Advancing community-level health data collection and health impact assessment practices for First Nations in British Columbia, Canada

by

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M.HSc., Simon Fraser University, 2013

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We acknowledge and respect the Lək̓ʷəŋən (Songhees and Esquimalt) Peoples on whose territory the university stands, and the Lək̓ʷəŋən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

This dissertation explores the collection and management of community-level health data by a First Nation in British Columbia (B.C.), Canada. Due to the geographical proximity of their communities and territories, First Nations tend to experience adverse project-related effects associated with on-going industrial development across the province. Despite the growing interest in health impact assessment (HIA) as a means of evaluating how projects influence community health and wellness, little research has focused on the importance of community-level data to achieve this. Chapter 2 utilizes case study research to examine the types of health data collected at the community level and the alignment of this data with community health priorities and industrial development risks. Chapter 3 explores the perspectives of First Nation Department and Project Managers concerning their experiences in data collection and the challenges they encounter. Chapter 4 transitions away from the concept of 'doing research for the sake of research' to adopting an applied research approach by translating technical knowledge into a visually-styled information resource for First Nations in B.C. The dissertation concludes by reflecting on the implications of the findings for the field of HIA and First Nation communities, highlighting avenues for future research, practice and overcoming challenges at the local level.

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Dedication

This dissertation is dedicated to the memory of my late father, David Jokinen, my mother, Dr. Nancy Jokinen, and my sister, Dr. Janis Shandro.

Chapter 1. Introduction

This dissertation aims to enhance community-level health data collection and Health Impact Assessment (HIA) practices specifically for First Nations communities in British Columbia (B.C.), Canada. This introductory chapter presents key topics, including the health and wellness of Indigenous populations, the principles and methodologies of HIA, and the critical role of community-level data in this context. The scope and objectives of the research are also outlined to provide a clear framework for this body of work.

1.1 Indigenous communities, health, and industrial development

Globally, there are an estimated 476 million Indigenous Peoples[1] who reside across 90 countries and represent 6% of the world's population. Indigenous communities across the world are diverse and hold unique histories, languages, knowledge systems, ancestral traditions, spiritual beliefs, governance structures and approaches to community health (UNDP, 2021; UNDRIP, 2007). In Canada, the term Indigenous refers to First Nations (both status and non-status), Métis and Inuit Peoples. The term 'First Nation' is used to identify Indigenous peoples of Canada who are neither Métis nor Inuit. First Nations people include both status and non-status, and the issue of status versus non-status is problematic and complex. Métis scholar Chelsea Vowel notes,

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[1] The term 'Indigenous' or 'Indigenous peoples' is primarily used throughout this dissertation to refer to the original inhabitants of Canada and their descendants, including First Nations, Inuit, and Métis peoples as defined by the Canadian Constitution. In some cases, the term is also used to describe the global Indigenous population, international guidance or when referencing specific literature. The research described by this dissertation involved the partnership with a First Nation (versus an individual), therefore study descriptions and findings contain the terms 'First Nation' or 'First Nation communities'.

> Not all status Indians are actually Indigenous (more on that in a bit), and there are many Indigenous peoples who do not have status. Status Indians are not the only Indians (First Nations) that exist. Non-status Indians are those who, through various pieces of legislation, lost their status, or were never eligible for status because their parents or grandparents lost status. Non-status Indians are still Indigenous; lack of status does not change this. (p. 27)

In B.C., Canada, there are approximately 203 diverse First Nations with an estimated total population of 172,520 (Statistics Canada, 2018; British Columbia Assembly of First Nations, 2019). With distinct histories, traditional customs, spiritual beliefs, governing systems and kinship patterns, there are over 35 First Nation languages and 61 dialects spoken across the province, representing 60% of all First Nation languages in Canada (First Peoples' Cultural Council, 2018). In terms of geographical location, approximately 50% of the Indigenous population (including First Nations, Métis and Inuit Peoples) in the province live in communities that are defined as rural or remote (BC Government, 2016).

An Indigenous perspective on health calls attention to the interconnectedness of mental, spiritual, physical and emotional domains. Many factors, which are specific to Indigenous populations, influence individual and community health (First Nations Health Authority, 2012; Gall et al., 2021; National Aboriginal Health Strategy, 1989). There is a consensus among Indigenous leaders, scholars, and knowledge holders regarding the significance of the natural environment to Indigenous health and wellness. The relationship Indigenous Peoples have with their traditional territory is intrinsically linked to their identity, culture and overall health and well-being (Atleo, 2011; Greenwood, de Leeuw & Lindsay, 2018; Hillier, Taleb, Chaccour, & Aenishaenslin, 2021; Richmond & Ross, 2009). Environmental stewardship, which includes

Indigenous Peoples exercising control over their lands and marine environments, is widely recognized as a critical determinant of Indigenous health (Loppie & Wien, 2022). Environmental stewardship practices also help maintain biodiversity, address climate change, and sustain cultural and economic livelihoods for future Indigenous populations (Atleo, 2011; Diaz et al., 2019). Emerging as a critical aspect of this stewardship role includes safeguarding Indigenous territories and communities against the potential impacts of industrial development activity (Scheidel et al., 2023; Schuster et al., 2019).

The relationship between Indigenous communities and industrial development projects can be characterized as complex and often traumatic (Hanna, Ingles de Sousa, & Fa'aui, 2022). Such development can perpetuate the on-going experience of colonization in communities and affect a range of determinants that influence Indigenous health and wellness (Hanna, Ingles de Sousa, & Fa'aui, 2022; Ninomiya et al., 2023; Scheidel et al., 2023). In response, procedures for evaluating industrial-related impacts on community health and wellness are essential safeguard requirements.

1.2 Health impact assessment: A brief description

The field of HIA has grown rapidly over the past 20 years and a number of global institutions, such as the World Health Organization (WHO) and the International Finance Corporation (IFC), have supported its use and application (Harris Roxas & Harris, 2010). HIA is defined as "a combination of procedures, methods and tools by which a policy, program or project may be judged as to its potential effects on the health of a population, and the distribution of those effects within the population" (WHO, 1999, p 4). The overarching purpose of an HIA is to understand the future consequences of plans, proposals, and policies on community health and wellness (Birley, 2011).

The field of HIA evolved from two disciplines; environmental impact assessment, and health promotion. Environmental impact assessment (EIA) is embedded in the environmental justice movement and dates back to the 1970s, when the United States first formalized environmental concerns by embedding them into the project-planning phase. EIAs identify and measure potential impacts on the receiving environment related to a specific development project (Kemm, Parry & Palmer, 2004). Components of HIAs can exist within the EIA framework, however, in 1999 the WHO-EURO released the Gothenburg Consensus, which proposed and legitimized HIA as a stand-alone practice by outlining a methodological framework (Pan American Health Organization, 2013). In addition to EIA, the second discipline, health promotion, also contributed to the development of HIA. Health promotion is the process of encouraging individuals to take increased control over their well-being, and emphasizes how social and environmental conditions influence health. Guided by the Lalonde Reports (1974) and the WHO's Ottawa Charter for Health Promotion (1986), population health was no longer considered the sole responsibility of the health sector. Rather, it was recognized that policy-makers in all sectors influence health. and commitments must be made collectively to improve or sustain population health and well-being. The field of HIA originates from both foundational concepts, EIA and health promotion, respectively. and strives to ensure proposals from various sectors undergo evaluation prior to approval, with appropriate safeguards outlined and in place to protect the health of people (Kemm, 2013).

This dissertation focuses on HIA as a tool for understanding the consequences of industrial development projects on community health and wellness. Through a systematic approach, HIA practitioners can employ a combination of qualitative, quantitative, and/or participatory methods to assess both positive and negative risks stemming from an industrial development project on community health and wellness (Buregeya, Loignon & Brousselle, 2020, Morgan, 1998; World Health Organization, n.d.). The relationship between risks and a proposed project can be defined as direct or indirect, and single or cumulative changes may be observed. The global field of HIA and those who practice within it, aim to ensure health is integrated into the assessment process to inform decision-makers and help prioritize prevention and mitigation strategies, while maximizing health opportunities (Kemm, 2001; International Finance Corporation, 2009).

A comprehensive HIA incorporates environmental, social, and culturally appropriate determinants of health, and is defined by the following phases: (1) screening; (2) scoping; (3) appraisal/risk assessment; (4) recommendations; (5) reporting; and (6) monitoring and evaluation (Quigley et al., 2006). The following section provides a brief overview of each HIA phase.

In general, the initial ***screening phase*** of an HIA determines whether a specific project proposal is likely to impact community health. Information garnered during this phase helps decision-makers determine the value and feasibility of a comprehensive HIA for the project. In general, the screening phase aims to evaluate if a proposed project will affect community health significantly, therefore providing justification for a more detailed assessment through an HIA. During the ***scoping phase***, health indicators are selected and affected populations are identified. This includes the identification of disadvantaged and marginalized subgroups within the population who may be disproportionately affected. Scoping phase activities also include the development of a scope of work (SoW), methodological procedures, data sources, timeline, and the delegation of HIA activities. The main objectives of the ***appraisal/risk assessment*** phase are to establish a community health profile and health baseline, collect primary data, conduct a secondary data review, and field observations, and determine the impact estimates. Following the risk assessment, the HIA team provides ***recommendations*** for avoiding, managing, and/or mitigating impacts to ensure changes to community health are minimal. For impacts that cannot be mitigated, compensation to community members may be recommended. These recommendations are provided in a ***report***, which is drafted by the HIA team for stakeholders and decision-makers. The final stage of the HIA includes ***monitoring and evaluation***, which provides the mechanism for measuring changes to baseline health conditions of a community over time, identifies new and emerging health risks, and allows for the assessment of the effectiveness of mitigation measures (Birley, 2011; Kemm, 2013; Pan American Health Organization, 2013; WHO, 2024).

1.3 The global use of HIA and IFC Performance Standards

In 1997, the fourth international conference on health promotion was held. The *Jakarta Declaration on Leading Health Promotion into the 21st Century* conference focused on international strategies to promote health and well-being (WHO, 2017). One defining element of this conference included the invitation and participation of the private sector and the recommendation that all sectors (i.e., both private and public) incorporate equity-driven HIAs into practice (Midell, Boltong & Ford, 2010).

In many parts of the world (e.g., Australia, New Zealand, Thailand, and the European Union), HIAs have become the standard for ensuring project-related health impacts are avoided, minimized, and/or compensated for (Byambaa, Janes & Davison, 2014). HIA is supported by a number of nations and jurisdictions that have developed regulations and provide direct resources to enhance local capacity to undertake HIAs (Harris-Roxay & Harris, 2010). One example of a regulated HIA includes the country of Thailand, where the public has the right to request (and participate in) an HIA, which is protected under Thailand's National Health Act, for any project that may impact individual or public health. (NHCO, 2010).

In 2006, major advancements in the field of HIA were made when the international development finance sector, specifically the International Finance Corporation (IFC), developed a suite of performance standards. The standards were attached to all financial lending for extractive sector projects in developing countries (Kemm, 2013). Known as the *IFC Environmental and Social Performance Standards*, the standards represent an international benchmark for identifying, managing, and mitigating environmental and social risk, and have been adopted by global organizations to help configure environmental and social risk management systems. In particular, the IFC has constructed specific guidelines pertaining to community health and safety (Performance Standard 1) and projects that may adversely impact Indigenous Peoples (Performance Standard 7) (IFC, 2012). Interestingly, in 2014, the Government of Canada announced an 'enhanced corporate social responsibility (CSR) strategy' for Canadian extractive companies operating abroad that includes an expectation that Canadian companies will align their practices with a series of internationally recognized frameworks including the IFC Performance Standards (Global Affairs Canada, 2021). While companies that operate in Canada are not required to follow the enhanced CSR strategy, the adoption of these standards by Canada suggests the government may be prepared to recognize international benchmarks for industry performance in the future.

1.3 HIA in Canada and British Columbia

Environment assessment (EA) at the most basic level, has been operational in Canada since 1974. During this time, a federal cabinet was established to assess the consequences resulting from environmental decisions (Pan American Health Organization, 2013). In 1990, the

Canadian Environmental Assessment Act (CEAA) was developed and fully implemented five years later. The establishment of the CEAA was largely influenced by the Supreme Court of Canada’s rulings associated with the Rafferty-Alameda Dam case (1986) and the Oldman River Dam case (1990) which formally recognized the Government of Canada’s duty to consult, consider, and accommodate Indigenous rights and interests in relation to environmental impact resulting from large scale industrial development/projects (Harrison, 1996). Similarly, in B.C., the first Environmental Assessment Act was established along with the British Columbia Environmental Assessment Office (BCEAO) in 1994, which underwent repeal in 2002 (Haddock, 2010). In general, the B.C. EA process has been described as “a proponent-driven, project-specific regime in which those proposing to carry out projects that are designated ‘reviewable’ must provide information according to requirements approved for each project and apply for an ‘environmental assessment certificate’ before building a project” (Haddock, 2010, p. 15).

At both the federal and provincial levels, the institutionalization of HIA has been characterized by highs and lows. During the 1990s, a group of environmental health professionals working for Health Canada advocated for the inclusion of holistic determinants of health within the EA framework (Kemm, 2013). This initiative led to the development of an internationally recognized HIA guide (i.e., three-volume *Canadian HIA Guidebook*), which, as McCallum, Ollson, & Stefanovic (2015) argue, has had more influence outside of the country, than within it. The handbook was permanently archived in 2013, most likely reflecting changes in government priorities (McCallum, Ollson & Stefanovic, 2015).

More recently, the CEAA was replaced in 2019 by the new Impact Assessment Act, which outlined changes to the review process of major projects. Depending on the scope and details of a project, a federal EA can be triggered. The "Impact Assessment Act (the Act) and its regulations establish the legislative basis for federal impact assessment in most regions of Canada." (Impact Assessment Agency of Canada, n.p., 2023). The Impact Assessment Agency of Canada leads federal assessments of designated projects identified as having the potential to yield the most significant adverse effects (IAAC, 2023). EA legislation in Canada is the topic of ongoing debates about the federal government's jurisdiction over proposed projects. In 2023, the Supreme Court of Canada ruled that sections of the IAA were unconstitutional and should be revised (SCC, 2023).

In jurisdictions such as Canada and the province of B.C., global standards and practices on HIA are voluntary and both provincial and federal EAs do not require stand-alone or integrated HIAs. Historically, in Canada and B.C., assessments including health were restricted to biophysical health impacts related to changes to the physical environment, and have struggled to accurately identify impacts on a broader suite of determinants that influence health and wellness (Freeman, 2019; Gibson, 2006). Currently, federal (Impact Assessment Act, 2019) and provincial (B.C. Environmental Assessment Act, 2018) legislation require the consideration of health during the EA processes. For example, the BCEAO utilizes a five-pillar approach and requires all project assessments to consider the "positive and negative direct and indirect effects [...], including environmental, economic, social, cultural and health effects and adverse cumulative effects." (BC EAO, p. 6, 2021). At the federal level, the IAA includes health as one of the factors to be considered in impact assessments, requiring the evaluation of health effects alongside the environmental, social, and economic impacts of proposed projects (Impact Assessment Act, 2019). Although federal and provincial EAs require the topic of health to be 'considered', Hoogeveen, Brubacher, Leduc & Lou (2022) argue there "is a lack of supporting documentation and policy identifying how health (including HIA) should be implemented" (p. 5). Furthermore, there is an absence of supporting documentation and policy on how to evaluate adverse effects on First Nation health and wellness. As such, "there are an increasing number of Indigenous-led IAs in B.C. that incorporate health into their review" (Hoogeveen, Brubacher, Leduc & Lou, 2021, p.18).

1.4 HIA as a tool for First Nations in British Columbia

Ongoing colonial practices and processes, continued mistrust of government and industry, concerns over the extraction and misuse of Indigenous Knowledge, and repeated failures of past EAs to meaningfully address community concerns continue to present significant challenges (Eckert et al., 2020). Over the past decade, the usefulness of HIA has transitioned from a framework that was never adequately adopted by provincial and federal legislation to a community resource that is being adapted to meet the needs of rural and remote populations (Hoogeveen, Brubacher, Leduc & Lou, 2021; McCallum, Ollson, & Stefanovic, 2016; Tsimshian Environmental Stewardship Authority, 2018). First Nations in B.C. are increasingly concerned about the risks and impacts to Indigenous health related to industrial development and have positioned themselves at the forefront of this movement to enhance the assessment process (Shandro, Jokinen, Stockwell, Mazzei & Winkler, 2017; Shandro, Ostry & Scoble, 2012; Shandro, Veiga, Shoveller, Scoble & Koehoorn, 2011).

