First Nations Health Authority
Health through wellness

Research Ethics Framework

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Introductions

- **Find someone at another table you haven't met before.**
- **Find one thing you have in common.**

Outline

1. What we've heard from you
2. Why do research and research ethics matter?
3. What can Community-Driven research look like?
4. FNHA Research Ethics Framework: Background
   - *Seeking consistency with BC First Nations standards*
5. Research Ethics Framework: Engagement
   - *What do you think of the Framework?*
6. Research provides benefits that outweigh potential risks
   - *Further exploration of this principle*

Research and Ethics

Research

- A journey of coming to know something more through observing, experiencing, and interpreting.

Research ethics

- Research is carried out in a way that ensures the rights and safety of participants and communities.
- First Nations control and decision making in research.

What we've heard from you

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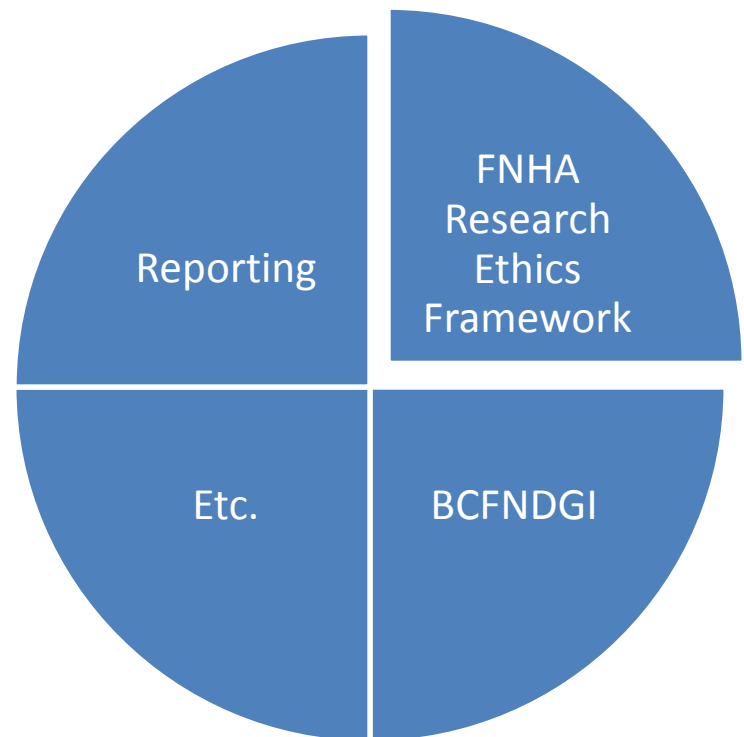
www.fnha.ca

Why do research ethics matter?

Research For Cultural Renewal

- "If we have been researched to death…maybe it's time we started researching ourselves back to life"

- No longer a "*smash and grab*" (Cleary, 2103, .p. 13) or "data and dash"

- For example, "*culturally rooted research can contribute to Indigenous wellness and cultural renewal by bringing awareness to the link between colonialism and addiction by actively re-centering an Indigenous worldview and governance in the research process*" (Hall, Dell, Fornssler, Hopkins, & Mushquash (2015, p. 4)

FNHA Research Ethics Framework: Mandate

- ▪ Tripartite Framework Agreement (2011).
- ▪ Consensus Papers (2011 and 2012).
- ▪ Mandate includes research and policy development.

- ▪ Highest standards of privacy, security, and ethics, as set by BC First Nations in the 7 Directives.
- ▪ Looking for input on how we've applied ethical principles in relation to the 7 Directives.

Reporting

FNHA Research Ethics Framework

Etc.

BCFNDGI

What can Community-Driven research look like?

- Community Advisory Council (CAC)- Heiltsuk Cultural Education Centre, Hailika'as Heiltsuk Health Centre, R. W. Large Memorial Hospital, and Heiltsuk College.
- Research Agreement – CAC authority to stop or change study.
- Community-based Research Assistant.
- CAC involved in interpretation of data, co-authors, approved publications.

