



First Nations Health Authority
Health through wellness

First Nations Data Governance Discussion Sheet

Research Ethics

Acknowledging a history of unethical or culturally inappropriate research practices in First Nations communities by outside researchers, research ethics requirements have emerged as an essential element in creating meaningful partnerships between researchers and First Nations communities. Examples from BC include, but are not limited to, research collaboration protocols or policies developed by Nuu-chah-nulth Tribal Council, Secwepemc Health Caucus, Ktunaxa Nation, and Intertribal Health Authority.

We have heard concerns from communities about research fatigue. As such, FNHA aims to support community-driven research, acknowledging that research is only as meaningful and relevant as it is useful to communities. The FNHA will describe its approach to developing an FNHA Research Ethics Framework, with the ultimate vision that research is done by us, for us. The Framework will be guided by the shared Seven Directives as a common vision of the values to which research must adhere. It will serve as the foundation for the governance and administration of research ethics approval at the FNHA.

To promote community ownership over the research process and more culturally relevant findings, a key question that will be asked is: How would you like to see culture and traditional knowledge included in research?

Wellness Indicators

Health reporting, from a conventional western perspective, is primarily disease focused and deficit based. We have heard from communities the need for wellness indicators developed by First Nations that reflect strength-based measures of wellness that are meaningful and relevant to First Nations in BC.

Wellness indicators will support self-determination by giving First Nations control over deciding what constitutes evidence of wellness, how that wellness is measured, and how the information will be used. Wellness indicators will be developed and driven by communities which will feed into global outcomes for the reporting process by the FNHA.

Identity Management

Have you ever had difficulties accessing your medical history at point of care?

This topic is focused on First Nations having access to accurate health information and to effectively govern that information to make decisions.

Having First Nations individuals properly identified in provincial or regional health systems is crucial for:

- First Nations individuals to have access to their up-to-date health records at point of care
- FNHA, Health Authorities and other service organizations to deliver effective services at point of care based on up-to-date patient information
- First Nations in BC to draw an accurate picture of health and wellness of themselves over time for program and service planning and transformation

First Nations people currently cannot be readily identified in provincial or regional health systems, with a few exceptions where First Nations identity is determined in a variety of different ways (e.g. self-identification or linkage with the “Indian Registry”).

Having a ‘source of truth’ for First Nations identity, is the basis for effective program planning and service delivery to improve on First Nations health. Robust structures to govern and manage data will help First Nations to achieve and exercise their inherent right for self-determination.

For more information, visit us online:

www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation

or email: RKEE@fnha.ca

