

BEYOND the DATA

A community arts-based pilot led by the CHIWOS Knowledge/Translation and Exchange (KTE) Champion Project and women living with HIV and AIDS.

Beyond the Data: A Community-led Storytelling Pilot Project from the Knowledge Translation/Exchange (KTE) Champion Project of the Canadian HIV Women's Sexual & Reproductive Health Cohort Study (CHIWOS)

This anthology is a stunning story book, where narrative meets art in the spaces where women's voices are heard in all their diversity and multiplicity. This is a feast for the senses and a privilege to read.

- Saara Greene, PhD.



PHOTO BY Park Sul Hae

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Beyond the Data: Facilitators' Guide & Activities

Written by Angela Underhill, Mina Kazemi & Shaz Islam



In this pilot, one of the CHIWOS RAs, now known as the KTE Champion, co-developed and co-led an innovative, reciprocal workshop series with the Research Manager for a group of CHIWOS participants. We discuss the process, lessons learned, and the final co-created anthology.

Beyond the Data's Purpose: An Arts-Based Pilot Project

Arts-based projects ranging from body-mapping, photo voice, and narrative writing are becoming staples of community-based programming in the HIV sector, and in HIV research¹.

There are numerous examples of the efficacy of community arts-based programs that focus on storytelling and storysharing activities in the HIV sector. AIDS Service Organizations such as the Toronto People with AIDS Foundation (PWA), Casey House, AIDS Committee of Toronto (ACT), former Voices of Positive Women, Asian Community AIDS Services (ACAS), and Alliance for South Asian AIDS Prevention (ASAAP) have all implemented successful arts-based projects for the communities they serve. These arts initiatives offer a creative outlet for people living with HIV/AIDS (PHA) communities other than the more institutionalized services, programs, and therapy that may be accessed to help them navigate their health, psychosocial, and economic needs. Since the focus has now expanded to a PHA's holistic health, arts-based programs are now viewed as just as essential as mindfulness meditation and yoga workshops to help promote health and well-being.

As part of the CHIWOS study's aim to improve the quality of life for women living with HIV and AIDS, this KTE pilot project will offer participants another avenue to articulate their lived experiences using arts-based methods and tools, further contributing to their emotional and mental wellness, and offering them an opportunity to strengthen their ties with other peer participants, which has been noted as a strong health need for women living with HIV^{2,3}.

1 Brett-MacLean, P. (2009). Body mapping: Embodying the self living with HIV/AIDS. *Canadian Medical Association Journal*, 180(7), 740-741; MacGregor, H. N. (2008). Mapping the body: Tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa. *Anthropology & Medicine*, 16(1), 85-95; Orchard, T., Smith, T., Michelow, W., Salters, K., & Hogg, B. (2014). Imagining adherence: Body mapping research with HIV-positive men and women in Canada. *AIDS Research and Human Retroviruses*, 30(4), 337-338; Willis, N., Frewin, L., Miller, A., Dziwa, C., Mavhu, W., & Cowan, F. (2014). "My story" –HIV positive adolescents tell their story through film. *Children and Youth Services Review*, 45, 129-136.

2 Andersson N, Loutfy M. Envisioning Women-Centered HIV Care: Perspectives from Women Living with HIV in Canada. *Women's Health Issues*. 2017 Nov 1;27(6):721-30; Carter, A... et al. (2013). Women-specific HIV/AIDS services: Identifying and defining the components of holistic service delivery for women living with HIV/AIDS.