Alienation and Resilience: The Dynamics of Birth Outside Their Community for Rural First Nations Women.

Regional Health Survey

First Nations Regional Health Survey

FNHA Ethics Framework: Purpose

- First Nations decision making and control over health information and research.

- Vision of a BC First Nations approach to the ethical conduct of research.

- A guide for information collection, analysis, reporting at FNHA.

- Framework will direct the policies and procedures for the governance and administration of research ethics approval at FNHA.

- Is the research following community protocols? Have communities agreed to this study?

- "Community" - First Nations community, and First Nations or Aboriginal organization, population, or community of interest involved in the research project.

Framework development

2012

Secwepemc Health Caucus

Drafted by: Hub Coordinator

Reviewed by:
Secwepemc Health Caucus
Adopted:

October 18th, 2012
Reviewed/Updated:
_____, 20___

SECWEPEMC HEALTH CAUC...
RESEARCH POLICY

Working for Health Excellence for the Secwepemc Nations Members

Ktunaxa Nation's Code of Ethics for Research
(adopted November 1998)

PURPOSE

1. The purpose of this Code is to ensure that, in all research that involves or relates to the Ktunaxa Nation, the Ktunaxa Nation is able to protect its people, culture and history and to ensure that appropriate respect is given to them.

APPLICATION

2. This Code applies to all persons conducting research projects that relate to the Ktunaxa Nation, including its treaty negotiations, who wish to consult with members of the Ktunaxa Nation and use their oral history, cultural heritage resources, the Traditional Use Study Library, the Ktunaxa Nation archives or other cultural information. This Code applies equally to researchers working on behalf of the Ktunaxa Treaty Council and to those working for other groups, agencies or organizations both within and outside the Ktunaxa Nation.

PRINCIPLES

3. Researchers must familiarize themselves with the Ktunaxa/Kinbasket Tribal Council (KKTC), the Ktunaxa Treaty Council, the Elders Group and the KKTC's member bands and observe their respective governing rules and protocols concerning communications within the community, such as approaches required to access the relevant information and knowledge.

4. All requests for information, use of cultural heritage resources, use of the Traditional Use Study Library and the KKTC library, resources and interviews with community members or groups must be addressed in writing to the Ktunaxa Treaty Council Administrator or another individual designated by the Ktunaxa Treaty Council. The request must set out the aims, scope and anticipated results of the research project, including the potential impacts and any possible risks. The Administrator or other designated individual will provide details of the request to the Elders Group, the Ktunaxa Treaty Council, the KKTC and any other appropriate group or person for their review. After receiving any comments and advice from the Ktunaxa Treaty Council, the KKTC and any other group or person who has been requested to provide advice, the Elders Group will approve or deny the request. *(Note: Cultural heritage resources include moveable heritage resources, sacred or heritage sites and documentary heritage resources.)*

5. If approval is given by the Elders Group for the research project to proceed, researchers

November 1998

PROTOCOLS & PRINCIPLES FOR CONDUCTING RESEARCH IN A NUU-CHAH-NULTH CONTEXT

...uu-chah-nulth Tribal Council
...search Ethics Committee

...gust 2008

Interpretation of the Framework

- The nature of research is complex, relationship-based.
- Not a checklist exercise.
- Practices offered as *examples*. Can vary depending on community protocols and nature of project.
- Principles and practices touch on multiple Directives.

FNHA Research Ethics Framework

Directive 1	Community-Driven, Nation-Based

- Communities are involved as partners throughout all stages of research.

Directive 2	Increase First Nations Decision-Making and Control

- OCAP® - Ownership, Control, Access, and Possession.

Directive 3	Improve Services

- Research is beneficial and relevant to communities' needs.

Directive 4	Foster Meaningful Collaboration and Partnership

- Cultural humility and safety.

Directive 5	Develop Human and Economic Capacity

- Capacity strengthening - local PI, research coordinators, etc.

