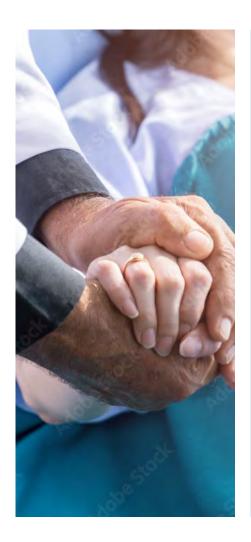
Research and Knowledge Translation Newsletter



There is growing interest and mandates to work in partnership with people seeking health care services, their families, and communities.





INTERESTED IN ENGAGEMENT BUT NOT SURE WHERE TO START? INTRODUCING AN ENGAGEMENT PLANNING TOOL

By: Tina Strudsholm, Lead Person and Community Engagement Kim Eggers, Patient Partner, Patient Voices Network Linda Weeks, Patient Partner, Patient Voices Network Rutendo, Madzima, Patient Partner, Patient Voices Network Marlene Apolzcer, Quality Improvement Lead Cathy Almost, BCPSQC Sarah Munt, Project Coordinator Lee Cameron, Physician Quality Improvement Coach

There is growing interest and mandates to work in partnership with people seeking health care services, their families, and communities. In fact, partnerships are foundational to Northern Health's definition of a Person and Family Centred Care approach:

"Person and family-centred care is an approach to the planning, delivery, and evaluation of health services grounded in mutually beneficial partnerships among health care providers, patients/clients, and families. It redefines the relationships in health care and leads to better health outcomes, wiser allocation of resources, and greater individual and family satisfaction" (emphasis added, Northern Health. Strategic Plan Looking to 2021 p.10).

Specifically, partnerships within the contexts of health services research, planning, implementation and evaluation have been lauded as a strategy to advance the quadruple/ triple aim1 and reduce the gap between evidence and practice. Northern Health explicitly links quality and continuous improvement in the current strategic plan, Looking to 2023, with a commitment to embed a PFCC approach (i.e., mutually beneficial partnerships) in everything we do.

found that the key to a successful partnership is showing up at any given "table" with an open mind; ready to truly hear each other and willing to apply our collective knowledge and wisdom in a collaborative manner, in order to co-create better healthcare for all involved. ##

Kim Eggers



¹ Northern Health. Quality framework. p.6.

Experienced Patient Partners also assert a connection between successful partnerships and optimizing the health care system:

To realize the full promise of engagement, Northern Health leaders in engagement and quality improvement, in partnership with the BC Patient Safety and Quality Council and experienced Patient Partners are pleased to present a "How to Guide" linking users to leading best practices and resources for planning engagements as well as tips to foster successful partnerships. This resource is accessible on ourNH or by request to: QualityandInnovation@ northernhealth.ca

To supplement the information presented in the guide, the following provides additional considerations when engaging health care users as partners on health care improvement projects, committees, or working groups:

- 1. Reflect on your own biases and consider how to address cultural safety. As stressed by patient partner Rutendo Madzima: "cultural safety should be considered in the planning stages of an engagement so that it becomes embedded in how engagements are done and not just an add on". Visit Northern Health Indigenous Health Cultural Safety for resources, and keep an eye out for a new guide from BCPSQC about planning for culturally safe engagements to be released 2021.
- For quality improvement and health system governance work, it is recommended that you

- reach out to the Patient Voices Network (PVN) through the **BC Patient** Safety & Quality Council (BCPSQC) where you will be connected to a BCPSQC Engagement Leader. They will ensure that you are able to include one or more of the many PVN Patient Partners that volunteer to help improve healthcare. (Visit BCPSQC Become a health care partner). Alternatively, consider recruiting through your existing networks.
- 3. When seeking partnership in health research, consider recruitment through ReachBC, a provincial online platform for Patient Partners and researchers interested in working together.



