

Panel on Research Ethics
Secretariat on Responsible Conduct of Research
secretariat@srcr-scr.ca

October 8, 2021

VIA Email

RE: Feedback interpretation and implementation of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 (2018))

This letter outlines Hotiì ts'eeda's feedback on two documents related to the interpretation of the Tri-Council Policy Statement: *Ethical Conduct for Research Involving Humans* (TCPS 2 (2018)). More detail and examples are provided in the attached Hotiì ts'eeda report: *Efet'ànìts'eᓃah: Implementing UNDRIP in Health Progress Report*. Hotiì ts'eeda is the CIHR-funded Northwest Territories (NWT) SPOR SUPPORT Unit, hosted by the Tłı̄chq̄ Government. Hotiì ts'eeda supports health research, training and knowledge mobilization (KM) that is rooted in Indigenous knowledge and methodologies, and is responsive to the needs of patients. This includes support for Indigenous control and ownership of research, policy development, and knowledge mobilization.

Indigenous individuals and communities in the NWT face significant colonization impacts. Indigenous individuals, cultural knowledge holders, and technical experts in the NWT have emphasized a need for health and wellness programming rooted in Indigenous culture and values as necessary for rebuilding their Nations. Health and social determinants of health indicators in the NWT tell us that Indigenous peoples in the NWT experience significant health disparities compared to their non-Indigenous residents. The United Declaration on the Rights of Indigenous Peoples (UNDRIP) was drafted and developed by Indigenous people, legal experts and government officials across the globe for over 20 years and was adopted by the United Nations General Assembly in 2007.

Canada was one of the few states which did not immediately sign the declaration. In 2016 the Canadian government finally endorsed UNDRIP and made a commitment to its implementation. UNDRIP is an international declaration composed of 46 articles describing minimum standards for Indigenous human rights worldwide, for all governments and institutions to recognize and uphold. UNDRIP does not create a new set of human rights standards. UNDRIP affirms rights that are already set out in international human rights treaties. The UNDRIP articles provides a way to measure whether their laws and policies are upholding the human rights of Indigenous peoples.

Therefore, Hotiì ts'eeda has been working with Indigenous government organizations and health leaders in the NWT with an interest in helping design effective, culturally relevant guidelines for implementing UNDRIP in all health and wellness programming and research in the NWT. This

approach aligns with Hoti ts'eeda's vision of a health system rooted in Dene Naowo, Inuvialuit and Metis knowledge, responsive to patients, communities and governments.

We invite the panel to review the attached report in full as you consider TCPS 2 (2018). In particular, we draw your attention to *Table 1: UNDRIP articles and questions necessary to determine their implementation* (p. 24) and invite you to consider taking a similar approach to advise researchers of their roles and responsibilities with respect to ensuring UNDRIP is both considered and respected in the design and implementation of research. We note that there are specific UNDRIP articles that relate to consent (2, 18, 19, 26, 32), and would encourage the panel to consider how the minimum Indigenous human rights standards described in the articles are accommodated and reflected in the TCPS and its interpretation and implementation documents.

With specific reference to the multi-Jurisdictional theme, we encourage the panel to further clarify the issue of multi-jurisdictional situations from the perspective of research partners, in this case Indigenous individuals and governments, and not just researchers and eligible institutions. This is an issue in Indigenous communities, including those with Modern Treaties (Comprehensive Land Claim, and/or Self Government Agreements). In these situations, researchers and Research Ethics Boards (REBs) will need to navigate Indigenous government jurisdiction, policies, and protocols, as well as territorial/provincial and federal requirements. The REB alone may not have sufficient authority and/or credibility within an Indigenous community or within a settlement area to enable a researcher to move forward in a culturally safe manner. REBs, as well as researchers, need guidance to navigate these situations. Using UNDRIP as the framework for issuing guidance in these situations will be helpful, but we also caution that individual communities may interpret and implement UNDRIP uniquely. In addition, Modern Treaty holders may have laws, regulations, and/or policies and protocols that apply in their geographic areas of authority. Guidance on this topic should encourage reflection on the spirit and intent of UNDRIP, rather than a set of rules. We invite you consider the guidelines, especially "Reciprocal Accountability" (p. 22) and "Relationship" (pp. 22-23) in *Elet'anits'eah: Implementing UNDRIP in Health Progress Report*, particularly with respect to the Ethics Review of Multi-Jurisdictional Research – Proposed Revised Guidance, and thinking of 'funders' (as referenced in the *Progress Report*) as researchers.

With respect to the Proposed Guidance Regarding Broad Consent for the Storage and Use of Data and Human Biological Materials, we encourage the panel to reflect on and reference the principles of ownership, control, access, and possession (OCAP). The principles assert Indigenous peoples' control over data collection processes, and ownership and control over the resultant information. This principle should be specifically referenced in the TCPS 2 (2018) Guidelines. This would also align with the spirit and intent of UNDRIP.

We suggest that a way for TCPS 2 (2018) to reflect and honour UNDRIP would be a series of questions encouraging deep reflection on the part of researchers, institutions, and REBs to really consider if their work is honouring UNDRIP with respect to the issues mentioned above, and others.

Finally, we caution the Panel on Research Ethics and Secretariat on Responsible Conduct of Research against viewing UNDRIP articles as independent parts – rather they must be considered as a whole and integrated into the TCPS 2 (2018) as a whole as well. We invite you to review the attached *E̱et'̀nits'e̱ah: Implementing UNDRIP in Health Progress Report* for more detail, including background and guidance on implementing UNDRIP in health and wellness research and programming.

Mahsi,



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Attachments (1)