Directive 6	Be Without Prejudice to First Nations Interests

- Researchers understand Aboriginal rights and title.

Directive 7	Function at a High Operational Standard

- TCPS2 – Tri Council Policy Statement on the Ethical Conduct of Research

Discussion: Research Ethics Framework

- What do you think of the principles? Other ethics values or wellness-based principles to add?

Discussion: FNHA Research Ethics Framework

FNHA Directives	Directives Applied to Research Ethics Principles
Directive #1: Community-Driven, Nation-Based	• Communities partners throughout all stages of research. • Communities agree to research based on whichever principles or practices communities choose.

Discussion: FNHA Research Ethics Framework

FNHA Directives	Directives Applied to Research Ethics Principles
Directive #2: Increase First Nations Decision-Making and Control	• Research is guided by OCAP® principles. • Agreement on ownership of data. • Data storage, security, and access. • Confidentiality. • Protection of sacred knowledge and traditions.

Discussion: FNHA Research Ethics Framework

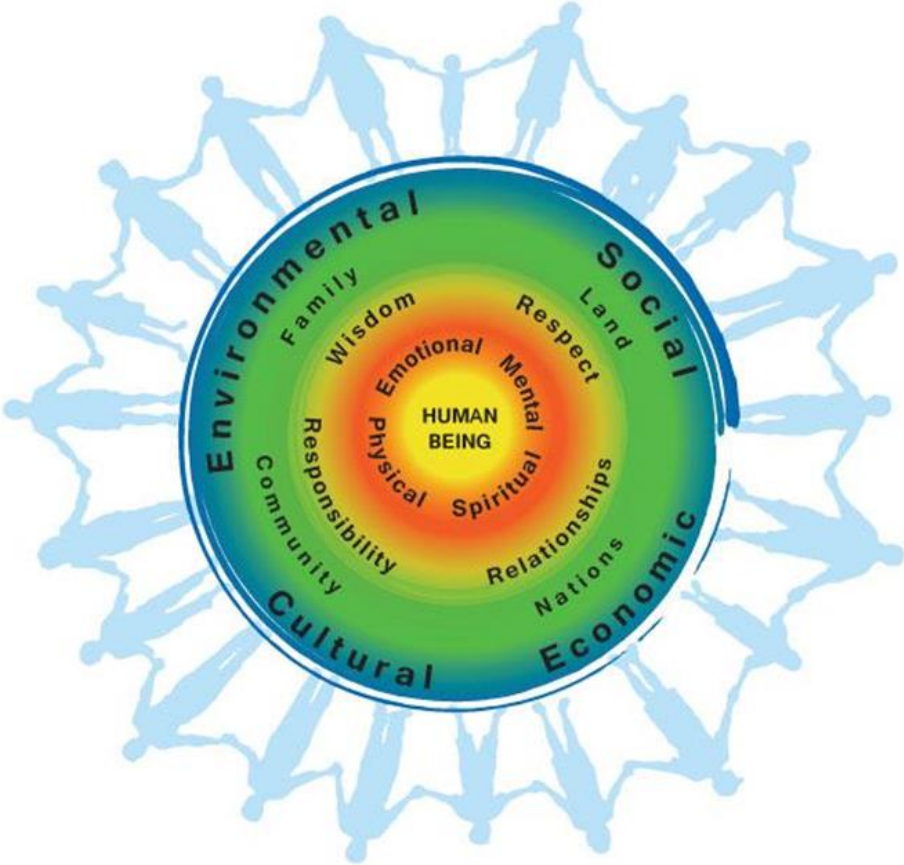| FNHA Directives	Directives Applied to Research Ethics Principles
Directive #3: Improve Services	• Research is beneficial and relevant to community information and research needs. • Knowledge exchange.

Discussion: FNHA Research Ethics Framework

FNHA Directives	Directives Applied to Research Ethics Principles
Directive #4: Foster Meaningful Collaboration and Partnership	• Meaningful collaboration and partnership in research. • Cultural humility and safety.

