

CHIWOS

Étude sur la santé sexuelle et reproductive
des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and
Reproductive Health Cohort Study



CHIWOS POLICIES AND GUIDELINES DOCUMENTS

English version

Revised September 2019

*Canadian HIV
Women's
Reproductive and
Sexual Health
Cohort Study*

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ACCRONYMS

CAB: Community Advisory Board

CBR: Community-Based Research

CIHR: Canadian Institutes of Health Research

CoIs: Co-Investigators

NMT: National Management Team

PRA(s): Peer research Associate(s)

PI(s): Principal Investigator(s)

RC: Research Coordinators

SC: Steering Committee

WCHC: Women-Centred HIV Care

WLWH: Women Living with HIV



CHIWOS POLICIES



CHIWOS POLICY CREATION AND REVISION POLICY

Last reviewed and revised – Dec., 2019

PURPOSE OF CHIWOS POLICIES

The CHIWOS team, lead by the National Management Team (NMT), will produce the necessary policies to help manage and guide the study team in their activities. Policies also serve as an official record of decisions made by the CHIWOS team. Policies are meant to provide continuity, consistency, and clarity to the research process for the numerous members of our team, including Coordinators, Principal Investigators, students, peers, and collaborators. The following provides additional information about the modes of policy creation and revision.

POLICY CREATION

CHIWOS policies will be created as required. Identification of the need for a policy may come from a diversity of sources including the NMT, the Steering Committee, or collaborators at large. Once a need for a policy has been raised, the NMT will decide if a policy is indeed required at the upcoming NMT teleconference meeting. On a yearly basis, a CHIWOS Coordinator will accept the responsibility of creating and circulating new policies. Once created, the policies will be circulated first to nominated Principal Investigator, Dr. Mona Loutfy, and then to the NMT. Policies are considered final for that year once feedback has been received from all members of the NMT. Feedback must be received within 10 working days, otherwise we will operate under the premise that no feedback provided means that no edits were required, and policies will be considered final for that year. Once finalized in English, all policies will be translated into French.

POLICY REVISION

All CHIWOS policies will be reviewed and revised if required each year to ensure that CHIWOS policies continue to respond to the needs of the project. The revision of document will be led by the CHIWOS Coordinator accepting the CHIWOS policy responsibility for that year and will work with the nominated Principal Investigator, Dr. Mona Loutfy on revisions. Revisions will then be sent to the CHIWOS NMT. Feedback must be received within 10 working days, otherwise we will operate under the premise that no feedback provided means that no edits were required, and policies will be considered final for that year. Policies for specific working groups (e.g. KTE or Project and Data Request) may be revised by appropriate working group members, such as the KTE or SRDM and then approved by the NMT. Finally, in order to facilitate the evolution of CHIWOS policies, the month and years should always be included at the top of the document. All revisions to policies will be translated into French once complete.

CURRENT CHIWOS POLICIES AND DOCUMENTS

	ENGLISH TITLE OF CHIWOS POLICY & DOCUMENTS	TITRE FRANCAIS DES POLITIQUES ET DOCUMENTS CHIWOS
	POLICIES	
1	Policy Creation and Revision Policy	Politique de création et de révision des politiques
2	Bilingual policy	Politique de bilinguisme
3	Authorship Policy	Politique d’auteurs
4	Data and Project Request Policy	Politique de requête de données et de projet
5	Studentship Policy	Politique pour les étudiants
6	New Members Procedures Policy	Politique d’inclusion de nouveaux membres
7	Social Media and Website Policy	Politique pour les médias sociaux et le site web
8	Safety and Psychological Wellbeing Policy	Politique de sécurité et de bien-être
9	PRA Activities and Expectations Policy	Politique des activités et attentes pour les PARs
10	Conference Attendance Policy	Politique de participation aux conférences
	OTHER DOCUMENTS	
11	CHIWOS Guiding Principles	Lignes directrices de CHIWOS
12	GAB Request Form	Formulaire de demande CCS (Comité Consultatif Spécifique)
13	Steering Committee – Terms of Reference	Comité directeur-Mandats
14	CAB –Terms of Reference	CCC - Mandats
15	KTE Working Group Terms of Reference	Groupe de travail ACE (Application des connaissances et échange)- Mandats



CHIWOS BILINGUAL POLICY

Last reviewed and revised – Dec. 2019

As a national project, CHIWOS is committed to the appropriate use of both official Canadian languages. This bilingual policy for operating in both French and English has been developed in consultation with our Quebec, Ontario, and British Columbia research team members.

STUDY MATERIALS

- Documents **produced or translated** in either French or English by native speakers of the CHIWOS National Management Team (NMT) (e.g. Principal Investigator or Coordinator) do not require certification for the language(s) in which they were created.
- If a member of the **CHIWOS NMT is not available to produce or translate** the materials, a translator (certified or non-certified) will be hired depending on the documents:
 - Participant materials and Research Ethics Board documents must be translated by a certified translator (e.g. Informed consent forms, questionnaires, interview guides).
 - Non participant materials (e.g. CHIWOS policies, meeting agendas, social media posts) may be translated by a certified or non-certified translator.
- All Peer Research Associate (PRA) materials (national email communication, training materials) will be available in both French and English.
- The PRAs Website will be fully bilingual – This is no longer available due to corrupted file.
- National CHIWOS documents (e.g. CHIWOS policies) will be produced in English first, and final versions translated into French.

KNOWLEDGE TRANSLATION AND EXCHANGE (KTE) MATERIALS

- CHIWOS publications will most often be produced and published in English and will be translated into French only if required by the target journal. Once published, the abstract of each manuscript will be made available in both French and English on the CHIWOS website. Abstracts of conference communications (oral or poster) will not be translated.
- The CHIWOS website will be fully bilingual.
- KTE activities at national level (e.g. Newsletter) as well as in Quebec will be available in both French and English. Provincial KTE materials in BC and ON may be produced only in English.
- Materials on social media (Facebook, Twitter) should be available in both French and English whenever possible. Posts and Tweets will be mainly in English.

TRANSLATION OF MEETINGS

- Steering Committee and NMT meetings and all other national meetings (e.g. CTN meetings) will be facilitated in English, and translation will be readily provided by one of the members of the CHIWOS team whenever requested. Questions or comments in French are encouraged, and French questions will be translated into English, and responded to in both French and English.
- All national communications with PRAs will be conducted in both French and English (e.g. meeting minutes, and documents). Both French and English communications will be sent simultaneously.
- PRA teleconference will be facilitated in English and simultaneous typing translation will be provided as needed. Organizers of the meeting have to inform coordinators 2 weeks before meeting. Coordinators will organize the translation, mostly using “join.me” a screen sharing application and “Google translate”.
- All provincial meetings in Quebec (e.g. PRA meetings, PRA trainings, CAB) will be conducted in French, with a written translation provided. Questions or comments in English are encouraged, and English questions will be translated into French and answered in both languages. All documents and slides will be available in both French and English.

TRANSLATION PROCESS AND PAYMENT

- Translation of documents time will be minimized wherever possible
- Three weeks is usually required for translation activities
- CHIWOS translation funds are housed in Quebec
- The Quebec CHIWOS team will do translations as part of regular CHIWOS work tasks when time and work load permits (see in [OTHER DOCUMENTS](#))
- When time and workload does not permit, an external translator may be hired.



CHIWOS AUTHORSHIP POLICY

Last reviewed and revised – Dec. 2019

The following document has been adapted from the CANOC and OCS authorship policies.

INTRODUCTION

One of the main principles of authorship is to properly acknowledge the people that have completed the bulk of the work, as well as the important contribution of collaborators and community members such as Steering Committee members, Community Advisory Board (CAB) members, collaborating sites, and PRAs. Proper acknowledgement of all persons who have contributed is necessary in order to reflect the CHIWOS values and guiding principles, and to ensure constructive collaboration between all contributors.

AUTHORSHIP

- The first author will be the **Manuscript Lead**, followed by the **Senior Author** and then the contributing **Primary Manuscript Preparation Team** members listed by name, followed by the CHIWOS **Principal Investigators (PIs)** listed by name (Angela Kaida, Alexandra de Pokomandy, Mona Loutfy), and finally followed by “on behalf of **the CHIWOS Research Team***”. The “*” will be hyperlinked to all authors listed at the end of article as an appendix.
- If there is no senior author as part of **Primary Manuscript Preparation Team**, Mona Loutfy will be listed as the senior author just before “on behalf of the **CHIWOS Research Team***” unless there is someone more appropriate. The other two PIs listed before the senior author will appear as above: Angela Kaida, Alexandra de Pokomandy.
- Note: if a PI is one of the primary manuscript preparation team members working on the paper, their name may appear closer to the start of the authorship list to ensure proper acknowledgement of their work (instead of at the end with the other PIs). Please refer to the following examples:

First Author (Manuscript leader), Primary Manuscript Preparation team,
Principal Investigators, Senior author, on behalf of the CHIWOS research
Team*

First Author (Manuscript leader), Primary Manuscript Preparation team
Including a PI (name PI as second or third author), Principal Investigators,
Senior author, on behalf of the CHIWOS research Team*

AUTHOR CATEGORIES AND RESPONSIBILITIES

1. Manuscript lead (first author)

- The **Manuscript lead** will be responsible for drafting the abstract and/or manuscript, circulating it for review, collating feedback, and finalizing it for submission.
- They will also be responsible for finalizing the list of co-authors (in consultation with the Senior authors and PIs and with guidance from the 'CHIWOS Manuscript Preparation Plan') and ensuring that all co-authors follow the CHIWOS Authorship Policy.
- If the Manuscript Lead does not take the responsibilities of lead authorship as outlined above authorship may be re-assigned by the CHIWOS PIs to ensure proper recognition of the work conducted.

2. Primary Manuscript Preparation Team

- The **Primary Manuscript Preparation Team** is the core group of individuals that worked on the Data Request, abstract, and/or manuscript.
- This group also includes: the data analyst and statistician who worked on the request (quantitative data only), at least the Provincial NMT PRA representative from which the author lead comes from, and at least the Provincial Research coordinator from which the author lead comes from. If the journal limited the numbers of authors, it is understood that a maximum of one PRA Representative and one coordinator will be include in author list. For more information about this, please refer to **Notes 3** below.
- For survey data requests, the survey-working group that developed the questions being used must be consulted and may be included in the **Primary Manuscript Preparation Team**.

3. Principal Investigators

- The Principal investigators (PIs) are list by name in this order:
Angela Kaida, Alexandra de Pokomandy, Mona Loutfy

4. The CHIWOS Research Team

- Current **CHIWOS Research Team** members will be listed in the **appendix** of publications and will be hyperlinked as individually named authors by provinces and then, in alphabetical order by last name. This list will exclude authors already named, such as members of the Primary Manuscript Preparation Team and Principal Investigators. The **CHIWOS Research Team** consist of:
 - Co-Applicants/Co-Investigators
 - Research Coordinators
 - NMT PRA Representatives
 - National and Provincial Core Research Team Members, including PRAs
 - National Steering Committee Members
 - Sampling, Recruitment, and Data and Management Team Members
 - **Please note that some members of the CHIWOS Research Team have requested to remain anonymous.**
- For a complete list of the **CHIWOS Research Team**, see the appendix section above.

5. Corresponding Author

- The Manuscript Lead, Senior Author or Nominated Principal Investigator (Mona Loufty) will act as the Corresponding Author, unless another research team member is deemed more appropriate; this will be chosen by the Manuscript Lead and the Principal Investigator.

Notes:

- 1. It is understood that the CHIWOS Research Team membership is dynamic and may change over time.**
- 2. Membership in the above groups is based on the associated Terms of Reference (please see those documents in [OTHER DOCUMENTS](#)). Membership is reviewed on a yearly basis.**
- 3. Please note that several journals have a limited number of authors for publications, for instance 5 or 10 authors maximum. As a large team this is a challenge that must be considered when initiating manuscript collaborations and when designating authorship. In these cases, the First author, the Senior author and PIs will discuss and decide. If there are still discrepancies on decisions, the First author, the Senior author and Mona Loufty will decide. Please consult with your Provincial Principal Investigator if you are unsure about authorship requirements.**
- 4. CHIWOS is a CIHR funded project. All research papers generated from CIHR funded projects are required to be made freely accessible through the Publisher's website or an online repository within twelve months of publication. Please ensure that your paper is published in an open access journal or you deposit the paper in your institution's repository within twelve months of publication.**
- 5. CHIWOS currently does not have the operating budget to contribute to journal open access fees for independent investigators. Independent investigators as the First author or Senior author are expected to cover the cost of open access fees for their students and their own CHIWOS publications.**

AUTHORSHIP CRITERIA

- Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Authorship credit will be based on¹:
 - (1) Substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; AND
 - (2) Drafting the manuscript or revising it critically for important intellectual content; AND
 - (3) Final approval of the version to be published (statistical analysis, administrative, technical or material support, and supervision).

All three conditions must be met to qualify as a CHIWOS author.

- Individuals (including PIs and all CHIWOS Research Team Members) who meet authorship criteria but do not wish to be acknowledged as authors are permitted to withdraw from authorship at any time before publication.
- If any current or potential author or CHIWOS Research Team member is unhappy with the authorship list or order, the principles of open and respectful communication and collegiality will be adopted to allow for immediate resolution. Please refer to the [CHIWOS SAFETY AND PSYCHOLOGICAL WELLBEING POLICY](#). These concerns must be discussed and resolved before submission for publication. Please raise them with the Senior author and your provincial PI. If there are still difficulties in resolving, please discuss with Mona Loutfy to help resolve.

ACKNOWLEDGEMENTS

The following excerpt will appear in the acknowledgement section of publications:

The CHIWOS Research Team would like to thank the women living with HIV for their contributions to this study. We also thank the national team of co-investigators, collaborators, and Peer Research Associates and acknowledge the national Steering Committee, our three provincial Community Advisory Boards, the National CHIWOS Aboriginal Advisory Board, CHIWOS African Caribbean and Black Advisory Board, and CHIWOS Trans Women Advisory Board, the BC Centre for Excellence in HIV/AIDS for data support and analysis, and all our partnering organizations for supporting the study.

Acknowledgement of funders:

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¹ International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals, Authorship and Contributions. <http://www.icmje.org>

KEYWORDS

CHIWOS publications will always include "HIV", "women", and "CHIWOS" in keywords.

REFERENCES

CHIWOS had published several manuscripts on Process, methods and cohort. Please reference to these publications in your manuscript.

O'Brien N, Greene S, Carter A, Lewis J, Nicholson V, Kwaramba G, Ménard B, *Kaufman E, Ennabil N, Andersson N, Loutfy M, de Pokomandy A, Kaida A; CHIWOS Research Team. (2017). Envisioning Women-Centered HIV Care: Perspectives from Women Living with HIV in Canada. *Women's health issues*, Epub ahead of print. doi:10.1016/j.whi.2017.08.001

Loutfy M, Greene S, Kennedy VL, Lewis J, Thomas-Pavanel J, Conway T, de Pokomandy A, *O'Brien N, Carter A, Tharao W, Nicholson V, Beaver K, Dubuc D, Gahagan J, Proulx-Boucher K, Hogg RS, Kaida A; CHIWOS Research Team. (2016). Establishing the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS): Operationalizing Community-based Research in a Large National Quantitative Study. *BMC medical research methodology*, 16(1), 101. doi:10.1186/s12874-016-0190-7

Abelsohn K, Benoit AC, Conway T, Cioppa L, Smith S, Kwaramba G, Lewis J, Nicholson V, *O'Brien N, Carter A, Shurgold J, Kaida A, de Pokomandy A, Loutfy M. (2015). Hear(ing) New Voices": Peer Reflections from Community-Based Survey Development with Women Living with HIV. *Progress in community health partnerships : research, education, and action*, 9(4), 561-9. doi:10.1353/cpr.2015.0079

Loutfy M, de Pokomandy A, Kennedy VL, Carter A, *O'Brien N, Proulx-Boucher K, Ding E, Lewis J, Nicholson V, Beaver K, Greene S, Tharao W, Benoit A, Dubuc D, Thomas-Pavanel J, Sereda P, Jabbari S, Shurgold JH, Colley G, Hogg RS, Kaida A, CHIWOS Research Team. (2017). Cohort profile: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS). *PloS one*, 12(9), e0184708. doi:10.1371/journal.pone.0184708

Kaida, A., Carter, A., Nicholson, V., Lemay, J., O'Brien, N., Greene, S., ... & Bernier, M. (2019). Hiring, training, and supporting Peer Research Associates: Operationalizing community-based research principles within epidemiological studies by, with, and for women living with HIV. *Harm reduction journal*, 16(1), 47.

Webster, K., Carter, A., Proulx-Boucher, K., Dubuc, D., Nicholson, V., Beaver, K., ... Kaida, A. (2018). Strategies for Recruiting Women Living with Human Immunodeficiency Virus in Community-Based Research: Lessons from Canada. *Progress in Community Health Partnerships: Research, Education, and Action* 12(1), 21-34. doi:10.1353/cpr.2018.0003.

All CHIWOS publications are available on CHIWOS website:

- <http://www.chiwos.ca/research-papers-and-summaries/?lang=en>

PROCEDURES and GUIDELINES

- A Data and Project Request Form must be filled out for an abstract or manuscript and submitted to your provincial coordinator for review and approval by the PIs. For conferences, please submit your request at least 6 weeks before the conference deadline.

Conferences

- A **minimum of 3 working days** will be provided for the **Primary Manuscript Preparation Team**, and the **National Management Team (NMT)** members to review a conference abstract and authorship prior to submission. An email to the NMT is required **3 weeks** prior to the conference abstract deadline to notify the authors of an upcoming abstract submission and to finalize the authorship list.
- A **minimum of 3 working days** will be provided for the **Primary Manuscript Preparation Team**, and the **NMT** members to review a conference presentation (Oral or Poster) prior to conference.
- If no response is received from members of the above groups in the allotted time period, it will be assumed that there is no feedback from those particular members and that they have read the document and approved it, and the abstract or publication will be submitted without further communication.
- Feedback at this stage of abstract and conference poster/presentation development is intended to be the major time of feedback on the analysis.

