



CARRIER SEKANI FAMILY SERVICES

Research Ethics Policy

1. INTRODUCTION

Carrier Sekani Families Services is committed to the healing and empowerment of community members by taking direct responsibility for health, social and legal and research services for First Nations peoples of the Carrier and Sekani territory. CSFS supports partnership and participation in research as an integral component of ensuring the Agency remains a forerunner in the development and delivery of community and evidence based professional services. While maintaining high standards of service delivery, CSFS has a responsibility to the communities we serve to ensure research is conducted in a respectful and ethical manner that adheres to the protocol of our Member First Nations. As such, the Agency supports and encourages the highest ethical standards in research through policy designed to guide research practice. Carrier Sekani Family Services has the responsibility to our First Nations communities to ensure that all research concerning member First Nations peoples and communities, including any research collaborations or agency/governmental/foundation sponsored projects, is conducted in a respectful and ethical manner. To that end CSFS supports the principles of OCAP (Ownership, Control, Access, and Possession), which recognize the rights of First Nations Peoples to own, protect and control all research/data collection processes in their communities and determine access to and how information is used.

2. PURPOSE

Policy regarding research conducted with, on or for Carrier Sekani Family Services and its member First Nations has been drafted for the following purposes:

- a. To outline the approval process and expectations for research being conducted with, on or for Carrier Sekani Family Services.
- b. To promote and facilitate the conduct of all research in a manner that respects and preserves the wellbeing of all research participants.
- c. To establish a set of ethical principles and ethics review procedures that reflect the commitment of the Agency and its members to such values and standards.
- d. To ensure that research is conducted in a respectful, professional and consistent manner that adheres to relevant legislation defining research guidelines and practice as well as protocol and practices of CSFS and its Member First Nations.
- e. To support knowledge translation and contribute to policy and practice improvements
- f. To enhance collaboration between CSFS, Universities, researchers and member First Nations when conducting community based research.



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3. DEFINITIONS

“Geographic Service Area” means the territory expanding from Member First Nations and immediate areas surrounding the Reserves, from Smithers to Prince George

“Member First Nations” for the purposes of this document, are the eleven First Nations communities that are members of the Carrier Sekani Family Services including Burns Lake Band, Cheslatta Carrier Nation, Lake Babine Nation, Nadleh Whut’en, Nee Tahi Buhn, Saik’uz First Nation, Skin Tye Band, Stellat’en First Nation, Takla Lake Band, Wet’suwet’en First Nation, and Yekooche First Nation.

“Participants” for the purposes of this document, are individuals who provide primary information for a specific research project.

“Research” for the purposes of this document, is the systematic investigation and presentation of information involving member First Nations and their community members. Generally, informal communication between a CSFS employee or those who provide services to CSFS communities and a community member used to gain understanding of community is not considered research under this policy.

“Researcher” for the purposes of this document, a researcher includes:

- a. Any person who conducts or advances research on behalf of, or in partnership with, the Agency.
- b. Any person who conducts research using Agency resources including research space, materials, equipment or financial or human resources.

4. SCOPE

This policy is in no way intended to abrogate the rights of individual member First Nations of Carrier Sekani Family Services. In keeping with the intent of the *Tri Council Policy Statement on the Ethical Conduct for Research Involving Humans*, CSFS asserts its governing authority, as mandated by Chief and Council from member First Nations, in the areas of health, social and legal services and promotes the collective rights of our nations while also serving individual well-being.

This policy is intended to apply when (taken largely from Tri Council Policy Statement):

- a. The analysis of research data will use Carrier Sekani identity or membership as a variable.
- b. Recruitment criteria includes Carrier Sekani identity as a factor for the entire study or for a subgroup in the study.
- c. Research involving health, social, or legal services is conducted within CSFS Geographic Service Area and intends to involve Aboriginal participants as an identified group or the study population will include a significant number of Aboriginal individuals
- d. The research involves cultural property, Indigenous knowledge, or input from a CSFS member First Nation.



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- e. The interpretation of research results will refer to Carrier Sekani peoples, health, history, language or culture.

5. ADOPTION AND INCORPORATION OF ETHICAL PRINCIPLES

All researchers and other persons involved research shall adhere to the following ethical principles and articles, as adopted in the CSFS standards. Researchers will also be responsible for following the *Tri Council Policy Statement on the Ethical Conduct for Research Involving Humans* (www.pre.ethics.gc.ca) which guides all human subject research in Canada. The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) describes the policies of the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), expressing the three Agencies' continuing commitment to the people of Canada to promote the ethical conduct of research involving humans.

