

Sharing our Strengths: Enhancing Research Collaboration



Report on an environmental scan undertaken for Northern Health, the Provincial Health Services Authority and the University of Northern British Columbia – Spring/Summer 2014

August 2014

Executive Summary

This report presents a summary of findings from an environmental scan undertaken in spring 2014 on behalf of Northern Health (NH), the Provincial Health Services Authority (PHSA) and the University of Northern British Columbia (UNBC).

In November 2013, these three organizations formalized a Memorandum of Understanding (MOU) to document their shared commitment to collaborate in establishing a mutually beneficial research partnership for northern British Columbia. This partnership anticipates a future state in which each organization shares its respective strengths so that:

- More health research is driven by northern priorities;
- Research participants in both the north and the south understand how they can contribute complementary skills, experience and resources that haven't been accessible to the other region in the past; and
- Synergies can be realized so the partners can together make a significant contribution to improved health outcomes in ways they could not have done on their own.

The environmental scan was conducted in two phases; this report summarizes findings from the first two: a stakeholder interview process conducted in April and May 2014, and a Validation Forum held in Prince George in June 2014.

Stakeholder Interviews

The interview phase of the environmental scan sought to gather insights from a wide range of health research stakeholders, including clinicians, investigators and health system administrators working with the partner organizations. A total of 54 clinicians, researchers, administrators, academics and health system leaders were interviewed on subjects including:

- Their past experiences with research collaboration between the partner organizations, if any
- The current state of research in their respective areas of interest, including future priorities and opportunities for collaboration in both research and graduate education
- Their views of assets essential to successful collaboration, including assets available via collaboration and resources they would hope to access via enhanced collaboration
- Barriers to collaboration
- Characteristics of an optimal collaboration

Interviews conducted for the environmental scan suggest there is significant willingness, interest, and good will present that could be directed to implementing enhanced research collaboration between the partner organizations. Interview respondents from each jurisdiction expressed anticipation that this MOU offers the opportunity for all of the partners to benefit and build research capacity through collaboration, based on complementary strengths and knowledge. A wide range of potential collaboration projects and topic areas was identified, and almost all interviewees exhibited support for the MOU's goals.

Three key topic areas emerged as top of mind for interviewees regardless of their institutional affiliations:

- Like most people working in health care and health research, individuals consulted for this environmental scan exhibited a high degree of basic good will and interest in collaborating on topics of mutual interest. This **willingness** to explore future collaboration was, however, tempered with a stress on the need for mutual understanding and respect for each other's perspectives.

Most important to maintain these fundamental supports was continuous communication, seen as the strongest characteristic of an optimal collaboration. Respondents from all three partners strongly expressed this view, with the greatest emphasis expressed by UNBC participants.

- A shared focus for research projects, or topic **alignment**, is also considered crucial to successful collaboration. Most interviewees spoke of the need to create some type of forum or venue to bring people together to identify relevant common ground, based on the belief that successful research collaboration is built on relationships.

Suggestions were provided for a range of mechanisms by which people would have forums and time to explore common interests and generate ideas for joint endeavours. Within that framework, however, most northern respondents noted the significance of recognizing the different ways in which research is often conducted in their region. They stressed the importance of, for example, conducting community-based, participatory research with First Nations and northern communities to build trust and ensure engagement, collaboration and knowledge sharing.

- Regardless of their location, everyone consulted for this project commented that successful collaboration requires sufficient **resources**. Specific resources included funding, time, skilled people, infrastructure, space, and technology. Many mentioned the potential benefit of some type of "research support commons" or linking resource for accessing information on who is doing what type of research across the many organizations, and a defined process for partnering. For northern partners, the issue of capacity is closely related to the issue of resources, since so few people are involved in research and service delivery over a vast and frequently challenging, underserved region.

As reflected elsewhere in this report, more northern respondents would like access to southern resources to increase research capacity than the other way around; nevertheless, this was a shared viewpoint across organizations. Respondents also noted a desire to build shared knowledge, expertise, resources and knowledge translation among the three partners. Interestingly, this view was expressed by more PHSA interviewees than those from the north. As with many large and ambitious multi-party endeavours, considerable questions remain for both southern and northern interviewees regarding the potential for success. These questions are reflected in the "equation for success" illustrated below, which summarizes the findings of the environmental scan.

As portrayed in the equation, the likelihood of collaborative success, with respect to research involving PHSA, NH and UNBC participants, is seen as function of the extent to which the current willingness to collaborate is mobilized via the identification of research topics or projects of common interest.

$L^S = W \times A \times R^3$	L^S	<i>Likelihood of collaborative success</i>
	W	<i>Willingness to collaborate</i>
	A	<i>Topic alignment</i>
	R^3	<i>Robust research resources (time, money, people, infrastructure)</i>

Figure 1: Equation for success

If that topic alignment exists to focus on the collaborative interest, success will still rely on the availability of practical resources to support the effort: time, money, people and a wide range of research and communication infrastructure to facilitate partnerships across distance and cultures. Without sufficient research resources, the project will be “multiplying by zero”, and chances of success are limited. Conversely, for each of the types of essential resources that are readily available, chances of success will be multiplied accordingly.

Validation Forum

The second phase of the environmental scan was an invitational Validation Forum. All those who were interviewed during the first phase were invited to the forum, held on June 23, 2014 at UNBC in Prince George, along with other selected stakeholders. Forum participants provided feedback on the interview findings and discussed priority projects and processes to launch the research collaboration between PHSA, UNBC and Northern Health.

Participants discussed two topics at the forum:

- Reaction to the findings: what was correct, what was missing, what was over or under-represented, and what new ideas did the findings generate?
- Given the findings about opportunities and barriers, what are the major areas the three organizations could work on together to support and enhance research collaboration over the next six to 12 months?

Overall, forum participants thought the environmental scan “shows symbiosis”: accurately identifying the realities MOU partners face and potential opportunities this partnership offers to strengthen research in the north. In addition to validating many environmental scan findings, they identified new ideas or areas missing from the findings. And, they noted that the partners need to determine:

- How research priorities for this partnership will be identified
- Where funding/resources will come from
- Whether the collaboration can leverage other funding opportunities
- What the goals and deliverables are for the partnership, and the timelines for achieving change

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In addition, participants commented that most of the forum discussion focused on research, rather than the need to improve education and training, and suggested a second or parallel process may be required to explore the needs of research trainees.

In the context of these discussions, forum participants provided feedback to assist the MOU partners in identifying concrete actions they might collaborate on during the next year. In summary, six areas were identified:

1. Create mechanisms to build mutual knowledge and familiarity
2. Map and evaluate research collaboration processes
3. Collaborate on planning/data analysis for PHSA services in northern BC
4. Identify northern priorities for research involving PHSA
5. Establish the Northern Biobank Initiative
6. Conduct action research to evaluate operational change

Looking Ahead

In the *Memorandum of Understanding*, UNBC, PHSA and Northern Health defined principles and a structure for supporting the partnership, which reflect many key points validated by the environmental scan and Validation Forum in Prince George.

Based on these principles and the findings of the environmental scan, the project's Reference Group will develop a series of recommendations for action to operationalize the MOU. These recommendations will be documented in a final project report prepared for presentation to the project sponsors in October 2014.

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Interview Perspectives

"Relationships don't happen unless you work on them, regardless of resources. I don't see any resistance, just a lack of investment of time and energy in the conversations that you need to engage in to make the relationships happen. And everybody's working flat out so time is a factor. Limited infrastructure is also a barrier; the health system isn't flush with resources for this sort of work."

"I'm thrilled the opportunity is there; I hope it's a first step in finding a way to support this. Most research enterprise is a struggle, and external support is dwindling across the country. There should be a way from a whole system perspective to build research into the fabric of our health system, rather than being an add-on. If the north could be a model that would be a wonderful example to the rest of the province."

Introduction

This report presents a summary of the findings from an environmental scan process undertaken in spring 2014 on behalf of Northern Health, the Provincial Health Services Authority and the University of Northern British Columbia. A brief description of these organizations is provided in Appendix Seven.

In November 2013, these three organizations formalized a Memorandum of Understanding that documented their shared commitment to collaborate in establishing a mutually beneficial research partnership for northern British Columbia. This partnership anticipates a future state in which each organization shares its respective strengths so that:

- More health research is driven by northern priorities;
- Research participants in both the north and the south understand how they can contribute complementary skills, experience and resources that haven't been accessible to the other region in the past; and
- Synergies can be realized so the partners can together make a significant contribution to improved health outcomes in ways they could not have done on their own.

About the Environmental Scan

The present environmental scan sought to gather insights from a wide range of health research stakeholders, including clinicians, investigators and health system administrators working with the partner organizations.

The environmental scan was conducted in three phases, and this report summarizes findings from the first two: a stakeholder interview process conducted in April and May 2014, and a Validation Forum held in Prince George in June 2014.

Stakeholder Interviews

Interview questions spanned four major foci:

- What current projects and links exist between health researchers in northern and southern BC?
- What works well in current research collaborations and what are the barriers to research?
- What are the priorities for

- research relevant to northern BC?
- What are the challenges and opportunities for synergy in future collaborations between health researchers in northern and southern BC?

A tripartite Reference Group (Appendix Three) representing the partner organizations provided direction on the interview questions and on selection of those to be interviewed. Invitations were sent by email to interviewees, as well as an Interview Guide with the questions to be explored during the interview.

Telephone interviews were conducted in April and May 2014 with 54 individuals (listed in Appendix Four.) Interviews were transcribed and the transcripts analyzed for common themes and notable comments, both of which are presented in this report. A bibliography (Appendix Six) provides additional references to documents consulted by the interview team in the course of preparing the report.

Throughout this report, sidebars present “Interview Perspectives”: quotations from interview transcripts that reflect common or noteworthy perceptions. Each is an actual comment from an interviewee, and interviewees have provided their permission for publication. However, the quotations are not attributed because they often reflect the views of more than one respondent.

Validation Forum

The second phase of the environmental scan was an invitational Validation Forum. All those who were interviewed during the first phase were invited to the forum, held on June 23, 2014 at UNBC in Prince George, along with other selected stakeholders. Forum participants provided feedback on the interview findings and discussed priority projects and processes to launch the research collaboration between PHSA, UNBC and Northern Health.

Final Report

Based on the input obtained through the environmental scan process, the project’s Reference Group will develop a series of recommendations for action to operationalize the MOU. These recommendations will be documented in a final project report and will be prepared for presentation to the project sponsors in October 2014.

Interview Perspectives

"We haven't been very good at putting the patient at the centre and organizing services around them; instead we put ourselves as providers at the centre and get patients to figure out what they need. This should be a future area of study to improve the health of populations."

"We are increasingly tuned to the north and already interested in children's health, so this is a good opportunity to feed that spark of interest."

"If we want successful collaborations, we need to go into it with our ears instead of our lips, so the process is about listening, hearing and understanding, before jumping to conclusions."

Research Priorities and Experiences

The first group of questions covered during the interviews sought to confirm the perspectives from which each respondent provided their views, and to better understand their past experience with research collaboration. Questions were also posed to identify potential areas of common interest and priority suitable for future research partnership activity.

Roles and Past Experience

To help understand the past experience and current state of research collaboration between NH, UNBC and PHSA, interviewees were asked a number of questions about their involvement in, or relationship to, health research.

The list of individuals to be interviewed was provided to the consulting team by the project Reference Group (see Appendix Three). The majority of interviewees work concurrently in multiple roles, allowing them to offer insights from a combination of perspectives including:

- **Leader:** CEO, Vice-President, "Chief", Dean, Executive Director, or other similar organizational leadership role
- **Academic:** University appointment, with teaching, administrative and/or research responsibilities
- **Health Service Administrator:** Clinical program leadership (e.g. Medical Director, Program Director, etc.)
- **Researcher:** Investigator (principal or co-investigator)
- **Clinician:** Physician, nurse or other health professional actively working in that capacity

This analysis confirms that a well-rounded mix of informants was consulted for this scan, with the possible exception of health service program administrators (only eight of the 54 individuals interviewed).

