Cultural adaptation of a child health resource to meet the information needs and preferences of Red River Métis parents in Manitoba

By

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Abstract

Background: The Truth and Reconciliation Commission has drawn attention to the inequalities and systemic harms experienced by Indigenous Peoples in Canada, calling on the Canadian government and healthcare professionals to close the gap in Indigenous communities' access to appropriate healthcare services. A fundamental step in achieving this objective is engaging Indigenous families in developing health information that: (a) adequately and respectfully engages Indigenous families and serves their information needs; and (b) includes Indigenous knowledge and practices as core and robust sources of information. The Canadian Constitution recognizes Métis, First Nations, and Inuit Peoples as the three Indigenous groups and first peoples of Canada. Métis have expressed a need for reliable health information, emphasizing that health systems have left many of their information needs unmet. This research arose from a need identified by the Manitoba Métis Federation (MMF) for Red River Métis families to have access to meaningful and appropriate resources when their children are sick.

Purpose: As part of a research partnership initiated by the MMF, the primary purpose of this dissertation is to contribute new knowledge regarding how to culturally adapt existing child health resources to meet the identified needs and preferences of Red River Métis parents looking for health information when their children are acutely ill. Gaining a better understanding of the experiences Red River Métis parents face about this decision-making process can inform how to provide accessible, useful and meaningful information to guide care. Understanding the barriers that prevent parents from obtaining necessary information can help expose and challenge existing colonial processes. The research objectives are to: (a) examine the experiences of Indigenous families seeking health information for their sick or injured children; (b) determine how a child health resource can be adapted to meet Red River Métis parents' knowledge needs and preferences; and (c) understand how to engage Red River Métis citizens in Manitoba in the development/adaptation of child health resources.

Methods: This dissertation consists of four related papers: (a) an editorial on the Translating Emergency Knowledge for Kids (TREKK) knowledge mobilization network, which developed the parent tools that will be culturally adapted; (b) a scoping review to map the literature on Indigenous families' experiences seeking child health information; (c) a qualitative study to understand Red River Métis parents' experiences and preferences for seeking child health information; and (d) a qualitative study to provide a better understanding of engagement strategies that can help expose Red River Métis parents to child health research opportunities and to build trust and transparency amongst research partners and participants.

Findings: Results from the scoping review demonstrate that Indigenous families do not have access to necessary child health information, which can lead to insensitive, ineffective and unsafe health care. Our qualitative study analysis revealed that the development/adaptation of this information can satisfy Red River Métis parents' information needs and preferences and support ongoing efforts to revitalize Red River Métis culture and language. Additionally, parents want to participate in culturally safe research that can improve child health, offering spaces to share food, stories, knowledge, and opportunities to listen and learn together. The scoping review and qualitative study findings highlight the lack of research focused on the distinct experiences of Red River Métis families. Through meaningful engagement in knowledge translation research, we can build, rather than break, trusting relationships and implement research in ways that respect and align with parents' preferences.

Conclusions: This dissertation provides a robust analysis of Red River Métis parents' experiences and health information needs when their children are acutely ill. The research

findings, methodological and practical contributions of this dissertation are a critical step in addressing an identified need by the MMF for Red River Métis families to have culturally relevant and meaningful information resources available when their children are sick. The findings provide substantial contributions that strengthen the role of knowledge translation and patient engagement science in supporting reconciliation and the pursuit of equitable care for all children in Canada. Nurses play a critical role in closing the gap of health inequities by improving access to appropriate child health information. However, the nursing profession must support nurses with the necessary training, education and resources. This dissertation can support how this can be achieved in a culturally safe way.

Preface

This thesis is an original work by Lisa Knisley Jones. The research projects comprising this thesis received ethics approval from the University of Alberta Research Ethics Board on July 21, 2021 (Project title: "Cultural adaptation of a child health resource to meet the information needs and preferences of Métis parents in Manitoba;" Pro00111866). Research approval for qualitative components was obtained from the MMF Research & Ethics Protocol on February 10, 2020.

Paper 1 has been published as:

Knisley, L., Hartling, L., Jabbour, M., Johnson, D. W., Lang, E. S., Macphee, S.,…Scott, S.D. (2022). Translating Emergency Knowledge for Kids (TREKK): Using research evidence to improve outcomes for children and families in emergency departments across Canada. *Canadian Journal of Emergency Medicine, 24*(1), 12-15.

I was responsible for the conceptualization, writing, and submission of this paper for publication. All authors suggested substantive revisions of the paper and approved the final manuscript.

Paper 2 has been published as:

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Ms. Linton created and conducted the systematic database search. I was responsible for the conceptualization, initial search guidance, screening, data extraction, data analysis, writing, and submission of this paper for publication. Ms. Sun assisted with screening and data extraction.

Dr. Scott was the primary supervisor for this doctoral research and provided key guidance on the conceptual development of this review. Drs. Scott, Driedger, and Hartling all contributed to the conceptualization and intellectual development of this paper. All authors suggested substantive revisions of the paper and approved the final manuscript.

Paper 3 has been submitted to the *International Journal of Health Equity*:

Knisley, L., Driedger, S. M., Hartling, L., Chartrand, F., Sanguins, J., & Scott, S. D. (2023). We're here too: Findings from a qualitative study of the experiences and preferences of Red River Métis families looking for health information when their child is sick.

I was responsible for the conceptualization, participant recruitment, data collection, data analysis, writing, and submission of this paper. Participant recruitment was facilitated by Dr. Sanguins and Minister Chartrand in the Health and Wellness Department at the MMF. Dr. Scott was the primary supervisor for this doctoral research and provided key guidance on the conceptual development of this study. Drs. Scott, Driedger, Hartling and Sanguins contributed to the conceptualization and intellectual development of this paper. All authors suggested substantive revisions of the paper and approved the final manuscript.

Paper 4 is being prepared for submission (Target journal*: Research Involvement and Engagement*):

Knisley, L., Driedger, S. M., Hartling, L., Chartrand, F., Sanguins, J., & Scott, S. D. (2023). Engaging Red River Métis families in Manitoba in the development of child health resources: Findings from a qualitative study.

I was responsible for conceptualization, participant recruitment, data collection, data analysis, writing, and submission of this paper. Participant recruitment was facilitated by Dr. Sanguins and

Minister Frances Chartrand in the Health and Wellness Department at the MMF. Dr. Scott was the primary supervisor for this doctoral research and provided key guidance on the conceptual development of this study. Drs. Scott, Driedger, Hartling and Sanguins contributed to the conceptualization and intellectual development of this paper. All authors suggested substantive revisions of the paper and approved the final manuscript.

Research for this thesis was conducted as part of a research collaboration co-led by Dr. Shannon Scott (supervisor) and Dr. Lisa Hartling at the University of Alberta. The methods employed in this dissertation build on the methodological process to develop a knowledge translation tool for parents/families established by Drs. Scott and Hartling. This process involves combining the results of knowledge synthesis (Paper 2) with the results of qualitative research (Papers 3 and 4) to inform the adaptation of an existing knowledge translation tool originally developed by Drs. Scott and Hartling. The infrastructure required to conduct this research was provided by Dr. Scott’s research program and funding awarded to her and Dr. Hartling from the Canadian Institutes of Health Research (CIHR) and the Stollery Science Lab's Distinguished Researcher funding. Additionally, the MMF and Strategy for Patient Oriented Research (SPOR) Evidence Alliance provided support to engage Red River Métis parents and Elders in this research. I was responsible for supporting the partnership with the MMF, engaging parents and Elders, collecting and interpreting the data, and compiling the final reports. Dr. Scott supervised this project and was extensively involved in study design and analysis.

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I am very grateful for all the parents and Elders who participated in this research and took the time to share their stories, experiences and ideas. I learned so much from you; thank you for your contributions to this research, which could not have been done without you.

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Thank you, Paul, for believing in me and finding ways to make me laugh just when I needed it.

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Merlin, thank you for cheering me on and reminding me that I can do this.

To my dear Mom: Thank you for a lifetime of love and support. I miss you every day.

During this research, I was generously supported by funding from Evidence in Child Health to advance Outcomes (ECHO), Women & Children's Health Research Institute (WCHRI), Translating Emergency Knowledge for Kids (TREKK), Children's Hospital Research Institute of Manitoba, SPOR Evidence Alliance, the MMF, and the University of Alberta. I am so very grateful for the support of these awards and funders.

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List of Abbreviations

CIHR = Canadian Institutes of Health Research

KT = Knowledge Translation

MLPF = Métis Life Promotion Framework

MMF = Manitoba Métis Federation

NSERC = Natural Sciences and Engineering Research Council

OCAS = Ownership, Control, Access and Stewardship

SSHRC = Social Sciences and Humanities Research Counci

CHAPTER 1.

Introduction

Background

Inequitable care is at the root of many of the health problems Indigenous children and youth face in Canada (Canadian Pediatric Society, 2017). The Truth and Reconciliation Commission (2015) has drawn attention to the inequalities and systemic harms experienced by Indigenous Peoples in Canada, calling on the Canadian government and healthcare professionals to close the gap related to Indigenous communities' access to appropriate healthcare services. A fundamental step in achieving this objective is engaging Indigenous families in developing health information that: (a) adequately and respectfully engages Indigenous families and serves their information needs; and (b) includes Indigenous knowledge and practices (e.g., rich oral traditions, experiential knowledge, and cross-cultural sharing) as core and robust sources of information (Estey et al., 2009; Morton Ninomiya et al., 2017).

Health information is a fundamental component of high-quality health care. Worried families often look for health information to help them decide how to care for their sick children, and what they find can have a crucial impact on children's health status (Kubb & Foran, 2020; Scullard et al., 2010). Understanding and prioritizing families' child health information needs can support their decision-making, healthcare access, and appropriate healthcare service delivery (Chapman et al., 2020; Clarke et al., 2016; Gagliardi et al., 2015; Morrison et al., 2013; Richards et al., 2013). It is also a critical step in developing information that is accessible, useful and meaningful (Kyoon-Achan et al., 2021).

This research arose from a need identified by the Manitoba Métis Federation (MMF; the national government of the Red River Métis) for Red River Métis families to have access to meaningful and appropriate information when their children are sick. The MMF saw existing parent tools developed by Translating Emergency Knowledge for Kids (TREKK; trekk.ca), a national knowledge mobilization network for children's emergency care, and offered to fund the cultural adaptation of these tools for Red River Métis families (Knisley et al., 2022). Having been invited by the MMF to partner in this research, the primary goal was to gain a better understanding of Red River Métis parents': (a) experiences and preferences for seeking child health information when their children are acutely ill; (b) preferences for which core elements of an existing child health parent resource should be retained/adapted; and (c) engagement preferences for participation in child health research. Findings from this research will inform the adaptation (Aarons et al., 2017; Barrera et al., 2017) and dissemination of existing child health resources to ensure they reflect Red River Métis parents' information needs and preferences. Furthermore, understanding the barriers preventing parents from obtaining the information they need can help expose and challenge existing colonial processes perpetuating inequitable care.

Red River Métis

The Canadian Constitution recognizes Métis, First Nations, and Inuit Peoples as the three Indigenous groups and first peoples of Canada (Government of Canada, 1982). Métis are people of mixed First Nations and European ancestry with historical ties to the Red River settlement area, the fur trade and westward expansion in the 17th and 18th centuries. The Métis developed a united and unique nation in North America's northwest, forming their language, traditions, and culture (Government of Canada, 1982; Logan, 2007; MMF, n.d.). Although some Métis might adopt more Indigenous or Western ways of knowing, the Métis remain in an interstitial space, as being neither First Nations nor European settler populations (Martens, Bartlett et al., 2010).

Like other Indigenous Peoples, the Métis have experienced and continue to experience the legacy of colonial policies that disrupt their ways of knowing and being (Cooper et al., 2020), including historical dispossession of lands and even outright war (Driedger et al., 2015; Tough & McGregor, 2007). Métis lived under a reign of terror (MMF, n.d.) and subsequently learned to hide their identity, downplay their First Nations heritage and emphasize their Euro-Canadian heritage to reduce their exposure to racism, social injustices and health inequalities (Fiola, 2015). Generations of people who previously had not formally identified as Métis have come forward with increased pride and a desire to reclaim their Métis identities, in part due to the formal development of Métis government structures and increased recognition of Métis in Canadian court cases (Bartlett et al., 2007; Fiola, 2015; Logan, 2007). It took until 2013 for the Supreme Court of Canada to rule that the Canadian government had failed to uphold its constitutional obligations towards the Métis following the creation of Manitoba in 1870 (Madden & Teillet, 2013).

The Canadian province of Manitoba is widely recognized as the birthplace of the Red River Métis Nation (Cooper et al., 2020; MMF, n.d.). The MMF represents Red River Métis in Manitoba and Citizens living outside of the province with historical connections to the Red River Settlement. In 2021, 96,730 people identified as Métis in the province (Statistics Canada, 2022); however, this figure is likely under-reported. The MMF governance structure divides the province into seven regions and 135 smaller divisions called Locals. Approximately half of the Red River Métis population live in Winnipeg, Manitoba's capital city, with the rest dispersed across the rest of the province. Red River Métis and First Nations people often live side-by-side within Manitoba, yet have unequal access to health services and supports due to the different fiduciary responsibilities held by the federal and provincial governments, which can breed health inequities and challenge the uptake of research, policies, programming and services (Cooper & Driedger, 2015). Red River Métis access health services through the province; they do not have access to federally supported health services available to on-reserve First Nations or Inuit Peoples.

Introducing the Problem and Knowledge Gap

Red River Métis have expressed a need for reliable health information, emphasizing that health systems have unmet many of their information needs (Driedger et al., 2015). Red River Métis history has been denied or silenced for centuries, and colonization continues to impact the relationship Red River Métis have with their identity and culture, including connections to language, key people (e.g., Elders), cultural teachings and traditional medicines (Fiola, 2015, 2021). Métis parents have recognized culture and a positive sense of Métis identity as essential elements of raising children and critical components missing from health services (Graham & Davoren, 2015). Furthermore, Red River Métis are rarely included in a distinctions-based approach. Most research that includes Métis tends to be pan-Indigenous, grouping Métis with First Nations and Inuit peoples (Logan, 2007), which can diminish their unique and diverse experiences.

In health care, there is increasing interest in the power of stories to motivate, communicate, heal, and engage with multiple audiences (Scott et al., 2013) and to facilitate the efficient use of health services (e.g., preventing readmission, shortening the length of stay) (DeWalt & Hink, 2009). Sharing stories can also decolonize research (Kovach, 2018). Educational tools (e.g., videos, infographics) that merge evidence, stories and art have successfully been created with parents to share information on common childhood conditions (e.g., croup, fever, ear infection), to provide broad accessibility and fit with the Canadian population (Archibald et al., 2018; Hartling et al., 2010, 2013, 2021; Scott et al., 2012, 2013). However, further research is needed on whether these resources are relevant for specific cultural groups and contexts (Elliott et al., 2022a, 2022b, 2022c; Reading & Wien, 2009). This dissertation builds on this knowledge by providing insights regarding how to culturally adapt (Aarons et al., 2017; Barrera et al., 2017) existing child health resources to ensure they meet the information needs and preferences of Red River Métis families. Understanding Red River Métis families' experiences seeking child health information can inform strategies to develop and share health information resources that recognize, respect and embrace diverse understandings, traditions and knowledge systems (Smylie et al., 2014).

