

# Research and Knowledge Translation Newsletter

## PARTNERING FOR IMPACT: REFLECTIONS OF A PATIENT-DRIVEN AND PATIENT-LED RESEARCH TEAM

By: Davina Banner (Principal Researcher, UNBC)  
Spring Hawes (Patient Co-Lead)  
John Chernesky (Principal Knowledge User, Praxis Spinal Cord Institute)  
Nicola Waters (Co-Principal Researcher)



*This article draws from a Five Days in May presentation given May 24th, 2022 organized by Northern Health, and reflects upon a research partnership exploring pressure injury risk and management in persons living with spinal cord injury (SCI).*

### WHAT DOES IT TAKE TO DEVELOP, PLAN, AND SUSTAIN MEANINGFUL AND IMPACTFUL PARTNERSHIPS IN PATIENT-ORIENTED RESEARCH?

This is a question that this BC based research team has continually been asking themselves over the last few years of working together. Led by Davina Banner (Principal Researcher, UNBC), Spring Hawes (Patient Co-Lead), John Chernesky (Principal Knowledge User, Praxis Spinal Cord Institute), and Nicola Waters (Co-Principal Researcher),

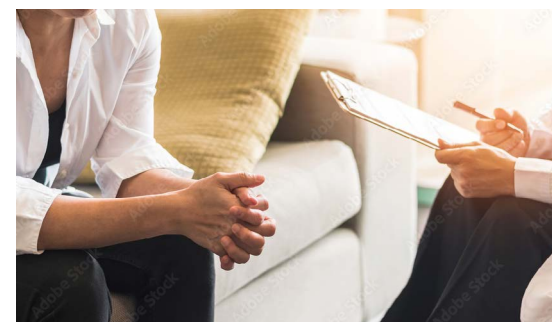
the team are undertaking a patient-oriented research study exploring pressure injury risk and management in persons with lived experience of Spinal Cord Injury (SCI).

### WHAT IS A SPINAL CORD INJURY?

Over 85,000 people in Canada live with SCI, a condition that is characterized by damage to the spinal cord (Noonan et al., 2012). Spinal cord injury can give rise to motor, sensory, and autonomic impairments and can result in up to 30 secondary complications, including bladder infection, neuropathic pain, psychosocial issues, cardiovascular complications, and pressure injuries (Ahuja et al., 2017). On average, a person with SCI can experience up to 15 secondary complications at any given time.

### WHY EXPLORE PRESSURE INJURY RISK AND MANAGEMENT?

Up to 95% of people with SCI will experience at least one pressure injury in their lifetime (NSCISC, 2005). Pressure injuries are a significant cause of morbidity and mortality among people living with spinal cord injury, causing 1 in 10 deaths. Despite the frequency and severe impacts of pressure injuries, few studies have explored this issue from the perspective of those with lived experience.



## HOW DID THIS STUDY COME TO FRUITION?

This research came about principally in response to patient co-lead Spring's own lived experience of pressure injury. In August 2016, Spring noticed a small red mark on her right iliotibial band, a strong thick band of tissue that runs down the outside of the thigh. After it persisted for a week, she had it assessed by a community nurse and was advised to treat it with a simple wound dressing. By November, the wound had grown considerably, and Spring was losing weight and in severe pain. She was diagnosed with osteomyelitis (an infection in the bone) and admitted to hospital for six weeks where she received intravenous antibiotics. After this, Spring returned home on complete bed rest. This resulted in 10 consecutive months of bed rest. Spring recalled that during the time, her life was on hold as she endured extended bed rest without any end time in sight. She recalled:

“ My healthcare team seemed satisfied with the state of care and there was no sense of urgency to resolve the wound. ”



After repeated requests to be referred to a plastic surgeon, Spring had successful flap surgery with bone reduction followed by another six weeks of recovery in hospital. Spring noted:

“ From start to resolution my journey with pressure injury lasted 20 months with well over 300 medical appointments. It was due to self-advocacy that it ended when it did. ”