One need only review cases where First Nations have had to bear health-related risks linked to ineffective EA processes in B.C. to understand the gravity of the situation, as highlighted by Shandro et al. (2017) following one of Canada's largest mining accidents:

> On August 4, 2014, the first day salmon fisheries opened for First Nations along the Fraser River, the Mount Polley Mine tailings storage facility was breached and released 25 million

> cubic metres of mine waste into the Fraser River watershed. Following the spill, the BC government and the Mount Polley Mining Corporation released technical, environmental, and assessment reports describing pre-event infrastructure issues, post-event impacts to the receiving environments, and future pathways for re-permitting. Notably lacking was a systematic, rigorous assessment that identified (a) First Nations who were impacted by this incident, and (b) impacts to Aboriginal health experienced by these communities. (p. 85-86)

To address the lack of effective EA management in addressing risks to community health in B.C, Canada, a number of HIA projects (including community-driven HIAs, health risk assessments and advancements in research) have taken a critical lens to this topic and/or been led by First Nations over the past decade (see as examples Harvard Law, 2010; Shandro, Jokinen, Kerr, Sam, Scoble, Ostry, 2014; Shandro, Ostry & Scoble, 2012; Shandro, Jokinen, Stockwell, Mazzei & Winkler, 2017). Recent research in the field of HIA and health risk assessment focuses on integrating Indigenous Knowledge systems with risk assessment methodologies to center Indigenous perspectives on health and wellness. Expanding on this, conventional assessment frameworks are also being co-developed with Indigenous communities to advance a more equitable and inclusive assessment process (Donatuto, Campbell & Gregory, 2016; Kwiatkowski, 2011; Larsen et al., 2018; Lewis et al., 2021). When reviewing Indigenous-led HIAs, it is important to note that many HIAs are conducted internally (and are not affiliated with academic institutions) and are therefore not released publicly, limiting broader discussion of approaches and subsequent assessment findings.

To further expand on the case provided above, in 2014, the First Nations Health Authority (FNHA) in B.C commissioned the first phases of an HIA following the Mount Polley

Mine tailings dam failure by partnering with twenty-two First Nations and global experts in the field of HIA. The two main objectives of this project were to: (1) identify the First Nations affected; and (2) identify adverse health risks and impacts of the tailings dam failure using global impact assessment standards. Findings from the scoping phase identified that communities across the province were experiencing critical post-breach impacts to the Indigenous determinants of health (Shandro, Jokinen, Stockwell, Mazzei & Winkler, 2017).

Following the Mount Polley Mine HIA scoping phase report, the Tsimshian Environmental Stewardship Authority commissioned their own HIA guidelines, titled *A Guideline for Conducting Health Impact Assessment for First Nations in British Columbia, Canada.* The guidelines provide an overarching HIA approach for government, proponents and agencies working with First Nations and communities who are leading their assessments. They also highlight a list of health determinants (some specific to First Nation populations) that an assessment may consider and emphasize the importance of integrating Indigenous knowledge into the HIA process (Tsimshian Environmental Stewardship Authority, 2018). Although the guidelines provide an overarching approach to conducting HIAs in partnership with First Nations, one challenge remains evident: an in-depth exploration of available community-level data required by HIA practitioners to implement HIA activities described by the guidelines.

1.5 A brief overview of Indigenous and Western knowledge

When a First Nation is identified as a project-affected community, HIA processes should incorporate both Indigenous and Western knowledge across the assessment process. By taking a holistic approach, the assessment is more likely to be comprehensive, accurate, and respect cultural and community values (IFC, 2012; Lawrence & Larsen, 2017; Tsimshian Environmental Stewardship Authority, 2018). Although a complete review comparing Indigenous and Western knowledge is beyond the scope of this dissertation, it is worth noting the importance of both when it comes to the field of HIA.

The terms ‘Indigenous knowledge’ (also referred to across the literature as ‘Traditional knowledge”, and ‘Indigenous ways of knowing’) was traditionally “conveyed orally, symbolically, or through experience, and was ‘embedded in the cumulative experience and teachings of Indigenous people’” (Battiste, 2002, p. 2). Bruchac (2014) elaborates that Indigenous knowledge is a “network of knowledges, beliefs, and traditions intended to preserve, communicate, and contextualize Indigenous relationships with culture and landscape over time... Indigenous knowledges are conveyed formally and informally among kin groups and communities through social encounters, oral traditions, ritual practices, and other activities.” (p.1). The sharing of diverse and complex systems of knowledge among Indigenous Peoples has been directly affronted by colonial policies and practices throughout history (an example of this includes the residential school system), which aimed at eradicating Indigenous knowledge (Maldonado-Torres, 2007; Smith, 2021). In contrast, Western knowledge is based on the principles of positivism and prioritizes knowledge gathered through scientific investigation, assuming there is a single ‘truth’ to be discovered (Martin, 2012).

The imposition of Eurocentric systems of governance, education, and research methodologies led to Indigenous Knowledge systems often being dismissed, and Western knowledge guiding decision-making processes (Maldonado-Torres, 2007; Smith, 2021). However, “Indigenous knowledge has sustained the survival of Indigenous peoples and communities for centuries and remains integral to the health and well-being of Indigenous peoples.” (Rogers, 2019, p. 12). To advance reconciliation objectives and adhere to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the federal and provincial governments in Canada provide guidance on incorporating both Indigenous knowledge and perspectives across the EA process (British Columbia Environmental Office, 2022). To understand how a proposed project may impact community health and wellness, best practices include centering Indigenous knowledge on health and incorporating determinants of health data that best reflect community conditions into the assessment (Mackenzie Valley Review Board, 2005; Kwiatkowski, 2011). Both qualitative and quantitative approaches to data collection may be useful within an HIA (Kemm, 2001). Although quantitative data can indicate what is occurring, qualitative data provides context that explains why it is occurring and may provide a pathway for incorporating Indigenous knowledge and perspectives, if permitted (First Nations Energy and Mine Council, 2019; Spoon, 2014; Tsimshian Environmental Stewardship Authority, 2018).

1.6 Ethics and data sovereignty in impact assessment

A discussion on incorporating different types of data into the IA process requires careful ethical consideration. The global HIA community recognizes the Gothenburg Consensus Paper (European Centre for Health Policy, 1999) as a foundational resource outlining processes for integrating ethical consideration into HIA practice. It emphasizes the ethical use of evidence in HIA, advocating for transparency, accountability, and inclusiveness. As a professional resource, it also underscores the importance of high-quality, recent, culturally appropriate evidence to make decisions that may affect the health of people and communities. Additionally, ethical HIA practice can be guided by IA professional bodies, such as the International Association for Impact Assessment (IAIA) and its code of conduct. Vanclay et al. (2013) note how best practice (across all fields of IA) requires full observance of 18 principles, including respect for participants, informed consent, voluntary participation and no coercion, data protection, enabling participation, and access to grievance procedures (for the full list of principles, see Vanclay, Baines & Taylor, 2013, *Impact Assessment and Project Appraisal*, 31(1), pp. 243-253).

When assessments involve Indigenous populations, Indigenous rights issues, as outlined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), particularly the concept of 'free, prior, and informed consent’, play a critical role in guiding ethical approaches across all IA disciplines. UNDRIP also lays the foundation for key components of data sovereignty including the rights of Indigenous peoples to control and protect their cultural heritage, traditional knowledge, intellectual property, and participation in decision-making that affects their rights (United Nations, 2007).

In Canada, the First Nations Information Governance Centre (FNIGC) developed a standard of practice for engaging in research with First Nation communities in 2002. Ownership, control, access, and possession (OCAP®) data principles are not a doctrine or a prescription; they represent First Nations’ commitment to use and share information in a way that brings benefit to the community while minimizing harm. These principles also express First Nation jurisdiction over information about the First Nation (FNIGC, 2014). Although OCAP® is specific to First Nations in Canada, both Inuit and Métis groups have adopted similar data principles (i.e., Inuit Quajimajatuqangit and ownership, control access and stewardship [OCAS] principles) (Centre for Aboriginal Health Research, 2013). Indigenous data principles, such as OCAP®, provide IA practitioners with a framework for conducting assessments with Indigenous communities and ensure a clear understanding that Indigenous peoples have the right to own and govern their data (Kukutai & Taylor, 2016). However, the application of OCAP® data principles within the field of IA is minimal despite the emphasis on utilizing traditional knowledge to predict risks related to a proposed development project. Without rigorous data safeguards in place during the impact assessment process, First Nations and other Indigenous groups are left vulnerable to the misuse of their information. This underscores the broader issues experienced by the field of HIA, the need for reliable community-level data to effectively identify and mitigate health risks associated with industrial development activity.

1.7 The data dilemma

Today, the field of HIA is plagued by a fundamental challenge: the need for good quality community-level health data and information. The availability and accessibility of First Nation-level health data and information emerges as a significant challenge, especially in light of the considerable industrial threats facing First Nations across the province. Addressing these threats requires comprehensive community-level data required to perform HIAs that safeguard people and communities. An assessment is only as good as the data that is available (Jokinen & Meuter, 2022; Meuter & Jokinen, 2023; Shandro and Apps, 2022). This leads to a very interesting question; what qualifies as ‘good data’?

Given the diversity of First Nation cultures, it is important to allow for contextually specific understandings of health and its determinants. However, time and again, when community health is integrated into an EA assessment, the assessors often rely on publicly available datasets that are not sensitive to local context and are frequently outdated (e.g., data from 2016 Census of Population Program). New health services and care models recognize that the measurement, monitoring, and reporting on health and wellness needs to shift to a holistic wellness approach that is led by Indigenous knowledge systems (FNHA, 2016). For First Nations in the province of B.C, community-level data available in the B.C. health surveillance system is missing, fragmented, and/or limited to a specific suite of indicators (e.g., life expectancy, mortality rate, youth suicide rate, infant mortality rate, and diabetes prevalence) (FNHA, 2013). With a lack of community-specific health data, incorporating publicly available data into HIA may result in the misrepresentation or inappropriate description of conditions in First Nation communities. By reflecting on data challenges experienced by First Nations, Mcbride (2018) notes how "community-driven data development and the creation of community-specific indicators is a powerful step towards emancipating community health. Communities can work towards developing their own indicators of well-being and collecting data to monitor these indicators." (p. 14). To achieve this, it is essential to first understand the data collection practices at the community level, as well as the obstacles First Nations experience when gathering and utilizing data effectively.

1.8 Underlying approaches to research

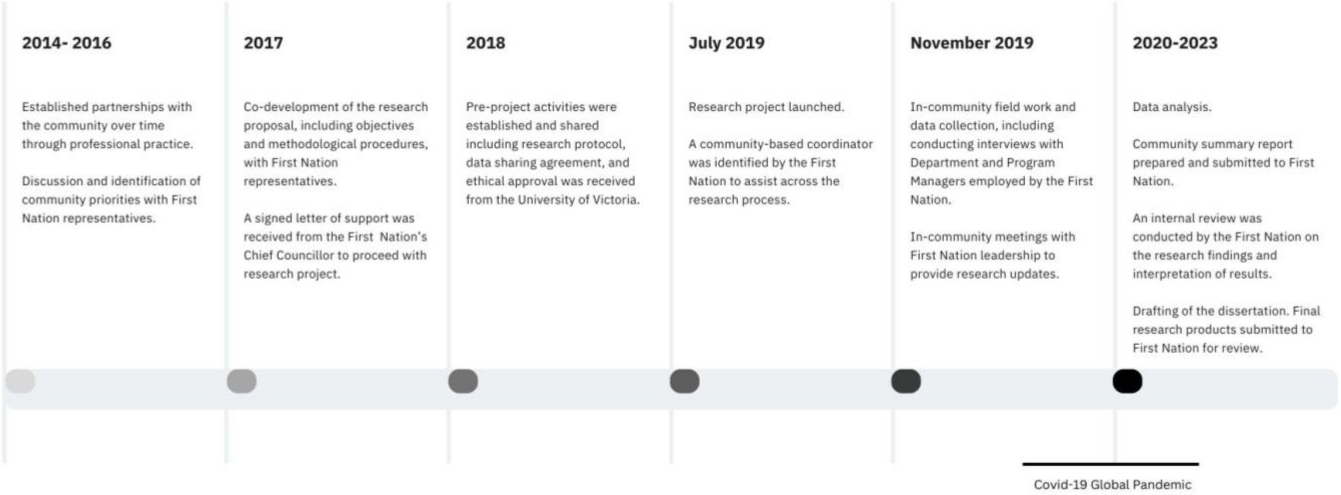
The overarching approach to this research involved a community-based participatory research (CBPR) framework. Israel et al. (2001) described CBPR as a research approach that involves collaboration among members of a community, organizational representatives, and researchers to support the sharing of expertise and responsibilities. This partnership not only enhances the understanding of a specific issue but also translates the knowledge gained into actions resulting in improved community health. The CBPR approach has gained increasing recognition as an appropriate framework to guide research when it includes collaborating with Indigenous communities, including First Nations. By empowering rural communities, CBPR can help address locally identified factors that impact their health, and leverage existing strengths to develop solutions (Snidjer, 2020). CBPR aims to build trust between researchers and communities, equalize power differences within the research process, and emphasize the importance of authentic participation of those who represent the study population (Wallerstein & Duran, 2006).

When working with Indigenous populations, including First Nations, CBPR advantages specific to this research include: (1) empowering a community to examine their priorities and participate in developing solutions; (2) facilitating a bi-lateral exchange of knowledge to enhance cross-cultural learning opportunities; (3) leveraging skills and knowledge drawn from members of the community to improve the research process; (4) involving an iterative and cyclical process of engagement, allowing for continuous refinement and adaptation of research activities based on community feedback.; and (5) translating the findings into a resource that can be accessed by all potential knowledge users (e.g., other First Nations in B.C, HIA Practitioners, government officials, academic researchers, etc.). (Dawson, Toombs & Mushquash, 2017; Holkup et al., 2004).

Ownership, control, access, and possession (OCAP) data principles® also lie at the heart of the research conducted for this dissertation and were formally recognized, through the establishment of a signed data-sharing and community research protocol agreement. OCAP data principles outline the need for respect, relevance, reciprocity, and responsibility when conducting research with partnering First Nations (First Nations Information Governance Centre, 2017). *Ownership* asserts that cultural knowledge/data is held or owned by the First Nation collectively. *Control* refers to the right of First Nations to exercise control over all aspects of their lives, including research being conducted in their communities. The principle of control extends to the entire research process, including how data is collected, stored, managed, disclosed and destroyed. *Access* requires that First Nations are able to access their data regardless of where it is being stored, and can determine who can access their collective information. Finally, *possession* refers to the mechanism that places First Nation data within a First Nation jurisdiction, which enables ownership and control. This is particularly important when mistrust is present (e.g., the misuse of data can occur when the owner does not possess the data) (First Nations Information Governance Centre, 2014; Centre for Aboriginal Health Research, 2013; Schnarch, 2004). Building on these principles, the following section provides a timeline of major research activities that were carefully organized to ensure a respectful and collaborative approach to community research, engagement and data principles were prioritized and upheld.

1.9 Timeline of major research activities

The following figure (Figure 1) provides an overarching timeline of major research activities that were conducted from 2014 to 2023. It begins with the establishment of a partnership with the community through professional practice and the identification of priorities (2014-2016), followed by the co-development of the research proposal and a signed letter from the Chief Councillor of the First Nation (2017-2018). The research project officially launched in 2019 with the identification of a Community-Based Coordination and initiation of fieldwork, which took place in the home community of the First Nation. The final phase, from 2020 to 2023, involved data analysis, community reporting, and the preparation of the final research products and this dissertation.



2014- 2016

Established partnerships with the community over time through professional practice.

Discussion and identification of community priorities with First Nation representatives.

2017

Co-development of the research proposal, including objectives and methodological procedures, with First Nation representatives.

A signed letter of support was received from the First Nation's Chief Councillor to proceed with research project.

2018

Pre-project activities were established and shared including research protocol, data sharing agreement, and ethical approval was received from the University of Victoria.

July 2019

Research project launched.

A community-based coordinator was identified by the First Nation to assist across the research process.

November 2019

In-community field work and data collection, including conducting interviews with Department and Program Managers employed by the First Nation.

In-community meetings with First Nation leadership to provide research updates.

2020-2023

Data analysis.

Community summary report prepared and submitted to First Nation.

An internal review was conducted by the First Nation on the research findings and interpretation of results.

Drafting of the dissertation. Final research products submitted to First Nation for review.

Figure 1 Timeline of major research activities.

1.10 Overarching objectives and scope of the dissertation

The overarching objectives of the research chapters (2, 3, and 4) aim to collectively inform an enhanced approach to HIA practice and help communities better understand challenges they may experience with data collection, and identify potential ways to overcome these challenges. Additionally, the chapters also aim to enhance knowledge related to the benefits of establishing community-based health monitoring programs through annual data collection initiatives. With these goals in mind, the following research questions were explored:

(1) What strategies are being used at the community-level to collect and manage health and determinants of health data based on the community's *own* definition of wellness?

