Walking-With Wellness: Understanding Intersections of Indigenous Literacy and Health Through Podcasting

by

Lydia A. I. Toorenburgh
B.A. (Honours), University of Victoria, 2018

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We acknowledge and respect the lək̓ʷəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt, and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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Abstract

Have you ever seen a doctor and been sent home with forms and pamphlets to read and fill out? Reading and writing in English is a key skill for patients to access quality health care in Canada. Recent research demonstrates that patients with low print literacy face greater barriers when accessing and navigating the health system (Rootman and Ronson 2005). Indigenous people often meet greater challenges and, on average, experience poorer health (Loppie Reading and Wien 2009). How do Indigenous people with low print literacy experience the health system? In this research project set in lək̓ʷəŋən territory (Victoria, B.C.), Bungi-Metis student researcher, Lydia Toorenburgh, seeks to amplify the voices of Indigenous people with low print literacy to understand the barriers and challenges they face as well as their strengths and calls to action for the health system. The methodology includes walking-with, *kiyokewin*, collaborative editing, podcasting, beading, and incorporation of ceremony, and was designed to raise up these underrepresented voices. Lydia embarked on six walking visits through locations the research partners identified as important to their health. Each walk was audio-recorded, collaboratively edited, and made into podcasts. By creating podcasts, the research partners' voices and knowledges are centralized, amplified, and conveyed untranslated by the researcher. Through collaborative editing and a beading circle, research partners had greater control over their knowledges and narratives. Research encounters were carried out with the Cree-Metis value turned research method, *kiyokewin* / the visiting way (Gaudet 2019), to share and create knowledge in a relational, culturally relevant manner. The powerful words of these community members help us better understand how low print literacy impacts the quality and accessibility of health care for Indigenous patients. Sharing stories of racism, intergenerational trauma, and clashing worldviews

alongside those of resilience, intergenerational healing, and community care, these six knowledgeable storytellers have much to teach all listeners.

Podcast Link and QR Code:

https://soundcloud.com/lydia_toorenburgh/sets/walking-with-wellness

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Dedication

During the summer of 2022, I went to visit my Elders, Deryl and Earl Henderson on Lheidli T'enneh territory in Prince George for the first time in three years. After a very long line of questions one afternoon, they laughed and said that if they did not already know that I am an academic and curious mind, then they would find my many questions rude. They reminded me not to barrage other community members in this way. I blushed and explained that I do not often get this time with them and that I was hungry to learn more about our teachings. When Earl asked me why this is, I said that my family does not have much traditional knowledge and I feel a responsibility to gather that knowledge to bring home and so that I can be an Elder for my family one day. Earl gave me the beautiful teaching that *we cannot know, do, or have everything, because then we would not need other people*. What relief that gave me. In this project, I was not alone, and I have many people I would like to thank.

I would like to thank my academic family: my outstanding supervisors, Alex, Christine, and Rob for their tireless support and guidance; my research partners and dear friends, Abigail, Arie, Daniel, Laura, Liz, Joseph, and Tiara for their time, labour, and knowledge; all the staff from the Office of Indigenous Academic and Community Engagement and all my friends under the roof of the First Peoples House for encouraging me over these 9 years; all the faculty, staff, and students in the anthropology department for lifting me up every day; and my many colleagues at the University of Victoria who have supported me in both my studies and career.

I would like to thank my family: my cheerleaders/coaches/parents Irene and Murk for being my launching berth and my safe harbour in a storm; my doting grandparents, Bob and Alice for their undying belief in me; my brother, sisters-in-law, cousins, aunt, and uncle for their love and laughter; my partner, Mike, for always offering the laugh, tissue, or cup of tea that I need; my amazing friends; and my dear Elders and Metis community, particularly Barb, Deryl, Earl, Jo-Ina, May, Skip, Doug, Cathy, Victor, and Lyle.

Finally, I would like to thank my funders: the Social Sciences and Humanities Research Council of Canada (SSHRC), the Canadian Institutes of Health Research (CIHR), the University of Victoria, the Mobilizing Insights in Defence and Security (MINDS) Program, the Irving K Barber BC Scholarship Society, the Chair in Transgender Studies, the Indigenous Mentorship Network of the Pacific Northwest (IMN-PN), and the Centre for Indigenous Research and Community-Led Engagement (CIRCLE). Without the financial support of all these organizations, I would not have been able to do this work in such a good way.

Kinanâskomitinawaw! (I am grateful to you all!)

Terms and Definitions

Literacy	"The ability to understand and use reading, writing, speaking and other forms of communication as ways to participate in society and achieve one's goals and potential" (Rootman and Gordon-El-Bihbety 2008, p 10).
Print literacy	"The ability to comprehend and create a variety of written texts, encompassing a knowledge of grammar, vocabulary and discourse features alongside reading and writing skills" (Dudeney, Hockly, and Pegrum 2013, p. 8).
Health Literacy	An individual's "ability to access, understand, evaluate, and communicate information to promote, maintain and improve health in various life course settings" (Kwan, Frankish, and Rootman 2006, p. ii).
Low Literacy	In western countries, those with less than 9 years of schooling are estimated to have not achieved a sufficient level of literacy to effectively navigate the demands of contemporary life (Rootman and Ronson 2005). For this project, research partners need only self-identify as having difficulty with reading and writing in English.
Indigenous	This project uses "Indigenous" to refer to First Nations, Metis, and Inuit in North America with particular focus on the nations whose territories are fully, or in part, located in so-called "Canada", but it is recognized that Indigenous peoples around the world may relate to the material, particularly those living in anglophone colonial contexts.
Research Partner	The research partners are the 6 Indigenous adults who worked on the project. I use *partner* rather than *participant* to better represent the agency and significant contributions of the partners in this project. At times, I use the word "participant" when speaking more generally about research to use common anthropological terminology and acknowledge that participation and participant roles vary across projects and disciplines.
Kiyokewin	Also written as *keeoukaywin* and in English written as, "the visiting way". The Cree-Metis value of visiting turned into a research method: the practice of gathering and visiting (sharing stories/experiences) as relatives (Flaminio, Gaudet, & Dorion 2020; Gaudet 2018; McDonald and Paul 2021).
Italicized Words and Phrases	I frequently use italics in this thesis to denote Indigenous words, language, teachings, and concepts. This helps to demonstrate when I am specifically implicating Indigenous teachings and language in my work.

Self-Location

Tansi kiyawow. Lydia Toorenburgh nitisiy̓igason. Otipemisiwak tastawiyiniwak niya. Katzie aski kayâhtê nitôhcin mâka lək̓ʷəŋən W̱SÁNEĆ aski mehkwâc niwikin.

Hello, my name is Lydia Toorenburgh. I was born in Katzie territory in Maple Ridge, B.C. and now live in lək̓ʷəŋən and W̱SÁNEĆ territory in Victoria, B.C. I am a *tastawiyiniwak* (Two-Spirit) person, I use she/her and they/them pronouns. I am *otipemisiwak* (Bungi/Cree-Metis) from the historic Red River settlement, as well as Scottish, Irish, French, and English settler on my mother's side. Her name is Irene Ives, and she is a retired teacher and administrator with a B.Ed., PDP, and M.Ed. from the University of British Columbia. My dad, Murk Toorenburgh, is also a retired teacher with a B.Ed. and PDP from the University of British Columbia. He was born in Amsterdam and immigrated when he was young. These three identities, settler, Indigenous, and immigrant remind me to reflect on my family, how we came to be in lək̓ʷəŋən territories, and the responsibilities I carry to be a good visitor. I am a beadworker, drag performer, and singer-songwriter. I am excited about creating research approaches that incorporate my love of sound, audio-visual media, and arts practices.

I completed my Bachelor of Arts (Honours) in Anthropology at the University of Victoria (UVic) in 2018. My focus is audio-visual, sensory, Indigenous, and community-engaged methods. Despite the colonial history of the discipline, I am drawn to Anthropology because of its engagement with culture, community, language, and creative methodologies. My Honour's supervisor, Dr. Alex Boudreault-Fournier, and her research partner, Dr. Christine Loignon, invited me to work on their Canadian Institute for Health Research (CIHR) funded research project working with adults with low literacy to create podcasts about their experiences accessing health care. What excited me most about this project is the collaborative, audio-based, and community-engaged methodology. My passion is working with Indigenous communities, so I asked if I could focus on the experiences of Indigenous adults in my master's research. Dr. Alex Boudreault-Fournier and Dr. Christine Loignon graciously accepted this request and noted that it would be a valuable addition to the project. This is how I came to the research.

As I began the literature review, I realized that there is research on Indigenous health, and Indigenous literacy, but there is little research connecting the two. Finding a gap in the research typically indicates a good research question but writing in the field of Indigenous research demonstrates the importance of community direction in the development of research projects. I struggled with the fact that my research project was not designed with community. I had to remind myself that I am a master's student and do not have the time or money to design and carry out such a large-scale project. Acknowledging my limitations, I began to feel more confident in the validity and importance of the project after meeting each of the research partners. They all expressed passion about the research topic and methodology and felt that they had important messages to share. This was the version of community approval that I could achieve within my limitations and allowed me to feel that I was doing good work.

I open my thesis with a self-location as doing such is part of an ethical Indigenous research practice (Absolon 2011) and is a decolonizing strategy (Kovach 2021). Indigenous ontologies accept that we make meaning through our relationships and unique position in the world; therefore, knowing and knowledge production are subjective processes (Kovach 2009). Acknowledging our subjectivity and naming our relations reminds us of what our responsibilities are and to whom we are responsible; “it is not possible to be accountable to your relationships if you are pretending to be objective” (Wilson 2008, p. 101). This thesis is based on gathering stories and so it is important that I share my own stories as well, as research must always start with our own stories and vulnerability (Kovach et al. 2013). Introducing oneself is also part of traditional cultural protocol in many Indigenous communities. I have been learning *nêhiyawewin* (Cree language) from my Elder, Lyle John. It is a privilege and a responsibility to practice introducing myself in the language and to start this thesis off *in a good way*.

Ekwa (Lets go)!

Introduction

This thesis project gathered Indigenous people with self-identified low levels of print literacy living in lək̓ʷəŋən territory (Victoria, B.C.) to share stories about their lived experiences of interacting with the B.C. health system with the intention of educating others and creating change in the health system. While previous research has produced strong statistical and quantitative data on the impacts of low print literacy on the accessibility and quality of health care services, the literature lacks qualitative descriptions of how these barriers and statistics are experienced in the daily lives of these individuals. Indigenous and community-engaged researchers are calling for research participants and communities to have greater control over the process and products of research and to center their voices in the research.

The methodology used in this project addresses these calls by using participatory, collaborative, audio-based methods to create a space for these community members to share their stories of barriers and obstacles as well as adaptation and resilience. Dr. Alex Boudreault-Fournier and I met with each of the six research partners at a location they identified as important to their health. We walked through that place together and audio-recorded our conversations about their health care experiences. These recordings were edited collaboratively with each research partner to produce podcasts to be shared as public education resources. The broader research project led by Dr. Alex Boudreault-Fournier and Dr. Christine Loignon contributed the methods of podcasting and semi-structured walking interviews. The Indigenous research methods I contribute are: walking-with (Sundberg 2013), *kiyokewin* (Cree-Metis visiting way), collaborative editing, beading, and ceremony. Using the model of *Two-Eyed Seeing* (Marshall, Marshall, and Bartlett

2015), I combined the anthropological ethnographic walking method with the walking-with approach and adhered to common Indigenous research protocols and ethics from the literature and from my own community to create an Indigenous walking methodology that is both respectful and culturally relevant. In this thesis, I have sought to facilitate a research project that is innovative, culturally affirming, reciprocal, and impactful both in process and product.

Research Questions and Intentions

The research questions are:

1. How do Indigenous people with self-identified low levels of print literacy navigate the Canadian health care system?
2. What are some of the barriers and challenges they encounter?
3. How do they respond to such challenges?

The intentions of this project are:

1. To bring to light how challenges accessing health care are concretely experienced in the daily lives of the research partners.
2. To highlight resiliencies and knowledges of the research partners.
3. To illuminate pressing issues or concerns raised by the research partners.
4. To identify potentials for improvement in the Canadian and B.C. health system.

Overview of Chapters

This thesis is presented across five chapters. Chapter 1 includes a literature review of existing research relating to literacy, print literacy, health literacy, Indigenous health, and Indigenous literacy and identifies the gaps in the research that I address. This chapter sets the context for this research project. Chapter 2 explains the methodology for this research project. This includes recruitment, walking methods in Indigenous and Western European contexts, *kiyokewin*, audio-visual methods and editing, beading circle, and ceremony. Chapter 3 introduces each of the research partners and summarizes the important findings from each visit. This section offers a deeper appreciation of the podcasts and highlights key themes and quotes. Readers should be able to engage fully with this thesis without listening to the podcasts by reading this section. While they are best appreciated together, both the thesis and the podcasts are intended to be effective, stand-alone learning tools. Chapter 4 draws connections between the podcasts and highlights common themes. I also demonstrate links to the existing literature as well as unique findings that contribute to knowledge in this field. Chapter 5 concludes the thesis by summarizing key strengths and findings from the research project. This chapter reports the common barriers and calls to action identified by the research partners. I return to the research questions and intentions to evaluate the success of the project. I close with a discussion of scope and limitations and opportunities for further research.

Chapter 1: Literature Review

In 2013, when I was 16, I was diagnosed with Dientamoeba Fragilis (D. Fragilis), a parasitic infection that caused me severe abdominal pain, difficulty eating, lack of hunger, and chronic fatigue. I underwent numerous tests in hospitals on Vancouver Island and at the B.C. Children's Hospital in Vancouver. It was extremely overwhelming, especially in my state of illness. In 2015, I embarked on my mental health journey which brought about weekly visits with psychiatrists and doctors. Throughout both of my long and arduous health journeys, my mother accompanied me and acted as what I called my "external hard drive," remembering information, interpreting between the doctors and myself, and explaining complicated medical jargon. My mother is highly educated and experienced, with a Master's in Education, professional experience supporting families in challenging circumstances, and years of advocating for and assisting many of our family members in their own journeys. She was an integral part of my healing and without her I believe it would have taken me much longer to achieve the level of health that I am happy to report now, if at all. In my place, she was able to use her *health literacy* to help me navigate the health care system.

Print Literacy and Health Literacy

Literacy is broadly defined by Rootman and Gordon-El-Bihbety (2008) as "the ability to understand and use reading, writing, speaking and other forms of communication as ways to participate in society and achieve one's goals and potential" (p 10). The word *literacy* has been combined with other concepts to describe different abilities (for example: financial literacy and physical literacy). In this thesis, I use the term *print literacy* to differentiate and refer to text-based skills such as reading, writing, and numeracy. Dudeney, Hockly, and Pegrum (2013) define print literacy as “the ability to comprehend and create a variety of written texts, encompassing a knowledge of grammar, vocabulary and discourse features alongside reading and writing skills” (p. 8). Print literacy skills directly and indirectly affect quality of health. Direct effects on health include struggling to read and follow prescription, aftercare, and safety instructions (Rootman and Ronson 2005). Indirect effects include lifestyle practices like alcohol and tobacco use, seatbelt wearing, contraception practices, and lack of awareness about health care options (Rootman and Ronson 2005). These direct and indirect effects of low literacy create measurable health disparities. Patients with low print literacy are nearly twice as likely to report being in poor health than those with higher literacy (Baker et al. 1997) and are one and a half to three times more likely to have adverse health outcomes (DeWalt et al. 2004). Individuals with low print literacy are more likely to struggle with self-management of health, have less access to screening and preventative services, and are more likely to require emergency services (Loignon et al. 2018). In contrast, patients with higher education levels have lower morbidity with common acute and chronic conditions, report better mental functioning and health, spend fewer days home when ill, and are more likely to have chronic conditions “under control” (Cutler and Lleras-Muney 2006).

