Understanding Indigenous Health Literacy

through Community-Led Engagement

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by

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ABSTRACT

Context: This is a community engagement model which evolved from a Mixed Methods Participatory Social Justice (MMPSJ) research project. This model evolved from engagement of Elders in co-creating the questions and then through authentic engagement with the participants in all aspects of the research processes including both synthesis and dissemination. Indigenous community members alongside Elders and researchers explored health literacy in an effort to illuminate root causes of the social determinants of health (SDoH) and to build community capacity.

Objective: To better understand the connections between health and literacy from a local perspective (living on Treaty Six Territory).

Research Questions: In what ways can literacy be considered a social determinant of health from an urban Indigenous community? What literacy issues marginalize the community? How would you like this information shared or disseminated?

Design: Mixed methods participatory social justice and community based participatory health research.

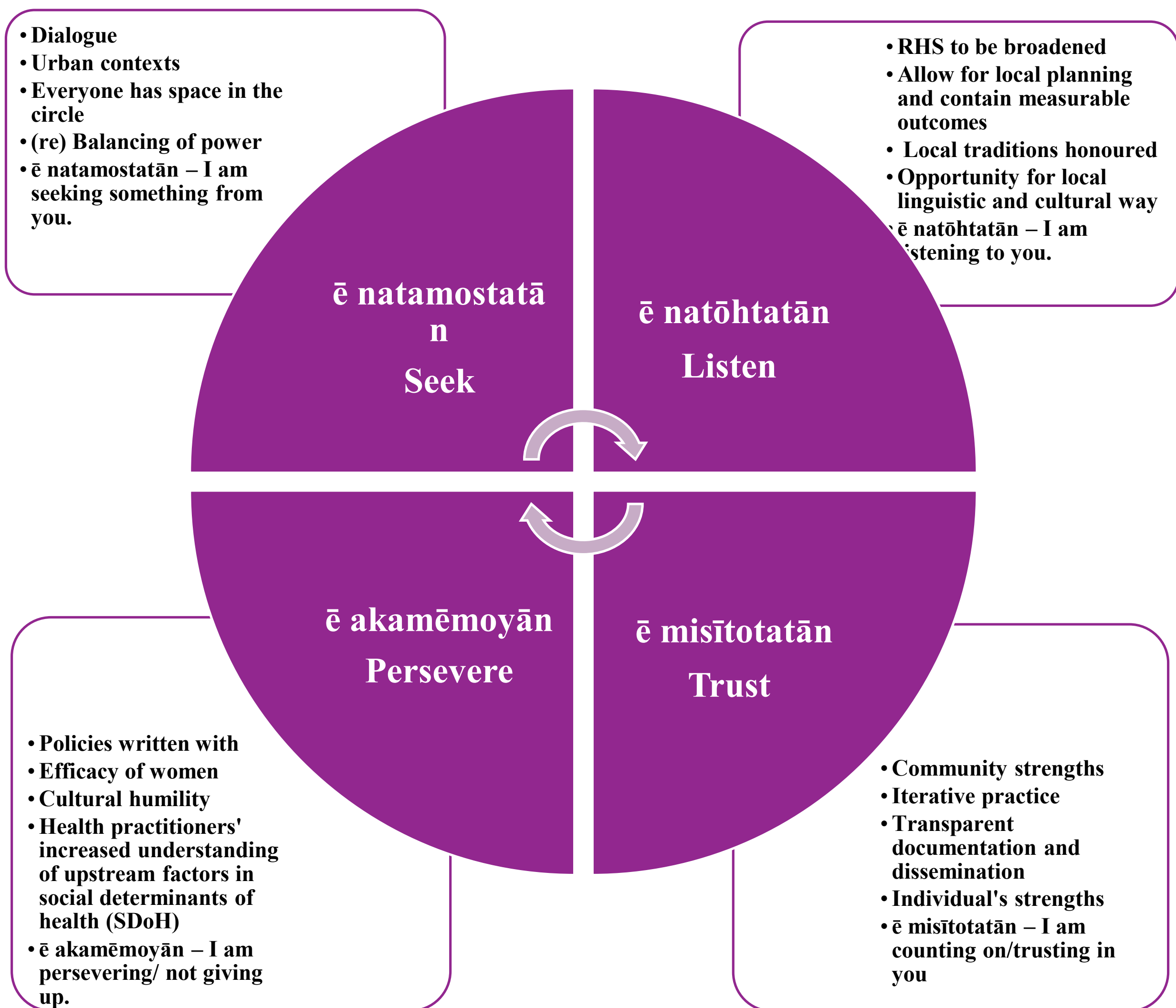
Participants: There were: 12 participants; ten Indigenous intergenerational family members including an Indigenous Elder and two researchers.

Results/Findings: Local, contemporary, Indigenous perspectives were shared in ways that were meaningful to the participants.

Conclusions: Appropriate engagement with local community can: inform the social determinants of health in an appreciative way; enhance ethical space; and provide a richer understanding within community-based research. This approach builds capacity in and with community

members, health care practitioners, educators and policy makers. This in turn will strengthen relationships across systems.

This research was reviewed and approved by the University of Saskatchewan's Behavioural Research Ethics Board (Beh ID #733).



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I would like to recognize Treaty Six territory and the traditional homeland of the Metis. I thank the ancestors who gathered here and kept the land such that we may be gathered in this time and place. To Creator, whom I felt was always part of the team, thank you for walking beside me and being the source of my strength.

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DEDICATION

To the participants who shared their stories, this work was truly co-created. May we continue to be seen and heard in the world.

To my Dad, who taught me to never give up.

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List of Abbreviations

SDoH: Social Determinants of Health

MMPSJ: Mixed Methods Participatory Social Justice

CBPHR: Community Based Participatory Health Research

OCAP: Ownership Control Access and Possession

PHR: Participatory Health Research

AR: Action Research

TCPS 2 (2018): Tri-Council Policy Statement

ICPHR: International Collaboration for Participatory Health Research

NIH: National Institutes of Health

RAC: Research Advisory Committee

UPC: Urban Plains Cree

KT: Knowledge Translation

Chapter One: Coming to The Question

"I still believe in education even though I never had one."[1]

Setting the Context

This research seeks to take a deeper, community-based look at the intersections among literacy and health with local Indigenous perspectives in mind. Social Determinants of Health (SDoH)[2] listed low-income levels, living in poverty, education and being of Indigenous ancestry as four foundational SDoH; however, the connections between education and health have largely left both communities and educators out of the conversation. I first became acquainted with the SDoH as a School Principal when I was serving in a community that was in a low-income neighbourhood. I went on to work in a lower income neighbourhood that served almost exclusively Indigenous families. At first blush, I recognized the limitations of non-educators writing about education as a determinant of health but as I grew in relationship with the community, I realized that the community itself was left out; I was further troubled by the nomenclature of disparity and determinacy. I came, and continue, to care about the people in the statistics and am determined to share the richness of their knowledge, appreciation, and strength that resides in the possibility of collaboration. While health disparity statistics are important, it was felt that by combining both quantitative and qualitative questions a richer understanding could be realized.

The enduring problem in research of non-Indigenous researchers writing 'about' or 'for' Indigenous peoples was a barrier. Through many consultations, community members and the researcher believed that co-writing 'with' was possible. If we are to examine root causes of health, this research holds to the adage: nothing about us without us. Thus, we set off on a walk that sent us on many paths, the sojourning well worth the resting place.

Introduction

The Social Determinants of Health (SDoH) speak to non-medical factors and conditions that affect health.[2] The specific factors vary somewhat geographically. Examples are income and socio- economic status, education, working conditions, food insecurity, early childhood development, and access to health care. Estimates show that the contribution of sectors outside of health to population health outcomes exceeds the contribution from the health sector.[3] They also demonstrate that policies, political systems and dominant (Western) social norms can further affect both positively and negatively the condition of health. Justice plays a role in health inequities as the distribution of money, power and resources are shaped at national and local levels.[4] Key actions include moving forward despite the unavailability of systemic data: researchers are called to use surveys and input from community to help prioritize the strengthening of systems to reduce disparities.[5] In Canada, the same gradient exists: the poorer the individual, the poorer the health. In the words of the Hon. Monique Begin, "social injustice is killing people on a grand scale."[6] Confounding the national context for Indigenous health is the role of colonialism, the lack of a unique approach to Indigenous health, and the fact that most of the research is written by non-Indigenous people about Indigenous peoples.[7]

Personal Motivation

My inspiration for this work has always been Indigenous families. Poverty seems to come hand-in-hand with increased crime rates, domestic violence, poor housing, high rates of rental properties, among others. Based on my experience, this instability affected education outcomes as students may miss school or move among schools. The potential is always there in the students, families and teachers, but instruction matters. As Dr. Julia O'Sullivan[8] stated in an op ed in the Globe and Mail in September 2020, outside of the most complex learning needs, there is little evidence that the vast majority of students cannot learn to read. *Health Disparity in*

Saskatoon: Analysis to Intervention described the regional extent of health disparity, as well as possible causes and preventative measures through extensive community consultation.[9] The health disparity numbers were both staggering and sobering; however, the writers also sought a deeper understanding about the connections among culture and health. As an educator, I too wanted to understand connections between education and health and believed there was a cultural perspective that would allow this to happen.

My first stop when I thought to begin this work was to have tea with an Indigenous Elder, and to ask permission to conduct this research for my PhD. My time as a School Principal serving in high poverty communities with high Indigenous populations for over a decade at that point had taught me to have a profound respect for not only people who were grandparents, but Indigenous Elders - the people that the community recognized as holding wisdom that was much more than knowledge and were highly respected in an Indigenous culture. By asking permission before I began, I felt it would be a lamppost marking the beginning – a light for our path:

"You know, I wouldn't have considered talking about this with a mooniau even five years ago. But I want to help, because I think you have a big challenge ahead of you, and because I am getting older; as you get older, you move close to the Creator. The first thing you are going to have to figure out is how to reach people when we have leaders who will object to what you are doing. I have been in the community for a long time, and people say they talk to the people, but they really don't. They also don't follow the protocols. I suppose because they don't know them. They are stuck in their ways. You have to understand, the systems and the structures, work for those who are employed within them, and they work for people in power, because they created them. Even the information that they collect, and the way they collect it serves to keep everything the same while saying that 'the problem' is with Indian People.[10]

Terminology

Key terms: Indigenous, Plains Cree, Literacy, Education, Health Disparity, Social Determinants of Health, Elder, Tobacco Protocol, Smudge.

This research is situated on Treaty Six Territory where the majority of Indigenous people are Plains Cree. It is also the traditional homeland of the Metis, alongside other Indigenous peoples such as the Saulteaux and Dakota. *Indigenous* refers collectively to First Nation, Métis, and Inuit.[11] For the purposes of this research, the terms Indigenous will describe the participants, and the term Plains Cree will describe the people, the place, and the protocols as led by the Elders.

Education as a determinant of health is a broad term used to describe early experiences of children. Unfortunately, the terms *education* and *literacy* are almost interchangeable in health journals; for example, "education and literacy are important not only for providing children with key experiences that may have lifelong effects but for setting individuals on a life course trajectory for either health or illness."[12] As an educator, I would have more discrete terms and commensurate forms of measurement. However, as this work is situated in community and health, I will use the term literacy in the research questions and describe it as it has been in the past by Freirean theory which is expanded upon in the literature review in Chapter Two, then seek to evolve literacy as understood by the people in the community and its connection to health. We will jointly also use the term *literacy* instead of education to narrow it because it aligns with the theoretical orientation of this work. The connections among Freirean theory, literacy, health and transformation were described by two Elders in the first phase of this research and will be illuminated in the methodology chapter of this thesis. My connection to the term *literacy* is similar to Freire's who took a meta-cognitive stance. He saw that the merit of any literacy program would be that people would see words as agents of transformation: "As

illiterate men discover the relativity of ignorance and wisdom, they destroy one of the myths by which the false elites have manipulated them. Learning to read and write has meaning in that by requiring men to reflect about themselves and about the world they are in and with, it makes them discover that the world is also theirs, that their work is not the price they pay for being men, but rather a way of loving and of helping the world to be a better place."[13] Hence, we will use this definition of literacy for the purposes of this research.

Health Disparity speaks to the gaps among health and illness; it also describes the living and working conditions that can lead to poor health. It is a term commonly used within the SDoH. It includes but is not limited to the key terms in this study such as being of Indigenous ancestry, living in poverty, and education levels.[14] *Social Determinants of Health* are the broad range of personal, social, economic and environmental factors that determine individual and population health.[15] Elders are people that are respected and recognized by a First Nations community. In Cree, also called the Nehiyaw language, the term for an Elder is Kehte-ayak. The offering of tobacco, also called following the *tobacco protocol*[11] is one that speaks to acceptance and participation. It is typically given in person as a sign of respect for the person and the place before commencing the work. *Smudging* is an act of purification, welcoming, and setting of intent to have a good gathering. The Elder chooses the traditional medicine or combination of medicines to use but it is usually sage, cedar or sweetgrass.

Aims and Objectives

The intersections among literacy and health are enduring within the SDoH research. Educational attainment is viewed as not only a determinant, but also as a root cause and potentially as a conduit to living a healthy life. The purpose of this research endeavour was to draw from the strength of community to describe a richer understanding of these intersections

with Plains Cree community members. It is relational work, drawing people together in respectful ways. It was launched from the belief that collective wisdom is more robust and has the power to transform those involved.

Research Questions

In what ways can literacy be considered a social determinant of health from an urban Plains Cree community? What literacy issues marginalize the community? How would you like this knowledge shared or disseminated?

Roadmap for the Journey

The big ideas in this research are described in the literature review in Chapter Two. Chapter Three is focused on building the Mixed Methods Participatory Framework from a historical, contextual, ethical, and local perspective with the participants. Chapter Four will discuss how the research played out in real time. Chapter Five will animate the dialogic of the gatherings. Chapter Six will explore recommendations and future possibilities; the synthesis comes in the form of a community engagement model.

Summary

We ask readers to use the introduction and context as a departure point. This research is steeped in primary health care, community-based participatory research, educational research, social justice, transformative learning, appreciative inquiry, and action research. We undertook our learning in stages. To our knowledge, this is the only application of MMPSJ work set within Plains Cree Territory with Indigenous peoples, incorporating engagement, leadership and knowledge reciprocity throughout.

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Chapter Two: Literature Review

The World Health Organization's Commission on the Social Determinants of Health[1] and Social Determinants of Health: The Canadian Facts[2] list and expand upon some common themes that correlate education as one of fourteen social factors in determining health. In 2006, the Saskatoon Health Region[3] released a report that showed a strong correlation between income and health - essentially 'the poor have poorer health'. The purpose of this research will be to take an in-depth look at education as a determinant of health within a community with high rates of poverty that is largely Indigenous. Specifically, to respond to the research question: *In what ways can literacy be considered a social determinant of health from an urban Plains Cree community? What literacy issues marginalize community? How would you like this information shared or disseminated?* By placing the community in the centre of their children's education and collaboratively querying about literacy and its impact on health, it is hoped that literacy outcomes will be improved. Both lower education outcomes and higher health disparities are more likely to be experienced when Indigenous populations' educational attainment levels are disaggregated whereas supporting opportunities for educational attainment, particularly for Indigenous populations, is critical to reducing health disparities.[4,5] Incorporating traditional knowledge and values into participatory processes and a sense of positive Indigenous identity can further increase opportunities for Indigenous children.[5-8]

The background literature on education as a social determinant of health speaks to early intervention programming, employment opportunities, literacy and improved access to training opportunities, and the role of public policy in shaping both education and health.[2] A number of statistical analyses that have separately controlled for the effects of education and income indicate that, while both are associated with ill health, lack of education is the predominant

factor.[3] There is also a gap in research by including new understandings from Indigenous Canadians about how literacy, health and culture are connected and to lend insight into the need for open, evolving definitions with input from populations that are served by the education and health care systems.[4]

For the purposes of this literature review, a simple graphic is provided. It serves as a compass to navigate the related topics to this research.

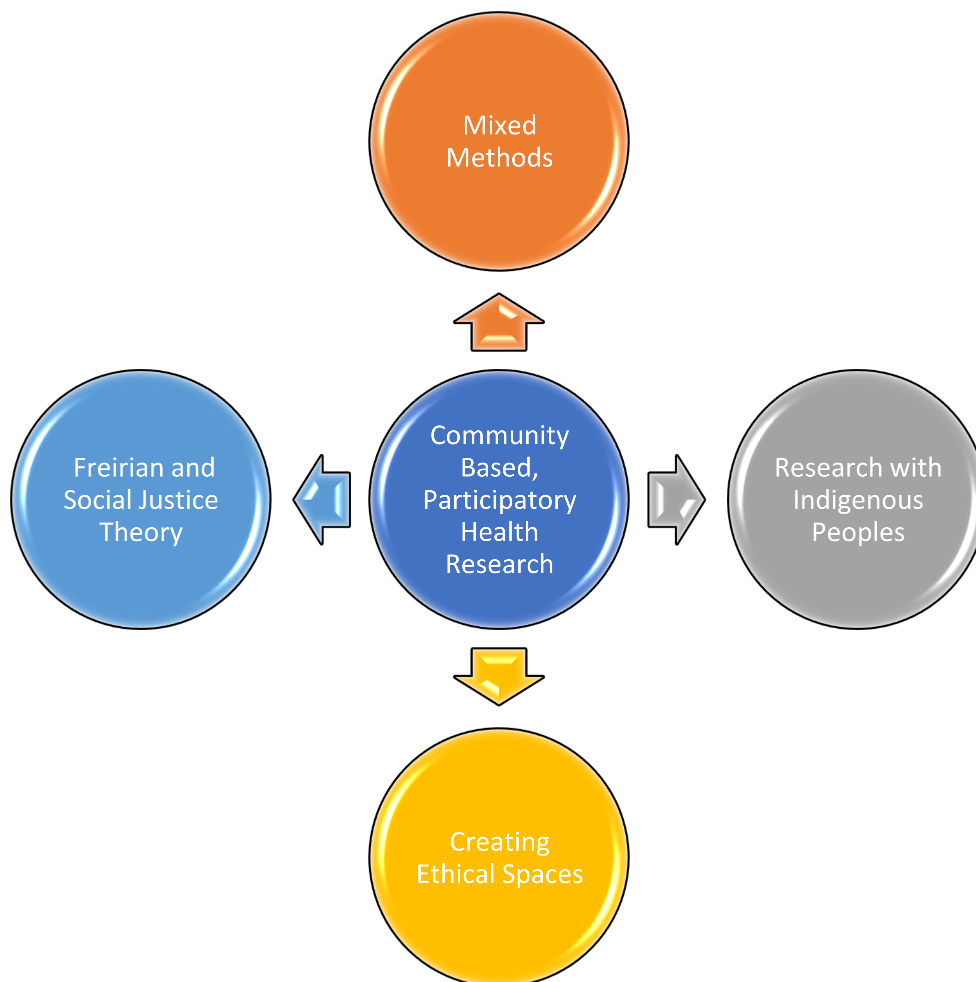

Figure 2.1: Key Concepts

<u>Community-Based Participatory Health Research</u>

The first word in the graphic is community. Community-based participatory health research (CBPHR) serves to integrate social action and education to reduce health disparities and improve health. It operates on the virtues of respectful relationships, reciprocity, commitment to community theories, and co- learning.[5] Its strength lies in its ideology; some of its limitations lie in the deep commitment that it takes to reflect on these virtues from the researcher(s) and community perspectives. There is a need to unpack power and privilege, the principles of OCAP® and to allow the research to enter into some possible borderlands or tensions.[6] CBPHR is also situated in the middle as it is by its nature a capacity building approach; in health research, there is heightened importance on engaging with individuals/patients and communities throughout and in all aspects of the research process.[7]

Participatory Health Research

Participatory health research (PHR) was an umbrella term that was linked to other forms of research, including action research, praxis research, collaborative inquiry, and participatory inquiry.[9] The theory, intent, process and outcome varied greatly; yet as PHR questions were locally determined and situated, this variance might have been attributed to different areas using this approach in different communities.[10] PHR involved people reflecting on and theorizing about their practices; as a starting point, it required people to be inquisitive about the relationships and forces between circumstances, actions and consequences in their lives.[11] It merged both the goals of enhancing the practice of researchers and the capacity of participants.[8] PHR emerged in an effort to provide a means for people most affected by poor health to partake in decision-making processes and subsequently influence how health problems can be addressed/solved.[8] PHR operated within a paradigm, not a methodology; it was and is an orientation to inquiry. PHR was informed by many traditions and positions and made a unique

contribution to knowledge and action particularly in the domains of health inequalities and social determinants of health (SDoH).[12] It was aligned with a social movement and sought to improve the lives of those involved. As a foundation, it was based on the principles of democracy and individuals or communities exercising their participation in a democratic society and democratic processes. Ultimately, together, PH researchers aimed to provide voice to community, enhance their participation in a democratic society and re-frame social practices.

