



29th Annual Canadian Conference on HIV / AIDS Research

29^e Congrès annuel canadien de recherche sur le VIH/sida



EPHP11.03: (Re)Defining Meaningful Engagement with Community: Lessons from a study on racial disparities in health outcomes of MSM living with HIV in a national HIV cohort study

Authors

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Affiliations

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Investigators

CANOC Principal Investigators: Robert S. Hogg, Zabrina Brumme, Ann Burchell, Curtis Cooper, Mark Hull, Deborah Kelly, Marina B. Klein, Abigail Kroch, Mona Loutfy, Nimâ Machouf, Julio Montaner, Kate Salters, Stephen Sanche, Réjean Thomas, Sharon Walmsley, and Alexander Wong

Conflict of Interest Disclosure for Christian Hui (past 2 years)

- I have been an Community Investigator of **CANOC**
- I have been a Consultant for **CANFAR, Casey House**
- I have been a member of the Community Advisory Board for: **CTN**
- I have been a Speaker for **CANFAR, Casey House, Ryerson University**
- In the past 2 years I have received honoraria from **CAAN, Simon Fraser University**
- There are relationships to disclose: **NO**

Conflict of Interest Disclosure for Ioana Nicolau (past 2 years)

- I have been an employee of: **St. Michael's Hospital**
- I have been a consultant for: **Ontario Tobacco Research Unit**
- I have received research support (grants) from: **CIHR, CANOC**
- There are relationships to disclose: **NO**



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Land Acknowledgement

The presenter and second author acknowledge the research has been performed on traditional Indigenous territories on Turtle Island and wish to express our commitment to ensure our research project does no produce harm to Indigenous Peoples and communities. We wish to express gratitude to Mother Earth and for the resources we are using and honour all Indigenous peoples who have been living on the land since time immemorial.

GIPA/MEPA/MIWA

The presenter and second author acknowledge the centrality of the Greater Involvement of People Living with HIV/AIDS (GIPA), the Meaningful Engagement of People Living with HIV/AIDS (MEPA) and the Meaningful Involvement of Women Living with HIV/AIDS (MIWA) in HIV research. We recognize that the ownership of research findings from research utilizing data sourced from People Living with HIV/AIDS should rest with the People Living with HIV/AIDS.

Acknowledgement

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Background

This poster provides a **critical community perspective on the challenges, lessons learned, and future considerations for researchers to respectfully engage diverse communities of people living with HIV (PLHIV) in research**. This process-based poster describes the research experience of a **Canadian HIV National Observational Cohort (CANOC) Community Investigator (CI)** who is **a community member living with HIV**, an HIV activist and community mobilizer, a recipient of an Ontario AIDS Network PHA Leadership Award, a CANFAR National Ambassador, and most recently, a Vanier Canada Graduate Scholar (2020-2023).

Since assuming his role at CANOC two years ago, the CI has worked with the research team to finalize his research questions. His two investigator-driven step-wise projects (e-DAR 229 and e-DAR 231) were guided **by the concept of privilege (DuBois, 1903; McIntosh, 2003)** and **utilized critical epidemiology (Edelman, 2018)** as an approach. The first project (e-DAR 229) explored a research question which the CANOC CI's supervisor had proposed the CI to undertake and explored racial disparities as a potential driver of viral suppression and related health outcomes among men who have sex with men living with HIV (MSM+).

The second project (e-DAR 231) was built upon the first project, and explored whether potential associations exist between the clinical health outcomes of people living with HIV and a variety of social demographic variables that inform the concepts of **structural health advantage** and **structural health inequities** based on the social sciences notion of privilege. This project further explores the findings of the **CANOC e-Poster at CAHR 2020 "Neighbourhood-Level Material Deprivation and Immune and Virologic Response in the Canadian HIV Observational Cohort Collaboration (CANOC)"** (McClean et al., 2020) that an association exists between socioeconomic status and HIV-related outcomes.