Manuscripts

- A **minimum of 10 working days** will be provided for the **Primary Manuscript Preparation Team** and the **CHIWOS NMT** to review a manuscript and authorship prior to submission.
- Feedback at this stage of manuscript development is intended to be minor with the intention of facilitating publication. *Major changes to the scope of the manuscript or analyses should be limited to the development of the idea at the Data and Project Request Form and of abstract and conference poster/presentation development stage.* If an author feels that major analyses or changes are required at this stage, please email the First and Senior authors privately as soon as possible to set up a teleconference. If there are discrepancies in views, Mona Loutfy is to be contacted to resolve.
- Subsequent drafts of the manuscript will not routinely be re-circulated. If an author wishes to view a subsequent draft before submission, a request must be made in writing within **10 working days** of the original email.
- If no response is received from members of the above groups in the allotted 10-day time period, it will be assumed that there is no feedback from those particular members and that they have read the document and approved it, and the abstract or publication will be submitted without further communication. Comments received after the 10 days will not be considered or included prior to initial submission. If an author anticipates a delay in providing feedback, the Manuscript Lead should be notified in writing as soon as possible after receiving the request for feedback and an extension can be arranged accordingly.
- A final version of the manuscript will be sent to the **Primary Manuscript Preparation Team** within two weeks after submission. Comments, edits, or withdrawal from the authorship list will still be possible until journal reviewer comments are received and the final article submitted for publication.
- **Once manuscript published, the First Author is responsible to send an electronic copy of**

the article to her provincial research coordinator to post it on the CHIWOS website, and to maintain CHIWOS publications folders (Dropbox) up to date.

- Provincial CABs will be notified of the manuscript submission in conjunction with their next meeting, and will be directed to the CHIWOS website for the full text of the article when published.
- CHIWOS publications will be translated into French if required by the target journal. The abstract of each publication will be made available in both official languages on the CHIWOS website. Please refer to the [CHIWOS BILINGUAL POLICY](#) for more information.

APPENDIX

***Removal of co-investigators from the authorship hyperlink must be done with the consent of the co-investigators and must also be officially removed from the CIHR grant on an annual basis.**

Complete CHIWOS Research Team List for Publications

CHIWOS RESEARCH TEAM: Rahma Abdul-Noor (Women's College Research Institute), Aranka Anema (Harvard Medical School), Jonathan Angel (Ottawa Hospital Research Institute), Dada Mamvula Bakombo (McGill University Health Centre), Fatimatou Barry (Women's College Research Institute), Greta Bauer (University of Western Ontario), Kerrigan Beaver (Women's College Research Institute), Marc Boucher (CHU Ste-Justine), Isabelle Boucoiran (CHU Ste-Justine), Jason Brophy (Children's Hospital of Eastern Ontario), Lori Brotto (University of British Columbia), Ann Burchell (St. Michael's Hospital), Claudette Cardinal (Simon Fraser University), Allison Carter (Kirby Institute), Lynne Cioppa (Women's College Research Institute), Tracey Conway (Women's College Research Institute), José Côté (Centre Hospitalier de l'Université de Montréal), Jasmine Cotnam (Canadian Aboriginal AIDS Network), Cori d'Ambrumenil (AIDS Vancouver Island), Janice Dayle, (McGill University Health Centre), Erin Ding (British Columbia Centre for Excellence in HIV/AIDS), Danièle Dubuc, (McGill University Health Centre), Janice Duddy (Pacific AIDS Network), Mylène Fernet (Université du Québec à Montréal), Annette Fraleigh (Women's College Research Institute), Peggy Frank (Simon Fraser University), Brenda Gagnier (Women's College Research Institute), Marilou Gagnon (University of Victoria), Jacqueline Gahagan (Dalhousie University), Claudine Gasingirwa (Women's College Research Institute), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Rebecca Gormley (British Columbia Centre for Excellence in HIV/AIDS), Saara Greene (McMaster University), Danielle Groleau (McGill University), Charlotte Guerlotté (COCQ-SIDA), Trevor Hart (Ryerson University), Catherine Hankins (McGill University), Roula Hawa (Women's College Research Institute), Emily Heer (Alberta Health Services), Robert S. Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Terry Howard (Glasshouse Consultants), Shazia Islam (Women's College Research Institute), Joseph Jean-Gilles (GAP-VIES), Hermione Jefferis (AIDS Vancouver Island), Evin Jones (Pacific AIDS Network), Charu Kaushic (McMaster University), Mina Kazemi (Women's College Research Institute), Mary Kestler (Oak Tree Clinic, BC Women's Hospital and Health Centre), Maxime Kiboyogo (McGill University Health Centre), Marina Klein (McGill University Health Centre), Nadine Kronfli (McGill University Health Center), Gladys Kwaramba (Women's College Research Institute), Gary Lacasse (Canadian AIDS Society), Ashley Lacombe-Duncan (University of Michigan), Melanie Lee (Simon Fraser University), Rebecca Lee (CIHR Canadian HIV Trials Network), Jenny Li (British Columbia Centre for Excellence in HIV/AIDS), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS), Elisa Lloyd-Smith (Vancouver General Hospital), Carmen Logie (University of Toronto), Evelyn Maan (Oak Tree Clinic), Valérie Martel-Lafrenière (Centre Hospitalier de l'Université de Montréal), Carrie Martin (Canadian Aboriginal AIDS Network), Renee Masching (Canadian Aboriginal AIDS Network), Lyne Massie (Université

du Québec à Montréal), Melissa Medjuck (formerly of the Positive Women's Network), Brigitte Ménard, (McGill University Health Centre), Cari L. Miller (formerly of Simon Fraser University), Judy Mitchell (Positive Living North), Gerardo Mondragon (British Columbia Centre for Excellence), Deborah Money (Women's Health Research Institute and Faculty of Medicine at UBC), Ken Monteith (COCQ-SIDA), Marvelous Muchenje (Women's Health in Women's Hands CHC), Florida Mukandamutsa (CASM), Mary Ndung'u (African Partnership Against AIDS), Valerie Nicholson (Simon Fraser University), Kelly O'Brien (University of Toronto), Nadia O'Brien (McGill University Health Centre and McGill University), Gina Ogilvie (University of British Columbia, Women's Health Research Institute), Susanna Ogunnaike-Cooke (Public Health Agency of Canada), Joanne Otis (Université du Québec à Montréal), Rebeccah Parry (Simon Fraser University), Sophie Patterson (Simon Fraser University), Angela Paul (Positive Living North), Doris Peltier (Canadian Aboriginal AIDS Network), Neora Pick (Oak Tree Clinic, BC Women's Hospital and Health Centre), Alie Pierre (McGill University Health Centre), Jeff Powis (Michael Garron Hospital), Karène Proulx-Boucher (McGill University Health Centre), Corinna Quan (Windsor Regional Hospital), Jesleen Rana (Women's Health in Women's Hands CHC), Eric Roth (University of Victoria), Danielle Rouleau (Centre Hospitalier de l'Université de Montréal), Geneviève Rouleau (Centre Hospitalier de l'Université de Montréal), Sergio Rueda (Centre for Addiction and Mental Health), Kate Salters (Simon Fraser University, British Columbia Centre for Excellence in HIV/AIDS), Margarite Sanchez (ViVA, Southern Gulf Islands AIDS Society, Simon Fraser University), Roger Sandre (Haven Clinic), Jacquie Sas (CIHR Canadian HIV Trials Network), Édénia Savoie (McGill University Health Centre), Paul Sereda (British Columbia Centre for Excellence in HIV/AIDS), Stephanie Smith (Women's College Research Institute), Marcie Summers (formerly of the Positive Women's Network), Wangari Tharao (Women's Health in Women's Hands CHC), Christina Tom (Simon Fraser University), Cécile Tremblay (Centre Hospitalier de l'Université de Montréal), Jason Trigg (British Columbia Centre for Excellence in HIV/AIDS), Sylvie Trottier (Centre Hospitalier Universitaire de Québec), Angela Underhill (Women's College Research Institute), Anne Wagner (Ryerson University), Sharon Walmsley (University Health Network), Clara Wang (British Columbia Centre for Excellence), Kath Webster (Simon Fraser University), Wendy Wobeser (Queen's University), Denise Wozniak (Positive Living Society of British Columbia), Mark Yudin (St. Michael's Hospital), Wendy Zhang (British Columbia Centre for Excellence in HIV/AIDS), Julia Zhu (British Columbia Centre for Excellence in HIV/AIDS). All other CHIWOS Research Team Members who wish to remain anonymous.

CHIWOS Research team list by provinces (For revisions only)

British Columbia: Aranka Anema (*Harvard Medical School*), Lori Brotto (*University of British Columbia*), Allison Carter (*Kirby Institute*), Claudette Cardinal (*Simon Fraser University*), Cori d'Ambrumenil (*AIDS Vancouver Island*), Erin Ding (*British Columbia Centre for Excellence in HIV/AIDS*), Janice Duddy (*Pacific AIDS Network*), Peggy Frank (*Simon Fraser University*), Nada Gataric (*British Columbia Centre for Excellence in HIV/AIDS*), Rebecca Gormley (*British Columbia Centre for Excellence in HIV/AIDS*), Robert S. Hogg (*British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University*), Terry Howard (*Glasshouse Consultants*), Evin Jones (*Pacific AIDS Network*), Hermione Jefferis (*AIDS Vancouver Island*), Mary Kestler (*Oak Tree Clinic, BC Women's Hospital and Health Centre*), Melanie Lee (*Simon Fraser University*), Jenny Li (*British Columbia Centre for Excellence in HIV/AIDS*), Viviane Lima (*British Columbia Centre for Excellence in HIV/AIDS*), Elisa Lloyd-Smith (*Vancouver General Hospital*), Evelyn Maan (*Oak Tree Clinic*), Melissa Medjuck (*Formerly of Positive Women's Network*), Cari L. Miller (*Simon Fraser University*), Judy Mitchell (*Positive Living North*), Gerardo Mondragon (*British Columbia Centre for Excellence in HIV/AIDS*), Deborah Money (*Women's Health Research Institute, Faculty of Medicine at UBC*), Valerie Nicholson (*Simon Fraser University*), Gina Ogilvie (*Women's Health Research Institute, University of British Columbia*), Rebeccah Parry (*Simon Fraser University*), Sophie Patterson (*Simon Fraser University*), Angela Paul (*Positive Living North*), Neora Pick (*Oak Tree Clinic, BC Women's Hospital and Health Centre*), Eric Roth (*University of Victoria*), Kate Salters (*Simon Fraser*

University, British Columbia Centre for Excellence in HIV/AIDS), Margarite Sanchez (ViVA, Positive Living Society of British Columbia), Jacquie Sas (CIHR Canadian HIV Trials Network), Paul Sereda (British Columbia Centre for Excellence in HIV/AIDS), Marcie Summers (Formerly of Positive Women's Network), Christina Tom (Simon Fraser University), Jason Trigg (British Columbia Centre for Excellence in HIV/AIDS), Clara Wang (British Columbia Centre for Excellence in HIV/AIDS), Kath Webster (Simon Fraser University), Denise Wozniak (Positive Living Society of British Columbia), Wendy Zhang (British Columbia Centre for Excellence in HIV/AIDS), Julia Zhu (British Columbia Centre for Excellence in HIV/AIDS)

Ontario: Jonathan Angel (Ottawa Hospital Research Institute), Fatimatou Barry (Women's College Research Institute), Greta Bauer (University of Western Ontario), Kerrigan Beaver (Women's College Research Institute), Breklyn Bertozzi (Women's College Research Institute), Tammy Bourque (The HAVEN/Hemophilia Program Health Sciences North/Horizon Santé-Nord), Jason Brophy (Children's Hospital of Eastern Ontario), Ann Burchell (St. Michael's Hospital), Lynne Cioppa (Women's College Research Institute), Tracey Conway (Women's College Research Institute), Jasmine Cotnam (Canadian Aboriginal AIDS Network), Annette Fraleigh (Women's College Research Institute), Brenda Gagnier (Women's College Research Institute), Claudine Gasingirwa (Women's College Research Institute), Saara Greene (McMaster University), Trevor Hart (Ryerson University), Roula Hawa (Women's College Research Institute), Shazia Islam (Alliance for South Asian AIDS Prevention), Mina Kazemi (Women's College Research Institute), Gladys Kwaramba (Women's College Research Institute), Ashley Lacombe-Duncan (University of Michigan), Carmen Logie (University of Toronto), Marvelous Muchenje (Women's Health in Women's Hands CHC), Mary Ndung'u (African Partnership Against AIDS), Kelly O'Brien (University of Toronto), Jeff Powis (Michael Garron Hospital), Corinna Quan (Windsor Regional Hospital), Jesleen Rana (Women's Health in Women's Hands CHC), Sergio Rueda (Centre for Addiction and Mental Health), Roger Sandre (Haven Clinic), Stephanie Smith (Women's College Research Institute), Wangari Tharao (Women's Health in Women's Hands CHC), Angela Underhill (Women's College Research Institute), Anne Wagner (Ryerson University), Sharon Walmsley (University Health Network), Wendy Wobeser (Queen's University), Mark Yudin (St. Michael's Hospital).

Quebec:

Dada Mamvula Bakombo (McGill University Health Centre), Marc Boucher (CHU Ste-Justine), Isabelle Boucoiran (CHU Ste-Justine), José Côté (Centre Hospitalier de L'Université de Montréal), Janice Dayle, (McGill University Health Centre), Danièle Dubuc, (McGill University Health Centre), Mylène Fernet (Université du Québec à Montréal), Marilou Gagnon (University of Victoria), Danielle Groleau (McGill University), Charlotte Guerlotté (COCQ-SIDA), Emily Heer (Alberta Health Services), Joseph Jean-Gilles (GAP-VIES), Maxime Kiboyogo (McGill University Health Centre), Marina Klein (McGill University Health Centre), Nadine Kronfli (McGill University Health Center), Gary Lacasse (Canadian AIDS Society), Carrie Martin (Canadian Aboriginal AIDS Network), Lyne Massie (Université de Québec à Montréal), Valérie Martel-Lafrenière (Centre Hospitalier de l'Université de Montréal), Brigitte Ménard, (McGill University Health Centre), Ken Monteith (COCQ-SIDA), Florida Mukandamutsa (CASM), Nadia O'Brien (McGill University), Joanne Otis (Université du Québec à Montréal), Doris Peltier (Canadian Aboriginal AIDS Network), Alie Pierre, (McGill University Health Centre), Karène Proulx-Boucher (McGill University Health Centre), Danielle Rouleau (Centre Hospitalier de l'Université de Montréal), Geneviève Rouleau (Centre Hospitalier de l'Université de Montréal), Édénia Savoie (McGill University Health Centre), Cécile Tremblay (Centre Hospitalier de l'Université de Montréal), Sylvie Trottier (Centre Hospitalier Universitaire de Québec).

Other Canadian provinces or international jurisdictions: Jacqueline Gahagan (Dalhousie

University), Catherine Hankins (McGill University), Renée Masching (Canadian Aboriginal AIDS Network), Susanna Ogunnaike-Cooke (Public Health Agency of Canada).

All other CHIWOS Research Team Members who wish to remain anonymous.

Email list:

Please contact your provincial coordinator for email list.

*Please note only those who have chosen to have their names acknowledged emails' are included



CHIWOS PROJECT AND DATA REQUEST POLICY

Last reviewed and revised – December 20, 2019

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CHIWOS PROJECT AND DATA REQUEST POLICY

The CHIWOS project and data request policy, including the data use agreement must be followed for all collaborations initiated as part of CHIWOS.

1. All researchers (CHIWOS PIs, CoIs, Students, or Collaborators) wishing to access CHIWOS survey, CHIWOS database, or focus group data, as well as conduct a CHIWOS process project must complete a Project and Data Request Form, outlining their proposed research.

2. All researchers are encouraged to review their proposed research with their respective Provincial Coordinator and Principal Investigator prior to submitting the project and data request form.

3. All Project and Data Request Forms must be submitted to the respective Provincial Coordinator who will review for completeness and provide feedback as necessary. For abstracts, posters, or oral presentations to conferences involving survey data, please submit your request at least **8 weeks** before the conference deadline (note: the BC-CfE has an internal deadline that may be earlier; a notification will be circulated as each conference approaches).

4. STEP ONE: PROJECT REQUEST: Once the Project and Data Request Form is submitted, the Provincial Coordinator will circulate it to the National Management Team (NMT) for review. The NMT members will have **1 week** (5 working days) to comment on the project request. Though comments may be received by multiple members of the NMT, the three provincial Principal Investigators (PIs) will decide if the concept was approved, approved with modifications, tabled - needs further clarification, or not approved. The Provincial Coordinator will communicate any revisions to the lead Investigator who initiated the request. At conference times, if numerous Project Request Forms are submitted for survey data, the PIs will rank them and up to a maximum of 2 requests per province will be accepted (if the analyses are requested by the BC-CfE).

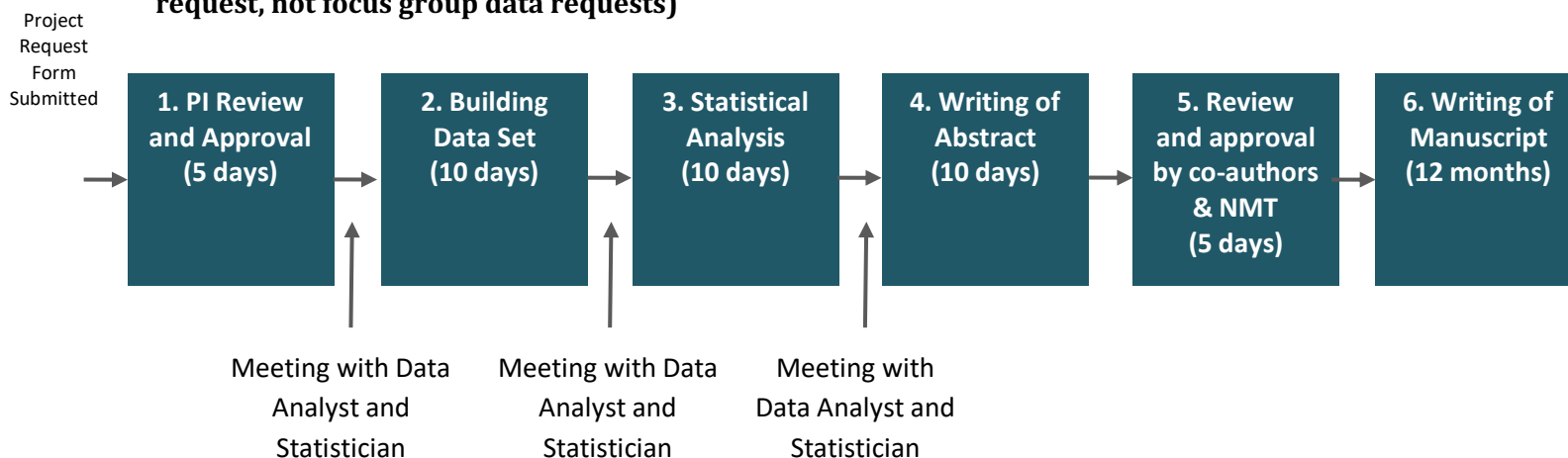
5. STEP TWO: DATA REQUEST AND ANALYSIS: For process or focus group data: Once the project is approved, the researcher can begin analyzing the data. Anonymized and password protected focus group transcripts will be sent to the lead Investigator by the Provincial Coordinators. **For survey data:** Once approved, the Provincial Coordinators will submit all requests to their respective data team for processing (note: at the BC-CfE investigators will be required to complete an online submission form; access will be facilitated by the BC coordinator). Then, the data request will be assigned to a data analyst and statistician. The assigned data analyst and statistician will work with the investigator and Provincial Coordinator to refine the protocol outlined in the Project and Data Request Form if necessary (e.g., clarifying study eligibility criteria, variables, and requested analytic approaches). Depending on how complete and/or complex the Data Request, please anticipate that this process may delay receipt of the final output. Once finalized, the data analyst will prepare the requested analytic dataset and will send it to the statistician. The Data Analyst will have at least **2 weeks** (10 working days) to prepare the dataset. The statistician will then run the analysis as per the protocol. The statistician will have **2 weeks** (10 working days) to run the analysis and send the output to the investigator. The investigator will then have 2 weeks left to draft an abstract and share it with the co-authors and the NMT prior to deadline. ***Note: Angela Kaida, Ann Burchell, Alexandra de Pokomandy, Carmen Logie, and approved graduate students are the only epidemiologists who may run an analysis in lieu of the data analysts and statisticians. However, they are NOT responsible for running all CHIWOS analyses; they may simply run their own analyses.***

6. Each participating cohort (or province) in CHIWOS will have the right to decide to participate or not participate in any scientific aim or sub-aim. By agreeing to participate, cohorts commit themselves to supplying the data elements as specified by the final study protocol. Data transmitted by an individual cohort will be used only to address the approved scientific aims. Additional analyses require the approval of the CHIWOS Principal Investigators.

