

29th Annual Canadian Conference on HIV / AIDS Research

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

SSP4.05 Beyond Building Bridges:

Decolonized, GIPA-Centered Research Recommendations Informed by Indigenous-Settler PHA Dialogues

Authors

Christian S. Hui ^{1,2,3,4}, **Michael R. Parsons** ^{4,5,6,7}, **Shane N. Young** ^{8,9}, **Sean Hillier** ¹⁰, **Trevor G. Stratton** ^{11,12,13} **There is no conflict of interest**

Affiliations

1. Canadian HIV National Observational Cohort (CANOC) Research Collaborative Community Investigator; 2. Ontario Positive Asians (OPA+), 3. Vanier Canada Graduate Scholar; 4. CIHR CTN Community Advisory Committee Member; 5. Canadian Aboriginal AIDS Network (CAAN) Indigenous IPHA Caucus; 6. CANOC e-DAR 229 & e-DAR 231 Community Advisory Committee Member; 7. Dalhousie University; 8. Ryerson University; 9. Trent University; 10. York University; 11. Canadian Aboriginal AIDS Network (CAAN), 12. International Indigenous Working Group on HIV/AIDS (IIWGHA), 13. International Indigenous HIV/AIDS Community

Land Acknowledgement

We acknowledge the research has been performed on traditional Indigenous territories 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 for the resources we are using and honour all Indigenous Peoples who have been living on the land since time immemorial.

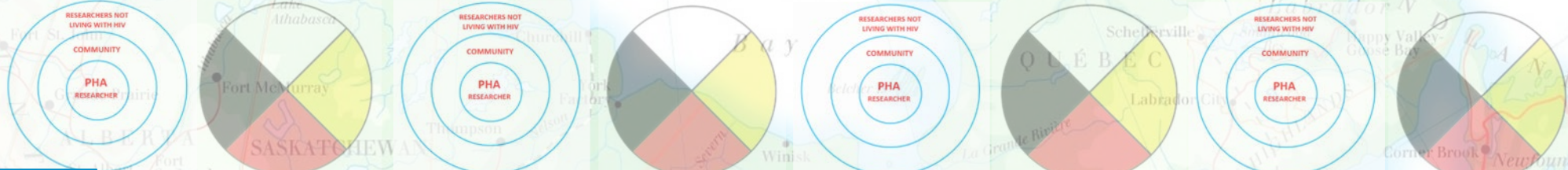
GIPA/MEPA/MIWA

We acknowledge the centrality of the Greater Involvement of People Living with HIV/AIDS, the Meaningful Engagement of People Living with HIV/AIDS and the Meaningful Involvement of Women Living with HIV/AIDS 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.



29th Annual Canadian Conference on HIV / AIDS Research

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



Background

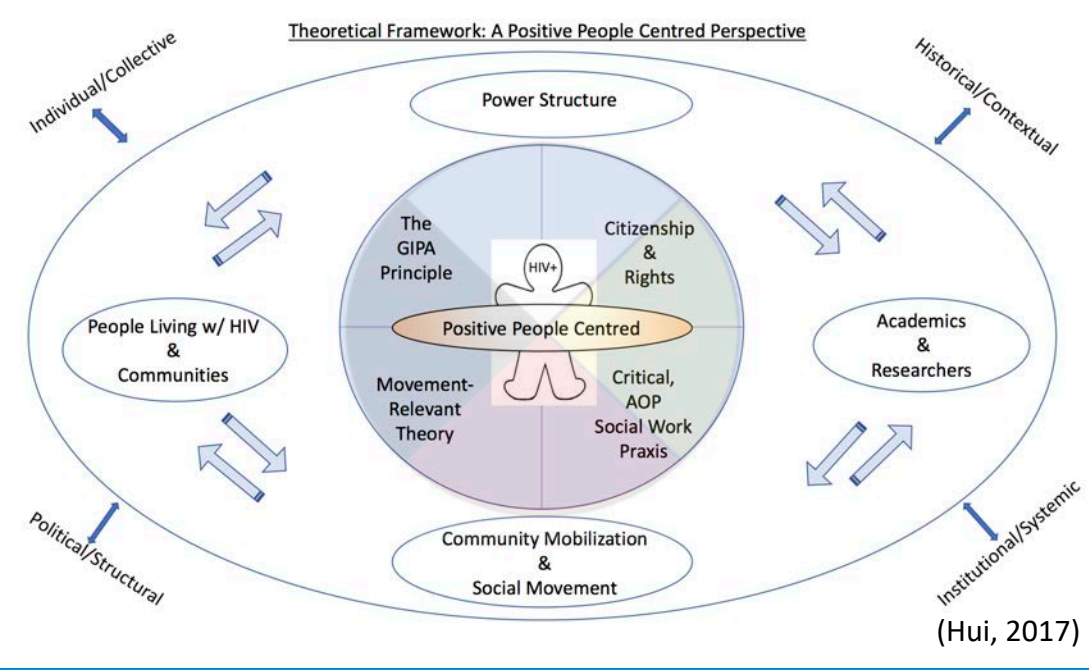
The creation of equitable Indigenous-settler partnerships in HIV research **can cause community harm if approached through neo-colonial processes /structures, and can reduce community harm if done in a good way** ¹.
¹https://www.ahacentre.ca/uploads/9/6/4/2/96422574/research_in_a_good_way_finaljune_2018.pdf

