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Kira Abelsohn, Anita C. Benoit, Tracey Conway, Lynne Cioppa, Stephanie Smith, Gladys Kwaramba, Johanna Lewis, Valerie Nicholson, Nadia O’Brien, Allison Carter, Jayson Shurgold, Angela Kaida, Alexandra de Pokomandy, Mona Loutfy, and the CHIWOS Research Team

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“Hear(ing) new voices”: Peer Reflections from Community Based Survey Development with Women Living with HIV

Abelsohn, K.1, Benoit, A.C.1,2, Conway, T.1, Cioppa, L.1, Smith, S.1, Kwaramba, G.1, Lewis, J.1, Nicholson, V.3, O’Brien, N.4, Carter, A.3,5, Shurgold, J.3, Kaida, A.5, de Pokomandy, A.4, Loutfy, M.R.1,2 and the CHIWOS Research Team*

*Additional Research Team members are listed at end of manuscript; we would like to have all additional research team members hyperlinked as authors.

Affiliations:
1Women’s College Research Institute, Women’s College Hospital, Toronto, Ontario, Canada
2University of Toronto, Toronto, Ontario, Canada
3British Columbia Centre for Excellence in HIV/AIDS
4McGill University Health Centre, Montreal, Quebec, Canada
5Simon Fraser University

Corresponding author:
Dr. Mona Loutfy,
Women’s College research Institute
Women’s College Hospital
790 Bay Street, Room 736
Toronto, Ontario M5G 2N8 Canada
Tel: 416-351-3732 ext. 2324
Fax: 416-351-3746
E-mail: mona.loutfy@wchospital.ca

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Abstract

Background: The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) engaged in an innovative community-based survey development process. Objectives: To provide (1) an overview of the survey development process; and (2) personal reflections from women living with HIV (“Peers”) on their own observations of strengths and short-comings of the process and opportunities for improvement.

Methods: Guided by the principles of community-based research (CBR) and meaningful involvement of women living with HIV (MIWA), CHIWOS coordinated a national, multidisciplinary research team, and facilitated a community based survey development process.

Lessons Learned: Four key lessons emerged highlighting the importance of: 1. accommodating different preferences for feedback collection; 2. finding the right combination of people and skills; 3. formalizing mentorship; and 4. creating guidelines on survey item reduction and managing expectations from the outset.

Conclusions: Peers discussed the strengths and weaknesses of participatory methodologies in survey development.

Keywords: Community based research (CBR), HIV, Women, Cohort Study, Questionnaire, Survey Development, CHIWOS
Introduction
Over the past three decades the incidence of HIV has shifted significantly, with women representing over 50% of the 35.3 million people living with HIV globally\(^\text{1}\). In Canada the pandemic has been predominantly characterized by men who have sex with men, however the proportion of women living with HIV (WLWH) has been steadily increasing. Furthermore, women from African, Caribbean, and Black (ACB) communities and Aboriginal communities are disproportionately represented among WLWH in Canada\(^\text{ii}\).

The gendered nature of HIV has been studied extensively, demonstrating both biological and socio-structural determinants that place women at increased risk of HIV acquisition\(^\text{iii,iv}\). Gender and systemic based violence, inequality, discrimination, as well as the intergenerational impact of trauma and poverty continue to contribute to the shifts in the global HIV pandemic. However, services and treatments have not been adapted to adequately respond to the new gendered and racial dynamics of the HIV epidemic. Many unique barriers to care for WLWH have been described in the literature\(^\text{v,vi}\), as well as distinct health concerns for WLWH\(^\text{vii,viii,ix,x}\).

What is CHIWOS?
The Canadian HIV Women's Sexual & Reproductive Health Cohort Study (CHIWOS) is a national, longitudinal community-based research (CBR) study (www.chiwos.ca). CHIWOS aims to investigate access to and the impact of women-centered HIV/AIDS services on sexual, reproductive, mental and women’s overall health outcomes. Through CHIWOS, gaps in knowledge on the epidemiology, health status, management and response to increasing positive HIV tests among women in Canada will be identified.

Guided by CBR\(^\text{xiv}\), MIWA, and GIPA (Greater Involvement of People with HIV/AIDS)\(^\text{xv,xvi}\), CHIWOS brought together a national, multi-disciplinary team, which included community experts, academic researchers, and clinicians, to engage in a community-based survey development process. An original survey tool was developed by compiling established validated scales, and unique questions crafted by the research team.

CBR for Survey Development
While there are many different definitions of CBR, in theory the goal is that all aspects of the research process are shaped by the partnership between community members and researchers. In practice CBR can take many different forms. There are many reasons for these variations, a discussion that goes beyond the scope of this manuscript\(^\text{xvii,xviii}\).