7. Investigators agree to follow CHIWOS authorship policy (posted on the web at www.chiwos.ca). Importantly, all abstracts and manuscripts **MUST** be submitted to the primary authors and CHIWOS NMT for review and approval before they are submitted to a journal or conference. For all survey data requests, the Data Analyst and Statistician who worked on the request must be listed by name as co-authors. Please note that a minimum of **3 working days** must be provided for review of a conference abstract and **2 weeks** (10 working days) for a manuscript. Further, all manuscripts and presentations must acknowledge data collected through CHIWOS and credit all collaborating cohorts and institutions.

8. In order to ensure the timely dissemination of CHIWOS data, we allot a 12-month period for the production of a manuscript, calculated from the time of NMT response to the project request. The end of the 12-month period is defined as the receipt of the completed first draft of the manuscript circulated to the NMT and listed authors. If the manuscript lead has started a manuscript but requires more time, a 3-month extension can be sought. Manuscripts that are not being actively worked on can be reassigned to another member of the team.

Figure 1. Project Request and Data/Analysis Flow Chart (Steps 2-3 only apply to survey data request, not focus group data requests)



WOMEN'S COLLEGE HOSPITAL DATA SHARING AGREEMENT

Women's College Hospital, the institution of nominated PI Dr. Mona Loutfy (here referred to as the "Principal Applicant") has a privacy protection policy for the collection, use and disclosure of data and CHIWOS investigators are asked to abide by this policy.

1. Investigators are asked not to use identifying data in databases and research, and present all data in an aggregate format.

2. Within the collaboration, the data for a project is owned by the principal applicant who holds the finances for the project (“the principal applicant”). When data is shared with a collaborator, the collaborator cannot use the data for any purpose without approval from the principal applicant including but not limited to: analysis, student projects, conference abstracts, presentations, manuscripts, and grant preparation. The approval must be requested in a timely fashion either at a research team meeting and documented in the minutes or via email with written approval. All approved uses of the data including but not limited to analysis, student projects, conference abstracts, conference posters and presentations, other presentations, manuscripts, and grant preparation must be reviewed and approved by all authors and collaborators prior to submission in a timely fashion.
3. Authorship must be agreed upon by all parties in a timely fashion prior to student projects, conference abstracts, conference posters and presentations, other presentations, manuscripts, and grant preparations (see CHIWOS authorship policy). Appropriate acknowledgment of all authors, investigators, funders, Project Advisory Committee/Community Advisory Board (PAC/CAB) members, coordinators, and participants must be made on all student projects, conferences abstracts, conference posters and presentations, other presentations, manuscripts, and grant preparations.
4. Once a project is finished, the database containing the data used by the collaborator must be either returned or destroyed by the collaborator and a written confirmation to this effect must be sent to the principal applicant.

CHIWOS PROJECT AND DATA REQUEST FORM

Date of request:

Name:

Contact phone:

E-mail address:

Province: British Columbia Ontario Québec Other: _____

Instructions:

Please complete an electronic copy of this form and submit to your Provincial Coordinator. Please review the 'CHIWOS Project and Data Request Policy' of this document before beginning. For most sections below you only have to write one or two sentences. If you have any questions, please contact your Provincial Coordinator.

BC: Becky Gormley, rgormley@cfenet.ubc.ca

ON: Mina Kazemi, mina.kazemi@wchospital.ca

QC: Alexandra dePokomandy, alexandra.depokomandy@mcgill.ca

1. Who is doing the analysis and what province:

2. Student-related work:

Yes No → If no skip to Question 2

Thesis related? Yes No **If yes, Supervisor's name & affiliation:** _____

Student project for coursework? Yes No

Student project for practicum? Yes No

Other student project? Yes No **Details:** _____

3. Main data source (check all that apply):

CHIWOS Survey Wave 1

CHIWOS Survey Wave 2

CHIWOS Survey Wave 3

CHIWOS Participant Database

CHIWOS Focus Groups **(If yes, please complete Qs 1-8 only).**

CHIWOS Process (no data required) **(If yes, please complete Qs 1-8 only).**

4. Provincial cohort inclusion:

British Columbia: Yes No

Ontario: Yes No

Québec: Yes No

5. Type of Knowledge translation:

Journal Manuscript - Yes No **Which journal:** _____

Conference Abstract: Yes No **Which conference:** _____

If yes, please specify abstract submission deadline: _____

Presentation: Yes No **Details:** _____

Other: Yes No **Details:** _____

6. Suggested study title:

7. Suggested Lead Team and co-authors:

8. Description of Study (Maximum 350 words):

9. Study objective(s) and hypotheses:

FOR SURVEY DATA REQUESTS ONLY:

10. Does the study require linking to other cohorts: Yes No

If yes, please specify which cohort:

DTP/HOMER (BC Only): Yes No

Vital Stats (BC Only): Yes No

CANOC: Yes No

Other cohorts Yes No

Please note that only BC data linkages are possible at this time.

11. Study design, and participant inclusion and exclusion criteria:

12. Main outcome measure(s) and their definitions:

Please contact provincial coordinator to request wave 1, 2, and/or 3 data files, including 1) survey, 2) data summary, 3) derived variables, and 4) scales. Please use derived variables and derived scales where appropriate. For longitudinal analyses: please be mindful that between survey waves, there may be variations in responses categories for certain questions, and account for these in your measures.

Example:

The primary outcome measure is sexual anxiety, measured by the following question: “Overall, during the past month, how frequently have you become anxious or inhibited during sexual activity with a partner?” (S8Q24b). Responses should be categorized as follows: “Always/usually became anxious” vs. “Sometimes/seldom” vs. “not at all”.

13. Explanatory variables of interest:

Please contact provincial coordinator to request wave 1, 2, and/or 3 data files, including 1) survey, 2) data summary, 3) derived variables, and 4) scales. Please use derived variables and derived scales where appropriate. For longitudinal analyses: please be mindful that between survey waves, there may be variations in responses categories for certain questions and account for these in your measures.

For example:

Demographic variables	Variable ID			Outcome
	Wave 1	Wave 2	Wave 3	
Age	AGE	W2AGE	W3AGE	Median, IQR
Education	S1Q9_1_dv	W2S1Q23_dv1	W3S1Q13_dv1	n (%) 1: Lower than high school 2: High school or higher 9: DK/PNTA *Note that the response categories in the raw variable change between W1 and W2-W3, and will see contradictions between W1-W2 (ie. move from high education in W1 – lower education in W2).
Meeting monthly housing costs	S1-Q18.	W2S1-36	W3S1-27	n (%) - Not at all difficult - A little difficult - Fairly difficult - Very difficult - Don't know / Prefer not to answer / Not applicable *Note that a “not-applicable” option is added to W3 only.

Etc.				
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14. Covariates:

Please contact provincial coordinator to request wave wave 1, 2, and/or 3 data files, including 1) survey, 2) data summary, 3) derived variables, and 4) scales. Please use derived variables and derived scales where appropriate. For longitudinal analyses: please be mindful that between survey waves, there may be variations in responses categories for certain questions and account for these in your measures.

For example:

Demographic variables	Variable ID			Outcome
	Wave 1	Wave 2	Wave 3	
Age	AGE	W2AGE	W3AGE	Median, IQR
Education	S1Q9_1_dv	W2S1Q23_dv1	W3S1Q13_dv1	n (%) 1: Lower than high school 2: High school or higher 9: DK/PNTA *Note that the response categories in the raw variable change between W1 and W2-W3, and will see contradictions between W1-W2 (ie. move from high education in W1 – lower education in W2).
Meeting monthly housing costs	S1-Q18.	W2S1-36	W3S1-27	n (%) - Not at all difficult - A little difficult - Fairly difficult - Very difficult - Don't know / Prefer not to answer / Not applicable *Note that a “not-applicable” option is added to W3 only.
Etc.				

15. Statistical analyses:

For each objective, please outline the proposed analyses. If unsure, please consult with Dr. Angela Kaida (kangela@sfu.ca) before submitting this form.

14a. Type of Model (yes or no): (if applicable)

Explanatory (e.g. In this case you are interested in answering the following question: “What explanatory variables best explain a higher risk of mortality?”):

Confounder (e.g. In this case you are interested in answering the following question: “Is depression associated with a higher risk of mortality?”. In this case you don’t care about any variable other than depression, however you want to control for them to make sure that when you interpret the results you can isolate the effect of depression):

Other:

Principal Investigator Decision

COMMENTS:

DECISION:

Approved

Approved with modifications

Tabled; needs further clarification

Not approved

Date **Dr. Alexandra de Pokomandy**

Date **Dr. Angela Kaida**

Date **Dr. Mona R Loutfy**

CHIWOS STUDENTSHIP POLICY

Last reviewed and revised – Dec 2019

Overview

CHIWOS supports the mentorship and training of students and other new investigators interested in women's health and HIV. The following document describes the process to apply for and engage in opportunities available to students interested in working with CHIWOS.

Opportunities

- Students at both the undergraduate and graduate level are encouraged to submit applications to access CHIWOS data for a thesis topic or to support research courses, research assistantships, practicum placements, and/or other volunteer capacities.
- Summer or term practicum placements may be available at a CHIWOS site in your province. Please inquire with your Provincial CHIWOS Coordinator.

Supervision

- Only students under the supervision of a **CHIWOS Investigator will be considered for CHIWOS data use**. External requests for CHIWOS data are not permitted at this time. For a full list of CHIWOS Investigators, please contact your Provincial Coordinator.
- CHIWOS supervisors must agree to oversee all stages of your research project.
- All data requests, abstracts, and manuscript drafts should be approved by your supervisor prior to being sent to your provincial coordinator for circulation to the CHIWOS National Management Team.

Data Request Procedures

- Students who are interested in using CHIWOS data must submit a **Project and Data Request Form** to their Provincial Coordinator. Please see the CHIWOS PROJECT AND DATA REQUEST POLICY on Page 19 for specific procedures and policies.
- If a PhD or Master's student uses CHIWOS data for their Thesis project, they have to submit their final approved Thesis Proposal.
- All posters, presentations, manuscripts, and theses based on CHIWOS data will have to follow the [CHIWOS AUTHORSHIP POLICY](#), and require approval from CHIWOS PIs.
- As a student, please submit your drafts to your Provincial Coordinator at LEAST 10 working days prior to any deadlines.
- As per the [CHIWOS AUTHORSHIP POLICY](#) all presentations should include acknowledgement of CHIWOS funders, CIHR, CTN, OHTN, and AHSC AFP and including logos.

- Your Provincial Coordinator will provide you with the standard poster and slide templates which you are required to adhere to.
- **Supervisors are responsible for the cost of journal open access fees and conferences fees/travel for their students.**

Conferences

- Students are encouraged to present their work at conferences and Student Research Days. Unfortunately, CHIWOS does not have funds to support travel and conference attendance. Students are strongly encouraged to seek out alternative funding opportunities through their institution or supervisor. Please see the [CHIWOS Conference Attendance Policy](#) for more information.

Authorship and Acknowledgement

- Please familiarize yourself with the [CHIWOS AUTHORSHIP POLICY](#), and consult your Provincial Coordinator with any questions.

Required Policies and Materials

- Consult the document, “**How to Write a Manuscript**” prepared by Dr. Mona Loutfy for an outline and some helpful information available on CHIWOS web site (<http://www.chiwos.ca/chiwos-study/chiwos-documents/?lang=en>).
- Adhere to the [CHIWOS AUTHORSHIP POLICY](#) and the [Error! Reference source not found.](#)
- Follow CHIWOS **manuscript examples** for method sections and use standard poster and slide **templates**.
- CHIWOS had published several manuscripts on process, methods, and cohort. Please refer to these publications in your manuscript. See [CHIWOS AUTHORSHIP POLICY](#)
- Refer to the [CHIWOS Conference Attendance Policy](#)
- Your Provincial Coordinator can provide you with these policies and templates. CHIWOS policies are also available on the study website www.chiwos.ca.



CHIWOS NEW MEMBERSHIP PROCEDURES POLICY

Last reviewed and revised – Dec. 2019

INTRODUCTION

CHIWOS is managed through various groups, including the CHIWOS National Management Team (NMT), the National Steering Committee (SC), three provincial Community Advisory Boards (CABs), the National Knowledge Translation and Exchange (KTE) Working Group and Group-specific Advisory Boards (GABs). It is understood that the membership of the various CHIWOS governing bodies is dynamic and may change over time. The following document outlines the current membership as well as procedures for new members to join these governing bodies while prioritizing both openness and safety and confidentiality of the existing members of the groups.

NEW MEMBERSHIP PROCEDURES

NATIONAL MANAGEMENT TEAM (NMT) MEMBERSHIP

1. The NMT is comprised of Provincial Peer Research Associates (PRA) representatives, Provincial Coordinators, and Principal Investigators.
2. Select students and staff (e.g. Data Manager) may join the NMT depending on the needs of the project.
3. Membership is based on staff positions within the team (e.g. Coordinator), or permanent role (e.g. Principal Investigator).
4. One PRA representative per provinces will sit on the NMT. This role is for one year, and prioritizes the mix of junior and senior representation on the NMT. New (junior) PRA representatives will be selected by the Provincial PRA Teams through an annual application and voting process.

NATIONAL STEERING COMMITTEE (SC) MEMBERSHIP

1. All requests for SC Membership must be reviewed and approved by NMT.
2. New CHIWOS National SC members will be sent the [SC TOR](#).
3. CHIWOS SC Membership will be reviewed on an annual basis.

PROVINCIAL COMMUNITY ADVISORY BOARD MEMBERSHIP

1. When recruiting a new member for the CHIWOS team, the appropriate Provincial Coordinator should send an introductory e-mail to the individual that includes the 'What Is CHIWOS' document, as well as a link to the CHIWOS website (www.chiwos.ca).
2. If the individual resides outside of the current study provinces (BC, SK, MB, ON, QC) they are invited to join whichever of the three CAB's they feel to be the most appropriate, with Ontario set as the default CAB if no preference is given.
3. New members who agree to join the CAB will be sent the [CHIWOS Provincial Community Advisory Board \(CAB\)](#)- Terms of references (TOR).
4. All Provincial Coordinators will keep an up to date list of CAB membership.

GROUP SPECIFIC ADVISORY BOARD (GABs) or WORKING GROUP MEMBERSHIP

1. GABs will address study issues pertinent to specific communities of women living with HIV in Canada.
2. Please refer to the [CHIWOS Group-specific Advisory Board \(GAB\) Request Form](#) for the procedures regarding GAB membership.

ADDITION OF CO-INVESTIGATORS

1. New Co-Investigators will be added to the CHIWOS grant on an annual basis, in January of each year. A completed CIHR CV is required from each co-applicant.
2. Co-Investigators who wish to be removed from the grant will be removed once a year.
3. As Co-Investigators are included in the authorship hyperlink “CHIWOS Research Team” membership will be revised on an annual basis. Please refer to [CHIWOS AUTHORSHIP POLICY](#).

ENSURING THE SAFETY AND CONFIDENTIALITY OF OUR MEMBERSHIP

The CHIWOS team prioritizes the safety and wellbeing of our community partners. As part of a CHIWOS working group disclosing one’s HIV-status (positive or negative), or other private information to other group members is not required. Please note that as a CHIWOS member you are never authorized to share private information (e.g. members' HIV status or personal lived experience) to members outside of the group. No breaches of confidentiality will be tolerated. If these occur, members will be asked to withdraw their involvement from CHIWOS.

SPECIFIC SAFETY STRATEGIES INCLUDE:

1. Coordinators may suggest the use of anonymous email addresses to be created. For example, mel.chiwos.research@gmail.com.
2. Allow all group members to introduce themselves using the language that they prefer to describe their role during meetings (e.g. PRA, Collaborator, ASO staff).
3. Coordinators will provide existing membership notification of new members (including a brief background) who are interested in joining a working group.
4. The existing team members will have a chance to raise any safety concerns about the addition of new members.
5. If no concerns are raised new members will be added to the group, including to email lists, teleconferences, and team meetings.



CHIWOS SOCIAL MEDIA AND WEBSITE POLICY

Last reviewed and revised – Dec 2019

CHIWOS Social Media Policy

The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) has decided to use social media tools to share information that is of relevance to the CHIWOS project in particular, as well as information pertinent to women and HIV in general. This policy governs online publications and commentary conducted on social media by the CHIWOS National Management Team (NMT). For the purposes of this policy, social media means Facebook and Twitter along with Hoot Suite (a dashboard for managing multiple social networks at once).

The CHIWOS NMT, which includes the Provincial Coordinators, and Provincial Principal Investigators (Angela Kaida, Mona Loutfy, and Alexandra de Pokomandy), and the nominated and voted in PRA NMT Representative(s) may publish or comment via social media in accordance with this policy. These individuals – referred to as “CHIWOS social media contributors”, henceforth – will have access to the study’s Facebook, Twitter, and Hoot Suite accounts, all of which will be password protected. All other CHIWOS team members will not be granted access to publish or comment via social media on behalf of CHIWOS.