Community-based Participatory Research and Knowledge Translation

Community-based participatory research (CBPR) is fundamentally driven by relationships. It aims to confront how established structures, processes and dominant powers monopolize the definition and engagement of knowledge (Reason, 1994). This dissertation has been intentionally designed following the principles of CBPR, which prioritizes the development of culturally-centred research designs (Wallerstein & Duran, 2010) and integrated knowledge translation (iKT) (Straus et al., 2013). Knowledge translation (KT) is the synthesis, dissemination, exchange and ethical use of knowledge to improve health, provide more effective health services and products, and strengthen the healthcare system (Straus et al., 2013). Using iKT methods that recognize, respect and build on pre-existing knowledge systems is fundamental to decolonizing the research process (Smylie et al., 2014). CBPR and iKT approaches support the engagement of MMF Health and Wellness staff, parents, and researchers to: (a) ascertain whether the research addresses the Red River Métis community's needs, to help with uptake; and (b) involve community stakeholders (e.g., Red River Métis parents, MMF leadership) in project design and delivery. CBPR promotes a strengths-based narrative focusing on positive health aspects or positive approaches/solutions to adverse health issues. It helps researchers view an issue in context, acknowledges the influences of colonization, reframes the issue and reassigns the shame to these influences rather than to Indigenous peoples (Hyett et al., 2018, 2019).

Philosophical Approach and Theoretical Foundation

A relativist philosophical approach resonated with me at the beginning of my Ph.D. studies, as it is grounded in the assumption that there are multiple realities (Baghramian, 2015) —that is, truth varies from person to person or across community contexts. It aligned with my belief that patients and their families have diverse experiences in our healthcare system and that gaining an in-depth understanding of these experiences can better position health systems, governments and organizations to respond to their health needs. However, as I progressed in my doctoral program, these multiple realities did not align with my commitment to anti-racism. Racism is a reality. As such, the theoretical underpinnings of this work were informed by the philosophical tenets of critical realism, which have elements of realism and relativism (Braun & Clarke, 2022). Critical realism is an ontological and epistemological position from which to conduct research within people's social/health context (Bhaskar, 2008). It views structures that may appear invisible, such as colonial structures, as real because their effects can be experienced or observed (Bryman, 2008; Walsh & Evans, 2014). Explanations for changes at the empirical level can be found in many sources, including why people may have or observe the same experience but relate to it in contrasting ways (Walsh & Evans, 2014). Within my research, I can centre and learn about the lived experiences of the participating parents and Elders while *also* recognizing how context, cultural and social resources enrich and/or limit their experiences.

Critical realism also aligns with an intersectionality lens, which promotes the understanding that people are shaped by different social locations or categories (e.g., gender, race, Indigeneity, class) and has a key goal of reaching people who encounter geographic and/or systemic barriers, such as racism and colonialism, or who refuse to engage due to experiences of unresponsive or disrespectful care (Shimmin et al., 2017). In other words, inequities are never the result of single, distinct factors but rather the outcomes of intersections of different social locations, power relations and experiences (Hankivksy, 2014). People's lives are multi-dimensional and complex. Lived realities are shaped by different factors and social dynamics operating together (Hankivksy, 2014). Intersectionality-informed research can promote a better understanding of similarities and differences among parents seeking health information within and across social categories (Walsh & Evans, 2014).

In addition to these philosophical traditions, I drew on theoretical sources to provide foundational directions for design and planning. McCallum and Perry (2018, p. 144) stated: "History is about the past, but we research, write and teach history in a political and social present that is neither independent of nor unconnected to it." The health information needs of Red River Métis parents cannot be understood without recognizing colonialism's effects in shaping perceptions and decisions (Driedger et al., 2015; Fiola, 2015). A decolonizing research framework (Bartlett et al., 2007) guided the use of methods that are ethical, iterative, culturally-based, and process-oriented (i.e., focus on the journey as well as the results) (Bartlett et al., 2007). A decolonizing approach means that the research process creates spaces to prioritize Indigenous perspectives and goals (Bartlett, 2003). Red River Métis physician and researcher, Dr. Judith Bartlett, developed a Métis framework for knowledge translation and development called the Métis Life Promotion Framework (MLPF). This framework combines Indigenous and

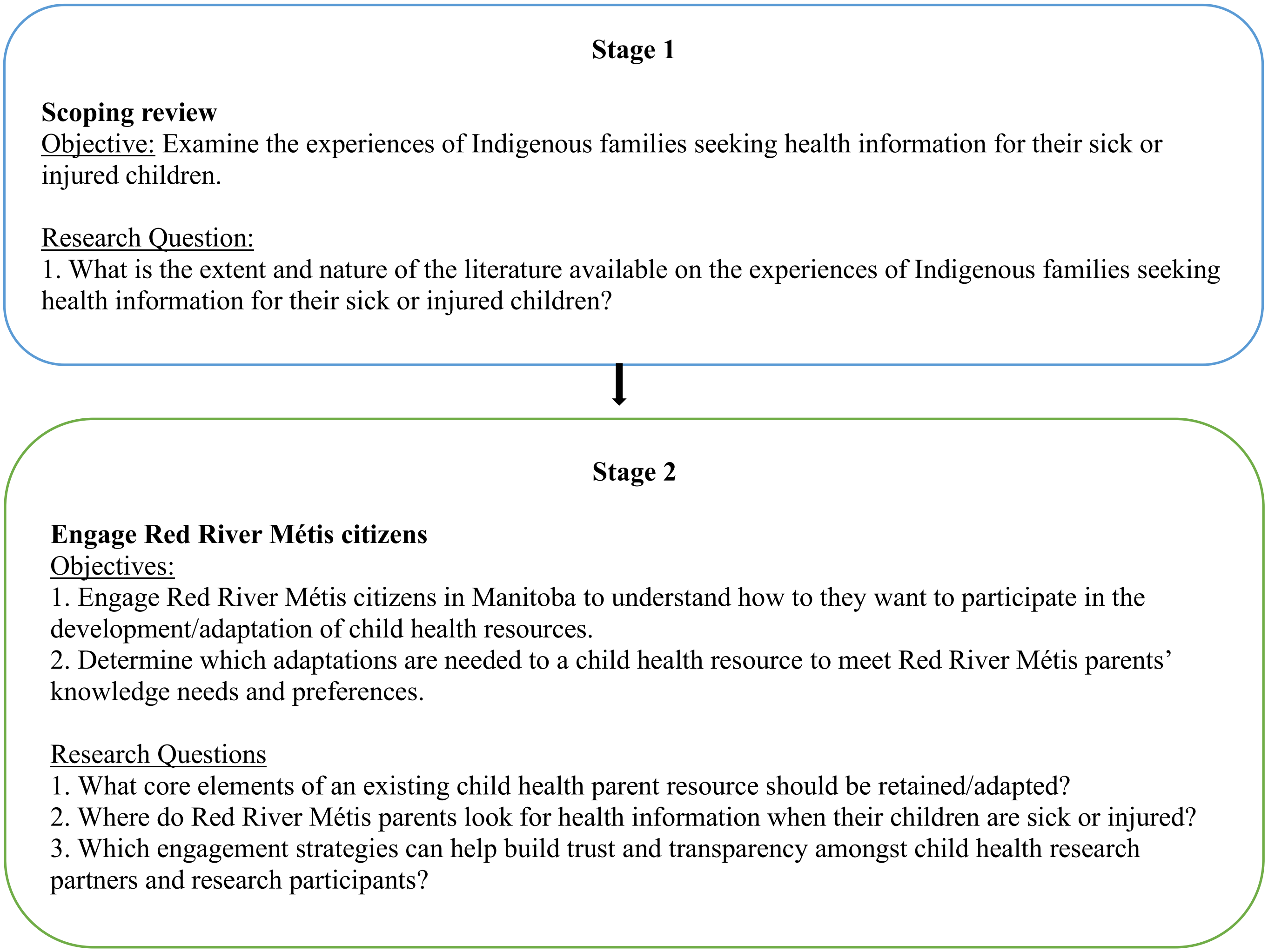
Western knowledge development approaches to create a holistic approach consistent with both Métis ancestral "ways of knowing" (Martens, Bartlett et al., 2010). Holistic Métis knowledge development is considered to combine Indigenous "myths & stories" (spiritual) and "experiences" (emotional) with Western "data & facts" (physical) and "information" (intellectual) (Martens, Bartlett et al., 2010). The framework is based on eight areas affecting wellness—nature, identity, development, relationships, networks, supports, environment and governance (Martens, Bartlett et al., 2010)—and provides important insights into the varied realities surrounding Métis identity and Métis determinants of wellness (Cooper et al., 2020). This framework also aligns with an intersectional lens (Shimmin et al., 2017), including the need to consider the different roles and functions that people play at different moments, as well as how people support one another, how governance is put into practice, and how health and well-being can be achieved (Cooper et al., 2020). This tool is not an ideology and does not represent Métis culture; rather, it was used to help organize thoughts and information (Martens, Bartlett et al., 2010) within this research. For example, the framework was used to plan study design, incorporating both Indigenous (spiritual and emotional; learning from parents/Elders' experiences and preferences through interviews, discussion groups and community events) and Western (physical and intellectual; gathering data through scoping review methods and demographic questionnaires) knowledge development approaches.

How researchers learn about what matters in Indigenous communities may be as critical to eliminating health disparities as the actual knowledge generated about a particular health problem (Cochran et al., 2008; Milner, 2007). Principles of relational, respectful, relevant, reciprocal and responsible research underpin all aspects of this research (Chilisa, 2020). The Tri-Council Policy Statement (CIHR, NSERC, & SSHRC, 2022) of ethical guidelines, and

Ownership, Control, Access and Stewardship (OCAS) principles followed by the MMF (University of Manitoba, n.d.) were followed.

Dissertation Stages and Objective

This paper-based dissertation represents the output of my doctoral research program with the overarching purpose to inform the adaptation of an existing child health resource to meet the identified experiences, needs and preferences of Red River Métis parents who seek health information when their children are acutely ill. To achieve this, a two-stage, multi-method approach was used (Fig. 1.1). The steps in each stage unfolded concurrently.



Stage 1

Scoping review
Objective: Examine the experiences of Indigenous families seeking health information for their sick or injured children.

Research Question:
1. What is the extent and nature of the literature available on the experiences of Indigenous families seeking health information for their sick or injured children?

Stage 2

Engage Red River Métis citizens
Objectives:
1. Engage Red River Métis citizens in Manitoba to understand how to they want to participate in the development/adaptation of child health resources.
2. Determine which adaptations are needed to a child health resource to meet Red River Métis parents' knowledge needs and preferences.

Research Questions
1. What core elements of an existing child health parent resource should be retained/adapted?
2. Where do Red River Métis parents look for health information when their children are sick or injured?
3. Which engagement strategies can help build trust and transparency amongst child health research partners and research participants?

Figure 1.1: Cultural adaptation of a child health resource to meet the information needs and preferences of Red River Métis parents in Manitoba

Positionality

The stories we tell about who we are, where we come from, what we understand, and how we belong connect us to our world (Iseke, 2013) and explain our connections to and motivations for doing research (Absolon & Willett, 2005). Telling my own stories while seeking to understand the stories of others (Carter et al., 2014) has helped me reflect on and better understand my assumptions, thinking and vulnerabilities.

I grew up in a two-parent household in a working-class suburb of Winnipeg. My parents and grandparents were all born in Canada and grew up in rural Manitoba communities. Through family reunions, stories and books documenting my family history, I learned of my European ancestors, who came to Canada in the late 1800s and settled in Western Manitoba communities. Colonial structures gave my ancestors opportunities to build farms and businesses. My parents worked hard and saved for my two sisters and me to travel, play sports, take music lessons, attend university and feel safe. But, I was unaware of my privilege as a white woman until adulthood. I was unaware that the community I grew up in and the health, education, and legal systems (to name a few) around me were built for people who looked like me. My education, entertainment and conversations were filled with stereotypes and inaccurate information.

I spent much of my teenage years visiting my father in healthcare facilities. When I was 15 years old, he became severely disabled following emergency surgery to remove a brain tumor. He spent two years as a patient in a neurosurgical hospital ward and then later as a resident of a long-term care facility until he died at the age of the 52. Within the walls of those healthcare centres I learned about loss, health care and patient advocacy. Countless hours were spent at my father's bedside. Hundreds of healthcare professionals cared for him over those six years, but only a few stick out in my mind. In particular, there were two nurses and a speech-language pathologist who, despite my young age, would ask me about my day, include me in my Dad's care, and ask for my opinions on his care. I felt seen, heard, and respected amid a devasting situation. My father was unable to talk as a result of the tumor. Yet, I felt like he could still share his story with me somehow, whether through the look in his eyes, his facial expressions or how strongly he would hold my hand. Perhaps that says more about the power of human touch or my need to help him, but I felt like I could help tell his story to the nurses, which could help them provide the care he needed. These experiences shaped me and undoubtedly influenced my decision to become a nurse. However, they also influenced my belief that *how* we communicate with each other in health care is just as important as the medicines and treatments available.

I left Winnipeg after obtaining my nursing degree, working in the U.S. before moving to England for over a decade. I knew there was more to see and learn beyond my childhood home, and I wanted to travel and experience other parts of the world. Early in my nursing career, it became clear how the information shared with patients and their families could dramatically affect their care. For example, walking through the steps of a procedure with a patient could help them feel a bit more relaxed and, in turn, help them remain still during a procedure. Ensuring they knew who to call with questions when at home could help prevent a trip to the doctor's office or emergency room. Clear pre-operative instructions could help decrease stress and prevent a cancelled surgery. These were my experiences as an English-speaking nurse educated and employed within Western/Eurocentric institutions. I had little understanding then of how communication (or lack thereof) within the healthcare system could also fuel racism and inequitable care.

My interest in communication led me to complete a Master of Arts in Journalism in the UK and join an initiative to improve the information provided to patients in large National

Health Service hospitals in London. A systematic process was implemented to develop clear, accessible patient information in collaboration with clinicians and patients. Although I believe good progress was made to encourage high-quality standards and patient participation in developing patient resources, the end results were not formally evaluated for impacts on healthcare or patients' experiences. When I moved back to Canada, my role within a national knowledge mobilization network, TREKK, helped link my interest in patient information and communications to research. Opportunities arose for me to be part of an exciting research team that was merging evidence, parents' stories and art to develop better ways to share evidence with parents and inform their decisions about their children's health care. These resources were developed in English and aimed at a broad audience. However, we knew this meant that gaps remained in offering resources that represented the languages and cultures of many parents in Canada.

When the MMF invited TREKK to adapt its child health resources to meet the needs of Red River Métis families, I was grateful for the opportunity to partner with them to plan the co-creation of resources to ensure Red River Métis parents' experiences in accessing information within our healthcare system, and their resource and engagement preferences were reflected in the adaptation process. I want our healthcare system to offer *all* families the information they need when their children are sick. In times of stress and uncertainty, I want families to feel genuinely part of their children's healthcare team, to be seen, respected and know that their preferences and decisions matter. Niigaan James Sinclair, department head of Indigenous Studies at the University of Manitoba, reminded us: "Reconciliation is everyone's business. How we step into a future together will determine the future of our children" (Daschuk, 2019, p. XIII). With this in mind, I am committed to working towards equitable health care for all children.

Dissertation Overview

This dissertation's four distinct but related papers focus on developing knowledge to adapt an existing child health resource to meet the identified experiences, needs and preferences of Red River Métis families looking for health information when their children are acutely ill. The papers have been formatted to the specifications of the journals to which they have been published or submitted.

Chapter 2 provides background information on the work of TREKK, a national knowledge mobilization network in pediatric emergency care created through the Government of Canada's Networks of Centres of Excellence program. The parent tools the MMF had seen were developed by TREKK. Chapter 3 shares the findings from the scoping review, which examined the extent and nature of the literature available on the experiences of Indigenous families seeking health information for sick or injured children. Chapter 4 describes the findings from a qualitative study of the experiences and preferences of Red River Métis families who seek health information when their children are sick. Chapter 5 focuses on increasing our understanding of the engagement strategies that can help expose Red River Métis parents to child health research opportunities and build trust and transparency amongst research partners and participants. In the following paragraphs, I briefly summarize each of the four papers and how they are connected. I conclude this dissertation in Chapter 6, summarizing the research and presenting implications of the findings for future research and practice.