(2) How can this information be used to reimagine the HIA processes?

(3) How can better community-level data and information help improve HIA practice to better meet the needs of First Nations?

(4) What challenges do First Nation Department and Program Managers experience when collecting and managing community-based health (and determinants of health) data?

(5) What internal strategies can be supported to improve data collection at the local level?

By partnering with a First Nation, I explored their data collection initiatives in relation to the determinants of health they prioritize, along with indicators described by the document titled *Guideline for Conducting Health Impact Assessment for First Nations in British Columbia, Canada* (Tsimshian Environmental Stewardship Authority, 2018) (Chapter 2). I further explored challenges related to data collection experienced by Department and Program Managers employed by the First Nation (Chapter 3). To ensure research for my dissertation benefits communities across the province, an information resource on designing and implementing community-based health monitoring programs was developed (Chapter 4). In conclusion, I discuss the significance of my dissertation findings in enhancing our understanding of community-level data initiatives for both the field of HIA, including professional practitioners, and First Nations (Chapter 5). The following sections will provide an overarching summary of each Chapter contained in this dissertation.

Chapter 2 is a manuscript that has been prepared for submission and potential publication in Impact Assessment and Project Appraisal. Through a CBPR framework and utilizing an instrumental case study approach, I partnered with a First Nation in B.C, Canada to evaluate their health model, which was shared by the Nation, and examine local-level data collection initiatives. An instrumental case study approach allows for the in-depth examination of a particular case (the First Nation community) to gain a better understanding of a broader phenomenon (data collection and management at the community-level) (Creswell, 2011). As a qualitatively-orientated study, I aimed to explore the types of health and determinants of health data being collected compared to the community's model of health and determinants outlined by *A Guideline for Conducting Health Impact Assessment for First Nations in British Columbia, Canada (Tsimshian Environmental Stewardship Authority, 2018)*. I travelled to the First Nation's home community to conduct twelve semi-structured interviews with Department and Program Managers working with the Nation. Using a thematic analysis approach, I identified common patterns and themes related to the types of data collected by each Department. Following this, a gap analysis was conducted to compare the identified themes and data collection practices with the community's health priorities and determinants included in the HIA Guideline, previously mentioned above. Current health data collection strategies (e.g., method of collection, frequency), the management of data (e.g., storage, access), data analysis and reporting, current gaps, and opportunities for implementing a standardized health monitoring program at the Nation-level are discussed. This research highlights opportunities for improving HIA practice involving First Nations in Canada.

In Chapter 3 I explore the perspectives of First Nation Department and Project Managers who collect community-level data as part of the requirements of their position through an instrumental case study design. Prepared for submission to *the International Journal of Indigenous Health*, the purpose of this qualitatively-orientated research is to describe the challenges and barriers experienced by local staff and provide recommendations for improving health data collection at the local level. Twelve semi-structured interviews were conducted with Department Managers working for a First Nation in B.C., Canada. By better understanding the perspectives of Department Managers who work for a First Nation, potential solutions for overcoming the identified challenges can be achieved.

Chapter 4 underscores the underlying purpose of my academic pursuit, which is to move away from the concept of ‘doing research for the sake of research’, to an applied research approach. At the core of conducting CBPR, is establishing co-equal and mutually beneficial relationships to create opportunities for “building critical consciousness, community capacity and social capital” (Delafield et al., 2017, p. 586). One principle of conducting CBPR includes the dissemination of results and knowledge to all partners and to those who can influence change. As a researcher and professional HIA practitioner, I have been humbled by the opportunity to work with communities on topics related to community health and safety. The work I complete as part of my dissertation must result in a tangible product that can benefit communities across the province. To help build on pre-existing strengths and opportunities across First Nations in B.C., I prepared an information resource for communities that provides a general introduction to community-based monitoring programs. In this context, I provide an overview of these programs, accompanied by a list of real-life benefits that are reported by communities that have successfully implemented them. Potential challenges, along with solutions, are also highlighted. My colleague, Christa Meuter, who is the former Health Director for a First Nation, reviewed the information contained in the community resource. Through my professional practice as an HIA practitioner, I partnered with Christa Meuter to successfully implement an annual determinant of Indigenous health monitoring program (Jokinen & Meuter, 2023). The information presented in the resource reflects findings from my research, as well as lessons learned from my professional practice. I also managed the design elements of the document by providing detailed instructions to a professional Graphic Designer, Petra Richli.

In **Chapter 5** I reflect on the value my dissertation findings add to understanding community-level data initiatives for both the field of HIA, including professional practitioners, and First Nation communities. Working alongside First Nations in the pursuit of health equity and reconciliation has deepened my understanding of allyship and what it means to move beyond doing ‘research for the sake of research’. By working through this process, I reiterate the importance of translating academic knowledge gained through research into tangible benefits for communities. The chapter concludes with identifying potential avenues for future work and research, including exploring appropriate methodologies for developing community models of health, establishing baseline health conditions for communities and the importance of expanding HIA training in Canada to prevent unintended harm to the very communities the field intends to safeguard.

1.11 Statement of positionality

The colonial context of academic research and impact assessment practice conducted with Indigenous communities represents a history of power inequality. There are an overwhelming number of research examples that have been conducted on, rather than with, Indigenous populations (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences, and Humanities Research Council of Canada [SSHRC], 2014; First Nations Information Governance Centre, 2014). The dehumanizing approach to conducting research *on* Indigenous Peoples is not isolated to the past, nor is it isolated to the academic research community. As a general practice, impact assessments which are mandated (either through the provincial or federal EA processes) have been criticized for failing to (1) establish meaningful relationships with Indigenous communities (although it can also be argued Indigenous communities should be positioned as leaders, not merely ‘included’ or ‘engaged with’); (2) evaluate project-related effects through the analysis of data that reflects true community conditions; and (3) integrating comprehensive and holistic approaches to health as defined by project-affected communities (Harvard Law School, 2010; McGregor, 2021).

I identify as a cis-gender female white settler with strong ties to my mother's and father's third-generation Finnish-Canadian settler heritage. I was born in the community of Thunder Bay, Ontario, on the traditional territory of the Anishinabek, which includes the Ojibwa of Fort William First Nation, signatory to the Robinson-Superior Treaty of 1850. Throughout my personal, academic, and professional career, I have had the opportunity to visit and reside in rural and remote communities across the country. For the past thirteen years, I have been a visitor to the traditional territory of the Coast Salish peoples, in Parksville, British Columbia.

As a non-Indigenous researcher, I have been involved in community-based research investigating the relationship between industrial development and impacts on Indigenous health and wellness for the past ten years. I express my profound appreciation as a white settler to participate in this type of work and I recognize the uneven power relations embedded between these two roles and the communities that I work with. Affiliation with an academic institute and its current systems may lend to colonial relationships being sustained and reproduced. Professionally, I work as a Community Health and Safety Specialist and HIA Practitioner for a global consulting firm specializing in health and safety. We support our clients in identifying and managing health and safety risks associated with large-scale development projects and industrial incidents. Our work spans various sectors, focusing on risk management and strategic health and development investments while applying due diligence, monitoring, and evaluation strategies.

In Canada, most of my work is contracted by Indigenous communities who commission their own impact assessments. One of my most significant achievements has been to collaborate with two First Nations located in B.C. to establish two of the largest long-term Indigenous health monitoring programs. My intent of this current research is to advance discussions on how the HIA process can be re-imagined to better serve communities who disproportionately bear the burden of industrial development project-related risks and impacts. I acknowledge that building meaningful relationships with communities makes this type of work possible and, in no way, do I claim to represent or ‘speak’ for the First Nations and individuals with whom I partner.

Chapter 2. Improving health impact assessment practice for First Nations in British Columbia, Canada

Chapter 2 is adapted from a manuscript prepared for Impact Assessment and Project Appraisal. The formatting remains similar to the requirements outlined by the journal.

2.1 Abstract

From a global perspective, Indigenous populations may be particularly vulnerable to adverse project-related risks, and bear the disproportionate burden of impacts from industrial development. There is growing interest in health impact assessment (HIA) as a means to identify and consider the impacts of proposed developments on community health and wellness. However, HIA is not one-size-fits-all, and to be relevant for Indigenous communities there is a need to identify HIA practices and processes that challenge Eurocentric biases. This case study, grounded in post-colonial theory embedded across a community-based participatory research approach, describes how HIA practitioners can improve their practice by partnering with Indigenous communities to address data-related issues. Twelve semi-structured interviews with First Nation Department and Program Managers provide further insight into data collection initiatives that have been implemented at the local level. These strategies demonstrate opportunities for improving HIA practice when meaningful partnerships between community and practitioner are established.

Keywords: *Indigenous health, health impact assessment, Indigenous health determinants, industrial development*

2.2 Introduction

From a global perspective, Indigenous populations may be particularly vulnerable to adverse project-related risks, and bear the disproportionate burden of impacts from industrial development (Horowitz et al., 2018). International performance standards acknowledge that projects such as mines, liquified natural gas pipelines, and hydroelectric dams can lead to adverse effects experienced by Indigenous peoples including environmental dispossession and loss of culture, identity, and traditional food security (IFC, 2012). In response, the International Finance Corporation (IFC) released its Environmental and Social Performance Standards, which represents an international benchmark for identifying, managing, and mitigating environmental and social risk (IFC, 2012). The performance standards have been adopted by global organizations to help configure environmental and social risk management systems. In particular, the IFC constructed specific guidelines pertaining to community health and safety (Performance Standard 1) and projects that may adversely impact Indigenous Peoples (Performance Standard 7). All investment and advisory clients who seek financing through the IFC must adopt the standards as part of their responsibility to manage environmental and social risks. Guidelines developed by IFC provide a ‘particularly systematic methodology to address health, assess health impacts and monitor the health of communities over time” (Leuenberger et al., 2019 pp. 6) and have been noted as a preferred source guiding practice for health impact assessment (HIA) practitioners operating globally, including in Canada (Winkler et al., 2020).

In Canada, the federal government endorses international corporate social responsibility (CRS) performance and reporting guidelines (including the IFC Performance Standards) with the expectation that Canadian extractive companies align their practices when operating abroad (Global Affairs Canada, 2021). According to the Canadian federal government, ‘where host country requirements differ from the international standards listed below, the Government of Canada expects Canadian companies to meet the higher, more rigorous standard' (Global Affairs Canada, 2021, n.p). While the federal government expects Canadian companies to meet higher international standards when operating abroad, rigorous community health and safety performance systems are not mandated for companies that operate *within* Canada. Despite recognition from provincial and federal governments, health authorities, and special interest groups on the importance of the inclusion of health in Environmental Assessments (EAs), current legislation at both federal (Impact Assessment Act, 2019) and provincial (B.C. Environmental Assessment Act, 2018) levels lack clear guidance on identifying, managing, and mitigating health risks experienced by First Nations in relation to industrial development activities (Aahus, Oak & Fumerton, 2018; British Columbia Environmental Assessment Office, 2018; Brown et al., 2020; First Nations Major Projects Coalition, 2020; Government of Canada, 2022; Hoogeveen et al., 2022). To address this challenge, "there are an increasing number of Indigenous-led IAs in B.C. that incorporate health into their review" (Hoogeveen, Brubacher, Leduc & Lou, 2021, p.18). The trend of Indigenous-led IAs have included health impact assessments (HIA) and in 2018, the Tsimshian Stewardship Authority commissioned their own guidelines for conducting HIA with First Nations in the province.

In general, HIA is defined as "a combination of procedures, methods and tools by which a policy, program or project may be judged as to its potential effects on the health of a population, and the distribution of those effects within the population" (WHO, 1999, p 4). The overarching purpose of an HIA is to understand the future consequences of plans, proposals, and policies on community health and wellness (Birley, 2011). HIAs can be used as a mechanism to incorporate environmental, social, and culturally appropriate determinants of health, and typically include the following phases: (1) screening; (2) scoping; (3) appraisal/risk assessment; (4) recommendations; (5) reporting; and (6) monitoring and evaluation (Birley, 2011). In comparison, the EA process follows similar phases and include some, but not all, considerations for health impacts (Birley, 2011). While EAs consider potential negative impacts to health a project or policy poses, HIA's take a more comprehensive approach and also consider the positive impacts of a potential project and strategies to enhance them. The initial *screening phase* of an HIA determines whether or not a specific project proposal may result in changes to community health. Information garnered from this phase helps stakeholders establish the value and feasibility of an HIA. During the *scoping phase*, health indicators are selected, and affected populations are identified. This includes the identification of disadvantaged and marginalized subgroups who may be disproportionately affected within the population. Scoping phase activities also include developing terms of reference (TOR) for the HIA, establishing spatial and temporal boundaries, providing phase-specific descriptions of a project, defining a timeline, and identifying methodological procedures and the availability/quality of data. The main objectives of the *appraisal /risk assessment phase* include profiling the project and location, establishing a health baseline for affected communities, and assessing potential impacts. In the fourth phase, the HIA team provides *recommendations* for avoiding, managing, and/or mitigating impacts to ensure negative changes to community health are minimal. For impacts that cannot be mitigated, compensation may be recommended. These recommendations are provided in a *report* drafted by the HIA team for stakeholders and decision-makers. The final stage of the HIA includes *monitoring and evaluation*. The decision to adopt and implement HIA recommendations will likely involve a joint implementation of a monitoring program. A monitoring program may establish a surveillance system to measure changes to baseline health conditions over time

(Kemm, 2013; Birley, 2011; PAHO, 2012; National Research Council (US) Committee on Health Impact Assessment, 2011).

Although, in theory, HIA can be a useful approach for addressing health-related impacts associated with industrial development, several data-related challenges (e.g., the lack of disaggregated community health and determinant of health data available) may undermine the process and subsequent findings or recommendations (Claudio et al., 2018). For First Nations, data quality challenges can contribute to an underestimation of health inequities when compared to non-Indigenous populations in Canada (Smylie & Firestone, 2015). Implementation of HIA in Canada will require that quality community health data is **both available for collection and accessible for review**.

Although efforts have been made to improve general statistics for First Nations in Canada (e.g., First Nations Health Authority Regional Survey, Government of Canada's Aboriginal Peoples Survey), there is currently no health data surveillance system operating at either the provincial or national level that regularly collects disaggregated data on a comprehensive set of health indicators and indicators that hold significant for First Nation populations – including locally-relevant and customized indicators that describe unique community conditions (Smylie, 2010). As a workaround to this underlying issue, common EA practice has involved project proponents and EA consulting firms utilizing regional health datasets to outline health profiles for Indigenous populations (Meuter & Jokinen, 2023). The reliance on regional information, however, can result in inaccurate community health profiling since regional datasets are limited and do not capture the unique health conditions or priorities of a specific community (Kemm, 2013). Across First Nations, there is cultural diversity, including differences in traditions, customs, government structures, and world views (FNHA, 2023). For example, in BC alone, there are at least 200 First Nation communities in the province, and more than 34 First Nation languages (UBC, 2018). Each community has their own unique history, territory boundary, culture, and view on health and wellness (FNHA, 2023). How a community views health and wellness can differ. By applying a 'cookie-cutter' approach that relies on regional data sets, the EA process (and any assessment that assesses risks to community health and wellness, including HIAs) may be flawed from the very start.

Good community data can reflect a First Nation’s worldview while supporting the identification of community priorities and evidence-based decision-making (Meuter & Jokinen, 2023). Good data can also serve as a tool to hold government agencies and project proponents accountable. When collected, controlled, and effectively used by a community, data can provide the evidence needed to elevate the importance of an issue, inciting action on an issue that might otherwise have been ignored (Trevethan, 2019). This article presents results from a recent case study that seeks to address three central questions: (1) what strategies are being used at the community-level to collect and manage health and determinants of health data based on the community’s **own** definition of wellness; (2) how can this information be used to reimagine the HIA processes; and (3) how can better community-level data and information help improve HIA practice to better meet the needs of First Nations?

2.3 Methods

2.3.1 Purpose and objectives

By understanding internal processes related to health data collection at the First Nation level, HIA practice in Canada will require new approaches to ensure community health is safeguarded. The overall objectives of the study included:

1. Reviewing the partnership First Nation's model of health and determinants identified by the HIA guidelines developed for First Nations in BC by the Tsimshian Environmental Stewardship Authority (2018);
2. Identifying current health and determinants of health data collection initiatives at the community-level;
3. Highlighting gaps in health data collection; and
4. Providing recommendations for decolonizing the HIA approach to better meet the needs of First Nations in B.C., Canada.

