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# "Hear(ing) New Voices": Peer Reflections from Community-Based Survey Development with Women Living with HIV

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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:** We sought to provide 1) an overview of the survey development process, and 2) personal reflections from women living with human immunodeficiency virus (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 (WLWH), 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

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.[1] In Canada, the pandemic has been predominantly characterized by men who have sex with men; however, the proportion of WLWH has been steadily increasing. Furthermore, women from African, Caribbean, and Black communities and Aboriginal communities are disproportionately represented among WLWH in Canada.[2]

The gendered nature of HIV has been studied extensively, demonstrating both biological and sociostructural determinants that place women at increased risk of HIV acquisition.[3,4] Gender- and system-based violence, inequality, and 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 respond adequately to the new, gendered and racial dynamics of the HIV epidemic. Many unique barriers to care for WLWH have been described in the literature,[5,6] as well as distinct health concerns for WLWH.[7–13]

## WHAT IS CHIWOS?

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) is a national, longitudinal CBR study (available from http://www.chiwos.ca). CHIWOS aims to investigate access to and the impact of women-centered HIV/acquired immunodeficiency syndrome (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 numbers of positive HIV tests among women in Canada will be identified.

Guided by CBR,[14] meaningful involvement of WLWH, and Greater Involvement of People with HIV/AIDS (GIPA),[15,16] CHIWOS brought together a national, multidisciplinary team that 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

Although 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 forum.[17,18]

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.[19] What the literature has shown to date are some of the challenges in engaging community in survey development. Garcia et al.[20] described some of the challenges and lessons learned in developing a bilingual mental health survey for the Latino community. Adhering to timelines was a major challenge, owing to the slow and resource-intensive nature of CBR. Flicker et al.[21] describe the process and lessons learned for practice from their community-based survey development process with youth in the development of the Toronto Teen Survey. 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.[21]