When John Chernesky, Lead of Consumer Engagement for Praxis Spinal Cord Institute, heard Spring's story he knew he wanted to explore this important issue, particularly as he also lives with a SCI and has experienced pressure injury. He connected with Davina at the BC SUPPORT Unit conference and Nicola at a SCI event, seeing an opportunity to bring together stakeholders from across British Columbia. The group connected and began to meet to explore a potential partnership. Team members each came with different expertise, but together provided an ideal group to begin to explore this issue. There was a desire to ensure that the voice of those with lived experience of SCI was at the heart of the work and a commitment to contribute actionable and impactful evidence that could improve the health and wellbeing of those living with SCI. As Spring commented:

“ Pressure injury is a leading cause of death for those living with spinal cord injury, but spinal cord injury research that is not patient-led often focuses on less crucial things, like walking, because non-disabled people make research decisions based on erroneous assumptions about what is important to people with spinal cord injury. ”

## HOW DID WE BUILD THIS PARTNERSHIP?

During our initial meetings, our team purposefully spent time getting to know each other and establishing collective goals and expectations. We then began to co-develop a research plan and grant application. Our team was awarded a Canadian Institutes of Health Research Catalyst Grant for Patient-Oriented Research in 2020. Taking the time to develop an engagement plan built on relationship, trust, and authentic partnership was essential if the team was to achieve the goal of contributing diverse perspectives of pressure injury in adults with research that optimizes the health of Canadians with SCI. This engagement plan addressed team members lived experience and strengths,







deliberately thought through to maximize inclusivity of all team members. This included accessible mechanisms for information sharing, scheduling team meetings well in advance and at times that work for team members, and regularly updating the team on study progress between formal meetings and research activities.

Here, we have shared a glimpse into how we have developed, planned, and sustained meaningful and impactful partnerships in this research study, however it is important to note that research teams must find the best practices that work for their particular teams. Maintaining a focus on ongoing communication, revisiting partnership plans and processes often, and supporting co-production at all stages can help teams conduct effective, meaningful, and safe patient-oriented research.

“ Safety lies in the power relationship between healthcare providers and researchers and patients, it can often be unequal. Our partnership space was always a safe place in that we paid attention to the power dynamics and feeling valued for the importance of lived experience.”

– Spring Hawes

From the very start, this work has remained patient-driven and patient-led, providing a vehicle through which to tackle this complex health issue. As a team, we remain deeply committed to advancing the health of

Canadians living with SCI through advocacy and the creation and mobilization of impactful, relevant, and timely evidence.

For more information, please contact: [Davina.Banner-Lukaris@unbc.ca](mailto:Davina.Banner-Lukaris@unbc.ca)

## ACKNOWLEDGEMENTS

We would like to acknowledge that this work is funded by the Canadian Institutes of Health Research and Michael Smith Health Research British Columbia and would like to recognize the contributions of all team members and participants

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# RECRUITING YOUR STUDY PARTICIPANTS MADE EASY WITH REACH BC

By Aisling Quigley REACH BC Marketing and Communications Specialist



Health research is crucial for the development of new treatments and better health care systems, but finding eligible study participants can be challenging. This is particularly reflected in rural and remote communities where recruitment is further challenged by geography. REACH BC would like to partner with researchers in the North to build a community of collaboration between researchers, patients and the public, giving communities greater access to meaningfully take part in health research opportunities.

**REACH BC is a recently created publicly funded online provincial platform that matches research opportunities with study participants across BC.**

It connects members of the public with health researchers for either direct participation in studies and/or allowing them become patient partners informing the research process.