Key determining factors for health include education and literacy, employment and income, housing and physical environment, community and social supports, and access to care services; an individual’s print literacy level impacts all these determinants (Korhonen 2006). The greater an individual’s literacy skills, the more likely they are to be in good health as “high-level literacy makes it possible for people to have the knowledge and the understanding they need for education, employment, and coping skills, and provides the best foundation in making healthy life choices" (Korhonen 2006, p. 2).

The literature on print literacy demonstrates a clear correlation between print literacy and health outcomes, but experts working in the field of health have noted that navigating the health system and tending to one's health requires more than just print literacy skills. Therefore, the concept of health literacy was developed. Print literacy remains a core skill under the umbrella of health literacy and those with low print literacy tend to also have low health literacy. Because of this connection, we can also glean much important information from the literature on health literacy.

Health literacy is a term that describes one's "ability to access, understand, evaluate, and communicate information to promote, maintain, and improve health in various life course settings" (Kwan, Frankish, and Rootman 2006, p. ii). Health literacy includes "reading, writing, listening, speaking, numeracy, . . . communication and interaction skills," all of which impact an individual's ability to attend to their health (Coleman et al. 2011, p. 1). Low health literacy is a serious concern that impacts 60% of Canadians (Canadian Council on Learning 2008). Health literacy is an important determinant of health that is closely tied to other sociopolitical and ethnocultural factors that contribute to social inequalities in healthcare such as language, culture, socioeconomic status, and discrimination (Ronson and Rootman 2009; Zanchetta and Poureslami 2006; Institute of Medicine 2004). Those with low health literacy are more than two and a half times more likely to be in poor or fair health than those with greater health literacy (Canadian Council on Learning 2008). Similar to the statistics for patients with low print literacy, patients with low health literacy report worse health and tent to have less knowledge of their own conditions and treatment plans; have less knowledge of, and participation in preventive care; and have a higher incidence of hospitalization (Institute of Medicine 2004).

While there is a deepening understanding of how print and health literacies interact with other health factors like age, socioeconomic status, and culture, there remains a need to explore how these factors intersect. Zanchetta and Poureslami (2006) state that "linguistic and cultural barriers, community and institutional discrimination, income disparity, and low health literacy level are interconnected" and so, health literacy must be understood as an "ethnocultural phenomenon" (p. S29). As such, ethnographic research is needed to better understand the current quantitative data by identifying and engaging with the lived experiences, perspectives, and calls to action of the individuals and communities which these studies discuss (LeBrun et al. 2013). Ethnographic methodologies can illuminate barriers to health care but more importantly, they can further explore the needs and preferences of those with lived experience (Poureslami et al. 2010). Loignon and her colleagues (2018) call for this engagement to be participatory as people with low print literacy are often underrepresented in conventional research. Research on health literacy benefits from participatory approaches as they create opportunities for community members to share their knowledge and expertise, and to take an active role in addressing the inequalities they experience (Gillis 2004). In other words, researchers, policy makers, and practitioners need to *listen* and *respond* to the experiences and needs of people with low print literacy as they articulate them.

There is also a need for more research on how the effects of low print literacy and health literacy uniquely impact Indigenous people (Rootman Gordon-El-Bihbety 2008; Thewes et al. 2018). This project is designed to address these gaps by listening to Indigenous people with low print literacy to understand the barriers and challenges they encounter, and to share their knowledge with patients, professionals, and the public alike.

Indigenous Health, Literacy, and Health Literacy

Prior to colonization, Indigenous peoples in what is now known as “Canada” had excellent health with few examples of disease and even cancer and bone fractures; however, by 2009, only about 38% of Indigenous people self-report having very good to excellent health compared to the much greater 61% of all Canadians (Ronson and Rootman 2009). While the measured indicators of population health for First Nations people in B.C. are improving, they still experience poorer health than their non-Indigenous counterparts (Office of the Provincial Health Officer and First Nations Health Authority 2018). The impacts of colonization on Indigenous health are complex and pervasive, so it can be difficult to summarize the many ways in which colonization directly and indirectly affects Indigenous individual, family, and community health. Loppie Reading and Wien (2009) articulate three categories of social determinants of Indigenous health: “distal (e.g. historic, political, social and economic contexts), intermediate (e.g. community infrastructure, resources, systems and capacities), and proximal (e.g. health behaviours, physical and social environment)” (p. i). Education appears as a determinant in the proximal category as literacy impacts an individual’s ability to acquire information about healthy and nutritious food, proper use of medication, and healthy living choices regarding tobacco and substance use (Loppie Reading and Wien 2009). At the intermediate level, education systems based in Western schooling structures often position Indigenous students at a disadvantage by not addressing systemic barriers and not providing culturally appropriate curricula, pedagogy, and support (Loppie Reading and Wien 2009). In the 2001 Canadian census, 50% of Indigenous adults over the age of 15 had not completed high school as compared to 30% of non-Indigenous people (Loppie Reading and Wien 2009). Low levels of education and literacy will have further impacts on individual and family health as they reduce employment opportunities, income level, and quality of living conditions (Loppie Reading and Wien 2009). In the distal category, the impacts of Indian Residential Schools are significant (Loppie Reading and Wien 2009). Trauma related to schooling, learning, and teachers has impacted feelings of belonging and self-confidence in western education settings. The message of the "stupid Indian" at the core of Indian Residential School "curriculum" continues to be a racist stereotype that is often internalized by Indigenous people. The internalization of this stereotype is discussed by the research partners as a contributing factor to their struggles in education and health care settings. Negative stereotypes such as this continue to be perpetuated by non-Indigenous people and contribute to the mistreatment of Indigenous people.

Recent allegations of staff at the Saanich Peninsula Hospital in W̱SÁNEĆ territory (Victoria, B.C.) playing a game called "The Price is Right," where staff guess the blood alcohol level of Indigenous patients, prompted a province-wide report on Indigenous-specific racism in the B.C. health system. The report found that "stereotyping, prejudice and racist treatment are common experiences for Indigenous people in B.C. health care at all levels, especially urgent care" (Turpel-Lafond 2020, p. 20). This finding is especially relevant to this project because, as discussed above, patients with low print literacy are more likely to access emergency services. The report found that negative stereotypes of Indigenous people are widespread, the most common of which were: being less “worthy” of care, drinkers/alcoholics, drug-seeking (presumed to be asking for pain medication for ulterior motives), bad parents, “frequent flyers” (over/misusing health services), irresponsible or non-compliers (perceived to be not taking responsibility for health and not following care plans), less capable, and unfairly advantaged (perceived as “always getting things for free”) (Turpel-Lafond 2020). Stereotypes such as these result in Indigenous people experiencing “harm, poorer quality of care and even death” (Turpel-Lafond 2020, p. 22). Racism in the health system also results in Indigenous people avoiding accessing health services and experiencing inequitable access to preventive and primary care services when they do attempt to engage (Turpel-Lafond 2020). This lack of adequate primary and preventive care causes Indigenous patients to resort to emergency services more frequently and also to be hospitalized at rates of three times higher than non-Indigenous people for conditions that are commonly regarded as preventable (Turpel-Lafond 2020). This is an example of the challenges cited in the field of Indigenous health that overlap with the challenges cited in the literature regarding low print and health literacy.

When the barriers created by colonialism and racism overlap with the barriers associated with low education and print and health literacy, we find an intersection of marginalization that can profoundly harm Indigenous individuals, families, and communities. This intersection is of particular importance as Indigenous people tend to have lower print literacy scores (Rootman and Ronson 2005) and are among the groups in Canada with the lowest average levels of health literacy (Kwan, Frankish, and Rootman 2006). There is still relatively little research on Indigenous health as it relates to literacy (Rootman and Gordon-El-Bihbety 2008) but it is clear that Indigenous people with low levels of print literacy are at greater risk of experiencing poor health and having difficulties in accessing quality health care.

The existing research that does examine Indigenous health literacy is challenging conventional conceptualizations of literacy to demonstrate that Indigenous peoples have "additional literacies" that include connection to family, community, language, and culture but which are not recognized in Western biomedical understandings of health literacy (Smylie, Williams, and Cooper 2006). Stewart and colleagues (2008) demonstrate that Western concepts of health literacy do not apply readily to Indigenous people. They call for a *holistic health literacy* that acknowledges the central role that culture and community play in health and health literacy. George (2003) proposes a model of literacy for Indigenous peoples, which she calls the Rainbow/Holistic Approach. In this model, each colour of the rainbow represents a different set of literacies: for example, red, representing traditional language; green, representing the languages of the dominant colonial culture; and violet, representing balance in the four aspects of spiritual, metal, emotional, and physical wellnesses. This separation of colonial and traditional language here is key. For many Indigenous people, particularly the elderly, the lack of health services offered in traditional languages is a barrier when their first language is their traditional language rather than French or English (Korhonen 2006; Vass, Mitchell, and Dhurrkay 2011; Schlesinger 2016; Webster 2018; Turpel-Lafond 2020).

Investing in Indigenous people learning and speaking their language is also an investment in Indigenous health. The 2012 *Aboriginal Peoples Survey* demonstrated that patients who speak their traditional language have greater connection to their culture as well as lower incidence of asthma, bowel disorders, obesity, anxiety, and suicidal ideation (Webster 2018). Pluralizing the concept of literacy is important as literacy is not simply about reading and writing but is about language more broadly and must be understood as culturally situated as it is “culture that gives meaning to health communication” (Kwan, Frankish, and Rootman 2006, p. 52). Oneida scholar Dr. Eileen Antone warns that “equating poor literacy with poor health… could be used for assimilationist policies if English literacy is viewed as a solution to health problems” (Canadian Public Health Association 2003, p. 14). Antone conceptualizes literacy for Indigenous people as “a way of life with a holistic worldview balancing mind, body, heart, and spirit as in the four components of the medicine wheel” (Canadian Public Health Association 2003, p. 15). While the Medicine Wheel is not a universal Indigenous philosophy, Antone’s definition expresses the need for a culturally emplaced understanding of Indigenous literacy. Indigenous concepts of literacy are more than just the ability to read and write, they are “a metaphor for living a healthy life” (Smylie, Williams, and Cooper 2006, p. S22).

Indigenous scholars are leading discussions on Indigenous health and literacy, yet there continues to be a need for research on Indigenous print and health literacy and the Indigenous-specific factors that influence it (Vass, Mitchell, and Dhurrkay 2011). The existing literature on Indigenous health literacy tends to be situated within the context of particular health concerns such as cancer (Thewes et al. 2018), diabetes (Hosey et al. 1990), dementia (Webkamigad et al. 2019), and cardiovascular disease (Crengle et al. 2014). There is need for research that can stitch together the gaps between the research that has already been done to create a more fulsome and therefore more actionable understanding of Indigenous health and literacy. Missing from the literature are the participation, voices, and stories of the Indigenous people living these statistics. This research project offers a resource bundle for academics, professionals, and the public to listen to, and learn directly from Indigenous adults with low print literacy.

Chapter 2: Methodology

I became interested in research methods in my second year of post-secondary education. As I walked between my anthropology, music and film studies, and Indigenous studies courses, I drew connections between what I was learning. Indigenous research values relational methods that centre storytelling, orality, sensory knowledge, and community engagement. In anthropology, I was interested by discussions of culture, sensoriality, Participatory Action Research (PAR), and audio-visual and qualitative methodologies. In the manner of *Etuaptmumk* / Two-Eyed Seeing (Marshall, Marshall, and Bartlett 2015), I brought together the tools of anthropological ethnography and Indigenous research to build a practice that incorporates my artistic, creative, sensory-engaged passions with my personal, cultural, and community-based ethics and values. Gathering the seeds of these disciplines to grow my own garden of scholarship has been a passionate process. In this thesis, developing a high-quality interdisciplinary methodology was one of my main intents. I looked for opportunities to incorporate ceremony and protocol and to find a balance between institutional, anthropological, and Indigenous ethics and standards. Indigenous epistemologies link knowledge with the responsibly to act, which requires researchers to mobilize the knowledge they gather (Smylie, Olding, and Zeigler 2014).

The participatory and activist orientation of this project aligns with the tenets of Indigenous community-based PAR where research is based off the "two-way, respectful conversation" (Evans et al. 2014, p. 182) between researchers and community members about both the process and products of the research and where the intent is to "*seek insight from, not simply information about,* people and communities in the context of research" (p. 181, emphasis added). In this way, I look to the research partners for insight into what changes in the health system could create real change in their lives. Therefore, it is key that the research process and products prove to be worthwhile for the academic, professional, and Indigenous community as well as worthwhile for myself, my supervisors, and the research partners. I knew that my supervisors and the broader academic community would evaluate whether this is a valid and valuable research project, but that it would ultimately be the approval and affirmation of the research partners that would truly decide whether I had done this work *in a good way*.

I believe that the social, artistic, relational, and participatory nature of the methodology in this project facilitated a research experience that went beyond the anthropological ethical tenet of "do no harm" toward a goal of "make life better" where all those involved are lifted and strengthened by having participated. The emphasis on social, relational, storied knowledge co-construction is a healing approach as "stories themselves can be perceives as holding 'medicine' and the process of sharing stories as acts of healing" (Smylie, Olding, and Zeigler 2014, p. 17). Sharing ceremony through smudging and prayer, and spending time visiting on the land and in the beading circle, are all acts of relationship-building, grounding, and connection. Both researchers and research partners often left our encounters feeling positive. It was so moving for me when one research partner, who had taken part in numerous other research projects, told me that this was their most positive research experience. This was the affirmation that I was hoping for: that being part of the project was a positive experience for the research partners. My first responsibility was to take good care of the community members and friends who had gifted me with their time, trust, stories, and vulnerability. I am proud to report that we all had good feelings throughout the project and built deep, supportive relationships.

Recruitment

The recruitment process was challenging and lengthy. It taught me to be patient, trust the process, and allow things to unfold in their own time. The most effective platform for recruitment was social media. Some of the research partners reached out to me after seeing my poster on Facebook and Instagram, and some were referred to me through mutual connections. Of the six research partners, I had a pre-existing relationship with three. While these prior relationships would raise concerns of conflicts of interest in a traditional, Western research ethic, these established relationships created a sense of familiarity and excitement at the prospect of working together. Indigenous scholars often choose to work with people that they have prior relationships with as it both gives back to these people and holds the researcher accountable (Wilson 2008). Working with those friends reminded me of the importance of creating a foundation of personal connection before moving forward with building a research relationship. It was my initial intention to have a café meeting with each potential research partner to treat them to some food, get to know each other, and verbally explain more about the project. Unfortunately, because of the COVID-19 pandemic, this was not possible. Instead, I met with each person over a phone or video call. These calls often lasted quite a while as we laughed, visited, and talked about the importance of the project. It was exciting that each research partner was enthusiastic about the project and the prospect talking about this important topic – and to be heard. To participate in the project, individuals needed to be above the age of 19, self-identify as Indigenous, and self-identify as having a “hard time with reading and writing” in English. I recognized that questioning or measuring the research partners’ print literacy skills would likely be challenging and intrusive; therefore, research partners needed only to self-identify as having challenges with their print literacy. Following the University of Victoria’s ethics policies, research partners needed to sign consent forms to participate, but these forms were explained verbally, and verbal consent was offered as an alternative. Ongoing verbal consent was garnered before each data-gathering meeting as well.

