First Nations Health Authority Chair in Cancer and Wellness at the University of British Columbia

2020 Annual Report

First Nations Health Authority
Health through wellness

THE UNIVERSITY OF BRITISH COLUMBIA
Faculty of Medicine

TABLE OF CONTENTS

This publication is the result of a collaborative initiative by the FNHA Chair in Cancer and Wellness at UBC, Dr. Nadine Caron and her Advisory Committee. This position is made possible through contributions from the First Nations Health Authority and the University of British Columbia.

INTRODUCTION

STATEMENT FROM THE CHAIR

It has been a great honor and privilege to serve as the Inaugural First Nations Health Authority Chair in Cancer and Wellness at the University of British Columbia for the past year. The excitement, support and potential of this role were truly palpable at the ceremony to celebrate this position on January 6, 2020. The stories, commitment, and ceremony reflected the priority First Nations Peoples in British Columbia have voiced regarding the journeys Indigenous peoples face in cancer and the uncertainties and disparities along this path. At the same time, the focus on wellness, resilience and empowerment to truly impact our paths in a good way was the main story that emerged.

The year 2020 unfolded in a way unlike any other. Indigenous communities faced three major health crises: the COVID pandemic, the opioid emergency, and systemic racism in the healthcare system. All three reinforce the need for the Chair and the knowledge that will be developed.

A core supportive group of colleagues and leadership was created and the subsequent FNHA Chair in Cancer and Wellness at UBC Advisory Committee was assembled to meet on a regular basis to provide guidance on the way forward. Knowledge Keeper Gwendolyn Point graciously agreed to play a primary role as my advising Elder as the initiatives for the Chair proceeded. Outreach with BC Cancer has been greatly appreciated and critical to this movement forward and planned partnerships with the Métis Nation of BC will hopefully be as fruitful as we anticipate based on our first few meetings this year.

It does go without saying that the COVID pandemic has cast a shadow over 2020 but at the same time provided opportunity to demonstrate collaboration, partnership and resilience. As the FNHA Chair, I continued existing projects such as the First Nations Biobank within the *Northern Biobank Initiative* and *Silent Genomes*, but I have also had the opportunity to be at national discussions regarding the importance of equitable access and opportunity for research regarding COVID-19 for First Nations in BC and Indigenous Peoples in Canada. What we are learning in these two major existing projects in terms of Indigenous governance, data sovereignty and research capacity is that there is indeed a role for Indigenous partnership, collaboration and inclusion in these National COVID-19 efforts; a global pandemic of this magnitude is novel to all of us. I am hoping that as we enter this next year of the FNHA Chair, and as a country and global nation we put the COVID pandemic behind us, that engagement and collaboration in the area of cancer can be expanded and grown. In the meantime, knowledge generated regarding the research projects currently underway and ongoing dialogue can ensure that 2021 is a safe, productive year where our communities see improved awareness, greater understanding in the realm of cancer and subsequent impact on guidelines and policies with respect to Indigenous research and expansion of the expectations regarding cultural safety and humility.

Thank you once again for this opportunity to serve as the FNHA Chair in Cancer and Wellness at UBC. My best wishes for a safe and happy 2021.

Dr. Nadine Caron, MD, MPH, FRCSC, FACS

Dr. Nadine Caron MD, MPH, FRCSC, FACS

Dr. Caron is a member of the Sagamok Anishnawbek First Nation. She is a practising surgical oncologist in northern British Columbia (BC) where she provides cancer screening, diagnosis and surgical care for individuals in rural, remote, and northern BC – a large percentage of whom are Indigenous.

Dr. Caron is the sole Indigenous physician within BC Cancer, the only Indigenous academic faculty member within the University of BC's (UBC) Faculty of Medicine, a Professor at UBC Northern Medical Program and Department of Surgery as well as a Senior Scientist at Canada's Michael Smith Genome Sciences Centre at BC Cancer.

Dr. Caron is the inaugural First Nations Health Authority (FNHA) Chair in Cancer and Wellness at the University of British Columbia (UBC). She is also a founding co-Director of the UBC Centre for Excellence in Indigenous Health (CEIH) and Consultant in development of BC's first-ever Indigenous Cancer Strategy to improve Indigenous cancer outcomes and experiences in BC ("Improving Indigenous Cancer Journeys: A Road Map").

Dr. Caron currently leads the development of the *Northern Biobank Initiative* (NBI), including a First Nations-governed and controlled biobank in partnership with the FNHA that aims to provide safe access to cancer research for First Nations people in Northern BC. She is also co-Lead investigator on the *Silent Genomes* project which aims to address the genomic divide by reducing access barriers to diagnosis of genetic disease in Indigenous children and facilitating a governance framework to inform policy in fields of data sovereignty, genomic research, Indigenous research processes, among others.

Dr. Nadine Caron
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WORDS FROM KNOWLEDGE KEEPER DR. GWENDOLYN POINT

January 29, 2021

Ts'itholetstel, Shoyshqwelwhet te xwélmexw ta Skwix, Halq'eméylem to xwélmexw te Stó:lô. I thank you, my traditional name is Shoyshqwelwhet and the language I speak is Halqeméylem.

It is an honour to yoyes/work with Dr. Nadine Caron. "Yoyes" means work in our language, however, the "work" we do is a noun and not a verb. Work takes on a higher meaning inclusive of the responsibility to one's self and others.

The yoyes with Dr. Nadine Caron as the Knowledge Keeper is a high honour. An opportunity to walk on this journey in medicine and provide assistance, cultural guidance and support to her important work.

My background is Indigenous Education and for over thirty years I have worked in the K-12 and Post-Secondary with a focus on Indigenous student success. Bringing the Indigenous world view and cultural awareness to all the levels of education has made a difference for Indigenous student success. Being involved and part of the decisions in every level of the education system is also important. I believe this approach works across the agencies whether it is medicine, law, social work and/or education. Indigenous peoples must be partners and decision makers to support Indigenous families and communities.

As the First Nations Health Authority Chair in Cancer and Wellness at the University of British Columbia, Dr. Caron strives to get our Peoples' perspectives and voices at the table and I will help to guide her on this challenging journey.

EXECUTIVE SUMMARY

This report summarizes the activities, partnerships and accomplishments for the First Nations Health Authority (FNHA) Chair in Cancer and Wellness at the University of British Columbia (UBC) in the period between January and December 2020. While the year 2020 presented unique challenges with many unknowns, we were provided with the opportunity to shift work perspectives and approaches which allowed for newfound strengths to be discovered. While in-person sessions and gatherings were replaced with virtual meetings, connections to people and projects continued to develop. The resilience of partners and community members and their continued involvement and support harnessed invaluable progress on various work fronts. To support and guide the Chair with content, planning and process expertise, an Advisory Committee made up of strategically chosen leaders in community, partners, and the health system was established. This necessary position and important partnership between the FNHA and UBC carves a path for the continuation of critical research priorities and wellness work.

On Jan. 6, 2020, Nadine Caron, Canada's first female First Nations general surgeon, was appointed to a newly created UBC position dedicated to improving cancer outcomes and wellness among Indigenous peoples. (Announcement)

This inaugural year of the Chair's position yielded many accomplishments. These include:

- Continued engagement with organizations, partners and steering committees resulting in critical progress towards the establishment of networks required to advance key areas of research and wellness.
- Opportunities to continue being an active leader in optimizing Indigenous health, addressing inequities in access to surgical services, cancer care and prescription medications in Canada, and addressing inequities in access to health research for Indigenous, rural, and northern Canadians.
- Optimizing the relationship with the FNHA and UBC regarding cancer care, data sharing, and research initiatives. Extensive consultations with various partners and Indigenous leaders that culminated in the formation of the Advisory Committee made up of strategically chosen leaders in communities, grant-funding and partner organizations, and the health system.
- Recruitment of an Indigenous Elder/Knowledge Keeper as an established role with UBC whose role includes, among other, to provide teachings on, or lead when Elder deems appropriate, traditional ceremonies to advance Chair and her team's learning, development, and strengthen cultural connection of Chair role.
- With guidance from Knowledge Keeper Point, planning for the development of an Indigenous Advisory Committee ("Indigenous Circle") to bring a strong presence of Indigenous voices to the table to consider ongoing and emerging research issues arising from current and potential projects.
- Developed a proposed process for ways of conducting business (e.g., responding to requests for research, appropriate community engagement and communications, incorporation of honoraria policy, appropriate reporting strategies, and promotion of cultural safety and humility).
- Engaging in discussions for potential partnerships with various projects including the Marathon of Hope, the New Frontiers in Research Fund Transformation study, the Extension for Community Healthcare Outcomes project (Project ECHO), and the Canadian Partnership Against Cancer (CPAC), among others.
- Finalizing the recruitment for a Data Analyst position, using mobilized resources from an FNHA sub-grant to BC Cancer, who will provide necessary, time-sensitive analytical support to the Chair in relation to any of the Chairs research priorities, among other duties.
- Development of Indigenous-themed logos by Indigenous artists for the *Northern Biobank Initiative* and *Silent Genomes* projects reflecting the inclusion of Indigenous voices right from inception of the projects.
- Promotion to Professor at UBC – first Indigenous Professor at UBC Health, first female Professor at UBC Department of Surgery, and first faculty member at a UBC distributed medical program site to be promoted from Assistant to Associate to Professor (the Chair is physically based at the Northern Medical Program).
- 5 peer-reviewed Journal Publications
- 2 Accepted peer-reviewed Journal Submissions awaiting publication in 2021
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- 1 Submitted Journal manuscript
- 2 book chapters
- 1 commissioned freelance article for *The Walrus – The O'Hagan Essay on Public Affairs* (accepted in 2020 and published for Jan/Feb 2021 edition).
- 8 presentations at an International (6) or National (2) level
- One documentary on inequity of access to evidence-based medicine, precision medicine, and genomic research through the lens of the *Silent Genomes* project entitled, "Voicing the Silent Genome."
- 8 new grants totalling over $23 million for projects related to genomic research, access to medical supplies in rural and remote Indigenous communities, COVID-19, improving teaching effectiveness for Indigenous Cultural Safety curriculum, engaging Indigenous communities in health professions educational programs at UBC, and more.

BACKGROUND - THE PARTNERSHIP HISTORY

The First Nations Health Authority (FNHA) in British Columbia is a unique, population-based health authority that strives to honour community health and wellness priorities, optimize health care with First Nations communities in BC, develop Indigenous research capacity and provide leadership across a broad spectrum from health policy, cultural safety in health care, respect for Indigenous healing, among others. The impact of ongoing colonialism and racism, marginalization and poverty has interrupted First Nations health and wellness and has contributed to poorer health outcomes among First Nations people in B.C. compared to the general population. In recognition of this, coupled with the urgent need to develop knowledge and holistic approaches to prevent and address cancer, a position dedicated to improving our knowledge of cancer outcomes and overall wellness among First Nations (and Indigenous peoples more generally) was created. This FNHA Chair in Cancer and Wellness at the University of British Columbia (UBC) is a 10-year faculty position supported by a $1.5-million contribution from the FNHA, with matching funds from the University of British Columbia (UBC). Dr. Caron was appointed as the inaugural Chair on January 6th, 2020 at a celebration in Vancouver**(1)**, BC, on the traditional, ancestral and unceded territory of the Musqueam people.

In BC, to positively impact health and wellness, Indigenous communities have prioritized work towards improving cultural safety and humility in the planning and delivery of health services. In the health system, efforts to advance cultural safety and humility have been shown and continue to progress as seen through signing of commitment declarations**(2)**. In BC, these commitments seek not only to ensure the involvement of Indigenous peoples in the design and developing of health policies and programs and the delivery of health services but also the promotion of measures to address discrimination and racism through their active participation**(2)**.

As a partner leading the implementation of the Indigenous Cancer Strategy, Provincial Health Services Authority (PHSA) created the Director of Indigenous Cancer Care at BC Cancer to support the BC Cancer Agency and Indigenous services across the province. This laid the foundation to improve the level of holistic services for First Nations and Indigenous cancer patients**(3)**.

A significant shift is underway in BC to resolve jurisdictional barriers and recognize the need to meaningfully involve First Nations in decision-making in health service planning and delivery. A unique First Nations health governance structure in BC, which includes the FNHA, has been established**(2)**. Emerging from this structure and work led by BC First Nations to improve cancer care services was this new Chair position.

The FNHA is the result of the unprecedented work by BC First Nations to assume the management and delivery of health services in BC previously delivered by the federal government. BC Cancer, FNHA, the BC Association of Aboriginal Friendship Centres and Métis Nation BC have since engaged with Indigenous families, cancer patients, and survivors to develop the province's first-ever Indigenous Cancer Strategy: "Improving Indigenous Cancer Journeys: A Road Map"**(4)**. The Indigenous Cancer Strategy is a strategic plan to improve First Nations cancer outcomes and experiences in the

province, and its implementation is a key priority of both BC Cancer and FNHA. This Strategy is based on years of community engagement and is a collaborative commitment to improve Indigenous cancer outcomes and experiences. At UBC, the Chair is positioned to collaborate with the university's Centre for Excellence in Indigenous Health to further research related to cancer and wellness with Indigenous Peoples and to improve capacity building to address Indigenous health concerns. Partnerships with the FNHA and BC Cancer are evident in publications leading up to the announcement of the Chair position; for example: 1) "Cancer in First Nations people living in British Columbia, Canada: an analysis of incidence and survival from 1993 to 2010"**(5)**; and 2) "Improving First Nations Cancer Journeys: Current Policy Perspectives and Approaches in British Columbia, Canada"**(6)**. The latter manuscript outlines policy development strategies and how cultural safety and humility would be incorporated into cancer care services and safe health care policy.