2.3.2 Theoretical approach

This research is grounded in postcolonial theory which is embedded across each phase of a community-based participatory research (CBPR) approach. Postcolonial theory is ‘often used to inform social work, nursing and medicine”. It emphasizes “race as a social construct, and ways in which racism and social processes are linked to colonial practices that adversely affect health outcomes, examining social justice and ways in which power relations are created, maintained and can be changed” (Schill et al., 2019, p. 864). It is important not to take the term ‘postcolonial’ as implying that colonialism is a past event. For example, the EA process in Canada has been criticized as a colonial approach, particularly when assessments impact First Nation communities and their traditional lands and resources. By perpetuating colonial dynamics, the EA process views First Nations as communities to be consulted, but not as equal partners with their own inherent rights to self-determination (Eckert et al., 2020). Although the EA process requires proponents to meaningfully consult and make accommodations for concerns and interests raised by First Nations, there is no explicit veto power granted to First Nations in Canada. Clearly, colonialism through the EA process continues to impact the social, economic, and cultural lives of Indigenous people across Canada and the world (Smith, 1999; Tsuji, 2022). Therefore, the term ‘postcolonial’ used by this study is in reference to Brown et al. (2005), who acknowledge colonialism, and its impact, as on-going.

This study employs a CBPR approach. CBPR is “predicated on trusting, reciprocal partner relationships, shared control over research projects, collaborative leadership and decision making, and methods, analysis, and dissemination planning that utilizes multiple forms of knowledge” (Gokiert et al., 2017, p. 1). CBPR aims to build trust between researchers and communities, equalize power differences within the research process, and emphasize the importance of authentic participation of those who represent the study population (Harding et al., 2011). CBPR approaches are embedded across each project activity.

2.3.3 Statement of positionality

The colonial context of academic research and impact assessment practice conducted with Indigenous communities represents a history of power inequality. There are an overwhelming number of research examples that have been conducted on, rather than with, Indigenous populations (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences, and Humanities Research Council of Canada [SSHRC], 2014; First Nations Information Governance Centre, 2014). The dehumanizing approach to conducting research *on* Indigenous Peoples is not isolated to the past, nor is it isolated to the academic research community. As a general practice, impact assessments which are mandated (either through the provincial or federal EA processes) have been criticized for failing to (1) establish meaningful relationships with Indigenous communities (although it can also be argued Indigenous communities should be positioned as leaders, not merely ‘included’ or ‘engaged with’); (2) evaluate project-related effects through the analysis of data that reflects true community conditions; and (3) integrating comprehensive and holistic approaches to health as defined by project-affected communities (Harvard Law School, 2010; McGregor, 2021).

Continually reflecting on my positionality is a key aspect of integrating a postcolonial approach to this research. I identify as a cis-gender female white settler with strong ties to my mother's and father's third-generation Finnish-Canadian settler heritage. I was born in the community of Thunder Bay, Ontario, on the traditional territory of the Anishinabek, which includes the Ojibwa of Fort William First Nation, signatory to the Robinson-Superior Treaty of 1850. Throughout my personal, academic and professional career, I have had the opportunity to visit and reside in rural and remote communities across the country. For the past thirteen years, I have been a visitor on the traditional territory of the Coast Salish peoples, in Parksville, British Columbia.

As a non-Indigenous researcher and HIA practitioner, I have been involved in community-based research investigating the relationship between industrial development and impacts to Indigenous health and wellness for the past eight years. I express my profound appreciation as a white settler to participate in this type of work and I recognize the uneven power relations embedded between these two roles and the communities that I work with. Affiliation with an academic institute and their current systems may lend to colonial relationships being sustained and reproduced. As an HIA practitioner, most of my work is contracted by Indigenous communities who commission their own impact assessments. My intent is to advance discussions on how the HIA process can be re-imagined to better serve communities who disproportionately bear the burden of industrial development project-related risks and impacts. I acknowledge that building meaningful relationships with communities makes this type of work possible, and in no way do I claim to represent or ‘speak’ for the First Nations and individuals with whom I partner.

2.3.4 Study design and underlying data collection protocols

An instrumental case-study design was used to examine the internal data management processes of a First Nation. A case study is a “research approach that is used to generate an in-depth, multi-faceted understanding of a complex issue in its real-life context. It is an established research design that is used extensively in a wide variety of disciplines.” Crowe et al., 2011, p. 1). Stake (1995) identified three main types of case studies, intrinsic, instrumental, and collective. Intrinsic case studies typically investigate a unique phenomenon to gain a comprehensive understanding of the specific case, In contrast, instrumental case study research, which informed this current study, aims to gain a broader appreciation of an issue or phenomenon by focusing on a single case (versus collective case study research that examined multiple cases). (Creswell, 2011, Crowe et al., 2011). The intent of this study extends beyond the local context of the findings. Instead, we focus on how the findings can contribute to the broader issue of enhancing HIA practice for First Nations in B.C.

In designing the study, a postcolonial framework guided the research process. This perspective is reflected by the design’s community-driven approach, which aligns with priorities identified by the partner First Nation and methodological procedures developed in collaboration with Nation representatives. A formal community research protocol was signed by both the First Nation and the researcher. The community research protocol places control within the community to define what ethical research entails and takes into account the community's priorities to ensure that the proposed research is both meaningful and relevant to the community. A critical component of the research methodology included the community-based coordinator

(CBC). The CBC, who is a member of the partnering First Nation, assisted with participant recruitment, field work, data collection, and provided oversight and feedback during data analysis. *OCAP data principles* lay at the heart of this study and are formally recognized through the establishment of a signed data-sharing agreement embedded within the First Nation's Research Protocol and supplemental data-sharing agreement (FNIGC, 2023). Additionally, ethical approval was granted through the Research Ethics Board at the University of Victoria.

2.3.5 Anonymity of partnering First Nation

For this research manuscript, the partnering First Nation wished to remain anonymous. The First Nations Information Governance Centre notes that the "recognition of collective privacy interests is based upon the principle that groupings of people, and not just individuals, have an interest in controlling access to information, particularly sensitive information, regarding that specific group or communities" (FNIGC, 2011, p. 12). By identifying the First Nation, negative impacts may result if the information is reported and used by industrial proponents outside of the intended purpose and context of the research. Therefore, anonymity helps safeguard the community from the misuse of information contained in this current study. Collective privacy interests were acknowledged upon discussion with representatives of the First Nation and this author removed or generalized identifying information including specifically naming the First Nation and geographic locations, community references, department names, and culturally-specific health terms. This process also included a search of publicly available information linking the lead author to the First Nation, which resulted in no affiliations found and/or reported. The final draft of this report was distributed to the partnering First Nation for their review.

2.3.6 Data Collection

The initial steps of this research included reviewing the First Nation's self-defined model of health to better understand domains that influence health and wellness at the community level. Each determinant was identified, defined, and recorded, along with determinants identified in the report, "*A Guideline for Conducting Health Impact Assessment First Nations in British Columbia*" (Tsimshian Environmental Stewardship Authority, 2018). Once the community's determinants of health and wellness were defined, the researcher travelled to the First Nation community to conduct a series of qualitative interviews.

In the fall of 2019, with assistance from the First Nation's Department that oversees research initiatives and the local CBC, eleven Department Managers and one Program Manager were purposefully identified as potential participants in the study. *Invitations to Participate* were sent to Department and Program Managers via e-mail with follow-up phone calls made by the CBC who arranged interview times and locations.

Between November 25-29, 2019, twelve in-person semi-structured interviews took place in the home community of the First Nation and a separate town (where several Department Managers were based) in British Columbia (B.C). At the beginning of each interview, participants were provided with an overview of the project and a consent form was reviewed and signed. Interviews lasted approximately one hour in length and were audio-recorded with participant's permission. If a participant did not want to be recorded, detailed notes were taken. During the interview, participants were asked to describe the types of determinants of health data collected by their department, how data is stored, and the frequency/quality of data collected. Following the interviews, the recordings were transcribed, and interview summaries were compiled. Using a thematic analysis approach, patterns and themes related to the types of data collected by each Department were identified. Following this, a gap analysis was conducted to compare the identified themes and data collection practices with (1) the First Nation’s model of health (developed for the Nation’s Wellness Plan); and (2) *A Guideline for Conducting Health Impact Assessment for First Nations in British Columbia, Canada (Tsimshian Environmental Stewardship Authority, 2018)*. The gap analysis assessment examined:

- Whether or not data sets were missing, unavailable, or not representative of current conditions;
- Whether data collection strategies were unidentified/unknown;
- Whether or not data sets were undergoing analysis and reporting for trends over time; and
- Whether data sets were representative of different population groups (e.g., stratified by place of living, age, and gender where appropriate).

2.4 Results

This section reports findings that are organized into three areas: (1) select indicators important to consider when conducting HIA in partnership with First Nations; (2) descriptions of community-level health and determinants of health data collection initiatives; and (3) a gap analysis summary that identifies current health data collection efforts at the local level in comparison to health and determinants of health indicators important to the First Nation.

2.4.1 Determinants of health to consider when conducting an HIA in partnership with First Nations

As a community initiative, the partnering First Nation collectively developed a wellness strategy for their Nation, which included a model of health. The strategy grounded an approach to health and wellness based on traditional concepts unique to their culture and traditions. Unlike Western approaches to health, the model emphasized the importance of environmental stewardship and identified resources that were critical for achieving optimal wellness. In order to maintain anonymity, the following determinants of health (see Table 1) have been generalized to ensure identification through cross-referencing with the First Nation’s health model is not possible.

Table 1

Community health determinants and brief descriptions

Determinant	**Brief Description**
Connection to the environment	How life has been sustained for thousands of years.
Physical well-being	Prioritizing traditional food harvesting and other cultural activities is critical for combatting complex health conditions including cardiovascular disease and diabetes. Colonization devastated the balance of the community's reliance on traditional foods, medicines, and healing practices.
Mental wellness	Mental wellness is affected by colonial actions and policies, and has been exacerbated by the lack of culturally appropriate mental health services available.
Supporting improved capacity	The prioritization of education, training, and the expansion of skills is critical to address health inequities experienced at the local level.
Community cohesion	Working together to reach common goals is critical component of any healthy community.
Sustainability of food sources	Engagement in harvesting practices and environmental stewardship are key priorities for the partnering First Nation. The community consumes resources harvested from their territory and sustainable access is critical to their health and wellness.
Community leadership & economic development	Economic goals must be balanced with cultural and ecological well-being.
Importance of family	The family system is viewed as unique and valuable. Every person in the family contributes to family wellness.

Note. The information in this table appears in an internal resource shared by the partnering First Nation. Identifying information has been removed to ensure anonymity.

The *Health Impact Assessment Guidelines for First Nation in British Columbia* (2018) was commissioned by the Tsimshian Environmental Stewardship Authority and describes a suite of Indigenous determinants of health that are important to consider when completing an HIA for First Nations in B.C. It is important to note that these determinants are generalized and may vary across Nations. The following determinants (listed in no significant order), are included in the guidelines:

- Access to traditional land and resources
- Engagement in traditional practices
- Cultural continuity
- Gender
- Food security
- Community infrastructure
- Access to health and social services
- Health behaviours and awareness
- Housing, living in urban/rural areas
- Education, employment, and income
- Barriers to self-determination
- Language
- Sense of belonging
- Environmental Stewardship

2.4.2 Current health and determinant of health data collection initiatives at the community-level

The partnering First Nation have been stewards of their land and resources for thousands of years and committed to protecting their territory for future generations. Indigenous knowledge guides almost all aspects of community life, for example; natural resource management, economy, and governance/social structure continue to be informed by traditional beliefs, values, and customs. Traditional knowledge also informs the type of data the community systematically collects, how the data is utilized to meet the priorities identified by the Nation, and appropriate procedures for the management and storage of data. Findings from this current study reveal each department has implemented a data collection initiative. The size and scope of these initiatives vary, as do the frequency of collection and method used to store data.

2.4.3 Data management systems

The research findings indicate several departments collect, input, and store data on basic computer software programs such as Microsoft Word, PowerPoint and other specialized web-based data programs, including some with GIS capabilities. Paper copies are also being used by multiple departments. In some cases, paper copies are used for auditing purposes and in others, paper copies are being kept until the department can transfer over to an electronic data management system. Community-level data was collected by past studies and this current research project. Much of this data was contained within technical reports, and had not been transferred to an internal database. Some technical reports were publicly available, while others were for internal use only.

2.4.4 Data reporting and sharing between departments

Data reporting refers to the coalition of internal data to meet the reporting requirements defined by internal processes, existing partnership agreements, and external agencies. Internally, each department was responsible for providing the First Nation Leadership (e.g., Hereditary Council, Chief and Council) with reports summarizing department-specific information of interest. Reporting schedules ranged between monthly and annually. Regular updates were also provided on a need-to-know basis to Council Members who held portfolios related to department operations. For example, the Council Member holding a health portfolio may request updates from the Health Centre. Information was also shared between departments. Access to data management systems was sometimes shared. An example of this included employment information being shared between the Social Assistance and Employment and Training Departments. Finally, departments were also responsible for sharing internal data with the community and individual members of the First Nation. Departments updated the community through a number of different communication channels, including a community newsletter, social media accounts, and during community events and meetings.

Data reporting requirements defined by partnership agreements and external agency processes are also in place across departments. In some cases, external funding the First Nation received included a specific reporting requirement for the release or partial release of funding. For example, the FNHA provides instructions for communities and health service organizations on financial and reporting accountabilities based on several criteria, including the funding model and type of Health Funding Agreement that is in place (FNHA, 2018).

2.4.5 Gap analysis comparing determinants of health to data collection initiatives

Determinants of health data systematically collected by each department were cross-referenced with the prioritized determinants outlined by both the First Nation’s model of health and the HIA Guidelines for First Nations in British Columbia (Tsimshian Environmental Stewardship Authority, 2018). Table 2 lists each health determinant and indicates what department (if any) regularly collects and stores data relevant to that specific determinant. Table

2 further identifies if there is a potential gap in health data being collected at the community level, related to each health determinant listed.

Table 2 ***Gap analysis of internal data collection initiatives across First Nation departments targeting specific determinants of health***

Health Determinants	**Current Data Sources by Department**							**Data Gap (Y/P/N)**
	Natural Resource Department	Health Department	Employment & Education	Income Assistance	Community Planning Program	Housing	Public Works	
First Nation's Model of Health								
Connection to the environment	*				*			**P**
Physical well-being		*						**P**
Mental wellness		*						**P**
Supporting improved capacity			*					**P**
Community Cohesion					*			**P**
Sustainability of food sources	*				*			**P**
Community leadership & economic development	*		*					**P**
Importance of family				*				**P**
HIA Guidelines								
Demographics			*	*		*		**N**
Access to traditional land and resources	*				*			**P**
Engagement in traditional practices	*				*			**P**

Health Determinants	**Current Data Sources by Department**							**Data Gap (Y/P/N)**
	Natural Resource Department	Health Department	Employment & Education	Income Assistance	Community Planning Program	Housing	Public Works	
Cultural continuity	*				*			**P**
Gender			*	*				**P**
Food security	*	*			*			**P**
Community infrastructure							*	**N**
Access to health and social services		*		*				**P**
Health behaviours and awareness		*			*			**P**
Housing, living in urban/rural areas						*		**P**
Education, employment, and income			*	*				**P**
Barriers to self-determination					*			**P**
Language								**Y**
Sense of belonging					*			**P**
Environmental Stewardship	*	*						**P**

Community-level data was collected on most health determinants identified as important to the First Nation and by recent literature on indicators to include when conducting HIAs for First Nation in BC. A ‘partial’ descriptor was given across most determinants to highlight opportunities for improving and expanding current community-level initiatives. ‘Partial’ designations identified gaps related to the following observations: (1) data sets were missing, unavailable, or not representative of current conditions; (2) data collection strategies were unidentified/unknown; (3) data sets were not undergoing analysis and reporting for trends over time; and (4) data sets are not representative of different population groups (e.g., stratified by place of living, age and gender where appropriate). The gap analysis determined community-level initiatives are not collecting data on one health determinant (i.e., language). This may be the result of a true gap in data collection at the community level and/or that the initiatives were not identified during interviews with key informants.

2.4.6 Limitations

The extent to which findings from case study research can be 'generalized' is commonly raised as an underlying limitation. Findings from this research cannot be generalized across First Nations; nor should it. Advancing HIA approaches will require an HIA practitioner to understand how the diversity of populations informs HIA processes and outcomes. This case study demonstrates the availability of pre-existing and culturally-specific data and information at the community level that, if used, may enhance HIA scoping processes and community profiling. Although each community will differ, the default of drawing from regional data sets may be outdated if meaningful partnerships can be established between HIA practitioners and project-affected communities.