Walking Methodologies

The primary data collection method in this research project is audio-recorded walking visits. Each research partner selected a location they identified as being important to their health. The research partner guided me, and sometimes Dr. Alex Boudreault-Fournier as well, on a walk through that place and together we talked about literacy, health care, and Indigeneity. These conversations were recorded with lapel microphones. Walking is a well-established and growing research practice that is dynamic, embodied, and emplaced, and that can create a new relationship between researcher and participant. Walking methodologies have been applied in many ways such as the guided walk (Brunette 2020), walking interview (Evans and Jones 2011), and soundwalk (Westerkamp 1974). More than just a new way to conduct interviews, walking has become a well-developed research methodology that emphasizes sociality (Lee and Ingold 2006), embodiment (Springgay and Truman. 2017), and sensoriality (Pink 2008). Walking through a place attunes the walker to the sensescape of that environment, the bodily experience of being present there, and to others with whom one walks. This creates a holistic knowing, as “we perceive not with the eyes, the ears or the surface of the skin, but with the whole body” (Ingold 2004, p. 330).

Walking in Western Theory

While walking is a relatively new trend in anthropology, it has been connected to numerous pre-existing theories. These include concepts such as embodiment, sensoriality, meshwork, flâneurialism, and phenomenology. For Moretti (2011), one of the most fruitful aspects of her walking tours with participants was that they called her attention to the public spaces through which they walked and the "power of ephemerality, embodiment, and imagination within them" (p. 251), thus allowing her a greater appreciation of the setting of the walk and of the inner landscape of the participants as they experienced the place. She describes the concept of a "moving positionality" where the participants' "speaking position was a walking position" (p. 249), which suggests that the knowledge they are sharing is deeply affected by, if not reliant on, the act of moving. This knowing while/through moving has been connected by numerous academics to the concept of flâneurialism.

The flâneur is a man of power, wealth, and privilege who could pass his time strolling through public spaces and taking in the sights of public life. Some scholars have criticized the applicability of this concept because it ignores the fact that not all people have the same access, safety, or ability to engage in flâneurialism (Springgay and Truman 2017 and 2018). Acknowledging the power imbalances inherit in this character as a wealthy, able-bodied, cisgender, heterosexual, white man, some have continued to use the concept but narrow it to signify the act of walking at a slow, strolling pace that allows for thoughtful and reflective observation of one's surroundings (Kothe 2019). In this way, the act of walking is conducted at a slower pace that allows for conversation, thought, and an openness to new trajectories and stopping points along the way (Kothe 2019). This slow pacing also allows walkers to savour and become attuned to the locale which enhances place-making and ethnographic inquiry (Pink 2008). Place-making is one of the core products of walking. In their seminal work, Lee and Ingold (2006) state that "the meaning of the place is constituted by [a walker's] bodily presence" (p. 77). Movement is essential to this process as "we do not perceive things from a single vantage point, but rather by walking around them" (Ingold 2004, p. 331). Movement is also key to the sensory aspect of place-making processes as it is through movement that "places are sensed, made sense of, and sensually made" (Myers 2010, p. 61).

Place-making through walking is not only a process of making a locale into a place, but also about creating and inhabiting one's place in that locale, as "selfhood and placehood are completely intertwined" (Basso 1996, p. 86). Indeed, walking is not just an act of place-making but also of identity construction (Myers 2011); walking with a participant can lead us to a greater understanding of both the place and our place there, as participants demonstrate and discuss both the place through which they walk, as well as their feelings of belonging or exclusion there (O'Neill and Hubbard 2010). The land is a powerful presence in walking methodologies. Walking through a locale can serve as a powerful "probe", encouraging deeper reflection, spurring conversation (De Leon and Cohen 2005) and increasing access to memories (Gröschel 2015). The act of walking itself can help us to remember, and this is particularly true when we walk through a familiar location (Schine 2010). Being together on the land brings the walkers "into relationship with their environment" where the locale as well as the path we walk becomes another participant, active in the knowledge production process (Kothe 2018, p. 43).

Walking through a location creates “lines” both physical (the path one walks) and intangible (threads of memory and imagination) and as they intersect, they contribute to a meshwork as these lines intertwine and converge (Saunders and Moles 2016). Myers (2011) argues that places are made through the weaving of a meshwork of journeys, knowledge, and memories. Again, this is both an environmental and embodied phenomena as our physical paths create lines of experience while our ideas and thought patterns also move along in intertwining threads like a “pedestrian wayfarer” where “every idea is a place that you visit” and it is this movement that creates thought and place (Ingold and Hallam 2007, p. 8). In walking together, a participant can guide the researcher through their lines in the meshwork, but they also create new lines as they walk together. Non-judgmental sharing of an experience contributes to an entanglement of even very different viewpoints (Thom 2017); therefore, as people walk together, they are immersed in the embodied experience of the other walkers as well as the land and the more-than-human surroundings in what Springgay and Truman (2017) term *transmateriality*. This sociality of walking with others is an essential aspect to this methodology.

Numerous scholars note the social aspect of walking methods. We build personal connections by sharing time, space, and a common experience (Gröschel 2015) as walking is a “profoundly social activity” (Ingold and Vergunst 2008, p. 1). The social aspect of walking is not just in the verbal exchange but also in the experience of shared bodily engagement with the place and the rhythm of walking, creating a sense of closeness (Lee and Ingold 2006). Walking together allows for the sharing of ideas, memories, and understandings in a phenomenon called “co-imagining” (Moretti 2016). Moving, talking, and sharing together facilitates meaningful connections, reciprocity, and understanding between walkers, even of diverse backgrounds

(O’Neill and Hubbard 2010). Anderson (2004) found that walking side-by-side with participants helped to equalize the power dynamic of researcher/participant. Brunette (2020) also found this to be true in her research with culturally diverse participants, describing the walking relationship as “open and pressure-free” (p.73). Walking group participants, who described themselves as struggling in social situations, expressed to Doughty (2012) that they found it easier to talk with others during their walks because of factors such as lower levels of eye-contact, more relaxed expectations around periods of silence, and the ability to move between walkers to enter or leave conversations more easily. More than walking alongside one another, we “walk-with” when “we share not only a physical direction but also an affective and emotional intention” (Doughty 2012, p. 144). She describes this “walkscape” as a “therapeutic landscape” where participants are attending to many needs including sociality, physicality, and time outdoors. It is my opinion that the strongest connection between Indigenous research and walking methodologies lie within this emphasis on the social, reciprocal, land-based engagement.

Walking-With Indigenous Research

There are few publications linking Indigenous and Western walking methodologies (one exception is Higgins and Maddon 2018 linking *flâneurialism* with Indigenous education) but there are excellent examples of Indigenous walking methods by Indigenous scholars like Brian Rice (2003) who embarked on a seven hundred mile walking journey as part of his dissertation. I believe that walking as research practice aligns with common Indigenous ways of knowing and being that inform Indigenous research paradigms: being out on the land, being in relationship, storytelling, listening, and witnessing. I also see that these methods could suit Indigenous paradigms as walking metaphors are a common motif in Indigenous imaginings. One example is that of the journey. I have been taught that each person's life is a journey that they walk; if I need to have patience with myself, I might say, "that's just where I'm at in my journey," or if someone is really not following social standards for behaviour, we might say they have "lost their way." This conceptualizes life as a path along which one walks. Some communities conceptualize a good path or a good lifestyle as *walking the Red Road*. The *Red Road* is the path of health, spirituality, culture, wellness, and often sobriety. Metaphors of walking have also been used in social movements and campaigns such as Walking With Our Sisters (www.walkingwithoursisters.ca 2020) which brought together thousands of hand-made, community-gifted, beaded moccasin vamps (the "tongue" of the moccasin) to represent the over 4,000 missing and murdered Indigenous women, girls, and Two-Spirit people in Canada. *Walking in two worlds* is a common expression which is used to describe how Indigenous people must know how to walk in the contexts of both their own culture and that of the dominant Western culture (for example, Medved and Brockmeier 2018). This metaphor is also used by Metis people who see themselves as living in between Indigenous and Settler worlds. *Walking in two worlds* has become a theoretical concept similar to *Two-Eyed Seeing* which describes the incorporation of Western and Indigenous paradigms and practices to find suitable middle ground that brings together the strengths of each approach (Marshall, Marshall, and Bartlett 2015). Rey and Harrison (2018) adapt this concept to better relate to Indigenous people in Australia in their theory of "goanna walking" which describes the movement of the goanna lizard: "walking within Western paradigms aligns with goanna's right-way steps and walking within Aboriginal relationships within Country as left-way steps" (p. 83) as its tail draws and leaves behind a line between the footprints. These concepts of walking are directly connected to relating to the land.

Land is a lynchpin of Indigenous epistemologies, ontologies and axiologies. Land, waters, and more-than-human beings are at the centre of Indigenous paradigms. Deloria (2003) explains that “American Indians hold their lands–places–as having the highest possible meaning, and all their statements are made with this reference point in mind” (p. 61). This can be extended to Indigenous communities around the world. It follows that land features prominently in Indigenous research, theories, and methodologies across disciplines. Budhwa and McCreary (2013) describe a “landed” methodology which “recognizes the importance of spending time on Indigenous territories and listening to the voices of Indigenous peoples” (p. 196). With Indigenous knowledges being so directly tied to land and place, it makes sense to gather knowledge while walking together. For the Cheslatta Carrier Nation in central B.C., the word for “land” literally translates to “the area in which one walks,” invoking ideas of mobility and place-making (Larson 2006); In their perspective, “land was walked into being” (Larsen and Johnson 2017, p. 26). If land was walked into being for the Cheslatta Carrier Nation, then might we walk our knowing into being by walking together through place?

Legat (2008) shares about the importance of talking and walking. In her description of the Tłı̨chǫ people, whose traditional territory is in the Northwest Territories, she demonstrates that to be knowledgeable in this community is to listen to stories and to follow the footprints of those who have walked before. This walking of paths repeatedly over generations honours and perpetuates this knowledge. Similarly, Somerville (2013) relays the concept of the storyline or songline from Indigenous Australia. These storylines and songlines are physical walking trails that both connect important places and connect these places to stories and songs, and therefore the people to land and culture. Through revisiting these connections, “each time the story is told, the person, the place and its creatures are sung into being in a process of becoming that recognized the mutuality of people, place, language and story" (p. 14). Saulteaux scholar, Linda Akan (1999) shares the teaching that walking and talking are metaphors to represent good, traditionalist Saulteaux education and discusses the teaching of the Elders that we must each use our gifts *in a good way* and be true to ourselves: to live "*pimadizewin*, or our walk in life, is how we arrive at that knowledge or make sense of that task" (Akan 1999, p. 18).

The concept of "walking-with" arose in several of the articles linking walking methodologies to Indigenous research. Geographer Juanita Sundberg (2013) drew on Zapatista concepts of "walking the world into being" to articulate a walking practice that is linked to political engagement, solidarity, and direct action. So, how does the concept of walking-with offer nuances from standard, Western walking methodologies? For Sundberg, walking-with is a decolonial activity that requires one to honour Indigenous paradigms in a way that is "built on reciprocity and mutuality, walking and listening, talking and doing" (p. 41). It requires of researchers a "serious engagement with Indigenous epistemologies, ontologies, and methodologies" (p. 40). Walking-with encourages flexible and relational thinking that is connected to embodiment, movement, and shared space (Larsen and Johnson 2017). Walking-with is therefore not just a physical activity, but a spiritual and intellectual activity that brings walkers into relationship with place and each other.

Walking-With Media

Walking is an imaginative and performative practice that lends itself well to the incorporation of audio-visual and multi-media methods through photography, video, and audio-recording (Moretti 2017). Boudreault-Fournier (2017) argues that audio or film recording "involves a careful attention to where one stands" (p. 79) and that this can contribute to a greater understanding of ones' own positionality and how it influences the meshwork of that walkscape. In addition to enhancing the research experience for the researcher, it can enhance the experience of the participants who can draw attention to particular things they want recorded, therefore inspiring new topics of conversation and/or insights (Bidwell and Winschiers-Theophilus 2012). Combining Indigenous knowledge, walking, and media, Bidwell and Winschiers-Theophilus state that walking with a video camera enabled them to capture the relationships between body, the environment, and the walkers, and because of this, they advocate for the inclusion of media and walking practices in work with Indigenous knowledges. Working with film and photography, Pink explains how photography is both emplaced and produced in movement through place (2011) and posits that filmmaking is also an act of place-making and strengthens the sociality between the filmmaker and participants as they move through place together (2007). She further explains that film can communicate effectively across cultural boundaries, echoing the statement by Brunette (2020) that walking can be an effective way of working with others from diverse cultures. Pink states that representations through film enable empathic understandings of the embodied experiences of those represented on screen. I believe that this is especially important when working with marginalized communities such as Indigenous people. Walking methodologies promote intercultural and interpersonal communication with an attention to place and embodiment.

Audio and film techniques offer a multisensory engagement with the material in the data analysis stage and provides a compatible dissemination medium that can effectively transmit the content and context of a walk. The cinematic technique of montage, Marcus (1990) suggests, "calls attention… to the essentially oral conventions and techniques of other cultures" and those forms of literacy that are often unacknowledged by Western standards (p. 8-9). Grimshaw and Ravets (2015) describe a critical film practice as not merely an act of preserving the knowledge shared and the research encounter; they explain that knowing is co-constructed through the filming process and argue for drawing with film as a means of "knowing-with", which returns us to walking-with. Therefore, one can walk-with a research participant, sharing a physical and emotional direction, and can co-create and share knowledge and findings by using audio-visual methods to think-with one another in a way that connects the minds and spirits of those producing and those consuming the research. Bringing our whole selves into conversation (body, heart, mind, and spirit) enables holistic learning and knowing.

Kovach (2009) argues that "holistic knowing is lost when stories are not delivered orally" (p. 147) and by that teaching, bringing together walking and audio-visual practices offer an exciting approach: walking methodologies enable the gathering and co-construction of oral knowledge and story while film and audio recording provide methods of transmitting the knowledge created and shared during that walk that does not lose the oral, aural, holistic knowing. Although relationship development is limited because speaker and listener are separated temporally, film and audio create greater sense of continuity and connection between the speaker and listener which is an essential aspect of disseminating relational knowledges. In many First Nations cultures in what is now called "B.C." where this research project takes place, the role of Witness is an important and formal position where an individual is tasked with observing an event and remembering and carrying that story forward. When walking-with someone and listening to their stories, one becomes a kind of witness. Myers (2010) says that she is "bearing witness through the effort of [her] walking, sensing, remembering and imagining, and this effort is significant" (p. 62). Though it was not explicitly her intention, this aligns with the responsibilities of First Nations witnessing. During this research project, I felt this sense of witnessing as with "listening [comes] the responsibility to tell" (Welsh and Olsen 2003, p. 149). The creation of a final audio-visual representation of that walk can fulfil that formal duty of the Witness to share and perpetuate that knowledge. As researchers, when are prepared for *the responsibility to tell*, it is important to select a dissemination method that suits the knowledge gathered and effectively transmits that knowledge. As I have argued, audio-visual methods provide an exciting and suitable methodology that maintains and enhances the relational, holistic, multi-sensorial aspects of Indigenous oral knowledge.

Bringing media and walking methodologies into Indigenous research is promising but should be done with care and attention. Rather than uniformly applying these Western theories, it will be important to "tease apart the contributions of Western science that maintain and perpetuate colonization from those that make space for Indigenous perspectives" (Martin 2012, p. 31). It is my aim to take anthropological methods like walking and audio-recording and apply them in my own way which attends to my Bungi Cree-Metis worldview and ethics. Many researchers using walking methods referenced a semi-structured interview approach. In this research project, I applied the Cree-Metis teaching/practice/value *kiyokewin* or "the visiting way."