THE MAIN OBJECTIVES OF THE CHAIR AS OUTLINED IN THE FNHA/UBC CHAIR FUNDING AGREEMENT:

- To conduct research and education into critical health policy related to cancer, disease prevention and control associated with chronic diseases among First Nations peoples;
- To develop wellness and preventive disease epidemiology programs and databases, particularly as they pertain to increasing the research infrastructure and capacity in First Nations communities and organizations;
- To improve health system outcomes with respect to wellness and disease prevention and translational research for best practices, risk factor control, economic and social analysis;
- To take an active leadership role locally, provincially, and nationally that advances the understanding of the strategies to develop a program of excellence in First Nations wellness and disease prevention and policy;
- To provide mentorship and training to University undergraduate, graduate and post graduate trainees in the area of First Nations wellness and disease prevention and policy;
- To provide outreach provincially and nationally to build care relationships that are responsive to First Nations community needs;
- To promote the health and wellness of First Nations people within their own communities; and
- To support and advance the goals of First Nations wellness and disease prevention and policy at the FNHA and UBC.

PROGRAMS IN PROGRESS

The Chair's cancer and wellness plan includes existing and new projects over a 10-year period. The main themes for project work include: 1) Infrastructure and Human resource deliverables, 2) Health care promotion, and 3) Relationships and Capacity building. These are divided into short term (1-2 years), medium term (1-5 years), and long term (1-10 years) stages of delivery (see Appendix B). Below we highlight three ongoing projects:

1) **First Nations Cancer Research & Surveillance Projects**
2) **Northern Biobank Initiative/Northern First Nations Biobank**
3) **Silent Genomes Project**

FIRST NATIONS CANCER RESEARCH & SURVEILLANCE PROJECTS

The main purpose of this work is to link the First Nations Client File (FNCF) to BC Cancer registries and databases every two years over a 10-year period for the development of First Nations specific cancer data. This includes two separate FNCF Data Access Requests, and is needed to support the ongoing surveillance and research activities between FNHA, BC Cancer and the BC Centre for Disease Control (BCCDC). The data developed will support the work of the Chair and allow the Indigenous Cancer Strategy to fulfill its promise to communities to better document and understand First Nations cancer journeys. With a 10-year timeframe, this process will gather the data resources required over the long term for FNHA and communities to be able to fully leverage their relationships with BC Cancer and health system partners.

As part of this work, the Chair continues to build new and unique partnerships between her position and existing BC Cancer and BCCDC research teams. This will enhance progress of other research projects, particularly those requiring BC Cancer data. The Chair priorities made in 2020 included the development of an analysis and publishing plan, which will ensure robust knowledge translation to support decision-making and planning efforts by communities and all health system partners.

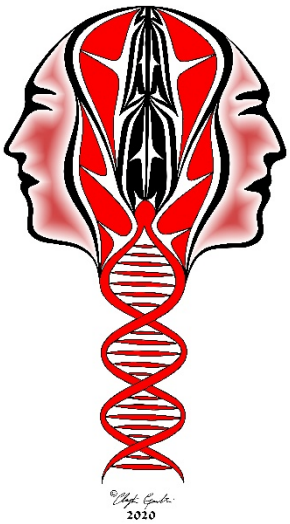
The following cancer statistics will be calculated for First Nations people and non-First Nations people using BC Cancer Registry data: incidence rate, mortality rate, survival, cancer center referral rates, and treatment rates. All statistics will be calculated overall and by cancer site, sex, stage and year. Where possible, all statistics will be broken down by region and sub-region pending appropriate confidentiality measures are in place.

The following immunization statistics will be calculated for First Nations people and non-First Nations people using cancer screening data: participation rate, retention rate, abnormal screen rates, cancer detection rates, interval cancer rates, and time to resolution of abnormal call rates by Program, year, age group, and sex. Where possible, all statistics will be broken down by region and sub-region pending appropriate confidentiality measures are in place.

The following screening statistics will be calculated for First Nations people and non-First Nations people using HPV vaccination data: Immunization coverage rate for adolescent girls and young women with year of birth between 1994-present eligible cohort; and immunization coverage rate for adolescent boys with year of birth between 2006-present eligible cohort. Where possible, all statistics will be broken down by region and sub-region pending appropriate confidentiality measures are in place.

NORTHERN BIOBANK INITIATIVE & EMBEDDED NORTHERN FIRST NATIONS BIOBANK

Genomics and its applications are playing an exponential role in health care (in prevention, diagnosis, and treatment). To ensure the BC Northern Health Authority's population has the opportunity to be involved in, and to reap the benefits demonstrated in this expanding field, the *Northern Biobank Initiative* (NBI) involves the creation and deployment of a population-based biobank. This involves clinical data and biospecimens donated from people in northern BC, which are systematically stored in the University Hospital of Northern BC (UHNBC) in Prince George (Caron et al., 2020a)**(7)**.



Phase I (NBI-I) began in 2012 and involved initial dialogue with the health leadership at BC Cancer, Northern Health executive, FNHA leadership, researchers, family practitioners, and First Nations Chiefs, health leads, and community members. Through the resultant partnership, Phase II then began in 2016 when the NBI team began formal consultations regarding governance, ethics, consent procedures, access, and cultural safety protocols, among others. The majority of these consultations focused on the unique Northern First Nations biobank which has the potential to be embedded within the NBI. This required the northern BC First Nations Chiefs to pass a resolution supporting the NBI consultations with First Nations through the FNHA Northern Regional Caucus, with the input and guidance of the newly formed Northern First Nations Biobank Advisory Committee (NFNBAC). The NBI also received input from leaders of the Canadian Tumour Repository Network (CTRNet) and other biobanks in Canada. Phase I of the NBI, termed "dialogue to permit dialogue," paved the way and nurtured support for the formal consultations in Phase II [NBI-II]. A documentary was produced, released to the public and shared extensively during First Nations community consultations entitled: Mshkikiininiikwe: Building the Northern Biobank. Additionally, a pamphlet was created as a resource for partnering First Nations communities to outline the objectives of the NBI, the consultation process, NCNBAC members, contact information and other key information (Appendix E).

The NBI is now transitioning into Phase III which is the creation of a prospective biobank and ongoing collaboration with First Nations in northern BC for the potential creation of a Northern BC First

Nations biobank to be embedded within the NBI with separate First Nations governance and protocols that have been drafted based on the extensive consultation in phases I and II.

Table 1. ***Five phases of the Northern Biobank Initiative: Initiation, planning and execution***

Initiation	Planning	Implementation and Execution			
Phase I	Phase II	Phase III	Phase IV*	Phase V*	Phase VI*
Business plan Establish collaborations Connect with CTRNet Preliminary consultations	· Creation of the Retrospective Northern Breast Cancer Biobank · Consultations & engagement; First Nations, PCPs, researchers, etc. Establish governance Sustainability plan	Prospective sample collection (cancers; starting with breast, colon and thyroid cancer)	Fresh tissue sample collection	Integration of other tumour types to NBI	Expansion of sample collection throughout NHA

***Phases IV to VI to be determined with ongoing consultation with NH and FNHA partners and governance. It is possible that the next phase after Phase III is actually expansion to other sites (the originally planned Phase VI).**

SILENT GENOMES PROJECT (SG)

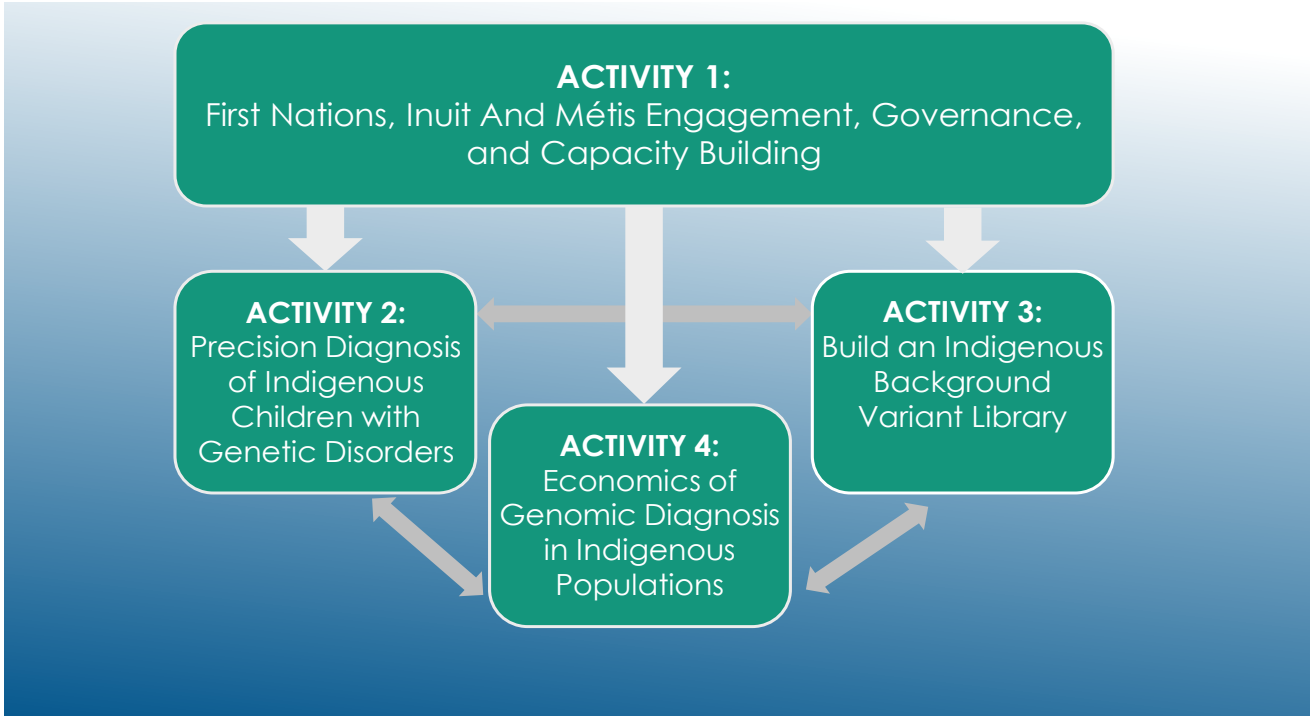
Genomics has seized modern medicine contributing to understanding of the etiology of disease, enabling genetic/genomic diagnosis, refining care strategies, and informing therapeutic development. However, genomic technologies are often less accessible – or even inaccessible – to Indigenous populations. This places Indigenous children and adults in Canada at risk of further increasing access barriers broadening the health care equity divide. This is secondary to the "genomic divide" **(8,9)** including the lack of reference variant data for these populations for the interpretation of targeted gene panels and genomic sequencing, now often considered a standard of practice in Canada for diagnosis. As such, genomic clinical tools, and the global resources supporting them, including "normal" variation databases, do not address all populations equally. Notably, these genomics resources are *silent* with respect to First Nations, Métis and Inuit (collectively Indigenous) populations – i.e., the implication and population frequency of variants detected in sequencing is not known – resulting in lost opportunity for a precise genomic diagnosis compared to well-represented populations.

The main goal of *Silent Genomes* **(10,11)** is to ensure equitable opportunity for precise genomic diagnosis and informed patient management for Indigenous Canadians. The program's

multidisciplinary team of experts continue to apply their demonstrated expertise throughout the process.

With Indigenous partners (community level, nationally, regionally), *Silent Genome*'s goals are to:

- Develop Indigenous governance for this end product of the Indigenous background variant library (IBVL), create policies for genomic research and clinical care, develop guidelines and establish best practice models for oversight of biological samples and genomic data (Activity 1);
- With our Indigenous steering committee, develop an Indigenous Background Variant Library (IBVL) and integrating governance approaches (Activity 3);
- Provide genomic testing to 200 Indigenous children with suspected genetic disorders and use the IBVL to provide precision diagnosis (Activity 2); and,
- Assess the utility and cost-effectiveness of genomic diagnosis with and without the IBVL (Activity 4).
- Integrate capacity-building for communities and students/trainees into each step.



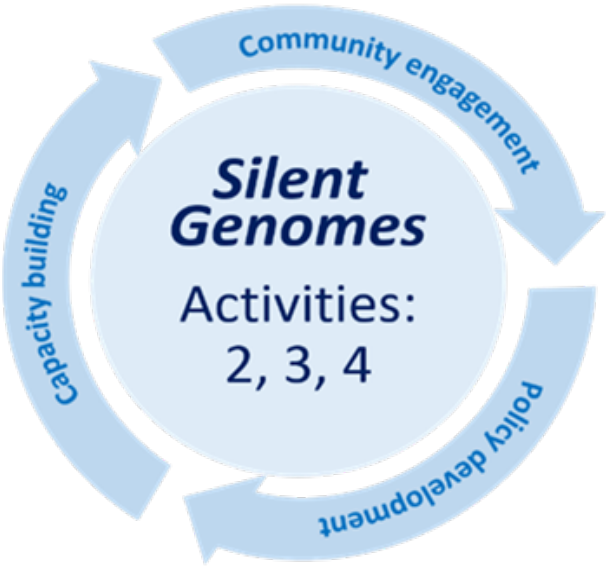


Figure 1. ***The four activities of the Silent Genomes Project (SG)***

FUTURE PROJECTS AND PARTNERSHIPS

In line with achieving the goals of the Chair position, and ultimately equity in healthcare delivery and access for Indigenous peoples, the Chair is in early discussions with various stakeholders and researchers, actively considering partnership in future research partnerships/projects.

