Identity as Visibility: Perspectives and Experiences of Indigenous Peoples in Manitoba with Racial, Ethnic, and Indigenous Identifier Data Collection within Healthcare.

by

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Abstract

Race, ethnicity, and Indigenous identity (REI) data collection, a strategy to address health and healthcare inequities, is emerging in Canada. Traditional teachings remind us to embrace our Indigenous identities. Yet, Indigenous identity within healthcare is often connected with racism, and mistreatment; an important context surrounding REI data. As Manitoba implements REI data collection at point of healthcare, reflecting on historical and current narratives surrounding REI data collection is beneficial. This dissertation advances collective knowledge of Indigenous understanding and experiences of REI data collection.

As an Anishinaabekwe, researcher, and Manitoba REI team member, I bring experiential knowledge and relationships to this dissertation. Informed by the Contemporary Indigenous Empowerment Theory (CIET), this dissertation highlights relationships of power, social justice, and Indigenous identity/voices. A qualitative research design includes four methods identified below with key findings.

Story-gathering with 20 self-identifying First Nations, Inuit, and Métis people in Manitoba opened space for Indigenous voices to inform our understanding of REI data collection and its impacts. Their meaning of Indigenous identity, experiences in healthcare, and perspectives on, and best practice for, REI data collection, informed how self-declaration of Indigenous identity is a highly complex matter.

An environmental scan of REI data collection in Manitoba was guided by CIET to highlight relations of power, social justice, and Indigenous voices, deepening our knowledge of REI data collection. Creating awareness and evidence for health organizations, researchers, practitioners, patients, and the public to understand the current context of REI data collection in Manitoba.

A scoping review examined how Indigenous identity, voice, and methodologies are upheld in health research. Findings suggest identity transparency of researchers and research participants requires strengthening and raising collective understanding and honouring of Indigenous research methodologies, ethical guidelines, and principles is imperative.

Tying these three studies together, are my reflections on the use of ceremony and traditional knowledge throughout the research process.

Indigenous identity empowerment is a pathway to healing. REI data collection within healthcare creates an opportunity to shift Indigenous identity from one of risk and harm to one of protective visibility and resistance against racism – if we are willing to do the relational work required.

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Dedication

To all my relations.

Contribution of Authors

This dissertation is written as a collection of manuscripts, which will be revised and submitted to peer-review journals (Chapters 2, 3, 4). These chapters are joined together through the "Chapter Relationship" sections which include details on the contribution of authorship and my sharing of knowledge gained through ceremony or traditional teachings that guided my research, supported my wellness, and sets the tone for each following chapter. My contribution to each dissertation chapters includes relationship building, idea formation, study design, knowledge gathering, meaning making, and writing of the chapters.

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Chapter 1: Introduction

Who am I? Where did I come from? What am I here for? Where am I going?

These are questions posed to me by Senator Murray Sinclair at my graduation ceremony from Kathleen Bird's four-year traditional medicine course, and these questions are ones I have learned to never forget. As a researcher, the importance of addressing these questions in my writing supports readers in understanding my work, my thoughts, my perspectives, as well as, who I am, where I come from, what I am here for, and where I am going. Identifying myself and how my experiences shape the way I understand the world, acknowledges who I bring to the writing and truth of the experiences of others.

"Locating within the research process is essentially both remembering who we are and re-membering within our Nations (Absolon & Willet, 2005, p. 117).

Introduction: Setting the Stage

Traditional teachings remind us of the importance of embracing our identity as Indigenous Peoples and honouring connections between identity with personal and collective strength. And yet, identification as an Indigenous person within the healthcare system, both in historical and contemporary contexts, exists within experiences of racism involving neglect, mistreatment, harm, and even death (Lux, 2016; McCallum & Perry, 2018; Razack, 2015; Smylie & Firestone, 2015); all of which demonstrate a system that fails to see Indigenous people as fully human and a discomfort and fear among Indigenous people to be seen. For Indigenous Peoples, a byproduct of colonial harm over centuries is that the concept of identity resides within conflicting spaces of uncertainty, shame, and fear. While the growing interest with the collection of Racial, Ethnic, and Indigenous (REI) identifier data within healthcare is framed as a strategy for research to address equity in health and healthcare, it is imperative to not forgot the historical and current context from which this has emerged. In Manitoba, the collection of REI data at

point of service use through a systematic and mandatory policy and practice within healthcare represents a first attempt in Canada to make visible anti-Indigenous racism and its impacts within the healthcare system.

The personal and collective feelings of shame around First Nations, Inuit and Métis identity is a significant consideration when thinking about revealing Indigenous identity to those who hold positions of power, especially within the healthcare system. It has been through the colonial abduction of Indigenous identity and forced replacement of Indigeneity as weak, worthless and defeated, that the feelings of shame surface and exist (Simpson, 2011). In order to move past the shame, there needs to be a lifting of the veil of colonial oppression and discrimination so that we can once again see the true history of our people and the strength and resiliency that defines Indigenous identity (Lambert, 2014). First Nations' prophecy holds that the seventh generation, through education, growth, development, and resiliency, will resist continued oppression of colonization, fight for Indigenous historical and contemporary reality to be recognized as valid, and experience healing, recovery, and resurgence (Kimmerer, 2013; Simpson, 2011). It is within this construct of Indigenous resurgence that the theoretical framework for my research began to emerge.

Reclaiming Indigenous self-respect, self-worth, value, and most importantly identity is the pathway to healing. Movements towards reconciliation and the recognition of Indigenous rights have fostered empowerment around the act of identifying as an Indigenous person. Indigenous Peoples have been reclaiming identity in ways that reflect traditional ways of knowing, being, and doing; embodying qualities of pride, strength, wisdom, intelligence, and peace, to name a few. The collection of REI data at point of access to healthcare services creates an opportunity to shift the meaning of Indigenous identity from one of risk, shame, and harm to

one of protective visibility and resistance against racism. Past attempts at REI data collection intended to benefit the healthcare system and Western-based health research driven by large data sets, and these discourses still drive much of the science and research around the collection of REI data. However, an equally important and more meaningful outcome for Indigenous Peoples is possible. Central to my dissertation is to move towards the reclamation and recontextualizing of the meaning of Indigenous identity; an act of resistance by disrupting ongoing silencing and marginalization of Indigenous Peoples within the healthcare system.

The collection of REI data has been acknowledged as an important tool in addressing health and healthcare inequities, however, without the proper preparation and knowledge around the purpose and procedures for this collection it can become another means of systemic enforced extraction of personal information; positioning it far from an act of empowerment and reclamation. The inclusion of knowledge from historically silenced groups assists in avoiding the perpetuation of oppression-based harm (Lambert, 2014). Through the inclusion of Indigenous knowledge, perspective, and oversight to inform the design and implementation of REI data collection at point of access to health service, the purposeful collection of this data can become much more than just a surveillance tool. The collection of REI data can generate evidence to give further context and clarity around the health and healthcare statistics of Indigenous Peoples. This becomes a tool of evidence to show where racism and discrimination are occurring within the healthcare system, a tool of accountability for healthcare staff at all levels dissuading denial and avoidance, and a tool of protection for Indigenous Peoples as systemic racism will become visible within the healthcare system to be acknowledge and addressed rather than ignored and hidden. The ability to self-identify and define Indigenous identity is strongly tied to self-

determination (Smylie & Firestone, 2015) - one of the strongest determinants of Indigenous health and well-being.

Given this contextual staging of Indigenous identity within the healthcare system, including key narratives surrounding REI data collection, my dissertation aims to broaden the narrative landscape for the collection of REI data. In this introductory chapter, I begin by setting the stage and presenting the foundational context and rationale underlying the dissertation. Next, I move to my positionality, locating myself within the research by addressing the questions raised to me by Senator Murray Sinclair, followed by a brief discussion of key concepts and relevant literature. This lays the foundation for a statement of the dissertation study purpose, overall objective, and introduction to methods chosen to address secondary objectives. With these foundations, I introduce the theoretical perspective underlying my work. Then, a brief description of Indigenous methodologies relevant to my dissertation is presented, along with an overview of the dissertation design. I also provide a discussion of ethical considerations, rigor and knowledge sharing specific to Indigenous methodologies. I outline the structure of my dissertation, through introducing the various chapters to come, and to conclude this introductory chapter I address the significance of my dissertation work.

Positionality Statement

As an Anishinaabe woman, my approach to health research is through an Indigenous paradigm and driven by a desire to close health equity gaps among Indigenous people in Canada and to assist Indigenous Peoples in achieving the highest attainable standard of health. As my ways of knowing and understanding are based in my identity as a First Nations woman, I seek out methodologies that allow me to honour my worldview and ways of knowing of my

communities. I honour and accept guidance from the Elders and Knowledge Keepers with which I have close relationships. Métis Elder Barbara Bruce, one of my teachers, has provided guidance and consultation throughout my dissertation research. My ways of knowing and understanding have guided and informed both my research and personal life, which has nurtured a vibrant and strong connection to my culture and Indigenous identity. I work closely with Elders, traditional medicine people and healers, as a student of traditional Indigenous medicine knowledge. Through this work I carry knowledge of 48 traditional medicines and will continue this lifelong learning as another way to honour my culture and help others. As Senator Murray Sinclair stated, we need to begin to do things differently to see change in the wellbeing of Indigenous Peoples in Canada. For me, this shapes how I approach research. My personal history inspires me to make change and to do things differently. Foundational to my position as a researcher in the field of REI data collection, is my role as a core team member of the provincial strategy to collect REI data within the Manitoba healthcare system. The Indigenous-led core team, which came together in 2019, has overseen all aspects of the development and implementation of the REI data collection strategy within Shared Health. My role involves participation on the steering committee, the BIPOC (Black, Indigenous, and People of Colour) advisory group, as well as the working groups (data protocol, governance, evaluation, training and education, communications). One of my specific roles within this team is to continue to bring an Indigenous lens to the work, as well as contribute Indigenous research and evaluation methodologies and content expertise.

Relevant Concepts

While the complexity surrounding identity is addressed above, further discussion is required for Indigenous identity; race and ethnicity; health equity, and REI data collection. Below, each concept is discussed prior to addressing relevant evidence from the literature.

Indigenous identity. Refers to identifying as a First Nations, Inuit, or Métis person - the three distinct groups which comprise the Indigenous Peoples of Canada. The declaration of Aboriginal peoples (here I chose to use the term Indigenous) as First Nations, Inuit and Métis peoples is contained within Section 35 of the Constitution Act of 1982 (Statistics Canada, 2021).

Race and Ethnicity. The terms race and ethnicity are often used interchangeably yet they are not synonymous. **Race** is a social construct, without any scientifically explained biological basis, used to categorize people based on perceived differences in physical features in ways that create and justify hierarchies of human value based on the idea of whiteness as optimal (CIHI, 2022; Reading, 2013). **Ethnicity** refers to membership or belonging based on sociodemographic categories which can include culture, nationality, language, ancestry, social background, religion and geographic origin (Kiran et al., 2019; Quan et al., 2006; CIHI, 2022; Reading, 2013). Within Canada, the focus has been collecting ethnicity information based on the belief that ethnicity is more representative of the cultural factors that can impact health and healthcare, and less to genetic traits such as skin colour (Quan et al., 2006). Statistics Canada acknowledges that ethnicity is an ambiguous concept that can include multiple different aspects and can change based on different individual and sociopolitical contexts and environments (Kiran et al., 2019; Varcoe et al., 2009). The results from the Canadian census and discussion by various researchers indicate that ethnicity has a fluid meaning in our Canadian context (Kiran et al., 2019; Varcoe et

al., 2009). Definitions of ethnicity may include aspects of race, nationality/country of origin, physical appearance, culture, language, religion, ancestor origin/ancestry, and self-perception/self-identification (CIHI, 2022; Quan et al., 2006; Reading, 2013; Varcoe et al., 2009). These concepts are complex and multidimensional and might not be fully understood by the patients or community members who answer REI data collection questions.

Health Equity. Health equity means "that all people can reach their full health potential and should not be disadvantaged from attaining it because of their race, ethnicity, religion, gender, age, social class, socio-economic status or other socially determined circumstance" (National Collaborating Centre for Determinants of Health, 2023, p. 2). Now recognized as an international core value in healthcare organizations and a major component of healthcare quality, the collection of reliable, standardized, patient-level disaggregated data for the purposes of research emerged (Lofters et al., 2011, Wray et al., 2013). In Canada, inequities in health and healthcare experienced by Indigenous and other structurally disadvantaged populations have sparked a growing interest in the collection of sociodemographic data in the healthcare system. This increasing interest points to the critical need for the systematic collection of REI data in order to begin to understand, address, and fully characterize inequities and disparities in health and healthcare linked to race and ethnicity, and to achieve the provision of equitable access to high quality health care (Kiran et al., 2019; Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Wray et al., 2013; Varcoe et al., 2009).

REI Data Collection. In this study REI is used to denote race, ethnicity, and Indigenous. Therefore, the collection of REI data throughout this dissertation, refers to the process where race, ethnicity, and Indigenous identity data is collected from individuals at point of service use within the healthcare system in Manitoba. The core team for the Manitoba provincial strategy

chose to use the REI acronym to denote race, ethnicity and Indigenous at the time of the initiation of the strategy within the provincial healthcare system. The REI acronym might hold different meaning in other locations and context (Balestra & Fleischer, 2018).

Relevant Evidence from the Literature

Understanding Indigenous Identity

There is no one single definition of Indigenous identity. Instead, both collective and individual identities are complex, changing, evolving, and multidimensional shaped, adapted, and adjusted by social and historical experiences which can include different types of identifying traits, levels of importance, and connection to these traits (Coates, 1999; Dorais & Searles, 2001; Jacobs, 2019; Madden et al., 2019). Indigenous identity is understood as a social construct (Coates, 1999) which identifies people in relation to relationships that span generations and involve families, communities, all living beings, and most importantly territories and connections to land. Impacts of colonization have also given rise to the generation of concepts of self-determination and sovereignty as components of Indigenous identity (Jacobs, 2019). In her work in Indigenous identity, Jacobs provides a definition as, "peoples who identify themselves as communities or nations with long established, that is pre-settler or treaty claim, to particular territory. This definition of Indigenous identity embeds the idea of ancestral territory enduring for future generations" (Jacobs, 2019, p. 149). Indigenous identity, largely shaped through the power of definition by settler/dominant governments has for decades, served the needs of colonial governments, resulting in federal government control over nearly all aspects of Indigenous life and Indigenous Peoples were not consulted on meaningful categories of identification (Madden et al., 2019). Over time, self-identification has become a more accepted and supported means of

determining Indigenous identity as it returns the power of choice to Indigenous Peoples. Indigenous bands, nations, and other organized membership structures have also stepped in to make determinations over membership and in turn Indigenous identities (Coates, 1999; Jacobs, 2019). Years of colonial oppression have resulted in disconnection from aspects of Indigenous identity such as family, community, culture, location, and language, however over the last few decades there has been a return to identity and a reclamation of what was taken, to heal the broken ties of the past. For others, Indigenous identity is tied to feelings of stigma and shame resulting from internalized racism impacting their openness to Indigenous identity. According to Madden et al., "there has been a shift with societies accepting Indigeneity more, but there are social, economic and political reasons at an individual level that may influence a person's decision to identify as Indigenous." (Madden et al., 2019, p. 25). Colonial history and relations of power must be taken into consideration in the systematic collection of Indigenous identity data. It is important to note that when it comes to the systematic collection of Indigenous identity data there are continued issues with the inclusion of Indigenous Peoples in the processes and planning of initiatives (Madden et al., 2019). As a result, there is a high amount of suspicion related to exploitation, misrepresentation, and misuse when it comes to data collection. When Indigenous Peoples are included in these processes of determining identifiers, and all aspects of the data collection process, there is a movement away from what Jacobs (2019) notes as a colonial legacy of invisibility within data through lack of inclusion, misrepresentation and inaccuracy. What has begun to come through is the shift in focus by seeing importance in places that were previously unseen and a realization that data also needs to address and demonstrate the resiliency of Indigenous identity (Jacobs, 2019). As Jacobs argues, "Indigenous people also represent some of the most remarkable aspects of resilient identity. Findings that exclude or

accept flawed data for Indigenous people diminish full understanding of the human condition and its rich, collective potential for understanding and for action" (Jacobs, 2019, p. 148). The meaning, history, and context of Indigenous identity cannot be separated from the act of Indigenous identifier data collection. In fact, awareness must be a central focus of all planning, decision making, and actioning of Indigenous identifier data collection in the healthcare system.

Valuing REI Data

There is high importance in collecting robust and usable REI data as racial discrimination and ethnic stereotyping have very significant impacts on healthcare quality and access to services (Varcoe et al., 2009). Moving beyond the broad category of 'visible minorities' is essential to support increased specificity through disaggregated data when studying differences between racial and ethnic groups in health and healthcare (Kiran et al., 2019). The primary reasons stated for REI data collection is for development of a disaggregated data repository to serve administration policy and health research. This includes monitoring access to health services, monitoring health outcomes, highlighting gaps in services, reducing health and healthcare disparities and inequities, healthcare quality improvement, healthcare and health promotion interventions, and the design and provision of culturally appropriate programming and services (Pinto et al., 2016; Quan et al., 2006, Varcoe et al., 2009; Wray et al., 2013). In Canada, the inability to create REI based disaggregated datasets from health registries and outcomes databases prevents analysis and identification of REI based disparities and outcomes (Lofters et al., 2011; Quan et al., 2006; Wray et al., 2013; Varcoe et al., 2009), which results in barriers to identifying, understanding, and addressing health and healthcare disparities faced by Indigenous Peoples. It is also important to note that where REI data has been collected in Canada, there are challenges with determining quality, utility, and impact of data. Current strategies for REI data

collection through self-identification have generated little evidence of high quality or accurate data on use of health services by Indigenous Peoples. While these narratives remain central to REI data collection, there is a critical need to move beyond these health systems focused purposes and to acknowledge how REI data collection can initiate a movement towards health equity through a return of personal and collective Indigenous agency within the healthcare system.

Canadian Contexts and REI Data Collection

Within Canada there are no provincial or federal governmental mandates requiring the collection of REI data within the healthcare systems. While self-reported REI data is routinely collected in the United States, New Zealand, and the United Kingdom, Canada has yet to establish mechanisms for consistent, systematic, and standardized collection of REI data in the healthcare setting (Grant et al., 2019; Kirst et al., 2013; Lofters et al., 2011; Quan et al., 2006; Wray et al., 2013; Varcoe et al., 2009). In an effort to improve national healthcare, the federal government of Canada announced an investment of $198 billion dollars to be transferred to provinces through the Canada Health Transfer program, as well as through bilateral agreements with provinces and territories. One of the requirements for accessing the Canada Health Transfer funding involves a provincial commitment to improving the collection, storage, use, and reporting of health information. In addition, two key principles of the bilateral agreements are focused on health service access and equity. The program also has specific funding allotted for Indigenous health priorities (Canada, 2023b). A statement from the federal government highlights their commitment to Indigenous health, “We recognize the right of Indigenous Peoples to fair and equal access to quality and culturally safe health services free from racism and discrimination anywhere in Canada” (Canada, 2023a). An agreement in principle between

the federal government and the Manitoba government includes commitments to collect, use, and share depersonalized health information (Canada 2023a). While there is no publicly available information on mandates to collect REI data, it has been suggested that the federal government could require the sharing of provincial REI data in exchange for transfer payments. The mandate to provide REI data could become an implication of this agreement provincially or at a national level. In Canada, First Nations and Inuit-specific identity datasets have been created through linkage of unique registration numbers to some provincial health registries. However, this process does not result in data representative of all Indigenous Peoples and is not self-identification of Indigenous identity. As a result, research and policy which attempts to study, report on, and respond to the health of Indigenous Peoples through the linking of health data-bases with population registries can only be done for a subset of the Indigenous population, resulting in an underestimation of the health disparities that exist between Indigenous and non-Indigenous Peoples in Canada (Smylie & Firestone, 2015).

Reported health and healthcare inequities driving the need for the collection of REI data are an international concern, and yet it is important to remember that inequities are associated with systemic factors which require contextual understanding to mobilize actions. The 2021 Canadian census reported that 1,807,250 or 5.0% of the population identifies as Indigenous. Of these 1,048,405 (58.0%) reported First Nations identity, 624,220 (34.5%) reported Métis identity and 70,545 (3.9%) reported Inuit identity, with 1.6% reported more than one Indigenous identity (Statistics Canada, 2022). The Indigenous population in expected to reach between 2.5 million to 3.2 million over the next twenty years (Statistics Canada, 2022). In Manitoba in 2021, the Indigenous population numbered 237,190 or 18.1% of the provincial population (Statistics Canada, 2022). Of these 134,890 (57%) reported First Nations identity, 96,730 (40.5%) reported

Métis identity and 725 (0.3%) reported Inuit identity. In considering the growing Indigenous population, it is critical to acknowledge, accept, and act upon the evidence that the quality of health and healthcare experienced by Indigenous Peoples in Canada is often far below the acceptable standards of care. It is noted that "Almost regardless of the health indicator used…. Aboriginal population typically have the greatest risk and experience the worst outcomes" (Wray et al., 2013, p. 10). For example, Registered First Nations health research data shows that gaps in health and health outcomes continues to increase between the First Nations and non-Indigenous populations (Katz et al., 2019).

Summary

REI data collection at point of access to health service use brings forth complex issues of comfort and concern that need to be further investigated. The process of being asked to identify with a racial or ethnic category is, for many patients, a process that becomes racializing in itself and may increase immediate risk of differential treatment. Due to the multiple levels of racism (Jones, 2000; Reading, 2013) that exist within the healthcare system in Canada, attempts to do this work will inevitably bring up suspicions and experiences of racism for many Indigenous people (Varcoe et al., 2009). As Indigenous Peoples often suffer from systemic racism deeply embedded within the healthcare system, it is crucial that REI data collection processes and purposes are informed by the experiences and perspectives of Indigenous Peoples. Through the review of the evidence and literature, it is apparent that in order for the recognition of REI data collection to be received as a source of resistance and empowerment for Indigenous Peoples, there is a need for an intense and thorough communication strategy which must address the apprehensions Indigenous people hold about sharing identity within the healthcare system. Also required to be addressed is attitudinal and systemic racism that may increase differential

treatment including nonadherence to clinical practice guidelines once Indigenous identity has been confirmed and documented in the medical record. A communication strategy which provides thorough explanations around why and how this information should be collected and used is of critical importance to the overall success of the policy and practice implementation plan and must be informed by the perspectives and understanding of Indigenous Peoples. Gathering, understanding, and acknowledging Indigenous perspectives and experience will be a critical initial step in the culturally safe and successful informing and supporting of this systems-change project.

As Manitoba will be the focus of this study, it is also of critical importance to understand how the collection of REI data has been considered or actioned within the healthcare system through both historical and current attempts. As Senator Murray Sinclair noted, it is important to consider our past when building pathways to move forward. The idea for the collection of REI data has been around for decades and through the unveiling and understanding of where this has succeeded or failed in Manitoba, there will be a better chance for success with the current provincial strategy.

There is also an abundance of literature describing and addressing the healthcare experiences of First Nations, Inuit, and Métis people in Canada, which without data disaggregated by REI, has been used to shape and inform understandings and beliefs about the experiences and contexts of Indigenous people's lives. Research is done, papers are written, and words of researchers become evidence. Yet, little is questioned about how that research has been done, who has been controlling that narrative, and how the research is truly honouring the voices and identities of Indigenous Peoples. With impending access to data separated by Indigenous

identities, there needs to a heightened caution and awareness of how that data is used to generate evidence of the context and realities of Indigenous people's health and healthcare.

Though seen as necessary for improvements, the collection of REI data will not be a simple task. Its consequences and impacts will extend deeply. There is the potential for this strategy to fully support the movement towards Indigenous empowerment, pride, and resurgence, but this will first involve understanding where we have come from, where we are now, what we are doing here, and where we are going. May this dissertation research support our knowledge discovery journey in a good way.

Study Objective

The **primary objective** of this study is to *advance knowledge of Indigenous understanding and experience around the concept and practice of REI data collection at point of service using an Indigenous paradigm and the inclusion of Indigenous voice and knowledge*. This knowledge will lead to further understanding of how the reclamation of empowered Indigenous identity can resist and dismantle anti-Indigenous racism in the healthcare system. Along with this, findings from this dissertation will be utilized within Manitoba to inform the implementation of a systematic and mandatory policy regarding REI data collection as part of healthcare service delivery. Within this dissertation, the focus is on Indigenous identity however, as the broader view of the data collection strategy within Manitoba is about the collection of race, ethnicity, and Indigenous identity, I have utilized the language of REI when engaging with people for the collection of data for this study. A qualitative multiple methods design includes story gathering and listening to perspectives and experiences of First Nations, Inuit and Métis peoples regarding the collection of REI data within the Manitoba healthcare system, an environmental scan of

historical and contemporary practices of REI data collection within the Manitoba healthcare system, a scoping review/knowledge discovery of academic peer-reviewed literature pertaining to Indigenous people's healthcare experiences in Canada, and researcher reflections on the use of ceremony and traditional knowledge as a way of generating understanding and maintaining personal well-being.

Theoretical Orientation

A theory in its most basic form is simply an explanation for why we do the things we do" (Simpson, 2011, p. 39*).* A theoretical lens describes and explains the viewpoint of the researcher and how they contextualize the phenomena being studied and discussed throughout the research. (Creswell, 2009). Here the theoretical orientations of anti-colonial theory (Carlson, 2017; Hart et al., 2017; Lewis, 2012; Max, 2005), anti-racist theory (Dei, 2005), and critical Indigenous methodologies (Brayboy & Chin, 2018; Denzin & Lincoln, 2014; Dunbar, 2008) lend themselves to the contextualization and understanding of the topic and situate well within an Indigenous paradigm. In the process of distilling down from each of these orientations, the parts which combine to provide clarity to my perspective and approach are woven together to create a stronger and broader lens to support a deeper and more encompassing examination and analysis of the data. The process of weaving them together provides added strength where they overlap and fills in gaps that are missing. Through this process I developed the Contemporary Indigenous Empowerment Theory (CIET), which serves as a guiding framework for the collection, analysis, and sharing of the data (Creswell, 2009). Below, I offer a discussion of the application of anti-colonial theory, anti-racist theory, and critical Indigenous methodologies which acts as guiding theoretical orientations for the development of CIET, and then move into a discussion on the structure and use of CIET.

Understanding of colonialism and its impacts

This research is based in the knowledge that we are not living in a post-colonial society. The refusal to accept the idea of a post-colonial society has also been presented in the work of Indigenous and non-Indigenous scholars (Carlson, 2017; Hart et al., 2017; Lewis, 2012; Max, 2005; Simpson, 2011; Smith, 1999). The violence, domination, suppression and oppression, assimilation, and destruction associated with colonialism continues today in the lack of self-determination and control over the meaning of Indigenous life and identity experienced by Indigenous Peoples in Canada (Hart et al., 2017). Contemporary Indigenous life now involves generations of Indigenous Peoples fighting to reclaim what was taken and destroyed. In the process of reclamation of culture, land, life, and identity, it is crucial that Indigenous Peoples find and nurture power and pride in our Indigenous identity and use this as a way to resist continued oppression and dispossession. We are now at a place where we can recognize and call out the continued presence and impact of colonialism within systems and structures of power. We have not yet arrived at a postcolonial society, and we are still in the process of creating the version of postcolonial society that is agreed upon by those who have been oppressed and exploited. Lewis (2012) states, "Colonialism has not disappeared, and therefore it is to anti-colonialism that we must turn" (Lewis, 2012, p. 231).

Anti-Colonial Theory. An anti-colonial theoretical perspective (Carlson, 2017; Hart et al., 2017; Lewis, 2012) will be used to discuss how colonial policy and practice continue to actively shape and drive contemporary health care and health care systems which results in continued inequities and multi-level experiences of racism within the Canadian healthcare system. Anti-colonial theory serves to disrupt the dominant ideology of a post-colonial state (Hart et al., 2017). However, through an Indigenous paradigm, anti-colonial theory also becomes

a means of advocating for Indigenous resurgence. In understanding that the continued presence and impacts of colonialism calls for continued work to overcome and resist colonialism, there is an increased urgency to reclaim the foundation of strength as Indigenous Peoples; culture, language, land, and knowledge (Carlson, 2017; Hart et al., 2017).

The anti-colonial theoretical orientation utilized through the Indigenous paradigm will allow for a deeper examination into how colonial oppression and dispossession has created historical and contemporary social suffering, and the steps needed to support the movement from oppression to resurgence. Lewis (2012) notes, "…an anti-colonial orientation stands as a holistic framework, takes into account previous and continued colonial relations, and centers Indigenous knowledges as the epistemological foundation of research that occurs within areas of continued colonization" (Lewis, 2012, p. 232). This lens supports the spectrum of this proposed research, as it encourages examination of the past and present to better understand the necessary actions for change.

Drawing on anti-colonial theory, I examine the collection of Indigenous identity data as another means of power and control over the lives of Indigenous people. This involves a deeper analysis of perception and understanding regarding the data collection and involves hundreds of years of oppression and dispossession which needs to be taken into account. This research will provide critical information that links the past with the present and provides means for understanding Indigenous perspectives in this matter. Healthcare practice and healthcare systems have deep roots in systems of Western dominant scientific thought as well as governmental regulation and control (Hollenberg & Muzzin, 2010). An anti-colonial perspective is, "one that begins from the standpoint of marginalized peoples, perspectives, or knowledges, with the main goal of providing different and often invisible viewpoints on often widely accepted, normalized

and dominant perspectives and knowledges" (Hollenberg & Muzzin, 2010, p. 40). Through recognition, acceptance, and promotion the validity of the non-dominant viewpoint or ideology becomes solidified. "While anti-colonial research uncovers the atrocities of the past, it is also important to search for seeds of hope and possibilities for future generations. Anti-colonial research addresses current social conditions from the root up, working from within a philosophy of hope" (Max, 2005, p. 91).

Anti-Racist Theory. Racism remains one of the most powerful directors of social order. An anti-racist perspective is one that looks at racism and colonial practices as the source and continued driver of a variety of societal problems and supports a conceptual understanding of the impacts of race-based oppression on production and validation of knowledge, the understanding of resistance, and the foundation for the fight for agency and resurgence (Dei, 2005). This lens will support my belief that it is crucial to examine the impacts of racism on Indigenous Peoples today. Anti-racist research examines the experiences of racialized peoples working, living, and existing within the institutions and structures that continue to hold the decision-making power within today's society. Through the investigation of racial domination and social oppression, anti-racist research makes room for the voices of the racially marginalized and oppressed by centering those voices and providing their knowledge as credible and valid. It is a lens in which racially marginalized people's perspectives on racism and social justice are upheld and given the ability to be heard louder, further, and with more force than when on their own, challenging others to rethink what they think they know about racialized differences. It is through this continual resistance against misinformed beliefs that anti-racist research creates a catalyst for change, and fundamental structural change is one of its main purposes (Dei, 2005). The addition

of an anti-racist theoretical lens will allow for a deeper examination of race-based oppression in relation to REI data collection.

Critical Indigenous Research Methodologies. Critical Indigenous research methodologies are defined as a theoretical lens which gives space for Indigenous Peoples to hold colonial ideology accountable for historical and contemporary trauma (Brayboy & Chin, 2018; Denzin & Lincoln, 2014). This blending of critical race theory and Indigenous methodologies allows for a theoretical lens that can apply the defining features of critical race theory to the issues and context of Indigenous Peoples specifically. The utilization of this theory works to resist race-based oppression, to look for and insist on social justice and equity, and to support emancipation and empowerment through the use of Indigenous knowledge, perspective, and worldviews (Brayboy & Chin, 2018; Denzin & Lincoln, 2014). Using an Indigenous lens, the application of critical race theory brings awareness to the historical and contemporary context which sets the foundations for the issues and struggles related to colonial and race-based oppression of Indigenous Peoples (Dunbar, 2008). This awareness promotes the reestablishment of the consciousness of race which allows for the visibility and examination of distinctions between Indigenous and non-Indigenous people, a distinction which has been dulled over time through the persistence of the idea that all people should be treated as equals (Dunbar, 2008). Misleading society to believe that race does not matter prevents a race consciousness and creates an expectation that racially marginalized people ignore race-based injustices that have been occurring for hundreds of years. It is through this theoretical lens that we can see and understand how colonial and race-based discrimination are still strongly influencing and perpetuating contemporary acts of racism and racial discrimination against Indigenous Peoples (Dunbar, 2008).

Contemporary Indigenous Empowerment Theory (CIET)

As a theoretical orientation that I developed specifically for my dissertation, CIET aims to reject systemic racism and discrimination by bringing forth and privileging the knowledge of Indigenous realities and holding that knowledge in positions of power and authority. This theoretical lens involves the work of an Indigenous researcher, working with Indigenous Peoples to gather and share Indigenous knowledge. This theoretical lens can be utilized to challenge dominant ideologies and misrepresentation of realities to generate meaningful, appropriate solutions rooted in Indigenous ways and truths. In turn, working to dismantle contemporary colonial and race-based systemic oppression and discrimination. Guided by CIET, this study examines the gathering of knowledge around Indigenous perspective and experience to inform health policy and programming, as a tool for resistance against the multi-levels of anti-Indigenous racism within the healthcare system, and to support resurgence through the reclamation of Indigenous identity. Thus, CIET aims to examine how Indigenous resurgence is tied to the phenomenon of REI data collection, and how the disclosing of Indigenous identity can become a tool for Indigenous resurgence. Indigenous Peoples' demonstrated desire to reclaim Indigenous identity and increase Indigenous visibility signifies a movement to dismantle the racism and colonial ideologies that allow for mistreatment of Indigenous Peoples in the healthcare system. Indigenous visibility will promote awareness of inequities, challenge white privilege, and empower the refusal of less-than-optimal standards of healthcare. Within CIET there are three main theoretical principles: uncovering and understanding relations of power, social justice, and Indigenous voice as evidence.

Uncovering and understanding relations of power. In knowing and understanding how power is obtained, manipulated, and maintained, a process of disrupting these processes can

begin. A first step is recognizing and resisting control measures established by those who have taken positions of power through acts of colonization and racism. Each of the theoretical orientations of anti-colonial theory, anti-racist theory, and critical Indigenous research methodologies address relations of power, the reality of how power and dominance was obtained, and how to push back and regain control over our identities and our strengths as Indigenous people (Brayboy & Chin, 2018; Carlson, 2017; Denzin & Lincoln, 2014). This interrogation pushes research practice beyond the acts of recognition of the differences between members of society and moves to a higher level of interrogation of power and privilege (Max, 2005). When we look at the intended effect of equalizing perspectives such as colour-blindness, diversity, and multiculturalism, there is a portrayal of the belief that all people have equal access to resources and rights. In believing this, it is socially acceptable for those in higher socioeconomic positions to ignore the fact that those who are racially minoritized face numerous inequities impacting all aspects of life. The focus on relations of power through the CIET lens, involves the resistance of colonial and race-based domination and oppression of Indigenous Peoples by upholding and centering the Indigenous worldview and knowledge over that of the dominant oppressor. Thereby, reviving and revealing the knowledge of the oppressed in a way that honours and privileges that knowledge as real, truthful, and valid, and supports the pace at which the knowledge is shared is important (Denzin & Lincoln, 2014; Lewis, 2012). It is about making oppression visible to uncover the myths of dominant ideology and to deconstruct the reality that has been previously set and currently maintained by those who hold positions of power.

This research examines the impact of these power imbalances on the health and healthcare of Indigenous Peoples specifically, shedding light on the locations of failures within

the healthcare system to respect the healthcare rights of Indigenous people. Recently, there has been an increase in public awareness of where failures in seeing Indigenous Peoples as deserving of healthcare rights have resulted in harm and death. Society is becoming more aware of these harms and tragic loss of Indigenous lives, as we think about the lives and deaths of Indigenous people reported in the media, however this has been going on unreported for over a century in Canada. This study will utilize Indigenous methodologies to support the locating and highlighting of the colonial and racial power imbalances, oppression, and marginalization that exists within the healthcare system. This research recognizes and calls out racism and discrimination to actively advocate for change through a progression to transparency, accountability, and dismantling systems of power (Dei, 2005). An intent for this research is to investigate how racialized Indigenous identity is still a powerful directing factor in the struggle for equitable health and healthcare and in doing so will make the invisible visible. This theoretical orientation is a means for examining how dominant colonial and racial ideologies came to hold those positions of power and the methodologies used to perpetuate them as if they represent one true reality. In making the oppressive and inequitable systems, ideologies, and institutions visible it creates space to challenge them and begin to dismantle their real and illusionary power.

Social justice. REI data collection is very strongly tied to social justice as it is about finding evidence of inequities along with defining appropriate, culturally safe, and meaningful solutions to disrupt the silencing of (unnoticed, ignored, or dismissed) race-based inequities in health and healthcare. Each of the theoretical orientations discussed above provide a lens which challenges the long history of acceptance of white settler ideology as the norm using the constructs of equity and social justice (Lewis, 2012). Through this principle of social justice,

there is support to focus not only on the existence of colonial and racialized oppression, but also on the reactions and resistance of the oppressed as a means to locate the most successful pathways to change. This study examines and challenges the ways that ideas about Indigeneity, colonialism, racism, race-based power, oppression, and subordination are generated and maintained in society, and the impact this has on perspectives around Indigenous health and healthcare. This work involves an interrogation, uncovering, and voicing of what is inherently wrong with the way that Indigenous Peoples in Canada are perceived and treated within Canadian society. While there has been some very meaningful work done in this area (McCallum & Perry, 2018; Razack, 2015; Talaga 2017, 2018), I feel compelled to contribute to this protest for accountability and social justice. It is about unraveling the complexities of how ideas and beliefs about race and racism have been negotiated and solidified in the perspectives and consciousness of society and finding ways to unravel and dismantle those beliefs to lift the pressures of oppression and discrimination in the name of social justice.

Indigenous voice as evidence. CIET focuses on the use of storytelling to gather and share the research participants' knowledge. Participants tell stories of their history as they know it, as they experienced it, and as they believe it. This is often a very different story than what has been accepted as reality by the dominant society. It is through this lens that the dominant and accepted story is peeled back, and opportunity given for the stories of the oppressed to hold place, value, and legitimacy. It is through this newly offered space that realities of Indigenous people become a tool to expose and critique the patterns, institutions, systems, structures, and policies that maintain the power of the dominant and the subordination of the oppressed (Dunbar, 2008).

Reflections on the Construct of Power

In challenging myself to bring to words my understanding of the construct of power, I must return to my teachings about the ways we have learned to work together with the surrounding world. Therefore, not just other humans, but with every animate and inanimate thing on mother earth. When placing the construct of power within an Indigenous worldview, it is understood as a mechanism for drawing in or together energy that will uplift and unite people and knowledge together. Power is not attainable for the purpose of overpowering another person or collectives. In connecting the idea of power to knowing, it is understood that when power is used in harmful ways, the underlying root of the problem lies in the act of using knowledge to control or hold power over others. Within an Indigenous ontology and epistemology, knowledge is relational (Wilson, 2008). And this is where my understanding of power arises. Through an Indigenous epistemology, knowledge is gained through sharing of knowledge already in existence. When we come to know, that knowledge does not belong to us individually, but instead belongs to the cosmos, the universe, and every human has an opportunity to hold that knowledge as well. There is no ownership of knowledge. Instead as humans, we are stewards of that knowledge, and our teachings let us know that we are only to do good things with that knowledge. This is quite different from Western-based or dominant paradigms where knowledge is understood as being gained and owned by individuals (Wilson, 2001). Power in this sense is held over others and comes into play through complex social constructs such as government, religion, gender, class, and economics (Hollenberg & Muzzin, 2010). Within an Indigenous worldview, it is never about claiming ownership and using that ownership to bring oneself above, or hold power over, others. Leaders may be tasked with making decisions for others, but the purpose is to benefit the collective, not the individual. This is far removed from the idea of the oppressive power

foundational to colonialism (Lewis, 2012). As Indigenous researchers, research is a commitment to examining relationship of power (Brayboy & Chin, 2018).

In my dissertation and through the application of CIET, the intention is to examine power relations within the healthcare system to understand how to disrupt and rise above power structures which are harmful and do not serve the well-being of Indigenous Peoples. I write about Indigenous empowerment in the context of REI data collection, which is not about obtaining power to overtake any person or group of people, but instead is empowerment to return from subjugation (Hollenberg & Muzzin, 2010). It is about taking back our inherent original power to advance beyond the constant fight aimed at keeping us beneath and below.

Before closing this reflection on power, another underlying importance for empowerment, is knowing that as knowledge of Indigenous empowerment becomes more widespread, possibilities of knowledge appropriation also grow (Hollenberg & Muzzin, 2010). Where non-Indigenous people absorb Indigenous knowledge and ways of doing and in turn benefit from it at the expense of Indigenous Peoples, for example, perceived ownership and misuse leading to harm. In order to protect against this type of knowledge and practice appropriation, it is crucial for Indigenous Peoples to come together in power for the benefit of our nations now and in the future.

Indigenous Methodologies

"…Indigenous research methods and methodologies are as old as our ceremonies and our nations. They are with us and have always been with us. Our Indigenous cultures are rich with ways of gathering, discovering, and uncovering knowledge. They are as near as our dreams and as close as our relationships" (Cardinal, 2001, p. 182).

Indigenous methodologies integrate the physical, emotional, spiritual, and intellectual parts of the self as researcher. It is about understanding and utilizing Indigenous ways of being, knowing, doing, and living (Simpson, 2011; Steinhauer, 2002). It is a way to maintain Indigenous identity, beliefs, and worldview while also working within the realm of academic research (Weber-Pillwax, 2001).

As an Indigenous researcher, I commit to doing research identified by Indigenous Peoples as important, desired, and which brings to light the experiences of Indigenous Peoples through the inclusion of Indigenous voice and stories. I commit to remaining accountable to the people with whom I work and to uphold my obligation to honour these people by working towards beneficial outcomes for participants, communities, and nations. I commit to honouring the knowledge that is shared through the recognition that the knowledge is not mine but is either shared with me or co-created through relationships. These commitments have been guided by principles of Indigenous methodologies articulated through the work of Indigenous researchers (Dunbar, 2008; Kovach, 2009, 2010, 2015; Lambert, 2014; Lewis, 2012; Simpson, 2011; Smith, 1999; Steinhauer, 2002; Weber-Pillwax, 2001; Weber-Pillwax, 2004; Wilson, 2001, 2008), and which hold a place within my internal and inherent knowledge base as an Indigenous person. My commitments have been supported through the relationships that I have with the Elders and Knowledge Keepers in my life. In particular, consultations with Métis Elder Barbara Bruce will help to guide me along the right path to do research in a good way. To honour this relationship, I passed tobacco to Métis Elder Barbara Bruce which she accepted and walked with me through the dissertation research and writing process as a keeper of knowledge and a spiritual and cultural teacher. Indigenous research methodologies have a special role in recognizing, interrogating, and disrupting historical and currently shared assumptions generated from colonial

or Western ideologies within the context of research (Lewis, 2012). As Max (2005) noted, "The challenge will be in creating research that is inclusive, creative, empowering, and relevant to the lived experiences of people as it moves beyond the realm of a mere academic exercise or a tool to justify oppressive policies" (Max, 2005, p. 92). The 5 principles which guide my dissertation are: *Importance of Relationship, Positionality, Strengths Based Perspective, Storytelling/ Narrative/ Discussion, Preparation, and Sacred Methodology (Dreams, Visions, and Ceremony)* **See Appendix A for a discussion of these principles of Indigenous methodologies. A visual framework of the Eagle Feather was chosen to represent the connection of this research to my Indigenous paradigm. **See Appendix B for a discussion and image of the Visual Framework.

Methods

I chose a four-method approach study design to address the primary research objective to *advance knowledge of Indigenous understanding and experience around the concept and practice of REI data collection at point of access to health service using an Indigenous paradigm and the inclusion of Indigenous voice and knowledge.* Methods for each quadrant address the objective using unique approaches to explore different points of time and focus. Methods are: 1) story gathering and listening to perspectives and experiences of First Nations, Inuit and Métis peoples regarding the collection of REI data within the Manitoba healthcare system; 2) an environmental scan of historical and contemporary practices of REI data collection within the Manitoba healthcare system; 3) a scoping review/knowledge discovery of academic peer-reviewed literature pertaining to Indigenous people's healthcare experiences in Canada; 4) researcher reflections on the use of ceremony and traditional knowledge as a way of generating

understanding and maintaining personal well-being. **See Appendix C for Research Questions Guiding Quadrant Objectives.

Analysis

Analysis involves a combination of thematic analysis and holistic content-focused narrative analysis (Kovach, 2009). This involves two distinct levels of analysis ongoing at the same time consisting of a) formation of distinct thematic groupings that emerge from the various data sources and b) maintaining large sections of the stories/narratives/discussions analyzed as a whole. Thematic analysis involves the analysis of documents and databases in the scoping review and the environmental scan, as well as the qualitative materials of the story gathering and traditional ceremony and Knowledge research. This type of analysis involves the sectioning of the materials based on reoccurring themes, or by using pre-selected thematic categories. While thematic grouping is more of a Western-based analysis technique (Kovach, 2009), I have learned to do this work through an Indigenous research perspective, maintaining the relationships between one part of the materials or story to the others. I chose thematic analysis to show what is presenting as similar between various data sources as well as what might be missing from the data. While important, this must be done with caution and with explanation for the breaking down of the materials and/or story from its whole, its context, and its speaker. Content focused narrative involves the keeping of the narrative together and discussing it as whole (Carlson, 2017). I chose content focused narrative to show the power of storytelling and the importance of hearing the story in whole in order to take what knowledge is needed from that story. Through an Indigenous lens, there was a need to understand the whole, before it was able to be understood as pieces of that whole. Both methods of analysis are important and meaningful to my work and were used in this research where appropriate. I used NVivo qualitative software for the

organization, coding, and analysis of the story gathering. I used Covidence software for the organization and extraction of data throughout the scoping review. During the process of analysis, I also examined the interactions and relationships between myself as researcher and the participants. The co-created knowledge created through these relationships, as well as the relationships themselves, are integral to understanding the outcomes of the research. Consultation and discussion with Métis Elder Barbara Bruce provided support during the process of analysis, guidance around the comprehension of the data, and encouragement to trust the Indigenous worldview.

Ethical considerations

Within the use of Indigenous methodologies, there are unique ethical responsibilities to be considered and addressed intended to support control, governance, and determination over Indigenous knowledge and the processes of research. Within the academy there has been a recognition of the harm caused by the use of Western based research paradigms to study Indigenous Peoples resulting in a shift in the nature of research involving Indigenous Peoples within the University (Kovach, 2009). The consideration of ethics goes much further than just protection of the researcher and the institution. Within the realm of Indigenous methodologies, the role of ethics is grounded in the need to protect the individual participants, the community, the nation, and the knowledge. Discussion of ethically responsible research practices has led to development of ethical guidelines and protocols that now guide the work of those working with Indigenous populations. Over the past few decades there have been a number of important documents developed by, and in consultation with, Indigenous Peoples, to assist researchers in developing research protocols that protect Indigenous Peoples, communities, knowledge, and practices. Guidelines and statements of principles clearly outline what are acceptable and

objectionable research practices when working with Indigenous Peoples. In order to proceed with research with Indigenous Peoples, these broader guidelines and protocols along with the local community or nation protocols must be understood and followed (Kovach, 2009; Max, 2005). I consulted with and followed the recommendations of these guidelines and principles for research with Indigenous Peoples including the Royal Commission on Aboriginal Peoples (RCAP) (Government of Canada, 1996; The Commission, 1997); Ownership, Control, Access, and Possession (OCAP) (First Nations Information Governance Centre, 2019b; Schnarch, 2004); CIHR guidelines for health research involving Aboriginal people (Canadian Institutes of Health Research, 2007); the Tri-Council Policy Statement (Chapter 9) Research Involving Indigenous Peoples (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2022; Government of Canada, 2018); the Truth and Reconciliation Commission Calls to Action (Truth and Reconciliation Commission of Canada, 2015); the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2008); and the University of Manitoba's Framework for Research Engagement with First Nations, Métis, and Inuit Peoples (First Nations Métis and Inuit Health Research Strategic Planning Committee, 2014). Approval for this research was sought and obtained from the Human Research Ethics Board at the Bannatyne Campus of the University of Manitoba. **See Appendix I for Ethics Approval. Community consultations involving Elders, community members, Indigenous Advisory Council, and an Indigenous leadership circle also supported all aspects of the research process and occurred at various points along the timeline of the research. Consultation with and guidance from Métis Elder Barbara Bruce provided space and support for discussion and appropriate addressing of Indigenous ethical considerations. The inclusion of Indigenous voice not only within the research but also in the development and

operationalizing of the research is another means of breaking down and changing colonial based research practices and is therefore an important element in Indigenous resurgence (Kovach, 2009).

Trustworthiness

"*As researchers, we are challenged to think about old terminology in new and creative ways. How will concepts such as reliability and validity be defined from within an anti-positivist stance" (Max, 2005, p. 91)***.** Within Indigenous methodologies the concept of validity requires a different understanding from what fulfills these parameters in Western-based research methodologies (Kovach, 2009). Kovach (2009) notes "Attempting to validate Indigenous knowledge's according to Western terms and assumptions creates an ethical problem" (Kovach, 2009, p. 148). The validity, credibility, or trustworthiness of Indigenous research must be evaluated though an Indigenous worldview, by Indigenous people, because there are certain ways of knowing, doing, and being, that allow those who evaluate the data to see things differently than non-Indigenous people would see it. Within Indigenous methodologies, trustworthiness is strongly tied to the context of the relationships between the researcher, the participants, the community, and the self, as well as the ability to honour and be accountable to those relationships (Kovach, 2010; Steinhauer, 2002; Wilson, 2001). More specifically this can look at how the researcher fulfills their obligations to the people, how the researcher remains accountable to the participants and community, and a measure of the participant's overall acceptance and satisfaction with the research. Overall, it is a measure of whether or not the research is being done through the Indigenous paradigm and done in a good way (Kovach, 2009; Wilson, 2001). I noted and recorded the nature of these relationships, the actions and accountability work that occurred within them, and my personal experiences of the research

process in reflection writings. These writings became evidence of my accountability to my relationships and are available as a tool for evaluating the trustworthiness of the research from an Indigenous perspective.