Kiyokewin / the Visiting Way

One way to adapt walking methods to my own practice as a Bungi Cree-Metis researcher is through the incorporation of *kiyokewin* (also written *keeoukeywin*) which is the practice and value of visiting in Cree-Metis culture (Flaminio, Gaudet, and Dorion, 2020; Gaudet, 2018; McDonald and Paul 2021). I prepared some guiding questions, which I shared with the research partners in advance, but the research partners were welcome to share whatever stories they felt moved to share. Asking specific questions can limit the dialogue to just the researcher's interests but using prompting questions and allowing the conversation to unfold naturally enables the community partners to direct the discussion and share what they feel is most important (Hutchinson et al. 2014). *Kiyokewin* centers relationship building and fosters intimacy and connection between the visitors (McDonald and Paul 2021). It is said time and again because it is true: relationship building is key to Indigenous research. Building good relationships is one of, if not the most important aspect of doing Indigenous health research, and to do that we must deconstruct the power imbalances inherit in the traditional researcher/participant dynamic (Anderson and Cidro 2019).

During the visits, I wanted to demonstrate reflective listening and to bring myself into the conversation as a form of reciprocity and knowledge co-production. If the research partners were asked to share, then I should share as well. *Kiyokewin* is related to the value of *wahkotowin*: the value of kinship and being in relationship to all living things (MacDougall 2006; Wildcat 2018; Gaudet 2018). It calls us to be responsible to our kinship relations. I reminded myself that first and foremost, I needed to be a good relation. *Kiyokewin* "leads us back to what is right" and calls us to our relational obligation and spiritual responsibilities (Gaudet 2018, p. 48). Like walking, *kiyokewin* fosters an "unscripted flow of ideas" that is pressure-free for all the visitors (Ferreira et al. 2021, p. 7). Flaminio, Gaudet, and Dorion (2020) state that visiting is often done while participating in an activity, creating a "learning-by-doing" experience (p. 55). We visited-while-doing during the walks and the beading circle. Sharing these activities and the time spent together created a feeling of connection and belonging. Gaudet (2018) shares that *keeoukaywin* "offers an Indigenous view of community-based, participatory research methodology" (p. 55) which is exactly the intentions for the methodology of this project.

Audio-Visual Methods and Collaborative Editing

In my undergraduate degree, I took an audio-visual methods course in the Cuban Ethnographic Field School with Dr. Boudreault-Fournier. In this course, my group members and I created an audio documentary with a local pigeon racer. It was during the editing stage that I realized that I could edit the interview however I wanted - reminding me of the common reality TV complaint of "getting a bad edit." I could cut up the interview and reorder the clips to construct narratives according to my own arguments and research intentions. I could make decisions about what I felt was most important and impose those ideas by including or excluding takes in such a way that might not actually align with what the community member values – therefore prioritizing my own analysis over that of the person from whom I am seeking to learn. I imagined a scenario in which the community member watched and listened to our documentary and felt misrepresented. This awakened me to the serious obligation I have as a researcher to create respectful and honest edits. I felt that for the research partners to meaningfully engage in the knowledge production, it would be essential that they have input into the editing process.

The walking visits were audio-recorded with lapel microphones and collaboratively edited with the research partners to produce podcasts. Audio editing is a long process and is sometimes hard to explain so it was challenging to determine how to best edit collaboratively with the research partners. I began by transcribing the recordings and reading through the transcripts to identify which parts of the visit were most salient. I listened for any sections that might be too personal or which might need further explanation by the research partner. Acknowledging that some material must be cut to make the podcasts a reasonable length, I identified which parts of the recordings I would keep and which I would cut out. I met with each research partner over zoom and shared my screen with the transcripts so I could highlight and help them visualize what I was proposing. I felt that this would help them to better understand the timeline I was building. I talked each research partner through their transcript and summarized what we were talking about in each section and explained my reasons for including or excluding it. I confirmed my selections with the research partners and offered for any material cut out to be included in the thesis. I was glad to hear each research partner tell me they trusted my decisions and felt that I had their best interest in mind. This helped me to make sure that I was properly representing our visits and that I was understanding what they felt was most important to share. Reviewing together also allowed me to ask for clarification on unclear sections and to assure proper spelling of traditional language for the transcripts. Finally, I was able to have a meta conversation with each research partner about the visit and their feelings about working on the project. Each editing session lasted about an hour. I was conscious not to take up too much of their time and knew we would not have time to listen to the full recording. I feel that reviewing the transcript allowed me to summarize the conversation in a succinct way and convey my intentions for the edit. Editing the content together created an opportunity for myself to confirm that I was interpreting the visits correctly and allowed the research partners to identify the content and themes they felt to be most important and to have greater control over their own representations. I took this direction and the confidence of the research partners into the final steps of editing where I completed and uploaded the podcasts on my own.

Audio-visual methods contribute to a decolonized, Indigenized praxis as they better suit the aural and oral nature of Indigenous cultures where listening is an act of documentation (Welsh and Olsen 2003). Indigenous knowledge is “active, personal and creative” and is not as compatible with written formats which “appropriates that voice and freezes that knowledge in a particular time and context” (Absolon 2011, p. 156). Using audio-visual methods in both the knowledge gathering and dissemination is important as “colloquial language is lost when it is written down, and poetic passages often appear inarticulate when transcribed verbatim” (Bourgois and Schonberg 2009, p. 12); this can lead to lower fidelity in relating a participant’s message and may make it more difficult for readers to comprehend.

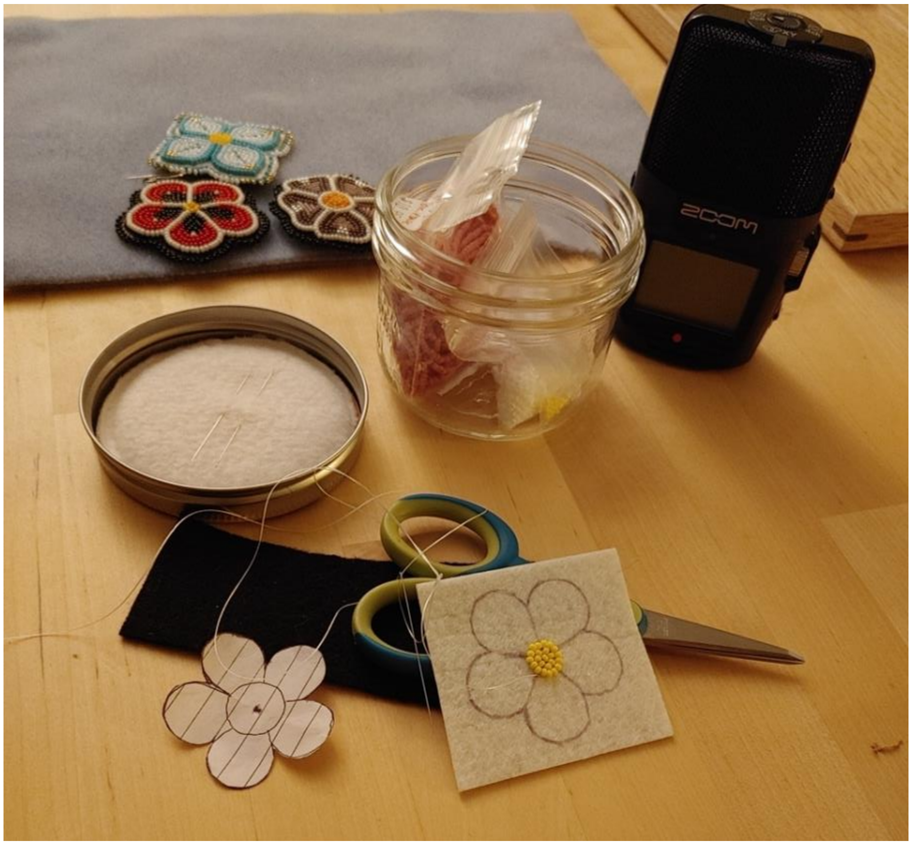
Audio-visual dissemination methods allow for greater accessibility and share-ability. Accessibility is key as Indigenous research should be useful to and easily understood by the community (Kovach 2018); this is especially important because this project is relating to print literacy and should be accessible to others with low print literacy. Previous research on health and literacy has been disseminated primarily in academic prose, rife with scientific jargon. In contrast, I hope the podcasts will offer a new access point to this topic for a broad range of listeners from community members, health care providers, educators, students, and policy makers. I acknowledge that this thesis will be long and difficult to read for many community members. The podcasts offer a learning resource that can be used in classrooms and can be accessed by broader community members which will contribute to the growing efforts to educate the Canadian public on Indigenous rights and settler-colonialism. The podcast format also enables the research to be easily shared on social media or flash drives and is not kept behind a paywall as is the case with many academic articles. Making podcasts also provided a creative format for the exploration of the topics in the research project.

In anthropology, audio-visual methods were once perceived as being completely objective (Mead 2003; Murdock and Pink 2005) but are now popularly understood as subjective tools to produce meaningful and creative research products. Visual media has been adopted by Indigenous peoples and scholars as "visual media provide an outlet for the communication, defence, and strengthening of cultural, national, or ethnic identities that pre-exist and thus transcend, the media form itself, as they are simultaneously shaped by it" (Poole 2005, p. 170). The subjectivity of audio-visual methods is key to my paradigm which emphasizes sensorial, embodied, and phenomenological knowledges and experiences. This is even more important as Indigenous ways of knowing "requir[e] understandings derived from all sources open to human perception" (van Meijl 2019, p. 157). Audio-visual methods can capture the sensory and embodied knowledge of the persons being documented which can then be conveyed to those consuming the texts produced by the research in ways that inspire sensory and embodied reactions and memories within themselves. This is a powerful way to explore health-related concerns as it can allow for a better understanding of how inequalities and structural violence are embodied (Farmer 2004). The recordings also capture the sounds of the place, enabling listeners to hear and feel the embodied experience of being in the locations that the research partners so thoughtfully selected. The podcast creation process is subjective, not just because of the sensory aspect and the subjectivity of what the researcher and/or research partners choose to record, but also because of the editing process.

Editing itself was part of the fieldwork process. While editing, I listened back to the conversations and arrived at new understandings and appreciation of the visits. This time of critical reflection is when the researcher draws out themes and connections as well as constructs a narrative and story arch. During the editing phase, the researcher is engaged in a process of sorting through the material and creating "meaningful representation(s)" of the ethnographic work (Boudreault-Fournier 2017, p. 82). Through the editing process, the researcher can create a space that conveys the "sensorial impressions felt at the time of the collection" (Boudreault-Fournier 2017, p. 82). In professional settings, editing is typically a process that is carried out by a small number of individuals with specialized skills, whether the medium is sound, photo, or film; but what can make the ethnographic editing process so special is the method of participatory editing where research participants are included in the process of editing (Pink 2013). This is impactful as it gives the participants greater control over their representation, allows for further conversation and knowledge sharing, and reorientates the relationship between researcher and participant which allows for "listening to and with" participants, rather than "listening in on them" (Waldock 2016, p. 66). These strengths of collaborative editing are particularly important when working with Indigenous participants as it meets the call for communities to have greater control in the research process and their representations (Schnarch 2004).

Beading Circles

The final stage of the fieldwork process was to gather the research partners for food, tea, and beading. Before the COVID-19 pandemic, I had intended to use the beading circle as an initial meeting to bring prospective research partners together to learn about the project, build a connection, and to see if they were interested in joining the project. Because of the pandemic, meeting in person was no longer possible. I transitioned the initial plan of beginning the project with beading to holding the circle after all walking and editing sessions were complete. This ended up being a wonderful change of plans. The beading circle was now a way to bring the research partners together to build connections between us all, create a sense of support and belonging, and to spend time engaging with culture. I felt that the research partners had shared a part of themselves and shared their knowledge with me, so I wanted to reciprocate and share something of myself and to give them some of my knowledge. Further, beading has been a huge part of my healing and connection to culture since I first learned with Métis Elder, Barb Hulme, in 2017, and I wanted to give this gift back to the research partners.



Beading kit, a few examples of completed beadwork, and an audio recorder.

I invited all the research partners, Dr. Boudreault-Fournier, and Metis Elder Barb Hulme to come to my home for the beading circle. One research partner brought their child, one was home sick, and one joined via Zoom. We gathered at my apartment and opened the gathering with a smudge and a prayer. I served mint and nettle tea and pizza. After we ate, I asked the research partners about some of the themes I noticed from the visits and was able to hear some feedback from the group. Each person received a beading kit and Elder Barb led us through the beginning of a traditional Métis flower. I had wished for more time to be able to discuss the research themes as a group, but we did not have much time and I wanted to make sure we got some beading time. Unfortunately, we ran out of time without doing as much beading as I was hoping. In the future, I realized I would need an auntie to help serve the food and tea so I could focus (my mom scolded me for not giving her that role) and that we needed more time. All lessons learned.

Beading circles are groups of individuals who come together, often around a kitchen table, to bead, share food, chat, and learn. Beading is an important practice in many Indigenous cultures, particularly mine as a Metis person. Our people are famous for our beadwork and we are often referred to as the Flower Beadwork People. Some of my favourite memories of spending time in community has been beading at the kitchen table with aunties and Two-Spirit cousins. Using beading in this project was not just a means of including culture but was also selected as an effective research method. By holding a beading circle, I created an opportunity to build relationships and trust. Being in a beading circle enhanced the co-creation and sharing of knowledge as beading is a "communal process" (Ray 2016, p. 371) and has an "intimate relationship with storytelling" (p. 368). As relatives bead together, they share teachings, stories, and techniques. In this way, "beading is an act of knowledge transmission" (Prete 2019, p. 39).

By articulating her beading as research method, Prete (2019) draws parallels between beading and research as both activities require the use of both qualitative and quantitative skills and the ability to identify patterns. She argues that beadwork is an act of knowledge, resistance, and resilience (Prete 2019). Marsden (2004) brought the teachings of Wampum, which are “beaded documents,” into her research practice after receiving the knowledge in her dreams. Through her *Wampum Research Model*, Marsden articulates a “process that could be used to design, analyse and represent responsible research with Aboriginal communities” where responsible research is “responsive to and resonant with the needs and contexts of a community, while meeting and incorporating the standards of the university and maintaining the congruency and integrity of the researcher” (p. 60). Beading can strengthen relationships and community knowledge (Ray 2016). For these many assets, beading was an important part of the field work and allowed me to enhance relationships, share culture, enact reciprocity, and to further our knowledge production.

Beadwork has been an important process for me as I have navigated the research project. I had initially intended to bead my research findings as well as bead gifts for the research partners and my supervisors, but soon realized that it would be too difficult to accomplish. Instead, I continued to work on my flower from the beading circle and plan to complete a medallion to represent my time in my master’s degree. I have used the time with that flower as a way to decompress after long hours writing and to reflect on what I have learned. I was also excited to receive pictures of progress that the research partners had been making on their flowers. Having this beadwork to return to has been a key part of recentering myself and processing my thoughts and feelings. As I sit with the beads, I sit with my ideas and learnings from the research.

Honouring Ceremony

Table settings at the Honouring Ceremony, made by Lydia's mom, Irene Ives.

With the field work complete, it was time to close the work of *in a good way*. I gathered my family, my supervisors, Elder Barb, the research partners, and their guests at the First Peoples House Ceremonial Hall on the UVic campus. We started the evening with lək̓ʷəŋən opening protocol offered by Diane Sam, the Cultural Protocol Liaison in the office of Indigenous Academic and Community Engagement. Next, Elder Barb opened the dinner table with a prayer before we ate. Sharing food is an important part of protocol and maintaining good relationships. After Barb closed the table, I began the presentation of our work.