CHIWOS social media contributors will use social media for these specific purposes:

- To provide basic information about the study to the public. This includes (but is not limited to) sharing progress updates and directing the public to new study publications.
- To share publically available news or open access journal articles pertaining to HIV and women’s health.
- To share links to other websites for information purposes such as positivelite.com (Canada’s Online HIV Magazine) or whatworksforwomen.org (a website providing international evidence on gender-sensitive programming for HIV positive women and girls).
- To post photos or videos relevant to the project’s topical focus such as a TED talk related to HIV, a video-recorded presentation about the study.
- To post photos of the study team. Previous to a picture or video being taken, individuals will be informed that the video or poster will be posted on the internet via our website or Facebook. Individuals who do not want their image to be shared will not be captured in the video or picture.
- To share research activities, including opportunities for participation in the study. Such notices will direct potentially interested participants to contact Provincial Coordinators directly via email or phone.

Publication and commentary on social media carries similar obligations to any other kind of publication or commentary. All uses of social media must follow the same ethical standards that CHIWOS team members must otherwise follow.

Establishing a CHIWOS social media account

The study's profile on social media sites must be consistent with its profile on the CHIWOS website or other CHIWOS documents and publications. Profile information must be approved by consensus by the NMT, with the co-PIs (and finally, the nominated PI) to make any final decisions if necessary. The official CHIWOS logo must be used for the study's profile picture.

Protecting the privacy of CHIWOS and its team members, partners, and participants

Social media sites will be used to share information and create dialogue with our research partners, however CHIWOS social media contributors are prohibited from publishing confidential information. Confidential information includes unpublished details about our research and data, as well private and personal information about CHIWOS team members, partners, and participants. Study participants who partake in confidential research activity (including surveys and focus groups) will never be identified by name nor will confidential details about them or their engagement with CHIWOS ever be discussed. While it is acceptable to post general information about the project such as study updates, the information shared must not violate any non-disclosure agreements, certificates of ethical approval, or informed consent forms that may be in place. Privacy settings on social media platforms will be set to allow anyone to see profile information similar to what would be on the CHIWOS website. Other privacy settings that might allow others to post information or see information that is personal will be set to limit access. CHIWOS social media contributors are to be mindful of posting information that they would not want the public to see.

Respecting CHIWOS and its team members, partners, and public audience

CHIWOS's team members and partners reflect a diverse set of values and viewpoints. CHIWOS social media contributors should not say anything contradictory or in conflict with the CHIWOS's website. They are encouraged to be themselves, but do so respectfully. This includes not only the obvious (no ethnic slurs, offensive comments, defamatory comments, personal insults, obscenity, etc.) but also proper consideration of privacy and of topics that may be considered objectionable or inflammatory such as politics and religion. CHIWOS social media contributors are asked to use their best judgment and to think about the consequences of posting information. Also, if a news article or website is shared with the public, it will be done so in a way that shares the information without taking a stance or posing judgment or opinion. CHIWOS social media contributors should try to make it clear that the views and opinions expressed are theirs alone and do not necessarily represent the official views of CHIWOS.

CHIWOS Website Policy

CHIWOS has decided to connect and engage with the public online, using a website to share information about the study. This policy governs the online publications of and commentary on the CHIWOS website by the CHIWOS NMT.

The CHIWOS NMT may publish on the CHIWOS website in accordance with this policy. All content that is published on the website will be created and approved by the NMT listed above. These individuals – referred to as CHIWOS website contributors, henceforth – will have access to the

CHIWOS website, which will be password protected. All other CHIWOS team members will not be granted access to publish or comment via social media on behalf of the CHIWOS study, or in any way that suggests they are doing so in connection with CHIWOS.

The CHIWOS website will be used for the following purposes:

- To describe the study. Please see the 'WHAT IS CHIWOS' document attached.
- To describe the study team - biographies of the NMT will be posted, with permission.
- To describe CHIWOS Collaborators - Steering Committee Members names will be published, with permission.
- To explain how to get involved and find out more information about CHIWOS. This will include contact information of provincial coordinators for participants who are interested in finding out more about the study.
- To provide a link to resources, presentations & publications (e.g. CHIWOS presentations, in pdf. or video broadcasted, and publications in journals, newspapers, etc.).
- To provide a link to the CHIWOS Twitter and Facebook pages.
- To describe the CHIWOS Vision/Mission/Values - (CHIWOS Guiding Principles).
- To provide CHIWOS study news.
- To acknowledge our Funders.
- To acknowledge broadly (and anonymously) the community members, students, and participants, who have generously contributed to CHIWOS.

Publication on the CHIWOS website carries similar obligations to any other kind of publication or commentary. All uses of the CHIWOS website must follow the same ethical standards that CHIWOS team members must otherwise follow.

Creating the CHIWOS website

The CHIWOS website will be consistent with other CHIWOS documents and publications. Website information must be approved by consensus by the NMT, with the co-PIs (and finally, the nominated PI) to make any final decisions if necessary. The official CHIWOS logo must be used for the website design, including the homepage.

Protecting the privacy of CHIWOS and its team members, partners, and participants

While it's perfectly acceptable to talk about the study and have a dialogue with the community, CHIWOS website contributors are prohibited from publishing confidential information. Confidential information includes things such as unpublished details about our research and data as well private and personal information about CHIWOS team members, partners, and participants. Study participants who partake in any confidential research activity (including surveys and focus groups) will never be identified by name and confidential details about them or their engagement with CHIWOS will never be discussed. While it is acceptable to post general information about the project such as study updates, the information shared must not violate any non-disclosure agreements, certificates of ethical approval, and informed consent forms that may be in place. CHIWOS website contributors are to be mindful of posting information that they would not want the public to see.

Key Principles for Social Media and Website

Respecting copyright laws

It is critical that CHIWOS website and social media contributors show proper respect for the laws governing copyright and fair use of copyrighted material owned by others, including CHIWOS' own copyrights and brands. One should never quote more than short excerpts of someone else's work, and always attribute such work to the original author/source. It is good general practice to link to others' work rather than reproduce it. Any photos or other media used on the CHIWOS website must be openly licensed and/or have permission to use (contributors can use websites such as www.creativecommons.org to find appropriate media sources).

Enforcement

Policy violations may be subject to disciplinary action.

Open Access

The CHIWOS PIs, NMT, and Team are in support of Open Access of created documents. Once finalized, any documents deemed useful to researchers and community will be made available on the website for use. CHIWOS's documents have listed ways to acknowledge the project and creators for work.

Sharing new CHIWOS publications

As a way to disseminate CHIWOS findings efficiently, we ask that the first author shares their newly published manuscript on their personal Facebook and Twitter account by including the following:

- A short 'nugget' about the paper, being specific about what was found and why it is important
- Post a screenshot of the abstract
- Add the link to the paper
- Tag @CHIWOSresearch and other authors handles (if possible)
- Add appropriate hastags
- If you do not use social media or would like further advice on how to create social media posts that will gain traction, please contact your Provincial Coordinator

Social Media and Website Tips

The following tips are not mandatory, but will contribute to successful use of social media.

- The best way to be interesting, stay out of trouble, and have fun is to write about what you know. There is a good chance of being embarrassed by an expert, or of being boring if you write about topics you are not knowledgeable about.
- Quality matters. Use a spell-check.
- The speed of being able to publish your thoughts is both a great feature and a great downfall of social media. The time to edit or reflect must be self-imposed. If in doubt over a post, or if something does not feel right, either let it sit and look at it again before publishing it, or ask someone else to look at it first.
- Nothing gains you notice in social media more than honesty - or dishonesty. Do not say anything that is dishonest, untrue, or misleading. If you have a vested interest in something you are discussing, point it out.

- Be the first to respond to your own mistakes. If you make an error, be up front about your mistake and correct it quickly. If you choose to modify an earlier post, make it clear that you have done so. If someone accuses you of posting something improper (such as their copyrighted material or a defamatory comment about them), deal with it quickly - better to remove it immediately to lessen the possibility of a legal action.
- If you see misrepresentations made about CHIWOS in the media, you may point that out with respect and with the facts. If you speak about news, make sure what you are saying is factually correct. Also, avoid arguments or inflammatory debates. Brawls may earn traffic, but nobody wins in the end.

***Note: This policy was drafted using *PolicyTool*, an online social media policy generator developed by "rtraction" in collaboration with lawyer David R. Canton, a Canadian expert in internet-related legal issues. The guidelines generated through this tool were tweaked for the purposes of this study.**



CHIWOS SAFETY AND PSYCHOLOGICAL WELLBEING POLICY

Last reviewed and revised – Dec 2019

INTRODUCTION

Personal safety can be defined as not only physical safety or freedom from physical harm, but also psychological safety, which includes physical safety and the freedom from being victimized through hostility, aggression, and harassment². Mental health is undoubtedly linked to personal safety and can be described as a psychological state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community³. A fundamental policy of CHIWOS is to maintain and support the physical and psychological safety and wellbeing of all individuals while working with the project. CHIWOS aims to ensure all Study Candidates, Participants, Peer Research Associates (PRAs), Research Coordinators, Investigators, Community Advisory Board (CAB) members and the entire Research Team feel safe and have the safest work environment and best psychological state possible while engaged in CHIWOS research activities. This document will outline the steps CHIWOS recommends for Safety and Psychological Wellbeing as well as procedures that have been put in place to prevent and also address any safety or psychological issues that may arise. This document is divided into two sections: 1) Safety and 2) Psychological Wellbeing. Both sections have been divided into sub-sections based on the multiple stakeholders involved in the project: i) Study Candidates and Participants, ii) PRAs, iii) Research Coordinators, and iv) Investigators, CAB members, and Research Team members. This Policy (as all CHIWOS Policies), will be a living document as items will be amended as the project progresses and matters arise and will be revised on a yearly basis.

SECTION 1- SAFETY

Ensuring that all members of the CHIWOS team are working in safe environments and are treated with respect and dignity is taken very seriously.

² Thompson Rivers University. (2013). Personal Safety. Retrieved from <http://www.tru.ca/hsafety/workinglearningsafely/personal.html>

³ World Health Organization. (2013). What is Mental Health? Retrieved from <http://www.who.int/features/qa/62/en/>

i) Safety of Study Candidates and Participants

The following items have informed the creation of the CHIWOS Safety Policy for Study Candidates and Participants. A Study Candidate is one that is eligible for the study but has not yet consented. A Study Participant is one who is eligible and has signed the Informed Consent Form.

a) *Declaration of Helsinki*

The World Medical Association has developed the *Declaration of Helsinki* which is a statement around ethical principles for medical research involving human subjects, including research on identifiable human material and data⁴. The *Declaration of Helsinki* guides the CHIWOS study and is the foundation reflected upon and referred to when engaging study candidates and participants.

b) *Research Ethics Board (REB)*

All policies, procedures, guidelines and operations of the CHIWOS study are submitted for approval by Research Ethics Boards (REB) at affiliated Universities and/or institutions in each of the five provinces (i.e. McGill University Health Centre REB in Quebec, Providence Health Care (UBC) REB and Simon Fraser University REB in BC, Women's College Research Institute REB in Ontario). REBs develop and enforce policies and procedures in compliance with national and international guidelines (i.e. Declaration of Helsinki). REBs therefore ensure CHIWOS is being held to the highest ethical standards and that the greatest protection is provided to participants.

c) *Informed Consent*

All CHIWOS candidates' will be provided with an informed consent form. The informed consent form will provide a brief, plain language description of the project, introducing researchers and their affiliations, describing the nature of participation and also explaining key ethical issues (i.e. confidentiality). Trained PRAs will carefully go through the informed consent form with each candidate to ensure they understand the informed consent form and all of their questions have been answered about the study. Only after a PRA is confident that the candidate is fully informed about the study and has signed the consent form will they proceed with the interview based survey. The informed consent form includes all contact information that a participant might need in case she feels that she was injured in its rights or insecure.

d) *Confidentiality*

All individuals working on CHIWOS (outside of participants and study candidates) have signed a confidentiality agreement to protect the identity and information shared by study candidates and participants. Furthermore, all data collected from participants will be stored in a secure system that is password protected, and survey data will be stored separately from personally identifying data. Participants will also be given a unique participant ID to ensure their name and contact information is protected.

ii) Safety for PRAs

⁴ World Medical Association. (2013). WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. Retrieved from <http://www.wma.net/en/30publications/10policies/b3/>

The following steps have been implemented to protect the safety of the PRAs. It is important to note that the Declaration of Helsinki and the REB Approval process are built to protect study candidates and participants and does not yet include the protection of research team members including PRAs.

a) **Communication with Research Coordinator**

Frequent communication between the PRAs and their provincial Research Coordinator will be facilitated by monthly or bi-monthly check-ins (via phone, Skype and in person). These meetings will help ensure PRAs continue to conduct interviews in an environment in which they feel safe. If a more urgent matter occurs PRAs are instructed to contact their Research Coordinator immediately (specific guidelines can be found in *Guidelines for Problem Solving Challenging Scenarios* and *How-to* documents).

b) **Check in process for unfamiliar or uncertain locations**

In order to ensure the safety of PRAs when conducting interviews we have developed a check in system for unfamiliar or uncertain locations. This system will ensure each PRA is checking in with their Research Coordinator before and after an interview is occurring in an **unfamiliar location**. At least 24 hours before an interview, PRAs will notify the Research Coordinator (via email, phone or text) to let them know the **date, time, and location's contact details** (i.e. location name, phone number and address for AIDS Service Organization or clinic) of their interview and also provide one **emergency contact person**. On the day of the interview, before it begins, the PRA will contact (text/email/call) their Research Coordinator to let them know they are beginning the interview. Once the interview has been completed the PRA will contact their Research Coordinator to say the interview is over and how it went. If the supporting Research Coordinator does not hear back from the interviewing PRA 3 hours after the initial contact (at commencement of the interview) they should follow the steps below in sequence (moving to the subsequent step if unable to get in touch with the interviewing PRA):

1. Text/email/call the PRA conducting the interview to check in (if no response in a half hour)
2. Contact the location where the PRA was conducting the interview (if unable to locate PRA)
3. The Research Coordinator will then contact the PRAs emergency contact
4. If no response the Research Coordinator will contact emergency services

If the PRA is feeling uncertain about a particular interview setting or participant, the interview is not permitted. Uncertain locations are not permit.

Interview at home: Before scheduling an interview at home, they must ensure that they will be alone with her participant. That means that the participant is living alone or in a shelter (secure place). If the participant lives with someone else (husband, brother, roommate, etc.), interviews at home are not authorized. If a PRA do not know her participant and feels uncomfortable with this participant, the interview at home is not authorized.

c) *The Phone Tree System*

A phone tree is a document, which identifies a network of people that have been organized in a way to best facilitate rapid dissemination of information. A phone tree will be created for each of the five provinces during provincial PRA training sessions to illustrate the best suited/first people to contact by the PRA in an emergency situation. This will ensure that the PRA (and potentially the participant) is receiving the support they need right away and the situation can be addressed in a timely manner (i.e. If a PRA feels triggered by an interview they would refer to the phone tree. The phone tree would indicate that they should first contact a fellow PRA to talk and debrief. If they are unable to get a hold of another PRA they would then contact the Research Coordinator. If unable to get a hold of the Research Coordinator or if professional help is required right away they would then call the on call counselor).

d) *PRA Interview Logistics and Difficult Scenarios Guide*

The Guidelines for Problem Solving Challenging Scenarios (

CHIWOS In Action
TERMS OF REFERENCE
Created – September 2019

WHAT IS THIS DOCUMENT?

These are the Terms of Reference which is a document used to describe the purpose and structure of a project, committee, meeting, negotiation, or any similar collection of people who have agreed to work together to accomplish a shared goal. ‘Knowledge to Action’ the framework commonly employed by the CIHR for the transfer of research findings into practice, and can be broken down into two concepts: knowledge creation and the action cycle. In practice, the two concepts are fluid.

PROJECT OVERVIEW

CHIWOS seeks to address a significant gap in knowledge related to the availability and utilization of women-centred HIV care. We aim to assess the barriers and facilitators that influence care usage patterns, and assess the impact of these services on the sexual, reproductive, women’s, and mental health of women living with HIV across Canada. This study will yield critical information which will help to fill knowledge gaps about women, HIV, and HIV/AIDS care, and will enable improvements in the health, care, and wellbeing of HIV positive women in Canada. CHIWOS is guided by community-based research and GIPA (Greater Involvement of People living with HIV/AIDS) principles. In conjunction and guided by women living with HIV providing opportunities for bilateral learning experiences and mentorship opportunities

PURPOSE OF CHIWOS In Action

CHIWOS In Action is considered the third phase of CHIWOS. With the formative phase and data collection phase now complete, this phase has been established in order to ensure that CHIWOS will be used to create meaningful changes in policy and practice that will promote the health and well-being of women living with HIV in Canada and beyond. This phase is in line with ‘Knowledge to Action’, the framework commonly employed by the CIHR for the transfer of research findings into practice. The CHIWOS National Management Team (NMT) will now turn its efforts to advising on, initiating, coordinating, and tracking the translation and dissemination of CHIWOS research findings into outputs targeted at various audience, including: women living with and affected by HIV, researchers, policy makers, clinicians, care and service providers etc.

KEY DUTIES AND RESPONSIBILITIES

The National Management Team will now lead CHIWOS In Action and strategize, plan and oversee different kinds of KTA activities and initiatives related to:

- The Women-centred HIV Care Model, Toolkit and Training
- The National Action Plan on the SRHR of women living with HIV
- CHIWOS quantitative findings
- CHIWOS qualitative findings

- Body Mapping
- CHIWOS PAW
- CHIWOS arts-based initiatives
- Learnings on community-based research
- The creation and implementation of tools or products
- Implementation Science studies

COMMITTEE COMPOSITION

- Mona Loutfy, Nominated Principal Investigator (NPI)
- Angela Kaida, Principal Investigator
- Alexandra de Pokomandy, Principal Investigator
- Marissa Becker, Principal Investigator
- Sharon Bruce, Principal Investigator
- Carrie Bourassa, Principal Investigator
- Carrey Sinclair
- Laverne Gervais
- Melanie Lee, CHIWOS Peer Research Associate
- Mina Kazemi, Ontario Coordinator
- Rebecca Gormley, BC Coordinator
- Sebastien Lefebvre, Saskatchewan Coordinator
- Miranda Keewatin, Saskatchewan Research Assistant

DETAILS

Term: This work will run from October 2019 and running until March 2025 (end of CIHR Foundation grant) and re-assessed at that time. Members are free to join and leave at any time. Membership will be verified on an annual basis.

Frequency of Meetings: The team will meet by teleconference every six months. These meetings will last for 90 minutes. Additional teleconferences will occur when required.

Confidentiality: is the principle that an institution or individual should not reveal information to a third party or others outside of the group with whom the agreement is held.