Recent investigation into the connections between PHR and action research (AR) beyond those stated were on the upswing. Involving patients and service providers in research made sense and was an increasing requirement in accessing research funding.[13] PHR and AR were similar in the domains of collaborative research and practice change, yet they can be differentiated by varying emphases on the role of collaborators or individuals, or whose knowledge is considered most valuable, if participants were seen as active or passive, and if the research is done *on* or *with* participants.[10,13] PHR promotes the understanding that health concerns were also caused by determinants outside of the individual's control or biology; these were described as social determinants of health (SDoH). PHR asked professionals to be critically reflexive to examine their individual practice yet seek collective strategies to address these social determinants.[13] It would be theoretically possible for researchers to undertake the action research cycle of reflecting, planning, acting and observing without involving stakeholders throughout the entire process; PHR required further, iterative cycles that engage participants throughout. A key characteristic of PHR can be described as a certain confrontation or messiness. This was part of the dialectic requiring new synthesis to ensure rigour. Within PHR, the process assumes that the residents of an affected community must be involved in the

research process in order to affect a cure/solution; this knowledge enhancement would lead to greater awareness and uptake.[13]

In PHR however, the choice of research methods was driven by the learning objective of the co-researchers (i.e., goal-driven choice), but also could be by the socio-cultural particulars of the community involved (i.e., context-driven choice). One of the key indicators was knowledge reciprocity and knowledge sharing throughout, in accessible and meaningful ways. Since PHR aims to make research findings accessible to all, knowledge produced in ways that are most familiar to the community is likely to be the most trusted. For example, a community with a strong oral tradition might attach a great deal of importance to knowledge and experience depicted in a traditional story telling form.[10]

Research with Indigenous Peoples

This research question is situated and inspired within a primarily Indigenous community with very low socioeconomic status. . The TCPS 2 2018[14] discusses the particular definitions and responsibilities for researchers in this context. It also describes ethical considerations where common interests may be explored. Predominantly, research involving Indigenous peoples has been carried out by non-Indigenous researchers. Such is the case with this research; where this occurs, researchers are to have heightened scrutiny around establishing trusting relationships and the value of reciprocity.[14]

So, what is a non-Indigenous researcher to do? How can I, and others, advance, collaborate and advocate? There are key criticisms to consider as a non-Indigenous researcher in an Indigenous community. The first is that non-Indigenous researchers have been criticized for imposing a Western way of knowing upon Indigenous communities. Linda Tuhuwai Smith[15] says in Decolonizing Methodologies*:* “the term research is inextricably linked to European

imperialism and colonialism. The word itself, ‘research’ is probably one of the dirtiest words in the Indigenous world’s vocabulary”[16]. In Phase One of the research that we will build upon in later Chapters, two Elders were engaged. One was quick to share:

And so, as a colonized people, the people were really so badly treated by settler Canadians, by John A MacDonald from the get-go. In 1867 when he was in the Department of Indian Affairs. As descendants, we inherited that schism created by settler Canadians in terms of racism. (Transcript from Elder)

Yet, Linda Tuhuwai-Smith[15] further remarks that, ‘non-Indigenous alliances are often unavoidable and tacitly necessary to get the work done’ and ‘community-based researchers offer something quite different because they are so well-placed within a community to document what is happening at a local level over long periods of time. They have the advantages and dis-advantages of being eye-witnesses to events and their aftermath; they lend a different kind of evidentiary authority because of the immediacy of their context’. Non- Indigenous researchers have to regard Indigenous people as not only having the ability, but having the right to initiate, contribute, critique and evaluate research as part of self-determination.

She goes on to describe a powerful remembered history where “it appalls us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce and based on brief encounters know all that is possible to know of Indigenous ways, while only meeting few of the people.” As someone who has worked with many Indigenous peoples in a variety of settings, I can relate to what she is saying. My Indigenous teachers have taught me that there are many ways of knowing that relate back to kinship and land; put another way, the way that Indigenous people live their culture can be as unique as the

community they come from, further informed by their lineage, participation (or not) in ceremony, ability (or not) to be a language keeper, and particularly in Saskatchewan how Residential School impacted them inter-generationally. Tuhuwai-Smith[15] sums up the crux of the problem in that Westerners believe that "understanding is viewed as akin to measuring" (p.44). How the West views research, she argues, is so hegemonic that western (or colonized) perspectives become invisible. "The sense of what the idea of the West represents is important here because to a large extent, theories about research are underpinned by a cultural system of classification and representation, by views about human nature, human morality and virtue, by conceptions of space and time, by conceptions of gender and race"[15].

Mere Berryman,[17] in Culturally Responsive Methodologies, encouraged a research stance 'where establishing respectful relationships with participants is central to both human dignity and the research - it requires researchers to develop relationships that will enable them to intimately know the "other" with whom they seek to study". In community-based research within an Indigenous community, where knowledge is co-created by the researcher and the participants, basic assumptions about how knowledge is created and whose knowledge is valuable must be taken into account within the research framework. "Conventional methodology, both quantitative and qualitative, lack commitment to inclusiveness, cultural diversity, and epistemological pluralism"[17]. She related that there was more than one way of knowing; that looking beyond to other ways of knowing may enhance understanding of complexities. Berryman[17] went on to explain that cultural competence can serve to 'maintain and reinforce the dominance of the researcher.' She believed that a culturally responsive researcher should 'develop contexts within which the researched community can define, in their own ways, the terms for engaging, relating and interacting in the co-creation of new knowledge'[17]. This aligns

with Freire who believed that the local people were the experts of their own lived experience. "Applying Freire's work to the relationship between the researcher and the researched, culturally responsive methodology reframes the researcher's stance as expert to one of learner where the people who come from 'another world' to the world of people who do so not as invaders"[17]. Freire[18] echoes this sentiment as 'conversely, the people/participants are not acted on by the researchers, instead they are leaders 'reborn in new knowledge and action'. Berryman[17] summed up the sentiment with, "humility and self-awareness of our mutual incompleteness can sustain our relationship and for and with one another". The immediacy of my content in the community, the relationships that have grown over time, and the incomplete conversations have provided the motivation for me to do the work of this research.

The term cultural humility captures the paradox and confluence on the situatedness of this research. John Van Maanen[19] described:

> "Culture is certainly one of the more contentious and complex words in our lexicon. Like the term 'force' to a physicist or 'life' to a biologist, or even 'God' to a theologian, culture to the ethnographer is multi-vocal, highly ambiguous, shape-shifting and difficult if not impossible to pin down. When put into use, contradictions abound. Culture is taken by some of its most distinguished students as cause and consequence, as material and immaterial, as coherent and fragmented, as grand and humble, as visible (to some) and invisible (to many)…"

While the term culture is seen through many lenses as noted, so is the construct of cultural competency, which is a factor when working with Indigenous communities. This research, however, is framed within the construct of cultural humility. The key shift is not in the reference to culture rather to the use of humility instead of competency. In a mixed methods study situated within an Indigenous community, Mary Isaacson[20] captured this by noting that despite competency education in health care, inequities in health care remain. Cultural humility refers to open, active listening, self-reflection, and self-criticism as parts of the process. Cultural

humility has a deeper recognition within cultures that cannot be learned; but it is impossible to be completely knowledgeable about cultures that are not your own.[21] Cultural humility does not open, then check the box of a module. It is about commitment to confronting possible negative stereotypes that have the potential to affect experience. It is also appreciative by nature where strengths and gifts are both the foundation and the recognized. In Canada, the Truth and Reconciliation Calls to Action[22] beckon us to work on employment gaps and to improve education attainment levels and success rates with full participation of Indigenous peoples. It is hoped that by adopting cultural humility as a construct in this research, the ability to engage in authentic participatory decision-making processes by everyone is made possible.

Willy Ermine's thoughts on creating ethical spaces[23] was a way to re-consider the TCPS2 2018 Ethical Guidelines on Research Involving First Nations, Inuit and Métis People of Canada[14]. There are many concerns and recommendations shared in Willy Ermine's discussion regarding ethics[23]. They include, but are not limited by, a conceptual development for ethical space; copyrighting of Indigenous People's intellectual and cultural property rights; and understanding the role of education in the process of knowledge and cultural transmission.

Creating ethical space were important, particularly for researchers that were contemplating crossing/bridging cultural borders. Ermine[23] described the necessity of dialogue, negotiation, and research agreements with Indigenous authorities as the foundation of ethical practice for any research undertaken with Indigenous peoples. He believed that by copyrighting and ensuring that Indigenous peoples can claim cultural knowledge as their own prior to funding being received from granting agencies would objectify or create Indigenous knowledge as an entity in and of itself. While he talks about further understanding education's role, he says that

it is important, but doesn't describe how to go about it in a good way. He does advocate for funding so that research of this nature can be supported.

Ermine[23] expounded on two key ideas: that Indigenous knowledge was told within oral traditions and that researchers needed to locate themselves in relation to their own kinship and place. He affirmed that, "One research milieu that incorporates the means to address social inequity is found in participatory action research (PAR). This approach to community issues is a culturally relevant and an empowering method for Indigenous peoples in Canada and worldwide as it critiques the ongoing impact of colonization. PAR can, therefore, be quite significant to the inclusion of Indigenous epistemology in the discourse of research"[23]. He further went on to postulate that an inclusive approach, research *with* Indigenous people promotes respectful relationships then the more applicable Western qualitative research will be to Indigenous people.[23] I agree with Ermine, and Denzin and Lincoln[24] who say that cultural safety protects the Indigenous worldview. Together, they argued that because there was/is not enough of a critical mass of Indigenous peoples in post-secondary populations, research with allies was important. That said, Ermine[23] defines research as 'an encounter between the West and the Other' and challenged researchers to question research hegemony. It was within this challenge that researchers needed to enrich their understanding of colonial history but further that it liberated the people through practical results. This means that colonization has impacted all peoples and that efforts need to be made to lift and support Indigenous peoples. He quotes Sinclair[25]: "In the contemporary context, the research agenda comprises political, emancipatory, and ameliorative objectives." Much like Freire, he espouses that without careful consideration of the structures that recapitulate knowledge production, research can 'prescribe the recreation of the very social

conditions that marginalize Indigenous peoples.' The structures, he believes, are complicit in the creation of intolerance.

Ermine[23] recommended a neutral space where the convergence of the Western and the Indigenous world views, two solitudes, could be encountered together. In my understanding, he was questioning on a deeper level where knowledge stood in the place of lived experience, and who it serves in ordinary time. He described the neutral zone as a fragile window of opportunity: "With the gazing eye of Western science, and the mental aptitude of Western philosophy, information obtained from Indigenous spaces is reformulated into propositions that stand as the reality of Indigenous peoples lived experience"[23].

Interrelated Pathways, Interrelated Barriers

Our graphic started with the community at the heart of our research question: *In what ways can literacy be considered a social determinant of health from an urban Plains Cree community*? *What literacy issues marginalize community*? *How would you like this knowledge shared or disseminated*? In examining issues that Indigenous families face in Western Canada in post- secondary educational institutions, the intersections among educational attainment and health are many, including the ability to make better health related decisions, higher employment rates, the shaping of employment opportunities, and the perception of greater self-control.[3] Parental level of educational attainment is a predictor of both the entry to post-secondary education and the persistence throughout. The disadvantages to Indigenous youth, particularly those whose family members would have attended Residential School is a deep barrier often coupled with the responsibility of accommodating squarely on the shoulders of the students. Failure to "leave behind the cultural knowledge, traditions and values they bring…{and} to develop a new consciousness and orientation and assume the trappings of a reality very different

from their own"[26] can further intersect with institutional racism where policies and practices serve predominantly dominant Anglo culture and norms. This research's response to the question should facilitate respectful processes and hopefully support a better understanding of a non-dominant perspective. Further, by placing an emphasis on early literacy skills, it appreciates the hope the resides in elementary aged children.

Freirean and Social Justice Theory

"What I have been proposing is a profound respect for the cultural identity of students—a cultural identity that implies respect for the language of the other, the color of the other, the gender of the other, the class of the other, the sexual orientation of the other, the intellectual capacity of the other; that implies the ability to stimulate the creativity of the other. But these things take place in a social and historical context and not in pure air. These things take place in history and I, Paulo Freire, am not the owner of history"[27].

Emphasis on Dialogue and the Role of Praxis

Paulo Freire believed that learners needed to be actively engaged in the world, in their world. He was in opposition to the traditional empirical-analytical approach where the teacher (or researcher) held the knowledge and the students were empty vessels. Freire worked with adult learners. He proposed a shift from the student-as-object to the student-as-subject. In order for this to happen, there needed to be dialogue. This construct was entrenched in Freirean theory and is based on the understanding of how action and reflection work together. Essentially, action without reflection resulted in acting without thinking. Reflection without action was just talking. *Dialogical action* involved a constant cycle of back and forth between action and reflection; when these two come together, the result is praxis. Praxis sets the foundation for transformation.

In, Education for Critical Consciousness, Freire[28] talked about the preconditions for the development for participatory behaviours. He referred to the vertical relationships among people

as ‘the great pressure on the upper strata to treat the lower as vulgar, innately inferior, a lower caste beyond the pale of human society’[28]. The sharp difference in the living style between those at the top and those at the bottom made this psychologically necessary; this vertical positioning created systems for superimposing solutions that were doomed to fail from Freire's perspective. He postulated that by considering horizontal relationships and requiring people to participate, the resulting actions were more likely to be successful.

<u>Conscientization</u>

This concept was first introduced in *Conscientization.*[29] Freire took an entirely optimistic approach about the possibilities of education. He was fully convinced that education, an exercise in freedom, was an act of knowing; a critical approach to reality.[30] This reality probing required involvement alongside a utopian attitude toward the world. Most notable about Freire was the underlying constructs of power: in his ideology power was appropriated to the people. Because he worked with oppressed people, his construct of conscientization required individuals to see that they were oppressed, then to commit to transforming the oppressed reality. People who do not have this level of historical involvement were not conscientized. He was concerned that even in times of revolution that if people were not educated towards freedom, the myths of one form of oppression would carry over; because people will think the same, they will act the same. Again, the cycle of action, reflection, and creation of action led to liberation: “the process of conscientization leaves no one with her arms folded. It makes some unfold their arms. It leaves others with a guilt feeling, because conscientization shows us that God wants us to act”[29].

In, Education for Critical Consciousness, Freire[28] further explored his idea of conscientization. He believed that the necessary critical consciousness was integrated with reality and that it was the naive who superimposed themselves or their ideology on reality.[28] The

core concept was faith - faith in people and all of their possibilities. Only with faith would dialogue and power have meaning.

Situating Education in the Context of Lived Experience of Oppressed Populations

Freire was important because he believed that if we want marginalized populations to have true choices in their lives and capabilities that are meaningful to them, they had to be participants in co-creating solutions. He believed that education was an act of love, and therefore an act of courage.[28] By using dialogue, people could discuss courageously the problems of their context. Without opportunities for debate and discussion, people would not make informed or reflective choices. The idea of knowledge as being exterior to the community was antithetical to a more humanistic didactic experience that was the cornerstone of a liberated education.

Literacy Definition

Freire took a meta-cognitive stance on literacy. He saw that the merit of any literacy program would be that people would see words as agents of transformation: "As illiterate men discover the relativity of ignorance and of wisdom, they destroy one of the myths by which false elites have manipulated them. Learning to read and write has meaning in that by requiring men to reflect about themselves and about the world they are in and with, it makes them discover that the world is also theirs, that their work is not the price they pay for being men, but rather a way of loving and of helping the world to be a better place"[28].

What stood out the most about Freire was that he was *doing the work with the people.* His insistence that education was the common, humanized experience aligned with the values of participatory health research. It was a well-placed conversation that we should continue having today; the translation of his work into practice means that how we treat and view people matters,

and what they were able to do in their every-day lives will be the conduit to empowering community towards a more just society.

Freire's insistence that dialogue and interchange was the foundation to self-empowerment aligns with both Action Research (AR) and CBPHR. In AR, (according to Lewin) researchers moved past the people-as-object stance and included others in determining "the problem".[31] In CBPHR, the central albeit idealistic premise was that everyone was equal throughout the process; this basic belief would lead to more relevant, responsive research. Put another way, usefulness was a measure of validity to the process. Specific participatory processes are not well described and less well described when working with an Indigenous community. This tension will be further explored in Chapter Three as the methodology is examined and discussed.

Freire's theme of humility also resonated with my research as I have been reflecting on the idea of practicing cultural humility. While Freire asked people to consider horizontal relationships among people, teachings from Indigenous Elders and Knowledge Keepers have highlighted the framework of circular relationships. Both horizontal and vertical relationships are still linear, with beginning and end points. In the development of theory, circular relationships ensure the necessary critical reflection of self; there are no openings or endings, just the imperative to continue the process. This theme is further explored in Chapter Four.

Mixed Methods and the Participatory Social Justice Connection

The classic design of mixed-methods research (MMR) involves three pillars: qualitative exploration with a small, purposeful sample using open ended questions and inductive analysis; quantitative inquiry that tests patterns larger than the sample, followed by a deepening of the

inquiry - a return to qualitative factors perhaps even as an in-depth interview to create richer understanding.[32] It emerged as a result of growing dialogue around the complexity of social phenomena and researchers' desires to consider multiple data sources and multiple perspectives.[33] Specifically, MMR used both quantitative and qualitative information to create unique meta-inferences to draw conclusions based on the integration of both of these sources of information.[34] It created a space to offset the either/or bifurcation between qualitative and quantitative data and methodologies; it was distinguished as an effort to be as inclusive as possible.[35]

The theoretical foundation of mixed methods draws from Greene et al[36] (1989) who described a conceptual framework to create a thoughtfulness in both design and implementation of MMR. They carefully described the constructs of triangulation as offsetting and contrasting information, and heterogeneity as convergence of results from multiple methods, theoretical orientations and varying political views.[36] The constructs of triangulation and heterogeneity set mixed methods apart from other methodologies.

Mixed methods participatory social justice (MMPSJ) was a framework first described in 2018 by Creswell and Clark[37]. It was considered a complex application; its origin was built on the work by Ivankova[33] who refined Lewin's[31] four stages of action research. The shift in MMPSJ work was that community was involved at every level, including potentially defining the research question.[37] The necessary stages involved: identifying the inequality, historical silencing, or oppression; including the voice of and being sensitive to the culture of the marginalized group; and, generating useful evidence.[33] Strengths of MMPSJ included: it appealed to both stakeholders and community; it fostered change and empowerment; everyone played an active role; and researchers themselves were guided by the community throughout the

process. Limitations highlighted were that variants and specific designs were not yet well documented. Researchers needed a variety of expertise including community connections while employing a theoretical lens. As MMPSJ is a relatively new framework, researchers may need to learn with participants; threading and involving the community throughout was recommended but is tricky as ideas emerge. Maintaining cultural sensitivity and demonstrating the researcher's cultural competency when working with marginalized communities was an additional challenge.[38]

Patton[32] suggested that there might have to be some sacrifice of methodological sophistication in MMR in order to produce timely evidence that could be used and further developed in the real time process of transformation. What was interesting was that the reduction of scholarly rigor might translate into better practices in promoting efficacy among participants in research; translation, the emphasis as on the quality of the work in doing what it sets out to do: "whether their practices were more efficacious, their understandings clearer, the settings in which they practice more rational, just, and productive"[35]. Which, ultimately, is the goal of good research.

To note, there are unique ethical concerns in conducting action research in education that relate to who or what was being researched. If teachers were using students as part of focus groups or studying how they learn, students may not feel authentically that they can withdraw from the study, or in fact to have the right to not be in the study at all.[23] As there are special considerations when engaging in research in any community, the power relationship between teachers, students, administration and families need to be carefully thought through.

Both education and health are driven by policy; if policy makers must accept research findings before they consider changing policies, then using both qualitative and qualitative sources might provide the contextual findings to justify change.[39] These points of convergence are explored in greater detail below, limitations are examined, followed by a synopsis and the graphic is revisited.

Points of Convergence

CBPHR is characterized by learning and problem solving with community. It has the potential to empower groups of people from varying backgrounds and interests to learn together and affect the community they lived and worked in to invoke and sustain pragmatic action. AR, PHR and MMR were all inquiry-based processes that could lead participants to evolve in their relationships with themselves, people and systems. These secondary results often were as important as the response to the primary research question.[23,32] Researchers were required to inquire from within in the hopes of creating richer data. In this context, critics believed that maintaining a scientific or objective distance can be a concern. Reflexivity was part of the process, but difficult to actualize when close to the data sources.

The complexity and criticisms of these approaches would be in the liminal space between knowledge to use: defining this gap illuminated the careful considerations needed to authentically engage all participants equally. Researchers whose own skill sets may be limited were encouraged to mind the space and deal with power, cultural and generic issues that arise in the interactive spaces. Further, a strength could be a limitation. For example, CBPHR can contribute to advancing theory and knowledge when there may not be a clear line to follow and does not let the researcher alone describe or explain information or data without the participants' involvement.[40] This process can be confusing or messy. CBPHR has a fundamental aim to

consider power and powerlessness and how these affect the daily lives and practices of those whose life or work is the focus of the research.[8] Yet, people's individual knowledge levels may vary and personalities may lead some to shy away from participating or encourage some to participate too vigorously. Theoretically, Freire talked about knowledge as a social process. This, in ideology, connects with CBPHR in that knowledge is constructed throughout, yet a personal criticism in practicality would be that a patient and a doctor operate within a balanced knowledge construct. Freire went on to describe different types of knowledge, from an unconscious level to a critical and reflective level. He theorized that beliefs were shaped into knowledge by critical reflection and discussion. He postulated that by seeking connections among understanding and feeling, delimiting the dichotomy of cognition and emotion, researchers could avoid or minimize the flaw of synthesizing opposites[41].