I shared an overview of the research project to explain what we did together and then summarized our findings. During the research process, I prayed for a song to come to me to use as the music for the podcast. One night during the transcribing phase, lyrics came to me as I was falling asleep. I worked with Elder Lyle John to translate the lyrics into *nêhiyawewin* (Cree language). I wanted to share the song at the ceremony but realized with horror that I had forgotten my drum, but my community cared for me! One of the research partners happened to have brought a drum that they made and were preparing to give to their commissioner. They generously shared their drum with me. I felt like this was such a wonderful symbol of how the work happened the way it was supposed to.

After the song and a warm hug from the research partner, I began the presentation of gifts and honouring of the research group. I gifted and thanked my supervisors and Elder Barb. Next, I read an acknowledgement for each research partner where I spoke about the unique contributions that each person made to the project, what I learned from them, and a few important quotes from their podcast. After each acknowledgement, the research partner would come up to receive their gift and give a hug. I was touched to see that two of them had tears in their eyes as they came to receive their gift. I worried about what kind of tears they were but was assured that they were good tears. After presenting the gifts, I had an open floor where anyone could share. I asked Dr. Alex Boudreault-Fournier to speak on behalf of my supervisors and the university, and for my mom to speak on behalf of my family. With the formal business done, it was time to close. As my family began taking down the tables, I had a moment with each research partner full of more hugs, thank-yous, photos, and laughter.

This Honouring Ceremony was extremely meaningful because it signified the transition between research relationships into friendship relationships. It was an act of gratitude and reciprocity, it was a celebration for our accomplishments, it was a chance to share our work with our families so they would understand, and it was part of my ethics. Indigenous research ethics require researchers to present the final research to the community for feedback and approval (Medicine 1998) as it is ultimately the community that are the judges of whether the research is valid and effective (Gaudry 2011). Food and gifting are also part of cultural protocol. I knew I wanted to put my grant money back into Indigenous pockets, so I bought all the thank-you cards from local artists and ordered personal care products from an Indigenous company for the gifts (https://www.standingspruce.com/) . In addition to the gifts, each research partner received a USB drive with all their research materials on it. I felt it was important for them to have their knowledge accessible to them and for them to be able to use and share it in the future. It was a huge push of work, but it went so beautifully, and the room was full of such love and connection. I cannot imagine ending a research project in any other way from now on.

Chapter 3: Introducing the Research Partners and Podcasts

Of 6 walking visits, 5 podcasts were made. One research partner asked not to have their recording turned into a podcast but gave permission to include her knowledge in this thesis. You can find the podcasts by using the QR code or the link: https://soundcloud.com/lydia_toorenburgh/sets/walking-with-wellness

Abigail: "The system was not made for us"

The path Abigail, Alex, and Lydia walked along Dallas Road.

Abigail Claydon was 26 at the time we met. She is *nêhiyaw* (Cree) from Treaty Six Territory. She is a Social Work student at the University of Victoria. Dr. Alex Boudreault-Fournier and I met Abigail on a windy summer day in August 2021 at the corner of Cook Street and Dallas Road. We walked along the water and had a very powerful conversation. Abigail has had many experiences with the health system and was able to explain to me the ways that the Western health system is failing patients with literacy and mental health challenges. Abigail is a university student and said that she comes from an educated background, but she pointed out that education "doesn't necessarily translate directly parallel to the systems we navigate." She explained that in health-related documents, "the language is more complicated." She also observed that the documents read like contracts rather than education tools; it seems that it is about "signing off and agreeing to things you don't necessarily understand the consequences of." She shared how emotionally, mentally, and spiritually draining it is to complete all the paperwork associated with accessing services; that often she would have to set aside a whole day to complete (or attempt to complete) paperwork and to plan for the inevitable crash that would come after the work. Something that would take her ten minutes over the phone became days of work and recovery at best, and months of avoidance and anxiety at worst because the work was daunting, overwhelming, and caused such emotional upset.

Abigail also highlighted that the B.C. health system is focused on intervention rather than prevention and shared stories about mistreatment by police and health care workers. She talked about feeling like crisis lines and other mental health teams often move to police-involved intervention and involuntary hospitalization. Instead, Abigail called for calm and compassionate listening and referrals to more community-based, ongoing care rather than simply referring to short-term crisis supports again and again. One of the most impactful quotes from her podcast was when she said: “it's just hard when like, people are basically telling you that, like, you're too much for the system. It's like, your system’s made me this way, like, 98% of the stress I have had from this past year has been dealing with this very system that's been created, because it's not created for me. It's created for white people.” This really moved me and brought to my attention how the Canadian health system is designed around Western concepts of illness and health and does not provide other options or approaches that would better suit patients from different cultural contexts. Despite the stress, frustration, and trauma that Abigail shared, she demonstrated such resilience and commitment to caring for her wellbeing. She spoke about themes of community care through support from her mother and then-partner and enjoying accessing cultural services and programs such as the First Nations Health Authority. She reflected that through her struggles, she has gained confidence and grown her ability to self-advocate. Her message to others was a call for more holistic care, a bridging of Western and Indigenous approaches, as well as greater preventive and community-based mental health services. In closing, Abigail shared an inspiring, positive vision for her future that is “bright” and full of friends and education, with some bad times, but good times too.

Arie: To get “proper care you really need to fight”

Lydia, Arie, Alex, and her son, Isaac, stand outside Paparazzi Night Club in Downtown Victoria.

Arie Smallwolf is a Tsimshian burlesque and drag performer and artist. She grew up on Salt Spring Island but was living in Victoria and since the conclusion of the project has moved with her partner to England. I had already known of Arie from the drag and burlesque scene, so I was really excited to get to know her more and to listen to her stories. On an early September 2021 evening, Dr. Alex Boudreault-Fournier and I met Arie downtown outside the Victoria Event Center and the gay nightclub, Paparazzi. These two venues frequently host drag and burlesque events and

Arie shared about the importance of performance in her life and these places at which she met many friends as well as her partner. As we walked, I realized that we had a lot of similar experiences with our health journeys so listening to her speak affirmed my experiences and showed me how these issues I had experienced are harming so many others, both Indigenous and non-Indigenous.

Arie highlighted the importance of continuity of care and having doctors and counsellors that patients can see for longer periods of time. We identified that the B.C. mental health system mostly offers short-term services, but that many mental health diagnoses are life-time issues. We also shared that as young people, we are quickly aging out of accessible and free services at age 20 or 25 even though we are still youth and still dealing with issues that began in our youth late into our twenties. I shared that often the Metis Nation B.C. uses age 30 as the limit for "youth" and how that was so helpful for me. Arie explained that losing care by aging out interrupted her healing and made it difficult to find the resources to continue that important work.

Arie talked about her struggles accessing quality care. She found that she had to fight to receive services and that she had to pursue diagnoses on her own because she was not taken seriously by health professionals. However, doing her own research meant going online and reading through text-based resources which also posed a challenge. Compounding the challenges of researching the diagnosis, Arie shared about her experiences with different screening and diagnosis processes and noted that they consisted of questionnaires and short appointments. Finally, after diagnosis, much of the treatment and aftercare brought on more paperwork and individual research. Feeling unwelcome and unsafe, and the reliance on document-based assessment and treatment caused Arie anxiety and so she would often avoid accessing health services. She said, “I almost avoid things because I know that I can't like get through the first couple steps.” She also said, “even just thinking about trying to get diagnosed, like, I almost don't want to even though it means getting the help I need just because of the process.”

Literacy is a complex issue for Arie. In school, Arie did not receive sufficient support both academically and personally. When she was struggling in school, school staff did not do enough to support her and did not bring her parents into the conversation. While her grades suffered and when she experienced a significant loss in her family, teachers did not check in on her. Staff only stepped in after overhearing Arie say that she wanted to skip school to attend an art conference. Arie attributed the lack of attention to her needs and learning to the “culture of low expectations” where Indigenous students are expected to perform poorly in the classroom. Arie was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) after high school and then pursued screening for, and diagnosis of dyslexia. Like Abigail, Arie needed to advocate for herself and fight for care: “to get the proper care that we need, whether it's in like health care or in, in school, you really need to fight for it.” She also found that health care professionals tend to not take her seriously and attribute her health concerns to weight or lifestyle.

I noticed that Arie spoke in such a calm and self-assured way. Through these great challenges, Arie shared about finding strength and support in her friends and family. She said that playing games with her loved ones, performing, making art, and cooking good meals all contributed to her wellness. Her message to others is to check in on one another and look after the ones we care about, even if everything seems fine. She reminds us that sometimes the people around us are just looking for someone to see us and show us that they care.

Daniel: The "care" is missing in "health care"

Alex, Daniel, and Lydia stand and sit in Meegan (Beacon Hill Park) after their walk.

Daniel Sands is *nêhiyaw* (Cree), French, and English and a proud Two-Spirit, non-binary, and openly gay person. They are HIV positive, and neurodiverse, including ADHD. They have experiences with homelessness, substance use, housing insecurity, poverty, bullying, sexual and physical abuse, and mental wellness challenges including depression, anxiety, and suicide. Now, they are a thriving and independent human who uses a manual wheelchair. I first met Daniel at the Victoria Pride festival in 2019. Daniel had a Two-Spirit flag flying from their wheelchair. We shared a nice moment, and I smudged them. It was fun to then meet each other once more in the weekly online *nêhiyawewin* (Cree language) class offered by the Victoria Native Friendship Center with Elder Lyle John. Now, to come together on this project was so good. It was a hot day in August 2021 when Daniel, Dr. Alex Boudreault-Fournier, and I met for the very first walking visit at Meegan, colonially known as “Beacon Hill Park.” Daniel’s warmth and kindness calmed my nerves and started the fieldwork off in a positive way. With such a wealth of experience, Daniel has a lot of truth to share. Like Arie and Abigail, Daniel talked about how ADHD impacted their reading and writing ability. Like Laura and others pointed out, Daniel argued that Indigenous people are storytellers and oral people, and Daniel talked about being very skilled with speaking and listening, which was apparent in our rich conversation.

At the beginning of the walk, Daniel listed all the things they do for self-care: feeding their plants and animals, feeding themselves, using the bathroom, brushing their teeth, braiding their hair, taking medications, and smudging. I was moved by all those different pieces being part of a holistic self-care practice. I am so used to hearing conversation about health focusing on diet, exercise, and medication that it was powerful to think about other important factors like connection to community, culture, living things, spirituality, and ceremony. Daniel talked about the Medicine Wheel as a guiding structure and how it teaches us about balance. Our conversation reminded me of the *nêhiyaw* and Metis teaching, *miyo pimâtisiwin*, which means “living a good life” by finding and keeping balance in the four aspects of the self as taught through the Medicine Wheel (Kopp et al. 2021, p. 213). Further, while balancing the four aspects of the self is good medicine for

Indigenous and non-Indigenous people alike, *miyo pimâtisiwin* is also connected to living and practicing *nêhiyaw* and Metis teachings, ceremony, protocol, and values; therefore, culture and tradition are part of good Indigenous health.

One of Daniel's many impactful quotes was that the "care" in "heath care" is missing. Daniel remembered what it was like when they switched to accessing services from the First Nations Health Authority, they said: "I instantly felt actually cared for, you know, and so I think it's totally missing out of the health care system, is the humanity, the care, the love, you know, like when I was in the psychiatric emergency, I felt like a criminal. Like, I felt like a violent criminal. You know, at my worst at my like, like most broken, vulnerable, you know, emotional time, you know, emotionally I wanted somebody to just like hand on the shoulder and be like, 'Hello human', like 'I see you, you're gonna make it through like, this sucks right now, but you're gonna make it through.' There was no humanity, there was no care, there was no love, which is seriously missing from, from the health care system." Daniel also stressed the importance of holistic care, particularly for those with multiple health conditions. Daniel said that it is important to have a team of experts to address complex and interrelated health concerns. However, Daniel made a key argument: while it is important that these practitioners bring their expertise to the table, we as patients are the ones who know ourselves best. Daniel said, "my doctor went to school, but never once was there a class called 'Daniel and their problems and their challenges'… I am the expert in me. I have a master's degree in Daniel." In their many interactions with the health system, Daniel found the system and many of the practitioners lack humanity. Their message to others was that health professionals must examine their biases and to see the human beyond their initial reactions to factors like substance use, homelessness, race, gender, sexuality, and ability.

Laura: No “faith or trust in any colonial, Canadian system”

Laura and Lydia stand in the Ross Bay Cemetery near Gonzales Beach on Dallas Road.

Laura Manson is a Two-Spirit, Tla-o-qui-aht woman and parent to a wonderful child, ʔinkc̓u (pronounced: Ink-tsu). She is an accomplished cedar weaver and bead worker with a passion for her culture and community. She is a dear friend of mine and I have come to respect, learn from, and love her in so many ways. We already knew each other because of our shared passion for beadwork and advocating for Indigenous rights. It was so nice to connect with her on my academic side because I knew that Laura has a lot of knowledge that could help educate others.

Dr. Alex Boudreault-Fournier and I met Laura at the Ross Bay Cemetery on a drizzling and grey December day in 2021. During our walk, Laura shared her mistrust of medications, vaccines, and the health system and explained that this mistrust is caused by her own experiences as well as those of other Indigenous relatives. Laura taught me about the Saugeen First Nation community that was given expired vaccines for a month before the mistake was realized (Dubinski 2021); she reminded me of Joyce Echaquan's mistreatment and death in a Quebec hospital (Nerestant 2021), as well as the forced sterilization of Indigenous women (Collier 2017), and the experiments conducted on children in Indian Residential Schools (Mosby 2013). Laura said: "I don't have any faith or trust in any colonial, Canadian system." She identified that living in the colonial world is part of the sickness she experiences and that she feels small and that she is not taken seriously in colonial spaces. This feeling of exclusion and experiences of violence cause Laura to avoid going to the doctor or hospital even when she in in severe pain or medical distress. Long wait times for appointments with her family doctor also cause her to resort to using walk-in clinics. When she has gone to doctors, she has been pressured to accept medication, even after clearly expressing that she wanted other options.

Laura's challenges with literacy have been influenced by her mother's experience and resulting trauma from Residential Schools. Her mother's trauma and Fetal Alcohol Spectrum Disorder (FASD) made it difficult for her to support Laura's reading and writing development. Further, Laura observed and experienced violence across colonial Canadian systems which make her suspicious of, and uncomfortable with the systems, authority figures, and policies of education, health, justice, and more. Laura's message to others was that health professionals need to learn about, and pay attention to the land they are living and working on as well as understand and have compassion for the sociopolitical context that impacts Indigenous peoples' health; that solving issues like substance use and FASD is not as simple as saying, "just don't drink." I want to honour Laura for the hard and heart work that she has done for herself and ʔinkc̓u. She is a shining example of intergenerational healing. Laura shared a beautiful story of returning to her ancestral lands and spending time there healing. Laura said, "we went camping there for two nights and our first morning there ʔinkc̓u I got up and, got up with a sunrise, and we went and *Oosimch*, which is like a spiritual bath. And so, we went and did that. And like, I will take that memory with me to my deathbed, because it was just like, the most wholesome thing that I could have ever done with my daughter. And to just go in and pray and be held by the water and the land." Hearing the emotion in her voice as she shared about the *Oosimch* and laying on a mossy bed reminded me of how important, and what a gift it is to be able to heal with and from the land.

Liz: “I am a survivor”

Lydia, Liz, and Joseph stand next to the water on Dallas Road near the Break Water.

Liz Thomas is from Cowichan First Nation and her husband, Joseph Thomas, is from the Esquimalt First Nation. Together they have five children and two grandchildren. Liz is an accomplished Cowichan knitter and dances with her family as the Esquimalt Dancers. I first met Liz when we were able to talk on the phone to see if Liz was interested in joining the project. I walked all the way around campus as we chatted. We got along so well and had so much to share with each other that I knew Liz would bring so much value to the project. I met with Liz and Joseph near the break water on Dallas Road on a chilly December day in 2021. I was really struck by how much Liz and Joseph love each other and their family, and how well they take care of each other. Joseph often stands with Liz as an advocate in health appointments and Liz keeps an eye on Joseph and the family, knowing when it is time to go to a doctor. But it was clear that accessing the health system is not an easy for her.