Impacts on research activities from the COVID-19 pandemic may have also contributed to limitations in these findings. Travel restrictions were in place in B.C. during the timing of this study, and the findings from this research were reported to the First Nation virtually, rather than in-person, which may have limited the amount of feedback and response received.

2.5 Discussion

This case study highlights several on-going data collection initiatives that have been launched by one First Nation in B.C. Further analysis identified gaps across health determinants, suggesting there is an opportunity for enhancing data quality by improving local-level initiatives. By making educated modifications when Western theories or methods are deemed inappropriate, practitioners can challenge some standards of practice that are common across HIA (and EA) processes, ultimately improving these processes to better serve Indigenous communities. (Datta, 2018).

When working alongside First Nations, HIA practitioners in Canada will benefit from re-evaluating how their professional practice can be improved. One approach to consider is applying a decolonizing lens, which emphasizes the worldviews of non-Western individuals in practice (Battiste, 2000; Datta, 2018; Smith, 2012). Drawing from theories of decolonization, Thambinathan and Kinsella (2021) outline four decolonizing practices, including embracing 'other(ed)' ways of knowing, which describes ‘unlearning and re-imagining how we construct, produce, and value knowledge’ as integral to decolonizing research (n.p). By considering such approaches, practitioners can explore alternative methods that may enhance their work with Indigenous communities.

This current study highlights an underlying HIA principle, which acknowledges the importance of *taking a comprehensive approach to health* when conducting an HIA (IFC, 2012). When completing HIAs in collaboration with First Nations, a comprehensive approach to health can involve centering a community’s voice as it relates to their understanding of community health and wellness. By working collaboratively with First Nations, community models of health (if available), including health determinants prioritized by the community, can directly inform and improve the HIA process and associated activities.

Traditionally, HIA activities are informed by social determinants of health models developed from a Westernized approach and cannot often characterize factors that influence

Indigenous health and wellness (Hackett et al., 2018; Robin et al., 2016). Further, critiques of conventional HIA note how an assessor may be biased in assigning preference to physical aspects of health (e.g., infectious disease incidence rates and injuries) compared to other determinants of health that are important to First Nation populations (e.g., environmental stewardship, cultural continuity, and self-determination), due to perceived difficulties in quantifying and measuring the latter (Denny-Smith & Loosemore, 2017; Loppie & Wien, 2022; Robin et al., 2016; Westman & Tara, 2019). The appropriateness of applying a quantitative lens to social inquiry is questionable in some cases and being able to contextualize potential impacts from an Indigenous health perspective will undoubtedly require community partnership, the centering of Indigenous knowledge, and the collection and analysis of qualitative data to contextualize. An instance of centering Indigenous perspectives on health and well-being into the HIA process is demonstrated by the recent screening and scoping phase of the Mount Polley tailings dam failure. The report detailed qualitative data on impacts described by twenty-two participating First Nations, including impacts to their traditional territory, individual fishing practices, commercial fisheries, emotional stress, and increases in community-level administrative burden. (Shandro, Winkler, Jokinen & Stockwell, 2016).

When deciding which health areas to scope into an assessment involving First Nations, this case study does not attempt to provide a ‘cookie-cutter’ template that can be applied to any community. Rather, it provides an example of priorities identified by **one** First Nation. Given the diversity across communities, a cookie-cutter approach to HIA is far from ideal and meaningful participation and partnership are needed to frame HIA approaches. However, findings from this case study **do** illustrate a roadmap forward for HIA practitioners. For example, a First Nation may not have a model of health to inform HIA scoping and health profiling activities. Arguing alongside Jones and Bradshaw (2015) and Lawrence et al. (2017), this current research recognizes that communities possess valuable insights and unique perspectives about their own health and wellness. It further emphasizes that the identification of community health indicators for inclusion in an HIA should always be led by the community.

2.5.1 The data dilemma for HIA practitioners

The standard practice of using regional-level health data to establish community health profiles (and measure health risks) for First Nation affronted by a proposed development project is inappropriate and outdated (Meuter & Jokinen, 2023; Shandro & Apps, 2022). This case study demonstrates data collection initiatives may be present at the local level and communities may possess information on a wide range of health and determinants of health-related topics. Nevertheless, it would be premature to presume that HIA practitioners will be authorized to review and integrate pre-existing community data into their assessments.

Current approaches to EA data collection practice, particularly those required by government institutions or financed by industrial development proponents, can resemble what is known as ‘parachute research’. Parachute research occurs when outsiders (often consulting firms) ‘parachute’ into a community, collect information for their assessments and depart. These types of actions further contribute to academic-community power dynamics, and deprioritize Indigenous community’s participation in research processes and interpretation of findings (Tobias, Richmond & Luginaah, 2013; Smith, 1999). Unregulated impact assessment practice has the potential to do real harm to individuals and communities. This is especially disturbing when practitioners lack appropriate credentials (e.g., a practitioner conducting an HIA for a First Nation who does not hold a background in health or has direct experience working with Indigenous populations) to lead these types of assessments. For example, practitioners may have no direct experience working with Indigenous Peoples, lack cultural sensitivity, and are unfamiliar with applying ethical considerations, particularly those specific to Indigenous data sovereignty, to their assessment methodology. Although the IA process at both the federal and provincial levels reference the importance of integrating Indigenous knowledge into the assessment process, no well-defined methodological approaches to the ethical use of data are provided.

When clear guidance is lacking, it becomes essential for HIA practitioners to undergo thorough training (this is especially true for the topic of Indigenous data sovereignty) before engaging with First Nations or requesting access to community-level data. This training is crucial to prevent any unintended harm to the very communities the field of HIA is meant to safeguard.

2.5.2 Ethical use of data and OCAP® principles/data sharing agreements

Data sovereignty asserts the rights of Indigenous peoples to govern their data. To ensure these rights are upheld, the First Nations Information Governance Centre (FNIGC) developed a set of guidelines for Indigenous data governance in 2002 (Schnarch, 2004). Ownership, Control, Access, and Possession (OCAP) Data Principles® are not a doctrine or a prescription. It is a set of principles that reflect First Nation commitments to use and share information in a way that brings benefit to the community while minimizing harm. It is also an expression of First Nation jurisdiction over information about their own communities (FNIGC, 2014, p. 5).

Ownership asserts that cultural knowledge/data is held, or owned, by the First Nation collectively. *Control* refers to the right of First Nations to exercise control over all aspects of their life, including research being conducted in their communities. The principle of control extends to the entire research process, including how data is collected, stored, managed, disclosed, and destroyed. *Access* requires that First Nations are able to access their data regardless of where it is being stored, and can determine who can access their collective information. Finally, *possession* refers to the mechanism that places First Nation data within a First Nation jurisdiction, which enables ownership and control. This is particularly important when mistrust is present (e.g., the misuse of data can occur when the owner does not possess the data) (First Nations Information Governance Centre, 2022; Centre for Aboriginal Health Research, 2013; Schnarch, 2004). OCAP asserts First Nations have an inherent right to govern their data and information, and ensures that data collected about First Nations is used ethically and respects community priorities and cultural protocols. The data principles also safeguard against exploitation, support self-determination, and help build trust between researchers and community partners (First Nations Information Governance Centre, 2024).

To date, the application of OCAP data principles within the field of IA is minimal despite the recommendation by provincial and federal IA guidelines to integrate traditional knowledge. Without data safeguards, First Nations and other Indigenous groups are vulnerable to the further exploitation of their intellectual property. The establishment of a mutually-agreed upon data sharing protocol (commonly referred to as a ‘data sharing agreement’) can help outline how OCAP principles will be addressed by both the HIA practitioner and community across the HIA process (Harding et al., 2011).

2.5.3 Reimagining HIA data needs and promoting community benefits

Moving away from practice that resembles ‘parachute research’, proponents, government and HIA professionals can reconsider what meaningful engagement and community participation means to the HIA process. There is a great opportunity for those who organize HIAs to work with First Nations to identify community priorities and enhance community-based data collection initiatives. Although HIA utilizes health and determinants of health data to establish health profiles for affected communities, identify indicators, and assess the risk to community health and wellness related to a proposed industrial project, communities can also be the recipients of tangible benefits when good HIA practice is conducted. For example, HIA practice in B.C. has led to the development of community-based health monitoring programs for two First Nations. The programs annually collect household-level data on determinants of health that are prioritized by each Nation. As a result, communities manage the data collection process (including identifying data priorities, methodologies, analysis, and reporting) and assert control over what data (if any) they share with proponents, government, and HIA practitioners. Community-based monitoring programs not only meet the requirements for the monitoring components of an HIA (and IA) process, but the data and information also informs health planning resource development, the application for external grants, the development of health services and programs and a pathway for community members to provide direct feedback to leadership (Meuter & Jokinen, 2023).

2.6 Conclusion

In conclusion, the global field of HIA asserts Indigenous populations are often increasingly vulnerable to the negative effects associated with industrial development projects, compared to non-Indigenous populations. Across Canada, there is a rising interest in HIA as a tool to identify and mitigate adverse effects on community health and wellness experienced by rural and remote First Nations. However, a cookie-cutter approach to HIA is not ideal, particularly when HIAs involve First Nations. Through partnering with communities, HIA practitioners are better suited to identify community-level data that can improve HIA processes and reimagine how HIA activities can be developed to better safeguard community health and wellness.

2.7 Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Chapter 3. Challenges and opportunities in community-level data collection initiatives: a case study from a First Nation in British Columbia

Chapter 3 is adapted from a manuscript prepared for submission to the International Journal of Indigenous Health. The formatting remains similar to the requirements outlined by the journal.

3.1 Abstract

Across Canada, First Nations experience significant challenges when it comes to accessing comprehensive health data that accurately describes the conditions in their communities. Drawing upon a postcolonial theoretical framework and applying a community-based participatory research approach, this paper presents a case study that explores the internal challenges, as they relate to data collection and management, experienced by Department and Program Managers working for a First Nation in British Columbia. Through qualitative analysis several key themes emerged, including enhancing skills related to data collection and management, challenges of workload and time management, reactive versus proactive data collection, and issues with community buy-in. Study findings emphasize the importance of First Nations controlling their internal data governance processes and building capacity for sustainable data management practices.

Keywords: *Community-level Data, First Nations, Indigenous health, Health Monitoring Programs, Qualitative data, Community-based Participatory Research, Data Sovereignty*

3.2 Introduction

In Canada, determinants of health data describing rural and remote First Nation communities are characterized as inconsistent, poor quality, and often fail to capture unique community health conditions at the local level (Jokinen & Meuter, 2022; Wright et al., 2022). This lack of comprehensive health information can lead to a significant underestimation of the health inequities experienced by First Nation populations (Smylie & Firestone, 2015). Improving data quality, as described by Article 19 of the *Truth and Reconciliation Calls to Action*, is crucial for addressing long-term trends and narrowing the gap in measurable health outcomes between Indigenous and non-Indigenous populations (Truth and Reconciliation Commission of Canada, 2015). The discussion of Indigenous data must extend beyond the topic of data quality improvement. Indigenous data sovereignty, as described by Kukutai (2023), is "a rallying cry for Indigenous communities seeking to regain control over their information while pushing back against data colonialism and its myriad harms" (n.p). Supported by the United Nations Declaration on the Rights of Indigenous Peoples (UNRIP), the declaration affirms the rights of Indigenous Peoples globally to access and manage data related to their communities, territories, ways of life, and traditional resources (United Nations, 2007). Asserting control over health data can ensure community health information is used in a manner that supports their values and priorities. Values-driven community data provides First Nations with 'important information about how people define what health means, their health priorities, and preferred actions to maintain or improve health' (Donatuto, et al., 2019, pp. 158). Community-level data is not only important for addressing health priorities but also for evaluating services and informing health planning initiatives. (Nsubuga, et al., 2006; Kukutai & Taylor, 2016; Jokinen & Meuter, 2022). Jagosh et al. note that health programs and interventions are most successful when developed collaboratively with the communities they serve and access to community-level data can help inform the development process (2015).

First Nations have a long-standing history of being concerned about how industrial development projects in their territory and region affect the health and wellness of their community members. The environmental assessment (EA) process in Canada, both federal and provincial EA processes, have been criticized for their inability to identify and mitigate effects on First Nation health and wellness (particularly to the social determinants of health) when an industrial project is being proposed (Shandro et al., 2017; Brisbois et al., 2019; Myette & Riva, 2021). One criticism includes the inappropriate use of data to establish health profiles, identify potential community health effects, and develop mitigation strategies. Due to the lack of publicly available community-specific data describing First Nations, EA applications submitted by proponents of industrial projects often rely on aggregated data sets (often regional in scope) to describe the health landscape in rural and remote First Nation communities. When discussing the concept of 'data' in relation to First Nation health and wellness, the conversation often centers on the historical injustices and misuse of data by non-Indigenous entities for political purposes. The collection and utilization of data has largely been determined by individuals who live outside First Nation communities (Otim et al., 2015). However, data collected by and for communities to address their own health and wellness priorities helps reshape the discourse by challenging the status quo. Western approaches to the selection of indicators (as reflected by regional health data sets across the province of B.C) may not accurately describe community health conditions. As Fox (2018) notes, "The key difference between scientific indicators and indigenous indicators is not the metrics and techniques used to define them. It is the principles that guide their development and the focus and perspectives included in their interpretation. Communities need to choose their own indicators to contextualize their data sources and become their own storytellers." (p. 5).

In British Columbia (B.C.), Canada, about half of the Indigenous population, encompassing First Nations, Inuit, and Métis peoples, in the province inhabit rural and/or remote communities

(BC Government, 2016). First Nation communities interface regularly with proposed and/or active industrial development, yet there is no mechanism in place to track and monitor how projects affect community health conditions over time. In response, many First Nations are now leading the impact assessment (IA) process, whether it be through their direct participation in the formal federal or provincial environmental assessment (EA) process or leading their own community-driven IA work (Hoogeveen, Brubacher, Leduc & Lou, 2022). For example, two First Nations in B.C, Gitga’at First Nation and Kitselas First Nation, have successfully established health baselines for their communities on determinants of health they prioritize. These initial efforts then led to the establishment of community-based monitoring programs operating annually. Data and information collected by the programs allow the Nations to better identify how a specific project will impact their community and make informed decisions when engaging with government agencies and private-sector proponents (Jokinen & Meuter, 2022; Meuter & Jokinen, 2023; Shandro & Apps, 2022).

Community-driven IAs are being led by First Nations to ensure community health risks related to industrial development are identified, captured, and mitigated appropriately. To understand the effects industrial development activity has on communities, “a spectrum of qualitative and quantitative information, attention to experience-based knowledge as well as scientific data and interdisciplinary and culturally informed perspectives” are needed (Arnold et al., 2023, p. 40). One critical aspect of the initiatives described above is that both First Nations own and control all data collected, which directly supports Indigenous data sovereignty (Jokinen & Meuter, 2022; Shandro & Apps, 2022). As these types of community-based monitoring programs continue to expand, there is a growing need for more information to better comprehend the capacity needs at the local level, which will further support their development and successful implementation in other communities. This current study aims to explore and answer the following research questions: (1) what challenges do First Nation Department and Program Managers experience when collecting and managing community-based health (and determinants of health) data?; and (2) what internal strategies can be supported to improve data collection at the local level?

3.3 Methods

3.3.1 Theoretical approach

This research applies a postcolonial theory to each phase of a community-based participatory research (CBPR) approach. Postcolonial theory emphasizes "race as a social construct, and ways in which racism and social processes are linked to colonial practices that adversely affect health outcomes, examining social justice and ways in which power relations are created, maintained and can be changed" (Schill et al., 2019, p. 864). The term 'postcolonial' used in this study is in reference to the term defined by Browne et al. (2005), which acknowledges colonialism, and its impact, as on-going. This approach recognizes that through this on-going process, colonialism continues to impact the social, economic, and cultural lives of Indigenous people across Canada and the world (Smith, 1999). This theoretical approach challenges existing and inherent power dynamics between researchers and communities, by upholding participants as experts on their own communities and lives.

This study established a research partnership with the community, aiming for mutual benefits and reciprocity. CBPR is "predicated on trusting, reciprocal partner relationships, shared control over research projects, collaborative leadership and decision making, and methods, analysis, and dissemination planning that utilizes multiple forms of knowledge" (Gokiert et al., 2017, p. 1). CBPR aims to build trust between researchers and communities, equalize power differences within the research process and emphasize the importance of authentic participation of those who represent the study population (Harding et al., 2012). CBPR advantages can include: (1) empowering communities to examine their own priorities and participate in developing solutions; (2) bolstering cross-cultural learning opportunities through the bi-lateral exchange of knowledge and training; (3) drawing skills and knowledge from members of the community; (4) involving an iterative and cyclical process; (5) using project funding within the community; (5) encouraging the translation of findings to all potential knowledge users; and (6) enhancing trust and fostering long-lasting relationships between researchers and the community (Drawson, Toombs & Mushquash, 2017; Harding et al., 2011; Holkup et al., 2004).