Critics of CBPHR were concerned with the role of oppressed people in research. When working with any community, there was a danger that the research will serve a simple purpose: to confirm what the people want to see happen. Further critics of CBPHR contended that the ideology of CBPHR was contentious - that only oppressed people know their truth and that this could lead to overall confusion about intended outcomes: what is needed to educate people, create new knowledge, or create action? While some texts might argue that the response could be all three, the clarity needed for research to proceed and subsequent tests of validity and reliability might not be cohesive.[8] Further, there are limitations on generalizability from one community to the next as the community involved would have different people, partners and stakeholders; thus, a researcher might be investigating an idiosyncratic problem. CBPHR was considered methodologically naive in assuming that all participants have the same ability to share, create and be critical about the process.[42] As the research questions evolved from the

community and were iterative, connecting the process seamlessly from beginning to end was and is always an authentic challenge. More importantly, from a transformative perspective, what could be the true test of nudging those in power, changing systems, or in fact changing the way people act and think in the world?[43] Thus, CBPHR's aim for critical reflexivity recognizes the uneven playing field for individuals within a system. It begs questions potentially out of the grasp of the group; what if the participants can't truly affect change/participate democratically- what if the systemic structures won't hold the weight of the plan? What if local leadership does not provide support? What if the lay people are not seen as knowledge producers? What if the local community is deplete of services? Recommendations were well intended, but as Lewin[31] suggested, the production of more reports and books wasn't the point in the first place.

CBPHR has come under recent and serious scrutiny particularly in Indigenous communities. Often, research is done *on* participants rather than *with*. Particularly in Canada, where the impacts of colonization affect both Indigenous and non-Indigenous peoples, researchers must pay special attention to the fact that Indigenous peoples have long been an *object* of inquiry. The term research itself is linked to colonialism and can create distrust. Researchers needed to recognize that a certain parachuting in and out of Indigenous communities resulted in over generalizing, creating pan-Indigenous constructs, and ultimately a rejection of Indigenous ways of knowing and their ability to create their own realities.[15] There was also an interesting space where non-Indigenous people researching in Indigenous communities (which is more common) have to be considerably more self-aware and self-reflective. Practicing cultural humility is important, but strategies to promote this level of consciousness are difficult to find.[44] Parallel to earlier concerns, how can researchers provide evidence of self-reflection? Further, researchers tended to cloak their understandings in academic jargon while dismissing the

knowledge of the community it had intended to serve.[10] Specifically, at the analysis and interpretation phase, humanistic and experiential Indigenous ways of knowing weren't incorporated, perhaps based on the limitations of the researcher. Finding specific ways to practice reciprocity in knowledge sharing for non-Indigenous researchers was a limitation in the examination of the literature.

Mixed-methods critics stated that this type of research was time consuming and maintaining interpretive consistency throughout remained a challenge.[33] There were varying understandings of the term triangulation and how mixing methods can mean mixing paradigms.[45] Pragmatically, the logic from one question may not flow. Critics also acknowledged that numbers and words produced different data, but also expressed different results; consider a narrative about how a patient feels paralleled to a dosage chart. While mixed methods researchers may provide a stronger emphasis on either qualitative or quantitative results, both types of data were needed to be robust. If one was weaker than the other, it created further challenges at the integration stages. Because the self-reflection and critical reflection are parts of the process, proving these may be even harder. This researcher would add that participatory processes around self-reflection and participatory reflection were difficult to find, though consistently recommended. There are broader questions that critics raised: what to do with conflicting data? Weak results? Dissenting voices that aren't related to the statistics or process? If the variance in the study lies in the disparity between the quantitative and qualitative method, the researcher may end up with ambiguous results. Particular to MMPSJ, critics questioned the ability to employ a theoretical lens throughout, specifically with a marginalized community. Developing trust and maintaining that trust with participants while facilitating the community to

truly shape the experience created new, potentially tense systemic challenges posed a further challenge.

Conclusion

Across the globe, there is mounting evidence that low levels of education are linked to low socioeconomic factors and that these are fundamental causes of a wide range of health outcomes.[46] "Meanwhile, researchers are calling into question the appropriateness of traditional criteria for assessing the evidence"[46]. Community-based, participatory health research represents the people in this research. It is my hope that they can see themselves within the key concepts and in the spaces between. Therefore, this re-search sought to inquire into spaces with equal relationship in an effort to disrupt the status quo: research that advocates for the needs of the community, is mindful, and does not re-colonize or continue to marginalize; and re-search that requires us to unfold our arms and examine our practices such that we create liberating, humanized structures and systems.

Freire asks researchers to operate with a consciousness that motivates involvement rather than commitment.[28] The 'results' may be already known or experienced by a group or a system; inductive methodologies were then put to use to design effective and sustainable plans with stakeholders. The problem was that while research undertaken using either CBPHR or MMR is frequently talked about but the literature on what *works* is sparse. Lists of strengths and limitations abounded, yet it was often still left to the researcher to clearly define and decide which methodology to use.

While the hallmark of most research is to create clear questions that result in better understandings, these methods came under scrutiny largely because it is impossible to create or maintain acuity when the necessary processes are generative and iterative. Exactness in planning

or outcome are concerns because of the many decisions made throughout.[47] Power relationships, particularly in education, health and Indigenous contexts needed to come under higher levels of scrutiny due to the nature of the relationships and the legacy of research impact. Although these methods were inherently value driven, the effects of the action had to be predicted and considered, such as the effects of raising some questions and not others, involving some people and not others, some methods and not others, making sense of it in one way and not considering alternate views. Given this work, considering the silent voice and the ethical space were further matters that needed to be taken into account.[23]

While research that involves the participants' daily lives was highly relevant work for health education, collaborative research with people who have a history of marginalization may be possible only on the basis of trust and time.[48] This trust must be allowed to develop; it builds on long-term, honest relationships that are characterized by closeness, empathy, and emotional involvement. The challenges for these methodologies may be abated by careful considerations of the methodology of choice: integrating questions; developing researcher expertise; and further research that defines participatory reflective analysis, particularly with Indigenous communities. The mixed methods participatory social justice framework is explored further with the community in Chapter Three.

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Chapter Three: Methodology

Mixed Methods

Mixed methods (MM) in its simplest form combines both numbers and stories. However, mixed methods are rich in tradition and can take multiple forms. Thus, the intent, timing and emphasis needs to be described at the onset. Some researchers describe this as sequence and weight. MM can include convergent, explanatory or exploratory designs. Basic mixed methods have elements that might appear as mathematical with capital letters for the weight; arrows, equal signs, and plus signs have meaning noting when and how the integration takes place. Definitions and samples are included here:[1,2]

QUANTITATIVE → **qual =** In this type of design, the researcher would have had greater emphasis on the quantitative data, it would have been collected first, and the qualitative data would have helped to explain the quantitative results.[1] The mixed methods elements of this research at its core was exploratory sequential. Exploratory sequential designs were typically asked of a small number of people. The information gathered was considered rich and relevant but had limited generalizability.

QUALITATIVE → **quant =** In this type of design, the qualitative data would have more emphasis. The quantitative strand would have been designed from the qualitative results and had a specific aspect that it measured. In the mixing phase, participants would review both elements together as they were grounded in the initial qualitative perspectives of the participants.[1]

In this research, a community-led design emerged as the community participated at each stage: the numbers, the stories, the mixing and the methodology. Initial steps involved designing meaningful qualitative questions with two Elders. We asked how to gather quantitative and qualitative information with respect to local Indigenous traditions. When we gathered to respond,

the community chose to use a health survey (quantitative) and then to have an Elder lead the talking circles (qualitative) then gathering to make sense of the information together. A graphic that describes the processes of the stages and the mixing is provided here:

Community-Led Design for Mixed Methods

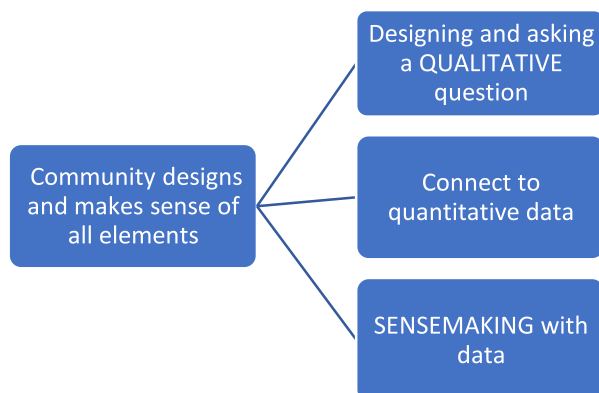

Figure 3.1 Community-Led Design for Mixed Methods

By having the community develop and lead the research questions, they were able to take the core design and evolve it in such a way that it could be transferable in another community setting. They were able to situate it within local Indigenous traditions and personalize it through story. Although not generalizable, the hope in sharing these strategies would be that another Indigenous community could use the processes within their local traditions for transferability. In MMPSJ, the social justice lens needs to wrap around the development of the questions at each stage of the work such that transformation is possible both on a micro and a macro level. Returning to the genesis of these questions (Chapter One), the community had been surveyed with many quantitative questions in the form of health surveys, however the qualitative elements weren't asked. It was believed that by asking them together, a richer understanding could be created. Further, by engaging in sensemaking collaboratively, participants could make personal

connections to the broader health surveys alongside their lived experiences. A graphic that shifts the mixed methods core design to community-led MMPSJ is provided below:

Community-Led Mixed Methods Participatory Social Justice

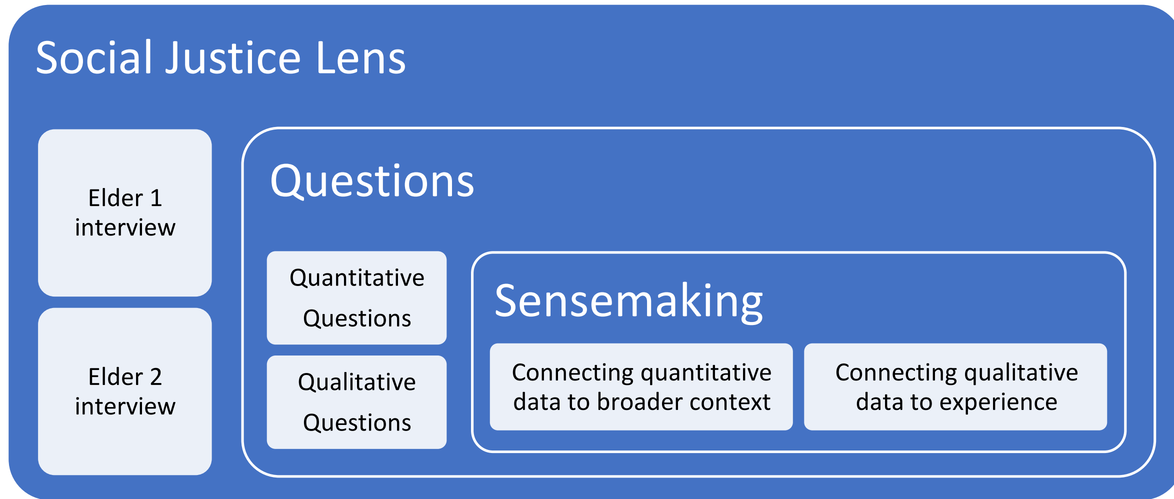

Figure 3.2 Community-Led Mixed Methods Participatory Social Justice

MMPSJ frameworks are limited as they are still evolving. It is time-consuming and relational. Researchers and participants are sometimes learning the methodology by doing it together; there is also an openness to learning, a space that affords questions to go where the community leads them. MMPSJ results were strengthened by the recommendations and the buy-in of participants. Rigor is addressed by the recruitment and sampling strategies, by being specific about the mixed methods design, and ensuring that the analysis and interpretation with the participants was iterative. Integration of the data sets have been described in research as merging, connecting, building or explaining; for the purpose of this study, the community chose *sensemaking*. These ideas are further elaborated on throughout and are summarized at the end.

Overview of this Chapter

Mixed methods design followed by community-led layers were provided to explain the design elements. An overview of the Four Phases of MMPSJ is outlined to share context (see

Figure 3.3). Each of the four phases will be described; then, there is a section on the qualitative and quantitative strands separately. Whole to part, part to whole describes the intersection of how the community used the framework to both design the questions, unpack them, then put them back together in meaningful ways. Readers will note two complete cycles of the framework as the question was designed, then evolved throughout time. Methodological considerations round out this Chapter including reliability, validity, rigor, integration, advantages and limitations. A step-by-step chart followed by a summary serve to connect the methods to chapter four.

Four Phases of Mixed Methods Participatory Social Justice

Figure 3.3 captures the Four Phases of MMPSJ. It was adapted from Creswell and Clark[1]. It will be used to anchor the four phases and describe the processes for coming to and responding to the research questions. These stages will be revisited in Chapter Four and further described when the full research question is responded to by participants.

Four Phases of Mixed Methods Participatory Social Justice

Figure 3.3 Four Phases of Mixed Methods Participatory Social Justice

Figure adapted from: Creswell JW, Plano Clark VL. Designing and conducting mixed methods research.[1] 3rd ed. Los Angeles (CA): Sage Publications; c2018. Figure 4.7,Flowchart of the basic considerations for implementing a mixed methods participatory-social justice design; p. 126.

Exploring Mixed Methods Participatory Social Justice Design

This study used a mixed methods participatory social justice (MMPSJ) design[1] to investigate the complexity of the research questions, *In what ways can literacy be considered a social determinant of health from an urban Plains Cree community? What literacy issues marginalize community? How would you like this knowledge shared or disseminated*? Both qualitative and quantitative data were collected and integrated with participants in four phases. MMPSJ was chosen as the combination of both qualitative and quantitative methods and their iterative mixing provided better insight into the research question than either of these methods alone. Put another way, the combination of text and statistical data helped to enrich the research and provide better insight especially to a complex question.[3]

Mixed-methods (MM) became popular in the early 2000's. There was an effort early on to distinguish MM as a unique form of research and not a simple a mixing of qualitative and quantitative methodologies. The importance of the distinctness of the question in choosing MM as the type of research was noted by Onwuegbuzie and Leech[4] in 2006. They described research questions that embedded both quantitative and qualitative data techniques and analysis. "Research questions occupy a place in the MM process that is central, interactive, emergent and evolving."[5]

The foundation for MMPSJ was laid in 2012 by Donna Mertens[5] who has written extensively about mixed methodologies. She talked about the transformative paradigm alongside the philosophical framework that helped to center the ethics involved. She spoke specifically of questions where cultural responsiveness, power differences and trusting relationships needed to be scrutinized in an effort to enact social change in a good way. Respecting cultural histories and norms as part of the interaction was part of the transformative axiological assumption. Further, participatory social justice work asked researchers to demonstrate particular respect for cultures

that had been historically denigrated and where the voice may not be typically integrated into the dominant narrative. Epistemological considerations asked about who was controlling the investigation. It wasn't enough to ask participants questions, the researcher needed to seek to understand the historical and social context.[5] This also aligned with the International Collaboration for Participatory Health Research (ICPHR)[6] who sought to find a means for people most affected by health problems to influence how these problems are addressed by society. Note the societal reference, the desire was not to simply de-construct systems but to support dialogical and diverse methods to support change. Within health research, this was often referred to as translational research. Translational learning occurred when researchers were asked to challenge their assumptions within the local context. A dialectical process was encouraged to offer fresh approaches for social action.[6]

The potential value of mixed methods was to help address social justice started to be described within the same timeframe. In August 2011, the National Institutes of Health (NIH)[7] released best practices for mixed-methods research and health sciences. "The essence of co-membership in the research endeavour is the hallmark of social justice oriented empirical inquiry."[7] Reflectivity and transformation for all participants, including the researcher, should lead to collective growth. The caution was to try not to accomplish too much or ask too many (layered) questions within the research as the process itself was typically broad in scope.[8] Research teams within MMPSJ were created to balance strength, promote inclusiveness, speak to rigor and relevance of the project while also empowering research participants. Making regular contact and connecting with participants was emphasized throughout as well as follow up and participant checks. Thus, the socially-just researcher within mixed methods employed both a design and a co-design lens.[9]

MMPSJ research within an Indigenous community needed to consider the principles of OCAP® (ownership, control, access, and possession).[10] As Indigenous peoples have disproportionately poorer health,[11] this might subject Indigenous peoples to more, potentially deficit-based research. As such, the how became ever more important. Community-based methods within participatory research was cited as showing promise for research that was both considerate and congruent with Indigenous traditions and their worldview.[12]

In 2016, Mertens et al[13] described creative opportunities within mixed methods research that contributed to answering complex questions. In its simplistic genesis, mixed methods was a way to combine quantitative and qualitative data sources; by now questions had evolved such that Mertens[13] herself queried about how can different designs be used more effectively to involve stakeholders at different points during the research? She defined wicked problems and provided examples of these such as poverty and lack of access to health and educational services. She asked researchers to "methodologically, technically and creatively bring mixed methods to finding solutions to wicked problems to increase citizen participation in science as well as appropriate respectful engagement with Indigenous peoples"[13]. A review of OCAP®[10] within knowledge translation refers to wise and promising practices. This research took up the challenge using MMPSJ and hoped to progress it further with co-created questions and authentic engagement with Indigenous community members throughout the research project.[13]

Problem Identification and Theoretical Orientation: Community-Led

A University of Saskatchewan's Behavioural Research Ethics Application was submitted and approved prior to the commencement of meeting with two Elders to define the 'problem' with community. Two Elders, at separate times, were invited to review the flow of the MMPSJ framework. Within this research, it was thought that by engaging with and asking Elders to

oversee, participate, and help integrate the findings it would start the work "in a good way". The meetings among the researcher and the Elders took place at a mutually agreed location, followed the tobacco protocol, and transcribed the findings. A Lay Summary (Appendix D) of the root causes of the social determinants of health was provided, alongside the theory of Paulo Freire where literacy was seen as liberatory when working with marginalized populations. Elders were asked to consider this summary and create a relevant question that advocated for change to help understand current connections between literacy and health within urban Indigenous families in schools. A third Elder was also a member of the Research Advisory Committee (RAC). They advised and made any recommendations on all aspects of the research project. The themes and recommendations are described in Chapter Four. Factors involving Phase One included allowing for and facilitating structures where the definition of the problem evolves from the community, the principles of trust and reciprocity are valued, and creating a question that advocated for change where local community knowledge and traditions were respected.

Collecting the Data to Involve and Honour Participants

Both Elders gave consent to have their stories heard, transcribed, and given back to them. Local traditions of tobacco, cloth, and smudging were followed as guided by the Elders; it was their choice on how, where and when to proceed. We poured tea and took the time that was needed to listen. It is important to note that asking Elders in a respectful way before asking community members to participate is part of the social justice perspective. This perspective is more than a view, it is a way of doing and being.

Both Elders located themselves in the context of community[14] and within their own families; they shared the importance of storytelling in the context of community.[15] They recognized that intellectual health is part of physical health, alongside spiritual and emotional

health; colonial systems separate/compartmentalize various aspects of health. Further, they expanded an individual's health into the context of the family, home, school and community. Akin to SDoH, they believed that we can better understand how to lift and support Indigenous communities when we consider that colonialism has yet to be fully accounted for as a determinant; when Indigenous health was considered as unique as opposed to a sub-set of non-Indigenous health; and lastly when Indigenous people created and contributed to the literature on SDOH.[16] Specific to moving the question(s) forward, the Elders stated the need for family engagement on literacy; yet wanted the families to have enough space to share their own concerns.

Introduce an Analysis that Highlights the Needs of the Participants of the Community

In the analysis phase of coming to the question(s), the transcriptions were given back to the Elders to see if it was an accurate depiction and to seek consent to create themes and advice from their words. As there is a danger in 'pan-Indigenizing' or thinking that certain protocols are appropriate across the country. The protocols they shared, and we participated in (for example smudging) may be unique to the individual Elder and/or community or local Treaty area. Ever concerned with how best to receive consent and theme words, one of the Elders was asked what s/he thought. The following was shared:

"I give her permission to talk to me about topics within nehiyaw knowledge and ways of knowing for her research. I understand that in your ethics world, that you question where someone like this body and the spirit that comes with it would have cultural currency and why would it be so. It does because I have been raised up within the nehiyaw culture and have been taught by Elders and knowledge keepers. Through protocol and oral tradition and ceremonial work with the old people, I have learned some things about nehiyaw-ness and Indigenous thinking and ceremony.

Yes, people have come to this body asking it to facilitate ceremony and to help them. Some would say this makes this body an Elder but that's not my call but rather, it's the people in the community who make that distinction. All I do is accept the tobacco that they offer this body, and I help them regarding ceremony or the sharing of nehiyaw knowledge. I do not have talking leafs that say I can do this or that, like the degrees which say I do, which I received in a colonial education system, but the understanding and knowingness is there that the body and intelligence can do what it required to do in the nehiyaw world. However, if it cannot do that, it deflects the request to another body who has that knowledge. Thank you."[17]

Recommending Change That Needs to Be Made

The Elders recommended a gathering of interested families that included generations to shed light on the connections between literacy and health. A talking circle[18] would be the conduit to sharing voice. Prayer in the form of smudging would be offered by one of the Elders prior to the talking circle to establish the intent. During the circle, the Elder would ask the research questions; this represented a significant shift in typical research and power relationships. After the talking circle, the Elders would remain to visit one-on-one with participants should they choose; they were concerned that the story of school may unearth some Residential School experiences that may trigger or upset participants. Thus, Phase Two of data collection that honoured participants and their experience would be conducted in this way. Engaging with Elders by following the tobacco protocol allowed for authentic relationships within research that seek to include Indigenous people. The Elders' shepherding asked future participants to learn about ceremony as a place where all will be welcome. They wanted to be an active part of the experience, to let their lived experience and their wisdom be considered as a form of knowledge.