These include:

1) **Coronavirus (COVID-19) impact study**
2) **Marathon of Hope Cancer Centres Network (MOHCCN) project**
3) **Frontiers in Research Fund Transformation (NFRFT) study**
4) **the Cancer ECHO Project (in collaboration with ROCHE)**
5) **Canadian Partnership Against Cancer**
6) **Spirit North: Partnership for Enabling Sport to Improve Wellness of our Indigenous Youth**

These six are highlighted here as they show great promise for better healthcare, improved access and optimized wellness and can be incorporated in the Chair's priorities. However, all are in various preliminary stages and require extensive dialogue and consultation with First Nations partners. The FNHA Chair will engage established longstanding partnerships with First Nations communities and Indigenous leaders and organizations as the starting point to open up formal consultations on how Indigenous Peoples in BC see their roles and participation in these projects.

CORONAVIRUS (COVID-19) IMPACT STUDY: Unintended Consequences

The effects of colonialism and resulting intergenerational trauma continue to manifest in structural and systemic barriers for First Nations people in achieving equitable access to health care services. These disparities, coupled with the Coronavirus disease (COVID-19) public health pandemic responses

will have significant negative effects on First Nations cancer care, including access to cancer screening, treatment, and outcomes. First Nations perspectives must be included in the research and reporting of the collateral consequences of the pandemic so that culturally safe and relevant responses can be planned.

Since the World Health Organization bestowed pandemic status upon the Coronavirus (SARS-CoV-2) outbreak on March 11th, 2020**(12)**, the COVID-19-related deaths in Canada continue to rise upwards of 19,664**(13)**. This neither measures the direct health impacts on individuals, families, and communities nor the collateral damage of unintended consequences of the necessary public health measures on the healthcare system or on the health of Canadians. There is concern founded on baseline disparities in access to healthcare, disease statistics, social determinants of health and historical failures in previous pandemics that Indigenous populations in Canada are at greater risk of enduring negative physical, mental, emotional and spiritual impacts from this pandemic**(14)**. By January 29, 2021, there were a total of 766,103 confirmed COVID-19 cases in Canada. Of that number, 16,160 people tested positive on First Nations reserves, with 1,628 of those cases originating in BC**(15)**. This number does not include First Nations people living off reserve, where 48% of First Nations people in BC live**(16)**. Some of these impacts are more amenable to quantifying in western science protocols and most will be done without the Indigenous lens unless Indigenous perspectives are embedded in the research realm during this urgent time.

The clinical understanding of the COVID-19 outbreak and its devastating effects are now being considered in light of the unintended consequences from the necessary Public Health measures enacted both external to and within the health care system. This includes cancelling and curtailing cancer screening, limiting diagnostic tests for potential cancer and dramatic limitations and delays on cancer surgeries. While cancer is a well-established priority identified by First Nations communities in BC, there has been a glaring lack of cancer data specific to this population that has impeded clinical decision making and policy development in cancer care. It has now become urgent to understand First Nations cancer data as many First Nations people and communities continue to endure social determinants of health that both elevate the risk of COVID-19 and cancer and heighten the impact of inequitable access to health care services.

This project will statistically model projected First Nations cancer outcomes from disruption in cancer screening services using relevant data collected and linked from: 1) the BC FN Client File, 2) BC Cancer Registry and BC Cancer Screening programs,3) BCCDC registry (for HPV related & cervical cancer) and 4) the BC Ministry of Health. Anonymized demographic tables detailing the age, sex, and calendar period make-up of the First Nations Client File will accompany the linked working files. These files will then be used for analysis, continued monitoring and reporting of BC First Nations cancer screening, diagnoses and outcomes by BC Cancer and the FNHA. This is needed to inform First Nations-specific policy and culturally safe and relevant Public Health responses towards prioritizing and scaling-up systems for screening, diagnostic testing, and therapy in the face of COVID-19 and societies' recovery from it. The modelling and findings from this project will be potentially applicable in understanding

the combined burden on other complex and/or chronic health conditions affecting First Nations peoples and incorporated into addressing the impact of the COVID-19 pandemic.

Progress will be made in data stratification and linkages to continually identify and update cancer screening, incidence, and survival rates in First Nations people in BC to inform relevant health care policy. Indigenous communities' quality improvement priorities will be used to sustainably improve cancer care and services through a cultural safety and humility lens. **STATUS:** CIHR grant submitted in 2020 was declined but plans to pursue this data analysis are ongoing via Chair funding and the additional funding mobilized for the Chair re: Data Analyst.

MARATHON OF HOPE PROJECT

Led by the Terry Fox Foundation and the Terry Fox Research Institute (TFRI), and in collaboration with many Canadian funding and research partners, the Marathon of Hope Cancer Centres Network (MOHCCN) aims to create a country-wide network of cancer centers designated for promotion and optimal delivery of Precision Medicine for cancer care**(17)**. The aim of this MOHCCN project, through its collaborative TFRI strategy, is to spearhead improvements in health outcomes for cancer patients by working with patients, Health Care Providers (HCPs), clinical and whole genome data, and novel infrastructure to drive advances more efficiently across the country, including Indigenous peoples in Canada. It is critical – and anticipated – that the MOHCCN grant Dr. Caron is part of will not proceed without Indigenous members as part of the proposal with the aim to seek equity in such opportunities (if desired) by Indigenous communities, leaders and organizations.

In BC, the health care system and the research that drives it are being held accountable for addressing the TRC Calls to Action, incorporating elements of the UN Declaration on the Rights of Indigenous Peoples (UNDRIP) and tackling racism in health care and research that starts as marginalization and subsequently leads to disparities. This is reflected in worsening incidence rates, delayed diagnosis, lower screening program access or utilization, inequitable access to treatment, and documented poorer survival rates in First Nations compared to non-First Nations peoples for most cancers. Recent studies report a glaring paucity of cancer data and statistics within First Nation peoples living in BC, highlighting gaps and subsequent lack of understanding that continue to impede clinical decision making and health policy in cancer care for First Nation peoples**(5,18,19)**. BC is well-situated to lead this dialogue given the two projects described earlier in which the Michael Smith Genome Sciences Center (GSC) plays integral roles: the NBI**(7)** and *Silent Genomes*. **STATUS:** LOI accepted; next stage of application submitted.

NEW FRONTIERS IN RESEARCH FUND 2020 (NFRF) TRANSFORMATION STUDY

Genetic testing and cancer care in Canada are provided in a fragmented manner and often under-utilized. Reasons for this range from lack of specialist capacity to appropriately manage patients (referral, assessment, follow up), to jurisdictional variations in recommendations across the country, to use of inappropriate and dated guidelines limited by the *genomic divide*, to exclusion from

provincial genetic testing (in BC) of individuals from families who fall under the hereditary "familial" cancer syndromes (FCS) spectrum. These health system navigation issues are compounded by both a lack of novel cancer detection tools/technologies and a lack of cross-cutting evaluation to improve outcomes. With respect to the FCS spectrum, these issues are particularly profound in Indigenous communities who already encounter greater health and socioeconomic barriers**(11)**, and those residing in rural and remote Canada, with most screening programs being centralized in large, southern, urban centers. To better address these problems and care gaps, development of a comprehensive FCS knowledge and action consortium is proposed through a New Frontiers in Research Fund (NFRF) that will bring together these components under a singular strategy driven by patient engagement and data transparency.

The NFRF program proposes three inter-related activities to overcome these problems: 1) creating a centralized digital navigation system for FCS patients and families to improve equitable access to standardized high quality care for Indigenous peoples and non-Indigenous Canadians alike; 2) establishing an integrated molecular cancer surveillance network (applying ctDNA technology) that serves the needs of Canadians with a strong family history of cancer, focused on consultations and partnerships to create such a choice for remote and Indigenous communities; 3) implementing sustainable and valued health system transformation for the management of FCS. This includes the evaluation of clinical utility and value for money to guide implementation of new digital navigation and molecular surveillance systems into FCS screening programs. **STATUS:** LOI accepted with long form application due in February 2021.

PROJECT ECHO

The Chair is currently in discussions with Roche Canada**(20)** regarding potential funding to partially support a Canadian Project ECHO (**E**xtension for **C**ommunity **H**ealthcare **O**utcomes) aimed at improving cancer care for First Nations communities. Project ECHO is an innovative tele-mentoring program designed to create virtual communities of learners by bringing together health care professionals and subject matter experts using videoconference technology, brief lecture presentations, and case-based learning, fostering a reciprocal "all learn, all teach" approach**(21,22)**. Project ECHO aims to increase workforce capacity by sharing knowledge through linking expert interdisciplinary teams with primary care clinicians in local communities. These clinicians become part of a learning community where they receive mentoring and feedback from expert interdisciplinary teams. This dramatically increases access to specialty treatment, particularly in rural and underserved areas.

Roche prides itself as a pioneer in healthcare, a global leader in cancer therapies, and a committed investor in innovation**(23)**. Roche recognizes that every healthcare system comes with different challenges. Among its priorities is therefore to work with many different local partners to promote community-responsive projects, reduce barriers to accessing healthcare, and establish innovative, sustainable ways to bring effective and affordable healthcare to patients. **STATUS:** In discussion with

ROCHE and FNHA (M. Hunt, P. Howard, S. McDonald) about potential partnership following an initial meeting on February 2, 2021. Presented to Chair Advisory Committee where FNHA CEO (R. Jock) was supportive of further discussion and BC Cancer (W. Clarmont, F. Bénard) welcomed the opportunity to be at the discussion table. Next meeting aimed for March 2021.

CANADIAN PARTNERSHIP AGAINST CANCER

With the goals of achieving less cancer-related morbidity and mortality, higher survival rates and better quality of life for Canadians affected by cancer, the Canadian Partnership Against Cancer (CPAC), herein "the Partnership," has previously extensively engaged, caucused and worked with the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK) and Métis Nation Canada (MNC) to build relationships, highlight the cancer data gaps and related inequities, identify opportunities for action, and advance action on cancer care priorities of First Nations, Inuit and Métis in culturally responsive and safe ways. CPAC is now looking beyond to Call to Action #19 that focuses on working in collaboration with Indigenous peoples towards a sustainable system change across cancer care (measurable goals, pragmatic action, and evaluation) in Canada. The Partnership's commitment to advancing whole person care throughout the cancer experience is reflected in their CPAC 10-year Canadian Strategy for Cancer Control booklet 2019-2029**(24)** – herein "the Strategy" which outlines three key cancer-care priorities from and for First Nations, Inuit and Métis. These are: 1) bringing culturally appropriate care closer to home; 2) promoting people-specific, self-determined cancer care; and, 3) promoting and engaging in Indigenous governed research and data systems.

Recognizing that the COVID-19 pandemic has created challenges for patients living with cancer, their communities, cancer agencies and programs, CPAC is working with partners across Canada to help restore and sustain cancer screening and clinical care, drive faster innovation in how cancer services are delivered, and implement system-level changes that address inequities in cancer care for Indigenous peoples and underserviced populations**(25)**. Many of the priorities of the Chair overlap significantly with the CPAC strategy. This emerging partnership can facilitate advancement of both provincial and national Indigenous cancer knowledge development priorities.

SPIRIT NORTH: Partnership for Enabling Sport to Improve Wellness of our Indigenous Youth

With wellness being a key component of the Chair priorities, Dr. Caron is working to develop early partnerships with Spirit North, an organization that supports and empowers Indigenous youth in sport and physical activity**(26)**. This organization was founded by Beckie Scott, a Canadian Olympic medalist, with the intention of bringing movement, self-development, confidence and joy to Indigenous youth across Canada**(26)**. Wellness is strongly connected to health and is the act of engaging with practices or activities that bring happiness and wellbeing. To further support Indigenous communities in accessing and engaging with wellness activities, and through a personal strong connection to sport, Dr. Caron is looking at possibilities to develop a program in BC similar to,

or in partnership with, Spirit North. **STATUS**: Meeting with Spirit North founders scheduled for March 9, 2021.

PERSONNEL AND RECRUITMENT

To support the Chair's position and ongoing priorities, the Chair has assembled a team that includes: **Dr. Gina Ogilvie**, a Tier 1 Canada Research Chair in Global Control of human papillomavirus (HPV) related diseases and prevention, who is also a senior scientist at BC Centers for Disease Control and Prevention (BCCDC) and a professor in the UBC School of Population & Public Health; **Kevin Linn**, a Senior Policy Analyst at the FNHA, who has led the development and implementation of the province's Indigenous Cancer Strategy and has managed data linkage projects with BCC and the BCCDC; and **Dr. Meck Chongo**, a Research Manager at UBC, who is helping with relationship-building, planning, and engagement activities with BC First Nations and Indigenous communities, FNHA, UBC, UNBC, BC Cancer, and other research agencies. The Research Manager also performs a variety of research activities in a community and academic environment that focuses on the Chair's portfolio, ensures project budgets and reporting requirements are carried out according to contract requirements to partners and funding agencies, conducts administration activities in line with timelines and protocols, and plays key roles in the development of presentations and publications.

This is in line with the UBC Centre for Excellence in Indigenous Health's (CEIH) dedication to advancing Indigenous peoples health through education, innovative thinking, research, and traditional practice to improve wellness, health care and patient outcomes and the FNHA mission to support BC First Nations individuals, families and communities to achieve and enjoy the highest level of health and wellness. The Chair has benefited from having an Elder Advisor/Knowledge Keeper on board to support her work, a Research Manager with significant experience in health care and research with Indigenous Peoples, a Research Assistant based in Northern BC who is experienced in community outreach with First Nations involved in cancer and other health research, and additional funding for a Data Analyst, which has been confirmed.

The incumbents will work in close partnership with the Chair's team, colleagues and collaborators, as well as other experts both internal and external to the FNHA, Provincial Health Services Authority (PHSA), Provincial cancer leads, relevant Ministries, data managers, health authorities and professional organizations.

