Research and Knowledge Translation Newsletter

northern health
the northern way of caring

ENABLING RESEARCH IN A PRIVACY APPROPRIATE MANNER

1

By: Ron Klausing
Privacy Officer, Research and Privacy Impact Assessments (PIA)

Research studies involving human participants typically require information about individuals in order to achieve study outcomes. Studies may be authorized to collect personal information directly from individuals or indirectly from organizations (under specific conditions), as governed by Canadian federal/provincial privacy law or organizational policy. The Northern Health (NH) Privacy Office has implemented several practices intended to streamline privacy process and increase transparency, where it relates to enabling NH related research studies in a privacy appropriate manner. A goal of these efforts is to help research studies more efficiently complete privacy compliance requirements.

CONTEXT FOR PRIVACY

The privacy laws of Canada and British Columbia (BC) apply a comprehensive scope, with limited exceptions. Northern Health (NH) is subject to BC public sector privacy laws, which include the Freedom of Information and Protection of Privacy Act (FIPPA),[1] plus provisions from other legislation (e.g. the Public Health Act, E-Health Act, Vital Statics Act).[2] Under FIPPA, personal information means "recorded information about an identifiable individual other than [business] contact information". BC privacy legislation contains specific provisions governing the collection, use and disclosure of personal information. BC's private sector privacy law, the *Personal Information Protection Act* (PIPA),[3] contains a similar definition and provisions. Canada's federal public sector and private sector privacy laws, the *Privacy Act*,[4] and *Personal Information Protection and Electronic Documents Act* →

1 (Freedom of Information and Protection of Privacy Act ([RSBC 1996] CHAPTER 165), 2022)
2 (Public Health Act ([SBC 2008] CHAPTER 28), 2022),(e-Health (Personal Health Information Access and Protection of Privacy) Act ([SBC 2008] CHAPTER 38), 2022), (Vital Statistics Act ([RSBC 1996] CHAPTER 479), 2022)
3 (Personal Information Protection Act ([SBC 2003] CHAPTER 63), 2022)
4 (Privacy Act (R.S.C., 1985, c. P-21), 2022)

(PIPEDA)[5] respectively, also contain similar definition and provisions. It is important to note that Canadian federal and BC provincial privacy laws are *similar* but not identical.

Additionally, the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2022),[6] contains specific privacy requirements, mainly in Chapters 3 Consent Process and Chapter 5 Privacy and Confidentiality, to which research studies subject to TCPS 2 (2022) must comply. Most health research studies in Canada are subject to TCPS 2 (2022) compliance requirements.

Privacy (Information Privacy) refers to the right of an individual to determine what information about themselves ("personal information") may be collected, used, and shared with others. Privacy is a fundamental human right enshrined in the Canadian Constitution,[7] under the Canadian Charter of Rights and Freedoms,[8] with privacy topics typically related to sections 7/8.

> "Privacy is essential to individual autonomy and the protection of human dignity."

Canadian privacy laws, give the individual certain options to decide how they want to interact with the world around them.

Under Canadian privacy law, public sector and private sector organizations (e.g. research studies) have no authority to collect, use or disclose personal information, other than the authority specifically granted through Canadian federal or provincial privacy law. In support of research studies that require personal information, Canadian privacy law includes specific provisions which allow such studies to collect personal information directly from individuals or indirectly from organizations (secondary use provisions). Secondary use is when an organization takes personal information it has collected for one purpose (e.g. the provision of healthcare), and uses it for an additional purpose (e.g. program planning and evaluation, surveillance activities) or discloses it for authorized purposes (e.g. law enforcement, research). Each *use* or *disclosure* is supported by specific legislative provisions.

COLLECTION OF PERSONAL INFORMATION

For research studies that have been approved by NH (refer to Research in Northern Health for requirements),9 data collection activity may occur. It is important to note that any personal information collected by a research study, may only be used for the purpose(s) stated in the informed consent process. The two primary collection methods are Direct collection and Indirect collection.