Understanding the Quantitative Aspects of the Questions

While Canada may be held up as exemplary in its social policies and access to health, quantitatively, the numbers gathered need to employ the same ethical principles as any qualitative research: herein lies the gap.[19] Given the recent discoveries at Residential Schools across the country and the staggering numbers that add to the tragedies, it is the contention of this research that the need for Indigenous leadership and participation in the design, gathering, analysis, ownership, and use of health information will help address unique social determinant inequities that Indigenous peoples may encounter. "In Canada, critical health assessment and monitoring information that is taken for granted by the large majority of Canadians, including population level tracking of the incidence course and risk factors related to acute and chronic disease, is simply not available or of substandard quality for Indigenous people."[19] Indigenous epistemologies have described the need for a wholistic approach to well-being with virtues of balance: physical; emotional; spiritual; and intellectual.[20] Concepts such as intergenerational kinship, direction from Elders, typical quantitative data collection were deficit-based, (hence the term health disparity) describing mortality and disease rates.[21] Further, experiential racism and the long-term effects of Residential School have yet to be accounted for within systems.[22] These data gaps represented a "missed opportunity to fully benefit from evidence-based interventions" alongside "data regarding the health and wellbeing of Indigenous women in Canada, gaps in information have been flagged by the United Nations Human Rights Council".[19] Thus, some of the health disparities experienced live in the data as it was collected.

As a foundational assumption to the quantitative questions, the community believed they were a hidden population. In the quantitative pieces, the community had the right to define their own identity, have ample time to read, reflect on and participate in the analysis of the

information, and to choose to withdraw from any part of the process. The community chose to re-write some of the questions in ways that were meaningful to them. The sampling strategy was snowballing. Snowballing is a sampling strategy where participants recruit other participants based on eligibility and people that they were acquainted with. In this instance, all participants were Indigenous people, they came from a fairly small geographic area, were interested in the research question and in participating in shaping that question and were familiar enough with each other to respond to the questions. They all had prior experience with working with an Elder and talking circles.

Snowball sampling was first described by Coleman[23] in 1958. This sampling style evolved into respondent driven sampling which "is known to effectively engage populations that may be missed by the Census, including persons who are homeless, highly transient or have low literacy skills."[19] The limitations of snowball sampling included the ability to make statistical inferences, the small number and choice of the participants, and the use of convenience in choosing participants. It is, however, commensurate with exploratory core mixed methods designs.

Understanding the Qualitative Aspects of The Questions

Literacy and health literacy hold significance for individuals and for society. [15, 24-29] The research questions originated with an inquiry into two social determinants of health (SDoH): education level and being of Indigenous ancestry. Both of these determinants predict a higher rate of health disparity; combining low literacy with being of Indigenous ancestry increased their impact. [30]

This question represented a shift from pelagic and all-encompassing terms such as 'social determinant', 'Indigenous', and 'education' and attempted to co-construct with community

specific, ethical, common understandings of these connections from their perspectives. It also sought to respond to recommendations from previous research including advocacy for multidisciplinary approaches and incorporating community voice.[26] The need for Indigenous communities to be in relation *with* and *part of* research instead of the being the researched was well documented as not only a necessary ethical component but a limitation of current research practices.[31-35]

Initial, historical definitions of literacy and health literacy were narrow in scope and related to an individual's skills; evolving and contemporary definitions placed more emphasis on navigation of systems, the importance of access to services, and question the roles of race, and of critical consciousness.[36-38] A quick search for the definitions of literacy or health literacy will yield a myriad of results. Yet while researching these terms in relation to Indigenous perspectives, almost no research existed; one article described a health perspective which mentions literacy.[39] No Indigenous community-based definitions or considerations of literacy or health literacy, the interrelationships or interdependence, were found in research reviews or in checking the grey literature. While the history of health literacy and literacy definitions have travelled a similar path of debate, the consensus lies in the general acceptance of a pragmatic theory: by improving literacy, we improve education; by improving health literacy, we improve health.[36] Thus, the research questions: *What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community? How would you like this knowledge shared or disseminated?*

Whole to Part, Part to Whole: MMPSJ

At the beginning of this chapter, we described mixed methods chronologically. The intent was to show that mixed methods are still evolving. This community used the framework

at the beginning to pull apart the pieces, reflect on them, and collaboratively designed what would be meaningful for them. We worked holistically by engaging with Elders in designing the questions, in describing the process in parts, and by asking both quantitative and qualitative questions in the hopes that the questions provide richer information than if they were asked alone. Further, the quantitative strand helped set the context for the quantitative questions (Appendix B).

To develop the questions, two Elders were interviewed, their responses recorded and transcribed, then returned to them. In those interviews, the Elders helped to establish the processes for gathering further information. An Amendment was submitted to the University of Saskatchewan's Behavioural REB and subsequently approved to engage in smudging, talking circles and review of the quantitative questions.

Reliability and Validity in Mixed Methods Participatory Social Justice

Mixed methods participatory social justice: each of these words need to be unpacked and connected to issues of reliability and validity. In the quantitative (validity) strand, the test is to see if "scores from participants are meaningful indicators of the construct being measured; reliability refers to stability over time".[1] The mitigation of risks in the quantitative strand was accomplished by establishing long term, positive relationships and by giving both the data and the meaning making back to participants. In Chapter Four, we will go into detail about the 'truth' in statistics. The reason for addressing procedures for reliability and validity here is to also query the other elements of rigour which are internal and external validity which express themselves in cause-effect claims and generalizations to other places, people or time. In the qualitative strand, validity was achieved by member-checking and by the presence of another co-researcher who is familiar with both the content area and the specific research. Reliability is

maintained throughout as participants were co-researchers as well. The coding or sense making of the narratives in our circles was done by the participants themselves and returned to them for review and editing. In the qualitative strand, reliability is more accurately described as credibility; some would say trustworthiness. Trustworthiness encapsulates research that is noteworthy and interesting.[40] Hence, reliability and validity have unique meanings within MMPSJ research.

The social justice lens was framed upon a Freirean theoretical foundation coupled with Indigenous participation and leadership throughout. The talking circles were led by the Elder with two opportunities for each participant to speak at each circle. This recognition of existing philosophical work with Indigenous epistemology is referred to as nayri kati: "For Indigenous peoples world-wide, knowing and seeking knowledge is never a solo enterprise. It also cannot be separated from our understandings of who knowers can be - that all knowers can be knowers and not all things can be known".[41] Critics of Indigenous statistics claim deficit-based assumptions (measuring the pathology or poor performance such as in health disparity work) "tend very strongly toward very simple comparisons and limited interpretations".[41] By working together, in community, over time, the justice elements of this research were not descriptive, but active in the dialogic, capacity building, and sense making. The social justice lens and Freirean praxis as described in Chapter Two provided a foundation for us to consider power and relationships which led to having the Elder ask the questions but also for the community to respond in ways that were meaningful to them.

Rigor in Mixed Methods Participatory Social Justice

Rigor in MMPSJ had to be considered both quantitative and qualitative strands. Rigor related to quantitative strand speaks to effect size, internal and external validity. In designing and asking the qualitative questions with rigor in mind, trustworthiness and credibility become central. Quantitatively, a n=12 was chosen. All participants that were invited took part. Even when the CoVID-19 pandemic presented itself which at some points halted the research completely and at other points had us repeat the circles in smaller formats, there were regular check ins, some initiated by the researcher and some by the participants themselves. As the community was involved at each step, the question was asked of the Elder: at what point do you think we have reached saturation? How can we connect the numbers so that it is credible to the community in a culturally sensitive way? He told us that it was time to have another talking circle to ask the members to connect the data to the bigger picture and to their daily experience. The stories were starting to repeat themselves (saturation). He was also interested in the recommendations that participants would make. One element of rigor within a social justice perspective is the consideration that the needs of community may be or have been over-looked. The literature that existed was either deficit-based or there was a paucity of research that informed policy and practice. Rigor related to the qualitative strand brings trustworthiness and credibility into the mix. Rigor also showed itself in the integration and analysis of the results. Rigor was demonstrated in the form of innovation or by seeking to address a gap in the literature. At its core, the mixed methods design was sequential exploratory with an emphasis on the qualitative aspect.

Advantages and Limitations of Mixed Methods Participatory Social Justice

One of the advantages of using MMPSJ was its practicality, by combining quantitative aspects into a qualitative question, it legitimizes the work. Grant applications, connections to policies and advocating for proper compensation and follow through were strengthened. This empowering approach drew people together and built individual/participant and community capacity. We met during the pandemic following strict protocols. People had been living in isolation for months before we were given the go-ahead to gather. A separate application to the University of Saskatchewan was submitted and approved prior to proceeding and special health protocols had to be in place; this all took time to ensure participant safety. However, participants shared how uplifting it was to gather safely and be in the presence of an Elder. Having access to ceremony in the form of smudge and gathering in a circle motivated participants to continue to pursue their own personal and academic goals. Talking about this makes me more motivated to finish my studies. The goal of MMPSJ is to produce results that are meaningful to participants but also credible to external audiences such as policy makers and stakeholders. Researcher transformation can be articulated as moving social justice to the front of how the world is seen. An example was by having the Elder (at his/her recommendation) ask the questions and lead the circles. This turn of power was respectful of community norms but not typical in most research practices.

Disadvantages could be found in the following domains: expertise; communication; using participatory approaches and time. As this work is relational, the participants are human, and there was a pandemic going on, the research project stretched out and took a hiatus for a while to keep everyone safe. That said, there was a willingness to make it work. On-going communication was key. Back to the idea that this community is a hidden community - what did that mean in relation to communication? If you live in poverty and perhaps don't have a car, you

might also not have cell phone minutes or be mobile within the community. Even while on a break during the talking circle, we checked in with each other to keep our circle strong.

Expertise was a challenge as researchers had to understand the theoretical lens, in this case Freirean, and be able to apply it to the research problem. The academic researchers were not Indigenous, so an encounter of differing world views had to be part of the process. Lay summaries and opportunity to learn were provided at each talking circle. Researcher expertise in the form of cultural humility was necessary to work with solely Indigenous participants as a non-Indigenous person. Participation in Indigenous ceremony through smudging, attendance at a sweat lodge and a pipe ceremony were encouraged by the Elders at the out-set.

> *"I think it is important for teachers and community workers, health workers to work together with Elders and give parents opportunities to practice ceremony and be part of ceremony with their own children. I think that would be so cool if that happened."* (Transcript from Elder).

Lastly, using participatory approaches could be a limitation as they were not well described in general, but certainly not within or designed by Indigenous community members. Elders, community members/participants, and researchers truly had to be co-creators. Trusting that the participants would shape the study as it unfolded and ceding control of who was asking the questions was difficult. Yet, the importance of trust and respectful relations permeated every aspect mitigating the tension of power and control by researchers.

Step by Step

The chart below maps out each step sequentially:

Phase	Task	Outcome	Timeline	Documents
One	Indigenous community Elder (s) are asked the question: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community? • Tobacco protocol: teaching (s) are scribed, given back to the Elders/knowledge keepers for permission; potential contributors and collaborators were discussed. • A Lay Summary of Paulo Freire's work was considered with the Elders to situate and evolve the work into theory.	• A teaching is received by the researcher. • Knowledge of community Elders and Knowledge Keepers is shared. • Researcher capacity is enhanced; ethical guidelines were followed. • Permission to share or own is given to the community. • Consent and invitation to participate in study was sent out. • A summary, called Ask before you ask, is presented to them. • Beh ID #733	• Tea with two Elders for 60-90 minutes. • Audio recording. • Transcripts reviewed and entered into Word. • Given back to Elders. • Protocols for following the Phases were discussed.	• Ask before you ask: setting the foundation for meaningful questions. • Chapter 4 of Dissertation.
Two	• Three talking circles with community members. • Community members are asked the same questions by an Elder as in Phase One. • n=12. • A fourth circle with the Elders and research team to plan for analysis with community.	• Oral recording. • Transcripts are kept. • Transcripts are given back to the Elders for sense making and to set up participatory analysis. • REB application Beh ID #733.	• Two to three hours per talking circle. • Held over three months for continuity and to allow for flexibility during COVID-19.	• Transcripts A, B, C, D for each of the talking circles. • Chapter 4 of Dissertation.

Phase	Task	Outcome	Timeline	Documents
Three	• Inductive thematic analysis for qualitative questions. • Coding of data for emerging themes to from the specific questions that were asked with community. • “Figuring out” of patterns, categories or themes. • Graphing of quantitative data for description of community and emergent questions.	• Description of the knowledge created. • Synthesis of the knowledge created. • Emergent questions were documented. • These were given back to community as part of this phase • Feedback will be incorporated before moving on to the next Phase. • Audio recording. • Transcriptions.	• Two months	• Chapters 4, 5 in Dissertation. • Lay Summary for community.
Four	• Analyses were given back to the Elders in advance for them to consider. • Each participant was contacted, visited and had time to review Chapter Four • Each participant was given the synopsis page	• Opportunity to make recommendations.	• One month	• Amended documents with recommendati ons. • One page synopsis written inter-generationally. • Chapter Five
Five	• Knowledge was disseminated with the community. • A celebration of sharing was held.	• Re-consenting was required.	• Everyone will be invited to the celebration (meal).	• Opportunities for future engagement we discussed.

Phase	Task	Outcome	Timeline	Documents
Six	• Met with Elder Roland to discuss community engagement model as a point of synthesis. • Met with a language keeper to ensure proper spelling.	• Community engagement model was reviewed.	• One month	• Chapter 6 of Dissertation • Community engagement model

On a softer note, in considering this methodology, there were factors that helped evergreen this work. These were: keeping field notes as participants were talking - thoughts that emerged that I thought I would remember but so enjoyed re-reading them; reflecting on before and after stories such as car-ride conversations; but mostly showing my appreciation for the knowledge provided by the participants. It was important to everyone that the Elder could participate with commensurate pay as defined by the University, gift cards and meals while we worked together, laughter and compassion while the inquiries were taking place. The field notes helped with thinking through the juxtaposition of being reflexive and reflective, taking stock of my white privilege while being fully present within this exceptional experience. Some of these are expanded upon in Chapter Five.

Summary

At the beginning of this Chapter, the rationale, or the *why* for choosing MMPSJ was unpacked to describe what the methodology encompasses and means. Mixed methods evolved from a sequential exploratory design to a community-led model that includes the social justice lens and encourages co-design and full participation with community members. An over-arching framework with four steps was included to help organize two iterative phases of coming together and responding to the research questions. Quantitative and qualitative strands were initially

connected to the research questions then to issues of reliability, validity, sampling and rigor. A step-by-step chart with the outcomes broken down by the *how* of the methodology were at the end of this Chapter.

To our knowledge, not only have these research questions not been asked, but unique to the community's responses was the leadership and control of all aspects; this research purports that the community contributed to both meaning and methodology with both rooted in relationships. Growth (reflexive) and transformation (reflective) should be demonstrated by all. We posit that by using a co-design and co-researcher lens throughout, the growth is both process oriented and demonstrable in the outcomes described in Chapters Four and Five. The social justice element in not limited to looking through a lens only by the researcher, it is an action that is also undertaken with the participants. Together, we responded to the research questions.

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Chapter Four: Results

Because we have a purpose, right? A purpose here in an urban landscape is education. That is what ceremony does-it reminds you that you are spiritual, that you are relational, that you have a purpose.[1]

Within mixed - methods participatory social justice (MMPSJ) methodology, both quantitative and qualitative data are necessary to facilitate a more robust analysis to answer the research questions. The quantitative questions (Appendix B) were adapted from similar questions asked in the First Nations Regional Health Surveys.[2] These were asked to link the understandings to a personal narrative and to the broader connections with the Social Determinants of Health (SDoH). The information was predicated on an appreciative stance from research; for example: "…occupational status and educational attainment were among the most important factors contributing to the pro-rich distribution of health of Indigenous Peoples living off-reserve."[3] The qualitative questions were asked to illuminate the connections among literacy, health and being of Indigenous ancestry.

This chapter is set up in sections that mirror the order of the research questions. First, two Elders were asked to assist with the co-creation of the questions and insights. Then, we gathered in talking circles where the quantitative questions were asked, followed by the qualitative questions and then followed by sensemaking. These were explained and a graphic provided in Chapter Three in the step-by-step section. Ethical Amendments and member-checking happened throughout the iterative cycles.

The First Iteration: Ask Before You Ask

Consistently employing a transformative lens in MMPSJ means collectively constructing knowledge. In this research, the community believed that co-constructing the research questions,

the data processes, and the dissemination of the data were commensurate with Freirean praxis. In developing the questions, a Lay Summary of Freirean ideology was explored with two Indigenous Elders. (Appendix D). This section was titled Ask Before You Ask to afford both the researchers' and the Elders' analyses of privilege, hierarchy and methodology within cultural traditions. Freirean social justice teaches about co-creation and dynamism "between the subject and the object, the self and the social, and human agency and social structure". [4]

The Elders met with the researcher at separate times, one male and one female. Tobacco was exchanged, we smudged, tea was poured, and we renewed the oral consent forms. Each was given a copy of a Lay Summary of Freire's theoretical perspectives, their connections to the social determinants of health, and some inquiry starters. The dialogue began as we started to sip our tea. The first Elder we will name Elara.

Elara situated herself at the confluence of her experience attending Residential School and contemporary struggles that her family had with school. Her children and grandchildren were having difficulty navigating the urban and reserve life resulting in moving around a lot; going from school to school with gaps of not attending. Her father hadn't learned how to read, but had told stories of how he wanted to. She herself articulated difficulties… "I had never checked myself out to see what the stumbling block was; was it my brain? I was willing to learn." In her re-counting of Residential School, she said that it wasn't a school like we know it today. The female children were taught to clean and cook and spent most of the days doing chores and going to worship. "The Catholic was brought out in a harsh way - that God was out to get you - every little thing you did in life - we were innocent little kids. And this is what we had to grow up with. That is what impacted me. I thought about it all the time. Had to be careful, be careful." She also told stories of her own resilience, moving to the city, upgrading,

and learning about fashion design. Her story of school was that she had to be perfect. She felt slow, but there was both a longing and a willingness to learn at school.

In terms of asking questions and gathering people, she believed that family members should be invited as they will help each other. They would understand any way or method, but that a talking circle with an Elder would be best. She asked for some preparedness, for people to be able to share what was on their minds: the telling of the challenges may be hard to hear but needed to be heard. "It is a good idea. I would love to do that, to do something like that, to see that for myself, to see the struggles. To be invited. It would be interesting. This thing you are talking about - nobody has ever asked - I have never really heard anybody ask or talk about that to help. There has never been a thing like that happen." She encouraged perseverance, and that we should see all people as able. If we start something, we should finish it: *kih-sih-tah.* Finish it.

The second Elder we will call Callisto. He began with a love for his language, moved readily between English and Cree. As we discussed SDoH and Freire, he taught that to be poor was a Western construct. He was rich in language, culture, ceremony. He grew up feeling the effects of colonization. He described it as 'a socially engineered thing' that the government created by rationing food on reserves using Indian agents. "To the point where Indigenous women had to beg, and to sell themselves to get food - that's how bad it was at one point." This carried forward to some of the extreme poverty seen today, coupled with the effects of Residential School. The intergenerational reverberations were for "great grandparents, grandparents, parents and children with respect to the school system, and epigenetically affecting Indigenous people at the cellular level to have an aversion possibly to school or Western education. That's part of the problem out there; eventually we have to heal from a cellular level." He described some connections to literacy in English as he saw it; but spoke to the

richness of his language as helping him be smart. He believed that the more languages that someone spoke, the more windows through which you can see the world. He remembered families that have prospered over time had strong connections to their culture despite colonization.

Callisto's recommendations included finding space where families could engage in ceremony with families and health workers. He believed that generations needed to be together as "young people may be intimidated by Elders because they don't know the language." By learning with Elders, we increase cultural literacy. "Once cultural literacy happens, then we can also bring in ideas on not only strengthening ourselves as Indigenous people, strengthening our spirituality but then strengthening our relationality. Then our mentality." He spoke of sharing the importance of becoming well. "Then you begin to express your innate joy, express your innate creativity. Create a world that you want to get well." He believed that some parents may need support to participate in ceremony in the short-term.

He affirmed that everyone was welcome, no harm would come to people that participate. Interacting within that ceremonial space helped people know that everyone belonged to the community, even in an urban setting. Once people saw each other and interacted, they could let each other know what they wanted: it's a process that doesn't happen right away; they had to trust each other first. In terms of understanding health and literacy, he said, "I think health people need to take off their health caps. First of all, not going in as a doctor or a nurse coming in hot; but coming in a kind way, as a human being, as a spiritual person." He encouraged coming together with people with no pretense. "There's that ethical space that Willy Ermine talks about. Come and just be. When a person is ready, they will be hungry enough: spiritually, emotionally, physically, mentally…*they will ask*."

The Elders helped identify some people that may be interested in carrying the questions forward: *What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community? How would you like this knowledge shared or disseminated?* And then the pandemic began in earnest.

COVID-19 Interruption

The point of this paragraph is to note that there was a delay for all research, especially the kinds of research that involved gatherings of people. New applications had to be written, new standards had to be adhered to. After a delay from March to Fall of 2020, there was another Amendment to Beh ID 733 submitted and approved which facilitated the start of talking circles.

The Quantitative Questions

The quantitative questions are adapted from a set of commonly asked indicators that provide a context for the qualitative questions. The foundation of these questions was meant to be more than factual; they were belief driven: on a deeper level, they sought to define and address literacy as an upstream factor in health disparities. Within the domains of the SDoH, Indigenous social inequalities should be considered unique within cultural and historical factors. The cultural and historical factors needed to be told and heard with Indigenous peoples. The numbers and the stories, as earlier described within MMPSJ, could inform each other to help address complex questions. An example is the number of participants that experienced Residential School, Sixties Scoop or Day School.[5] It became very important to the community that Residential School alone not be the only impact on participants' health as a direct result of government policy. These experiences were all part of colonization. In an effort to reduce the impacts of colonization, it was recommended that self-determination could help restore control

of Indigenous peoples' lives and destinies.[5] The construct of liberation was also commensurate with Freirean theories. A full recounting of the quantitative questions is found in Appendix B.