The objective of this study aligns with current health priorities identified by the partnering First Nation and methodological procedures have been developed in collaboration with First Nation representatives and a community-based coordinator (CBC). The CBC directly assisted with participant recruitment and data collection and provided oversight and feedback during data analysis. Prior to initiating the research, a research agreement (including a data-sharing agreement) was reviewed and agreed upon between the lead author and First Nation representatives. The data-sharing agreement outlines the protocols for how data used by this research is managed, shared, and protected. The agreement is designed to ensure transparency and respect for the community's control over their information and specifies the conditions under which data can be used and shared, emphasizing the importance of the internal review process. Additionally, this study was approved by the University of Victoria's Research Ethics Board. A community report detailing the findings of this study was workshopped and reviewed with the partnering First Nation to ensure the accuracy of research findings.

3.3.2 Statement of positionality

The colonial context of academic research and impact assessment practice conducted with Indigenous communities represents a history of power inequality. There are an overwhelming number of research examples that have been conducted on, rather than with, Indigenous populations (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences, and Humanities Research Council of Canada [SSHRC], 2014; First Nations Information Governance Centre, 2014). The dehumanizing approach to conducting research *on* Indigenous Peoples is not isolated to the past, nor is it isolated to the academic research community. As a general practice, impact assessments which are mandated (either through the provincial or federal EA processes) have been criticized for failing to (1) establish meaningful relationships with Indigenous communities (although it can also be argued Indigenous communities should be positioned as leaders, not merely 'included' or 'engaged with'); (2) evaluate project-related effects through the analysis of data that reflects true community conditions; and (3) integrating comprehensive and holistic approaches to health as defined by project-affected communities (Harvard Law School, 2010; McGregor, 2021).

I identify as a cis-gender female white settler with strong ties to my mother's and father's third-generation Finnish-Canadian settler heritage. I was born in the community of Thunder Bay, Ontario, on the traditional territory of the Anishinabek, which includes the Ojibwa of Fort William First Nation, signatory to the Robinson-Superior Treaty of 1850. Throughout my personal, academic, and professional career, I have had the opportunity to visit and reside in rural and remote communities across the country. For the past thirteen years, I have been a visitor on the traditional territory of the Coast Salish peoples, in Parksville, British Columbia.

As a non-Indigenous researcher and HIA practitioner, I have been involved in community-based research investigating the relationship between industrial development and impacts to Indigenous health and wellness for the past eight years. I express my profound appreciation as a white settler to participate in this type of work and I recognize the uneven power relations embedded between these two roles and the communities that I work with. Affiliation with an academic institute and their current systems may lend to colonial relationships being sustained and reproduced. As an HIA practitioner, most of my work is contracted by Indigenous communities who commission their own impact assessments. My intent is to advance discussions on how the HIA process can be re-imagined to better serve communities who disproportionately bear the burden of industrial development project-related risks and impacts. I acknowledge that building meaningful relationships with communities makes this type of work possible, and in no way do I claim to represent or ‘speak’ for the First Nations and individuals with whom I partner.

3.3.3 Study design

An instrumental case study, which provides detailed insight into an issue, was used to better understand local-level data management challenges experienced by staff working for a First Nation (Stake, 1995). This approach was chosen since it can help facilitate the exploration of complex issues related to community-based monitoring programs and data management in the “real-world” settings in which they are implemented. In taking such an approach, the research findings will be more relevant and useful to the Nation and involved staff. In contrast to traditional research designs, which aim to test a set hypothesis or intervention, a case study approach allows researchers to capture information about the ‘how’, ‘what’, and ‘why’ of different issues (Crowe et al, 2011). An instrumental case study approach, which aims to gain a broader appreciation of an issue or phenomenon by focusing on a single case was selected, as the flexibility allows for the researcher to gain a deeper understanding of the community’s unique challenges, as well as their inherent resiliencies and strengths. It also allows for exploring how the findings from this study can inform strategies for other First Nations who experience similar challenges when it comes to community-level data collection and management (Creswell, 2011; Crowe, 2011).

3.3.4 Anonymity of partnering First Nation

To report on this research, the partnering First Nation wished to remain anonymous. The First Nations Information Governance Centre notes that the “recognition of collective privacy interests is based upon the principle that groupings of people, and not just individuals, have an interest in controlling access to information, particularly sensitive information, regarding that specific group or communities” (First Nations Information Governance Centre, 2011, p. 12). By identifying the First Nation, negative impacts may result if the information is reported and used by external stakeholders outside of the intended purpose and context of the research. Collective privacy interests were acknowledged upon discussion with representatives of the First Nation and the removal or generalization of identifying information has been done including specifically naming the First Nation and geographic locations, community references, department names, and culturally-specific health terms. This process also included a search of publicly available information linking the lead author to the First Nation, which resulted in no affiliations found and/or reported. The final draft of this report was distributed to the partnering First Nation for their review. In summary, anonymity in this context serves as a safeguard to protect the community's privacy, autonomy, and safety while still allowing them to participate in and benefit from the research.

3.3.5 Participants and recruitment

Participants were recruited using a purposeful sampling method, by which ‘information-rich’ groups are identified and selected for recruitment (Palinkas et al., 2015). This process involved identifying and selecting individuals who are especially knowledgeable about or experienced with the topic of interest (Creswell & Plano Clark, 2011). Department managers working for the First Nation were identified as having a rich understanding of the challenges experienced by their teams, governance, and administrative processes, as well as their community as a whole. This sampling method contrasts with random sampling procedures used by quantitative research, which is based on statistical probability theory and aims to generalize findings from a sample to the larger population.

In the fall of 2019, with assistance from the First Nation’s internal staff, all department managers were informed that a Community-based Coordinator (CBC) who was assisting with the research project would be contacting them with an invitation to participate in the project. Invitations to participate were sent to department managers via e-mail, with follow-up phone calls by the CBC who arranged interview times and locations.

3.3.6 Data collection

The interview guide was reviewed and approved by the First Nation’s Research Coordinator. The questions focused on the challenges First Nation staff members experienced when collecting and managing community-level data. When needed, probing questions were asked such as, “can you expand on what you just discussed?” or additional questions based on the participant’s previous answers. In total, 12 semi-structured interviews were conducted by the first author. At the beginning of each interview, participants were provided with an overview of the project and a consent form was reviewed and signed. Interviews lasted approximately one hour and were audio-recorded with the participant’s permission. If a participant did not want to be recorded, detailed notes were taken. During the interview, participants elaborated on challenges they experienced when collecting and/or managing data for their department.

3.3.7 Data analysis

Following the interviews, the recordings were transcribed, and a six-stage process was used to analyze the interviews and identify key themes: (1) becoming familiar with the data through reading transcripts as well as the first author’s notes, (2) generating codes, (3) generating themes, (4) reviewing themes, (5) defining and naming themes, and (6) identifying key examples or quotes (Braun & Clarke, 2006). Following the analysis, interview data was summarized and a findings report was presented to the First Nations’ Research Coordinator by the first author for review and confirmation.

3.4 Results

Four interrelated themes emerged from the data, which include enhancing skills related to data collection and management, challenges of workload and time management in data collection, reactive vs. proactive data collection, and issues with buy-in. Overall, these themes position the knowledge, capacity, and buy-in of staff as critical elements that support the management of community-level data. Although findings seem to focus on challenges and barriers that Department and Program Managers experience when conducting data collection and management, these thematic areas can also be viewed as “levers” through which advancement and improvements can occur. Each theme is discussed in the following sections.

3.4.1 Enhancing skills related to data collection and management

Across departments and programs, First Nation staff require comprehensive training to support the successful implementation and maintenance of community data collection and health monitoring initiatives. For example, one respondent indicated "*I know that there's still stuff that I need to learn about the system. But when we learned about it, it was very quick and dirty, like, we need to get this going now."* Capacity constraints impact all elements of data and monitoring initiatives at the local level including data collection, maintenance (e.g., updating databases, ongoing data entry, etc.), as well as reporting and sharing information across departments (e.g., ensuring data is presented in usable products). Many participants noted the level of knowledge of data collection and management systems was limited in some cases and identified the need for further training within their specific department or program. As one participant stated, *"We have a problem finding skilled workers."* Learning how to use software programs for data management, such as Excel, is challenging for some staff who do not have experience, and substantial support is needed during training. Further, high turnover rates of staff required training to be ongoing and happen in coordination with other priorities. Some participants noted the limited training they received was not comprehensive and additional knowledge is needed to effectively enter their department data regularly.

3.4.2 Challenges of workload and time management in data collection

The collection and management of community-level data is a process involving continuous updating, oversight, and general management. This process is timely and requires additional resources to ensure high-quality data is appropriately inputted and 'cleaned' when required. Prioritizing data entry and record keeping is challenging where other, more urgent priorities require attention. Many participants shared that they were already extremely busy. As one participant put it bluntly, *“There's a lot to do around here. Yes. I'm busy.”* When it comes to prioritizing data entry and management, Department Managers recognize it can be difficult given the number of other tasks they are required to complete. For example, one participant shared "*The record keeping…it is trying to keep on top of it, you get sidetracked and do something else and it gets dropped*.” Internal capacity was noted as a barrier to the collection and management of community-level data across departments. When considering the overall capacity of the Nation, one Department Manager shared *“... people are way too busy. And there's not enough time. As a whole, the Nation is understaffed.”* Some Department and Program Managers also described feeling overwhelmed by the workload associated with one specific task related to data collection and management: transferring community-level data from hard copy formats to electronic databases. As one participant noted, *“Yeah, man-hours [is a challenge], for sure.”* Not only would this process take hours to complete, but as previously discussed, the level of internal capacity to address this process was deemed to be limited. Additionally, the tasks associated with data collection and management may not always be perceived as engaging or stimulating by First Nation employees. This can impact an individual’s overall motivation to perform the required data collection and management tasks. In the words of one participant, *“I wasn’t so used to sitting behind a desk. Yeah, you get used to it but I'd rather be outside. It took a long time and I’m still learning [to enter things into a computer].”*

3.4.3 Reactive vs. proactive data collection

Department and Program Managers reported a reactive approach to data collection is more common than a proactive approach. What this means is that community data is often collected in response to external requirements, such as funding or project-driven requests. These types of project-related requests typically have limited scopes, timeframes, and available funding that prevent long-term initiatives from being implemented. Rather, data collection is considered a 'one-off' to meet a specific objective. Further, the data collected is often incomplete and stored in silos based on the project type and affiliated department. Participants shared their experiences receiving requests for data on tight timelines and indicated that this is a source of frustration, "*Is that it's like, it's a sudden thing. And we have to do it. Like, they'll call you Monday. And on Tuesday, we're coming out and we have to get this in a day."*

3.4.4 Issues with the buy-in by community members

According to study participants, encouraging community members to participate and provide information during data collection activities is one of the biggest challenges when conducting this work. As a result, certain populations and subgroups of the community are not represented. For example, during any type of health initiative, particularly events where data collection is involved, one participant noted it is always challenging to get Nation members to participate. Often, the same people will participate, therefore there is always a proportion of the population who is not represented at the events (or by the data that is collected). One participant shared *"I think one of the main challenges is really just trying to get people out to get people to respond."* Research fatigue and feelings of being "over-studied" are common in First Nation communities and represent a significant challenge to data monitoring initiatives. A major barrier discussed by participants was a lack of trust from community members when it pertains to research activities, including data collection. In the words of one participant *"… I think a lot of it just sort of has to do with trust. It's, it's not only I feel like people are learning to trust me more now. But then it's also just learning for themselves to trust that they're not going to get in trouble if they say something. Where I think there's a lot of fear around like, some type of repercussion if they speak their mind. So that sort of limits a lot of people from speaking out in public anyways."*

In addition, data collection activities at the community-level may be interpreted unfavourably by individuals in the community who have experienced the adverse effects of colonialist policies and practices. As one participant shared *"I remember my grandfather, who was First Nations telling me he didn't trust men in suits. And I think there could be some cultural things like, because it is a federal government program. There can be issues with the buy-in."*

3.5 Limitations

While case studies are often utilized in academic research and are viewed as valuable tools for providing in-depth insights into specific phenomena, they also hold limitations when establishing generalizability. Generalizability relates to the extent to which findings and conclusions deduced from a study can be applied or generalized beyond a sample or setting examined (Crowe et al., 2011). Critics argue that generalizability is difficult to obtain in case study research as a case study is often defined as "the study of the singular, the particular, the unique, whether that single case is a person, a project, an institution, a programmes or a policy (Simons 2015, p.175). However, Blaikie (2002) asserts it is possible to generalize from case studies, depending on which cases are selected, and Flyvbjerg (2006) notably made a similar argument, emphasizing that single cases, when strategically selected, can provide valuable insights and contribute meaningfully to scientific development. Generalizing findings may be appropriate if the cases studied can be shown to be 'comparable with other cases in terms of relevant characteristics' (Priya, 2021, n.d.) This current case study included interviewing Department and Program Managers from a First Nation located in B.C., Canada. Although governance structures across communities may differ (e.g., traditional versus elected Indian Act Band Council governance structure or some adapted contemporary form), communities typically have internal departments that manage the day-to-day operations and services available in-community. Further, a lack of internal capacity has been reported as a limitation many rural and remote First Nation communities experience (Trevethan, 2019). Therefore, it is argued that findings from this case study may be similar if repeated for other First Nations.

Additionally, as a non-Indigenous researcher and ‘outsider’ of the community, my own biases must be raised as a limitation. To minimize bias, I took several steps. First, as a qualitative researcher, I continually reflected on my assumptions and values that could influence the research process, including data collection and analysis. Second, real-time member checks were conducted with participants during the interview to ensure I was interpreting the information they shared with me accurately. Third, an external review of my work was completed by representatives from the First Nation and I solicited and integrated their feedback into final study documents.

3.6 Discussion

In Canada, health data on Indigenous populations is frequently cited as inconsistent, of poor quality, and inadequately representative of actual conditions in communities (Jokinen & Meuter, 2022; Wright et al., 2022). Through the development and implementation of community-led data initiatives, First Nations can assert sovereignty over their data and information, which emphasizes the rights of First Nations to govern the collection, ownership, and use of their data. Other benefits of initiating or improving community-level data collection include supporting evidence-based decision-making across First Nation leadership and staff, supporting self-determination through data sovereignty, improving the development of health planning resources, ownership control access possession, and monitoring new and emerging health risks (Jokinen & Meuter, 2022; Kukutai & Taylor, 2016).

Research findings from this current study highlight challenges associated with community-level data collection and management experienced by Department and Program Managers working for a First Nation in B.C., Canada, and provide critical insights into barriers and opportunities for First Nation-led community data initiatives. Key challenges identified through the qualitative analysis relate to internal capacity and factors impacting the participation of First Nation members in data collection activities.

Improving internal capacity, including staffing resources, is an issue facing Indigenous and non-Indigenous communities that are geographically situated in rural and remote locations. As Bob Joseph (2017) notes, one potential solution includes leveraging current partnerships to access capacity funding to meet the needs of the First Nation and an external partner. When it comes to the duty to consult (when industrial projects are being proposed within First Nation territories) and community-level data, there is an opportunity to request that direct funding be provided by a proponent to support environmental assessment activities (including monitoring). Increased funding can be used to hire additional employees and improve data collection initiatives across departments.

Improving internal capacity will likely involve more than merely accessing external funding. Establishing strategic partnerships with private sector experts and university-based researchers to develop and support the implementation of a community-level data collection initiative may provide opportunities to enhance internal capacity. Additionally, on-going collaboration with regional health authorities and academic institutions provides increased access to training programs that help bolster community capacity in the future. First Nations may consider facilitating access to targeted training programs for interested members to gain knowledge and skills related to data management, including collection, storage, and the principles of data sovereignty.

Findings from this study also indicate that training programs for community-level data initiatives should focus on expanding internal competency with data entry, management, and reporting, as well as how to use basic computer software programs (e.g., Microsoft Word, Excel, and PowerPoint). Internal training for health data initiatives is highly context-specific and should be customized and designed based on the community's unique priorities and the needs of its staff. This includes understanding the community's overall level of access, comfort, and familiarity with technology and digital instruments (e.g., computers and tablets), and designing data collection policies and procedures that build off existing strengths, meet the community's needs, and address any privacy concerns.

When staff are highly skilled, competing priorities and time constraints in the workplace are barriers to effective data collection (and entry). To address this barrier, data-related tasks must be realistic, and effectively consider staff's pre-existing responsibilities. In some cases, the creation of dedicated roles for data collection initiatives may be required.

