Making It Work:

Supporting Indigenous, Community Approaches to Integrated Service Models for People Living with HIV, Hepatitis C and/or challenges with mental health or substance use

Knowledge Exchange and Authorship Guidelines

These guidelines are intended to help support decision-making around sharing findings or information from the Making It Work research project including designating roles and responsibilities and/or the assignment of authorship. As with all Making It Work study operations, these guidelines intend to prioritize Indigenous Ways of Knowing and Doing and highlight our commitment to finding ways of sharing knowledge that are consistent with cultural values and perspectives (Cochran et al., 2008; Kincheloe & Steinberg, 2008; Simonds & Christopher, 2013).

Our approach to community-based research (CBR) is rooted in the understanding that community must drive research, be actively engaged throughout the entire research process, and directly benefit from knowledge generated through CBR. We work to centre values that support empowerment and cultural safety through CBR; we aim to foster trust, transparency, and long-lasting relationships with all partners. (REACH 2.0, n.d.) Given that this project was conceived of and supported by our community partners, we will take our direction from these partners in how they want information shared. Research staff and academics within the Making It Work study team are working to support the knowledge generation needs of these community partners. The guidelines we outline here are meant to affirm our commitment to participatory methods during knowledge exchange, however, we also want to acknowledge our flexibility and willingness to adapt our approach to include creative methods of knowledge sharing as long as they are consistent with the following key principles:

- Ownership and control is held by the community that shared their stories and consent to use this data can be refused.

- Results will first be presented to community partners ahead of any publication or public sharing of results. We will also follow local protocols to share draft results with the appropriate bodies within the community. For example, the Ktunaxa Nation's Code of Ethics for Research (1998) states "Researchers have an obligation to provide the Elders Group, the Ktunaxa Treaty Council and the KKTC [Ktunaxa/Kinbasket Tribal Council] with an opportunity to review the research results and provide comments before the final product is completed." (page 3).

- Results will be presented in formats that are accessible, useful and culturally appropriate to stakeholders in oral, visual and/or written material as appropriate. We will seek guidance from the community to determine strategies that would work best in their community.

- Research product development will be a collaborative process and involve the meaningful participation of team members including Indigenous community members, and people with lived experience of HIV, hepatitis C, and/or challenges with mental health or substance use.

- Research products will answer questions that are relevant and beneficial to the community.

- Knowledge exchange will emphasize an integrated KT approach, where stakeholders are engaged as the research progresses, and not solely at the end of the project.

- Language will be used to communicate in an accessible and responsible way to present a balanced picture, working wherever possible to emphasize resilience and strengths in the community avoiding focus on and sensationalizing problems (Canadian Aboriginal AIDS Network, 2013).

- Knowledge shared through this project will not be treated as found or newly created; rather, we will acknowledge that knowledge has been shared with us in a gradual uncovering, leading to deeper awareness and understanding (Smylie et al, 2014).

When authoring publications, the following guidelines will be used which follow the criteria for authorship developed by Huth (1986):

1. Participation must include three steps: (1) conception or design of the work represented by the article, or analysis and interpretation of the data, or both; (2) drafting the article or revising it for critically important content; (3) final approval of the version to be published;
2. Anyone assigned authorship should be engaged enough in the publication to be able to defend it publicly; and
3. That an individual who participates in only one of the steps, while having contributed to the work, should not receive authorship.

As cited by Canadian Aboriginal AIDS Network, 2013, page 3

Additionally, we subscribe to the following which has been described by the Canadian Aboriginal AIDS Network (2013):

- Research project staff and study team members (including people with lived experience and peer research associates) may participate as authors provided that they fulfill the criteria outlined above.

- Research team members who do not fulfill the authorship criteria listed above will be included in the acknowledgement section by name with their permission, or listed as "*part of the Making it Work Research Team*" if they do not want to be listed by name.

- All members of the study team will be provided the opportunity to review and comment on findings prior to publication or presentation.

- Members of the research may further analyse, publish or present findings resulting from the above-mentioned research project with the agreement of the [co-Principal Investigators] the other research team members and communities involved.

- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.

- A Research Team member may choose to include a disclaimer if they do not agree with the content or views presented in a publication.

- All publications based on research from a First Nation community will include a member of that community as an author (First Nations Innovations, 2012).

References

The following works were consulted in the crafting these guidelines.

Canadian Aboriginal AIDS Network. (2002). *Ownership, control, access and possession fact sheet.* Ottawa, ON: Canadian Aboriginal AIDS Network.

Canadian Aboriginal AIDS Network. (2013). Principles of Research Collaboration. Available from http://caan.ca/wp-content/uploads/2010/03/Principles-of-Research-Collaboration.doc

Cochran, P.A.L., Marshall, C.A., Garcia-Downing, C., Kendall, E., Cook D., McCubbin, L, *et al.* (2008.) Indigenous Ways of Knowing: Implications for Participatory Research and Community. *Am J Public Health*, 98:22–27.

First Nations Innovations. (2012). Publication Policy. Available from https://fn-innovation-pn.com/publication_policy.aspx.

Huth, E. (1985). Guidelines on authorship of medical papers. *American College of Physicians - Annals of Medicine, 104,* 269-274.

Jackson, R. & Masching, R. (2016). Knowledge translation in Indigenous communities: A review of the literature*. The Canadian Journal of Aboriginal Community-based HIV/AIDS Research*, 8.

Kahnawake Schools Diabetes Prevention Project. (2007). Code of Research Ethics. Available from http://www.ksdpp.org/media/ksdpp_code_of_research_ethics2007.pdf

Kincheloe, J.L., Steinberg, S.R. (2008). Indigenous knowledges in education: Complexities, dangers, and profound benefits. In: *Handbook of critical and indigenous methodologies*. Denzin NK, Lincoln YS, Smith LT (editors). Los Angeles, CA: SAGE Publications, pp. 135–156.

Ktunaxa Nation. (1998). Ktunaxa Nation's Code of Ethics for Research. Available from https://icwrn.uvic.ca/wp-content/uploads/2013/08/KKTC-Code-of-Ethics.pdf

Oikle, D. (2017). Indigenous KT and ways of knowing — what do they mean for public health? Available from http://nccdh.ca/blog/entry/indigenous-kt-and-ways-of-knowing-what-do-they-mean-for-public-health

Simonds, V.W., Christopher, S. (2013). Adapting Western Research Methods to Indigenous Ways of Knowing. *Am J Public Health*, 103:2185–2192.

Smylie, J., Olding, M., & Ziegler, C. (2014). Sharing What We Know about Living a Good Life: Indigenous Approaches to Knowledge Translation*. Journal of the Canadian Health Libraries Association*, 35, 16-23.

REACH 2.0 (n.d). Our CBR Principles. Available from http://www.reachprogramscience.ca/our-cbr-principles/