Survey development is primarily carried out by academics, and community input is often sought after the survey has been completed. For those who wish to engage in community based survey development, published information on methodology is in short supply\(^\text{xix}\).

What the literature has shown to date are some of the challenges in engaging community in survey development. Garcia et al.\(^\text{x}\) described some of the challenges and
Adhering to timelines was a major challenge, due to the slow and resource intensive nature of CBR. Flicker et al. describes the process and lessons learned for practice from their community based survey development process with youth in the development of the Toronto Teen Survey (TTS). Similarly, they commented on the large resource investment required for this work. They additionally noted mentorship, sustaining commitment, and the appropriate matching of skills to tasks as challenges unique to this work

The benefit of using CBR in survey development has been somewhat explored in the literature. For example, the above TTS resulted in one of the largest and most diverse youth sexual health samples in Canada, largely attributed to their CBR approach. Etowa et al. in their work with women of African descent from Nova Scotia, Canada, explained how active involvement of the community reduced the likelihood of the research instrument alienating the participants, and the questions asked were more likely to be effective in enabling discussions of priority issues to the community.

Garcia et al. describe how the use of a community-based participatory research (CBPR) process by community and academic partners resulted in a culturally relevant survey instrument.

The CHIWOS survey development process has emerged as a compelling model of survey research. The objectives of this paper are twofold: (1) to provide an overview of the survey development process; and (2) provide personal reflections from WLWH on their own observations of strengths and short-comings of the process, as well as opportunities for improvement. The following section will describe the methods used but the CHIWOS team to engage in a community based survey development process.

Methods: CHIWOS Questionnaire Development

CHIWOS leveraged partnerships with community members, organizations, and other stakeholders in HIV, to guide the study goals and design, and to put into practice the results of the research as best seen by WLWH. WLWH were at the table during the conceptualization of CHIWOS, and contributed to all stages of the study. The study’s Core Research Team and Steering Committee includes many representatives of stakeholder communities who have traditionally been marginalized, including WLWH, Aboriginal women, ACB women, lesbian, bisexual and queer women, trans women, women who inject drugs and many more. Community Advisory Boards were formed in each participating province (Quebec, Ontario and British Columbia) to further collaboration and cater to local and regional needs. Two to five Peer Research Associates (PRAs) (also referred to as “Peers”) were hired in each study province during the study’s formative phase to guide the study. The Peers in this study were all WLWH with diverse backgrounds, and included women with significant research and
community experience, and some with no prior research or advocacy experience within the HIV/AIDS community. Much of the survey development process was lead by the more experienced peers thus providing mentorship to those with less experience. These and other steps were taken to ensure that a diverse range of community voices were embedded throughout the study.

Figure I: CHIWOS Study Team Structure

It was important to the CHIWOS Team that the survey reflected community priorities. Survey development groups were established for the initial 12 survey topic sections and 12 group-specific domains (Table I). Survey sections were chosen based on the objectives of the study, which had been guided by WLHIV. Group-specific domains were chosen based on the populations most affected by HIV in Canada and those who are often under-represented in research. These original sections were refined throughout the survey development process.

A lead and a co-lead were assigned to each group, and the groups were populated with members of the Steering Committee, and other stakeholders. A consistent effort was made to achieve balance within each group in terms of membership of WLWH, academics, clinicians, and other community representatives. Over 100 people from across the country participated in this phase of the survey development process. Table II provides a summary of the CHIWOS survey development methods.

All groups were given guidance on how to proceed with survey development (Table II), including a list of constructs/domains of interest to build on. Each group was assigned one of three CHIWOS study coordinators to provide administrative support including booking meetings, conducting literature reviews, and summarizing and incorporating group feedback.

Multiple stages of survey testing and piloting were conducted throughout survey development to assess face validity and survey length, ensure ongoing community involvement in the process, and to gauge the flavour of the survey. Pre-testing was conducted with two PRAs in each province to test the timing and flow of the survey, in addition to question specificity, language and wording.

Additional survey feedback from each Provincial Community Advisory Board was sought. Feedback from survey groups representing communities who have traditionally been marginalized was incorporated. This feedback transformed the language used throughout the survey to ensure that it was inclusive to the diversity of WLWH in Canada.