Elder Advisor/Knowledge Keeper – Dr. Gwendolyn Point

Dr. Point has kindly accepted the request to fill this position to support the Chair. This role will include teachings on or lead, when appropriate, traditional ceremonies to advance the learning and development of the Chair and her team, and strengthen the cultural connection of the Chair role.
It has also been decided that the Chair will benefit from the development of an Indigenous Advisory Committee ("Indigenous Circle"). This will bring a strong presence of Indigenous voices to the table to consider ongoing and emerging research issues arising from current and potential projects. The creation of this Indigenous Circle is a priority of the Chair in 2021 recognizing some limitations in outreach due to the pandemic.

Data Analyst – position to be filled

Using available resources from an FNHA sub-grant to BC Cancer, the Chair is finalizing recruitment for a Data Analyst position. The general duties of the Data Analyst include: providing ongoing ad-hoc analytical support to the Chair in relation to any of the Chair's research priorities; stewarding the FNHA and BC Cancer Memorandum of Understanding on the development, analysis and reporting on First Nations specific cancer data at BC Cancer; stewarding the FNHA/BC Cancer Information Sharing Agreement at BC Cancer that outlines the data linkage plan using BC Cancer data and First Nations Client File (FNCF) data; facilitating the consolidation of BC Cancer data to be linked with the First Nations Client File at the Ministry of Health; leading analysis of linked BC Cancer and FNCF data; and supporting the reporting of linked data according to outlined requirements in partnership with FNHA and the Chair. The Data Analyst is also expected to work on special future projects such as the COVID-19 impact study. An amendment will be sought to the FNCF Data Access Request through standard FNHA protocols to utilize BC Cancer and FNCF linked data to model and project impact of COVID-19 response on First Nations cancer screening and treatment outcomes.

Research Assistant – Alexanne Dick

Alexanne Dick was recruited to work under the direction of the Chair and Research Manager, and to work closely with UBC, FNHA and BC Cancer Agency, to implement an effective system of research support for the efficient and professional functioning of the unit and its partnered initiatives. The position will involve attending research meetings with diverse stakeholders (researchers, Indigenous leaders and Elders, clinicians, patient partners, Advisory Committee meetings, etc.), assisting in preparation of various project and Chair research documents, procedures and presentations, and assisting with general project reporting, literature searches and manuscript development, among other tasks.

The FNHA in Cancer and Wellness will continue to support FNHA's goals towards the expansion of Indigenous recruitment and retention at all cancer centers, including positions uniquely targeted at assisting Indigenous people in navigating a cancer care system that serves their needs.

WAYS OF CONDUCTING BUSINESS

The Chair and her team are committed to responding positively to invitations initiated by various communities, organizations and researchers (both Indigenous and non-Indigenous) for requests for engagement in study participation and/or collaborative research, and as often as possible, meet in person or virtually, and utilize existing partnership structures. To facilitate this process, the Chair's team developed a "Research Proposals Standard Questions" template (see Appendix C) to be used in conjunction with the Chair's priorities document to guide prospective partners and researchers on relevant and respectful research.

APPROPRIATE COMMUNITY ENGAGEMENT AND COMMUNICATIONS

The Chair recognizes the strength in taking a collaborative approach to improving Indigenous cancer experiences and outcomes, including for First Nations (Status and non-Status), Métis (Citizens and self-identified) and Inuit people living in BC. Therefore, the word Indigenous is being used as much as possible in this document when referring to all First Nations, Métis and Inuit people to reflect this perspective.

Appropriate community engagement, constructive dialogue, and ongoing communication with Indigenous leaders, peoples, partners, and other stakeholders remains vital to achieving the goals of the objectives of the Chair's position. Respectful engagement and communication that recognizes that people will only feel safe when receiving health care in an environment devoid of racism and discrimination is a vital part in the process of achieving cultural safety**(2)**.

The Chair acknowledges that Indigenous Peoples in Canada have different ways of understanding or relating to research. In the face of atrocities committed by colonial governments that led to a lack of trust, it is thus encouraging that many Indigenous peoples are engaging and consulting with researchers. Given this evolving atmosphere of trust, the Chair's position, from conceptualization to inception and throughout the tenure, aims to identify ways to promote the protection of interests of Indigenous peoples across a diverse range of settings that engage in research. Indigenous peoples understanding, concerns, and hopes with regard to research will be highly regarded in processes and progress. The aim is to foster trust, self-determination, and respect to the community leadership, its peoples and their needs.

Further, researchers and all those involved in research are expected to be cognizant that Indigenous peoples are heterogeneous in their culture, beliefs, and practices. This diversity mediates how they engage as individuals and communities with researchers and how Indigenous peoples view research and its benefits. Cultural safety and cultural humility can only be hardwired into researcher encounters through ongoing, meaningful relationships and partnerships with Indigenous communities and organizations, allowing for their direct involvement in decision-making, both in what concerns them and in what excites them.

The Chair's work continues to be informed by engagement and relationships developed across communities, B.C. First Nations Health Directors, B.C. Regional Health Authorities, the provincial and federal government, and Indigenous organizations to support collaboration, planning, and work related to cancer care and wellness as well as promoting equity in health services accessed by Indigenous Peoples in Canada.

HONORARIA AND ELDER CONTRACTS

The Chair is committed to provide honorariums for services offered by Elder Advisors/ Knowledge Keepers in accordance with FNHA policies and procedures (see Appendix D). Given that the services

needed may be long-term, the Chair has discussed with Knowledge Keeper Gwendolyn Point and set up a mutual agreement describing services to be provided, process mechanism, time period, and remuneration through a new Adjunct Faculty position at UBC that recognizes her vast Indigenous knowledge that is so vital to this process and the Chair's priorities.

The Chair will utilize the FNHA Honoraria Policy, acknowledging that the COVID pandemic has restricted travel and limited vital in-person meetings with Elder Advisors/ Knowledge Keepers. During in-person meetings there is ample time to sit with Elder Advisors/ Knowledge Keepers and other Indigenous Leaders to update them and discuss not only upcoming meeting contents but also other important issues. However, in the COVID-19 era, with the requirement to conduct virtual meetings, helping Elder Advisors/ Knowledge Keepers and other Indigenous Leaders prepare for meetings means asking them to spend more time familiarizing themselves with project information and/or meeting details by attending Zoom briefings, reading relevant documents/ handouts, viewing PowerPoint presentations or project videos online, among other tasks. The current FNHA Honoraria Policy (approved August 1, 2019 does state on page 2 under section 3.5 that "The Chief Executive Officer (CEO or delegate may approve Honoraria (a for a service that has not been designated as eligible at a rate determined by the CEO, or (b for a Designated Service at a rate above the maximum rates determined by the Board." This is encouraging as it may provide a precedence to do the same in our situation through UBC as we see the FNHA Honoraria Policy as a best practice.

Having said this, it is important to note that many meetings with Indigenous Elder Advisors/ Knowledge Holders and other Indigenous Leaders were postponed due to the COVID-19 pandemic. Considering the unknown duration of the COVID-19 pandemic, Indigenous Peoples voices may not be heard as they will likely continue to face challenges with full and effective participation in both physical and virtual meetings. We recognize that using virtual portals may not fully support, accommodate, or promote the different advocacy styles that Indigenous Elder Advisors/Knowledge Holders and other Indigenous Leaders employ during in-person meetings. However, in light of the pandemic-related circumstances, new ways to make Indigenous participation more effective ought to be tabled, this includes a consideration for the wide use of virtual portals and promotion of reliable internet connectivity and access in Indigenous communities.

COMMUNICATIONS AND REPORTING STRATEGY

In order to share the progress and accomplishments of the Chair position with both communities and partner organizations, communication and reporting strategies are being established. An Annual Report highlighting updates, accomplishments and processes for all projects connected to the Chair will be developed and distributed. This annual report will include updates from January to December and will welcome contributions from partnering Elders, as well as representatives from FNHA, UBC and BC Cancer. Additionally, the Chair will work in collaboration with the FNHA Communications team to develop materials based on information in the Annual Report. These additional materials will provide alternative ways of engaging with the material included in the report and include audiovisual updates, reflection pieces, letters from Elders, process maps, and more. This Chair Report for UBC is

the first version of communications that will unfold over the next month. **Note:** a Chair Advisory meeting on January 18, 2021 was a virtual "face-to-face" annual update with focus on next steps.

APPROPRIATE CULTURAL SAFETY AND HUMILITY

The Chair and her team acknowledge the importance of reviewing and optimizing structures and policies that support cultural safety[1] and humility[2] in the face of ongoing policies of colonization and oppression throughout the healthcare system. The Chair continues to be proactive in supporting cultural safety and humility implementation in cancer care delivery to Indigenous peoples in BC, their communities and within the healthcare system as a whole. This is in line with FNHA's initiative of 2016**(27)**.

In work that the Chair greatly contributes to, such efforts that seek to improve First Nations cancer outcomes and experiences while incorporating BC First Nations perspectives on health and wellness were formalized through the Indigenous Cancer Strategy**(6)**. The Chair is thus well-positioned to promote, in partnership with health care professionals (HCPs), 1) supports for patients to navigate the cancer care system, and 2) the Declaration of Commitment, Cultural Safety and Humility in Health Services Delivery for First Nations and Indigenous People in BC, signed by the Provincial Health Services Authority, FNHA**(4)**, and other service delivery organizations**(28)**.

With the COVID-19 pandemic still an ongoing crisis, the health system faces an even greater demand for tools for cultural safety and humility, training and resources. This means that our front lines of health service delivery remain in dire need of support from our partners. It is vital that processes of reconciliation continue in Canada as the lack of cultural safety and humility in our institutions, service delivery workforce, and facilities is more visible. Compounding this is the climate for discrimination and systemic racism discussions which continues to change in light of the recent report "In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in BC Health Care"**(29)** by Dr. Mary Ellen Turpel-Lafond (Aki-Kwe) that proved that embedded racism is still a critical issue not only in the education system of HCPs but also in health care delivery, in this case affecting First Nations. The Chair joins other leaders in health care service delivery and partners in BC in accepting the findings of this report**(30)** and affirms that we are not only responsible and accountable to Indigenous peoples but also to each other.

With respect to Cultural Safety training and "reciprocal" capacity building, and in line with the priorities of the Indigenous Cancer Strategy, the Chair contributed to the creation of San'yas: Indigenous Cultural Safety Training Program**(31)** for health authorities and partners. Designed for

[1] **Cultural safety** is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.
[2] **Cultural humility** is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

self-awareness and skill enhancement, and the cultivation of knowledge of those who work with Indigenous peoples, the San'yas program continues to be an essential starting tool available for those working in the health care system**(4)**. The Chair has also played an integral part in developing and delivering Cultural Safety training modules for future leaders and HCPs through the novel interdisciplinary curriculum "UBC 23 24" – a cultural safety and humility curriculum for UBC students based on the TRC Calls to Action #23 and #24. From a professional basis, the rationale and impact of these programs continues to be shared by the Chair with audiences nationally and globally. However, with the lessons from this pandemic and going forward, it is disheartening to note that the Cultural Safety training provided by these programs, and others, has not always been free and has faced setbacks in its expansion. Based on exceptional demand, and the responsibility and accountability the Chair's position carries, the Chair continues to be fully embedded in advocacy and discussions with partners and institutions for prioritizing programs like San'yas and UBC 23 24 and making these essential educational opportunities free to all and a mandatory part of students, staff and faculty training. Additionally, participation should be extended to all health organizations and professional bodies who work with Indigenous communities, including researchers. It is the Chair's hope that the change leadership strategy for embedding cultural safety and humility across the health system developed by the FNHA and set to be released soon**(28)**, will gather enough data, evaluate, and adopt best practices for responsive health care provision to First Nations and other communities.

ADVISORY COMMITTEE FOR THE FNHA CHAIR IN CANCER AND WELLNESS AT UBC

The Chair established an Advisory Committee (see Appendix A) made up of strategically chosen leaders in communities, grant-funding and partner organizations and the health system. The Chair and her team consulted extensively and took advice from various partners and Indigenous leaders without which the formation of the Advisory Committee would not have been supported or facilitated. Through this process, the Chair has worked hard to reflect diversity in the makeup of Advisory Committee members. The purpose of the Advisory Committee is to help establish and guide FNHA Chair research priorities (see Appendix B) and work in collaboration with the FNHA Chair, providing strategic advice to advance the work of the Chair.

The Chair and her team will continue to create safe and accessible meeting spaces to co-develop documentation and discuss matters pertinent to the communities. This will be done on Indigenous territory while respecting cultural safety and local Indigenous protocols. Taking into account the COVID-19 pandemic and subsequent public health restrictions, meetings will be conducted virtually and continue to respect protocols for Indigenous Elders and community members to open, attend and close meetings. The Chair will continue to collaborate with Indigenous and other partners virtually to review appropriate considerations.

The Chair will meet with Indigenous leaders and partners periodically to strengthen partnerships and review levels of involvement to fit their preferences. First Nations right to self-determination will be respected. The Chair will respect the choice of Indigenous communities, health service organizations, and other partners to attend meetings and participate at levels with which they are comfortable.

The Advisory Committee will have no formal reporting requirements to any organization or person. The purpose of the Advisory Committee is solely to work in collaboration with the Chair to support and advance the work of the Chair to ensure success. However, we are currently looking at inviting representatives from FNHA Communications to a future meeting to discuss options for sharing updates on projects with communities.

INTRODUCTION: CORE COMMITTEE MEMBERS

Dr. Gina Ogilvie, Tier 1 Canada Research Chair in Global Control of human papillomavirus (HPV) related diseases and prevention, is a senior scientist at BC Center for Disease Control and Prevention (BCCDC) and a professor in the UBC School of Population & Public Health. She is the Primary Investigator in a FNHA-led study using linked data to understand First Nations HPV vaccination rates and is lead of the FNHA Chair in Cancer and Wellness' Advisory Committee.

