

The 2023 OCS Questionnaire

Every year, OCS participants, researchers and other stakeholders provide invaluable feedback on our questionnaire and recommend possible changes or additions. We are very grateful for the time and effort they put into this process. Thanks to them, we have completed the annual review of the questionnaire and submitted the final version for research ethics review at OCS sites.

To reduce burden on OCS participants, the 2023 version has been streamlined. We've also limited the number of new additions. Based on feedback from the community and researchers, we've included questions on:

- **Religion, faith, and/or spirituality**, and adopted three separate assessment tools related to religiosity, faith, and spirituality: Religiosity Scale; Spirituality Well-Being Scale (FACIT-SP-12) for all participants; and Spirituality Scale (22-Item) for Indigenous participants only. The Spirituality Scale was developed by a team of Indigenous and non-Indigenous researchers from across Canada, Elders, Indigenous Knowledge Keepers, cultural practitioners, service providers, and decision makers.
- **MPox**¹ to assess participants' concerns as well as their experiences accessing vaccination and treatment.
- **Sexual satisfaction** to understand the role of sexual activities in participants' overall quality of life.

Two recent OCS publications

Dr. Brandon Christensen, Dr. Darrell Tan (www.optionslab.ca) and colleagues recently published a study in the academic journal *Sexually Transmitted Diseases* looking at the cognitive effects of syphilis and neurosyphilis in people living with HIV (PLWH) in Ontario, using data from the OHTN Cohort Study. Their findings demonstrate it is unlikely that past syphilis and neurosyphilis are associated with cognitive and memory problems, but depression and substance use are risk factors that are likely to contribute to cognitive decline among PLWH. Dr. Christensen, who led the study during his internal medicine residency training at the University of Toronto, is now a first-year infectious diseases fellow at the University of Calgary. You can read the full publication [here](#).

OCS Quick Facts

Women living with HIV often go through menopause at an earlier age than women not living with HIV². From 2020-2021, the OCS collected data on gynecology/menopause to learn more about the experience of menopause among women living with HIV.

187 women had experienced natural menopause or were perimenopausal:
14% experienced/are experiencing premature menopause
21% experienced/are experiencing early menopause
65% experienced/are experiencing normal menopause

These women reported they were most likely to talk about gynecological issues with:

60% with a primary care/general or nurse practitioner
17% with a gynecologist
15% with an HIV specialist
9% with no provider

Postmenopausal women were asked if their menopause needs were being addressed by their healthcare provider (n=138).

62% strongly agreed/agreed
20% neutral/disagreed/strongly disagreed
18% had not discussed menopause with any provider

¹ The preferred term for Monkeypox to reduce stigma and discrimination

² Van Ommen CE, King EM, Murray MCM. Age at menopause in women living with HIV: a systematic review. *Menopause*. 2021 Dec 1;28(12):1428-1436.

Dr. Ann Burchell and colleagues recently published a research article, “Low human papillomavirus vaccine uptake among women engaged in HIV care in Ontario, Canada,” in the journal of *Preventive Medicine*. Previous research has shown that women living with HIV have six times higher risk of cancer of the cervix (the opening of the uterus) than women who do not have HIV. The higher cancer risk is caused by chronic infection with certain types of human papillomavirus (HPV). Highly effective vaccines against the cancer-causing types of HPV have been available in Ontario since 2008. During interviews conducted between 2017 and 2020, the researchers asked 591 women participating in the OCS whether they had ever received HPV vaccine. Overall, self-reported rates of HPV vaccination are low among women. Only 13.2% (95% confidence interval 10.5-15.9%) reported ever receiving at least one dose of HPV vaccine. Of those 13.2% who had received at least one dose, 64.6% had received the recommended three doses. Vaccine initiation (≥ 1 dose) was more common among women aged 20-29 years at 31.0% but fell to 13.9% in those aged 30-49 years and $<10\%$ in those aged 50 years and older. Vaccine initiation was also more common among women who were employed, married/living common-law and living with children, had annual incomes $>\$20,000$, were university educated, non-smokers, in HIV care for longer, and who were not recent immigrants. Ontario’s publicly funded school-based HPV vaccine program targets adolescents before they become sexually active. Older women who were missed by that program due to age or having immigrated from a country without an HPV vaccine program must bear the high cost of the vaccine themselves. Based on these findings, the research team recommends:

- educational campaigns for health care providers caring for women living with HIV to promote HPV vaccination. Physician recommendation is one of the strongest predictors of being vaccinated.
- provincial funding of HPV vaccine for women living with HIV, as is done in other Canadian provinces.

You can read the full publication [here](#).

OCS Governance Committee Updates

We are pleased to announce that three OCS Governance Committee members – Mary Ndung'u, Viviana Santibañez, and Barry Adam – have kindly agreed to serve an additional three-year term (from June 2022 to June 2025). We are grateful for their time, continued dedication, service and contributions to the OCS. For the full list of committee members, visit [here](#).

Changes to the study team

We are very excited to welcome three new members to the OCS team.

Mustafa Karacam has taken on the role of Lead, Research and Partner Management, and will be coordinating all OCS research. Mustafa graduated with a PhD from the School of Kinesiology and Health Studies at Queen’s University, Kingston, Ontario, where he specialized in gender and sexuality issues in sport. We also welcome two new data collectors to the team: Eliana Orrego at the Kingston General Hospital and Rizani Ravindran at the Toronto General Hospital. OCS data collectors develop unique relationships with participants, and support OCS enrolment and ongoing engagement. Eliana and Rizani have completed their training and are already contributing to the study. In addition to welcoming new members, we would like to acknowledge all our data collectors for their dedication and commitment to the work.

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 (PLHIV) 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.ohcn.cohortstudy.ca or email ocs@ohcn.on.ca.