- 4. Leadership is key! Once you have found the right Patient Partners, make sure to let the other team members in your group know that these partners are equal representatives going forward on the project, ensuring that their feedback and suggestions are considered throughout. During meetings, ensure that the Patient Partners know that they are welcome, as well as, welcome to contribute, whether by verbal encouragement or by adding a specific time slot on an upcoming meeting agenda for them to address or present to the group.
- 5. Appoint a Liaison.
 Have one key contact person from within the group that Patient Partners can reach out to ensure that they can be fully participating members.
 The liaison can answer any questions they may have, especially if they
- are joining the project or committee later than the other members. They can also enable better communication between Patient Partners and the healthcare or research partners. As well, they can ensure that any reading materials necessary in order for the Patient Partners to be fulsome contributors within the group, such as backgrounder materials, previous minutes and agendas, previous presentation slides, and upcoming meeting agendas, are sent out within a certain timeframe so that they have enough time get up to speed or consider an orientation if they have not been a member of the group from the beginning. Make sure that the liaison you appoint has time to review the following document on how to liaise in the best way possible. (Alberta Health Services.
- In my view successful engagements happen when the expected outcomes from patient partners are clear, and the individual leading the engagement is able to act as a facilitator and steer the discussions to capture what is most relevant to the engagement.

Rutendo Madzima, Patient Partner

- A Resource kit for engaging patients and families at the planning table. p 7-8)
- 6. Ensure that the Patient Partner(s) understand the scope of the project or committee that they will be working on. As well, inform them at what level of involvement they will be participating at according to the International Association of Patient Participation (IAP2)

 Spectrum of Engagement.
- 7. At regular intervals throughout, ensure that the Patient Partner(s) are kept up-to-date on any new developments during a project or on committee business.
- 8. Just like many jobs, Patient Partners sign up for a specific "term". Once their term has been fulfilled, make sure that they are appropriately thanked and acknowledge their contribution to the group.
- 9. Close-the-Loop with the Patient Partner. It is important that the Patient Partner(s) know that all the time and effort they have contributed as volunteers, has hopefully helped improve the healthcare system that they are so passionate about. The following link will give you some great ideas on how to do so (BCPSQC & PVN. 10 Tips for closing the loop).



10. If the group or committee continues on regardless of the Patient Partners' participation and you feel that their contributions continue to be applied to the success of the engagement aims, continue to reach out occasionally, by email, for example, to update them on the positive progress of the project/committee.

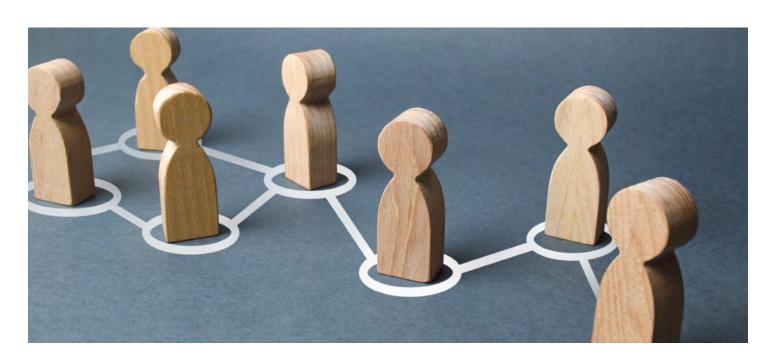
ADDITIONAL TIPS AND RESOURCES TO SET YOUR PARTNERSHIP UP FOR SUCCESS:

- Ask the Patient Partner what information they need to be able to fully participate and contribute to the group,
- Determine how to provide equal access to the group's documents and resources.

- Cover costs incurred by the Patient Partners. Things such as parking, printing, or travel,
- Consider remuneration such as honorariums (<u>Northern Health</u> Honoraria Policy),
- Be considerate of
 Patient Partners' needs,
 such as possible chronic
 health conditions,
 scheduling issues, self-care
 needs, accessibility,
 or mobility issues,
- Use inclusive language (BCCDC Language Guide),
- Include as many Patient
 Partners as possible on any
 given project, committee,
 etc., in order to ensure
 that diverse perspectives
 are considered.

As a final tip about planning for engagement, consider the contribution of your engagement "process" vs. "content" in determining your success. For example, Linda Weeks, Patient Partner, attributes success of an engagement to the process itself: "I feel that the top characteristic of a successful engagement is when after weeks of meetings and discussion the panel is satisfied with their achievement of working together and sharing their own experiences, thoughts; and ideas". Engagement leaders echo this distinction and often herald the importance of "process" over "content" to emphasize the importance of planning for engagement. As you work through the steps to plan your engagement, rest assured that you are creating a clear engagement process and setting your partnership up for success.

You are not alone! Reach out to the key contacts listed in the guide for support and guidance.