Why do we need to understand empirical information from a transformative world view as social justice asks us to? The hope of transformative researchers is to develop a goal to serve the ends of creating a more democratic and just society.[7] It begins with the *how* we collect information in ways that will not further marginalize the community. All of the participants in this study were of Indigenous ancestry, living primarily in an urban setting. An expression of interest was generated through the first iteration (Ask before you Ask) of the questions. Elders identified/consulted with some interested people followed by a phone call, and an invitation to participate in the talking circles. Participants were encouraged to bring interested family members if they so chose, commensurate with snowballing sampling. The purpose of the study and 'opt-out' was reviewed both over the phone and in person when the participants arrived. The Indigenous community can be small and the knowing each other and coming to know each other through the talking circles was part of the cultural process. It was important ethically that passing, not answering some of the questions, and member-checking by giving all information back to participants afforded a safe place. Below, we chart and explore the quantitative data; sensemaking is discussed further in Chapter Five.

Variables in the Quantitative Questions

Initial data collected were demographic including gender and age range. All participants were female except for Elder Roland. An average of the ages is presented (see Table 4.1); noting that we had decided not to involve young children due to COVID-19 restrictions but had considered their participation in the original design of the study. Questions of Indigenous ancestry, first language, and the Indigenous group participants most identify with are also

presented in Table 4.1. All participants were of Indigenous ancestry. This was important as families were given choice as to whom to invite to the talking circles. Table 4.2 reflects the years of schooling, access to post-secondary and university training, as well as employment.

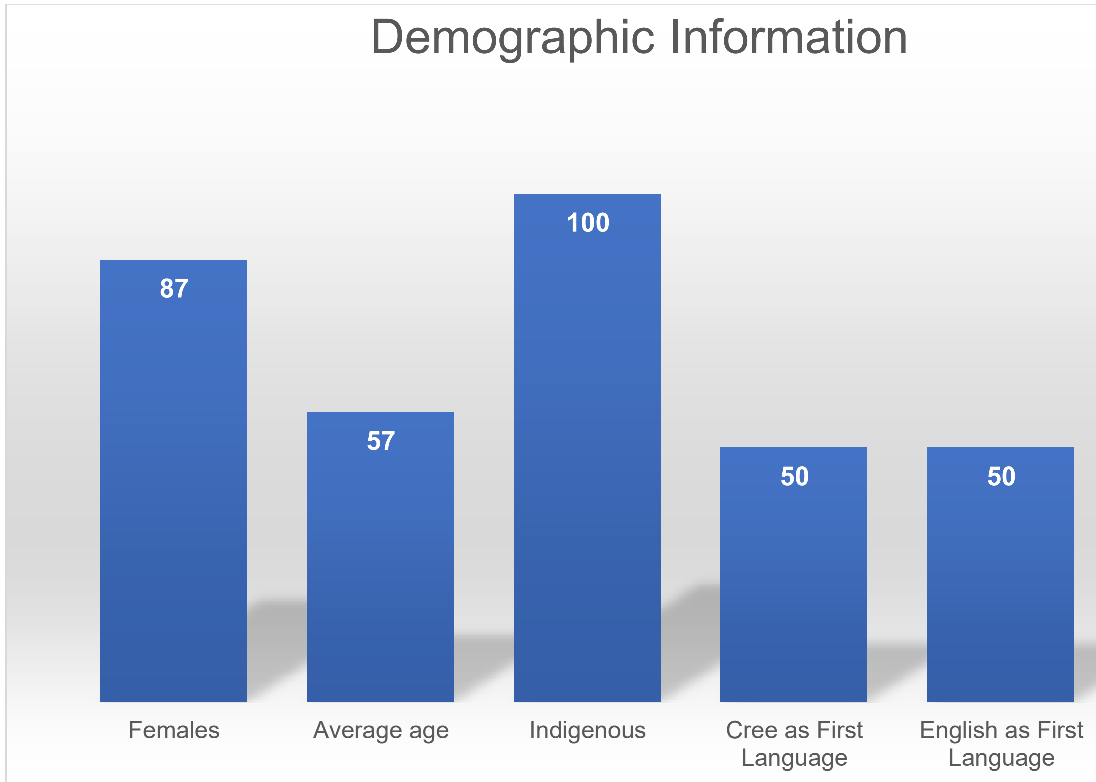

Table 4.1: Demographic Information

The connection among education and employment are often asked in health surveys. On the list of key determinants of health, education and employment levels are often cited in broad, general terms; this chart demonstrated what the participants chose to share. This work seeks to locally understand health and literacy through community engagement; although employment is not an explored area it bears noting that there is an obvious close connection to education level, employment, and socio-economic status. Improving conditions of employment may help to improve the well-being of Indigenous peoples and may be worth exploring through a similar community engagement model.

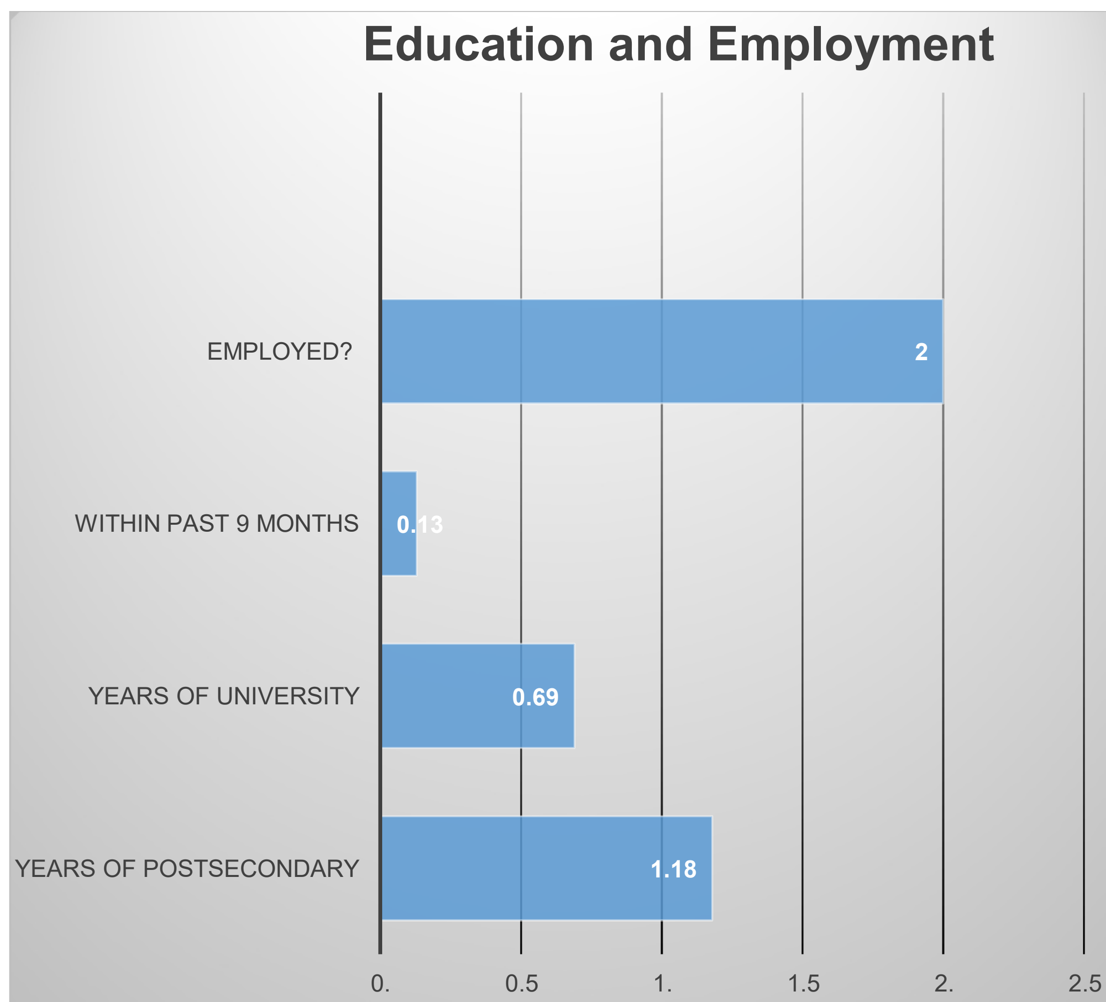

Table 4.2: Education and Employment

Another question was whether or not the participant attended Residential School with an option not to answer. The last three questions speak of intergenerational health: a five-point ranking system commensurate with the Aboriginal Peoples Health Survey[2]: How would you describe your health/the health of your children/grandchildren? One was Very Good with five being Poor; hence, the lower the score, the better the health.

While the attendance in Residential School was Yes, No, or Choose Not to Answer, the participants responded with two participants saying Yes; three saying No; one indicated attending Day School and one identified as being part of the Sixties' Scoop.

The health question involved ranking personal, child, and grandchildren's health on a five-point Likert scale; with the higher the score representing poorer health (see Table 4.3).

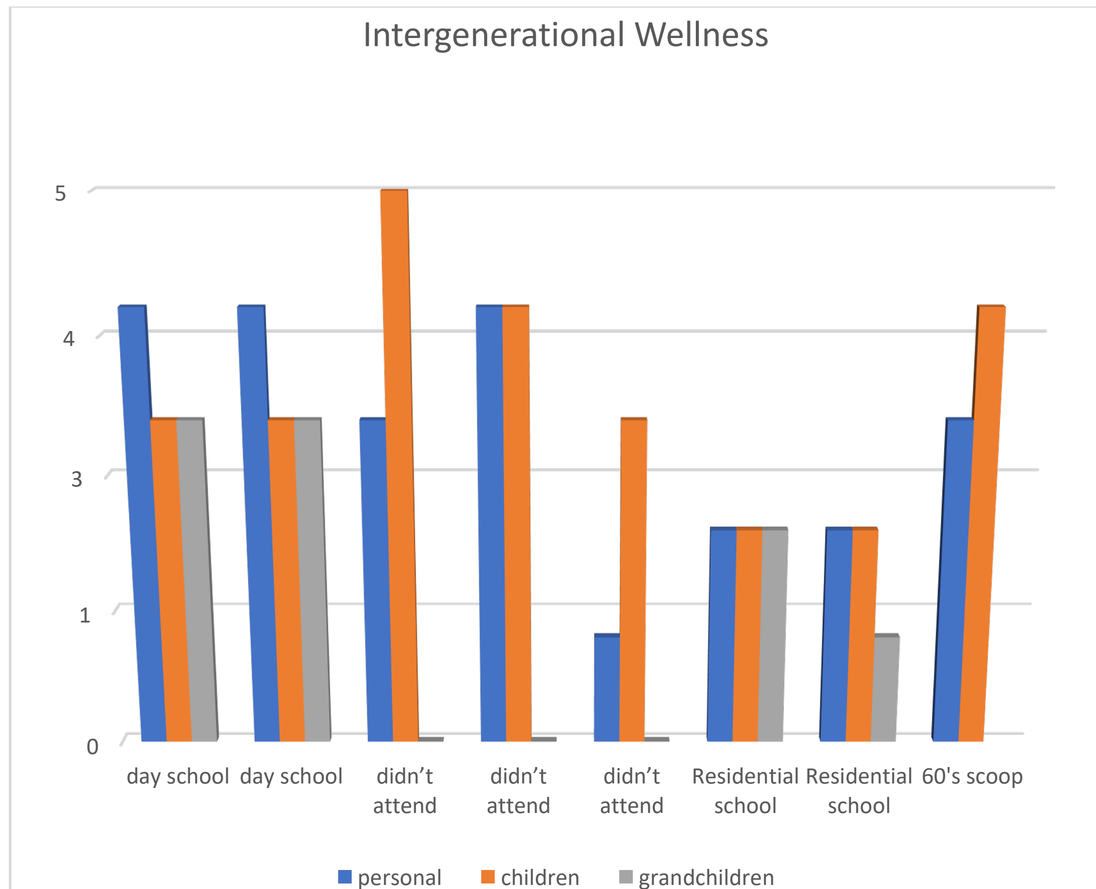

Table 4.3: Intergenerational Wellness

<u>The Second Iteration: The Qualitative Questions</u>

Our first talking circle was held on a blustery day, so much so that the Elder decided it was too windy to smudge. His name is Elder Roland Duquette. He had asked that his name be used throughout, and anonymity be waived. We gathered in a distanced circle, acknowledged the treaty area and each other. We went to a large room that afforded all the COVID-19 pandemic protocols. We reviewed the questions and people filled out the quantitative questionnaire. Once they were completed, Elder Roland opened by telling parts of his story. As a Residential School survivor, he noted that school created in him a different culture than he

would have had with his parents. He felt he had no home; when he left Residential School he was graded at grade two. He felt he couldn't function, because he knew he knew things, but couldn't read and write well; the shame that he felt inside was too deep. But we all have the capacity within ourselves to reach within ourselves and reach out towards others and let life teach us. Returning to his cultural ways and understanding morals and humanness helped him to become strong. The whispering of Cree at Residential School kept his language alive and he uses it in his teachings today. If there was a gift from Residential School, it was the gift of humility. "Our people, we were skilled in a whole different way through the lens, and I think that's one of the questions that pertain to this. Why are we not advancing as we should through society and what is our worldview? Sometimes our skills are so intricate that we don't need more than what we need to know. Maybe we were too satisfied with what we had." Elder Roland learned to take the shame of his early schooling and turn it into a way to approach people: whether it is someone "higher up" or a person such as a struggling student, each person deserves to be listened to in a respectful way. He went on to encourage the women to assert themselves. "All of you here are the matriarchs in your home…as men, we listen. The men are like the children, we listen to the women." He spoke of the teachings that women have, that it needs to be acknowledged and celebrated within community. "When the women start taking on their roles as leaders then things start to happen. Things start to move; that's how I see that happening. We can't question that because of where we came from. The love that women have for everything, the sensitivity, the caring and understanding is important. That's how I understand the question: it's quite broad and we can dissect it as time goes on."

The first family at the circle was comprised of a grandmother and two of her adult daughters. The Grandmother we will call Carme and her two children Ersa and Dia. Ersa went

first. She recalled her schooling as similar to Elder Roland's. She felt that schools in low income areas have lower standards than what was expected of students in different areas of the city. She wasn't quite sure about what Residential School was as a child, but she knew not to be proud. She felt as if at home she should tell the children that education was important, but the families couldn't because of the history. The connection between Residential School and literacy today united the survivors to people through being part of the system of brokenness. Ersa spoke of people not being able to see beyond, being discouraged to pursue any education past Grade Twelve, if she could pass Grade Twelve. Dia nodded and passed her turn to speak on this round.

The second family was a mother (Erinome) and a daughter (Aitne). Aitne described having troubles at school which she attributed to a learning disability. Erinome was part of the Sixties Scoop, taken from her family and raised by white people on a farm. She spoke of early trauma and how that can play out in addictions. She believes that governments and policy makers need to be held accountable for teaching Treaty and Treaty relationships. She works within a support group: "We support each other, and our group sees what happens when that literacy isn't there. I guess I'm getting into deep. I can go on and on about that."

The next person was a participatory, community-based researcher with long rooted connections to Indigenous communities. We will call her Sinope. Over the last twenty years, she has been working with communities to develop and respond to important questions that honour meaning-making. She was interested in the 'cycling back' phenomenon within prison systems and creating well communities in remote locations. In her health role, she activates new perspectives on how people see themselves within systems and by working with physicians and health care providers. Sinope believes that by writing and disseminating with community

members, the processes could change how people who are called to work together by systems could see each other. “It’s about helping people to help themselves.”

The next participant was a Day School survivor, with multiple siblings, but the only one sent to live with grandparents. We will call her Lysithea. Both her grandparents were Residential School survivors. Within the Day School system, she ‘failed ’grades as the primary goal was to teach obedience. She spent five years there but then was able to move to another school where she felt loved. She describes teacher attrition - a new set of teachers every year - as contributing to a lack of supports for students. Her third phase in schooling was in a Residential School where she suffered abuse “as if the boys thought my body was not my own.” It made her not want to speak the Cree language carefully taught by her grandparents as she attributed the language with the shame of the abuse. “And I did not speak it for many years, until I met my husband (another Cree speaker), until I felt loved again.”

Elder Roland helped us return to our questions as we went around again in the circle. He taught us that by sharing stories of early schooling, we can develop trust within our circle. Relating our stories would help us feel not alone, and stories of school and literacy might trigger what happened in families at Residential School. We might think that when people do bad things, there needs to be some kind of societal payback. His advice was to start by listening: “We have to take the time and get a broader mind within our own mind. We need to do that within systems.” Further, he taught about the role of forgiving a system, a way of thinking: “The healing, we know we can have that if we put our minds to it. If we open our hearts to forgiveness. Forgiving is very hard and sometimes, we never forgive. We never forget, but forgiving is another step. So that’s where I work from, that’s also where I come from.”

The family of Carme, Ersa and Dia took turns back and forth describing connections between literacy and health. It began with cultural well-being and with a challenge: “We also had Elders telling us we were going to hell; there are differences among our people.” Ersa talked about being grounded in her own beliefs as providing the resilience she needed to graduate and to help others. “I needed to prove to the Elders and to the teachers that I was going to be more than they ever thought I was going to be.” She described helping siblings and friends in varying ways and summarized it by “What I’m trying to say is that students need to be guided from where they are strongest.” She described the importance of safety at school. When her son was not feeling safe at school, it contributed to absenteeism, feeling sick to his stomach and eventually to moving schools. She felt that there were some awesome teachers and leaders in her son’s schooling, but that “it starts with teacher training.” Teachers need to be expected to care about what happens at school.

Carme, who is a grandmother of thirty-one children, started by saying that to her education was everything. She believed that the importance of literacy belonged squarely on teachers. In describing her connections to health and literacy, she told this story:

“ When we were small, we did not end up in the system because my father was a farmer. And he took us all. As soon as he knew the grey truck was coming, he would take us to the far field and tell us we had work to do. And sometimes we would be there the whole day. So that’s where I learned my education from, from that field. And then we came back to school. I had to miss a lot of school, because my dad did not want them to take us. But today I think the teachers were very good. We learned our math. I did good at English because I am good at writing stories and making up stories. We were always together, that’s why we kept our Cree. We would go in the corner and sit so someone could see if the teacher was coming. Our grandparents also spoke Cree. And we learned our English by writing out our lines for punishment- ‘I must not talk Cree! I must not talk Cree! ’(laughter) My siblings, all of them are teachers now.”

Erinome followed by relating to the story. “I know you said leave the past in the past, but trauma works differently with different people. They will never understand it until you have lived it. Sorry. I lived in my adopted family. My adopted parents were good to me, but I

suffered trauma from a sibling who was also suffering from his own trauma. That affects you in your schooling as well as being the first Indigenous person in my community. I started to hate myself and my community." She wondered how systems in health and education come to understand who people are. "Reconciliation? There is no reconciliation. It's out the door. I want to see it. I am not seeing it. Our kids are still being taken. Racism is still going on." The impact she described as "You were not living the life you should have been living. You were always under pressure. Those pressures change how you learn." She believed that Indigenous children in the city were being diagnosed with learning disabilities or post traumatic stress disorder. She described her family's return to the right road, the Red Road. She believed that supports for children who are in the school may come with the help of diagnoses coupled with counselling. "If you can address the counselling part of it, it may help them get through that day, or help them to focus on that day." She also recommended recognizing the treaty area that we are in, "recognizing Treaty Six and that we are all treaty people. Maybe then reconciliation can happen." Erinome went on to say that to improve literacy and health, Indigenous people needed to develop a sense of pride and a love of the Nehiyaw language. Her granddaughter did a class presentation on who she was. "If my granddaughter can teach them about Treaty Six, she can also teach them that we all have to get along. It's not just First Nations against the white people or the non-Indigenous people. We all have to work together."

Lysithea spoke of how her son's braids made him a target at school. A lack of racial understanding and the significance of his braids resulted in teasing and bullying at school. He couldn't do well at school because he didn't fit in. We changed schools where the family was connected with teachers and the principal in a good way. "He did so well there, he thrived." In

making connections, she advised, “So health and literacy. I think the mental health should be a part of that too. Not just physical health, mental health and emotional health.”

Elder Roland wrapped up the circle with this advice: “I want to thank the parents and the grandparents for their contributions. I was intrigued by their personal stories. And I think that is what it is all about. For our people, to relate and surface our hurts, our pains, is the start of healing. When you start healing, the literacy will be the driving force. We will recover. And I think that is what this is all about as well. When we start recovering, we start healing. The root word of health is heal. So work with the two words because they go together.”

Our second talking circle involved another family as we gathered more information following the COVID-19 guidelines. It had a similar pattern: Elder Roland made contributions at the beginning and the end of the two rounds. The personal story was different, as were the connections to health and literacy with what issues continue to marginalize. Elder Roland spoke about connecting with people through story telling. In Nehiyaw tradition, when you speak Cree, you are that person who has that language, and it is land-based. Language was and is identity; it helps Nehiyaw people identify the land they are from. “It has a sense of spirituality that gives an onus on yourself that you take that role… it gives us a sense of empowerment that you walk the land, Mother earth, you can feel that in the language. Cree is a feeling language. When you speak it, it has a sense of knowing that you are heard.”

Elder Roland told us a story of a time when his own literacy was questioned. He responded in Cree, for about ten minutes. He queried around who was being called illiterate, and by what standard. He reminded us that language is a beginning, that in Nehiyaw culture it is entrenched and brought to life through ceremony. “It gives you an opening to try to figure out what people are saying. That is the first connection you need to have. That is what develops

into the ceremonies, the things that we do." He further asked about how Nehiyaw people are known in a system. The pain in the stories was important. How children were taken, the abuse that happened. The coming to know, the *how* of the coming to know could be an indicator for a system to think about. The challenge comes in understanding each other in a loving way. "You try to distance yourself because you don't want to know those people. Once you find out we are very loving people. We will help you. That is where you need to adopt/adapt to our way. That is the offering we give you as Indian people. If you take advantage of that, that is the offering we give you."