Dr. Gwendolyn Point, a respected Stó:lō leader and mentor, who has held a number of provincial government and regional posts supporting education, children and family services and First Nations communities. A member of the Skowkale First Nation, Dr. Point completed her Bachelor of Education in the Indigenous Teacher Education Program (NITEP) at the University of British Columbia in 1987. She followed her bachelor's with a Master of Education, and is near completion of her doctorate.

Kevin Linn, Senior Policy Analyst at FNHA, collaboratively led the development and now FNHA's implementation of the province's Indigenous Cancer Strategy, and has managed data linkage projects with BCC and the BCCDC, including the already established linkage noted in this report.

Dr. Meck Chongo, Research Manager, FNHA Cancer and Wellness at UBC**.** Meck works with Dr. Caron on the *Silent Genomes* project to address the genomic divide by reducing access barriers to diagnosis of genetic disease in Indigenous children and facilitating a governance framework to inform policy. Dr. Chongo completed his PhD working with Indigenous populations looking at the impact of historic trauma, resilience and adherence to therapy in those living with HIV/AIDS. A member of the NBI team, he brings project management and medical data analysis experience.

INTRODUCTION: ADVISORY COMMITTEE MEMBERS

Dr. François Bénard, trained in medicine and nuclear medicine in Sherbrooke, Quebec. After undertaking a Research Fellowship in Positron Emission Tomography at the University of Pennsylvania, he is now the Head of Nuclear Medicine, a Professor with the Department of Radiology at the University of British Columbia, and holds the BC Leadership Chair in Functional Cancer Imaging at the University of British Columbia. He is also the Scientific Director of the Centre of Excellence for Functional Cancer Imaging at the BC Cancer Agency and is a distinguished scientist at BC Cancer.

Dr. Shannon McDonald, Acting Chief Medical Officer with the First Nations Health Authority (FNHA), is Métis/Anishinaabe with deep roots in the Red River Valley of Manitoba. She leads the operational, day-to-day functions for the Office of the Chief Medical Officer (OCMO), including providing supervisory and human resource management to the OCMO team. Prior to joining the FNHA, Dr. McDonald was Executive Director of the Aboriginal Health Directorate with the BC Ministry of Health and a Regional Medical Officer with FNIHB Health Canada.

Richard Jock, Chief Executive Officer (FNHA), is a member of the Mohawks of Akwesasne and previously served as the Chief Operating Officer for the First Nations Health Authority. Richard's position provides leadership for the building, functioning and implementation of strong partnerships within the First Nations health governance structure and within the B.C. health system more broadly. Prior to joining the First Nations Health Authority, he held the position of Chief Executive Officer for the Assembly of First Nations (AFN) and many previous positions in the health field including, community, regional and national levels.

Ashley Turner is a citizen of the Métis Nation of British Columbia and is an advisor to the Partnership's First Nations, Inuit and Métis Cancer Control portfolio. She is based in Vancouver, British Columbia. While she joined as the Provincial Wellness Manager with Métis Nation BC, she is now situated at BC Cancer and is working with Dr. Caron to identify a new MNBC representative. Ms. Turner will remain part of the Chair's Advisory Committee.

Namaste Marsden, Masemtxoxw, is from the Wilp Gamlaxyeltxw, Lax Ganeda (Frog Clan). Namaste is a mother to two sons and is from a close-knit family from Gitanyow and Gitsegukla on her late father's side. Namaste has over twenty years of professional experience with Indigenous programs and organizations in health, policy, and research at the local, provincial, and national levels. She is currently Director, Health Economics & Analytics for the First Nations Health Authority in Vancouver, holds an Adjunct Faculty position with Simon Fraser University Faculty of Health Sciences, and joined the Research Ethics Advisory Council (BC) in June 2019.

Dr. Ryan Woods, is Director, Data and Analytics, and a Scientist in Cancer Control Research at BC Cancer. He is also an Assistant Professor in the Faculty of Health Sciences at Simon Fraser University. His expertise is in biostatistics, epidemiology and health services research, with particular interest in using routinely available health system data and registries for cancer outcomes research and policy evaluation.

Dr. Peter Berman is a health economist with forty years of experience in research, policy analysis and development, as well as in training and education in global health. Peter is a Professor with the UBC School of Population and Public Health, and Adjunct Professor in Global Health at Harvard T. H. Chan School of Public Health, Harvard University.

Warren Clarmont, BC Cancer Director Indigenous Cancer Control, was born and raised in the Hazelton area which is located in the northwest central part of BC. Warren is of mixed ancestry with his mother being from the Gitxsan First Nation and his father a 3rd generation settler Canadian. Warren graduated from the University of Victoria where he studied political science and went on to work for the BC Association of Aboriginal Friendship Centres for 14 years, leading the Indigenous health policy department. Warren is also a cancer survivor of 10 years and currently resides in Victoria in the traditional territory of the Lekwungen peoples (Songhees and Esquimalt First Nations) with his wife and 2 children.

Darrel Fox, Community Member, is the younger brother of Terry Fox for whom the Terry Fox Foundation, the Terry Fox Research Institute, (TFRI) and the Terry Fox Centre are named. In 1990, Darrell became the Provincial Director for the Terry Fox Foundation in British Columbia. To date, the Foundation has raised over $800 million for cancer research worldwide. Today Darrell serves on the TFRI's Board of Directors and is a Senior Advisor to the Institute. A holder of the Queen's Diamond Jubilee Medal, Darrell continues to be involved in projects and activities related to Terry Fox and his legacy.

Dr. Dermot Kelleher is the Dean of the UBC Faculty of Medicine and Vice-President, Health at UBC. Dr. Kelleher graduated from medicine from Trinity College Dublin in 1978, going on to specialize in gastroenterology. Under his leadership, the UBC Faculty of Medicine has consulted and drafted the FOM Response to the Truth and Reconciliation Commission's Calls to Action and he is a strong advocate for cultural safety and humility training for UBC students, staff and faculty.

NATIONAL AND INTERNATIONAL PARTNERSHIPS

The Chair recognizes the multi-jurisdictional system barriers and data gaps in Canada that complicate delivery of cancer services and continues to advocate for equity in health service delivery for Canada's Indigenous Peoples in this respect. Part of the efforts to remedy these issues culminated in the development of the Canadian Indigenous Research Network Against Cancer (CIRNAC)**(32)**, a vital means to address cancer with, for, and by Indigenous peoples that is evolving through reciprocal learning with major global initiatives, with the aim of formally becoming a national network that is internationally linked. The CIRNAC was developed through an extensive consultative process aimed at

increasing networking and enhancing partnerships with Indigenous communities and other researchers internationally.

Within Canada, the CIRNAC would promote authentic community engagement, cultural safety, humility, and Indigenous governance, and focus on identifying and aligning research priorities with Indigenous patients' cancer care and research needs, advocate for research and training in identified priority areas to be driven by Indigenous Elders/knowledge holders and community voices, and foster research partnerships to investigate alternative Indigenous cancer prevention, care, treatment, and support models that benefit the communities.

The Chair acknowledges the strong partnership *Silent Genomes* has with the Canadian Alliance for Health Hearts and Minds (CAHHM) [Alliance]. CAHHM hosted a half-day virtual "First Nations Data Analysis Workshop" on September 15th, 2020. Along with their own project updates, they presented a project update on *Silent Genomes* and gauged participant interest on moving forward with virtual engagement. Due to the current pandemic, all communication will continue to occur virtually.

As we continue to engage and strengthen our networks and partnerships, the Chair and her team will seek to leverage our key resource in the International Indigenous Genomics Advisory Committee (IIGAC) and knowledge from other key steering and advisory committees for the various ongoing local projects.

In promoting and advancing the understanding of Indigenous Data Sovereignty (IDS), the Chair and team are collaborating with and engaging in reciprocal learning from the IIGAC members. One member in particular, Dr. Maui Hudson from New Zealand, has also contributed to the Research Data Alliance IDS interest group that is drafted the CARE principles (Collective benefit, Authority to control, Responsibility, and Ethics) for Indigenous Data Governance (https://www.gida-global.org/care).

The Chair is a partner in the World Indigenous Cancer Conference (WICC) Network, which is dedicated to improving cancer outcomes for Indigenous peoples around the world. When planning begins for the next WICC 2021 to be held in New Zealand, the Chair will be part of the planning/scientific committee. The Chair is also collaborating with other university, hospital, public health, and Indigenous Leaders/experts in work towards alleviating the effects of the COVID-19 crisis provincially and in Canada. The Chair is part of the Indigenous Advisory Circle of the COVID-19 Task Force, formed by Dr. Carrie Bourassa (Scientific Director at CIHR), whose aim is to generate reliable estimates of SARS-CoV-2 immunity by catalyzing, supporting, and harmonizing the design and implementation of population-based studies in priority populations across Canada.

APPENDICES

Appendix A – FNHA Chair in Cancer and Wellness at UBC - Terms of reference

Appendix B – FNHA Chair in Cancer and Wellness at UBC - Plan

Appendix C – Research Proposals - Standard Questions

Appendix D – FNHA Honoraria Policy and Procedures

Appendix E – Northern Biobank Initiative Pamphlet

ADDENDUMS

PUBLICATIONS

PEER-REVIEWED JOURNAL ARTICLES

Indigenous Genomic Databanks: Pragmatic Considerations and Cultural Contexts. **Caron NR,** Wilcox P, Chongo M, Arbour LA, Wasserman W, Correard S, Hudson M. *Front. Public Health,* (2020) *8:111.* https://doi.org/10.3389/fpubh.2020.00111 Published 24 April 2020

Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. Hudson M, Garrison NA, Sterling R, **Caron NR.** *et al. Nat Rev Genet* (2020). https://doi.org/10.1038/s41576-020-0228-x Published 6 April 2020

Indigenous Men Adhering to Highly Active Antiretroviral Therapy: Navigating Through Culturally Unsafe Spaces While Caring for Their Health. Chongo M, Lavoie JG, Mignone J, **Caron NR,** Harder H, Chase R. *Front. Public Health*, (2020) 8:569733. https://doi.org/10.3389/fpubh.2020.569733 Published 22 September 2020

Creating a Canadian Indigenous Research Network Against Cancer to Address Indigenous Cancer Disparities. Letendre A, Garvey G, King A, King M, Crowshoe R, Bill L, **Caron NR**, Elias B. *JCO Glob Oncol.* (2020) 6:92–8. https://ascopubs.org/doi/full/10.1200/JGO.19.00049 Published online 13 January 2020

Partnering with Northern British Columbia First Nations in the spectrum of biobanking and genomic research: Moving beyond the disparities. **Caron NR**, Boswell B, Deineko V, Hunt MA. J Global Oncol: 6, 2020, 120-123. DOI: 10.1200/JGO.19.00096 Published online 13 January 2020.

NON-PEER-REVIEWED JOURNAL ARTICLES

Unmasked: What Canada's Health Care system has learned from COVID-19. The Myth of Universal Health Care. *The Walrus*. **Caron, NR,** Martin, D. (2020). https://thewalrus.ca/the-myth-of-universal-health-care/

BOOKS

Caron, NR. 2020. Nadine Caron. In Fox, D. Forever Terry: a legacy in letters. Pages 88 – 93. Penguin Canada. ISBN - 10:0735240698

Caron, NR. 2020. Trust. In Mansbridge, P., Bulgutch, M. Extraordinary Canadians: Stories from the Heart of Our Nation. Pages 67-78. Simon & Schuster. ISBN13: 9781982134525

ACCEPTED MANUSCRIPTS

Sociodemographic Characteristics of Women with Invasive Cervical Cancer in British Columbia, 2004-2013: A Descriptive Study. Simkin J, Smith L, van Niekerk D, Caird H, Dearden T, van der Hoek K**, Caron NR,** Woods RR, Peacock S, Ogilvie G.

Accepted for publication in CMAJ Open. Preparing the proofs.

Perioperative Outcomes of Indigenous Peoples in Canada: A Systematic Review. JA McVicar, A Poon MD, **NR Caron,** MD Bould, J Nickerson, M Doucette Issaluk, C Sheffield, C Champion, N Ahmad, DI McIsaac. Canadian Medical Association Journal**.**

Accepted for publication in CMAJ Open CMAJ-19-1682.R3 January 20, 2021

SUBMITTED MANUSCRIPTS

The Cedar Project: Colonial harms, childhood maltreatment, and HIV and hepatitis C infection among young Indigenous people who use drugs in two Canadian cities**.** Pearce ME, Jongbloed K, Pooyak S, Christian KWM, Teegee MMG, **Caron NR**, Thomas V, Henderson, Zamar D, Yoshida EM, Schechter MT, Spittal PM, For the Cedar Project Partnership.

Submitted to BMJ Open July 7th - Manuscript ID is bmjopen-2020-042545**.**

MANUSCRIPTS IN PROGRESS

Indigenous-led policy initiatives on addressing equity in genetics/ genomics research.
Garrison N, Hudson M, Taualii M, **Caron NR**, Brown N, Arbour L, Ballantyne L, Wilcox P, Wihongi H, Brown A.

Plan for submission to *Nature Genetics* by Summer 2021.

Breast Cancer in Northern British Columbia: Where do we stand?
Caron NR, Woods R, Speers C, Alexander, C, Chongo M, Tang T, Lester TA, Tyldesley S

Writing in progress with plan to submit by Spring 2021.

Northern Biobank Initiative: Consultations with First Nations in Northern British Columbia.
Caron NR, Boswell B, Chongo M, Deineko V, Hunt M, Howard P, Anderson K.