Paper 1

Paper 1 (Chapter 2) provides background on TREKK (trekk.ca). In 2011, TREKK was established through the Government of Canada's Networks of Centres of Excellence Knowledge Mobilization initiative to accelerate the sharing of the latest evidence in pediatric emergency care with two key receptor communities: (a) healthcare professionals working in general emergency departments, where the majority of children needing emergency care in Canada are first seen; and (b) parents/families seeking emergency care for their children. A key goal of TREKK is to mobilize knowledge to parents/families through the co-creation of knowledge translation (KT) tools (e.g., videos, infographics) *with* parents (Knisley et al., 2022). This robust development process merges evidence, stories and art to share information on common childhood conditions in ways that are broadly accessible to and align with the needs of the Canadian population.

Connection: Paper 1 provides essential background information about TREKK and the existing KT tools that the MMF had seen. The MMF approached TREKK and offered to fund the adaptation of these tools for Red River Métis families. Research was needed to identify how to adapt these resources to make them relevant, useful and meaningful. Paper 1 has been published as:

> Knisley, L., Hartling, L., Jabbour, M., Johnson, D. W., Lang, E. S., MacPhee, S., Reid, S., Scott, S.D. … Klassen, T.P. (2022). Translating Emergency Knowledge for Kids (TREKK): Using research evidence to improve outcomes for children and families in emergency departments across Canada. *Canadian Journal of Emergency Medicine, 24*(1), 12-15. https://doi.org/10.1007/s43678-021-00205-9

Paper 2

In Paper 2 (Chapter 3), I conducted a scoping review to map the literature on Indigenous families' experiences seeking child health information when their children are sick and to identify barriers to and facilitators of information access. Like other Indigenous groups, Red River Métis have experienced and continue to experience the legacy of colonial policies that disrupt traditional ways of knowing and being (Clarke et al., 2016; Driedger et al., 2015; Tough

& McGregor, 2007). This scoping review was not limited to Red River Métis Peoples to enable exploration in a broader Indigenous context. Our analysis documents that Indigenous families do not have access to the necessary information to care for sick children, which can lead to insensitive, ineffective and unsafe health care.

Connection: This scoping review was foundational in highlighting the gap in knowledge on the distinct experiences and preferences of Red River Métis families seeking child health information. It concludes that strategies to improve information available to Indigenous families cannot be developed without learning from families' experiences, and the responsibility for finding this information should not rest solely with Indigenous families. The scoping review also highlighted that future research is needed on the co-creation of informational tools with Indigenous families and communities to expose and challenge existing racist and colonial processes that are perpetuating inequitable access to child health information. Findings will inform the process to culturally adapt the existing TREKK child health resources. Paper 2 has been published as:

Knisley, L., Linton, J., Driedger, S. M., Hartling, L., Sun, Y., & Scott, S. D. (2023). Examining the experiences of Indigenous families seeking health information about caring for sick or injured children: A scoping review. *BMJ Open, 13*(3), e069697. https://doi.org/10.1136/bmjopen-2022-069697.

Prior to undertaking the scoping review, a protocol was developed and published as:

Knisley, L., Linton, J., Driedger, S. M., Hartling, L., & Scott, S. D. (2022). Examining the experiences of Indigenous families seeking health information for their sick or injured child: A scoping review protocol. *medRxiv*. doi:10.1101/2022.04.18.22273999

Paper 3

Paper 3 (Chapter 4) aimed to understand Red River Métis parents' experiences and preferences for seeking child health information when their children are acutely ill. A qualitative descriptive approach underpinned by a participatory paradigm was used. Individual, semi-structured interviews were completed via Zoom or over the phone to explore child health information needs and preferences, necessary changes to existing TREKK resources, trusted sources for health information, preferred topics and formats, and experiences finding health information. An inductive thematic analysis approach was used to explore patterns and themes across the data. Data collection and analysis were performed concurrently. Analysis of 19 interviews (16 parents and 3 Elders) generated four major themes: (a) we're here too; (b) we are not all the same; (c) finding trustworthy information; and (d) information needs to be widely available.

Connection: This study also highlighted the lack of child health information for Red River Métis families. Developing culturally appropriate informational tools can help satisfy families' information needs and preferences and support revitalizing Red River Métis culture and language. Parents and Elders provided tangible ways to modify existing parent resources, including adding information on how to access Elders, healers and/or traditional medicines, showing different family structures, transport and living situations, using Métis names, and incorporating Métis languages. These results contribute evidence to support the cultural adaptation of existing parent tools. Paper 3 was submitted to the *International Journal for Equity in Health* in September 2023:

Knisley, L., Driedger, S.M., Hartling, L., Chartrand, F., Sanguins, J., Scott, S. D. We're here too: Findings from a qualitative study of the experiences and preferences of Red River Métis families looking for health information when their child is sick.

Paper 4

Paper 4 (Chapter 5) aims to increase our understanding of the engagement strategies that can help expose Red River Métis parents to child health research opportunities and build trust and transparency amongst research partners and participants. A qualitative descriptive approach was used. Individual, semi-structured interviews were completed via Zoom or telephone to explore ways to make it easier for Red River Métis families to be involved in research, including helpful recruitment strategies and creating safe spaces in research. Patterns and themes were explored across the data using an inductive thematic analysis approach. Data collection and analysis were performed concurrently. Analysis of 19 interviews (16 parents and 3 Elders) generated four major themes: (a) show me why you are here; (b) make it easier for me to take part; (c) create welcoming spaces; and (d) it should be a give and take experience.

Connection: Lack of respect and understanding diminishes the safety of participants who engage in research, and our interactions as researchers with participants throughout the research process provide opportunities to build cultural safety. We cannot effectively improve child health without engaging families. The results of this study provide valuable information about Red River Métis parents' experiences and preferences for participating in child health research and make a clear contribution to understanding how to build transparency, trust and safe spaces with research participants and partners. Findings will inform the cultural adaptation process. Paper 4 has been prepared for submission to *Research Involvement and Engagement* in 2023:

Knisley, L., Driedger, S. M., Hartling, L., Chartrand, F., Sanguins, J., Scott, S. D. "It needs to be more than words". Understanding how to engage River Métis families in Manitoba in the development of child health resources: Findings from a qualitative study.

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CHAPTER 2.

Paper 1: Translating Emergency Knowledge for Kids (TREKK): Using Research Evidence to Improve Outcomes for Children and Families in Emergency Departments across Canada

Paper 1 has been published as:

Knisley, L., Hartling, L., Jabbour, M., Johnson, D. W., Lang, E. S., Macphee, S., Reid, S., Scott, S. D., Sinclair, D., Stang, A. S., Vincent, M., & Klassen, T. P. (2022). Translating Emergency Knowledge for Kids (TREKK): Using research evidence to improve outcomes for children and families in emergency departments across Canada. *Canadian Journal of Emergency Medicine*, *24*(1), 12–15. https://doi.org/10.1007/s43678-021-00205-9

Introduction

In Canada, up to 85% of children who need emergency care are treated in general emergency departments (ED) [1] that care for children and adults. Children have unique healthcare needs due to physiological, development and psychological differences. ED teams in these general ED settings have identified gaps in accessing pediatric-specific training and resources, including opportunities for hands-on practice during courses or training experiences [2-4]. Moreover, they have expressed concerns in maintaining pediatric expertise and competencies particularly if they don't often treat children or certain pediatric conditions [2,4]. These concerns are well- founded; the gap in pediatric care between pediatric and general EDs has been associated with a disparity in health outcomes [5]. Efforts are needed to improve ED pediatric readiness, ensuring children have access to timely, well-resourced, and effective emergency care [6].

Families also face challenges making decisions on how best to care for their acutely ill or injured child. Health information filled with medical jargon and no consideration of parental literacy skills and language competencies is less effective [7]. Information needs of families must be prioritized to support their decision-making, shape treatment expectations, and optimize healthcare utilization [8,9].

Canada has been at the forefront of pediatric emergency medicine research since 1995, when *Pediatric Emergency Research Canada (PERC)* was created [10]. PERC has been instrumental in advancing pediatric emergency knowledge in numerous clinical areas [10]. PERC was also a founding member of the international *Pediatric Emergency Research Networks* (PERN), which has led observational studies and clinical trials for topics including sepsis, H1N1, COVID-19 and pneumonia [11]. However, unless research findings are effectively implemented into clinical practice within *all* EDs that treat children, we cannot truly bridge the 'research-to-practice' gap and raise the overall standard of emergency care for children.

In 2011, *Translating Emergency Knowledge for Kids* (TREKK) was established to address this research-to-practice gap. Supported by the Government of Canada's Networks of Centres of Excellence (NCE) Knowledge Mobilization (KM) initiative, infrastructure was built that initially connected 12 PERC sites (based in pediatric institutions) [10] with 37 general EDs in nine provinces/territories. Together, clinicians and researchers at these sites set out to accelerate the speed at which the latest evidence in pediatric emergency care was shared with two key receptor communities: 1) healthcare professionals working within general EDs; and 2) parents/families seeking emergency care for their child. The goals were to: 1) determine the knowledge needs of our receptor communities; 2) assemble evidence and develop educational tools to help general EDs access, adapt and implement new knowledge; and 3) build a sustainable KM network in pediatric emergency care.

Determining knowledge needs

TREKK began with a national needs assessment that surveyed over 1400 general ED clinicians and 1000 parents in 32 general ED sites (rural, remote and urban) across Canada to identify their pediatric information needs/preferences and more fully understand the context of care delivery at these sites [2]. In-person survey data collection was followed by focus groups with ED healthcare professionals to discuss the survey findings. A review of pediatric transport data, coroner reports and medical claims explored unperceived information needs. Some of the pediatric topics of greatest interest to healthcare professionals (e.g., multi-system trauma, meningitis, severe head injuries) were infrequent but high stakes events. Needs assessment findings were fundamental in prioritizing topics and KM strategies.

Developing educational tools and resources

TREKK established resource development infrastructure that brings together evidence synthesis experts, leading child health researchers, communication specialists and clinicians within a variety of specialties to identify, review, curate and create evidence-informed resources [12]. The TREKK website has links to vetted, existing resources. When a gap exists, TREKK develops new resources. To date, over 145 TREKK resources have been developed, including:

- Pediatric Packages (PedsPacs) - comprehensive bundles of practical tools (e.g., management algorithms, pocket cards, order sets, transport checklist, triage screening poster) on a range of topics (Fig. 1). When a lack of evidence exists for specific treatment recommendations, guidance is based on the consensus of pediatric experts across Canada.

- Bottom Line Recommendations (BLR) - 1–2-page summaries that highlight key issues and offer a review of current, available evidence for managing children in emergency settings. The BLRs (Fig. 1) are not intended as step-by-step guides, rather they summarize existing evidence and provide practical information on a given pediatric emergency topic.

Resources are available in French and English, updated every two years at minimum, and openly accessible via the TREKK website (Trekk.ca) and app (Trekkca), allowing clinicians ready access at any time. The TREKK app was developed with over 30 healthcare professionals and purposefully designed to store resources offline for use in remote settings with no internet access. The development of these novel resources represents a national effort to reduce delays and improve efficiencies in evidence uptake. For example, when a large multicentre pediatric DKA trial was underway [13], TREKK was in regular contact with the investigators and started modifying its DKA resources. Once the results were published, TREKK released the updated resources. Changes in practice that would typically take years to implement were reduced to months, allowing emergency clinicians across Canada to implement new evidence immediately.

TREKK researchers also co-create resources *with* families (Fig. 1) through a process that merges evidence, parents' stories, art, and digital media to share information on common childhood conditions. Parents are actively involved in the development process, which includes parent interviews, systematic reviews, prototype development with professional writers and media designers, review by healthcare professionals for clinical accuracy, review by parents for content and aesthetics, and usability testing [14]. The parent tools are available online and within ED waiting rooms and health centres in several provinces, reaching millions of families.

Figure 2.1: Examples of TREKK resources and reach

Flexibility to adapt TREKK resources to local contexts prevents developing resources 'in silos', reduces duplication of effort and gives healthcare professionals more time to focus on clinical care and training. A collaboration with Indigenous Services Canada led to modification of TREKK's sepsis and status epilepticus resources, to make them more applicable to nursing station use. Additionally, TREKK resources have been adapted by the Emergency Medical Services for Children (EMSC) Innovation and Improvement Center (EIIC) for use in EDs in the United States (https://emscimprovement.center/about/). Collaboration between TREKK and EIIC has new resources being jointly created for use by the two organizations.

TREKK resources have had 61,640 downloads from trekk.ca as of August 2021. TREKK teams have facilitated 165 education sessions with general EDs across Canada, reaching over 2400 physicians, nurses, respiratory therapists, pharmacists, and paramedics. Whenever possible, these education sessions occur in-situ within general EDs and use simulation to identify environmental and systemic issues such as equipment concerns, medication availability and team dynamics. Virtual education sessions have taken place during the COVID-19 pandemic, and a longer-term virtual education platform is being explored.

Sustaining pediatric emergency knowledge mobilization

TREKK is a not-for-profit organization governed by a national Board of Directors, fueled by the in-kind support of over 40 steering, editorial and advisory committee members, and supported by staff at the Children's Hospital Research Institute of Manitoba (CHRIM). The NCE funding program ended in 2020. Generous support from Children's Hospital Foundations allows TREKK's central operations to continue. A collaboration with the Manitoba Metis Federation is supporting the cultural adaption of parent tools. Grant funding is supporting specific projects, such as developing parent tools [14] and assessing how ready EDs are to treat children. However, infrastructure that accelerates access to evidence and linkages to expertise (e.g., researchers, knowledge brokers, librarians) and people with lived experiences (e.g., parents/families) are foundational for enabling, sustaining, and evaluating consistent evidence-informed health care [15]; funding for such infrastructure is not available through traditional granting mechanisms.

To scale up TREKK's impact and reach all general EDs and nursing stations in Canada will require appropriate investment in both human and financial resources. Within the US, this infrastructure has been supported by federal funds and legislation for over 30 years (https://emscimprovement.center/about/) and has shown that general EDs can improve how ready they are to manage a sick or injured child when high-quality resources and best practices are shared [5,6]. Investment in a pan-Canadian strategy for pediatric emergency KM is needed whereby health systems can work together to focus on common problems, while maintaining independence to address issues relevant to local contexts. Without this investment, the potential for disparity in healthcare outcomes and quality within pediatric emergency care will continue to exist.

Conclusion

TREKK's collaborative approach has determined the information needs of both emergency healthcare professionals and families. TREKK's infrastructure provides instant, online access to thousands of pediatric emergency resources, including Canadian developed, evidence-based clinical and educational resources. Education sessions, meetings and technology are building connections between over 165 rural, remote, and urban EDs across Canada. Scaling, spreading and sustaining these achievements will require a move beyond collaborative relationships and the in-kind support of passionate clinicians, parents and researchers. Sustained investment in TREKK, which integrates pediatric emergency knowledge within our health systems and supports the pediatric readiness of general EDs, is needed. Only then can we truly move towards equitable emergency care for all children in Canada.

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CHAPTER 3.

Paper 2: Examining the experiences of Indigenous families seeking health information about caring for sick or injured children: A scoping review

Paper 2 has been published as:

Knisley, L., Linton, J., Driedger, S. M., Hartling, L., Sun, Y., & Scott, S. D. (2023). Examining the experiences of Indigenous families seeking health information about caring for sick or injured children: A scoping review. *BMJ Open*, *13*(3), e069697. https://doi.org/10.1136/bmjopen-2022-069697

Abstract

Objective Mapping literature on Indigenous families' experiences seeking child health information and identifying barriers and facilitators to information access.

Design Scoping review

Data Sources In April 2021, we searched Medline, EMBASE, PsycINFO, Scopus, and CINAHL for peer-reviewed literature and Google Advanced for grey literature. We screened tables of contents of two Indigenous research journals not consistently indexed in online health databases and used snowball sampling to supplement searches.