Liz spoke about her struggles with reading and writing and how it makes it challenging to understand what doctors are asking or recommending. Without the assistance of Joseph or her daughter, Liz said she “can’t do anything for herself” when interacting with the health system. Liz explained that she can read but that her skills are “not that great” and the large, unfamiliar health terms make questionnaires, consent forms, requisitions, and patient information forms illegible. Reflecting on why she struggles with reading and writing, Liz shared with me that she is a Residential School survivor. She remembers the trauma of the nuns tying her left hand behind her back to force her into right-handedness. Liz’s experiences in Residential School created a sort of “mental block” where she felt like she could not read and could not learn. We also talked about how Residential Schools were not intended to foster genuine learning, but focused on manual labour, Christianization, and assimilation. This left Liz with the belief that she was unable to read, write, learn, or succeed in education. But Liz overcame this mental block by working through that trauma with a counsellor and was able to return to school with Joseph and they both graduated with their Dogwood Diplomas in 2017! They both talked about how welcome they felt in the classroom and that taught me that education is not just a matter of personal ability or quality of education, but that everyone needs to feel safe and have their basic needs met and mental health looked after in order to succeed. Like the others, Liz and Joseph shared frustrations at how long wait times are to get appointments with doctors and therefore needing to resort to walk-in clinics and emergency room visits.

Liz explained that there is a history of prescription and illicit drug addiction in her family. Speaking about when she was first prescribed Codeine for her chronic pain, she said, “they said, ‘oh, this will help you’ but in all reality I was in more pain with the Codeine in me then I was living day-to-day like this.” Already a survivor of a cocaine addiction and having been cocaine-free for 22 years, Liz identified that she was becoming reliant on the Codeine and worked to reduce her use of the medication and will now only request a week’s supply when her arthritis pain becomes unmanageable. In the meantime, she uses heat and her knitting to keep her joints warm and mobile. Seeing her family struggle with prescription medication addiction as well as her own experiences contributed to a mistrust and dislike of medication where she would do “anything to keep [herself] from being on those pills.” Like many of the other research partners, Joseph and Liz explained that they preferred to heal with cultural medicines rather than prescription medications. Joseph talked about the importance of traditional healing practices, including traditional foods. Liz talked about her knitting practice, how it helps her meditate and keep her joints moving. Her incredible skills and love for knitting have been passed down through 7 generations. I can see how Liz and Joseph are passing down so many gifts, connection to culture, and so much love to their children and grandchildren. They had clear calls to action for the health system: more emergency same-day appointment slots, for language to be simpler and clearer, for practitioners to take the time to explain things simply and verbally, and to thoroughly explain medications: how they work, why they are being prescribed, possible side effects, risks, and dose/usage.

Tiara: “Your ancestors, they are with you, and they have your back.”

Tiara Glendale is Kwakwa̱ka̱’wakw on her mother’s side and Vietnamese on her father’s side. Her grandmother is a Residential School survivor, and her father came to so-called “Canada” as a child refugee fleeing the Vietnam War. Tiara explained how these violences and traumas shaped her family and her experiences growing up. In 2010, Tiara became a Camosun College student and since then she has been building her skills and education working in Indigenous community support work and education. Tiara first reached out to me on Instagram to talk about the project. Like I did with Liz, I went on a walk as we talked on the phone. We talked for so long and had so much in common, I knew right away that I had met a friend. For our walk, Tiara chose Saxe Point, where she married her husband, Brad. We sat together on a beautiful day in March 2022, surrounded by plants and birds and talked and talked. Tiara had some very challenging stories of pain and struggle as well as some inspiring messages of love and perseverance. Tiara has since asked that our visit not be turned into a podcast, but I still learned so much and am grateful that she gave permission for me to share some of the stories and learnings from our conversation.

Similar to what the other research partners shared, Tiara explained that her struggles with reading and writing are connected to other mental and emotional factors such as Complex Post-Traumatic Stress Disorder and possible undiagnosed learning disabilities and ADHD. She explained that her struggles with mental and emotional health and the demands of school and work compounded her challenges with literacy, making it extremely difficult to complete paperwork and applications which delayed her access to services by months. The lack of doctors in Victoria is a serious problem, and because of this, Tiara has been unable to switch doctors even though she feels unsafe with her current doctor. Instead, Tiara has been making use of online doctors. While the developing infrastructure for telemedicine has many advantages, seeing a new doctor every time forces Tiara to retell her story again and again which is retraumatizing and leaves her feeling like she is "stuck on a treadmill" and not getting anywhere.

Echoing what the other research partners had called for, Tiara stressed the importance of holistic healing practices. Tiara added an important detail to the conversation around holistic care, the treatments that contribute to holistic health all cost money: medication, supplements. counselling, acupuncture, massage, herbal and Chinese medicine, and I would add chiropractor, physiotherapy, and naturopathic medicine. Some might argue that extended health benefit packages are sufficient; however not all people have benefits and even those who do need to manage deductibles, partial coverage, and coverage limits. Tiara also argued that education, medical care, overdose prevention, housing, and disability supports should all be free and accessible. This makes me think about how so many health outcomes are linked to social, political, and economic inequality. This also connects with Abigail's observation that B.C. health services focus on intervention rather than prevention. Tiara's comment reminded me that prevention starts with having everyone's basic needs met. I finished the visit by asking Tiara what message she has for others and her response was so touching. She wanted others to know that they have the power to make change and to "break the cycle." She hoped that other Indigenous people and folks with literacy challenges would listen to the podcasts and feel inspired and know that they are not alone. I want to finish off by sharing one of Tiara's closing quotes: "We've all been through so much, us, our parents, our grandparents, their ancestors and so on. Your ancestors, they are with you, and they have your back. They're there for you and their teachings will come to you when you need them.”

Chapter 4: Reflection and Discussion:

Across the visits, I heard many of the challenges cited in the literature manifesting in the lives of the research partners. The visits with the research partners offer a more nuanced understanding of the data in the literature and contribute new knowledge of Indigenous-specific experiences of the challenges associated with print literacy and anti-Indigenous racism. There are already promising recommendations for best practice for health workers to serve Indigenous and low print/health literacy patients, but in this research project, the research partners have identified gaps and barriers as well as recommendations for better service that are specific to urban Indigenous people living in B.C. While more research is needed to address the specific context of on-reserve / on-settlement / rural Indigenous people and those in other regions, the findings of this project provide a quality case study that can be used to begin further research and to continue work to improve health care and services for these individuals. This chapter discusses the common themes and findings of the project and draws connections to the literature.

Print Literacy is Not Solely a Matter of Education Level

Many studies demonstrate that there is a clear correlation between level of education and health outcomes where the more educated are less likely to report having poor health, access more preventive care, and are more likely to have chronic conditions "under control" (Cutler and Lleras-Muney 2006, p. 5). However, this project demonstrates that print literacy levels are not solely a matter of level of education. Three of the research partners had some degree of post-secondary schooling and yet still self-identified with struggling to read and fill out health related documents. It is important to note that number of years in school does not always indicate level of literacy attained, and that reading heath materials is more demanding than every-day reading (Institute of Medicine 2004; Baker et al. 1997; Williams et al. 1995). Further, the kind of reading skills that medical prose requires is different from standard prose. Text in a medical context often has a different structure and style than standard prose, for example, the labels on prescriptions (Institute of Medicine 2004). Abigail reflected that her educated background does not "translate directly parallel to the systems we navigate."

Many research partners noted that readings are full of jargon and asked for simpler language. Arie noted that she struggled with the long and complicated words and when she would try to search for definitions on the internet, it would lead to more reading as she sifted through the results to find reliable sources. Arie proposed the inclusion of indexes and point form summaries of key points. Laura noted how helpful it was to have her post-secondary reading assignments read aloud using a text-to-speech software. However, using supportive software such as text-to-speech is not possible when given printed materials such as the book on Lymphoma that Daniel was given upon their diagnosis. Practitioners might consider giving patients digital copies of print materials to enable use of this software, but all the research partners preferred in person, verbal communication.

Literacy is Impacted by Other Personal and Structural Factors

Struggles with print literacy was connected to many other factors such as neurological, mental, and emotional conditions. ADHD was common factor, being cited by four of six research partners. Mental and emotional factors like anxiety and stress exacerbated the demands of reading and writing tasks, causing avoidance and sometimes discontinuation of pursuit of care. Traumatic experiences in school and the health system, and diagnoses of Post-Traumatic Stress Disorder (PTSD) impacted research partners' feelings about attempting print-based health tasks. Further, all research partners explained that reading and writing tasks invariably cause extreme anxiety, burn-out, trauma responses, exhaustion, and frustration; the effects of which could last hours to weeks. Learning disabilities and physical disabilities were listed as contributing factors. Those with disabilities tend to have greater literacy challenges (Rootman and Gordon-El-Bihbety 2008). This is significant for Indigenous people as well because by 2003, one in five Indigenous adults reported having a disability (Statistics Canada 2003) and by 2017, 32% of off-reserve First Nations people, 30% of Métis people, and 19% of Inuit reported one or more disabilities that impact daily activities (Hahmann, Badets, and Hughes 2019). Here we can see an important intersection where literacy struggles and disabilities create new and compound existing barriers.

There are many factors that can influence one's attainment of literacy skills as well as their ability to use those skills at any given time. Arie attributes much of her literacy challenges to her negative experience in grade school where she did not receive sufficient support. Due to the legacy of Residential Schools, many Indigenous parents have had struggles with success and feelings of safety at school. This creates intergenerational impacts, not just because of intergenerational trauma, but also because children are more likely to have print literacy challenges if their parents also have limited print literacy (Puchner 1993). Laura shared stories of her mother's FASD and trauma from Residential School and how that impacted her family. Taking lessons from her challenging childhood, Laura shared many examples of how she is working hard to create a better life for her daughter and how well she is doing in school. I noted how Laura has been providing her child with the support she needs to focus on school and learning and how this will enable her to learn and grow.

Liz recounted the traumas of Residential School where she was taught that she was stupid and could not learn, but proudly shared her success in her adult upgrading courses which she attributed to the welcoming environment, the investment of the teacher, and the personal work she did in counselling. These conversations made me think about the conditions necessary for learning. Children who are tired, stressed, and/or hungry struggle with their learning (Anderson 2003). Adult learners too cannot focus on learning when their bodies, minds, hearts, and spirits are hurting. With so many Indigenous people living in challenging conditions both at home and in institutions like hospitals, prisons, and schools, it is not surprising that literacy levels tend to be low. Loss of culture via colonialism has also impacted Indigenous literacy levels. Professionals working in the field of Indigenous literacy have found that studying one's traditional language before or during English or French studies has a positive impact on literacy development because "when one feels more grounded, included, and connected in one's own culture, language, and traditions, literacy will improve (Ronson and Rootman 2009, p. 174).

Orality is More Legible for Many Indigenous People

Despite challenges with print literacy, the research partners spoke of their great speaking and listening skills. It is clear in the podcasts how articulate and thoughtful each research partner is and how well they can share their stories. Five research partners spoke about our Indigenous ways of knowing and being as people of oral traditions. Laura said, "I'm a firm believer in blood memory too, right? Like, because like our people were storytellers. We learned by hands-on right?

So, we didn't have time to write and read how to do things. We just did them." Daniel explained that due to their print literacy challenges, their verbal and listening skills had to take more of the weight but that their oral skills have always been a strength of theirs; they said, "in school, I always got, always got in trouble for, for like, not listening and talking. Like, I can do both. I can talk and listen to a big conversation. Like my aunties and grandmas, sitting around beading, or having coffee and laughing. I can talk and listen to people at the same time. Like, you can't?" These skills are, as Laura said, in our blood but they are also muscles that we strengthen because of our cultural ways of living: storying, sharing, listening, laughing. Laura said, "I think is like just who we are as Indigenous people… we didn't have books and stuff. So, you know, we are storytellers. And we learned by being told how to do things not by sitting down and studying." This preference for verbal communication was clear.

All research partners noted that written tasks like questionnaires could take five to ten minutes if done verbally over the phone but become hours to months long struggles. Phone calls were preferable to document-based communication, but in-person appointments were the desired format. Liz said, "I would like for the doctors to explain what they want to know. Instead of just giving you the paper and say 'here, go home and fill this out and come back.' Explain and help women like me that don't understand." It is particularly important for screening and diagnosis to be carried out, and for treatment and aftercare to be explained verbally, in person, and with compassion.

Mistrust of Systems, Practitioners, and Medication is Common

For numerous reasons, each research partner shared feelings of mistrust of the Western Canadian health system and approaches. Abigail explained that there was a particular voice in medical documentation that felt unwelcoming and untrustworthy. Rather than feeling like an "education tool," these documents feel like a "contract" asking you to "sign off" and agree to things "you don't necessarily understand." Abigail recounted a time when a doctor was too busy to see her, so she decided to leave the hospital. She was asked to sign a document stating that she was declining care and leaving against medical advice, while the real reason she was leaving was because the doctors were too busy to see her. Negative experiences or lack of adequate care cause Indigenous patients to avoid seeking care (Turpel-Lafond 2020). In 2015-2018, First Nations patients in B.C. were more than two times as likely to leave a hospital against medical advice as compared to other residents (Turpel-Lafond 2020). Arie reflected that her feelings of mistrust and lack of safety are partly attributed to her father's fear of doctors. Indigenous patients are influenced by their own personal experiences as well as those of others as attitudes towards the health system are shaped by individual and community relationships and experiences.

Laura, Joseph, and Liz shared their mistrust of the COVID-19 vaccine. Joseph felt that the distribution of COVID-19 vaccinations to Indigenous people ahead of the general public was an act of experimentation: "we'll see how they all react and then we'll start distributing that to everybody else." Suspicions of experimentation are founded in the realities of past experiments on Indigenous people carried out in Residential Schools and Indian Hospitals. This history of experimentation and the reports of expired vaccines being distributed to the Saugeen First Nation directly impacted Laura's feelings about the vaccine. She said, "I don't have any faith or trust in any colonial, Canadian system, health care, education, you know, political, anything of Canadian or colonial systems. So, for the vaccine, I didn't want it. I had learned that an Indigenous community had received expired vaccinations and were giving it to the community for quite some time before they realized that it was actually expired. And so, for that reason, I was really against it.” Lining up at the vaccine clinic, Laura said she felt like cattle. Compounding the anxiety of getting the vaccine despite feeling unsafe with the process and the product, Laura was given a sheet of paper that explained the possible risks and side effects. “When I got my vaccine, like you, they handed me a piece of paper and I'm like, it was so anxiety provoking because like, one, I didn't want it, two, you know, I really struggle with reading, and three, my anxiety is really bad. Yeah, so it was really tough.” She added, “Yeah. So, the sheet of paper was just explaining, you know, symptoms or side effects that I might have from having received the vaccine. And so, I just cried. And it was embarrassing, because yeah, it's just a shot, right? To most people, most people would think, oh, it's, you know, ‘it's nothing, it only hurts for a moment,’ or whatever. But again, just like, thinking back on how I have no trust in any Canadian system, and like, not knowing exactly what's in there. And just like, knowing Canada's history against Indigenous people, and like, you know, forced sterilization of our Indigenous women and the, the studies done on like malnutrition for Canada, and like doing those studies on Indigenous children in Residential Schools, like the list goes on, like… So, yeah, reading that paper was just too much for me.”