Measures of trustworthiness also comes from how the various aspects of the research align with the Indigenous worldview. Therefore, a measure of the extent to which Indigenous methodological procedures have been followed (Kovach, 2009; Weber-Pillwax, 2004). This process again highlights the importance of relationship within Indigenous methodologies. It is often through relationship that research is possible, and through trusting relationships that we are able to honour our worldview by conducting our research through its lens. Within these relationships, the researcher and participants work together so that there is full transparency around the research design and process. I conducted this research according to Indigenous paradigm and methodologies, and it is my responsibility to demonstrate how I have adhered to this plan. Therefore, the building of trusting relationships is crucial to ensuring the trustworthiness of the research (Kovach, 2009). As Kovach (2009) notes, within an Indigenous paradigm, "truth is bound in a sacred commitment" (Kovach, 2009, p. 102). Through this trusting relationship, stories and shared knowledge become part of the historical truth. Kovach (2009) talks about how truth was symbolized through the exchange of tobacco. I have chosen to use the eagle feather as a symbol of the speaking of our truth. I carry an Eagle Feather that was gifted to me by Métis Elder Barbara Bruce which is a reflection of the strength of the relationship that exists between us. Elder Barbara has been a strong support during this research in helping me to honour my worldview and align my work a good way.

Knowledge Sharing

As the unique contexts of Indigenous communities have been and will continue to be considered in the dissemination of research knowledge, consultation with Indigenous participants and communities will inform knowledge sharing strategies to arrive at the most appropriate and meaningful ways to share study outcomes (Smylie, 2009; Smylie et al., 2004). Advancing our knowledge and understanding of REI data collection from an Indigenous perspective to benefit patients, public, healthcare staff, researchers, and policy makers are central aims of this dissertation, which include story sharing among research participants, community members, the university, the healthcare system (healthcare professionals, healthcare administration, healthcare leadership), provincial and federal governments, and the broader Indigenous and non-Indigenous populations within Manitoba, and Canada. It is my responsibility to honour research relationships and remain accountable to these relationships at all points during the presenting of the research findings to each applicable audience (Wilson, 2008). Drawing from Kovach (2009), there are three audiences that Indigenous researchers need to considers when presenting their findings of the knowledge of the research; the Indigenous community who must be able to make sense of the research, the academy who expects clarity around the validity of the study, and other Indigenous researchers who will evaluate the process and the results of the research from an Indigenous perspective (Kovach, 2009, p.134). Through consultation with Indigenous community, as well as my dissertation committee, continued dissemination plans will aim to satisfy these three audiences. Knowledge translation activities can include peer-reviewed publications in appropriate journals and community-based materials, and presentations at local, national and international forums and conferences. Indigenous participants will be invited to participate in knowledge sharing activities and invited and encouraged to share their voice and

knowledge. An important knowledge translation activity will involve the formatting of the study results into a usable source of knowledge for the development of the communication strategy to inform the development and implementation of policy and practice pertaining to the collection of REI data within the healthcare system. In all aspects of knowledge sharing, the framework for dissemination will be developed and evaluated within an Indigenous context (Smylie, 2009; Smylie et al., 2004).

Describing the structure of my dissertation

The structure of this dissertation includes this first introductory chapter, followed by three chapters which address each component of the dissertation; a qualitative story gathering study (Chapter 2); an environmental scan (Chapter 3); and a scoping review/knowledge discovery (Chapter 4). A conclusion (Chapter 5) brings together the three chapters and provides a final discussion and conclusion for the dissertation as a whole. As a unique way of including and honouring the importance of knowledge gained through ceremony and traditional knowledge, excerpts from personal reflective writings will be interwoven between the chapters to share how these pieces of my own identity contributed and supported me, as an Indigenous researcher, through the process of completing my dissertation. Appendices are located after the dissertation chapters. As a map to the dissertation, I provide a short description of each of the chapters below.

Chapter 2: Being seen where we were never intended to be seen: Indigenous experiences and perspective of REI data collection in the healthcare system in Manitoba.

The objectives of this chapter were to: 1) To listen to Indigenous perspectives and experiences related to REI data collection within the healthcare system; 2) To advance knowledge of Indigenous perspectives on best practices for REI data within the healthcare system; 3) To

advance knowledge of Indigenous perspectives on the desired outcomes of REI data collection. These objectives were addressed through story gathering sessions carried out through the use of Indigenous methodologies. Story gathering sessions involved 20 self-identifying Indigenous people in 3 categories: community members, healthcare registration staff, and healthcare leadership. Indigenous storytellers (participants) shared their perspectives on the meaning of Indigenous identity, Indigenous experiences in healthcare, perspectives on REI data collection, and best practice for REI data collection. This study opened space for Indigenous voices to inform our understanding of the impacts of the collection of REI data on the lives of First Nations, Inuit, and Métis people in Manitoba. Findings from the analysis come together to determine that asking Indigenous people to declare their Indigenous identity is a highly complex matter and that asking the REI question is not a simple task. Although all participants agreed that REI data collection was valuable and generally a good idea, there was a collective understanding that the racism which exists in all form and within all levels of healthcare creates an unsafe environment for Indigenous Peoples. It is understood that the success of REI data will require involvement of First Nations, Inuit, and Métis people, efforts to ensure the safety of people and data, and full commitment from healthcare leadership to dismantling racism within the healthcare system.

Chapter 3: Indigenous skin, red flags: an environmental scan of past and current attempts at REI data collection in Manitoba.

The objectives of this chapter were to: 1) To map current policies and work concerning REI data collection in the Manitoba healthcare system and reveal current knowledge gaps; 2) To present a critical review concerning policies and processes of REI data collection and the impacts on Indigenous Peoples and Indigenous identities. These objectives were addressed through an

environmental scan to identify and document past and current practices within Manitoba related to the collection of REI data within the healthcare system. This environmental scan utilized a mixed methods qualitative design which involved 1) key informant discussions, 2) document review, 3) review of policies and practices within the healthcare system 4) knowledge and experience gained through involvement in current REI project (MB healthcare system). Indigenous methodologies guided the environmental scan and supported the use of CIET theoretical framework in the analysis. Through the application of CIET, it was apparent where the three components: uncovering and understanding relations of power, social justice, and Indigenous voice as evidence were evident through the attempts at REI data collection, and the impacts that this has on Indigenous Peoples and communities. In contrast, it also revealed where gaps did and still do exist. The environmental scan raises awareness and availability of evidence for health systems organizations, researchers, practitioners, patients, and the public to understand the current context of REI data collection in Manitoba.

Chapter 4: Raising Indigenous Voice: the impact and importance of Indigenous identity in research on Indigenous healthcare experiences in Canada.

The objectives of this scoping review were to: 1) to better understand how Indigenous identity is considered in research describing Indigenous people's experiences in healthcare; 2) to document the use of guiding principles of Indigenous research within the academic peer-reviewed literature on Indigenous experiences in healthcare in Canada. The scoping review design drew on multiple authors including the seminal work by Arksey and O'Malley (2005) and Levac et al. (2010) updates but also Chambers et al. (2018), decolonizing approaches to scoping reviews among Indigenous Peoples and knowledge. Through an Indigenous lens, this scoping review generated an in-depth examination into how the concept of Indigenous identity is included and discussed in

this literature, and how Indigenous identity and ways were considered during the research process. Findings highlight the need for transparency around identity of researchers and the research participants, especially when the research claims to present Indigenous voice as evidence. As well, there is need for increased understanding and honouring of Indigenous research methodologies, ethical guidelines, and principles for research involving Indigenous Peoples. This scoping review critically examined how Indigenous identity, voice, and methodologies are upheld in research. As this paper focuses on experiences in healthcare specifically, it can be used as model for examining other areas of health research literature involving Indigenous Peoples.

Chapter 5: Discussion and Conclusion

The dissertation closes with final discussion bringing together the findings from all three studies to highlight their important connection and values. While each of the three chapters are important on their own, together they tell the story of the impact of REI data collection for Indigenous Peoples and the potential for further impacts within health policy, practice, and research as we prepare for a systematic collection of REI data in Manitoba. The conclusions highlight the contributions of the dissertation to the larger body of Indigenous health research, and shares recommendations for next steps and considerations for further research opportunities.

Significance of the Dissertation Study

Through prioritizing Indigenous voices and experiences, this research offers a deeper examination of the perspectives, experiences, needs and desires of First Nations, Inuit, and Métis peoples in relation to REI data collection within the healthcare system. In addition, it provides a timeline and context of the previous and current attempts at REI data collection in a healthcare

context in Manitoba and examines how REI data collection has aligned, or not, with the theory of Indigenous empowerment. Finally, it gives grounds for the need to take careful consideration of how research generates and determines the evidence of Indigenous people's experiences in the healthcare system. These three important perspectives come together to offer an examination of the collection of REI data and its potential impacts, positive and negative, on the lives of First Nations, Inuit, and Métis people in Manitoba. Findings from this research will inform a larger provincial project involving the implementation of REI data collection in provincial and federal healthcare systems within Manitoba, and will touch on process and practices used in the collection of REI data during the Covid-19 pandemic. In gathering perspectives of Indigenous patients, health data collectors, and health decision makers; reporting on barriers and facilitators of REI data collection initiatives in Manitoba; providing a critical review of the literature on Indigenous healthcare experiences, Indigenous voice is upheld to bring light to requirements for successful REI data collection and use in the Manitoba healthcare system. In turn, Indigenous people will better understand that their voices matter and can result in the generation of a deeper connection to resulting healthcare services and systems. This study is an integral part of the larger provincial project as nothing should be done concerning the health of Indigenous Peoples without including the voice and knowledge of Indigenous people. Furthermore, together the components of this research and larger implementation project exist as an act of Indigenous resistance against the continued anti-Indigenous racism that exists within the healthcare system. In making racism visible it will no longer be able to be ignored or dismissed. This is a reflection of the work that Indigenous scholars have committed to in order to support the reclamation of our strengths and identities as Indigenous people and to break apart from the ties of colonialism and the resulting racist ideologies that still exist today. Through both the act of research and the

area of research, I feel that this dissertation ushers forward opportunity for Indigenous knowledge to confront and dismantle the colonial-based power and privilege that still has a hold on many of our social systems, institutions, policies, and practices and which prevent Indigenous Peoples from being seen and heard as fully human (Denzin & Lincoln, 2014; Hart et al., 2017, Razack, 2015).

Chapter 2 Relationships – In between chapter sharings

At the onset of my dissertation, I noticed gaps in the evidence related to First Nations, Inuit and Métis people's perspectives, understanding, and experiences of REI data collection. Closing this knowledge gap will be imperative to successfully implementing of REI data collection in Manitoba. In this chapter, we are able to listen to First Nations, Inuit, and Métis people speaking up and sharing their perspectives and experiences of Indigenous identity data collection and use. The story gathering method (Kovach, 2009) invited exclusively Indigenous voices to share their understandings of Indigenous identity, resurgence, healthcare experiences, best practices for data collection, protection, and reporting, as well as communication and training strategies. I am grateful for all that I have learned with the storytellers. I am reminded that traditional ways of learning through sitting together sharing story, is paramount in passing knowledge amongst each other to the next generations.

Contribution of Authors

My contribution to Chapter 2 includes relationship building, idea formation, study design, theoretical framework development, knowledge gathering, meaning making, and writing of the chapters. My primary supervisor Dr. Schultz provided critical feedback in the development of the chapter. Revisions to the writing were based on feedback from my dissertation committee; Dr. Schultz, Dr. McPhail, Dr. Anderson, Dr. Smylie, and Métis Elder Barbara Bruce.

Appendices Located within this Chapter

Appendix D: Call for Research Participants
Appendix E: Study Announcement Poster
Appendix F: Invitation Letter

Appendix G: Consent Form

Appendix H: Research Discussion Guides for Indigenous Storytellers

Appendix I: Ethics Approval

Traditional Knowledge Sharing

I am thankful my committee afforded me the space to think about the inclusion of ceremony and traditional knowledge in my dissertation and to articulate what this means to me. Through this reflection I was reminded of the potential for sharing traditional knowledge within the academic setting. Throughout history, there are numerous examples of where sharing of our knowledge, spirituality, ceremony, medicines, and even our bodies was used against us and caused harm. As a response, there is a hesitancy now to share knowledge, or to share with extreme caution. I have been on a personal learning journey related to traditional knowledge, medicines, and ceremonial practices with my medicine teacher, but this knowledge sharing is limited to those who identify as Indigenous, by choice of the teachers. This is a current living example of the impact of feeling that we must now be cautious when sharing knowledge. Our knowledges are sacred and we are taught to protect that knowledge. In thinking about how this inclusion of knowledge was to take place within my dissertation, I had to consider how much I wanted to share and how much I could safely share. We are also given the teaching of protecting our ceremonies; done in prayer and not meant to be shared openly as we connect to the creator and our ancestors. I now carry teachings and knowledge to guide me to include traditional ceremony and knowledge in my daily life. I began to think about what would serve this research best, what would serve myself best, and what would serve other Indigenous students/scholars best. Through this work I knew I had an obligation to all three. I decided that there would be a recording of specific details for myself so that I could better understand my location within the research and research process, as well as

descriptions and explanation of how traditional knowledge guided me throughout the research process. I moved forward with this work knowing that the writings I was creating might or might not be shared openly, but they would be used to ensure space and place for my knowledge development and strengthening of my relationship to the research and research process.

My connections to land and all my relations are strong. I experience my world in consideration of all of the webs of relationships that hold it together. For others, and for myself, I understood the value in taking dedicated time and space to taking a closer look at these webs, especially the webs of ceremony and traditional knowledge that I carry. This is where this work has taken me and so I am honouring this path. Much of this has been held in my body, heart, mind, and spirit. I am so thankful to be able to hold this knowledge in this new, more accessible way, and to share with others how traditional knowledge and ceremony have guided and supported me through this process of researching and writing my doctoral dissertation.

Chapter 2: Being seen where we were never intended to be seen: Indigenous experiences and perspective of REI data collection in the healthcare system in Manitoba.

Introduction

Over the last couple of decades there is growing interest with the systematic collection of race, ethnicity, and Indigenous identity (REI) data within Canadian provincial healthcare systems. While the idea of requesting patients to self-identify their race, ethnicity or Indigenous identity seems straight forward and simple, in reality the colonial histories, current day structures, and diverse local contexts suggest simplicity is not the appropriate adjective. Current Canadian-based literature draws on research conducted in four provinces: Ontario, Manitoba, Alberta, and British Columbia. Evidence emerging from these studies focus on: patient and public opinions and perspectives, evaluation of data collection tools, evaluation of data collection system, implications of REI data collection, and approaches to REI data collection (Gibbens & Bowen, 2009; Kiran et al., 2019; Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Quan et al., 2006; Varcoe et al., 2009; Wray et al., 2013). A notable gap within this literature is the absence (or silencing) of Indigenous voices, perspectives and ways, which demonstrates an inherent racial bias within current day evidence. REI data collection generates mixed reactions among patients, both within individual and community contexts (Kirst et al., 2013); see Table 1 for a list of key themes derived from Canadian literature.

Table 1

Key Themes

Key Theme	References
There is a need for public education and communication strategies around REI data collection.	Gibbens & Bowen 2009; Kirst et al., 2013; Lofters et al., 2011
Challenging racism for minority populations remains difficult without empowerment and visibility.	Varcoe et al., 2009
There are differences in the recognition and understanding of harm and benefits of REI data collection based on identities and backgrounds of individuals.	Varcoe et al., 2009
There is a need for transparency around the use of REI data.	Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Varcoe et al., 2009
There is a comfort level associated with REI data collection related to generational age of individuals.	Kirst et al., 2013; Lofters et al., 2011
There is concern, anxiety and fear related to REI data collection in the healthcare system.	Gibbens & Bowen 2009; Kirst et al., 2013; Lofters et al., 2011; Varcoe et al., 2009

Clear and detailed communication is imperative to support REI data collection, which includes defining the concepts of race and ethnicity, outlining the processes and reasons for REI data collection, and addressing how REI data should be used. Each of these details will influence patients and healthcare staffs' comfort and acceptance with collection of REI (Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Quan et al., 2006; Varcoe et al., 2009; Wray et al., 2013). For example, research shows best practice for REI data collection is self-reporting (Pinto et al., 2016; Quan et al., 2006; Wray et al., 2013). However, when the purpose is unclear and staff feel uncomfortable posing the question, staff were observed reporting race and ethnicity data based on a judgement of appearance or assumptions about last names (Quan et al., 2006). In Manitoba, the first attempt to collect REI data failed primarily due to inadequate patient and public engagement and communication, along with lack of systematic education and training for data collection staff (Gibbens & Bowen 2009). While important evidence to consider, it is equally important to note this evidence centers the voices of white people or minorities who are not

Indigenous. In order to understand the impact among Indigenous Peoples accessing healthcare, it was imperative that First Nations, Inuit, and Métis people be invited to share their conversations providing space for people to share their perspective, and experiences, and knowledge on this topic.

Despite the history of colonization and the impacts on the health of Indigenous Peoples in Canada, there were no studies that focused exclusively on the perspectives and experiences of Indigenous Peoples in relation to REI data collection within healthcare settings, and no studies that utilized Indigenous research methodologies, mentioned consultation with Indigenous Peoples, or included discussion of adhering to protocols for respectful research involving Indigenous Peoples. There was one study that included Indigenous people along with other non-Indigenous participants, which provides a glimpse into Indigenous perspectives on the implications of REI data collection in the healthcare setting (Varcoe et al., 2009). In this article, an Indigenous-led study exploring Indigenous Peoples' experiences and perspectives of REI data collection within healthcare settings is discussed. To address the evidence gap, story gathering sessions (interviews) with self-identified First Nations, Inuit, and Métis individuals in 3 groups: community members, healthcare registration staff and healthcare leadership creates space for Indigenous voices to be part of the conversation and heard.

Study Context

As the study location is Winnipeg, Manitoba I am sharing relevant provincial contextual details. Manitoba is on traditional and current homelands of First Nations, Inuit, and Métis people. As Indigenous populations are growing (Statistics Canada, 2022) understanding how REI data collection might impact Indigenous Peoples is imperative. In the 2021 Canadian census,

Indigenous Peoples (First Nations, Inuit, and Métis) made up 18.1% (237,190) of the Manitoba population (Statistics Canada, 2023). A distinctions-based approach shows that 57% (134, 890) were First Nations people, 40.5% (96, 725) were Métis, and 0.3% (725) were Inuit. In 2021, the city of Winnipeg had the largest Indigenous urban population of any Canadian city with 102,080 Indigenous people living in the city (Statistics Canada, 2022). The numbers of Indigenous people are growing, and so is the demand to have our voices heard. It is important to note here that although efforts are being taken to determine Indigenous population sizes, First Nations, Inuit, and Métis peoples are consistently undercounted and underestimated, especially in urban contexts (Rotondi et al., 2017; Smylie & Firestone, 2015).

In May 2019, Shared Health, the provincial health authority of Manitoba, encouraged the initiation of REI data collection across Manitoba healthcare systems. While there had been previous attempts, which were not provincial initiatives, most were unsuccessful (See Chapter 3 of dissertation). In 2019, a team led by Dr. Marcia Anderson, guided by a Black, Indigenous and People of Colour (BIPOC) advisory group of diverse representatives from health, academic, community, and Indigenous specific organizations came together to work on a strategy for the collection of REI data in the Manitoba healthcare system. I am a member of the core REI data collection team. After four years of work, the implementation of REI data collection within Manitoba healthcare settings began in May 2023.

Positionality Statement

As a doctoral candidate and researcher of Ojibwe ancestry, I ground my work within an Indigenous paradigm and the use of Indigenous research methodologies. Both within and outside of the academy, I honour my Indigenous identity, and relationships are the foundation from

which everything is understood. Part of this work involves the inclusion of Indigenous participants and partnerships in all research endeavors. Throughout my dissertation research I consulted with an Indigenous Advisory Council (IAC) developed in partnership between Ongomiizwin and the Centre for Healthcare Innovation (CHI) of which membership includes self-identified First Nations and Métis people. The IAC provided feedback and guidance on the overall study design. In addition, a circle of Indigenous leadership with membership from each of the three recognized Indigenous groups in Canada - First Nations, Inuit, and Métis - was formed to review my full dissertation proposal, and offered feedback and mentorship. Due to considerations regarding COVID-19, all consultation interactions occurred through virtual meetings. As a member of the core team for the provincial REI data collection strategy, I carry a broad base of knowledge around the development and implementation of the REI data collection initiative in Manitoba.

Methods

"Contemplated within an Indigenous episteme and applied to Indigenous methodologies, collecting data is the gifting of another's story to a researcher: data are more than things; they are living connection animated through the exchange of story" (Kovach, 2021, p. 156)

As a First Nations researcher, with the intention of honoring Indigenous people through the inclusion of their voices, I chose to situate this story gathering study within Kovach's (2009, 2010, 2021) Indigenous conversational qualitative methods. Three objectives guided this study: 1) To listen to Indigenous perspectives and experiences related to REI data collection within the healthcare system; 2) To advance knowledge of Indigenous perspectives on best practices for REI data within the healthcare system; 3) To advance knowledge of Indigenous perspectives on the desired outcomes of REI data collection. Story gathering is rooted in conversational methods

and is based on the use of oral tradition to gather knowledge. It involves the sharing of story through the building or nurturing of a trusted relationship for the purpose of seeking ways to benefit others (Kovach, 2010).

Sampling and Recruitment Processes

In this study, I sought to recruit three groups of self-identifying Indigenous people: community members, healthcare registration staff, and healthcare leaders. All participants will be identified as storytellers within this dissertation in alignment with the Indigenous methodology of story sharing and conversational method (Kovach, 2021). All storytellers were required to self-identity as First Nations, Inuit, or Métis. Registration staff were required to have some experience with the collection of patient demographic data, while healthcare leadership were required to hold a healthcare leadership role. **See Appendix D for the Study Announcement. **See Appendix E for the Study Announcement Poster. **See Appendix F for the Invitation Letter. **See Appendix G for the Consent Form.

As the city of Winnipeg is home to First Nations, Inuit, and Métis people, and the collection of REI data will happen at health centers that serve peoples of all three distinct nations, I made the decision to include perspectives of individuals from all three nations. Never intending to take a pan-Indigenous approach, this research recognizes the distinctness of First Nations, Inuit, and Métis people while honouring the importance of including experiences and perspectives from all three nations. Recruitment utilized a purposive sampling approach (Creswell, 2009) drawing on existing personal and community-based relationships within the recruitment strategy. An invitation for participation was shared through social media (Facebook, Instagram) and through emails shared within organizations in which I had previously established relationships including

the First Nations Health and Social Secretariat of Manitoba and the Aboriginal Health and Wellness Clinic. Notifications contained details about the study, contact information, and an invitation to participate. Eligible storytellers were then contacted and provided a Letter of Invitation which outlined the details of the study and officially welcomed them into the study.

Data Collection

A series of semi-structured questions facilitated story gathering sessions, where storytellers were invited to share their perspectives and experiences of REI data collection within healthcare settings. In-person story gathering session were held between July 21, 2022 and October 16, 2022 in locations based on storyteller preference, and included private workplace offices, a private residence, and a public restaurant. One session was done virtually using Zoom. Prior to beginning the story gathering session, storytellers were guided through the study consent form, and consent was obtained. To set the tone, each session opened with an explanation that the conversation could flow back and forth with sharing between both researcher and storytellers. I explained that the intention was to have the interaction feel more like a conversation rather than an interview where the flow of sharing was one way. Storytellers were encouraged to share their knowledge around the collection of REI with the intention of holding space for Indigenous Peoples voices to become evidence for planning and development of REI data collection policy and practice. Tea and/or food were shared with storytellers during the sessions. Each storyteller was gifted tobacco as a sign of valuing the knowledge that was shared, along with a small smudge kit that I created with shells from Manitoba waters and sage from Manitoba land. Storytellers received a $50 honorarium. Story gathering sessions addressed questions pertaining to perceptions and experiences in the following areas: facilitators/positive aspects of the

collection of Indigenous identity data; concerns/fears/apprehensions around collection of Indigenous identity data; implications of the collection of Indigenous identity data; origin of storyteller perception, experience, and knowledge; steps to ensure that REI data is collected in a good way; training and education; communication strategies; best location/personnel for data collection; desired outcomes from REI data collection; access and use of REI data; meaning of Indigenous identity; and ideas around Indigenous resurgence. **See Appendix H for Research Discussion Guides for Indigenous Storytellers (community members, registration staff, healthcare leadership).

Analysis

Story gathering sessions were audio-recorded and transcribed verbatim for the purpose of analysis. Analysis of each session involved a combination of thematic analysis and holistic content-focused narrative analysis (Kovach, 2009). This involves two distinct levels of analysis ongoing at the same time consisting of a) formation of distinct thematic groupings that emerge from the various data sources and b) analyzing and understanding large sections of the stories/narratives/discussions as a whole. Thematic analysis, the sectioning of the materials based on reoccurring themes or by using pre-selected thematic categories, is often understood as a Western-based analysis technique (Kovach, 2009). However, the use of an Indigenous methodological lens supported efforts to maintain the relationships between one part of the materials and/or story to the others. Thematic analysis highlights similar ideas shared by storytellers as well as to acknowledge those that stood out as unique. While important, this must be done with caution and with explanation for the breaking down of the materials and/or story from its whole, its context, and its speaker. Content focused narrative involves the keeping of the

narrative together for discussion as a whole (Carlson, 2017). Narrative analysis is used to show the power of storytelling and the importance of hearing the story and receiving knowledge from that story. Both methods of analysis are important and meaningful to this study. Qualitative software NVivo was used for the organization, coding, and analysis of the data. Consultation and discussion with Métis Elder Barbara Bruce provided support during the process of analysis, guidance around the comprehension of the data, and encouragement to trust the Indigenous worldview.

Ethics

Ethical approval for this study was obtained from the University of Manitoba, Heath Research Ethics Board. **See Appendix I for Ethical Approval.

Results

Storytellers

A total of 20 First Nations, Inuit, and Métis people shared their stories regarding REI data collection within healthcare settings. This included: 10 Indigenous community members (patients/potential patients/Elders and Knowledge Keepers), 5 Indigenous healthcare registration staff involved in the collection of demographic information, and 5 Indigenous healthcare leaders who worked at a decision-making level (policymakers/researchers/data users). All storytellers lived and worked in Winnipeg, Manitoba. Storytellers self-identified as First Nations (10), Métis (7), and Inuit (3). Registration staff and healthcare leadership storytellers held positions in various organizations including a resource center, primary care clinics, hospitals, an Indigenous health transformation entity, an Indigenous health agency, Indigenous governance organizations,

the Government of Manitoba, the Government of Canada, and the University of Manitoba. Most of these organizations provide health and social services to Indigenous Peoples in Winnipeg and, in some cases, more widely within Manitoba. A minority provided services to both Indigenous and non-Indigenous patients.

Analysis of the gathered stories has been synthesized into four key topics. The first two topics, Our Identity, and Our Experiences, provide important insights into the complexities surrounding identity among First Nations, Inuit, and Métis people, and experiences with entering into healthcare settings in general. The next two topics, Our Perspectives, and Our Vision, focus specifically on ideas of REI data collection and best practices. Key topics and subthemes are presented in Table 2.

Table 2

Key Topics

Key Topics	Subthemes
Our Indigenous Identities	Indigenous Identity Impact of Indigenous Identity Impacts of Racism on Indigenous Identity Standing up in Identity Impacts of Colonialism on Identity
Our Experiences	Experience with patient registration Experience with Indigenous Identifier data collection COVID-19 Indigenous identifier data collection Experiences of Assumptions
Our Perspectives	Perspectives on Indigenous identifier data collection Purpose Benefits Worries Experience with patient registration Self-identification
Our Vision	Best Practices for REI Data Collection Location People Method Communication Training Reporting Needed Information or Process Role of Leadership

Our Indigenous Identities

As storytellers opened up about their lives, perspectives of what their identities as Indigenous people meant to them were shared. While a sense of pride and empowerment was described as their identities were central to their lives, this was not without sharing darker realities. The experiences shared opened up the reality of how Indigenous identity operates historically and currently within the healthcare system. Despite decades of awareness of the need for change, healthcare is a site of potential harm for many First Nations, Inuit, and Métis people. As a result of the history of colonization and continued colonial oppression, First Nations, Inuit, and Métis people often struggle with identity. For some, Indigeneity is still tightly connected to feelings of shame, embarrassment, resentment, and wanting to be something other than Indigenous. This agonizing reality lies just beneath the surface for so many who are trying to exist and survive in a society that diminishes their core.

In focusing on experiences of racism in healthcare specifically, it is important to highlight that each storyteller spoke about racism within the healthcare system. This and other strong statements provided clear reasoning why racism can no longer be denied or ignored. One storyteller shared:

I literally don't know any Indigenous person who is not concerned about racism in the healthcare system. (HL3)

There was a recognition that the narrative that supports racism in the healthcare system stems from ideologies deeply engrained within people. Previous experiences of racism have created an ongoing sense of fear of accessing the healthcare system. Racism remains both subtle and direct and it takes effort to navigate through the different levels and intensities of racism. Indigenous

staff and providers continue to advocate wherever possible to help Indigenous patients feel supported and heard, especially when their perspectives and past experiences create resistance and fear of the healthcare system. One participant noted that change will come when Indigenous people are able to shift the focus away from the intergenerational trauma that has existed for so long and begin to have a different perspective in order to become unstuck from a trauma mentality.

Storytellers frequently shared their healthcare experiences. While this was not a question that was specifically asked, the knowledge shared was valuable for putting into perspective their view of the system, providers, and facilities which all impacted their overall perspectives on REI data collection. Some of the storytellers opened up and spoke about experiences that caused discomfort or even harm. However, they also shared how in those instances, they made decisions to stand up for themselves, their communities, or even Indigenous people they did not know personally by speaking and voicing their issues to those who were causing harm.

Indigenous identity. The requirement to identify as a First Nations, Inuit, or Métis person within the healthcare system was seen as similar to other government-controlled systems of Indigenous identification. Immediate responses from storytellers often included discussions of having or not having Indigenous identity cards such as First Nations Status cards, Inuit beneficiary/enrolment cards, Inuit N numbers, or Métis Nation Citizenship cards. Within the healthcare system, this type of identity categorizing determines where one accesses healthcare, what services and medications are available, and how healthcare is funded. These type of identification systems also drive narratives around Indigenous Peoples and identities. While Indigenous identity is often determined in this way within healthcare currently, this is not how all

Indigenous people identify themselves. These nation-based identifier labels are constructs of the Canadian government. While many have adopted them, some Indigenous people who choose not to identify this way.

I think more and more, that the labels that we've been given or – yeah, given by the government are not necessarily like labels that resonate with us. And I feel like more the – when I think about my patients and their stories, they're usually more tied to land and to connections with people and land. And not necessarily to, like, well I'm non-status, or I'm First Nations, or I'm – and sort of the structure that the federal government has delineated people into. (HL4)

Within the government-controlled systems of Indigenous identification, there are issues with accessing the processes that define and determine Indigenous identities. Increasingly, Indigenous organizations are finding ways to determine identity, learn about populations, and connect families and communities that go beyond the requirement of having the federal government involved. Storyteller shared how issues that arise in relation to Indigenous identity, and whether or not you have a particular identification card on you, can lead to experiences of shame.

For many storytellers, identity and being identified was connected to outward appearances. Stories were heard of consciously choosing to appear either Indigenous or not. As well, skin tone is often an identifier of Indigeneity. Listening to these experiences strengthened the existing dichotomy between Indigenous and white, and perceptions/experiences of how each is treated within healthcare. Storytellers spoke about options for concealing Indigenous identity or the ability to pass as white, often sharing the benefits or differences in subsequent experiences. One community member participant voiced this by sharing:

And then like even consciously – so I'm a white-presenting Indigenous person so I can be as Indigenous or not Indigenous as I want, … I'm going into that space trying to be as white-

presenting as possible in the hopes that I'm going to get the best healthcare as possible. … I consciously make a choice when we're going into those situations …to be not Indigenous. (CM8)

Storytellers shared thoughts about the differences in the ways Indigenous Peoples identify and how preconceived notions of Indigenous identity can lead to an experience of identity issues. One example is the inclusion of cultural practices/traditions in the lives of some Indigenous Peoples but not in others. Another example is single Indigenous identities vs multiple or mixed Indigenous identities. A component of this is connected to the reality that for many reasons, people are also on different timelines for learning about culture or building connections with their Indigenous identities. Therefore, the idea of intersectionality of identities needs to be considered. For some people, Indigenous identity is about a rediscovering of who you are, for others it is a recovering of things that were lost and yet, for others, it is about taking back things that were never lost but were disconnected. As a result of the way families, communities, and nations were disconnected through colonialism, there is much (re)learning to be done about the meaning of identity, how we identify, and where we belong. Indigenous Peoples are not all-knowing and do not know all the same things or have the same experiences. One storyteller spoke to their own relearning of their identity by sharing:

And a lot of us growing up in Nunavut not realizing there's other Indigenous people. Like I didn't know there was Cree and – like it was so crazy to me when I moved here because I was like wait, what. But then they're like, "Oh yeah, go to this Indigenous organization," and you'll walk in and it's like but there's nothing Inuit. Like there's nothing, what do you mean Indigenous, what? And so it was always a struggle for me like the term Indigenous… (CM10)

Another storyteller spoke about how preconceived notions of Indigenous identity can cause identity issues. They shared that:

Yeah, we all grew up in a different environment, but just because we are Aboriginal doesn't mean all Aboriginals grow up to smudge. (CM5)

Storytellers shared their perspectives on how putting all Indigenous people together into one category does not honor the distinct identities of the nations or differences in cultural practice. In the collection of REI data, understanding the differences between and within these distinct identity groups will be critical for ensuring the success of providing patient-centered quality healthcare. They also noted that on the other hand, it is also important to understand that there are aspects that connect all Indigenous Peoples together in strong ways.

Impacts of Indigenous Identity on perception of self and perception by others.

Descriptions of shame or embarrassment attached to Indigenous identity came up often in the story gathering sessions. Despite outward discussion about standing up and being advocates for our communities, it was evident that many Indigenous Peoples live with internalized racism. Some storytellers denied personal experiences of internalized racism while readily admitting that they regularly see it in others. While there is a history of negative impacts of identifying as Indigenous, there was a shared experience of starting to see Indigenous identity as an act of empowerment. People are beginning to align with and openly express their identities. Sotrytellers shared how in the healthcare field, health providers are increasingly expressing their Indigenous identity, which result from being empowered and connected to other members of their community. They also shared how giving opportunities to engage with cultural beliefs and practices is healthy, as barriers to connecting with people, community, and culture often negatively impacts health and wellbeing.

Throughout our conversations, storytellers shared their perspectives on the impacts of identity on individuals, communities, and nations in the healthcare environment. It was recognized that Indigenous people worry about or even deny their Indigeneity for many reasons within the healthcare setting, including the denial of services, increased wait times, quality of care, feelings of shame, and judgements from non-Indigenous people. This also extends beyond healthcare in regards to access to housing and other supports, treatment from neighbors, treatment by police, and being treated differently in stores or other public places. As this constant awareness of the potential for harm related to identity exists in the minds of Indigenous people, it is crucial that there is awareness of this by those who work in the health care system, especially when asking about Indigenous identity. For years, Indigenous Peoples have attempted to educate non-Indigenous Peoples and advocate for/advance their worldviews and needs based on those worldviews because it is vital to their health and healthcare. Yet, stories from storytellers show evidence of, time and again, where Indigenous identities have not been honoured or valued resulting in harm.

But one of the most important themes that arose, … was the right to be Indigenous in the engagement and that was the most powerful thing. And it came about and the traumatizing part and I realize now when I looked at the data again a number of times when I tried writing, was that people were interrogated about their beliefs as Indigenous people. They were interrogated about using Indigenous medicines, interrogated about their philosophy on how they come through, interrogated, interrogated, interrogated so that the therapeutic relationship in fact was a violent encounter for them. You have to think about that, so they're wanting to express who I am, the values I have, in this biomedical engagement parameter and it's not happening and it fucking hurts. (HL2)

Storytellers shared how negative experiences related to Indigenous identity within the healthcare system impacts Indigenous Peoples perceptions about their own identities. Therefore, there is a painful loop of Indigenous identity causing harm, followed by that harm impacting Indigenous

identity. When there is ignorance, disregard, or denial, or discrimination of a patient's identity as an Indigenous person or the ability to contextualize the Indigenous person's experiences in their identity, the resulting failure to acknowledge how identity shapes one's health and healthcare is an act of violence in itself. This identity loop can become a matter of life and death for Indigenous Peoples.

Impacts of Colonialism on Identity. Storytellers acknowledged a connection between the issues impacting their lives now and colonialism's historical and contemporary effects. This included discussions about the impacts of residential schools, day schools, the Sixties Scoop, Child and Family Services, relationships with parents and caregivers, the refusal within families to talk about the past, current infighting about religion and faith, lack of trust in the government, impact on economy and livelihood, Indigenous slavery, tuberculosis sanatoriums, Indian hospitals, and government definition of Indigenous identities. Despite the ongoing systems of oppression, storytellers still shared hope that the country can come together to acknowledge the need for change and to step into that work together. It is evident that there is awareness of what is required to repair the harm of the past, but there are still challenges in knowing how to put these changes into practice. Storytellers shared varied perspectives on the pathway to this healing. For some, this was described as a need to replace misinformed truths with Indigenous realities. For others, it was about shifting the energy forward to move past the intergenerational trauma that has existed for so long. While for others, it was about continuing to break down colonial barrier so that visions for equity and equality come together and all people can understand the true purpose for this data collection.

There's going to be a lot of decolonizing work that's needed to be done in parallel. … I think understanding the impacts of colonization and acts of genocide amongst First Nations, Métis, Inuit people is critical to understanding the importance of being seen within data. (HL5).

Our Experiences

Within the Manitoba strategy for REI data collection within the healthcare system, patient registration staff will be the primary data collectors of REI data. Listening to experiences with the patient registration process in general, both from a patient and staff perspective, is valuable.

Experience with patient registration. Of the 10 community members, two had been previously asked to declare their Indigenous identity during a healthcare registration process, one recalled being asked about her children's cultural backgrounds in conversation but was not herself asked to identify, and one had experience collecting Indigenous identity data through their role at work. Those in the healthcare leadership group who were healthcare providers acknowledged informal identity collection through provider/patient interactions or other demographic data markers but not formally collecting data from patients to enter into a data collection system. A number of the healthcare leadership group also spoke about involvement with collecting Indigenous identifier data for public health reporting purpose during the COVID-19 pandemic. All of the registration staff had experience with collecting REI data, with 4 of the 5 having direct experience with collecting the data and entering it into electronic medical records and the fifth person having frequently witnessed the collection REI data. One registration staff storyteller had shared their experience with being asked to declare their Indigenous identity during a healthcare encounter. While not frequent, there were instances where registration staff collected REI data by making assumptions about a patient's identity prior to receiving training on Indigenous identity data collection protocols.

Community members also shared their experiences and perceptions of the patient registration process. Storytellers spoke of similar experiences where attending a registration desk or processes of registration is experienced as a place of heighten awareness of Indigenous identity. With a perception that registration staff exert racist behaviors towards Indigenous patients, these encounters create a sense of fear and internalized shame upon entrance to a healthcare facility. For some, the openness of the registration area made them feel uncomfortable disclosing personal information. There were also stories of positive registration experiences, which left a positive impact on the patient, however, these good experiences often occurred when they obscured their Indigenous identity or were passing as white. One participant shared:

I know a lot of people that unless they're dying, they don't bother to come in here or anywhere and I try not to either for that reason. (CM2)

One storyteller, recalled being asked to identify and not minding declaring their identity, but feeling concerned it might impact their care.

Usually, I'm OK with telling people that I'm Indigenous, but I usually wait to see what happens after the question is asked and then that determines how I feel for the rest of my time here. … Like that's been my experience and I'm pretty educated and I present well and as soon as the label is applied like my care has been – it's just – it is what it is so I've had to be OK with that and just accept it for what it is. That's all. Then I don't really expect it to change, unfortunately, but I don't. I can't because like I don't want hope if no hope is going to be given to me. (CM2)

Another storyteller spoke of a time when healthcare staff asked her about her children's background. When she questioned why they were interested in her children, the reasoning provided was because of her high vulnerability to diabetes as an Indigenous person, which was followed by comments about her children's identities that made her feel uncomfortable. Another community member storyteller shared her experience of refusing to respond when asked about

Indigenous identity during a healthcare encounter as she was not provided with a reason as to why she was being asked. Preexisting concerns about identity connected to racism and poorer quality healthcare created a sense of worry for almost all storytellers. Storytellers who had never been asked about their own identity told similar stories from times when family members were asked about Indigenous identity or through information gained through their employment in the health sector.

Despite their own Indigenous identities, Indigenous registration staff shared that they also felt uncomfortable asking patients to declare their Indigenous identity because they did not want to upset patients by asking the question, and therefore stopped asking the questions. Alternately, these registration staff who identified as Indigenous themselves and worked within Indigenous spaces, suggested that patients were more comfortable disclosing their identity to other Indigenous people. Those who work within the healthcare system also acknowledge that staff are under pressure.

I think everybody gets so frustrated. Because the clerks get frustrated too when the patient gets with the mouth going … And there's a wait time. We all want to get them in. But we can't because we don't have beds. We don't have the resources. We don't have the nurses. Do you know that apparently, they're supposed to be 20 to 24 nurses in Emerge in a 12-hour working period? Sometimes we're down to ten or eight. And we close 16 beds. (RS4)

Experience with Indigenous Identifier data collection. Registration staff and healthcare leadership storytellers spoke about the lack of consistency or ability across healthcare settings for staff to document or contextualize patient identity information. For example, the fast pace, and context of patient interactions in the emergency room limits this type of work, whereas in a primary healthcare clinic setting there is more time and opportunity to collect and

understand this type of information. One story teller discussed how they learned years ago that they must first understand the needs of the patient for their healing to be supported and successful. They shared how they now offer space for patients to share about themselves in less formal ways.

So, to me at the time it really revealed that identity was a powerful determinant at the point of contact. (HL2)

I've shifted my practice now to lead a lot with story and generally in telling someone's story and introducing themselves. I try to give patients that space and they will talk about their identity and connections to the land and the communities and their ancestors in that kind of space when we open that up. Because I think that is – it's such an important way for us to engage with each other. And I think to feel confident or safe in a space, to be able to allow people to bring that into the interaction. Which was not taught at medical school or asked in any kind of health care facility. … So, it's a slightly different, I guess – yeah, it's a slightly different way of perceiving identity that I don't know we could ever capture on a form or like a triage process. (HL4)

Storytellers shared that in some clinics, the electronic medical record system has fields for collecting REI data, but these fields are not being populated consistently or systematically even after attempts to support staff to collect the data.

And like I said, we used to and I think we just got away from it because being uncomfortable doing it, right. So I think, like the front desk was like, I'm not asking anymore and then the nurses probably can't, right? Like you get to a point where like, not that you can tell a person, right, depending on the reaction that you've had. So then after a while, you just get you just, it's like anything else, you just stop doing it. (RS1)

The perspectives and experiences shared by those involved in the data collection provides evidence that the process of collecting Indigenous identity data can negatively impact those who are asking the question, highlighting the need for awareness and planning by the healthcare system.

COVID-19 REI data collection. Storytellers shared that when Indigenous identity was collected during specific COVID-19 operations, there was a noticeable impact on patients when this was done in a good way with a message of Indigenous pride. A positive impact was also more likely where there was a majority of Indigenous staff. One site in particular had the opportunity to train non-Indigenous nurses who came to support the site on how to ask the questions in good ways honouring and respecting Indigenous identities. Interestingly, when staff at the COVID-19 Indigenous community testing sites advocated for the collection of Indigenous identity data, they were told by provincial health leadership that they could not collect the data due to the absence of governance agreements. The site resolved to designing an internal system for collecting this data to be used within their organizations only.

During COVID-19, REI data collection was perceived by storytellers to be successful due to the amount of media coverage and heightened awareness of the need for disaggregated data. One storyteller shared that without an intense focus of this magnitude, there might not have been the acceptance from the public or the provincial health leadership for REI data collection. However, the agreement to collect the data for COVID-19 public health measures occurred quickly and likely without fully realizing what it meant and what it would require. It was noted that in this case, with a small number of people making decisions around the data collection and reporting, there was an increased ability to protect the data. One storyteller shared how the issue of power was quite central as the details of REI data collection related to COVID-19 took shape. A COVID-19 working advisory group comprised of members of the BIPOC community of Winnipeg with expertise in a several essential areas including human rights, education, health, anti-racism, and research, took on the role of overseeing the planning, policy, and practice of REI data collection. However, despite best attempts to protect the data and to put power to

control and protect the data into the right hands, there were still attempts from government leadership to gain power at every opportunity. This created a learning experience that provided considerable insight to transfer over to the larger attempt at provincial REI data collection.

Other positive examples shared by storytellers regarding REI data collection during the COVID-19 pandemic included the governance of First Nations data utilizing sharing agreements, supportive leadership, and good working relationships. In particular, one storyteller shared how during the COVID-19 pandemic, there was a common understanding of "being in it together", which is very different from their post-COVID-19 experience of healthcare strain. They noted that this raises questions about the differences that will emerge between the COVID-19 data collection attempts and the larger provincial attempt at REI data collection. None of the storytellers mentioned being personally asked by public health nurses or vaccination site staff about REI identity through the COVID-19 positive case contact process or on the vaccination consent forms in Manitoba.

Our Perspectives

Storyteller perspectives on the collection of REI data included several important understandings of the process and recommendations for successful implementation, which includes hearing their hopes and worries related to REI data. Storytellers spoke of REI data being useful if collected appropriately and used to inform strategies to achieve health equity priorities, holding the system accountable for care provisions, and addressing racism. However, many storytellers admitted that there has been a lack of information shared about the overall purpose. In fact, one registration staff member shared that they did not fully understand the purpose, despite having collected

Indigenous Identity data in her role. This indicates the need for, and importance of, education on the intended purposes of the collection of REI data and in particular Indigenous identifiers.

So I mean it is absolutely critical to collect this data, like I absolutely believe that, so that we can do things going forward. But we do it in a way that's not trauma-inducing is going to be the challenge. (CM8)

I think the collection of race-based identifiers really improves that quality care, so that if they do see a higher – an increase in a certain population or a certain race, then they can adjust as needed to really suit the cultural needs of that nation because right now, healthcare is not a safe space for everybody. And there's really dramatic historical events and ongoing events that still continue. So the more that we can create a safer place for individuals to seek care willingly and providing that equitable care in return, that safe equitable care, I think we will see better outcomes and people won't be afraid to come forward to actually seek health care to address their healthcare needs or their health care needs will no longer be ignored. (HL5)

Beyond data available to inform systems change and to support health research, the identifier questions can also support healthcare providers in gathering information about their patients to inform approaches to providing care. Healthcare providers need to understand the context of the patient's life, understandings, perspectives, and beliefs to address their needs. They must contextualize the experiences of their Indigenous patients in the patient's identity as an Indigenous person. Alternately, there was a recommendation by storytellers to also collect the identifiers of providers in order to hold providers accountable.

your PhD is very interesting to me because we don't, interestingly we don't, ask about the perspective or what can identifying as an Indian or a Métis do to amplify my own sovereignty and why is that important to me?… I do love the concept of sovereignty and identity through the process, I really love that. You give me new ideas. (HL2)

Storytellers shared that if there is to be a successful attempt at collecting of REI data, the harm experienced by Indigenous Peoples in the healthcare system must be acknowledged, believed,

and accepted as the reality of Indigenous Peoples. In order to avoid causing additional harm, practice must be put into place from the moment of implementation to satisfy the expressed needs of Indigenous patients, to alleviate pre-existing fears and hesitation related to accessing healthcare. Identifying as Indigenous in the healthcare system, for many reasons rooted in colonial oppression and racism, comes with a high risk of discrimination and related harm. Therefore, mechanisms must be in place to support Indigenous people's safety and diminish the effects of ongoing harm.

Storytellers reflected on their impressions of how the larger population of Manitoba might feel about REI data collection. Most suggested there might be resistance due to a lack of trust in the healthcare system, and it will take time and adjustments to reach a place of comfort with questions regarding REI. While provincial health leadership might think it is a great initiative now, a lack of preparation and readiness to proceed in respectful and good ways will diminish the possibility of seeing the benefits of collecting REI data. This will require resources of time, money, and many minds. One storyteller also frames this implementation as a process where peoples' perceptions of REI data collection will change over time. As people gain more understanding and experience of the impacts of REI data collection on racism, there could be less hesitation to share their identity.

if we frame this as accountability to address systemic racism in healthcare, I think people will be on board with that. (HL3)

As concerns about privacy and safety with the actual moment of responding to the question about identity is common, storytellers suggested that identity information could be uploaded to all health system computers or added to the Manitoba health card. Then REI data is visible to all

healthcare facilities after the first time it is shared. Some also recommended having Indigenous identifiers attached to status card numbers, Inuit identifiers numbers, and Métis registry/citizenship numbers.

Given the preparation and experiences during the COVID-19 pandemic with REI data collection, storytellers felt that there is now evidence that this can be done successfully. The successes with REI data collection regarding First Nations data in particular, increased awareness and acceptance of the purpose and usefulness of REI data collection. Moreover, some storytellers feel that Manitoba is a leader in the provincial systematic collection of REI data at point of health service.

Hopes and Dreams. Storytellers shared how a primary hope for the collection of REI data, in particular Indigenous identifiers, is a better understanding of the number of Indigenous Peoples accessing services, what those services are, and where they are accessing them. It was noted by healthcare leadership storytellers that having accurate healthcare services numbers is useful when making decisions related to services, resources, access points, and capacities. This data can assist in advancing our understanding of what is working well and what is causing issues and harm. It was also shared that having REI data will be beneficial to understanding the context and numbers of Indigenous patients who experience barriers to accessing required healthcare services. Collecting REI data with these contexts, will improve advocacy; for example, the need to increase the numbers of providers and other staff where the data indicates there are deficits and inequities. Alternately, storytellers shared how the data can also support a rationale for increased diversity in the healthcare workforce, including healthcare leadership. Finally, having this evidence will increase the ability to determine common occurrences and

locations of improper care, critical incidents, or complaints of discrimination and racism. Storytellers' hopes for REI data collection revolved around the need for evidence-informed decision making. Overall, population measurements of First Nations, Inuit, and Métis people in Manitoba, and specifically in Winnipeg, were considered to be important due to the awareness of the inaccuracy of population-based statistics describing Indigenous Peoples.