Findings from this study also indicate that when designing community data collection tools, careful consideration must be made to ensure communities are not overburdened by frequent and repeated data collection efforts. Historical and ongoing exploitative and unethical research practices have contributed to a significant level of mistrust in First Nation communities concerning data collection initiatives (Oster & Lightning, 2022). Research fatigue is a phenomenon that occurs when First Nations are repeatedly studied, questioned, or asked to participate in research projects without clear reciprocal benefits for the community (Kater, 2022). While specific projects, departments, and external stakeholders (e.g., industry, government) all have unique data needs and requirements, data collection at the community-level should prioritize proactive and collaborative approaches and dovetail different evaluation/research needs. Initiatives such as an annual community survey can help break down silos and meet the data needs of different First Nations departments and their projects (Shandro & Apps, 2022).

The participation and buy-in of community members are essential for the success and longevity of data collection initiatives that are used to establish long-term health monitoring initiatives (Jokinen & Meuter, 2022; Meuter & Jokinen, 2023). Some procedures for improving engagement include campaigns to raise awareness of planned data collection efforts, clearly outlining the benefits and risks for participants, explanations of what data will be used for, assurance of confidentiality, compensating participants fairly for their time and input, and sharing findings back with community members. Staff training on research ethics [e.g., Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)] and confidentiality policies could work to combat mistrust and improve community members' confidence that their data will be protected. Findings also indicate that offering different formats for participation is important to meet community members where they are.

3.7 Conclusion

In conclusion, this research highlights the challenges one Indigenous community in British Columbia, Canada, experiences when collecting and managing local-level data and information. The key takeaways from this study underscore the need for specialized training programs, manageable workloads, and a more proactive and collaborative approach to data collection across departments. Additionally, it emphasizes the importance of building trust with community members and actively involving them when data is being collected at the local level. By addressing these challenges, First Nations in BC can move closer to achieving data sovereignty. Ultimately, this manuscript provides valuable insights that benefit other First Nations and offers ideas for improving community-level data collection initiatives that can help lead to better health and well-being outcomes.

3.8 Declaration of conflicting interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

3.9 Funding

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Chapter 4. Community-based health monitoring programs: An overview for First Nations in British Columbia

Chapter 4 is an information resource that has been graphically designed using Adobe InDesign. The resource is presented in its entirety to showcase the end product. The intended purpose of this resource is that it will be shared with First Nation Health Departments across B.C. and my academic and professional networks.

Community-based health monitoring programs:

An overview for First Nations in British Columbia

Prepared by Laura Jokinen and Christa Meuter

2024

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Disclaimer

The information provided in this public resource for First Nations in British Columbia is intended for general educational purposes only. It blends academic knowledge, professional expertise and real-life experiences to provide insights and guidance. Interested readers are encouraged to reach out to the co-authors if they want personalized guidance related to their own community.

What is a community-based health monitoring program?

Community-based health monitoring programs are being designed and implemented by First Nations in British Columbia to assert control and responsibility over their health information.[1] These types of annual programs support First Nations in identifying, managing, and addressing current and emerging priorities in their community. They are informed by a holistic approach to wellness and can be developed using a community's model of health. Specific determinants of Indigenous health that are prioritized by the Nation, such as access to territory, harvesting practices, rate of traditional food consumption, engagement in cultural events, and cultural continuity, are tracked and measured over time. Additionally, other important determinants of health can also be captured by a monitoring program as well.[2,3] For example, you may want to better understand the health needs in your community to improve service delivery. Alternatively, you may need community feedback on current health programs available in your region to make them better. Community-based health monitoring programs are not developed using a cookie-cutter approach, rather, they can reflect the unique characteristics, information needs and health priorities of your Nation.

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[1] Galbraith, M., Bollard-Breen, B., & Towns, D. R. (2016). The community-conservation conundrum: Is citizen science the answer? Land, 5, 37. https://doi.org/10.3390/land5040037

[2] Jokinen, L. & Meuter, C. (2022, May 4-7). Safeguarding Indigenous Coastal Communities and Marine Environments. IAIA Conference, Vancouver, BC, Canada.

[3] Shandro, J. & Apps, C. (2022, May 4-7). Health and safety is our everyday: Outcomes of community-led Indigenous HIAs. IAIA Conference, Vancouver, BC, Canada.

Annual community health and wellness monitoring program

COMMUNITY-DRIVEN

The program is community-driven and centers on community priorities that change over time.

NATIONS OWN THE DATA

All data is owned by the Nation and used for their own priorities.

COLLABORATIVE

The program requires collaboration across departments. Health is not just a priority of the health department but is the responsibility of everyone!

ENABLES RAPID RESPONSE

The program aims to adapt and successfully respond to new and emerging health priorities. As we have all recently learned with COVID-19 the health landscape can quickly change.

What are some of the benefits of these programs?

Self-determination and control over community data

Self-determination is one of the most critical determinants of Indigenous health and wellness.[4] Indigenous Peoples have an inherent right and responsibility to manage and control initiatives that impact the health and wellness of their membership.[5] Community-based monitoring programs are designed, implemented, and owned by the First Nation. Local data is controlled, stored and managed by the community (typically by the Health Department) and used to address emerging priorities.

Improving the allocation and distribution of resources

Data collected by a community-based monitoring program can identify new and emerging priorities at the community level. By understanding the health priorities your Nation experiences, financial and human resources can be appropriately allocated based on current need.[6]

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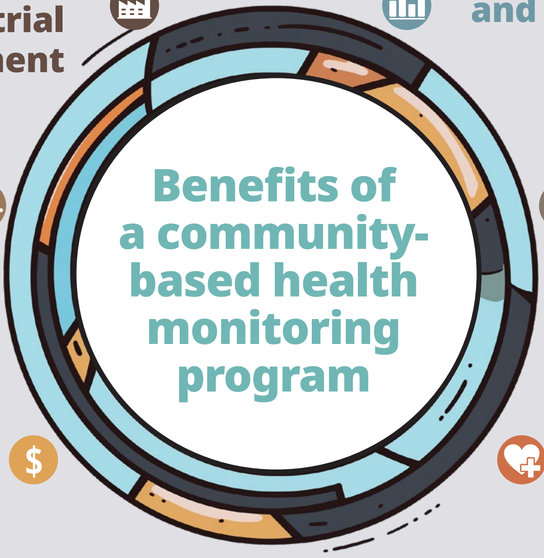
[4] Reading, C., & Wien, F. (2013). Health inequalities and social determinants of Aboriginal Peoples' health. Prince George, BC: National Collaborating Centre for Aboriginal Health.

[5] Halseth, R. & Murdoch, L. (2020). Supporting Indigenous self-determination in health: Lessons learned from a review of best practices in health governance in Canada and internationally. Retrieved from: https://www.nccih.ca/Publications/Lists/Publications/Attachments/317/Ind-Self-Determine-Halseth-Murdoch-LC-2023-06-08-VS-EN-003-WEB.pdf

[6] Shandro, J. & Apps, C. (2022, May 4-7). Health and safety is our everyday: Outcomes of community-led Indigenous HIAs. IAIA Conference, Vancouver, BC, Canada.



Benefits of a community-based health monitoring program

Enabling health risk management for industrial development

Support self-determination and control over data

Establishes a community health baseline

Improves allocation and distribution of resources

Can be used to access external funding and apply for grants

Supports evidence-based decisions making and community health initiatives

Enhancing support for Urban and Away from Home population

Informing evidence-based decision making and community health initiatives

Community-based monitoring programs establish First Nations as the owners of their health data and supports self-determination and advances data sovereignty (as outlined in OCAP® principles).[7] Data collected through these programs can support evidence-based decision making by First Nation's leadership, including hereditary Chiefs, Chief and Council and Department Managers. The programs can include a direct pathway for engaging with all members on priority topics, such as their perspective on a proposed industrial project in the territory. Additionally, information can also be shared with First Nation staff, health service providers and other agencies that are working on initiatives for the community. Community-based monitoring programs can directly inform initiatives that aim to improve community health and supports the development of health planning resources. For example, FNHA requests First Nations to develop their own Health Plans, Mental Health Action Plans and Communicable Disease Emergency Response Plans. These plans require Nations to create a vision for health and wellness, including health goals, objectives, initiatives, and evaluation activities.[8] First Nations who have implemented these programs use their local data and information to develop these types of resources.[9]

Can be used to access external funding and apply for grants

The data from community-based monitoring programs can directly inform grant and funding applications, and ensure that funds and resources are effectively allocated.

Urban and away from home: The urban and away from home population includes any status and non-status First Nations person who lives in an urban area, rural region, remote location, or isolated area, which is not in a First Nations community or reserve. People living on reserves that are located outside of a their home community are also included.[10]

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[7] The First Nations Information Governance Centre. (2014). Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance. (Ottawa: The First Nations Information Governance Centre, May 2014). Retrieved from: https://achh.ca/wp-content/uploads/2018/07/OCAP_FNIGC.pdf

[8] First Nations Health Authority (n.d.) Submitting a community health and wellness plan. Retrieved from: https://www.fnha.ca/what-we-do/health-system/community-health-and-wellness-planning

[9] Jokinen, L. & Meuter, C. (2022, May 4-7). Safeguarding Indigenous Coastal Communities and Marine Environments. IAIA Conference, Vancouver, BC, Canada.

[10] First Nations Health Authority. (n.d). Urban and Away from Home. Retrieved from https://www.fnha.ca/what-we-do/urban-and-away-from-home

Enhancing support for urban and away-from-home members

In Canada, it is estimated that over 61% of First Nation people live in urban or rural areas that are outside their home community and traditional territory.[11] Often, a person's decision to move away from their home results in the migration towards urban centres or other rural areas where there is better access to services and economic opportunities.[12] Although access to health and social services can improve when relocating to an urban area, urban and away-from-home (UAH) members can experience distinct challenges related to their health and well-being. This can include increased experiences of discrimination and racism, limited access to culturally appropriate services, and challenges in maintaining connection to traditional culture and land.[13] Unlike traditional monitoring programs led by the Federal and Provincial governments, First Nation members can participate in a community-based monitoring program, regardless of where they live. These programs can be designed to identify the health priorities of urban the UAH population and provide a pathway for engagement between the Nation and this group.

Establishes a community health baseline

Baseline data provides an initial snapshot of your community's health. Not only does this identify current health priorities, but allows for the comparison of changes to community health over time. Establishing baseline health conditions is required to understand how different events, such as the construction of a new industrial project, impacts affected communities.

Examples of the type of information a community health monitoring program can track[14]:

- Health achievements in the community
- How often people are required to travel outside of their community to access health services
- Types of cultural programming people are interested in
- How often traditional food is eaten and how people like to prepare their food
- Number of houses that require renovations to support members who have mobility issues
- What types of health programming people need in the community
- Prevalence of chronic diseases in households
- Awareness of industrial projects in the territory
- Household's health and wellness goals
- The most common factors that contribute to stress in a home
- People's health and safety concerns when accessing the marine territory
- Experience interacting with tourism/recreational users and industrial workers when people are spending time in the territory

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[11] Government of Canada (2020). Annual Report to Parliament 2020., Retrieved from: https://www.sac-isc.gc.ca/eng/1602010609492/1602010631711

[12] First Nations Health Authority (2022). Urban and Away-from-home health and wellness framework. Retrieved from: https://www.fnha.ca/WellnessSite/WellnessDocuments/FNHA-Urban-and-Away-From-Home-Health-and- Wellness-Framework.pdf

[13] National Collaborating Centre for Aboriginal Health (2012). The health of aboriginal people residing in urban areas. Retrieved from: https://www.ccnsa-nccah.ca/docs/emerging/RPT-HealthUrbanAboriginal-Place-EN.pdf

[14] Meuter, C., & Jokinen, A. (2023, September 12). Gitga'at First Nation's health monitoring program: Successfully applying innovative approaches to enhance health planning resources and outcomes. Project presented at Healing Our Spirits Worldwide Conference, Vancouver.

Enabling health risk management for industrial development

Community-based monitoring programs are also a powerful tool for Nations to monitor the health risks associated with industrial development in their traditional territory, and in the communities their members live and access services. More and more, impacts to community health are being considered by regulatory authorities when conducting environmental assessments of proposed projects in B.C. The data collected through community-based monitoring programs can inform decision making, and support assessments of the impacts of proposed or ongoing projects on community health and safety. In B.C, environmental assessments follow a standardized process which includes:[15]

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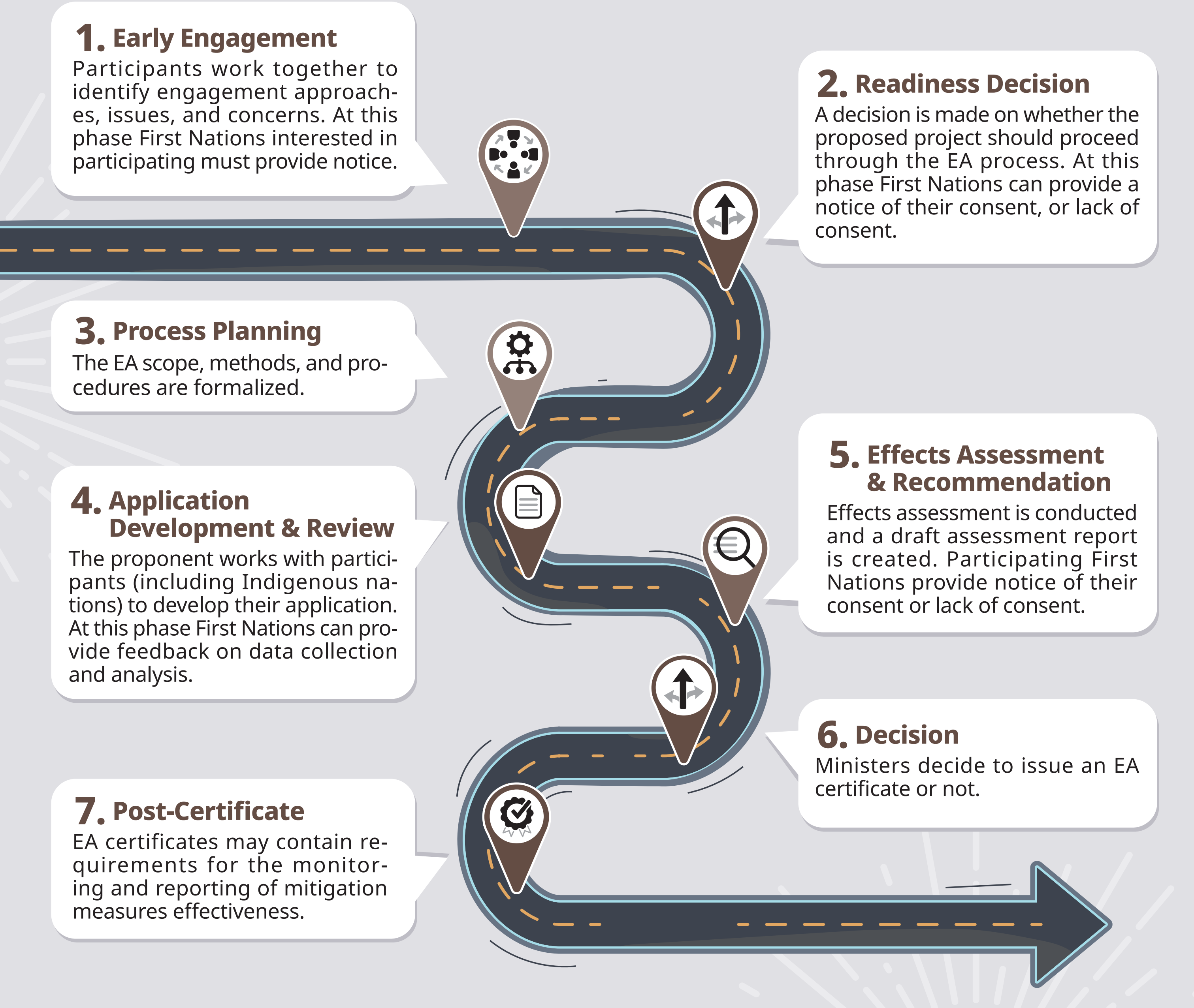
[15] BC EAO (2018). 2018 Act – Environmental Assessment Process. Retrieved from: https://www2.gov.bc.ca/gov/content/environment/natural-resource-stewardship/environmental-assessments/the-environmental-assessment-process/2018-act-environmental-assessment-process

BC Environmental Assessment Process Road Map



1. Early Engagement

Participants work together to identify engagement approaches, issues, and concerns. At this phase First Nations interested in participating must provide notice.

2. Readiness Decision

A decision is made on whether the proposed project should proceed through the EA process. At this phase First Nations can provide a notice of their consent, or lack of consent.

3. Process Planning

The EA scope, methods, and procedures are formalized.