Eligibility Criteria We included full-text, English language articles based on: *participants* (Indigenous families), *concept* (experiences of families seeking health information), and *context* (child health).

Data Extraction and Synthesis Two independent reviewers extracted: citation details, study purpose, country of study, publication type, study design, data collection method, Indigenous group, family member participants, home/healthcare setting, child health area, how health information was accessed, and information-seeking barriers and facilitators. Data were examined for patterns and trends, results, and implications.

Results Among 19 papers (representing 16 research projects) included, 9 described family/friends and 19 described healthcare professionals as sources of child health information. Barriers include racism/discrimination during healthcare visits, ineffective communication with healthcare providers, and structural barriers (e.g., transportation). Facilitators include easy access, improved communication and relationships with healthcare providers, and culturally safe healthcare.

Conclusion Indigenous families perceive they do not have access to necessary child health information, which can lead to insensitive, ineffective and unsafe healthcare. A critical gap exists in understanding Indigenous families' information needs and preferences when making decisions about children's health.

Keywords: pediatrics, knowledge synthesis, child health, Indigenous, First Nations, Inuit, Métis

Strengths and Limitations of this Study

- Comprehensive search strategy of five electronic databases for peer-reviewed and grey literature.
- Review is part of a multi-stage project addressing an identified need for Red River Métis families to have access to appropriate child health resources.

- Review limited to literature in English, potentially impacting comprehensiveness and generalizability.
- Methodological quality/risk of bias of individual studies not assessed.

Introduction

Rationale

The Truth and Reconciliation Commission in Canada[1] documented inequalities and systemic harms experienced by Indigenous peoples in the residential school system. The Commission heard the testimony of First Nations, Métis, and Inuit people affected indirectly or intergenerationally by this brutal form of colonization which legally, racially, and systematically separated Indigenous children from their families, communities, cultures, and traditions for approximately 150 years. Seven of the Commission's 94 Calls to Action are directly related to healthcare and emphasize the responsibility of the Canadian government and healthcare professionals to improve Indigenous communities' access to appropriate healthcare services. An essential component is to work alongside Indigenous families to better understand and prioritize their health information needs, which in turn can support decision-making, healthcare access, and appropriate healthcare service delivery [2-6]; and co-develop health information that serves their needs and respectfully incorporates Indigenous knowledge (e.g., rich oral traditions, experiential knowledge, cross-cultural sharing).[5, 6]

The Canadian constitution recognizes Métis, First Nations, and Inuit peoples as the three Indigenous groups and first peoples of Canada.[7] The Manitoba Métis Federation (MMF), the democratically elected government of the Manitoba Métis,[8] highlighted a gap in accessing meaningful and appropriate information for Red River Métis families when seeking emergency care for their children. Understanding Indigenous families' experiences can: 1) inform strategies to develop and share health information resources that embrace diverse understandings and recognize and respect pre-existing knowledge systems;[9] and 2) help promote strengths-based approaches that focus on positive aspects of health and healthcare solutions, including contextualization, acknowledging the influence of colonization, reframing issues, and reassigning shame to these influences rather than to Indigenous peoples.[10, 11]

Here, we present a scoping review of literature examining the experiences of Indigenous families seeking child health information. Like other Indigenous groups, the Métis have experienced and continue to experience the legacy of colonial policies that disrupt their ways of knowing and being.[3, 12, 13] Importantly, this scoping review explores findings in a broader Indigenous context.

Health information offered to patients and families influences both the content and outcomes of healthcare encounters.[14] When people can access and understand health information, self-care, coping skills, and lifestyles improve.[15-18] Cultural beliefs and differences in communication styles must be considered, as they affect health-related thoughts and feelings, when and where people seek health care, and understandings of health information.[14, 19]

A better understanding of Indigenous families' experiences seeking child health information is necessary to improve access to useful and meaningful information to guide care. To date, no scoping review has synthesized literature on Indigenous families' experiences seeking child health information. We address this gap to inform cultural adaptation [20, 21] of an existing child health resource for Red River Métis families.

Study Objectives

The objectives of this scoping review are to map the literature on Indigenous families' experiences seeking information about how to care for sick or injured children, and to identify barriers and facilitators affecting information access.

Methods

Protocol and Registration

This scoping review was registered (10.17605/OSF.IO/875RY) and followed a protocol[22] based on JBI methodology.[23-25] For reporting, we followed the PRISMA extension for scoping reviews (PRISMA-ScR) Checklist.[26]

Eligibility Criteria

We based eligibility on the PCC mnemonic:[26] *Participants* (Indigenous families of children aged 0–21 years,[27]), *Concept* (experiences of families seeking health information), and *Context* (child health, excluding maternal/antenatal care) [Supplemental File 1]. We included all study designs and both published literature and grey literature, such as government reports, conference proceedings/abstracts and dissertations.[28] Only literature published in English was included due to budget and time restrictions.[29] We included articles published in 2000 or later to reflect information-seeking in the Internet era.[3]

Search

An academic health sciences librarian (JL) with over 20 years of experience in Indigenous peoples' health designed the search strategies. Five databases (Medline, EMBASE, PsycINFO, Scopus, and CINAHL) were searched in April 2021 [Supplemental File 2]. LK and YS screened all tables of contents of two Indigenous research journals, *First Peoples Child & Family Review* and *Journal of Indigenous Wellbeing – Te Mauri - Pimatisiwin,* because they include relevant articles but are not consistently indexed in major online health databases.

LK and YS used Google Advanced to identify grey literature, including online dissertations, examining the first 100 results for relevance [Supplemental File 3].[30] They also scanned reference lists of relevant journal articles and grey literature.

Selection of Sources

LK and YS screened titles and abstracts and classified each article as 'include', 'exclude', or 'unsure'. Results were compared, and discrepancies resolved with SS when necessary. Full texts of articles classified as 'include' or 'unsure' were retrieved and assessed against the eligibility criteria, documenting reasons for exclusion. Missing articles were found with librarian assistance and by contacting authors.

Data Extraction

LK and YS independently refined the data extraction procedure on three articles,[25] extracting citation details, study purpose, country of study, publication type, study design, data collection method, Indigenous group, family member participants, home/healthcare setting, child health area, how health information was accessed, and information-seeking barriers and facilitators. Critical appraisal was not conducted as we aimed to provide an overview of existing evidence, regardless of quality.[31]

Synthesis of Results

We displayed data within a table to facilitate comparisons of commonalities and differences across the studies,[32,33] examining for patterns, trends and findings.[24, 25]

Deviations from the Protocol

To better capture the most relevant aspects of included studies, we modified the proposed data extraction procedure by including studies published in 2000 and beyond. Barrier and facilitator measurements were not analyzed due to limited information in the included studies.

Patient and Public Involvement

This scoping review is one part of a multi-part project to culturally adapt a child health resource, based on an identified need from the MMF. Numerous meetings, phone calls and emails have taken place with the MMF to plan and conduct the project. Findings will be shared with the MMF, and their feedback will inform the adaptation of a child health resource.

Results

Nineteen articles (representing 16 research projects) were included (Figure 1, Table 1 and Supplemental File 4). All employed qualitative methods: participant interviews (n=7), focus/discussion groups (n=3), or both (n=9). Twelve studies are based on data collected only from parents/family members. Seven studies include data from parents/family members and others (e.g., children, healthcare providers, community members), clearly differentiating between parents/families and other participants in the findings. Data were collected from Indigenous peoples in Canada (n=8; First Nations/Métis: n=4; First Nations only: n=4), Australia (n=6; Aboriginals/Torres Strait Islanders), the U.S. (n=4; Native Americans: n=2; Native Hawaiians: n=2) and Aotearoa New Zealand (n=1; Māori)

Most studies were published in 2020 (n=5) and 2019 (n=6), with the remaining studies published between 2003 and 2017, no more than one per year (Table 2). The increase in publications mostly aligns with the publication of the Truth and Reconciliation reports and Calls to Action in 2015,[1] as well as national patient-oriented research initiatives launched in

Canada[34] and the United States in 2010,[35] and Indigenous-led research initiatives launched in Aotearoa New Zealand in 2017[36] and Australia in 2018.[37, 38]

Almost half of the articles did not report participants' genders (n=8) (Supplemental File 4). Six papers focused exclusively on women, and five included both men and women participants. Articles described the experiences of mothers (n=7), multiple family members (e.g., parents, aunties, grandparents) (n=6), and parents/guardians only (n=6) (Table 1).

Studies described the experiences of families seeking information on burn injuries,[39] respiratory conditions,[40-45] skin infections,[46, 47] and pain.[48] Rather than focusing on specific conditions, other studies described experiences in the contexts of parenting,[15, 49, 50, 51] primary care,[52] early child development,[53] an inpatient unit,[54, 55] or caring for a technology-dependent child.[56]

Studies reported families use extensive networks to access health information. Nine studies described family and friends as vital sources of advice and support when children are sick,[15, 43, 44, 48-51, 53, 56] and all studies reported healthcare professionals (e.g., family doctors, telehealth nurses, pharmacists, and clinicians in emergency departments or community clinics) as sources of health information, reassurance, and advice regarding the best course of treatment.[15, 39-56] Parents reported turning to other sources (e.g., Internet) if they did not receive health education during primary healthcare visits.[52] In one study, parents accessed health information via Facebook and Google, but also lacked confidence in recognizing trustworthy online information.[15] Overall, we identified three barriers and three facilitators affecting Indigenous families' access to child health information (Table 3 and Supplemental File 5).

Barriers

Racism and Discrimination during Healthcare Visits

Fourteen articles reported families experience racism and discrimination in healthcare settings.[39, 40-42, 45-50, 52-55] Families reported feeling judged based on their appearance and/or last name,[48, 52] their children being labelled as lazy,[42] and being treated differently by healthcare providers when seeking healthcare for children.[40, 48] Some parents reported they were given incomplete information or treated disrespectfully because they are Indigenous.[42]

Studies reported mothers feeling healthcare providers are unaware of the historical trauma and social inequities that can impact their health behaviors,[54] and reported being judged and treated insensitively when nurses learn of past substance abuse or involvement with child protection services.[54, 55] Single mothers with medically fragile children reported being watched or treated differently by healthcare providers.[50] Mothers also reported experiencing discrimination from healthcare providers for having children at a young age.[42, 52]

Parents experienced fear, judgment, and shame when accessing healthcare for their children, which influenced when, where, or if they accessed healthcare.[41, 46] Families also reported feeling unable to ask questions or engage with healthcare providers confidently.[40, 41, 46, 49] Not having culturally relevant care also affected families' decisions to return to providers.[52] Some parents preferred managing their children's pain at home to avoid experiences of discrimination in the hospital.[48]

Parents described a critical responsibility to future generations to counteract colonization,[51] but that advocating for information creates stress and requires significant energy.[48, 49, 54] There are barriers to accessing Indigenous healers, traditional care providers,[41] and traditional medicine,[53] which healthcare providers tend to dismiss.[54] Families also experienced difficulties accessing information in their preferred language[46-48] and a lack of acknowledgement of the spiritual and emotional aspects of care.[48]

Ineffective Communication with Healthcare Providers

Ineffective communication with healthcare providers was identified as a barrier to accessing information in 14 papers. Families described receiving little to no child health information during their healthcare visits,[39, 40-47, 49, 52, 56] and reported feeling confused when they were not given enough information to manage care at home for children with technology dependencies (e.g., oxygen, tracheostomy),[56] burn injuries,[39] asthma,[43, 44] and skin infections.[47] Additionally, families often were not informed how to recognize trustworthy information online.[15]

Families reported feeling unsettled when information is laden with medical jargon.[39, 41, 42, 47, 48, 50] Additionally, confusing and/or insensitive communications with healthcare providers left families feeling fearful and angry,[39] and unclear about how to use medicine[42, 46, 47] or confidently manage their children's care at home.[49] For example, healthcare providers may not explain procedures in child-friendly ways,[39] involve families in decision-making about their children's treatment,[46, 47] or recognize families' knowledge and expertise about their own children.[41] Families also reported being less likely to trust a healthcare provider's opinion [52, 54] and more likely to seek care elsewhere [52] if they do not feel listened to.

Structural Barriers

Geographical and transport barriers were reported in 10 studies.[39, 41-43, 46, 48, 50-52, 55] Finding and paying for transportation to take a sick child to an emergency department and/or primary care clinic were major concerns for families.[41, 52, 55] Families also reported not having access to adequate health information and support close to home.[39, 42, 43, 46, 48, 50, 51] Parents felt stress, heartache, and anxiety when they were unable to visit hospitalized children regularly because they lacked transportation and/or needed to care for other children.[39] Cost, work schedules, family commitments, inaccessible programs, and lack of childcare were barriers to participating in health education and support programs.[42]

Facilitators

Easily Accessible Information

The importance of easy access to clear and trustworthy information was reported in 15 articles.[15, 39, 40, 42-49, 51, 53, 55, 56] Parents gathered as much information as possible when their children were sick to help manage their feelings of uncertainty and anxiety.[56] Families wanted access to practical, clear,[47, 48] consistent,[51] culturally-appropriate,[39] information on topics including treatment options and medication safety.[45, 47] Families also needed information in their preferred language.[47, 48] Families of children with burn injuries wanted to access information in community clinics to decrease the stress and burden of travel and family separation.[39] Other families preferred accessing information in their local communities,[46, 48, 53] including at schools[43] and daycares.[40]

When, for example, seeking healthcare for a child’s wet cough, families wanted to access health information in a variety of modalities, such as flip charts, audio recordings (e.g., wet cough sounds), social media/radio/TV advertisements, and posters in clinic waiting rooms.[40] Some families suggested using text messaging to allow timely answers from healthcare providers.[40] Parents wanted instructions on navigating online health information to help identify credible sources.[15, 56] Families of children with asthma expressed a need for an online repository with up-to-date, applicable information.[44]

Peer support through informal learning opportunities, such as parents gathering to socialize and share questions, thoughts, ideas, stories, and details about (in)effective approaches, may help improve access to information.[42, 44, 51] Families reported having knowledge and information to care for their sick children is critical to health-related quality of life [49] and affects whether they seek and/or receive appropriate healthcare for their children.[40]

Improved Communication and Relationships with Healthcare Providers

Ten papers reported the need for better communication with healthcare providers.[42, 45-47, 49, 52-56] Parents understood that healthcare providers cannot always answer their questions, but they wanted honest information and realistic expectations about caring for their children.[56] Strong and respectful communication between families and healthcare providers was reported as essential to effectively and meaningfully navigating the healthcare system and ensuring children receive the best possible care.[49]

Parents wanted to be listened to by healthcare providers [52, 53, 56] and to build trusting relationships across multiple visits.[46, 53, 54] For example, mothers shared that having healthcare providers listen to them validated their concerns, and having healthcare providers acknowledge their expertise and insights as parents contributed to building relationships and positive interactions.[52] Another study shared how Elders believe that being listened to is part of healing.[48]

Families felt more confident caring for their children's health when anticipatory guidance (e.g., what to expect) and collaborative care (e.g., holding children during painful procedures, being involved in decisions about their children's health) were available.[52, 54, 55] Families also wanted healthcare providers to recognize that their information needs change depending on the stage of a child's illness; parents seek information at diagnosis, but desire a more collegial partnership once they have experience managing their children's care.[56] Strong and respectful communication not only promotes positive interactions with health services, but provides a path for knowledge acquisition which ultimately affects health and well-being.[49]

Culturally Safe Healthcare

Eleven articles emphasized the importance of providing culturally safe care, including the ability to understand, respect, and engage with Indigenous families' beliefs and experiences of health, healing, and illness, as well as recognizing the detrimental effects of colonization, racism, and prejudice on healthcare behaviours and experiences.[39, 41, 42, 46-48, 51, 52, 54-56] Families wanted healthcare providers to have more awareness and understanding about the importance of connections to extended families and communities.[39] Parents reported they feel safe in their communities and prefer to seek care there.[48]

Families in several studies described the importance of access to culturally appropriate health information [39, 41, 42, 51] and wanted healthcare providers to acknowledge the role of traditional medicines and ceremonies in promoting health.[54] For example, families living in remote Australian Aboriginal communities highlighted the benefits of traditional 'bush medicine' in treating their children's skin infections.[47] Families wanted the option to connect with Elders, traditional medicines, or ceremonies in healthcare settings.[42, 44, 51, 52, 54, 55,] Although healthcare providers may not be able to incorporate traditional Indigenous medicines and healing practices into treatment plans, parents wanted them to respect their roles in health and healing and direct parents to appropriate cultural resources.[47, 52] Cultural health is important for health and well-being and can go beyond practice and ceremony to focus on identity and one's place in the world.[49] It is important for families to have access to Indigenous healthcare workers/liaisons/peers who can communicate information needs, support outreach activities, and/or build relationships with healthcare providers.[39, 40, 42, 46, 51, 52, 54-56]

Discussion

Our findings reveals a critical gap in the child health information available to Indigenous families. Families act as facilitators, coordinators, caregivers, and advocates,[56] often putting children's health needs above their own.[15] Strategies to improve information available to Indigenous families cannot be developed without learning from families' experiences. Because responsibility for finding this information should not rest solely with Indigenous families, we focus our discussion on actions that healthcare providers, organizations, and researchers can take to improve Indigenous families' access to meaningful child health information.