Interviewees affiliated with PHSA and UNBC were asked, in thinking about the Canadian Institutes of Health Research's (CIHR) four "pillars" of health research¹, how they would categorize the bulk of research in which they/researchers affiliated with their organizations take part. Responses were provided by 19 individuals from PHSA and 15 from UNBC.² Most mentioned research activity in more than one pillar, particularly those who commented on behalf of a research institute or health authority.

Research activity was reported in all four pillars for multiple respondents at both UNBC and PHSA. UNBC research activity was most often reported in pillars 3 and 4 (health systems and services, and social/cultural/environmental and population health research), compared to the emphasis on pillars 1, 2 and 3 (biomedical, clinical and health systems and services research) at PHSA.

Individuals with an active involvement in research were asked about their research priorities for the next three to five years. Most responses related to studies currently funded and underway, aligned with the respondents' areas of research specialization.

Northern Health respondents were most likely to comment on quality improvement, quality assurance and system evaluation projects. They stressed the importance of putting limited research time and resources into projects that would directly impact their ability to provide better, more effective and cost-effective service in a relatively short time frame.

All PHSA interviewees were asked whether they had been involved in a collaborative project that involved colleagues at Northern Health or UNBC; northern interviewees were asked about involvement in any research projects that involved investigators at PHSA agencies.

In the latter case, many responses indicated a relatively low awareness of PHSA as an organizational umbrella. For example, some people mentioned collaborating with colleagues at specific agencies (e.g. UBC, BC Cancer Agency (BCCA), BC Renal Program, BC Children's Hospital) but did not recognize these as affiliates or parts of PHSA.

¹ As defined by CIHR, the pillars are:

Biomedical Research: Research seeking to understand normal and abnormal functioning at the molecular, cellular, organ system and whole-body levels. This includes the development of tools and techniques that can be applied for this purpose, and the development of new therapies or devices that can improve health and quality of life up to the point where they are tested on human subjects. These studies generally do not have a diagnostic or therapeutic orientation.

Clinical Research: Focused toward improving the diagnosis and treatment of disease and injury and improving the health and quality of life of individuals as they pass through normal life stages. This also includes research on animal models of human disease, clinical trials and other therapeutic interventions.

Health Services/Systems Research: The multidisciplinary field of research that seeks to improve the efficiency and effectiveness of health professionals and the health care system through changes to practice and policy.

Social, Cultural, Environmental and Population Health: Research that explores the way in which our social and physical environments impact our health. The ultimate goal is to use this information to improve the health of the population, or defined sub-populations, through a better understanding of the ways in which social, cultural, environmental, occupational, and economic factors determine our health status.

² On the advice of the project Reference Group, NH respondents were not asked this question, since the majority of NH interviewees were not researchers.

In all, 25 of 54 individuals interviewed reported at least one past collaboration; 23 said they had no past north-south research experience involving the partner organizations; and six said they do not personally take part in research.

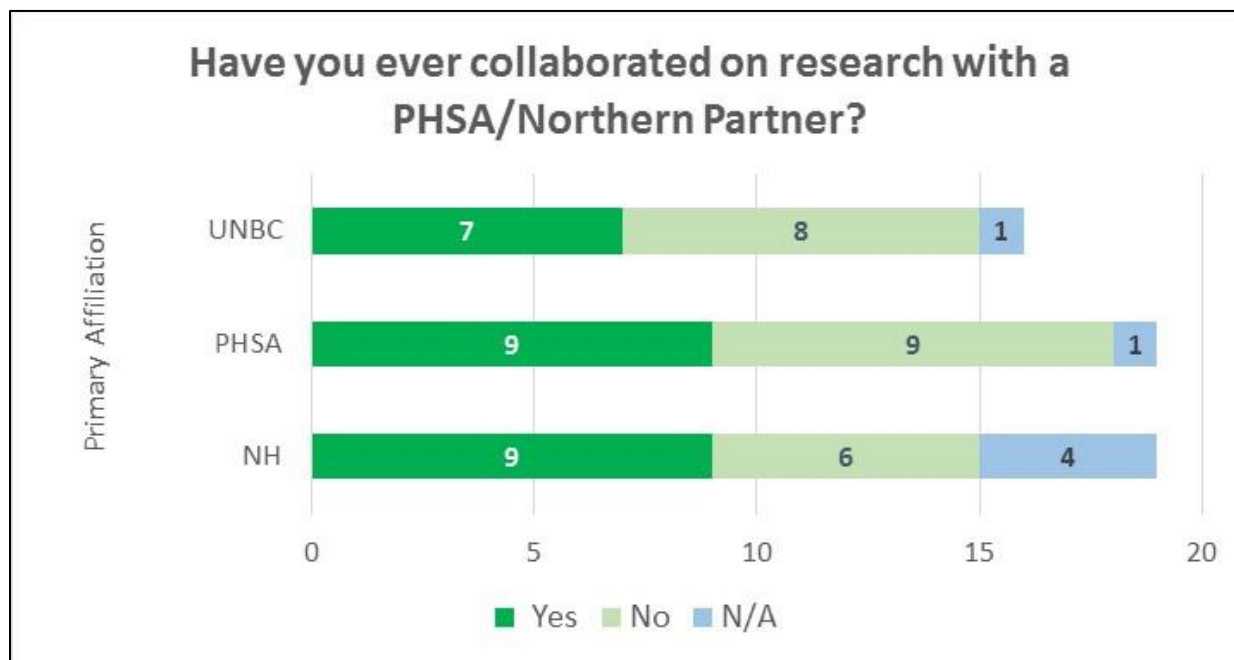


Figure 2: Past research collaboration

The 25 interviewees who reported past or current research collaboration were asked for their views on the experience: what worked, what didn't, and whether they would do anything differently if they pursued a north-south research collaboration again.

Eight of these respondents characterized their experience as generally positive, and almost all said they would consider future collaboration. Many commented on things that didn't work well from their perspective, resources that would help improve collaboration, or things they would do differently in future. These comments included (paraphrased and condensed here):

- *Relating to relationships:*
 - People are very appreciative of added support and expertise from our PHSA agency.
 - Relationships are in development and are rewarding when they work. A good relationship is always the foundation and will take you through any protocols, government policy; together we can figure pretty much everything out.
 - It's been opportunistic when I happen to learn about people. We need to visit and be more purposeful and develop relationships with investigators and faculty up there.
 - Until recently there haven't been natural opportunities for many province-wide interchanges that really make this happen, or I'm not aware of them.
 - Our biggest handicap is not being familiar enough with all of the players involved in research in the north in our subject area. I know a handful of individuals interested in engaging with us and have patients from the north in a variety of our studies.

- What worked relies on the goodness of some individuals. I was fortunate to have a southern agency partner who is really keen and helped set things up. Interacting with individuals at PHSA can be very hard; our priorities are not always seen as an important enough project, lacking important enough outcomes in the short term.
- There have been a number of very interesting meetings with PHSA organizational representatives where the point of view makes us feel they want to do it THEIR way, which may not take northern needs into account.
- There are really significant differences between Prince George and other northern communities. This is both a positive and a challenge that many First Nations communities and the new First Nations Health Authority (FNHA) are working on with us.
- We're trying to use different ways of communicating like Skype which helps with distance.
- Success depends on partnership and the agencies involved. All too often southern-initiated research uses a model that is very urban-oriented, and sometimes there have been challenges with having applicability to more northern and rural environments.
- *Relating to resources and capacity:*
 - Capacity issues in the north are huge; most people don't have the capacity to do a lot of research, it's always challenging to get funding, and there are competing priorities.
 - We try to foster research skills, to cooperate and not tell northerners what to do just because it works well with us.
 - The best collaborations are based in strong relationships, but in a constant state of limited resources and wide geographic areas, that's difficult.
 - The institutional approval and review processes are more onerous for us in the north than for someone in Vancouver who has access to the RISE system at UBC.
 - There has been a long history of trying to get things started, but it's really been quite challenging. A lot of people in a lot of academic departments are interested in various research topics, but the integration with service providers hasn't been very strong. So there may be some things happening in the system that we don't know about.
 - There are too few providers in many cases to meet the clinical needs, and so they get quickly over-subscribed. It's hard to say no when there's a need.
 - Having a standard ethics review would be helpful, as would having a research office to facilitate research proposals and applications.
- *Relating to sharing information in a timely and useful manner:*
 - We might have been naïve going in, we were looking for documents and reports out of the research that we could share with our colleagues in the province and weren't able to.
 - When there has been collaboration I've never seen a single report come back. I don't know where the research results have gone.
 - A number of partnerships and primary investigators had different investments than ours, to do with their publications and career. What we wanted was to use the information and share it in a practical application way. A number of articles came out of that project but not in a practical, usable way for us to impact service delivery.
 - From my perspective, up to now it seems like collaboration has been supported through the Northern Medical Program, not PHSA.

Interview Perspectives

"I think there are opportunities for our PHSA agency to partner with Northern Health and the First Nations Health Authority; the three of us could do good work together."

"Our medical leads are all part time now, including our VP of Medicine. That leads us to really focus on our priorities. We don't do 'nice-to-have'."

"There is enormous frustration that the whole province looks to the north to be the major income generator, but is unwilling to invest to prevent the harms of industrial expansion. I heard a vociferous, passionate call for research into the good and bad health impacts of industry and ways to mitigate harm."

Looking Ahead

Interviewees were asked to identify any research areas in which there is a particular interest or fit with respect to collaboration, now or in the immediate future, from their personal and institutional perspectives. The wide range of specific project or topic examples mentioned by all interviewees is listed in Appendix One. Of the seven broad topic areas identified in the appendix, interest was expressed by one or more interviewees from each of the three partner organizations and many were cited as high priorities by individuals from two or three of the partner organizations.

Research from an Academic Perspective

Responses from PHSA (UBC) and UNBC researchers were heavily focused on their current projects and the grant applications they are currently writing. Several also mentioned topics in which they have a long-standing interest, but for which establishing a north-south collaboration has proven challenging in the past.

To greater and lesser degrees, many of these individuals also have concurrent clinical appointments, and particularly in the case of those who provide clinical services in Northern Health, their interests tend to relate to questions arising out of their service area.

Although not large in numbers, biomedical researchers at UNBC expressed a strong desire to be included in the university's Health Research Institute (HRI) priorities to build capacity and opportunities for collaboration with southern partners like the Genome Science Centre (GSC, part of the BC Cancer Agency and PHSA).

For its part, the GSC is aware of and interested in biomedical research being conducted at UNBC. In addition, the GSC is partnering with UNBC to find funding for its proposed Northern Biobank Initiative, described as a "magnet for research in the north" and an important tool for representing northern populations in health research.

Health System and Clinical Service Focus

Responses from Northern Health interviewees were consistently focused on clinical quality improvement, health system enhancement and improving service delivery.

Their interest in collaborative research lies squarely on projects that will result in usable knowledge to assist them in meeting the unique and challenging needs of remote and rural communities, where populations are small and geographically distant, and providers are not always available.

The turnaround time for such research is a crucial consideration for the health authority; many referred to a preference for a “PDSA cycle”³ approach over a typical multi-year academic study, both in terms of duration and usability of knowledge generated.

The desire to collaborate on research to inform improved service delivery was often framed in terms of specific client groups, including aboriginal populations and those living in remote and rural communities, particularly communities that are currently undergoing rapid change due to economic development and disruptive expansion of resource extraction industries. The resulting changes for social determinants of health, their impacts on population and public health, and the increasing demands for primary care service are all seen as priority research collaboration topics.

Closely related is the interest on the part of both PHSA and NH interviewees in collaborating on areas where their respective service responsibilities overlap. These include the interfaces between primary and secondary/tertiary care, particularly where transport or partnership is required to serve the same patients at different points in their treatment trajectories.