Efforts to bridge differences between Indigenous-settler research approaches offer important lessons to inform action in **western neo-colonial practices and research structures**.

This poster describes the **co-creation of a respectful, equitable partnership between Indigenous and settler PLHIV community researchers** through dialogue regarding the realization of **GIPA/MEPA/MIWA principles**.

Who: Person living with HIV/AIDS (PHA) Community Investigator
 Indigenous Pipe Carrier Living with HIV Community Advisory Committee (CAC) Member

When: After researchers not living with HIV paused a research project led by the PHA CI citing the reason of inadequate community consultation with Indigenous community



Where: In a culturally-safe PHA only space where the PHA CI & Indigenous CAC member can talk as peers

How: Knowledge exchange between PHA CI & Indigenous CAC member listened respectfully, supported each other, and acted collaboratively

Methods

When the use of neo-colonial processes by settler researchers contradicted **GIPA/MIWA/MEPA**, two HIV+ community researchers utilized a **positive-people centered framework (Hui, 2017)**¹ in a decolonized manner to engage in a **culturally-safer, bilateral reflexive knowledge exchange (KE)** based on **Indigenous spiritual and anti-oppressive research principles**.

The KE process, which took place **outside of a western neo-colonial research space**, led to a **respectful, equitable, co-development of community-led recommendations** for researchers who engage PHAs in research or conduct research which includes data from PHAs.

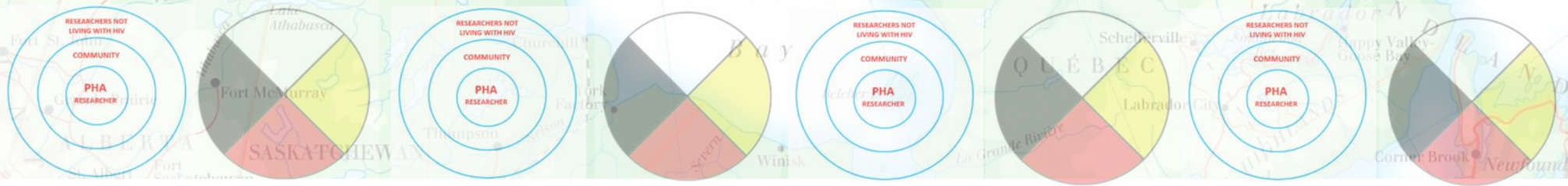
These recommendations are **centered on the GIPA/MEPA/MIWA principles** and have incorporated lessons learned regarding previous experiences in Indigenous health research **to not cause further harm in Indigenous communities**.