Lo is the name of the next family. Her connections were more about health as the beginning of literacy and how health issues marginalized her and her family. She described that herself, her children and some of her friends were talking about how they don't feel safe fully talking about their health concerns. She thought that there are too many drugs, and that the stereotypes of Indigenous people play into Social Services: *they will come and take our children away.* For some people struggling with health issues, such as chronic pain, or past traumas, there is a reticence to share fully if they are using drugs to cope. "People don't want to be drunks because when it comes to Social Services you know they write down things; they write down everything. They exaggerate. I think it just scares people right off." She told of how she was judged, and her children taken away. She described returning to school at over fifty years of age as something she did for herself to work past the judgment. "I am not blaming the system. Actually, I am… I think all these years, I never thought of how kids need somebody to look up to. I did not know that or see that the way I see it now. I still try to encourage my big kids to do hard things and hopefully they will." By going to university, she believed that she could role model persistence; that schooling could serve as a tool for empowerment. "Literacy is a big one.

It’s hard because I think a lot of people just gave up. But I always like to encourage people. Don’t give up.”

Sinope recounted her curiosity in the dialogic that happens within advocacy. Developing questions with community in ways that are meaningful can also be empowering. She congratulated Lo for completing her first year of university and encouraged her by saying that the first year is typically the hardest. She spoke of community connections with people from Sturgeon Lake as her mentors. Lysithea said that she knew some of the same people as Sinope, furthering connections within the circle.

Elder Roland recounted that literacy to him could “help people open their eyes a bit more. It could help people be more aware of their surroundings. Make you more willing to learn more, do research and things like that.” Literacy was connected to knowledge; it was what helped him through his shame of being graded at Grade Two. His culture helped him feel special. “I knew there was something in here (touches heart) that needed to come out so I could show people that I wasn’t a failure.” He spoke of his persistence and hard work, each day trying to learn new things. He had worked in both Justice and Social Services but encountered barriers when it came to developing relationships within homes. “So that is one of the things that the system has to understand. How can we work with these families as parents? So literacy you know, that’s where I developed myself so that I could help others.”

Lysithea, at this point, seemed sad. We asked how she was doing, if she wanted to tell us about what was happening. I said, “I was thinking about all the potential that is sitting in people’s stories as they share them. I am learning lots about taking time to listen.” She wanted to wait. At my turn, I spoke of the principles of OCAP® (ownership, control, access and possession).[2] “So when we work with Indigenous peoples, anybody, any researchers, we are

supposed to not only have ethical guidelines, we give it back to them. That's one layer but another layer - and we have cycles of that, iterations. Making sure people are comfortable. So Lo, when you were talking about this person writing and you didn't know what they were saying or writing down. They did not go to you and say - is this what happened? You never got to see it?" Lo shook her head.

Elder Roland recounted that even in prisons, everyone gets to see the reports at parole hearings. Sinope shares that health has not been that progressive, even to the point that "We have our own language, as you know. We try not to share that language much with anyone. We try to keep that language here so that you don't have much knowledge or ask too many questions. It's a variety of issues…you can see what X person said. And if you don't think that it is right, then you can get it redacted or taken away or improved. But it has been a long time coming. A long, long time."

Lysithea talked about accessing records to support her documentation about Day School. She also made a connection to her health. "I had so much body pain issues. I had breast pain, pelvic pain, shoulder pain, my throat and my body aches from my childhood growing pains. My doctor and therapists heard and acknowledged my Day School story; so today my memory pain and body pains are not as burdensome and heavy. I cannot say I am fully recovered as in pain free. I physically survived my childhood but my spirit was harmed beyond repair and that is who I am today…cautious and distant."

Lo added that she needs to start her Day School documentation. "But at that time, Day School was not. They did not call it Day School yet. Then when that first came out, the Day School thing, I just cried my head off. I remembered everything." Elder Roland recommended to

Lo that she needed someone to walk with her, to listen. Once you start the first sentence, you will make it. It does not get easier, but you can do it."

Lysithea explains how she felt as a young child at the time:

"But that time, in the 60's and 70's, it was acceptable for boys to be sexually aggressive. They had that air. It was okay to abuse or view you as the little girl. Then people would say "boys will be boys" so they missed a lot of the abuses. I don't know why those teachers - they didn't really do well for me. I guess they seemed that they just didn't care. Because I didn't belong to that community on top of that. Everybody helped themselves on me too much. There were other boys. So when you are kind of a throw-away child, it means that everyone can step on you."

Elder Roland helped both Lo and Lysithea by looking at it through a healing lens. He told them it is okay to still be that child, then to wonder what is happening with that child. Healing could begin when that child is heard. Providing moral support and walking with each other was vital.

Summary

This Chapter was set up in sections to describe the order of the data collection cycles. The first cycle involved asking two Indigenous Elders how to shape the questions and perhaps more importantly how to encounter with each other using dialogue. Intent, and a "sincere interest for justice", needed to govern our time together.[8] The initial title *Ask Before You Ask* was written as part of social justice theory for researchers to examine not only what they don't know, often explored through limitations of quantitative data alone, but also what they do know in how they experience the world. As a non-Indigenous person working with Indigenous people, a deep examination needed to happen before the data collection cycles could begin. What I came to better understand about situatedness and location will be further explored in Chapter Six.

The two Elders initially involved in setting the context wanted to talk and share stories about Residential School and colonialism impacting literacy and, in turn, health. First language became important as both were fluent Nehiyaw (Cree) speakers. The sharing of local customs

from the treaty area such as cloth, tobacco and smudging were also important and helped connect back to setting intent. It was thought that there might be some reticence to share painful stories but we encountered that the telling of the pain became a necessary part of interconnectedness in our circles. The stories told were connected with a theme of resilience and strong family connections. Hence, it was recommended that participants be able to invite family members that they chose. This helped build a strength-based, appreciative foundation from which to move forward. Both Elders spoke of the confluence of ceremony within urban contexts as a source of struggle and opportunity for participants to cohere. The theme of reciprocity in enhancing each other's cultural literacy also came through. Honestly, the Elder's recommendation of *kih-sih-tah* was almost prophetic when the pandemic occurred.

In the quantitative questions, the long-term effects of Residential Schooling, literacy and health were the questions that were responded to by everyone; questions around income, employment, and schooling each had some level of opting out by participants. It was interesting that when asked about Residential School, all participants wrote in more details than had been asked; Day School and Sixties Scoop were added to the list without any prompting. As there were at times generations within a family in the circle, the average age range wasn't a good indicator. In examining the connection between early schooling and health, the scores got lower (or better according to the scale) as time went on.

The overarching theme of the talking circles was that language and culture should not be separated; in fact, by building cultural and language competencies, literacy can enhance health. Perhaps not the type of health literacy that involves being able to better read and follow prescriptions, but the type of literacy that affects the encounters that participants have with health. For example, the Elder who led the questions talked about how literacy in English

created a different culture than what he would have had with his Nehiyaw parents. Learning English as a second language and having to operate in English made him feel less competent and ashamed. He knew the intricacies of his literacy in his own culture, but they didn't translate into the Western context of health. The strength of this was a lesson in humility. It was re-iterated by a participant who shared that there is a hesitation to tell the truth to health practitioners: when people write things down in a language you aren't fluent in, they might come and take your children away as happened to her. Is this a contemporary form of Residential School? Another participant spoke of the significant physical pain she had while working through her application for Day School compensation. Once the application was submitted, with the help of health practitioners, her pain was gone.

Can a system be healing? If so, how? The participants talked about the importance of starting with listening. While it was thought that the construct of literacy might morph in its relation to health, it was more the construct of health and healing that rose to the surface. No one sought to forget the past, but rather focused on healing and forgiveness as the necessity. This was true for all relations among Indigenous people and non-Indigenous people alike. Seeking reconciliation in our hearts and in our families was a challenge put forth by the group. When our personal and family relations are strong, we can contribute to building better systems of health. Participants felt that systems of health and education could work cooperatively in urban settings to include community members in building a stronger path towards more social cohesion.

Throughout the data collection phases, there was an invitation for cultural expression through language and local traditions. By connecting with Indigenous role models and authority from within the community, participants shared what they felt comfortable with. Opportunities to opt out, pass, or not complete questions were present throughout. The spirit of our gatherings

was positive and uplifting, but there were queries about the untried nature of our questions. If people are aware of Indigenous people providing their own responses to health disparities, rather than them being imposed, what are the current structures that could enable this? How could we provide further feedback to health practitioners and disseminate what we learned in an effective way? Chapter Five will explore sensemaking and seek to connect it to the broader narrative from participants.

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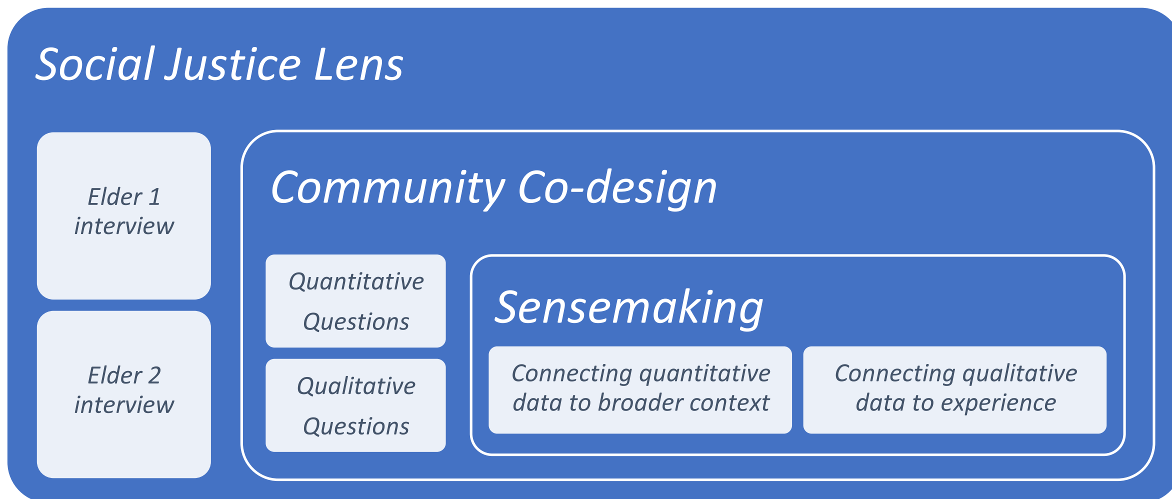
Chapter 5: Integrating the Questions and Knowledge Translation

"Research is needed to develop and test measures of early learning and program effectiveness that are culturally relevant but that also are not entirely idiosyncratic and reliant upon unwieldy phenomenological or public opinion, survey type research. The past decade has seen a growing recognition of the value of collaborative approaches to research whereby investigators, policy makers, and program designers can compensate for their cultural blinders by collaborating at every step with skilled members of cultural communities."[1]

Introduction

In Chapter Three, mixed-methods participatory social justice (MMPSJ) was described in detail, including how nesting the questions with a community enhanced MMPSJ design. Figure 3.1 was used to visualize the elements and iterations of the questions.



Community-Led Mixed Methods Participatory Social Justice: Figure 3.1

This Chapter will focus mainly on the sensemaking stage where we worked to connect the quantitative data to the broader context and the qualitative data with the participants' meaning-making. In MMPSJ, the common term was *integrating* the questions, but as these questions were situated in community, *sensemaking* seemed more relevant both academically and to the people involved. The second part of this Chapter involves using KT or knowledge

translation practices to coalesce the connections made by the participants. To note, a gathering circle was used for member-checking where the KT pieces as well as the transcripts were given back to participants such that they could amend and/or make recommendations.

Sensemaking was limited by how the participants responded to the questions. For example, originally, there was a question about Residential School, but the participants changed it to include Day School and the Sixties Scoop. This question was in the quantitative strand which was a pencil and paper survey that was done individually; put another way, they did this on their own. This told me when we were putting the data together, it was important to the community to 'tell the story well and get the details right.'[2] Some questions weren't completed; however, all participants wanted to participate in self-declaring as Indigenous and making connections to health and well-being. Each question gave them their own opportunity to respond or not to respond. In the qualitative questions, the sensemaking was limited to what was meaningful to the participants. We did two rounds at each of the talking circles, led by Elder Roland. We met for approximately two hours each time, including the data collection phases, member-checking and KT phase. Throughout each Phase, with participant permission, the data were transcribed and notes taken in real time which was followed up with a personal journal to reflect on the content. This was important as part of social justice research is researcher's intent.

> "That is, research can be used either to perpetuate or to disrupt the social status quo, to oppress or to empower marginalized groups, to provide an experience that blames people for their victimization or seeks to liberate them and transform their lives. It is not the method alone that determines the outcome, but rather the *intention* behind and the use of that method to support social justice aims."[3]

The intent was ameliorated by the presence of Elder Roland. Invitations to smudge and gather briefly prior to starting the circles was offered, as was the opportunity to meet with Elder

Roland after the circles and outside of the research process per se. The reflections and Conclusions are included in Chapter Six.

Connecting Quantitative Data to a Broader Context

The quantitative questions used in this research are commonly asked in health data systems (Appendix B). They were adapted from the Aboriginal Regional Health Surveys[4]; they are also common census questions. The intent of the demographic questions around age, gender, education levels, etcetera were to set a context for the third set of questions which was a general perceived health score for participants, their children and their grandchildren. The qualitative questions connecting literacy to health was purposeful as it is seen as an upstream factor in supporting primary care advancements.[5] It is important to note that the questions that connect to Indigenous identity represent a significant gap in current health information systems. More importantly, the MMPSJ framework asks researchers to consider empowerment as a critical stance in addressing these gaps.

"In order for health data to become a tool for Indigenous social empowerment and social change, the social structuring of data, governance, and management must change from systems that reinforce social exclusion by marginalizing systematically disadvantaged populations from their data, to systems in which they are fully and centrally involved in data decision making."[6]

Quantitative data typically allows information to be drawn from a local context, standardized, removed from context, then delivered to a central point of calculation.[7]

Before we examine the quantitative data further, it is important to review the snowballing sampling strategy. This played out as a small number of participants being asked to join (n =3), with a corollary invitation for them to invite whomever they wanted, based on interest and availability. It was purposeful as a further gap in quantitative data sets have been described as such: "it can be assumed that within specific socioeconomic strata, persons who choose to

participate in a survey are different than those who choose to not participate, with the former group likely experiencing relative socioeconomic, literacy, and housing advantage compared to the latter."[8] In the health data examined that connected literacy to health, there were a myriad of ways the term literacy was used; moreover, the relationships were not clearly defined. The construct of interconnectedness became an important theme to the participants. Allowing personal choice, opting out, having the ability to pass on each question, having family together, and reviewing the questions orally helped to create a mutually supportive atmosphere. It was interesting that some of the demographic questions, particularly about income, were the ones that most opted out. Where did the participants have 100 percent participation? In the connecting to Residential School and their choice to self-identify. In addition, the participants chose to write over top the question of Residential School and add the Sixties Scoop and Day School to create a more meaningful, personal response.

Intergenerational wellness responses were scored on a five-point scale and are commensurate with perceived health questions. Interested readers can compare with the table from Statistics Canada here: Table 41-10-0001-01 Perceived general health by Aboriginal identity.[9] The Regional Health Surveys[4] can be found at https://fnigc.ca/. There was a plethora of data to connect, but not to compare these results to. To set context, here are some general trends that were noticed:

⇒ Connections to health were limited to Residential School (called IRS) alone,

⇒ No direct connections to literacy and health, although approximately 42 % cited "poor education" as an intergenerational reverberation from IRS,

⇒ Perceived general health scores trend upwards the further the generations are removed from IRS,

⇒ Chronic health connections included speech and language disorders, chronic ear infections and learning disorders,

⇒ Over 50% cited they were "not able to talk about" the impacts of IRS.

There were two gaps, or silent stories, that were pervasive. The first was a lens of disparity: long lists of chronic diseases and barriers with no strength-based, positive, or upstream factors noted. The second was that some of the wording was front ended with judgement. For example, there were demographic charts with "portion of First Nations youth that live with at least one of their biological parents, according to mutually exclusive categories of IRS."[4] It was difficult to determine what the difference would be or if there needs to be data collected on the portion of FN youth that live with one or both of their parents, but I do think that adding 'at least' was diminishing and further how it would/could be connected to health was not qualified.

In summary, critics of quantitative data collection of Indigenous peoples' health describe them as deficit-based, unbalanced, under-represented, and leaving groups of people out. Hence, how data are collected could contribute to social inequity. Put another way, "Indigenous scholars in particular view quantitative methodologies with suspicion…Historical data collectors often had only the barest relationships with those whose information they collected"[6]. Within this research, an Elder was engaged throughout to not only be present, but to ask all the questions. This is commensurate with recommendations in community-based, participatory research with Indigenous peoples, as an Elder can use his or her wisdom to help balance traditional and contemporary well-being. Further recommendations included being flexible and providing multiple opportunities for engagement.[10]

It is obvious that current connections among health, literacy and being of Indigenous ancestry are situated in a colonial mindset. This research would put forth that this mindset was

and continues to be imposed on data, particularly quantitative data. One of the over-arching goals of this work was to examine with community what connections between literacy and health could be identified in an appreciative light. The next section will use knowledge translation practices commensurate with community-based, participatory health research for the qualitative strand. It was important to participants that their stories be seen and heard so that they could attest to a forward moving energy towards health and harmony: participants evidenced interconnectedness with each other and to the spirit world as a necessary part of the process.

Sensemaking with Qualitative Data

Knowledge translation (KT) practices were chosen to make sense and to integrate the results/findings of the questions in ways that were meaningful to participants. Current critics of research *on* Indigenous people insist that it may inhibit contributions to said research resulting in research not benefitting the people involved. Moreover, participants needed to contribute to all aspects to mitigate power relationships. At the core, KT is promoted with wise practices (OCAP®) that advances the well-being of Indigenous peoples.[4] In Canada, KT is about sharing knowledge in ways that the local community develops and contextualizes: in addition to putting knowledge into action.[11] In considering rigour, some forms of KT may be at odds with mixed-methods research. As social justice and community is at the heart of this research, it required us to locate ourselves and be transparent about relationships (particularly power relationships) while safeguarding the four ethical r's: responsibility, respect, reciprocity and relevance.[12] Thus, our work in KT is innovative as there was not a solid foundation of published research on how best to disseminate the results/findings yet there are many recommendations that have been developed to evaluate these processes.[13-16]

Wise practices as described in OCAP® included but were not limited to embracing local traditions, involving a sharing system, or story-telling: "knowledge development work is actively transformative as it is linked to life-long processes of human development. Stories themselves can be perceived as holding "medicine" and the process of sharing stories as acts of healing"[17]. The KT is written in six pieces: from the perspectives of the Elder, first family, second family, third family, fourth family and the researchers. It used a template designed specifically for this study to represent and highlight the key areas. Participants had an opportunity to review the unedited transcripts; as well as the KT template and make any changes they would like. There were additional efforts to continue to view the insights in an appreciative light. Thus, readers will note there is a justice-oriented section on empowerment in each KT piece.

The recommendations were organized on 'one-page' so as families read the transcripts, they could make changes to them, they also could edit the recommendations and were given an opportunity to change any information or opt out. An Amendment to the original Ethics Application was made to include the question: *How would you like the knowledge to be shared or disseminated?* (Beh ID #733). The organization of the recommendations reflect their responses and made them reader friendly as we worked to make sense but also to follow up with summaries and the engagement model proposed as an analysis in Chapter Six. The groupings reflect the families as described in Chapter Four.

ELDERS ELARA AND CALLISTO: SETTING THE FOUNDATION FOR THE QUESTIONS

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Local traditions and advice should be sought prior to developing questions. There needed to be a recognition that families were struggling moving in and out of a home community and an urban setting.

CONNECTIONS TO LITERACY AND HEALTH

There should be some extra supports for families that move around accessing health care and schooling, such that there is a continuity of care and learning. Health practitioners should include the use of advocates as an added support.

EMPOWERMENT

The Elders felt empowered by having their traditions honoured. It helped situate the questions in a ceremonial space. Everyone belonged to a community, even in an urban space. They recommended a talking circle as a way to gather people. Continued Elder presence was recommended both during the asking of the questions and after. The telling of story would be important, as the literacy and health questions could invoke the historical relevance of Residential School; planning for additional supports that situated power with Elders was the right way to go about inviting people, as well as creating an ethical space.

RECOMMENDATIONS

Mobility should be addressed as a determinant. An advocate, or extended family, should be invited to promote wholistic health.

Increase access to ceremony for all people. Strengthening spirituality strengthens relationality.

Epigenetics should be considered. Healing needed to take place from a cellular level.

Elders should be included in every way possible. Indigenous families might participate more fully and freely if they know in advance who is attending, but also who is asking the questions.

"Then you begin to express your innate joy, express your innate creativity. Create a world that you want to get well."

"There's that ethical space that Willy Ermine talks about. Come and just be. When a person is ready, they will be hungry enough. Spiritually, emotionally, physically, mentally…they will ask."

ROLAND: OUR ELDER

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families?
What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Roland is a Residential School survivor who described a culture that was created within him that was different than if he had not attended. He shared that we all have a capacity within us to reach within and reach to others.