Writing in progress with plan to submit to either *Nature Genetics* or *International Journal of Environmental Research and Public Health* by April 2021**.**

PRESENTATIONS

Invited Speaker	The *Silent Genomes* Project for Indigenous Governance of Genetic Variation Data. Equity in Genomic Medicine: Giving Voice to Indigenous Genetic Variation. American Association for the Advancement of Science 2020 (AAAS) Annual Meeting. [February 13-16th 2020].

Invited Panelist	Panel: "How to get mentors and build relationships for the journey!" "Find a mentor, be a mentor." American Indians Accessing Health Professions Virtual Conference with host organization the Association of American Indian Physicians. [August 14th, 2020 | via Zoom, hosted at University of California, Davis. USA]
Invited Panelist	Panel: The Walrus Educational Review Committee "Panel on the Future" [August 14,2020 | via Zoom, previously planned for Toronto, ON]
Invited Speaker	The Northern First Nations Biobank: Partnering with First Nations in Northern British Columbia to Reduce Inequity in Access to Genomic Research. Indigenous Biobanking: Global Perspectives on Keeping Our Genomic Data Local. American Society of Human Genetics. [October 30, 2020].
Keynote Speaker	Improving cancer outcomes and wellness among Indigenous peoples. Resilience. BC Cancer Summit 2020. [November 6, 2020]
Invited Speaker	"The limitations of generalizability: Perspectives from Northern BC" presented by Julia Bickford, Nadine Caron and Viktor Deineko. Diversity in Clinical Trials Forum. [January 26, 2021]

MEMBERSHIPS ON COMMITTEES

2020 - present	National: National Research Council (NRC) of Canada's Core Group on Technology Horizons. Members were selected as "a Core Group of thought-leaders who will help us identify the key challenges facing Canada over the next 10 to 15 years along with the technologies and capabilities needed to address them." Selected by the NRC to serve on the Sub-group on Health-Care Futures.
2020 - present	Faculty of Medicine, School of Population and Public Health Assistant Professor, tenure track in Indigenous Health Services – Search Committee
2020 – present	Selection committee for Undergraduate Medical Education Curriculum Lead: Indigenous Health
2020 - present	Canadian Space Agency - UBC Joint Working Group
2018 - present	Faculty of Medicine Indigenous Health Advisory Council
2020 - present	Northern Health Authority Clinical Research Advisory Committee
2020 - present	Indigenous Advisory Circle on COVID-19 Immunity Task Force https://www.covid19immunitytaskforce.ca/indigenous-advisory-circle/#
2020 - present	Indigenous Science Council on COVID-19; Appointed from Indigenous Advisory Circle
2020	Faculty of Medicine Executive Associate Dean, Research (EADR) – Search Committee
2020	Faculty of Medicine Mini Medical Interview (MMI) Question Writing Group

MEDIA

Invited Panelist	CBC BC Today interactive radio talk show about racism in the BC health care system. Caron Nadine R, Varley Leslie, Michelle Eliot [June 19, 2020]. https://podknife.com/podcasts/bc-today-from-cbc-radio-british-columbia
Project Lead/ Key speaker	"Voicing the Silent Genome" Telus Communications documentary on *Silent Genomes* Research Project. Spotlight Productions Inc. Filmed on location in Prince George, Canada, to highlight the *Silent Genomes* research project and its relevance to Indigenous Peoples in Canada. [March 11, 2020]. https://youtu.be/MoMyNYPDBbI
Project Lead/ Key speaker	*Silent Genomes* Project: Getting Involved in BC. UBC Learning Circle. [September 29, 2020.] https://www.youtube.com/watch?v=yTAlqcTisHc&t=1426s
Project Lead/ Invited speaker	"Genomics Aotearoa" SING alumni gathering 2020, and the first SING Indigenous Genomics Conference. New Zealand. The editorial "Necessary Voices" published by Nature Publishing Group on the SING gatherings emphasizing the strong message on ethics, genomic science, and the interface with Indigenous knowledge. [January 2020]. Necessary voices | Nature Genetics. https://www.nature.com/articles/s41588-020-0585-6
Featured Extraordinary Canadian	Extraordinary Canadians: Stories from the heart of Our Nation. [November 2020]. https://www.thepetermansbridge.com/book
Invited Interviewee	Peter Mansbridge and the Famous Five foundation. [December, 2020]. F5F VPTC Dec.4.20, Dr. Nadine Caron & Peter Mansbridge https://www.youtube.com/watch?v=OTP5YFSUpOc&feature=youtu.be
Project Lead/Key speaker	"The Northern First Nations Biobank: Partnering with First Nations in Northern British Columbia to Reduce Inequity in Access to Genomic Research. A community outreach webinar – "Learning Circle" by Nadine Caron, Elder Wilf Adam, Patricia Howard, Viktor Deineko, Meck Chongo. [February 11, 2021] https://learningcircle.ubc.ca/2020/12/18/the-northern-first-nations-biobank-211/
Media coverage of Chair announcement in January 2020	
Toronto Star	"Dr. Nadine Caron named as First Nations Health Authority chair at UBC" Amy Smart [January 6, 2020] https://www.thestar.com/vancouver/2020/01/06/chairwoman-named-to-improve-cancer-outcomes-from-indigenous-peoples-in-bc.html
CTV News	"Chairwoman Appointed to Improve Cancer Outcomes among B.C. Indigenous Peoples" [January 6, 2020] https://bc.ctvnews.ca/chairwoman-appointed-to-improve-cancer-outcomes-among-b-c-indigenous-peoples-1.4755380
CBC	"New UBC Chair will study how cancer outcomes of Indigenous Peoples in B.C. can be improved" Ashley Moliere [January 7, 2020] https://www.cbc.ca/news/canada/british-columbia/chairwoman-named-improve-indigenous-cancer-rates-1.5416936

Healthing.ca	"Chairwoman to improve cancer outcomes for First Nations" Amy Smart [January 8, 2020] https://www.healthing.ca/news/chairwoman-named-to-improve-cancer-outcomes-for-indigenous-peoples-in-b-c
Canada's National Observer	"New Chair to take a hard look at cancer outcomes for Indigenous Peoples in BC" Amy Smart [January 9, 2020] https://www.nationalobserver.com/2020/01/09/features/new-chair-take-hard-look-cancer-outcomes-indigenous-peoples-bc
University of British Columbia: Faculty of Medicine	"Improving Indigenous Cancer Outcomes and Wellness" [January 2020] https://www.med.ubc.ca/news/improving-indigenous-cancer-outcomes-and-wellness/
UBC Family Practice Residency Program: Abbotsford-Mission Site	"Wellness and Outcomes" [January 23, 2020] https://abbotsfordfamilymed.com/2020/01/23/wellness-outcomes/

AWARDS

2020	**9th Annual Chanchlani Global Health Research Award** (at McMaster University) Selected by committee "to recognize you for your tireless efforts and contributions to improving the health of Indigenous peoples." This award was created "to recognize a leading scholar in the area of Global Health." https://fhs.mcmaster.ca/chanchlani/ChanchlaniResearchAward.html Notified on September 11, 2020. To be awarded with Keynote Address in March 2021 entitled: "Perspectives of a First Nations physician in Canada: Do you ever wonder what we think"

NEW GRANTS RECEIVED IN 2020

Note: Does not include grants that were active in 2020; please see 2020 UBC Annual Report for these details

Granting Agency	Title	COMP/ Non COMP	# per year	Duration mo/yy to mo/yy	Principal Investigator	Co-PI(s)
TD Ready Challenge: Better Health-Innovative Solutions	UBC's Remote Communities Drone Transport Initiative (DTI) – Enhancing Equity of Access to Health Services by Use of Bidirectional Unmanned Aerial Vehicle	C	$750,000	1 Nov 2020 - 31 Oct 2021	Allard M	**Caron NR**, Humber N, Kang D, Lynd L, Mah J, Markham R, McDonald S, Ogilvie G, Pawlovich J, Petrella R, Ratnarajah E, Tham D, Zahra M, Zed P. Patrick A (Partner) Holland R (Partner)
Public Health Agency of Canada in partnership with the COVID-19 Immunity Task Force	Journeys Through COVID-19: Development of a National Indigenous Seroprevalence Cohort Study		$18.5 million	2020-TBC	Reading J (NPI) **Caron NR** Walker J Elias B Et al.	Co-Is to be determined from Network Environments for Indigenous Health Research (CIHR funded research platform)

Granting Agency	Title	COMP/ Non COMP	# per year	Duration mo/yy to mo/yy	Principal Investigator	Co-PI(s)
Canadian Institutes of Health Research Top up for Genomics and Precision Health	Silent Genomes - Rare disease personalized medicine approaches	C	$750,000	2020-2022	Arbour L **Caron NR** Wasserman W	Reading J, Isaac-Mann S, Garrison N, Burgess M, Lehman A, Tarailo-Graovac M, Marra MA, Anand S, Malhi R, Gravel S, Regier D, Laberge A, Bernier F, Lavoie J
UBC Grant for Advancing Education and Renewal	Improving Teaching Effectiveness of Faculty Delivering UBC 23 24 Indigenous Cultural Safety Curriculum	C	$50,000	2020-2022	**Caron NR**	Spittal P, St. Laurent D, Smith C, Schechter M
Canadian Institutes of Health Research	Operating Grant: Network Environments for Indigenous Health Research (NEIHR)	C	$3,500,000	2020 - 2025	Adams E **Caron NR** Greenwood M NPI: Loppie C	Reading J Ward A Allan B Bingham B Corntassel J Goodwill A Holyk T Multiple other Co-Is

Granting Agency	Title	COMP/ Non COMP	# per year	Duration mo/yy to mo/yy	Principal Investigator	Co-PI(s)
UBC Teaching and Learning Enhancement Fund	A Community-Based Approach to Decolonizing and Indigenizing the Pharmacy Curriculum	C	$127,380 confirmed for 2020 ($250,000 over 3 years TBC)	2020 - 2022	Leung L Min J	UBC Knowledge Experts (Co-I's) **Caron NR** Smith C Chondoma L Dupont S Lawson K Nelson K
Strategic Investment Fund (SIF) Funder & UBC Administrative Body: UBC, Faculty of Medicine	Recognizing the responsibility of understanding what we mean by "Decolonizing health professional education": A UBC learner and faculty project in response to the Truth and Reconciliation calls to action	C	$94,735	2020 - 2021	Jarus T, Smith C, Quinn A	Holmes C, **Caron NR**, Walker L, Andrew J, Campbell A, Albon S, Brown H, Donnelly L, Kurtz D, + 6 others-information available upon request

Granting Agency	Title	COMP/ Non COMP	# per year	Duration mo/yy to mo/yy	Principal Investigator	Co-PI(s)
UBC Teaching and Learning Enhancement Fund Innovation Grant Funder & UBC Administrative Body: UBC, TLEF Office: Projects and Faculty Partnerships	Engaging Indigenous communities in health professions educational programs at UBC	C	$26,650.00	2020 - 2021	Jarus T, Smith C, Quinn A	Holmes C, **Caron NR**, Walker L, Andrew J, Campbell A, Albon S, Brown H, Donnelly L, Kurtz D, + 9 others – information available upon request

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FNHA Chair in Cancer and Wellness at UBC
Advisory Committee

Purpose:

The purpose of the Advisory Committee is to work in collaboration with the FNHA Chair in Cancer and Wellness at UBC and provide strategic advice to advance the work of the Chair.

Specifically, the purpose of the Committee will be to:

- Help identify and validate research priorities and research opportunities
- Open and grant access to knowledge and data sources to advance research priorities
- Review and guide Chair research plans, activities and public-facing publications
- Identify opportunities for cooperation, collaboration and inclusion of the Chair into partner organization and community networks (Indigenous and non-Indigenous), structures, teams, programs, committees, etc. Ideally, relationships are to be made first with Indigenous partners and then proposals developed based on those relationships and emerging priorities.

The Main Objectives of the Chair as outlined in the FNHA/UBC Chair Funding Agreement:

- To conduct research and education into critical health policy related to cancer, disease prevention and control associated with chronic diseases among first Nations peoples
- To develop wellness and preventive disease epidemiology programs and databases, particularly as they pertain to increasing the research infrastructure and capacity in First Nations communities and organizations;
- To improve health system outcomes with respect to wellness and disease prevention and translational research for best practices, risk factor control, economic and social analysis;
- To take an active leadership role locally, provincially, and nationally that advances the understanding of the strategies to develop a program of excellence in First Nations wellness and disease prevention and policy;
- To provide mentorship and training to University undergraduate, graduate and post graduate trainees in the area of First Nations wellness and disease prevention and policy;
- To provide outreach provincially and nationally to build care relationships that are responsive to First Nations' community needs;
- To promote the health and wellness of First Nations people within their own communities; and
- To support and advance the goals of first Nations' wellness and disease prevention and policy at the FNHA and the University.

Structure and Membership:

The Committee will be made up of strategically chosen leaders in community, grant-funding organizations and the health system to help support and guide the Chair with content, planning and process expertise.

The Chair recognizes the strength in taking a collaborative approach to improving Indigenous cancer experiences and outcomes, including for First Nations (Status and non-Status), Métis (Citizens and self-identified) and Inuit people living in BC. Therefore, the word Indigenous is being used as much as possible in this document when referring to all First Nations, Métis and Inuit people to reflect this perspective. The Chair will also strive to reflect this diversity in the makeup of Advisory Committee members.

Delegations or substitutions for Committee members will be acceptable, upon discussion with the Chair. If a member delegates their participation, they will aim to ensure their replacement is able to knowledgeably share the opportunities and perspectives of the Advisory Committee member they are replacing.