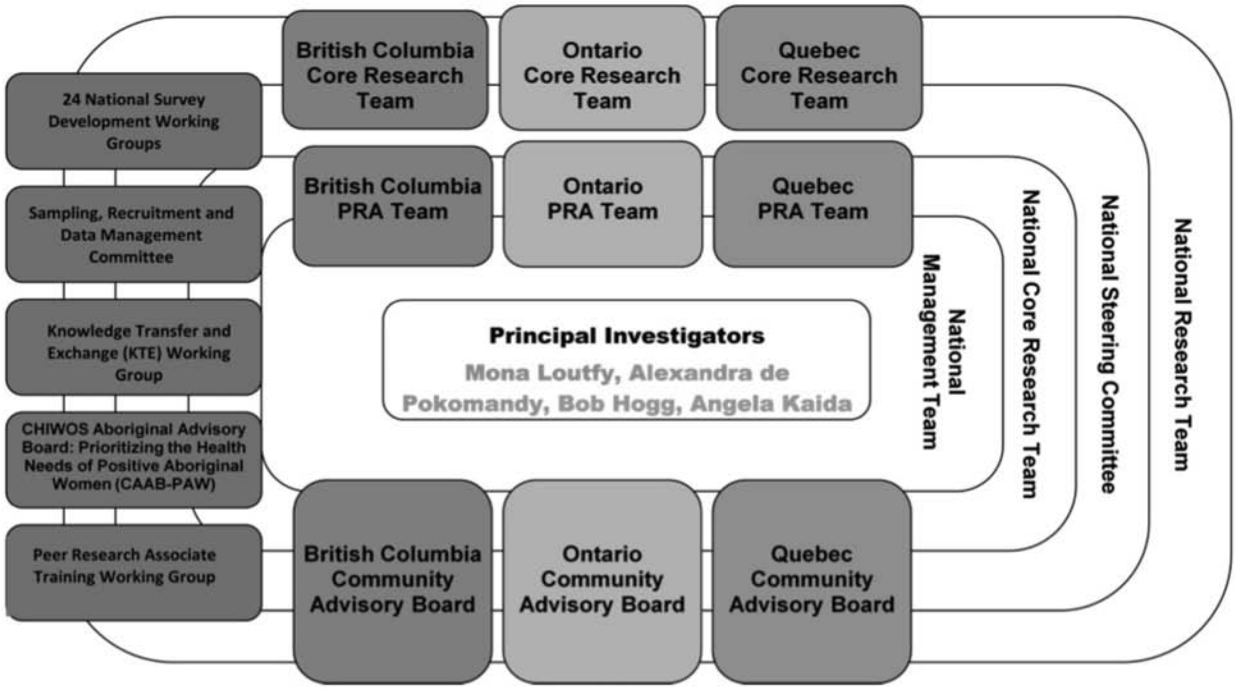

**Figure 1. Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Study Team Structure**

The benefit of using CBR in survey development has been somewhat explored in the literature. For example, the Toronto Teen Survey resulted in one of the largest and most diverse youth sexual health samples in Canada, largely attributed to their CBR approach.[22] Etowa et al.[23] in their work with women of African descent from Nova Scotia, Canada, explained how active involvement of the community decreased 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.[23,24] Garcia et al.[25] describe how the use of a community-based participatory research 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 article are twofold: 1) to provide an overview of the survey development process and 2) to 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 describes the methods used by 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 (available from http://www.chiwos.ca/chiwos-collaborators-and-co-investigators/?lang = en) includes many representatives of stakeholder communities who have traditionally been marginalized, including WLWH, Aboriginal women, African, Caribbean, and Black 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 led by the more experienced peers, thus providing mentorship to those with less experience (Figure 1). These and other steps were taken to ensure that a diverse range of community voices were embedded throughout the study.

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 1). Survey sections were chosen based on the objectives of the study, which had been guided by

**Table 1. Survey Development Groups**

| Table 1. Survey Development Groups |
|---|
| Section 1: Demographics and Socioeconomic Status and Social Determinants of Health |
| Section 2: Health Care and Social Service Utilization, Quality and Satisfaction and Women-centered HIV/AIDS Care |
| Section 3: HIV Disease Information |
| Section 4: Mental Health and Health-related Quality of Life |
| Section 5: HIV-related and Other Types of Stigma |
| Section 6: Women's Reproductive Health |
| Section 7: Women's Sexual Health |
| Section 8: Women's Health |
| Section 9: Substance Use |
| Section 10: Domestic Violence and Abuse |
| Section 11: Resiliency/Strengths-Based Approaches |
| Section 12: HIV Disclosure and Criminalization |
| Group-Specific Domains |
| LBQ Women |
| Trans Women and Trans People Who Access Women's Services |
| Aboriginal Women |
| Young Women |
| Older Women |
| Sex Working Women |
| Newcomer and Immigrant Women |
| ACB Women |
| Women Transitioning From Pediatrics to Adult Care |
| Incarcerated Women, or Women who have been Incarcerated |
| Women Living in Rural or Remote Areas |
| Street Involved or Homeless Women |

ACB, African, Caribbean, and Black; AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus; LBQ, lesbian, bisexual, queer.

WLHIV. Group-specific domains were chosen based on the populations most affected by HIV in Canada and those who are often underrepresented 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. More than 100 people from across the country participated in this phase of the survey development process. Table 2 provides a summary of the CHIWOS survey development methods.

All groups were given guidance on how to proceed with survey development (Table 2), 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 gauge the flavor of the survey. Pretesting 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 five interviewers and five participants in each province. An a priori document for ensuring validation and reliability of the CHIWOS questionnaire was developed and used (available from http://www.chiwos.ca/wp-content/uploads/2012/04/CHIWOS-Questionnaire-Development-Description_Feb-11-2014.pdf).

Many WLWH participated in the development and refinement of the CHIWOS survey through their membership on survey development teams and the piloting process. This article was inspired by WLWH who participated in survey development in Ontario (herein referred to as Peers). All Peers from Ontario who participated in survey development were contacted to reflect on their experiences with this process. They voiced an interest in writing an article that reflected their experiences to share their learning and the overall value that