So we're going to see that if the population is then greater that means that there is going to have to be more money put towards supporting Indigenous Peoples. That is a massive benefit that will happen as a result of this. (HL1)

Because if that's like a main population that's accessing those services, then those services should be almost like tailored I guess, to fit that community and what their needs are and what's important to them. And so hopefully that could create more culturally safe and relevant care in the long run. (CM3)

Data collectors and health leadership storytellers shared how evidence on health outcomes, experiences, access, and utilization is valuable information for First Nations, Inuit, and Métis communities in order to support the funding needs of the people governed under their leadership and is beneficial for planning, funding, education, and advocating. This will lead to evidence-informed decision-making to increase health and healthcare equity and ensure that Indigenous Peoples can access appropriate and safe healthcare in community. As well, for those who have experience applying for funding to support Indigenous healthcare services and initiatives, this data will also contribute to the evidence required for proof of service utilization required on funding applications. Storytellers shared that it can be difficult to show the required evidence without collecting Indigenous identifiers.

But I also think like what is happening in community that we don't know is happening because we aren't collecting this data, right; like when we talk about statistics and where we should be putting our funding to support our communities if we don't know how people are affected by this. One of the things that I research is around Métis-specific data and the lack thereof especially in

healthcare. So I mean it is absolutely critical to collect this data, like I absolutely believe that, so that we can do things going forward. (CM8)

In addition, many member storytellers spoke about the importance of contextualizing people's experiences through knowing their identities as Indigenous people. This was seen as a benefit because there was recognition and understanding that for healthcare providers to be able to provide the best services to their patients, they must understand their patient and the context of their life or the life of their family and/or community.

And I feel like if my doctor had a better understanding of where I've come from and what I've grown up around, then that might be able to help with how he provides care to me and have a better understanding of the messages I received growing up or you know. (CM3)

Beyond the ability for surveillance and comparison reporting purposes, storytellers share how an alternate purpose is for Indigenous sovereignty in a system that has historically prevented Indigenous people from having a voice. Through being asked to identify in a system that honours and respects Indigenous identities, REI data collection becomes a means to support people in fully existing in their identity from start to finish of a healthcare expereince.

But there's another level to it so that that data really at the end has to be about what people's experiences have been like, that's actually really vital. Because the data is only collected to ensure real equity and accountability by the system and contextualization for Indigenous identity. …the other important thing I think is that you want people to exit a system fully intact in their identity, that's really want you want. … But it also is around our sovereignty, so you started exposing what's happening in the health system, then our sovereign states get to actually hold the system accountable, but also direct the kind of care that we may need, that we may need to focus on. (HL2)

Worries and Nightmares. Storytellers also shared their worries and nightmares about the collection of REI data and in particular, with identifying as First Nations, Inuit, or Métis

within healthcare settings. There was concern that, for many reasons, the news of the implementation of the data collection might be difficult for Indigenous Peoples to receive at first. A worry shared by the majority of storytellers was that identifying as Indigenous would lead to negative impacts on healthcare. This included being denied service, compromised or poorer quality care, increased wait times, inaccurate diagnosis, and bad or negative experiences overall.

And there's a lot of fear around that in terms of, OK, well, if I'm going to disclose my race, am I going to be treated differently? Because right now, we know our people are treated differently based on just the way that we look. The colour of our skin and just our overall race, a nation. We know that there's racism within the healthcare system that is often those remains unaccountable to the people that they provide that service to. (HL5)

Specifically, experiences of prejudice, stereotyping, discrimination, and racism came up as worries that Indigenous people might experience as a result of identifying as Indigenous. Storytellers shared their worry that patients may feel fearful, scared, triggered, uncomfortable, worried, reluctant, nervous, and unsafe if they felt forced to declare their Indigenous identities. Recognizing that racism, stereotyping, and discrimination already happen frequently during healthcare encounters for Indigenous Peoples, examples being negative assumptions being made about a person or the display of body language indicating negative judgement, having the wrong people asking the REI question creates potential for increased prejudice, stereotyping, discrimination, and racism.

So we know that many of our community members feel, for example, the Health Sciences Centre emergency department or the entire Health Sciences Centre can be triggering and can be unsafe. And so to walk in and then be asked a question about your race, culture, and then to have to say that out loud when you know that space is not welcoming to Indigenous people, would that either create an unsafe environment for somebody or potentially lead to staff acting in a different way because of being aware of someone's identity. (HL4)

Because of this reality, there is a worry that Indigenous people will choose not to identify in order to protect themselves from racism and discrimination, resulting in incomplete data collection and skewed results.

especially for Métis folks who hide in plain sight often if they can and there's a history of that; for very good reason a history of that. So I wonder. I wonder about that. I wonder if even in that moment if everyone would be entirely honest, right, if sitting, if walking into the clinic and it's full of people and they ask that question and you go, "Oh no, no" and then you just go sit down, right. And so then have we actually collected the data of white-presenting First Nations, Inuit, and Métis people? (CM8)

Knowing that answering Indigenous identity questions will be a new experience for most people, storytellers expressed worry that people will be weary of why the question is being asked, which can lead to heightened stress and anxiety for patients during the registration process. It also might be too much information to take in and understand in moments of emergency or stress, leading to confusion around the purpose for data collection even with explanations by staff. Adding to the worry is the existing lack of trust in the healthcare system. It was explained that this lack of trust comes from the understanding that declaring identity is like giving away something of yourself, making people feel vulnerable in a system that has a history of being harmful. Added to that is the perception that Indigenous Peoples are still harmed within the healthcare system despite the giving away of self. In addition, a lack of meaningful action from the collection of REI data will increase feelings of distrust of the healthcare system and the government of Manitoba. Storytellers were worried that despite REI data collection, racism will continue to exist without holding the perpetrators accountable.

And you know what, like this conversation – like just listening and being a part of this conversation like shows me how scared us Indigenous people are about that. Like about being able to ask those questions, you know. I don't know, because everyone is so scared, they don't

trust anyone… They don't trust like the information that they've shared is going to do anything because everything that they've ever shared was always taken away from them or they were silenced. (RS5)

There is considerable concern over using identity data to exploit and harm Indigenous Peoples by either manipulating data to support or reinforce a deficit narrative, or using data to expose people or communities in vulnerable situations. Worries that data would be leaked or misused were expressed by more than one storyteller. There is also a worry about not knowing who will have access to data and the ability to use it.

It's going to take a lot more leap of faith and trusting that they won't access it inappropriately and use it inappropriately. I'd be very worried that people will use it in teams that don't have the right expert analysis around it and construct really harmful narrative. And sometimes those are just frankly racist narratives and sometimes they're just wrong. (HL3)

I think in the past my worry about identifiers in health was that they might be used kind of against us as a way to dismiss a validity of what we're trying to do in general but also to raise their own validity in a very ethnocentric violent way. (HL2)

Due to the impacts of colonialism on families, communities, and nations, there is always a concern for harm when people are not aware of their identities as Indigenous people. Storytellers acknowledged that people might be confronted with feelings of shame as a result of not knowing their ancestry and family history. This must be taken into consideration when planning for the collection of REI data.

I think there's going to be some really complicated conversations. And then like you're there because you're ill and I don't think you need to be ashamed for your identity or lack thereof of a card, right. So I think that there's those pieces that aren't going to be very good for Métis folks in that collection, right. Like they're going to feel bad that they don't, you know – that they haven't yet registered or that they themselves believe to be and they can't quite make that connection. And I think that will be – it will be churning up all sorts of things… (CM8)

Storytellers who collect data shared their worry about offending someone by asking about their identity, and possible confrontations that may arise from asking the REI data questions. Both staff and patients worry that there may be the potential for creating unsafe spaces for patients due to REI data collection processes.

Yeah, I don't want to offend someone and I just, yeah. …So get nervous that people think like, oh, like, oh, why does that matter? And more like that. But try to explain it, we're not collecting it for any reason like that, just to try to collect it but yeah, I feel people kind of get nervous too. And then I just don't want anyone to, I'm not into confrontation … (RS3)

There are also worries that despite training efforts, staff will not follow the training, leading to additional harm during data collection rather than creating safe data collection experiences and resulting meaningful change.

And I'm concerned that if people don't follow the training, don't follow the script that it could re-mistrust, because then we won't even get to that point where we are able to use the data in a way that is effective and beneficial and further mistrust people or people might feel stereotyped because they don't see an end product that it seems to be worst to me. (HL3)

Or would somebody just not access care at all because they don't want to answer that question because they would feel unsafe or – and then – yeah, I mean there's always – even if we tell people ways that you could safely ask questions and give them a script there will be people who will not follow that, right? And so I guess the weaponization of identity and how could that play out in a scenario where you're coming in, in a very vulnerable state, possibly in a lot of pain. (HL4)

Storytellers shared their worries about how data could be used to inappropriately apply for funding or other resource if power is in the wrong hands. This is connected to the fear of identity fraud and non-Indigenous people benefiting from resources to support Indigenous people. There was a reminder of the "white savior" type of people who proclaim to be doing work to benefit Indigenous Peoples, only to benefit themselves. Worries extended to concerns about the

readiness of leadership to acknowledge and address the truths that will come out due to disaggregated health and healthcare data and commit to the requirements necessary to take quick action for meaningful change. Actions described by storytellers include the development of safe and supportive pathways for patients who have negative experiences with the REI data collection process, and a pathway to support patients who feel that their care has been compromised due to identifying as Indigenous. There is concern over challenges in expanding the systems change outside of the healthcare system directly. One example shared by a storyteller, is a concern that the schools of medicine will continue to graduate racist practitioners despite evidence of racist treatment of Indigenous patients. There is a shared perspective that there will be complicated conversations that will come with the collection of REI data.

Self-identification. Finally, storytellers spoke about the differences in collecting identity data based on identification cards or geographical location vs the act of self-identification at point of service. There was agreement that in using methods based on government-determined identifications, Indigenous Peoples are not being accurately counted and acknowledged. Alternately, self-identification also gives the option for choosing not to disclose identity. Some storytellers questioned the ability to have Indigenous identity connected to the provincial health card.

I don't understand why it can't be connected to your actual Manitoba health card and that you don't have to say a single thing to anyone. Like why – like if this is a thing, if you have a card, if you're a registered treaty Indian, right, like if you have a status card you have a status number and why isn't it just automatically linked in the back-end. You could do that piece self-identify through their website or something. The same with Métis cards, the same with Inuit identification cards so that it isn't something in that space. (CM8)

In regards to the positive benefits of self-identification in particular, storytellers shared how the act of self-identifying has the potential to help people to feel seen in that healthcare moment. If self-identification is respected, it can foster increased comfort in identifying.

They could potentially feel more in that moment, there was a commitment on the health care system to see who I am and treat me well. It could be an important signal setting in that way and that could be a positive impact for all. (HL3)

… I think importantly this whole provincial change has to enhance, augment and amplify sovereignty for every Indigenous person coming into the healthcare system. (HL2)

There is a sense of empowerment in proudly self-identifying, feeling safe, and belonging in the healthcare encounter space. Storytellers reflected on the connection between honouring Indigenous identities, safe spaces, community connections, and better healthcare experiences and outcomes.

While self-identification on a systematic level within healthcare is something new and different for the province of Manitoba, one storyteller recalls this being done during the COVID-19 pandemic as a first attempt at self-identification.

We were one of the first regions to actually provide that opportunity for individuals to self-identify in that way, which I think is really a unique way of … collecting that information. (HL5)

Alternately, some storytellers discussed the concern that people will take advantage of the option for self-identification to obtaining resources.

…so because of that whole conversation about identifying just for the sake of identifying because of the perks that they think that they can get with funding or sponsorship or whatever. How will that be – like I know like this isn't the right term but I'm just going to use it because I don't know what other term, like policing whether or not – if you're saying you're Indigenous but you're

really not, how are we going to know that if you're self-identifying. … And so if they know that if they self-identify as one of these and that means they're going to have access to these programs, now that's going to be taking away from the very people that it's meant for, right. So how do you make sure that doesn't happen? That part is scary too. (CM10)

Our Vision

Storytellers expressed their vision of a successful and safe collection of REI data. From listening to these stories, we heard ideas for best data collection practices, communication strategies, training, and reporting.

Best Practice for Data Collection

Location - Best Practice. Storytellers offered several options for best locations to collect REI data. A common suggestion was to have data collected in an area that affords privacy and safety vs. asking the question in an open area where other people can hear responses. Ideas offered for more private locations included the triage area or a private room in hospitals or clinics. One storyteller suggested data be collected upon exit after the healthcare encounter was completed.

You wouldn't want to be asking somebody questions in the waiting room with everybody around us. That's real personal type of information. (CM1)

While others felt that the point of registration/registration desk would be the best option as it would fit in with the regular flow of demographic data entry for registration staff.

People - Best Practice. Registration staff/administration staff/reception staff/clerks were the most commonly named people to collect REI data. Most felt that data should be collected at

the first point of entry into the healthcare system and by the person who a patient first interacts with. However, there was concern with this collective of clerks due to racism commonly experienced by Indigenous patients at healthcare reception/registration desks.

I'm not too sure but the biggest barrier for people to see physicians are front staff, they could be very disrespectful, dismissive. And so that's a really common thing for a lot of people, so I'm not too sure, they'd have to be fairly well-trained people. (HL2)

A solution to this concern was to have Indigenous Peoples as the data collectors to manage the racial bias within the healthcare system. This could be Elders, community hosts, resource staff, greeters, helpers, or supports.

it has to be Indigenous collecting from Indigenous (HL1)

but I think it would be very powerful for them to have an Indigenous staff member there who could greet and welcome people and ensure that they have what they need from a humanity perspective. Which could also – which would definitely link to identity, because as soon as somebody walked in the door there would need to be this conversation about well, where do you come from? And how long have you been travelling? And what do you need? And who can I connect you with? Because there are so many networks of support from many communities in Manitoba and Nunavut that exist in Winnipeg. And you know, how do we link you to those supports? Whether they're official supports like KIA or you know, like MKO, or whether they're unofficial kind of networks through Facebook of community members who can show up and be supportive. (HL4)

A third group mentioned were the healthcare providers, including nurses and doctors, as some suggested this group should be making space to have discussions about identity with their patients.

It just seems like it fits more in the flow of the conversation and it might be more well-received by patients, if it's being asked by their provider because they might already have a – if it's a family doctor or someone they've seen multiple times, more of a repetitive relationship with them – they might feel more comfortable. (CM3)

However, some storytellers felt that due to a perception of racism and discrimination from healthcare providers, nurses and doctors could not yet be the ones to collect the REI data.

Method - Best Practice. Face-to-face interactions were suggested as a possible option for best practice because of the human interaction aspect, but this might challenge the need for privacy.

But in thinking of the Indigenous population in Manitoba, I think maybe face-to-face would be the best option just because that's more in keeping with our ways of communicating. And I think it allows people to have a chance to ask questions and share their concerns. It's probably, in my opinion, what people would be the most responsive to – and I'm thinking about Elders and older people – it might just be more inviting. (CM3)

Over the telephone is another option discussed, but also seen as less personal than face-to-face. Digital technology tablet was another option, which would be discreet and could be programmed with multiple languages and updated easily. As well it could prevent harmful interactions with racially biased staff. Concerns with the tablet included: the possibility of the tablet being taken/stolen, keeping the tablet charged, and patients needing help/support to use the tablet. This led to a discussion of having a person available to support the use of multiple tablets, especially in high stress/high traffic area such as the emergency department.

I think if an iPad – just like in Emergency at HSC – I couldn't imagine half of those people being able to concentrate or being in a good – well enough condition to be able to use an iPad. So I think the triage part is the best part. … But in a dream world if it had to be done then that's a way that it could be a done in a safe space and a safe way that you didn't have to share with everyone. (CM8)

While paper forms were suggested as this method could provide more privacy than conversations out in the open, there were concerns about issues with patients' reading or writing abilities and the risk of patients not fitting into the categories due insufficient options.

Storytellers agreed that multiple options should be available to meet the different needs of patients. Having only one option to collect REI data would likely only work for some, and those that experience difficultly with the process, as a result of varying abilities, would likely choose to not identify.

I mean I worked a little bit with MMF during the pandemic, and so we talked a lot about this because you know, initially people wanted to do like pamphlets or flyers. Which I think is relevant to some of our elders because I think they like paper, pieces of paper. And then, you know, there was lots of conversation about Facebook to reach the younger generation. I think there are still a significant amount of people who watch TV and the news, and so I think catching some community that way. (HL4)

Finally, there were some other suggestions related to method of data collection. First, when posing the question, to include an option of *I believe I am*, which would support those who are not certain of their Indigenous identity but through various reasons believe that they may belong to an Indigenous nation. Second, was a suggestion for a process to evaluate Indigenous people's experiences of declaring Indigenous identity. Third, was the idea to offer an honourarium for patients who are asked to share their identity. Fourth, story tellers encouraged that with any method used for collection, that the information was offered in multiple languages to meet the needs of all patients.

Communication

In order for this process to be successful, there needs to be clear and consistent communication from senior healthcare leadership stating their commitment to addressing racism. Because of the abundance of health-related information that is currently in circulation, the communications need to be attention-grabbing and understandable with visuals and enhanced graphics. To facilitate understandability, communications should include multiple languages, including Indigenous languages. Additionally, information about how this data will be used to address the impact of racism on health and healthcare must be clearly communicated, along with how this data will be governed and protected to support dismantling systemic racism. However, there was concern about including mention of the data being used within research. Developing a communications strategy will require much time and effort; having a communication lead or working with a communications department involved in health systems will be important.

Well, to give people a heads-up again where they're not blindsided, and why are you all of a sudden asking this, I've been coming here for as a patient for how long and you've never asked me that or I got asked that however long ago right? (RS1)

Not for research - I remember when the vaccine came out – a lot of Indigenous people felt like they were the guinea pig. That's what my clients at the Ab centre would say. They'd use that terminology that they were being tested on or seen as a research subject. And so I think – I don't know what language you can use in place of it – but just something that doesn't sound so clinical, to get a better understanding of – I don't know, maybe not to say, "For research." ...I think that could be triggering for some people. (CM3)

Multiple strategies are imperative for effective communication to reach diverse audiences. Some suggestions include paper-based advertisements such as posters, pamphlets, flyers, mailbox stuffers; bulletins and billboards; digital advertising including television and radio commercials/programming/news broadcasts (national, local, and community-based); music

productions; social media such as Facebook, YouTube, Instagram, and other digital media platforms; in person presentations; press releases; health clinic telephone recordings, digital screens in waiting rooms; signs at the front desks of health providers; and through Indigenous organizations and networks such as MMF communications and an Auntie's stream network.

Any type of posters or commercials and that, need to be done in a really good way…. So, many times we'll see posters that depict Indigenous people in the wrong light and so many times communications are turned around and the wrong words come out and people get offended. It took 500 years to get where we are today, it's going to take another 500 before we all sit together at the same table and we can converse like human beings. Yes, it's good that we have the beginnings of it with truth and reconciliation and we're doing things like this to better the healthcare system, we're doing things with the social service system to better the lives of the children. (CM7)

Communications must come from leadership, including chief and councils, mayors, and senior healthcare leadership. Representative Indigenous organizations and urban Indigenous organizations should be making public statements about the collection of Indigenous identifiers data. Communications should also be coming directly from community leaders and members so that people feel connected to the message and see that communities are involved. Examples include recognizable and trusted faces from the community, health directors, and Indigenous youth.

I think that like for Métis compliance if the nation shares out their communications department that this is happening and how supportive David Chartrand is of that that you're going to get a higher uptake on people who would normally not say anything to say something in those spaces if they understand what is the value of declaring this, right. And to kind of dissuade them from thinking all the terrible things that will come from it, but what are the actual benefits for the nation and their people I think that will be really helpful. (CM8)

I think there's various models of communication that need to be accessed and communication strategy is critical to ensure the success of this. I think having those champions, having those health care leads actually endorse having our leadership, our First Nations leadership endorsed, the strategy as well, and actually becoming the faces of this data collection piece. Because this

data collection piece will not only impact First Nations, Métis and Inuit people and other races, it will actually improve health care right across the board in terms of ensuring accountability of systems. (HL5)

I think again, like community taking a leadership role in that, because I feel like if shared health and HSC comes out and says, like, hey, we're going to start collecting all this data, again I think a lot of people were going to ask why and what's the purpose of it? Whereas if you know, some of our Indigenous leadership organizations come out and explain the benefits and how it could help to reshape the health care system, knowing how Métis people use the health care system and how is that going to impact, maybe, clinics or flow through the emergency department, or if there's tools and different ways that leadership organizations can work with the information that they might gather from this. I think that could be a whole different conversation, and a lot more impactful than it coming from the government side. (HL4)

Alternately, some suggested the importance of having communication coming from places that people are naturally tuning into, including community gatherings, meetings, feasts, and other such locations. In regards to communicating from the healthcare system to the patient, storytellers noted that even with all of the communication material options, the ability to communicate effectively still depends on the trusting relationships between clients and providers. One of the challenges will be to get people on-board with the importance of this data collection so that they can be part of the communication plan.

Because I think about how powerful the dissemination of this can be for community but sometimes with the political fields that exist, there's going to have to be some extra work and savviness with regards to how you're going to sell this to community leadership because not all of us are at the same level of thinking… (HL1)

It was noted that consideration of how to share the message with those who experience marginalization from mainstream society is necessary and may require targeted approaches. This could include outward communication but could also be a means for gathering their perspectives and including that input into the larger process of REI data collection.

You really need to speak with people who our tribal councils don't speak with, they're on Main Street because they really need to have that voice. The other voice really importantly is First Nation's women's voice without influence by heteropatriarchy, OK, to really understand some of those juxtapositions. That's what I would do and that's where I think I'd get my probably best data to take to leadership… (HL2)

Training

Training discussions tended to focus on those collecting the data, including manual data entry training for staff, and video-based training for staff, management, and leadership. It was noted that both data collectors and management/leadership need to know the script, the rationale for the collection, and the frequently asked questions and answers. Although not asked specifically about data collection training, community member storytellers mentioned how those collecting the data need to be trained to treat people with respect.

Healthcare leadership and registration staff storytellers suggested that in addition to training on how to collect REI data, there should be a requirement for education on cultural competency, cultural safety, trauma-informed care, Indigenous healthcare history, structures of colonialism, Indigenous identity, and self-determination. There was a recommendation for a greater understanding of the context of Indigenous Peoples lives, especially experiences in healthcare. Interestingly, for some, the focus was not on the process of demographic data collection in the electronic patient record system, but instead on what needs to accompany the data entry training that will be mandatory for data collection staff.

I think one piece would be understanding this historical piece of the lack of collection and the implications of not collecting race based data, especially around First Nations, Métis, Inuit given the our experience with Indian residential school, given the experience of the recently found grave sites and the treatment around the TB sanatorium era, including the establishment of Indian hospitals, and how individuals were sent all over the place without any return to their

home territory because they didn't know where individuals were coming from. … So it's a lot of dispelling a lot of those stereotypes and acts of discrimination based on those understandings or lack of understanding of who we are. (HL5)

I mean if the health care staff themselves don't know who Métis, Inuit and First Nations people are I feel like we've lost the battle in terms of how we're going to have people collect safe data. Or collect the data safely. (HL4)

I think you could just ask if people can understand maybe why Indigenous people are hesitant in health care because there were obviously pieces in there about what kind of, not so nice things that happened to them when they got involved with health care. So maybe some background you know might, to help explain the hesitancy on people and their fear of kind of answering and they're ashamed maybe to even answer because it wasn't good to be Aboriginal. So maybe just that shame that maybe they just don't deal with it anymore. Like nope, I'm not Indigenous, like. (RS3)

One storyteller spoke about requesting access to the Manitoba cultural safety training for their staff to increase staff knowledge, but unfortunately the request had yet to be honoured. A concern that came up for a number of storytellers, was how to address time away from work and backfilling positions for the purpose of training. One storyteller shared how this concern is validated by the challenges experienced with communicating with healthcare leadership. The value of cultural safety training is not always understood and this can lead to challenges as one storyteller shared how at one mostly Indigenous-staffed clinic, they thought that they might not need cultural safety training. However, they realized that there was information in the cultural safety training that they did not know, and so felt it was a good idea to take it.

But I think that is good foundational training that can support more culturally safe anti-racist interactions and if people who've maybe never really thought about it, some insight into why people might be present in different way like mistrust, for example. That comes from somewhere very, very rational. (HL3)

A cultural safety training is nice for everyone though. It gives you a chance to learn about a lot of because we did it here too. And there was a lot of things even as Indigenous that I didn't know. So it was nice to always learn more and understand their side of it, maybe why they're hesitant to answer, hesitant to identify... (HL3)

It was also believed that there should be room in the training for staff members to examine their own beliefs, reasoning, and expectations around the collection of REI data. A registration staff storyteller shared how training can open up people's comfort in asking about things they do not know. They noted that once a person learns that it is ok to ask something, they ask more questions and want to know more. In their opinion, a benefit of this training might be that people will feel more comfortable asking and learning more about Indigenous Peoples, culture, history, and lifestyle. Mock training or role-playing was suggested as a powerful and effective training method. This also could include digital training platforms that includes role-playing where you could also benefit from being able to go back to revisit the training as needed. Storytellers noted that if the goal is to collect identity data from Indigenous Peoples, Indigenous Peoples need to be involved in the training processes. This will be critical in breaking through the stereotypical responses and common reactions of discomfort that have arisen alongside attempts at REI data collection.

I think there's really a role for sort of in real time coaching or mentorship by Indigenous people around this type of work. And this is where I could see either like community representatives or Indigenous health, but somebody in different roles who could do that kind of one-on-one coaching or mentorship. (HL4)

so you've got to get the system to de-coach, stop the eye fluttering when Amanda comes in for belly pain assuming that she's looking for narcotics stop it. Because those kinds of very subtle and not so subtle things tell the young people exactly how to treat the next Indian woman…. it still is an intersection of violence that our First Nations person can experience because these people have been coached to do the same thing over and over. They should keep that concept in mind when you're trying to develop a system, what kind of coaching occurs? How do you de-coach that system to allow people to be very comfortable? (HL2)

It was felt that much of this discomfort resulted from people's whiteness and their internal struggles over the history of settler colonial relations that oppressed and harmed Indigenous

Peoples. There were discussions about how this discomfort may also translate into the excuse that there is not enough time for training or for the REI questions to be asked to each patient. However, this was seen as another excuse that is likely related to something other than time and will need to be considered second in importance to data collection. With skepticism about the perceived barrier of time, one storyteller noted,

Nobody likes change, and we all think we're too busy already. (HL4)

There was also a suggestion for evaluating the training to determine what is working and where more efforts might be needed.

You actually have to go back and measure those outcomes of those trainings and to ensure that individuals who undertake that training continue to provide that safe, equitable care to all people. (HL5)

Additional required processes for the successful collection of REI data included close monitoring and follow-up evaluations to ensure that the data collection processes are following protocols and that patients are not experiencing harm due to being asked to identify. Evaluations should be carried out by a dedicated team rather than done off the side of a desk. Also important is a process to respond to patients who experience harm through the REI data collection process, who then may require follow up supports.

If you identify with me whether you're First Nations, Métis, Inuit, status, non-status, then we need to talk about safety. And if you are met with not feeling safe what's your pathway so that you feel heard, protected, those types of things. Because there's going to have to be, I imagine, a closing the loop of some sort to they identify they're Métis, they walk in, and their experience is all some fricking horrible. Right? Then what happens? ...Because they're going to think you did that because you tracked it. Right? Like what pathway exists for them if they have a bad experience. That's going to be important. (HL1)

Reporting

Most storytellers focused on having reports be meaningful and usable by Indigenous Peoples, communities, and nations, which supports Indigenous Peoples in making decisions on how the data is used. Indigenous Peoples should be involved in deciding how they would like to obtain the data and what methods of sharing would be best for them.

And so I feel like taking that data and bringing it back to the community and saying, "OK. We're seeing a high number of the Indigenous community here. What would make you feel more comfortable here? What kind of things do you need in this space?" … rather than just another statistic for non-Indigenous people to see where Indigenous people are suffering? (CM1)

And I think that by providing it to the nations so that they could then advocate for their people at the provincial and federal level, you know, better for pointed – for things are very pointed. So when we say, "Oh our people are suffering from, you know, substance abuse" and they go, "Yeah" we're like, "No, no, no like they're actually suffering and they're suffering in this area the most." (CM8)

if we have this information and we're able to share it with our community then it makes impact. If you're just going to collect it and wait for researchers to have access to it so they can write blasphemous things against the healthcare system that's not important to me. (CM8)

Well, the reporting, I think you need an instructive reporting. … You need reporting that is instructive to systems that support First Nations, … tribal councils, chief and councils, the systems within communities. You need to actually have as formative learning and a reporting that's summative. (HL2)

It was also important to storytellers that the data be shared in real-time such as annual reporting vs. waiting years in-between reports on Indigenous people's health and healthcare. Real-time reporting will lead to real-time interventions.

I would like to see – from this data, I personally would think that an annual report of data collected would be good and to have it broken down for – in whatever questions are asked. I'm not sure. Or even if you're able to access where Indigenous people are getting their healthcare – what services they are needing – that kind of thing. (CM4)

So that our arm – we have a health department, you know what I mean, could then do those things that I was talking about, about education and speaking to our community about things that are affecting them and, you know, the best ways that they could support, you know, support our elders and support our youth who are suffering… (CM8)

Reporting on healthcare utilization was seen as important and valuable.

I absolutely want to know how many Indigenous people are tapping into the healthcare system on a given date, week, month, year…. Seeing evidence of the number of Indigenous people accessing systems and services in certain areas can also be empowering, because it is evidence that we are out there and there are a lot of us. (HL1)

More detailed data, say, if it's being reported to MMF, just about patterns of use of particular community members or rural community members so that in their own program planning and requests for funding that they can really focus on areas where there's maybe some obviously identified gaps in services. And that they can take that data, which would hopefully be owned by them, and be able to use that data to be more powerful in advocating for their community and their nation. …And then again use that information to try to strengthen the system or add the supports that are needed. (HL4)

…see how many Indigenous people are actually able to access health care. Like, see how many actually have a family doctor if there's a need for more of that. If there is a need for more services in certain areas. (RS3)

Reports must also be presented to decision-makers, politicians, government and medical administrators, and the broader Manitoba community. Options for the public included various forms of media including television and radio news programming, newspaper, brochures, videos, posters, pictures, and social media.

It will be helpful if the data that is generated can be used to focus on immediate data priority areas. So if we get the government to make announcement where we can also connect this data, that would have people's attention and we can show direct connections and interventions. (HL3)

Along with these suggestions for sharing reports with healthcare leadership groups and wider audiences is the reality that this will take time to be taken seriously. One suggestion was to partner with academic researchers to generate reports.

I think for all of – like for health care leaders as well as researchers who are going to do work further on this idea, like I think that type of reporting could be really helpful in academic settings. (HL4)

And I think you know the more we use it, the more kind of routine that's going to get. It is a distinct skill set to be able to use and respond to this kind of data with a lot of practice with and a new way of working and sharing power and decision making for the healthcare system as it relates to this data. We'll have to practice that a lot. (HL3)

Required information and processes

Storytellers shared how processes related to the governance and sovereignty of the data are important considerations. There is worry that if the healthcare system owns the data, then there is the potential for problems with sharing the data.

…that power balance is going to be the important part of, like, are you extracting data and then using it for your own purposes within a health care system but not sharing. Or is that data still owned by an advisory group who then can help to link into the health care system. (HL4)

An alternate reason shared for how this data will be important is in developing processes and tools for reporting and sharing experiences of harm within healthcare. One storyteller told of her family member's life-altering harmful healthcare experience and her awareness that Indigenous Peoples are frequently harmed in healthcare. For them, evidence will allow for increased ability to communicate to Indigenous Peoples potential harm within the healthcare system. For her, sharing the data that will be gained from the collection of REI identifiers is a matter of Indigenous survival.

We want everybody to know that this is happening to our people and that people are being hurt, hurt by the health system. (CM5)

All storytellers discussed the need for clarity of purpose and process and the need for consistent processes at all healthcare sites. It is also imperative that the public know that this data is being collected for all race and ethnicity groups and not just Indigenous Peoples, and there should be a clear message that while staff are mandated to ask the REI questions, providing answers is optional. Staff must be trained to respond to patient questions in transparent and respectful ways.

I think a thorough explanation to the native people and a very compassionate explanation are very helpful to maybe put people at ease, because if they're being told we're collecting this data, then it sounds like colonization, you know, it's like, you have no choice. We're collecting this data. … Whereas we would like to collect this data. And this is what it would be used for. Not in the negative way, but in a positive way to try and help the native population. (CM1)

Oh, definitely the reason why, like a statement around the organization's commitment to racial justice, or racial equity and providing high quality care. I think people need to know that asking the question and answering will not change their healthcare experience. And yeah, a brief statement around how it will be used. I think those are pretty key. (HL3)

Storytellers highlighted the need for translators and interpreters to be made aware of the process for collecting REI data to become familiar with the information that will be shared with patients.

Role of Leadership

Healthcare leadership must be supportive and give space for Indigenous Peoples to direct strategies for REI data collection in ways that will be the most beneficial.

…so think the best thing that our non-Indigenous partners can do when it comes to supporting Indigenous endeavors, is simply step out of the way, in a good way but step out of the way. And I think there's just huge benefit for that because we still are boxed into this idea, and no fault of their own, it's their training, makeup and everything about them, but it's this idea that if this is a

partnership, trust me, trust us, trust that we know what we're talking about. Give me a shot, let me show you that there's some benefit and value here to what I'm talking about because this messaging comes from community, we know what our community needs. And so really again it's releasing some of that control, that's the epitome of what the partnership can look like, we're not there yet, not by a long shot. (HL1)

if leaders – all health care system leaders, allowed the Indigenous voice to be the one driving the decision making around how data is used and how it's collected I think that's probably the key piece where we often fall off, right? In terms of making decisions for and often health care leaders kind of drive ahead and make all the decisions and move forward and then community says later, like, this isn't going to work for us. (HL4)

Additionally, leadership must be transparent about their thoughts and plans, willing to have meaningful and supportive conversations about issues that impact Indigenous Peoples, and fully invested and accountable for long-term efforts.

So, I think that just like having that mutual respect for each other and knowing that all these parties are on the same page in terms of these conversations that are happening, that would only just benefit everyone. (RS5)

I think it's going to take some hard-core concerted effort. It's going to take strong leadership. It's certainly one thing to introduce something, it takes another thing to keep it going. … it's going to take money, effort, leadership. (HL1)

Leadership must also know how to understand and make decisions based on the data; if they do not, they must support those with that expertise. It will also be crucial to have leaders who take a stand against racism and make an effort to make a change. They need to be fully invested.

that's why health leaders are extremely important for this because you know what, I think what I learned in that little experience is that there aren't these hatred provoking white people, they are products of a system that's structurally racist and so they're responding to that. But when you can kind of cut that off, shave it a little bit, allows them to think a bit critically. (HL2)

I think they should be expected to have a really clear understanding of what it is we're collecting the data… I think they need to be messaging that and that expectation, and that the data is tied to a commitment to providing equitable, high quality health care to all of the people that we serve. … And that's done across the different levels of the team and that they're checking in with

the managers of the people who are actually collecting the data to see how it's going and holding the accountability there. … I think we need to have discussions around those governance roles and that they need to demonstrate a willingness to engage differently and with more diverse people to look at their healthcare teams and look at what the gaps there are in expertise and representation for that the potential benefits of the data could be realized. … I think too many people kind of see this as a standalone thing that some people are going to be responsible for managing and looking at the data and all of that, as opposed to really seeing it as a signal and an intervention that is going to impact the entire healthcare system. So really deepen their understanding and get onboard with that. (HL3)

and then task health care leaders to really make sure that it happens if we move forward so that we don't sort of have a partial dataset, because that's probably worse than not collecting the data at all, because then we're going to make decisions that will impact the care of our Indigenous people in Manitoba based on erroneous data. (HL4)

As the power rests in the hands of the healthcare leaders, who are often trusted by their patients and communities, it is this group who has the opportunity to set this off in a good way.

I think just like pushing for indicators at every level at every table that they sit at in terms of that support and even becoming champions around the collection of this data, whether or not that turns into a communication strategy or marketing strategy…. Because people look to health care leaders, health care healthcare providers as leaders. They trust them. … They trust them with their own care of themselves and their children and their families. Otherwise, they wouldn't take them to seek health care if they didn't trust them. And they do trust their diagnosis. That's also really educating the healthcare team and leaders that this isn't something to be afraid of. And it's just a reminder of the oath that they signed to do no harm and to really deliver the best possible care as needed. (HL5)

Discussion

Opening of spaces for Indigenous voices to inform our understanding of REI data and collection within the lives of First Nations, Inuit, and Métis people in Manitoba addresses current evidence gaps where Indigenous voices and ways have been silenced. By intentionally turning towards Indigenous people and listening, we hear about the complex reality of asking questions regarding Indigenous identity. As well, we hear about what it is like to access healthcare in general, and

insights into the added layers of being asked questions about identity. Indigenous registration staff and healthcare leadership spoke about their experiences of asking for and collecting data on Indigenous identities, which brought up complex perspectives of both connection and relationship and internalized racism when Indigenous staff were asking Indigenous patients to self-identify. The importance and impacts of kin-based relationships between Indigenous healthcare practitioners/staff and patients has been examined in previous research (Churchill et al., 2020) and is a reminder that the identities of the staff asking the questions must also be considered.

While findings echo what previous studies reported, this Indigenous-led study that only involved self-identified First Nations, Inuit, and Métis people, created space for Indigenous voices and knowledge to reside within the center (rather than margins) of these narratives. The result is gaining a richer and deeper understanding of how this apparent simple act of asking about one's identity collides with centuries of colonial relationships, which in turn has shaped the storytellers' lives and how they manage current day colonial spaces, like healthcare settings.

Previous studies concerning REI data collection, reported on the need for public education, communication, and the need for transparency with use of REI data (CIHI, 2022; Gibbens & Bowen, 2009; Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Varcoe et al., 2009). In this study, the Indigenous storytellers also spoke at length about the need to for transparent communication strategies to educate and inform the public about REI data collection. However, what was unique about the perspectives of Indigenous Peoples was the message that all communication - before, during, and after data collection - must be done in partnership with Indigenous Peoples. The importance of this connection between communication and ways that

honour Indigenous identities was missing from the literature. This involvement must extend broadly to include leadership and nations-based Indigenous governance organizations so that information is shared in the most appropriate and meaningful ways for each nation. As well, considerable attention was given to the governance of Indigenous identifier data which is in alignment with recent work focusing on the importance of Indigenous data governance and data sovereignty (Bruhn, 2014; CIHI, 2020; Research Data Alliance International Indigenous Data Sovereignty Interest Group., 2019; Walter & Suina, 2018). While the concern over REI data privacy, storage, usage and access might be a reflection of the Canadian public concern over the disclosure of public health information (Kirst et al., 2013), through Indigenous perspectives, this concern extended to involve a history of harm based on misuse of data and research, and the potential for the proliferation of new harm if the data falls under the power and control of people not committed to Indigenous data governance and sovereignty. Indeed, if governance is not handled appropriately, Indigenous Peoples may refuse to answer the question, leading to another reason to avoid entering into the healthcare system.

The failure of the previous attempt at the systematic collection of REI data in the Manitoba healthcare system was primarily a result of a lack of appropriate education and staff training in how to collect data in a safe way (Gibbens & Bowen, 2009). In this study, the perspectives of the Indigenous storytellers not only spoke to the importance of staff training to collect data with respect that honours Indigenous pride, but also to educate staff on the history and impacts of colonialism and the structures of oppression that continue to harm First Nations, Inuit, and Métis people. Varco et al. (2009) does mention the need for “extensive training of data collectors” (Varco et al., 2009, p.1665) but does not take it any further. In this sense, the training should have direct focus on cultural safety, all levels of racism and its impacts, and the importance of

the contextualization of Indigenous people's circumstances and experiences in the realities of their lives. To proceed with REI data collection without the above-mentioned education and staff training would have the potential for replications of past harm and failures. The internalized racism that impacts the abilities for Indigenous staff to collect the data cannot be healed with the use of a script.

Varcoe et al. (2009) wrote how the perception of benefits and harm depends on individual and collective identities and experiences. While they highlighted that people are concerned over how REI collection might harm Indigenous Peoples, there was limited discussion of the context and nature of those harm (Varcoe et al., 2009). In this study, where Indigenous identities were centered, we can listen to their thoughts regarding harm and benefits and understand the Indigenous experience on a much deeper level. We heard that due to the layered complexity of Indigenous identity, an incredible amount of internal processing occurs when asked to identify. While it might be possible for Indigenous people to go through the motions of answering the questions, waves of additional internal and external impacts continue to affect the Indigenous person long after the question is asked and answered, or refused. The requirement to sort through thoughts and feelings of potential harm accompanies the act of seeking healthcare and in turn, being asked about identity, even in times of extreme illness or emergency. The discomfort is not only felt by patients, but is also felt strongly by Indigenous staff tasked with collecting Indigenous identity data. While this experience of patient and provider discomfort has been reported elsewhere (Baker et al., 2005; Baker et al., 2007; Hasnain-Wynia et al., 2006; Hasnain-Wynia et al., 2010; Kandula et al., 2009; Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Quan et al., 2006; Varcoe et al., 2009) this study can shine a light deeper down into the layers that are involved with Indigenous identity specifically.

We cannot ignore the reality of deep-rooted and frequent experiences of anti-Indigenous racism that persist within healthcare spaces. We must acknowledge this reality to address the issues. Storytellers shared their personal experiences of racism and its impact on healthcare access and service, but it can be imagined that these experiences are familiar to many if not most Indigenous Peoples in Manitoba. As previous research has highlighted (Browne et al., 2011), anticipation of discrimination and experiences of racism are common experiences for Indigenous Peoples seeking healthcare. Being asked to self-declare Indigenous identity can become an additional stressor if not done correctly.

By creating space for Indigenous voices only, we can clearly hear their hopes and worries without competing non-Indigenous voices and experiences. REI data collection is about people and their identities. Previous research has spoken to the need for safety and respect with the process (Varcoe et al., 2009) however, from listening to Indigenous voices this study has generated a richer story of how colonial histories have, and continue to, dominate identity. An Indigenous concept of identity is often not considered when designing policies and procedures for data collection and reporting. The reality is that being identified as Indigenous within health care can have harmful outcomes even to the extreme of death. It is imperative that work continues to consider and address the impact of REI data collection on Indigenous Peoples though the involvement of Indigenous Peoples and the commitment of support by others.

While narratives of the benefits of big data sets and utilization of disaggregated data for research and health service decisions often underlie rationales for the collection of REI data (Bierman et al., 2002; Pinto et al., 2016), Varcoe et al. (2009) raised an alternate reason for the collection of REI data: the challenging of racism within the healthcare system. While storyteller voices echoed

the need for data for monitoring and systems change, their voices also offered solutions for addressing racism through an Indigenous worldview. In order to begin the disruption of anti-Indigenous racism, both the injustices that Indigenous Peoples face, as well as all of the resiliency and deep-rooted strengths and gifts that Indigenous people hold, must be spoken, heard, believed, and acted upon. Kurtz et al. (2008) wrote how the silencing of voice is an act of structural violence against Indigenous people. Empowering those who commonly are silenced and invisible within colonial structures becomes increasing plausible with REI data sets. Similarly, the storytellers in this study spoke about holding the healthcare system and providers accountable for poor quality care and racism. Within an Indigenous understanding, REI data collection is about Indigenous sovereignty and finally having a mechanism for their voice to be seen, heard, and most of all matter within healthcare. Indigenous Peoples continue to face incidents of racism within the healthcare system, evidence and discussion of which is abundant in the literature (Allan & Smylie, 2015; Ashworth, 2018; Matthews, 2017; Phillips-Beck et al., 2020; Wylie & McConkey, 2019). However, this study goes beyond the acknowledgement of racism and utilizes Indigenous voice as evidence of the gathering of strength and the standing up to and against colonial-based structural oppression and all forms of racism. REI data will become evidence of the pain and suffering of inequities and disparities, and a source of strength and pride through the evidence of resiliency, resistance against racism, and determination to thrive.

Future Directions

In consideration of the differing contexts of the lives, locations, cultures of First Nations, Inuit and Métis people across Canada and in honouring these distinct identities of nations, communities, bands, and individuals, there is the opportunity for this research to be replicated

and expanded to gather the voices of Indigenous Peoples in other locations and contexts. For example, even within Manitoba to replicate the study with First Nations, Inuit, and Métis people living outside of Winnipeg. Alternately, another future direction will be for research conducted post-implementation of REI data collection to commence in Manitoba in May of 2023.

Promoting the safe and appropriate collection and use of REI data will be key to ensuring that additional harm is not generated through the collection of data. In response to increasing requests for guidance on collecting REI data, the Manitoba REI team developed a Key Considerations: Race, Ethnicity and Indigenous Identity Data Collection and Use document (REI Governance Working Group, 2022). This document offers quick access to information and an Organizational Readiness Assessment Guide that will assist those interested in collecting REI data to understand their readiness and ability to collect the data according to best practice. Future research will be valuable in advancing guiding documents and strategies to evaluate REI data collection processes and experiences.

Limitations

This study was not without limitations. One could consider the small sample size a limitation; yet, this size is not unusual with qualitative studies. The findings provide a well-rounded discussion of REI data collection by including participation across three groups of Indigenous people interfacing with healthcare settings and entry into the system. Another limitation was the unbalanced representation of First Nations, Inuit, and Métis peoples. While study announcements were distributed broadly, information might not have reached all those eligible to participate, resulting in limitations to the perspectives and experiences included in this study. All storytellers lived and worked within Winnipeg, which did not allow for hearing perspectives and experiences

of First Nations, Inuit, and Métis people living outside of Winnipeg. As REI data will eventually be collected province-wide, it will be necessary to also understand the perspectives and experiences of those living outside of the Winnipeg boundary.

Conclusions

The healthcare system has been, and remains, a location where the safe care of Indigenous Peoples is not guaranteed. In fact, instances of racism and discrimination are experienced at high rates, perpetrated by systems and individuals who are not held accountable. REI data collection has been promoted as one solution to the problem in that it will allow for data disaggregated by race and ethnicity to inform about disparities, gaps, inequities, and harm within the healthcare system. While the health, healthcare, and health system change possibilities which can result from REI data collection are desirable, a crucial piece of data missing from this discussion in a Canadian context is the understanding how REI data collection impacts Indigenous Peoples in Canada. Until now, we have not listened to or included Indigenous voices specifically into the understanding, planning, implementation, and management of REI data collection, nor have Indigenous methodologies been used in any of these processes.

As Indigenous Peoples continue to suffer from the systemic racism that is deeply embedded within the healthcare system, it is crucial that REI data collection is informed by the experiences and perspectives of Indigenous Peoples; not simply left to reside within colonial relationships. Gathering, understanding, and acknowledging Indigenous perspectives and experience is a critical component to this systems-change strategy to ensure we are proceeding with culturally safe, respectful of the needs of First Nations, Inuit, and Métis peoples, and achieving the desired outcomes expressed by Indigenous Peoples. Deep thanks and gratefulness are extended out to

those First Nations, Inuit, and Métis relatives who shared their perspectives and experiences to advance the knowledge and understanding of REI data collection and for those who supported and guided this research to ensure it was done in a good way.

Through the conversations with the First Nations, Inuit and Métis storytellers, the importance of the ability to collect REI data as an intentional way to better understand the health and healthcare of Indigenous Peoples as three distinct but connection nations was held strong. The ability to measure healthcare inequities by distinct nations is needed and is not possible without this type of data collection. Storytellers shared how no longer can there be measurements and reports on health and healthcare disparities done through colorblind perspectives.

…incredibly needed because the longer we stay hidden within datasets, within systems, the least likely we are to get equitable treatment…. And I think one of the underlying reasons for the collection of REI data is really to measure the inequities that exist that cannot be seen when races and nations are hidden within datasets. …So I think it's incredibly important to measure outcomes of distinct nations, because if there's inequities that exist based on race, then systems actually need to be held accountable for those intentional disservices. (HL5)

Chapter 3 Relationships – In between chapter sharings

While Chapter 2 creates the space to hear from First Nations, Inuit, and Métis voices speaking up about REI data collection within healthcare, in Chapter 3 our focus shifts to healthcare systems and strategies for REI data collection. My thoughts around REI data collection often were directed to wanting to know the history of REI data collection in Manitoba so that I could better understand where we had come from and where we were going. This chapter presents an overview and mapping of where REI data has been collected within the healthcare system in Manitoba, through an Environmental Scan of past and present initiatives of REI data collection. The majority of initiatives were located in Winnipeg, though some served patients from within Winnipeg and Manitoba more broadly. Within Chapter 3 the application of Contemporary Indigenous Empowerment Theory (CIET) was used to guide the analysis of the data to better understand the impact of Indigenous voice and leadership where Indigenous identity data is collected. This chapter provides contexts around these initiatives as well as information regarding their successes and failures. I am grateful for all of the key informants who shared their knowledge and opened up about the connections between their work roles and the collection of REI data.

Contribution of Authors

My contribution to Chapter 3 includes relationship building, idea formation, study design, theoretical framework development, knowledge gathering, meaning making, and writing of the chapters. My primary supervisor Dr. Schultz provided critical feedback in the development of the chapter. Revisions to the writing were based on feedback from my dissertation committee; Dr. Schultz, Dr. McPhail, Dr. Anderson, Dr. Smylie, and Métis Elder Barbara Bruce.

Appendices Located within this Chapter

Appendix J: Data Extraction List for Scoping Review

Traditional Knowledge Sharing

With the onset of COVID-19, options for attending traditional ceremony with others were abruptly halted. For me, this meant a pause on sweatlodges, pipe ceremonies with others, sweep down/cleansing ceremonies, medicine camp gatherings, and work in the traditional medicine clinic. What remained for me was smudging, pipe ceremonies at home, using traditional medicines at home, and medicine harvesting with my family. I felt a deep loss for what needed to be put on hold and the pull to go to ceremony became stronger over time. In ceremony, it is not often that I have visions. There are times when I see shapes and colours, images and lights, but for me, I have come to realize that ceremony provides time and space where I can specifically and safely open my mind to receive messages, knowledge, teachings, wisdom, connections, and insights. I realized how important it is for me to connect with and absorb this knowledge. I can then allow this insight to permeate and flow to wherever it needs to go to continue to guide me, to answer my questions, and to remind me. I realize that while it is not always something visible to me, the knowledge and the insight that I receive through ceremony has brought me to where I am today. Upon reflection in recent weeks, I recognize that visions, knowledge, teachings, are flowing back to me. Through this process I am reminded of the importance of taking care of my wholistic health, body, mind and spirit in preparation for receiving. In slowing down, I have learned what it means to be in ceremony and to receive. Our ceremonies as Indigenous Peoples were done as a means of communicating our needs, as well as asking for knowledge, to better

understand our lives and worlds around us. This is very much in alignment with what happens during research.