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



29th Annual Canadian Conference on HIV / AIDS Research

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



Decolonized, GIPA-Centred Indigenous-Settler Dialogues Amongst PHAs

Respectful, equitable Indigenous-settler HIV research partnerships require researchers to:

"When consulting with Indigenous members, researchers need to know that each Indigenous person can only speak for themselves, and not for the entire Indigenous community"

1) recognize that Indigenous Peoples and settlers have different world views, ways of knowing and doing

-Indigenous Traditional Pipe Carrier Community Advisory Member

"The researcher was wrong when he spoke on behalf of the Indigenous community as opposed to allowing the Indigenous group he asked the PHA Investigator to consult with speak for themselves"

-Indigenous Traditional Pipe Carrier Community Advisory Member

2) understand Indigenous Peoples are not homogeneous within Canada or internationally due to past and current displacement and genocide of cultures and communities, yet Indigenous solidarity work is vital

"As the researchers made executive decisions without consulting me, I asked them to pause and reflect on the fact that all their data from this cohort are sourced from PHAs..."

-Person living with HIV/AIDS Community Investigator

3) not speak for or on behalf of communities and respect all consulted views

4) understand HIV research has personal significance for PHAs, spiritual significance for Indigenous PHAs, & community members

"These HIV researchers should not tell me I have not consulted the community adequately when they do not even know how to treat PHAs respectfully"

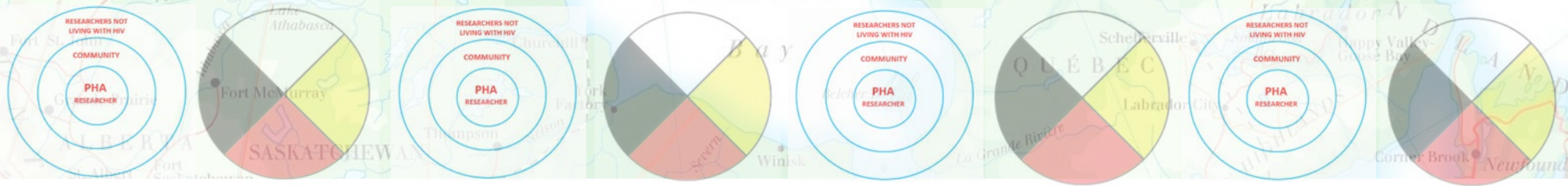
- Person living with HIV/AIDS (PHA) Community Investigator

5) know when to step back and support community in making decisions autonomously



29th Annual Canadian Conference on HIV / AIDS Research

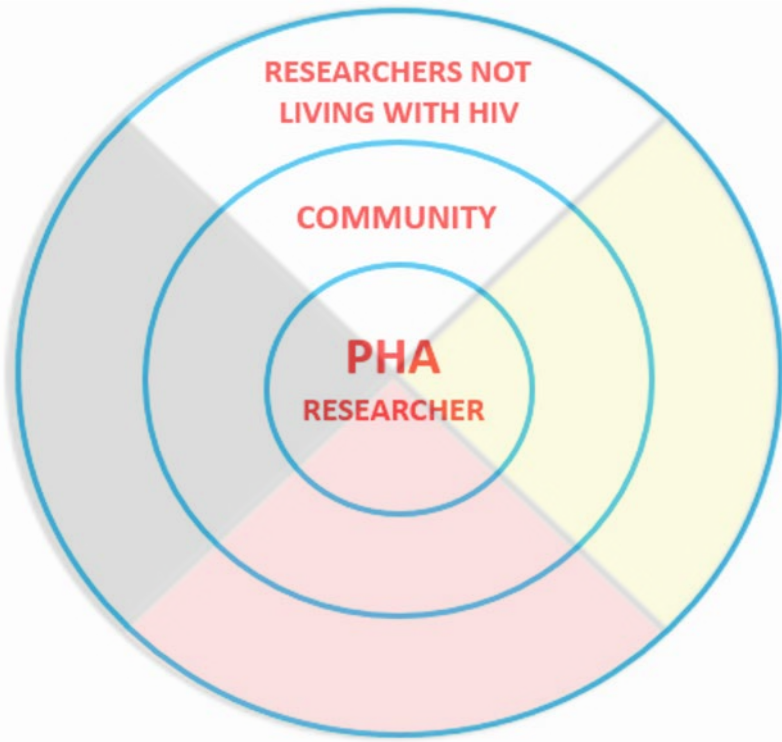
29e Congrès annuel canadien de recherche sur le VIH/sida



