HEARING FIRST NATIONS VOICES: FIRST NATIONS DATA, RESEARCH AND GOVERNANCE

Research Decision-Making Toolkit

Background of the Toolkit

First Nation communities are often approached by researchers looking to enter into a research relationship with them. The goals of a researcher are not always the same as the priorities of the First Nations communities. This underscores the importance of amplifying community voices in shaping and decolonizing the intricate layers of research practices. Knowledge gaps between community and researchers are a threat to the safety and holistic well-being of these communities. They can lead to misrepresentation, culturally insensitive research management practices, and the risk of pan-Indigenization. This document is designed to support your community to ensure that proposed research reflects the needs and priorities of YOUR community and remains culturally-safe for First Nations peoples.
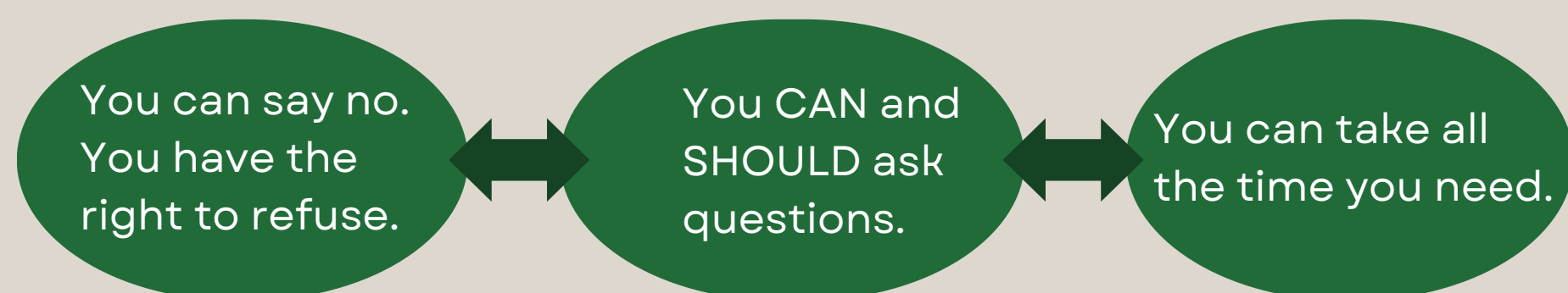
What is Ethical Research

Ethical research feels safe, is culturally significant, and is defined by YOU

It should be (not limited to):
- Community-specific and culturally safe
- Indigenous-led
- Meaningful and intentional
- A long-term commitment
- Transparent
- Open-minded
- Reciprocal, Respectful, Relevant & Responsible (Pidgeon, 2019)

If a Researcher/Institution Approaches Your Community Asking for Permission/Participatory Input:

You can say no. You have the right to refuse. ⟷ You CAN and SHOULD ask questions. ⟷ You can take all the time you need.

Indigenous Data Sovereignty

Data sovereignty is YOUR community's right to govern YOUR data through the various stages (planning, collecting, managing, evaluating and disseminating) of research.

Examples of Guiding Principles of Data

OCAP ®	FAIR	CARE
Ownership	**F**indable	**C**ollective Benefit
Control	**A**ccessible	**A**uthority to Control
Access	**I**nteroperable	**R**esponsibility
Possession	**R**eusable	**E**thical

WHAT IS DATA?

- Indigenous data is what your community defines it to be
  - E.g. ancestral knowledge, languages, arts
- Data is not limited to numbers
- It does not have to be scientifically driven

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GENERAL RESEARCH GUIDELINE

Recommended Questions for Reflection

PRE-RESEARCH STAGE
Establishing meaningful relationships, building trust, and reciprocity
- What are the priorities of the researcher(s)? Are they aligned with the priorities of your community?
- Does your community have a pre-existing meaningful relationship with the researchers? If not, does your community want to?
- How have researchers taken the initiative to foster long-term relationships?
- Have researchers shared and acknowledged their worldviews?
- Do you feel safe collaborating with the researchers? Do you feel heard and respected?
- Is there a clear intention to establish a long-term relationships with your community?
- Is there effective, transparent, and meaningful communication between you and the researchers?