Reporting Requirements: Team members will be expected to verbally report to each other during teleconferences. The members will be accountable to the CHIWOS NPI and PIs who are in turn accountable to their Institutions and the Funders. The members are also accountable to their own Institutions. It is also hoped that the members will see themselves accountable to women living with HIV in Canada. Minutes of the CHIWOS In Action meetings will be finalized and circulated by the CHIWOS Coordinator within 10 days of each meeting to facilitate reporting if required. CHIWOS In Action updates will be sent to the SC members yearly.

Decision Making: Decisions will be made by consensus as much as possible. In some circumstances, the Committee Chair and/or the CHIWOS NPI will be nominated to make final decisions.

Communication: CHIWOS operates with the principles of open communication. Formal research communications will not be made public until conference presentations or journal publications

CHIWOS Project and Data Request Policy Page 43 of 89

are presented or published. Abstracts and/or oral presentations will then be circulated to the public, and posted on the CHIWOS website for public access.

Grievance Process: Sometimes, differences of opinion or disagreements happen. CHIWOS prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see the CHIWOS Coordinator to help resolve the problem. If still not resolved, the person, and the Coordinator will involve the nominated PI (Mona Loutfy). However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to the nominated PI.

Appendix 1) document will provide PRAs with procedures on how to handle challenging situations and difficult participants (i.e. If a participant becomes aggressive what do you do?). It will also provide advice on how to prevent challenging situations (i.e. do not leave personal items unattended; make sure the PRA sits closest to the exit). The following items are general guidelines for PRAs to consider when conducting an interview in order to maximize their safety:

1. Ensure your Research Coordinator knows the time and place of interviews you are conducting
2. If you get a sense that you are unsafe, schedule interview in a public institution (i.e. ASO, hospital, university) at normal hours of operation, and contact you RC at the beginning and at the end of your interview. Feel free to cancel, reschedule, or end an interview if you feel unsafe.
3. Always sit with your back to the door, positioning yourself between the door and the participant so you can have easy access if required
4. Keep the door slightly ajar in order for others to hear if participant becomes loud and/or aggressive.
5. It is best not to do an interview in a space where you are completely alone with a participant unless you know the participant and feel very safe and comfortable.
6. Do not leave your belongings (laptop, phone, bag) unattended with the participant.

iii) Safety of Research Coordinators

The following steps have been implemented to protect the safety of Research Coordinators. Also, Research Coordinators are protected under their provincial legislation regarding Labour Laws.

a) *Communication with Provincial Study Principal Investigator*

Frequent communication between the Research Coordinators and their provincial Principal Investigator (PI), likely on a weekly basis, will ensure review of safety for the Research Coordinator.

b) *Open Door Policy*

Dr. Mona Loutfy, the nominated PI, has an Open Door Policy for Research Coordinators and all involved in CHIWOS to review any item particularly an issue of Safety and/or Psychological Wellbeing. If there is any issue, please email her at mona.loutfy@wchospital.ca or call/text her cell phone.

c) *Research Coordinator Communication*

Frequent communication between the Research Coordinators themselves, and Research Coordinators meetings (likely every two months) will ensure review of safety.

iv) Safety of Investigators, CAB members, and all Research Team members

CHIWOS and all its stakeholders are sensitive to the extreme importance of creating safer spaces for women.

SECTION 2-PSYCHOLOGICAL WELLBEING

The CHIWOS questionnaire touches upon some very sensitive topics (i.e. mental health, HIV stigma, violence, etc.). Due to its sensitive nature, the psychological wellbeing of all those involved in CHIWOS is taken very seriously.

i) Psychological Wellbeing of Participants

The following items are available for the psychological wellbeing of Study Participants. The psychological wellbeing of Study Participants is also covered under the Safety Section through the REB approval, Informed Consent, and the Declaration of Helsinki.

f) *Transparency*

It is important for all participants to know that when completing the CHIWOS questionnaire, there may be questions which trigger unpleasant and traumatizing experiences due to their extremely sensitive nature. At the beginning of every survey PRAs will have to prepare the participants for the content of the survey. This will involve them letting the participant know they may be sensitive to and/or emotionally triggered by some of the questions. Throughout the survey and especially when it has been completed, the PRA will check in with the participant to make sure they are feeling emotionally stable and will provide referrals and resources when needed.

g) *Mental Health Support and Resources*

Participants will receive a list of counsellors and support services in their province who have agreed to see participants if there is a mental health concern during or after completing the survey. PRAs will contact the Research Coordinator immediately if a participant is negatively impacted or triggered by the questions in the survey. The Research Coordinator will immediately connect the participant with a counsellor in their region or the counsellor on call who they can speak with up to 7 days after the interview.

h) *Participation is Voluntary*

It is important to recognize that participating in the CHIWOS Study is 100% voluntary and at any time (even after a survey has been started) the participant can decline participation or withdraw from the study.

i) *Skip Sections or Questions*

When completing the questionnaire, participants always have the option to skip sections or refuse to answer any question(s) that makes them feel uncomfortable.

ii) Psychological Wellbeing of PRAs

When working on CHIWOS, PRAs are not only confronted with the lived experience of participants, but may also be revisiting their own lived experience. This can put PRAs in a very challenging and emotionally demanding position.

a) *Communication with Research Coordinator*

Frequent communication between the PRAs and the Research Coordinator will be facilitated by monthly check-ins (via phone, Skype and in person). These meetings will help ensure PRAs are feeling supported in their work and that they are feeling mentally and emotionally prepared to take on the tasks of their position. Also, PRAs will be involved in regular (weekly/bi-weekly) team emails, and in-person /over-the-phone follow-up conversations as necessary. All Research

Coordinators have an open door policy and encourage PRAs to phone / email at any time during regular work hours (i.e. don't have to wait until monthly meeting to connect with the Research Coordinator).

b) *Multi Phase Training*

This will include intensive training in research methods, privacy and confidentiality, facilitating interviews, the CHIWOS survey, and computer literacy, and place a specific importance on supporting participants and PRA's own self-care. This training will help prepare the PRAs for the challenges they may face in the field.

c) *Annual in-person/video conference PRA meetings*

If funding permits, having an in person meeting on an annual basis with all the PRAs (provincially) would offer the opportunity for capacity building workshops, dialogue between PRAs and investigators, team building, and brainstorming around the future direction of CHIWOS.

d) *Appreciation Events*

If funding permits, CHIWOS plans on hosting a yearly appreciation event (i.e. luncheon, dinner etc.) in order to support the PRAs and demonstrate appreciation for all of their hard work. These events will hopefully bring the PRAs together and demonstrate that their work is valued by the larger research team. This may also be conducted in tandem with an annual PRA meeting.

e) *Buddy System and Phone Tree*

The check in system and Phone Tree described in Section One will also be used to ensure PRAs have the psychological support they need before and after conducting an interview. If the PRA has been triggered throughout the interview process, they can call a fellow PRA, the Research Coordinator, or the on call counsellor.

f) *Mental Health Support and Resources*

As for participants, PRAs will receive a list of counselors and support services in their province who have agreed to see/speak with PRAs if there is a mental health concern after completing the survey. PRAs will contact the Research Coordinator immediately if they are negatively impacted or triggered by the survey process. The Research Coordinator will immediately connect the PRA with a counsellor in their region or the on call counsellor who they can speak with up to 7 days after the interview.

ii) *Psychological Wellbeing of Research Coordinators*

The following items are available for the psychological wellbeing of Research Coordinators.

a) *Employee Assistance Programs (EAP)*

Employee Assistance Programs help employees and their household members manage issues in their personal lives and work. EAP counselors can offer assessments, support, and referrals to additional resources such as counselors for a limited number of program-paid counseling sessions. Having employee assistance programs available through their affiliated institution will help Research Coordinators better deal with some of the challenges they may experience while working on CHIWOS.

b) **Mental Resources**

Research have access to the list resources in their they can contact support. They will contact details for the on call psychological distress counselor who they can speak with as needed.



Health Support and

Coordinators will also of mental health community, which should they need also receive the

c) **Personal Check-ins and Self Care**

CHIWOS fully supports and encourages Research Coordinators to regularly engage in personal check-ins and self-care. It is important for Research Coordinators to reach out when they need support from other Research Coordinators and the rest of the Research Team.

d) **Communication with Provincial Study Principal Investigator**

The Research Coordinators are encouraged to check-in with their provincial PI to review psychological wellbeing issues and CHIWOS advises a quarterly check-in even if no problems exist.

e) **Open Door Policy**

Dr. Mona Loutfy, the nominated PI, has an Open Door Policy for Research Coordinators and all involved in CHIWOS to review any item; particularly an issue of Safety of Psychological Wellbeing. If there is any issue, please email her at mona.loutfy@wchospital.ca or call/text her cell phone.

iv) Psychological Wellbeing of Investigators, CAB members, and all Research Team members

a) **Personal Check-ins and Self Care**

CHIWOS fully supports and encourages Investigators, CAB members, and Research Team members to regularly engage in personal check-ins and self-care. It is important for Investigators, CAB members, and Research Team members to reach out when they need support from the Research Team.

Items and steps listed above for Psychological Wellbeing also apply to Investigators, CAB members and Research Team members involved in CHIWOS.

CHIWOS PEER RESEARCH ASSOCIATE ACTIVITIES AND EXPECTATIONS

Last reviewed and revised – Dec 2019

We recognize the integral role that CHIWOS PRAs play at all stages of the research process. We also recognize that CHIWOS PRAs have many competing demands (work, volunteer, family) and we want to be transparent to allow PRAs to be able to make informed decisions about their involvement with this project. The following document lists various CHIWOS activities that occur on an ongoing basis, and describes whether these are paid or volunteer activities.

Activity	Role
National KTE Working Group PRA representative	Paid
National Management Team PRA representative	Paid
Provincial Core Research Team Meetings PRA representative	Paid
PRA Trainings	Paid
Survey revision and piloting	Paid
Focus Group conduction	Paid
Interview Administration (including recruitment, retention, scheduling interviews, interview, debriefing with participant, and rescheduled if needed it).	Paid
CTN Meetings	Expenses reimbursed; time in attendance volunteer
Steering Committee Meetings	Volunteer
Provincial CAB Meetings	Volunteer
National and provincial PRA teleconferences	Volunteer
National Core Research Team Trainings i.e. Aboriginal Women's Training	Volunteer
Working Group meetings and activities	Volunteer
Conference Attendance	Volunteer



CHIWOS CONFERENCE ATTENDANCE POLICY
Last reviewed and revised – Dec 2019

CHIWOS strongly encourages the participation of team members at conferences, research days, and other research forums. CHIWOS supports team members in using CHIWOS data and analyses to submit for conference abstracts, and can provide personnel in-kind assistance in doing so if required. Please consult the [Error! Reference source not found.](#) as well as the [CHIWOS AUTHORSHIP POLICY](#) for more information on manuscript creation.

Unfortunately, CHIWOS currently does not have the operating budget to contribute to the cost of the attendance of conferences for CHIWOS presenters (e.g. flights, registration, accommodation, food).

CHIWOS encourages team members to apply for conference scholarships to assist with conference attendance expenses. A CHIWOS Coordinator or Investigator can write a letter to assist with scholarship applications if required. Please contact a CHIWOS Coordinator if you would like assistance identifying potential scholarship opportunities.



OTHER DOCUMENTS



CHIWOS Guiding Principles

Reviewed and revised – Dec 2019

The CHIWOS Guiding Principles Policy document details the project’s vision, mission and values, as well as the guiding frameworks and principles upon which the CHIWOS project was conceived and now operates. It is essential to the success and integrity of the CHIWOS project that all members of the National Management Team, the National Core Research Team, the Provincial Community Advisory Boards (CABs), and the Steering Committee, understand these principles and work within these frameworks for all their CHIWOS-related activities.

CHIWOS VISION, MISSION & MANDATE

Vision: CHIWOS envisions a country where all women living with HIV are able to achieve optimal health and well-being, no matter where they are in their experience of HIV and in their lives. CHIWOS aims to contribute to this vision through transformational women-specific community-based research and action that is driven by women living with HIV, researchers, care providers and policy makers, in all of their diversity, together, within an equitable and mutually respectful environment.

Mission: CHIWOS is committed to creating new knowledge that will be used to support women living with HIV in Canada to achieve optimal health and wellbeing through meaningfully involving them in every stage of the research process by providing a safe, innovative, and transformational research environment.

Mandate: To assess the barriers to and facilitators of women-centred HIV/AIDS service use and the impact of such patterns of use on sexual, reproductive, mental, and women’s health outcomes of women living with HIV across Canada, through excellence in women-specific community-based research.

CHIWOS is governed by the following core values:

- **Integrity:** CHIWOS believes that integrity should be at the core of everything we do. Integrity is the quality of being honest and responsible. It is the willingness to act according to the ethics, values, beliefs and principles that we hold as members of

CHIWOS.

- **Respect:** CHIWOS strives to promote feelings of esteem and conduct representative of that esteem among all members. This means having a sense of worth, or excellence of oneself and others, both as professionals and human beings. It also means behaving in ways that would bring credit and honor upon oneself and the team to which one belongs.
- **Accountability:** CHIWOS encourages its members to accept responsibility for their actions and work. It is hoped that members of this project will see themselves accountable to each other as well as to women living with HIV in Canada.
- **Inclusivity:** CHIWOS acknowledges the multiple, complex, and overlapping identities that create a rich and vibrant community with many different experiences of health and wellness. All of these experiences will be shared and honored.
- **Equity:** CHIWOS understands that disparities in health result from systemic inequalities that are unjust and unfair, and will work to address these disparities holistically.
- **Partnership and Collaboration:** CHIWOS is committed to working in partnership with community members, and other stakeholders in HIV-positive women's health, at all stages of our research. Diverse forms of knowledge are valued and inform our work. Collaboration deepens and strengthens our impact.
- **Empowerment:** CHIWOS strives to create a forum for the celebration of existing capacities and skills, and to create an opportunity to build on the skills, abilities and the courage of individuals and communities to make informed choices, and to transform those choices into desired actions and outcomes.
- **Social Action:** CHIWOS aims to be transformational. The research process and the knowledge produced will act as vehicles for positive and sustainable social change that will promote health and wellness among women living with HIV.

CHIWOS GUIDING FRAMEWORKS

Critical Feminist Framework

A critical feminist framework looks at the overlapping and intersecting issues of gender, racism, homophobia, classism, sexuality, ableism, ageism and HIV-related stigma, and how these issues intersect at individual and structural levels to create oppression; thus, there is an interdependent and mutually constitutive relationship between social identities and social inequities. These structural factors put women at increased risk of gender inequity, violence, poverty, and HIV transmission. A critical feminist approach examines how women are affected by patriarchal systems and structures that affect their social status in relation to men, and intersect with systemic inequality related to women's many other identities. Employing a critical feminist framework also involves looking at how the role of women in society is culturally limited and impacted by legal, financial, religious, and economic discrimination against women. This type of systemic and structural inequality has meant that women are not provided with equal opportunities to participate meaningfully in society, or be involved in decisions that directly impact their lives. Critical feminism draws on principles of social justice, anti-racism, and anti-oppression, which seek to challenge rather than perpetuate systems of oppression.

Anti-oppression, Intersectionality, and Social Justice

The integration of principles of anti-oppression into our critical feminist framework means that we recognize the systemic gendered oppression that women face without homogenizing the experiences of women. An anti-oppressive approach acknowledges that women throughout the world are situated differently, experience oppression in a multitude of ways, while other women experience privileges based on their social locations or identities. Through an understanding of anti-oppression, we are able to deepen our analysis in understanding the complexities of power relations, and how these power relations have an influence on the ways in which women experience their lives.

Intersectionality should be at the core of any conceptual framework that seeks to understand the multiple issues and concerns that face women living with HIV in Canada. Intersectionality moves beyond the assumption that health outcomes may be caused by a number of contributing causes, by asserting that numerous factors are always at play and that “intersectionality examines gender, race, class and nation as systems that ‘mutually construct one another’” (Collins, 1998, p. 63). Intersectionality encourages a contextual analysis that probes beneath single identities, experiences and social locations to consider a range of axes of difference to better understand any situation of disadvantage (Hankivsky & Christoffersen, 2008). Researchers who are committed to social justice and working toward creating change in health and social care prevention policies can view intersectionality as more than merely a concept, but a term that can be enacted on to address social inequalities. “Intersectionality can inspire political action and policy development...by understanding how individual stories are politically embedded and have political consequences” (Phoenix, 2006, p. 189).

The use of a social justice framework, particularly within research is connected to emancipatory resistance with the objectives of confronting oppression, and demanding – and moving towards – social justice. In order to achieve social justice, research must support communities through collaborative approaches that demand social change, and incorporate, inform, and are guided by community-members; thus, community-based research approaches and practices are often used. Research that is working towards social change should have an impact on policies and practices in Canada in order to improve the lives and health of women living with HIV in Canada.

Social Determinants of Health Framework

A Social Determinant of Health (SDoH) framework, as established by the World Health Organization (WHO) in 2005, acknowledges that many interacting social factors have a large impact on health outcomes and service use. The premise for addressing the SDoH in a broad sense is that while good medical care is a vital component of good health, the underlying social causes that undermine people's ability to access these services must be addressed in order to have an opportunity for good health and well-being. Poverty and gender inequity are SDoH, given that these factors impact the lives of women and children on a global scale, affect access to secure housing, food security, health care, services, resources, and susceptibility to HIV.

However, this more traditional notion of SDoH does not go far enough in recognizing the unique and intersectional social positioning that women occupy in Canadian society. As such, we have recognized the need to understand the experiences of HIV-positive women within a ‘Social

Determinants of Women’s Health’ framework. A ‘Social Determinants of Women’s Health’ framework recognizes the importance of differences between women, men and other gender groups, as well as differences between and within groups of women based on social factors, identity statuses, geographical locations and access to key material and ideological resources. It also recognizes that although women play multiple roles in our society, including mothering, they continue to have unequal access to power suggesting that a Social Determinants of Women’s Health framework is necessary when engaging in applied research aimed at developing more effective practice and policy based outcomes.

CHIWOS COMMUNITY-BASED RESEARCH GUIDING PRINCIPLES

Community-Based Research Approach

Community-Based Research (CBR) is an approach which seeks to genuinely democratize research, breaking down hierarchical power relations and problematic dichotomies between the researchers and the ‘researched’. CBR moves beyond simple consultative relationships and instead to build collaborative relationships of co-research, by and for those implicated in the research subject. It involves *all* relevant parties – particularly, in this case, women living with HIV – in identifying problems, priorities and questions, shaping and implementing the research process, and actively working to change and improve conditions seen as problematic. CHIWOS seeks to bring together a research community which includes People Living with HIV, doctors, scientists, social scientists, AIDS Service Organization workers, service providers, activists, academics, and others. In and through this community, all members’ contributions and diverse experiences will be valued and respected, critical self-reflection will be prioritized, and those to be helped will be able to determine the purposes and outcomes of their own inquiry.