The term for committee membership will be two to three years to allow for smooth transition leaving no gaps in knowledge transmission.

Guests and ad hoc advisors may be invited to join the meeting where their contributions are relevant to an agenda item under discussion

Advisory Committee Members

- First Nation Knowledge Keeper - Gwendolyn Point
- Metis Elder (TBC)
- Inuit Elder (TBC)
- Community Member - Darrel Fox
- Community Member (Cancer patient - TBC)
- FNHA Chief Executive Officer - Richard Jock
- FNHA Research Representative - Namaste Marsden
- FNHA Chief Medical Officer - Shannon McDonald
- FNHA Senior Policy Analyst - Kevin Linn
- Métis Nation BC, Provincial Wellness Manager – Ashley Turner
- BC Cancer VP Research - François Bénard
- BC Cancer Director Indigenous Cancer Control - Warren Clarmont
- BC Cancer Registry - Ryan Woods
- UBC SPPH - Peter Berman
- UBC Cancer Research Chair holder - Gina Ogilvie

Meeting Operations:

- Advisory Committee meetings will be held every six months (core members will meet more frequently with the Chair to provide more direct support to the Chair as needed)
- Meetings will be 1.5 hours in duration and may be held in person and/or video/tele-conference
- Agenda will be sent out 2 weeks in advance of meeting for input by Advisory Committee members
- Meetings will be rescheduled where fewer than half of the members are available to participate

Role of the Committee Chairperson:

The Chairperson of the Committee will be an Advisory Committee member, who will:

- Oversee administration of the committee, and support member participation
- Facilitate meeting discussions, and confirm the agenda at the outset of meeting
- Lead reporting and implementation of committee advise and perspectives
- Scheduling meetings, and circulating meeting agendas and materials
- Preparing and circulating a record of decisions for each meeting, and tracking action items

Reporting:

The Committee will have no formal reporting requirements to any organization or person. The purpose of the Advisory Committee is solely to work in collaboration with the Chair to support and advance the work of the Chair to ensure success.

First Nations Health Authority
Health through wellness

Briefing Note	
SUBJECT	FNHA Chair in Cancer and Wellness Advisory Committee Meeting Background Document
TO	Advisory Committee Members
FROM	FNHA Chair in Cancer and Wellness
DATE	January 30th, 2021

Purpose

This note is for information as it pertains to the First Nations Health Authority Chair (FNHA) in Cancer and Wellness at UBC, and the Development of the Chair's research agenda.

Background

FNHA and BC Cancer released an Indigenous Cancer Strategy in December 2017, in partnership with Métis Nation British Columbia and the BC Association of Aboriginal Friendship Centers. The strategy is a commitment to collaboratively improve cancer experiences and outcomes from prevention through to survivorship/end-of-life, and identifies partnerships and knowledge development as enabling factors (see Appendix A).

The Strategy is based on First Nations-specific cancer incidence and survival data that was developed, analyzed and reported jointly by FNHA and BC Cancer (see Appendix B). Findings showed that First Nations people are more likely to experience commonly diagnosed cancers (prostate, colon, and cervical cancer) and less likely to survive cancer once diagnosed (majority of cancers reviewed). This data was developed from a one-time linkage between the BC Cancer Registry and the First Nations Client File.

Through the Provincial Health Services Authority (PHSA), BC Cancer and FNHA report progress on implementation of the Strategy through the Tripartite Committee on First Nations Health (TCFNH). TCFNH is a legal requirement within the BC Tripartite Framework Agreement on First Nation Health Governance between BC First Nations, the Province and Federal government to coordinate and align planning, programming and service delivery between FNHA, BC Health Authorities, and the BC Ministry of Health. The TCFNH meets twice annually.

As a major commitment to the knowledge development priority within the Strategy, FNHA and UBC have committed $3 million over ten years to establish and support an FNHA Chair in Cancer and Wellness at UBC. The position has been awarded to Dr. Nadine Caron. Dr. Caron lead the initial cancer surveillance paper that informed the development of the Strategy, and is a Senior Scientist with the BC Cancer Research Centre's Michael Smith Genome Science Centre. Dr. Caron currently leads the development of the Northern Biobank Initiative (NBI), which includes a First Nations-governed and controlled biobank (see Appendix D). She is also co-Lead of the *Silent Genomes* project that addresses the genomic divide by reducing access barriers to diagnosis of genetic disease for Indigenous children and is currently facilitating a governance framework to inform policy in these areas (See Appendix E).

Chair Priorities

The Chair has established an Advisory committee of representatives from partner organizations and communities to establish and guide Chair research priorities (see Appendix C). The following short, medium and long-term research priorities have been identified:

Timelines	Program	Deliverable categories	Priorities
Short term (1-2 years)	General	Infrastructure and Human resource deliverables	1) Establish the Advisory Committee for Chair 2) Build partnership between Chair position and existing BC Cancer research. This will enhance progress of research projects particularly those requiring BC Cancer data. 3) Link First Nations Client File with BC Cancer Registry, HPV vaccination data, BC Screening Program and MSP data on biannual basis and establish publishing plan 4) Establish a 0.5 FTE BC Cancer Analyst position to support Chair research priorities with BC Cancer. Less support would be needed after the initial 2-year period. 5) Establish finance operational procedures for efficient facilitation of Chair's role
		Health care promotion	1) Work with FNHA and BC Cancer and Advisory Committee regarding potential role of Chair in health care promotion. 2) Advocate for institutions to take up responsibilities on development of policies for cancer research and care promotion in Indigenous communities.
		Relationships and Capacity building	1) Marathon of Hope: utilize Chair position to embed Indigenous voice at the table in Personalized Oncogenomics Project (POG) applications. 2) Student engagement through schools of Public Health at UBC, SFU and other universities 3) Engage and work towards formalized relationships/partnerships with the MNC/ MNBC 4) Engage Indigenous cancer patients and survivors for a potential patient experience advisory committee
	Silent Genomes	Infrastructure and Human resource deliverables	1) Establish policy, guidelines and processes for Indigenous-led and informed governance of biological samples and genome data.
		Health care promotion	1) Activity 2 equitable access to genomic diagnosis and cultural safety
		Relationships and Capacity building	1) Bring in, work with and mentor students in practicums and other project-related activities; includes surgical trainees, MPH, PHD and post-doc students, etcetera with priority given to Indigenous students and others with the passion, dedication

			and willingness to learn and work with Indigenous communities
	Northern Biobank Initiative (NBI)	Infrastructure and Human resource deliverables	1) Establish governance and protocols for NBI Phase III including planned NFNB
		Health care promotion	1) Increasing health literacy regarding the role of cancer research including genomics 2) Increasing inclusion of FN in genomic research
		Relationships and Capacity building	1) Complete Northern First Nations Biobank (NFNB) consultations
	Emerging research priorities	Infrastructure and Human resource deliverables	1. Continue to be poised to respond rapidly to calls for grant application submissions 2. Establish pivot for flexibility of harnessing CIHR funds for trainees/students capacity building
		Health care promotion	1) CIHR grant application for urgent COVID research with focus on collateral impact of COVID re: delayed diagnosis due to interruption of screening, diagnosis and treatment of cancer as impacted by Public Health measures on our health care system. 2) Join national effort on National Immunity Task Force's Indigenous Advisory Circle re: research priorities and equitable distribution of resources for the subsequent Indigenous Science Council that has emerged as part of this initiative (Chair now a member of both the Indigenous Advisory Committee and Indigenous Science Council)
		Relationships and Capacity building	1) Consult and facilitate inclusion of Northern BC and potential role of First Nations inclusion in Provincial COVID biobank.
Medium term (1-5 years)	General	Infrastructure and Human resource deliverables	1) Link, analyze, and publish ongoing findings from the First Nations Client File linkage with BC Centre for Disease Control HPV vaccine data on biannual basis 2) Link, analyze, and publish ongoing findings from the First Nations Client File linkage with BC registry data on a bi-annual basis
		Health care promotion	1) Knowledge translation of findings from data linkage projects and other research
		Relationships and Capacity building	1) Enhance collaborations with additional funders for initiatives including in Chair portfolio. 2) Engage and work towards and formalize relationships with Inuit Tapiriit Kanatami (ITK)
	Silent Genomes	Infrastructure and Human resource deliverables	1) Develop an Indigenous Background Variant Library (IBVL) of genetic variation from a diverse group of First Nations in Canada. 2) Participate in economic analysis of IBVL and plan for long term use of IBVL for Canadian Indigenous children and adults

		Health care promotion	1) Address barriers to accessing genetic/genomic health care and bring genomic testing to Indigenous children with suspected genetic disorders. 2) Advocate for change in the research milieu re: Indigenous data governance and equity
		Relationships and Capacity building	1) As per above
	Northern Biobank Initiative (NBI)	Infrastructure and Human resource deliverables	1) The creation and deployment of a population-based biobank of bio-specimen and clinical data from people in Northern BC. with sub-biobank specific for and governed by First Nations in Northern BC
		Health care promotion	1) To help transition of cancer care delivery to personalized and person-centered, predictive, preventive and participatory approaches relevant to rural, northern and First Nations communities.
		Relationships and Capacity building	1) Sustaining the FN Biobank steering committee and knowledge translation of NBI progress
	Emerging research priorities	Infrastructure and Human resource deliverables	As appropriate
		Health care promotion	As appropriate
		Relationships and Capacity building	As appropriate
Long term (1-10 years)	General	Infrastructure and Human resource deliverables	1) Explore applicability of IBVL for cancer care (and research)
		Health care promotion	1) Personalized Oncogenomics 2) Optimise access to genetic/ genomic diagnosis to Indigenous people across Canada
		Relationships and Capacity building	1) Apply to host the World Indigenous Cancer Conference in Canada (held every 2-3 years with next WICC planned for New Zealand) 2) Enhance collaborations with additional funders for initiatives including in Chair portfolio. 3) Commit to knowledge translation (KT) and networking; register for and attend International Conferences as Chair and/ delegation of team members 4) Promote other KT appointments where the Chair, other team members or trainees present
	Northern Biobank Initiative (NBI)	Infrastructure and Human resource deliverables	1) Sustain, expand and enhance role of NBI and NFNB
		Health care promotion	1. Optimize the access of Indigenous peoples in Canada to genomic research and applicable health care

		Relationships and Capacity building	1. Work with partners to increase capacity for Indigenous researchers, scholars, Health Care Providers in this field
	Emerging research priorities	Infrastructure and Human resource deliverables	As appropriate
		Health care promotion	As appropriate
		Relationships and Capacity building	As appropriate

Appendices

Appendix A – Indigenous Cancer Strategy

improving-indigenous-cancer-journeys

Appendix B – Surveillance Research Paper

BC First Nations Cancer Incidence an

Appendix C –Steering Committee Terms of Reference

Chair Advisory Committee ToR.docx

Appendix D – Northern Biobank Initiative

Appendix NBI.docx

Appendix E – Silent Genomes

Appendix SG.docx

Appendix F – Policy Perspectives – Indigenous Cancer Strategy

Policy Perspectives - Indigenous Cancer S

Research proposals - standard questions

Name of Researcher		
Title and abstract of project		
Is this a community priority or new opportunity		
Engagement level with (community, FNHA, health system). Include date(s) or time period		
Alignment with OCAP principles*		
Support FNHA's seven directives**		
Has your proposal already received REB approval? Indicate stage at which proposal is currently		
Perceived role of the Chair in funding approval		
Are you seeking	Letter of support?	
	Other – specify	

*OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC) www.FNIGC.ca/OCAP
OCAP principles are where First Nations peoples have a right to have Ownership, Control, Access and Possession of their data and information regardless of where it is held (First Nations Information Governance Centre, 2019). As such OCAP operates as a set of specifically First Nations—not Indigenous—principles. https://fnigc.ca/what-we-do/ocap-and-information-governance/

** FNHA's seven directives describe the fundamental standards and instructions for health governance relationships. They include 1) a Community-Driven, Nation-Based foundation, 2) promotion of increase in First Nations Decision-Making and Control, 3) Improving services, 4) fostering Meaningful Collaboration and Partnerships, 5) Developing Human and Economic Capacity, 6) Being Without Prejudice to First Nations Interests, and 7) Functioning at a High Operational Standard. https://www.fnha.ca/about/fnha-overview/directives

First Nations Health Authority Board Policy

First Nations Health Authority
Health through wellness

Name	**Honoraria Policy**
Category	Finance
Type	Corporate

For Board Secretariat (do not fill this in)		
Document #		**Effective**
FIN-19-008-004		August 1, 2019
Board Approved Date	**Verified By**	**Authorization (BoD Motion #)**
August 1, 2019		MOTION 0819-BOD-1i

1.0 Purpose

1.1 The purpose of this policy is to establish principles and guidance for the administration and control of Honoraria provided by First Nations Health Authority (FNHA) for the performance of Designated Services at events hosted by FNHA, First Nations Health Council (FNHC) or First Nations Health Directors Association (FNHDA).

1.2 This policy supports all 7 Directives and the Shared Values.

2.0 Scope

2.1 This policy applies to Workers who arrange and administer Honoraria.

2.2 This policy applies to Honoraria for Designated Services performed at FNHA, FNHC, and FNHDA events.

2.3 This policy does not apply to remuneration for work performed by individuals within their roles as Elder Advisors/Knowledge Keepers for the FNHA Board, FNHC or FNHDA Board.

3.0 Policy Statements

3.1 FNHA will provide Honoraria in a culturally appropriate manner that respects the cultures and traditions of First Nations communities.

3.2 FNHA will administer all Honoraria for the performance of Designated Services at events hosted by FNHA, FNHC, and FNHDA.

3.3 Designated Services for which Honoraria may be paid, and the maximum amounts paid for these services, will be determined by the Board.