**REACH BC launched in April 2020, and we have now close to 5,000 Volunteer participants on our platform, and about 398 Research Study Opportunities.** An upcoming recruitment campaign will focus on increasing recruitment of rural and remote volunteers in BC, and we would like to have as many research opportunities as possible from the North



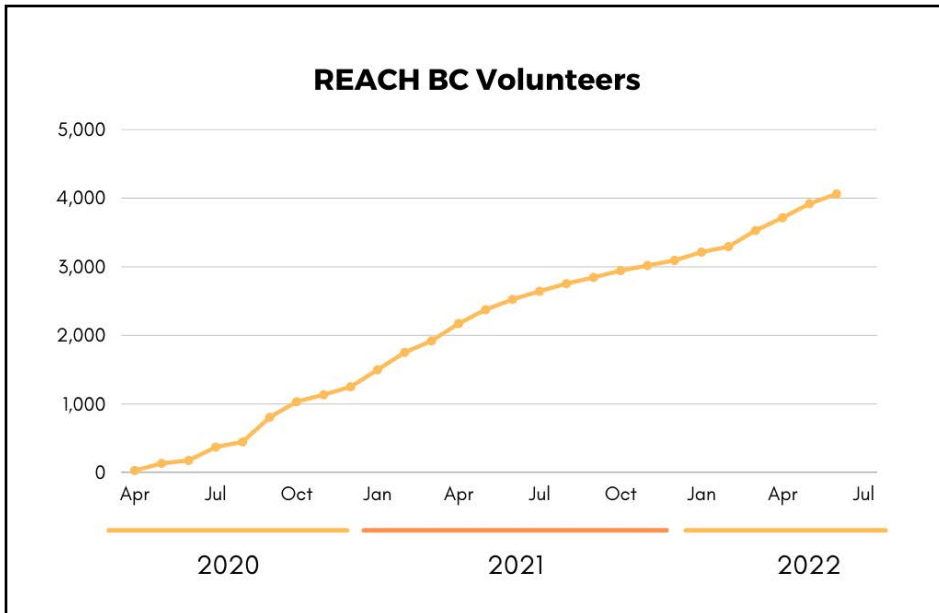
for new volunteers to engage with. Working together, we can build more audiences in rural populations and provide access to as many health research opportunities as possible.

**Important:** volunteer personal information is stored on a secure encrypted server housed in BC, REACH BC is compliant with the BC Freedom of Information and Protection of Privacy Act (FIPPA) and accepted by Research Ethics Boards in BC as a recruitment method.

REACH BC is an initiative of BC's health authorities and partner universities. It is also made possible thanks to valuable input from research institutes, patients, and the public. REACH BC is governed under the Clinical Trials BC unit of Michael Smith Health Research BC.

WATCH what other Researchers had to say on **Leveraging REACH BC as a Researcher in British Columbia:** ([www.youtube.com/watch?v=IWLZPpH\\_lvU&t=62s](https://www.youtube.com/watch?v=IWLZPpH_lvU&t=62s))





### HOW IT WORKS?

When a member of the public (Adult 16+) creates their free Volunteer profile online at [www.reachbc.ca](http://www.reachbc.ca) they get to select which Health Categories are of interest to them, and they can also browse the full directory listing all studies. They choose which study they wish to participate in by clicking I'm Interested which then sends their contact information to the Researcher.

It is very easy to volunteer with only three steps:

- Create a profile with your health research interests
- Get matched and notified with research opportunities by email
- Patient reviews and decides if she/he want to connect with the research team

From the researcher side, projects on REACH BC (both studies and patient partner opportunities) are shared in the publicly searchable online [REACH BC Directory](#). If a volunteer indicates interest in a study, the researcher receives an email notification with the volunteer's contact information. Importantly, researchers can also share study results with the public via the REACH BC platform, therefore supporting knowledge mobilization and increase the visibility of findings and research efforts.

Watch WHY past study participants Volunteered with REACH BC on our brand-new REACH BC Study Participant YouTube video series ([www.youtube.com/channel/UC-vXabxkTlvWAmhfdFNRHag](http://www.youtube.com/channel/UC-vXabxkTlvWAmhfdFNRHag))

“ It's fun! You're interacting with the people who are really dedicated to what they're looking for. They're really receptive to you and they'll answer the questions you have.”