The BC Cancer Agency, BC Centre for Disease Control, Perinatal Services BC, Cardiac Services BC, BC Transplant, BC Emergency Health Services, the BC Renal Agency, and BC Mental Health & Addiction Services integrate services across regions and seek to establish provincial service delivery standards. They also gather and report provincial data from frontline providers including across Northern Health, and as such are an invaluable resource for quality improvement and research activities.

In addition, some research topics proposed as future collaboration priorities relate to clinical care areas of particular population needs or service delivery pressure. These include care for patients with cardiac and respiratory diseases, diabetes and other chronic conditions; those who require treatment or services for mental health and problematic substance use; for cancer including breast cancer and cervical cancer screening; for renal disease, metabolic diseases, obesity; and for Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD).

Research Involving First Nations Health

Researchers in the north and south share expertise, infrastructure and an appetite for research focused on First Nations health and social determinants. These communities, while small, experience a higher incidence of many serious and lifelong health conditions when compared with the non-aboriginal population.

³ The PDSA cycle is a method for testing a change by developing a plan to test the change (Plan), carrying out the test (Do), observing and learning from the consequences (Study), and determining what modifications should be made to the test (Act). Championed by the Institute for Healthcare Improvement (IHI) in Cambridge MA, it has been used by hundreds of health care organizations including IMPACT BC in this province. It is also an approach championed by the Canadian Foundation for Health Innovation, in partnership with IHI. For more, please see <http://www.ihl.org/resources/Pages/HowtoImprove/default.aspx>; <http://www.impactbc.ca/>; and <http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/triple-aim>

The new First Nations Health Authority, which aims to address these health disparities, has been identified as a potential partner.⁴ Interviewees noted that community-based, participatory research is crucial to success in First Nations communities, and northern researchers have a unique depth of experience in these approaches.

Educational Collaboration

Interviewees were asked to identify potential opportunities for educational collaboration between the north and south. In particular, they were asked their views on any potential benefits that might arise from collaboration with respect to research priorities for PhD students and post-doctoral trainees.

Respondents from PHSA, UNBC and NH expressed a desire to collaborate on training opportunities for PhD students and post-docs in northern BC, and in particular, mentioned north-south co-supervision to:

- Expose students to the differences encountered in health issues/research in the north and south
- Help students build the relationships needed to become established researchers
- Broaden the scope of research activities
- Engage students in research focused on clinical quality improvement
- Potentially build capacity in the north by attracting more students to return or stay

However, despite the openness to the concept of joint supervision, respondents also identified several significant barriers to educational collaboration:

- Co-supervision is logistically challenging
- University incentive structures do not often reward professors for supervising students from other institutions
- People lack time and funding to support co-supervision
- Due to workload, many UNBC faculty have limited capacity to supervise more PhD students and post docs

Some respondents were unaware that faculty in the Northern Medical Program currently supervise PhD students and post-doctoral fellows. This suggests that knowledge of the full scope of educational activities underway at UNBC is not universally known across NH or PHSA.

In addition, PHSA identified opportunities to expand Autism Spectrum Disorder (ASD) education in northern BC and to co-organize a mini-med school by digital technology/local sessions to engage high school students in the north with researchers.

⁴ See further information on FNHA on pages 29 and 39.

Interview Perspectives

“From the south, we bring resources and bandwidth in certain areas of research capacity, things that aren’t there and not sustainable in places like the north.”

“One of the key areas would be some sort of infrastructure funding that allows frequent interaction with collaborators to express experimental ideas and propel science forward. We operate in a bit of a vacuum up here due to our isolation, so access to people to discuss ideas would be powerful.”

“Northern researchers can bring knowledge of northern perspectives on the barriers people face. Unless you’ve been here, it’s difficult to understand rural medicine and challenges in the north.”

Assets to Share

Interviews sought to identify the perceived benefits that each partner might offer, and might seek access to, through increased research collaboration:

- Thinking about potential future collaborations, what are the assets or strengths that you’d hope to access or gain through collaboration with the other partner organizations?
- What skills, experience, infrastructure and/or resources might your organization and its people be able to offer to the other partners?

Six recurring themes were identified across all responses. Analysis suggests both concurrence and significant contrasts when northern and southern perspectives are compared within these themes.

Relationships, Collaboration and Information

More than any other type of benefit that increased research collaboration might offer, interview respondents mentioned the potential for increasing access to research partners, through increased knowledge and awareness of potential collaboration projects, identification of new co-investigators with complementary interests, and strengthened north-south links.

Infrastructure, Research Support Skills and Methodology

Most responses to these questions reflect the view that the health research enterprise in northern British Columbia is relatively young and rapidly growing. Central to future success is the development of a robust foundation for all types of health research, including institutional infrastructure and the addition of individuals with skills and methodological training to support research.

Many UNBC and NH respondents indicated they would hope to increase access to such resources through enhanced collaboration with PHSA, and southern interviewees were most likely to suggest these resources as assets their organizations might bring to future partnerships with the north.

Within that common perspective, northern respondents often commented on the specific need to grow infrastructure in the north, and to develop northern capacity at NH and UNBC, rather than simply increase access to and dependence on PHSA institutions in Vancouver.

Some PHSA interviewees noted that increased collaboration might offer them access to specialized methodological skills and insights developed by northern researchers, in particular with respect to community-based, participatory research and effective approaches to working with First Nations communities. In addition, BCCDC representatives noted their organization offers people with experience supervising theses, PhDs, post docs, writing grants, research implementation, plus epidemiologists, biostatisticians, and modelling resources to support the work in the north.

Funding and Opportunities

Almost a third of Northern Health respondents, and a similar number of PHSA interviewees, suggested that they hoped to access research funding and/or project opportunities through enhanced collaboration. In addition, some northern respondents stated a desire to see more research funding distributed to the north for projects relevant to regional priorities. Further analysis of these responses suggests that it could be important to clarify sources of funding for the research currently undertaken by PHSA investigators.

As a health authority, PHSA rarely funds research directly. As with UNBC health research, the bulk of research conducted at PHSA-affiliated research institutes and agencies is grant-funded, as the result of researchers applying to (e.g.) Tri-Council agencies, hospital foundations, health charities, etc.

For example, funding support for research provided by hospital foundations at PHSA agencies (e.g. BC Children's Hospital Foundation, the BC Cancer Foundation) is not controlled by PHSA. Notwithstanding the close working relationships between the Foundations and the related PHSA agencies, the charitable organizations have separate boards of directors and fund-disbursement priorities. They respond to funding requests from PHSA agencies, however all decisions on the scope of and eligibility for their funding lie solely with the foundations.

There was some indication that the BC Cancer Foundation is beginning to allocate regional donations to regions with cancer treatment centres. For example, close to \$1 million has been raised in the Interior and allocated to research projects prioritized by the Southern Interior centre; this approach has not yet begun at the Centre for the North.

These circumstances suggest the potential value of PHSA facilitating contacts and communications between northern partners and PHSA-affiliated foundations, to explore stronger relationships. And, in a related vein, it was also noted that there may be fundraising opportunities related to the resource extraction boom in the north, with more potential large corporate philanthropists coming to the region. Ideally, potential philanthropy targets and fundraising approaches would need to be discussed with the larger "provincial" foundations to create a complementary, rather than competitive, approach.

Further, many aspects of research infrastructure that support studies conducted at PHSA-affiliated research institutes are provided via the researchers' concurrent appointments as university faculty (mostly at UBC but including appointments at e.g. SFU, UNBC and UVic). Research services including grant administration and ethics review are provided by UBC, for example; only a relatively small proportion of such services are provided by PHSA.

It was also noted that the Tri-Council National Centres of Excellence may offer a funding source for trainees (e.g. for NeuroDevNet (NDN), which focuses on Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder and Cerebral Palsy research across all four pillars, these are usually partnerships where the host institute contributes 50%, matched by NDN).

Rural and Northern Perspectives and Knowledge

Northern Health and UNBC respondents most often identified knowledge and perspectives related to research involving northern and rural communities as an asset they would offer to PHSA collaborators. However, relatively few PHSA interviewees identified this as a type of resource or asset that they seek in relation to their research priorities.

Regional Issues and Populations

Closely related to the previous theme was the idea from northern interviewees that collaboration with them would offer southern researchers access to opportunities to engage in studying issues and populations unique to the north or particularly relevant to this largest health region in the province.

Examples included indigenous health; rural and remote service delivery issues; topics related to health of populations impacted by rapid economic growth, environmental change and development of transformative resource extraction industries. While these topics were also identified as potential assets sought by PHSA interviewees, relatively fewer mentions were made by southern respondents.

Data for Research Use

Because PHSA agencies are in many cases the repository of provincial service data, several northern respondents noted they would hope to enhance the scope and ease of their access to such data through enhanced collaboration with PHSA.

Interviews with PHSA respondents showed a similar interest in accessing system and service data collected by NH. And many commented on the overall challenges of accessing data essential to health systems research, particularly in a timely and usable fashion. This issue appears to persist as a barrier to research for both northern and southern investigators.

Interview Perspectives

“It’s hugely important for northern and aboriginal communities that research truly is a collaboration, a continuous conversation with mutual respect on all sides and involvement to the extent that all partners can provide.”

“We can’t just think collaboration will happen by magic. We need to put a process in place to identify how it will work, projects that work for both of us, and a way to move them forward, with respect for what everybody brings to the table and good communication.”

“People in the north have seen themselves as the guinea pigs for researchers in the south for a very long time.”

Planning for Success

Three questions sought insights into the factors that might strengthen or get in the way of future north-south health research collaboration:

- From your perspective, what would be the characteristics of an optimal collaboration?
- What’s getting in the way or preventing you from collaborating with PHSA/the north right now?
- One of the things we’ve heard is that people don’t necessarily know what’s going on at PHSA/the north or who they might be able to contact to pursue collaboration. Is there information that could help you in that regard, which you don’t have right now?

Characteristics of an optimal collaboration

Four main themes emerged to describe the nature of an optimal collaboration, each with multiple layers of meaning:

Equal, mutually respectful partnerships

The greatest number of interviewees identified mutual understanding and respect for each other’s perspectives, with continuous communication, as the strongest characteristic of an optimal collaboration. Respondents from all three partners strongly expressed this view, with the greatest emphasis expressed by UNBC participants.

Northern respondents stressed in particular that researchers, clinicians and patients in the north want to be active participants in research of relevance to the north, not simply an “add on” to southern-led research projects.

Further, northern respondents noted the importance of conducting community-based, participatory research with First Nations and northern communities to build trust and ensure engagement, collaboration and knowledge sharing.

Optimal collaboration is reported to work well when people “get on the same page”. For example, BCCDC and NH have a strong partnership built on relationships that meet northern needs. BCCDC representatives said this partnership is successful because NH helps set research priorities that are relevant to the community. NH is looking for data to drive programs before the research is even done, so knowledge translation is often a given outcome.

[Greater capacity needed to support collaboration](#)

Interviewees identified adequate capacity as the next greatest requirement for the partners to conduct collaborative research: funding, time, people, infrastructure, some type of “commons” for accessing information on who’s doing what type of research across organizations, and a defined process for partnering.

As reflected elsewhere in this report, more northern respondents would like access to southern resources to increase research capacity than the other way around; nevertheless, this was a shared viewpoint across organizations. Several northern and one PHSA respondent queried potential opportunities to access PHSA-affiliated foundation funds with the north, particularly when the foundations are fundraising actively across the province. As noted earlier in this report, further relationship-building efforts may be called for in that regard, since these foundations are not party to the MOU.

Respondents also noted a desire to build shared knowledge, expertise, resources and knowledge translation among the three partners. Interestingly, this view was expressed by more PHSA interviewees than those from the north.

[Bring people together to build relationships and explore ideas](#)

Equal numbers of southern and northern respondents spoke of the need to create some type of forum or venue to bring people together. Interviewees stated that research collaboration is built on relationships, where people have time to explore common interests and generate ideas for joint endeavours.

A few respondents from PHSA and UNBC noted that the use of technology can break down barriers to communication and distance—Skype, teleconferencing, the cloud (storing and accessing shared data over the Internet)—but said this works best to sustain relationships after creating connections face-to-face.