Our findings show that healthcare providers are key sources of health information for Indigenous families, in line with extant literature.[57, 58] While difficulties accessing information can be experienced by non-Indigenous families from different racial backgrounds,[59] these barriers are intensified for Indigenous families.[39] Our scoping review highlights actions that individual healthcare providers can take: listening to patients/families, including them in decision-making, providing honest information and answers, and sharing information within families' communities. This may not require spending more time providing care rather, using time differently (e.g., acknowledging that people are doing their best in overwhelming situations) is a critical part of equity-orientated care.[60] Many healthcare providers lack training in culturally informed approaches.[61] Healthcare providers must be open to lifelong learning, including critical self-reflection on their professional role and institutional power in contributing to culturally (un)safe care.[62] Nevertheless, critical changes to organizational structures, policies and practices are also needed to support equitable information access[60]

Social, economic, and political circumstances influence parenting.[51] Ensuring safety in seeking health information requires moving beyond the patient-provider relationship and challenging the structural and systemic causes of colonial-based racism in health.[63] Health literacy is a central focus of the U.S. Healthy People 2030 framework[64] including organizational health literacy, which is how organizations equitably empower individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. A commitment to organizational health literacy requires infrastructure that supports respectful, relevant, reciprocal, and responsible processes[65] to co-create child health information *with* Indigenous families to ensure it reflects their experiences, needs, and preferences.[66] Furthermore, it requires investment to increase representation of Indigenous clinicians and provide anti-racist training for all healthcare providers.[61]

The provision of culturally-safe care is mandated through the Truth and Reconciliation Commission's Calls to Action,[1] and the United Nations Declaration on the Rights of Indigenous Peoples.[67] Colonialism deeply embedded structural segregation in institutions, including residential schools and hospitals, creating health inequities and a decline in overall health of Indigenous people.[68] The legacy of colonization lives on through people's thoughts, behaviours, actions, and relationships,[69] and communities are still healing from this ongoing trauma. Indigenous families' information needs cannot be understood without also recognizing the effects of colonialism in shaping perceptions and decisions.[12]

Indigenous people cite racism as a common reason for mistrusting healthcare providers;[70] impacts of racism are reflected in the majority of included papers.[39-42, 45-50, 52-55] Racism is 'a system of beliefs (racial prejudices), practices (racial discrimination), and policies based on individuals' presumed race, which operates to advantage those with historical power in most Western nations'.[61] Racism operates systemically and permeates healthcare through power and resource imbalances that lead to inequitable and unfair treatment of Indigenous peoples through laws, policies, rules, and regulations.[62, 63, 71] Within these systems are individual implicit biases, attitudes, and beliefs about race, ethnicity, and other characteristics that operate outside a person's conscious awareness[72] and underlie most aspects of racism. Many of the barriers identified in our scoping review (e.g., lack of culturally appropriate health information, no access to translated health information, stereotypical assumptions) contribute to unsafe spaces that limit access to child health information, further reinforcing racism.[39, 73] Moreover, our scoping review reveals a lack of studies in Canada focused on the distinct experiences of Métis or Inuit families, which aligns with the limited health research available for these populations.[69, 74-77]

The *way* we create and share knowledge matters;[78, 79] researchers have a role in embedding strengths-based and decolonizing approaches into the development and dissemination of child health information for Indigenous families. Decolonizing approaches involve creating spaces for prioritizing Indigenous perspectives and goals,[80] and developing a better understanding of the problems faced by Indigenous parents in the healthcare system and how some stories remain dominant (e.g., those that maintain existing power dynamics) while others remain marginal.[81] Moreover, incorporating an intersectionality lens, which promotes the understanding that people are shaped by different social statuses or categories (e.g., gender, race, Indigeneity, class), may help reach families who experience geographic and/or systemic barriers, such as racism and colonialism, or refuse to engage after experiencing unresponsive or disrespectful care.[82]

Community-based participatory research (CBPR) prioritizes the development of culturally-centred research designs [83] and promotes a strengths-based narrative. Knowledge translation (KT) is ‘a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system’.[84] Using integrated KT [85] approaches that recognize, respect and build on pre-existing knowledge systems is fundamental to decolonization.[9] Although integrated KT and CBPR open the door to co-create child health information with Indigenous families, it is important for researchers to acknowledge that co-creation along two epistemologies and ontologies may not result in neatly packaged resources. In some cases, they cannot be reconciled and must remain two perspectives.[86] Ermine [86] explored the idea of an ‘ethical space’ (or neutral zone) which is formed when societies with contrasting worldviews are poised to engage each other. Conversations can involve issues like language, distinct histories, knowledge traditions, values, and social, economic, and political realities and how these issues impact and influence agreements to interact.[86] Interactions in this space have not received adequate attention in KT scholarship.[87] Researchers must be aware of power in research relationships and work with families to find strategies that respectfully and meaningfully equalize relationships [87] to create useful child health resources.

Strengths and Limitations

Given the complex nature of accessing health information and the various ways this access is defined or understood, we may have missed studies relevant to our review. However, a strength of this review is the involvement of an academic librarian with significant expertise in creating robust search strategies for Indigenous-focused research. Another strength is that multiple reviewers were involved in screening and data extraction.[24, 25] We only included literature published in English due to budget and time restrictions, which may impact comprehensiveness and generalizability. Methodological quality/risk of bias of individual studies was not assessed, however this is consistent with methodological guidance.[31]

Conclusion

Health information is a fundamental component of high-quality healthcare. Results of our scoping review indicate that Indigenous families perceive they do not have access to necessary information to care for sick children, which can lead to insensitive, ineffective and unsafe healthcare. Additionally, there is a critical gap in understanding the information needs and preferences of Indigenous families when making decisions about children's health. Strategies to improve information available to Indigenous families cannot be developed without learning from families' experiences and the responsibility for finding this information should not rest solely with Indigenous families. Our findings will inform the adaptation of a child health resource for Red River Métis families in Canada. Future research is needed on the co-creation of information with Indigenous families and communities to expose and challenge existing colonial processes that are perpetuating inequitable access to child health information. This research must be supported at an organizational level to translate findings and address diverse child healthcare information needs and preferences for Indigenous families.

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Table 3.1: Included articles

<table>
<tr><td>n=19 articles</td><td colspan="6">All included articles employed a qualitative design. One article was a dissertation (Bell, 2015) and the rest were journal articles. A more detailed version of this Table with additional study information (e.g., participant numbers, gender, child health area, home/healthcare setting, how information was accessed, identified barriers/facilitators) is in Supplementary File 4, .</td></tr>
<tr><td>Author</td><td>Year</td><td>Study Purpose</td><td>Country of Study</td><td>Data Collection Method</td><td>Indigenous Group of Interest</td><td>Description of Family Member Participants</td></tr>
<tr><td>Amgarth-Duff et al. [47]</td><td>2019</td><td>Explore the attitudes and practices of Aboriginal parents/carers, healthcare practitioners and service providers regarding skin infection treatments and document their perspectives, preferences and the perceived barriers and enablers to treatment.</td><td>Australia</td><td>interviews, focus groups</td><td>Australian Aboriginal</td><td>mother, auntie, uncle</td></tr>
<tr><td>Bell[45]</td><td>2015</td><td>Understand Indigenous contexts and perceptions of risk for respiratory illness in Indigenous children.</td><td>Australia</td><td>focus groups, yarning</td><td>Australian Aboriginal, Torres Strait Islanders, neither (but identifies as Indigenous)</td><td>parent, guardian</td></tr>
<tr><td>Butten et al.[49]</td><td>2020</td><td>Gather Australian Aboriginal and Torres Strait Islander parent/carer perspectives of health-related quality of life in children to inform the development of a culturally informed tool.</td><td>Australia</td><td>yarning circles and face to face interviews</td><td>Australian Aboriginal, Torres Strait Islander</td><td>mother, father and carer</td></tr>
<tr><td>Coombes et al.[39]</td><td>2020</td><td>Report the barriers or facilitators to culturally safe and appropriate burn aftercare experienced by children and their families.</td><td>Australia</td><td>interviews</td><td>Australian First Nations</td><td>mother, father, auntie, cousin, grandparent, sibling</td></tr>
<tr><td>Docherty et al.[50]</td><td>2007</td><td>Explore the influence of poverty on the parenting experience and maternal developmental trajectory of Lumbee mothers with medically fragile infants.</td><td>United States</td><td>interviews</td><td>American Indian (Lumbee Indian)</td><td>mother</td></tr>
<tr><td>D'Sylva et al.[40]</td><td>2019</td><td>Identify barriers to and enablers for seeking medical help for chronic wet cough in Aboriginal children.</td><td>Australia</td><td>interviews, focus groups</td><td>Australian Aboriginal</td><td>parent/carer (father, mother, grandmother)</td></tr>
<tr><td>Eni and Rowe[51]</td><td>2011</td><td>Provide a knowledge base for First Nations communities to develop health promotion programs to meet the health needs of pregnant women and young families.</td><td>Canada</td><td>interviews</td><td>First Nations</td><td>mother, father, step-father, uncle, grandparent</td></tr>
<tr><td>Hendrickx et al.[46]</td><td>2020</td><td>Explore factors that affected health service utilization for childhood skin infections in remote Aboriginal communities.</td><td>Australia</td><td>interviews, focus groups</td><td>Australian Aboriginal, Martu</td><td>mother, auntie, uncle</td></tr>
</table>

Henry[56]	2008	Report experiences and perceptions from Māori parents/caregivers/whanau on the coordination of care for their technology dependent child.	New Zealand	interviews	Māori	parent/caregiver
Kealoha & Kataoka-Yahiro[44]	2017	Explore contemporary native Hawaiian parents' perspective and experience of caring for their children with asthma in the context of uncertainty.	United States	focus groups	Native Hawaiian	mother, father
Kealoha et al.[43]	2019	Explore native Hawaiian parents' perspective and experience of caring for their children with asthma.	United States	focus groups	Native Hawaiian	mother, father
Latimer et al.[48]	2020	Gather First Nation communities' perspectives related to pain expression, care experiences and strategies to improve the healthcare encounter.	Canada	interviews	First Nations, Mi'kmaw and Wolastoqey First Nations	parent
Rempel et al.[15]	2016	Investigate the health literacy skills and health information needs of young First Nations mothers.	Canada	interviews	First Nations	mother
Rose and Garwick[41]	2003	Identify barriers to effective management of childhood asthma as perceived by urban American Indian family caregivers.	United States	interviews	American Indian (Ojibwe)	mother, auntie, grandmother
Stewart et al.[42]	2013	Assess the health and healthcare inequities experienced by Aboriginal children with respiratory conditions and their parents.	Canada	individual interview, group interviews	First Nations, Métis	mother, father, guardian, grandparent, aunt
Wright et al.[53]	2019	Explore the experiences of Indigenous mothers who select and use early childhood development services.	Canada	interviews, discussion groups (member checking)	First Nations, Métis, Not sure of specific Indigenous identity	mother
Wright et al.[52]	2019	Understand how Indigenous mothers living in urban areas experience selecting and using primary healthcare services to meet the health needs of their infants.	Canada	interviews, discussion groups (member checking)	First Nations, Métis, Not sure of specific Indigenous identity	mother
Wright et al.[55]	2019	Understanding the experiences of Indigenous mothers selecting and using acute healthcare services for their infants.	Canada	interviews, discussion groups (member checking)	First Nations, Métis, Not sure of specific Indigenous identity	mother
Wright et al.[54]	2020	Understand how Indigenous mothers experience accessing and using the health care system for their infants within a neonatal intensive care unit.	Canada	interviews, discussion groups (member checking)	First Nations	mother

Table 3.2: Number of articles per year and country

Year	**Number of Articles**	**Country**
2003	1	US
2004	0	
2005	0	
2006	0	
2007	1	US
2008	1	New Zealand
2009	0	
2010	0	
2011	1	Canada
2012	0	
2013	1	Canada
2014	0	
2015	1	Australia
2016	1	Canada
2017	1	US
2018	0	
2019	6	Canada (n=3), Australia (n=2), US (n=1)
2020	5	Canada (n=2), Australia (n=3)

Table 3.3: Barriers and Facilitators

Barriers (n = no. of papers)	**Facilitators** (n= no. of papers)
Racism and discrimination during healthcare visits (n=14)	*Easily accessible information (n=15)*
Feeling misunderstood, marginalized, disrespected,[45] judged.[49, 52, 55] Treated differently.[40, 48, 50] Experiences of prejudice views,[41, 46] racism or discrimination,[39, 42, 45, 48, 50, 54, 55] unwelcoming, run-down clinics.[52]	Easy access to information that is: consistent,[49] about medicines and treatments,[45, 47, 51, 56] culturally appropriate,[39] clear,[47] in preferred language,[47, 48] on how to find online information.[15, 56]
Lack of access to: healers/traditional care providers,[41] traditional medicines,[53] cultural understanding,[41, 45, 54] culturally appropriate information,[39, 42] or information in preferred language.[46, 47, 48]	Information/care available closer to home,[43] within local community,[46, 48, 53] in community clinics,[39] schools,[43] daycare,[40] peer support.[42, 44, 51]
	Information in multiple formats: social media,[40, 56] websites,[56] online repository,[44] flip charts, audio radio/TV, posters,[40] written,[39] illustrated, [47] text-messaging.[55]
Ineffective communication by healthcare providers (HCP) (n=14)	*Improved communication and relationship with healthcare providers (HCP) (n=10)*
Poor communication/relationship with HCP.[45, 48, 56] Talking with multiple HCP,[50] lack of continuity and limited time with HCP,[41] do not feel listened to,[52, 54] not included in treatment decision-making,[47] inadequate/unclear information,[41] medical jargon,[39, 42, 47, 48, 50] conflicting advice.[42]	HCP empowers families with information,[45] provides anticipatory guidance, acknowledges family concerns and involves parents in collaborative care,[52, 54, 55] recognizes parents' information needs at different stages,[56] tailors health teachings to parents' preferences,[53] values parents as experts of their own children.[52]
Lack of information on: emotions families may go through,[39] medicines,[42, 46] what to expect,[52] treatment options,[46] asthma,[42, 43, 44, 45] allergies, [42] respiratory infections,[45] discharge instructions,[39, 40, 49, 56] recognizing trustworthy online information.[15]	Communication is clear,[47] respectful and appropriate. [49] Parents feel heard and listened to by HCP.[52, 56] Trusting relationship developed through honesty (e.g., HCP say if they don't know something),[56] and consistent care.[46, 53, 54]
Structural (n=10)	*Culturally safe health care (n=11)*
Geographical: information/care not available closer to home.[39, 42, 43, 46, 48, 50, 51] Lack of transport/parking costs to access care.[39, 41, 42, 52, 55]	Access to culturally appropriate information (e.g., how traditional medicines would interact with prescribed medications),[39, 41, 42, 46, 47, 52,] information on accessing cultural resources in their community,[44, 50, 52, 54,] and is respectful of traditional Indigenous medicine place in health and healing.[47, 52]

Health System: walk-in clinic charges,[52, 55] medication costs.[41, 42]	Offer opportunities to connect with someone families can identify with (e.g., similar cultural background) [56]: education programs delivered by Indigenous peers and health professionals,[42] access to Indigenous health staff and Elders.[39, 40, 46, 51, 54]
Limited/unreliable access to internet or phone service.[41, 42] Lack of child care, work schedule conflicts with accessing health care.[42]	HCP demonstrate culturally secure practices [56] and have knowledge on creating safe-spaces [48]: welcoming health care environment [42, 52] (e.g., display diverse art work and languages in clinic space),[52] use strengths-based approaches,[47] ask about parents' community, cultural and spiritual needs,[54] offer support that considers how contextual factors (historical trauma, social inequities) impact health behavior.[53, 54]

Table 3.4

Supplemental File 1. Eligibility Criteria

	Eligibility Criteria
Participants	Indigenous families (parents, relatives, guardians) of children aged 0-21 years within Canada, Australia, Aotearoa New Zealand, and the United States. We recognize that there is great diversity among and within different Indigenous groups. For the purpose of this scoping review we wanted to include countries which share familiar stories of colonialism, systemic racism, social exclusion, geographic dislocation and cultural persecution that have had lasting impact on the health and social inequities that persist between Indigenous and non-Indigenous populations.
Concept	Peer-reviewed and grey literature (that refers to a completed study) on the experiences of families seeking health information (e.g., verbal, online or print information, materials or resources) when their child is unwell or injured, as part of a healthcare encounter or independent of this.
Context	Within child health (excluding maternal/antenatal care) and includes experiences of Indigenous families seeking health information at home, in hospital or other healthcare setting.