– Sharon Williams  
Research Participant

“ It doesn't take a lot of effort on your part, it's easy to do and you have that warm fuzzy feeling that you're helping other people.”

– Ianna Folkes  
Research Participant

“ My wife went through breast cancer... but the reason she is in remission is because of previous generations doing what I'm doing, contributing to medical research.”

– Jeff Churchill  
Research Participant



# Why Participate in Health Research?

*It's fun! You're interacting with the people who are really dedicated to what they're looking for. They're receptive to you and they'll answer the questions you have.*



Sharron Williams  
Research Participant



Ianna Folkes  
Research Participant

*It doesn't take a lot of effort on your part, it's easy to do and you have that warm fuzzy feeling that you're helping other people.*



Jeff Churchill  
Research Participant

*My wife went through breast cancer... but the reason she is in remission is because of previous generations doing what I'm doing, contributing to medical research.*

Create your REACH BC Researcher Account [HERE](https://www.reachbc.ca/researcher) today (<https://www.reachbc.ca/researcher>)

**Please contact us below with any questions you may have:**

Stef Cheah REACH BC Manager  
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Aisling Quigley REACH BC Marketing and Communications Specialist  
[aquigley@healthresearchbc.ca](mailto:aquigley@healthresearchbc.ca)

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## GRADUATE SUMMER INTERNSHIPS



In June 2010 Northern Health (NH) provided a grant to University of Northern British Columbia (UNBC) to support a joint initiative between the School of Business and the Planning and Performance Improvement Department.

The initial focus of the initiative was on Project Portfolio Management (PPM) the focus subsequently changed to Business Process Management (BPM) and Enterprise Architecture (EA) with representatives of University of Northern BC (UNBC) and Northern Health (NH) signing a letter of agreement in December of 2014. This partnership has expanded with a renewed focus on funding internship and research opportunities for students in the UNBC School of Business and Economics in order for them to gain 'hands on', practical experience within the health system. Through this partnership we are creating an enriched and sustained learning and research environment across both NH and UNBC, while addressing

NH organizational challenges associated with operating a complex system.

During the summer of 2022, five UNBC students embarked on internships through this partnership. They focused on unique projects in various areas such as health communication, developing a data inventory for research purposes, and predictive modeling for future planning operations. Recently, we sat down with three of these interns to learn more about their projects and learnings:

### **PROJECT: ADVANCED ANALYTICS**

**By:** Galen Sailis UNBC  
MSc Candidate

**NH Supervisor:** Jim Condon,  
Regional Lead, Data Science

### **ACTIVITIES**

#### **Unplanned Surgery Forecasts**

My main project was forecasting the number of unplanned surgeries at University Hospital of Northern British Columbia (UHNBC). The purpose of this forecast was to inform stakeholders of how to best allocate resources in the coming year to meet demand of operational services.

I used a combination of exploratory and predictive modelling techniques to understand the data generating process, and forecast the demand for the next year. The best model had a combination of a very slight trend and three strong periodicities.





Beyond the core deliverables of the project, I developed an end-to-end process for updating the forecasts. With a single command we can now pull fresh data, retrain the model, make new forecasts, and push those fresh forecasts to a database. With the guidance of my colleagues in Strategic Analytics, I developed a Tableau dashboard which presents the latest forecasts in a visual summary. This provided a precedent for future projects that we can leverage automation to reduce the human resources normally required to refresh our forecasts.

### Data Science Presentations

The data science presentation series is an opportunity to educate and share ideas about how data science can provide value at Northern Health. I gave five such presentations on topics including forecasting models such as Seasonal Auto-Regressive Integrated Moving Average with Exogenous factors (SARIMAX), interval arithmetic for handling uncertainty in measurements, and a deeper dive into correlation than what typical introductions to statistics offer. I had a lot of fun prepared and giving these talks, and the following questions and discussion were thought-provoking.