CONNECTIONS TO LITERACY AND HEALTH

Literacy can be a driving force to promote healing. Early literacy can contribute to our well-being by allowing us to communicate with each other in a good way. Relating our stories help people to not feel alone. We grow in community by listening to each other. Literacy and language are integral parts of developing a strong identity. Roland helped us understand that we can see the word heal in health: we can also view painful stories with a healing lens.

EMPOWERMENT

Roland felt empowered by leading our circles, by feeling liberated to speak his language and by sharing some of his traditions. Roland shared that he felt authentically included beyond our circles with our member-checking and by participating in meetings. This consistent invitation throughout helped deepen his participation and build relationships in community. By expanding his network with health practitioners such that he could share with them his insights helped create a new space for him to step into and co-create outcomes.

RECOMMENDATIONS

Love of Language: that Nehiyaw terms be seen and heard

A listening space where people can surface their pain and their story

A humble stance: everyone deserves to be treated the same

Respect for women: increased efficacy in having voice and making decisions to promote health in community

“Who are you calling illiterate? Language is a beginning. In Nehiyaw tradition, it is entrenched and brought to life through ceremony. Language is the first connection you need to have. The challenge comes in knowing each other in a loving way. We are a loving people. Literacy was the way I developed myself so that I could help others.”

“When you start healing, the literacy will be the driving force.”

CARME, URSA, DIA: FAMILY ONE

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Families that come from Residential School, Day School, Sixties Scoop are survivors from a system of brokenness. Indigenous families in urban settings are further removed from the land, and in turn, their culture.

CONNECTIONS TO LITERACY AND HEALTH

Cultural well-being was a form of health; having access to Elders and ceremony was a form of healing. Literacy could come from a place, from the land; so could health: how could we practice place-based health?

EMPOWERMENT

Standards in schools for literacy should be the same and not be relative to geography; poverty shouldn't matter. Poverty is a Euro-Western term that is deficit based. Richness came from culture and tradition. By keeping language alive, it helped keep their family well. A shift in the mindset was necessary: people needed to be guided from where they are strongest. Families needed to be gathered to see beyond school.

RECOMMENDATIONS

Seeing beyond: Literacy needs to be connected to other areas beyond schools so families can co-construct and share governance.

Increase access to Elders and ceremony for families to promote health and well-being.

Increase access to language through schooling and health practitioners- by seeing and hearing language, particularly Cree, families may feel that a more wholistic view of health is possible.

"It's going to take a very long time. I hope we can figure it out so that my son can be taught today's modern stuff and that's what I'm getting from this question."

"Literacy is?"

"Being able to read. Fluently."

LYSITHEA AND FAMILY

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Lysithea saw that interconnectedness and relationships were foundational for feeling successful. She was the only one of her multiple siblings who was sent to live with grandparents.

CONNECTIONS TO LITERACY AND HEALTH

Lysithea shared that her child and grandchildren did not always feel like they fit in. An example was her son wearing a traditional braid. Because the students didn't understand the significance of it, it made him a target and he was unable to fully engage in school. In her life, she felt that language and love were intertwined, that Cree was a love language with its own beauty.

EMPOWERMENT

Lysithea felt empowered by telling her story and being able to apply for a response to Day School. Her throat and her body were painful because of the trauma suffered. Once she got a chance to work with health practitioners to document and share her story, some of her pain was lessened. She also used her story as a source of strength to advocate for her son when he was struggling with literacy at school.

RECOMMENDATIONS

Practice community health through belonging.

Provide moral support and walk alongside people.

Increase racial importance and understanding.

Have consistent teachers and care givers for families that are accessing school and health; relationships take time and the turnover of staff affect people.

Recognize that each person owns their body.

"So health and literacy. I think the mental health should be a part of that too. Not just physical health, mental health and emotional health."

ERINOME AND AITNE

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

The Sixties Scoop laid a foundation of trauma for this family. Making sure that not just Residential School is factored into Indigenous Health Data systems was important. The daughter said that she felt that she was discouraged to see beyond grade twelve. As the only Indigenous person, displaced in a white community, Erinome started to hate herself and hate her community.

CONNECTIONS TO LITERACY AND HEALTH

Literacy can be a driving force to promote healing. Early literacy can contribute to our well-being by allowing us to communicate with each other in a good way. Relating our stories help people to not feel alone. We grow in community by listening to each other. Literacy and language are integral parts of developing a strong identity. Health practitioners needed to better understand the impacts of trauma in people and how it works differently, perhaps both intergenerationally and individually.

EMPOWERMENT

Erinome and Aitne were empowered through their own work of starting a support group. They believe that as long as children are being taken, racism is still going on. Reconciliation was another failed government promise. They believe the empowerment piece can come from within by keeping generations together so they can support each other. The right road is the red road.

RECOMMENDATIONS

Indigenous data systems should afford a space to declare or have families record their experience to Residential School, Day School, or other forms of family separation such as foster care or the Sixties Scoop.

Indigenous youth who are displaced in non-Indigenous settings, for example urban landscapes, should have access to supports that scaffold identity and pride.

If we are all treaty people, then we all have to get along.

Reviewing the truth and reconciliation calls to action within local community contexts was still necessary: the bridges that could be built from there should manifest in local policies.

“We support each other, and our groups see what happens when literacy isn’t there. I guess I’m getting in too deep. I can go on and on about that.”

LO AND FAMILY

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Lo described how she and some of her friends didn't feel safe talking about their health concerns. There wasn't a level of checking to see what was written down on the records - she worried about what was written down. Would someone come and take her kids away if she talked about addictions? What about people that were dealing with chronic pain?

CONNECTIONS TO LITERACY AND HEALTH

Lo described how health issues marginalized her and her family. Health was the beginning of literacy as health people were more likely to interact with families prior to school.

EMPOWERMENT

Lo was empowered as she has returned to school after fifty years away. The group encouraged her to keep going, offering help in any way. She talked about the need for role models: Indigenous youth need role models. Lo also felt empowered by spending time with the Elder: "Once you start the first sentence, you will make it. It doesn't get easier, but you can do it."

RECOMMENDATIONS

Primary caregivers should help build the connections between literacy and health, both in the short term and long term.

Indigenous youth need role models. Families can build resiliency by being resilient themselves.

Building family capacity throughout generations is important.

"Literacy is a big one. It's hard because I think a lot of people just gave up. But I always like to encourage people. Don't give up."

SINOPE: PARTICIPATORY HEALTH RESEARCHER

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

Sinope was able to make connections among participants in the circle. As a health practitioner, she represented a person of status. One participant posed a challenging question: "Do you want to know why we don't tell you the truth?"

CONNECTIONS TO LITERACY AND HEALTH

Sinope was curious about connections between literacy and health in prison systems. Currently there is a gender gap between what men and women can access to promote individual literacy. She sees literacy as increasing an individual's choices among systems. The more literate the individual was, the more able he or she was able to navigate and develop their questions regarding their health.

EMPOWERMENT

Sinope felt empowered through the writing and disseminating process. She believed that writing with people could change how people saw themselves. Further, it could help how people saw themselves navigating within a system.

RECOMMENDATIONS

Meaning making with Indigenous people is important for all people.

Analyze power: a predicating relationship is necessary as the current structures support research on as opposed to with Indigenous participants.

A lens of disparity will perpetuate the status quo; the disruptive measure is to connect with community throughout.

Develop questions *with* and checking personal meaning making is an important part to documentation.

Attend to gender equity, especially in prisons where pervasive inequities exist in the areas of literacy and health.

"It's about helping people to help themselves."

RESEARCHER

Knowledge Translation: What are the current connections between literacy and health within urban Indigenous families? What literacy issues marginalize the community?

INTEGRATING INSIGHTS

The process of seeking insight, asking the questions and being mindful of relationships was time-consuming, but worthwhile. Member-checking with reciprocity in mind created a mutual atmosphere of trust.

CONNECTIONS TO LITERACY AND HEALTH

Literacy is a supportive and upstream factor that can serve to increase health within the social determinants of health. By factoring in local context, historical factors, gathering both quantitative and qualitative information, the possible intersections were clarified.

EMPOWERMENT

Empowerment was felt by listening and reflecting. As this research took place over time, the principle of reciprocity was enhanced as the knowledge exchange took place within and without the research context. Opportunities to discuss as the pandemic played out helped us connect to a broader, community-based health imperative. The collective insistence on keeping it positive created an energy that made completing this work possible.

RECOMMENDATIONS

Take the time, it will be worth it.

Mixed Methods Participatory Justice research was enhanced by including community at every step. While it morphed a simple design into a complex design, a richer response was made possible.

The ethical considerations of being a non-Indigenous researcher in an Indigenous context can be lifted by seeking advice and power sharing. Participating in ceremony where invited was especially important in power sharing.

The social determinants of health on initial examination such as literacy, housing, nutrition, etc. appear to be outside the domain of health. By understanding collaboratively how determinants can relate to a place and to people, we can better understand how to help each other.

Synthesis: Throughlines and Branches

In an effort to synthesize this information, the subheadings of 'through-lines' and 'branches'were chosen. The reason for this was that the research took place over time. It had to be stopped and started partially due to the COVID-19 pandemic but also because of the methodology. Ownership and control of the study was a challenge as the methodology was evolving, and as Elara shared, "Like what you are talking about, this not being able to read…Nobody has ever asked."

Was there a thread we could weave as a common experience? Initially, the Health Disparity Report[4] provided shocking statistics relative to this community. We appreciated a sense of urgency to act; this coupled with the Truth and Reconciliation Calls to Action[18] set a foundation that the work was now and present. Freirean theory was connected as in *Conscientization*,[19] he states: "the process of conscientization leaves no one with his arms folded. It makes some unfold their arms. It leaves others with a guilt feeling, because conscientization shows us that God wants us to act." Both Freirean theory and this research upheld the social justice lens that has an entirely optimistic view of the individual, the potential that lies within, and the hope that lies in building from strength. The mixing of mixed methods research comes of dialogic akin to Freirean and social justice theory.

Uptake was a common thread. The invitation to participate, to invite others, to opt in and out of quantitative and qualitative questions was manifested by just that: while everyone participated and invited others, there were some quantitative questions not responded to, a nod or a pass taken at the circles, and consistent member-checking. On the surface, this might appear as good process within the methodology, but on a deeper level, it created a common, ethical space

that we stepped into together. The paradox of pain and laughter was also embraced. Participants shared their complex histories alongside their joys and their hopes that we would see each other soon.

Elder participation was an important thread in this tapestry. This will be expanded upon as to location and where it is situated in Chapter Six but note that shifting understandings are inherently connected to Elder participation throughout. As a researcher, I had preconceived notions that Elders might want to not authentically include a non-Indigenous researcher. That didn't happen. While I learned that I needed to change some of my ways (listen more, talk less), I experienced a call to move closer towards the Elders. At no time did I feel unwelcomed; rather, I felt embraced. Often there was common gratitude sharing about participating in this research together. The construct of invitation to ceremony helped me move past my own ill-conceived barriers to participation. Elder guidance and leadership helped create a shared space where everyone could participate as they chose.

Encouragement with another mutual thread. Whether it was sharing stories, talking about interconnectedness, making connections with each other, or turn taking: the sentiment that we were gathered together to ask, seek collective guidance, and help each other was woven with the theme of encouragement. Persistence manifested itself as a sub-theme as there was a repeated pattern of finishing, and returning to, questions around what we could do to help each other, and simply keep going, keep going.

I refer to branches in the title because as much as we tried to limit the questions, they were mired in a deep context. Participants took the questions and used them for their own sensemaking. Thus, the sorting of what was to be included and what was not included was taken up very carefully with the community. Transformation was made possible both on the personal

level and the collective level. This macro level transformation is evidenced in the community-led engagement model.

Summary

This Chapter started out with the visual of the community-led mixed methods participatory social justice model. The quantitative questions were analyzed and presented as family members responded to similar questions as would be asked within a Regional Health Survey. The quantitative data were then used to set the contexts to a perceived intergenerational health scale and to connect said data to the broader context. We then used the qualitative data to describe each person's turn(s) in the talking circle. Participants' connections to literacy and health, their integrating inside, empowerment and recommendations are presented as one-page synopses. We then analyzed the quantitative and qualitative data to inform a community-led engagement model further described in Chapter Six. Chapter Six will begin with a review of the visual created in Chapter Two. It is hoped that by revisiting these, the writing itself demonstrates the iterative nature of this work. By separating out the quantitative and qualitative questions and then analyzing and synthesizing them through knowledge translation, readers can easily assess the meaningful content that the community provided.

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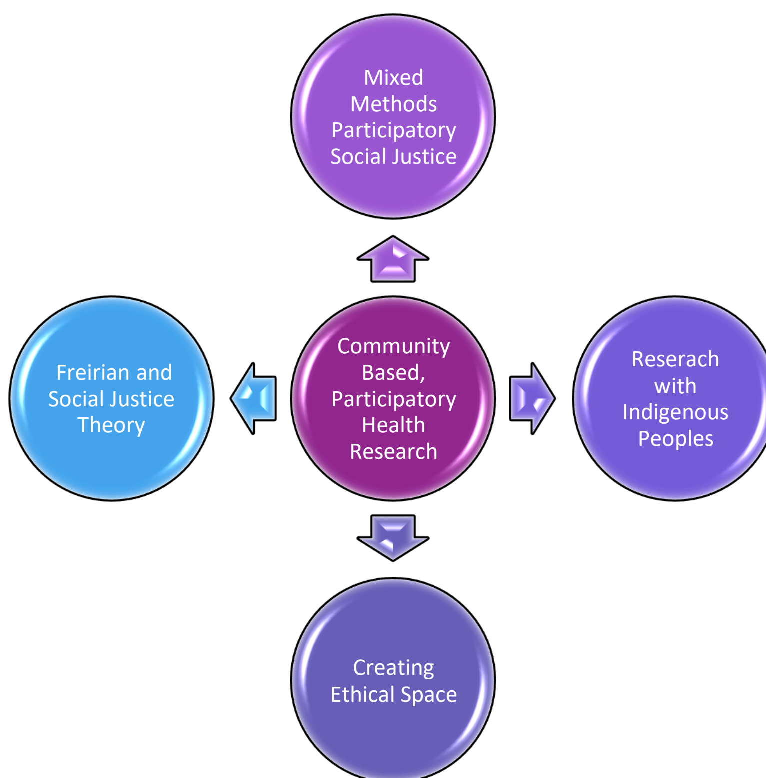
Chapter 6: Conclusion and Synthesis

"Education does not make us educable. It is our awareness of being unfinished that makes us educable and that same awareness in which we are inserted makes us eternal seekers."[1]

Introduction

Using mixed-methods participatory social justice (MMPSJ) within a community-led model requires a predicating relationship with participants and a presence in the community. Engaging in this research afforded connections and access during a time when health considerations were at a premium due to the pandemic. More importantly, it provided insights and a local voice to inform the framework, protocols, and transformation. Put another way, we believed that the community would use the framework within their local context, their way of knowing and seeing the world, and made meaning with it. Thus, MMPSJ research itself was enhanced. In Chapter Two, we used the following graphic to guide key considerations:



Each of these key considerations will be expanded upon in drawing this work to its conclusion, and to consider recommendations for future engagement.

Community-Led Based Participatory Health Research

The Social Determinants of Health (SDoH) described globally had several factors that effect health that at first glance might seem outside of the purview of health such as housing, food availability, and income level.[2] The juncture of this research was to illuminate education as another factor, and within that was the hope that by talking about literacy and health we could intersect the conversation from the educational side and thereby improve the knowledge and understanding about health fits in ways that were meaningful to community members. The SDoH also described upstream and root factors[3] that could both add complexity to health indicators while supporting the big picture of how to improve health and well-being. The genesis of the questions were framed within the values of how to respectfully, locally, and appreciatively examine how we could work together within CBPHR to make meaning from the following questions: *In what ways can literacy be considered a social determinant of health from an urban Indigenous community? What literacy issues marginalize the community?* A further question was added in the later stages: *How would you like this information shared or disseminated?* As CBPHR[4] has its primary focus on committing to community theories and co-learning, we situated community decision-making in front of the questions. As we worked together to pull the information together, it was thought to be best if the participants decided how this work could be disseminated in meaningful ways. When asked, the participants requested a small outdoor gathering to have a meal together and to have a copy of the work once it was

completed. This also gave us opportunity to do another round of member-checking. Once again, everyone was able to come except for one person and we were able to follow all COVID-19 protocols commensurate with the time.

Enduring in this research was that local voice and sustaining relationships were vital to the community members. Throughout, there was a sense that they hadn't been asked before. They shared concerns about how information was gathered about health, the truth within the numbers, and their feeling of being hidden. At the final gathering/celebration, Elder Roland was able to share his teachings and to ask us to pray in our own way for each other's well-being and for the community's well-being. As discussed in Chapter Five, they provided recommendations on how listening to their stories intergenerationally, socially, and historically helped build relationships within our circle and within the community. Participants felt affirmed, encouraged, and the engagement levels were high.

Mixed Methods Participatory Social Justice

MMPSJ is a fairly new addition to mixed-methods research.[5] While initially there was some hesitation to dive into this work from my perspective due to the contemporary nature of it, it also provided a window of innovation. It took lots of time, consideration, iterations and balance points to work through each dimension. That said, this framework was made better by facilitating the community's shaping of meaning by including their experiences, addressing their inequities, and respecting their cultural perspectives. Donna Merterns,[6] in a presentation in 2018, spoke of the importance of optimism in MMPSJ with this interesting query, "Optimism - what is the other choice?"[2] Of particular importance to all of us was taking the time with local Indigenous leaders to ask, prior to gathering data, the *why* and the *how* of both quantitative and

qualitative data streams, then integrating the essential ontological, axiological and epistemological epithets of MMPSJ into data collection. Thus, attention was paid to:

- *Within Axiology*: principles of reciprocity and resilience: was this research a recapitulation of the status quo?
- *Within Ontology*: principles of privilege and local history: did we recognize that while varying forms of reality exist, were they based on equality?
- *Within Epistemology*: principles of interaction and trust: whose worldview is being shared and valued?

Research with Indigenous Peoples

The ethical considerations of research with Indigenous peoples cause considerable pause for non-Indigenous researchers. Careful thought was put into creating a space that each of us could step into; a space that we co-created over time, built on relationships that were known before and during and will be present after the completion of the work. This work was not a brief encounter; having the community outline how they wanted to express themselves was an integral aspect of the work undertaken.

It is common for people to locate or situate themselves as part of the research process. It would be one-dimensional for a researcher to only say that they are non-Indigenous. Although true, there are other aspects that need to be considered such as being female and relationships that have been created by relating with Indigenous peoples both professionally, personally, and spiritually. What is more important, particularly in CBPHR, is for researchers to wonder how the community saw them. The principles shared above within the MMPSJ understandings helped and should be considered in terms of location.

Yet, I had no courage to ask. Until Elder Roland called me on his own one day. He was checking in. Here, he continued to model the principle of reciprocity. We had had a Research Advisory Committee (RAC) meeting the day prior and he phoned to let me know that he felt honoured to be part of the process; that because of the invitation to participate in every aspect, to be heard and listened to, he had felt empowered to further his own work. Humbly, I submit that he told me that I hold a light that I have chosen to lift up to let others shine. It comes through my eyes when I look at people and shines brightly when we take the time to listen to each other. Thus, our inter-connectedness became a way that we could locate each other within our circle.

Ownership, Control, Access and Possession (OCAP®)[7] were manifested in the opt-out option for each question. The community chose also to change and add details to the questions. This was especially important in the quantitative questions where the participants added Day School and Sixties Scoop. True ownership was evidenced in this way alongside the personal stories that came to light. Within knowledge translation and member-checking, participants recognized that the stories shared will continue to grow and change over time. By locating their stories in the past, and present, they also believed that there was a future for the stories within them. As families grow, and time moves on, so do the perspectives that an individual telling their story may hold in a different re-telling.

Creating Ethical Space

Creating ethical space[8] with Indigenous peoples started for me by acknowledging that we cannot truly know what we cannot or have not experienced as outlined by Willy Ermine's considerations[8] on learning together as part of ethical practice.

As a non-Indigenous researcher, I did feel beckoned by the Truth and Reconciliation Commission's Calls to Action - 18, 19 and 21[9] that referred to the past hurts of Residential School and closing the gaps between Indigenous and non-Indigenous peoples' health outcomes. I would hope that the path towards reconciliation is one that all people walk together on, side by side. I learned from the participants a willingness, as well as a welcome about sharing the experience. I encourage other researchers to try, perhaps even to reach inside, to become more open to learning with all peoples. Understanding that people come from different perspectives may seem simple at first but taking the time to seek out and understand different perspectives is crucial to research in the future.

Freirean and Social Justice Theory

People know themselves and their experiences. Freire fundamentally believed that every person has capacity; that transformation is truly possible if we could encounter each other within horizontal relationships.[10] Historical context was socially constructed and needs to be examined. By believing in the hope that lies within each of us, research questions didn't need to take a linear or scientific trajectory. By affording true choice throughout, it is believed that we engaged in Freirean's research praxis. Through reflection and action, people become critically aware and agents of their own transformation.

Conclusions

Since beginning this research, MMPSJ was made clearer by Mertens'[6] foundational MMPSJ query: "How do I take into account the expertise, knowledge and strengths of the

community in order to provide a platform as a fundamental for authentic engagement between the researcher and the community?"

For further clarity, I met with Elder Roland to share themes he heard throughout. We also met as a group to celebrate and also to provide closure. Elder Roland chose to share some thoughts in this way, as he believes that words live in a place, and these words belong here. These reflections rest on these pages, as future considerations, and as a testimonial to the community's voices.