Northern interviewees and a single PHSA respondent also defined multisite, multidisciplinary research projects/networks with co-investigators from the north and south as the optimal approach to support research collaboration driven by northern health priorities.

One suggested approach—a forum where potential collaborators could meet—presents a short-term opportunity to initiate building north-south research relationships. A second, using technology to collapse distance, offers a medium-term and ongoing opportunity to sustain relationships. A third—support for multisite, multidisciplinary efforts—represents a longer-term mechanism to sustain and grow north-south research collaborations.

[Research should enhance quality and recognize unique northern characteristics](#)

Some NH respondents expressed the belief that research should focus on evidence-based, rapid cycle quality assurance and improvement for service delivery, with priorities driven by leaders in the field, not identified from the top down. This view results from carrying an intense workload focused on meeting ever-growing service delivery pressures, without time or resources available to investigate in other areas. Respondents described this difference as allocating their efforts based on an analysis of what is “nice to do” versus “need to do”.

A small number of PHSA and UNBC respondents concurred with the need to focus research on shorter term efforts that can directly contribute to clinical quality improvement, but acknowledged that grant-funded research tends to take a more traditional, longer-term academic view.

Several interviewees noted the north has unique characteristics that create compelling challenges for service delivery compared to the south: vast, sparsely populated geographic areas; rural, remote and aboriginal populations; different cultural and environmental challenges; and a single major urban centre, Prince George. In addition, some UNBC researchers and one PHSA respondent were of the opinion that Northern Health research priorities should be led by NH clinician-investigators.

Barriers to Partnership

Interview respondents identified barriers to research collaboration that are, for the most part, the mirror image of optimal collaboration qualities. The following barriers emerged, each with layers of nuance reflected in interview comments.

Lack of connections between north and south

More than twice as many northern respondents cited a lack of relationships with southern investigators—and ignorance of potential partners—as a barrier to collaboration than southern respondents did vis-à-vis having northern connections. However, fewer, but in this case equal, numbers of northern and southern interviewees said physical distance and lack of face-to-face time to build relationships presented a barrier.

Northern interviewees also said a lack of knowledge about potential research opportunities was a barrier to collaborating. Only one PHSA respondent noted this concern as a barrier.

In addition, some respondents working as career academic clinicians in the north noted feeling “out of step” with colleagues in both the south and north, with a foot in both worlds: a cultural affiliation with the north, but organizational affiliation with the south.

Research not generated in the north, lack of equal partnership

Northern interviewees expressed concern that research topics and projects tend to focus on Lower Mainland priorities, with people in the north expected to facilitate northern participation and data collection, but not to act as research partners. No one from PHSA raised this concern. Further, a few UNBC respondents stated that northern researchers are not seen as equal partners by their southern counterparts, while again no one at PHSA noted this issue.

Lack of capacity to conduct collaborative north-south research

Again, more than twice as many northern as southern respondents identified a lack of capacity to conduct research as a barrier to north-south research collaboration. Capacity issues include carrying a heavy clinical workload with limited time for research, and lack of money, resources, infrastructure and/or access to data. (Some people at UNBC noted they do not have protected research time like some academics in the south.) In addition, two northern respondents noted a lack of research expertise among northern clinicians as a barrier to collaboration.

A common barrier for newer faculty is the need to focus on the requirements of promotion and tenure, leaving them less flexibility to participate in additional research projects.

The predominance of northern respondents citing the three barriers above may indicate a perception among some northern respondents that UNBC and Northern Health need to establish more capacity to participate as research organizations.

Another barrier mentioned by a handful of interviewees is related to capacity, but presents a different challenge: differing bureaucratic requirements for ethics reviews, privacy rules, and human resources make these processes overly time consuming and frequently require duplication of effort for separate institutions. As a result, time is spent dealing with bureaucracy rather than on the research itself. Northern respondents noted this concern more than PHSA respondents; however, people from all three partner organizations expressed frustration with the lack of a single provincial ethics review process.

Communication and Information

Interviewees identified a wide range of communication and information mechanisms to help address barriers and support optimal collaboration:

- Events/venues to build north-south relationships, learn about priorities, and explore opportunities:
 - Respondents noted that knowledge of common interests drives partnerships and this mechanism would build awareness of mutual interests among northern and southern researchers/clinicians
 - Four times as many northern as southern respondents identified this mechanism, likely reflecting the challenges distance and capacity create in the north
- Greater information sharing across the three partner organizations to raise awareness of and increase ability to capitalize on potential opportunities for research collaboration:
 - More northern than southern respondents suggested this approach to increase mutual awareness
- A common site/database listing all projects and investigators at PHSA, possibly linked to the Innovation and Development Commons (IDC) developed by NH and UNBC:
 - Only northern respondents suggested a common data source to facilitate research connections and collaboration, presumably based on the IDC's success in creating links among northern researchers, practitioners and students; however, two PHSA respondents said more information on potential research collaborators and topics would be helpful
 - In addition, several UNBC respondents suggested the UNBC Research Office and/or Health Research Institute take on the role of facilitating north-south research collaborations with support for proposal writing, data collection and protocol development

Several northern and southern interviewees recommended that people in both areas should take the initiative to learn about each other's organizations, research priorities/activities, and potential collaborators by exploring the information available on their respective websites and phoning departments to ask about people to contact in areas of interest. While this is a reasonable suggestion, responses to other questions suggest that this approach has not occurred a great deal to date.

A cursory consultation of websites for PHSA, NH and UNBC reflects the presence of much of the information noted above, particularly with respect to the PHSA agencies and their respective research institutes. However, the information is typically not presented in a format designed to serve potential research collaboration or to help “matchmaking” across distances. In many cases, people would need to know who to look for or spend considerable time searching to find relevant details.

A small number of respondents in each organization said they knew who to contact and where to find information about research in the partner organizations.

Interview Perspectives

“We already have good collaboration within the north, so with PHSA we need to have respect and work together on joint issues and finding solutions.”

“There’s a general view that Vancouver comes in to extract things from the north. We want people who are intellectually driven in the north to engage us in the south in a partnership.”

“Physical distance is an issue; we just don’t bump into each other in the corridor. Research is driven by relationships, so we need to build relationships with northern investigators and faculty.”

The Context for Collaboration

The memorandum of understanding signed by NH, PHSA and UNBC is being executed within a context of a rapidly changing provincial health research landscape. A number of significant initiatives are underway with the potential to impact various aspects of the MOU collaboration and were noted during the environmental scan interviews, including the:

- | | |
|--------------------------|-------------------------------|
| Infrastructure Network | • BC Clinical Research |
| Initiative | • BC Ethics Harmonization |
| | • BC Health Research Strategy |
| Oriented Research (SPOR) | • CIHR Strategy for Patient- |

In each case, it will be essential for NH, PHSA and UNBC to consider how their efforts to enhance health research collaboration in northern BC intersect with these provincial initiatives. Information on these initiatives is presented in Appendix Two for reference by collaboration stakeholders.

Several interviewees also mentioned the importance of determining if and how the new First Nations Health Authority (also briefly described in Appendix Two) will interact with health research efforts focusing on northern BC.

Innovation and Development Commons

Another key contextual consideration raised by interviewees was the value of having some sort of formal linking infrastructure to mobilize collaboration. This sort of asset was frequently mentioned by northern informants who cited the benefits of the Innovation and Development Commons, a joint initiative of UNBC and NH. Further description is included here for readers who may be unfamiliar with this linking resource.

In 2010, UNBC and Northern Health signed a Memorandum of Understanding that aimed to build on their relationship in education and research to improve the delivery of health services in northern BC and beyond. While UNBC had previously formalized protocol agreements with a number of colleges and aboriginal communities for the purpose of delivering educational programming, this MOU was the University's first such agreement with a health authority.

Building on the momentum generated by the institutions together and separately, and by their collaboration with the Northern Medical Program training physicians in the north, the MOU created several new structures to support integration. The partners set up a new Executive Oversight Committee, Steering Committee, and created the ***Innovation and Development Commons***, a virtual and real environment for educators, researchers, health professionals, physicians and administrators to interact, share information, and develop new partnerships.⁵

The IDC has operated since then as a partnership between NH and UNBC working to facilitate education, research, and innovation in the north, with the goal of ultimately improving the quality of life and health outcomes for northerners.⁶ Among its activities is “matchmaking”: linking university investigators and student researchers with clinical and administrative partners in the health authority for research collaboration.

Each year since 2010, the IDC has presented a major event known as “Northern Research Days”. In 2013 the third annual IDC Northern Research Days were held concurrently with the 12th Annual Canadian Rural Health Research Society Conference. Such events provide invaluable opportunities for researchers and clinical service leaders to meet, discuss topics of common interest, and explore potential future collaboration.

⁵ <http://www.unbc.ca/releases/2010/06-22health-rally>, accessed May 30, 2014

⁶ <http://www.northernhealth.ca/YourHealth/ResearchandEvaluation/ResearchDays.aspx>, accessed May 30, 2014

Forum Participant Perspectives

“Bringing people together is very important for the effective establishment of partnerships. And it’s important for folks here in northern BC to understand the pressures PHSA folks are under and vice versa.”

“The scan gives a good characterization of how and why partnerships work: synergies, complementarity, respect, forums for information exchange and collaboration.”

“When there is a northern focus, it needs to be explicit that research is worked on together with a two-way exchange in the collaboration.”

“Practitioners need more support to do research and utilize research.”

“What are the projects to help build relationships and what are the relationships to help build the projects?”

Validation Forum

Interviewees were invited to an invitational Validation Forum, held on June 23, 2014 at UNBC in Prince George, along with other selected stakeholders. Forum participants provided feedback on the interview findings and discussed priority projects and processes to launch the research collaboration between PHSA, UNBC and Northern Health. In all, 25 people attended the forum, and those unable to attend had an opportunity to submit feedback on the environmental scan report electronically.⁷

Participants discussed two topics at the forum:

- Reaction to the findings: what was correct, what was missing, what was over or under-represented, and what new ideas did the findings generate?
- Given the findings about opportunities and barriers, what are the major areas the three organizations could work on together to support and enhance research collaboration over the next six to 12 months?

Reaction to the Findings

Overall, forum participants thought the environmental scan “shows symbiosis”: accurately identifying the realities MOU partners face and potential opportunities this partnership offers to strengthen research in the north. In addition, they validated many environmental scan findings, and identified new ideas or areas missing from the findings. Details of both of these themes are provided below.

Validating Findings

In keeping with the purpose of the session, forum participants validated a number of topics identified during the environmental scan from their diverse perspectives and experiences:

- Desire to collaborate is strong and must be based on mutual respect for the value of what each partner brings to the table and recognition of the challenges and gaps each faces
- It is important to bring people together in person to make connections and share priorities and perspectives

⁷ Please see Appendix Five for a list of those who participated/provided comments.