Table 3.5 (Supplemental File 2). Search Strategies

Medline

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to April 08, 2021>
Search Strategy:
----

1 exp indigenous peoples/ or american native continental ancestry group/ or alaska natives/ or indians, north american/ or inuits/ or Oceanic Ancestry Group/ (28685)

2 (Indigenous or First Nations or First Nation or Inuit* or metis or Aboriginal or Native American* or alaska native* or (Alaska* adj1 Native*) or Ojibw* or Cree or Athapaskan or Athabaskan or Athabascan or Saulteau* or Wakashan or Dene or Inuk or Tlicho or Haida or Ktunaxa or Tsimshian or Gitsxan or Nisga'a or Haisla or Heiltsuk or Oweenkeno or Kwakwaka'wakw or Nuu chah nulth or Tsilhqot'in or Dakelh or Wet'suwet'en or Sekani or Dunne-za or Dene or Tahltan or Kaska or Tagish or Tutchone or Nuxalk or Salish or Stl'atlimc or Nlaka'pamux or Okanagan or Sec wepmc or Tlingit or Anishinaabe or Anishinabe or Blackfoot or Nakoda or Tasttine or TsuuT'ina or Gwich'in or Tagish or Tutchone or Algonquin or Algonkian or Nipissing or Kahnawake or Mohawk* or Cherokee or Potawatomi or Innu or Maliseet or Mi'kmaq or Passamaquoddy or Haudenosaunee or Cayuga or Lakota or Navajo or Zuni or Hopi or Oneida or Onondaga or Seneca or Tuscarora or Wyandot or Indigeneity or Nunavut* or Iqaluit* or Nunavummiut or Kitikmeot or Kivalliq or qikiqtani or Baffin or Kuujjuaq or Inuvialuit or Nunavik or nunatsiavut or Inupiat or inupiaq or innu or yupik or Yellowknife or northwest territories or Yukon or Whitehorse or Fairbanks or quajigiartiit or eskimo* or maori* or torres strait island* or koori or goori or murri or nyoongah or Nyoongar or Noongar or Nyunga* or koorie or yolngu or Anangu or palawa or nunga or Ngarrindjeri or murray island or mer island or american Indian* or aborigine* or indigen* or Hawaii* or ha waii* or Menominee or Ahousat or Apache tribe or Arapahoe or Bella Coola or Paiute or Shoshone or Blackfeet or Cherokee or Cheyenne or Sioux or Siouan or Choctaw Indian* or Choctaw Nation* or Comanche nation or Kootenai Tribes or Dogrib or Flathead Nation or Flathead Reservation or Havasupai or Pima or Tohono O'odham).mp. (87508)

3 Health Services, Indigenous/ (3444)

4 1 or 2 or 3 (94285)

5 exp adolescent/ or exp child/ or exp infant/ or (infant disease* or childhood disease*).ti,ab,kf. or (adolescen* or babies or baby or boy? or child* or girl? or infant* or juvenil* or kid? or minors or minors* or neonat* or neonat* or newborn* or new-born* or paediatric* or pediatric* or pediatric* or perinat* or preschool* or puber* or pubescen* or school* or teen* or toddler? or underage? or under-age? or youth* or offspring).ti,ab,kf. (4619357)

6 (parent* or family or families or guardian* or mother* or father* or grandparent* or grandmother* or grandfather* or carer* or caregiver* or lay person* or lay people* or lay man*).ti,ab,kf. (1584278)
7 consumer health information/ or health literacy/ or patient education as topic/ or teach-back communication/ (95298)
8 information seeking behavior/ or literacy/ or consumer behavior/ (25759)
9 exp access to information/ or exp patient rights/ or right to health/ or patient advocacy/ or help seeking behavior/ (104823)
10 communication/ or exp communication barriers/ or exp computer literacy/ or exp disclosure/ or exp health communication/ or exp information dissemination/ or exp information literacy/ or internet access/ or "internet use"/ or exp social networking/ (152801)
11 publications/ or pamphlets/ or information services/ or exp library services/ (27486)
12 exp Communications Media/ (341444)
13 exp attitude to health/ or health knowledge, attitudes, practice/ or "patient acceptance of health care"/ or patient participation/ or exp patient satisfaction/ (432949)
14 exp Health Services Accessibility/ (115530)
15 exp "Quality of Health Care"/ or Cultural Competency/ (7213498)
16 professional-patient relations/ or duty to recontact/ or nurse-patient relations/ or physician-patient relations/ (135466)
17 hospital records/ or exp medical records/ or nursing records/ or disease notification/ (161991)
18 (disclos* or navigat* or discharge* or website* or web site* or book or books or library or libraries or blog* or support group* or peer* or social media or app or apps or phone* or telephone* or smartphone* or iphone* or android or mobile device* or podcast* or youtube or video or videos or videorecording* or audiovisual or Online or internet or facebook or written or writing or advice or helpline* or hotline* or leaflet* or brochure* or instruction* or information or pamphlet* or booklet*).ti,ab,kf. (2418553)
19 or/7-18 (9186346)
20 health services/ or adolescent health services/ or exp child care/ or exp community health services/ or exp emergency medical services/ or health services for persons with disabilities/ or exp mental health services/ or exp nursing care/ or exp nursing services/ or exp patient care/ or exp patient escort service/ or exp personal health services/ or exp pharmaceutical services/ or exp rehabilitation/ or exp rural health services/ or exp urban health services/ (1660564)
21 (hospitaliz* or hospitalis*).ti,ab,sh. (325343)
22 20 or 21 (1827064)
23 4 and 5 and 6 and 19 and 22 (1117)
24 limit 23 to english language (1100)
25 limit 24 to yr="1860 -Current" (1100)

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EMBASE

Database: Embase <1974 to 2021 Week 13>
Search Strategy:
----
1 indigenous people/ or alaska native/ or american indian/ or canadian aboriginal/ or first nation/ (26950)
2 eskimo/ or eskimo-aleut people/ or exp inuit/ or "yupik (people)"/ (2899)
3 native hawaiian/ (781)
4 "hawaiian (citizen)"/ or polynesian/ (234)
5 indigenous australian/ (1063)
6 "maori (people)"/ (1087)
7 exp oceanic ancestry group/ (7434)
8 (Indigenous or First Nations or First Nation or Inuit* or metis or Aboriginal or Native American* or alaska native* or (Alaska* adj1 Native*) or Ojibw* or Cree or Athapaskan or Athabaskan or Athabascan or Saulteau* or Wakashan or Dene or Inuk or Tlicho or Haida or Ktunaxa or Tsimshian or Gitsxan or Nisga'a or Haisla or Heiltsuk or Oweenkeno or Kwakwaka'wakw or Nuu chah nulth or Tsilhqot'in or Dakelh or Wet'suwet'en or Sekani or Dunne-za or Dene or Tahltan or Kaska or Tagish or Tutchone or Nuxalk or Salish or Stl'atlimc or Nlaka'pamux or Okanagan or Sec wepmc or Tlingit or Anishinaabe or Anishinabe or Blackfoot or Nakoda or Tasttine or TsuuT'ina or Gwich'in or Tagish or Tutchone or Algonquin or Algonkian or Nipissing or Kahnawake or Mohawk* or Cherokee or Potawatomi or Innu or Maliseet or Mi'kmaq or Passamaquoddy or Haudenosaunee or Cayuga or Lakota or Navajo or Zuni or Hopi or Oneida or Onondaga or Seneca or Tuscarora or Wyandot or Indigeneity or Nunavut* or Iqaluit* or Nunavummiut or Kitikmeot or Kivalliq or qikiqtani or Baffin or Kuujjuaq or Inuvialuit or Nunavik or nunatsiavut or Inupiat or inupiaq or innu or yupik or Yellowknife or northwest territories or Yukon or Whitehorse or Fairbanks or quajigiartiit or eskimo* or maori* or torres strait island* or koori or goori or murri or nyoongah or Nyoongar or Noongar or Nyunga* or koorie or yolngu or Anangu or palawa or nunga or Ngarrindjeri or murray island or mer island or american Indian* or aborigine* or indigen* or Hawaii* or ha waii* or Menominee or Ahousat or Apache tribe or Arapahoe or Bella Coola or Paiute or Shoshone or Blackfeet or Cherokee or Cheyenne or Sioux or Siouan or Choctaw Indian* or Choctaw Nation* or Comanche nation or Kootenai Tribes or Dogrib or Flathead Nation or Flathead Reservation or Havasupai or Pima or Tohono O'odham).ti,ab. (91768)
9 indigenous health care/ (950)
10 or/1-9 (102877)

11 exp adolescence/ or exp adolescent/ or exp child/ or exp childhood disease/ or exp infant disease/ or (adolescen* or babies or baby or boy? or child or child* or children* or girl? or infant* or juvenil* or juvenile* or kid? or minors or minors* or neonat* or neonat* or newborn* or new-born* or paediatric* or peadiatric* or pediatric* or perinat* or preschool* or puber* or pubescen* or school or school child* or school* or schoolchild* or schoolchild* or teen* or toddler? or underage? or under-age? or youth* or offspring).ti,ab,kw,hw. (5626772)

12 (parent* or family or families or guardian* or mother* or father* or grandparent* or grandmother* or grandfather* or carer* or caregiver* or lay person* or lay people* or lay man*).ti,ab,kw,hw. (2185501)

13 information/ or consumer health information/ or drug information/ or information center/ or information literacy/ or information seeking/ or information service/ or library/ or medical information/ or exp misinformation/ or patient information/ or publication/ or visual information/ or health literacy/ (386584)

14 access to information/ or digital divide/ or internet access/ (21784)

15 exp patient right/ (170826)

16 exp health care access/ (67186)

17 patient advocacy/ (22265)

18 help seeking behavior/ (12487)

19 interpersonal communication/ or "cell phone use"/ or exp communication barrier/ or exp verbal communication/ (478263)

20 exp mass communication/ (587973)

21 attitude to health/ (117011)

22 patient attitude/ or patient participation/ or patient preference/ or patient satisfaction/ (253476)

23 health care quality/ or health care survey/ or "quality of nursing care"/ (265084)

24 cultural competence/ (6970)

25 exp professional-patient relationship/ (49192)

26 exp medical record/ (265836)

27 (disclos* or navigat* or discharge* or website* or web site* or book or books or library or libraries or blog* or support group* or peer* or social media or app or apps or phone* or telephone* or smartphone* or iphone* or android or mobile device* or podcast* or youtube or video or videos or videorecording* or audiovisual or Online or internet or facebook or written or writing or advice or helpline* or hotline* or leaflet* or brochure* or instruction* or information or pamphlet* or booklet*).ti,ab,kw,hw. (3813599)

28 or/13-27 (5055975)

29 10 and 11 and 12 and 28 (2981)

30 exp "health care facilities and services"/ (6551961)

31 (hospitaliz* or hospitalis*).ti,ab,kw,hw. (639483)

32 30 or 31 (6811693)

33 29 and 32 (1491)

34 limit 33 to (article or article in press or conference abstract or conference paper or "review") (1472)

35 limit 34 to english language (1461)

36 limit 35 to yr="1883 -Current" (1460)

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PsycINFO

Database: APA PsycInfo <1806 to April Week 1 2021>
Search Strategy:
----

1 exp Indigenous populations/ or alaska natives/ or american indians/ or inuit/ (14144)

2 Hawaii*.mp. (3617)

3 (Indigenous or First Nations or First Nation or Inuit* or metis or Aboriginal or Native American* or alaska native* or (Alaska* adj1 Native*) or Ojibw* or Cree or Athapaskan or Athabaskan or Athabascan or Saulteau* or Wakashan or Dene or Inuk or Tlicho or Haida or Ktunaxa or Tsimshian or Gitsxan or Nisga'a or Haisla or Heiltsuk or Oweenkeno or Kwakwaka'wakw or Nuu chah nulth or Tsilhqot'in or Dakelh or Wet'suwet'en or Sekani or Dunne-za or Dene or Tahltan or Kaska or Tagish or Tutchone or Nuxalk or Salish or Stl'atlimc or Nlaka'pamux or Okanagan or Sec wepmc or Tlingit or Anishinaabe or Anishinabe or Blackfoot or Nakoda or Tasttine or TsuuT'ina or Gwich'in or Tagish or Tutchone or Algonquin or Algonkian or Nipissing or Kahnawake or Mohawk* or Cherokee or Potawatomi or Innu or Maliseet or Mi'kmaq or Passamaquoddy or Haudenosaunee or Cayuga or Lakota or Navajo or Zuni or Hopi or Oneida or Onondaga or Seneca or Tuscarora or Wyandot or Indigeneity or Nunavut* or Iqaluit* or Nunavummiut or Kitikmeot or Kivalliq or qikiqtani or Baffin or Kuujjuaq or Inuvialuit or Nunavik or nunatsiavut or Inupiat or inupiaq or innu or yupik or Yellowknife or northwest territories or Yukon or Whitehorse or Fairbanks or quajigiartiit or eskimo* or maori* or torres strait island* or koori or goori or murri or nyoongah or Nyoongar or Noongar or Nyunga* or koorie or yolngu or Anangu or palawa or nunga or Ngarrindjeri or murray island or mer island or american Indian* or aborigine* or indigen* or Hawaii* or ha waii* or Menominee or Ahousat or Apache tribe or Arapahoe or Bella Coola or Paiute or Shoshone or Blackfeet or Cherokee or Cheyenne or Sioux or Siouan or Choctaw Indian* or Choctaw Nation* or Comanche nation or Kootenai Tribes or Dogrib or Flathead Nation or Flathead Reservation or Havasupai or Pima or Tohono O'odham).mp. (34036)

4 or/1-3 (34481)