A final pilot was conducted using the survey’s electronic platform with approximately 5 interviewers and 5 participants in each province.
An a priori document for ensuring validation and reliability of the CHIWOS questionnaire was developed and utilized and can be found at [http://www.chiwos.ca/wp-content/uploads/2012/04/CHIWOS-Questionnaire-Development-Description_Feb-11-2014.pdf](http://www.chiwos.ca/wp-content/uploads/2012/04/CHIWOS-Questionnaire-Development-Description_Feb-11-2014.pdf)

Table I: Survey Development Groups

Table II: Summary of Survey Development Approach

Many WLWH participated in the development and refinement of the CHIWOS survey through their membership on survey development teams and the piloting process. This paper was inspired by WLWH who participated in survey development in Ontario (herein referred to as ‘Peers’). All Peers from Ontario that participated in survey development were contacted to reflect on their experiences with this process. They voiced an interest in writing a manuscript that reflected their experiences, in order to share their learning and the overall value that this work could bring to the field of CBR. Evaluation questions were drafted, and Peers responded to them either in writing or over the phone. Notes and direct quotes were reviewed for accuracy by Peers. Group writing sessions to consolidate evaluation findings, and write this manuscript were facilitated in order to engage Peers in the writing process. The following section will describe the lessons learned from the survey development process from the perspective of the Peers in Ontario.

Lessons learned

Despite possessing years of research experience, the opportunity to participate in survey development was something the Peers had never experienced:

“As a PRA in these (other) studies, you receive a set amount of questions and you are asked to ask those questions...whereas in CHIWOS you get to put your input in the questionnaire and be part of team.”

“(In other studies) I was involved in every stage of the study after the project had been developed...I had no involvement with the questionnaire development...there were several points in (that) questionnaire where the wording of questions was either inappropriate, offensive or simply incorrect. There (was also) information that wasn’t collected that I wish had been.”

Overall, participating in the development of the CHIWOS survey was a positive experience for Peers. They described some of the strengths of the CHIWOS process:
“Being part of the survey development process made me feel listened to. I never felt like only a data collector. I felt what I said was as important, or MORE valuable than what others said.”

“Yes we are women living with HIV, but some of us were actually going through personal experiences that allowed us to answer the questions very truly. Having women with lived experience gave a true meaning to GIPA principle and gave an opportunity to hear new voices. That was a great reflection for me.”

“The process of being involved was a huge thing for me personally.”

Peers commented on the added value of involving women with HIV in survey development:

“You get a lot of training and you get to feel involved. You’re not just the PRA, it’s not just a job. You feel like you are appreciated for your knowledge and you are part of a team.”

“It shows other researchers that PRA’s can work alongside the researcher and not just as ‘you are the researcher and you are a PRA and as a PRA you only (administer) the survey.’ In CHIWOS, they made us feel like an equal and the researchers aren’t up there so there is less of a power struggle. So we all bring the same amount of expertise and different experiences to the table.”

Peers talked about how their contributions increased the quality of the questionnaire, and the data it would eventually be used to collect:

“My biggest contribution to the questionnaire development process was as an experienced PRA. I have done enough interviews to be able to see where problems might develop during an interview, to know what sections drew out conversations from the participants and what sections shut them down, to recognize errors in language etc.”

“Peer participation is necessary in order to get richer data, to get more honest response from participants.”

They additionally commented on some of challenges with the CHIWOS questionnaire development process, and the lessons learned from this experience:

“Some of the barriers were related to comfort level in speaking out in a group of professionals or experts, and some of the newer contributors may have felt intimidated or shy in voicing their opinion. Some type of mentoring system or orientation prior to starting the actual work or teleconferences could be beneficial.”
“The teleconference process was the biggest challenge, a lot of people find them challenging. I didn't always know who was on the phone, and how many were there. It’s not a good opportunity for getting to know people and it’s hard to develop working relationships. Most people do not participate as fully as they would in a face to face.”

The diversity of strengths that Peers bring to studies was discussed. Some Peers had years of academic experience, whereas others were completely new to research. The diversity of strengths were invaluable, however it raised the role of mentorship in future studies:

“There are different levels and abilities among the individuals who assisted in the (survey) development. Some type of a mentorship process may be of assistance in the future to overcome some of these issues in the future.”

One Peer reminded us of challenges surrounding PRA recruitment, and the voices that are often missed due to the nature of who is able to participate as a PRA, and who is not:

“We are losing huge perspectives from a lot of marginalized women. I’m a Caucasian woman who is stably housed, employed, educated, etc. This is NOT the same as someone who is under housed, not employed, not educated, etc.”