- The partners should draw on examples of success using technology to overcome geographic challenges and enhance collaboration
- A lack of resources—people, time, money—presents a major challenge to north-south collaboration; consequently, MOU partners need to be prepared to commit resources to build capacity to support partnerships
- Many providers in northern BC must focus on care delivery and are, therefore, primarily interested in health service research focused on KT and quality improvement; as well, individuals can carry multiple oversight responsibilities in the north, with less opportunity for specialization than those in the south
- In the north, community-based research is of crucial importance to innovation and development, and is based on the strong community connections researchers have established
- The MOU partners need to fully explore the implications of working with the new First Nations Health Authority
- Access to data and alignment of shared processes would help enable north-south research collaboration (e.g. a shared ethics review process; shared funding/process for hiring research staff; shared, defined process for linking on north-south research topics)

New Ideas/Observations

Forum participants also identified a number of new or missing ideas and issues:

- PHSA and the north have not aligned research priorities; consequently, the partners need to define concrete areas of alignment in research:
 - Identify specific opportunities to connect around specific research topics and people; then bring people together to resolve issues and initiate research
 - Articulate clear expectations for the focus/goals/outcomes of collaboration
 - Determine how to access established resources and what purpose they will be used for
 - Use PHSA platforms to identify and enable areas of alignment (e.g. clinical trials, tissue banks, databases, technology)
 - Identify opportunities for clinical research/trials and synergies related to research trainees
 - Consider the differences in scale, focus and language between the north and south; for example, the challenge isn't necessarily one of north-south differences, but rather urban versus rural and remote
 - Capitalize on access to underserved/specific local populations in areas of shared priority (e.g. First Nations, resource development areas)
 - Given PHSA's province-wide program and service responsibilities, there is an absence of research related to PHSA planning for services delivered in the north; studying this area would offer an opportunity for quality and process improvement
- The expected increase in demand for health services in the north (due to factors including overall population growth, industrial expansion and an aging population) will undoubtedly enhance pressures on available funding, further restricting access to research funding

- One challenge is the potential for the smaller, northern partner to be dominated by the larger, southern partner (e.g. the north has fewer people to support the interface between researchers and clinicians than the south; NH and UNBC have more to gain as they will be building capacity from working relationships)
- The Northern Medical Program was identified as a key stakeholder in building research capacity, and there are opportunities for synergies with the UBC medical school, north and south, particularly with regards to training doctors
- Similar research training/capacity building should be explored as part of the Nursing faculty training programs for nurse practitioners
- Research in northern BC will be relevant to other rural and remote regions
- Difficulties in obtaining funding for rural research need to be considered
- Explore access to mentorship opportunities

Partnership in Practice

Forum participants identified six priority research areas for UNBC, Northern Health and PHSA to collaborate on during the next year, which reflect some areas of the discussion above:

1. Create mechanisms to build mutual knowledge and familiarity

- Provide travel funding for north-to-south and south-to-north research exchanges and orientation at relevant locations to develop capacity for northern research projects and principal investigators
- Develop a framework to incubate collaboration and match researchers and research interests, sponsored by MOU partners
- Provide networking resources to bring people together for face-to-face meetings to discuss specific opportunities for collaboration based on common interests
- Identify a small number of quick win projects to support from this process and provide seed resources (i.e. grant funding, time); this approach will, in turn, gain momentum to expand projects while building relationships
- Once face-time connections are established, use technology to lower barriers and sustain communication and information exchange among the three partners

2. Map and evaluate research collaboration processes

- Clarify the supports, systems, research platforms available for north-south research collaboration
- Identify where gaps exist
- Determine which collaborative research processes do/do not work well and how/why

3. Identify northern priorities for research involving PHSA

- Identify specific UNBC/NH priority research topics for rural and remote health, where PHSA involvement is desired
- Facilitate this process with support for travel, navigation and data gathering on specific research interests
- Identify clear goals, outcomes and evaluation criteria for collaborative research priorities
- Strengthen links between UNBC and Northern Health
- Strengthen the UNBC Health Research Institute to build capacity for more northern research collaboration

4. Collaborate on planning/data analysis for PHSA services in northern BC

- Enable PHSA and northern researchers to work together to share/examine/gather data to strengthen planning for northern delivery of provincial services
- Bring PHSA and northern data stewards, practitioners and researchers together to identify anomalies/gaps in provincial data sets and brainstorm areas to investigate
- Develop a research agenda for northern populations, services and outcomes, based on recommendations from this group

5. Establish the Northern Biobank Initiative

- Provide resources to establish the Northern Biobank Initiative, proposed by UNBC and the Genome Science Centre as equal partners, with the north providing “cultural authority” leadership
- Create the NBI tissue bank to provide data that can be used to:
 - Increase capacity for cross pillar research and collaboration
 - Target research projects to northern populations and develop expertise in rural areas
 - Improve clinical care in the north
 - Be involved in global innovative research questions
- Integrate a networked training environment, with research/education opportunities for northern and PHSA graduate students and post-docs

6. Conduct action research to evaluate operational change

- Gather data on collaborative operational change projects to:
 - Study the effectiveness of implementation methodology and impact on standards of care
 - Learn from the change process and share findings with other health authorities
 - Identify strengths and opportunities for quality improvement

Sharing our Strengths: Enhancing Research Collaboration

- Current projects to assess include NH/BC Transplant's program expansion in northern BC, and a pilot project by Emergency Health Services and BC Bedline on transferring critically ill patients
- Collaborate on a research proposal to evaluate the effectiveness of technology-enabled service delivery models such as telehealth
- Initiate an action research process at the beginning of new operational change projects

Next Steps

From the beginning of this process to expand north-south health research collaboration, UNBC, PHSA and Northern Health—partners to the *Memorandum of Understanding*—recognized the critical importance of many key points validated by the environmental scan and Validation Forum in Prince George. The principles and structure the partners defined for the partnership in the MOU reflect the aspirations and concerns expressed in scan interviews and at the Validation Forum. The original MOU principles and structure are highlighted on this page to illustrate how the process has, to date, come full circle from its genesis.

Based on these principles and the findings of the environmental scan, the project's Reference Group will develop a series of recommendations for action to operationalize the MOU. A final report will document the recommendations for presentation to the project Steering Committee in October 2014. The Steering Committee will then decide which recommendations and activities to implement based on the results of this process, taking into consideration organizational priorities, and human/financial resource availability.

Interview Perspectives

"I feel enthusiastic about the opportunities but have a bit of a challenge thinking about how they would be operationalized."

"PHSA has all the resources given to them by the government to support the whole province and with that comes an obligation to understand the special circumstances that should shape research relevant outside the Lower Mainland. I have to constantly remind people of this at conferences: some process or system which was developed and tested in Richmond might not work in Haida Gwaii."

"The benefits for both have to be obvious, including that the research being conducted is actually informing change in practice in northern communities, and then also provincially. They need to see how our mandate fits and aligns with their mandate."

Appendix One: Collaboration Opportunities

Many interview respondents identified specific areas for potential north-south health research collaboration. While the resulting list is not presented as definitive or complete, it does present a striking sense of the enormous opportunities for collaboration that presently exist should the intentions of the tripartite institutional MOU be fully realized. These opportunities are detailed in this appendix within seven categories (in alphabetical order):

- Biomedical research (expanding and integrating northern activity)
- Cancer research
- Clinical quality improvement
- First Nations health
- Health impacts of resource/industrial development
- Health system integration and improvement
- Research focusing on rural and remote populations

Biomedical Research (Expanding and Integrating Northern Activity)

- The Northern Biobank Initiative has been created in partnership with the Genome Science Centre; funding is currently being sought to implement the tissue bank. This platform is expected to drive northern research programs, projects and collaboration.
- UNBC has a small number of biomedical researchers; funding and a system for regular interaction with BCCA and the Genome Sciences Centre would improve access to people, resources, equipment and training there. In turn, this would build biomedical capacity and expertise in the north.
- Biomedical research into the mechanisms of obesity and Type II Diabetes at UNBC offers the opportunity to build biomedical-clinical research collaborations to improve knowledge translation.

- The only scientist in BC studying RNA splicing, which is connected to approximately 60% of diseases, is based at UNBC. Effort is underway to develop research strength in Canada in rare diseases (CIHR application being discussed).
- Northern communities and, in particular, Prince George, have the opportunity to become a hub for north-south collaboration into autism spectrum disorder research and clinical work. Brain imaging work on Autism Spectrum Disorders at PHSA could be linked with medical schools in Prince George and Kelowna.
- A new Pacific Autism Family Centre is planned to provide a resource for improving services and research in BC, using a hub and spoke model, with the hub in Vancouver and spokes in Prince George, Vancouver Island and Kelowna.
- The Child and Family Research Institute (CFRI) is interested in investigating the impact of social determinants at the genetic level, where the programming of genes from conception can have long term life effects, and would like to engage populations interested in assessing children.
- Identify ways to bridge the gap between people doing molecular work and clinicians working with patients, such as training people to speak in each other's language or finding people who do speak both sides to facilitate communication.

Cancer Research

- The Women's Health Research Institute (WHRI) wishes to collaborate with northern partners on the interface between infection and cancer (HPV and cervical cancer, barriers to screening, self-testing as an alternative mechanism).
- Research into the environmental/population health factors unique to the north that have an impact on cancer (lifestyle, smoking, pollution, etc.).
- With poor ventilation, exposure to radon gas is a very significant issue for lung cancer. In the north, people tend to be in a more sealed type dwelling when it gets cold. The US has completed and published radon mapping but BC hasn't yet done so.
- A joint effort with NH and BCCA is underway to create a northern breast cancer database to address the paucity of research data for northern populations. Standards of care remain time sensitive issues in the north for people in remote locations far from treatment options.
- NH's Northwest Health Service Delivery Area (HSDA) is leading several cancer research projects, in partnership with BCCA/PHSA, that will deliver research data/opportunities to UNBC and other NH HSDAs:
 - NH will be the first health authority in BC to have an integrated data collection system and support network to follow cancer survivors and collect data not yet available, as well as direct care. This survivorship/surveillance project has a provincial mandate as well.
 - A new breast cancer navigation project, the NH iteration of a provincial diagnostic breast pathway. Data will be collected and disseminated, providing a research and quality improvement opportunity. In future, the same principles can be applied to other cancer groups like colorectal cancer.

- NH is the only health authority to have a cancer strategy, the Northern Cancer Control Strategy (NCCS), which covers the entire cancer journey. Having stronger UNBC/BCCA involvement could help define what is relevant to NH and what data to collect. Some believe the NCCS is not strongly reflected in current provincial BCCA research priorities.
- Lifestyle behaviour modification versus treating people will become a bigger field and NH has a strong public health emphasis and potential for research with UNBC.

Clinical Quality Improvement

- NH public health staff members with PhDs are experienced with research, so there are opportunities to conduct situational research with PHSA and learn how to move forward.
- Research involving PHSA provincial programs (renal, cardiac, mental health and addictions, etc.) with facilitated discussion and some collaboration/alignment that supports our shared responsibility for patient care and system performance.
- NH critical care is completely focused on several urgent priorities: understanding referral patterns, resource use and case mix, all in a quality improvement and quality assurance context.
- Chronic disease functions in PHSA are being amalgamated at the BC Centre for Disease Control, which will open new priority areas around healthy eating, weight, the built environment, and community and road health.
- BCCDC/NH want to broaden the pool of people tested for TB and acute HIV and have them understand their HIV status.
- Clinical trials with the northern BCCA and a population that is rarely served through clinical trials.
- Northern Health's main foci with changes to improve the system emphasize public and preventive health, instead of tertiary care, and primary care, so partnerships should support those areas. For example:
 - Partner with CFRI on a study to integrate infant mental health services into primary care
 - Study a more holistic approach to the patient journey (look at the treatment side where PHSA focuses, and on the prevention side where NH has expertise)
 - Multidisciplinary teams across the continuum of care and patient hand-offs between PHSA
- BC Transplant (BCT) is interested in partnering with clinical researchers to improve outcomes, from clinical information regarding the quality of graft and care to quality of life studies (e.g. care closer to home, less travel, rather than moving to Vancouver and waiting for an unknown period, comparative data to identify barriers to donation in the north).
- WHRI is looking to collaborate on access to and methods of contraception to reduce unplanned or unwanted pregnancies, and CHIWOS, the Canadian HIV Women's Sexual and Reproductive Health Study, a community-based, peer-driven survey to understand the needs of women living with HIV.
- Research into what works to support healthier populations (e.g. what works and doesn't with smoking cessation and active living?)
- UNBC's Department of Psychology is interested in collaborating on applied psychology and behaviour change and promotion, as well as FASD.

- UNBC has assigned a Canada Research Chair to the Northern Medical Program and is interested in developing a clinical research component.
- Child Health BC is interested in partnering on creating modules that define how pediatric services should be delivered, a provincial oral health strategy, concussions prevention and awareness, home health and nursing services for children, complex care for children with disabilities, and palliative care.