5 adolescent development/ or childhood development/ or pediatrics/ or exp Congenital Disorders/ or child characteristics/ or child abuse/ or exp child welfare/ or chronically ill children/ or child neglect/ or child psychiatry/ or child psychopathology/ or exp child care/ or (pediatric* or paediatric* or child* or newborn* or congenital* or infan* or baby or babies or neonat* or pre term or preterm* or premature birth or NICU or preschool* or pre school* or kindergarten* or elementary school* or nursery school* or schoolchild* or toddler* or boy or boys or girl* or middle school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or prepubesc* or pre pubesc*).mp. or (child* or adolesc* or pediat* or paediat*).jn. (1333345)

6 (parent* or family or families or guardian* or mother* or father* or grandparent* or grandmother* or grandfather* or carer* or caregiver* or lay person* or lay people* or lay man*).mp. (704699)

7 information seeking/ or computer searching/ or health information/ or information literacy/ or exp information services/ (8417)

8 internet/ or exp communication systems/ or exp information systems/ (58088)

9 health knowledge/ or exp health attitudes/ or health awareness/ or mental health literacy/ or exp Health Care Seeking Behavior/ (26594)

10 exp websites/ or exp computer mediated communication/ or exp internet/ or exp social media/ (55478)

11 exp "information and communication technology"/ (179028)

12 4 and 5 and 6 and 11 (28)

13 exp client rights/ or client participation/ or empowerment/ or "quality of care"/ or cultural sensitivity/ or cross cultural communication/ (35273)

14 exp advocacy/ (5331)

15 (disclos* or navigat* or discharge* or website* or web site* or book or books or library or libraries or blog* or support group* or peer* or social media or app or apps or phone* or telephone* or smartphone* or iphone* or android or mobile device* or podcast* or youtube or video or videos or videorecording* or audiovisual or Online or internet or facebook or written or writing or advice or helpline* or hotline* or leaflet* or brochure* or instruction* or information or pamphlet* or booklet*).mp. (1216333)

16 or/7-15 (1318393)

17 4 and 5 and 6 and 16 (1648)

18 exp health care services/ or integrated services/ or exp mental health programs/ or outreach programs/ or "quality of care"/ or "quality of services"/ or self-referral/ (227782)

19 (hospitaliz* or hospitalis*).mp. (69012)

20 18 or 19 (283768)

21 17 and 20 (181)

22 limit 21 to (bibliography or chapter or clarification or "column/opinion" or "comment/reply" or editorial or encyclopedia entry or "erratum/correction" or letter or obituary or poetry or publication information or retraction or review-book or review-media or review-software & other) (17)

23 21 not 22 (164)
24 limit 23 to ("0200 book" or "0280 edited book") (52)
25 23 not 24 (112)
26 limit 25 to english language (112)
27 limit 26 to yr="1860 -Current" (112)

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Scopus (April 12, 2021)

((TITLE-ABS-KEY ({first nation} OR {first nations} OR indigenous OR aboriginal OR metis OR inuit* OR nunavut OR iqaluit OR nunavik OR yukon OR whitehorse OR yellowknife OR {northwest territories} OR {native American} OR {Native Americans} OR {alaska native} OR {Alaska Natives} OR {Alaskan native} OR {Alaskan Natives} OR {native Alaskan} OR {Native Alaskans} OR maori OR {torres strait islander} OR {torres strait islanders} OR {Indians north American} OR {American native continental ancestry group} OR {american Indian} OR {oceanic ancestry group} OR aborigine* OR indigen* OR hawaii* OR {ha waii} OR hawaiian)) AND ((TITLE-ABS-KEY ({consumer health} OR {health literacy} OR communication OR talk* OR disclos* OR navigat* OR discharge* OR {patient education} OR website* OR {web site} OR {web sites} OR book OR books OR library OR libraries OR blog* OR {support group} OR {support groups} OR peer*) OR ABS ({social media} OR app OR apps OR phone* OR telephone* OR smartphone* OR iphone* OR android OR {mobile device} OR {mobile devices} OR podcast* OR youtube* OR video OR videos OR videorecording* OR audiovisual) OR TITLE-ABS-KEY ({physician patient relations} OR {doctor patient relationship} OR {medical information} OR {nurse patient relations} OR {patient record} OR {medical record} OR {health record} OR {patient records} OR {medical records} OR {health records} OR {health communication}) OR ABS (online OR internet OR facebook OR brochure* OR instruction* OR pamphlet* OR written OR writing OR reading OR advice OR helpline* OR hotline* OR leaflet* OR brochure* OR instruction* OR booklet* OR {information seeking} OR {health knowledge} OR {medication knowledge}))) AND (ABS (pediatric* OR paediatric* OR child* OR youth* OR adolescen* OR {young adult} OR {young adults} OR teen* OR offspring)) AND (ABS (parent* OR family OR families OR guardian* OR mother* OR father* OR grandmother* OR grandfather* OR carer* OR caregiver* OR {lay person} OR {lay people} OR {lay person} OR {lay people} OR {lay man}))) AND (TITLE-ABS-KEY (hospital* OR {health care} OR healthcare OR doctor* OR physician* OR clinic* OR nurses OR nursing OR dental OR dentist* OR {oral health} OR {health facility} OR {health facilities} OR outpatient* OR ambulatory OR diagnos* OR illness* OR injur* OR patient* OR inpatient* OR outpatient* OR medical OR medicin* OR {primary care} OR {general practice})) AND (LIMIT-TO (AFFILCOUNTRY,"United States") OR LIMIT-TO (AFFILCOUNTRY,"Australia") OR LIMIT-TO (AFFILCOUNTRY,"Canada") OR LIMIT-TO (AFFILCOUNTRY,"New Zealand")) AND (LIMIT-TO (DOCTYPE,"ar") OR LIMIT-TO (DOCTYPE,"re") OR LIMIT-TO (DOCTYPE,"cp")) AND (LIMIT-TO (LANGUAGE,"English"))

CINAHL on EBSCOhost (April 7, 2021)
(MH "Indigenous Peoples+") OR (MH "Aboriginal Canadians+") OR (MH "Eskimos+") OR (MH "First Nations of Australia+") OR (MH "Maori") OR (MH "Native Americans") OR “first nation” OR “first nations” OR indigenous OR aboriginal OR metis OR inuit* OR Nunavut OR iqaluit OR Nunavik OR Yukon OR Whitehorse OR Yellowknife OR “northwest territories” OR “native American*” OR “alaska native*” OR “Alaskan native*” OR “native Alaskan*” OR maori OR “torres strait islander*” OR “american Indian*” OR aborigine* OR indigen* OR hawaii* OR “ha waii” OR Hawaiian OR (MH "Medicine, Native American") OR (MH "Medicine, Traditional") OR (MH "Health Services, Indigenous")

AND

(MH "Information Resources+") OR (MH "Medical Records+") OR (MH "Health Education+") OR (MH "Telecommunications+") OR (MH "Computers and Computerization+") OR (MH "Professional-Patient Relations+") “consumer health” OR “health literacy” OR communication OR disclos* OR navigat* OR discharge* OR “patient education” OR website* OR “web site*” OR book OR books OR library OR libraries OR blog* OR “support group*” OR peer* OR “social media” OR app OR apps OR phone* OR telephone* OR smartphone* OR iphone* OR android OR “mobile device*” OR podcast* OR youtube OR video OR videos OR videorecording* OR audiovisual OR Online OR internet OR facebook OR brochure* OR instruction* OR pamphlet* OR booklet*

AND

(MH "Parents+") OR (MH "Guardianship, Legal+") OR parent* OR family OR families OR guardian* OR mother* OR father* OR carer* OR caregiver* OR “lay person” OR “lay people” OR “lay man*”

AND

(MH "Adolescence+") OR (MH "Child+") OR (MH "Infant+") OR (MH "Minors (Legal)") OR pediatric* OR paediatric* OR child* OR youth* OR adolescen* OR “young adult*” OR teen* OR offspring

Sources consulted [JL] for keywords and search terms for Indigenous People

Appropriate Terminology, Representations, and Protocols of Acknowledgement for Aboriginal and Torres Strait Islander Peoples. [Internet]. Bedford Park, SA.: Flinders University; 2012. Available from: https://www.flinders.edu.au/content/dam/documents/museum-of-art/obl/multimedia/terminology-representations-and-protocols-yunggorendi.pdf

Campbell, S, Dorgan, M, Tjosvold, L. Rev. March 8, 2016. [Internet]. [Edmonton]: John W. Scott Health Sciences Library, University of Alberta. Available from: https://guides.library.ualberta.ca/health-sciences-search-filters/indigenous-peoples

King, J, Masotti, P, Dennem, J, Hadani, S, Linton, J, Lockhart, B, et al. The Culture Is Prevention Project: Adapting the Cultural Connectedness Scale for Multi-Tribal Communities. Am Indian Alsk Native Ment Health Res. 2019;26(3):104-135. doi:10.5820/aian.2603.2019.104

Lowitja Institute. LIt.Search [Internet]. Carlton South, Vic.: The Lowitja Institute; 2020. Available from: https://www.lowitja.org.au/page/research/lit-search

Native Health Database [Internet]. Albuquerque, NM: University of New Mexico, [nd]. Available from: https://hslic-nhd.health.unm.edu/

Table 3.6 (Supplemental File 3). Google Advance Searches

Google Advanced Searches for Online Grey Literature and Dissertations Key Words and Key Phrases Searched		
	Search **all** of these words [AND]	Search **any** of these words
Search #1	Children "health literacy" parents "hospitalization"	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori
Search #2	Children "health literacy" parents healthcare	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori
Search #3	Children "seeking information" parents "hospitalization"	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori
Search #4	Children "seeking information" parents healthcare	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori
Search #5	Children "seeking information" parents healthcare dissertation	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori
Search #6	Children "health literacy" parents "hospitalization" dissertation	"First Nations" Metis Inuit Indigenous Aboriginal "Native American" "Alaska Native" Maori

Notes: two-word phrases entered with double quotation marks to search as phrase; double quotation marks used on single terms to limit searching for word variations by Google algorithm

Table 3.7 (Supplemental File 4): Detailed version of Table 1: Included Articles

n=19 articles															
Author	**Year**	**Study Purpose**	**Country of Study**	**Publication Type**	**Study Design (approach/theory)**	**Data Collection Method**	**Participants (n=)**	**Indigenous Group of Interest**	**Description of Family Member Participants**	**Gender of Participants**	**Home/ Healthcare Setting**	**Child Health Area**	**How was Information Accessed?**	**Barriers Identified**	**Facilitators Identified**
Amgarth-Duff et al. [47]	2019	Explore the attitudes and practices of Aboriginal parents/carers, healthcare practitioners and service providers regarding skin infection treatments and document their perspectives, preferences and the perceived barriers and enablers to treatment.	Australia	journal article	qualitative (not clear)	interviews, focus groups	48 (15 parents)	Australian Aboriginal	mother, auntie, uncle	not clear	not clear	skin infections	speaking to healthcare professional	language; medical jargon/complex information; lack of clear treatment/medication instructions in preferred language; parents seldom included in treatment decision-making	holistic and culturally appropriate care; more information given on skin health/treating infections; healthcare providers (HCP) acknowledge 'bush' medicine; clear communications; strengths-based approach; clear, illustrated, plain (and Martu) language instructions around treatment options (what the medication is for, how to apply or take it and why it is important)
Bell[45]	2015	Understand Indigenous contexts and perceptions of risk for respiratory illness in Indigenous children.	Australia	dissertation	qualitative (not clear)	focus groups, yarning	24	Australian Aboriginal, Torres Strait Islanders, neither (but identifies as Indigenous)	parent, guardian	female and male	home and hospital	respiratory	speaking to healthcare professional	lack of preventative/public health asthma/respiratory infection education; poor communication/ relationship with healthcare providers (HCP); feeling misunderstood/ marginalized/ disrespected by HCP; HCP unwillingness to discuss traditional medicine; racial stereotyping	courses/workshops on medicines and treatments; empowering families with information and education

Butten et al.[49]	2020	Gather Australian Aboriginal and Torres Strait Islander parent/carer perspectives of health-related quality of life in children to inform the development of a culturally informed tool.	Australia	journal article	qualitative (phenomenology)	yarning circles and face to face interviews	26	Australian Aboriginal, Torres Strait Islander	mother, father and carer	female and male	not clear	chronic illness	speaking to healthcare professional	not having enough information or resources communicated to them so that they could confidently manage their child's care at home; feeling judged and unable to ask questions or engage with healthcare providers confidently; racism	positive interactions with health services; appropriate and respectful communications that includes a pathway for knowledge
Coombes et al.[39]	2020	Report the barriers or facilitators to culturally safe and appropriate burn aftercare experienced by children and their families.	Australia	journal article	qualitative (Indigenous methods - yarning [dialogue], Dadirri [deep listening])	interviews	59	Australian First Nations	mother, father, auntie, cousin, grandparent, sibling	not clear	hospital inpatient unit	burns	speaking to healthcare professional	medical jargon; lack of discharge information; lack of information on the emotions families may go through; geographical (information not available closer to home, transport/parking costs); racism; culturally unsafe communication	access to written, easily understood and culturally appropriate information; practical information located in community clinics (i.e., less the burden of travel, stress); access to First Nations Health Workers/Liaison Officers; contact person to ask questions once discharged
Docherty et al.[50]	2007	Explore the influence of poverty on the parenting experience and maternal developmental trajectory of Lumbee mothers with medically fragile infants.	United States	journal article	qualitative (case study using secondary data from a longitudinal study)	interviews	5	American Indian (Lumbee Indian)	mother	not clear	hospital inpatient unit	medically fragile	speaking to healthcare professional	communicating with multiple healthcare providers, stigmatizing and labelling by healthcare providers; feeling that being treated differently by healthcare providers medical jargon; geographical/financial barriers to visiting child	emotional support from mother and grandmother

D'Sylva et al.[40]	2019	Identify barriers to and enablers for seeking medical help for chronic wet cough in Aboriginal children.	Australia	journal article	qualitative (participatory)	interviews, focus groups	40	Australian Aboriginal	parent/carer (father, mother, grandmother)	not clear	local clinic, hospital, Aboriginal Medical Service	respiratory	speaking to healthcare professional	lack of discharge information; racism; feel get treated differently than white people; not able to challenge health practitioners if concerns dismissed	healthcare providers give clear health information; provide audio sounds of cough; information format (e.g., poster, pamphlets, flip charts); share information on social media, TV, radio; use local champions to share information - teach at playgroups/day care/early education settings & share information via their newsletters; improve cultural security through Aboriginal workforce
Eni and Rowe[51]	2011	Provide a knowledge base for First Nations communities to develop health promotion programs to meet the health needs of pregnant women and young families.	Canada	journal article	qualitative (Grounded theory)	interviews	96	First Nations	mother, father, step-father, uncle, grandparent	not clear	not clear	parenting	speaking to healthcare professional, website, speaking to family/ friends/ community	lack of/poor quality health education in schools	consistent educational programming; parent group to share information/feast together; incorporate culture, language and heritage in programming; strengthen Elder and youth connections and communication; build on existing strengths

Hendrickx et al.[46]	2020	Explore factors that affected health service utilization for childhood skin infections in remote Aboriginal communities.	Australia	journal article	qualitative (not clear)	interviews, focus groups	56 (16 parents)	Australian Aboriginal, Martu	mother, auntie, uncle	not clear	primary care	skin infections	speaking with health clinic staff	language; negative past experiences in the clinic, fear of judgement; prejudiced views from healthcare providers; treatment options not discussed during consultations; insufficient instructions on medicine use; insufficient knowledge within community on skin infections; lack of community outreach and health promotion activities.	Established relationships with clinic staff; demonstration of culturally secure practices; access to Aboriginal Community Health Workers; prioritizing culturally appropriate education; increase awareness among parents of the importance of skin infections
Henry[56]	2008	Report experiences and perceptions from Māori parents/caregivers/ whanau on the coordination of care for their technology dependent child.	New Zealand	journal article	qualitative (ethnographic)	interviews	8	Māori	parent/ caregiver	not clear	hospital inpatient unit; community-based care	technology-dependent children	speaking to healthcare professional, speaking to Māori whanau worker	structural barriers (e.g., parking); lack of discharge information; differences in communication styles with healthcare providers (HCP)	Accessible information to manage uncertainty; being heard and listened to by HCP, care coordination (e.g., access to key worker with specialist knowledge), cultural values; honesty (HCP saying if they don't know something) to develop trusting relationships; access to someone they can identify with (e.g., similar cultural background); home visits; accessible online information and user skills; connecting through social media and other websites