Some gifts come in unexpected and unpredictable ways. As Indigenous people, our learning happens in ways that are natural, and which have supported our existence since the beginning of time, but overtime is often forgotten. When we are able to reconnect with that way of knowing it feels natural again. I like the idea of blood memory as an explanation for this phenomenon. I am thankful for what I have learned during this slow season of ceremony, as I know it will bring me closer to where I need to be.

Chapter 3. Indigenous skin, red flags: an environmental scan of past and current attempts at REI data collection in Manitoba.

Introduction

"While it is important for Indigenous people to maintain their cultural and communal boundaries as a way of rejecting colonization and protecting their identities, they must do so in a way that is flexible, contextual, and which incorporates the various ways of being Indigenous, so as to ensure the survival of their cultures for future generations" (Palmater, 2011, p. 24).

Within healthcare contexts there is growing interest in the collection of race, ethnicity and Indigenous identity (REI) data as part of registration at point of access to healthcare services. Previous research has suggested best practice for REI data collection is self-identification (Smylie & Firestone, 2015; Wray et al., 2013), where the patient is given the opportunity to declare their identity themselves, rather than recording identity based on staff members' assumptions or government issued identification. However, with the recent unmasking of Indigenous identify fraud, this has been called into question and community or nation-based verification processes are now being discussed. As well, as we have seen in Chapter 2, evidence shows that the process of asking about REI is more agreeable when patients know the rationale for collecting data, how the data will be used, and how patients will be protected from any harm as a result of declaring identity (Baker et al., 2005; Baker et al., 2007; Gibbens & Bowen, 2009; Hasnain-Wynia and Baker, 2006; Wray et al., 2013). In the literature, common rationales in support of REI data collection include disaggregated administrative data sets by race, ethnicity, and Indigenous identity to monitor and improve health systems; enhancing culturally safe and responsive programs and services (Lurie & Fremont, 2006; Pinto et al., 2016; Quan et al., 2006, Smedley et al., 2003; Varcoe et al., 2009; Wray et al., 2013) and research (Lu et al., 2022; Lurie & Fremont, 2006; Sheldon & Parker, 1992). While growing interest can lead to related system

changes, a reflective review of previous attempts to collect REI can reveal valuable evidence to shape future strategies.

In this Chapter, an environmental scan of REI data strategies over the last two decades within Manitoba are presented. Two objectives guided the environmental scan: 1) To map current policies and work concerning REI data collection in the Manitoba healthcare system and reveal current knowledge gaps; 2) To present a critical review concerning policies and processes of REI data collection and the impacts on Indigenous Peoples and Indigenous identities. Overall, the chapter aims to raise awareness and available evidence for health systems organizations, researchers, practitioners, patients, and the public to understand the current context of REI data collection in Manitoba.

Background Context

Previously published research has explored perspectives of REI data collection, including perspectives of some minority populations (Baker et al., 2005; Baker et al., 2007; Gibbens & Bowen, 2009; Gomez et al., 2014; Hasnain-Wynia & Baker, 2006; Kandula et al., 2009; Kiran et al. 2019; Kirst et al. 2013; Lofters et al., 2011; Petkovic et al., 2018; Pinto et al., 2016; Quan et al., 2006, Varcoe et al., 2009; Wray et al., 2013) but has largely silenced Indigenous perspectives on and requirements for the collection of identity data. In Chapter 2, we listened to Indigenous community members, registration staff (REI data collectors), and healthcare leaders shed light on these previously dismissed voices. While these people echoed the importance of having available disaggregated health administrative data, as seen in the literature, their reasonings contained nuances reflecting the importance of serving Indigenous people and their health, identifying racism within healthcare, and spoke about the importance of data governance agreements. High

quality REI data can support the visibility of Indigenous Peoples within the healthcare system. This occurs when health and healthcare disparities are reported, made visible, and addressed using evidence generated through REI data collection. Most importantly, the REI data collected can support the documenting of racism and its impacts, and hold systems accountable, with the intention of dismantling racism within the healthcare system.

Anti-Indigenous racism is a constant threat to First Nations, Inuit and Métis people who access healthcare systems in Canada (Allan & Smylie, 2015; Castleden at al., 2016; Leyland et al., 2016; Loppie et al., 2014.; Phillips-Beck et al., 2020; Reading, 2014). Considerable evidence that Indigenous Peoples frequently experience various forms of racism leading to difficulties and harm during healthcare experiences exists, along with stories of how these harms often go unaccounted for (Allan and Smylie, 2015; Brown, 2008; Browne and Fiske, 2001; Castleden at al., 2016; Hole et al., 2015; Kurtz et al., 2008; Lux, 2010; Meijer Drees, 2010; Phillips-Beck et al., 2020). The tragic deaths of Brian Sinclair in Manitoba (McCallum & Perry, 2018) and Joyce Echequan in Quebec (Council of the Atikamekw of Manawan and the Council de la Nation Atikamekw, 2020) at the hands of the healthcare system are just two examples of tragic outcomes. As Indigenous Peoples, we frequently hear these stories of our friends, loved ones, and community members, and members of our nations. However, it is often not until these stories, which can involve the death of a person, are shared through news/media that they are believed by those who experience these issues less frequently or not at all. Despite Indigenous voices sharing this knowledge for decades, it is often not until it is reported by academics or government, with data as evidence, that it is finally acknowledged, and still, some remain ignorant. Therefore, despite research, despite the strong Indigenous voices sharing knowledge, despite advocacy for change, Indigenous Peoples are still often left out of health system decision

making and implementation of meaningful solutions for safety and support. Tragically, healthcare experiences of Indigenous Peoples continue to be inadequate, harm inducing, and at worst, life threatening. REI data can be an important mechanism to reveal when and where racism is occurring within the healthcare system and can provide evidence of the gaps and breaks in the system which contribute to health and healthcare disparities experienced by Indigenous Peoples. Indigenous identity data, combined with voices as evidence will allow for stronger advocacy and a refusal to be denied recognition.

The literature addresses how, compared to non-Indigenous people in Canada, Indigenous Peoples receive inequitable healthcare services, suffer from heath disparities, experience worse health outcomes, do not feel safe in healthcare systems, and experience unmet healthcare needs (Adelson, 2005; Hole et al., 2015; Kent et al., 2017; National Collaborating Centre for Indigenous Health, 2019; Phillips-Beck et al., 2020; Ramraj et al., 2016; Reading & Wein, 2009; Tang & Browne, 2008; Wilk et al., 2018). Indigenous Peoples have not been silently suffering, Indigenous voices have been strong and loud regarding the need for change. Statements, declarations, and calls to action have voiced Indigenous people's truths regarding what is needed for reconciliation, healing, and addressing the harm stemming from colonization and continued structural oppression. In 2015, the Truth and Reconciliation Commission (TRC) of Canada released 94 Calls to Action, of which number 19 is a call to "establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long terms trends" (Truth and Reconciliation Commission of Canada, 2015, p. 161). Despite this clear Call to Action, the ability to accurately report on progress and long-term trends is limited by the lack of systematic collection of Indigenous identifier data for First Nations, Inuit and Métis people (Allan &

Smylie, 2015). High quality healthcare is a right of Indigenous Peoples as determined by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (United Nations, 2008) and the right to health and healthcare is a determinant of health that is referred to in numerous others documents and reports including the Royal Commission on Aboriginal Peoples (RCAP) (The Commission, 1997), the final report of the TRC (Truth and Reconciliation Commission of Canada, 2015) and the final report of the inquest into Murdered and Missing Indigenous Women and Girls (MMIWG) (Canada, 2019). Indigenous Peoples have been raising voices and clearly stating what is needed to meet the physical, mental, emotional, and spiritual needs of our nations for years, which is work that is often difficult, exhausting, and relentless and done without a guarantee of improvement or lasting solution.

Manitoba Health Care Context

The Manitoba healthcare system serves many Indigenous patients, who represent 18% of the provincial population; and Winnipeg has the largest Indigenous urban population among all Canadian cities (n=102,080 Indigenous Peoples); (Statistics Canada, 2022). However, it must be noted that Indigenous Peoples are consistently undercounted and underrepresented when it comes to determining Indigenous population sizes (Smylie & Firestone, 2015). Despite years of researcher advocacy for the collection of REI data (CIHI, 2020; CIHI, 2022; Smylie & Firestone 2015), health administrative data sets remain devoid of REI data collected through consistent and systematic processes of self-declaration. Moreover, there is yet to be a systematically implemented strategy to collect data in ways that are safe and supportive of Indigenous people's identities. An inability to determine, track and report on healthcare gaps, disparities, inequities and most importantly, presence and impacts of racism is an ongoing concern and health priority that must be addressed. In Manitoba, there is a history of strong Indigenous leaders who have

been impacting health, healthcare, and health research decisions; for example, Dr. Catherine Cook, Dr. Marcia Anderson, Dr. Barry Lavallee, and Leona Star. Their actions have included advocating for Indigenous partnership in collecting and reporting on Indigenous health data (Katz et al., 2019) as well as REI data collection policy and practice. This work is carried out through the embracing of an Indigenous worldview, and guided with the understanding of how data collection and reporting can either move away, from or stays entrapped within, colonial influences of white power holding.

Established in 2018, Shared Health, the provincial health authority, leads the coordination of healthcare services across the province and serves as a Service Delivery Organization operating Manitoba's largest tertiary/ quaternary care facility in the province, including the Health Sciences Centre, and both the Children's and Women's Hospitals. Regional health authorities (RHAs) and service delivery organizations (SDOs) are responsible for the delivery of province wide healthcare services. Each work together along with other stakeholders and communities to ensure that the health needs of Manitobans are fulfilled (Shared Health, 2023a). There are 5 RHAs in Manitoba: Winnipeg Reginal Health Authority (WRHA), Interlake-Eastern, Southern Health-Sante Sud, Prairie Mountain Health, and Northern Health Region. RHAs are the governing bodies for healthcare delivery in their regions. WRHA is the largest health authority which provides services for the city of Winnipeg as well as Churchill Manitoba and 2 rural municipalities near Winnipeg. In addition, the WRHA provides healthcare supports and referrals to specialty services to those outside of the Winnipeg boundary (WRHA, 2023a). There are 6 hospitals in the Winnipeg health region as well as numerous health facilities, programs and services (WRHA, 2020). Shared Health is leading the provincial strategy for the collection of REI data, with plans to collect REI at all healthcare sites connected to the provincial electronic

patient records (EPR) system. Without the systematic collection of REI data, there is limited ability to accurately count and understand patterns of health care access by Indigenous Peoples in Manitoba. However, it is known that Indigenous Peoples do not have equitable access to healthcare services (Allan & Smylie, 2015; National Collaborating Centre for Indigenous Health, 2019).

In May 2023, Manitoba will begin the systematic collection of REI data at points of access/registration into the healthcare system. For the majority of the public, the collection of REI data will be new, but for others who have been working behind the scenes or who have been involved in this type of data collection there will be familiarity. This is not the first, nor an isolated attempt at systematic collection of self-declared REI data at point of access/registration to health services in Manitoba. Within Manitoba, there is a history of attempts to collect REI data within the healthcare system, and there are currently still a number of locations where identity data is being collected or being prepared to be collected. The history of provincial attempts at REI data collection is worthy of documenting and reflecting on to shed light on previous barriers and facilitators to REI data collection. Of equal importance is understanding the history of Indigenous identity data collection and data set generation through linkage processes using unique identification numbers including Treaty numbers and Inuit N numbers (First Nations Information Governance Centre, 2019a; Health Canada, 2014; WRHA-Indigenous Health, 2023), which demonstrates issues both with respect to governance and technical processes with identification. While this dissertation does not focus on how identity is defined, studying the complexities which can conflate REI data and Indigenous identity is an area of research exploration for future consideration. On a final note, while the environmental scan discussed in this chapter focuses primarily on Indigenous identity, the strategies in Manitoba have focused on

the collection of race, ethnicity, and Indigenous identity. In this chapter the language of REI was used when people engaged with me in collecting data for this study.

Positionality Statement

As a doctoral candidate and researcher of First Nations ancestry, I ground my work within an Indigenous paradigm and the use of Indigenous research methodologies. Both within and outside of the academy, I honour my Indigenous identity, and relationships are the foundation from which everything is understood. Part of this work involves the inclusion of Indigenous participants and partnerships in all research endeavors. Throughout my dissertation research I consulted with an Indigenous Advisory Council (IAC) developed in partnership between Ongomiizwin and the Centre for Healthcare Innovation (CHI) of which membership includes self-identified First Nations and Métis people. The IAC provided feedback and guidance on the overall study design. In addition, a circle of Indigenous leadership with membership from each of the three recognized Indigenous groups in Canada - First Nations, Inuit, and Métis - was formed to review my full dissertation proposal, and offered feedback and mentorship. Due to considerations regarding COVID-19, all consultation interactions occurred through virtual meetings. As a member of the core team for the provincial REI data collection strategy, I carry a broad base of knowledge around the development and implementation of the REI data collection initiative in Manitoba. The core team has overseen all aspects of the development and implementation of the REI data collection strategy within Shared Health. My role involves participation on the steering committee, the BIPOC advisory group, as well as the working groups (data protocol, governance, evaluation, training and education, communications). One of my specific roles within this team is to bring an Indigenous lens to the work, as well as contribute Indigenous research and evaluation methodologies and content expertise.

Methods

Environmental scan methodology is a valuable tool to address the two guiding objectives: 1) To map current policies and work concerning REI data collection in the Manitoba healthcare system and reveal current knowledge gaps; 2) To present a critical review concerning policies and processes of REI data collection and the impacts on Indigenous Peoples and Indigenous identities. The key aims of an environmental scan are to identify strengths, weaknesses, and relationships within an organization, which become evidence to inform strategic decisions and solutions regarding organizational issues or development of new programs and policies (Albright, 2004; Graham et al., 2008; Rowel et al., 2005). In the health and healthcare field, environmental scans are increasingly being used to support healthcare system decisions and raising awareness of specific issues and contexts (Graham et al., 2008; Rowel et al., 2005). While gaining in popularity, the theory and/or frameworks for environmental scan methods within health and public health contexts remain fluid and adaptable (Graham et al., 2008; Rowel et al., 2005). Without an established definitive methodology for environmental scans, design and interpretation often works to best fit the purpose and environment (Rowel et al., 2005). Environmental scans tend to follow four principles: maximizing existing resources, provision of timely responses to issues in public health, resourcing previously established knowledge as a foundation, and building on established knowledge and enhance community participation (Rowel et al., 2005, p. 527).

Design

The environmental scan followed a passive methodology, defined as data collection using pre-existing relationships/contacts/networks or sources such as databases and documents (Aguilar,

1967; Choo, 2001; Graham et al., 2008). Below, details related to sources of data, data collections procedures, and analysis are discussed. As well, the theoretical perspective informing the environmental scan is presented. Finally, as data collection is focused on work-related discussions of healthcare system strategies rather than gathering personal information, Research Ethics Board (REB) approval was not required based on consultation with the University of Manitoba Health REB.

Sources of Data

Sources of information with environmental scans vary and can include organizational internal data such as policy documents, reports, memos and meeting minutes; informal personal communications; and formal discussions with informants. In addition, information can be retrieved from organizational external sources concerning relevant social, economic, and political and technological contexts (Albright, 2004; Graham et al., 2008; Rowel et al., 2005). "Environmental scans allow the researcher, clinician, or policy maker to account for diverse types of knowledge" (Graham et al., 2008, p. 1022) in support of addressing guiding objectives. In this environmental scan data sources included: 1) key informant discussions, 2) reviews of internal organizational documents, 3) review of policies and practices within the healthcare system 4) knowledge and experience gained through involvement in current REI project (Shared Health, provincial healthcare system), and relevant public documents discussed with key informants and located through internet searches.

Key informants were individuals who had knowledge of, or experience with, the creation of REI data collection initiatives within the Winnipeg healthcare environment and who I had previously established working relationships with through my membership on the provincial REI strategy core team.

Data Collection

Key informant data gathering occurred over a period of 8 months (November 2021 – July 2022) using in-person, virtual/video, and telephone meetings, as well as the sharing of documents through email. Through this gathering of data, relevant documents were shared, or simply mentioned, which prompted online searches to locate documents. As the focus on this environmental scan aimed to document past and current REI data collection initiatives, conversations with key informants along with review of documents were guided by the questions found in Table 3.

Table 3

Environmental Scan Guiding Questions

1.	What types are REI data are currently being collected?
2.	Who is collecting REI data currently?
3.	What is the purpose of the data collection?
4.	What is the process of the data collection?
5.	How are Indigenous Peoples involved in this data collection?
6.	How are Indigenous identities represented in this data collection?
7.	Are the data collection processes culturally safe?
8.	Who determines how the data is governed and used?
9.	Has there been quality checks around the data that is collected and used?

Data gathered through key informants and related documents was supplemented through my experience and knowledge gained through my involvement as a core team member of the MB strategy for REI data collection. This team came together in 2019 to develop the strategy for the collection of REI data within the MB healthcare system and included executive sponsors from Shared Health, leadership and staff from Ongomiizwin Indigenous Institute of Health and Healing, Rady Faculty of Health Sciences, University of Manitoba, and project management from the George and Fay Yee Centre for Healthcare Innovation (CHI).

Data Analysis

Collected data was analyzed to first address the aim of identifying and mapping REI data collection initiatives in the Manitoba healthcare system over the last couple of decades, which drew on key informant conversations, documents reviewed, and knowledge drawn from my involvement in the core Manitoba REI team. The second aim was to work with the Contemporary Indigenous Empowerment Theory (CIET) framework, developed as part of my dissertation, to guide analysis of data concerning various REI data collection initiative within Winnipeg healthcare settings. The CIET framework guides the analysis of the information through Indigenous ways of being, knowing, and doing. In general, theories explain an intention or direction of thought for how a phenomenon is going to be examined and explained and will utilize a series of connected ideas and perceptions to reach that explanation (Saskamoose, 2017). The intention set with CIET is to uncover movements of empowerment, through elevating Indigenous knowledge, practice, and voice to reveal structures of oppression and reclaim Indigenous space and place in society which was abruptly and ongoingly erased through years of painful ignorance and colonial violence. While CIET can support fighting against the oppressor, more importantly, the intention is to highlight the use of Indigenous strength, power, resilience, and brilliance to find alternatives where Indigenous Peoples rise higher and shine brighter than ever before (Simpson, 2016). Simpson leans into a connection between Indigenous scholar Glen Coulthard's notion of grounded normativity and the idea of Indigenous intelligence to imagine the pathway to Indigenous resurgence (Simpson, 2016). Highlighting the use of alternative pathways to empowerment is a central component of CIET.

In her writing on resurgence, Simpson (2016) discusses the idea of embracing Indigenous intelligence, also referred to as grounded normativity, which is explained as the connections to

our world around us and all our knowledge of how to live a good life that comes through these relationships. In this sense, Indigenous intelligence is seen as an alternative pathway to a reclamation of empowerment (Simpson, 2016). Seeking out this alternative pathway, which is what emerges through applying the lens of CIET, invites us to recognize the highest version of ourselves as Indigenous Peoples through uncovering and understanding relations of power, social justice, and Indigenous voice as evidence. In her discussions on resurgence, Simpson (2016) has alluded to this idea of alternative pathways as "flight paths or fugitive escapes from the violences of settler colonialism" (Simpson, 2016, p. 22). Witnessing and naming this era of Indigenous power regeneration, along with individual and collective strengthening of Indigenous identity is at the core of CIET. The layering of CIET overtop of the examples of REI data collection attempts, revealed spaces where, or where not, there was systemic acknowledgement, support, or even investment in creating and providing safe and anti-oppressive healthcare practices related to REI data collection initiatives. Table 4 provides brief descriptions of CIET components.

Table 4

Contemporary Indigenous Empowerment Theory (CIET)

Theoretical Principle	**Key Points**
uncovering and understanding relations of power	Disruption of settler colonial power and oppression through knowing and understanding how power is obtained, manipulated, and maintained. Resistance of settler colonial domination and oppression by centering Indigenous worldviews and knowledges over that of the dominant oppressor. Deconstruction of previously colonial constructed realities (Denzin & Lincoln, 2014; Lewis, 2012).
social justice	Locating the successful pathways to change through examining the reactions and resistance of Indigenous Peoples to settler colonial oppression. Finding evidence of inequities and defining appropriate, culturally safe, and meaningful solutions to the persistence of race-based inequities (Lewis, 2012).

Indigenous voice as evidence.	Indigenous stories voiced as a way to disrupt the dominant white narrative to replace it with an accurate reality of Indigenous oppression. Indigenous Peoples speaking out and exposing the mechanisms that maintain the power of the oppressor (Dunbar, 2008).

Results

Key informants shared their knowledge of previous and current REI data collection attempts which came through either their employment or committee involvement within the healthcare system. While key informant identity details were not formally collected or reported, it is important to note that this is the only place within the dissertation where both Indigenous and non-Indigenous voices are presented as evidence.

Mapping REI Data Collection Initiatives in Winnipeg

Meetings with nine key informants included: one in-person meeting, one telephone meeting, six video meetings; and one email correspondence. At two of the meetings, two key informants attended the meeting together, and one key informant participated in two video meetings (initial and follow-up). A review of 20 documents included: six documents shared by key informants, seven documents obtained through internet searches, and 7 documents obtained through work on the MB REI strategy. or other means related to the provincial REI project. Additional internet searches were completed to verify details not listed in documents. Table 5 lists of all documents reviewed as part of this environmental scan.

List of Abbreviations for Tables 5, 6 ,7

ADT - Admission, Discharge, and Transfer
AHWC – Aboriginal Health and Wellness Centre
CIHI – Canadian Institute for Health Information
FN/I/M – First Nations, Inuit, Metis
NIA – no information available
REI – Race, Ethnicity, Indigenous
RLEISC - Regional Language & Ethnicity Indicator Steering Committee
SBH – St. Boniface Hospital
WRHA – Winnipeg Regional Health Authority

Table 5

Environmental Scan Documents Reviewed

Document Publication date	Author	Organization
Key Informant documents		
Briefing Note: Developing Capacity for Adopting Mechanisms for Including Ethnic Indicators in WRHA Health Data April 3, 2006	RLEIC - Michael Moffatt	WRHA
Briefing Note: Language and Ethnicity Indicators Ethnicity Go Forward Plan June 21, 2010	RLEIC - Michael Moffatt, Catherine Cook, Jeanette Edwards, Jeanine Roy, Evelyn Fondse, Colleen Metge	WRHA
Community ADT Meeting Minutes: Present Language and Ethnicity requirements from WRHA Language Access and Interpreter Services July 7, 2010	RLEIC - Presenters: Evelyn Fondse, Jeannine Roy	Manitoba eHealth
Change Request Form: CR01697 SDE 340883 Dictionary Change - Ethnicity Remove Required Flag Hide Field 04/08/2010 July 7, 2010	ATD Community Project - Sharon Wiebe	Manitoba eHealth
Quick Reference Guide & FAQ: Patient Relations Process to Collect Indigenous Identifiers June 15, 2020	n/a	WRHA WRHA Indigenous Health
Indigenous Health Patient Referral Form No date	WRHA Indigenous Health – Patient Services	WRHA WRHA Indigenous Health
Provincial REI Project documents		
Supporting the Implementation of Regional Language & Ethnicity Indicators: Summary	WRHA Research & Evaluation Unit Michelle Gibbens, M.S.W.	WRHA

Report of Key Research & Evaluation Findings July 2009	Sarah Bowen, Ph.D.	
REI Indicators Evaluation (COVID-19 Implementation) February 18, 2021	Evaluation Platform, George & Fay Yee Centre for Healthcare Innovation (CHI)	CHI
Briefing Note: Collection of Race, Ethnicity and Indigenous Identifiers in Manitoba May 9, 2019	Marcia Anderson	Shared Health
Racial, Ethnic, Indigenous Identified Data Governance Principles November 15, 2021	Provincial REI project - Governance Working Group	CHI/Ongomiizwin Indigenous Institute of Health and Healing
Key Considerations: Race, Ethnicity and Indigenous Identity Data Collection and Use October 2022	Provincial REI project - Governance Working Group	CHI/Ongomiizwin Indigenous Institute of Health and Healing
COVID-19 Infections in Manitoba: Race, Ethnicity, and Indigeneity External Report March 1, 2021		Manitoba Health
COVID-19 Script for Racial, Ethnic, Indigenous Identity: Collection of Identifiers May 1, 2020	Provincial REI project team	Shared Health Manitoba Health
Online Search Documents		
Resident Assessment Instrument (RAI) RAI-MDS 2.0 User's Manual. Canadian Version February 2021	John N. Morris, Catherine Hawes, Vincent Mor, Charles Phillips, Brant E. Fries, Sue Nonemaker, Katharine Murphy	CIHI
COVID-19 Novel Corona Virus - REI Analysis Wave Three July 5, 2021		Manitoba Health
COVID-19 Novel Corona Virus - Immunization and COVID-19 Cases: REI Analysis February 1, 2022	Marcia Anderson Jill Waruk	Manitoba Health
Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada 2022	CIHI	CIHI
Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada Supplementary Report 2022	CIHI	CIHI
A Path Forward Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI August 2020	CIHI	CIHI
Interim Guidance Public Health Measures		Manitoba Health

Managing Novel Coronavirus (COVID-19) Cases and Contacts in Community March 15, 2022		

This environmental scan reports on 12 REI data collection initiatives that occurred over the past 2 decades in Manitoba. Figure 1 displays a timeline of these initiatives, which includes 14 initiation dates as two initiatives each involved unique aspects with different start dates. Finally, Tables 6 and 7 display additional details of the 12 initiatives. As the retrospective collected data relied on key informants' memories and familiarity of initiative details, data found in the boxes can vary in specificity. Table 6 focuses on key drivers and activities of the initiatives, and Table 7 reports additional relevant details for each initiative. Tables 6 and 7 address the first objective of mapping policies and work related to REI initiatives in Manitoba healthcare systems.

Figure 1 ***Timeline of REI Initiatives***

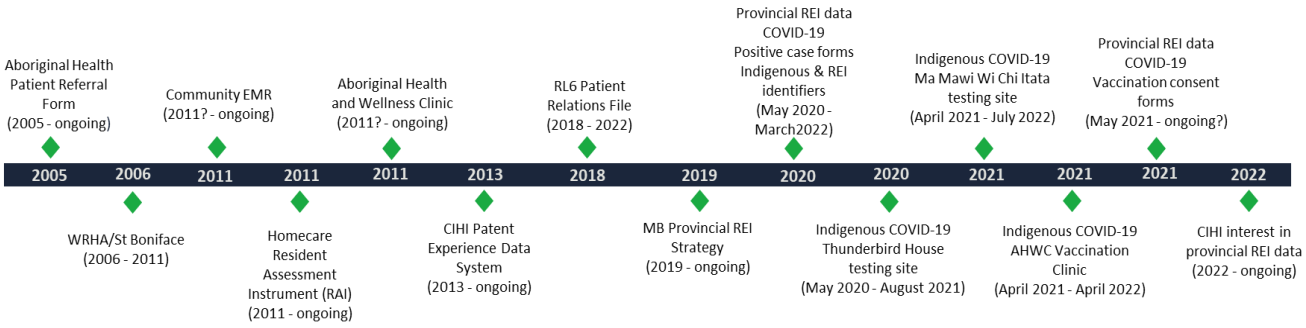


Table 6

REI Initiatives Key Drivers and Activities

Initiation Date **Initiative Title** **Leads**	**Key Drivers**	**Activities**
2005 Aboriginal/ Indigenous Patient Health Referral Form WRHA Indigenous Health	-to facilitate referral for Indigenous patients to Indigenous Health Patient Services	2005 – implementation of paper-based regional Aboriginal health referral form in WRHA -later revised to electronic, available on the EMR system where possible
2007 WRHA/ SBH WRHA / RLEISC	**First Attempt:** -to determine the effect of language barriers on access to services -to determine frequency of certain health conditions among "Aboriginal" persons -to determine how immigrant health status changes over time -to inform the development of interpreter services -identification and action on health disparities -participate in cutting edge research related to health disparities	April 2007 - ethnicity questions were introduced to the patient registration process at SBH (**first attempt**) June 2007 - the ethnicity questions were discontinued at the recommendation of the WRHA Research and Evaluation Unit until key issues could be addressed June 2010 - the WRHA RLEISC revisited the implementation of the ethnicity data collection (**second attempt**) 2011 - change in leadership led to a decrease in support for the collection of Indigenous identifiers and denial of funding from the provincial government

	Second Attempt: -planning and monitoring of health systems performance and services addressing needs of growing diversity of Manitoba and Winnipeg -improve patient experience and patient safety -improve quality and integration -integrate REI data collection into electronic medical record (ADP-EPR, EMR)	2013 - formal data collection processes still not implemented as original RLEISC members leave committee 2016 - REI self-identification implementation revisited and Working Group formed following the release of the TRC Calls to Action -endorsement received from the First Nations, Métis and Inuit Committee of the WRHA Board -REI Advisory Committee formed by Shared Health and including invited representation from E-Health, Manitoba Health Information Management and Analytics, Centre for Healthcare Innovation, Cancer Care Manitoba, WRHA, First Nations Health and Social Secretariat of Manitoba (FNHSSM), Manitoba Métis Federation (MMF), and Manitoba Inuit Association (MIA). -project paused during health care system transformation
2011 Community Electronic Medical Records (EMR) Lead unknown	-to add the REI questions to the EMR at the same time as the system development -challenges in obtaining information regarding the key drivers -likely has connection to the 2010 second attempt of the WRHA/SBH initiative and therefore similar key drivers	2011 - field for Indigenous identifiers added to the EMR system
2011 Homecare Resident Assessment Instrument (RAI)	-identifying resources or supports for clients to meet the needs of Indigenous patients -WRHA/SBH initiative laid the groundwork for the collection of ethnicity data in the RAI	-data is collected by homecare staff upon intake of new patients/clients -data is held by CIHI

2011 AHWC AHWC Director of Primary Care	-accurate measurement of data pertaining to Indigenous Peoples accessing healthcare at the AHWC clinic (location, types of services -address existing gaps and needs	2018 – initiation of staff training to educate and support staff in the safe and supportive collection of Indigenous identifiers data (in a good way)
2013 CIHI Patient Experiences Data system CIHI	-capture data that would allow for analysis of the experiences in healthcare of racialized groups including Indigenous Peoples	2013 - patient experience data system created by CIHI 2014 - survey first implemented - "Aboriginal" was the only response option 2016 - survey edited to include options for First Nations, Métis, Inuit, as well as other ethnic and geographic related categories August 2020 - adopted a policy aligned with the principles of Indigenous data sovereignty
2018 RL6 Patients Relations File WRHA Indigenous health leadership	-obtain evidence of client experiences in order to better plan for support and intervention where necessary -accurate systems of understanding Indigenous client access and experience -garner support from the health region -further examine their internal quality improvement processes. -examine data around preventable patient safety events to determine how much is actually due to racism and discrimination	2018 - WRHA Indigenous health leadership approached the patient relations department with a request to better understand that people that are being served. June 2020 - A section was built in the feedback module of the RL6 system database to allow for the collection of Indigenous identifiers and implementation of data collection started. -pilot project was developed and was in progress form approximately 2 months until impacted by COVID-19 September 2021 - decision made to expand data collection form Indigenous identifiers only to a range of racial and ethnic and Indigenous identifiers 2022 (summer) - focus returned to the REI data collection process with plans for continued development of the REI data collection process over time October 2022 - REI questions were no longer being asked

2019 MB Provincial REI strategy Shared Health & Provincial REI Team	-improved health reporting as well as target information for First Nations, Métis and Inuit peoples and other racialized groups -accountability for health systems performance to First Nations, Métis and Inuit peoples and other racialized groups -obtaining data to support the disruption of racism in the healthcare system -achievement of equitable health care quality -improved evidence for health planning	May 2019 - REI project initiated -formation of working groups (Data Protocol, Training and Education, Governance, Evaluation) -update/change the ADT EPR -develop and implement training -develop communications materials -develop governance framework document -develop and implement evaluation May 11, 2023 - REI data collection implementation
2020 Provincial REI data collection during the COVID-19 pandemic Shared Health & Provincial REI Team	-reporting of COVID-19 impacts disaggregated by REI -support health systems to respond to disproportionate impacts of COVID-19 on Indigenous and other racialized communities -monitor and respond promptly to racism -assist community organizations who provide health and social service in planning, resourcing, and evaluation of programming and services -improved health systems planning and reporting for First Nations, Inuit, and Métis peoples and other racialized groups -accountability for health systems performance to First Nations, Métis and Inuit peoples and other racialized groups -equitable health care quality and freedom from racism	April 3, 2020 - collection of Indigenous identifiers began on COVID-19 positive case contact forms May 1, 2020 - collection of REI data began on COVID-19 positive case contact forms May, 2021 – collection of REI data on COVID-19 vaccination consent forms
2020/2021 Indigenous COVID -19	-to collect and report on data pertaining to access to testing and vaccination sites by Indigenous Peoples.	May, 2020 - AHWC staff collected Indigenous identity data at the Thunderbird House testing site

Testing and Vaccination Sites at Thunderbird House / Ma Mai Wi Chi Itata /AHWC AHWC and Ma Mawi Wi Chi Itata Leadership		April, 2021 - Ma Mawi Wi Chi Itata staff collected Indigenous identity data at their testing site April, 2021 –vaccination clinic initiated at AHWC
2022 CIHI & Provincial REI data CIHI	-CIHI request to collect REI data nationally -CIHI request for national alignment on type of data being collected -CIHI would like to utilize already developed provincial strategies for REI data collection	2022 - CIHI initiated a request for the province to collect REI data to transfer to CIHI. July 2022 - CIHI released a discussion paper which proposes standards for the collection of race-based and Indigenous identity data in healthcare. -establishment of a bilateral sharing agreement between the province of Manitoba and CIHI

Table 7

REI Initiative Additional Details

Initiation Date **Initiative Title** **Leads**	**Indigenous inclusion**	**Data collected**	**Training /Script**	**Indigenous Governance/ Public Reports**	**Successes/Failures**	**Outcomes/Evaluation**
2005 Aboriginal/ Indigenous Patient Health Referral Form WRHA Indigenous Health	NIA	Treaty Numbers (First Nations) N numbers (Inuit) Home Community Ask: NIA Answer: NIA	Training: no Script: Yes	Indigenous Governance: NIA Public Reports: NIA	NIA	Outcomes: Indigenous Health Referral Forms still being used to collect data Evaluation: NIA
2007 WRHA/ SBH WRHA Regional Language & Ethnicity Indicator	First Attempt: One Indigenous team member RLEISC member	REI data Ask: Mandatory Answer: Voluntary	Training: Yes Script: Yes	Indigenous Governance: No Public Reports: No	Successes: -original concept created -raised awareness -pilot project -EPR-created a place holder for ethnicity Failures: -community consultation revealed concerns about the	Outcomes: -data never formally collected at WRHA/St. Boniface Evaluation: Yes

Steering Committee (RLEISC)	Second Attempt: First Nations, Métis and Inuit Committee of the WRHA Board				ethnicity questions and reasons for these -significant staff concerns about the ethnicity questions -patient complaints -variations in staff training content and quality -staff noncompliant in asking the questions -lack of consultation with Indigenous Peoples	
2011 Community EMR Lead unknown	NIA on Indigenous inclusion Possible link with one Indigenous RLEISC member	FN/M/I data Ask: Voluntary Answer: Voluntary	Training: No Script: No	Indigenous Governance: No Public Reports: No	Successes: -added the fields for Indigenous identifiers data collection to the EMR system Failures: -lack of training/education on purpose/process -lack of knowledge in how to ask the question or respond to patients -staff felt uncomfortable asking the questions -staff refusal to ask the question	Outcomes: -inconsistent collection of Indigenous identifier data -poor quality datasets Evaluation: No
2011 Homecare Resident Assessment Instrument (RAI)	No Indigenous health support in the homecare program at	FN/M/I data Ask: Mandatory Answer: Voluntary	Training: Yes Script: Yes	Indigenous Governance: No Public Reports: NIA	Successes: -staff felt more comfortable asking about Indigenous identity following training Failures:	Outcomes: -data still being collected on the Resident Assessment Instrument (RAI) RAI-MDS 2.0 Evaluation: No

Lead: unknown	the time of implementation				-challenges with obtaining data on Indigenous identity -staff felt uncomfortable asking the question -lack of Indigenous health support in the homecare program	
2011 AHWC AHWC Director of Primary Care	Indigenous leadership Indigenous staff	FN/M/I data Ask: Mandatory Answer: Voluntary	Training: Yes Script: No	Indigenous Governance: No Public Reports: No	Successes: -data collection more consistent at the AHWC -staff developed practices for honouring distinct Indigenous Failures: -staff discomfort with asking -questions not always asked	Outcomes: -Indigenous identity data collection continues -data used internally to respond to the needs of community -better understanding of clinic outputs Evaluation: No
2013 CIHI Patient Experiences Data system CIHI	Indigenous heath team within CIHI	Original: Aboriginal Updated: REI identifiers	Training: NIA Script: NIA	Indigenous Governance: No Public Reports: Yes	Successes: -CIHI has since created an Indigenous Health team -CIHI engages and works with a number of FN/M/I organizations and partners, individually and collectively Failures: -CIHI did not have a strong presence or role in the Indigenous health environment	Outcomes: -data still being collected through the Canadian Patient Experiences Reporting System. Evaluation: NIA
2018 RL6 Patients	Indigenous led	Original: FN/M/I data Ask: Voluntary	Training: Yes Script: Yes	Indigenous Governance: No	Successes: -acknowledgement of racism in the RL6 file data collection script and use of racism terminology in FAQs	Outcomes: -data is inconsistent and incomplete -data collection was discontinued in 2022

Relations File WRHA Indigenous health leadership		Answer: Voluntary Updated: REI identifier data Ask: Mandatory Answer: Voluntary		Public Reports: No	-rationale refers to the TRC Calls to Action Failures: -staff did not ask the question. -staff discomfort with asking clients to identify -staff stopped using script	-no information provided as to why -plans to restart the collection of REI data in patient relations Evaluation: No
2019 MB Provincial REI strategy Shared Health & Provincial REI Team	Indigenous led Indigenous members on the Steering Committee	REI identifier data Ask: Mandatory Answer: Voluntary	Training: Yes Script: Yes	Indigenous Governance: Yes Public Reports: Yes	Successes: -provided the foundation for the collection of REI data during the COVID-19 pandemic -internal development of training with CHI staff -internal development of change management strategy Failures: -loss of contract with key REI data collection training company due to delays caused by Shared Health - resulting in a failed contract negotiation between Shared Health and the contracted company	Outcomes: -REI data collection implemented May 2023 Evaluation: ongoing
2020 MB Provincial	Indigenous led	REI identifier data	Training: Yes	Indigenous Governance: Yes	Successes: -first attempt at provincial REI data collection	Outcomes:

REI data collection during the COVID-19 pandemic Shared Health & Provincial REI Team	Indigenous members on the Steering Committee BIPOC Advisory Group	Ask: Mandatory Answer: Voluntary	Script: Yes	Public Reports: Yes	-most people were comfortable answering the questions Failures: -staff (public health nurses) were uncomfortable asking the question -not all staff watched the training video -not all staff asked the questions at first – though this did improve over time in most region with interventions	-data used for reporting on COVID-19 data disaggregated by REI -information was used for planning and community-based responses to disproportionate negative impacts of COVID-19 Evaluation: Yes
2020/2021 Indigenous COVID 19 Testing and Vaccines Thunder-bird house / Ma Mawi Wi Chi Itata Centre/ AHWC AHWC and Ma Mawi Wi Chi Itata Centre Leadership	Indigenous led	FN/M/I data Ask: Mandatory Answer: Voluntary	Training: Yes Script: No	Indigenous Governance: No Public Reports: No	Successes: -staff worked to create an environment where Indigenous Peoples could feel safe and supported -staff fostered Indigenous pride by verbally expressing their pride in their ability to serve the Indigenous community and to make it known that the site existed to serve the Indigenous population -staff were trained to know how to share this message with appropriate tone, body language, and positive attitude -the model of Indigenous people supporting Indigenous people contributed to the successful collection of Indigenous identity data in this environment	Outcomes: -Indigenous identity data was collected until the closing of the Indigenous specific vaccination clinic at the AHWC in April 2021 Evaluation: Yes

					-AHWC and Ma Mawi Wi Chi Itata designed a method for collecting Indigenous identifier data within their organizations Failures: -Indigenous sites were denied the request to collect Indigenous identifiers within the EMR	
2022 CIHI & Provincial REI data CIHI	Indigenous heath team within CIHI	REI identifier data Ask: Mandatory Answer: Voluntary	Training: No Script: Yes	Indigenous Governance: Yes Public Reports: No	Successes: -CIHI released a discussion paper which proposes standards for the collection of race-based and Indigenous identity data in healthcare Failures: -lack of clear and transparent communication between CIHI, Shared Health, and provincial REI team -lack of Indigenous governance agreements between Manitoba and CIHI	Outcomes: -no Manitoba REI data has been collected or shared to CIHI -no plan to send REI data to CIHI without proper governance agreements in place Evaluation: NIA

Viewing through CIET lens - Critical reflections on REI data collection initiatives

The CIET guided critical reflections of REI data collection initiatives which are presented as a series of narratives that look beyond the mapping of actual activities for each initiative, to address the second objective of the scoping review. Through the analysis process, the focus was on uncovering and understanding relations of power, noticing spaces where social justice activities were present, and valuing Indigenous voice as evidence. This analysis identifies trends over the last two decades including the impacts on Indigenous Peoples and communities, along with key gaps.

Evolving purpose of REI data collection. Noted trends over time suggest the purpose for REI data collection is shifting away from solely supporting health system decisions concerning Indigenous Peoples and towards a stronger focus on understanding the health and healthcare needs of Indigenous people by listening to them. In contrast to past healthcare practices and decisions, the intent is moving away from finding ways to make Indigenous people more suitable to the mainstream healthcare system and opening to identifying where the healthcare system does not meet the needs of Indigenous Peoples. Thereby learning how the healthcare system is failing First Nations, Inuit, and Métis people and bringing forward the knowledge necessary to change the system.

Inclusions of Indigenous specific drivers. During the first attempt of the WRHA/SBH initiative, an early initiative that has impacted the collection of REI identifiers in other locations, Indigenous-specific considerations are mentioned only once in the list of key drivers, and "Aboriginal", the chosen identifier at the time, was used infrequently within the related documents shared by key informants. Key drivers for the collection of REI data were based on the need to understand the patient populations better to establish translator services, and the

desire to better understand and respond to health disparities. However, there is no discussion of the origin of the health disparities or whom the disparities were impacting. The second attempt of the WRHA/SBH, approximately 5 years later, saw an increased recognition of the growing diversity of the Manitoba population, however, references to "Aboriginal" peoples were still infrequent. While there was mention of the need to make health disparities visible, there was no further discussion of what those disparities were, what their cause was, who were suffering from them, evidence of a lack of visibility or awareness into what was happening within the healthcare system in regard to Indigenous health.

Recent initiatives show more consideration and involvement of Indigenous governance, cultural safety training and education, timely reporting of results for deliberate improvement action, real-time evaluations to determine barriers and facilitators and monitor for undesired harm, and Indigenous involvement at all stages and processes of the initiatives. During more recent initiatives, key drivers for REI data collection has focused on identifying and measuring health and healthcare disparities impacting Indigenous Peoples and finding solutions for improving Indigenous healthcare quality. REI data collection was now understood as a means to hold systems accountable for the treatment provided to Indigenous Peoples and for improving accurate health reporting involving Indigenous Peoples. Recently, as we near the implementation of provincial REI data collection in Manitoba, the message being communicated is that REI data is necessary to address and disrupt anti-Indigenous racism.

Earlier established initiatives had a heavier focus on equality over equity. Reasons for REI data collection were explained as ways to ensure that the same quality of care was provided to everyone. With more recent initiatives, such as the Indigenous COVID-19 response, efforts were made to show how care for the Indigenous community could involve culturally safe, appropriate,

and compassionate services and supports. By focusing on achieving equitable healthcare and health outcomes, there is an understanding that knowing more about the identity of individuals supports the provision of different types of patient care to meet patients' specific needs. This is what is required to balance the equity scale.

Other initiatives throughout the environmental scan fall somewhere in-between with key drivers being connected to supporting the wellbeing of Indigenous Peoples, but without being centered within the work being done. It also depends on the type of healthcare site, as sites that involve working closely with Indigenous Peoples specifically have a much stronger focus on making sure that the collection of REI data is done by meeting the needs of the Indigenous patients they serve.

Inclusion of Indigenous Peoples. When examining the inclusion of Indigenous individuals and collectives in the development, drivers, and implementation of these REI data collection initiatives, over time, there is an increase in the frequency of Indigenous inclusion. During the first attempt of the WRHA/SBH initiative, ethnocultural community consultations occurred as part of the evaluation, however, there was no Indigenous community consultation. When the WRHA/SBH attempt was revisited approximately five years later, there was and increased focus on Indigenous health which involved endorsement from the First Nations, Métis, and Inuit Committee of the WRHA Board. A proposal to include representation from WRHA Aboriginal Health Services on the RLEIC, demonstrated a shift in perspective over time. In 2016 and again in 2019, the idea for REI data collection was brought forward at the request of WRHA and Shared Health respectively. With these two initiatives, the safety and protection of Indigenous Peoples and Indigenous data have become a priority.

Looking forward to the RL6 file, Indigenous COVID-19 response, the MB COVID-19 REI data collection, and the current MB REI data collection strategy, these initiatives have been Indigenous-led, and have included Indigenous Peoples as critical members of the planning and implementation teams. The importance of Indigenous involvement is centered in these later initiatives and occurs at the earliest stages. These Indigenous-led initiatives involve intentional work to learn about the health and healthcare experiences of Indigenous Peoples, increase Indigenous healthcare quality, achieve health outcomes that meet the needs of and support the health and wellbeing of Indigenous Peoples, and design and implement data collection processes that will not cause additional harm to Indigenous patients. When Indigenous people are involved, the insight into what is needed supports a purpose beyond simply collecting data for research or systems transformation. Instead, the intention to identify and measure racism in healthcare systems is brought into focus, along with the development of interventions to address racism. Monitoring and evaluation are understood as necessary to ensure protection against harms, and to support the drive for the disruption racism within the healthcare system.

However, the involvement of Indigenous people in REI data collection may not always result in REI data collection being done in the best way possible. Several initiatives, while involving Indigenous leadership, needed more clarity with the intention or purpose of REI data collection. In these instances, key informant discussions and related document reviews suggested the intention to address racism, but initiatives often lack the required elements to ensure REI data could achieve this goal. Earlier initiatives also appeared to hold the potential to cause harm through the lack of governance agreements, evaluation, and public reporting. These earlier gaps became a place from which to learn lessons, and which have generated the emerging standard requirements for REI data collection.

Acknowledging the presence and impacts of racism. During the early REI data collection initiatives, the presence of racism within the healthcare system was often denied or deflected, notable by the absence of the word racism in documents. Despite the systemic tendency to deny the existence of racism within the healthcare system, some individuals certainly saw and understood the impacts of racism on patients and their families, even though this was not reflected in official documents. It was this awareness that drove the initial attempts to collect REI data within the MB healthcare system. In recent years, the recognition of racism and its impacts has become more visible through increased acknowledgement, discussions, and inclusion of racism terminology. For example, the word racism is used in the RL6 file script developed for staff in its explanation of the reasoning for the collection of the data. The presence and impacts of racism were acknowledged in key informant discussions acknowledging how a key driver for the collection of REI in the RL6 file is the ability to build a case for the existence of racism in the healthcare system and to understand better how much of the patient experiences or complaints are the result of racism. From the initiation of the MB REI data collection strategy in 2019, the word racism has been used often, without hesitation, and has never been questioned. As well, the initiation of the MB COVID-19 REI data collection reported on disproportionate effects of COVID-19 on Indigenous Peoples and the impacts of racism in relation to the pandemic.

Reactions to the asking of REI data collection questions. Across all initiatives, there is a shared experience of staff discomfort in asking patients the REI identifier questions. The result of this discomfort is that staff often stop asking the REI questions to patients. Common explanations for the discomfort included not wanting to offend the patient, fear of patient reactions, the context of the patient's experience (illness or injury or serious incident), and

interactions with patients being too brief. Notably, the discomfort was not limited to non-Indigenous staff members as self-identifying Indigenous staff also reported feeling uncomfortable asking Indigenous patients to identify. Even staff who reported feeling comfortable enough to forgo the use of scripted questions, reported feeling discomfort in asking the REI questions. The discomfort was not confined to the staff; several key informant discussions and reviewed documents highlighted patient complaints regarding discomfort and disagreement with the collection of REI data. Where there was an opportunity for staff to provide explanations to questions about the collection of REI data *(why was it was being collected? who was going to have access? how was it going to be protected? how was it going to be used? what impact was is going to have on healthcare?)* there was evidence to show that this eased feelings of discomfort and uncertainty for patients who were then more likely to agree to answer the REI questions. The evaluation of the MB COVID-19 REI data collection initiative found that less than 2% of patients declined to declare their identity. It was found that patients felt comfortable, safe, and respected when answering the REI questions when provided scripted statements about why REI data is being collected and scripted answered to frequently asked questions. Transparency and the proper staff training in answering patient questions and concerns were crucial in generating positive reactions to the collection of REI data in the healthcare system.

Both staff and patients' perceptions of REI data collection and responses to asking or being asked to identify are aligned with the provision of adequate training and education on how to collect REI data. Across the initiatives, a lack of proper staff training made staff feel unprepared and uncomfortable with the process, which dissipated once proper training was introduced. Unfortunately, a lack of recollection or documentation of staff training for a number of the early initiatives made it challenging to determine how training, or the lack of it, impacted these early

initiatives. However, the development of training has been a central component of the more recent initiatives, generating evidence of the importance of training scripts, videos, and modules, and highlighting the progression over time of what is recognized as critical to the process of REI data collection. While training commonly involves guidance on asking and recording the REI data, key informants agreed that an additional necessary component involves education on the history and context of Indigenous Peoples lives and experiences in healthcare specifically.