GIPA

The principle of GIPA (Greater Involvement of People living with HIV/AIDS) demands the meaningful and emancipatory participation of people living with HIV (PHAs) in every stage of research and knowledge translation. GIPA recognizes the rights of PHAs to a voice in directing the decisions that impact their lives, and to self-determination and autonomy. The absence of meaningful participation of PHAs, as well as violating these rights, will render the research project, service-delivery or support program, or policy initiative significantly less effective. CHIWOS is striving to embody this principle in a genuinely transformative way, benefiting women living with HIV as well as researchers, and to avoid the pitfalls of tokenism and a shallow commitment to meaningful engagement.

The following CBR principles have been adapted from the CBR principles of the Women and HIV Research Program, Women’s College Research Institute for the CHIWOS project.

Commitment to Equitable Partnerships

CHIWOS recognizes that power imbalances may exist among team members and will work together to ensure that all involved in CHIWOS are equal partners and have equal voice:

- CHIWOS will collaboratively co-create knowledge and mobilize knowledge to inform practice and policy aimed at improving the overall health of women living with HIV in Canada;

- All investigators, collaborators, partners, coordinators, assistants, advisors and participants bring varied expertise, strengths and resources to CHIWOS which are valued equally. CHIWOS recognizes and will build on these and other strengths and resources available in the community;
- All involved in CHIWOS have potential to benefit from training provided by research team members, women living with HIV and various advisors and experts and CHIWOS is committed to the skills development of all team members;
- All involved in CHIWOS should feel free to voice their views, opinions and comments freely.

Reporting Structure

The PRAs report to the provincial coordinators, the provincial coordinators report to the assigned provincial PIs (BC – Angela Kaida, SK – Carrie Bourassa, MB – Marissa Becker and Sharon Bruce, ON – Mona Loutfy, QC – Alexandra de Pokomandy). The Provincial Team reports to the National Management Team (NMT), which is composed of provincial community representative positions for PRAs (BC, ON, QC), provincial coordinators, and principal investigators.

Decision Making

CHIWOS functions in a collaborative fashion and decisions are to be made by consensus as much as possible; in some circumstances, the co-PIs are to make final decisions, and finally the Nominated Principal Investigator Mona Loutfy.

Conflict resolution

Sometimes, differences of opinion or disagreements happen, CHIWOS preferred mechanism for handling such differences is for those directly involved to resolve their disagreement. If external support is required the Provincial Coordinator, Provincial Principal Investigator or the Nominated Principal Investigator may be requested to assist or intervene.

Disclosure of HIV status and confidential information

Peer Research Associates (PRAs) and those involved in CHIWOS are to understand that being involved in this project could result in some degree of disclosure for the PRAs amongst the members of the National Management Team (Coordinators, Principal Investigators). However, it is up to each PRA to manage their own disclosure with participants and potential participants, as well as in Community Advisory Board Meetings and wider dissemination events such as workshops or conferences where CHIWOS may present. PRAs and those involved in CHIWOS are to understand that confidentiality is essential and that participants' and PRAs' lived experiences are not to be disclosed. Please see [CHIWOS NEW MEMBERSHIP PROCEDURES POLICY](#) for more information on navigating disclosure within open working groups and committee.

Emotional Safety

Working within a CBR model may lead to emotional triggering or cause distress for those involved in CHIWOS, including PRAs, coordinators, research staff and participants. In consideration of this reality, the CHIWOS National Management Team has devised a [CHIWOS SAFETY AND PSYCHOLOGICAL WELLBEING POLICY](#). This document provides clear directions on who to contact, and what services are available when experiencing distress. These include a social worker, a

nurse, therapists, and the Nominated Principal Investigator (NPI) Mona Loutfy's contact information. Please see the [CHIWOS SAFETY AND PSYCHOLOGICAL WELLBEING POLICY](#), also available on the CHIWOS website (www.chiwos.ca) for more information.

References

- Collins, P. H. (1998). It's all in the family: Intersections of gender, race, and nation. *Hypatia*, 13(3), 62-82.
- Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, 18(3), 271-283. doi: 10.1080/09581590802294296
- Phoenix, A. (2006). Intersectionality. *European Journal of Women's Studies*, 13(3), 187-192. doi: 10.1177/1350506806065751



CHIWOS Group-specific Advisory Board (GAB) Request Form

Last reviewed and revised – Dec 2019

Introduction

CHIWOS is a women-centered, community-based research project that is grounded in the principles of Greater Involvement of People Living with HIV/AIDS (GIPA), Critical Feminism, Anti-Oppression, Intersectionality and Social Justice, Social Determinants of Health, and Social Justice Frameworks. CHIWOS values the ongoing and meaningful participation of women living with HIV from diverse communities, and other stakeholders and community members with a vested interest in this work at all stages of the research process. This study is particularly interested in understanding and incorporating the lived experiences of women. As such, we acknowledge the need for CHIWOS Group-Specific Advisory Boards (GABs), and feel that this is the best way to ensure that our work continues to meet the complex and intersecting needs of the diverse communities of women living with HIV in Canada.

GABs will address study issues pertinent to specific groups, such as survey development, participant recruitment, and knowledge transfer and exchange strategies for specific communities. These groups of women living with HIV may include, but are not limited to*:

- Indigenous women
- Women from countries with a high prevalence of HIV/AIDS
- Women with a current or past experience of injection drug use
- Women with a current or past experience of incarceration
- Women living in rural and/or remote areas
- Women who identify as lesbian, two-spirited or bisexual
- Women who identify as Trans women, have transitioned, or Trans-people who access women's services
- Women with current or past experience of sex work
- Street-involved women (homeless)
- Young women
- Older women
- And other priority populations

*Note: We recognize women’s multiple and overlapping identities. We also understand that women living with HIV face multiple issues and concerns simultaneously. All of these factors mutually construct one another and contribute to the health of women living with HIV. (For more information on “intersectionality”, please see the [CHIWOS Guiding Principles](#).) Specific GABs may be formed to help facilitate productive engagement and collaboration among certain stakeholder groups. However, it is important that each GAB, along with the CHIWOS research team, continuously address the intersections between diverse groups of women in their discussions and procedures.

The following describes the steps required for those interested in creating a GAB.

Procedure

A GAB Request Form (see attached) is to be completed and submitted to your CHIWOS Provincial Coordinator, which will be reviewed by the CHIWOS National Management Team (NMT). This document should outline the rationale for why a GAB is needed, and the proposed structure for membership of this group. This summary sheet should be no longer than **one-page**.

CHIWOS is committed to supporting the development and maintenance of GABs, however GABS are required to have a partnering organization, designated chair(s), a secretary, one CHIWOS National Core Research Team member (e.g. PRA, co-investigators), and a membership structure, all of which are to be self-organized and maintained by the GAB (e.g. organizing meetings, setting agendas, taking minutes). A Terms of Reference document must be completed by the GAB and approved by the NMT. A **CHIWOS Terms of Reference Template** can be provided upon request. CHIWOS will support GAB operations through the provision of meeting space if needed in Toronto, Vancouver or Montreal; and access to the CHIWOS teleconference line if needed. The GAB secretary will be responsible for drafting and finalizing GAB meeting minutes and forwarding these minutes to their provincial CHIWOS Coordinator. When key recommendations or issues arise at GAB meetings, they should be specified separately at the end of the minutes or in a separate letter, to allow the CHIWOS NMT and Steering Committee (SC) to address them in a timely fashion.



CHIWOS Group-specific Advisory Board (GAB) Request Form

Nominated Group Chair(s)	
Contact Information	
Partnering Organization	
Group Secretary, Affiliation	
CHIWOS NCRT member(s)	
Other group Members, Affiliations	
Date Submitted	

Group Title

Group Rationale: (maximum 500 words)

Number of Recommended Meetings/Year	
Proposed meeting schedule and logistics i.e. meeting space, by teleconference, etc.	
Person responsible for drafting Terms of Reference and Minutes (Name and contact) (i.e. Group Secretary)	
Is \$500 funding required if available?	<input type="checkbox"/> NO <input type="checkbox"/> YES

PLEASE EMAIL COMPLETED FORM TO YOUR PROVINCIAL COORDINATOR

Decision:



CHIWOS Topic-specific Advisory Board (TAB) OR WORKING GROUP Request Procedures

Last reviewed and revised – Dec 2019

Introduction

CHIWOS is a women-centered, community-based research project that is grounded in the principles of Greater Involvement of People Living with HIV/AIDS (GIPA), Critical Feminism, Anti-Racism, Anti-Oppression, Intersectionality, Social Determinants of Health, and Social Justice Frameworks. CHIWOS values the ongoing and meaningful participation of women living with HIV from diverse communities, and other stakeholders and community members with a vested interest in this work. This study is particularly interested in understanding and incorporating the lived experiences of women at all stages of the research process, especially as it relates to sexual and reproductive health, HIV and mental health and access to care. As such, we acknowledge the need for CHIWOS topic-specific advisory boards (TABs) or working group in addition to group-specific advisory boards (GABs), and feel that this is the best way to ensure that our work continues to meet the complex and intersecting needs of the diverse communities of women living with HIV in Canada.

TABs will address study issues pertinent to specific topics. These topics of women living with HIV may include (but are not limited to)*:

- **Emotional and Mental Wellbeing**
- **Stigma and Discrimination**
- **Sexual and Reproductive Health**
- **Migration**
- **Criminalization of HIV non-disclosure**
- **Incarceration**
- **Women-centred HIV Care**
- **Resiliency**
- **Substance Use**
- **Motherhood**
- **Violence**
- **Physical Health and Co-morbidities**

*Note: We recognize some topics may overlap. We also understand that women living with HIV face multiple issues and concerns simultaneously. All of these factors mutually construct one another and contribute to the health of women living with HIV. (For more on “intersectionality”, please see the [CHIWOS guiding frameworks](#).) Specific TABs may be formed to help facilitate productive engagement and collaboration among certain stakeholder groups. However, it is important that each TAB, along with the CHIWOS research team, continuously address the intersections between topics impacting women in their discussions and procedures.

The following describes the steps required for those interested in creating a TAB.

Procedure

A Group TAB Summary Sheet (see attached) is to be completed and submitted to the CHIWOS central research coordinator (ON), which will be reviewed by the CHIWOS National Management Team (NMT). This document is to outline the rationale for why this TAB is needed, and the proposed structure for membership of this group. This summary sheet should be no longer than **one-page**.

CHIWOS is committed to supporting the development and maintenance of TABs, however TABS are preferred a partnering organization, designated chair(s), a secretary, one CHIWOS NMT member, and a membership structure, all of which are to be self-organized and maintained by the TAB. A terms of reference document must be completed by the TAB and approved by the NMT. A **CHIWOS Terms of Reference Template** can be provided upon request. CHIWOS will support TAB operations through the provision of meeting space if needed in Toronto, Vancouver or Montreal; and access to the CHIWOS teleconference line if needed. The TAB secretary will be responsible for drafting and finalizing TAB meeting minutes and forwarding these minutes to the CHIWOS central coordinator. When key recommendations or issues arise at TAB meetings, they should be specified separately at the end of the minutes or in a separate letter, to allow the CHIWOS NMT and Steering Committee (SC) to address them in a timely fashion.



CHIWOS Topic-specific Advisory Board (TAB) or WOKING GROUP Request Form

Nominated Group Chair(s)	
Contact Information	
Partnering Organization (if available)	
Board Secretary, Affiliation	
CHIWOS NMT member(s) on Board	
Other Board Members, Affiliations (required)	
Date Submitted	

TAB Title

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TAB Rationale (maximum 500 words)

Number of Recommended Meetings/Year	
Proposed meeting schedule and logistics i.e. meeting space, by teleconference, etc.	
Person responsible for drafting Terms of Reference and Minutes (Name and contact) (i.e. Board Secretary)	

PLEASE EMAIL COMPLETED FORM TO THE CHIWOS CENTRAL COORDINATOR, MINA KAZEMI AT mina.kazemi@wchospital.ca



CHIWOS National Steering Committee

TERMS OF REFERENCE

Last reviewed and revised – Dec 2019

Project Overview

The project seeks to address a significant gap in knowledge related to the availability and utilization of women-centred HIV care, and the barriers and facilitators that influence these usage patterns, as well as assessing the impact of these services on the sexual, reproductive, women's, and mental health of women living with HIV across Canada.

Formative Phase

Before the usage and impact of 'women-centred HIV care' could be assessed CHIWOS determined how women living with HIV themselves defined and envisioned these services. Focus group discussions were conducted as part of this initial phase to determine community definitions and perceptions of women-centred HIV care. The formative phase also included the hiring and training of provincial peer research associates (PRAs) and the creation of the study questionnaire through a national collaborative process. Survey testing and piloting was also conducted to collect feedback and input on the preliminary survey instrument before it was employed on a larger scale.

Survey Phase

The CHIWOS cohort enrolled 1,422 WLHIV from the three study provinces British Columbia (n=356), Ontario (n=713), and Quebec (n=353). Wave One of the study launched October 1st 2013 and closed May 1st 2015. Participants were recruited through AIDS service organizations (ASOs), HIV-clinics and PRA's personal networks. Following this baseline interview, follow up interviews for Wave 2 started in July 2015, approximately 18 months after the baseline. A third follow-up interview (wave 3) started on February 1st, 2017 (approximately 18 months after wave 2 interviews), and ended on September 16th, 2018. The CHIWOS surveys are PRA-administered on an electronic platform and lasts approximately two hours.

Body mapping (BM)

BM is an important component of the CHIWOS-Renewal as it will allow a deeper and more contextualized understanding of WCC using artistic narrative expression and stories from WLWH. BM is an arts-based qualitative research method that uses drawing and painting exercises, visualization, and talking and reflecting in groups. It uses art to tell life stories while engaging in a process of self-healing, facilitating a less directive style of interviewing than would otherwise be possible. Ideas and issues can be explored that may be more difficult to access through verbal discussion alone. Women's own classifications and visual descriptions can be used as a basis for exploration. The map acts to free interviews from being intrusive and to generate themes for further discussion. BM offers a metaphor and a means of recognizing the "fluid tracings of the personal, social, geographical, political, and emotional experience of journeying with illness through life". BM requires significant community participation, in line with our theoretical frameworks of CBR and critical feminism. Furthermore, BM can be used to support both research and advocacy goals, whereby the art is used as data themselves, supplemented by stories. It can bring to life both the temporal and social aspects of women's HIV care throughout the life course, an essential aspect of our research goals.

Following the approach of Jane Solomon, the participants will participate in the three-day workshop, which will include moving through 17 activities that build on one another. The workshop will be held in 2018-2019, in BC, ON, QC, SK, and MB.

Project Funding

The project is funded by the Canadian Institute of Health Research (CIHR) and is supported by the CIHR Canadian HIV Trials Network (CTN, study number: CTN 262), the Ontario HIV Treatment Network (OHTN) and the Alternative Funding Plan (AFP) Academic Health Sciences Centre (AHSC) Innovation Fund. The original project was funded from April 2011 to March 2016. Additional funding from CIHR was secured to extend CHIWOS by another five years to 2021. With this funding CHIWOS will also expand to the provinces of Manitoba and Saskatchewan.

PURPOSE OF THE STEERING COMMITTEE

The purpose of the CHIWOS National Steering Committee is to provide national support and guidance to the National Management Team (NMT) and the Provincial Core Research Teams. The NMT includes the five provincial Principal Investigators (PIs) Angela Kaida (BC), Carrie Bourassa (SK), Marissa Becker and Sharon Bruce (MB), Mona Loutfy (ON) and Alexandra de Pokomandy (QC), the Research Coordinators and provincial Peer Research Associate Representatives. The Provincial Core Research Teams includes WLHIV, community representatives, ASO members, researchers, and clinicians.

Key duties and responsibilities

The National Steering Committee will:

- Support and guide the National Management Team and Provincial Core Research Teams;
- Act within the vision, mission, mandate, and guiding frameworks of the project;
- Provide feedback and insight into the strategic vision and mandate of CHIWOS, as well as the purpose, objective, methods, and results of the overall project;

- Consult with and represent their particular region, community or stakeholder group to ensure that stakeholders across Canada involved in women and HIV issues have a forum to provide direction, input and support to the project;
- Provide advice on the relevance and comprehensibility of the study materials including the focus group guide, recruitment flyers, and national survey instrument;
- Assist in the recruitment and retention of participants;
- Provide support to Peer Research Associates including, but not limited to the provision of space for them to conduct focus groups and interviews;
- Provide direction and participate in knowledge translation activities;
- Provide input into capacity building activities including, but not limited to development of training materials.

Committee composition

- Members of Provincial Core Research Team
- Peer Research Associates
- Co-investigators
- Collaborators
- CAB members
- Women living with HIV
- Students
- Community service providers
- Policy makers

DETAILS

Term

The duration of the project will run for ten years from April 2011 – September 30, 2019 with the possibility for extension, pending future funding. Membership will be reviewed on a yearly basis and members are free to join and leave at any time.

Frequency of Meetings

The National Steering Committee will meet by teleconference once a year.

Reporting Requirements

The National Steering Committee will be expected to verbally report to each other during yearly teleconference meetings. The members will be accountable to the PIs who are in turn accountable to their Institutions and the Funders. The members are also accountable to their own Institutions. It is also hoped that the members will see themselves accountable to women living with HIV in Canada. Minutes of the National Steering Committee meetings will be finalized and circulated by a CHIWOS Coordinator within 10 days of each meeting to facilitate reporting if required. Steering Committee slides will also be available on CHIWOS web site within 10 days of each meeting.

Decisions Making

Decisions will be made by consensus as much as possible. In some circumstances, the PIs are to make final decisions, and finally the nominated PI.

Grievance Process

Sometimes, differences of opinion or disagreements happen. CHIWOS prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see a provincial coordinator to help resolve. If still not resolved, the person and coordinator will involve one of the PIs. However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to one of the PIs or the nominated PI.



CHIWOS Provincial Community Advisory Board (CAB)

TERMS OF REFERENCE

Last reviewed and revised – Dec 2019

Project Overview

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The project is funded by the Canadian Institute of Health Research (CIHR) and is supported by the CIHR Canadian HIV Trials Network (CTN, study number: CTN 262), the Ontario HIV Treatment Network (OHTN) and the Alternative Funding Plan (AFP) Academic Health Sciences Centre (AHSC) Innovation Fund. The original project was funded from April 2011 to March 2016. Additional funding from CIHR was secured to extend CHIWOS by another five years to 2021. With this funding CHIWOS will also expand to the provinces of Manitoba and Saskatchewan.