At first, I felt frustrated to hear resistance to the COVID-19 vaccine because of my own value of the importance of vaccination but after listening to the research partners’ feelings, it made perfect sense why they would feel that way. I also reflected on my experience getting my first vaccine at the Victoria Native Friendship Centre (VNFC) versus my experience of my second vaccine at the Victoria Conference Centre (VCC). At the VNFC, it was calm and quiet, there were snacks, and I was in a familiar place with familiar staff. At the VCC, I felt that sense of being cattle, there was no privacy, and I too felt anxious. Laura agreed that the VNFC would have provided a different experience. She said, “I didn't ask questions. I didn't ask what was in the vaccine. I didn't ask. Like, I just didn't feel like my questions were valid, you know, so like, I don't, I feel small when I'm in colonial spaces. Because, you know, like, we've never been taken seriously from the get go, right?” People who struggle with print literacy often feel ashamed and try to hide their challenges and avoid asking questions to avoid appearing ignorant (Institute of Medicine 2004), but Laura encourages others like her to ask questions when they can. This mistrust also applies to medications.

Many of the research partners expressed a mistrust and distaste for both prescription and over-the-counter medications. Laura recounted an experience where she was referred to a psychiatrist. Not wanting to waste anyone’s time, Laura expressed that she was not willing to take medication and that she rarely ever even takes Tylenol for headaches. Yet, after two long phone calls, the psychiatrist recommended that she take medication. We shared frustrations that medication and counselling are often recommended without inclusion of other options. Joseph said he has felt like a “guinea pig” most of his life. He felt that doctors would say, “‘we’ll try this on you, we’ll give this to you, we’ll see if this works.’” He said, “I even explained to a doctor, I says, ‘you can give me all the fucking medication you want.’ Not to be racist, but it's not going to fucking help [like] all the white people. White people live different than First Nations people. We live off of the sea, we live off of the land, we can have that stuff, it's going to help us. And here you guys come and say, ‘this’ll work, this’ll work, this will give you a better benefit of your body.’ No, it doesn't. Some of the things that they give doesn't benefit us, the First Nation. But they're using it to see, to experiment on us."

Liz and Joseph also spoke of rarely using medication, even over-the-counter products like Tylenol. Liz said, "I refuse to, like rely on the White Man medicine." However, following Joseph's diagnosis of diabetes and through Liz's extreme rheumatoid arthritis pain, the couple has begun incorporating medication as needed. Joseph stressed the importance of practitioners carefully and clearly explaining the medications they prescribe: "I want to see the change of doctors and nurses explain more what the medications are. Help the people understand what it is and what does, what they're trying to attempt to do. Not just say, 'this pill is going to help you. Go home. See you in two weeks.' You know, help them understand, you know? … Help them what it's going to do in their body, what it may do, what side effects they may get, you know. I get more information out of a pharmacist than I do doctors. Pharmacists will sit down with you, explain to you, 'it may do this to your body, maybe that to your body.' The doctors need to learn more of what they're giving … Doctors come in, give you medication, 'this is for you, here you go.' 'What's wrong with you? There you go.' So, they need to learn more what they're giving, and help them understand. If not, take the pharmacist or take the nurse with you to help because those are the two people that I see help you understand more than the doctor. Any doctor I've spoken with, the pharmacists and nurses will explain more than the doctor will."

Daniel, who also takes daily medications, said they have "mixed feelings" about their medication. They know that their medication is helping but feels that by taking medication they are "condoning" Western health approaches and supporting the pharmaceutical industry. They felt they lack alternative choices to medication but that they are able to effectively use their medication in tandem with their traditional health practices like smudging and connecting with community. Daniel argued that bringing Indigenous and Western health approaches into parallel is a positive way forward.

Experiences of Violence in One System Affects Feelings of Safety in Other Systems

At the beading circle, we discussed experiences of violence in the medical system. Laura began to cry as she spoke about the murder of her brother, Julian Jones, and relative, Chantel Moore, at the hands of police. I noticed that in my experiences with my friend, these horrible losses often come to the front of her mind. Clearly these losses impact her life in a profound way. As she was speaking, a realization washed over me: experiences of violence in one system affects one’s experience in all systems. Each research partner told stories of violence and mistreatment across Western systems of health, policing, education, and social services. Systems of policing and law, government and policy, education, and health are all related, so trauma and injustice in one system influences how we feel in other systems. It became clear that police are over-involved in these systems. This was particularly clear in Abigail’s visit as she recounted police “wellness checks” and involuntary hospitalizations facilitated by police. When Abigail called 911 because of an incident where her physical safety and that of her landlord was at risk, she felt that the dispatcher was not listening and understanding her needs. She said, the dispatcher was “completely not understanding like the safety, like, compromise that I was like in, and I just was like, I wasn't yelling at him, but I did raise my voice and I was like, ‘look, you're not listening to me.’ Like I don't have a lot of time to be on the phone making calls, like, I have a list like that's literally crushing me of things to do. So, like the fact that you're treating me this way isn't making things better. And because I advocated for myself, he phoned a wellness check on me and then I had police entering my apartment without my permission, taking pictures of my medication bottles and like… next thing you know, I'm in a cruiser, in the psych ward again, and I'm like, just because I have depression doesn't mean I need to be locked up." With so many Black, Indigenous, and People of Colour (BIPOC) people like Chantel Moore being murdered during police "wellness checks," we can imagine how an Indigenous person would feel when police arrive to "check on them" and if they are detained and transported to the hospital for an involuntary hospitalization.

When Daniel was in psychiatric emergency, they said they felt like they were being treated like "violent criminal." Abigail said of police, "you also don't have the mental health training to even handle this situation. So, like, why are you being called? So, it's kind of hard because it's like, you're like, you have one issue, but you're getting like… it's like when you like call 911 and they are like "police, fire, or ambulance?" and it's like, I don't have… the option I need isn't even there." Abigail stressed the insufficiency and violence of the current interventionist, crisis approach in the Canadian health system.

Crisis and Interventionist Approaches are Failing Indigenous Patients

In the Island Health system on Vancouver Island, there are emergency, intervention-based, crisis services for mental health like the Urgent Short-Term Assessment and Treatment (USTAT) and PES, which stands for Psychiatric Emergency Services (or, Pathetic Excuse for Support, as coined by a local Facebook page, according to Abigail). Abigail said that after a mental health crisis and hospital visit, she was discharged with a "not cool amount of Ativan." She recognized the dangers of giving someone in crisis a significant amount of medication without supervision. I also related my experience of being on a multiple medication treatment plan with no medical supervision as there is an extreme shortage of psychiatrists in B.C. Arie shared that on multiple occasions, she had been given a new medication to try and was assured that she would see a psychiatrist for further treatment and yet has never actually been offered an appointment. In the absence of adequate psychiatric services, Arie noted that there are no publicly funded, long-term treatment options. The services that she was able to access were limited to youth (often limited to age 20 and under). She said, “especially like with mental health, it's not a short-term thing. It's, in a lot of cases, it's a lifetime thing and to have only short-term solutions is not something we need, we need long-term solutions that you know, carry on until we're in our 30’s, or just at least options.”

Often the only services offered to people are crisis lines. Abigail communicated her frustration with crisis lines in this expanded quote: “I exceed what they can handle like. It's like, it's, it's just hard when like, people are basically telling you that, like, you're too much for the system. It's like, your system’s made me this way, like, 98% of the stress I have had from this past year has been dealing with this very system that's been created, because it's not created for me. It's created for white people. I don't mean to be so blunt, but like it is, like… I when I was in the hospital up in Campbell River, like, first thing you hear is once someone gets here, like care card is just like, hear a few whispers. You hear like a mention of like when your last stay was and then it's like, ‘oh, she's Indigenous’ and then it's like, they treat you a completely different way. And it says, just like I almost wish it wasn't listed there, because it's like, I felt like actually got treated worse than I probably would have if I wasn't.”

The focus on interventionist approaches in the health system fails Indigenous patients. Indigenous mental health programs often run on limited, short-term funding, lack enough Indigenous practitioners, and the high rate of turnover of non-Indigenous practitioners lead to a lack of continuity of service, lack of availability of specialised treatment, and waitlists that are excessively long (Boksa, Joober, and Kirmayer 2015). While there is more research needed to understand the prevalence of severe and persistent mental illness in Indigenous populations, there is a correlation between chronic illness, disability, and severe and persistent mental illness (Reading 2009); this is particularly relevant for Indigenous health as 56% of First Nations, 55% of Métis, and 43% of Inuit reported having a diagnosis of one or more chronic conditions, in contrast to the 48% of non-Indigenous people (Gionet and Roshanafshar 2013). This is a key issue as mortality and morbidity rates for Indigenous people are increasingly resultant of chronic illness (Loppie Reading and Wien 2009). Treatments to mitigate and manage chronic illnesses include medication, nutrition, counselling, occupational therapy, and other mental and physical therapies – many of which cost money. With so many Indigenous people and people with low print literacy struggling with employment and income, we can see how Indigenous people with low print literacy are more likely to experience chronic mental and physical illness and yet lack the resources and supports to address these issues in a sustainable and long-term capacity.

The Health Literacy of Indigenous Patients Benefits from the Promotion and Appreciation of Existing Literacies

While the research partners have limited print literacy and struggle with their health literacy, they are not completely without health literacy. They have particular skills which I connect to our cultural approaches to communication, care, and health. The research partners talked about, and demonstrated confident listening and speaking skills, which was attributed to our inherited and maintained cultures of orality as Indigenous people. They also demonstrated a keen awareness of the cultural practices that would support their wellness: art, kinship relations, community connections, ceremony, traditional foods, and time on the land and water. It struck me that 5 of 6 research partners selected walking locations that are connected to land and water while the outlier, Arie, chose a location that was significant to her community connections. While the research partners struggle to navigate the Western Canadian health system and access services, they are active agents in the pursuit and maintenance of their individual, family, and community wellness. Each research partner referenced a number of relationships in which they are providing or receiving care including friends, partners, children, relatives, and communities. I believe that this is because of our common Indigenous cultural values of caring for our relatives, especially in the context of not receiving adequate care from Western Canadian systems. This knowledge of individual and community needs, and cultural values such as holism and healing with and from the land signify that Indigenous people are well positioned to be/become positive agents in their individual, family, and community health. I emphasize that maintaining relationships of giving and receiving care are part of an Indigenous value set, but the involvement of family and friends in Indigenous health is of particular importance within the context of the Western Canadian health system.

Some of the research partners talked about working with their partners, friends, and/or family to navigate and access the health system. Many Indigenous patients bring non-Indigenous friends and family to appointments to be their witness or advocate as a strategy to mitigate racist and discriminatory behaviour on the part of the health workers (Turpel-Lafond 2020). Patients whose first language is their traditional language also often bring a friend or family member to help translate (Turpel-Lafond 2020). Patients with print literacy challenges also often receive support from family members when engaging with health services (Williams et al. 1995). This becomes a barrier when a patient's support people are not allowed to attend appointments (Turpel-Lafond 2020; Williams et al. 1995).

Moving from an individualized approach to health and literacy toward a family and community model is promising. Efforts to increase print literacy skills have found that family literacy programs that include the whole family are more effective and much can be learned from Indigenous models of family literacy programs (Ronson and Rootman 2009). Indigenous approaches to family and community literacy are based on the concept that Indigenous literacy "is not individualization; it is about relationship" between "self, community, nation, and creation with a focus on words, language, listening, and comprehension" (Antone 2003, p. 9). In the absence of, or in addition to family supports, the Richmond County Literacy Network launched the Bringing Health Literacy Home to Richmond County initiative in 2005 and as part of their programming, volunteer "community helpers" provided community-based support while "community champions" were used as advocates at "all levels of government" (Gillis 2004, p. 16).

Involving family, community, and nation in health and wellness is part of Indigenous communities taking control of their health as the "Indigenous right to health is also inextricable from the Indigenous right of self-determination and the inherent right of self-government" where nations and communities direct and control the laws, policies, practices, and institutions that relate to their community's health (Turpel-Lafond 2020, p. 7). The desire for self-determination of health appeared during the visits: the research partners demonstrated that they know what good care is for them and their families. Daniel started by saying that we do need experts and specialists on our health teams, but that we as patients are the experts of our own body/self; stating, "I have a master's degree in Daniel." These specialists have high levels of education but "never was there a class called 'Daniel and their life and their problems.'" Indigenous patient must be treated as active and knowledgeable agents in their individual, family, and community health. The strong speaking, listening, and communication skills and the knowledge of self, family, and community health that the research partners demonstrated indicate that their health literacy has both strengths and weaknesses. Again, I think of George's Rainbow Model (2003), where there are multiple colours for different aspects of literacy. Health literacy is also a rainbow of different skills and it would be unfair and unhelpful to view an individual's literacy rainbow as though it were on a dimmer switch where all aspects are uniformly high or low. It is important that practitioners identify, acknowledge, and build on the strengths of their patients' literacies (verbal skills, technology-based skills, sign language, visual skills, etc.) and recognise the multiple ways these individuals and communities are "already literate" (Smylie, Williams, and Cooper 2006, p. S22). Smylie, Williams, and Cooper (2006) provide examples of "additional literacies" for Indigenous people which "might include building healthy family relationships, nutrition, mother tongue language instruction, learning and following traditional ceremonial practices, and family literacy" (p. S22). They argue that these literacies and one's relationship to learning and developing these skills are clearly linked to social determinants of health and to "being and becoming a healthy person, family member, community member, and member of society” (p. S22). In this way, literacy is more than just a skillset, “it becomes a metaphor for living a healthy life” (Smylie, Williams, and Cooper 2006, p. S22). Therefore, Indigenous print and health literacy must be understood as part of a range of literacies and efforts to improve literacy should not be focused solely on the development of individual skills such as reading and writing in English but include developing the rainbow of skills and knowledge discussed to maintain holistic wellness.

Chapter 5: Conclusion

Print and health literacies and Indigenous health have each been conceptualized as individualized, deficit-based issues; however, addressing the barriers associated with Indigenous print and health literacies will require change in both health care practitioners' approach to working with Indigenous patients as well as systemic change to make the health care system safer and more accessible for Indigenous patients (Thewes et al. 2018; Lambert et al. 2014; Smylie, Williams, and Cooper 2006; Institute of Medicine 2004). Across the literature on print and health literacies and Indigenous health, there are countless recommendations for best practice. The Institute of Medicine (2004) encourages practitioners to ask patients how they learn best and what help they need to understand their illness and treatment, and to ask follow-up questions to confirm the patient's understanding; they also stress the importance of cultural competence when working with patients from diverse cultural backgrounds. Williams and colleagues (1995) call for the health system to involve patient's support people and/or provide "surrogate readers" and they suggest the use of audio-visual or multimedia resources to aid with comprehension.

Another approach to patient support is the use of health navigators, who are sometimes professionals but are often peers from the same demographic as the patients they are trained to support (The Change Foundation 2012). This model has been implemented by the Metis Nation of B.C. through the hiring of regional mental health navigators who are Metis citizens that support other citizens with accessing and navigating mental health services. Turpel-Lafond's comprehensive report (2020) offers 24 recommendations to address Indigenous-specific racism in the B.C. health system, including calls for health practitioners to receive quality and Indigenousdirected education on Indigenous health and racism, more training and employment opportunities for Indigenous health practitioners, and for Indigenous people to have greater control over policies and system change. Many of these recommendations are echoed in this research project. In this project, the research partners identified the following barriers to care and calls to action:

Common Barriers Identified by the Research Partners:

1. Lack of culturally appropriate care.
2. Lack of alternative and traditional healing options, especially in relation to medication.
3. Over-reliance on document-based assessment and communication, causing stress, triggers, avoidance, and discontinuation.
4. Lack of practitioners, rapid practitioner turn-over, and long wait times interrupt continuity of care, causing anxiety, hesitance to pursue services, and greater reliance on emergency services.
5. Appointment times are limited to ten to fifteen minutes, which is insufficient to adequately discuss and understand health concerns.
6. Reading materials and verbal communication is too technical and uses too much jargon.
7. Lack of "humanity," "care," "understanding," and "compassion" from practitioners, especially in the context of the fear and distress associated with illness, literacy barriers, and navigating the Western health system as an Indigenous person.
8. Racism, discrimination, and stereotyping continues to be perpetuated by practitioners.
9. Involvement of police in "wellness checks" and institutionalizing approaches like involuntary hospitalization cause trauma, fear, distress, and avoidance of accessing services.