3 O'Brien N, Greene S, Carter A, Lewis J, Nicholson V, Kwaramba G, Ménard B, Kaufman E, Ennabil N,

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

Ten-year, multi-provincial longitudinal cohort study that aims to improve the care of women living with HIV in Canada. Operating under Community-Based Research (CBR) and Greater Involvement of People with HIV/AIDS (GIPA) philosophies, CHIWOS prioritizes and values the leadership of women living with HIV at all stages of the research process, including analysis and dissemination activities^{1,2}. In the first wave of CHIWOS interviews, research associates (RAs) living with and affected by HIV and AIDS interviewed 1,422 women living with HIV in Ontario, Quebec, and British Columbia¹. RAs then followed up with participants 18 and 36 months following their initial interview. Now with the third and final wave of data collection complete, CHIWOS has evolved into a dynamic, engaging, and inclusive community of researchers, healthcare and social service providers,

Beyond the Data: Plan, Process, Pilot

Beyond the Data is a must have piece of work to own. I loved the autonomy of each story yet it came full circle in how it related to the reader in one way or another. Beautifully done. Gladys Kivaramba, Peer Research Associate, CHIWOS.



PHOTO CONTRIBUTED BY Angela

The team created a facilitators guide which laid out all of the activities that were used for the six-week workshop series. The interactive workshops involved a presentation about CHIWOS data followed by skill-building activities related to creative nonfiction writing and photovoice. The guide was organized week-by-week and the learning components were progressive in that each skill builds on the one before. Participants were given evaluation forms after each session.



PHOTO BY Anjalee Aman

Participants from the KTE Champion's CHIWOS interviewee list were invited to participate; six accepted. Workshops were co-facilitated by the Peer Facilitator/participant, KTE Champion, and the Research Manager. Six workshops occurred in September 2019 and included: a check-in, meal, presentation/discussion regarding CHIWOS findings, and writing/creative exercises not tied to CHIWOS findings. We worked with participant one-to-one; the wider CHIWOS Ontario team also contributed.



PHOTO BY Chhiring

Reading this book is not an escape from our own lives, but to find out how these authors have dealt with theirs, whether it be a past predicament or through self-care rituals, or perhaps a key principle that explains all the situations in one woman's life. Some are told in poetry, others are in prose, one is explained in a beautiful painting, and another using photovoice. Whatever the format, they each represent unique retellings, which ultimately attest to universal truths.

RESULTS

Each participant submitted at least one piece to the final, 21-page anthology that includes poetry, autobiographical works, art, photography, and more. The co-creation process required personalized adaptations to enable each participant to complete the workshop series and anthology contribution. The discussions and contributions reflected and offered more nuance regarding the CHIWOS quantitative findings; for instance, some elaborated on who they considered a 'peer'. Many of the submissions reiterate the CHIWOS Women-Centred HIV Care Model – specifically, person-centred and community-centred care.

We will launch *Beyond the Data* online shortly and distribute print copies to the CHIWOS participants who contributed to the book and the project team.

Beyond the Data was a pilot project with a small number of women participants. We would like to offer it as a full program within the CHIWOS KTE umbrella and add to the story collection. *Beyond the Data* has a future with many more participants involved.

Wow. This anthology is so moving and reminds me of the importance of storytelling. As the principal investigator of CHIWOS, I can say that I am truly humbled by this piece of work; reading the stories, poems and words and looking at the photos brought me to tears. I can see our research brought into action by women living with HIV who participated in the study and who were the frontline research assistants. While at the same time, I can see myself in the stories and acknowledge my own vulnerability.

Thank you.

- Dr. Mona Loutfy, MD, FRCP(C), MPH, CHIWOS Principal Investigator



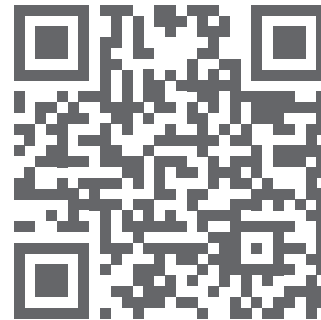
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**For My Mother
by Louise**

"And when I reach for you,
I feel the rough,
hewn texture
Of Love
And when I look at you,
I see a wary lioness,
Ready to die for her cubs,
Not realizing that there are
predators,
Even you cannot vanquish
(1994)"

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