representative of the population of people living with HIV in Ontario.

OCS Productivity in 2022

OCS productivity was on track for 2022. Data collectors completed a total of 2,305 interviews.

- Questionnaire completion was 18% higher in 2022 than in 2020 but slightly lower than in 2021.
- The number of active participants across the 15 OCS sites at the end of 2022 (4,381) was up 2% compared to 2021.
- Data collectors consented 235 new participants into the study. These individuals made up 10% of the participants who completed the OCS questionnaire in 2022 and 5.7% of the total cohort.

We thank our sites, data collectors, and participants for their dedication and contributions to the OCS.

Changes to the OCS Study Team

Data collectors are the heart of the OCS team. We are very grateful to all of them for their dedication and commitment to the work.

OCS is pleased to welcome four new data collectors to the team:

- Lianne Thai, Muna Abdullahi and Adeola Latona at the Unity Health Network;
- Brie Fraser at Kingston General Hospital.

We bid farewell to Suzanne Chung (UHN), and we wish her success in her future endeavours.

OCS presentations at CAHR

OCS research aims to improve our understanding of the experiences and needs of people living with HIV to improve prevention, care, treatment and quality of life for people living with HIV in Ontario.

The OCS team and collaborators presented at the 32nd Canadian Conference on HIV/AIDS Research (CAHR) – *A Boomerang Effect: From HIV to SARS-CoV2 and Back Again* – held in Quebec City, April 27th and 30th, 2023. Presentations included issues relating to: vaccine uptake (COVID-19, influenza, and pneumococcal pneumonia); pre-HIV diagnoses HIV and STI testing behaviours; experiences of menopause and menopause care; quality of life; and representativeness of the OCS. External OCS researchers made presentations on: experiences of discrimination among Indigenous Peoples, and the relationship of chronic pain and histories of trauma.

Posters and slides can be found at <https://ohtncohortstudy.ca/research/>

- [Bekele et al., Uptake of COVID-19, Influenza, and Pneumococcal vaccines among PLWH.](#)
- [Hillier et al., Experiences of Discrimination among Indigenous Participants in the OHTN Cohort Study.](#)
- [Kesler et al., STI and HIV Testing Behaviours Prior to HIV Diagnosis among People Living with HIV in Ontario.](#)
- [Kroch et al., Representativeness of the OHTN Cohort Study by key populations and geography.](#)
- [Light et al., Women living with HIV are in need of adequate menopause care.](#)
- [O'Brien et al., Measuring Quality of Life for People Living with HIV in Ontario.](#)
- [Zhabokritsky, et al., Painful Memories Associations between pain and history of trauma and stigma among people living with HIV.](#)

CAHR Red Ribbon Award to Joanne Lindsay

Joanne Lindsay, a former co-chair of the OCS Governance Committee, was honoured with the Red Ribbon Award at the 2023 CAHR conference. This prestigious award, established in 2001, is presented annually to someone who has made outstanding contributions to HIV/AIDS research, treatment, and prevention. You can learn about the award and former awardees [here](#).

Congratulations to Joanne. We remain grateful to Joanne for her expertise and knowledge, which that have had a lasting impact on the OCS.

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 (PLWH) 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 ohtncohortstudy.ca or email ocs@ohtn.on.ca.