Where research **involves PHAs** and the data is **sourced from PHAs**, research priorities should be considered in the following way, even when Indigenous or other Key Population communities are involved

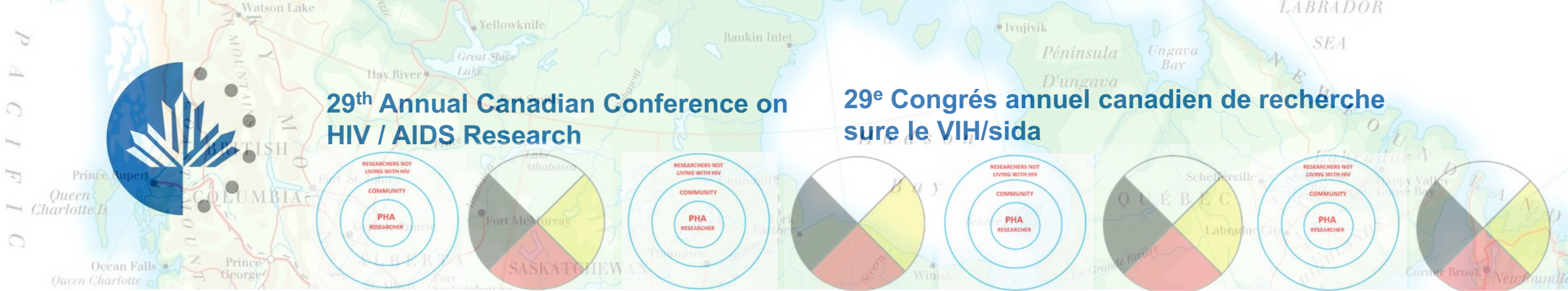
1. In HIV research, when it is done **in a good way (harm is mitigated)**, researchers not living with HIV will recognize that **Indigenous PHA** and **settler PHA researchers** are imbedded within the community. Likewise, researchers not living with HIV **will not pit marginalized PHA groups against one another.**

3. **GIPA/MEPA/MIWA centered research** means **PHAs** make up the centre of the community. Researchers not living with HIV (i.e. from outside of community) should respect the **ownership and self-determination** of **PHA researchers** and the **PHA community.**



2. **PHA researchers** have a special relationship with HIV/AIDS research, especially when research data has been **sourced from PHAs.** Similar to the OCAP principles where Indigenous research is owned by Indigenous Peoples, these research and their results must be **owned, controlled, accessed and possessed** by PHAs.

4. While **meaningful community consultation** with Indigenous and other key population communities is important, **GIPA/MEPA/MIWA** must be honored. The ability to **engage PHAs meaningfully and respectfully through GIPA/MEPA/MIWA** is the **key critical element** in conducting meaningful consultations amongst diverse PHA communities.



29th Annual Canadian Conference on HIV / AIDS Research

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

- ### Discussion
1. Decolonising research in colonial research structures requires clear, written ethical research guidelines which must be implemented in culturally safer ways.
 2. As communities of people living with HIV are diverse, the co-creation of equitable, decolonizing HIV research should be centered on GIPA/MIWA/MEPA.
 3. Indigenous-settler partnerships require researchers to go beyond a western research approach and to understand that Indigenous worldviews are not static (one's worldview changes from a colonized to a traditional spiritual perspective as one crosses "the half moon") (Parsons, 2019 NSPIRG Circles)
 4. Creating equitable Indigenous-settler partnership requires researchers to continuously and proactively engage in critical reflexivity



Conclusion: Doing GIPA/MEPA/MIWA in a Good Way

Despite harm was done to PHAs, reconciliation is possible if researchers not living with HIV can recognize they have committed harm, and that they commit to conduct HIV research by 1) having PHA researchers & the community take the lead, and 2) recognize PHAs own and possess the data of the research.