DEVELOPMENT OF RESEARCH QUESTION(S), DESIGN & AGREEMENTS
Co-Creating the Research Process
- Are researchers approaching you with a pre-determined framework?
- Will this research benefit your community's well-being?
- How will community be honoured for their time and knowledge?
- Are community-specific research methodologies being used? How are Indigenous knowledge systems being incorporated?
- How will community voices be amplified and respected in decision-making throughout all stages of research?
- Is this research ON or WITH your community?
- Are the objectives of this research co-developed with your community?
- Did the researcher(s) approach your community with ample time to co-create the project prior to the deadlines?
- Is the researcher open to modifying the research objectives to align with community priorities?
- Will this project further the interests of the community? Will it detract from community capacity?

ETHICS
Establishing meaningful relationships, building trust, and reciprocity
- How will ethical research be practiced?
- Is the research proposal reviewed and approved by the Research Ethics Board (REB)?
- Are there Indigenous/community voices on the REB?
- How will the researcher(s) address power dynamics between themselves as a professional researcher and community members?
- What is the researcher(S) practice of research ethics beyond those required by the University research ethics board?

RESEARCH AGREEMENT
A contract outlining the project
- Is the agreement true to what was discussed between community and researchers?
- Do you have any questions or concerns about specific words, language use or lines in the agreement?

PARTNERSHIP AGREEMENT
A contract outlining partners and roles
- Are the roles and responsibilities of partners clearly identified?
- Are all the partners identified?

LETTER OF PARTNERSHIP/ SUPPORT
Letter used in grant applications for commitment/support
- Who is the letter directed to?
- Is the level of support clearly stated in the letter?

DATA SHARING AGREEMENT
A contract regarding data, research, and data management
- Will community have control and ownership over data?
- Will community have control and ownership over who has access to your data?
- Will community have control and ownership over who has access to your data?
- What are security measures taken to safeguard data?
- How will misuse/secondary use of data be prevented?
- How will authorship be determined?
- Who is determining what data is being collected?
- How will the confidentiality of community members be maintained and respected?

DATA COLLECTION
Gathering of relevant evidence to answer the research question(s)
- Are cultural/community protocols being practiced?
- Are Indigenous methodologies being practiced?
- Do you/your community feel safe and respected?
- Do you want to withdraw from the research process?
- Are you being continually informed about the progression of data collected?
- Have you been able to communicate any feedback, changes, or concerns? Have they been actioned?
- What data is being collected? Is it relevant to the research?
- Are community members invited to participate in the data collection?

DATA ANALYSIS
Interpretation and verification of data collected
- Is your community involved in the analysis? How?
- Is your community verifying the accuracy of the analysis? How?
- Is data accessible to your community?
- How will your community be continually informed during analysis?
- Are members of the community invited to analyze the research findings?
- How will your Nation-specific ways of knowing be incorporated into the analysis?

DISSEMINATION OF RESULTS
Sharing the findings with the public and community
- Has community reviewed and approved all reports before publication?
- Has there been an accurate translation of knowledge?
- Are the results being shared in a culturally safe and community specific way?
- Does the community have ownership of their data?
- Are the results accessible to community?
- If community does not want certain findings reported on or wants to be involved in shaping how they are written about - is that an option?
- Is there funding for knowing translation materials and events to share the findings with community?
- Who owns the findings of this research?
- Will community members be invited in conferences about this work, or will only the researcher?

POST RESEARCH PHASE
Reinforcing and maintaining of long-term relationships
- Has your community been able to share feedback and reflect on the research process?
- Have the researchers stayed in touch and followed up with your community habitually?
- Have researchers extended their support to other community interests?