CULTURE SHIFT: RESEARCH IS PART OF CARE. STRENGTHENING CLINICAL RESEARCH OPPORTUNITIES IN THE NORTH

by Julia Bickford and Catherine St. George

Ten years ago, soon after my second daughter was born, we received news that a close family member was very ill with cancer, for the fourth time. Her health care team tried everything they could as part of routine care and established best practice but the chemo, radiation, and surgery were just not working. The cancer continued to spread. Fortunately for this family member, she lives within an hour drive of a major metropolitan centre with an established clinical trials unit. She was offered the choice to either pursue palliative care or access cutting edge clinical trials as part of her care. She decided to participate in a clinical trial. Several times a week she drove into the city to receive her therapy. Her treatment had side effects; it ended up damaging her heart but thankfully it also eliminated the cancer in her body. Through participants like her, scientists learned important insights about the safety of this therapy, about effective dosing, and about the impact on other organ systems. This month, my daughter turns eleven and this family member will be flying out to visit and join the birthday celebration. Without access to that trial ten years ago, her only option would have been palliative and she

likely would not be alive today.

There are many reasons why I'm motivated and excited to be involved in the development of clinical research infrastructure and capacity, along with many other dedicated people in Northern BC. The family experience that I have shared above has profoundly impacted the way I view the relationship between research and care. I have witnessed first hand how clinical trials can increase the options and choice available to patients. I firmly believe that research is part of excellent care and that access to this care should be available for everyone, whether you live in Atlin, Haida Gwaii, Valemount or anywhere else in the north.

According to the Canadian Institutes for Health Research. clinical trials are "studies used to evaluate the safety and effectiveness of a treatment. For example, a clinical trial might compare a new drug to a placebo, or to a drug already used to treat the condition (a comparator), if one exists. Once the safety of the new drug has been demonstrated in tests on animals, it goes through a rigorous, multi-phase testing process to determine its safety and efficacy in treating human patients.
All clinical trials
conducted in
Canada must
first have Health
Canada approval."
(CIHR-Jargon
Buster, 2021).



Health Canada approval for a clinical trial requires a Clinical Trial Application (CTA) and Clinical Trial **Application-Amendment** (CTA-A) if any changes are made. This process screens all applications for acceptability and deficiencies. Should the application pass this step the process continues to evaluate the clinical safety and efficacy as well as the quality of the trial and manufacture of the drug under study. A successful CTA receives a No Objection Letter (NOL). The NOL, approval of the local Research Ethics Board (REB) and any other required local reviews must be completed and approved before a Clinical Trial can start.

The ongoing review of these drug products, even following their initial approval, provides Canadian care providers and patients with the best body of knowledge on each Health Canada approved product.

that research is part of excellent care and that access to this care should be available for everyone.



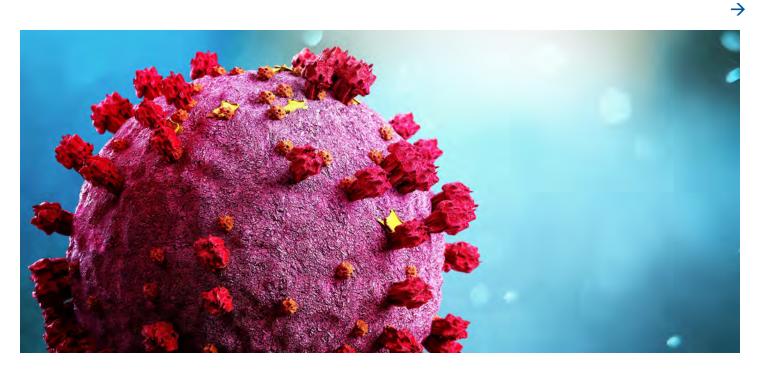
WHAT WE LEARNED FROM COVID-19

During the last 21 months since COVID-19 first appeared, many weaknesses have been exposed in our fragile clinical research ecosystem in British Columbia. Innovative biotech companies in our own backyard were not able to test novel treatments within the BC Health Authorities. These BC biotech companies tested their novel therapies in other regions of Canada and the United States because the research infrastructure and capacity were not well established here. We have a culture in which research and care are believed to be distinct and there is a common perception that research is a costly diversion from "real" clinical care. Several researchers in Canada have begun to look to the United Kingdom (UK) as an example where research is integrated in

care (Lamontagne et al., 2021; Murthy, Fowler & Laupacis, 2020). The UK infrastructure required to run clinical studies is funded through the National Health Service (NHS). In this case, the UK was able to rapidly mobilize this existing clinical research infrastructure embedded in routine clinical care to enrol patients into clinical trials making substantial contributions to the global understanding of effective COVID-19 treatments (94% of the data informing recent WHO guidelines came from the UK) (Lamontagne et al., 2020). We can do this too!