Wellness break

Discussion: FNHA Research Ethics Framework

FNHA Directives	Directives Applied to Research Ethics Principles
Directive #5: Develop Human and Economic Capacity	Research capacity is strengthened in communities.

Discussion: FNHA Research Ethics Framework

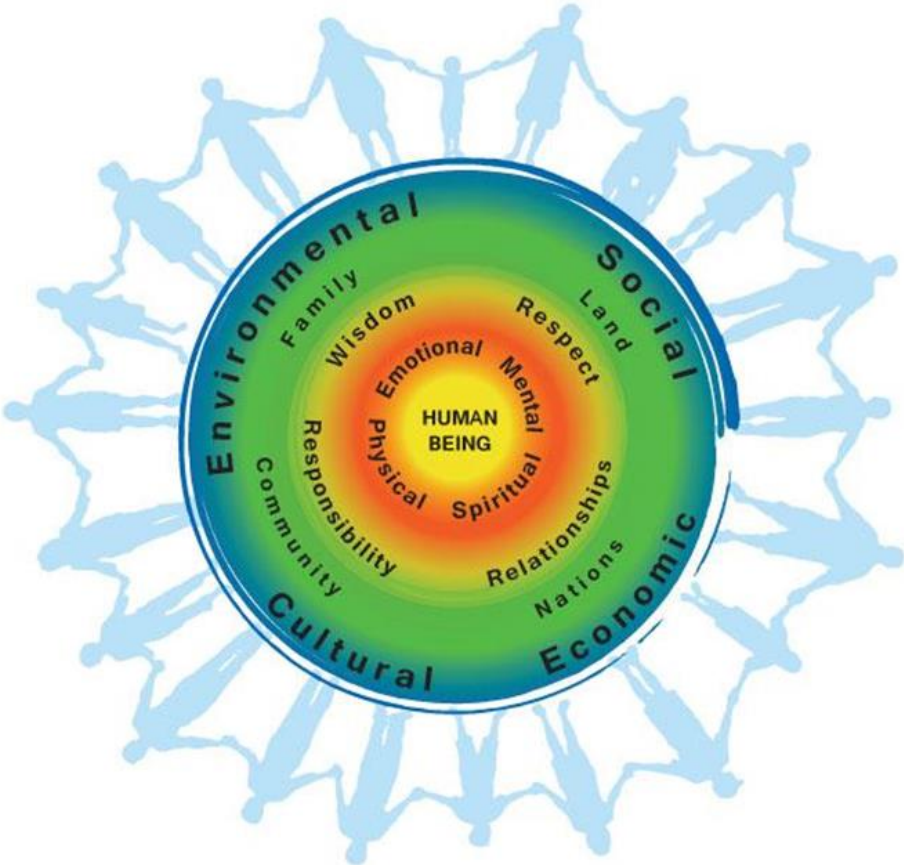| FNHA Directives	Directives Applied to Research Ethics Principles
Directive #6: Be Without Prejudice to First Nations Interests	Researchers understand Indigenous rights and title. Researchers recognize that the communities are the rightful owners and carry full authority to govern their territories.

Discussion: FNHA Research Ethics Framework

FNHA Directives	Directives Applied to Research Ethics Principles
Directive #7: Function at a High Operational Standard	Power and privilege. TCPS2: Respect for Persons, Concern for Welfare, and Justice. Research provides benefits that outweigh potential risks.

Wellness break

Research provides benefits that outweigh potential risks

- The dynamics of research relationships may pose risk or vulnerable circumstances for participants.

- The research ethics framework provides principles and practices that aim to ensure:

  - Benefits of research outweigh risks.

  - Safety and security, especially for those who need more support and protection.

Who needs more support and protection?

EXAMPLE Circumstances:

Situations

- **Poverty-** incentives shouldn't be too high. May cause participant to overlook potential risk
- **Poor health-** recruit participants that are in good health, so participants aren't tempted to overlook risks due to desperate health situation
- **Negative research experiences-** have a Community Advisory Council that is carefully involved in all stages of research.