Governance and Reporting of REI data. Differences in the understanding of the meaning of governance, data sharing agreements, and Indigenous sovereignty are driving factors in the lack of consistency of presence or application of governance frameworks or agreements for REI data collection. Within some initiatives, Indigenous governance of data implies that consultation and approval of Indigenous Peoples must be obtained prior to collection along with including Indigenous Peoples in decisions regarding Indigenous data collection, storage, access, use, and reporting. For others, Indigenous data governance relates to health data only, which was different from what was being collected or shared through their process of REI data collection, and therefore was not required. Turning to the first attempt of the WRHA/SBH initiative, there was no mention of partnerships, discussions, agreements, or approvals from any Indigenous representatives. As it appears from the shared documents, this first attempt was the catalyst for the implementation of identifier collection at other sites, such as the community EMR system, the AHWC, and the RAI tool; as there was no mention of Indigenous engagement or governance/sharing agreements in place during these initiations.

Over time, the importance of Indigenous engagement to support data protection, management, and governance has emerged. For example, while key informants noted the lack of Indigenous engagement in CIHI's early REI data initiatives, they have since developed an Indigenous health

team along with governance policies requiring approval from Indigenous authorities prior to reporting on data identifying Indigenous Peoples. These additions are evidence of the progression of recognizing the importance of the proper governance of Indigenous data. Collection of REI data during the COVID-19 pandemic and the MB REI data collection strategy prioritized having established governance agreements prior to the collection of data. REI data collected within COVID-19 positive case forms and vaccination consent forms was supported by both existing sharing agreements and community consultations where transparent sharing regarding the data collection purpose and procedures led to approvals and acceptability. Data was carefully protected by having the approval for data access run directly through the leadership of these initiatives. This work was guided by a BIPOC working group with members of various racialized communities with experience and expertise in a number of key areas who continue to influence and support the MB REI data collection strategy. Furthermore, the MB REI strategy has a governance working group dedicated to establishing a governance framework to be officially established through provincial legislation.

REI data collection is now drawing connections with existing frameworks for Indigenous research, reconciliation, governance, and ethical considerations. While early initiatives lack evidence of this connection, in 2016, following the release of the TRC Final Report and the Calls to Action (Truth and Reconciliation Commission, 2015), the connection between REI data and the responsibility to align with and respond to the existing and critically important documents such as the RCAP (The Commission, 1997), TRC (Truth and Reconciliation Commission, 2015), UNDRIP (United Nations, 2008), and the report of the MMIWG inquest (Canada, 2019) became more prominent. An increased recognition and inclusion of Indigenous rights-based framing for REI data collection is recently notable. Part of this is the realization that this data can no longer

serve the healthcare system only and must benefit the Indigenous people. Reporting must extend beyond the internal organizational reporting, not create additional harm to Indigenous Peoples, demonstrate direct outcomes/impacts, and be intentional in addressing and disrupting anti-Indigenous racism.

Discussion

An environmental scan of Indigenous identity data collection initiatives implemented in Winnipeg over the last two decades revealed both successes and failures, and sheds light on how we came to our current positioning. It is crucial to sharpen our understanding of what led to the mistakes of the past and barriers preventing successful and sustainable REI data collection. One key insight is to open a narrative of who has been involved with planning and implementing these initiatives: who holds the power in the collection, utilization and reporting of REI data. In other words, how power and control determine the narratives told regarding REI data collection initiatives. A critical analysis through an Indigenous lens opens spaces to examine the impacts on Indigenous Peoples. Application of the CIET framework reveals where and where not REI data collection has supported the empowerment and resurgence of Indigenous identity.

While there has been an increased awareness of the need for Indigenous inclusion and partnership in processes for REI data collection, there is still a lack of awareness and discussion of how to do this work in ways that honours distinct Indigenous identities and worldviews (ways of being, knowing and doing). While there has been work on nation-specific research guidelines, which include protection of peoples, knowledge, and specifically data governance (Hayward et al., 2021), this has yet to become a central component of discussions, understandings, and initiatives for REI data collection in Manitoba, In highlighting the need for First Nations, Inuit,

and Métis inclusion and partnership in all processes of data collection, it brings light to the issue of ongoing inequities in the social determinants of health that impact abilities to further progress in this area. Not only does there need to be efforts to open spaces for Indigenous Peoples in positions of power and leadership, but there also needs to be in place systems to support the processes to prepare us for those positions. CIET opens new ways to imagine pathways of progress and empowerment for Indigenous Peoples, rather than simply identifying systemic barriers. However, ongoing work is required to ensure that First Nations, Inuit, and Métis peoples walk into that empowerment together.

Altering the stigmatization of Indigenous identity narrative

With the collection of REI data, there have been reports of discomfort from staff tasked to ask the question and collect the data (Gibbens & Bowen, 2009; Hasnain-Wynia et al., 2010; Petkovic et al., 2019). In a rapid review of literature discussing the impacts and perceptions of demographic data collection, Petkovic et al. (2019) found that healthcare providers and other staff who collect REI data commonly felt uncomfortable or worried about asking patients about their REI identity. Concerns included fear of making patients feel uncomfortable, making patients feel discriminated against, creating fear about the misuse of data or privacy issues, offending patients, generating adverse patient reactions, and causing patients to worry about the quality of their care (Petkovic et al., 2019). In this environmental scan, staff discomfort was commonly cited as a reason for the hesitation or refusal to ask the REI data questions. Questions about Indigenous identity are stigmatized as negative, shameful, uncomfortable and, in some cases, racist. This raises the question of why there is a stigmatization of the collection of REI data and who has held the power to spread and uphold this stigma. Discomfort in collecting demographic data does not exist when it comes to asking about religion, marital status, income

and other points of demographic data, but discomfort is felt strongly when it comes to REI data, especially Indigenous identity data. Interestingly, this response to REI data collection and asking about Indigenous identity was reported to even occur amongst Indigenous-identifying staff.

The CIET lens drew attention to uncovering and understanding relations of power when considering the narrative of staff discomfort with REI data collection. The narrative was heard from those in positions of power who make decisions about healthcare policy and practice, and appears to be an accepted narrative with limited or no questioning of what is underlying the discomfort. REI data is being red-flagged regularly in the presence of Indigenous Peoples. The comfortable position among healthcare leadership and staff they manage has been to frame staff discomfort being a response to the Indigenous patient's reaction; rather than seeing the discomfort as an act of colonization, stigmatization, and discrimination of Indigenous Peoples. While there is a narrative acknowledging the difficulties with Indigenous identity and feelings of discomfort, any connection to stigmatization is deflected as far away as possible. This is facilitated by those in positions of power and again raises questions about whose needs are being given priority or are being met with acceptance of the discomfort narrative. Without looking deeper, the current situation reveals how these relations of power impact Indigenous Peoples' ability to safely identify within the healthcare system and receive care that meets their needs. Allan and Smylie (2015) give context to this practice of reinforcing the legitimacy of racist stereotypes and how it becomes normalized to ignore, dismiss, or justify racist behaviours because of the perceptions of Indigenous Peoples as insignificant and unworthy. Through this ignorance and silence, the cycle of stigmatization and colonial violence continues and strengthens. Staff discomfort bleeds into the system so much that leadership becomes consumed with the concern that asking staff to collect REI data will inconvenience the staff; and without

questioning the roots of this perception. Moreover, this ingrained stigma perpetuates another commonly held narrative that there is something inherently wrong and burdensome in asking about race, ethnicity, and Indigenous identity. Calling this out, challenging the legitimacy of these 'discomfort' claims, and unraveling the complexities of how relations of power work to maintain and solidify oppressive practices is an act of social justice. In doing so, a movement can be made to disrupt power relations and dismantle stigmatizing ideology around Indigenous identity.

Awakening to see how power is obtained, manipulated, and maintained gives power to challenging harmful and oppressive narratives. Seeing and unveiling oppressive realities reminds us as Indigenous Peoples that we are not the problem. Uplifting Indigenous identity by the disruption of white settler norms through Indigenous empowerment is social justice in action. The stigma-based hesitation in asking the question about Indigenous identifiers is an act of racism in itself. It solidifies a connection that has been building since the beginning of colonization, that Indigenous identity equates with shame, insult, guilt, and aversion; therefore, creating the belief that it is an insult to ask about Indigenous identity. It is time to disrupt these processes of power-holding through resistance to the narratives that are driving these beliefs and interrogating power and privilege. This is a strong example of the power of Indigenous voice as evidence, where the dominant and accepted version of the story is shattered, and legitimacy is given to the story of the oppressed.

Fortunately, and as seen through the environmental scan, ideological changes are occurring over time. Twenty years ago, the existence of racism or the idea that racism could be impacting healthcare experiences was often denied or absent in healthcare system planning meetings. Today, progress has been made towards accepting the existence of all forms of racism in the

healthcare system, instigated through strong Indigenous leadership and advocacy in Manitoba. Shared Health's commitment to disrupting racism (Shared Health, 2023b) and the College of Physicians and Surgeons' statement and apology on Truth and Reconciliation and Indigenous-specific racism in medical practice (College of Physicians and Surgeons of Manitoba, 2023) both indicate we are shifting and awakening to acknowledgement of the impact of relations of power on health and healthcare.

Required support through invested and Indigenous leadership

Systematic change requires full leadership support for disrupting and dismantling racism within the healthcare system, which is imperative for Indigenous Peoples' acquisition of healthcare at the highest attainable standard of physical and mental health (United Nations, 2008). As the loss of invested leadership has led to key relationship breakdowns and failure of initiatives, invested leadership is required across diverse considerations and must commit to both the value and importance of REI data collection (Wray et al., 2013). For example, during the MB REI data collection initiative, disjointed leadership at the top level contributed to the breakdown of relationship with an educational training consultant with expertise in the area of REI data collection. In addition, space for Indigenous leadership is imperative when addressing the collection of Indigenous identity data to ensure Indigenous voices and worldviews are at all planning tables. As an Indigenous worldview brings unique understandings and considerations to a table, it is critical to have invested leadership that includes Indigenous leadership. For example, Indigenous leadership will center the existence of colonization and the racialized oppression that continues to impact Indigenous Peoples, an underlying social justice issue informing REI data collection initiative. Holding this leadership space and doing this important work of challenging

the norms is necessary to move Indigenous Peoples out of the margins, and empowering Indigenous Peoples to have space to challenge oppressive relations.

The environmental scan revealed a lack of evidence of Indigenous involvement in a number of the early REI data collection initiatives. This raises questions of who is making decisions and what perspectives of Indigenous health and healthcare were shaping decisions. REI data collection processes today are led by Indigenous and other people of colour whose voices are defining and shaping processes for data collection, storage, access, and reporting. These leaders speak publicly about the importance of REI data collection and the critical need to protect both the data and the people who share their identities. In some cases, this requires others to step back and make space for Indigenous leadership to step in and hold positions of power. Successful and safe collection of Indigenous identity data within colonial/Western-based systems is only plausible with strong and consistent involvement of Indigenous Peoples; that is, leadership, organizations, communities, and individuals. As well, transparency of REI data collection in regards to leadership, management, contributing voices, and decision-making is required to build trust and demonstrate how Indigenous-led decision-making shapes these initiatives.

Impacts of Transparency and Consistent Information

Transparent communication about all aspects of REI data collection pertaining to purpose, use, access, and impacts of the data collection are noted to be beneficial for success. Being able to question healthcare staff and healthcare policies and practices, and receive appropriate and satisfactory responses, is a social justice right that should not be denied of Indigenous people. It is no longer acceptable to expect Indigenous Peoples to accept obscured answers or lack of information shared. Indigenous Peoples are recognizing their rights to equitable and high-quality healthcare. In their rapid review, Petkovic et al. (2019) found that both patients and providers

expressed concerns over misuse of data and patient privacy, which was also heard through this environmental scan. A key barrier limiting identity sharing lies uncertainty about how it will impact healthcare (Petkovic et al., 2019). To address this issue, REI data collection initiatives must provide consistent information on the purpose of data collection, processes, quality and quality assurance, protection, management, and use of the data. Scripts can provide clear and consistent information and should be co-developed with Indigenous Peoples to ensure their voices guide related decisions. Equally essential is a mandatory training program for all staff who are collecting REI data (Wray et al., 2013). REI data collection training which includes education on the colonial-based history and experiences of First Nations, Inuit, and Métis people, the practice of cultural safety, and the importance of health equity, and which challenges the acceptance of white settler ideology should be mandatory. Health systems must commit to funding and supporting cultural safety training and education programs such as the Manitoba Indigenous Cultural Safety Training course (WRHA, 2023b).

Creating space to explore how the healthcare system can acknowledge and honour Indigenous people's reactions and resistance to oppression will support REI data collectors in asking the questions and, more importantly, knowing how to address questions posed to them. Ongoing education of critically important teachings and lessons learned from the RCAP (The Commission, 1997); the Tri-Council Policy Statement (Chapter 9) Research Involving Indigenous Peoples (Government of Canada, 2018), the TRC Calls to Action (Truth and Reconciliation Commission of Canada, 2015); the UNDRIP (United Nations, 2008) the inquest into the death of Brian Sinclair (McCallum & Perry, 2018) and other significant bundles of knowledge are required to shift relations of power and respect for Indigenous people and their voices and to disrupt the current common reactions of discomfort and shame. These teachings

are legitimate ‘data’ demonstrating how the system fails Indigenous Peoples and reveals the need to move away from the negativity that still seeps through from a long history of harm. While not entirely silenced, these teachings were infrequently included in discussions or documents examined for the environmental scan. Questioning why this silencing is common and creating ways for this knowledge to be integrated content of REI data collection training and education are priorities. To realize action on this priority will require moving rationale for REI data collection beyond administrative health datasets to also building tools to address and disrupt racism, which will also improve the health and healthcare for Indigenous Peoples. Identifying a pathway to Indigenous identity empowerment within healthcare as an outcome of REI data collection initiatives is also a social justice issue. Giving staff a script without the above-described training and education closes off opportunities to break cycles of ignorance around the history of colonial violence against Indigenous Peoples and the discrimination and racism that continues to impact Indigenous Peoples, jeopardizing the success of REI data collection.

Indigenous Governance

Indigenous sovereignty and data governance discussions within Indigenous spaces have existed for some time (Smylie & Firestone, 2015). In the field of REI data collection, data governance can be discussed, but as learned through this environmental scan, until very recently these discusses led to limited actions. As MB and other Canadian provinces are about to embark on formal provincial-level systematic REI data collection initiatives, there will be greater opportunity to establish data sharing or governance agreements in support of using REI data to support evidence-informed healthcare decisions to address healthcare equity. Public reporting of REI data in ways that benefit Indigenous people will increase the success of REI data collection, and most likely the quality of REI data sets. There must be transparency around how REI data is

being used and how the process adheres to principles for the data governance agreements with Indigenous Peoples. The success of REI data collection will depend on the visibility of the concrete and deliberate action stemming from the data. To take identity data and do nothing meaningful for Indigenous Peoples will be detrimental to any attempt to collect REI data.

The recent MB REI data collection strategy and MB COVID-19 REI data collection initiatives both came with an Indigenous governance plan. Key informants noted the discussions about the the importance of education regarding Indigenous sovereignty and the practice of Indigenous data governance, including what it means, how to honour governance agreements, and how to achieve it. This is an indication of the gaining of awareness of the necessity of these agreements. If Indigenous people declare their identities with the assurance of collected data resulting in improvements in the provision of safe and equitable healthcare, transparency around the use of Indigenous voices is a reasonable expectation. Moreover, Indigenous people have the capacity to designate how data is to be governed. Reflecting on the work of Smylie and Firestone (2015) the lack of Indigenous leadership in the governance of Indigenous data is a barrier to obtaining accurate and useable Indigenous health information. Indigenous leadership in data governance issues holds high importance as it is seen as a component of the inherent right to self-determination (Smylie & Firestone, 2015), which is known to be the most important determinant of health for Indigenous people (Reading & Wien, 2009). As formal strategies are being implemented, it is time to move forward with formal governance agreements concerning collecting, using, and reporting Indigenous identities and data; this is an act of social justice. Returning power to Indigenous people through sovereign governance of data capable of producing legitimate evidence of previously ignored or muted healthcare issues is the change Indigenous Peoples have been advocating for decades.

Limitations

Key informant discussion revealed that while REI data collection has been occurring within Winnipeg, it is challenging to build a complete history or understanding of the processes involved in each initiative. Key informants took time during their work hours to meet and share their knowledge and recollections of their involvement in the initiatives. Being conscious of time and the busy schedules of key informants limited the length of discussion sessions. For some key informants, this work happened many years ago, making it challenging to recall specific details. There is also the issue of staff turnover, as staff involved in early REI data collection strategies are no longer working in these positions and cannot share their knowledge. At times, key informants suggested other possible informants, but upon contact, they were not interested in discussing the issue or did not respond to the request for discussion. REI data collection was not a current work priority for many people contacted and therefore, they might not have been able to prioritize additional time for further discussion. Finally, the impacts of COVID-19 restricted the ability to meet with people in person. Meetings with key informants needed to be done via video or telephone, which might have impacted responses given or information shared. Each of these considerations could affect the completeness of data to reflect initiative; however, efforts were made to supplement key informant sharing with shared documents and online resources. On a final note, while questions and examination of the quality of data collection are very relevant to REI data collection and the promise of quality disaggregated data sets, this was not within the scope of the environmental scan designed and conducted.

Conclusion

As the province of Manitoba is about to implement the collection of REI data within the provincial healthcare system, examining the past and present contexts of this data collection in Winnipeg produced valuable evidence. From an Indigenous perspective, it is important to look back and know where we have come from, as it informs what it is that we are bringing forward into the future. It is essential to go into this process of REI data collection knowing this historical and contemporary knowledge, as each of these initiatives, whether they succeeded or not, have all contributed valuable knowledge that has aided the progression of REI data collection.

Application of the CIET lens drew attention to actions empowering Indigenous Peoples to reclaim their identity in spaces where their existence was regulated through white-settler norms. CIET opened the way for a deeper examination of REI data collection initiatives, which revealed that while there is still much work to do, recent initiatives demonstrate the power of Indigenous voices and advocacy. Through the growing space for Indigenous leadership, REI data collection initiatives are becoming more transparent, supported by sharing of adequate information, along with appropriate training and education of staff, and patient supports. It is important to point out where initiatives have not supported empowerment, to learn about where growth is required. There is clear evidence to celebrate the ways and spaces where progress is unfolding in a good way. CIET shifted our attention to advance our understanding of progress achieved with strong Indigenous leadership, advocacy, and through hearing Indigenous voices.

Chapter 4 Relationships – In between chapter sharings

I was inspired to take on a critical perspective on how evidence on Indigenous Peoples is created and who controls the narrative. Chapter 4 aims to answer questions around how we come to know what we think we know about Indigenous people's healthcare experiences and how Indigenous identity is upheld and honoured throughout the evidence generating processes of research. This comes at a critical point where access to health data disaggregated by REI identity is on the horizon. As such, a critical review can shed light into the various evidence production structures that the use of REI identity data will be subjected to within academic contexts.

Contribution of Authors

My contribution to Chapter 4 includes relationship building, idea formation, study design, theoretical framework development, knowledge gathering, meaning making, and writing of the chapters. My primary supervisor Dr. Schultz provided critical feedback in the development of the chapter. With the scoping review, Dr. Schultz played a more significant role due to the iterative nature of the scoping review method and the common practice of including multiple reviewers. This chapter utilizes third-person language as well as the word "we". Revisions to the writing were based on feedback from my dissertation committee; Dr. Schultz, Dr. McPhail, Dr. Anderson, Dr. Smylie, and Métis Elder Barbara Bruce.

Traditional Knowledge Sharing

I have heard many teachings where people have been given tasks or have understood their purpose in life through their visions and dreams. As a First Nations' woman, I understand the importance and realness of visions and dreams as they can be powerful connections between the

living and spirit worlds. This is often a place of meaningful and important work and I admire the respect that is held for dream and vision work within First Nations culture. It is understood and accepted as real and valid knowledge. I have been taught that what comes to me in these spaces is meant to be interpreted as lessons or guidance that will bring clarity or purpose to my life.

In this section I wanted to share a personal story as an example of how traditional knowledge keeps me well and motivated to do good things. While I don't often have visions, when I do, they are powerful, evoking emotion in a remarkable way, and becoming anchored in my mind. Sometimes they come when I pray to have a vision, or a sign brought to me but other times they happen randomly and unexpectedly. It was a summer day when I finally found some time to run at the track. It was a gloriously hot morning and I had set my music and started running. Running felt amazing and I was feeling good about the improvements I was making to my physical health. Nearing the end of my run a particular song came on, into my headphones. The drum beat brought shivers to my body, the voices started, and I felt an emotional tightness building in my chest. Something was happening. Then all of a sudden like a movie flashing in my mind, I had a vision. What I saw was flashes of myself in graduation robes walking on the stage up to the podium to receive my graduation diploma, adorned with an eagle feather and beading. This then switched to a vision of my walking into a room of my family and friends to celebrate my graduation from my PhD program. These were such strong visions. At this point I was still running on the track, sweating profusely due to the hot and humid weather and tears were flowing out of my eyes because I was overcome with emotions of joy. The visions were so colorful, so powerful, so strong that they reverberated through my whole body. Everything felt so big in that moment, like all energy was flowing around me. It was completely unexpected but amazingly awesome. A few days later I was talking to a very dear colleague about this and I kept

saying how I had no idea where this vision came from. To which she simply replied two words, The Creator. In that moment it all made sense. When I open myself up to receive, I am often given exactly that I need. This is how I understand relationship with The Creator. In addition to the improvements to my physical health, I had also recently taken a focus to writing my dissertation. The run happened a few weeks into this new outlook on my work, my progress, and my self-worth. I had been working extremely hard at getting myself back on track with my dissertation progress and had been feeling good about myself. In this moment, I was given this gift of a vision as encouragement to keep working hard and a reminder that I already have everything in me that I need to reach my goals. It was one of those moments that will stay with me as a component of my dissertation journey and how my connection to traditional knowledge has guided me and my work.

Chapter 4: Raising Indigenous Voice: Uncovering how First Nations, Inuit, and Métis identity informs, impacts, and influences research on Indigenous healthcare experiences in Canada.

Introduction

"Indigenous re-search methodology has been a process for me whereby I make visible what has been erased and rendered invisible" (Absolon, 2022, p. 4).

Healthcare delivery and policy development involve evidence-based processes, reliant on research evidence primarily found within peer-reviewed published and grey literature, and experiences of practice. Both research and practice evidence shape our collective understanding of health and inform strategies to address identified concerns (Reimer-Kirkham et al., 2007). Health researchers and healthcare leaders access databases, journals, books, and reports to advance their knowledge when strategizing ways to restructure healthcare systems to address health priorities. There are growing bodies of research evidence within the fields of Indigenous health and healthcare which describe the lives and experiences of First Nations, Inuit, and Métis peoples in Canada, along with population-based health information derived from quantitative and mixed methods studies and information sources (Firestone et al., 2014; Hayward et al., 2020; Katz et al. 2019; Kitching et al., 2020; Monchalin et al., 2020a; Monchalin et al., 2020b; Smylie et al., 2018). Given that this body of research evidence aims to advance our collective understanding of Indigenous people's health and health care experiences and outcomes, we suggest a closer look at this evidence as critical reflection upon evidence production is warranted.

Research methodologies which embrace and support Indigenous world views are emerging and setting methodological standards (Absolon, 2022; Cardinal, 2001; Hyett et al., 2018; Hyett et al.,

2019; Katz et al., 2019; Kovach, 2009; Kovach, 2010; Lambert, 2014; Lewis, 2012; Rotondi et al., 2017; Simpson, 2011; Smith, 1999; Steinhauer, 2002; Weber-Pillwax, 2001, 2004; Walter & Andersen, 2013; Wilson, 2001; Wilson, 2008). Common topics of inquiry include Indigenous Peoples' culture, knowledge, health, healthcare experiences, determinants of health, health status, and health service access which aim to address documented health disparities. In Canada, there is growing interest in utilizing Race, Ethnicity, and Indigenous identity (REI) data collected within healthcare settings (CIHI, 2020; Grant et al., 2019; Kirst et al., 2013; Lofters et al., 2011; Pinto et al., 2016; Quan et al., 2006, Smylie & Firestone 2015; Varcoe et al., 2009; Wray et al., 2013), which will support research designed to report disaggregated results. The attraction to working with disaggregated data by race and ethnicity, and specifically Indigenous identity, is the potency of data to produce research evidence of successes and failures of the systems to support the health and wellbeing of Indigenous Peoples (Smylie, 2009; Wray et al., 2013). Research that produces and applies high quality population-based Indigenous specific data can and has advanced our understanding of healthcare systems and our ability to meaningful respond to substandard care rooted in systemic racism (Allan & Smylie, 2015; Katz et al., 2018; McBride, 2017; McNally & Martin 2017; Nestel, 2012; Rotondi et al., 2017; Smylie et al., 2018). The collection of Indigenous identity data specifically, can support the design and implementation of research and policies specifically for First Nations, Inuit, and Métis peoples. While the potency of data disaggregated by REI identity is easily appreciated, taking a moment to critically reflect is essential; in particular, to reflect upon how Indigenous Peoples, voices, and ways are respected and integral throughout all phases of research. When working with Indigenous specific data sets, close attention must be paid to how colonial-based structures that erode the identities and voices of Indigenous people, are being disrupted through evidence

production. Otherwise, production will result in the reporting of skewed evidence concerning Indigenous health and healthcare disparities in which Indigenous voices are silenced through erasure of large subpopulations of Indigenous people (Kurtz et al., 2008; Matthews, 2017; Smylie & Firestone, 2015). Evidence that this already happens unchecked in some locations increases the urgency to monitor First Nations, Inuit, and Métis data collection to mitigate harm of the data collection process and presses us to work diligently to find safer ways to accomplish high-quality First Nations, Inuit, and Métis specific identification in datasets. Local context in which the data collection is or will be happening must be taken into consideration. Specifically, the unique identities and histories of First Nations, Inuit, and Métis people will have impacts on best practice methods for REI data collection. Ensuring that First Nations, Inuit, and Métis sovereignty is honoured throughout research and data processes is part of reconciliation.

A critical review of health research and data collection processes is imperative to moving forward in good ways with the data collection of First Nations, Inuit, and Métis data in healthcare. While critical discussions on the need to improve quality and appropriateness of health research involving Indigenous Peoples are occurring (Hyett et al., 2018, Hyett et al., 2019), at this point raising the following critical questions to guide a review of literature is beneficial. Questions such as: What do we know about who is doing this research? What do we know about how this research is being done? How are Indigenous identity and voices respected, or not? What do we know about how this research is or is not serving Indigenous Peoples? To address these questions, we designed a scoping review study of academic peer-reviewed literature concerning First Nations, Inuit, and Métis people's experiences in healthcare in Canada. In particular, we focused on how the concept of Indigenous identity is included and discussed, or not, in this literature, and how Indigenous identity and ways were considered, or

not, during the research process. In addressing these two foci, we deepen our understanding of how Indigenous identity impacts and influences the production of evidence on Indigenous people's healthcare experiences and identify guidance to shape mechanisms for the collection and use of REI data.

Co-author locations

Amanda Fowler-Woods is an Anishinaabe woman born in Thunder Bay and a member of Couchiching First Nation in Ontario, but has lived more than half of her life in Winnipeg Manitoba. Amanda is a Research Associate and a PhD candidate with a research focus on Indigenous health equity and healthcare quality; anti-racist healthcare practice, and Indigenous resurgence. Amanda is a student and carrier of 48 traditional medicines. She is a pipe carrier and learner of ceremonial protocols. As the PI of this study, Amanda designed and carried out the research as part of her doctoral dissertation. **Annette Schultz** is a settler from Alberta with French and German ancestry. She has worked within healthcare for several decades as a direct care provider, health policy analyst, and health researcher. Over the past decade, Annette has been involved with research concerning Indigenous people, and primarily heart health.

Methods

Scoping review studies aim to map the breadth of a topic, which is presented as a narrative description of evidence revealed through a systematic review of relevant literature (Arksey & O'Malley, 2005, p. 30). Descriptive narratives commonly address key concepts related to the topic, and on processes used to generate research evidence (Arksey & O'Malley 2005, p. 21). Given these two aims and the novelty of our topic, a scoping review study was designed to capture the breadth of, and describe how, Indigenous identity is addressed within health research

focused on Indigenous experiences in healthcare. We will reveal the complex and subtle ways that identity is held up or erased (Chandna et al., 2019). In designing our study, we drew on multiple authors including the seminal work by Arksey and O'Malley (2005) and updates by Levac et al. (2010), and the decolonizing approaches of Chambers et al. (2018) to scoping reviews among First Nations, Inuit, and Métis people and knowledge. The reporting of our scoping review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews (Tricco et al., 2018).

As an Indigenous led study, Chambers et al. (2018) guided our work with adaptations, to decolonize process and open spaces for Indigenous ways of being, knowing, and doing; thereby, disrupting Western-based worldviews and means of knowledge production (Chambers et al., 2018). For example, the term knowledge discovery reflects a subjective, reflexive, and context aware examination of the literature (Chambers et al., 2018) which aligns with the Indigenous research paradigm. "Scoping reviews need to move towards more reflexive and subjective engagement with literature and that they can become critical methodologies if researchers engage in an 'unpacking of a problematic that situates the work historically and methodologically" (Rieger et al., 2020). In our study, the initial review of early database searches involved conversation between AFW and AS, but also ceremony and conversation with Métis Elder Barbara Bruce, all of which led to subtle shifts of the scoping review objectives. While scoping review methods provided guidance and structure for study design, the outlined iterative processes were devoid of relational contexts commonly respected by Indigenous research methodology. Moreover, Chandna et al. (2019) reminds us to acknowledge critical self-reflection as part of the web of relational ties surrounding a topic. The Indigenous worldview is defined by relationships and accountability; knowledge that is sought within research is relational and exists

in relation to everything else in all of creation (Kovach, 2009; Lambert, 2014; Steinhauer, 2002; Weber Pillwax, 2001; Wilson, 2001).

Holding spaces for iterative exploration and relational contexts revealed and acknowledged tensions with Indigenous epistemologies. These spaces of tension demonstrate the disruption of dominating Western thought, and enhances cultural responsiveness and respect among Indigenous people – for whom the research is to benefit (Chambers et al., 2018, p. 175). Moving across spaces of tension opens capacity for relational accountability, foundational of Indigenous research (Wilson, 2008), which also leads to knowledge discovery not remaining confined to evidence in the literature. Rather, knowledge discovery also embraces learnings about self, ways of being, knowing and doing, and about all of the relationships. Indigenous research comes with a commitment to all possible relationships that ties the research together, which includes "critical self-reflection and learning" (Chandna et al., 2019). With these understandings of ways for Indigenous methodologies to work with scoping review approaches, we designed a scoping review study, which is described using the six stages outlined in Arksey and O'Malley (2005).

Stage 1: Identification of research objectives

The first step is to identify research objectives which then guide how search strategies are built, and decisions related to eligibility, data extraction, and eventual interpretation of data found in literature (Arksey & O'Malley 2005, p. 23). Through an iterative approach we identified two objectives: 1) to better understand how Indigenous identity is considered in research describing Indigenous Peoples' experiences in healthcare, and 2) to document the use of Indigenous methodologies and guiding principles of Indigenous research within the academic peer-reviewed literature on Indigenous experiences in healthcare in Canada. These objectives were informed by insights gained from preliminary searches of the literature, subsequent conversations and

ceremonies, which guided refinement and narrowing of focus. The key concepts of relevance that have guided scoping review decisions are Indigenous identity, Indigenous research methodologies, Indigenous healthcare experiences, and Indigenous guiding principles of research. See Table 8 for further details. The populations included are: First Nations, Inuit, and Métis peoples in Canada. The outcomes of interest are: 1) how Indigenous identity is considered in research relating to Indigenous experiences in healthcare; 2) background and context around the research, writing, and reporting of evidence related to Indigenous healthcare experiences; 3) evidence of inclusion of research methodologies guided by principles for conducting research with Indigenous Peoples**.**

Table 8

Scoping Review Key Concepts

Indigenous Identity	In Canada, the term Indigenous refers collectively to the descendants of the original inhabitants of the land, the First Nations, Inuit and Métis peoples who each carry distinct identities, histories and cultures (Canada, 2022).
Indigenous Research Methodologies	Research paradigm components including ontology, epistemology, axiology and methodology are practiced through an Indigenous worldview to develop and conduct research in ways that are beneficial to Indigenous Peoples and follow and honour Indigenous ways of being, knowing and doing (Walter & Andersen, 2013; Wilson, 2001).
Indigenous Healthcare Experiences Research	Research reporting on the experiences of First Nations, Inuit, and Métis people within healthcare encounters and evidence that the experiences are from the voices of Indigenous people.
Indigenous Research Guiding Principles	Principles/frameworks/guidelines for conducting research with Indigenous Peoples/communities/nations. These include but are not limited to the Royal Commission on Aboriginal Peoples (RCAP) (The Commission, 1997); Ownership, Control, Access, and Possession (OCAP) (Schnarch, 2004); the Tri-Council Policy Statement (Chapter 9) Research Involving Indigenous Peoples (Government of Canada, 2018); the Truth and Reconciliation Commission Calls to Action (Truth and Reconciliation Commission of Canada, 2015); the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2008); and the University of Manitoba's Framework for Research Engagement with First Nations, Métis, and Inuit Peoples (First Nations Métis and Inuit Health Research Strategic Planning Committee, 2014), and other community based guiding principles or frameworks (Hyett et al., 2019). Culturally rooted First Nations, Inuit, and Métis teachings/ principles/ laws guide ways of moving in the world including within the realm of research, the pursuit of knowledge, and interacting with the world

	around us (people, animals, water, land, spirits). Examples include the Four R's - Respect, Relevance, Reciprocity, Responsibility (Kirkness & Barnhardt, 1991), wahkotowin (Napier & Whiskeyjack, 2021), mino-bimaadiziwin (Stark, 2021), and the Seven Sacred Teaching (personal communication with Elders).

Stage 2: Search strategy

Scoping reviews seek to comprehensively search relevant data bases to identify primary studies and reviews, which can address study objectives (Arksey & O'Malley 2005, p. 23). We began the development of our search strategy in conversation with AFW, AS, and Janice Linton, an Indigenous Health Librarian & Liaison Librarian for Community Health Sciences at the University of Manitoba. The databases chosen included and were searched in the following order: Scopus, Ebscohost and Google Scholar. Development of the search strategy was informed by a University of Manitoba library guide for locating information on Indigenous health (Linton, 2022).

The following search terms were entered into databases using appropriate Boolean operators: "first nations" OR "first nation" OR Métis OR inuit* OR aboriginal OR indigenous AND Health OR disease* OR wellness OR wellbeing OR "well-being" OR hospital* OR healthcare OR "health care "OR morbid* OR mortality AND identif* AND canad*. Searches were limited to articles published between 1996 and 2021, and articles written in the English language. Google Scholar search was limited to the first 40 pages. A decision was made to set the inclusion start date as 1996 based on the release of the RCAP final report which outlines the first statement on the need for Indigenous research ethics (Hyett et al., 2018). This report was a historic marker for identifying systemic raced-based discrimination and brings to the forefront the importance of the maintenance of Indigenous identity for Indigenous Peoples across what is now called Canada (Palmater, 2011).

As noted previously, the objectives emerged through an iteratively process that refined the focus on Indigenous identity, which was informed by a preliminary review of titles and abstracts, conducted by AFW. Once clarity of how to explore 'identity' within literature was refined, a second Google Scholar search was conducted. As Arksey and O'Malley (2005) note "It is likely that as familiarity with the literature is increased, researchers will want to redefine search terms and undertake more sensitive searches of the literature… The process is not linear but iterative, requiring researchers to engage with each stage in a reflexive way and, where necessary, repeat steps to ensure that the literature is covered in a comprehensive way" (Arksey & O'Malley 2005, p. 22).

Stage 3: Study selection

The final search results underwent a deduplication process and then search results were uploaded into Covidence. Inclusion criteria are displayed in Table 9. The study selection process included three steps: 1) AFW conducted a title and abstract review using the eligibility criteria, and consulted with AS as needed; 2) AFW and AS conducted full article reviews independently, and discussed articles where there were discrepancies; 3) a hand search was conducted by AFW through a review of eligible article reference lists. As the inclusion and exclusion criteria evolved, a large number of articles were not retrieved or were excluded from the study during the title and abstract screening and full article review processes in Covidence.

Table 9

Inclusion and Exclusion Criteria

1) Articles must describe/discuss healthcare experiences of First Nations, Métis, or Inuit peoples in Canada. 2) Participants must include First Nations, Métis, and/or Inuit peoples. 3) The voices of Indigenous participants must be clearly defined by the author. 4) Publication date of 1996 or later. 5) Articles written in English language.

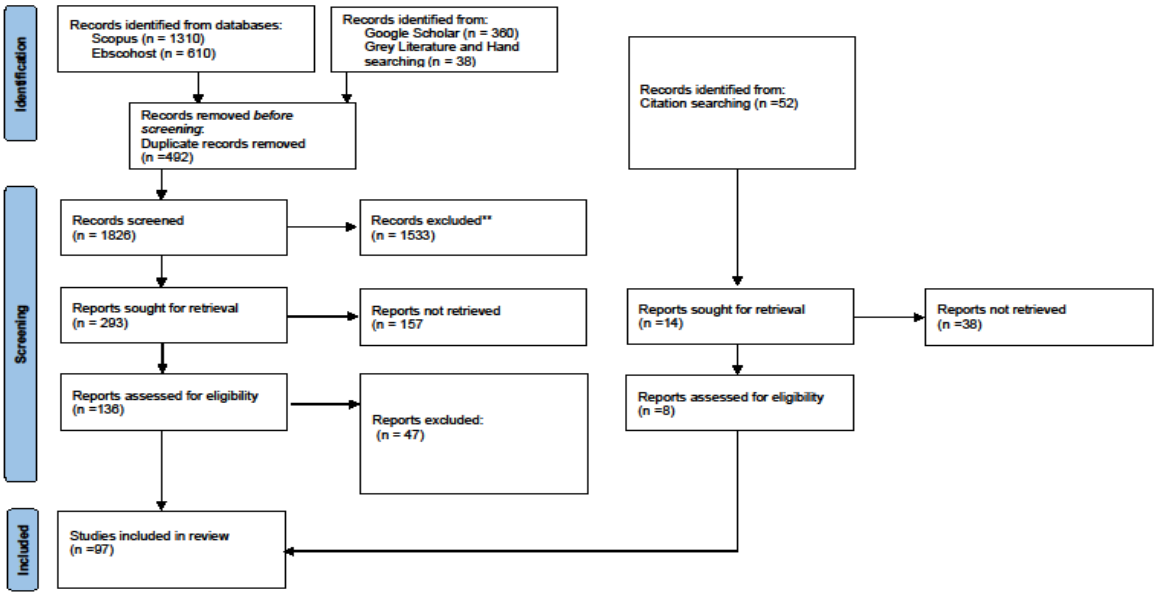
Stage 4: Charting data from the eligible literature

Data extraction was completed by AFW within Covidence, using a customized template consisting of 72 categories that were inductively created. **See Appendix J for Data Extraction List for Scoping Review. Pilot testing with 3 articles led to refinement of categories to capture all possible relevant data. Although a uniform approach of charting the data was applied to all studies, not all studies included all the relevant data and therefore information could not always be added to each category for each study.

Stage 5: Mapping, Summarizing, Analyzing, and Reporting of findings

As Arksey and O'Malley (2005) remind us, this stage of a scoping review draws the researchers' attention to priorities that emerge within the literature. Often reporting on the findings begins with descriptions of the eligible articles, which is followed by narrative description of thematic analysis aimed to address study objectives. The results of the scoping review are reported below and encourage the opening of space for further consideration of how identity is, or is not, central. See Figure 2 for the PRISMA flow diagram.

Figure 2 ***PRISMA flow diagram***



Results

Analysis of 97 eligible articles led to three key foci; each addressed individually below. We present an overview of article descriptions before addressing narrative descriptions of key foci topics revealing evidence of how Indigenous identity exists within the articles. Finally, we provide a narrative of evidence revealed of Indigenous methodologies and governance.

Describing the Articles

The articles reported on healthcare experiences involving First Nations, Inuit, and Métis people and were published between 1996 and 2021. Over these years, there was an increase in the number of articles published in this area of research; with 2019 (n = 12) and 2021 (n = 11) having the greatest number of publications. Articles were published in a wide variety of journals

(n = 64), with many journals having only one published article. Journals are primarily health related, and 6 are Indigenous specific-journals. Social Science & Medicine published the greatest number of articles (n = 5), with the International Journal of Circumpolar Health, the International Journal of Indigenous Health, and the International Indigenous Policy Journal each publishing eligible articles.

An analysis of study designs revealed that selected articles consist of qualitative studies (n = 80), mixed methods (n = 12), quantitative studies (n = 2), scoping reviews (n = 2), and a process evaluation (n = 1). Articles reported on primary research (n = 90) and secondary analysis (n = 7) studies. Most articles included Indigenous participants from within Canada only (n = 94), while 3 articles reported on studies that involved Indigenous participants from Canada along with one or more of the following: United States, Australia, and New Zealand.

Article analysis included reviewing the research purpose, healthcare topic, and study location. Eight themes captured research purposes. The first theme includes studies documenting and discussing the healthcare experiences of Indigenous people (n = 48). The second theme focuses on Indigenous perspectives of health, experiences, and ways of living, being, and doing (n=36). Six other themes are related to healthcare programming (n = 12), cultural safety/competency in healthcare (n = 9), discussion of contributing factors to illness (n = 6), healthcare provider perspectives and experiences (n = 6), healthcare service utilization (n = 2), and discussion on the development of a theoretical framework (n = 1). Healthcare topics were diverse, with the greatest number of articles being categorized as general experiences in healthcare (n = 38). The remaining categories include mental health (n = 7), cancer (n = 5), diabetes (n = 5), pregnancy/birthing (n = 5), addictions (n = 4), HIV/AIDS (n = 4), arthritis (n = 3), dementia (n = 3), Indigenous provider experiences (n = 3), palliative care (n = 3), tuberculosis (n = 3), child

health (n = 2), kidney (n = 2), maternal/child (n = 2), and sexual abuse and violence (n = 2). Location of research was reported (n = 43), with a number of those reporting a healthcare setting (n = 25). The analysis of funding sources found that some articles stated that there was no funding (n = 4) while others did not include information regarding funding (n = 22). Of the 71 articles that listed a funding source, they frequently reported Canadian Institute of Health Research (CIHR) funding (n = 36) and specifically by the Indigenous People's Health Institute of CIHR (n = 9). Alternate funding sources were provincial government (n = 18), academic institution funding (n = 16), federal government funding (n = 14), SSHRCC (n = 8), Michael Smith Foundation (n = 7), international funding (n = 6), Indigenous organization (n = 2), local municipal funder (n = 1), and personal finances (n = 1).

The inclusion of Indigenous identity

Indigenous identity is a complex phenomenon (Palmater, 2011). The complexity of how Indigenous identity, voices, and people are respected or erased, is a main interest of this scoping review. With this in mind, our search for evidence of how Indigenous identity was respected among these articles reporting on Indigenous Peoples' healthcare experiences was found through seven spaces, including article keywords, author/research team positionality, nation-based distinct identities, identities/descriptions of participants, voice, language, and discussions of Indigenous identity.

Journal **article keywords** signify important descriptors of the article, assist with indexing and finding relevant articles during database searches (Springer, 2023). Out of 71 articles that included keywords, most included an Indigenous identity term (n= 66), and some included it as the first or second word in the list (n = 22). Indigenous identity keywords listed included Indigenous, Aboriginal, First Nations, Inuit, Métis, Indian, and Gitxsan. Inclusion of Indigenous

identities within the keywords can be a first location of acknowledgement of the involvement of Indigenous Peoples and knowledge in the research.

Author positionality is another place that demonstrates creating space for Indigenous identity. Of the 97 articles, information about **author positionality** about racial, ethnic or Indigenous identity was reported (n = 37), and of these, many articles mentioned at least one author identifying as Indigenous (n = 34). Disclosure of Indigenous identity took a variety of forms. One author, under a section titled "Situating the researcher", described herself with the statement, "I am an Aboriginal midwife from Namegosibiing (Trout Lake, Lac Seul First Nation, Treaty 3), and an academic researcher" (Lawford et al., 2019, p. 1303). In another, under the heading "Researcher's characteristics", is a description of "both Indigenous (TW, LC, CB) and settler (DL, RH, ALS, IPB) backgrounds" (Loyola-Sanchez et al., 2020, p. 4). For most articles, this information was not organized under a specific heading but instead was inserted within the text in various locations. Some articles made clear statements about Indigenous identity, for example, "the third and fourth authors, who are Indigenous men working… The remaining team members involved in the research are white settler scholars" (Waddell et al., 2021, p. 2). While in other articles, identity descriptions were vague, such as "Two members were Indigenous" (Thurston et al., 2014, p. 3) with no additional descriptions or explanations. One article used superscript numbers to link the names of authors to an identity disclosure list on the first page of the article, while another chose to list the identities of authors in italics on the final page of the paper following the references (Clark et al., 2013). There were 5 articles that disclosed that no authors identified as Indigenous. There were 18 articles that addressed the positionality of other **research team members**, for example, one article noted that "The majority of the data in this study were collected by three research associates who identified as Indigenous Peoples and more

specifically, as affiliated with Northern Cree, Haida, and Okanagan First Nations", (Tang & Browne, 2008, p. 112), although there was no mention of author positionality.

Indigenous Peoples within Canada share similar experiences of colonization and its impacts; however, there is a strong movement towards **nation-based distinct recognition** in research and reporting on First Nations, Inuit, and Métis, peoples and populations. While there are shared realities, there are also important distinctions across nations. In this review, we explored how and where authors noted distinct nation-based identifiers to describe research participants. Of the 97 articles, 70 used language that specified the distinct nations-based identity terms of First Nations, Inuit, or Métis. The number of times each nation-based Indigenous identifier category appeared included First Nations (n = 60), Inuit (n = 18), and Métis (n = 18). More than one identifier was used in several articles where the research involved people from more than one specific nation. We examined nation-based identifiers used throughout each article generally. The majority of articles used the broad identifiers of Aboriginal (n = 43) or Indigenous (n = 42), while others used the nation-based identifiers of First Nations (n = 35), Inuit (n =17), Métis (n = 15). Other identifiers used included non-capitalized aboriginal (n = 3) or indigenous (n = 2), as well as Native (n = 2) and Indian (n = 1). Finally, we noted descriptions for the **identities of research participant populations**. In 61 articles, it was clearly articulated only Indigenous participants were involved; however, there was less clarity when it came to research that included mixed Indigenous and non-Indigenous participants (n = 36). The clarity in participant identity came with statements such as "Thirty-seven patients with diverse Indigenous backgrounds from at least 20 First Nations (12 patients did not provide information about their bands or territories of origin) participated in the study (Hadjipavlou et al., 2018, p. E610). Where there was a lack of clarity, we saw the statement, "Each focus group was made up of Two-Spirit people of all ages,

their families, community activists and health care professionals from a broad array of health care organizations and institutions" (Brotman et al., 2002, p. 72). While the authors clearly defined Two-Spirit as directly pertaining to Indigenous identity, the identities of the other mentioned participants were not described.

Evidence of how Indigenous identity is respected or erased can be found in the presentation of **voice**, in particular, whose voices are easily distinguishable in quotes and discussions in an article. This determination applies only to the qualitative and mixed methods studies. Inclusion of Indigenous participants' voices only (n = 58), and either mixed Indigenous and non-Indigenous or undefined voices (n = 39) were noted among the articles. There were also many instances where the voices were not Indigenous Peoples', but instead, voices of non-Indigenous healthcare staff, or other care providers, speaking about Indigenous peoples' experiences. An example of erasing identities was when Indigenous and non-Indigenous peoples' voices were included but no signifier distinguished between the two. This evidence was presented by including quotes or discussions of knowledge sharing by participants.

While all articles were written in English, some authors included **Indigenous languages** or discussions about Indigenous languages within research articles. Some articles indicated that interviews were conducted in an Indigenous language (n = 10), some mentioned the use or availability of interpreters (n = 9), and others acknowledged that Indigenous languages were spoken by study participants (n = 3). Some articles also included Indigenous language within the text of the article (n = 6). The inclusion of Indigenous language(s) demonstrates respect for Indigenous ways of knowing; rather than the sole requirement of erasing language to a Western English default position.

Discussions of Indigenous identity varied, which reflects the diverse understanding of the importance of identity. **Descriptions and discussions of Indigenous identity** were located in multiple locations throughout the articles. Of the 97 articles, 76 contained specific Indigenous identity information. Common themes seen within the literature include discussions or descriptions of Indigenous identity terms (n = 52), history and use of Indigenous identity terms (n = 19), specific nations/bands/territories (n = 18), Indigenous diversity (n = 10), urban Indigenous identities (n = 3), Indigenous statistics (n = 14), political documents (n = 14), and Indigenous identities as original or first peoples (n = 7).

Indigenous Research Methodologies and Governance

Research approaches influence the evidence generated from a study, including the type of questions asked, what data and knowledge is valued, how data is collected and interpreted, and the narrative that describes research findings. Dr. Tuhiwai Smith, Māori scholar, is a research methodology pioneer who shed light on diverse methodologies and the importance of disrupting Western-based methodologies (Smith, 1999). As our scoping review focuses on articles reporting on Indigenous people's healthcare experiences, we explored how Indigenous ways were included in the research processes reported in the articles. Specifically, we address research methodologies, principles/ frameworks/ guidelines/ protocols, ethics, Indigenous cultural protocols, relationship and relationality, partnerships, participation, addressing of history and context, benefits of the research to Indigenous people/community, knowledge translation/dissemination, and Indigenous research governance. Results within these areas demonstrate awareness of Indigenous ways of doing and knowing in the field of Indigenous health research.

There were 38 articles that discussed or described **Indigenous methodologies,** including Indigenous way of knowing, being, doing (n = 15), sharing circle/talking circles (n = 12), conversational method/storytelling/narrative (n = 7), two-eyed seeing (n = 4), relationality and relational accountability (n = 4), partnerships (n = 3), Indigenous methodologies in general (n = 2), capacity development (n = 2), benefit to the community (n = 2), medicine wheel framework (n = 1), Kaupapa Māori methodology (n = 1). One article acknowledged not using Indigenous research methodologies (I. Scheim et al., 2013). Thirty-two articles identified **principles/ frameworks/ guidelines/ protocols** for respectful research involving Indigenous Peoples that influenced their research including, OCAP (n = 18), TCPS (n = 10), TRC (n = 5), RCAP (n = 3), UNDRIP (n = 3), CIHR (n = 3), Inuit Qaujimajatuqangit (n = 1), Piliriqatigiinniq Partnership Community Health Research Model (n = 1), and the National Inuit Strategy on Research (n = 1). Some articles referred to only using one of these guiding ways, while others noted the use of multiple. Some articles aligned their research with Indigenous ethical research principles/wise practices without specifying a specific title (n = 7). **Ethical approvals** were mentioned within 77 of the 97 articles included in our scoping review. Ethics approvals were obtained from academic institutions (n = 60), healthcare systems (n = 33), Indigenous organization/community ethics process (n = 18), community programs (n = 4), and government (n = 1). One article mentioned ethical approval but did not provide any specific details. There were some articles that stated that ethical approval was not obtained (n = 5). Many articles mentioned more than one type of ethical approval obtained.