First Nations Health

- The new BC Leadership Chair for Aboriginal Environmental Health at UNBC is looking at the relationship between the environment and mental well-being of BC's rural and indigenous communities. UNBC has expertise in community engagement and partnerships with indigenous people.
- Health impacts/outcomes in aboriginal communities (UNBC has a National Collaborating Centre for Aboriginal Health).
- The new UBC Centre for Excellence in Indigenous Health, which will apply to all health authorities including the north, has a UNBC co-director. Research is one of three foci for the centre.
- Diabetes and obesity have a higher prevalence rate in the north than in the rest of the province, especially among some First Nations (and South Asian) populations, so biomedical-clinical research in these areas is relevant to the region.
- A BCCDC clinician developed M-Health that uses mobile technology to help people in African countries adhere to HIV treatment. BCCDC/NH are examining if this approach can help northern aboriginal youth at risk too.
- The BC Inherited Arrhythmia Program (BCIAP) hopes to be a key partner to ensure NH is included in all BCIAP initiatives and has access to this program's care/research. (PHSA has a long-standing research partnership into Long QT Syndrome with the Gitksan community and Health Society Board.)
- An area of interest for future opportunities with organ donation and transplantation relates to First Nations cultural competencies and greater involvement with Aboriginal patient liaison.
- NeuroDevNet can share its experience and infrastructure, such as registries for FASD, cerebral palsy and autism across Canada, to examine incidence/effectiveness relative to circumstances. Since FASD has a higher incidence in Aboriginal communities, northern participation would be valuable. In addition, NDN has engaged FN populations in northern Ontario on a co-production of what they want to see from diagnostic/intervention processes, and this could be done in northern BC too.
- Involve the First Nations Health Authority to identify their research priorities.
- Perinatal Services BC sees strong opportunities to partner with NH and FNHA.
- CFRI researchers are working with northern aboriginal populations experiencing an overabundance of Type II Diabetes and one with a genetic form of epilepsy.

Health Impacts of Resource/Industrial Development

- Collaboration on community preparedness, resilience, the impacts and social determinants of health resulting from natural resource extraction and the boom of industrial activity in the north.
- BCCDC's environmental health program is working with NH on a health assessment that will entail research on how to measure the impacts of industry.
- There is not a strong history of research methods available for understanding how big resource projects affect the small populations around them.
- Aim research projects around the good and bad impacts of the enormous industrial investment in the north and mitigate harms. Investigate all impacts on immediate health, heart, lungs, STIs, infections, social impacts, access to education, etc.

Health System Integration and Improvement

- Chart UNBC/NH organizational change as the health authority shifts to a primary health care driven organization.
- Develop a UNBC HRI unit with a rural lens on knowledge development, translation and mobilization to support research across all four pillars.
- Expand/link the UNBC/NH Innovation and Development Commons to include PHSA.
- Examine patient transport questions: When is it best to transport, to where, why, and when not? Where should specialty services be developed to reduce the need for transport south and east?
- System change is about holistically looking after people with multidisciplinary teams and should be a future area of study to improve population health, a large multi-year longitudinal opportunity.
- Child Health BC is keen to partner on evaluating the implementation of its province-wide service delivery models/initiatives.
- Both NH and PHSA have a strong quality orientation with LEAN approaches to quality improvement and service delivery, offering the opportunity to share/exchange learning and insights.
- Examine the health impacts of north-south differences in distances, culture, geography, demographics, funding models, team service delivery, and access to care.
- Explore the impact of telehealth outreach/technology in the north; for example:
 - Test whether telehealth interactions with the kidney team are as effective as in-person interactions as a way to deliver the best care for remote populations
 - CFRI wants to develop better digital medicine, online and app-based programs to reach populations
 - Child Health BC is looking at technology-enabled access to care for children, and how much happens in the north depends on the capacity to engage within pediatric and primary care resources
- Examine rural perspectives to understand the aspects of emergency medicine where the north needs support, implement a system to help those needs, and evaluate the effectiveness on both patient care and costs (linked to education and KT).
- BC Transplant works with the Canadian Institute for Health Information to provide data sets on health systems and services, and wants to talk to critical care directors about what data to collect.

Research Focusing on Rural and Remote Populations

- NH is the only health authority with a single integrated data system for mental health and addictions, is the lead for the province, and has a half-time analyst to run questions, a unique and potentially invaluable research resource. The Ministry of Health uses the system to gather accurate baseline data. NH mental health and addictions staff can provide a northern, rural perspective and participate in research into urban versus rural differences.
- The Women's Health Research Institute wants to collaborate with faculty from the north (rather than just including women from the north in its studies) to:
 - Gain a better understanding of the knowledge gaps and needs in the north
 - Expand research and build a network of individuals interested or involved in women's health research in northern BC
 - Collaborate on examining geography and distance to health centre as predictor of neonatal health outcomes following caesarean section
- Clinical practice innovations created to address persistent service issues in the north need to be evaluated for outcomes, costs and patient/provider satisfaction. For example, an Enhanced Surgical Skills (ESS) program is being developed for rural GPs to address a rural crisis in access to care in urgent situations. ESS will train rural family doctors to do a set of surgical procedures (e.g. obstetrics). A study has been conducted with residents and presented to various organizations to build support, including UBC's Department of Family Practice.
- Perinatal Services BC is interested in enhancing system planning, especially with rural and remote maternity care.
- Draw on BCCDC expertise in statistics to create joint post docs and jointly sponsored summer institutes on issues addressing research and knowledge translation with rural and northern populations.
- BC Transplant would like to engage in opportunities for collaboration in research, education and knowledge translation with northern researchers, clinicians and patients:
 - BCT is expanding the Prince George renal clinic to include liver transplants with more pre/post care provided locally; potential opportunities to study standards/quality of care, effectiveness, patient outcomes, telehealth, barriers to donation in the north
 - Identify gaps in the north and ways to improve processes along the continuum
 - BCT is planning a northern tour for September to look at ways to support the north
 - Transfer patterns in remote areas are not unique to BC and could have implications for other areas across Canada
 - Quality of life study based at UNBC, co-investigate with someone on BCT Data Committee
 - Participate in Canadian National Transplant Research Program project identifying data elements and variables across the continuum to increase donation nationally
- Northern community organizations are open to connecting with researchers (e.g. Alzheimer's, women's and mental health organizations in Prince George).
- NeuroDevNet is interested in collaborating with northern populations to assess the effectiveness of a suite of computer neuro games for enhancing cognition and executive function in children with developmental disorders.

Sharing our Strengths: Enhancing Research Collaboration

- Child Health BC seeks research partners to better understand rural and remote access to care for children requiring complex care.
- CFRI is well placed to work with those in the north in priority areas like Healthy Starts (includes social determinants), digital medicine, population data, nutrition, epigenetics, healthy pregnancies, autism, outreach to communities, infection (some north populations have higher rates).

Appendix Two: Provincial Initiatives

As noted in the Context for Collaboration section, a number of significant initiatives are underway with the potential to impact various aspects of the MOU collaboration. These initiatives may address many of the issues raised during the interviews conducted for this environmental scan, and include:

- BC Academic Health Sciences Network
- BC Clinical Research Infrastructure Network
- BC Ethics Harmonization Initiative
- BC Health Research Strategy
- CIHR Strategy for Patient-Oriented Research
- First Nations Health Authority

Further information on each is provided below.

BC Academic Health Sciences Network

In February 2014, the BC Government published ***Setting Priorities for the B.C. Health System***. The document presents the strategic and operational priorities for the delivery of health services across the province. According to the document's overview:

The plan is founded on a vision of achieving a sustainable health system that supports people to stay healthy and provides high quality publicly funded health care services that meet their needs when they are sick.

The plan builds upon on successes achieved through the health sector's transformational guiding framework, the Innovation and Change Agenda, and is focused on delivering a patient-centred culture across all health sector services and programs, while incrementally improving on the quality of service outcomes.

The strategies and priorities outlined in this document are based on thoughtful analysis of population health and service utilization data, best practices from the research literature, lessons learned from B.C.'s efforts over the last four years to drive province-wide system change and consultation with many key stakeholders.⁸

One paragraph in this plan has raised considerable interest across the provincial health research community. Strategy 3, Quality, states: "The third key action establishes an academic health science network in B.C. to drive effective teaching, placements, and applied health research that will promote and encourage improved quality and innovation linked to identified health care and service needs."⁹

No details appear to be available as yet regarding the implications of this proposed action.

⁸ <http://www.health.gov.bc.ca/library/publications/year/2014/Setting-priorities-BC-Health-Feb14.pdf>, accessed June 4, 2014

⁹ Ibid, page 36.

BC Clinical Research Infrastructure Network

The British Columbia Clinical Research Infrastructure Network (BCCRIN) is a collaborative partnership of provincial health authorities, research institutions, universities, industry associations and funding agencies, a first of its kind, focused on transforming the clinical research landscape in British Columbia, thereby enhancing our ability to compete in what has become a highly competitive global marketplace for clinical research. The vision of BCCRIN is that:

British Columbia will be among the world leaders in clinical research, driven by patient needs, and enabled by advanced science and methodologies.

BCCRIN pursues an optimized provincial environment for clinical research that results in the best patient care decisions and strategies for a sustainable health care system. The membership is committed to the goal of developing and promoting BC as a premier location for clinical research to benefit all stakeholders, especially the patients we serve.

BCCRIN is working to strengthen the existing clinical research environment in BC by building on our strengths and opportunities, integrating best practices from other research networks, and applying new ways to support the research community. BCCRIN is engaging the research community, research participants and their families, and the pharmaceutical industry. The network is coordinating and building resources, and incorporating new science and methods into clinical research; accomplishments to date include:

- Launched the *BC Model Clinical Trial Template Agreement* (BC mCTA), for use when a pharmaceutical industry sponsor is interested in initiating a Phase II or III clinical trial at a BC academic health care organization or research institution
- Launched the *BC Clinical Trial Participation Survey*, an online survey providing a unique opportunity for the public to provide feedback on clinical trial experiences and a foundation piece to the strategy on clinical research engagement
- Developed a business plan for provincial implementation of a *Permission to Contact Program*, providing an engagement mechanism to enable patient participation in research
- Enabled the certification of over 30 clinical research professionals
- Sponsored and hosted clinical research symposiums, speaker series, and *Audit and Inspection Preparedness Workshops*
- Completed an *economic impact study* of the BC clinical research environment
- Launched the *BC Clinical Research Asset Map*, an online searchable tool connecting the sponsors of clinical research to subject matter experts

BCCRIN is an active participant in the BC Strategy on Patient Oriented Research (SPOR) Support Unit Business Plan development team (see below).

Dr. Geoff Payne, Associate Professor & Assistant Dean, Education & Research, Northern Medical Program at UNBC, has served on the BCCRIN Steering Committee for the past three years and on the network's board of directors for the last year. The network ensures at least one member of the NH research community sits on the BCCRIN task force and northern input is sought in focus groups relating to major projects. BCCRIN has also participated in meetings and UNBC/NH research days over the past few years, and has been invited back to make another presentation in the fall of 2014.

With respect to developing more activity involving clinical research/trials activity outside the province's major southern urban centres, BCCRIN's approach is to build expertise and capacity across BC as a whole, primarily by facilitating clinical research through the online Clinical Research Asset Map. There are no network initiatives specific to northern BC at present.

BC Ethics Harmonization Initiative

During the interviews conducted for this environmental scan, the need to pursue multiple levels of ethics and institutional review was repeatedly cited by UBC/PHSA researchers as a barrier to collaborative research involving UNBC and/or Northern Health. Duplication of processes, effort and documentation, with the attendant loss of time and productivity, were frequently mentioned.

Researchers who have access to UBC's automated system Researcher Information Services (RISe) are used to its relative speed and convenience, compared to what they see as slower and duplicative review processes for research involving northern partner agencies.

In the view of most applicants involved in multisite studies, the burden of institutional bureaucracy seems to multiply exponentially with the need to pursue review processes for each additional site or institution with authority over some portion of a given study. And due to the relatively smaller numbers of faculty and volume of research activity in the north, partner agencies do not have the capacity to process review applications in the same fashion as UBC and its affiliated teaching hospitals.