Purpose of the Community Advisory Board

For the purposes of this study, we are working from an inclusive definition of 'community' in an effort to seek consultation from the many stakeholders on this issue. While the voices of WLHIV should always be prioritized, we are also including academics, researchers, policy makers, clinicians, community workers, activists, and others in the field of HIV/AIDS and women's health in our conception of what the 'community' entails.

Bringing together diverse voices from various backgrounds and areas of knowledge – prioritizing the lived experience of women living with HIV – the CABs will provide essential consultative input to the CHIWOS research team. They will ensure that the study's design, documents, and roll-out plans are appropriate and acceptable to WLHIV and other community members. CABs will also provide a regional voice, to ensure that the study is tailored to distinct provincial realities.

ACTIVITIES

The Provincial Community Advisory Boards will:

- Provide expert advice to the provincial research teams and the CHIWOS National Management Team (NMT) on all aspects of the study
- Review and advise on the relevance and comprehensibility of study documents including consent forms, recruitment flyers, and national survey instruments
- Assist with the development of materials and strategies for the recruitment of HIV-positive women to the study
- Bring up any concerns or hesitations to the provincial research teams, the NMT and/or the Steering Committee as appropriate
- Provide direction and participate in knowledge translation activities

COMMITTEE COMPOSITION

The Provincial CAB will be composed of:

- Women living with HIV/AIDS including, but not limited to
 - Aboriginal women
 - Women from countries with a high prevalence of HIV
 - Women with current or past experience of injection drug use
 - Women with current or past experience of incarceration
 - Women living in rural and/or remote areas
 - Women who identify as lesbian, two-spirited or bisexual
 - Women who identify as Trans women, have transitioned, or Trans-people who access women's services
 - Women with current or past experience of sex work
 - Street-involved women (homeless)
 - Young women
 - Older women
 - And other priority populations
- The partners, children and families of women living with HIV
- Physicians, nurses and other healthcare professionals
- Clinical and social science researchers
- Representatives of Community Service Organizations and Health Centers
- Policy-makers, and representatives from the relevant governmental bodies
- Provincial members of the CHIWOS National Core Research Team, including Coordinators, Principal Investigators, National Steering Committee, and Provincial Peer Research Associates (PRAs).

DETAILS

Term

The duration of the project will run for ten years from April 2011 – March 2021 with the possibility for extension, pending future funding. Membership will be reviewed on a yearly basis and members are free to join and leave at any time.

Frequency of Meetings

Provincial CABs will set their respective meeting schedules; typically, once or twice a year. Frequency may vary as the study progresses.

Reporting Requirements

The CAB members will be expected to verbally report to each other during meetings. The members will be accountable to the PIs who are in turn accountable to their Institutions and the Funders. The members are also accountable to their own Institutions. It is also hoped that the members will see themselves accountable to WLHIV in Canada. Minutes of the CAB meetings will be finalized and circulated by the provincial CHIWOS Coordinator within 10 days of each meeting to facilitate reporting if required.

Decisions Making

Decisions will be made by consensus as much as possible. In some circumstances, the PIs are to make final decisions, and finally the nominated PI.

Grievance Process

Sometimes, differences of opinion or disagreements happen. CHIWOS prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see a provincial coordinator to help resolve. If still not resolved, the person and coordinator will involve one of the PIs. However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to one of the PIs or the nominated PI.



CHIWOS National Knowledge Transfer and Exchange (KTE) Working Group

TERMS OF REFERENCE

Last reviewed and revised – October 2017

WHAT IS THIS DOCUMENT?

These are the Terms of Reference which is a document used to describe the purpose and structure of a project, committee, meeting, negotiation, or any similar collection of people who have agreed to work together to accomplish a shared goal. Knowledge to Action the framework commonly employed by the CIHR for the transfer of research findings into practice, and can be broken down into two concepts: knowledge creation and the action cycle. In practice, the two concepts are fluid.

PROJECT OVERVIEW

CHIWOS seeks to address a significant gap in knowledge related to the availability and utilization of women-centred HIV care. We aim to assess the barriers and facilitators that influence care usage patterns, and assess the impact of these services on the sexual, reproductive, women's, and mental health of women living with HIV across Canada. This study will yield critical information which will help to fill knowledge gaps about women, HIV, and HIV/AIDS care, and will enable improvements in the health, care, and wellbeing of HIV positive women in Canada. CHIWOS is guided by community-based research and GIPA (Greater Involvement of People living with HIV/AIDS) principles. In conjunction and guided by women living with HIV providing opportunities for bilateral learning experiences and mentorship opportunities

PURPOSE OF National KTE Working Group

The National KTA working group has been established in order to ensure that CHIWOS will be used to create meaningful changes in policy and practice that will promote the health and well-being of women living with HIV in Canada and beyond. Integral to this process is the engagement of key *stakeholders - a person, organization, and/or group who has a key interest or concern in the project*. In women and HIV, and the collaborative development of KTA strategies throughout all stages of this project for a wide variety of audiences including but not limited to academics, students, support workers and community.

CHIWOS DEFINITION OF KTE

CHIWOS has adopted an integrated KTA approach, which is an *iterative* (repeating/repetitive), collaborative, *participatory and action-oriented model is an approach to research in communities that emphasizes participation and action. It seeks to understand the world by trying to change it, collaboratively and following reflection.* A diverse range of “*knowledge users an individual who is likely to be able to use research results to make informed decisions about health policies, programs and/or practices*” have been and will continue to be engaged with CHIWOS at all stages of the research process, including the study conception, grant preparation, survey development, data collection, analysis and *dissemination the act of spreading something, especially information, widely.* Ensuring the usability and relevance of CHIWOS data is integral to our KTA approach, which will allow for the continuous and cyclical movement of research into action.

KEY DUTIES AND RESPONSIBILITIES

The National KTA Working Group will contribute to the CHIWOS KTE Work Plan and strategize, plan and oversee different kinds of KTA activities including:

Knowledge Creation:

Knowledge becomes more refined as it moves through the research process including the steps of inquiry (e.g. primary research), synthesis (e.g. systematic review) and creation of tools or products (e.g. guidelines, decision-making tools).

The Action Cycle:

The Action Cycle is the implementation of the knowledge. There are several steps in the Action Cycle, all of which may inform each other. The steps are as follows:

1. Identify the problem as well as the knowledge needed to address this (as well as addressing the usefulness and validity of the knowledge).
2. Adapt the knowledge to the local context by assessing its worth and utility to the setting for which you intend it.
3. Assess barriers and facilitators related to the knowledge to be adopted, the potential adopters, and the context in which the knowledge will be used.
4. Develop and execute your KT plan and any strategies to promote awareness and use of the knowledge.
5. Monitor knowledge use to determine whether your plan was effective, and implement any changes that this monitoring may indicate is necessary. This is also the time to consider reassessing your barriers and facilitators if uptake or use has been low.

6. Evaluate the impact of the knowledge use to determine if you have achieved the desired outcomes, as well as the success of the KT plan itself.

7. Sustain the use of the knowledge over time. Challenges to ongoing use of the knowledge may be very different than the challenges during implementation. Consideration needs to be given to sustaining the use of the knowledge.

Inclusion of WLWH and affected population is essential to the success of the implementation of the KTA strategy

COMMITTEE COMPOSITION

- Tracey Conway, Committee Chair
- Jacque Gahagan, Health Promotion Academic
- BC, ON, QC Provincial KTE Representatives (Tammy, Tracey, Danièle), Committee Chairs
- Nadia O'Brien, CHIWOS PhD Student
- Mona Loutfy, Nominated Principal Investigator (NPI)
- Mina Kazemi, KTA Working Group Coordinator
- Members of the CHIWOS National Management Team (NMT) and Steering Committee (SC)
- Other Co-investigators and Collaborators that are leaders on the topic of women and HIV with expertise in KTE, policy, research, clinical practice, and other community experience
- CHIWOS Peer Research Associates and other women living with HIV in Canada
- Other participants from key populations (e.g. Indigenous women, African/Caribbean/Black women and trans women groups)

DETAILS

Term: The Working Group will run for the duration of the entire CHIWOS project, from the August 2017 and running until December 2018. Members are free to join and leave at any time. Membership will be verified on an annual basis.

Frequency of Meetings: The National KTA Working Group will meet by teleconference once every two months. These meetings will last for 90 minutes. They will usually occur on the third Friday of the month from 12:30pm to 3:00 pm EST. Additional teleconferences will occur when required.

The Provincial KTA Representatives will also join the NMT meetings that same month to report back on their provincial KTA updates.

Confidentiality: is the principle that an institution or individual should not reveal information to a third party or others outside of the group with whom the agreement is held

Reporting Requirements: The National KTE Working Group will be expected to verbally report to each other during bimonthly meetings. The members will be accountable to the Committee

Chair and the CHIWOS NPI who is in turn accountable to their Institutions and the Funders. The members are also accountable to their own Institutions. It is also hoped that the members will see themselves accountable to women living with HIV in Canada. Minutes of the National KTE Working Group's meetings will be finalized and circulated by the CHIWOS Coordinator within 10 days of each meeting to facilitate reporting if required. National KTE Working Group updates will be sent to the SC members yearly.

Decision Making: Decisions will be made by consensus as much as possible. In some circumstances, the Committee Chair and/or the CHIWOS NPI will be nominated to make final decisions. All decisions that are made by the National KTA Working Group are brought to the NMT, the National Core Research Team, National SC and CABs for consultation and feedback.

Communication: CHIWOS operates with the principles of open communication. Formal research communications will not be made public until conference presentations or journal publications are presented or published. Abstracts and/or oral presentations will then be circulated to the public, and posted on the CHIWOS website for public access.

Grievance Process: Sometimes, differences of opinion or disagreements happen. CHIWOS prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see the CHIWOS Coordinator to help resolve the problem. If still not resolved, the person and the Coordinator will involve the NPI. However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to the nominated PI.

References

^aLavis JN. Research, public policymaking, and knowledge-translation processes: Canadian efforts to build bridges. *J Contin Educ Health Prof.* 2006;26:37-45.



CHIWOS In Action

TERMS OF REFERENCE

Created – September 2019

WHAT IS THIS DOCUMENT?

These are the Terms of Reference which is a document used to describe the purpose and structure of a project, committee, meeting, negotiation, or any similar collection of people who have agreed to work together to accomplish a shared goal. 'Knowledge to Action' the framework commonly employed by the CIHR for the transfer of research findings into practice, and can be broken down into two concepts: knowledge creation and the action cycle. In practice, the two concepts are fluid.

PROJECT OVERVIEW

CHIWOS seeks to address a significant gap in knowledge related to the availability and utilization of women-centred HIV care. We aim to assess the barriers and facilitators that influence care usage patterns, and assess the impact of these services on the sexual, reproductive, women's, and mental health of women living with HIV across Canada. This study will yield critical information which will help to fill knowledge gaps about women, HIV, and HIV/AIDS care, and will enable improvements in the health, care, and wellbeing of HIV positive women in Canada. CHIWOS is guided by community-based research and GIPA (Greater Involvement of People living with HIV/AIDS) principles. In conjunction and guided by women living with HIV providing opportunities for bilateral learning experiences and mentorship opportunities

PURPOSE OF CHIWOS In Action

CHIWOS In Action is considered the third phase of CHIWOS. With the formative phase and data collection phase now complete, this phase has been established in order to ensure that CHIWOS will be used to create meaningful changes in policy and practice that will promote the health and well-being of women living with HIV in Canada and beyond. This phase is in line with 'Knowledge to Action', the framework commonly employed by the CIHR for the transfer of research findings into practice. The CHIWOS National Management Team (NMT) will now turn its efforts to advising on, initiating, coordinating, and tracking the translation and dissemination of CHIWOS research findings into outputs targeted at various audience, including: women living with and affected by HIV, researchers, policy makers, clinicians, care and service providers etc.

KEY DUTIES AND RESPONSIBILITIES

The National Management Team will now lead CHIWOS In Action and strategize, plan and oversee different kinds of KTA activities and initiatives related to:

- The Women-centred HIV Care Model, Toolkit and Training
- The National Action Plan on the SRHR of women living with HIV
- CHIWOS quantitative findings
- CHIWOS qualitative findings
- Body Mapping
- CHIWOS PAW
- CHIWOS arts-based initiatives
- Learnings on community-based research
- The creation and implementation of tools or products
- Implementation Science studies

COMMITTEE COMPOSITION

- Mona Loutfy, Nominated Principal Investigator (NPI)
- Angela Kaida, Principal Investigator
- Alexandra de Pokomandy, Principal Investigator
- Marissa Becker, Principal Investigator
- Sharon Bruce, Principal Investigator
- Carrie Bourassa, Principal Investigator
- Carrey Sinclair
- Laverne Gervais
- Melanie Lee, CHIWOS Peer Research Associate
- Mina Kazemi, Ontario Coordinator
- Rebecca Gormley, BC Coordinator
- Sebastien Lefebvre, Saskatchewan Coordinator
- Miranda Keewatin, Saskatchewan Research Assistant

DETAILS

Term: This work will run from October 2019 and running until March 2025 (end of CIHR Foundation grant) and re-assessed at that time. Members are free to join and leave at any time. Membership will be verified on an annual basis.

Frequency of Meetings: The team will meet by teleconference every six months. These meetings will last for 90 minutes. Additional teleconferences will occur when required.

Confidentiality: is the principle that an institution or individual should not reveal information to a third party or others outside of the group with whom the agreement is held.

Reporting Requirements: Team members will be expected to verbally report to each other during teleconferences. The members will be accountable to the CHIWOS NPI and PIs who are in turn accountable to their Institutions and the Funders. The members are also accountable to their own Institutions. It is also hoped that the members will see themselves accountable to women living with HIV in Canada. Minutes of the CHIWOS In Action meetings will be finalized

and circulated by the CHIWOS Coordinator within 10 days of each meeting to facilitate reporting if required. CHIWOS In Action updates will be sent to the SC members yearly.

Decision Making: Decisions will be made by consensus as much as possible. In some circumstances, the Committee Chair and/or the CHIWOS NPI will be nominated to make final decisions.

Communication: CHIWOS operates with the principles of open communication. Formal research communications will not be made public until conference presentations or journal publications are presented or published. Abstracts and/or oral presentations will then be circulated to the public, and posted on the CHIWOS website for public access.

Grievance Process: Sometimes, differences of opinion or disagreements happen. CHIWOS prefers the mechanism of handling such differences directly with the person that the disagreement occurred with. If still not resolved, please see the CHIWOS Coordinator to help resolve the problem. If still not resolved, the person, and the Coordinator will involve the nominated PI (Mona Loutfy). However, please understand that if anyone is uncomfortable speaking directly to another about a matter, you can go directly to the nominated PI.

Appendix 1

GUIDELINES FOR PROBLEM-SOLVING CHALLENGING INTERVIEW SCENARIOS



GUIDELINES FOR PROBLEM-SOLVING CHALLENGING INTERVIEW SCENARIOS

(Updated May 24th 2013)

INTRODUCTION

This document is intended to provide guidance around approaches for dealing with challenging interview scenarios that the Peer Research Associates (PRAs) and other interviewers may face while conducting interviews with study participants. Please see below for a list of possible scenarios and the CHIWOS policies for dealing with them.

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SECTION 1: INTERVIEW / DATA-RELATED SCENARIOS

1.0: INTERVIEW/DATA-RELATED SCENARIOS

1.1: HOW TO CARRY OUT CONSENT

You may encounter a participant who would like to read or review the form alone. Or alternatively, you may sit down with a participant who wants you to explain and review it with them. Either scenario is fine. In general, if the participant has no preference, CHIWOS advises the following:

Share the consent form with the participant and go through each section verbally explaining the details. It is okay to read the form word-for-word or you may prefer to ad-lib (improvise), but be sure to cover each heading: the purpose of the study, procedures, confidentiality, data storage and security, data linkage, the benefits and risks of participation, and contact information.

Encourage the participant to ask questions throughout.

After reviewing the entire consent form, give the participant the opportunity to read the consent form alone and encourage them to ask any remaining questions.

If the participant consents to participate in the study, the participant and interviewer must sign, date, and complete any initial lines or checkboxes that appear on the form.

Keep the signed copy of the form (it must be safely stored and returned to the Coordinator), and welcome participants to take a copy of the consent form home.

1.2: PARTICIPANT DOES NOT WANT TO READ/LISTEN TO THE FULL CONSENT FORM

You might encounter a participant who does not want to read or listen to the full consent form. Perhaps the participant is a friend and trusts you, or maybe the participant is in a hurry to complete the interview. Whatever the reason, it is important to explain to participants that informed consent is an important and necessary part of the interview process. It involves sharing information and addressing questions and concerns about the study, rather than simply obtaining a signature on a form. Therefore, the consent form must be explained to, or read by the participant prior to starting the survey. While shorter explanations may be provided if the participant wishes, we advise our interviewers to make sure all headings of the consent form have been covered and any questions answered before proceeding.

1.3: PARTICIPANT IS NOT ABLE TO GIVE INFORMED CONSENT

Impairments to reasoning and judgment may make it impossible for someone to give informed consent. A common scenario interviewers may encounter is a participant who is intoxicated (e.g., drunk or high). In these cases, interviewers are advised to not begin the interview. Explain to the participant that the survey questions are quite long and involve a lot of detail that require their full attention. We are also required to have informed consent before an interview starts and intoxication voids the ability to give informed consent. Ask the participant if they'd like to re-schedule the interview at a time when they're able to give informed consent. If the participant is persistent about completing the survey and argues that they are able to give informed consent, emphasize again that this is a legal document, they must understand the study and risks/benefits, and they cannot sign it while under the influence. If becoming more aggressive and argumentative, move to safety protocols (e.g., Walk to and open door, saying something like: "I'm sorry. I'm going to have to end the interview. Thank you for coming.")

1.4: WHEN TO GIVE PARTICIPANTS THEIR HONORARIUM

The consent form states that participants will be reimbursed \$50 upon completion of the survey. Therefore, it is CHIWOS policy to give participants their honorarium at the end of the interview process.

1.5: PARTICIPANT WANTS TO PAUSE OR END THE INTERVIEW

Participation is entirely voluntary and participants may skip questions or stop the interview at any time. If they want to simply pause the interview and complete it at another time, re-schedule the interview for another date and time and inform the participant that they will receive their honorarium upon completion of the survey at the end of the interview process at their next visit. If they want to end the interview altogether, thank them for coming; let me know that their consent form and survey data will be deleted; and encourage them to take the consent form and resource list home and call any of the numbers provided should they have any questions.

1.6: PARTICIPANT HAS CONCERNS/QUESTIONS ABOUT DATA LINKAGE

As part of this study, we plan to link data from the CHIWOS surveys to other provincial health database files. When explaining how data linkage works, it's important to mention the following:

Two different files are linked on the basis of common personal identifiers (e.g., provincial health card number and date of birth). If this information is unavailable, name and other available information may be used. This process is done by one authorized person following strict privacy and security guidelines and agreements. Once two different files that belong to same individual are identified / linked, the files are assigned an anonymous ID and any personal information is never accessed again.