Direct Collection

Direct collection of personal information requires an ability to *contact individuals*, in order to obtain their *informed consent*. BC and Canadian privacy laws and Canada's →

5 (Personal Information Protection and Electronic Documents Act (S.C. 2000, c. 5), 2022)
6 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2022, 2022)
7 (The Constitution Acts, 1867 to 1982, 2021)
8 (Constitution Acts Part I - Canadian Charter of Rights and Freedoms, 2021)
9 (Research in Northern Health, 2023)

anti-spam legislation (CASL),[10] place certain constraints on how an individual's personal information may be used to contact them. There are two primary methods for a study to contact individuals:

a. Open invitation ~ publish advertisements (internet, radio, newspaper), place posters/signs or pamphlets/ handouts in appropriate locations (may be in a clinical office where permission has been obtained) or some other form of public broadcast, which invites interested individuals to contact the study (click a weblink, send an email, call phone number). This allows the interested individual to 'opt-in' to receive study communications, by providing to the study their personal contact information (name, email, phone number).

b. Direct invitation ~ complete the BC Government Request to contact BC Residents process. In this case, the BC Data Stewardship Committee adjudicates requests from researchers to contact B.C. residents before approval by the BC Office of the Information & Privacy Commissioner. Should the study's request be approved, the Ministry of Health or Population Data BC will work with the study team to coordinate the data extraction of personal contact information. Once the contact information has been provided, the study team can communicate with those specific individuals, inviting them to 'opt-in' to study communications.

After an individual has chosen to 'opt-in' to study communications (via open or direct invitation above), subsequent steps to obtain informed consent can be initiated. Personal information may only be collected, after informed consent has been received from the individual (with certain exceptions typically related to public safety or law enforcement). The privacy law requirements to obtain informed consent are stated in FIPPA (plus FIPPA regulations) and PIPA, for public sector and privacy sector organization studies respectively. Additional requirements are stated in TCPS 2 (2022).

Once the study has obtained informed consent from study participants (and all other required approvals are complete), collection of personal information from study participants can begin.

Indirect collection

BC FIPPA s.33(3)(h) authorizes NH to disclose (i.e. secondary use) personal information for a research purpose without consent, under certain conditions. One of the conditions states that personal information disclosed is not to be used for the purpose of contacting a person to participate in the research (certain exceptions apply). To ensure appropriate safeguards are applied to any identifying or de-identified information disclosed by NH, an information sharing agreement is required.

Information Sharing Agreement (ISA)

The ISA is a formal agreement which describes the terms and conditions under which information is being shared. It documents the roles and responsibilities of all parties involved. The ISA must be completed and signed (with all other approvals complete, refer to Research in Northern Health for requirements), before NH can begin data disclosure activity. To help streamline the ISA process, NH has implemented a detailed ISA template to support disclosure of identifying information and a simpler template to support disclosure of de-identified information. A simpler ISA template for de-identified information is required due to the increasing potential to re-identify individuals as technology advances. Sample ISA templates and the high level NH ISA process flow are published on the Privacy ~ Research in Northern Health page to help increase transparency of NH requirements. →

10 (Canada's anti-spam legislation (S.C. 2010, c. 23), 2023)

IMPLEMENTING NEW OR CHANGED TECHNOLOGY

When a study requests to introduce new technology or change existing technology within Northern Health, the study must submit an NH privacy impact assessment (PIA) to the NH Privacy Office. The requirement for a PIA is stated in NH policy and BC privacy law. NH uses the PIA to evaluate privacy compliance issues, privacy risks and related mitigations before an initiative is launched. NH still requires a PIA even if no personal information is involved. A signed PIA, completes the process. To help increase transparency a high level NH PIA process flow is published on the Privacy ~ Research in Northern Health page, along with a guidance document about privacy definitions - personal information.

LOOKING FORWARD

The NH Privacy Office is continually seeking ways to improve transparency, process and communication in order to help research studies move forward more efficiently. Our goal is to enable NH related research studies in a privacy appropriate manner. Wherever possible, privacy review of research studies is conducted in tandem with ethics and operational approval activity. This helps to shorten the overall review cycle, with most privacy clarification requests being addressed through initial provisos to the study team. The Research in Northern Health page contains a rich set of information reflecting NH privacy guidance. Should a research study have additional privacy questions, they may reach out to the NH Privacy Office to schedule a consultation

> “Wherever possible, privacy review of research studies is conducted in tandem with ethics and operational approval activity.”