Over the last year, Northern Health (NH), UNBC and UBC have been writing a proposal to develop a Northern Centre for Clinical Research. The north is too small to build infrastructure in silos. If we work together in partnership and share resources where they need to be in place, patients and researchers in the north will benefit. This proposal is currently making its way through the Boards and Senates of these three governing institutions with hopes that the Centre will be running in 2022.

Importantly, through an emergency funding award from the Michael Smith Foundation for Health Research (now Michael Smith Health Research BC), Northern Health has begun to build the necessary capacity and infrastructure to enable more northern residents to participate in clinical trials. We now have dedicated resources to support privacy and ethics and to establish standard operating procedures and policies. Moreover, COVID-19 has brought Health Authority research leaders together and there is momentum and open willingness to share and learn from one another.





One of the exciting new additions to the Northern Health Research Department is our first ever Regional Manager of Clinical Research, Catherine St. George. Recently, I sat down with Catherine to hear about her insights and vision for clinical research in the north.

1. You have been involved in clinical trials research for many years. What is the most important lesson you've learned that would be helpful for NH to attend to?

I have been involved in Clinical Research for over twenty years. In this timeframe, I have worked for large pharmaceutical and academic sites, small biotech companies, and even smaller not for profit investigator sites. In all cases, success is achievable when you start with what you know well and build over time. While working with a small group of physicians in Prince Edward Island they became the top Canadian recruiter in a Phase II anesthesiology trial with larger participant numbers than sites in both Toronto and Montreal.

The Northern Health
Community has many strengths
to build on. The interest
expressed by the citizens,
NH senior leadership, health
care providers, and Canadian
research funding partners
alone is a major building block
for ongoing and future
research success.

2. What gets you excited about this new opportunity for clinical research in northern BC?

There is nothing I enjoy more than "thinking outside the box", devising and implementing ideas that enable clinical research team members to bring their projects to successful outcomes. Bringing research to a large geographical area with a small diverse population will take excellent listening skills on my part to help create strategies that reflect the interests of researchers and Northern Health communities and patients.

3. How do you feel this new area of research might impact patients and communities in the north?

Clinical research provides patients with additional treatment options allowing the patients to participate while maintaining contact with their local health care providers. surrounded by the comfort of family. A key point in initiating projects in Northern Health will be to ensure that these projects have a research question that engages and values the needs of staff and community. Ideally, these projects will bring results and conclusions that can be disseminated and utilized to improve patient care within the region.

4. What advice do you have for NH clinicians or staff who might be interested but brand new to clinical research?

Every hour of preparation before you start a clinical research project decreases bumps along the way and leads to successful experiences for both participants and medical staff. Involvement in clinical research is definitely worth the effort for anyone in Northern Health no matter their initial experience level.

There is still much work to be done to facilitate clinical trials in the north. One of the most important gaps that we need to address is how to work closely with communities in order to ensure that patient experience and culturally safety are valued throughout the entire clinical research process. In addition, we look forward to working with new investigators and NH staff to facilitate access to training

and education to support regulatory compliance in clinical research. We have recently adopted a new clinical trials management software (with funding through Clinical Trails BC) and will be implementing a Quality Management system to ensure proper document management.

As we near the end of another calendar year, it is exciting to look back on the many small ways we are collectively building clinical research capacity and gradually changing culture in Northern Health. We look forward to further strengthening our relationships with patients, communities, and academic partners in 2022.

If you are interested in getting involved in clinical research or if you have any questions about the work we're doing, we would be delighted to connect with you! Please reach out to:
research@northernhealth.ca

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SPOR WORK MOVING INTO PHASE II

by Marcelo Bravo and Leana Garraway



The Strategy for Patient Oriented Research (SPOR), a CIHR multi-year funded initiative is transitioning to its Phase II of operations. Its new phase overarching vision is to bridge the gap between research evidence and health-care practice and policy through the provision of Patient-Oriented Research (POR) services and supports. In the last 5 years, Phase I work was pivotal while laying the foundations to develop structures, capacity, and renewed interest from various stakeholders¹ in the healthcare space to adopt a more patient-centred approach in the evolving health sector work.