As mentioned in the Voluntary Participation section of the consent form above, participants can choose not to provide their provincial health card number if they do not feel comfortable.

Also, participants may ask why the study wants to make these links, and interviewers should be prepared to explain why it is important. The reason we want to do this linking is because we cannot ask about everything in 2.5 hours. This linkage and data will provide us with extra information which will help us know a lot more and better understand positive women's health.

For more detailed information about data linkage and security, please see the document entitled: "Health Information Linkage and Security for CHIWOS."

1.7: WHAT TO DO IF A PARTICIPANT IS A NEIGHBOUR OR A FRIEND

Imagine you try to organize an interview with a participant who is one of your neighbors or friends. Before you schedule the interview, it is important to let them know that she may share highly personal information about her life during the interview. You may want to use examples here (e.g. number of sexual partner, mental health diagnosis, abortions and miscarriages) to illustrate how personal the survey gets. It's important that she knows she has the option to complete the survey with you, or we can connect her with another interviewer. Ask her what she prefers. If she decides to complete the survey with you, then you may want to begin the interview a little differently than you normally would. For example, you might want to acknowledge your friendship with her and let her know that today you're wearing the hat of "interviewer". Everything that is said between the two of you will remain confidential and you will not discuss anything with her or others (e.g., mutual friends) outside this interview. Say, during the interview, she does share new highly sensitive information that you didn't know about before, how you react may depend on your relationship with this person, what / how information is being shared, and her response/mood. You'll have to be observant and use your judgment to decide how to respond. In general though, we'd encourage you to remember that you're wearing the hat of "interviewer" – this means remaining neutral and non-judgmental (e.g., not reacting with shock if you learn something new) and re-affirming confidentiality of any information that she shares. Also, please remember to never bring the topic up again with her – either during or outside the interview – unless your friend brings it up and wants to talk to you about it.

1.8: PARTICIPANT WANTS SOMEONE ELSE PRESENT DURING THEIR INTERVIEW

You might encounter a participant who wants someone else to be present while filling out the survey. Perhaps they have a young child and need to bring them to their visit, maybe English/French is not their first language and they'd like their friend present to help translate, or perhaps they want a partner or other family member present for support. However, given the nature of the survey and our commitment to confidentiality and safety of participants and PRAs, it is CHIWOS policy to strive to do the interview 1-on-1. In cases where a participant requests that someone else be present:

Before scheduling or beginning the interview, let the participant know about the nature of the survey. Inform them about its length (2 hours) and the personal and sensitive topics to be covered (e.g., demographics, sexual health, reproductive, mental health, violence). Because of this, we would prefer to do the interview 1-on-1. Then we suggest the following steps depending on the companion involved:

If it's a child: Try rescheduling the interview for a better date/time.

If it's a support person: Suggest that the person be close by but not in the interview room (e.g., in a chair outside the office).

If it's a person there to help with translation: You can allow this person into the room, but care must be taken.

After this initial discussion, if you and the participant are both comfortable with their companion being present, then it's okay to proceed with the interview. However, for any person that you do allow to stay in the room, be sure to take the following precautions during the consent and throughout the survey:

Remind participants that this companion will hear the stories shared.

Tell them that unless you are told otherwise, you will assume that their companions may hear the discussion.

Inform them that they do not have to answer any questions that may make them feel uncomfortable and they can pause or stop the interview (and res-schedule) at any time.

Introduce each section in advance (e.g., "Now, we're moving onto to questions that deal with emotional health") so that they have an opportunity to proceed as normal or to ask their companion to leave the room.

Take extra precaution with the information that you decide to self-disclose.

If at any time, you feel uncomfortable or unsafe, stop the interview and re-schedule.

1.9: PARTICIPANT IS PROVIDING FALSE OR CONTRADICTIONARY RESPONSES TO THE SURVEY

Imagine, in an interview, a participant shares information that you know or highly suspect is untrue. Perhaps the participant says they haven't had a smoke in the last month, but you think you smell cigarettes on their breath. Your response may depend on whether the participant is a close friend or an acquaintance/stranger. However, in general, as an interviewer, it is important to remain neutral, maintain trust and rapport, and not question or confront people about their responses. All you should do is say things throughout the process to help them feel comfortable and confident in sharing accurate information (e.g., "everything you say will remain confidential", "you don't have to answer anything that makes you feel uncomfortable", "think carefully about the response options and choose the one that you think is most accurate", etc).

Imagine a participant provides responses to the survey that are contradictory. For example, when asked “do you use condoms?”, they say “all the time”, but when asked “if they used a condom the most recent time they engaged in sex”, they said “no”. What would you do? The first thing to know is that we have programmed the survey to detect some of these contradictory responses (mostly questions pertaining to dates) – so, if this happens, an error message might pop up indicating that their answer to these two questions must be similar. However, it was impossible to program all contradictory responses. So if you think two responses might contradict and no error message has popped up, it’s okay to double-check with the participant that they have selected the right answer. For example, you could say: “I think you mentioned on the last question that you use condoms “all the time”, and in your most recent sexual encounter you said “no”. Do you want to take a moment to think about your responses to be sure you’re selecting the response options that you think are most accurate?”

1.10: PARTICIPANT ASKS INTERVIEWER FOR THEIR OPINION

What if the participant asks you if their response is “right” or if they answered “correctly”? Or what if the participant asks you what their opinion is of one of their responses? What might you do? As an interviewer, your job is to capture the participant’s stories/perspectives, not your own, and to remain neutral to what is being shared. Therefore, we’d advise you to NOT say whether their response is “right” and to NOT provide your opinion. Maybe you can say: “There is no right or wrong answer. My opinion doesn’t matter. What matters is that you’ve thought carefully about the response options and chosen the one that you think is most accurately tells your story. Shall we read the question again?”

1.11: PARTICIPANT CHANGES MIND ABOUT SHARING INFO AFTER COMPLETING SURVEY

Imagine the participant consents to participate in the study. They provide you with their personal contact information and they complete the survey. Afterwards, they change their mind about participating and sharing all this information and they want to withdraw from the study. Also perhaps they told you this right away or maybe after they left the site. In either case, let them know that that is okay – they are free to withdraw from the study at anytime. Then, tell them that you will follow-up with the coordinator to inform them of the situation and the coordinator will destroy (e.g., delete or shred) all study materials on file for this participant. If the participant did complete the survey (even if she doesn’t want it to be shared), you should still give the participant her honorarium.

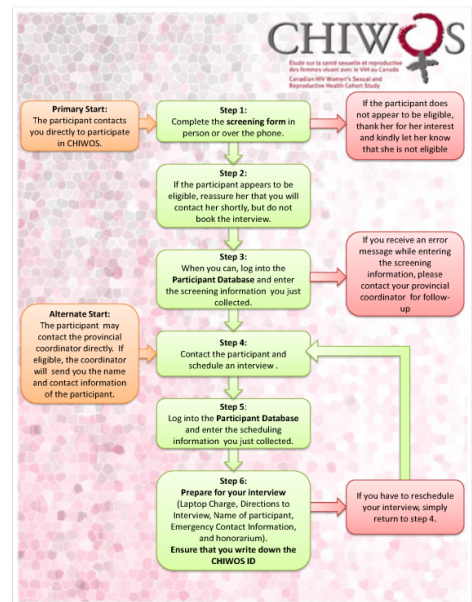
1.12: PARTICIPANT IS USING SLANG DRUG TERMS AND YOU DON'T KNOW THEIR MEANING

A participant may use slang drug terms during the “substance use” section of the survey. We anticipated that and included those slang terms in the survey. Below is the list of drugs that appears in the survey, with slang terms in brackets. If they use another term that’s not listed, simply ask them: “Is there another name for that?” or “Do you see that drug on this list?”.

Heroin (dust, horse, junk, down, or downtown)	Morphine
Heroin + Cocaine (speedballs)	Talwin & Ritalin ("T's & R's")
Cocaine alone (non-injected) (uptown, up)	T3s T4s (codeine)
Crack	Ecstasy (x-tasy, E, X)
Methamphetamine (crystal meth, ice, jib, gak)	MDA
Benzodiazepines	Speed (amphetamines, uppers)
Dilaudid (hydromorphone hydrochloride)	Acid (LSD, PCP, angel dust)
Oxycontin/Oxycodone	Mushrooms (magic mushrooms, mush)
Methadone	

1.13: YOU SUSPECT PARTICIPANT HAS ALREADY COMPLETED SURVEY

We have developed a series of steps that must be completed prior to scheduling an interview (see picture of flow-cart below). In step 3, you may discover that the participant is already in our database – in this case, contact the Coordinator who will follow-up with the participant. If they give a false name and thus do not appear to be in the database, but you still suspect they may have completed the survey, still do the interview. Afterwards, let the Coordinator know so that they can flag this interview for data-quality checks.



1.14: PARTICIPANT WANTS TO COMPLETE THE SURVEY BUT NOT WITH A PRA

Given our commitment to CBR and GIPA principles, we plan to prioritize having the PRA administer the survey. However, we recognize that this approach may not always be possible. For example, there may be women who do not want to be interviewed by a peer. In these cases, we can offer the participant an alternative (e.g., they can complete the survey with the Coordinator). However, the survey is NOT to be self-administered for data quality reasons.

1.15: PARTICIPANT HAS LANGUAGE / COMPREHENSION ISSUES

There may be cases where English/French is not the participant's first language or they have reading / comprehension issues. CHIWOS is committed to including women who have diverse backgrounds and who may be marginalized from research. Thus, we welcome their inclusion and suggest the following strategies to support them in the interview process:

Consider scheduling the interview when you have more time available (the survey may take longer if the participant has language/comprehension issues)

Check to see if there is a translator at the clinic or organization where you are based who may be able to assist

Ask the participant if they have a family member or friend who speaks both their native language and English or French and may be willing to attend the interview for translation support

1.16: PARTICIPANT IS DOING A LOT OF STORY-TELLING OR ASKING A LOT OF QUESTIONS

You'll find the interview process is more than just sitting down and asking survey questions. It can actually feel like a conversation between two people, where stories are told and information shared. While it is important to allow for this type of conversation to happen, it is also important to be aware of your own time and that of the participants. You'll have to use your discretion for when to stop and chat, and when to move on. It'll be a bit of a balancing act or dance. If participant is sharing a lot of stories and you're concerned about time, you might say "I really want to hear this story. But I'm just conscious of time and that we have a few more questions to get through. How about we chat more at the end of the interview if there's still time?" Or alternatively, if the participant is asking a lot of questions or their seeking more information on one of the topics covered (e.g., pap tests), you might be able to answer some quick questions on the spot, but you can also remind the participant that you can discuss this at the end of the interview and provide the appropriate referrals for her questions.

SECTION 2: SAFETY-RELATED SCENARIOS

2.0: SAFETY-RELATED SCENARIOS

2.1: PARTICIPANT IS LOOKING AROUND FOR THINGS TO STEAL

It's best to do all that you can to prevent theft from happening in the first place. Here are some tips to help minimize the chances:

Leave valuables at home. Keep expensive items—especially those with nostalgic value that you can't replace—at home. Also, keep a slim wallet, taking only the items you need and leaving items, such as your Social Security card, at home.

Take only what you need. Refer to the checklist of what you need to bring with you (e.g., computer and power cord, pen and paper, etc). Only take those items that you need and leave everything else at home.

Keep the desk/office clean and clear: Put or lock away everything you don't need. Store things in a desk drawer or put items in a locker, so that they are out-of-sight and hopefully out-of-mind.

Don't leave items unattended. You might spend plenty of time at the interview office and might be tempted to leave your belongings unattended at times. Resist the urge. If you look away or leave your desk/office without locking the door, a participant or a stranger walking by might nab your purse, phone, cash honoraria study computer, or anything else of value. Keep things on you at all times. Maybe even keep the cash honorarium in your pocket.

Keep study materials and documents in a safe place. Consent forms, cash honoraria, receipt logs, computers and any other study materials/documents should be stored in a safe place, such as a locked drawer.

Be careful about online information. Make sure to create strong passwords for your computer and accounts, and do not share these passwords with anyone else. If you need to access personal accounts such as email on the study computer, you must log in to the 'Guest' account (do NOT use the CHIWOS account for personal use). Also, a participant may ask to use your computer for a minute to look something up – this is NOT allowed, as the computer contains confidential information.

If something is stolen, don't panic! The most important thing is your safety! If the theft is major (e.g., computer stolen): (1) stay calm, (2) inform on-site security and Executive Director of the organization (3) phone the police, and lastly (4) call the coordinator to let them know what happened.

2.2: PARTICIPANT IS DRUNK OR HIGH

There are several different signs/signals that may suggest that a participant is high and they vary depending on the type of drug used. In general, here are some signs / signals that someone may be drunk:

Lower inhibitions/caution

Lowered reasoning ability

Staggering walk or inability to walk / Weakened balance

Slurred speech; too-loud or too-fast speech

Glossy appearance to eyes

Slower reaction times

Slower pupil response. After more drinks: pupils constricted.

Nausea and vomiting

Loss of consciousness

Smell of alcohol on the person

There are several different signs/signals that may suggest that a participant is high and they vary depending on the type of drug used. In general, here are some signs / signals that someone may be high:

Lowered ability to focus on the conversation/pay attention

Picking on their skin (e.g., looking for bugs/worms)

Nodding off (→ methadone or heroin)

Pupils dilated

Profusely sweating (-> jib)

Uncontrollable actions (all over the place)

Wild look in their eyes / can't keep their eyes focused

Please note, sometimes these symptoms can be actually be sign of a health issue (weak, fainting, on medication), so it is important not to judge. Ask the person if they are OK, or if they need help.

If you notice that a participant is drunk or high at the start of the interview during the consent process, do not begin the interview. Explain to the participant that the survey questions are quite sensitive /

personal and may even be triggering, so it is important that the participant fully understands what they're signing up for. If they're drunk or high, their reasoning and judgment is likely impaired, making it impossible for them to give informed consent. Ask the participant if they'd like to re-schedule the interview at a time when they're able to give consent.

What if you consent the participant and start the survey, and only notice that they are drunk or high half way into the interview process? You will have to use your discretion. Every situation can be different. Sometimes it's okay – e.g., only mildly impaired so can keep going. But if it's a data quality issue, for whatever reason (including distracted or sleepy because of methadone), then it would be best to take a break, or end and re-schedule the interview. This is the preferred strategy but will depend on the situation (e.g., participant may resolutely deny being under the influence and insist that the interview be completed at the current sitting). Move to safety protocols (e.g., Walk to and open door, saying "I'm sorry. I'm going to have to end the interview.>").

2.3: PARTICIPANT IS ANGRY AND YELLING AT YOU

If a participant is angry or yelling at you, your response may vary depending on the situation (e.g., is this a stranger or a friend? If they are the clearly aggressive and hostile or they are upset and unaware that they're yelling?). If this happens, here's some advice to help you navigate the situation:

Open door – may diffuse situation because people will hear

Recognize their feelings and try to diffuse things: For example, try saying: "I'm sorry, it seems like something has really triggered you hear. Do you want to take a break?"

(If they persist...) Ask them to stop: If someone is yelling they might be so upset they are unaware of what they're doing. Asking them to stop not only lets them know you wish them to stop, but it also alerts them to their own behavior.

(If they don't stop or calm down) Ask them to leave: Walk to the door, open it, and speak loudly "I'm sorry. This is not a good time. We're going to have to end the interview. I'd like you to leave now" so that others in the office can hear.

Walk/run away: If they refuse to leave, walk away yourself. In order to be able to do this, you should always try to position yourself closest to the door.

Call 9-1-1

Get help from someone in the clinic (e.g., security, support worker, Executive Director)

Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.

Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).

Remember: Your personal safety is ALWAYS more important than an interview, laptop, or \$50.

2.4: PARTICIPANT IS GETTING PHYSICALLY AGGRESSIVE

If anger and yelling turns to physically aggressive behavior, here's what you can do about it:

Respond quickly

Walk/run away

Scream for help

Call 9-1-1

Get help from someone in the clinic (e.g., security, support worker, Executive Director)

Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.

Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).

Remember: Your personal safety is ALWAYS more important than an interview, laptop, or \$50.

2.5: PARTICIPANT IS TRIGGERED/UPSET AND STARTS CRYING

Imagine the following scenario. You are interviewing a participant who becomes emotionally triggered by one of the survey questions and begins to cry. How might you handle the situation? The answer is: it depends. Every participant may deal with sadness differently depending on their culture, values, self care practices, inner being, etc. Ask them what they need. Maybe they need a tissue, a hug, or a break. Perhaps they would like to cry it out with no interruptions, or maybe enjoy some laughter/jokes to take their mind off of it. Maybe they'd like to pause the interview and re-schedule it for another day, or maybe they want to try and plow through it. Try to be observant and tailor your response depending the person and situation. Also, be sure to spend some time at the end of the interview debriefing / checking in, and provide them the resource list so they know who to call if they want to debrief further. Also remind them that they can call the on call counsellor at any point of time a week after the appointment if they need someone to talk to right away. Bring tissues with you to each interview.

Note: For women of Aboriginal ancestry: Valerie advises to not touch or hug them, unless they initiate it. Also, let them cry it out with no interruptions (this is a part of the recovery/healing process). When they have finished crying / talking, ask them if they need anything.

2.6: YOU, THE INTERVIEWER, ARE TRIGGERED/UPSET AND STARTS CRYING

Now, imagine you are interviewing a participant and you are the one who becomes emotionally triggered and begins to cry. How might you handle this situation? Again, it may depend on the situation and your own coping strategies. Feel free to ask if they don't mind if you take a break. If you feel like you need to re-schedule, that's okay too. Afterwards, be sure to follow-up with a peer, coordinator or other person for debriefing and support. You can also call the on call counsellor at any point in time if you need to talk.

2.7: YOU AND/OR THE PARTICIPANT ARE VERY TIRED

If you and/or the participant are feeling very tired, consider taking a break. A good stretch, fresh air, or a beverage (e.g., coffee, tea or water) might help. If the interview has been particularly long and draining, discuss re-scheduling for another day.

2.8: PARTICIPANT MAKES YOU FEEL UNCOMFORTABLE WITH ADVANCES/COMMENTS

If the participant hits on you or makes you feel uncomfortable with certain advances or comments, here's some suggestions about what you can do about it:

Let them know that you feel uncomfortable

Ask them to stop

End the interview and ask them to leave

Get help from someone in the clinic (e.g., security, support worker, Executive Director)

Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.

Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).

Remember: Your personal safety is ALWAYS more important than an interview, laptop, or \$50.