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DATA SHARING AGREEMENT TEMPLATE

TITLE OF RESEARCH PROJECT
[Title that is reflective of the project and includes "data sharing agreement"]

This Data Sharing Agreement is made on [date - include day, month, year].

BETWEEN:
[First Nation Community, Organization, or First Nation Parties] Name(s):
Address:
Telephone:
Email:

AND:
[Principal Researcher(s), Organization, Research Partner(s)] Name(s):
Address:
Telephone:
Email:

INTRODUCTION
Identify parties involved, their roles in agreement and relationships.

The [First Nation Community] and the [research partner(s) or organization] are collaborating together on the [title] research project. The [First Nation Community] consents to collaborate with the [research partner/organization] in the fostering of a meaningful partnership….

PURPOSE
What is the purpose of the research project? What data/knowledge is being collected? How? What data/knowledge is being shared? Why? How will data be used to help the research?

This data sharing agreement protects the rights of the [First Nation Community] during the [research project] and after.

DATA USAGE
What will the data collected be used for? What should it not be used for? This section needs to identify how the data collected will be used.

The data collected in the [Research Project] will be used for _____. The [research partner(s) or organizations] will not be using the data for any external use, other project or any other purpose without written consent of the [First Nations].

DATA SHARING AGREEMENT TEMPLATE CONT'D

OWNERSHIP

Who owns data? Identify who has access to data.

The [First Nation Community] possesses <u>full control</u> over all the data, intellectual property of the First Nations, and traditional knowledge. Access to data will be at the discretion of the [First Nations] and can be revoked at anytime.

DATA STORAGE and SHARING

Where and in what format will data be stored? Is it accessible to community? How will data be protected and respect confidentiality?

Data will be stored (e.g. secure file transfer, portable hard drives, password protected folders, physical location). Data and information will be shared [frequency] to ensure ongoing collaboration.

DISSEMINATION OF RESULTS

Who can see the results of the research?

Data will not be shared or published without the consent of the [First Nations].

DATA DISPOSAL & RETENTION

How long should data be stored for after research? Specify date relative to expiration of agreement.

INTELLECTUAL PROPERTY

The [First Nations] has all the intellectual property rights and copyrights to the data. Any data that has been created during the project will be owned by the [First Nation Community].

WITHDRAWAL/TERMINATION

In the case of unsafe research practices, the community has a right to withdraw at any time.

DEFINITIONS

Any relevant terms that are to be clarified.

Suggestions: First Nations data, OCAP (Ownership, Control, Access, Possession), traditional knowledge, data collection, anonymized data...

SIGNATURES

Identification of signing parties involved/signing parties consenting to the agreement.

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PARTNERSHIP AGREEMENT TEMPLATE

TITLE OF RESEARCH PROJECT

This Collaborative Partnership Agreement is made on [date - include day, month, year].

BETWEEN:
[First Nation Community, Organization, or First Nation Parties] Name(s):
Address:
Telephone:
Email:

AND:
[Principal Researcher(s), Organization, Research Partner(s)] Name(s):
Address:
Telephone:
Email:

PURPOSE
Identify the research question and goals.

PROJECT OVERVIEW
Detailed description of the research study including objectives.

ROLES OF PARTNERS
Identification of partners/collaborators and their roles and responsibilities to adhere to throughout the study. This will be dependent on the unique First Nations community and their values.

OCAP principles may be determined as foundational principles to guide partnership.

The roles can be but are not limited to developing research plans, research questions, interview questions, funding proposals, study participation, data collection, data analysis, data dissemination and publication. These roles should be collaborative, and community led.

It may be recommended to outline how partners benefit and are at risk if any, from outlined roles and responsibilities.

FUNDING
Clarification of roles and responsibilities regarding applications, funding and grants. Most often principal researcher will take on this responsibility.

TIMELINE
Duration of partnership.

WITHDRAWAL
In the case of unsafe research practices, community has a right to withdraw at any time.

SIGNATURES
Identification of signing parties involved/signing parties consenting to the agreement.