### Various

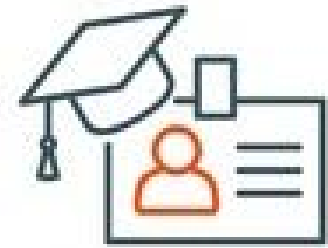
I was involved in other projects during my term at Northern Health in addition to my main project.

Jim Condon introduced me to Dr. Andrew Deonarine (Medical Lead, Informatics), and I have been collaborating with him ever since. We're developing a novel approach to evaluating the effects of geography on the relationship between COVID-19 outcomes and chronic health factors. Very exciting stuff!

Another project I started work on was rapid estimates of length of stay. There is an existing process to estimate length of stay, but it often takes longer to get those estimates than it does for the patient to be discharged after admission. I set up data pulling and engineering features for machine learning models, and prepared a proof of concept for a graphical user interface to present results. We want to make further improvements to the model before deployment, but I made significant progress in getting that project up and running.

### OVERALL, WHAT ARE YOUR LEARNINGS?

We found that unplanned surgeries do not vary much, with 99% of observations falling within 2-15 surgeries per day. The trend since 2014 to the present is negligible, giving a practically-constant forecast for the coming year. And the three aforementioned periodicities indicated that the number of unplanned surgeries approximately repeated every 7 days, 3.5 days, and 2.33 days. Naturally, most people live according to a 7 day week so the former was unsurprising. But the story behind the other two seasonalities remains unexplained.



While not an explicit goal of the analysis, it was interesting to note that COVID-19 had no substantial effect on the demand of unplanned surgeries at UHNBC. Given that COVID-19 has had an immense impact on many areas of healthcare, including planned surgeries at UHNBC, this was a non-obvious finding.

Finally, I was a contributing member to the Data Science Team within Strategic Analytics. This internship was an opportunity for me to see if I would enjoy working in data science within a healthcare setting. Sufficed to say, it was an extremely positive experience for me this summer. There were lots of interesting problems to sink my intellectual teeth into, and the people I worked with were exemplary.

For more information about this project or follow-up activities, please send an email to: [Jim.Condon@northernhealth.ca](mailto:Jim.Condon@northernhealth.ca)

### PROJECT: CERTIFIED, SAFE, AND ANALYTICS READY DATA SOURCES

**By:** Sanjeev Rohilla  
UNBC Student

**NH Project Supervisors:**  
Julia Bickford, Andrea Lorette & Connie Crittin



## OVERVIEW

The overall intent of the project was to create a list of data sources along with the metadata information from numerous databases and systems that stores data within Northern Health, to be accessed by researchers.

NH uses a wide array of Health Applications for gathering data from encounters between patients and various health facilities across Northern Health. This data ranges from Administrative, Clinical Care, Assisted Care, Lab, Imaging, Pharmacy, Drugs, and Vaccinations.

## WHAT IS THE REAL PROBLEM?

There are numerous databases and systems that store data within Northern Health. Some are developed for easier analyst access, apply standard definitions, and have supporting metadata, while others do not. Identifying data sources that are Certified, Safe, and Analytics-Ready for sharing with the research community required discussion with NH stakeholders. NH must follow the Privacy Impact Assessment (PIA) and the method used to share the information will be assessed with a Security Threat and Risk Assessment (STRA); the data requested by researchers will be made available only after proper due diligence. NH must ensure the data source is Certified, Safe, and Analytics Ready to

accomplish this. However, this needs to be addressed for a specific data request on a case-by-case basis.

## WHY IS THIS RELEVANT?

There is a need to define a proper subsequent methodology to identify the criteria for ensuring the data source requested by the research community is Certified, Safe, and Analytics-Ready.

## HOW WILL THE PROBLEM BE SOLVED?

The problem is vast, and the solution involved interacting with business and technical stakeholders at NH. These stakeholders understand the finer details about the data sources as they are responsible for utilizing applications and systems interacting with the data sources. During the process, we created a checklist document containing a list of questions to help gather responses from the business and technical stakeholders to identify whether a data source is Certified, Safe, and Analytics-Ready before sharing for research purposes.