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NH and UNBC affirm their collaboration in a new Memorandum of Understanding (MOU) that reflects new opportunities to advance the health of northern British Columbians through the integration of practice, education and research.

2

By: Editorial team & Dr. Julia Bickford, Director of Research, Evaluation and Strategic Analytics

In December 2022, a new MOU amongst both institutions was renewed. This MOU builds upon earlier agreements in recognition of prior shared achievements, new contexts, regional opportunities, and ongoing challenges. The overall spirit of previous and the new MOU is to reaffirm a shared commitment to furthering knowledge about, and developing the capacity for, the advancement of the health of northern British Columbians through the integration of practice, education and research. The new MOU explicitly recognizes the "unique commitment between our organizations to collaboratively seek and develop opportunities to further education, research and innovation for the purpose of improving the quality of life for people who live in the North" (UNBC-NH MOU, 2022, p.2).

A relevant point in the MOU is that it opens possibilities for the integration of additional partners or stakeholders beyond UNBC and NH. With this idea, the MOU allows ample opportunities to stimulate innovation and transformation in both organizations that will further advance a closer integration of health services and policy, health professional education, and enhanced health research.

In addition, both organizations recognize the importance of evidence generation and mobilization for improved decision-making as well as the recognition and enabling spaces for meaningful involvement of people/patients and families in prioritization and decision-making related to health service and future health developments.

The new MOU also includes a detailed governance structure composed of an Executive Oversight Committee EOC, a steering committee, and four working groups or sub-committees. During 2022, UNBC and NH MOU working group developed a Guiding Framework that provides orientation to shared-identified priority areas summarized as:

1. Recruitment and retention of people involved in delivery of health care in the north;
2. Integration of quality and improvement of practice with research and education programs;
3. Enhanced opportunities for research involving clinical trials and access to trials by northern patients;
4. Connecting people to services (e.g., telehealth, transportation, etc.);
5. Industry/resource economy and its impact on the health of northern peoples;
6. Training, education and capacity development to promote and support cultural safety and humility;
7. Rural health and rural networks of clinical services;
8. Generalism and inter-professionalism.

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> "The overall spirit of previous and the new MOU is to reaffirm a shared commitment to furthering knowledge about, and developing the capacity for, the advancement of the health of northern British Columbians through the integration of practice, education and research."

These priority areas will be operationalized in the MOU Strategic Plan and subsequent Annual Implementation Action Plans with a focus on measurable outcomes.

The following is a conversation with Dr. Julia Bickford, a NH Research leader who participated in many of the NH-UNBC consultations prior to the renewal of the current MOU.

1. IN WHAT WAYS THIS AGREEMENT IS DISTINCTIVE TO OTHER TYPE OF AGREEMENTS OR MOU'S?

There has always been a really strong partnership between NH and UNBC. We've had these types of MOUs in place for over a decade; however, what's special about the current MOU is the time and effort that was devoted to mapping out shared activities and workplans to the benefit of both of our organizations.

2. WHAT ARE SOME MECHANISMS TO KEEP TRACK OF THE ADVANCEMENTS ON THE PRIORITY AREAS AND UPCOMING ACTIVITIES OF THE MOU?

A working group structure and steering committee are built into this MOU design. The working groups have annual action plans and are meeting monthly to keep each other accountable and maintain momentum. The groups will report annually on progress toward their stated goals. We have also hired a coordinator to support communication and collaboration.

> "There are many opportunities in this MOU to support transformational change."

3. IN WHAT WAYS DOES THE MOU COULD STIMULATE INNOVATION AND TRANSFORMATION IN YOUR INSTITUTION?

There are many opportunities in this MOU to support transformational change. The cultural safety working group, which aims to decrease anti-Indigenous racism, continues to implement the curriculum that was jointly developed with the National Collaborating Centre for Indigenous Health (NCCIH). The curriculum is very thoughtfully designed. I can say that this curriculum has sparked ongoing conversations and reflection on the team I lead about the way we work with communities and patient partners, the types of questions we explore, principles around data ownership and sharing, and relationship building. There are other areas of innovation that will be supported through this MOU as well. For example, collaborative research projects are being developed together to address health care workforce challenges in the north.