10. Feelings that “white man’s” sicknesses, foods, medications, and medical interventions lead to further illness.

Calls to Action Articulated by the Research Partners:

For the Province of B.C.:

1. Provide fully funded, accessible, and culturally affirming mental health services for Indigenous patients, including non-status First Nations, Metis, and Inuit.
2. Address the urgent doctor and psychiatrist shortage.
3. Promote public health initiatives which invest in prevention and early-intervention, including supports for housing, safe substance use, disability support, education, employment, and early-childhood initiatives.
4. Fund essential health services that are currently regarded as “extended” health services such as dentistry, mental health and substance use, prescription medication, and other mental and physical therapies such as massage, chiropractic, and occupational therapy.
5. Create funding and infrastructure to allow practitioners to offer longer appointment times.

For Health Services and Practitioners:

6. Provide longer, in-person appointments where screening, diagnosis, treatment, and aftercare is conducted or explained verbally, using plain language, and with compassion.
7. Prioritize and regularize ongoing cultural competency and sensitivity training.
8. Raise age limits for youth services.

9. Integrate Indigenous health practices, such as holistic care (which includes all four aspects of the self: mind, heart, spirit, body), with Western approaches and approach them as being of equal value and importance.
10. Listen to and work with Indigenous patients as active expert agents in their individual and family health.

Returning to the Research Questions and Intentions

My research questions were:

1. **How do Indigenous people with self-identified low levels of print literacy navigate the Canadian health care system?**

The research partners spoke about the challenges and importance of self-advocacy and emphasized the role of family and friends as supports and advocates. They also spoke about barriers accessing primary care and their resultant reliance on emergency and walk-in services. There were themes of avoidance due to print literacy barriers and racism / discrimination as well as persistent efforts to pursue diagnosis and treatment in the face of these challenges.

2. **What are some of the barriers and challenges they encounter?**

The burden of document-based communication, negative experiences with practitioners and programs, racism, and culturally insensitive and/or inappropriate approaches caused avoidance and discontinuation of participation in or pursuit of treatment. Long wait times, lack of services and practitioners, and lack of community-based mental health supports led to more emergency visits, walk-in clinic usage, and hospitalizations. Research partners explained patterns of not being taken seriously and lack of compassion. It was also clear that there is a lack of holistic care practices that care for emotional, mental, and spiritual wellness, not just physical treatment. There was a desire for greater treatment options, including extended health services, traditional medicines, and alternative or supplementary treatments for prescription medication.

Trauma from Indian Residential Schools, police encounters, and past negative experiences in the health, education, and justice system contributed to feelings of low confidence, lack of safety, and mistrust as well as high levels of anxiety and distress. The high cost of transportation, medication, therapies, and other basics like housing also contributed to challenges accessing care. As people with many pressures such as financial, emotional, physical, and social challenges like racism and discrimination, the research partners all spoke of multiple diagnosis and/or conditions which painted a complex picture of care needs which are not effectively managed by the siloed, interventionist, and short-term approaches to physical and mental health that characterizes the B.C. health system.

3. How do they respond to such challenges?

The research partners all referenced the importance of self and community care. As was clear in the selection of the walking visit locations, connections to land, water, and community are key sources of comfort and healing. Some of the research partners appreciated being able to access services from Indigenous-specific programs such as the First Nations Health Authority. Arts and cultural practices emerged as a central wellness support. Traditional foods, ceremonies, and healing practices were emphasized as important aspects of healing and there was a great desire to increase their access to and use of these traditional treatments. In times of extreme frustration, some research partners shared stories of *putting their foot down*, where they more forcefully demanded adequate care and which sometimes caused them to be seen, as Abigail describes, as a "difficult patient," these firm requests sometimes resulted in practitioners *getting the message* and offering better solutions. Unfortunately, Abigail shared that sometimes this approach led to her being hung-up on and even having a police "wellness check" being called on her. Yet, she continued to acknowledge the importance of self-advocating.

The Intentions of This Project Are:

5. To bring to light how challenges accessing health care are concretely experienced in the daily lives of the research partners.
6. To highlight resiliencies and knowledges of the partners.
7. To illuminate pressing issues or concerns raised by the partners.
8. To identify potentials for improvement in the Canadian health system.

I believe that I was able to achieve the intentions of this project and was successful in answering my research questions. In the context of the scope and limitations of this research, this work contributes a set of successful methodological tools for further Indigenous research as well as a finer understanding of the lived experiences of Indigenous people with low print literacy in the context of the B.C. health system that can enrich the existing and future literature on Indigenous print and health literacy.

Reflecting on the Process and Methodology

In the recruitment phase, I was encouraged to hear that each prospective research partner was very interested in the research methods and often expressed excitement about being able to go for a walk and participate in a beading circle. I believe the methodology aided the recruitment as these activities reinforced the partners' initial interest in the subject of the research. This made participation enticing because we would be contributing useful knowledge about issues that we would like to see change, and we would also be healing, sharing, learning, and connecting in social, creative, and cultural ways. In their community-based, participatory health literacy research project, Gillis (2004) noted that "members of the advisory panel, and many of the participants, saw their involvement in this research process as one way they could be an active player in working for structural change" (p. 16); this was also true of this project.

In this research project, the research partners were motivated right from the beginning because of their desire to see the challenges and barriers that they face meaningfully changed. It was clear that they were passionate about sharing their stories and, once the audio recorder was turned off, we often winded down with thank-yous, laughs, and hugs. The research partners were given $50 honorariums for both the walking visit and the collaborative editing session, at the beading circle they received a beading kit and dinner, and at the Honouring Ceremony they were gifted, given all their research materials, and provided with dinner. The research partners expressed gratitude for the honorariums and the food. After the Honouring Ceremony, I was able to send everyone home with boxes of leftovers from the dinner to feed their families. I was pleased to be able to offer these gifts to all those who were involved. Gifting, and feeding guests is part of proper protocol in many Indigenous communities in the territories now called "Canada" and is accepted as best practice in Indigenous research along with providing honoraria. Sharing resources and food was also a very tangible way I could support and thank the research partners for their time, effort, and knowledge. Further, many Indigenous people and those with low print literacy live with economic challenges and this was true for many of the research partners as parents, students, young people, and low-income households. Considering my grant money helped me pay my bills, it is fair that I share that wealth with the research partners, without whom I would not have been able to do this work and earn my degree.

The incorporation of ceremony was a lynchpin for the cultural relevance and safety of the project. Before each walk and before the beading circle, we began with a smudge (a smoke-cleansing practice where sacred medicines are burned and then drawn over the body). I used sage to clear away negative thoughts and energy, sweetgrass to call in good feelings and energy, and asked each person to add some tobacco to the abalone shell to add their prayers and intentions. Then, I offered a vulture feather, which I described as a symbol of the constant search they undertake as a metaphor for the search for knowledge, or an eagle feather, which I shared was given to me by my best friend and fellow master's student, Connor Williamson, and that using it together symbolized us becoming friends. I thought my vulture idea was clever, but all 6 research partners selected the eagle feather because of the greater spiritual significance of the eagle and because they liked the symbolism of becoming friends.

On August 31st, after my walk with Arie, I wrote in my journal: "today I was grateful to start with a smudge, it 'got my head on straight' and prepared me to do the good work." The smudge was grounding and helped us to set our intentions. I also had the medicines prepared to use in case anyone felt upset and needed some care and medicine to come back into a good place.

I also believe that showing attention to protocol through smudging, asking Elder Barb to offer prayers, and asking Diane Sam to offer protocol also demonstrated to the research partners that I had knowledge of and respect for protocol and common Indigenous cultural values. This also helped me to convey my commitment to doing the work and moving through the process with a *good heart and good mind.*

During the open floor at the Honoring Ceremony, Daniel affirmed the *kiyokewin* method. They said that the walk truly felt like a visit rather than an interview in that it was more connected, safe, and natural, and that there was less pressure and a more even power dynamic. This supports the merits listed in the literature of both walking methods and *kiyokewin*. Ultimately, Daniel said the research was less extractive. Laura admitted that she was nervous about walking and did not feel like going out that day, but that it ended up being pleasant. Liz said being by the water is healing and I feel being next to the ocean as we visited brought that grounding to the encounter. Many times, Laura told me she was proud of me. Each time I felt so uplifted and also so humbled to have her see and acknowledge me and my work. She said after one of our meetings that these are the conversations that need to be happening and that even though the work happens slowly, it starts with telling these stories. In this way, although the research questions and methodology were not co-developed by community in a more formal sense, I was receiving affirmation and encouragement throughout this year of work that the methodology and questions were valid, valuable, and done *in a good way*.

Scope and Limitations

Like all research projects, this thesis has limitations. An important discussion when considering walking methodologies is accessibility. Walking methodologies are not accessible for everyone and the literature tends to assume that walkers are moving and using their legs. I found that walking methods and movement are not reserved for those who can use their legs. The walking experience with Daniel, who uses a manual wheelchair that they lovingly call, Diva, was not inhibited by using wheels rather than legs; all the merits of walking methodologies were present. However, one must assure that walking locations are selected with accessibility needs in mind. For example, Meegan (also known as Beacon Hill Park) has paved walkways. Tiara and Liz explained that they were not feeling well enough to walk for the whole time, so we began in a common location, had our smudge, and then walked to a nice sitting point. Again, the intent of going outside, moving our bodies, being side-by-side, and sharing our internal and external visas remained in our seated position and still positively influenced the visit. I do not feel that anything was sacrificed by us sitting rather than continuously walking and that mobility aids should not disqualify one from participating. However, it is important to acknowledge that many mobility, accessibility, and safety concerns may make it unsafe or impossible for some people to participate in walking methodologies. While I am confident that modifications are possible and effective, walking methodologies simply may not be the best choice for some projects and demographics. However, visiting methodologies can take place in many settings and therefore, visiting could be applied in a way that meets people where they are most comfortable whether it be at bedside, at a kitchen table, or in the heart of a city. We must meet participants where they are at, as the goal of walking and visiting is to make sure the participants feel comfortable, safe, under less pressure, and have a more equal power balance. If physical activity is not possible, a researcher might consider using a hands-on activity instead which also maintains the merits of movement, sociality, and shared focus.

Anonymity is often a key aspect to research and research ethics, however, in this project, it was impossible to be completely anonymous. The walking visits all occurred in public places and therefore we could have been (and were) overheard, interrupted, or seen. The research partners also came together with our families at the beading circle and Honouring Ceremony, and finally, they have their photos, names, and voices on the publicly posted podcasts. While modifications were offered (for example, not joining group activities, not using their names or photos, and not having their podcast posted), there are inherent limitations to anonymity. While this may deter some participants, there is also merit in building community and relationships between these people who often feel alone or isolated and to produce a creative product, like the podcast, that they can be proud to share and put their name on.

Finally, there are some practical limitations. This methodology was time consuming and required a larger budget for costs such as honoraria, food, materials, equipment, and gifts. The nature of sound recording outside requires quality recording equipment to avoid excessive noise from masking sounds like traffic and wind. The recruitment process was also challenging because Indigenous people with low print literacy are a demographic that can be hard to reach. In Victoria, there are no Indigenous-specific literacy services or organizations and general literacy organizations like the Victoria Literacy Connection Society do not have Indigenous-specific services, programs, or staff to help identify potential participants. It also felt challenging to promote this project as I did not want to make any potential participants feel insulted by questions about their literacy or being identified coldly as having low literacy without further context about their other literacies and strengths. I wanted to find an approachable and compassionate way of talking about literacy challenges, leading me to use language like, “do you struggle with reading and writing?”

Another challenge to the recruitment process was that most of my recruitment was through posters on social media, which prioritizes those who can read online posters and social media posts. I was able to connect with one research partner through community connection and I think this would be an important strategy for further research projects. I also did not do any literacy testing because it was beyond my expertise and was going to add many more steps to the project, but most importantly, I worried that it would discourage and deter potential research partners from participating. I also worried that it might make potential partners mistrust or feel judged by me. Finally, I felt that what was most important was that they *felt* like literacy was a barrier for them because that would best reflect their lived reality. The lack of testing may be seen as a limitation of this project as some might want more quantitative data to accompany the qualitative data. A larger-scale project might consider incorporating literacy testing but I would advise a careful selection of which test and which delivery method would be most approachable and compassionate for the specific demographic.

Finally, the small scale of this research poses a limitation. While the research partners came from many different Nations from within and without B.C., they are all living in lək̓ʷəŋən territory and therefore their stories are specific to the Vancouver Island Heath Authority (also known as Island Health). There were status and non-status First Nations as well as on and off reserve research partners, however, there were no Metis or Inuit research partners. While some of the research partners also shared stories from when they were living in rural communities, the research partners were all urban Indigenous people. In addition, this project had six research partners, further research would benefit from having a larger participant pool.

Opportunities for Further Research

Following my discussion of the limitations of this thesis, I reiterate some areas for further research. Researchers might consider a combined qualitative and quantitative approach which includes literacy testing. However, I caution researchers to think carefully about how the testing would impact the participants' feelings of trust, safety, and self-confidence. The findings of this thesis would benefit from expansion to include those whom were not represented, such as Metis and Inuit people and those living in rural or remote areas.

The existing literature on print and health literacy demonstrate that the elderly are among the groups with the greatest print and health literacy challenges and yet have the greatest health needs (Kwan, Frankish, and Rootman 2006; Williams et al. 1995). In Indigenous communities, the elderly are also more likely to be Residential School survivors and/or Indian Hospital survivors, and are more likely to speak their traditional language as a first language, all of which can contribute to lower print literacy, health literacy, and feelings of safety and confidence in health care settings. Undertaking a project specifically designed for elderly Indigenous people would provide critical and necessary insight to improve health care for these important and often under-served people.

In 2008, B.C., Alberta, Saskatchewan, and the Yukon reported higher literacy levels than the national average; therefore, it would be important to conduct further analysis in other provinces and territories, particularly those whose population scored below the national average, including Nunavut, New Brunswick, Newfoundland, and Labrador (Rootman and Gordon-El-Bihbety 2008). Further, as health services are the jurisdiction of provincial and territorial governments, each province or territory will have its own unique barriers, challenges, contexts, strengths, and opportunities regarding print and health literacies, Indigenous-specific racism, and Indigenous community needs and desires. Future research should be designed according to the particular protocols and ethics of the local Indigenous communities as a one-size-fits-all approach would be inappropriate.

Ultimately, I argue that those wishing to do further research on Indigenous literacy, print and health literacy, and health should make every effort to design a project that will be culturally relevant, appropriate, and affirming. It should strengthen all those who participate in the research and should be accessible and provide Indigenous communities and those working in the field of health with knowledge that can create change. I believe this thesis followed these guiding tenets, fully answered the research questions, and achieved the research intentions. This research project and methodology proved to be innovative, successful, and culturally affirming. Together we created a wonderful resource bundle: a scholarly document to further research in this field and a public podcast series that enables anyone to walk-with us, listen to, and learn from these moving visits.

Ekosi maka (that is all from me).

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