Of the 97 articles reviewed, 24 discussed the inclusion of **Indigenous cultural protocols** in their research. Cultural protocols mentioned included sharing circles (n = 7), opening/closing prayers (n = 6), ceremony/smudging (n = 5), honouring traditional knowledge/beliefs (n = 5), offering

tobacco (n = 4), feasts (n = 4), use of traditional items (n = 2), practicing cultural activities (n = 2), verbal consent (n = 2), practicing respect (n = 2), sharing of teachings (n = 2); community approvals (n = 1). While among the 24 at least one of these protocols was mentioned, some included more than one cultural protocol.

Of the 97 articles, 39 discussed **relationship and relationality** between researchers and the Indigenous Peoples involved in the research, which included project-specific relationship building between researchers and participants (n = 18), previous or long-term relationships (n = 15), Indigenous research team members facilitating relationship building (n = 7), and extended lengths of relationship building in preparation for research (n = 3). Thirty-eight articles mentioned **Indigenous partnerships,** which included community members/groups (n = 14), Indigenous health organizations (n = 13), Indigenous Friendship centers (n = 7), Indigenous leadership (n = 5), and health directors of communities (n = 2).

Most articles discussed **Indigenous participation** in the research beyond authors and research participants (n = 81). Indigenous participation included involvement of Indigenous research team members (n = 37), member checking (n = 36), community/stakeholder consultation (n = 33), involvement of an advisory committee/council (n = 23), inclusion of Elders (n = 17), and pilot studies with Indigenous participants (n = 5). Within these 81 articles, compensation with Indigenous partners to acknowledge and compensate for their time was mentioned (n = 22). It included money (n = 15), transportation and/or reimbursement (n = 5), gift cards (n = 4), meals/food (n = 4), tobacco (n = 3), and childcare (n = 1). In a small number of articles, there was no description of the honorarium (n = 4). Evidence of relationships was also found in acknowledgements, which were located in the main text area (n = 8), in the pre-text area (n = 7), and in some combination of in-text, pre-text, or post-text (n = 2). Of the 67 articles with

acknowledgements, 56 recognized Indigenous Peoples, relationships, participation, or knowledge. There were 30 articles that did not include any acknowledgements.

The inclusion of **historical and contextual details of Indigenous Peoples lives and experience** within colonial states is an evolving phenomenon with no standardized approach. Thereby, among the 97 reviewed articles, the authors included components of this information several ways. Beginning with the location of these details, most of these articles included content on Indigenous history and context within the first few paragraphs of the article (n = 65). In contrast, others included this content further into the article (n = 8). Next, we note different ways of including the content which included within the first few sentences of the article's main text (Kitching et al., 2020; Maranzan et al., 2018; Watson et al., 2012), within footnotes and endnotes compartmentalizing the information outside of the main text (Benoit et al., 2003), and at the end of the article (Pauly et al., 2016). A deeper look at the content revealed a number of themes related to Indigenous history and contexts including definitions (Indigenous, Aboriginal, First Nations, Métis, Inuit) (n = 52), history of terminology/identifiers (n = 19), specific nations/bands/territories (n = 18), Indigenous diversity (n = 10), Indigenous statistics (n = 14), political documents (Constitution Act, Indian Act) (n = 14), original/First peoples of the land (n = 7), and urban Indigenous (n = 3). There quite a few articles that did not include a discussion of Indigenous history and context (n = 24).

An important consideration in research involving Indigenous Peoples is how the research will **benefit Indigenous Peoples/communities.** Out of 97 articles, 20 mentioned direct benefits for the individuals/communities/nations involved in the research. Examples of this include the hiring of mental health and outreach workers and expanding community partnerships (Firestone et al., 2019), development of a mental health wellness program (George et al., 2019), production of

videos for healthcare providers and families (Hampton et al., 2010), setting up of Pap clinics specifically for First Nations women (Hislop et al., 1996), informing of the planning and development of an Indigenous health center (Kelly et al., 2009), development of a community needs assessment tool and documentary video for communities (Kurtz et al., 2008), development of educational workshops (McAtackney et al., 2021; Mill et al., 2008), development of an Aboriginal cancer care strategy and hiring of Aboriginal cancer care coordinator (Olson et al., 2014), and training of community-based researchers (Watson et al., 2012).

Knowledge translation/Dissemination activities were mentioned (n = 21), with a number of these addressing the inclusion of Indigenous participants involved in knowledge translation strategies and decision making (n = 7).

Formalized **Indigenous research governance** strategies were rarely discussed within the articles (n = 21) and included formal governance agreements (n = 10), listing the organization/people who govern the data (n = 7), and naming the governing body (n = 5).

Discussion

The growing interest in Indigenous Peoples' healthcare experiences is evidenced by the large number of primary research articles, including a growing practice of scoping and systematic reviews, and the increasing number of articles published each year. Published research involves a variety of healthcare settings and health conditions, covering a breadth of topic areas and purposes for exploring Indigenous healthcare experiences. Inclusion of Indigenous perspectives, voices, and experiences as evidence is becoming more prevalent, demonstrating Indigenous people sharing their experiences and advocating for their voices to be heard. Despite evidence of progress, there is still a lack of clarity on how Indigenous identity is upheld and respected in the

research process from development through to reporting on the conduct of research. Further discussion of how Indigenous identity influences academic literature on Indigenous healthcare experiences is warranted, as well as an effort to generate knowledge and learning opportunities to support this work.

What we know about who is doing this research and why is this important

Several papers examined in this scoping review certainly show evidence of centering Indigenous identity and voice, yet others demonstrated the erasure of identity. Despite long-standing discussions on the importance of author positionality and self-location (Absolon, 2022; Kovach, 2021), author positionality details are not being consistently reported in research on Indigenous people's healthcare experiences. A central rationale for positionality statements, especially the disclosure of racial, ethnic, or Indigenous identity, is to reveal a researcher's worldview and their personal and collective relationships with participants and data. The concept of inclusion of researcher positionality statements has been discussed and promoted by numerous Indigenous scholars (Absolon, 2005, 2022; Chilisa, 2012; Kovach, 2009, 2021; Wilson, 2008). Recognition of this practice aligns with guidelines for respectful research with Indigenous Peoples, which state the importance of inclusion and support for Indigenous researchers as well as self-reflection on power and privilege by non-Indigenous researchers (Anderson, 2019). "Location anchors responsibility, relevance and relational accountability. Location speaks to who you are and who you are not. It established parameters about what you know and what you do not" (Absolon, 2022, p. 7). The paucity of positionality statements in the articles examined during this scoping review signals a requirement for increased education to ensure the alignment of research with the needs of Indigenous Peoples and expectations for good research practice.

Where the racial, ethnic, or Indigenous identity of the author(s) was mentioned, there was fairly consistent mention of author Indigenous identity, but less mention of any other type of REI identity. This raises the question of why there is a hesitancy to declare non-Indigenous race or ethnicity and a readiness to identify Indigenous researchers. Despite the tendency to deny tokenism, emerging Indigenizing within the academy must be held accountable for building authentic inclusion and being transparent about power and privilege. No longer can researchers conceal their identities behind the pages of published reports. In recognizing the impact of identity on research, disclosing positionality, particularly REI identity, indicates a commitment to transparency, and in consideration of Indigenous methodologies, that transparency aligns with relationality and relational accountability (Wilson, 2008). Authors must find comfort in identifying themselves, despite the perceived impacts that result. If the impacts are perceived to be negative, then work must be done to unpack why that perception exists. Understanding the perspectives from which knowledge is generated, or in other words, knowing who is conducting the research and presenting the evidence, is imperative to understanding the context of the research. It is crucial to have clarity around how author identity and overall positionality impacts or influences the research processes and results (Absolon, 2022). Increasingly, journals publishing Indigenous health research are advocating for the inclusion of author positionality statements and other identifying information (Roach & McMillan, 2022).

In addition to researcher positionality, attention should also be directed to the publishing bodies that are producing the journals, books, and other knowledge translation materials. Literature is obtained and utilized as evidence without a full understanding of the people behind the publications, including the reviewers, the editors, and editorial boards. In addition, there are publication biases and barriers imposed by academic publishing bodies which prevent authors

from having the ability to include positionality or fully describe their use and understanding of Indigenous methodologies and governance processes. Increasing transparency around publisher background, decision-making, and commitments to equity can lead to supportive collaboration, while on the other hand, publishers that do not support diversity or transparency around process or context can perpetuate power-driven gatekeeping (Flanagin et al., 2021; Patrick, 2021; Roach & McMillan, 2022; Sexton et al., 2021).

Alternately, increased scrutiny in understanding the processes and powers involved in producing research on Indigenous healthcare experiences requires a closer look at the funding bodies. Knowing who is funding research can provide information about what research is supported by funding bodies and their commitment to Indigenous research. Transparency regarding funding organization boards and proposal review panels is imperative; Indigenous Peoples have called for inclusion and representation among those who make funding decisions (Canada, 2023c). Employing funding review and decision-making models that hold space for Indigenous perspectives, can bring a lens of understanding and knowledge to funding that is not available to non-Indigenous people. This can broaden the understanding of the purposes and benefit to Indigenous research that might not otherwise be visible, along with disrupting further harm to Indigenous Peoples and communities perpetuated through research. In Canada, governmental funding bodies require that research involving Indigenous Peoples is guided by the Tri-Council Policy Statement Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2022). Beyond these large funding organizations, there are others who fund Indigenous health research where commitment to supporting respectful research with Indigenous populations is less clear.

As the number and breadth of Indigenous researchers and research involving Indigenous Peoples continue to increase, the influence of Indigenous identity on funding and publications will gain more attention and require increased transparency.

Over the last few decades, emerging principles, guidelines, and frameworks for involving Indigenous Peoples in research have resulted in the creation of tools to educate researchers and raise awareness of how to conduct research in ways that honor the need and expectations of Indigenous Peoples (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2022; First Nations Information Governance Centre, 2019a; Hyett et al., 2019, Hayward et al., 2021; Inuit Tapiriit Kanatami, 2018; Jull et al., 2020; Kirkness & Bernhardt, 1991; National Aboriginal Health Organization, 2010; Schnarch, 2004; The Commission, 1997; Truth and Reconciliation Commission of Canada, 2015; United Nations, 2008; University of Manitoba, First Nations Métis and Inuit Health Research Strategic Planning Committee, 2014). As Hayward et al. (2021) note in their discussion on Indigenous research ethics, these various frameworks aim "to establish meaningful and mutually beneficial relationships to guide reciprocal research that is community-driven, self-determined, action-oriented, and culturally responsive and that upholds Indigenous sovereignty of data and information" (Hayward et al., 2021, p. 404). Adherence to these principles for ethical research involving Indigenous Peoples has altered ways of doing research, with the aim to increase the power and control that Indigenous Peoples have over the research process and to increase protection from exploitation, misrepresentation and other associated harm (Alcock et al., 2017; Bharadwaj, 2020). Those involved in research with Indigenous Peoples are expected to be aware, knowledgeable, and adherent to these principles, guidelines, and frameworks (Jull et al., 2020). This scoping review

highlights a lack of consistent acknowledgement of Indigenous research principles, guidelines, or frameworks and indicates a need for continued education on understanding and incorporating practices that support adherence. With an increasing number of Indigenous researchers and allies advocating for adherence to principles of Indigenous research, Indigenous influence and control over the content, processes and peoples involved in Indigenous research is building. Absolon (2022) highlights resurgence based on efforts to restore Indigenous ownership, connection, and pride in Indigenous knowledge (Absolon, 2022, p. 6). In particular, Indigenous Peoples are regaining control over the creation and representation of knowledge and data on Indigenous health and Indigenous historical and contemporary experiences of healthcare. When we create space and place for the inclusion of Indigenous identities and acknowledgement of Indigenous worldviews, respectful research relationships are built, and the stage is set for the requirement of accountability for all researchers.

Within colonial-based research practices, Indigenous knowledge and knowledge systems are not recognized as important or valid knowledge (Hayward et al., 2021; Hyett et al., 2018). This failure to appropriately acknowledge Indigenous knowledge, strengths, skills, needs, and worldviews among academic and institutional research systems is now acknowledged (Alcock et al., 2017; Bharadwaj., 2020; Hayward et al., 2021; Jull et al., 2020). Indigenous methodologies hold space for the inclusion and acknowledgement of Indigenous ways of being, knowing, and doing and provide a strong critical lens to watch for unethical research while creating mechanisms of protection from research-related harm. As Indigenous methodologies gain popularity, there is a growing awareness and body of evidence of Indigenous methodology practices within published literature. Examples of reclaiming space and honouring Indigenous identities were evident with the inclusion of Indigenous languages, acknowledgements of

cultural protocols, acknowledgement of Indigenous history and context, and discussions of Indigenous ethical protocols, honourariums, knowledge translation, limitations, and governance strategies. While at this time, these reclaimed spaces remain limited, it indicates that work is required to expand space for research directed and approved by Indigenous Peoples, which will demonstrate the nurturing of respectful research relationships (Wilson, 2008). Research involving Indigenous Peoples must include Indigenous Peoples in all phases of the research. While most articles included some discussion of Indigenous participation and Indigenous partnerships in the research, there is a lack of a standardized process for reporting these details. As well, not all articles included discussions about relationship building indicating a need for improved understanding and effort.

Inclusion of Indigenous identity discussed in the literature

Within the scoping review articles, discussions and acknowledgements of Indigenous identity often occur in a pan-Indigenous context through the use of broad Indigenous identifiers such as Indigenous or Aboriginal, instead of distinct nation-based identifiers of First Nation, Inuit, and Métis, or the use of community-specific identifiers. The use of both capitalized and non-capitalized Indigenous identifier terms such as Indigenous and indigenous, Aboriginal and aboriginal also appear in the literature. Indigenous Peoples continue to advocate for distinct nation-based identity recognition with a call to honour and recognize the uniqueness of different nations. The increasing use of nation-based distinct identifiers over time corresponds to the shift in increasing awareness of the call to use distinct nations-based identifiers when discussing Indigenous Peoples in Canada. We must listen to the voices of our nations and utilize distinct identity terms when possible and as requested by nations and communities as an important means of honouring and respecting Indigenous sovereignty. The inclusion of Indigenous

identifiers in ways that acknowledge and honour the participation of Indigenous Peoples is critical to the integrity of the research.

Research involving Indigenous Peoples must be done in ways that honour the Indigenous identities of research participants, partners, and stakeholders. We are now surrounded by discussions on how to do research in a good way that was not available even a few decades ago. The efforts to drive awareness and education on research principles, guidelines, and frameworks for research involving Indigenous Peoples can no longer be ignored. Researchers cannot make decisions in the absence of consultation, discussion, negotiation, and agreement with Indigenous individuals, communities, and nations involved in the research. Research is strongly veering away from colonial-based practices as an activity that was done on Indigenous Peoples to one that is done 'with' or 'for' or 'by' Indigenous Peoples, and which is based on collaborative and authentic engagement (Alcock et al., 2017; Bharadwaj, 2020; Brunger & Wall, 2016; Hayward et al., 2021). Minds, eyes, and hearts must be opened to understand how Indigenous identity silently shapes, informs, and limits research and published academic literature regarding Indigenous people's experiences. All research processes and practices need to be brought into the open for consideration and examination. There is still much to be learned from the study of how Indigenous identity informs and influences research.

Inclusion of Indigenous voice in the literature

Indigenous sovereignty is evident through the inclusion of Indigenous voices in the research. Finding evidence of including both Indigenous and non-Indigenous participants can be problematic. Where blended voices are present, some authors attempted to clearly differentiate Indigenous from non-Indigenous voices, but in other cases, voices are blended without efforts to differentiate. When Indigenous and non-Indigenous voices are presented in ways that make them

indistinguishable, this erases evidence of how Indigenous Peoples were part of the study, and how Indigenous identity was honoured. Making Indigenous voices clearly distinguishable upholds commitments to honouring Indigenous knowledge, perspectives, participation, and identities. The presentation of indistinguishable voices in research raises questions about the purpose of that practice, specifically what might be blurred in doing so. In taking a step further back and seeing the implication of this practice, the potential for a severe evidence gap around Indigenous people's healthcare experiences is revealed. When evidence on Indigenous people's healthcare experience is controlled and narrated by non-Indigenous people, there is potential for misrepresented, inaccurate, or incomplete information. Much of the existing health research data on Indigenous healthcare experiences has been determined by the research and reporting by non-Indigenous Peoples. This raises a series of critical questions regarding the impacts of this evidence on understanding Indigenous health experiences. For example, why is there a tendency to use the voices and perspectives of non-Indigenous people to provide evidence on Indigenous healthcare experience rather than transparent inclusion of voices, knowledge, experiences, and evidence directly from Indigenous Peoples? Without clear differentiation of the voices, the research purpose and findings are blurred, which dishonours Indigenous people, their experiences, and adherence to the guiding principle of accountability for those involved in the study. As the number of Indigenous health research scholars grows, Indigenous-led research will shine a light on quality research that honours Indigenous people, voices, and ways and is accountable to Indigenous Peoples' health and well-being. As Indigenous identity is more visible in research publications, Indigenous Peoples will remember we belong here, we have always been here, and our presence and position within all aspects of research is strong and sovereign.

Limitations

In balancing the breadth and depth of the scoping review with feasibility, we decided to search a limited number of databases as searching a large number of databases would be impractical due to time limitations. This scoping review initially intended to include only articles authored by First Nations, Inuit, and Métis researchers. Challenges in determining the Indigenous identity, race, and ethnicity of authors based on what was included (disclosed) in the article led us to expand the inclusion criteria to allow for Indigenous and non-Indigenous authors. A decision was made not to investigate beyond the article itself, meaning no additional searches beyond the article to identify Indigenous identity, race or ethnicity.

With this scoping review, our intentions were to map the contents of the articles, and not to evaluate quality, level of depth, or appropriateness of what was reported. We did not apply any quality scales to measure the type of engagement but instead reported on what is visible while reading the paper.

This review did not investigate possible influencers or barriers, such journal specific editorial policies, to the inclusion/preclusion of ways of honouring Indigenous identity and upholding the principles of research in reporting and publishing, including author positionality (Absolon & Willet, 2005) and discussion of relationships and relationality (Wilson, 2008). This can include the exclusion of Indigenous paradigms, perspectives, and language. Issues including but not limited to publisher guidelines, journal limitations and restrictions, and editor choice need to be accounted for to generate a more robust understanding of the issue.

The objective of the study to reveal how Indigenous voices shaped the evidence concerning Indigenous people was supported through the inclusion criteria of requiring clearly defined

Indigenous voices sharing the healthcare experiences, however, this inclusion criteria may have limited the inclusion of quantitative research articles, where Indigenous voice is shared in a different context when presenting data regarding healthcare experiences.

Conclusion

A critical lens is required to review research involving Indigenous (First Nations, Inuit, and Métis) peoples of Canada. We must move away from assuming accurate representation and completeness of information in peer-reviewed publications on Indigenous people's health and healthcare and take a critical view of who controls the narrative and in which ways. In both the past and present, research caused harm, supported by a hierarchy of status based on race and ethnicity, and through the use of findings to maintain power and social positioning of a dominant Western-based white society. Indigenous health research has been and continues to be done without the appropriate involvement of Indigenous Peoples nor the inclusion of an Indigenous worldview. Without close monitoring of research for adherence to Indigenous principles, frameworks, and guidelines, there is the risk that this type of research will continue, along with resulting misinformation, harm, and gaps in knowledge. Often missing from the practice of quick access to and use of literature and the 'evidence' within, is a deeper examination of the context around the research.

Indigenous Peoples and our allies are becoming critically aware of the intertwining background pieces of the research process. Previously, these behind-the-scenes details might have been unseen or silenced. However, in this contemporary space and place of Indigenous empowerment, we have the ability and obligation to investigate the often-hidden components of research to ensure that Indigenous identity is being upheld throughout these processes. Researchers must

commit to respectful, transparent, and ethically sound research practices through to publication. This is another step towards ensuring research accurately depicts the realities of Indigenous Peoples, and realities that draw Indigenous Peoples out from the margins while interrogating processes and outcomes manufactured to uphold white supremacy. As Indigenous Peoples increasingly hold space within research activities and publications, there will also be increased accountability for all to conduct research in ways that honour Indigenous Peoples, perspectives, and knowledge. Context does matter, and data is influenced in a variety of ways; thus, it is crucially apparent to raise awareness of how Indigenous identity impacts research and data.

There is a need to shine light on the importance of understanding how Indigenous identity has and still does influence the literature and the evidence utilized to understand, describe and analyze the healthcare experiences of Indigenous Peoples. Readers should challenge their own beliefs of how research and the publication of literature can both uplift and center, or push to the margins Indigenous identity, and the impact of either action. This scoping review work has only become possible with the evolution of understanding and acceptance of the reality of colonial history on Indigenous life. With the recognition that in the past, research was done and information was reported in ways that we would not want to replicate today, this paper is a stepping stone for renewed advocacy for accountability and adherence to guidelines for Indigenous health research. With an increased understanding of the importance of identity, and the development of standard ways to discuss and acknowledge identity, it will become more comfortable to self-identify through author positionality and recognize the impacts of identity on knowledge production. While positionality is important, and its recognition is an excellent step in the right direction, the impacts of Indigenous identity on our understanding on what we think we know are deep and lasting. There is much more work to be done to continue our

understanding. This work is opening the door to making acceptable and necessary this level of examination and invites the practice of opening space for Indigenous voice and knowledge to inform and move out of silenced margins.

Chapter 5: Conclusion

Introduction

"I argue here that although we have been quite shaken up from the impacts of these policies, the assimilative efforts failed to make us completely forsake our lands, languages, and cultures in favor of the imposed ones. We are emerging and regaining confidence in and asserting our traditions, our elders' knowledge, our stories, wisdom, cultures, languages and philosophies and in ways our elders from the past had prophesied!" (Fitznor, 2006, pp. 56-57)

Advancing our knowledge of race, ethnicity and Indigenous identity (REI) data collection at the point of healthcare access by opening spaces to listen to and learn from Indigenous people's voices and knowledge was the primary objective of my dissertation. To address the objective, an Indigenous paradigm informed the research, which sought to privilege Indigenous voice and knowledge. To open our eyes, minds and hearts regarding REI data collection and research, the dissertation covers three broad areas that individually contribute to the field and also collectively advance our understanding of how REI data can support the reclamation of empowered Indigenous identity. Thereby disrupting anti-Indigenous racism and white-supremacist systems of control within the healthcare system that also operate within Indigenous health research. Evidence of colonial systems of power and process which create barriers to hinder and damage acts of Indigenous resurgence are revealed. Through this Indigenous-led dissertation, the breadth of methods employed supported deepening our understanding of the impacts and influence of REI data collection on Indigenous people's lives. The four methods of examining REI data collection and its implications for Indigenous Peoples in Canada, involved story gathering, an environmental scan, and a scoping review/knowledge discovery (addressed in Chapters 2, 3, and 4). The fourth method involved the inclusion of traditional knowledge and ceremony, which

guided the research and my personal wellbeing throughout the research process and is shared within the in-between chapter sections.

The final chapter opens with an overview of key contributions based on finding reported in the previous chapters. I then proceed with a reflective discussion of: 1) how CIET functioned as the guiding theoretical framework for the dissertation; 2) my personal experience of the research process; 3) how this research contributed to my own understanding of REI data collection; 4) contributions to the theory and practice of REI data collection and use. The chapter moves to a discussion of the strengths and limitations of the dissertation, research validity, and knowledge-sharing activities. Implications for health systems, policy change, and health research are offered. Finally, there is a brief discussion of future directions for the continuation of the advancement of knowledge around REI data collection and research governance.

Overview of Key Findings from Chapters

My dissertation research was driven by a number of objectives. See Table 10 for the objectives by chapter. Key contributions from these objectives are discussed by highlighting findings that emerged in Chapters 2, 3, and 4, followed by a summary of these discussions which weaves in highlights from traditional teachings and ceremony.

Table 10

Dissertation Objectives by Chapter

Chapter	Objectives
Chapter 2	• To listen to Indigenous perspectives and experiences related to REI data collection within the healthcare system • To advance knowledge around Indigenous perspectives on best practices and desired outcomes for REI data collection within the healthcare system
Chapter 3	• To reveal current policies and practices of REI data collection in the Manitoba healthcare system, to address the current knowledge gap • To present a critical review concerning the quality of data collection related to REI
Chapter 4	• To critically examine health research literature reporting on Indigenous people's experiences within healthcare in Canada

In-between Chapter	• To include reflexive experiences of ceremony and traditional teachings as means to share the use traditional knowledge and Indigenous ways of knowing, being, and doing to better explore and understand the research process and outcomes

Key Findings from Chapters

Chapter 2: Being seen where we were never intended to be seen: Indigenous experiences and perspective of REI data collection in the healthcare system in Manitoba.

The wealth of evidence and insights rooted in Chapter 2 demonstrates the significant gap that existed due to silencing of Indigenous voices regarding the topic of REI data collection process, storage, and reporting. Addressing this rich source of evidence begins with three points stemming from the study design itself, followed by a brief discussion of three key findings that make significant contributions to this field.

Study design points. Knowledge generated through story gathering with 20 self-identified Indigenous community members, data collectors, and healthcare leadership revealed insights into Indigenous people's perspectives, opinions, and experiences of REI data collection. Or in other words addressed the question*, "What do First Nations, Inuit, and Métis people think and say about REI data collection".* Design and conduct of this study were supported by preexisting relationships, consultation with First Nations, Inuit, and Métis Elders/leaders, and the Indigenous Advisory Council. In addition, stories shared with me, a First Nations woman researcher, were influenced by traditional knowledge of connecting and building relationships to support an understanding of safety and acceptance that allowed for a sharing of stories that might not have been heard had the interviews been with a non-Indigenous person. Worthwhile to mention, this was research with Indigenous Peoples, led by an Indigenous researcher, who used Indigenous research methodologies (ways of knowing, being, and doing).

Through this study, First Nations, Inuit, and Métis voices were brought into the center of the discussion of REI data collection within the healthcare system. Through listening to their stories of various aspects of REI data collection, four topics emerged: Our Indigenous Identities, Our Experiences, Our Perspectives, and Our Vision. The opening of space for the Indigenous voice allowed for a much richer and deeper understanding of the connection between the act of REI data collection and historical and contemporary experiences of colonialism as experienced within Indigenous people's lives. This work directly addresses evidence gaps that exist due to the silencing of Indigenous voice.

While Indigenous storytellers echoed previous research reporting public and staff experiences, opinions, and perceptions of REI data collection, in this study, Indigenous voices were privileged. Thereby, bringing to light the experience of being asked about Indigenous identity within the mainstream healthcare system and what this means as an Indigenous person; these experiences had not been heard before. Privileging Indigenous experience exclusively opened space to discuss the lack of safety for Indigenous Peoples tied to harmful healthcare and research practices, which are current experiences impacting the lives of Indigenous Peoples. As a result of research that took and used Indigenous information and knowledge in ways that did not honour Indigenous identities and healthcare systems that remain sites of dismissal and various type of harm, considerable work is required to support the safety of REI data collection. In addition, once data is collected, governance policies that address safe practices for data storage, access, and reporting will be required in order for REI data collection to be successful.

Key finding contributions. One key finding noted from listening to Indigenous community member, staff, and leadership stories of answering REI questions is that asking questions about Indigenous identity is a complex simple task. This question is not a one-

dimensional construct summarized quickly for the purposes of answering a question. For Indigenous Peoples, this act is rooted to deep feelings and experiences of colonial oppression and current-day continued racism existing with systemic discrimination that underlies inequitable healthcare care for Indigenous Peoples. A second key finding is that all storytellers spoke of racism as a barrier to equitable and high-quality healthcare experiences, and previous experiences of racism influenced worries concerning perceptions and expectations of the REI data collection strategy being implemented in Manitoba. For those who had experienced either being asked or asking the REI questions, racism, discrimination, and stereotyping impacted how people felt about asking the question and their desire or ability to respond to the question. However, despite these concerns linked to perceptions and past experiences, both individual and collective, there is hope that having a data repository disaggregated by REI will provide evidence of, and be the foundation for, solutions to health and healthcare disparities experienced by Indigenous Peoples.

A third key finding is that every aspect of decision-making, planning, design, implementation, communication, training and education, governance, reporting, and evaluation, must be done in consultation or partnership with Indigenous Peoples. Further suggestions for best practice indicate that the local patient population needs to be considered when determining details around REI data collection. This reflects the understanding that alongside shared colonial experiences, Indigenous Peoples in Canada hold distinctive aspects of our identities between nations, communities, and rural vs. urban-based populations, which creates differences that must be recognized and honoured in order to meet the specific needs of First Nations, Inuit, and Métis people. Involvement of Indigenous Peoples extends to leadership and nations-based organizations, which supports information being shared in appropriate and meaningful ways. A

fourth key finding is that reporting must be accessible, timely, and demonstrate actions for direct changes to improve the lives of Indigenous people. Demonstrating direct outcomes benefitting First Nations, Inuit, and Métis people is critical for building trust and supporting safer interactions with the healthcare system.

A final key finding is that for REI data collection to honour Indigenous people and Indigenous identities, personal, institutional, and financial investment is imperative. These investments include 1) committed healthcare leadership, 2) transparent explanation of purpose and process for REI data collection, 3) demonstrated understanding of Indigenous data sovereignty and governance of data, 4) initial and continued REI data collection education for all staff involved in the collection, storage, and reporting of data. These commitments are critical to successful REI data collection. Without sufficient and appropriate education, REI data collection strategies will likely fail, either through refusal to ask or respond to the question, or diminished data quality. If people do not understand the purpose for the data collection there is little to no commitment to follow through.

Chapter 3: Indigenous skin, red flags: an environmental scan of past and current attempts at REI data collection in Manitoba.

An environmental scan of REI data initiatives over the last two decades within Manitoba supported the important action of taking a step back to reflect on where we have traveled to get us to this place. This chapter reports on findings from key informant discussions, document reviews, and knowledge gained as a member of the MB REI data collection strategy core team. Manitoba is implementing the collection of REI data in the provincial healthcare system and building a data set that can be linked with provincial health administrative data to then provide disaggregated reporting by race, ethnicity, and Indigenous identity. Currently in Manitoba, we

have an Indigenous-led implementation strategy for the collection of REI data across the provincial healthcare system; our current reality is the first of its kind in Canada. While REI data collection will be new for many in Winnipeg, this point is preceded by decades of work, primarily done without adequate Indigenous involvement or advocacy. This chapter aimed to raise awareness and available evidence for health systems organizations, researchers, practitioners, patients, and the public to understand the current context of REI data collection in Manitoba. Or in other words, to address the question, *"Where has this data been collected and what are the details?"* Analysis involved the application of the CIET framework which drew attention to: 1) where Indigenous Peoples are rising above and finding alterative pathways to Indigenous empowerment, and advocating for the use of voice as evidence of Indigenous realities, 2) where social justice is informing and driving movements for Indigenous resurgence, 3) where the uncovering and understanding relations of power informs the use of power as a tool for empowerment rather than a tool of oppression.

Key finding contributions. The exposure of systemic racism within healthcare that disrupted earlier REI data collection attempts over the last two decades is a key finding. Evidence of this was heard in the continual surfacing of staff feelings of discomfort. By examining of this discomfort narrative, it became clear that the opportunity to collect race-based data and develop evidence for race-based health disparities and inequities was halted due to feelings of discomfort among data collection staff and managers, which is an act of racism. Instead of attempting to fully understand why Indigenous Peoples might react negatively to the request to self-identity in the healthcare system, the surface level fact that the negative reaction of the patients will cause the staff to feel uncomfortable became enough to stop the collection of data.

In Manitoba, we have the opportunity to do this work respectfully, which includes education for all. We have strong Indigenous health leadership leading the current implementation strategies that have enhanced Indigenous power and authority in areas that impact Indigenous people's health and healthcare. The healthcare system can be an enhancer of this process or act as a barrier – current leadership of the MB REI data collection strategy holds significant power to challenge barriers that led to the failure of past initiatives. The current implementation strategy has been guided by Indigenous voices who have insisted on a focus on data governance and inclusion within decision-making, voices of those who face structural oppression and disadvantage. Learning from the past attempts of REI data collection can support the collection of identity data that honours Indigenous people and their identity. For this to be realized, staff must be knowledgeable of the big picture underlying data collection to be prepared to collect data in a good way. The emerging key findings provide valuable information to the current MB REI data collection strategy to avoid barriers that led to failures and create facilitators to assist in successful data collection.

Chapter 4: Raising Indigenous Voice: the impact and importance of Indigenous identity in research on Indigenous healthcare experiences in Canada.

A scoping review/knowledge discovery of academic peer-reviewed literature concerning Indigenous people's experiences in healthcare in Canada aimed to uncover how Indigenous identity and ways of being, knowing, and doing are considered, included, and discussed, or not, in the literature and during the research process. Or in other words, to address the question, "*What do we know about the existing research on Indigenous health and healthcare?"* A total of 97 articles met inclusion criteria for analysis, which led to three discussion points; what is known about who is doing this research and why is this important; inclusion of Indigenous identity

discussed in the literature; inclusion of Indigenous voice in the literature. As the field of Indigenous health research grows, which includes research on the healthcare experiences of Indigenous Peoples, an examination into how Indigenous identity influences academic literature on Indigenous healthcare experiences is warranted.

Key finding contributions. The scoping review revealed the need for increased researcher transparency, which is necessary to ensure clarity about whose world view is contributing to the narratives shaping our collective knowledge of Indigenous people's health through the use of REI data. Having large data sets disaggregated by REI is appealing and could benefit Indigenous people, but for this promise to become reality, it is necessary to know how evidence of Indigenous Peoples and their experiences with healthcare is generated. The ways in which identity was visible or erased in the scoping review articles generated concern. When there is a blurring of whose knowledge is informing the evidence, the most likely influence will be white supremacist structures, which dismiss cultural relevancy and Indigenous voices and evidence generated will likely include misrepresentations of Indigenous Peoples and will support entrenched stereotypes.

Evidence of Indigenous people's health and healthcare is most commonly generated by non-Indigenous researchers through dominant Western-based paradigms of thought. As a starting point, through this scoping review, the importance of collecting data directly from Indigenous Peoples and having Indigenous Peoples involved in the production of research evidence is apparent. Yet, it is also clear that REI data collection and generation of disaggregated data are highly influenced by how Indigenous identity is honoured. Having Indigenous leadership within data management and research administration is an option to support the use of Indigenous data

in ways that support, encourage, and require transparency of author /researcher positionality, relationships and partnerships with Indigenous Peoples, and use of Indigenous research methodologies. This will help to ensure that research is conducted with Indigenous people in respectful ways that honour Indigenous identities. With this leadership in place, we will see how upholding Indigenous identity impacts and influences the production of evidence on Indigenous people's healthcare experiences.

Systematic collection of REI data will change how health research is conducted, due to data availability and the types of results reported. The risk of continuing past mistakes is real, such as where data is used to support deficit-based research or where white supremacy shapes the standards for measurement. Disruption of these mistakes requires a solid grounding in the impact of Indigenous identity on research and how it influences the evidence generated. In other words, if we agree to the collection of REI data, then we must also commit to understanding the power and control that exists in research and how identity plays a large role in this today. Understanding how consideration of Indigenous identity must be present within all research phases and locations, including funding bodies, academic institutions, and academic publications is imperative to support use of REI data within research.

Considering how data governance was evident in the scoping review articles also revealed useful insights relevant to REI data. As we heard in Chapter 2, there is a strong desire to uphold Indigenous data governance, which is also heard among many Indigenous research guidelines and can be heard within the strong advocacy of several Canadian nation-based organizations. Yet, within the reviewed literature reporting on Indigenous experiences, there was a lack of consistent inclusion of governance practices. This leads to questions about the perceived

importance of Indigenous data governance and how to support adherence to this practice. As we have heard in the voices of Indigenous Peoples in Manitoba, there is, at times, pushback by leadership through questioning the need for data governance documents. However, without strong mechanisms for adherence, there is a good possibility of stepping backwards.

REI data collection and the disaggregated data sets generated will be powerful research tools that can generate positive outcomes for Indigenous Peoples such as evidence for healthcare disparities and inequities or location of anti-Indigenous racism and discrimination. However, it is imperative that before this can happen, there must first be the assurance that data disaggregated by Indigenous identity enters into a research environment that supports and honours Indigenous people and identities. Otherwise, we may be circling back to past practices of harm and further discrimination, or where misinformation and misrepresentations of Indigenous Peoples are reported as evidence and truth. The scoping review demonstrated that within the literature, there is a lack of clarity in how Indigenous identity is upheld and respected throughout all aspects of the research process; rather, the ongoing silencing, marginalization, and whitewashing of Indigenous identities, voices, and people is often occurring.

Summary

Each chapter contributes knowledge of relevance to the collection and use of REI data. By privileging and listening to Indigenous voices, perspectives, experiences, and opinions of REI data collection through story gathering, our understanding of the complexity surrounding the question about identity is revealed. Through taking a step back to reflect on the past two decades of REI data collection initiatives in the environmental scan, we now have a roadmap of the various contextual layers shaping successes and failures that have led to current-day. Finally, the

scoping review sheds light on how Indigenous identity is seen (or not) within research concerning Indigenous people's healthcare experiences, along with significant gaps in Indigenous methodologies, guiding frameworks for research, and governance practices. All of these core insights are important to current-day REI data narratives and strategies and will be useful in future actions.

In this dissertation, there is a final method to mention and was located in-between the already discussed chapters; that is, my reflexive experiences with ceremony and traditional knowledge as means to share Indigenous ways of knowing, being, and doing which guided my research and helped me to better understand the research process and outcomes. Over time, the role of ceremony and traditional knowledge expanded to include a mechanism to maintain my holistic well-being during the writing of the dissertation. Each time an opportunity was presented to attend or practice ceremony, visit with an Elder, or take in traditional teachings, I made space for a writing reflection that allowed me to capture my experience of that event or sharing of knowledge. This led to the writing of 19 reflections sections, 3 of which are shared in the dissertation. Through these reflections, I felt more connected to where I was at in the research process, how the research was impacting me, and how I was impacting the research. By giving myself space to reflect, I could better understand how traditional ceremony and knowledge shapes my own Indigenous identity drawing me closer to the context of my dissertation.

Reflective Discussion

Reflecting on CIET

When presented with the challenge of developing a theoretical framework to situate my research, it seemed to be a task beyond my abilities. However, with focused thought and a continual shifting between big and little-picture views of the overall research, the theoretical framework emerged from the knowledge I hold as an Indigenous woman researcher and the worldview that guides how I see the world around me. Three main theoretical principles emerged; *Uncovering and understanding relations of power; Social justice; and Indigenous voice as evidence*, and through completing my dissertation, application to each area of research grew the theory. Some brief examples are presented. In Chapter 2, I saw increased confidence in the storytellers with sharing their voices, stories, and experiences, along with seeing how they can make a difference if held by someone who protects them from dismissal, misinterpretation, and other traumas. Having Indigenous Peoples situated within positions of power to do this important work is the embodiment of CIET. In addition, storyteller reflections on the meaning and importance of Indigenous identity and Indigenous resurgence are evidence of the increasing ability to recognize ourselves as people who can thrive through our own strengths and brilliance. Through this recognition, we are enacting ways of being, knowing, and doing that enable alternate pathways to empowerment, rising above the hurt and trauma that has previously inhibited the resurgence and empowerment of Indigenous people. In Chapter 3, the evolution of the REI data collection initiatives demonstrated how over time, the increase in the inclusion of Indigenous leadership and partnerships had refocused the intention of REI data collection from one that would serve the needs of the healthcare system to one that is focused on bringing accountability to the system in order to address the gaps and disparities in order to meet the needs of Indigenous patients. In Chapter 4, the increasing critical awareness that research involving Indigenous Peoples and Indigenous knowledges must be protected through the use of ethically sound research practices

signals a shift towards the increased scrutiny within this field of research. While there is still work to do in this area, there is support to highlight where research is not being done in a good way, and develop solutions to ensure safe research going forward.

Throughout this work, I was continually amazed by the strength, resilience, and brilliance of the Indigenous people I spoke with or whose work I studied along the way. The surging empowerment within contemporary Indigenous societies is remarkable and impossible to ignore. Visual representations of resurgence are seen in the increase in popularity of cultural-based items such as ribbon skirts and other cultural base clothing items, beading, braiding, and the use of traditional medicines. This can also be seen in cultural practices such as drum and song groups; ceremonies such as sun dances, sweat lodges, and smudging; and traditional language revival. These practices have become so vivid in the minds of our people with the message that it is good and healthy to have these in our lives and to be proud of what we have as Indigenous Peoples.

A strong contributor to this increase is the speed and ease of which information can be shared. The use of social media and other forms of technology have broken down barriers that previously limited connectedness. In contemporary society, people across all lengths of distance can connect, share, unite, and inform immediately and often. The rise in technology has supported the ability to strengthen voices through numbers for advocacy issues and has shone a light on the beauty and brilliance of Indigenous Peoples across the country, which carries forward in waves of inspiration for others. CIET is utilized to explain and contextualize what is happening all around in relation to the growing empowerment of Indigenous Peoples, and it will only become more powerful over time.

Reflecting on my research experience

The dissertation research process has led me down many paths of exploration and required the use of several research methods. When I started the dissertation process, the path to knowledge discovery around Indigenous perspectives, understanding, and experience of REI data collection and the idea of Indigenous identity as a construct was seen as an arch that involved examination of past, present, and future experiences of Indigenous identity. As I reach the conclusion of the dissertation, the original plan has actualized, and indeed this is the journey of this dissertation.

Through my worldview as a First Nations researcher, I understood that my dissertation research could only proceed with the input from community. As such, consultations with the Indigenous Advisory Council and the Circle of Indigenous Leadership were integral to this work being done in the right way. I have also been incredibly fortunate to have been supported through this work by Indigenous scholars on my committee.

Many of the teachings that I carry with me into my work, are on motherhood and preparing the next generation through the nurturing love and life teachings as a mother. My role as a mother undoubtedly impacted my research experience in numerous ways. I have always understood that as an Indigenous person, we must always think of how the thoughts and actions of our lives impacts the next generations and so my thoughts were often centered on how my research will impact my next generation and all those that come after me. I also understand that my compassion as a mother led me to care for those I interacted with throughout my research process to ensure the safety of their stories and to honour their voices.

This dissertation research answered questions and met the objectives it set out to do. It also generated many additional questions and avenues for future research. At times, great suggestions were made to consider areas outside of the scope of the original research design, Yet, when I considered expanding into new or additional areas of exploration, I would be reminded of the teachings to of listen to your spirit around what feels right or not, and that not everything has to be completed in that moment in time. This dissertation was a massive practice of listening to my spirit, and it was through a specific ceremony that this teaching came through with force and reminded me to listen to my spirit. I have honoured this teaching and feel grateful to have received this knowledge, and to share it through my dissertation.

The ability to make space for the inclusion of traditional ceremony and knowledge within my dissertation was not taken lightly and signified to me a major shift within the academy in the acceptance of Indigenous ways of being, knowing, and doing as valid forms of knowledge. Taking into account the experiences of Indigenous scholars who came before me who did not have the ability to discuss how traditional knowledge shaped their lives and worldviews, I feel fortunate to be at this time and place where this was not a barrier but a facilitator of my development as an Indigenous scholar.

Reflecting on what I have learned about REI data

Through the dissertation process, I have learned that the collection of REI data is easily impacted by racism and how the system supports REI data being red-flagged as risky, inherently negative, and deserving of a discomfort narrative. This is one of the drivers for the determination to expand upon the rationale for REI data collection. When REI data is seen and understood as a means of enhancing Indigenous visibility, it becomes a tool of Indigenous empowerment. The

red flag is removed from the Indigenous person and placed on the system itself. The rationale moves to hold the system accountable for providing equitable healthcare and addressing gaps that leave Indigenous Peoples to experience disparities in health and healthcare. It is time to move beyond the acceptance that REI data collection questions are uncomfortable to ask and demand that tools are in place to support education and understanding of why asking about REI identity causes feelings of discomfort. Canada's healthcare system has a very long history of providing inequitable, poor quality, harmful, and racist healthcare to Indigenous Peoples. Concern over causing patients to feel shame or insult associated with Indigenous identity data collection is likely a reflection of individual and collective guilt about a healthcare system that causes harm and an inability to change the system. It would be less uncomfortable to ask about REI identity if a healthcare system was anti-racist and fully able to support Indigenous people's right to equitable and quality health care.

Indigenous Peoples have been advocating for inclusion in determining healthcare policies and practices that impact individuals and collective nations. Power sharing when it comes to healthcare policy and systems-change decisions is challenging and often unsustainable. Understanding relations of power and observing Indigenous Peoples in power holding decision-making roles within healthcare influencing REI data collection strategies has been inspiring. This evidence also solidifies an understanding that continued decision-making about healthcare practices and policies that impact Indigenous Peoples without full inclusion of Indigenous voice, perspective, and expertise in these processes is no longer acceptable.

Through the shared experiences and perspectives of storytellers, it was clear that there is a desire to celebrate Indigenous identity. There is also a desire to have the wider population recognize the

feelings of pride and power that come through the positive energy of resiliency, resurgence, healing, and connectedness experienced as Indigenous people. However, there is still a darker side to identity deeply layered within Indigenous realities due to the history of oppression and generations of attempts to reclaim our best state of being. Despite the progress that has been made, healing that has taken place, and resiliency enacted, the continued heaviness of ongoing oppressions creates a weight that has yet to be fully lifted. Therefore, the work of REI data collection in Manitoba cannot proceed without considering the impact of those oppressions and full buy-in by healthcare systems and leadership to the efforts to avoid adding additional weight to carry. The presumed simple task of asking a question or providing an answer becomes a much larger consideration when we account for what it means to Indigenous people.

Research shows the healthcare system has been an unsafe environment for Indigenous Peoples for decades. From the history of the Indian hospital system to the current experiences of Indigenous people across Canada, evidence is abundant. By including Indigenous voice, this study contributes to this evidence and sheds light on plausible solutions for change. This ability to have voices heard, and offer contributions that are recognized as valuable, deserves attention. There was a time were the inclusion of Indigenous voice in healthcare policy and planning would never have been invited. The perspectives shared by storytellers clearly show that experiences of racism are still a driving force in the decisions they make regarding accessing healthcare. The implementation of the collection of Indigenous identity at the point of healthcare access must be acknowledged as a potential contributor to those decisions. Their open sharing of the need to consider identity and the need to alter identity prior to accessing healthcare is shaped by a consideration of the type of treatment, or not, that might be provided to the Indigenous person. This sharing demonstrates how people find ways to navigate acts of racism. First Nations, Inuit,

and Métis people have a right to the highest attainable level of healthcare and for their healthcare to not be negatively impacted by their Indigeneity or, more precisely, racist reactions to identity. It is understood that it will require some time to see the direct benefits of this data collection on the lives of Indigenous Peoples. However, even then, there is an expectation that data is used to create timely responses to issues in health equity, disparities in healthcare access and quality, and the disruption of racism in the healthcare system. However, if the leadership of the healthcare system cannot guarantee that racism will not be perpetuated against Indigenous Peoples through the collection of REI data processes and policies, then the collection of REI data should not be implemented. If REI data is to be collected, it is imperative that the voices of Indigenous Peoples and the perspectives, opinions, understandings and recommendations shared must be accounted for when planning and implementing the collection of REI data. It has been known for quite a while now that practices and policies that will impact Indigenous Peoples must not proceed without the input and directions of Indigenous Peoples themselves.

Strengths

This dissertation research involved privileging of Indigenous voice, developed and carried out by an Indigenous researcher, using Indigenous research methodologies. This work is guided and informed by traditional teachings provided by numerous Elders and teachers, especially Métis Elder Barbara Bruce. This work was also done in consultation with an Indigenous Advisory Council and an Indigenous Leadership Circle consisting of First Nations, Inuit, and Métis leaders. This is the type of research that Indigenous Peoples have called for decades. This research was done in ways that align with an Indigenous worldview and addresses issues that

will support the movement towards the highest attainable standard of health for Indigenous Peoples.

This work addressed teachings shared with me regarding the need to consider where we have come from to know where we are going. These are questions that we need to consider in our daily lives, especially when we are in ceremony or asking for something from The Creator. Through this work, the intentional arched pathway, similar to the gentle arc of the eagle feather, has supported this discovery of knowledge by examining the past, present and future. This is a true example for myself and others of how we can continue to honour our traditional teachings through research, and which solidifies Wilson's (2008) statement that research is ceremony.

Through the examination of past and current practices of REI data collection, the provision of Indigenous perspectives and experiences of REI data collection, and the impact and influence of Indigenous identity on the production of research evidence on Indigenous healthcare experiences, this research addresses the gaps created by the absence of Indigenous voices and the marginalization of Indigenous people in the understanding of the impact of Indigenous identity on healthcare practice and health research.

Limitations

As with any research, there are limitations that emerge through design decisions. In my dissertation, I began with an intention to honour distinct nation-based Indigenous identities by steering away from a pan-Indigenous approach and seeking ways to include First Nations, Inuit, and Métis identities and voices. While with guidance from Elders and Indigenous leaders I invited in distinct nations, within the three methods an unbalanced representation of First

Nations, Inuit, and Métis peoples resides. In Chapter 2, there were voices from each nation, however, the majority were First Nations. In Chapter 3, as the data was based on health system policies and actions, the study was limited by how Indigenous people had been identified in documents and discussions pertaining to the REI data collection initiatives. Finally, similarly with Chapter 4, data regarding distinct nations was sought in the literature; however, what was reported in the articles limited the ability to speak to distinct nations.

Another limitation rooted in the study design was the focus on Winnipeg. This is the case with storytellers, leaving us wondering if experiences and perceptions of REI data collection would be similar or different among Indigenous people living outside of Winnipeg. With the environmental scan, many of the strategies reviewed were implemented in Winnipeg, and stories of the initiatives were heard from key informants working within Winnipeg. This limitation supported the feasibility of this study as a dissertation but limits knowing how the findings could inform activities occurring elsewhere in Manitoba or across Canada. As REI data will eventually be collected province-wide, it will be necessary to also understand the perspectives and experiences of those outside the Winnipeg boundary.