Further information about UNBC-MOU will be communicated via NH channels as well as UNBC appropriate units. A public communication from UNBC about the MOU can be found here:

Northern Health and UNBC renew partnership in learning and research | University of Northern British Columbia →

THE IMPORTANCE OF "PARTIAL POOLING" IN MODELLING NORTHERN HEALTH DATA

By: Galen Michael Seilis, Data Scientist

Northern Health data has a type of structure in it. In this short article I will give a summary description of what this structure is, and how we can take advantage of it to improve our estimates.

The province of British Columbia is divided into regions that are each overseen by a health authority, such as Northern Health. Likewise, each health authority's region is divided into health service delivery areas (HSDAs) that are in turn divided into local health areas (LHAs). For example, the HSDAs of Northern Health are Northwest, Northern Interior, and Northeast. The Northern Interior HSDA is further composed of the Quesnel, Burns Lake, Nechako, and Prince George LHAs. This hierarchical structure is illustrated in Figure 1.

Suppose we wanted to statistically estimate a quantity from Northern Health data, like the average length of stay (LOS) among multiple sclerosis (MS) patients. How should we consider this hierarchical structure within Northern Health? Let us consider some possibilities.

One approach is to ignore it by plugging all the data into our estimator of the average. This approach is called complete pooling, and it has a distinct advantage of being easy to calculate. The resulting average will be influenced by the underlying differences in the populations across Northern Health, and it does not tell us anything about whether some populations had longer or shorter LOS for MS patients. It likewise does not give us an estimate of LOS in which the effects of Northern Health's structure have been removed. In summary, complete pooling gives us a rough and aggregated understanding when we ignore population structure. This motivates the next approach: no pooling.

A more sophisticated approach would involve somehow accounting for the effects of population structure. Not pooling at all can be a very effective approach for accounting for different groupings in data. What this involves is splitting up the data into different groups (e.g. LHAs) and computing the separate estimates for each grouping. This conditional averaging allows us to account for the fact that different populations within Northern Health are statistically different from each other. This approach is natural to many analysts because their tools such Excel's pivot tables or SQL's "GROUP BY" statements readily facilitate this kind of operation. Unfortunately, not pooling can be wasteful. As we split our data into more groups, →

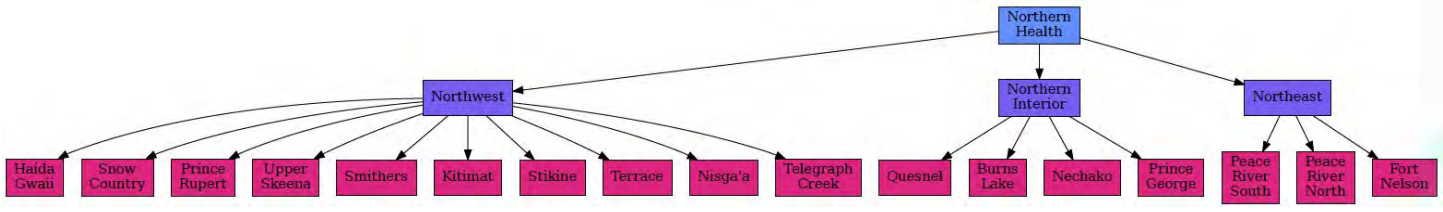


Figure 1: The Northern Health region is divided into HSDAs which are themselves divided into LHAs.

we will have a smaller number of measurements per group. Treating each estimation for each grouping as independent in this way makes our estimates more uncertain. Would our estimates of LOS really be independent between Terrace and Kitimat within the Northwest HSDA, or Peace River South and Peace River North nested within the Northeast HSDA? While not pooling at all has accounted for the fact that populations are distinct, it has ignored how they are similar. We are still ignoring some of the structure of the data, which brings us to ***partial pooling.***

We would like to somehow account for the fact that different populations are not the same in their statistical properties, and yet also take advantage of these populations not being entirely independent to improve our estimates. This can be done with partial pooling, which is a balance between complete pooling and not pooling at all. How this really works involves mathematical machinery that is beyond the scope of this article. But the intuition is straightforward: our model must account for the hierarchical structure of Northern Health! The model needs to "know" about the different LHAs, but also know about how they are nested within HSDAs, which are in turn nested within Northern Health. Metaphorically, partial pooling captures the fact that there is both diversity and unity. With estimates of LOS of MS patients, we can use partial pooling to estimate both an average for Northern Health and the average differences of each part from that general average.