Item reduction proved to be much more difficult than anticipated. An extraordinary amount of time went into crafting the unique survey sections, and questions that were important to community needed to be cut from the survey. A lot of thought went into this process, knowing that there would be frustration from those who put time and effort into creating them. Despite the engagement of several WLWH in the editing of the survey, this was a disappointing process for all:

“I was extremely upset that (the survey section) was essentially left out of the final questionnaire, although I was assured that the questions would be captured in other sections... I felt unsure that the concerns raised while participating in this section had actually been heard and although I had a number of discussions with various staff members it almost felt like a waste of time for me and for a period I felt devalued.”

Conclusions
This manuscript was crafted based on the reflections of WLWH who felt that they benefitted from this process, and who wanted to share their experience with others engaging in similar processes. See Table III for a summary of key lessons learned.

The CHIWOS survey development process helped to focus priorities with issues that were most important to WLWH. It allowed for the unique challenges and issues that are often faced when creating a survey, rolling it out, engaging communities, and so on, to
be addressed in the development phase of the study, rather than letting those issues surface and become a concern later on when it is too late to meaningfully address them.

Table III: Final questionnaire sections

The quality of the survey tool developed, and the anticipated high quality of the data it will collect was noted as a major strength of this process. Having stakeholder engagement built into the survey development process was extremely important to the Peers writing this manuscript, as they felt that by shaping the survey to answer questions that they cared about would promote the use of this data for changes that would really impact their lives. The Peers felt that they would be more confident recommending the study to people because of their active role in its development.

Many challenges that the Peers experienced throughout this process were discussed, and are important lessons for future work in this area. CBR is a resource heavy process, and this was no exception. From start to finish, the survey development process took over a year and a half. The significant time commitment involved in this kind of work impacts who is able to participate, regardless of how much effort is directed into making the process as barrier free as possible. The Peers reflected on the diversity of WLWH who were involved in this process, noting both that they could not speak for all WLWH, and that many voices of marginalized WLWH may not be represented in this type of work. The consideration of who is able to participate is just as important as acknowledging those who are not.

The importance of mentorship and flexibility around the method of feedback emerged as an important theme. Teleconferences work well for some people, and are intimidating for others. Allowing multiple channels of feedback (i.e. email, one on one conversation, etc.) was valuable for Peers in this study, however having more concrete mentorship opportunities would have made the learning experience more meaningful. Finally, setting more realistic item limitations and being more diligent about enforcing them during the development process would have reduced the need for the enormous and unfortunate cuts required later in the process. Table IV summaries some of the key lessons learned, and some suggestions on how to address these in future research projects.

Table IV: Key Lessons Learned

This paper has described the strengths, challenges and lessons learned from the CHIWOS community-based survey development approach. We have highlighted Peer recommendations for other researchers interested in incorporating this approach into their projects, and have outlined some suggestions for addressing the lessons learned during the CHIWOS experience. CBR is generally not a methodology that can be followed like a recipe; the context, resources, and goals of the project, among other things, will determine the steps needed to make it a relevant and meaningful CBR
process. Our hope is that the steps outlined from the CHIWOS process help to give readers a sense of what might be involved in a community based survey development process, with the understanding that these steps may need to be adapted to fit the study context. While it is clear that the CHIWOS survey development method may not benefit all survey-based studies, we hope that our findings will encourage others to explore ways in which to engage community prior to study implementation in order to achieve a more inclusive, reflective and rigorous survey tool, and honour the incredible capacity of community to lead and innovate.

As CHIWOS moves forward with data collection and analysis, the CHIWOS team will further reflect on this process, continue to share findings with community and other stakeholders, and refine our key learnings in order to continue contributing to the CBR methodology literature, with the goal of supporting community based and other researchers looking to explore new methodologies for survey development. CHIWOS has always been grounded in notion that research can be a tool for the empowerment of WLWH, not only through the implications of the research findings but through the research process itself. Building knowledge, skills, experience and overall capacity for community to lead research has been the cornerstone of CHIWOS since its’ inception, and will continue to guide this work throughout the data collection, analysis and dissemination phases. We look forward to learning from and building on the survey development experience in future projects, and hope that others can benefit from this work in their own research processes.