Recommendations for Further Action through an Engagement Model

The social determinants of health show that Indigenous peoples have poorer health. Yet, improvements to health services alone will not improve Indigenous health or well-being; the participants believed that they could help effect social change by advocating for the following recommendations: to seek, to listen, to trust and to persevere. Elder Roland offered these understandings with Nehiyaw words and wanted to see some Nehiyaw words shared with readers. Broadly, he hoped that by remembering the stories of Residential School, Day School and the Sixties Scoop would remind participants of their resilience and a return to culture would foster their resilience. He wondered not as much how Indigenous people were represented in research, rather *who* was represented in research. How were hidden populations, given every-day barriers, be able to be seen and heard? Local languages and traditions should be a right. As someone who has helped others with battles of addiction, he spoke of the 'promise-moment': the time when you know within yourself that you are worth it to get through what is in front of you, and not take the whole blame for the struggles within and without. It was his wish to share some of his understandings of what the four orientations of community engagement could mean in this

place: to seek, to listen, to trust and to persevere. After his teaching, I have analyzed the key understandings that the participants brought forward; I have further reflected upon the fact that in a proposed community-led model for MMPSJ future considerations. Elder Roland asked me to double check all the spellings and meanings with another Cree speaker. He asked about the feeling of the verbs; he wondered how to denote not just the future, but the relationality within them as a new beginning place. The Cree speaker, a language keeper, suggested that we use the subjunctive form of these verbs to denote this form. When I took the spellings back to Elder Roland, he was very pleased. This tense has not been seen in previous writings but perhaps poet Emily Dickinson says it best in *I Dwell in Possibility.*[11]

To Seek: **ē natamostatān**: Elder Roland's understanding of this word is to run to someone; something is important, and you need to quicken your pace. The need is here and among us, you need to find someone to talk to.

- ❖ Dialogue and Inquiry are part of the process: pre-determined questions with predictable outcomes may be a recapitulation of the status quo.
- ❖ Urban contexts are part of addressing Indigenous health: working with Indigenous peoples in urban settings is necessary.
- ❖ Community-Led research needs to include how to engage participants who may not have access to a car or phone: everyone needs to have space in the circle.
- ❖ Re-balancing of power in who is asking the questions - who starts and stops the meetings is important.

To Listen: **ē natōhtatān**: when you listen, you are addressing something that is invisible for the time being. There are many translations and connections of this word. It was important that we listened to the stories; hard issues require reciprocity ie: I am listening to you.

- Health surveys need to include the Sixties Scoop, Day School and Residential School and their impacts.
- Local Indigenous traditions need to be honoured.
- Engagement plans need to consider local interests, historical and social contexts, allow for local planning and contain measurable outcomes.
- Participants need to be able to operate within their own linguistic and cultural frame.

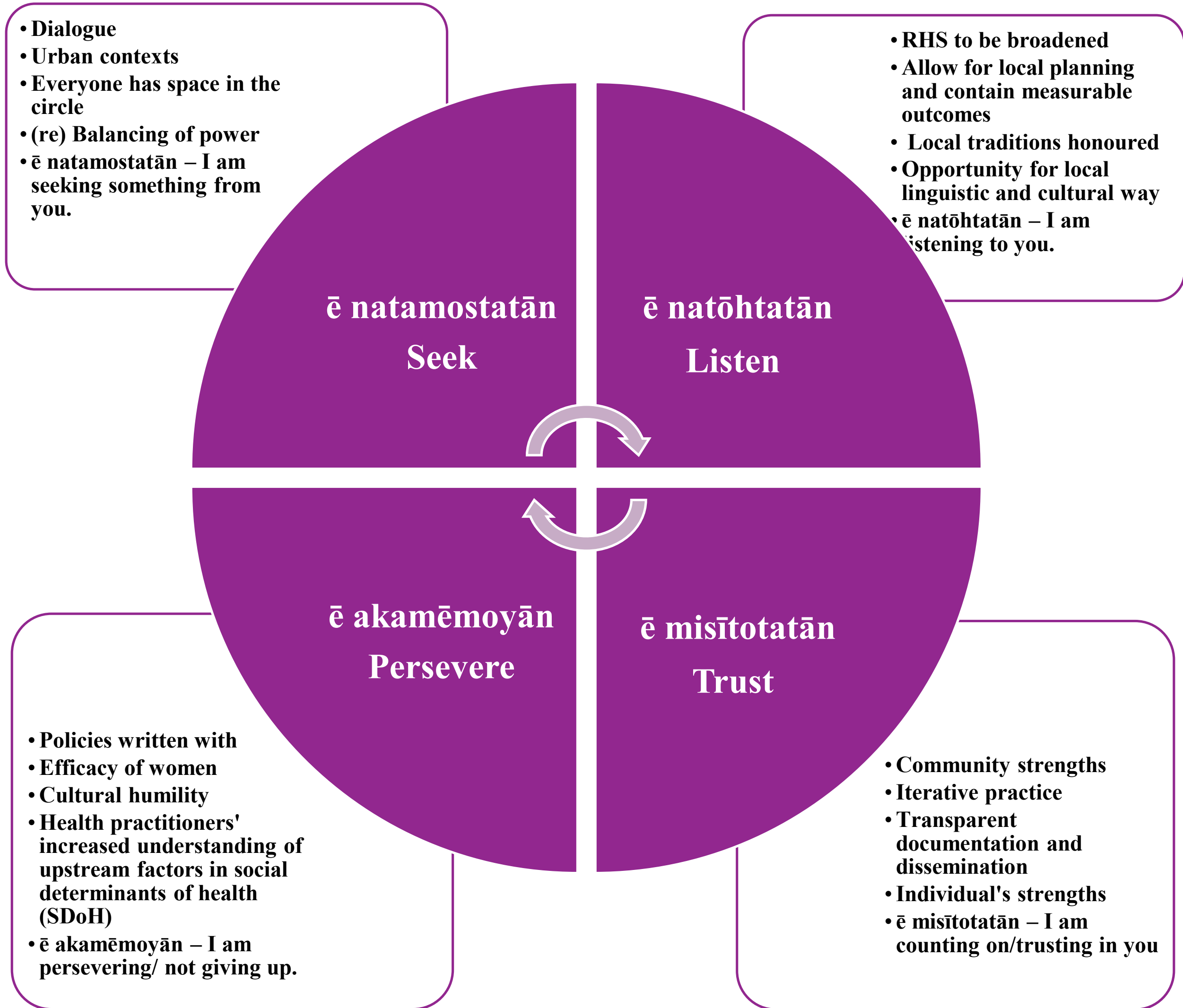
To Trust: **ē misītotatān**: Trust is a big word. Individuals have the right to open the door to trust. If researchers want to gain leadership in the form of Elder participation, they should ask themselves: what is the reason you are here? In the opening of trust may come ceremony, and the importance of humility. Break bread together, be present in the community. Listening to story, being willing to share your own story, letting go of your guard may result in another form of trust which he described as 'they will adopt you.' The formal titles people may hold aren't as important as coming to know people.

- Health surveys need to identify individual strengths.
- Health surveys need to include community strengths.
- Multiple, iterative opportunities to inform practice - bring people together to learn from and with each other over time.
- Documentation needs to be transparent and disseminated in a way that is meaningful to participants.

To Persevere**: ē akamēmoyān**: Through lifetimes, through generations, there is an understanding in this word: it is more noble to persevere than to tell someone of their mistakes.

- Policies that affect Indigenous peoples need to be re-written with Indigenous peoples.
- The efficacy and voice of women needs to be measured as part of the process.
- Cultural competency is not enough: a shift to cultural humility and access to ceremony needs to be part of the engagement process.
- Integrating literacy into health conversations: health practitioners need to understand the importance of education as a determinant of health.

Community Engagement Model Co-Created with Participants



Community Engagement Model: Figure 6.1

Closing of Our Circles

We gathered again to close our circles, review our opportunities to opt in or out of any part of the writing and to review knowledge translation and dissemination. We discussed challenges along the way. Transcripts and the knowledge translation pieces were dropped off earlier to give participants ample time to read, reflect and make changes to any aspect. True to form, participants all shared feedback and did change some parts which were amended then given back; everyone participated in these processes. Elder Roland led us in prayer and shared some stories. He encouraged us to consider how we felt today. He acknowledged the power of women. He acknowledged how love can help healing. He recommended we meet again at some time in the future to share these stories with our children. All participants wanted to own a print copy of the work and suggested that they do share these stories as time goes on. Elder Roland encouraged us to pray in our own ways to bless the stories; we knew they will move off the pages as readers take these stories with them.

We would ask readers to do the same: ask yourself how you feel today, share gratitude in a way that is personal to you, and to take up these stories in ways that are meaningful. I feel more than blessed to have travelled on this journey with these beautiful people, am thankful for the readers of this work, and know that I am forever changed for being part of the process:

"There can only be a conversation drawing in voices kept inaudible over the generations, a dialogue involving more and more persons. There can only be - and ought to be - a wider and deeper sharing of beliefs, an enhanced capacity to articulate them, to persuade others as the heteroglossia conversation moves on - never reaching final conclusion, always incomplete, but richer and more densely woven, even as it moves through time"[12].

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Appendix A: Ethics Approval

Behavioural Research Ethics Board (Beh-REB) 19-Feb-2020

Certificate of Approval Amendment

Application ID: Principal Investigator:

Locations Where Research Activities are Conducted:

Student(s): Funder(s): Sponsor: Title: Approved On: Expiry Date: Approval Of:

Acknowledgment Of: Review Type:

CERTIFICATION

733

Vivian Ramsden Department: Department of Academic Family Medicine

Saskatoon, Canada
West Winds Primary Health Centre, Canada

Katrina Sawchuck

In what ways is literacy considered to be a social determinant of health?

19/02/2020

04/02/2021

Amendment Form (30-Jan-2020); Updated Consent Form; Demographic questionnaire; Participant information

Delegated Review

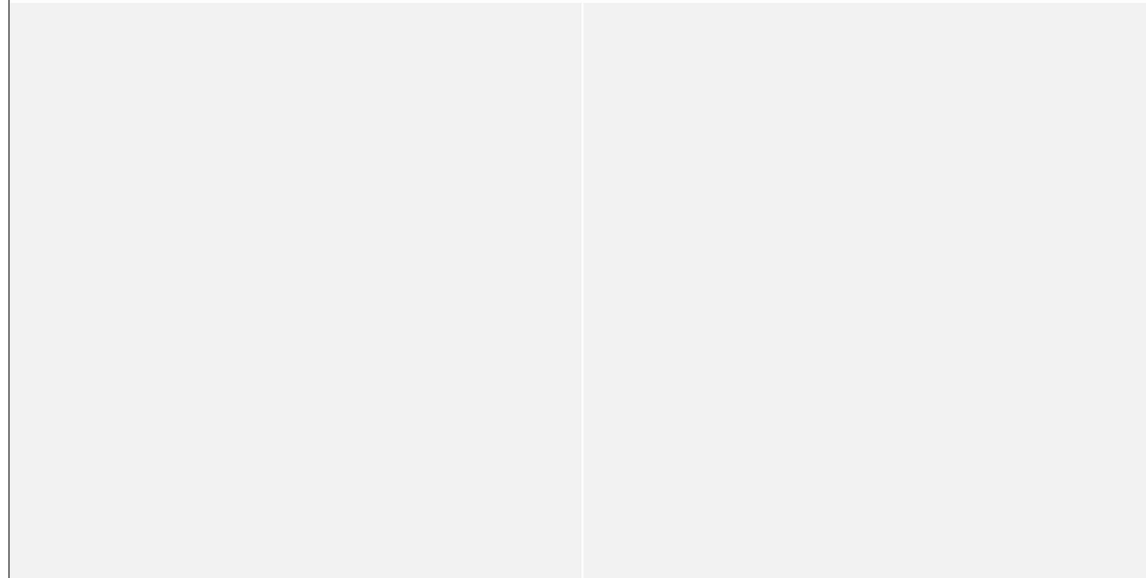
The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this project, and for ensuring that the authorized project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the project remains open, and upon project completion. Please refer to the following website for further instructions: https://vpresearch.usask.ca/researchers/forms.php.

Digitally Approved by Diane Martz, Chair ***University of Saskatchewan***



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Appendix B: Quantitative Questions

Phase One Quantitative Questions

Demographics of the individual answering the questionnaire**:**

1. What is the **gender** of the individual answering the questionnaire?
   ☐ Male ☐ Female ☐ Other

2. What is the **date of birth** of the individual answering the questionnaire?
   D____ M_____ Y______

3. What is the **first language** of the individual answering the questionnaire?
   ☐ Cree ☐ Dene ☐ English ☐ Other (specify):____________

4. Are you a person of Indigenous ancestry? If so, What Indigenous group do you most identify with? _____________________.

5. How many years of schooling have you ever completed at an institution other than a university, a secondary (high school) or an elementary school?
   ☐ None ☐ <1 year ☐ 1-2 years ☐ 3-4 years ☐ 4-5 years ☐ 6+ years

6. How many years of education have you completed at university?
   ☐ None ☐ <1 year ☐ 1-2 years ☐ 3-4 years ☐ 4-5 years ☐ 6+ years

7. In the past nine months, were you attending a school, college or university? ☐ Yes ☐ No

8. Are you currently employed? ☐ Yes ☐ No

9. What was your total household **income** last year?
   ☐ less than $10,000 ☐ $10,000-$19,999 ☐ $20,000-29,999 ☐ $30,000-$39,999
   ☐ $40,000-$59,999 ☐ $60,000-$79,999 ☐ $80,000+

10. Did you attend a Residential School?
    Yes No Choose not to answer

11. How would you describe your health?
    Very good Good Satisfactory Less than Satisfactory Poor

Comments:

12. How would you describe the health of your children?
    Very good Good Satisfactory Less than Satisfactory Poor
    I don't have children

Comments:

13. How would you describe the health of your grandchildren?

Very good   Good   Satisfactory   Less than Satisfactory   Poor

I don't have grand-children

Comments:

Appendix C : Participant Information

Participant Consent Form

Researcher:
Katrina Sawchuk
Graduate Student
Health Sciences
College of Medicine
kfs784@usask.ca
Tel: 306-659-7391

Supervisor/Principal Investigator:
Vivian R Ramsden, RN, PhD, MCFP (Hon.)
Professor & Director, Research Division
Department of Academic Family Medicine
University of Saskatchewan
West Winds Primary Health Centre
3311 Fairlight Drive
Saskatoon, SK S7M 3Y5
viv.ramsden@usask.ca
Tel: 306-655-4214

Dear _______________ you are invited to participate in a research project.

Purpose of the Research
The purpose of this research is to engage educators, Elders and families to learn together about education, in this case, specifically literacy and how it addresses some of the root causes of the social determinants of health.

The purpose of this study is to better understand the connections between literacy and health within urban Indigenous families. We want to come together to co-construct meaningful experiences with nehiyawak (Cree) families; the first step to that was to engage in dialogue with Elders following the tobacco protocol. The second step is to engage with community alongside Elders to collectively respond and to gather demographic information. This is the second step in the collection of information.

The information collected will be audio recorded, transcribed and given back to you prior to being used or shared. Please find attached a Lay Summary and questions for you to consider.

This consent is for Stage Two of four stages. Approximately 12 Indigenous families will be invited to participate in a Talking Circle with an Elder present. You will be invited to fill out a Consent Form and a demographic questionnaire then the Elder will offer prayer in the nehiyaw language and encourage others to pray in their own way. The Talking Circle will follow at which you will be specifically asked:

1) What are the current connections between literacy and health within Urban Indigenous families?
2) What literacy issues continue to marginalize the community?
3) What format would the community like in order to disseminate the data collected?

Potential Risks
There is a risk to you as a participant as the history of Residential School has affected many families in Saskatchewan. You may have your own history with Residential School or want to share stories that are emotional. This risk may be mitigated by the story telling itself and/or by the following of the tobacco protocol and/or by practicing the principle of reciprocity. An Elder will be present during the Talking Circle and afterwards as we share a meal. By sharing the stories back with you after they (may) have been

told, you have time to consider and re-consider them. There may be some relational risk as some of your family and friends may be in the stories. If you feel that any part of the research is too painful, you have the right to withdraw at any time. As we may be known to each other, we want to make sure that you feel that there is no relational risk should you choose to withdraw.

Potential Benefits
Including the families in the community in responding to questions should create a more authentic experience for participants as the research moves forward. Showing respect for each family's knowledge and insight should provide a voice and an opportunity for insight.

Compensation
You will each be given tobacco as well as each family will receive a gift card for $50.00. You will receive this compensation even if you choose to withdraw.

Confidentiality
The principles of OCAP stand for Ownership, Control, Access and Possession and speak to unique aspects of working with Indigenous peoples. Ownership acknowledges that communities collectively own their history; hence your knowledge comes from a community. Control means that you can control how the data is collected, disclosed and ultimately destructed. Access recognizes that Indigenous peoples have a right to manage and make decisions about who can access the information; possession speaks to the right to see and potentially keep your own copy should you choose. To employ these principles, we need to work together relationally and ethically in the following ways:

You will be invited to participate in and provide consent at each step in the research process, as well as for future publications and the PhD Dissertation. We will work together to maintain your confidentiality, although the confidentiality of this research may be limited as there are not that many Cree speaking Elders in Saskatchewan that work in the City of Saskatoon. Due to the personal interaction between us, total confidentiality is not possible. If there is a third party that helps to transcribe the data, that individual will also sign a Confidentiality Agreement. We will store the information on a USB in a cabinet in the office of the Principal Investigator, Dr. Vivian Ramsden and the de-identified data will be backed up in Cabinet on PAWS (a University server). We will arrange to meet when you have had an opportunity to review your participation and revise your transcripts should you choose. You will have the opportunity to waive confidentiality should you choose. The data will be stored for a minimum of five years post-publication. After it is no longer required, it will be appropriately destroyed and/or erased. You will be provided with an opportunity for informed consent at each step along the research process, as well as future presentations/publications and the PhD Dissertation.

Right to Withdraw
Your participation is voluntary and you can answer only those questions that you are comfortable with. If you wish to withdraw part way through the data collection, it may not be possible to completely remove what was said, but any information gathered will stop at the point at which the participant withdraws. You may withdraw at any time by communicating with the researcher.

After the data has been collected, and you have reviewed its content, you can choose to withdraw your data within three months of your consent without giving a reason.

Follow up
A second gathering will be set up to give the data back to the community. We will be asking the best format for follow up with (third question above) the community. Results/findings will be co-created and shared as appropriate with others.

Questions or concerns

This research project has been approved on ethical grounds by the University of Saskatchewan's Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that Committee through the Ethics Office by phoning 306-966-2975 or via e-mail at ethicsoffice@usask.ca. The Ethics Office is located in Room 223 Thorvaldson, 110 Science Place, University of Saskatchewan, Saskatoon, SK S7N 5C9. The Ethics Office toll free number is 1-888-966-2975.

Consent

You have the option of being named in the data and/or publications. If you wish to be de-identified or have a pseudonym used, do not hesitate to let me know. You may also be identified as a co-researcher in some of the publications and in the PhD Dissertation.

I read and explained this Consent Form to ________________ on the day listed below.

Do you wish to be named in data and/or publications? Yes No

Do you wish for your contributions to be de-identified or masked using a pseudonym? Yes No

Name of participant: ___________________________________

Oral Consent obtained by:

________________________ ____________________________

Katrina Sawchuk, Date
Researcher

A copy of this Consent Form has been left for you should you wish to contact:
the researcher, Principal Investigator of the Ethics Office at some time in the future.

Appendix D: Lay Summary

Lay Summary of Social Determinants of Health for the Elders/Inquiry starters
Sunday, December 02, 1018

A. The Social Determinants of Health were first described by the World Health Organization as the conditions in which people are born, grown, live, work and age in. They are the factors outside of health which affect health; fundamental among many factors are the indicators of growing up in poverty, being of Indigenous ancestry, and having low education levels, typically defined by literacy rates in education systems.
The theory and work of Paulo Freire, who worked with marginalized people in Central America is based on the belief that literacy is liberatory, or freeing. My theory, much like Friere's is that if we can increase literacy rates and engage community in that process, we will address some of the root causes of poor health among families who suffer from the affects of poverty, are Indigenous, and struggle with literacy. By better understanding the connections among literacy and health, we will help each other build higher literacy rates and potentially healthier families.

Inquiry Starter:
1) What are the current connections between literacy and health within Urban Indigenous families?
2) What literacy issues continue to marginalize the community?
3) Is there a question that you have, based on your Cree ways of knowing, that could help the community fully engage?

B. The methodology that we plan to use in subsequent work with the community will continue to ask for your guidance. There are four stages, and you are participating in stage one: asking the community/Elders to inform questions that continue to marginalize. The second stage is the data collection stage. Twelve families will be asked to participate in a sharing circle that will be designed to illuminate and better understand the connections between literacy and health from the perspectives of the families. In the third phase, we will take the insights gleaned and connect them to other data sources to build a stronger case for advocacy. At the final phase, the families will be re-invited to share what has evolved from the third phase. The results will be framed and shared to provide a continual flow of support and information to participants.

Inquiry Starters:
1) How should the sharing circle be designed?
2) Do you have any suggestions in how best to frame or share the information with the participants?
3) Any other recommendations?

Appendix E: Transcript Release Form

Research Ethics Boards (Behavioural and Biomedical)
TRANSCRIPT RELEASE FORM

Title:

I,___________________________________, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with [name of the researcher]. I hereby authorize the release of this transcript to Katrina Sawchuk to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

I acknowledge that the consent forms will be stored separately. Electronic data will be deleted using a program that will not permit its recovery.

__________________________ Name of Participant __________________________ Signature of Participant

__________________________ Date

__________________________ Signature of researcher