What if we find some candidate structure for our data, but it isn't obvious whether the structure matters? How do we determine if it matters? This is where the statistics of model comparisons becomes important. Model comparison is about assessing which model is better for some purpose, which involves tools and approaches beyond the scope of this article. Fortunately, the general idea is simple. If a model with a proposed structure does better than a model without that structure, then that structure has some importance for our estimates.

Does this mean we should **always** opt for using partial pooling? No. It always matters what the goals and constraints of a project are, and it also matters whether such structure is supported by the data. Often there will be structure in healthcare data. But sometimes complete pooling captures a useful description of an overall population, and sometimes we have enough data to make useful estimates without pooling. Utilizing partial pooling introduces its own complexities in identifying and fitting suitable models. It is a wonderful tool, but the adage *"There ain't no such thing as a free lunch"* applies to all statistical models and approaches.

Developing and implementing approaches that utilize partial pooling is one of the ways that the new Data Science team, including myself, at Northern Health is working to improve our analytics and modelling. For questions, comments, or consultation, please email me at galen.seilis@northernhealth.ca.

PLAIN LANGUAGE HELPS READERS UNDERSTAND HEALTH SCIENCES

4

By: BC SUPPORT Unit

Accessibility starts with words. Research can be full of jargon that prevents many from truly engaging with scientific work.

Writing in plain language can be challenging for health researchers working in a field immersed with jargon; and it can be extremely difficult for non-scientifically trained patient partners to know where to start with a scientific summary.

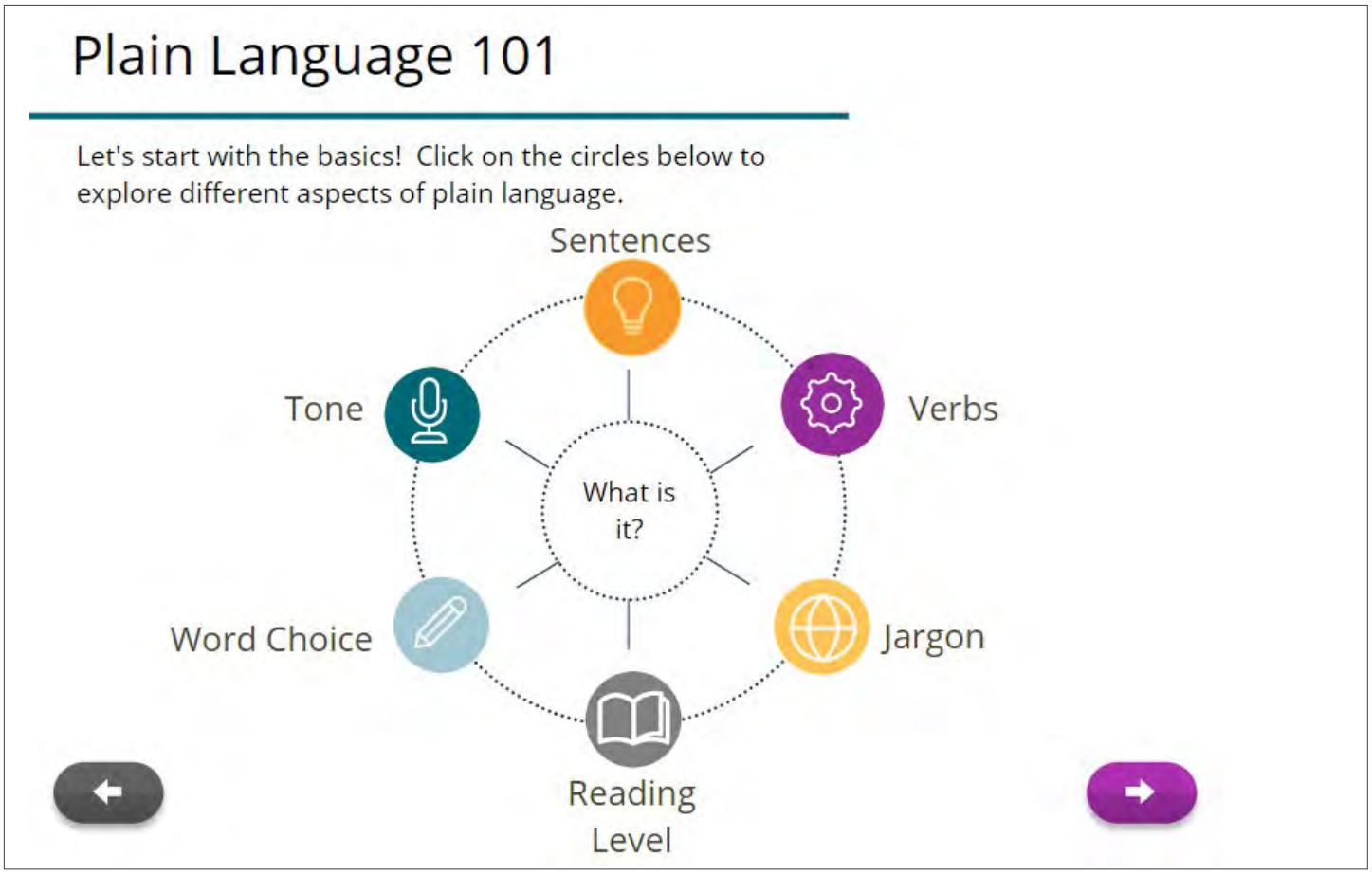
To address this issue an interactive digital guide was developed by the BC SUPPORT Unit.