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APPENDIX I
The CHIWOS Research Team:
Principal Investigators: Mona R. Loutfy (Women’s College Research Institute), Alexandra de Pokomandy (McGill University Health Centre), Angela Kaida (Simon Fraser University), and Bob Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University). Research Coordinators: Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Karène Proulx Boucher (McGill University Health Centre), and Jamie Thomas-Pavanel (Women’s College Research Institute). National Community Representative: Valerie Nicholson. National and Provincial Core Research Team Members: BC: Claudette Cardinal, Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Angela Cescon (British Columbia Centre for Excellence in HIV/AIDS), Bob Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Angela Kaida (Simon Fraser University), Valerie Nicholson, Christina Tom, Kath Webster. ON: Rahma Abdul-Noor, Fatimatou Barry, Kerrigan Beaver, Anita Benoit (Women’s College Research Institute), Ann Burchell (Ontario HIV Treatment Network), Lynne Cioppa, Tracey Conway, Jasmine Cotnam, Janette Cousineau, Marisol Desbiens, Brenda Gagnier, Claudine Gasingirwa, Mercy Saavedra, Saara Greene (McMaster University), Shazia Islam, Logan Kennedy (Women’s College Research Institute), Gladys Kwaramba, Johanna Lewis (Women’s College Research Institute), Mona R. Loutfy (Women’s College Research Institute), Marvelous Muchenje (Women’s Health in Women’s Hands), Mary Mwalwanda, Mary (Muthoni) Ndung’u, Yasmeen (Ashria) Persad, Stephanie Smith, Tsitsi Tigere, Wangari Tharao (Women’s Health in Women’s Hands), and Jamie Thomas-Pavanel (Women’s College Research Institute). QC: Mélina Bernier, Janice Dayle, Alexandra de Pokomandy (McGill University Health Centre), Hania Dubinsky, Danièle Dubuc, Lyne Massie, Brigitte Ménard, Nadia O’Brien (McGill University Health Centre), Joanne Otis (Université du Québec à Montréal), Alie Pierre, Karène Proulx Boucher (McGill University Health Centre).
Centre). National Steering Committee Members: Pat Allard (Canadian HIV/AIDS Legal Network), Aranka Anema (British Columbia Centre for Excellence in HIV/AIDS), Denise Becker (Positive Living Society of British Columbia), Mélina Bernier, Jason Brophy (Children’s Hospital of Eastern Ontario), Ann Burchell (Ontario HIV Treatment Network), Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Angela Cescon (British Columbia Centre for Excellence in HIV/AIDS), Janice Dayle, Janice Duddy (Pacific AIDS Network), Alexandra de Pokomandy (McGill University Health Centre), Jacqueline Gahagan (Dalhousie University), Saara Greene (McMaster University), Bob Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Terry Howard (Positive Living Society of British Columbia), Evin Jones (Pacific AIDS Network), Angela Kaida (Simon Fraser University), Alexandria Keating (ViVA and Southern Gulf Islands AIDS Society), Mary Kestler (Oak Tree Clinic, BC Women’s Hospital and Health Centre), Marina Klein (McGill University Health Centre), Gladys Kwaramba, Rebecca Lee (CIHR Canadian HIV Trials Network, Johanna Lewis (Women’s College Research Institute), Mona R. Loufyy (Women’s College Research Institute), Renee Masching (Canadian Aboriginal AIDS Network), Melissa Medjuck (Positive Women’s Network), Brigitte Ménard, Deb Money (Women’s Health Research Institute), Valerie Nicholson, Nadia O’Brien (McGill University Health Centre), Susanna Ogunnaike-Cooke (Public Health Agency of Canada), Joanne Otis (Université du Québec à Montréal), Andrea Langlois (Pacific AIDS Network), Ali Palmer (British Columbia Centre for Excellence in HIV/AIDS), Doris Peltier (Canadian Aboriginal AIDS Network), Neora Pick (Oak Tree Clinic, BC Women’s Hospital and Health Centre), Janet Raboud (Ontario HIV Treatment Network), Stephanie Rawson, Sean Rourke (Ontario HIV Treatment Network), Margarite Sanchez (ViVA and Southern Gulf Islands AIDS Society), Jacquie Sas (CIHR Canadian HIV Trials Network), Stephanie Smith, Marcie Summers (Positive Women’s Network), Wangari Tharao (Women’s Health in Women’s Hands), Sharon Walmsley (Toronto General Research Institute), and Jessica Yee (Native Youth Sexual Health Network). Sampling, Recruitment, and Data Management and Analyst Team Members: Ann Burchell (Ontario HIV Treatment Network), Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Alexandra de Pokomandy (McGill University Health Centre), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Bob Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Angela Kaida (Simon Fraser University), Mona R. Loufyy (Women’s College Research Institute), Karène Proulx Boucher (McGill University Health Centre), Janet Raboud (Ontario HIV Treatment Network), Wangari Tharao (Women’s Health in Women’s Hands), Jamie Thomas-Pavanel (Women’s College Research Institute), and Wendy Zhang (British Columbia Centre for Excellence in HIV/AIDS). All other CHIWOS Research Team Members who wish to remain anonymous.
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