Since 2007, Michael Smith Foundation for Health Research (MSFHR) has been working with BC's health research community to facilitate enhanced harmonization and rationalization of their various systems for ethical review of health research involving human subjects. This challenge has proven durable and complex.

Most recently, in 2011 MSFHR provided \$1 million over four years to support the BC Ethics Harmonization Initiative (BCEHI), a collaborative effort between eight partner organizations representing BC's provincial health authorities and major research universities. MSFHR is facilitating the process by providing funding and project management support for the initiative aimed at developing a more effective, coordinated provincial approach to ethics review of health research studies involving multiple Research Ethics Boards.

The BCEHI is aimed at developing a more effective, coordinated provincial approach to ethics approval of research involving human subjects. Its long-term goal is to make BC a more attractive environment for health research involving multiple sites, regions, and populations.¹⁰

Over the last two years, work has taken place to build trust among the partner organizations involved in the BCEHI, creating a solid foundation to develop and implement the review model(s) needed to achieve harmonized ethics review in BC. The BC Ethics Harmonization Reciprocity Agreement authorizes the 14 ethics review boards under their jurisdiction to collaborate on the development of streamlined ethics review processes between institutions, and there is agreement in principle to develop a centralized approach to provincial ethics review.

¹⁰ <http://www.msfhr.org/our-work/activities/bc-ethics-harmonization-initiative>, accessed May 29, 2014

As of May 2014, with the endorsement of the senior leaders of the partner organizations, MSFHR is taking on direct project management of BCEHI as it enters a new phase of development. According to the MSFHR website, “A new advisory committee will be appointed, with representation from each of the partner organizations, to bring together their experience and knowledge to the development of centralized research ethics board review models. Development of the models will take place over the spring and summer, with implementation to follow on a test basis over a six-month period starting this fall. The aim is to have the models approved by partner organizations by spring 2015.” The Foundation is currently recruiting for a new staff member to support these activities.

BC Health Research Strategy

Health research and health care leaders met in 2012 to discuss the potential of a health research strategy to shape a more comprehensive, coordinated and systems-oriented approach to health research in BC. Participants agreed on the need for such a strategy, and endorsed the Michael Smith Foundation for Health Research to consult with the community and facilitate its development.¹¹ The strategy initiative has two aims:

- To identify specific actions for collaborative implementation by the health research community
- To provide a framework from which other organizations can determine their own priorities, plans and investment decisions

Preliminary planning included the establishment of an advisory board, planning team and reference group as well as key informant interviews. Analysis conducted by the planning team resulted in five directions as a framework for consultation. In spring 2013, these directions were discussed in focus groups involving stakeholders with a range of relevant experience and expertise. An online survey tested elements of the emerging strategy with a broad audience. Workshops were held to engage regional players in assessing the potential of the emerging health research strategy to support local needs. The final consultation element was a validation workshop—an opportunity to bring the results back to a diverse subset of key stakeholders to validate what was heard during the previous consultation activities.

At the conclusion of these consultation activities, three directions for health research in BC, along with associated actions emerged. As of May 27, 2014, MSFHR announced that “a printed version of the strategy document is being finalized and will be ready for distribution in a few weeks.” It is anticipated that key directions included in the strategy will speak to some of the barriers to research identified during this environmental scan, such as (for example) enhanced and more timely access to linked data.

As of May 2014, MSFHR is also working with stakeholders to support the transition from strategy development to implementation, including a review of implementation models and development of recommendations regarding leadership and guidance for the implementation process. The provincial research strategy initiative has been developed in harmony with the BC submission to CIHR’s Strategy for Patient-Oriented Research (see below), and in anticipation of the implementation of a provincially harmonized ethics review for research involving human subjects and creation of a BC academic health sciences network, as described earlier in this section.

¹¹ <http://www.msfhr.org/our-work/activities/bc-health-research-strategy>, accessed May 29, 2014

Canadian Institutes of Health Research Strategy for Patient-Oriented Research

The CIHR Strategy for Patient-Oriented Research was announced in March 2012. The strategy aims to provide a framework for research that enhances the Canadian health care system by “ensuring that the right patient receives the right intervention at the right time.”¹²

As CIHR has stated, “The objective of SPOR is to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, so as to ensure greater quality, accountability, and accessibility of care.”¹³ CIHR defines SPOR as a coalition of federal, provincial and territorial partners, “all dedicated to the integration of research into care:

- Patients and caregivers
- Researchers
- Health practitioners
- Policy makers
- Provincial/territorial health authorities
- Academic institutions
- Charities
- Pharmaceutical sector”¹⁴

Across Canada, provinces and territories are working on initiatives to take advantage of SPOR funding and related opportunities. A central element of SPOR is the creation of Support for People and Patient-Oriented Research and Trials (SUPPORT) Units, which CIHR describes as “locally accessible, multidisciplinary clusters of specialized research resources, policy knowledge, and patient perspective.”¹⁵ On behalf of the BC Ministry of Health, MSFHR is facilitating the development of a business plan for a provincial SUPPORT Unit designed to increase and enhance patient-oriented research in BC.¹⁶

As MSFHR has reported, “Individuals, teams, and organizations from across BC’s health research and health care sectors were invited by MSFHR to participate in the development of a SUPPORT Unit business plan. A call for Expressions of Interest was issued broadly in late July 2013. Expressions of Interest were reviewed by representatives of MSFHR and the BC Ministry of Health, as well as members of an external expert group, to identify those interested in assuming a leadership role in the development of BC’s SPOR SUPPORT Unit business plan.”¹⁷

Development of this plan was informed by a consultation process that engages BC’s health care leadership, as well as experts on patient perspectives and members of the health research community who are potential providers and users of SUPPORT Unit services. The business plan is currently undergoing final revision, and is expected to be submitted to CIHR for review in summer 2014. There is no formal deadline so the business plan development team has indicated it will not submit a plan until there is confidence that the proposal presents “the best case meeting the ambitious goals for BC.”¹⁸

¹² <http://www.cihr-irsc.gc.ca/e/41204.html>, accessed May 29, 2014

¹³ CIHR, Ibid

¹⁴ CIHR, Ibid

¹⁵ <http://www.cihr-irsc.gc.ca/e/45859.html>, accessed June 6, 2014

¹⁶ <http://www.msfhr.org/our-work/activities/strategy-patient-oriented-research>, accessed May 29, 2014

¹⁷ <http://www.msfhr.org/our-work/activities/patient-oriented-research/about-spor>, accessed May 29, 2014

¹⁸ MSFHR, Ibid

Within the SUPPORT Unit business plan, a number of proposed components would contribute to building capacity for health research in and about northern British Columbia. These include the proposed creation of a virtual network connecting patients, providers, decision makers and researchers through a provincial hub, regional centres, and specialized methods clusters. One of the regional centres anticipated in the plan is proposed for the north, and like other regional centres it is envisioned as providing a key integration function, ensuring that research evidence is implemented to improve patient care, experience and outcomes.

According to a draft of the plan prepared for discussion in May 2014, these regional centres “will be based in the regional health authorities and will build on existing alliances and collaborations such as the University of Northern British Columbia-Northern Health, University of Victoria-Island Health, and Simon Fraser University-Fraser Health collaborations.”

The business plan’s vision is that, “regional centres will ensure patient-oriented research capacity is strengthened across the province, and will build on existing expertise, infrastructure and connections among health authorities, universities and other organizations in each region.”

“A research navigation function will link researchers and knowledge users with regional and provincial services, and a knowledge translation function will focus on application of research results into practice and policy within each region.” The plan calls for regional centres to link with each other and with methods clusters through the provincial coordinating hub.¹⁹

Each of these new regional centres, “will be resourced to fulfill its mandate and will determine how best to allocate new investments, while taking advantage of alignments with existing resources. New investments will ensure that key functions are in place in each region”, including:

- *Research priority setting and projects*
 - Managing patient-oriented research priority setting within the region
 - Participating in provincial patient-oriented research priority setting to ensure reflection of regional needs
 - Participating in pan-provincial patient-oriented research initiatives
- *Research navigation*
 - Support for navigating the research landscape and linking to provincial hub services
 - Enabling patient/public engagement in research
 - Measuring and evaluating progress
- *Knowledge translation and implementation*
 - Disseminating and implementing research results
 - Contributing to a provincial evidence base in KT and implementation science
 - Providing or linking to KT and implementation resources
- *Methods clusters/communities of practice*
 - Where appropriate, leading an area of methods expertise
 - Participating in a provincial community of practice in a particular methodology

¹⁹ **Strategy for Patient-Oriented Research, BC SUPPORT Unit Business Plan: Summary Overview**, Draft: May 20, 2014, pp 4-5.

- *Networking with other regional hubs and the provincial hub*
 - Promoting sharing of expertise and knowledge, reducing duplication of services and promoting provincial collaboration
- *Administrative services*
 - Managing linkage among regional partners (health authority, university, and others) and between the regional centre and provincial hub; managing regional budget; maintaining records and documents; managing communications²⁰

This model builds on and expands the philosophy already in place in northern BC and operationalized in the Innovation and Development Commons. However the SUPPORT Unit model has a specific focus on patient-oriented research, rather than anticipating support for activities encompassing the full spectrum of health research.

First Nations Health Authority

BC First Nations, the Province of BC, and the Government of Canada have all determined that First Nations health disparities are no longer acceptable. A new relationship between these tripartite partners was forged and a series of precedent-setting agreements led to the creation of a First Nations Health Authority.

On October 1, 2013, the First Nations Health Authority made history in Canada with the official transfer of all programs and services from Health Canada's First Nations Inuit Health branch to the FNHA. The FNHA has now assumed responsibility for all health services delivered to status First Nations individuals in British Columbia.

Recognizing that statistically significant health disparities exist for First Nations people in BC and across Canada, the FNHA aims to reform the way health care is delivered to BC First Nations to close these gaps and improve health and well-being. The FNHA's vision is to support, "Healthy, Self-Determining and Vibrant BC First Nations Children, Families and Communities", and will achieve this through adherence to seven directives put forward by First Nations communities in BC with a commitment to community, collaboration, and quality care.

This new health authority has taken over the administration of federal health programs and services previously delivered by Health Canada's First Nations Inuit Health Branch – Pacific Region, and will work with the Province and First Nations to address service gaps through new partnerships, closer collaboration, and health systems innovation.

To date, FNHA's evolution has focused on the devolution of these programs and services, and creating a robust and culturally-aligned health authority structure. While using research evidence is amongst the drivers of quality service delivery for FNHA, the health authority does not yet have a major research infrastructure or focus to facilitate and promote evidence use.

As noted by several interviewees during this environmental scan, FNHA and NH will increasingly share responsibility for different aspects of service delivery to northern First Nations citizens. Concurrently, PHSA and UNBC share an interest in collaborating with FNHA and NH on research and knowledge translation to inform planning for and effectiveness of service delivery.

²⁰ Ibid, pp 6-7.

Appendix Three: Project Leadership

MOU Steering Committee

Dr. Mark Dale, Interim President, University of Northern British Columbia

Mr. Carl Roy, President & Chief Executive Officer, Provincial Health Services Authority

Ms. Cathy Ulrich, President & Chief Executive Officer, Northern Health Authority

Implementation Reference Group

Mr. Fraser Bell, Vice President, Planning, Quality & Information Management, Northern Health Authority

Ms. Ellen Chesney, Chief Administrative Officer, Research, Provincial Health Services Authority

Dr. Martha MacLeod, Professor and Chair, School of Nursing, and Co-Leader, UNBC Health Research Institute, University of Northern British Columbia

Appendix Four: Interviewees

The following list identifies all individuals who were interviewed for this environmental scan, whose comments are summarized and analyzed in this report. With respect to the institutional partners their names are identified within the list below, please note that several have cross-appointments (both at the three partner agencies sponsoring this project, and with UBC, the University of Alberta, and other academic and clinical organizations). Thus the affiliations noted below may reflect only part of the perspectives they generously offered to this project.