Phase I was successful in leveraging patients' roles to become key partners in many provincial and regional health initiatives. As a result, SPOR work made significant efforts in including patient-partners² as a way to provide meaningful opportunities for patient engagement in health research, as well as to open and expand spaces for patient representation in health improvement work.

Phase I was successful in leveraging patients roles to become key partners in many provincial and regional health initiatives. As a result, SPOR work made significant efforts in including patient-partners²

as a way to provide meaningful opportunities for patient engagement in health research, as well as to open and expand spaces for patient representation in health improvement work. Phase I also dedicated significant investments to exploring challenges and opportunities of working with research data. Specifically, the development and use of Research Electronic Data Capture (RedCap) webapplication, signals a new phase of data services integration and portability that will allow the province to have a shared data platform and services that will streamline POR research supports. A successful component of Phase I was the development of methods, tools and guides for effective training and work with researchers. patients, health care staff and care-givers. These methods and tools are now archived and available to everyone on the BC Support Unit site: https://www. bcahsn.ca/learning.

Another unique aspect of Phase I work was in the area of supporting knowledge translation (KT) while working with health researchers to better mobilize research outputs to audiences and decision makers beyond academia.



¹ BC Support Unit work aligns with the Canadian Institutes of Health Research (CIHR) definition, identifying POR stakeholders to be inclusive of patients, researchers, health-care providers, and health systems decision-makers.

² Particularly, people with lived experiences and caregivers.

This stream of work also included supporting evidence based practices and various forms of KT work in Health Authorities. KT work in our province continues to evolve allowing new approaches of working with patients (integrated Knowledge Translation³), as well as better and improved scientific communication tools for broader impacts. Finally, a structural part of Phase I was in the realm of Capacity Development, this work included a renewed commitment to working with partners outside of the healthcare sector but that are strategic in the healthcare ecosystem such as universities, research centres, governmental agencies, citizen's groups, etc.

In this regard, the Northern Centre, which is the regional representation of the BC Support Unit for BC's north, is a living example of a partnered initiative between NH and UNBC. This unique partnership allows for joint identification of regional priorities, shared work, synergies, and joint supports for researchers, health practitioners, and training for a new generation of health leaders in the region. From the perspective of BC Support Unit, Phase I capacity development work put an emphasis on developing a healthy balance between centralized and regional areas of work and supports.

A major achievement of Phase I was to effectively work in coordination with regional health authorities, – Northern Health being one of them. This centralized-regional approach to work signifies a priority of supporting localized Patient-Oriented Research work to better respond to regional interests and contextual realities in the north, and that allows for sustainability of operations.

Phase II of SPOR with formal planning underway, constitutes a unique opportunity for the consolidation of efforts and achievements of Phase I and leading now towards sustainability while working towards the advancement of a Learning Health System at a Provincial level and at the regional levels.

A Learning Health Systems as explored by Menear et al. (2019, p.3) refers to "dynamic health ecosystems where scientific, social, technological, policy, legal and ethical dimensions are synergistically aligned to enable cycles of continuous learning and improvement". It is expected that health authorities will continue working for systematized comprehensive learning cycles that allows faster identification of areas of concern based on aligned emerging evidence, and faster and better coordination amongst teams and stakeholders for continuous improvement and a culture of learning. The LHS's maximize data alignments coming from patients, practicing clinical teams, and new research evidence with the ultimate goal to improve patient's

outcomes, support providers' experience, optimize health care investments, and inform health research agendas.

In addition to its LHS broader work. Phase II will include two new areas of focus: Indigenous Health Research, and Justice, Equity Diversity and Inclusion & Gender Based Analysis. These two new areas of focus and the opportunity to work with new partners are a direct response to calls to continue working on the transformation of our healthcare system and research environments. A fundamental tenet of POR is to support initiatives where patients and community members can be seen. heard, and treated according to their dignity. Historically, the geographical distances and diversity of communities in the north have created challenges to health care access and delivery, many of these challenges are embodied in real health inequities that are reflected in varied health outcomes. At BC Support Unit Northern Centre, there will be a renewed interest to connect and extend opportunities to communities that are interested to be engaged, and that bring the richness of rural and remote diversity into an ecosystem of health research that values and embraces diverse patient participation. We will co-develop mechanisms of meaningful participation, allowing diverse voices to be heard, and to extend patient representation in priority setting agendas and implementation work.