The CI **consulted with a community advisory of 10 people living with HIV/AIDS (PHA) from a wide intersection to ensure the research questions were appropriate, do not pose harms to the communities being researched, and explored topics of value to PHAs**—which made these two projects community-informed studies. **This e-Poster focuses on the first of the two CANOC CI projects (e-DAR 229) and provides GIPA-centered recommendations for HIV researchers to consider.**



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Methods

The **CANOC Research Collaborative** engaged PHA and community members in capacity-building positions such as **Community Investigators** or funded post-graduate level researchers through **CANOC Scholars fellowships**.

To verify the relevancy of the research questions being conducted, the CI of the e-DAR 229 project engaged PHAs as community advisory roles. The CI, PHA community advisory members, and ally researchers/CANOC scholar engaged in a **collaborative and reflexive process grounded in the GIPA/MEPA/MIWA principles** to debrief on the challenges which arose during the project.

Drawing from the critical reflection of the CANOC CI on his experience in completing the community-informed e-DAR 229 project, we employed a **positive-people centered framework (Hui, 2017)¹** to guide the reflection on three key components of the project:

- 1) **capacity building,**
- 2) **community consultations, and**
- 3) **decision-making.**

The process engendered **critical, community-informed points of considerations** as guidance tools for future researchers.

¹<https://digital.library.ryerson.ca/islandora/object/RULA%3A5891>

Results

1) Capacity building: Active engagement by research team mentors can foster environments that encourage deep learning and development for community investigators/researchers.

- **CANOC meetings provided unique opportunities for the CI to garner feedback from diverse perspectives to enhance the study design and gain insights about research policies and practices.**
- **While CIs are expected to benefit from the support from a variety of CANOC team members, the CI of this project was specifically grateful for the mentorship he received from fellow CANOC Scholars and peer support from fellow CIs.**

2) Community consultation: Meaningful consultations with communities should start early during project development. Clear guidelines and processes facilitate respectful and reciprocal engagement with diverse communities such as Indigenous peoples, key population groups and PHA, which help engender safer environments and inclusive settings that support diverse perspectives in research.

- **In studies where data are sourced from PHA, the CI engaged researchers in discussions on the centrality for respectful community consultation to be grounded in GIPA/MEPA/MIWA.**



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Results

- 3) Decision-making:** Processes should be open, horizontal, transparent and facilitate bilateral relationship building and learning. Ongoing initiatives to mitigate power imbalances inherent in traditional western, positivist health research is critical to respectful engagement, such that all team members can feel valued.
- **The CI followed up and sought for clarifications from the research team when ambiguous situations arose.**
 - **To facilitate equitable decision-making, the CI engaged researchers and community advisory committee members in team meetings or correspondence, and proactively maintained open and transparent communication with the entire team.**
 - **Maintaining written documentation on research processes and decisions made by the team is recommended and can serve as a research best practice.**

Recommendations

- 1) Capacity building:** Create synergy. Cross-collaborate across levels (e.g. trainee, early career researcher, community investigator), and recognize **supportive supervision is essential driver to success.**
- 2) Community consultation:** **Honouring that the data are sourced from diverse communities of PHAs,** research team members should approach meaningful and respectful community consultations through the lens of **GIPA/MEPA/MIWA.**
- 3) Decision-making:** As mentors, **researchers should acknowledge when something is not going well and take steps to ameliorate experiences of community investigators,** setting an example for other researchers.

Conclusions

Capacity building initiatives, collaborative community consultations, and equitable decision-making processes are key to operationalizing **GIPA/MEPA/MIWA** and **respectful ways of conducting community-informed research** with diverse PHA community members and **research where data are sourced from PHAs.**

When conducting research with PHA or research where the data is sourced from PHA, **researchers should center the research on the experiences of positive people.** Failure to implement these principles can **further disenfranchise the people and communities the research intends to support** and **may inadvertently produce preventable harms.**