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LETTER OF SUPPORT TEMPLATE

Should be on the First Nation or organization's letter head and signed by a director, leader, chief

DATE

FUNDING BODY

RE: Letter of Support for <project title>

Dear Review Committee,

In the past <X (number)> of months, <First Nation or organization name> have been working with <Researcher name> in the development of <project name>, which will assist us to <understand/explore/determine/evaluate> for our community/organization's purposes.

At <First Nation or organization name>, we endeavor/work for First Nations peoples who deal with <main purpose of the organization or community> and have seen <problem/issue/concern> that requires <intervention/exploration/understanding/evaluation>. We have knowledge of that will inform the <project name>. The purpose of this project is to...

In collaboration with <researcher name>, we are pleased to provide in-kind support in the form of <meeting space, materials, traditional medicines, training, people's time, etc> that would be valued at <dollar amount>. We have entered into a partnership with <researcher name> and will co-govern and develop the project to ensure that it meets the needs of our community.

We are excited to be a part of this project, <project name>, and believe this partnered research will provide us with further knowledge about <main purpose of the research> , which will be <policy, program, service, intervention, networking, public knowledge, digitization, etc> that will benefit how we address <main purpose of the research>.

We fully support and will be taking part in <project name> with <researcher name> to ...

Sincerely/Respectfully/Regards,

Name

Title

LETTER OF SUPPORT/ PARTNERSHIP TEMPLATE

[Date]

Re: Letter of Partnership and Support for [Research Project] between [First Nation Community] and [Partner/Organization]

To [Grant Provider],

PARAGRAPH 1
Statement of Support and identification of partner/research project

PARAGRAPH 2
Background of Community and Connecting Research Question to Community

PARAGRAPH 3
Outlining research goals, outcomes of study and benefits to community (long term/short term). Identify community roles in the research project.

[Signature]

TEMPLATE FOR EVALUATING RESEARCH PROPOSALS

What our community/organization wants	Red Flags
• Clearly benefits community • Research team requests community relationship building time before the grant or other opportunity would occur • Community-led and based with the community having control or co-governed with researcher • Has community members as part of the research team • Research question co-developed with community • Follows cultural and community protocols – like giving tobacco ties or a gift for time (money or otherwise) • Works with community to determine the ways to collect the knowledge – talking circles, interviews, surveys, photos, videos, policies, case studies • Follows up with participants from the community to ensure data accuracy and fostering further community engagement • Preliminary analysis is given to the participants and community members for review • Collaboration to how and where to make this data public (like journal articles, reports, videos, social media) • Uses a strengths-based approach showing the way community/participants in a positive way	• Not community-led or in collaboration • Time-limited or sensitive with no time to get to know the researcher • Brings concept or grant with expectations of working with community with no previous relationship • Academic or organization team with no community input • Exclusively designed by a researcher or their team • Helicopters in and does not know or follow protocols • Methods are not culturally appropriate and exclude the community(s)' input • Does not have a plan to allow participants to see the analysis or the themes that emerge from the data before publishing or making public • Uses inappropriate or colonizing language that can harm the community or individuals who participated • Writes and presents the findings without input from the community and/or participants • Doesn't advocate for change regarding the main issue in the research

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REFERENCES

Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., LoveEe, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J., Anderson, J., & Hudson, M. (2020). The CARE Principles of Indigenous Data Governance. *Data Science Journal.* https://datascience.codata.org/articles/10.5334/dsj-2020-043

Pidgeon, M. (2019). Moving between theory and practice within an Indigenous research paradigm. Qualitative Research, 19(4), 418-436. https://doi.org/10.1177/1468794118781380

Wilkinson, M., Dumontier, M., Aalbersberg, I. *et al.* The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* 3, 160018 (2016). https://doi.org/10.1038/sdata.2016.18

Wilson, S. (2008). *Research is ceremony: Indigenous research methods.* Winnipeg: Fernwood Publishing.

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