Additionally, a list of data sources has been prepared with relevant high-level business metadata. The list is expected to be published on the NH Web portal. The information will be handy for the data requestors and the research community. As a first step, they can refer to the metadata published for readily available data sources within NH.

## OVERALL LEARNINGS

I enjoyed working on the data sources project this summer. I am sure it will help me expand and seek future career opportunities at NH and in the health care sector of Canada. Below are some of the highlights of my learning:

- Learned about various data sources and health applications being used at NH
- Utilized my previous healthcare experience to relate to the project requirement at NH
- Gained insights into Canada-wide and Northern Health specific healthcare standards
- Enjoyed the working culture at NH
- Connected with several stakeholders and made new friends.

For questions or clarifications about this project, please email: [andrea.lorette@northernhealth.ca](mailto:andrea.lorette@northernhealth.ca)

## PROJECT: DEVELOPMENT OF AN AUTOMATED AID FOR HEALTH COMMUNICATION PROFESSIONALS<sup>1</sup>

**By:** Ankit Bhatia UNBC Graduate Student and Mitacs Accelerate Intern

**NH Project Supervisor:** Steve Raper Vice President, Communications & Public Affairs

(1) This research project obtained Ethics Review approval.



## OVERVIEW

This project received matched funding through a Mitacs Accelerate award. As it was directly related to the students' Master's theses, it received ethics approval. This was a team project where I handled the Business side, and my colleague Colton Aarts developed the tech side. The project built on the findings of a former student Aiden Winkel. Over the course of the COVID-19 pandemic, Aiden analyzed the ways and need to automate the daily practices in the digital communication department of Northern Health. This project and its subsequent advances recognize the fact that in addition to the importance of effective health communication, there is a realization that about 60 % of Canadian patients lack the necessary health literacy skills to effectively navigate the healthcare system (O'Donnell, 2017). According to Beaunoyer et al., 2017, when presented with health materials that are difficult to read or understand, patients are likely to move toward accessible yet unprofessional health resources such as Wikipedia. This moves the locus of control away from reputable health organizations. Furthermore, it causes patients to miss vital and accurate health information.

## PROCESS AND GOAL

Based on the background described above, a key objective of the project was to develop and automated

Information System to aid the requirements of the NH Communications department. Interviews were conducted to understand the specific needs and specifics about the project. The goal was to follow an organized approach as a Systems Development Life Cycle or SDLC. While conducting interviews, the whole process of forming the context from the data to posting was analyzed, keeping in mind different perspectives, approaches used, and problems encountered.

A 6-7 feature, algorithm-based, tool (Solution) was proposed to make an automated system to help professionals work more efficiently and effectively, removing out all the disturbances/problems encountered and narrowing it to a semi-automated tool. This also helped us to eliminate the multiplatform use while constructing a message. The features of the tool included a sentiment analysis, reading level assessment, Northern health style guide etc. While in the development stage, the shift from SDLC to a more agile approach happened, making the project more "feedback" based that professionals can easily use. This also helped to evaluate the tool again and amend it to finish the project in the desired timeframe. It was so informative to study the resources (such as the public concerns database) at Northern Health and how the professionals navigate through them.

This research project obtained Ethics Review approval.

## WHAT ARE YOUR OVERALL LEARNINGS?

To begin with, I would like to thank everyone, whom I worked with this summer and that provided an exceptional learning experience for me. I had a bit of experience in working with small organizations, but this was the first time I worked with a huge organization. I surely learned a lot in this internship. I learned how an idea itself cannot change anything and there is a big process of implementing an idea into an already established system. I used all my academic knowledge and research in the project which gave me real-world experience and different applications. I am still linking all my findings from this project to my current MIS courses at UNBC.

## REFERENCES

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# RESEARCH HIGHLIGHTS



## 1. NEW RESEARCH STUDIES IN THE NORTH

NH has been revamping and expanding its research capacity. The following list includes the newest research projects happening across the North and authorized during Q1 of 2022.