Who needs more support and protection?

EXAMPLE Circumstances:

Relationships

- Patient and doctor is the researcher- have an objective third party recruit patients. Assure patients that their decision to participate will not affect the provision of health care in any way.

- Employees and employer is the researcher- ensure anonymous feedback and privacy of information, so there are no repercussions for participating

- Students and teacher is the research

Who needs more support and protection?

EXAMPLE Circumstances:

Individual circumstances

- Age- consent from authorized third party
- Mental health- onsite counsellor or 1-800 help line
- Language- translators available to support those who only speak Traditional languages.

Examples: Security & Safety Conditions

- Research agreement between the community and researcher.
- Clinical &/or community support(s) following research participation.
  - E.g. 1-800 Help Line or onsite counseling.
- Application includes questions on the resources dedicated to these conditions.
- Annual reports monitoring of researcher accountability to research agreement.

How much support and protection based on the circumstances?

Research project objective: A survey of adults on their daily fruit and vegetable intake.

- General Canadian Population

A. Low
B. Medium
C. High

How much support and protection based on the circumstances?

Research project objective: A survey of adults on their daily fruit and vegetable intake.
- First Nations individuals in BC

A. Low
B. Medium
C. High

How much support and protection based on the circumstances?

Research project objective: A survey of adults on their daily fruit and vegetable intake.

- Residential school survivors

A. Low
B. Medium
C. High

How much support and protection based on the circumstances?

Research project objective: A survey of adults on their knowledge of the residential school system.

- General Canadian Population

A. Low
B. Medium
C. High

How much support and protection based on the circumstances?

Research project objective: A survey of adults on their knowledge of the residential school system.

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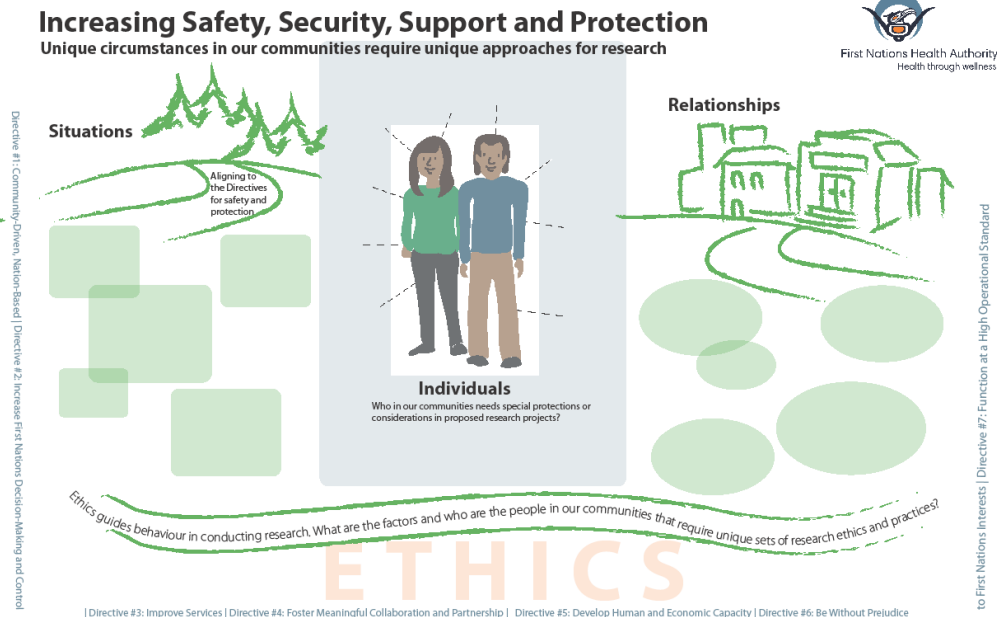
A. Low
B. Medium
C. High

Discussion: How do you want your community members to be kept safe and secure in research?