6. GUIDING ETHICAL PRINCIPLES

6.1. CSFS Vision and Mission

Research projects must adhere to Carrier Sekani Family Services Vision and Mission statement and must be consistent with the guiding principles and values of the Carrier and Sekani First Nations. The research project must assist in developing CSFS capacity regarding research and/or service delivery to Carrier and Sekani peoples.

6.2. Respect for Participants

Carrier Sekani Family Services shall protect the (cultural, mental, spiritual, physical, emotional) interests of participants throughout the research process. This principle forms the foundation for all other ethical principles outlined below.

6.3. Respect for Free and Informed Consent

Carrier Sekani Family Services shall comply with the exercise of individual consent. The process includes dialogue, process, rights, duties and requirements for free and informed consent by the research participant.

Participants have given free and informed consent when they have freely agreed to participate in a study based on well-understood information regarding objectives of the study and all risks and possible benefits of their participation. Objectives of the study include information regarding the ways in which the research results shall be published and how the participants will be informed of the results.

Continuing voluntary participation requires that participants understand that at any time their withdrawal of consent to the research shall not result in penalty, including loss of promised benefits, which are not contingent on completion of participation.



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Any incentive provided to participants must be in line with standard remuneration for participation in research studies and must not be so large as to undermine the voluntariness of their participation.

Evidence of free and informed consent by the participant or authorized third party should ordinarily be obtained in writing. If community members would rather provide oral consent, all reasonable measures shall be utilized to document this method of consent.

6.4. Respect for Vulnerable Persons

Carrier Sekani Family Services shall ensure high ethical obligations are maintained regarding those who are vulnerable or lack decision-making capacity. Our ethical obligations include special procedures taken to protect their interests.

Carrier Sekani Family Services will make every effort to ensure participants understand information presented, appreciate the potential consequences of a decision, and provide free and informed consent.

Subject to applicable legal requirements, individuals who are not legally competent shall only be asked to become research participants when:

- a. Free and informed consent is sought from an authorized representative(s) (who is not the researcher or a member of the research team); **and**
- b. Research participation does not expose the participant to foreseeable risk.

Where free and informed consent has been obtained from an authorized third party, and in those circumstances where the legally incompetent individual understands the nature and consequences of the research, the researcher shall establish the wishes of the individual concerning participation. If a legally incompetent participant expresses a desire to cease participation at any point their wishes shall be respected and the procedure shall be terminated.

6.5. Respect for Anonymity and Confidentiality

Carrier Sekani Family Services shall respect participant's rights to anonymity and confidentiality. Our standards of anonymity and confidentiality include protection of access and dissemination of personal information.

Researchers shall comply with all applicable privacy legislation in which information collection takes place.

Where possible, participants must be guaranteed anonymity and confidentiality. If anonymity and confidentiality cannot be assured, potential participants must be made aware of the limitations and of possible consequences before they consent to participate.



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6.6. Respect for Intellectual Property

Carrier Sekani Family Services shall respect and preserve rights to sensitive or personal information in order to maintain the cultural integrity of information provided. The Agency shall uphold collective rights to information.

6.7. Minimizing Harm and Maximizing Benefit

Carrier Sekani Family Services shall ensure anticipated benefits far outweigh potential harms when conducting community based research. In the process of conducting research the Researcher will ensure participants are not subjected to unnecessary risks of harm and shall be obligated to assist the participant in reducing or eliminating any adverse effects that may arise.

7. CSFS RESEARCH REVIEW COMMITTEE

The CSFS Research Review Committee will be comprised of the CSFS Chief Executive Officer, the Executive Director Research, Primary Care and Strategic Services, and up to three of the following individuals depending on the nature of the Research:

- a. A University Faculty Member
- b. A CSFS Executive Director or her appointee
- c. A CSFS Board member
- d. A Chief or Council member or appointee from a participating Nation
- e. A CSFS Research Steering Committee Member

8. RESEARCH AND ETHICS REVIEW

In order to ensure there is knowledge about and support for research involving CSFS member First Nations, all health, social or legal research undertaken in a CSFS member First Nation requires review and approval by the CSFS Research Review Committee regardless of:

- a. Whether or not it is funded
- b. Whether participants are paid or unpaid
- c. Whether or not it is conducted at CSFS offices
- d. Whether it is conducted in person or by other means
- e. Whether the research is a pilot study or fully developed project
- f. Whether or not findings are intended for distribution
- g. Whether or not the participants are family members



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9. RESEARCH ETHICS APPROVAL

All research proposals involving community members shall be directed for approval to the Research Review Committee prior to the research commencing. The research must not begin without approval from the Research Review Committee. For the project to be acceptable the researcher must demonstrate adherence to the following ethical principles:

- a. The appropriate methods will be used to protect the rights and interests of participants and Member Bands in the course of the research.
- b. The project contains sufficient safeguards to ensure primary ethical principles related to informed consent, anonymity, confidentiality, protection of vulnerable individuals, protection of sensitive or privileged information and minimization of harms are adequately addressed.
- c. All appropriate and applicable safety standards shall be maintained.
- d. The CSFS and the Member First Nation(s) participating in the research have been adequately involved in research design and any protocol agreements arranged will be established prior to commencement of research.
- e. The Research project develops new knowledge and a plan for distribution of that knowledge to the community as well as external stakeholders.