	Principal Investigator	Institution	NH Affiliated Research Team Member	Study Title	HDSA / Area	Facility
1	Nelly Oelke	UBCO	N/A	Transport Stories	All	Emergency Departments throughout NH Region
2	Zaid Mammo	UBC	N/A	Dr. Altitude	PG	No NH Facilities; only Dr. Lukaris ophthalmologist clinic in PG
3	Floyd Besserer	UBC	N/A	Door-to-ECG time at UHNBC	PG	UHNBC, Emergency Department
4	Shannon Freeman	UNBC	N/A	eReader project	NI	Jubilee Lodge, PG Gateway Lodge, PG Laurier Manor, PG Dunrovin Park Lodge, Quesnel
5	Michelle E. Pidgeon	SFU	N/A	Sonography Practicums	All	Fort St. John Hospital, Ultrasound Dept GR Baker, Quesnel Kitimat General Hospital Mills Memorial, Terrace UNBC
6	Erin L. Martin	NH	N/A	SB-NETs Northern BC FLEX	All	No NH Facilities
7	Robin Roots	UBC	N/A	Mentorship Recommendations for New Physiotherapists in Northern, Rural or Remote Settings	All	All
8	Shannon Freeman	UNBC	Aaron Bond	End users' perspectives on the feasibility and/or usability of emerging technologies for supporting persons who are aging and care partners in rural and northern BC	All	Virtual



	Principal Investigator	Institution	NH Affiliated Research Team Member	Study Title	HDSA / Area	Facility
9	Wendy Young	Royal Roads	Rebecca Borton, OD, Psychological Health & Safety Consultant /  Peter Martin, Executive Lead - Recruitment and Retention Initiatives Committee	Supporting a Northern Health Employee's Post Parental Leave Return to Work	NE	Fort St. John HSDA
10	Karen Dahri	VCH	N/A	Perspectives on Adherence Screening Tools by Hospital Pharmacists	All	Pharmacy staff
11	Jeffrey R. Brubacher	UBC	Floyd Besserer / Catherine St. George	National Drug Driving Study	PG	UHNBC, Emergency Department & Medical Lab
12	Jude Kornelsen	UBC	N/A	Outreach specialist experience in rural BC hospitals	NW	Communities: Hazelton, Smithers, Vanderhoof  Bulkley Valley Hospital/Smithers

For specifics about these projects or related information, email: [marcelo.bravo@northernhealth.ca](mailto:marcelo.bravo@northernhealth.ca)

## 2. NEW PUBLICATIONS

### Book release: Introduction to Determinants of First Nations, Inuit, and Métis Peoples' Health in Canada

By Margo Greenwood, Sarah de Leeuw, Roberta Stout, Roseann Larstone, Julie Sutherland

#### Overview

This critical new volume to the field of health studies offers an introductory overview of the determinants of health for Indigenous Peoples in Canada, while cultivating an understanding of the presence of coloniality in health care and how it determines First Nations, Inuit, and Métis peoples' health and well-being.

The text is broken down into the What, Where, Who, and How, and each part contains a comprehensive and holistic approach to understanding the many factors, historical and contemporary, that are significant in shaping the life and health of Indigenous Peoples in Canada and beyond. Comprising wisdoms from First Nations, Inuit, and Métis leaders, knowledge holders, artists, activists, clinicians, health researchers, students, and youth, this book offers practical insights and applied knowledge about combating coloniality and transforming health care systems in Canada.

Compiled by experienced editors associated with the National Collaborating Centre for Indigenous Health, Introduction

to Determinants of First Nations, Inuit, and Métis Peoples' Health in Canada draws together the work and writings of primarily Indigenous authors, including academics, community leaders, and health care practitioners. This accessible and timely introduction is a vital undergraduate resource, and invaluable for introducing key concepts and ideas to students new to the field.

\*With information from: Canadian Scholars.

For complete information about this book release, visit: [Introduction to Determinants of First Nations, Inuit, and Métis Peoples' Health in Canada - Canadian Scholars](#)