Northern Health

Ms. Lucy Beck, Regional Director, Public Health – Population & Protection
Mr. Fraser Bell, Vice President, Planning, Quality & Information Management
Dr. Jan Burg, Co-Lead, Critical Care Program
Mr. Jim Campbell, Executive Lead, Mental Health & Addictions
Dr. Ronald Chapman, VP Medicine & Clinical Programs, Medical Affairs
Ms. Beth Ann Derksen, Co-Lead, Critical Care Program
Dr. Jaco Fourie, Oncologist, Terrace
Dr. Brian Galliford, Medical Lead, Perinatal Program
Dr. Candida Graham, Academic Physician, Psychiatry, Northern Medical Program
Ms. Tanis Hampe, Regional Director, Quality and Innovation
Ms. Tammy Hoefer, Regional Manager, Innovation & Development Commons
Ms. April Hughes, Health Services Administrator, Lakes/Omineca
Dr. Suzanne Johnston, VP Clinical Programs & Chief Nursing Officer
Ms. Kathy MacDonald, Regional Director, Preventative Public Health
Dr. Sheona Mitchell, Researcher, Women’s Health Research Institute and Obstetrics and Gynecology physician in Prince George
Ms. Betty Morris, Chief Operating Officer, Northeast
Ms. Rose Perrin, Executive Lead, Perinatal Program (retired May 2014)
Dr. Anurag Singh, Lead, Renal Program
Ms. Cathy Ulrich, President & CEO
Ms. Bonnie Urquhart, Regional Director, Planning & Performance Improvement

Provincial Health Services Authority

Dr. Sam Abraham, Vice President, Research, BC Cancer Agency
Dr. Laura Arbour, Professor, Department of Medical Genetics, UBC
Dr. Anthony Bailey, Professor and Chair in Child and Adolescent Psychiatry, PHSA
Ms. Sandra Bazley, In-hospital Donation Coordinator, Hospital Development, BC Transplant
Dr. Jim Christenson, Professor and Head, Department of Emergency Medicine, University of British Columbia Faculty of Medicine
Mr. Ed Ferre, Director of Program Development and External Relations, BC Transplant
Dr. Daniel Goldowitz, Interim Director, Centre for Molecular Medicine and Therapeutics; Scientific Director, NeuroDevNet
Dr. Sarah Henderson, Senior Scientist, Environmental Health Services, BC Centre for Disease Control

Dr. Bonnie Henry, Medical Director, Communicable Disease Prevention & Control Services and Public Health Emergency Services, BC Centre for Disease Control

Dr. William Honer, Jack Bell Chair in Schizophrenia, Professor and Head, Department of Psychiatry; Director, Institute of Mental Health, UBC; Vice President, Strategic, BC Mental Health and Substance Use Services

Dr. Adeera Levin, Head, Division of Nephrology, UBC and Executive Director, BC Provincial Renal Agency

Dr. Marco Marra, Director and Distinguished Scientist, Genome Sciences Centre, BC Cancer Agency

Dr. Deborah Money, Vice President, Research, Women's Health Research Institute

Dr. Maureen O'Donnell, Developmental Pediatrician and Executive Director, Child Health BC

Dr. Gina Ogilvie, Medical Director, Clinical Prevention Services, BC Centre for Disease Control

Dr. Rob Olson, BCCA Physician, Affiliate Assistant Professor, Regional Faculty Development Director, Northern Medical Program

Ms. Pam Tobin, Regional Director, Operations, BC Cancer Agency (to June 2014)

Dr. Wyeth Wasserman, Executive Director, Child & Family Research Institute

Ms. Kim Williams, Provincial Executive Director, Perinatal Services BC

University of Northern British Columbia

Dr. Davina Banner-Lukaris, Assistant Professor, Nurse Researcher, Cardiovascular

Dr. Ranjana Bird, Vice President, Research

Dr. Nadine Caron, Oncology Surgeon, BC Cancer Agency – Centre for the North; Co-director, UBC Centre of Excellence in Indigenous Health

Dr. Sarah de Leeuw, Associate Professor, Northern Medical Program

Dr. Sarah Gray, Assistant Professor, Northern Medical Program

Dr. Margo Greenwood, Professor, First Nation Studies, UNBC; Academic Lead, National Collaborating Centre for Aboriginal Health; VP, Aboriginal Health, Northern Health Authority

Dr. Neil Hanlon, Associate Professor and Chair, Geography

Dr. Henry Harder, Professor and Immediate Past Chair, School of Health Sciences; Donald B. Rix Leadership Chair in Aboriginal Environmental Health

Dr. Cindy Hardy, Associate Professor and Chair, Department of Psychology

Professor Dawn Hemingway, Associate Professor and Chair, School of Social Work

Dr. Martha MacLeod, Professor and Chair, School of Nursing and Co-Leader, UNBC Health Research Institute, University of Northern British Columbia

Dr. Margot Parkes, Associate Professor, School of Health Sciences/Northern Medical Program; Canada Research Chair, Health, Ecosystems and Society, UNBC

Dr. Geoff Payne, Associate Professor & Assistant Dean, Education & Research, Northern Medical Program

Dr. Stephen Rader, Professor, Chemistry

Dr. Paul Winwood, Vice Provost Medicine, Northern Medical Program

Information on the *provincial context for collaboration planning* was also provided via interviews with Dr. Bev Holmes, Vice President, Research Impact, Michael Smith Foundation for Health Research, and Ms. Heather Harris, Director, Operations, BC Clinical Research Infrastructure Network.

Appendix Five: Validation Forum Participants

The following list identifies everyone who participated in the June 2014 Validation Forum in Prince George.

Northern Health

Mr. Fraser Bell, Vice President, Planning, Quality & Information Management
Dr. Jan Burg, Co-Lead, Critical Care Program
Mr. Jim Campbell, Executive Lead, Mental Health & Addictions
Ms. Beth Ann Derksen, Co-Lead, Critical Care Program
Ms. Tanis Hampe, Regional Director, Quality and Innovation
Ms. Tammy Hoefer, Regional Manager, Innovation & Development Commons
Ms. Bonnie Urquhart, Regional Director, Planning & Performance Improvement

Provincial Health Services Authority

Dr. Sam Abraham, Vice President, Research, BC Cancer Agency
Ms. Ellen Chesney, Chief Administrative Officer, Research, Provincial Health Services Authority
Dr. Sarah Henderson, Senior Scientist, Environmental Health Services, BC Centre for Disease Control
Dr. Marco Marra, Director and Distinguished Scientist, Genome Sciences Centre, BC Cancer Agency
Dr. Rob Olson, BCCA Physician, Affiliate Assistant Professor, Regional Faculty Development Director, Northern Medical Program
Dr. Wyeth Wasserman, Executive Director, Child & Family Research Institute
Ms. Julie Wei, Manager, Quality Analytics, BC Emergency Health Services

University of Northern British Columbia

Dr. Davina Banner-Lukaris, Assistant Professor, Nurse Researcher, Cardiovascular
Dr. Nadine Caron, Oncology Surgeon, BC Cancer Agency – Centre for the North; Co-director, UBC Centre of Excellence in Indigenous Health
Dr. Candida Graham, Academic Physician, Psychiatry, Northern Medical Program
Dr. Neil Hanlon, Associate Professor and Chair, Geography
Dr. Cindy Hardy, Associate Professor and Chair, Department of Psychology
Professor Dawn Hemingway, Associate Professor and Chair, School of Social Work
Dr. Martha MacLeod, Professor and Chair, School of Nursing and Co-Leader, UNBC Health Research Institute, University of Northern British Columbia
Ms. Rachael Wells, Manager, UNBC Health Research Institute
Dr. Paul Winwood, Vice Provost Medicine, Northern Medical Program

Other Affiliations

Dr. Gabe Kalmar, Vice President, Sector Development, Genome BC

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Appendix Seven: About the Partner Organizations

Northern Health – NH

Northern Health provides a continuum of health services to 300,000 residents of the northern two-thirds of the province of British Columbia. The health authority's strategic plan 2009 through 2015 outlines four strategic priorities, which together recognize that NH needs to undertake, support and evaluate a transformation to continually improve service quality and to ensure system sustainability. The plan focuses attention and activities on the health of populations and communities and on establishing a strong, unique foundation in primary care.

In particular, Northern Health's strategic plan includes a commitment to fostering a learning environment and engaging in research, in partnership with academic organizations and in ways that complement its other strategic directions including:

- Integrated Accessible Health Services
- A Focus on Our People
- A Population Health Approach
- High Quality Services

Provincial Health Services Authority – PHSA

PHSA agencies conduct approximately \$180 million worth of health research every year, improving the health of British Columbians and contributing to the sustainability of our health care system. PHSA researchers attract about 25 percent of all health research money that comes into BC. This research funding supports the activities of more than 1,200 researchers and staff involved in lab-based, clinical, and community health research.

The PHSA's agencies and their associated research entities include:

BC Cancer Agency

- **The BC Cancer Research Centre** is an integral part of the BCCA, supporting its research mandate by providing scientific investigation into the causes of cancer, treatment improvements, and better ways of managing and curing the disease.
- **The Michael Smith Genome Sciences Centre** is a leading international centre for genomics and bioinformatics research. Its mandate is to advance knowledge about cancer and other diseases; to improve human health through disease prevention, diagnosis and therapeutic approaches; and to realize the social and economic benefits of genomics research.

BC Centre for Disease Control – The BCCDC operates in close collaboration with the UBC Centre for Disease Control and, increasingly, Simon Fraser University. BCCDC is a partner in the Pan-Provincial Vaccine Enterprise (PREVENT), a \$25.5 million national research centre of excellence designed to fast-track development of vaccines for pandemic influenza and a number of other viral and bacterial conditions.

BC Children's Hospital and Sunny Hill Health Centre for Children: Child & Family Research Institute – With 200 investigators and more than 350 trainees, CFRI is the largest institute of its kind in Western Canada.

BC Mental Health & Addiction Services – Researchers at BCMHAS and the BC Mental Health and Addiction Research Institute are engaged in both basic and translational research.

BC Women's Hospital & Health Centre

- **Women's Health Research Institute** serves as a catalyst for research in women's health and supports an expanding national network of women's health researchers, policy makers and health care providers.
- **British Columbia Centre of Excellence for Women's Health** is funded by Health Canada and co-located at BC Women's. The Centre provides a women-centred approach and partners with local community agencies, provincial initiatives, national organizations and international agencies to conduct research and/or to exchange knowledge among community members, academic researchers, policy makers and health care professionals.

BC Provincial Renal Agency is known for its clinical information system, unique in North America. This system provides real-time, accurate data to support a broad range of functions and is an essential tool for renal research leading to improved care.

BC Transplant research ranges from basic scientific investigation to exploring the ethical and social issues related to transplantation.

Cardiac Services BC operates one of the most comprehensive clinical databases in Canada. This cardiac services database collects data from BC's cardiac care hospitals, providing a valuable tool for research to improve cardiac care.

Perinatal Services BC maintains a provincial data registry that records a broad range of data on all deliveries and births in BC, supporting perinatal health services research to improve delivery of care.

University of Northern British Columbia – UNBC

The objectives of UNBC's Strategic Research Plan are to:

- Strengthen research at UNBC that is of outstanding quality and pioneering in its innovation, especially in strategic interdisciplinary research areas that are of marked importance to our region and similar areas;
- Enhance the training of researchers by increasing the number of graduate students and by providing a highly stimulating research environment for all students (undergraduate and graduate) that establishes UNBC as a leader in the integration of research and teaching;
- Guarantee our researchers access to superior research resources and infrastructure, and manage these to ensure their effective and efficient use;
- Develop new research relations with communities, businesses, industries, other academic institutions and other partners regionally, nationally and internationally; and
- Enhance access to the results of our research, through improved knowledge translation, transfer and application, in order to maximize their benefits to society in northern British Columbia and beyond.

Northern, Rural and Environmental Health, one of UNBC's four strategic research areas, along with Environment and Natural Resources; Community Development, and First Nations and Indigenous Studies is spearheaded through the UNBC Health Research Institute.

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