The CSFS Research Review Committee may approve, reject, propose modification or terminate any proposed or ongoing research conducted by a researcher if the research fails to uphold ethical standards.

10. RESEARCH MISCONDUCT

Any complaints regarding research misconduct will be directed to the Chief Executive Officer, or the Executive Director of Research, Primary Care and Strategic Services for presentation to the Research Review Committee. Consent forms will ensure there is contact information for the Executive Director of Research, Primary Care and Strategic Services in case of complaints.

Disciplinary rules and procedures will follow the guidelines outlined in the CSFS Administrative Procedures Manual and CSFS Integrity in Research and Scholarship Policy and will be forwarded to any other governing body or institution to which the researcher is affiliated.

11. CONSULTATION WITH MEMBER FIRST NATIONS

Collaboration with the communities we serve is an essential component of community based research completed by the agency. In keeping with this strategy the following questions must be answered prior to conducting research:

- a. **Responsiveness/Relevance**
 - How will the research benefit the communities we serve?
 - How will the research be provided to the community?



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- How is direct involvement by the community being ensured?
- What is the extent and the nature of community involvement in the identification of the research problem, development and implementation of project strategies?
- How is the research community-based?

b. **Innovation/Advancement**

- How original are the research questions being provided?
- How important and/or original are the contributions expected from the research proposed?
- What is the potential for important new knowledge?
- How does this research support community development?

c. **Approach**

- How appropriate are the methodologies and the proposed analyses of data (are they respectful of the community and community protocol)?
- Is the research being completed primarily in the care and custody of community members (ie. Community researchers)?
- Does the research increase community capacity to implement research?
- Who will keep the research materials?

A protocol agreement shall typically be created between Member First Nations and the Researcher in order to outline each party's responsibilities in the research process.

11. RIGHTS TO MATERIALS ARISING FROM RESEARCH

CSFS will be the owner of any research reports created by or on behalf of the agency and will maintain research materials commissioned by CSFS or created involving significant use of Agency personnel, funds or other resources unless:

- a. A written agreement is developed between CSFS and the principle investigator/author involved in producing a final report.
- b. The final report is created involving arrangements with third parties, which may involve a level of ownership by the sponsor.
- c. A written agreement is developed between CSFS and a Member First Nation to return research materials from community members to their respective Member First Nation.

Written agreements as to the rights of the Agency and investigator(s)/author(s), third parties or Member First Nations may be established before the work begins if there is a question as to whether ownership of the research materials created will belong to the author(s), third parties, Member First Nations or the Agency.



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12. GUIDELINES FOR AUTHORSHIP

Authorship shall be reserved for those who have made significant intellectual contributions to the research and manuscript writing including:

- a. All authors should have made a substantial contribution to the conception, design, analysis and interpretation of data
- b. They should have been involved in writing and revising the manuscript for intellectual content.
- c. They typically have approved the final draft.

Those who have made contributions to the work including data collection or only parts of the above mentioned criteria shall be credited in the acknowledgements but not receive authorship. To avoid misunderstandings authorship should be discussed and agreed upon well in advance of the manuscript being completed.

The primary author shall be listed as such, typically by being listed first, and all other authors listed in descending order of contribution.

13. SECONDARY USE OF DATA

Secondary use of data refers to the use of materials in research or other reports beyond the research uses consented to by the participant.

If the researcher is attempting to access primary sources of information, such as audio/video tapes or transcripts and the participant has agreed to the tapes being used only for the initial research, participant consent shall be gained prior to its use in subsequent research.

If a person is no longer able to give consent, consent may be gained from the executor of her/his estate or a person deemed to be appropriate under Carrier Law.

14. RESPONSIBILITIES OF RESEARCHERS

Researchers are primarily and ultimately responsible for the protection of research participants. In order to fulfill this responsibility, researchers must be competent in their areas of inquiry and must be familiar with the above-mentioned CSFS ethical standards as well as other ethical and legal standards guiding research conduct. Program Executive Directors or other bodies overseeing research must ensure that all research personnel are familiar with and comply with CSFS research guidelines.