Limitations with the scoping review are notable with the decision to search a small number of databases, which was based on feasibility. Alternately, the decision not to evaluate quality, level of depth, or appropriateness of what was reported might have influenced reported findings. However, with scoping reviews evaluation of data quality is uncommon due to the nature of analysis.

As we are experiencing a growth in the interest and the implementation of REI data collection, questions around the quality of REI data being collected are being raised. While this is an important topic area, this was not explored in this study. Had discussions regarding data quality arisen when gathering stories or in discussions with key informants during the environmental scan, the idea would have been followed; however, data quality measurement was not brought up in discussions. As the environmental scan was intended to understand what and where initiatives were taking place, the next step could involve examining the quality of data collected during this period.

Another interesting topic that could add to the discussion but that was never intended to be part of this study is the differences in data collected through data linkage mechanisms (First Nations status card numbers and Inuit N numbers) vs. self-declaration through REI data collection processes at point of access to health services. With discussions regarding identity fraud on the rise, this might be another location for future research. While there could be the exploration of how to identify Indigenous people upon entry into the system, it was not an intended focus of this dissertation.

Trustworthiness

In Chapter 1, it is noted that trustworthiness within Indigenous methodologies is evaluated through the alignment with an Indigenous worldview and through the use of Indigenous research methodologies, which reveals if and how Indigenous ways of being, knowing, and doing were honoured or not (Kovach, 2009, 2021; Steinhauer, 2002; Wilson, 2001; Weber-Pillwax, 2004).

For my dissertation design and work, validity measures focus on evidence of alignment with the Indigenous paradigm and foundational aspects of Indigenous research methodologies (Kovach, 2009; Steinhauer, 2002; Wilson, 2001; Weber-Pillwax, 2004). When thinking about trustworthiness in Indigenous research, one would expect to see visible author/researcher positionality, expressed and fulfilled benefit(s) to Indigenous Peoples and/or communities, research process transparency, practices of relationship building, and actions that support maintaining accountability to those relationships (Absolon & Willet, 2005; Kovach, 2009, 2021; Weber-Pillwax, 2001; Wilson, 2008, 2001).

In my research, consultations with Indigenous community members, Indigenous leaders, Indigenous scholars, and Elders, opened space for sharing my positionality and personal context in relation to this research. In addition, it allowed for open sharing of research purpose, design, and process, the worldview/theoretical lens which guides my research, and the use of Indigenous methodologies guided through an Indigenous paradigm. Consultations facilitated the transition to transparent writing and the inclusion of this information within the written document.

Throughout my dissertation research, I have prioritized the building of relationships with those involved, including consultants, participants, Elders, my committee, and others who have supported and guided me along the way, which grounded my responsibility to being held accountable to these relationships in an act of relational accountability (Wilson, 2008, 2001). I have been guided in this work through the practice of traditional teachings passed to me along my journey. One example is the teaching to lay tobacco and to turn to The Creator to ask for what I require in my time of need. Another has been keeping my medicines near at all times for ceremony, such as smudges and sweep downs. Métis Elder Barbara Bruce has been a strong

support throughout my research, and I carry an Eagle Feather that Elder Barbara gifted me as a reminder of the teaching to speak the truth.

While collecting data during my dissertation work, I ensured that each person involved understood the purpose of my research, the nature of their involvement, and my plans for the knowledge generated through my dissertation. The passing of tobacco or sharing of a small handmade gift of medicine occurred prior to each story-sharing session to signal my request for knowledge and assistance with my research. I have also maintained close contact with my committee, sharing developments, progress, and findings as they occur. Reflections on my research experience (field notes) increase the transparency of my research and are available to inform others about my research process as necessary.

Finally, in an act of accountability and honoring the relationships of those who have been part of my research journey, the sharing of the dissertation with those involved in my research will signify the closing of our research relationship and will be celebrated through ceremony and feasting the finalization of the dissertation.

Knowledge Sharing

As mentioned in Chapter 1, consultations with Indigenous Peoples advising my research along the way will assist in the finalization of plans for the disseminating research knowledge. This research practice aligns with the recognition that the unique contexts of Indigenous communities require research dissemination that meets their needs and desires (Smylie, 2009; Smylie et al., 2004).

One of the central aims of this dissertation, stated in Chapter 1, was the advancement of knowledge and understanding of REI data collection from an Indigenous perspective to benefit patients, the public, healthcare staff, researchers, and policymakers. This will be considered when sharing the data to ensure that the groups mentioned above will be included in audiences. As suggested by Kovach (2009), there are three audiences to consider as an Indigenous researcher; Indigenous community, the academy, and other Indigenous researchers, all of which will be included in the sharing of this dissertation research.

As a requirement of my doctoral program, the dissertation document will be submitted to the University of Manitoba, where it will become available through the library system. My dissertation was written in a paper-based chapter format to support the publication of three manuscripts based on chapters 2, 3, and 4. These manuscripts will be prepared for submission to appropriate peer-reviewed journals. Additional knowledge translation activities will include publication in community-based materials and presentations at local, national and international forums and conferences. Indigenous participants will be invited to participate in knowledge-sharing activities and invited and encouraged to share their voice and knowledge. An important knowledge translation activity will involve formatting the study results into a usable source of knowledge to inform the development and implementation of policy and practice pertaining to the collection of REI data within the healthcare system.

Implications

The dissertation journey and four studies produced knowledge that sheds light on where and how Indigenous Peoples, voices, and ways are essential sources of guidance required to support the successful collection of REI data, along with best practice for data usage and reporting. While

there had been talk of listening to Indigenous people and recommendations for research to include Indigenous people, REI data collection strategies had not taken up action. Below I share implications for: 1) REI data collection strategies, which includes details for the Manitoba implementation, 2) Indigenous leadership and voices within healthcare system and policy decisions, 3) future healthcare leaders and decision-makers, 4) research funders, publishers, and ethics review boards, 5) emerging Indigenous scholars.

Implications for REI Data Collection Strategy

Findings from this dissertation, particularly Chapters 2 and 3, provide foundational evidence of relevance to the development, implementation and evaluation of REI data collection strategies. Within Manitoba, where their provincial strategy is being implemented in May 2023, listening to the Indigenous storytellers and reflections on previous attempts has informed educational needs for data collectors within healthcare. This knowledge will aid managers and decision-makers in addressing any pushback that asking 'the question' is uncomfortable. This study is unique in that it is the first to involve Indigenous voices exclusively to inform best practices for REI data collection in meaningful and acceptable ways to First Nations, Inuit, and Métis people. In particular, this study has shown that the notion of Indigenous identity will highly influence REI data collection and the generation of disaggregated data.

A new narrative can counter the concern for people's comfort level. Educational materials developed in Manitoba could be useful for other Canadian jurisdictions implementing REI data collection strategies. For example, the MB strategy developed an REI data collection simulation training module. This is currently available for staff on the Shared Health Learning Management System (online portal). Other useful materials include guides for frequently asked questions

(FAQ), communications materials (pamphlets, posters, digital slides, videos), evaluation protocols for training and process experience, and a framework for data governance. The health of Indigenous people relies on our ability to rise above the resistance, and any barriers must be faced with brave and compassionate action.

The environmental scan clearly indicates what has unfolded with previous attempts, including what led to successes or failures. Listening to the storytellers also led to a list of recommendations for best practices. This work requires commitment and investment of healthcare leaders to ensure that REI data collection in MB is collected and utilized within practices informed by anti-racism. This involves monitoring practices and policies employed to collect the data, appropriate and necessary staff training to ensure patient safety, and the protection of data so that it is utilized in ways that will work towards locating and dismantling racism in healthcare. REI data must be used to address health and healthcare inequities that result from all forms of racism and structures of oppression still existing within the healthcare system.

Prior to the provincial REI data collection strategy, there had been a glaring lack of consideration for data governance agreements with the collection of REI data. It was only through Indigenous leadership that governance agreements were developed. This awareness, as well as the awareness of the failures that resulted when data governance was not considered will be helpful in guiding future systems change and policy development work. The importance of data governance was also echoed by the storytellers, who shared that their overall comfort with REI data collection was based on the ability of the system to ensure that data would be safe and used in ways that would not cause further harm to Indigenous people. Only through the protection of shared

Indigenous identity data can REI data collection achieve its potential of becoming a means of Indigenous empowerment.

Implications for Indigenous leadership and voices within healthcare system and policy decisions

A key finding from the environmental scan is the evidence of the progress that can be made when Indigenous voices are at decision-making tables and what does not unfold when those voices are absent. In Manitoba, this work has been Indigenous-led to address inequities in healthcare and measure where and how systemic racism is occurring in healthcare so that interventions can be deployed to address and dismantle it. As evidenced in the environmental scan, this purpose differs greatly from the drivers for REI data collection a decade ago. When the tables include people who see the need to address systemic racism within the healthcare system as a matter of life and death, often based on personal experiences, developing systems and policies to respond to substandard care rooted in systemic racism is done differently and with increased urgency. It is imperative that any systems of policy change that impacts the lives of Indigenous Peoples are done in consultation or partnership with Indigenous Peoples. This is a right of Indigenous Peoples that must be honored and respected.

Implications for future healthcare leaders and decision-makers

This research demonstrates the critical need for increased awareness and education on the history of colonization and its continued impacts on health and healthcare, the benefits of anti-racist healthcare practice, and the requirement for the disruptions of all forms of racism within healthcare systems for those positioned to become healthcare leaders, and decision-makers, and researchers. Healthcare systems and the people working within them must understand the history

and context of Indigenous Peoples who seek care if there is to be a provision of care that is free from racism and discrimination.

The collection of high-quality REI data can be a solution to closing health and healthcare quality gaps and achieving health equity. However, there needs to be a willingness to open minds and hearts to learning the complex layers that underly the presumed simple notion of asking a question and using the data. This shifting towards an understanding of power as something that works to uplift, and move away from an understanding of power used to oppress, will create pathways for future learning and systems change making Indigenous identities visible and finally fully human.

Implications for research funders, publishers, and ethics review boards

To date, the collection of REI data in MB has focused on system and policy change practices. It was always intended that the potential for research would be addressed at a later date. Currently there is a lack of discussion on potential uses for research and processes that will be required to access data, utilize and report using data disaggregated by REI identity. One of the narratives around REI data collection has been about disaggregated data and what this can do for research, leading to a conversation about data governance. In previous chapters, data governance has been discussed, which often comes with concerns over who is controlling the data and whether Indigenous voices are being honoured and respected. The scoping review shed light on the reality of these concerns existing within current knowledge production, reflecting the potential context of where REI data will land. That is, imbedded with a system of research that privileges Western-based thought and white supremacist standards, and often fails to include, privilege, the inclusion of Indigenous voice and identity when reporting on Indigenous people.

Much of what is known about Indigenous people's health and healthcare has been shaped by non-Indigenous researchers through dominant Western-based paradigms of thought and understanding. In understanding this starting point, we can begin to see why it is important to collect data from Indigenous Peoples and the importance of having Indigenous researchers collect and report on the data. For far too long, the excuse has been that the inability to document Indigenous people's experiences, outcomes, or pathways through the healthcare system was due to a lack of REI data collection. In addressing the excuse through the introduction of REI data collection, large health data sets disaggregated by REI will be available. This dissertation contributes to the discussion by noting that Indigenous people and their voices are required to inform and monitor research reporting about Indigenous specific health and healthcare data. This is an example of the uplifting of Indigenous identity and understanding the impacts and influences of Indigenous identity on the production of knowledge about Indigenous Peoples.

There needs to be critical interrogation into the context surrounding Indigenous health research so that decisions can be made regarding the validity of research evidence of successes and failures of the systems to support the health and wellbeing of Indigenous Peoples. For years, research on the healthcare experience of Indigenous Peoples has been accepted as evidence without full consideration of who is developing and presenting the evidence and how Indigenous Peoples are involved in the production of the evidence. With the impending influx of data repositories containing data disaggregated by REI, it is of high importance that these unchecked practices within research are addressed. While there has been some movement towards the inclusion of self-identified Indigenous people on review and editorial boards to address power imbalances and broaden perspectives, the inclusion of work that discusses racism and anti-racism, and recommendations for reporting of race and ethnicity in health research and

recommendations must now be put into practice. These dissertation findings will add to the assurance that these are steps in the right direction and provide a rationale for the expansion and strengthening of these actions throughout the field of research.

Implications for emerging Indigenous scholars

This research stands as an inspiration for emerging Indigenous scholars to explore research designs and methods that honour their worldview and assist in building relationships and keeping them accountable to those relationships. The adaptations made to the scoping review and the environmental scan demonstrate how these methods can serve to meet the vision/requirement of the Indigenous researcher in their search for required knowledge. This dissertation is also evidence of the purposefulness of the inclusion of abductive knowledge (Kovach, 2010), the inclusion of knowledge from visions, dreams, ceremonies, and traditional knowledge. In taking the lead from Indigenous scholars who have come before me, it is time to take up space within the field of health research by honoring our own identities and the identities of our families, communities, and nations.

Future Directions

As a CIHR doctoral fellow – Indigenous stream - training in Patient Engaged Research, my next steps are framed during the second phase of this fellowship award. This includes my role on the MB provincial REI data collection strategy team and newly emerging relationships with Manitoba Centre for Health Policy, both of which provide a rich context for future research and advocacy work rooted in my doctoral dissertation. Below, I outline two envisioned next steps; while not exhaustive these are anticipated focal points in the near future.

Post implementation evaluation

While pre-implementation knowledge is extremely valuable to understanding Indigenous perspectives on REI data collection, post-implementation evaluation on the experiences and impacts of REI data collection for Indigenous Peoples is imperative. A follow-up study of REI data collection post-implementation to understand the perspectives, experiences, and reactions of First Nations, Inuit, and Métis patients is crucial to ensure REI data collection is not causing additional harm and challenges to Indigenous Peoples who access healthcare in the Manitoba healthcare system. The follow-up study will work with Indigenous methodologies to enhance the spaces for Indigenous knowledge and voice to be privileged to track barriers and facilitators to the collection of the REI data. This will allow for timely feedback to the MB REI data collection team to ensure the process is achieving its intended goals, that training is successful and effective, and that the process does not cause additional harm. Indigenous governance of the monitoring and evaluation of REI data collection, storage, analysis, and reporting is an act of Indigenous resistance against the continued anti-Indigenous racism within the healthcare system.

National data governance network

With the increased interest in the collection of REI data for health and healthcare monitoring and research, along with systems/program development, it is critical to host dialogues regarding the governance of Indigenous data and Indigenous data sovereignty. Keeping these narratives at the forefront of REI data collection is imperative to support advancements landing in good ways to benefit Indigenous people and prevent trauma. While building large data sets of disaggregated REI data is critical to fully understand disparities and successes in health and healthcare for Indigenous Peoples, there must be extreme care and caution taken in how REI data is collected,

stored, reported, and utilized. Involvement of Indigenous Peoples who can guide the development of culturally respectful processes for managing Indigenous data is imperative. A future direction, working with national colleagues, is to gather First Nations, Inuit, and Métis people to build of a network of Indigenous scholars working in the field of Indigenous data governance and sovereignty. In hosting dialogues and activities in this area, increased opportunity for collaboration and expanding awareness of the need for data governance can be realized. The specialized attention and process for managing Indigenous health data can no longer remain a footnote or afterthought. The overall network purpose is for data governance and sovereignty to hold a position of importance in the development and building of Indigenous health data repositories.

Conclusion

It must be understood that the process of identifying as Indigenous can mean more than just having numbers counted for big data purposes. For some, this may be internalized as another way of taking back space as Indigenous Peoples who hold a right to the highest form of health and healthcare, despite the history demonstrating a different reality. It is an opportunity to hold onto and bring to light an Indigenous-driven narrative of Indigenous health and healthcare realities. Indigenous Peoples are leading the revolution in REI data curation in Manitoba as researchers, collectors, analyzers, stewards, reporters, and decision-makers of the data. No longer on the margins looking in, but taking back space and place as leaders.

Over the years there, has been progress in the inclusion of Indigenous ways of being, knowing, and doing in research, however, this recent emergence faces the difficult challenge of changing systemic perspectives entrenched in white supremacy. Continuous efforts led by Indigenous

scholars is required, along with support from non-Indigenous people who are invested and committed to driving the necessary change. With REI data being rationalized as essential to change how we see and understand how Indigenous Peoples experience healthcare encounters, taking time to critically examine how evidence is shaped by various structures existing within health research is mandatory. Otherwise even high-quality data may be skewed through systems that support Western-based thought and hold white supremacy as the gold standard. While there is work to be done with implementing strategies to collect REI data, it is imperative that we also pay attention to and work on mechanisms that will guide how the data is used and the results reported.

REI data bring promise of new avenues and evidence to address health and health equity and disrupt anti-Indigenous racism in the healthcare system. However, through this dissertation, it becomes evident that an additional pathway is one of Indigenous empowerment. As mechanisms for Indigenous-voiced experiences are supported in the acquisition of high-quality, anti-racist, and culturally safe healthcare, by enhancing processes to hold systems and individuals accountable for harm that they cause, new possibilities, empowerment, and healing are possible. For some, Indigenous empowerment through declaring identity is unrelatable to REI data collection for building disaggregated data sets. But really, the latter only happens when the former is realized, as it is only with respect, engagement, and trust can we collect REI data properly and successfully.

The collection of REI data is an act toward reconciliation. Having the data will allow for addressing a number of the TRC Calls to Action, in particular, Call to Action #19, which states:

"We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services" (Truth and Reconciliation Commission of Canada, 2015, p. 322).

However, an earlier reconciliation action is required, that is, to shift perspectives away from resistance to challenging dominant ideologies towards one that privileges and legitimizes Indigenous knowledge, experience, and realities. This also demands relationship changes and accountability among newly formed relationships, otherwise, trust remains broken. If commitments to decolonizing our healthcare structures are absent and relationships do not accompany the required reconciliation actions, the intended promises of REI data collection benefits will never be met. As with REI data collection, this work must be done to make significant improvements to the experiences and outcomes of Indigenous people's health and healthcare. Anything less will not be satisfactory and will simply repeat broken promises noted throughout history.

As I was writing this dissertation, the Manitoba provincial strategy for REI data collection was designed, developed, and implemented. REI data collection commenced on May 11, 2023, as a culmination of 5 years of work. Promising, is that Shared Health, the provincial health authority of Manitoba, recently released a statement on their commitment to disrupting racism in any form. Before releasing this statement, one of the Indigenous health leadership storytellers shared a

sense of weariness that government would ever agree to make a public statement around racism in health care. Their continued commitment to the informed and appropriate collection of REI data will support the success of the initiative and the benefits of disaggregated data. With progress being made in both minute and drastic ways, there is hope for the future.

To conclude my dissertation writing, I was drawn to share the following teaching gifted to me as part of the journey. I close this work with a final reflection on how traditional knowledge has guided me through this work.

I have received gifts with my medicine work, and those gifts were passed to me in ceremony. When I use those gifts, I do not take them further than what I know. I can tell when something is beyond my knowledge or abilities at that time. My spirit gets called back to safety when I am pushed too far. This has turned out to be a vital lesson in awareness of authenticity and to hold back from going beyond my knowledge when it does not feel right. Staying in authenticity allows me to continue learning and absorbing the knowledge meant for me to hold and carry, and to leave that which is not. This is an important lesson for me to carry in all life circumstances and the roles, big or small, in which I find myself.

This has been a journey of discovering, understanding, and knowing,
Miigwetch. All my Relations. Zhaawanong Binesi Ikwe.

References

Absolon, K., & Willet C. (2005). Putting ourselves forward: Location in Aboriginal research. In S. Strega & L. Brown (Eds.) *Research as Resistance* (1st ed., pp. 27-56). Canadian Scholars Press.

Absolon. K. (2022). *Kaandossiwin: how we come to know: Indigenous re-search methodologies* (2nd ed.). Fernwood Publishing.

Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health*, *96*(S2), S45–S61. https://doi.org/10.1007/bf03403702

Aguilar, F. (1967). *Scanning the business environment.* The MacMillan Company.

Albright, K. (2004). Environmental scanning: radar for success. *The Information Management Journal*, 38(3), 38.

Alcock D, Elgie J, Richmond C, & White J. (2017). Developing ethical research practices between institutional and community partners: A look at the current base of literature surrounding memorandums of understanding in Canada. *International Indigenous Policy Journal*, 8(4). https://doi.org/10.18584/iipj.2017.8.4.3

Allan, B. & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous Peoples in Canada.* The Wellesley Institute. https://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Full-Report-FPSCT-Updated.pdf

Anderson. M., (2019). Indigenous health research and reconciliation. *Canadian Medical Association Journal*, 191(34), E930–E931. https://doi.org/10.1503/cmaj.190989

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodologic framework. *International Journal of Social Research Methodology*, *8* (1), 19–32.

https://doi.org/10.1080/1364557032000119616

Ashworth, A. (2018). Understanding the factors influencing the Aboriginal health care experience. *Canadian Journal of Dental Hygiene*, 52(3), 208–212.

Baker, D., Cameron, K. A., Feinglass, J., Georgas, P., Foster, S., Pierce, D., Thompson, J. A., & Hasnain-Wynia, R. (2005). Patients' attitudes toward health care providers collecting information about their race and ethnicity. *Journal of General Internal Medicine*, *20*(10), 895–900. https://doi.org/10.1111/j.1525-1497.2005.0195.x

Baker, D., Hasnain-Wynia, R., Kandula, N. R., Thompson, J. A., & Brown, E. R. (2007). Attitudes toward health care providers, collecting information about patients' race, ethnicity, and language. *Medical Care*, 45(11), 1034–1042. https://doi.org/10.1097/MLR.0b013e318127148f

Balestra, C., & Fleischer, L. (2018). Diversity statistics in the OECD: How do OECD countries collect data on ethnic, racial and indigenous identity? *OECD Statistics Working Papers*, 2018(9), 0_1–55. https://doi.org/10.1787/89bae654-en

Benoit, C., Carroll, D., & Chaudhry, M. (2003). In search of a healing place: Aboriginal women in Vancouver's downtown eastside. *Social Science & Medicine (1982)*, 56(4), 821–833. https://doi.org/10.1016/S0277-9536(02)00081-3

Bharadwaj, L. (2020). A framework for building research partnerships with First Nations communities. *Environmental Health Insights*, 8(1). https://doi.org/10.1177/EHI.S10869

Bierman, A., Lurie, N., Collins, K. S., & Eisenberg, J. M. (2002). Addressing racial and ethnic barriers to effective health care: The need for better data. *Health Affairs*, 21(3), 91–102. https://doi.org/10.1377/hlthaff.21.3.91

Brayboy, B., & Chin, J. (2019). A match made in heaven: tribal critical race theory and critical

Indigenous research methodologies. In Decuir-Gunby, J., Chapman, T., & Shutz, P. (Eds.), *Understanding critical race research methods and methodologies: lessons from the field.* Routledge.

Brotman, C., Ryan, B., Jalbert, Y., & Rowe, B. (2002). Reclaiming space-regaining health: The health care experiences of Two-Spirit people in Canada. *Journal of Gay & Lesbian Social Services*, 14(1), 67–87. https://doi.org/10.1300/J041v14n01_04

Browne, A. (2008). Seeking health care at emergency departments - Access issues affecting Aboriginal people. *Visions (Vancouver)*, 5(1), 24–.

Browne, A., & Fiske, J-A. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research*, 23(2), 126–147. https://doi.org/10.1177/019394590102300203

Browne, A., Smye, V. L., Rodney, P., Tang, S. Y., Mussell, B., & O'Neil, J. (2011). Access to primary care from the perspective of Aboriginal patients at an urban emergency department. *Qualitative Health Research*, *21*(3), 333–348. https://doi.org/10.1177/1049732310385824

Bruhn, J. (2014). Identifying useful approaches to the governance of Indigenous data. *International Indigenous Policy Journal*, *5*(2), 5–. https://doi.org/10.18584/iipj.2014.5.2.5

Brunger F, & Wall D. (2016). "What do they really mean by partnerships?" Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research. *Qualitative Health Research*, 26(13), 1862–1877. https://doi.org/10.1177/1049732316649158

Canada. (2019). *Reclaiming power and place: The final report of the national inquiry into*

Missing and Murdered Indigenous Women and Girls, (Volume 1a and 1b) https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Final_Report_Vol_1a-1.pdf https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Final_Report_Vol_1b.pdf

Canada. (2022). *Indigenous Peoples and cultures*. https://www.canada.ca/en/services/culture/canadian-identity-society/indigenous-peoples-cultures.html

Canada. (2023a). *The Government of Canada and Manitoba reach agreement in principle to improve health services for Canadians*. https://www.canada.ca/en/health-canada/news/2023/02/the-government-of-canada-and-manitoba-reach-agreement-in-principle-to-improve-health-services-for-canadians.html

Canada. (2023b). *Improving health care*. https://www.canada.ca/en/health-canada/services/priorities.html?utm_campaign=not-applicable&utm_medium=vanity-url&utm_source=canada-ca_healthpriorities.html

Canada. (2023c). *Reference Group for the Appropriate Review of Indigenous Research*. https://cihr-irsc.gc.ca/e/52136.html

Canadian Institutes of Health Research (CIHR). (2007). *CIHR guidelines for health research involving Aboriginal people.* https://icwrn.uvic.ca/wpcontent/uploads/2013/10/ethics_aboriginal_guidelines_metis_e.pdf

Canadian Institute for Health Information (CIHI). (2020). *Proposed standards for race-based and Indigenous identity data Collection and health reporting in Canada.* https://www.cihi.ca/sites/default/files/rot/proposed-standard-for-race-based-data-en.pdf

Canadian Institute for Health Information (CIHI). (2022). *Race-based and Indigenous identity*

data collection and health reporting in Canada (Supplementary Report). https://www.cihi.ca/sites/default/files/document/race-based-and-indigenous-identity-data-supplementary-report-en.pdf

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2022). *Tri Council Policy Statement: Ethical Conduct for Research Involving Humans.* https://ethics.gc.ca/eng/documents/tcps2-2022-en.pdf

Cardinal, L. (2001). What is an Indigenous perspective? *Canadian Journal of Native Education*, 25(2), 180–182.

Carlson, E. (2017). Anti-colonial methodologies and practices for settler colonial studies. *Settler Colonial Studies: Pathways to Settler Decolonisation*, *7*(4), 496–517.

Castleden, H., Martin, D., & Lewis, D. (2016). From embedded in place to marginalized out and back again: Indigenous Peoples' experience of health in Canada. In M. Giesbrecht, & V. Crooks (Eds.), *Place, Health, and Diversity* (1st ed., pp. 29–52). Routledge. https://doi.org/10.4324/9781315600598-3

Chambers, L., Jackson, R., Worthington, C., Wilson, C., Tharao, W., Greenspan, N., Masching, R., Pierre-Pierre, V., Mbulaheni, T., Amirault, M., & Brownlee, P. (2018). Decolonizing scoping review methodologies for literature with, for, and by Indigenous Peoples and the African diaspora: dialoguing with the tensions. *Qualitative Health Research*, *28*(2), 175-188.

Chandna, K., Vine, M. M., Snelling, S. J., Harris, R., Smylie, J., & Manson, H. (2019). Principles, approaches, and methods for evaluation in indigenous contexts: A grey literature scoping review. *Canadian Journal of Program Evaluation*, 34(1), 21–47.

https://doi.org/10.3138/cjpe.43050

Chilisa, B. (2012). *Indigenous research methodologies*. SAGE.

Choo, CW. (2001). Environmental scanning as information seeking and organizational learning. *Information Research*. 7(1).

Churchill, M. E., Smylie, J. K., Wolfe, S. H., Bourgeois, C., Moeller, H., & Firestone, M. (2020). Conceptualising cultural safety at an Indigenous-focused midwifery practice in Toronto, Canada: qualitative interviews with Indigenous and non-Indigenous clients. *BMJ Open*, *10*(9), e038168–e038168. https://doi.org/10.1136/bmjopen-2020-038168

Clark, N., Walton, P., Drolet, J., Tribute, T., Jules, G., Main, T., & Arnouse, M. (2013). Melq'ilwiye: coming together- intersections of identity, culture, and health for urban Aboriginal youth. *Canadian Journal of Nursing Research*, 45(2), 36–57. https://doi.org/10.1177/084456211304500208

Coates, K. (1999). Being aboriginal: the cultural politics of identity, membership and belonging among First Nations in Canada. *Canadian Issues (Association for Canadian Studies: 1999*), 21, 23–.

College of Physicians and Surgeons of Manitoba. (2023). *Statement and apology on Truth and Reconciliation and Indigenous specific racism in medical practice.* http://www.cpsm.mb.ca/news/statement-and-apology-on-truth-and-reconciliation-and-indigenous-specific-racism-in-medical-practice

Council of the Atikamekw of Manawan and the Council de la Nation Atikamekw. (2020). *Joyce's Principle.* https://principedejoyce.com/sn_uploads/principe/Joyce_s_Principle_brief___Eng.pdf

Creswell, J. (2009). *Research design: qualitative, quantitative, and mixed methods*

approaches (3rd ed.). SAGE Publications.

Dei, J., (2005). Critical issues in anti-racist research methodologies: an introduction. In G. Dei & G. Johal (Eds.), *Critical issues in anti-racist research methodologies.* P. Lang.

Denzin, N., Lincoln, Y. (2014). Introduction: critical methodologies and Indigenous inquiry. In N. Denzin, Y. Lincoln, & L. Smith, L (Eds.), *Handbook of critical and indigenous methodologies*. SAGE Publications. https://doi.org/10.4135/9781483385686.n1

Dorais, L., and Searles, E. (2001) Identités inuit / Inuit identities. *Études/Inuit/Studies*. 25, (1/2) 9-35.

Dunbar, C. (2008). Critical race theory and Indigenous methodologies. In N. Denzin, Y. Lincoln, & L. Smith, L (Eds.), *Handbook of critical and indigenous methodologies*. SAGE. https://doi.org/10.4135/9781483385686.n5

Firestone, M., Smylie, J., Maracle, S., Spiller, M., & O'Campo, P. (2014). Unmasking health determinants and health outcomes for urban First Nations using respondent-driven sampling. *BMJ Open*, 4(7), e004978–e004978. https://doi.org/10.1136/bmjopen-2014-004978

Firestone, M., Syrette, J., Jourdain, T., Recollet, V., & Smylie, J. (2019). I feel safe just coming here because there are other Native brothers and sisters: findings from a community-based evaluation of the Niiwin Wendaanimak Four Winds Wellness Program. *Canadian Journal of Public Health*, 110(4), 404–413. https://doi.org/10.17269/s41997-019-00192-6

First Nations Information Governance Centre. (2019a). First Nations data sovereignty in Canada. *Statistical Journal of the IAOS*, 35(1), 47–69. https://doi.org/10.3233/SJI-180478

First Nations Information Governance Centre. (2019b). *The First Nations Principles of OCAP®*. https://fnigc.ca/wp-content/uploads/2021/08/OCAP-Brochure-2019.pdf

First Nations, Métis, and Inuit Health Research Strategic Planning Committee. (2014) *Framework for research engagement with First Nation, Métis, and Inuit peoples*. University of Manitoba Faculty of Health Sciences. (2014). https://umanitoba.ca/faculties/health_sciences/medicine/media/UofM_Framework_Report_web.pdf

Fitznor. L. (2006). The power of Indigenous knowledge: Naming and identity and colonization in Canada. In J. Kunnie & N. Goduka (Eds.), *Indigenous Peoples' Wisdom and Power* (1st ed., pp. 51–77). Routledge. https://doi.org/10.4324/9781315252414-4

Flanagin, A., Frey, T., & Christiansen, S. L. (2021). Updated guidance on the reporting of race and ethnicity in medical and science journals. *JAMA: the Journal of the American Medical Association*, 326(7), 621–627. https://doi.org/10.1001/jama.2021.13304

George, J., Ninomiya, M. M., Graham, K., Bernards, S., & Wells, S. (2019). The rationale for developing a programme of services by and for indigenous men in a first nations community. *AlterNative: an International Journal of Indigenous Peoples*, 15(2), 158–167. https://doi.org/10.1177/1177180119841620

Gibbens, M., & Bowen, S. (2009). *Supporting the implementation of regional language & ethnicity indicators: summary report of key research & evaluation findings.* WRHA Research and Evaluation Unit. Unpublished Report.

Gomez, Lichtensztajn, D. Y., Parikh, P., Hasnain-Wynia, R., Ponce, N., & Zingmond, D. (2014). hospital practices in the collection of patient race, ethnicity, and language data: A statewide survey, California, 2011. *Journal of Health Care for the Poor and Underserved*, *25*(3), 1384–1396. https://doi.org/10.1353/hpu.2014.0126

Government of Canada. (1996). *Report of the Royal Commission on Aboriginal Peoples.*

https://www.bac-lac.gc.ca/eng/discover/aboriginal-heritage/royal-commission-aboriginal-peoples/Pages/final-report.aspx

Government of Canada. (2018). Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2 - Chapter 9 Research Involving the First Nations, Inuit and Métis Peoples of Canada. Panel on Research Ethics. https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf

Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: how useful are they for primary care research? *Canadian Family Physician*, 54(7), 1022–1023.

Grant, M., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*, 26(2), 91–108. https://doi.org/10.1111/j.1471-1842.2009.00848.x

Hadjipavlou, G., Varcoe, C., Browne, A. J., Tu, D., Dehoney, J., & Price, R. (2018). "All my relations": experiences and perceptions of Indigenous patients connecting with Indigenoua Elders in an inner-city primary care partnership for mental health and well-being. *Canadian Medical Association Journal*, 190(20), E608–E615. https://doi.org/10.1503/cmaj.171390

Hampton, M., Baydala, A., Bourassa, C., McKay-McNabb, K., Placsko, C., Goodwill, K., McKenna, B., McNabb, P., & Boekelder, R. (2010). Completing the circle: elders speak about end-of-life care with aboriginal families in Canada. *Journal of Palliative Care*, 26(1), 6–14. https://doi.org/10.1177/082585971002600103

Hart, M., Straka, S., & Rowe, G. (2017). Working across contexts: Practical considerations of

doing Indigenist/anti-colonial research. *Qualitative Inquiry*, *23*(5), 332–342. https://doi.org/10.1177/1077800416659084

Hasnain-Wynia, R., & Baker, D. W. (2006). Obtaining data on patient race, ethnicity, and primary language in health care organizations: Current challenges and proposed solutions. *Health Services Research*, 41(4p1), 1501–1518. https://doi.org/10.1111/j.1475-6773.2006.00552.x

Hasnain-Wynia, R., Van Dyke, K., Youdelman, M., Krautkramer, C., Ivey, S. L., Gilchick, R., Kaleba, E., & Wynia, M. K. (2010). Barriers to collecting patient race, ethnicity, and primary language data in physician practices: An exploratory study. *Journal of the National Medical Association*, 102(9), 769–775. https://doi.org/10.1016/S0027-9684(15)30673-8

Hayward, A., Sjoblom, E., Sinclair, S., & Cidro, J. (2021). A new era of Indigenous research: community-based Indigenous research ethics protocols in Canada. *Journal of Empirical Research on Human Research Ethics*, 16(4), 403–417. https://doi.org/10.1177/15562646211023705

Hayward, A., Cidro, J., Dutton, R., & Passey, K. (2020). A review of health and wellness studies involving Inuit of Manitoba and Nunavut. *International Journal of Circumpolar Health*, 79(1), 1779524–. https://doi.org/10.1080/22423982.2020.1779524

Health Canada. (2014). Your Health Benefits A Guide for Inuit to Access Non-Insured Health Benefits. https://inuuqatigiit.ca/wp-content/uploads/2015/11/Inuit-N-Handbook-EN-FINAL.pdf

Hislop, T. G., Clarke, H. F., Deschamps, M., Joseph, R., Band, P. R., Smith, J., Le, N., & Atleo, R. (1996). Cervical cytology screening. How can we improve rates among First Nations

women in urban British Columbia? *Canadian Family Physician*, 42, 1701–1708.

Hole, R., Evans, M., Berg, L. D., Bottorff, J. L., Dingwall, C., Alexis, C., Nyberg, J., & Smith, M. L. (2015). Visibility and voice: Aboriginal people experience culturally safe and unsafe health care. *Qualitative Health Research*, *25*(12), 1662–1674. https://doi.org/10.1177/1049732314566325

Hollenberg, D., & Muzzin, L. (2010). Epistemological challenges to integrative medicine: An anti-colonial perspective on the combination of complementary/alternative medicine with biomedicine. *Health Sociology Review*, *19*(1), 34–56.

Hyett, S., Marjerrison, S., & Gabel, C. (2018). Improving health research among Indigenous peoples in Canada. *Canadian Medical Association Journal*, 190(20), E616–E621. https://doi.org/10.1503/cmaj.171538

Hyett S., Gabel, C., Marjerrison, S., & Schwartz, L. (2019). Deficit-based Indigenous health research and the stereotyping of Indigenous Peoples. *Canadian Journal of Bioethics = Revue Canadienne de Bioéthique*, 2(2), 102–109. https://doi.org/10.7202/1065690ar

I. Scheim, A., Jackson, R., James, L., Sharp Dopler, T., Pyne, J., & R. Bauer, G. (2013). Barriers to well-being for Aboriginal gender-diverse people: results from the Trans PULSE Project in Ontario, Canada. *Ethnicity and Inequalities in Health and Social Care*, 6(4), 108–120. https://doi.org/10.1108/EIHSC-08-2013-0010

Inuit Tapiriit Kanatami. (2018). *National Inuit strategy on research*. https://www.itk.ca/wp-content/uploads/2018/04/ITK_NIR-Report_English_low_res.pdf

Jacobs. B. (2019). Indigenous identity: Summary and future directions. *Statistical Journal of the IAOS*, 35(1), 147–157. https://doi.org/10.3233/SJI-190496

Jones, C. (2000). Levels of racism: a theoretic framework and a gardener's tale. *American*

Journal of Public Health (1971), *90*(8), 1212–1215.

Jull J, King A, King M, Graham, I. D., Morton Ninomiya, M. E., Jacklin, K., Moody-Corbett, P., & Moore, J. E: (2020). A principled approach to research conducted with Inuit, Métis, and First Nations people: Promoting engagement inspired by the CIHR guidelines for health research involving Aboriginal people (2007-2010). *International Indigenous Policy Journal*, 11(2):1-30. https://doi.org/10.18584/iipj.2020.11.2.10635

Kandula, N R., Hasnain-Wynia, R., Thompson, J. A., Brown, E. R., & Baker, D. W. (2009). Association between prior experiences of discrimination and patients' attitudes towards health care providers collecting information about race and ethnicity. *Journal of General Internal Medicine*, 24(7), 789–794. https://doi.org/10.1007/s11606-009-0991-z

Katz A, Kinew KA, Star L, Taylor C, Koseva I, Lavoie J, Burchill C, Urquia ML, Basham A, Rajotte, L, Ramayanam V, Jarmasz J, & Burchill S. (2019). *The health status of and access to healthcare by registered First Nation peoples in Manitoba.* Winnipeg, MB. Manitoba Centre for Health Policy. http://mchp-appserv.cpe.umanitoba.ca/reference/FN_Report_web.pdf

Kent, A., Loppie, C., Carriere, J., MacDonald, M., & Pauly, B. (2017). Xpey' relational environments: an analytic framework for conceptualizing Indigenous health equity. *Health Promotion and Chronic Disease Prevention in Canada*, 37(12), 395–402. https://doi.org/10.24095/hpcdp.37.12.01

Kelly, L., Linkewich, B., Cromarty, H., St Pierre-Hansen, N., Antone, I., Giles, C., & Gilles, C. (2009). Palliative care of First Nations people A qualitative study of bereaved family members. *Canadian Family Physician*, 55(4), 394–395.e7.

Kimmerer, R. (2013). *Braiding sweetgrass.* Milkweed Editions.

Kiran, T., Sandhu, P., Aratangy, T., Devotta, K., Lofters, A., & Pinto, A. (2019). Patient perspectives on routinely being asked about their race and ethnicity: qualitative study in primary care. *Canadian Family Physician*, *65*(8), e363–e369.

Kirkness, V., & Barnhardt, R. (2016). First Nations and Higher Education: The four R's—respect, relevance, reciprocity, responsibility. *The Journal of College and University Student Housing, 42(2), 94–*.

Kirst, M., Shankardass, K., Bomze, S., Lofters, A., & Quiñonez, C. (2013). Sociodemographic data collection for health equity measurement: a mixed methods study examining public opinions. *International Journal for Equity in Health*, *12*(1), 75–75. https://doi.org/10.1186/1475-9276-12-75

Kitching, G., Firestone, M., Schei, B., Wolfe, S., Bourgeois, C., O'Campo, P., Rotondi, M., Nisenbaum, R., Maddox, R., & Smylie, J. (2020). Unmet health needs and discrimination by healthcare providers among an Indigenous population in Toronto, Canada. *Canadian Journal of Public Health*, 111(1), 40–49. https://doi.org/10.17269/s41997-019-00242-z

Kovach, M. (2009). *Indigenous methodologies: characteristics, conversations and contexts.* University of Toronto Press.

Kovach, M. (2010). Conversation Method in Indigenous Research. *First Peoples Child & Family Review*, *5*(1), 40–48.

Kovach, M. (2015). Emerging from the margins: Indigenous methodologies. In L. Brown & S. Strega (Eds.), *Research as resistance: revisiting critical, indigenous, and anti-oppressive approaches* (2nd ed.), Canadian Scholars' Press.

Kovach. M. (2021). Indigenous methodologies: characteristics, conversations, and contexts (2nd ed.), University of Toronto Press.

Kurtz, D., Nyberg, J. C., Van Den Tillaart, S., Mills, B., & (OUAHRC), T. O. U. A. H. R. (2008). Silencing of voice: An act of structural violence urban Aboriginal women speak out about their experiences with health care. *International Journal of Indigenous Health*, 4(1), 53–63. https://doi.org/10.18357/ijih41200812315

Lambert, L. (2014). *Research for indigenous survival: indigenous research methodologies in the behavioral sciences.* Salish Kootenai College Press.

Lawford, K., Bourgeault, I. L., & Giles, A. R. (2019). "This policy sucks and it's stupid:" Mapping maternity care for First Nations women on reserves in Manitoba, Canada. *Health Care for Women International*, 40(12), 1302–1335. https://doi.org/10.1080/07399332.2019.1639706

Lewis, A. (2012). Ethics, activism and the anti-colonial: Social movement research as resistance. *Social Movement Studies*, 11(2), 227–240.

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(1), 69–69. https://doi.org/10.1186/1748-5908-5-69

Leyland, A., Smylie, J., Cole, M., Kitty, D., Crowshoe, L., McKinney, V., Green, M., Funnell, S.,Brascoupé, S., Dallaire, J., Safarov, A. (2016). *Health and health care implications of systemic racism on Indigenous Peoples in Canada.* The College of Physicians and Surgeons of Canada. https://www.cfpc.ca/CFPC/media/Resources/Indigenous-Health/SystemicRacism_ENG.pdf

Linton, J. (2022) *Identifying information for Indigenous Peoples' health: Finding interdisciplinary, evidence-based research and community-based resources.* University of Manitoba. https://libguides.lib.umanitoba.ca/ld.php?content_id=36536024

Lofters, A., Shankardass, K., Kirst, M., Quiñonez, C. (2011). Sociodemographic data collection in healthcare settings: an examination of public opinions. *Medical Care*, *49*(2), 193–199. https://doi.org/10.1097/MLR.0b013e3181f81edb

Loppie, S., Reading, C., and de Leeuw, S. (2014). *Aboriginal experiences with racism and its impacts.* National Collaborating Centre for Aboriginal Health. http://www.nccahccnsa.ca/Publications/Lists/Publications/Attachments/131/2014_07_09_FS_2426_RacismPart2_ExperiencesImpacts_EN_Web.pdf

Loyola-Sanchez, A., Pelaez-Ballestas, I., Crowshoe, L., Lacaille, D., Henderson, R., Rame, A., Linkert, T., White, T., & Barnabe, C. (2020). "There are still a lot of things that I need": a qualitative study exploring opportunities to improve the health services of First Nations People with arthritis seen at an on-reserve outreach rheumatology clinic. *BMC Health Services Research*, 20(1), 1076–1076. https://doi.org/10.1186/s12913-020-05909-9

Lu, C., Ahmed, R., Lamri, A., Anand, S. (2022). Use of race, ethnicity, and ancestry data in health research. *PLOS Global Public Health*, *2*(9).

Lurie, & Fremont, A. (2006). Looking forward: Cross-cutting issues in the collection and use of racial/ethnic data. *Health Services Research*, 41(4p1), 1519–1533. https://doi.org/10.1111/j.1475-6773.2006.00553.x

Lux, L. (2010). Care for the "Racially Careless": Indian hospitals in the Canadian west, 1920–1950s. *The Canadian Historical Review*, *91*(3), 407–434. https://doi.org/10.1353/can.2010.0018

Lux, M. (2016). *Separate beds: a history of Indian hospitals in Canada, 1920s-1980s*. University of Toronto Press.

Madden, R., Coleman, C., Mashford-Pringle, A., & Connolly, M. (2019). Indigenous

identification: Past, present and a possible future. *Statistical Journal of the IAOS*, 35(1), 23– 27. https://doi.org/10.3233/SJI-180467

Maranzan, A. K., Hudson, R., Scofich, R., McGregor, M., & Seguin, R. (2018). "It's a lot of work, and I'm still doing it": Indigenous perceptions of help after sexual abuse and sexual violence. *International Journal of Indigenous Health*, 13(1), 140–156. https://doi.org/10.18357/iiih.v13i1.30312

Matthews, R. (2017). The cultural erosion of indigenous people in health care. *Canadian Medical Association Journal*, 189(2), E78–E79. https://doi.org/10.1503/cmaj.160167

Max, K. (2005). Anti-colonial research: working as an ally with Aboriginal peoples. In G. Dei & G. Johal (Eds.), *Critical issues in anti-racist research methodologies*. P. Lang.

McAtackney, D., Gaspard, G., Sullivan, D., & Sebastian, M. (2021). Improving dementia care for Gitxsan First Nations people. *International Journal of Indigenous Health*, 16(1), 118–145. https://doi.org/10.32799/ijih.v16i1.33225

McBride, K. (2017). *Data resources and challenges for First Nations communities*. Prepared for the Alberta First Nations Information Governance Centre. https://www.afnigc.ca/main/includes/media/pdf/digital%20reports/Data_Resources_Report.pdf

McCallum, M., & Perry, A. (2018). *Structures of indifference: an indigenous life and death in a Canadian city.* University of Manitoba Press.

McNally, M., & Martin, D. (2017). First Nations, Inuit and Métis health: Considerations for Canadian health leaders in the wake of the Truth and Reconciliation Commission of Canada report. *Healthcare Management Forum*, 30(2), 117–122. https://doi.org/10.1177/0840470416680445

Meijer Drees, L. (2010). The Nanaimo and Charles Camsell Indian hospitals: First Nations" narratives of health care, 1945 to 1965. *Histoire Sociale*, 43(85), 165–191. https://doi.org/10.1353/his.2010.0002

Mill, J., Lambert, D., Larkin, K., Ward, K., Harrowing, J. (2008). Challenging lifestyles: aboriginal men and women living with HIV. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health.* 5(2).

Monchalin, Smylie, J., & Nowgesic, E. (2020a). "I guess I shouldn't come back here": Racism and discrimination as a barrier to accessing health and social services for urban Métis women in Toronto, Canada. *Journal of Racial and Ethnic Health Disparities*, 7(2), 251–261. https://doi.org/10.1007/s40615-019-00653-1

Monchalin, Smylie, J., & Bourgeois, C. (2020b). "It's not like I'm more indigenous there and I'm less indigenous here.": Urban Metis women's identity and access to health and social services in Toronto, Canada. *AlterNative: an International Journal of Indigenous Peoples*, 16(4), 323–331. https://doi.org/10.1177/1177180120967956

National Aboriginal Health Organization. *Principles of ethical Métis research*. (2010). https://achh.ca/wp-content/uploads/2018/07/Guide_Ethics_NAHOMetisCentre.pdf

National Collaborating Centre for Determinants of Health. (2023). *Let's talk: health equity* (2nd ed.). NCCDH, St. Francis Xavier University. https://nccdh.ca/images/uploads/NCCDH_Lets_Talk_Health_Equity_EN_June5.pdf

National Collaborating Centre for Indigenous Health. (2019). *Access to health services as a social determinant of First Nations, Inuit and Métis health.* https://www.nccih.ca/docs/determinants/FS-AccessHealthServicesSDOH-2019-EN.pdf

Nestel, S. (2012). *Colour coded health care: The impact of race and racism on Canadians'*

health. Wellesley Institute. https://www.wellesleyinstitute.com/wp-content/uploads/2012/02/Colour-Coded-Health-Care-Sheryl-Nestel.pdfOlson

Olson, R A., Howard, F., Turnbull, K., Munroe, D., Zirul, C., Manji, R., Tobin, P., & Ward, A. (2014). Prospective evaluation of unmet needs of rural and aboriginal cancer survivors in Northern British Columbia. *Current Oncology (Toronto)*, 21(2), e179–185. https://doi.org/10.3747/co.21.1729

Palmater. (2011). *Beyond blood: rethinking indigenous identity*. Purich Publishing.

Patrick. K., (2021). CMAJ and antiracism. *Canadian Medical Association Journal*, 193(13), E453–E454. https://doi.org/10.1503/cmaj.210494

Pauly, B., Gray, E., Perkin, K., Chow, C., Vallance, K., Krysowaty, B., & Stockwell, T. (2016). Finding safety: a pilot study of managed alcohol program participants' perceptions of housing and quality of life. *Harm Reduction Journal*, 13(1), 15–15. https://doi.org/10.1186/s12954- 016-0102-5

Phillips-Beck, Eni, R., Lavoie, J. G., Avery Kinew, K., Kyoon Achan, G., & Katz, A. (2020). Confronting racism within the Canadian healthcare system: Systemic exclusion of First Nations from quality and consistent care. *International Journal of Environmental Research and Public Health*, 17(22), 8343–. https://doi.org/10.3390/ijerph17228343

Pinto, A., Glattstein-Young, G., Mohamed, A., Bloch, G., Leung, F., & Glazier, R. (2016). Building a foundation to reduce health inequities: routine collection of sociodemographic data in primary care. *Journal of the American Board of Family Medicine*, *29*(3), 348-355. https://doi.org/10.3122/jabfm.2016.03.150280

Petkovic, J., Duench, S. L., Welch, V., Rader, T., Jennings, A., Forster, A. J., & Tugwell, P. (2019). Potential harm associated with routine collection of patient sociodemographic

information: A rapid review. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 22(1), 114–129. https://doi.org/10.1111/hex.12837

Quan, H., Wong, A., Johnson, D., & Ghali, W. (2006). The public endorses collection of ethnicity information in hospital: implications for routine data capture in Canadian health systems. *Healthcare Policy, 1*(3), 55–64.