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³ To know more about integrated knowledge translation, visit: https://cihr-irsc.gc.ca/e/45321.html#a3

Significantly, SPOR II points out to dedicated and respectful work in Indigenous Health Research area; this new focus area of work is in line with renewed Northern Health and UNBC commitments to meaningful efforts and dedicated actions towards reconciliation and cultural safety work. Efforts on this front will be done in close alignment with British Columbia Network Environment for Indigenous Health Research (BC NEIHR)⁴ northern representatives upholding the values of respect, reciprocity, and close coordination amongst programs and institutions. BC's north and its diverse Indigenous communities are uniquely



positioned to play an important role in the work of Indigenous health research and cultural safety in our province. In spirit of allyship, SPOR Phase II work will aspire to develop respectful and meaningful partnerships and programs to advance in jointly identified Indigenous Health Research objectives.

Phase II will also provide the opportunity to work with major provincial and national initiatives identified by CIHR as signature Patient Oriented programs whose sustainability will continue providing benefits beyond Phase II years. These SPOR funded entities are: SPOR Evidence Alliance (EA), SPOR National Training Entity (NTE), SPOR Canadian Data Platform, and network entities such as: CHILD-BRIGHT, Chronic Pain Network, Diabetes Action Canada, IMAGINE, Can-Solve CKD, Primary and Integrated Health Care Innovations and Youth and Adolescent Mental Health. These extended areas of work will allow further collaborations. national synergies, as well as new spaces for BC's north to effectively contribute to provincial and national Patient Oriented Research work.

Finally, Phase II of SPOR is a major call to ensure sustainability of operations, particularly in critical areas such as Patient Engagement, Clinical Trials, POR methods, KT and evidence based practice, respectful participation of

Indigenous communities, and meaningful inclusion of diverse populations including rural and remote communities.

In response to the COVID-19 pandemic, the healthcare sector and partners have shown they can rapidly change and adapt to confront new challenges, many of them of collaboration and coordination. However, this healthcare challenge has also pointed out that regional approaches are required to better serve the specific needs of our truly diverse communities. At this unique crossroads of time, the BC Support Unit Northern Centre is committed to advancing Patient-Oriented Research for a more responsive and patient-oriented healthcare with the ultimate goal to improve health systems that advance the experience and health outcomes of our communities.

For further information about SPOR, support services and activities, click here: https://www2.unbc.ca/health-research-institute/bc-support-unit-northern-centre

REFERENCE

Menear, M., Blanchette, MA., Demers-Payette, O and Denis Roy (2019). A framework for value-creating learning health systems. Health Research Policy and Systems. No. 17, Article number 79. https://doi.org/10.1186/s12961-019-0477-3

⁴ For more information about BC NEIHR, vision, programs and opportunities, visit: BC NEIHR – British Columbia Network Environment for Indigenous Health Research (uvic.ca)

UPCOMING EVENTS

REMINDER — REGISTRATION IS OPEN FOR THE 2021 NORTHERN BC RESEARCH AND QUALITY CONFERENCE! DECEMBER 7-9, 2021.

The Northern BC Research and Quality Conference is a forum enhanced with resources and skill development workshops to share health and health services research, evaluation, evidence-based practice and quality improvement initiatives in the North.

Join in workshops, presentations, and discussions about these timely themes in health care:

- Innovations
- Equity
- Cultural Safety
- Health and Wellness
- Sustainable Systems

Connect virtually with other health care providers, researchers, quality improvement experts, students, and people seeking health care services.

Key Note Speaker:

Dr. Mary Ellen Turpel-Lafond,

Senior Associate Counsel, Woodward and Company

Plenary Speakers:

Dr. Danielle Lavallee,

Scientific Director for the Michael Smith Health Research BC

Shirley Wong,

Executive Project Manager, Strategic Data Initiatives at the Ministry of Health

Conference Highlights:

- Patient Partner engagement
- 36 oral presentations
- 5 rapid fire presentations
- Over 40 posters
- Door prizes and prizes throughout the event
- Connect and network with Quality and Research colleagues across the North

This is a free virtual event open to everyone, but registration is required. <u>Please register here</u>.

Feel free to join the sessions that appeal to you. Your attendance is not required for the whole event.

If you have any questions, please email: research@northernhealth.ca.