4. Application Development & Review

The proponent works with participants (including Indigenous nations) to develop their application. At this phase First Nations can provide feedback on data collection and analysis.

5. Effects Assessment & Recommendation

Effects assessment is conducted and a draft assessment report is created. Participating First Nations provide notice of their consent or lack of consent.

6. Decision

Ministers decide to issue an EA certificate or not.

7. Post-Certificate

EA certificates may contain requirements for the monitoring and reporting of mitigation measures effectiveness.

General overview of program development and implementation

1

Acquire Funding

Identify funding sources to establish your community-based monitoring program. This may include independently funding the program or seeking external funding opportunities. Examples of funding sources include: government grants and funding programs, FNHA funding, health research grants and partnerships with private sector companies.

2

Identify Roles and Responsibilities

Determine which of your departments will manage the community-based monitoring program. Given the program is aimed at improving community health and wellness, the Health Department may be the most appropriate department to assume control over this type of initiative. Support from First Nation leadership, other departments, and members of your community will also directly contribute to the overall success of this program.[16] If internal capacity is limited, you may want to consider outsourcing the work to a contractor who has the expertise and resources to fill the capacity gaps.

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[16] Meuter, C., & Jokinen, A. (2023, September 12). Gitga'at First Nation's health monitoring program: Successfully applying innovative approaches to enhance health planning resources and outcomes. Project presented at Healing Our Spirits Worldwide Conference, Vancouver.

3 Model of Health

Developing a model of health by and for your community helps provide cultural relevancy to health and wellness initiatives and is an important first step to complete before developing your health monitoring program. Through community engagement, work with your knowledge holders and members to develop a model which reflects your cultural values, beliefs and traditions. Your model of health provides a framework for understanding the priorities in your community and guides the data collection process.

> "An Indigenous model of health is a holistic framework rooted in Indigenous worldviews, knowledge systems, and cultural practices that addresses the physical, mental, emotional, spiritual, and cultural dimensions of health within Indigenous communities."[17]

Indigenous determinants of health to consider when developing your model of health:

- Connection and sustained access to traditional territory and food
- Engagement in traditional practices (e.g., hunting, fishing, medicines)
- Cultural continuity
- Gender
- Food security
- Community infrastructure
- Access to health and social services
- Health behaviours and awareness
- Housing
- Education, employment and income
- Economic resources your Nation has a responsibility to manage, share, and sustain for future generations
- Colonial policies and practices
- Racism and social exclusion
- Barriers to self-determination
- Traditional language
- Spirituality, ceremonies, traditional teachings
- Sense of belonging
- Environmental stewardship[18]

4 What type of data is your community collecting?

Using determinants that are important to your community as a guide, work with department and program managers to identify pre-existing data that is being collected by your community. For example, you can ask your Housing Department Manager what information they collect annually. Pre-existing housing data may include number of homes in the community, number of people on the housing waitlist, and number of houses in need of major repairs. This process may include speaking with First Nation staff directly, reviewing community reports (e.g., 5-Year Health Plans, Traditional Land Use Studies, and Communicable Disease Response Plans) and understanding research

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5 Identify the gaps in your data

Complete a gap analysis that identifies any information that is missing. This step includes comparing your model of health with the pre-existing information you have reviewed. For example, if your community considers traditional food security an important determinant of wellness, does your Nation have any information on this topic? If not, then there is a 'gap' in data. A 'gap' in data may be identified if:

- Data is missing, unavailable, or not representative of current conditions in your community
- If you do not know who collected the data
- If you do not know how the data was collected
- If the data is old (collected over 10 years ago)
- If you do not have access to the data

6 Collect community-level data

Develop data collection tools and methods to address any data gaps identified at the local level. There are many ways communities can collect information on health-related topics. This could include holding community discussions, talking with elders and knowledge holders, and developing your own community health and wellness survey that is launched annually. Community health and wellness surveys can be a collaborative process between First Nation departments, members and knowledge holders in your community. In addition, consider how your program can be inclusive, by including those members who live in-community and UAH members, so no one is overlooked or left out when it comes to discussing the health and wellness of your Nation.

7 Analyze the data

Analyze data and prepare an internal report for your Nation. As a community-driven initiative, you may want to prepare a community report describing key findings to share with your members. A community report should be written in plain language to promote accessibility and understanding among readers of different levels.

8 Store your data

Identify the most appropriate options for data storage and management. Consider factors like security, accessibility, and user-friendliness when making your decision.

9 Hold an annual community event

Reporting back to the community involves more than writing a report. Hosting a community event, like a celebration dinner, provides the opportunity for you to share information about your program and key findings from that year. During the event, members can ask questions, give ideas on improving the program and celebrate their health and wellness achievements together. This is an important way to ensure community members understand the importance of the program and participate in the future.

10 Ensure data is collected annually

It is important to collect data annually in a community-based monitoring program for several reasons:

1. to track changes to community health over time;
2. to evaluate the effectiveness of health services and programs;
3. to inform resource allocation;
4. to provide pathways for First Nation leadership to engage with community members and provide opportunities for them to contribute to the decision-making process; and
5. identify new and emerging health risks related to industrial development in your territory and region.[19, 20]

11 Protect your data!

Establish a data-sharing policy for managing internal and external data requests. Once your program is up and running, you may receive multiple requests to use the data you have collected (both from other departments and external agencies). Data collected by and for your community should only be used to serve the interests of your community.

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[19] Indigenous and Northern Affairs Canada. (2017). Community-Based Monitoring: A Framework for Inuit, Métis and First Nations Health and Well-Being. Retrieved from https://www.rcaanc-cirnac.gc.ca/eng/1530217844011/1557516320277

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Potential challenges and solutions[21]

Funding

First Nations may have enough funding to cover the costs associated with designing and implementing a community-based monitoring program. When funding resources are needed, there are external grants that may cover the associated costs. Additionally, First Nations have also leveraged relationships with regional proponents to fund these types of programs.

Capacity

Community-based monitoring programs are no easy feat! Their successful launch and implementation involve specialized skills, and dedicated staff. Staff working for First Nations Departments and/or Band Offices may already have enough on their plates or may lack the necessary skills to get these programs up and running. Further, a lack of resources and competing priorities may be ongoing challenges a monitoring program face. If financially feasible, hiring an external group with experience in this area may ease the burden on staff and ensure successful implementation.

Training

As mentioned above, staff may lack the skills that are required for a community-monitoring program. This includes using data management softwares (e.g., excel), continually maintaining databases, and performing regular and accurate data entry. Although this may pose a significant challenge, these are all skills that anyone can learn if they are provided proper training and support. Pursuing a training programs, or embedding training/capacity building into services provided by an external group can help provide staff with the necessary skills. Further, establishing standard operating procedures and processes regarding data will ensure that staff turnover does not threaten the program.

Participation

Getting community members on board and encouraging them to participate is one of the biggest challenges when conducting data collection efforts. Community members may be hesitant to participate for several reasons, including feelings of mistrust and concerns regarding confidentiality. There are a number of ways to address these challenges including:

- using data collection methods that can be conducted in privacy (e.g., web-based surveys, take-home paper copies)
- having a clear statement that explains where the data will be stored, who will have access to it, and what it will be used for
- offering incentives for participation (e.g., grocery giftcards, door prizes, etc.)

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[21] Jokinen, L. (2024). Lessons learned: Data-related challenges experienced by an Indigenous community in British Columbia, Canada (Chapter 3). Unpublished doctoral dissertation, University of Victoria.

Conclusion

This resource provides an overview of community-based monitoring programs as it related to maintaining and enhancing First Nation Health and Wellness. This resource provides a general description of the benefits of these types of programs and the initial considerations that are needed for design and implementation. It also discusses some potential challenges, solutions and the importance of reporting back to community.

Chapter 5. Discussion

5.1 Summary of research findings

The concept of ‘data’ in relation to First Nations health and wellness, the conversation often centers on the historical injustices and misuse of data by non-Indigenous entities for political purposes. The collection and utilization of data have largely been determined by individuals who live outside First Nation communities and whose interests are elsewhere (Otim et al., 2015). Simonds and Christopher (2013) provide an overarching summary of the issue when stating,

> Past researchers have disempowered communities, imposed stereotypes that reinforced internalized racism, and conducted research that benefited the careers of individual researchers, or even science at large, but brought no tangible benefit to the communities struggling with significant health disparities. Many tribal nations have provided accounts of researchers who have exploited tribes by coming in, taking information from tribal members, and providing nothing in return.15 This is not distant history; rather it characterizes much of present behavior (p.2185).

In contrast, data collected by and for communities to address their own, self-determined health and wellness priorities helps reshape the discourse by challenging the status quo. Western approaches to the selection of indicators (as reflected by regional health data sets across the province of B.C.) may not accurately describe community health conditions. As Fox (2018) notes, “the key difference between scientific indicators and Indigenous indicators is not the metrics and techniques used to define them. It is the principles that guide their development and the focus and perspectives included in their interpretation. Communities need to choose their own indicators to contextualize their data sources and become their own storytellers." (p. 5).

Good, high-quality, community data can reflect a First Nation's worldview as well as support the identification of community priorities and evidence-based decision-making (Meuter & Jokinen, 2023). Good data can also serve as a tool to hold government agencies and project proponents accountable. When collected, controlled, and effectively used by a community, data can provide the evidence needed to elevate the importance of an issue, inciting action on an issue that might otherwise have been ignored (Trevethan, 2019).

Through this case study research, the findings from this dissertation help better understand the generation and management of community-level health data by one First Nation in B.C., and highlight opportunities across the province for other Nations to consider. First, the findings demonstrate that communities may be actively collecting information on determinants of health that are guided by their own Indigenous knowledge systems and managed by their internal departments. Secondly, identifying gaps in pre-existing data in relation to health indicators prioritized by a First Nation helps inform a 'roadmap' for future data collection initiatives. Finally, enhancing information at the community-level can better position First Nations to lead and inform the HIA processes when projects are proposed within their territory. By delineating the challenges experienced by one First Nation through qualitative exploration described by this dissertation research, other communities can reflect on their own adversities and develop solutions informed by the experiences of others.

Research findings from this dissertation are also important for the field of HIA and those who conduct assessments on the effects of industrial projects on community health and wellness. This case study illustrates that pre-existing and culturally specific health data at the community-level may exist, and if integrated into an HIA, can enhance the scoping process and improve community profiling. Although each community will vary, the reliance on regional data sets will become an outdated practice when meaningful partnerships are established between those conducting HIAs and project-affected communities who generate, manage, and control their own health information. Good HIA practice includes applying an ethical approach to activities across each phase of an assessment, paying particular attention to standards required to protect and safeguard the rights of Indigenous peoples to their data and information.

Finally, as a non-Indigenous academic researcher and HIA practitioner, my relationship with First Nations is foundational to both my research and professional endeavours. These relationships are not built overnight and require time, commitment, and the ability to reflect on my own position and privilege as a non-Indigenous person. Working alongside First Nations in pursuing health equity and reconciliation has deepened my understanding of allyship and what it means to move beyond doing ‘research for the sake of research’. The final chapter of this dissertation is a product developed to share the knowledge and experience I have obtained through my academic and professional career working with over 30 First Nations across Canada. My co-author (Christa Meuter, former Health Director for a First Nation) and I, aimed to translate academic and professional knowledge into a resource for First Nations across B.C. The information resources provide a generalized ‘road map’ for communities who are interested in enhancing their community-level data through developing and implementing a determinants of health monitoring program. The resource summarizes lessons learned by communities and the private sector and is supported by research findings described in this dissertation (Chapters 2 and 3).

5.2 Future work

As a PhD candidate, I partnered with a First Nation for this research project. The First Nation had previously developed an Indigenous model of health reflecting their cultural values, beliefs, and traditions. A model of health developed by and for the community helps provide cultural relevancy to health and wellness initiatives. Instead of framing the research methodology of this study on determinants of health from my perspective as a non-Indigenous person, the community shared their model of health with me. This process included contextualizing each determinant to ensure a shared understanding was reached. Given the diversity of First Nations across Canada, Indigenous research methods that assist communities in developing their own models of health may be a beneficial endeavour. For example, the development of a First Nation’s model of health can enhance partnerships and collaborations between First Nations and external partners by fostering a shared understanding of community health priorities, values, and community context.

To build upon the findings from this research, future community-based studies should not only describe gaps in existing local health data but also initiate data collection activities to address these gaps. The research should bring tangible benefits to the community that participates in and guides the process. One conceivable benefit would also be to have the use of the data to establish a health profile (also sometimes referred to as ‘baseline by the field of HIA’) for the First Nation. A comprehensive health profile that highlights strength-based approaches to health will provide First Nation leadership with essential information about the health status, strengths, needs, and challenges their community members experience. Baseline information can also be used to develop health planning resources and is an essential first step in establishing a community-based monitoring program.

Currently, HIA is not mandated within the federal or provincial EA process and therefore, certain regulations pertaining to HIA have not been formalized yet. Although an entire review of the limitations related to HIA is outside the scope of this dissertation, there remain a few critical issues involving HIA practice and Indigenous health data that require attention. HIA represents a form of research involving human subjects. The process often involves primary and secondary data collection and analysis and the development of effective mitigation and management strategies. Therefore, ethical standards of practice are needed when collecting, analyzing, reporting, and storing data for HIA purposes (Huria et al., 2019; Smith, 2012). Even at the population and community level, health data contains sensitive information and HIA practitioners must ensure those who consent to participate in the HIA are protected from potential intentional or unintentional harm caused by HIA practitioners themselves or from industry influences.

Unregulated HIA practice has the potential to do real harm to individuals and communities. This is especially true when practitioners have not established meaningful relationships with First Nations and lack the appropriate credentials to lead these types of assessments. For instance, practitioners may have no direct experience working with First Nations, lack cultural sensitivity, do not have a background in Indigenous health, and are unfamiliar with applying ethical considerations, particularly those specific to Indigenous data sovereignty, to their assessment methodology. In Canada, EA guidance frequently highlights the importance of incorporating Indigenous knowledge into an assessment, yet the practical methods for achieving this integration seemingly remain unclear. When clear guidance is lacking, it becomes essential for HIA practitioners to receive thorough training before engaging with First Nations. Currently, there are no training programs available in Canada offered privately or affiliated with a post-secondary institution. However, HIA training can be provided by private sector experts, organizations such as the International Association for Impact Assessment (IAIA), and through collaborative programs with universities that specialize in impact assessment and related fields. Canadian universities have the potential to offer specialized courses and workshops designed to equip practitioners with the necessary skills and knowledge for effective Health Impact Assessment. HIA training is crucial to prevent any unintended harm to the very communities the practice intends to safeguard.

5.3 Concluding remarks

One of the overarching objectives of this dissertation is to explicitly discuss the data dilemma when it comes to understanding how industrial projects affect the health and wellness of communities, particularly for rural and remote First Nations in B.C., Canada. Findings from this dissertation provide a rationale for redefining how we characterize this dilemma. The use of aggregated regional health data sets to characterize the health conditions of First Nations in B.C. largely stems from the underlying assumption that there is a lack of community-level data available. Despite several internal challenges described in Chapter 3 of this dissertation, First Nations may be in the process of collecting data on the determinants of health prioritized by their community. Therefore, the dilemma may not be the existence of data, but rather, the ability of HIA practitioners to access and incorporate this data into their assessment. To overcome this, the field of HIA (and any impact assessment, including EAs that aim, in part, to investigate the potential adverse effects on community health in the province of BC) will need to reconsider their approach. As a professional body, the field of HIA does not have to ‘reinvent the wheel’. Decolonizing the HIA process can involve recognizing the similarity between HIA methodology and academic research and applying comparable approaches to ethical practice. Initial steps towards this goal can include incorporating processes outlined by community-based participatory research (or other Indigenous research methodologies, such as Two-Eyed Seeing) to establish meaningful relationships between the HIA practitioner and the community. Further, proactively implementing professional protocols to safeguard and protect community-level health data is critical to ensure unintentional harm is not experienced by First Nation partners.

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Appendix A

Interview Guide

1. Can you describe your current position with the (insert First Nation's name) for me?

2. What are the current priorities for the department/program you manage?

3. Does your department/program have a vision statement?

4. Please describe some of the short and long-term goals of your department/program.

5. What types of data does your department/program currently collect?

    - What is the data source?
    - What is the frequency of data collection (once, monthly, weekly)?
    - How is the data stored (electronically/paper)?
    - What is your perception of the quality of data (low, medium, high)?
    - Can the data be stratified by different subgroups in the population?

6. Does your department/program regularly use community-level data to make decisions?

7. Does your department provide updates to First Nation leadership on the data your department/program collects? If yes, please explain.

7. From your perspective, what data should your department/program collect? Is there any type of information that would benefit you/your department?

8. What challenges does your department/program experience when it comes to data collection?