Ramraj, Shahidi, F. V., Darity, W., Kawachi, I., Zuberi, D., & Siddiqi, A. (2016). Equally inequitable? A cross-national comparative study of racial health inequalities in the United States and Canada. *Social Science & Medicine* (1982), 161, 19–26. https://doi.org/10.1016/j.socscimed.2016.05.028

Razack, S. (2015). *Dying from improvement: inquests and inquiries into Indigenous deaths in custody.* University of Toronto Press.

Reading, C. (2013). *Understanding racism.* National Collaborating Centre for Aboriginal Health. http://www.nccahccnsa.ca/Publications/Lists/Publications/Attachments/103/understanding_racism_EN_web.pdf

Reading, C. (2014). *Policies, programs and strategies to address Aboriginal racism: a Canadian perspective.* National Collaborating Centre for Aboriginal Health. http://www.nccahccnsa.ca/Publications/Lists/Publications/Attachments/132/2014_07_09_FS_2426_RacismPart3_PoliciesStrategies_EN_Web.pdf

Reading, C., & Wein, F. (2009). *Health inequalities and social determinants of Aboriginal peoples' health.* National Collaborating Centre for Aboriginal Health. https://nccih.ca/docs/determinants/RPT-HealthInequalities-Reading-Wien-EN.pdf

REI Governance Working Group (2022). Key considerations: Race, ethnicity and Indigenous

identity data collection and use. https://umanitoba.ca/health-sciences/sites/health-sciences/files/2022-11/Key%20considerations.pdf

Reimer Kirkham, S., Baumbusch, J.L., Schultz, A.S.H., & Anderson, J.M. (2007). Knowledge development and evidence-based practice: Insights and opportunities from a postcolonial feminist perspective for transformative nursing practice. *Advances in Nursing Science*, 30, 26-40. https://doi.org/10.1097/00012272-200701000-00004

Research Data Alliance International Indigenous Data Sovereignty Interest Group. (2019). *Care Principles for Indigenous Data Governance*. https://static1.squarespace.com/static/5d3799de845604000199cd24/t/5da9f4479ecab221ce848fb2/1571419335217/CARE+Principles_One+Pagers+FINAL_Oct_17_2019.pdf.

Rieger, K., Gazan, S., Bennett, M., Buss, M., Chudyk, A. M., Cook, L., Copenace, S., Garson, C., Hack, T. F., Hornan, B., Horrill, T., Horton, M., Howard, S., Linton, J., Martin, D., McPherson, K., Rattray, J. M., Phillips-Beck, W., Sinclair, R., & Schultz, A. S. H. (2020). Elevating the uses of storytelling approaches within Indigenous health research: a critical and participatory scoping review protocol involving Indigenous people and settlers. *Systematic Reviews*, 9(1), 1–257. https://doi.org/10.1186/s13643-020-01503-6

Roach, P., & McMillan, F. (2022) Reconciliation and Indigenous self-determination in health research: A call to action. *PLOS Glob Public Health,* 2(9): e0000999. https://doi.org/10.1371/ journal.pgph.0000999

Rotondi, M., O'Campo, P., O'Brien, K., Firestone, M., Wolfe, S. H., Bourgeois, C., & Smylie, J. K. (2017). Our Health Counts Toronto: using respondent-driven sampling to unmask census undercounts of an urban indigenous population in Toronto, Canada. *BMJ Open*, *7*(12), e018936–e018936. https://doi.org/10.1136/bmjopen-2017-018936

Rowel, R., Moore, N., Nowrojee, S., Memiah, P., & Bronner, Y. (2005). The utility of the environmental scan for public health practice: Lessons from an urban program to increase cancer screening. *Journal of the National Medical Association*, 97(4), 527–534.

Saskamoose, J., Bellegarde, T., Sutherland, W., Pete, S., & McKay-McNabb, K. (2017). Miỳo-pimatisiwin developing indigenous cultural responsiveness theory (ICRT): Improving indigenous health and well-being. *International Indigenous Policy Journal*, 8(4). https://doi.org/10.18584/iipj.2017.8.4.1

Schnarch. B. (2004). Ownership, Control, Access, and Possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, 1(1), 80–.

Sexton, S., Richardson, C. R., Schrager, S. B., Bowman, M. A., Hickner, J., Morley, C. P., Mott, T. F., Pimlott, N., Saultz, J. W., & Weiss, B. D. (2021). Systemic racism and health disparities: Statement from editors of family medicine journals. *Canadian Family Physician*, 67(1), 13–14. https://doi.org/10.46747/cfp.670113

Shared Health. (2023a). *Organizational Structure.* https://sharedhealthmb.ca/about/organizational-

Shared Health (2023b). *Racism, Disrupted*. https://sharedhealthmb.ca/about/community/racism-_disrupted/

Sheldon, A., and Parker, H. (1992). Race and ethnicity in health research. *Journal of Public Health Medicine*. 14(2).

Simpson, L. (2011). *Dancing on our turtle's back: stories of Nishnaabeg re-creation, resurgence and a new emergence.* Arbeiter Ring Publishing.

Simpson, L. (2016). Indigenous Resurgence and Co-resistance. *Critical Ethnic Studies*, 2(2), 19–

34. https://doi.org/10.5749/jcritethnstud.2.2.0019

Smedley, B., Stith, A.Y., Nelson, A. R., & Alan R. (2003). *Unequal treatment: confronting racial and ethnic disparities in health care.* National Academy Press.

Smith, L. (1999). *Decolonizing methodologies: research and Indigenous Peoples*. Zed Books.

Smylie, J. (2009). Indigenous knowledge translation: Baseline findings in a qualitative study of the pathways of health knowledge in three Indigenous communities in Canada. *Health Promotion Practice*, 10(3), 436–446. https://doi.org/10.1177/1524839907307993

Smylie, J. & Firestone, M. (2015). Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada. *Statistical Journal of the IAOS*, 31(1), 67–87. https://doi.org/10.3233/SJI-150864

Smylie, J., Firestone, M., Spiller, M. W., & Inuit, T. (2018). Our health counts: population-based measures of urban Inuit health determinants, health status, and health care access. *Canadian Journal of Public Health*, 109(5/6), 662–670. https://doi.org/10.17269/s41997-018-0111-0

Smylie, J., Martin, C., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2004). Knowledge translation and indigenous knowledge. *International Journal of Circumpolar Health*, 63 (sup2), 139–143. https://doi.org/10.3402/ijch.v63i0.17877

Springer 2023. *Writing a journal manuscript: Title, abstract, keywords*. https://www-springer-com.uml.idm.oclc.org/gp/authors-editors/authorandreviewertutorials/writing-a-journal-manuscript/title-abstract-and-keywords/10285522

Stark. K. J. (2021). Anishinaabe Inaakonigewin: principles for the intergenerational preservation

of mino-bimmaadiziwin. *Montana Law Review*, 82(2).

Statistics Canada (2021). *Dictionary, Census of Population, 2021. Indigenous identity.* https://www12.statcan.gc.ca/census-recensement/2021/ref/dict/az/definition-eng.cfm?ID=pop001#:~:text=Indigenous%20identity%20is%20a%20derived,First%20Nation%20or%20Indian%20band

Statistics Canada. (2022). *Indigenous population continues to grow and is much younger than the non-Indigenous population, although the pace of growth has slowed.* https://www150.statcan.gc.ca/n1/daily-quotidien/220921/dq220921a-eng.htm?utm_source=cst&utm_medium=smo&utm_campaign=statcan-2021census-diss-R5-22-23-en

Statistics Canada. 2023. *Statistics on Indigenous Peoples*. https://www.statcan.gc.ca/en/subjects-start/indigenous_peoples

Steinhauer, E. (2002). Thoughts on an indigenous research methodology. *Canadian Journal of Native Education*, 26(2), 69–81.

Talaga, T. (2017). *Seven fallen feathers: racism, death, and hard truths in a northern city*. Anansi.

Talaga, T. (2018). *All our relations: finding the path forward*. Anansi.

Tang, S. Y., & Browne, A. J. (2008). "Race" matters: racialization and egalitarian discourses involving Aboriginal people in the Canadian health care context. *Ethnicity & Health*, 13(2), 109–127. https://doi.org/10.1080/13557850701830307

The Commission. (1997). *Guide to the principal findings and recommendations of the final report of the Royal Commission on Aboriginal Peoples*. The Commission. https://publications.gc.ca/collections/collection_2017/bcp-pco/Z1-1991-1-51-1-eng.pdf

Thurston, W., Coupal, S., Jones, C. A., Crowshoe, L. F. J., Marshall, D. A., Homik, J., & Barnabe, C. (2014). Discordant indigenous and provider frames explain challenges in improving access to arthritis care: a qualitative study using constructivist grounded theory. *International Journal for Equity in Health*, 13(1), 46–46. https://doi.org/10.1186/1475-9276-13-46

Tricco, A., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. https://doi.org/10.7326/M18-0850

Truth and Reconciliation Commission of Canada. (2015). *Final report of the Truth and Reconciliation Commission of Canada. Volume one, Summary: honouring the truth, reconciling for the future.* James Lorimer & Company Ltd., Publishers.

United Nations (2008). *United Nations Declaration on the Rights of Indigenous Peoples.* https://www-un-org.uml.idm.oclc.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

Varcoe, C., Browne, A., Wong, S., & Smye, V. (2009). Harm and benefits: Collecting ethnicity data in a clinical context. *Social Science & Medicine*, *68*(9), 1659–1666. https://doi.org/10.1016/j.socscimed.2009.02.034

Walter, M., & Andersen, C. (2013). Indigenous statistics: A quantitative research Methodology. Routledge. https://doi.org/10.4324/9781315426570

Walter, M., & Suina, M. (2019). Indigenous data, indigenous methodologies and indigenous data sovereignty. *International Journal of Social Research Methodology*, 22(3), 233-243.

https://doi.org/10.1080/13645579.2018.1531228

Weber-Pillwax, C. (2001). What is Indigenous research? *Canadian Journal of Native Education*, 25(2), 166-174.

Weber-Pillwax, C. (2004). Indigenous researchers and Indigenous research methods: cultural influences or cultural determinants of research methods. *Pimatisiwin: a journal of Aboriginal and Indigenous community health*, 2(1).

Napier, K., & Whiskeyjack, L. (2021). wahkotowin: Reconnecting to the Spirit of nêhiyawêwin (Cree Language). *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning*, 7(1), 1–24. https://doi.org/10.15402/esj.v7i1.69979

Waddell, C., de Jager, M. D., Gobeil, J., Tacan, F., Herron, R. V., Allan, J. A., & Roger, K. (2021). Healing journeys: Indigenous men's reflections on resources and barriers to mental wellness. *Social Science & Medicine (1982)*, 270, 113696–113696. https://doi.org/10.1016/j.socscimed.2021.113696

Watson, R., Castleden, H., Masuda, J., King, M., & Stewart, M. (2012). Identifying gaps in asthma education, health promotion, and social support for Mi'kmaq families in Unama'ki (Cape Breton), Nova Scotia, Canada. *Preventing Chronic Disease*, 9, E139–. https://doi.org/10.5888/pcd9.120039

Wilk, P., Maltby, A., & Phillips, J. (2018). Unmet healthcare needs among Indigenous Peoples in Canada: findings from the 2006 and 2012 Aboriginal Peoples Surveys. *Journal of Public Health*, 26(4), 475–483. https://doi.org/10.1007/s10389-017-0887-z

Wilson. (2001). What Is an Indigenous research methodology? *Canadian Journal of Native Education*, 25(2).

Wilson. (2008). *Research is ceremony: indigenous research methods*. Fernwood Publishing.

Winnipeg Regional Health Authority (WRHA). (2020). *Guide to Accessing Acute Care Services in Winnipeg – For Use by Health Care and Insurance Providers Arranging Patient Transfers to Winnipeg Hospitals.* https://wrha.mb.ca/files/acute-care-services-guide.pdf

Winnipeg Regional Health Authority (WRHA). (2023a). *About the WRHA*. https://wrha.mb.ca/about/

Winnipeg Regional Health Authority (WRHA). (2023b). *Manitoba Indigenous Cultural Safety Training (MICST).* https://wrha.mb.ca/indigenous-health/education-and-training/micst/

Winnipeg Regional Health Authority (WRHA) - Indigenous Health. (2023). *Navigating First Nations & Inuit health branch FNIB non-insured health benefits (NIHB) (formerly medical services) – transportation referral unit (TRU)* https://wrha.mb.ca/files/indigenous-health-navigating-fnihb.pdf

Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Tuck, A., Lam, R., Mohamed, A., & Hyman, I, for the Tri-Hospital + TPH Steering Committee. (2013). *We ask because we care: The Tri-Hospital + TPH health equity data collection research project: Full Report.* http://torontohealthequity.ca/wp-content/uploads/2017/05/We-Ask-Because-We-Care-Report.pdf

Wylie, L., & McConkey, S. (2019). Insiders' insight: Discrimination against Indigenous Peoples through the eyes of health care professionals. *Journal of Racial and Ethnic Health Disparities*, 6(1), 37–45. https://doi.org/10.1007/s40615-018-0495-9

Appendix A: Principles of Indigenous Methodologies

The Importance of Relationship. The Indigenous worldview is defined by relationships and accountability to those relationships (Kovach, 2009; Lambert, 2014; Weber Pillwax, 2001; Wilson, 2001). Knowledge that is sought within research is relational and exists in relation to everything else in all of creation (Steinhauer, 2002; Wilson, 2001). Within Indigenous methodology, there is a strong focus on the fact that despite a shared history of oppression, there is a uniqueness that exists for each nation, each community (Denzin and Lincoln, 2014; Lewis, 2012). The context of land and place create important relationships that should be examined as unique. This will be very important to consider in trying to understand the idea of relationship to the land and history of Manitoba specifically and provides reason to why it is important to look at this issue in the context of Indigenous Peoples of Manitoba.

Positionality. Indigenous researchers often write from a personal place and perspective and situate the work within their own relationality (Absolon & Willett, 2005). Reflexivity will occupy a central place in my research as this openness and truthfulness will act as the foundation for all other aspects of my research and will allow the participants and community to determine the validity of the research and my accountability to the people and the knowledge shared (Kovach, 2009). Therefore, who we are as Indigenous researchers, and the life memory that we hold, is an integral part of how we proceed through our research work, including how we design our research through to how we collect, analyze, and interpret our findings.

Strengths Based Perspective. Reducing and eliminating harm inducing practices of research that were "extractive, dispossessing, and pathologizing" (Carlson, 2017, p. 3) has been the intent of Indigenous researchers. Through the use of Indigenous methodologies, there is hope that the perspective of research turns from dirty and destructive to one that is uplifting, enriching, and

revitalizing (Steinhauer, 2002). Through my research, I will be focused on creating a culturally safe research experience, which provides space for Indigenous knowledge and perspective to be heard, validated, and honoured.

Storytelling/Narrative/Discussion. "…story is research. It provides insight from observations, experience, interactions, and intuitions that assists in the developing a theory about a phenomenon… Story as methodology is decolonizing research. Stories of resistance inspire generations about the strength of the culture" (Kovach, 2009, p. 102-103). It is often through stories that Indigenous Peoples come to understand the world around them because it is through stories that we are encouraged to think about and process our actions and reactions to our involvement in events (Kovach, 2009; Lewis, 2012). Teaching and learning happen through the use of story, and connections and relationships are formed between the story teller, the listener, and the shared knowledge. Flexibility and openness of storytelling and discussions allow the participant to hold a more balanced position of power in the encounter compared to the Western based interview method, which is very important considering the history of exploitative and damaging research with Indigenous Peoples (Kovach, 2009). The story must also be presented alongside an understanding of the knowledge system from which it is produced. Those without the ability or desire to understand an Indigenous epistemology will not be able to fully understand the meaning of the story (Kovach, 2009). As I understand my approach to be more about relationship building through discussions, I will refer to my research method as a narrative inquiry using a research discussion approach as the back-and-forth discussion between the researcher and participant leads to the creation of knowledge (Kovach, 2009, 2010; Weber-Pillwax 2001). Listening to the stories and experiences from Indigenous participants aligns with the Indigenous paradigm which is the foundation for my research.

Preparation. Indigenous methodologies require specific and important steps for preparation which requires time and careful consideration to make sure relationships are in place, relationships are honoured, and that the participants are as prepared for the research as the researcher. This might include activities such as discussions about the research before the official data gathering activity, spending time with the individuals and/or community to build feelings of safety and comfort and acceptance, gathering input from participants so that their needs can be considered and met, participating in ceremony, generating feedback and recommendations on the research prior to the finalization of research plans and protocols, and preparing systems of support to assist participants through emotional or mental effects of research. (Kovach, 2009, 2010). Within my research, planning and preparation for the research process will include the provision of time and transparency to ensure that the research is not harm inducing and that participants and communities are prepared and supported.

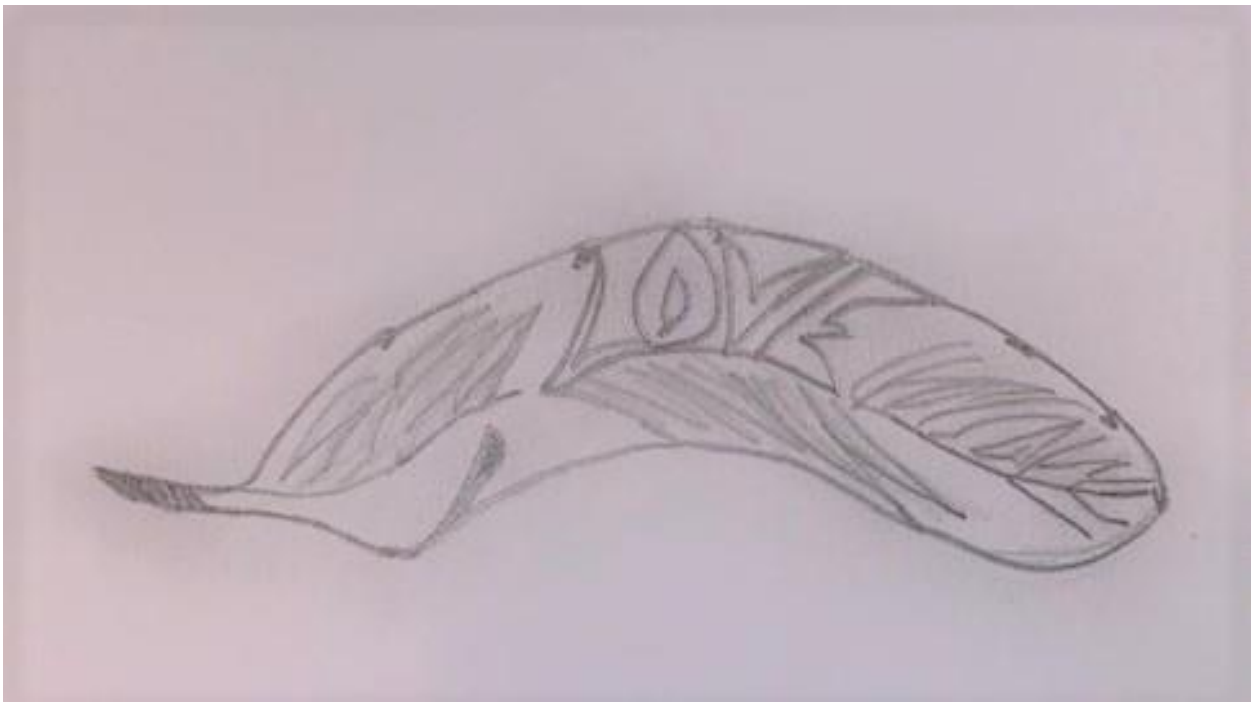
Sacred Methodology. Spirituality holds a very central place within the Indigenous paradigm and is imbedded within the multiple sources of knowledge that are often found within the use of Indigenous methodologies. Steinhauer (2002) described these sources of knowledge as traditional teachings (knowledge handed down); empirical knowledge (look, listen, learn); and revealed knowledge (dreams, visions, intuition). “The sacredness of Indigenous research is bound in ceremony, spirit, land, place, nature, relationships, language, dreams, humour, purpose, and stories, in an inexplicable, holistic, non-fragmented way, and it is this sacredness the defies the conventional” (Kovach, 2009, p. 140). The sacred element within Indigenous methodologies requires continued connection to self and community, and continued learning about cultural protocols within the context of individuals and communities (Kovach, 20010; Steinhauer, 2002). It is important that this part of the research is not left out of the formal academic writing as it has

been in the past (Weber-Pillwax, 2001). I have chosen to include writing around the generation of knowledge through ceremony within my dissertation as this holds importance in explaining the research paradigm and in turn validating the research process and results.

Dreams and Visions and Ceremony. One of the components of the sacred methodology which Indigenous which is often omitted within academic research is the inward knowledge which comes through ceremony. This can include spiritual connection, prayer, intuition, visions, reflections, and dreams (Cardinal, 2001; Kovach, 2009). In her work Simpson (2011) notes that "…dreams and visions propel resurgence because they provide Nishnaabeg with both the knowledge from the spiritual world and processes for realizing those visions. Dreams and visions provide glimpses of decolonized spaces and transformed realities that we have collectively yet to imagine" (Simpson, 2011, p. 35). There is yet to be a formalized method for recording and analyzing this knowledge and it remains a very personal experience. However, the importance of this knowledge needs to be recognized and accepted as valid knowledge as it is an important component of the Indigenous paradigm (Kovach, 2009). Inward knowledge has and still is a very important way of knowing within Indigenous life (Cardinal, 2001). Inclusion of my experience of knowledge as ceremony will contribute to the literature in this area and will be a very meaningful component of my research process.

Appendix B: Eagle Feather Visual Framework

"Conceptual frameworks make visible the way we see the world" … "it provides insight into a researcher's beliefs about knowledge production, in general, and how those beliefs will impact the research project" … "The content of the conceptual framework itself assists in illustrating the researcher's standpoint, this giving the reader insight into the interpretive lens that influences the research" (Kovach, 2009, p.41).



The Eagle feather holds much importance to me in my life, both in day-to-day life and in ceremonial life. My teachings of the eagle feather include both teaching of love and truth.

The Eagle represents love and is a constant reminder that we need to live our lives according to the sacred teaching of love. The eagle flies the highest, the closest to the Creator and is the one that can bring our prayers of love to creator. A core reason for my commitment to research, is because of the love that I have for my Indigenous brothers and sisters. My passion is driven by

the knowledge that we will find our strength and our power if we keep working hard to find ways to support our resurgence.

The Eagle feather also represents truth. When we are holding a sacred Eagle feather, we are making the commitment to only speak the truth. I know that the research that I will be doing will be uncovering the truth so that it can be spoken. There is no other purpose in my mind, than to being to reveal the truth, so that the reality of the effects of colonial and racial oppression, discrimination, and marginalization on the lives of Indigenous Peoples is known and understood by all in this country.

In basing my research on a framework based both visually and spiritually on the Eagle feather, I am making a commitment to speak the truth and to work from a place of love for the Indigenous Peoples of this land.

The arc of the Eagle feather is a representation of a path through time, and symbolizes how my research will examine this issue through the past, present, and future. The strong centre stem represents the path forward that I am committed to through my research and the path forward for Indigenous people.

The soft feathers that extend outwards represent the many different paths that will need to be taken in order to gather and understand the knowledge that will come through this research, always strongly anchored to the centre path of intention.

Appendix C: Research Questions Guiding Quadrant Objectives

In designing the methods for each quadrant, these research questions guided decisions. As well, these questions will continue to guide completion of proposed methods.

	Scoping Review – Guiding Research Questions
1.	What information is available within this topic area?
2.	Who has been writing about this topic?
3.	Where is this information located?
4.	When has this writing taken place?
5.	What has been the impetus for this writing?
6.	How have Indigenous Peoples participated in the writing?
7.	How is the historical context addressed within the writing?
8.	How are Indigenous identities represented in this writing?
9.	What are the key findings?

	Environmental Scan – Guiding Research Questions
1.	What types are REI data are currently being collected?
2.	Who is collecting REI data currently?
3.	What is the purpose of the data collection?
4.	What is the process of the data collection?
5.	How are Indigenous Peoples involved in this data collection?
6.	How are Indigenous identities represented in this data collection?
7.	Are the data collection processes culturally safe?
8.	Who determines how the data is governed and used?
9.	Has there been quality checks around the data that is collected and used?

	Story Gathering - Guiding Research Questions
1.	What are the perceived positive aspects of the collection of Indigenous identity data during the healthcare encounter?
2.	What are the concerns/fears/apprehensions around collection of Indigenous identity data during the healthcare encounter?
3.	What are the perceived implications of the collection of Indigenous identity data during the healthcare encounter?
4.	How do people come to have this knowledge/these perspectives and understandings?
5.	What steps should be taken to ensure that REI data is collected in a good way?
6.	Where would be the best location to collect REI data?
7.	Who would be the best people to collect REI data?

8.	What would be the desired outcome from the collection of REI data?
9.	Who should be able to use REI data?
10.	How should REI data be used?

	Ceremony and Traditional Knowledge - Guiding Research Questions
1.	How has my participation in this ceremony or learning/practice/sharing of cultural impacted my understanding/perspective/connection to this research study.

Appendix D: Call for Research Participants

Call for Indigenous Research Participants

Study Title: Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.

Hello! As a current student in the doctoral program in the Department of Community Health Sciences at the University of Manitoba I am conducting research as part of the requirements of my degree. I am an Indigenous student, First Nations ancestry, and I will be using an Indigenous research framework for my study.

The purpose of the research is to expand and advance our knowledge on the perspectives and experiences of Indigenous peoples in regards to the collection of Race, Ethnicity, and Indigenous Identifier (REI) data within the Manitoba healthcare system.

We are inviting self-identified Indigenous patients/public, healthcare registration staff, and healthcare leadership, within Manitoba to participate in this study.

Participants will be asked questions about their perspectives and experience in regards to being asked about, or having to ask about, race, ethnicity, or Indigenous identity (REI) within the healthcare system, as well as questions around the collection, use, and governance of this information.

Each research discussion will approximately 1 - 2 hours and can take place in a location that is most comfortable and convenient for the participant. In light of Covid-19, the use of telephone or video communication is suggested. Participation is voluntary and confidential; your identity will not be disclosed.

Information gathered through this study will help to better understand the needs, desires, experiences, and expectations of Indigenous peoples in regards to REI data collection.

Each participant will receive an honorarium as a gesture of appreciation for their participation in the research study.

If you would like to participate in the research study or have any questions please contact:

Amanda Fowler-Woods - Email: [redacted]

Appendix E: Study Announcement Poster



Appendix F: Invitation to Participate

Dear _____

Thank you for your interest in sharing your thoughts about the collection of racial, ethnic, and Indigenous (REI) identifier data within the healthcare system. I am sending you this email to provide you with information and to invite you to participate in the study.

I am an Indigenous PhD student in the Department of Community Health Sciences doctoral program at the University of Manitoba, and this study is in fulfillment of the degree requirements for the doctorate program. The title of my study is, Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.

The purpose of this study is to advance the knowledge around Indigenous understanding and experience of the concept and practice of REI data collection within the healthcare system. This information, while currently not collected within the Manitoba healthcare system, is planned to be collected province-wide within the next few years. It is very important that Indigenous peoples in Manitoba provide their perspective on this matter, as findings from this dissertation will be utilized within Manitoba to develop a communication plan for the collection of REI information.

Your participation in this study will involve taking part in a research discussion (sometimes called an interview) that will last between 1 to 2 hours. The interview will be completed either virtually (telephone or video) or in-person. In person interviews will take place at a location comfortable and convenient for you. Your participation in the study is voluntary. You do not have to answer any questions or share any information if it makes you feel uncomfortable.

You will be asked questions around your perspective and/or experience with being asked, or asking, questions about race, ethnicity, and Indigenous identity during a healthcare encounter. For this study, discussion with take place with those who access the healthcare system (patients/public), those who work in the healthcare system (registration staff), and those in leadership positions within the healthcare system (healthcare administrators, managers, officers of health).

To show appreciation for your time and your knowledge, an honourarium of $50.00 will be provided.

If you would like to participate or would like more information, please contact me at [redacted] This research will be done under the supervision and direction of my PhD Advisors Dr. Annette Schultz [redacted] and Dr. Deborah McPhail [redacted]

Thank you,

Amanda Fowler-Woods

Appendix G: Consent Form

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Individual Interview

Title of Study: Identity as Visibility: gathering knowledge around the perspectives and experiences of Indigenous peoples in Manitoba in relation to the collection of racial, ethnic, and Indigenous identifiers data within the healthcare system.

Principal Investigator: Amanda Fowler-Woods, [redacted]

Academic Advisors: Dr. Annette Schultz, Dr. Deborah McPhail

Sponsor: **CIHR**

Funder: **CIHR**

You are being asked to participate in a research study involving an individual interview. Please take your time to review this consent form and discuss any questions you may have with the study staff, your friends, family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of this Study

This research study is being conducted to better understand and document the perspectives and experiences of Indigenous Peoples in regards to the collection of Race, Ethnicity, and Indigenous Identifier (REI) data within the Manitoba healthcare system.

Participants Selection

You are being asked to participate in this study because as a self-identified Indigenous patient/potential patient, data collector, and/or healthcare leader within Manitoba, your perspective and experience in regards to the collection of REI data within the healthcare system is very important in order to understand how to do this work in a culturally safe and appropriate way which honours Indigenous identity and contributes to positive changes towards health and wellness.

A total of 20 participants will be asked to participate.

Study procedures

- The method of data collection for this study will be interviews/research discussions. Within Indigenous methodologies, importance is given to the conversations that occur between participants and researcher and the knowledge that is generated through that relationship.
- Participation in the study will consist of one interview/research discussion approximately 1 hour in length.
- All interviews will be conducted by Amanda Fowler-Woods, PhD candidate, Principle Investigator.
- You will be asked some questions relating to your perspectives and/or experience in regards to being asked about, or having to ask about, race, ethnicity, or Indigenous identity (REI) within the healthcare system, and about the collection, use, and governance of this information. These questions will help us to better understand how to proceed with the planning and implementation of REI data collection in the healthcare system as it will help us to better understand the needs, desires, and expectations of Indigenous peoples in regards to this practice.
- The sessions will be audio-recorded and the audio-recordings will be transcribed by Transcription Heroes to ensure accurate reporting of the information that you provide.
- Transcribers will sign a form stating that they will not discuss any item on the recording with anyone other than the researchers.
- All identifying information will be kept confidential.
- The audio-recordings will be stored in locked files before and after being transcribed. Recordings will be destroyed within 5 years of completing the transcriptions and the transcriptions will be destroyed 5 years after the completion of the research.
- Summaries of the participants interview will be shared back with each participant for the purposes of checking for accuracy.
- Reports and presentations at the completion of the study will be shared with participants through various mediums including paper-based reports, journal articles, video media related to the study, public presentations, and the final dissertation.

Risks and Discomforts

There are no anticipated physical risks to participants.

There are very few risks. However, you may find talking about Race, Ethnicity, and Indigenous Identity to be upsetting or emotional. You do not have to answer any question that makes you feel uncomfortable or that you find too upsetting.

Should you need any additional help or support we will refer you to Elder support or help you to find other counseling help.

List the procedures in place and potential resources should an individual indicate they wish to harm themselves or are severally depressed in response to questions asked during the individual interview or focus group discussions.

Benefits

Being a participant of this research may not help you directly, but information gained will assist with developing and implementing a culturally safe model and procedures for the collection, use, and, governance of REI data within the healthcare system.

Costs

There is no cost to you to attend the interview/research discussion.

Payment for participation

You will be given an honorarium of $50 to show appreciation for your time and shared knowledge.

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality

We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study records. A list of names and addresses of participants will be kept in a secure file so we can send you a summary of the results of the study. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. The collection and access to personal information will be in compliance with provincial and federal privacy legislations.

Audio recordings of the research discussion will be typed and used to prepare a report. The audio recordings and typed notes will be kept for 5 years in a secure locked file cabinet and office. Only the research staff Amanda Fowler-Woods and her PhD Advisors Dr. Annette Schultz and Dr. Deborah McPhail will have access to them and know your name.

Some people or groups may need to check the study records to make sure all the information is correct. All of these people have a professional responsibility to protect your privacy.

These people or groups are:

- First Nations Health and Social Secretariate of Manitoba – Governance body for First Nations Peoples of Manitoba
- Manitoba Métis Federation - Governance body for Métis Peoples of Manitoba
- Manitoba Inuit Association - Governance body for Inuit Peoples of Manitoba
- Canadian Institute of Health Research
- The Health Research Ethics Board of the University of Manitoba which is responsible for the protection of people in research and has reviewed this study for ethical acceptability
- Quality assurance staff of the University of Manitoba who ensure the study is being conducted properly

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave The University of Manitoba.

Permission to Quote:

We may wish to quote your words directly in reports and publications resulting from this. With regards to being quoted, please check yes or no for each of the following statements:

Researchers may publish documents that contain quotations by me under the following conditions:	
☐ Yes ☐ No	I agree to be quoted directly (my name is used).
☐ Yes ☐ No	I agree to be quoted directly if my name is not published (I remain anonymous).
☐ Yes ☐ No	I agree to be quoted directly if a made-up name (pseudonym) is used.

<u>Voluntary Participation/Withdrawal from the Study</u>

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time.

If you are a student, your participation or discontinuation in this study will not constitute an element of your academic performance nor will it be part of your academic record at the University of Manitoba.

If you are an employee of the University of Manitoba your participation or discontinuance in the study will not constitute an element of your job performance or evaluation nor will it be part of your personnel record.

Questions

If any questions come up during or after the study contact the principal investigator and the study staff: Amanda Fowler-Woods at xxx-xxx-xxxx

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at xxx-xxx-xxxx

Consent Signatures:

1. I have read all *(indicate the total number of pages)* pages of the consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator and the agencies and organizations listed in the Confidentiality section of this document.
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
6. I understand I will be provided with a copy of the consent form for my records.
7. I agree to participate in the study.

Participant signature_____ **Date** _____

(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____Date _____

(day/month/year)

Signature: _____

Role in the study: _____

Relationship (if any) to study team members:_____

Appendix H: Research Discussion Guide for Storytellers

COMUNITY MEMBERS

Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.

Introduction:

I like to begin each interview with some conversation to get to know each other. Once we feel more comfortable, we can then begin to have some discussion around the topic area that we are here to discuss. I will go ahead and tell you a bit about myself and then you can tell me about yourself.

Background Questions

1. Can you tell me about yourself?
    - Where are you from?
    - Who is in your family?
    - What are your interests?

2. In thinking about going to the doctor, hospital, clinic, or any other type of medical care, how often would you say you access healthcare services?

3. Can you tell me about where you access health services, for example, in the city of Winnipeg or somewhere else?

Experience Questions

In thinking about the process of checking in or registration at a hospital or clinic:

1. What is that registration process like for you?

    - Can you describe your experience or perspective with the process of registration?
    - How do you feel during the registration process for a healthcare visit?

2. Have you ever had an experience when you have been asked to identify your race/ ethnicity/ Indigenous identity during a healthcare visit?

    - If, yes, can you tell me about that experience?
    - How did you feel about being asked to identify during a healthcare visit?

3. If no, in thinking about this idea of being asked about your race/ ethnicity/ or Indigenous identity, how would you feel about being asked to identify this information during a healthcare visit?

Perspective/Opinion Questions

The province of Manitoba is preparing to introduce the collection of REI data at the point of registration for healthcare visits. This is question will be asked to every patient that is registering for healthcare. For example, after being asked information such as your name, your address, your first language, you will be asked if you identify as an Indigenous person, and whether you identify as First Nations (registered/non-registered), Métis, or Inuit.

In thinking about this idea of being asked about your race/ ethnicity/ or Indigenous identity during the registration process at a healthcare visit:

1. What is your opinion or perspective of the decision to ask and collect Indigenous identity information during the registration for a healthcare visit/appointment?
    - Do you feel that it is a good idea?
    - Do you feel that it is bad idea?
    - Can you tell me more about why you feel this way?

2. In your opinion, how do you feel the people of Manitoba will react to this decision?

3. What benefits can you imagine in regards to the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

4. What worries/concerns do you have regarding the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

5. Can you talk about any other impacts that you feel self-identifying as an Indigenous person at the point of registration might have?

6. What would you say is the purpose in asking about race/ethnicity/Indigenous identity in the healthcare setting?
    - Do you agree with this purpose? Do you disagree with this purpose?

7. Are there any other reasons why it might be important to collect this data that we have not yet talked about?

If we as Indigenous peoples, have the chance to have our say in how this should be done:

8. What type of information should be provided to people who are asked this question?
    - Is there any specific information you would like to know before answering this question?

9. What would be the best method for collecting REI data?
    - For example: face to face verbal communication, paper survey, electronic tablet.
    - Can you tell me more about your decision?

10. Who would be the best people to collect this information?
    - For example: clerks, nurses, physicians
    - Can you tell me more about your decision?

11. Where would be the best location to collect this information?
    - For example: registration desk, clinic room, over the phone
    - Can you tell me more about your decision?

12. How do you think this information COULD be used?

13. How do you think this information SHOULD be used?

14. What would you like to see happen as a result of the collection of race/ ethnicity/ Indigenous identity information in the healthcare setting?
    - How would you like to see the data utilized?
    - What types of outcomes would you like to see?

Communications Strategy Questions

If there was to be a communication strategy or plan about how and why race/ethnicity/Indigenous identity information is being collected in the healthcare system:

1. Do you feel that it is important to have a communication plan?
    - Why or Why not?
    - Can you explain more about why you feel this way?

2. What do you think would be the most effective communication strategy?
    - What should the messaging say or not say?
    - Who should the messaging address?
    - What types of media or materials should be used?
    - Can you talk/explain more about your decisions around this topic?

3. What types of reports/reporting would you like to see communicated?
    - Why is this important?

Identity Questions

I use the term Indigenous identity frequently throughout my dissertation study.

1. Are you familiar with the term Indigenous identity?

2. If yes, can you explain to me in your words, what this means?

3. What does your identity as an Indigenous person mean to you?

I also use the term Indigenous Resurgence frequently throughout my dissertation study.

4. Have Are you familiar with the term Indigenous Resurgence?

5. If yes, can you explain to me in your words, what this means?

6. In your opinion, what is the importance of Indigenous resurgence?

Conclusion Question

1. Is there anything that you think it is important for me to know**?**

2. Is there anything else that you would like to talk about that we haven't talked about?

REGISTRATION STAFF

Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.

Introduction:

I like to begin each interview with some conversation to get to know each other. Once we feel more comfortable, we can then begin to have some discussion around the topic area that we are here to discuss. I will go ahead and tell you a bit about myself and then you can tell me about yourself.

Background Questions

4. Can you tell me about yourself?
    - Where are you from?
    - Who is in your family?
    - What are your interests?

5. Can you tell me about your position/role within the healthcare system?
    - How long have you worked at this position?
    - Have you worked anywhere else within the healthcare system?

Experience Questions

1. Have you ever been required to ask a patient to identify their race/ethnicity/Indigenous identity?
    - If yes, can you describe when this would occur?
    - Can you tell me about that experience?
    - How do you feel asking patients to self-identify?
    - How do patients respond to be asked this question?

2. If no, in thinking about this idea of asking patients about race/ ethnicity/ or Indigenous identity, how would you feel about asking patients to self-identity at the point of registration?

3. As an alternative to asking the patients, have you ever needed to determine the race/ethnicity/Indigenous identity of a patient based on physical appearance or last name?

4. Is information on race and ethnicity captured in the system anywhere else?

Perspective/Opinion Questions

The province of Manitoba is preparing to introduce the collection of REI data at the point of registration for healthcare visits. This is question will be asked to every patient that is registering for healthcare. For example, after being asked information such as your name, your address, your first language, you will be asked if you identify as an Indigenous person, and whether you identify as First Nations (registered/non-registered), Métis, or Inuit.

In thinking about this idea of asking patients about their race/ ethnicity/ or Indigenous identity during the registration process at a healthcare visit:

15. What is your opinion or perspective of the decision to ask and collect Indigenous identity information during the registration for a healthcare visit/appointment?
    - Do you feel that it is a good idea?
    - Do you feel that it is bad idea?
    - Can you tell me more about why you feel this way?

16. In your opinion, how do you feel the people of Manitoba will react to this decision?

17. What benefits can you imagine in regards to the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

18. What worries/concerns do you have regarding the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

19. Can you talk about any other impacts that you feel self-identifying as an Indigenous person at the point of registration might have?

20. What would you say is the purpose in asking about race/ethnicity/Indigenous identity in the healthcare setting?
    - Do you agree/disagree with this purpose?

21. Are there any other reasons why it might be important to collect this data that we have not yet talked about?

If we as Indigenous speoples, have the chance to have our say in how this should be done:

22. What type of information should be provided to people who are asked this question?
    - Is there any specific information you would like to know before answering this question?

23. What would be the best method for collecting REI data?
    - For example: face to face verbal communication, paper survey, electronic tablet.
    - Can you tell me more about your decision?

24. Who would be the best people to collect this information?
    - For example: clerks, nurses, physicians
    - Can you tell me more about your decision?

25. Where would be the best location to collect this information?
    - For example: registration desk, clinic room, over the phone
    - Can you tell me more about your decision?

26. How do you think this information COULD be used?

27. How do you think this information SHOULD be used?

28. What would you like to see happen as a result of the collection of race/ ethnicity/ Indigenous identity information in the healthcare setting?

- How would you like to see the data utilized?
- What types of outcomes would you like to see?

Training Program Questions

1. If you have had to collect information regarding race/ ethnicity/ Indigenous identity, can you talk about the training that is involved for the collection of this information?

2. Can you talk about your thoughts and feelings regarding this training?
    - Was the training valuable, useful, sufficient?

3. What type of training would you see valuable to assist staff in the collection of race/ ethnicity/ Indigenous identity information in the healthcare setting?

Communications Strategy Questions

If there was to be a communication strategy or plan about how and why race/ethnicity/Indigenous identity information is being collected in the healthcare system:

4. Do you feel that it is important to have a communication plan?
    - Why or Why not?
    - Can you explain more about why you feel this way?

5. What do you think would be the most effective communication strategy?
    - What should the messaging say or not say?
    - Who should the messaging address?
    - What types of media or materials should be used?
    - Can you talk/explain more about your decisions around this topic?

6. What types of reports/reporting would you like to see communicated?
    - Why is this important?

Identity Question

I use the term Indigenous identity frequently throughout my dissertation study.

7. Are you familiar with the term Indigenous identity?

8. If yes, can you explain to me in your words, what this means?

9. What does your identity as an Indigenous person mean to you?

I also use the term Indigenous Resurgence frequently throughout my dissertation study.

10. Have Are you familiar with the term Indigenous Resurgence?

11. If yes, can you explain to me in your words, what this means?

12. In your opinion, what is the importance of Indigenous resurgence?

Conclusion Question

3. Is there anything that you think it is important for me to know**?**

4. Is there anything else that you would like to talk about that we haven't talked about?

HEALTHCARE LEADERSHIP

Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.

Introduction:

I like to begin each interview with some conversation to get to know each other. Once we feel more comfortable, we can then begin to have some discussion around the topic area that we are here to discuss. I will go ahead and tell you a bit about myself and then you can tell me about yourself.

Background Questions

1. Can you tell me about yourself?

- Where are you from?
- Who is in your family?
- What are your interests?

2. Can you tell me about your position/role within the healthcare system?

- How long have you worked at this position?
- Have you worked anywhere else within the healthcare system?

Experience Questions

1. Do you have any previous or current experiences with the collection of race/ ethnicity/ Indigenous identity data within the Manitoba healthcare system?

- If yes, can you explain more about this experience and your role within this work?

Perspective/Opinion Questions

The province of Manitoba is preparing to introduce the collection of REI data at the point of registration for healthcare visits. This is question will be asked to every patient that is registering for healthcare. For example, after being asked information such as your name, your address, your first language, you will be asked if you identify as an Indigenous person, and whether you identify as First Nations (registered/non-registered), Métis, or Inuit.

In thinking about this idea of asking patients about their race/ ethnicity/ or Indigenous identity during the registration process at a healthcare visit:

1. What is your opinion or perspective of the decision to ask and collect Indigenous identity information during the registration for a healthcare visit/appointment?

- Do you feel that it is a good idea?
- Do you feel that it is bad idea?
- Can you tell me more about why you feel this way?

2. In your opinion, how do you feel the people of Manitoba will react to this decision?

3. What benefits can you imagine in regards to the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

4. What worries/concerns do you have regarding the collection of race/ethnicity/Indigenous identity information in the healthcare setting?

5. Can you talk about any other impacts that you feel self-identifying as an Indigenous person at the point of registration might have?

6. What would you say is the purpose in asking about race/ethnicity/Indigenous identity in the healthcare setting?

- Do you agree/disagree with this purpose?

7. Are there any other reasons why it might be important to collect this data that we have not yet talked about?

If we as Indigenous peoples, have the chance to have our say in how this should be done:

8. What type of information should be provided to people who are asked this question?

- Is there any specific information you would like to know before answering this question?

9. What would be the best method for collecting REI data?

- For example: face to face verbal communication, paper survey, electronic tablet.
- Can you tell me more about your decision?

10. Who would be the best people to collect this information?

- For example: clerks, nurses, physicians
- Can you tell me more about your decision?

11. Where would be the best location to collect this information?

- For example: registration desk, clinic room, over the phone
- Can you tell me more about your decision?

12. How do you think this information COULD be used?

13. How do you think this information SHOULD be used?

14. What would you like to see happen as a result of the collection of race/ ethnicity/ Indigenous identity information in the healthcare setting?

- How would you like to see the data utilized?
- What types of outcomes would you like to see?

15. What role do you feel the healthcare leaders within the Manitoba healthcare system should take throughout the implementation and practice of REI data collection?

Training Program Questions

1. What type of training would you see valuable to assist staff in the collection of race/ ethnicity/ Indigenous identity information in the healthcare setting?

2. Have you had any experience with this training?

Communications Strategy Questions

If there was to be a communication strategy or plan about how and why race/ethnicity/Indigenous identity information is being collected in the healthcare system:

1. Do you feel that it is important to have a communication plan?

- Why or Why not?
- Can you explain more about why you feel this way?

2. What do you think would be the most effective communication strategy?

- What should the messaging say or not say?
- Who should the messaging address?
- What types of media or materials should be used?
- Can you talk/explain more about your decisions around this topic?

3. What types of reports/reporting would you like to see communicated?

- Why is this important?

Identity Question

I use the term Indigenous identity frequently throughout my dissertation study.

1. Are you familiar with the term Indigenous identity?

2. If yes, can you explain to me in your words, what this means?

3. What does your identity as an Indigenous person mean to you?

I also use the term Indigenous Resurgence frequently throughout my dissertation study.

4. Have Are you familiar with the term Indigenous Resurgence?

5. If yes, can you explain to me in your words, what this means?

6. In your opinion, what is the importance of Indigenous resurgence?

Conclusion Question

1. Is there anything that you think it is important for me to know?

2. Is there anything else that you would like to talk about that we haven't talked about?

Appendix I: Ethical Approval

University of Manitoba | Research Ethics and Compliance

Research Ethics Bannatyne
P126-770 Bannatyne Avenue
Winnipeg, MB R3E 0W3
T: 204 789 3255
F: 204 789 3414
bannreb@umanitoba.ca

HEALTH RESEARCH ETHICS BOARD (HREB)
CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES
Full Board Review

PRINCIPAL INVESTIGATOR:	INSTITUTION/DEPARTMENT:	ETHICS #:
Amanda Fowler-Woods	University of Manitoba/Community Health Sciences	HS25147 (H2021:319)
HREB MEETING DATE:	**APPROVAL DATE:**	**EXPIRY DATE:**
September 27, 2021	October 15, 2021	September 27, 2022
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable):		
Dr. Annette Schultz		

PROTOCOL NUMBER:	PROJECT OR PROTOCOL TITLE:
NA	Identity as Visibility: perspectives and experiences of Indigenous peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare.
SPONSORING AGENCIES AND/OR COORDINATING GROUPS:	
CIHR	

Submission Date(s) of Investigator Documents:	REB Receipt Date(s) of Documents:
August 12 and October 13, 2021	August 27 and October 13, 2021

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version (if applicable)	Date
Protocol:		
Study Protocol along with proposal as outlined in the University of Manitoba Bannatyne Campus Research Ethics Board submission form and Letter of Response dated October 13, 2021		August 20, 2021
Consent and Assent Form(s):		
RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM Individual Interview		October 13, 2021
Other:		
Letter of Invitation		August 23, 2021
Interview Guide – Community Members		August 23, 2021
Interview Guide – Data Collectors		August 23, 2021
Interview Guide – Healthcare Leadership/Decision Makers		August 23, 2021
Study Announcement/Poster		August 23, 2021
Demographic Information Collection Form		August 23, 2021
Participant Master List with Participant Code Number		August 23, 2021
Honourarium Form	V. 1	August 23, 2021

CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this ***Certificate of Final Approval*** at the ***full board meeting*** date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

Appendix J: Data Extraction List for Scoping Review

Publication Information
• Title
• Author(s)
• Date of publication
• Publication type
• Journal
• Country/Research Setting
• Funding Source
Author(s) Information
• Number of authors
• Author geographic location
• Author role
• Author race, ethnicity, Indigenous identity
• Authors academic background/discipline
Context of the Published Material
• Purpose
• Location
• Date range of research/writing
• Impetus for writing the material
• Inclusion/Exclusion criteria
• Participant demographics (age, gender, community, health condition)
• Methodology
• Methods
• Theoretic Orientation
• Research Ethics
• Language
Indigenous specific contexts
• Initiation of the research
• Intention of the research
• Inclusion of historical context
• Perspective on Indigenous identity
• Indigenous participation in the research/writing/KT
• Use of Indigenous research guiding principles (i.e., OCAP, TCPSChp9, UNDRIP)
• Inclusion of Indigenous governance models (i.e., in partnership, advisory, collaboration)
• Cultural Protocols
• Key finding(s)
• Recommendations and conclusions
• Deficit or Strengths based research
• Benefits to the research community