- **<u>Situations</u>** (e.g. negative research experiences)
- **<u>Relationships</u>** (e.g. patients, employees, students)
- **<u>Individual circumstances</u>** (e.g. age, mental health, language)
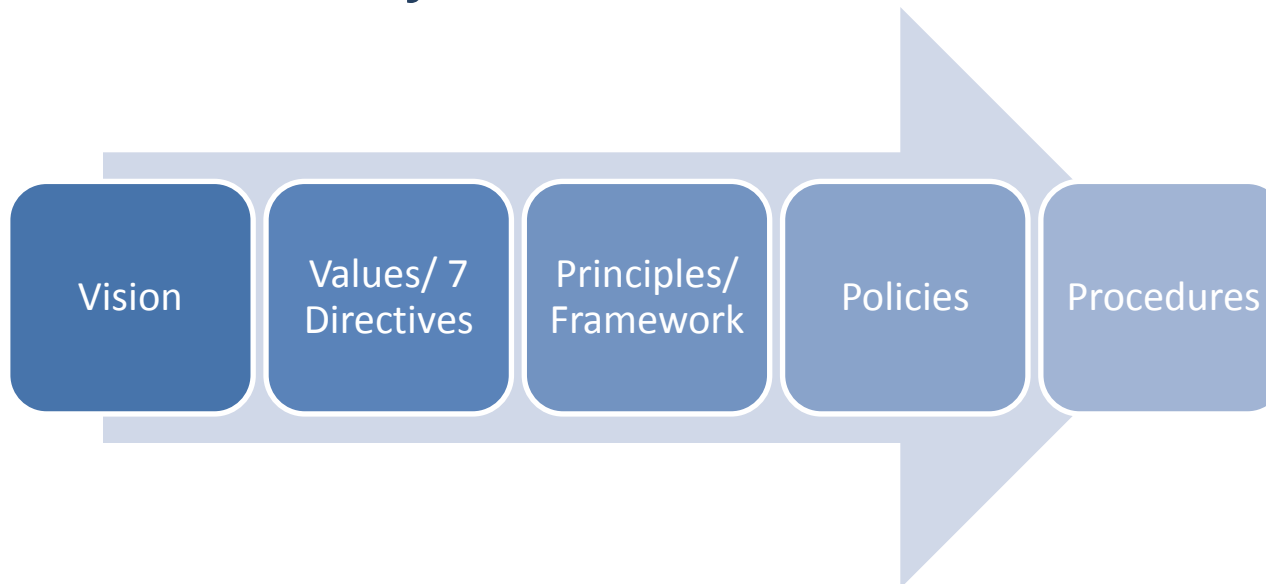
Example safety and security:
- Onsite counseling or other supports.
- 1-800 Help Line.
- Budget dedicated to safety conditions.
- Annual monitoring of researcher accountability.

Increasing Safety, Security, Support and Protection
Unique circumstances in our communities require unique approaches for research

First Nations Health Authority
Health through wellness

Situations

Relationships

Aligning to the Directives for safety and protection

Individuals
Who in our communities needs special protections or considerations in proposed research projects?

Ethics guides behaviour in conducting research. What are the factors and who are the people in our communities that require unique sets of research ethics and practices?

E T H I C S

Directive #1: Community-Driven, Nation-Based | Directive #2: Increase First Nations Decision-Making and Control

to First Nations Interests | Directive #7: Function at a High Operational Standard

| Directive #3: Improve Services | Directive #4: Foster Meaningful Collaboration and Partnership | Directive #5: Develop Human and Economic Capacity | Directive #6: Be Without Prejudice

Application to research

- **To operationalize the Framework within FNHA research.**
- **Grant administration aligned with standards and priorities as set by First Nations in BC.**
- **Research Ethics Body mandate.**
  - **FNHA research.**
- **Research Ethics Body will be available for communities use.**

Vision → Values/ 7 Directives → Principles/ Framework → Policies → Procedures

Thank you!