**Table 2. Summary of Survey Development Approach**

| Step | Description |
|---|---|
| 1. Determine section constructs/domains | Core research team determined constructs and domains of interest based on the submitted proposal to the funding agency which had been identified through meetings with community stakeholders |
| 2. Develop survey teams | Collaborative survey development groups established for each survey section, led by a chair or two co-chairs, with support from a CHIWOS coordinator. Aimed for a balance of skills, diversity of backgrounds, and experiences on each group. |
| 3. Circulate survey section draft | Survey section draft circulated to section teams and meetings were coordinated for feedback via teleconference and email. |
| 4. Identify validated scales and priority questions | Validated scales and questions were identified and screened for relevancy by survey teams |
| 5. Item reduction | Survey teams asked to limit items in section<br>National Management Team conduct item reduction based on study goals and priorities<br>PRA item reduction through piloting process |
| 6. Survey testing and piloting | Pretesting conducted with two PRAs in each province to test the timing and flow of the survey, in addition to question specificity, language and wording |
| 7. Community feedback | Community feedback obtained to inform relevance of questions |
| 8. Piloting survey: Paper | PRAs administered paper versions of the survey following item reduction |
| 9. Piloting survey: Online | Conduct final pilot testing of online version of questionnaire with PRAs. |

CHIWOS, Canadian HIV Women's Sexual and Reproductive Health Cohort Study; PRA, peer research associate (women living with HIV trained to be research assistants).

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 to engage Peers in the writing process. The following section describes 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 the 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 owing 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 underhoused, 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 the 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 article 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. Table 3 shows the final questionnaire sections.

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 3. Final Questionnaire Sections |
|---|
| Section 1: Demographics and Socioeconomic Status |
| Section 2: Medical and HIV Disease Information |
| Section 3: Health Care and Support Service Utilization |
| Section 4: Women's Reproductive Health |
| Section 5: Stigma and Discrimination |
| Section 6: Substance Use |
| Section 7: Violence and Abuse |
| Section 8: Women's Sexual Health |
| Section 9: Emotional Well-being, Resiliency, and Health-Related Quality of Life |

The quality of the survey tool developed and the anticipated high quality of the data it will collect were noted as major strengths of this process. Having stakeholder engagement built into the survey development process was extremely important to the Peers writing this manuscript, because they felt that 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 (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 4 summaries some of the key lessons learned and provides some suggestions on how to address these in future research projects.

This article 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, 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. Although 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 before study implementation to achieve a more inclusive, reflective and rigorous survey tool, and honor 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 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.

The final CHIWOS survey can be found in English online (http://www.chiwos.ca/wp-content/uploads/2014/08/CHIWOS-May-13-2014-En.pdf) and in French (http://www.chiwos.ca/wp-content/uploads/2014/08/CHIWOS-May-13-2014-Fr.pdf).

## ACKNOWLEDGMENTS

Listed here are all research team members and affiliated institutions; all those not listed by name on the title page are listed in Appendix A.

The (CHIWOS) Research Team would like to especially thank all of the WLWH who participated and entrusted CHIWOS with their stories and their experiences of HIV treatment, care, and support. We also thank the entire national team of Co-Investigators, Collaborators, and Peer Research Associates. We would like to acknowledge the three provincial Community Advisory Boards, and the national CHIWOS Aboriginal Advisory Board, the National and Provincial Core Research Teams, the National Steering Committee, and the Sampling, Recruitment and Data Management and Analyst Team. We also thank our partnering organizations for supporting CHIWOS. CHIWOS has been made possible by funding from the Canadian Institutes of Health Research, the CIHR Canadian HIV Trials Network (CTN 262), and the Ontario HIV Treatment Network.

**Table 4. Key Lessons Learned**

| Lesson | Details |
|---|---|
| Accommodating different preferences of feedback | Different processes lend themselves to different kinds of technology, and some work better for others. Allow the time to check in and see how the process is working for all parties, and try to accommodate different preferences of feedback collection where possible. |
| Finding the right mix of people and skills | It will not always be possible to achieve the right balance of skills and experiences on your survey development teams. Acknowledging the strengths as well as the limitations of this process is key. Who is at the table is just as important as who is missing. |
| Mentorship | Just because you have the right mix of people does not mean that the experience will be as engaging for all. Ensure that you have the capacity to support all team members regardless of prior experience with this work. |
| Item reduction | Item generation can easily get out of control when skilled people work collaboratively on issues they are passionate about. Create strict guidelines and manage expectations from the onset, and be diligent about monitoring them regularly. |

## Appendix A. The CHIWOS Research Team

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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 Canadian HIV Women's Sexual and Reproductive Health Cohort Study CHIWOS Research Team Members who wish to remain anonymous.

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