3.4 FNHA will undertake periodic reviews of Honoraria rates established by other provincial organizations and will meet or exceed those Honoraria rates.

3.5 The Chief Executive Officer (CEO) or delegate may approve Honoraria

(a) for a service that has not been designated as eligible at a rate determined by the CEO, or

(b) for a Designated Service at a rate above the maximum rates determined by the Board.

3.6 Honoraria will be authorized in writing prior to paying or making a commitment to pay. Documentation will be maintained to identify the recipient, the event, the Designated Service provided and the amount paid.

3.7 Honoraria will be approved by the appropriate delegated Signing Officer, in accordance with the *Delegation of Financial Authority* Policy Documents.

3.8 Workers who select individuals to perform Designated Services will recuse themselves from the selection process if there is a Conflict of Interest.

3.9 Workers are not eligible to receive Honoraria from FNHA for the performance of Designated Services.

Compliance

3.10 Any violations of this policy may result in Disciplinary Action, up to and including termination, in accordance with the *Progressive Corrective and Disciplinary Action* Policy Documents.

Exceptions

3.11 Exceptions to this policy require approval by the CEO.

Delegation

3.12 This policy will be further defined and elaborated upon through an executive directive of the CEO.

4.0 Responsibilities

4.1 Board of Directors (Board): approve the *Honoraria Policy*; determine Designated Services and maximum rates.

4.2 Chief Executive Officer (CEO): provide overall leadership and support to Senior Executives in the oversight and management of Honoraria; approve exceptions as appropriate.

5.0 Definitions

Conflict(s) of Interest: a situation that places Workers' personal, professional, or financial interests in a real, potential, or perceived conflict with Workers' duty to act in the best interests of FNHA.

Designated Service(s): services performed at events hosted by FNHA, FNHC and FNHDA for which the payment of Honoraria is authorized.

Disciplinary Action(s): a process for dealing with job-related behaviour that does not meet expected and communicated performance standards, including non-compliance with Policy Documents.

Honoraria/Honorarium: nominal payments made as a gesture of goodwill and appreciation to individuals, recognizing their gratuitous, special or voluntary services and/or participation at meetings, for which fees are not typically paid.

Policy Document(s): all existing documents within a policy set, including the Board-approved policy that provides principles and guidance and delegates authority to the CEO; consistent with approved policy, CEO-approved executive directives that provide direction for the approach, outline required and prohibited actions, and delegate accountabilities to Senior Executives; and, consistent with approved executive directives, any procedures approved by Senior Executives that outline specific steps to be followed.

Senior Executive(s): includes the Chief Executive Officer, Chief Officers, and Vice Presidents.

Signing Officer(s): budget holder or cost centre manager; a person who holds an organizational position that has been delegated Financial Authority in accordance with the *Delegation of Financial Authority* Policy Documents.

Worker(s): includes individuals employed or contracted with FNHA while engaged in a FNHA work activity; specifically, employees (union, non-union; permanent, term, casual; full-time, part-time); people working at FNHA through an Interchange Agreement; people paid via third party agencies (temporary workers); contractors; consultants; trainees; students; volunteers.

6.0 Related Documents

Mandatory Compliance Documents

None

Supporting Documents

Honoraria Executive Directive

Other FNHA Policy Documents

Delegation of Financial Authority Policy Documents

Progressive Corrective and Disciplinary Action Policy Documents

Travel Policy Documents

7.0 Rescind and Interpretation Statements

7.1 With the approval of this policy, older versions are considered to be replaced and/or rescinded and are no longer in effect.

7.2 Where interpretation is required regarding the relationship between Policy Documents, the CEO has sole discretion to provide the interpretation.

First Nations Health Authority Board Policy

First Nations Health Authority
Health through wellness

8.0 Summary of Changes

Replaces	Dated	Key Changes to Previous Version
FIN-19-008-003 Honoraria Policy	February 8, 2019	• Added a scope statement to clarify crossover with Elder Advisor/Knowledge Keeper remuneration.

9.0 Attachments

9.1 Honoraria Designated Services and Maximum Rates

9.1 Honoraria Designated Services and Maximum Rates

Designated Services	**Honorarium Amount** *(Note 1, 2)*
Opening prayer (this may include other services, such as brushing, smudging, etc.)	$150 for one person for each event day
Closing prayer (this may include other services, such as brushing, smudging, etc.)	$150 for one person for each event day
Elder or cultural meeting participant that attends a half-day meeting. During this time, the participant may provide service(s) including, but not limited to, opening prayer, closing prayer, brushing, smudging, storytelling, consultation, etc.)	$200 for one person per half day meeting. This rate covers all services performed during the meeting.
Elder or cultural meeting participant that attends a full-day meeting. During this time, the participant may provide service(s) including, but not limited to, opening prayer, closing prayer, brushing, smudging, storytelling, consultation, etc.)	$400 for one person per event day. This rate covers all services performed during the meeting.
Speakers	$300 per speaker per event day
Witnesses	Nominal (use of petty cash and quarters)
Firekeepers	$100 per event day
Sweat lodges (e.g., cold water bath or other ceremony appropriate for the region etc.)	$400 per event day
Individual Dancers/Singers/Drummers (outside of contracted cultural performance group)	$150 per person per dancer/singer/drummer per event day

Note 1: 'Event day' means each day of an event during which the designated service is performed. A "half day" is up to 3.5 hours and a full "event day" is up to 7 hours.

Note 2: Rates include preparation time required for the performance of Designated Services. Expenses for related travel are not included in the rates and will be approved and reimbursed separately in accordance with the *Travel* Policy Documents.

Can I donate my sample to the biobank?

The First Nations biobank is not currently accepting samples. However, if you would like to be in touch with us about donating a sample, please use the contact information provided overleaf.

Who can speak with me about the First Nations biobank?

When the biobank goes live in NBI Phase III, information about the biobank will be made available to family doctors, health personnel at community health centres, and the FNHA Northern Regional Team, among others. You will have the option to select who you would most prefer to talk to about the First Nations biobank.

How will my samples be kept secure at the biobank?

The physical biobank could be housed within the NHA at the University Hospital of Northern BC (UHNBC), where infrastructure such as secure servers and back-up generators are already in place. All samples, and the clinical information stored with them, are deidentified.

Mshkikiininiikwe: Building the Northern Biobank:
youtube.com/waatch?v=Bl6Kc8zPw6c

Funding Partners

Academic Partners

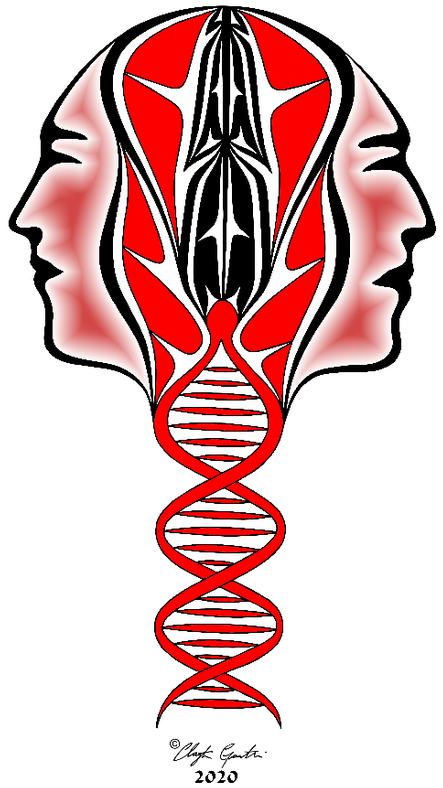
Contact Us

+1 250 960 5198

nbi@unbc.ca

From the logo artist, Clayton Gauthier:
"This piece depicts Woman, Man, a feather, and DNA. As we (Woman And Man) share love, through DNA we create the new generation to come through mother earth to live and learn. In the art there are subtle differences in the man and woman's faces—I did my best to not have one look stronger than the other. In the piece the woman is on the left and the man is on the right. It's a balance of love and respect. In the middle is a feather. Feathers represent the road of life—each feather is different and sacred, as all are. Some feathers are small, some feathers are long, each strand of hair in the feather are lessons and teachings we need to learn in this life. The middle of the feather is the road we walk, at the tip of the feather is where we all meet when we are done here on mother earth. We all have a road to walk—let's walk together with love and respect, learning the lessons we need for generations to come."

Northern Biobank Initiative



Establishing a Northern BC First Nations Biobank

February 2021

What is a biobank?

A biobank is a place where samples (such as tissue or blood donated by a patient) and the information that goes with them can be systematically stored and databased for the purposes of genomic research.

What is genomic research?

A genome is like a dictionary of our body, with words made up of DNA. Conditions like cancer can be caused by misspellings (mutations) in these words. Genomic researchers look at DNA inside a person's cells and may be able to identify which misspellings could be causing a condition.

What is the northern BC First Nations biobank?

The First Nations biobank will be able to house First Nations samples and clinical data with governance, consent procedures, access, and cultural safety (among others) designed and driven with input from northern BC First Nations Chiefs, Health Leads, and community members.

How will the First Nations biobank benefit me?

This biobank is a dynamic opportunity for First Nations in northern BC to participate and be represented in genomic research, to drive the questions that concern them, and to control the governance of their data, samples, and the research that can access them. The knowledge created has the potential to address important health concerns for First Nations people and future generations.

NBI Timeline

Phase I
Dialogue to permit dialoque
2012-2016

Focus group with Family Practitioners

Discussion with scientists & researchers

Dialogue with leadership of NH, BCCF & FNHA

Development of a plan & discussion with funders for Phase II

Phase II
First Nations Consultations
2016-2022

April 2016
Start of NBI Phase II

October 2016
Northern BC First Nations Chiefs pass resolution to support NBI

November 2017
Northern First Nations Biobank Advisory Committee first meeting

April 2018
Consultations with First Nations in northern BC begins

November 2018
Key informant interviews complete

October 2019
Community member focus groups complete

Qualitative analysis of data from interviews & focus groups

Spring 2019
Knowledge translation & dissemination

Incorporation of First Nations input in final reporting, planning documents, & funding applications for Phase III

March 2022
Close of NBI Phase II

Phase III
Establishment of Northern & First Nations Biobanks

Prospective sample collection begins in Phase III
(Breast, colon, thyroid cancer & adipose)

Phase IV-VI
Expansion of biobank to other cancers/ conditions

Integration of other tumour types, potential addition of non-cancer samples, expansion of sample collection across NHA

Northern Biobank Initiative

The overall Northern Biobank Initiative (NBI) involves the creation of a population-based biobank, where clinical data and samples donated from people across northern British Columbia can be systematically stored and databased in Prince George, with potential to build a First Nations biobank within it.

Sensitive to the unique geography and cultures in northern BC, the NBI will foster excellence in genomic research that is important to northern, rural, remote and First Nations communities, aiming to become an integral part of standardized healthcare and contributing to improved patient outcomes, cancer care, and quality of life for all in northern BC.

The NBI Timeline

Beginning with "dialogue to permit dialogue," **Phase I of the NBI (NBI-I)** involved preliminary discussions between Dr. Caron and the leadership of Northern Health (NH) and the First Nations Health Authority (FNHA), with Family Practitioners and First Nations Chiefs and community members.

Phase II of the NBI (NBI-II), the current phase, includes two parts. One is the creation of a biobank to house breast cancer samples collected in northern BC from 2004-2012. The other is engagement with the public living in the NHA, and consultations with First Nations in northern BC on a First Nations biobank to be created within the larger Northern Biobank.

Phase III (NBI-III) The biobank will be prepared to go live, and sample collection will begin.

Consultations with First Nations

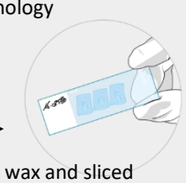
Consultations with First Nations in northern BC were conducted to receive input from First Nations on the governance, consent procedures, access, cultural safety and protocols, among others, of a First Nations biobank.

This included community member focus groups and Key Informant interviews with Chiefs and Health Directors/Leads. To date, 7 focus groups were held across Burns Lake, Fort St. John, Fort Nelson, Terrace, Prince George and Haida Gwaii. 32 Key Informant interviews were conducted.

The results from consultations will be used to inform the governance framework of the northern First Nations biobank.

How do samples get into the biobank?

1. After a tumour is removed the surgeon sends it to the pathology department.



2. There, the tumour is embedded in wax and sliced thinly so it can be placed on a slide.

3. A pathologist will be able to look at the sample in a microscope to inform the surgeon of the proper diagnosis.

If you have signed a form to provide your informed consent, a part of your sample can be sent to the biobank for genomic research. A representative from the biobank can speak with you about your consent form, and it does not have to be signed immediately before or after surgery.

Northern First Nations Biobank Advisory Committee (NFNBAC)

The NFNBAC was established to provide input to the NBI team on the research methods and strategy for the NBI consultations with First Nations in northern BC.

Nadine Caron, Principal Investigator, NBI

Nicole Cross, Regional Executive Director, Northern, FNHA

Megan Hunt, Provincial Director, Primary Care, FNHA

Patricia Howard, Regional Manager, Primary Care, Northern, FNHA

Namaste Marsden, Manager, Research and Knowledge Exchange, FNHA

David Loewen, Regional Director, Indigenous Health, Northern Health

Beverley C. Percival, Northwest Subregional Rep

Dawn George, North Central Subregional Rep

Sarah Gauthier, Northeast Subregional Rep

Laura Arbour, Genomic Researcher

Maui Hudson, International Indigenous Rep

Kate Anderson, Advanced Qualitative Analyst

Wilf Adam, Elder

With input from consultations, the NFNBAC could evolve into a board to represent First Nations in decision-making about which research can access First Nations samples.