This interactive guide helps research teams understand plain language, and provides tools, resources, and best practices to shape more clear, concise and accessible writing.

The guide:

- Provides users with a brief overview of what plain language is; and
- Supports research teams to craft their own plain language summary.

Access the plain language guide here:



For original article and more useful resources, visit: https://healthresearchbc.ca/bc-support-unit/info-and-resources/information-for-researchers/plain-language-guide/

Credits: The plain language guide was developed by the BC SUPPORT Unit.

UPCOMING EVENTS, AWARDS AND OPPORTUNITIES

5

FUNDING OPPORTUNITY: CAFÉ SCIENTIFIQUE PROGRAM

CIHR is pleased to announce the launch of a refreshed Café Scientifique Program! Cafés are knowledge mobilization events that enable knowledge sharing and foster dialogue between the general public and researchers on health topics of public interest. They are designed to be engaging and accessible, and can be held in-person, in a hybrid format, or virtually. We encourage diverse teams to apply.

Learn more: https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtlsdo?prog=3808&view=search&terms=scientifique&type=EXACT&resultCount=25&next=1

Application deadline: March 15, 2023

COLLABORATION FOR HEALTH RESEARCH IN NORTHERN BC SEED GRANT

The Seed Grant Program is sponsored by The University of Northern BC (UNBC), Northern Health (NH) and the Provincial Health Services Authority (PHSA).The goal of the Seed Grant Program is to enable collaborators at PHSA, NH and UNBC to work in partnership and initiate new research projects that focus on improving the quality of health services and improving the health of the population in northern BC.

The maximum amount for each award is $10,000 for a 12-month period.

Elegibility

1. **A new research team (3 or more applicants) led in partnership by individuals from UNBC, NH, and PHSA**

- The nominated Co-Principal Investigator lin role of Researcher) must hold an academic appointment at UNBC and be eligible to hold research funding.
- One Co-Principal Investigator (in role of Researcher and/or a Knowledge User) from PHSA. Eligible PHSA applicants will be primarily affiliated with a PHSA agency. Please see the PDF for a list of eligible PHSA agencies.
- One Co-Principal Investigator (in role of Research and/or a Knowledge User) from NH. Eligible applicants will be primarily affiliated with NH.

2. **Northern/Rural/ remote Health Focus**

- The proposed team and research activity/plan must address a health challenge identified in northern BC

Key Dates

- RFA Closing Date | February 6, 2023
- Anticipated Notice of Funding Decision | March 14, 2023
- Funding Term | April 1, 2023 - March 31, 2023 (12-Months)

More information is available here: Funding Opportunities | University of Northern British Columbia (unbc.ca)