

Moving from theory to practice: Ensuring capacity building and the application of GIPA/MIWA principles in conducting community-engaged research among Women Living with HIV in Canada

J Gahagan¹, N O'Brien^{2,3}, A Carter^{4,5}, T Conway^{7,11}, J Thomas-Pavanel⁷, S Wertheimer⁶, K Proulx-Boucher³, W Tharao⁸, S Greene⁹, D Dubuc³, S Buhler¹⁰, K Beaver⁷, A Kaida⁴, A de Pokomandy^{2,3}, M Loutfy⁷, CHIWOS Research Team.

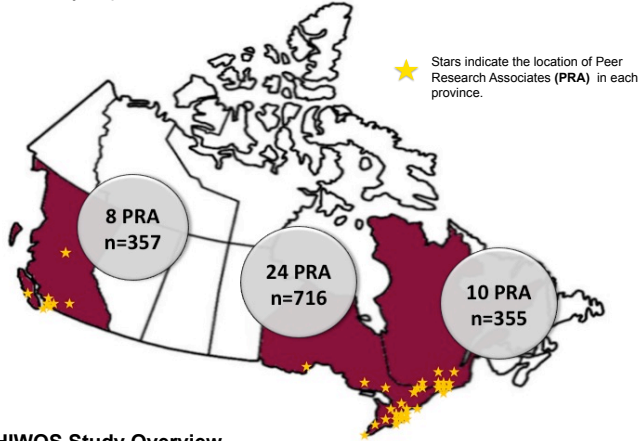
1. Dalhousie University, 2. McGill University, Family Medicine, 3. McGill University Health Centre, 4. Simon Fraser University, Faculty of Health Sciences, 5. British Columbia Centre for Excellence in HIV/AIDS, 6. Canada's source for HIV and hepatitis C information (CATIE), 7. Women's College Research Institute, Women's College Hospital, 8. Women's Health in Women's Hands CHC, 9. McMaster University, 10. Interagency Coalition on AIDS and Development, 11. International Community of Women living with HIV, North America (ICWNA).

BACKGROUND

The Greater Involvement of People Living with HIV/AIDS (GIPA) and the Meaningful Involvement of Women Living with HIV/AIDS (MIWA) are core principles of capacity building initiatives such as community-engaged, participatory research with Women Living with HIV (WLHIV). However, deeply rooted ethical tensions continue to stymie the realization of these principles in practice. How we contend with these tensions can have significant implications for WLHIV, particularly those who are engaged in HIV research as Peer Research Associates (PRAs).

METHODS

Drawing on the process of implementing a large, longitudinal, community-based research study currently operating across three provinces (British Columbia, Ontario, and Quebec), the **Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)** examined the ethical tensions that emerge when moving GIPA and MIWA principles from theory to practice in the Canadian context.



RESULTS

A variety of tensions were noted in moving GIPA/MIWA from theory to practice. Among these tensions were issues of meaningful participation of PRAs, including appropriate compensation; role clarity, recognition, and a sense of overall well-being. Among these tensions were: needing transparency around having WLHIV working in CHIWOS while balancing the need to protect HIV-status confidentiality; facilitating maximum involvement while ensuring proper recognition and compensation under budget constraints; balancing the need to be supportive given the diversity of PRAs and the impact of the research on their personal lives while maintaining professionalism; and supporting PRAs to navigate insider versus outsider roles on the research team and community they are researching.

| Recognizing PRA contributions while preserving HIV-confidentiality | |
|---|---|
| Challenges | Useful Strategies |
| The title of peer is important, it signals our CBR principles, and signals to our partners that their voices speak with the strength of lived experience. It can also be powerful in creating trust and mutual understanding in peer to participant interactions. However, in the context of persisting HIV-stigma, discrimination, increased surveillance, and women balancing their multiple roles as mothers, employees, employers, and citizens of close knit and rural communities, HIV-disclosure, implied by the peer role, is not always possible. This challenge presented itself in working groups with evolving membership, peer-participant interviews, and when presenting our research. | - Creating peer led policies around <i>if and when</i> HIV-status is required to be disclosed (e.g. in interviews) - Letting peers dictate when they disclose to participants, - Introducing new members of working groups to PRAs previous to meetings - Introducing peers as collaborators - Verifying disclosure preference in each new circumstance - Recognizing that disclosure comforts for each PRA changes with time, and each differing context and audience |
| Supporting meaningful involvement and capacity building amongst diverse PRAs | |
| Within our team of nearly 40 PRAs varying research experiences and life circumstances (employment, caregiving, etc.) has meant differing skills and time to dedicate to the study. This raised the need for strategies to adapt to various PRAs interests, experience, and capacities to ensure meaningful and supportive engagement. | - Instituting a policy of hiring PRAs with diverse experiences - Creating new PRA opportunities on working groups - PRAs electing PRA representative - Involving PRAs in data analysis, manuscript, grant writing - Supporting PRAs in their decision to do few or numerous interviews - Offering ongoing support and training - Pairing experiences and junior PRAs - Facilitating peer led endeavors - Outlining clearly what opportunities are financially compensated and which are voluntary - Recognizing that capacity building is reciprocal between peer and academic researchers |
| Ensuring PRA wellbeing | |
| As a CBR project we recognize that the peer-to-peer interview model may at once be deeply rewarding and emotionally challenging for PRAs. | - Incorporating self-care and grieving into PRA trainings - Discussing how to navigate wearing multiple hats as community members and researchers within their organizations and communities - Providing explicit support and resources such hiring an on-call counselor - Supporting PRA buddy systems - Instituting an open-door policy with PIs and coordinators - Doing yearly one-on-one check in's - Allowing PRAs to scale back on interviews when needed - Maintaining a supportive but professional environment |

CHIWOS Study Overview

- Prospective cohort study, comprised of 1428 WLHIV
- Five year initial funding (2011-2016), renewal granted (2016-2021)
- Expanding to Manitoba and Saskatchewan in 2015
- Draws on Community-Based Research Principles
- Investigating the impact of Women-Centred HIV Care on sexual, reproductive, mental and women's health outcomes
- PRA-administered survey at baseline, with 18 month follow-ups
- Hired, trained, and supported a team of 38 PRAs (+allied PRAs)
- PRAs represent the diversity of WLHIV across Canada, including different languages, Indigenous, ACB, newcomer, and LGBTQ women, and differing research experience, community engagement, and levels of HIV- disclosure.

| Community-Based Research Approach | | |
|---|--------------------------------------|---|
| Principles | Advantages | In CHIWOS |
| Equitable involvement of those affected by the research in the research | Strengthen stakeholder collaboration | Over 40 PRAs lead study recruitment and data collection |
| Shared decision making over life of study | Improve research effectiveness | National Steering Committee |
| Focus on action and change | Ensure relevance and cultural safety | Three Provincial Community Advisory Boards |
| | Enable empowerment | ACB Advisory Board |
| | Facilitate knowledge to action | PAW Advisory Board |

CONCLUSIONS

The importance of recognizing these intersecting tensions is paramount to the shift from GIPA/MIWA as theoretical constructs to the practice of undertaking community-engaged research in Canada. In an effort to proactively address tensions which can emerge when moving GIPA/MIWA from principle to practice, research teams must embrace open, flexible, and creative approaches. Such approaches are aimed at recognizing and engaging WLHIV within the broader funding landscape, ongoing HIV-related stigma, including issue of disclosure, and the intersecting determinants of health all of which can negatively impact on the ways in which we animate GIPA/MIWA principles.

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