Kealoha & Kataoka-Yahiro[44]	2017	Explore contemporary native Hawaiian parents' perspective and experience of caring for their children with asthma in the context of uncertainty.	United States	journal article	qualitative (not clear)	focus groups	10	Native Hawaiian	mother, father	female and male	home and primary care	asthma	speaking to health professional, 'ohana (family)	lack of information provided on symptoms, triggers, management, medicines; conventional health education not engaging; multiple socioeconomic factors adversely affected the parent's capacity to process information about asthma (e.g., school/work commitments; feeling overwhelmed)	a central repository containing up-to-date, pertinent asthma information; using cultural healing practices and comfort measures before or with Western medicine; information and support from Elders, 'ohana (large circle of nuclear and extended family members); learning by informally sitting in small group of parents/share stories
Kealoha et al.[43]	2019	Explore native Hawaiian parents' perspective and experience of caring for their children with asthma.	United States	journal article	qualitative (not clear)	focus groups	33	Native Hawaiian	mother, father	female and male	asthma education classes	asthma	speaking to health professional, 'ohana (family), American Lung Association, school personnel, teachers, community, healing practitioner, naturopath	geographical (travel to see pediatrician, specialists or get emergency care); lack of asthma care information	care closer to home; asthma information within schools
Latimer et al.[48]	2020	Gather First Nation communities' perspectives related to pain expression, care experiences and strategies to improve the healthcare encounter.	Canada	journal article	qualitative (interpretive description; Two-Eyed Seeing)	interviews	188 (25 parents)	First Nations, Mi'kmaw and Wolastoqey First Nations	parent	not clear	community health centre	pain	speaking to healer, speaking with healthcare professional	miscommunication or misunderstandings between English and Mi'kmaq language; medical jargon; receiving information in English when first language may be Mi'kmaq; being seen as different people/treated differently; discrimination in the hospital; difficulty describing pain	healthcare providers have cultural sensitivity and knowledge about the community; safe-space; healthcare resources available within local community

Rempel et al.[15]	2016	Investigate the health literacy skills and health information needs of young First Nations mothers.	Canada	journal article	qualitative (participatory, exploratory)	interviews	8	First Nations	mother	female	not clear	not clear	speaking to healthcare professional, speaking to family/ friends, social media, online	lack of confidence in ability to recognize trustworthy online information	instructions in navigating the internet and online information literacy to differentiate credible from less credible websites and information
Rose and Garwick [41]	2003	Identify barriers to effective management of childhood asthma as perceived by urban American Indian family caregivers.	United States	journal article	qualitative (participatory, family-centered care; Bronfenbrenner's ecological model)	interviews	16	American Indian (Ojibwe)	mother, auntie, grandmother	female	clinic, emergency room	respiratory	speaking to healthcare professional	inadequate/unclear information from healthcare provider (HCP); limited time with HCP; lack of continuity with HCP; prejudice from HCP; lack of cultural understanding by HCP; lack of access to healer or traditional care providers; socioeconomic (transport, cost of medications, no phone)	culturally appropriate information
Stewart et al.[42]	2013	Assess the health and healthcare inequities experienced by Aboriginal children with respiratory conditions and their parents.	Canada	journal article	qualitative (participatory)	individual interview, group interviews	132 (76 parents)	First Nations, Métis	mother, father, guardian, grandparent, aunt	female and male	community centre/ event	respiratory	speaking to healthcare professional, emotional and practical support from Elders	stigma of Aboriginal status; lack of community awareness of asthma/allergies; gaps in information about asthma/allergies and how to manage their conditions; medical jargon/complex information by healthcare providers (HCP); lack of information on the short/ long-term side effects of lung inflammation, cause of asthma/allergy triggers; inadequate information about medications, side effects and medication use; education not culturally appropriate; geographical/transport barriers to seeking care; limited access to computers, unreliable internet or phone service; cost (transport, prescriptions), lack of child care, work/other commitments; inaccessible programs to participate in health education; conflicting	peer support in the community; information on how traditional medicines would interact with prescribed medications; access to culturally appropriate education programs delivered by Aboriginal peers and health professionals

														advice from difference HCP; Inadequate educational resources/supports	
Wright et al.[53]	2019	Explore the experiences of Indigenous mothers who select and use early childhood development services.	Canada	journal article	qualitative (interpretive description; Two-Eyed Seeing)	interviews, discussion groups (member checking)	26 (19 parents)	First Nations, Métis, Not sure of specific Indigenous identity	mother	female	mainstream and Indigenous early childhood development services	early childhood development	speaking to healthcare professional; speaking to/texting lay family home visitor; talking to family/ friends/ experienced parents	difficulty obtaining traditional medicines in the city	consistent, long-term and trusting relationship with healthcare providers; holistic approach; information within the community; tailored health teaching and help with transportation barriers
Wright et al.[52]	2019	Understand how Indigenous mothers living in urban areas experience selecting and using primary healthcare services to meet the health needs of their infants.	Canada	journal article	qualitative (interpretive description; Two-Eyed Seeing)	interviews, discussion groups (member checking)	24 (19 parents)	First Nations, Métis, not sure of specific Indigenous identity	mother	female	primary care	primary care	speaking to healthcare professional	unwelcoming, run-down clinic; not getting a same day appointment to see healthcare provider (HCP); feeling judged for Indigenous culture; racism/discrimination; assumptions based on their appearance and/or last name, or for having child at young age); not explaining what to expect; not being listened to	welcoming environment (e.g., display art work and languages of different cultures in clinic space); trusting relationship with the HCP; effective communication (e.g., time to listen, acknowledge concerns, valuating mothers as experts of their own children); female HCP (i.e., trust of women); HCP provides anticipatory guidance/told what to expect, and collaborative care (i.e., engaged in decision making); culturally relevant care; offer links to cultural resources in their community, and respect traditional Indigenous medicine place in health and healing

Wright et al.[55]	2019	Understanding the experiences of Indigenous mothers selecting and using acute healthcare services for their infants.	Canada	journal article	qualitative (interpretive description; Two-Eyed Seeing)	interviews, discussion groups (member checking)	19	First Nations, Métis, not sure of specific Indigenous identity	mother	female	ED, community walk-in clinics, telehealth	acute care	speaking to healthcare professional	financial - charged for walk-in clinic, parking, transport; experiences of racism or discrimination - dissolved feelings of trust of healthcare provider; feeling judged by past history (e.g., substance abuse)	promoting engagement in programming: range of strategies including text-messaging and incentives, use of text-messaging to allow timely answers and confirm appointment times; trusting relationships and anticipatory guidance from healthcare providers; access to Elder, traditional teachings
Wright et al.[54]	2020	Understand how Indigenous mothers experience accessing and using the health care system for their infants within a neonatal intensive care unit.	Canada	journal article	qualitative (interpretive description Two-Eyed Seeing)	interviews, discussion groups (member checking)	5	First Nations	mother	female	hospital inpatient unit, neonatal intensive care unit (NICU)	NICU	speaking to healthcare professional; speaking to family/ friends	experiences of racism, discrimination - more difficult to trust nurses, fear of child apprehension; healthcare provider (HCP) dismissive of traditional medicine; HCP unaware of the historical trauma and social inequities that can impact health behaviors; not being listened to	access to nurses with effective communication skills (e.g., listening, validating concerns) to share worries - build relationships and space to feel comfortable disclosing concerns and needs; being involved in decision-making - build trust with HCP; holistic approach that considers physical, emotional and spiritual needs; HCP support the role of traditional medicines ceremonies in promoting health/link to community resources that can do this; access to an Indigenous person to talk to (e.g., social worker, Elder); support that considers contextual factors (historical trauma, social inequities) that impact health behavior; HCP ask about parents' cultural and spiritual needs and how they can help in addressing them; collaborative decision-making and consistent care

Table 3.8 (Supplemental File 5). Detailed version of Table 3: Barriers and Facilitators

Barriers (n = no. of papers)	**Facilitators** (n= no. of papers)
Racism and discrimination during healthcare visits (n=14)	*Easily accessible information (n=15)*
Feeling misunderstood, marginalized, disrespected by HCP;[45] treated differently;[40, 48, 50] prejudiced views from HCP [41, 46]	Easy access to consistent information to care for their sick child,[49] on medicines and treatments [45, 47, 51, 56]
Unwelcoming, run-down clinics give a feeling that HCP do not care about them [52]	Access to culturally appropriate information [39]
Experiences of racism or discrimination: dissolved feelings of trust of HCP;[54, 55] seen as different people;[48] racial stereotyping/stigma [39, 42, 45, 50]	Information/care available closer to home,[43] within local community,[46, 48, 53] in community clinics,[39] schools,[43] daycare [40]
Feeling judged: for Indigenous culture, appearance and/or last name, for having child at young age, for history of substance abuse [49, 52, 55]	Information in multiple formats - social media,[40, 56] websites,[56] online repository,[44] flip charts, audio radio/TV, posters,[40] written,[39] illustrated,[47] text-messaging [55]
Fearful: of judgement,[46] of child apprehension [54]	Clear information,[47] in preferred language [47, 48]
Lack of access to healers/traditional care providers,[41] traditional medicines [53]	Access information through peer support in the community [42, 44, 51]
Lack of cultural understanding by HCP [41, 45, 54]	Instructions available for finding online information [15, 56]
Lack of culturally appropriate information [39, 42] or information in preferred language [46, 47, 48]	
Ineffective communication by healthcare providers (HCP) (n=14)	*Improved communication and relationship with healthcare providers (HCP) (n=10)*
Poor communication/relationship with HCP [45, 48, 56]	HCP empowers families with information,[45] provides anticipatory guidance and involves parents in collaborative care [52, 54, 55]
HCP gives inadequate/unclear information,[41] uses medical jargon,[39, 42, 47, 48, 50] gives conflicting advice [42]	Communication is clear,[47] respectful and appropriate;[49] HCP recognize parents' information needs at different stages (e.g., diagnosis vs. parent experienced caring for child)[56]

Lack of information provided on the emotions families may go through,[39] medicine use,[42, 46] what to expect,[52] treatment options,[46] asthma care,[42, 43, 44, 45] allergies,[42] preventing respiratory infections;[45] discharge instructions;[39, 40, 49, 56] recognizing trustworthy online information [15]	Parents feel heard and listened to by HCP:[52, 56] HCP acknowledge family concerns,[52, 54] and value parents as experts of their own children [52]
Communicating with multiple healthcare providers,[50] lack of continuity and limited time with HCP,[41] don't feel listened to [52, 54]	HCP tailor health teachings to parents' preferences [53]
Parents seldom included in treatment decision-making [47]	Trusting relationship developed through honesty (e.g., HCP say if they don't know something),[56] and consistent care [46, 53, 54]
Structural (n=10)	*Culturally safe health care (n=11)*
Geographical: information/care not available closer to home,[39, 42, 43, 46, 48, 50, 51] Lack of transport/parking costs to access care [39, 41, 42, 52, 55]	Access to culturally appropriate information (e.g., how traditional medicines would interact with prescribed medications),[39, 41, 42, 46, 47, 52] information on options for cultural resources/support/practices in their community,[44, 50, 52, 54] and respect traditional Indigenous medicine place in health and healing [47, 52]
Health System: charged for going to a walk-in clinic;[52, 55] cost of medications [41, 42]	Culture, language and heritage incorporated into educational programming [51]
Limited access to phone, computers; unreliable internet or phone service [41, 42]	Offer opportunities to families to connect with someone they can identify with (e.g., similar cultural background):[56] Education programs delivered by Indigenous peers and health professionals;[42] Access to Indigenous health staff and Elders [39, 40, 46, 51, 54]
Lack of child care [42]	HCP demonstrate culturally secure practices [56] and have knowledge on creating safe-spaces:[48] HCP use strengths-based approaches,[47] ask about parents' community, cultural and spiritual needs and how they can help in addressing them,[54] offer support that considers how contextual

	factors (historical trauma, social inequities) impact health behavior [53, 54]
Work schedule conflicts with accessing health care [42]	Welcoming health care environment [42, 52] (e.g., display art work and languages of different cultures in clinic space)[52]
Barriers (n = no. of papers)	**Facilitators** (n= no. of papers)
Racism and discrimination during healthcare visits (n=14)	*Easily accessible information (n=15)*
Feeling misunderstood, marginalized, disrespected by HCP;[45] treated differently;[40, 48, 50] prejudiced views from HCP [41, 46]	Easy access to consistent information to care for their sick child,[49] on medicines and treatments [45, 47, 51, 56]
Unwelcoming, run-down clinics give a feeling that HCP do not care about them [52]	Access to culturally appropriate information [39]
Experiences of racism or discrimination: dissolved feelings of trust of HCP;[54, 55] seen as different people;[48] racial stereotyping/stigma [39, 42, 45, 50]	Information/care available closer to home,[43] within local community,[46, 48, 53] in community clinics,[39] schools,[43] daycare [40]
Feeling judged: for Indigenous culture, appearance and/or last name, for having child at young age, for history of substance abuse [49, 52, 55]	Information in multiple formats - social media,[40, 56] websites,[56] online repository,[44] flip charts, audio radio/TV, posters,[40] written,[39] illustrated,[47] text-messaging [55]
Fearful: of judgement,[46] of child apprehension [54]	Clear information,[47] in preferred language [47, 48]
Lack of access to healers/traditional care providers,[41] traditional medicines [53]	Access information through peer support in the community [42, 44, 51]
Lack of cultural understanding by HCP [41, 45, 54]	Instructions available for finding online information [15, 56]
Lack of culturally appropriate information [39, 42] or information in preferred language [46, 47, 48]	
Ineffective communication by healthcare providers (HCP) (n=14)	*Improved communication and relationship with healthcare providers (HCP) (n=10)*

Poor communication/relationship with HCP [45, 48, 56]	HCP empowers families with information,[45] provides anticipatory guidance and involves parents in collaborative care [52, 54, 55]
HCP gives inadequate/unclear information,[41] uses medical jargon,[39, 42, 47, 48, 50] gives conflicting advice [42]	Communication is clear,[47] respectful and appropriate;[49] HCP recognize parents' information needs at different stages (e.g., diagnosis vs. parent experienced caring for child)[56]
Lack of information provided on the emotions families may go through,[39] medicine use,[42, 46] what to expect,[52] treatment options,[46] asthma care,[42, 43, 44, 45] allergies,[42] preventing respiratory infections;[45] discharge instructions;[39, 40, 49, 56] recognizing trustworthy online information [15]	Parents feel heard and listened to by HCP:[52, 56] HCP acknowledge family concerns,[52, 54] and value parents as experts of their own children [52]
Communicating with multiple healthcare providers,[50] lack of continuity and limited time with HCP,[41] don't feel listened to [52, 54]	HCP tailor health teachings to parents' preferences [53]
Parents seldom included in treatment decision-making [47]	Trusting relationship developed through honesty (e.g., HCP say if they don't know something),[56] and consistent care [46, 53, 54]
Structural (n=10)	*Culturally safe health care (n=11)*
Geographical: information/care not available closer to home,[39, 42, 43, 46, 48, 50, 51] Lack of transport/parking costs to access care [39, 41, 42, 52, 55]	Access to culturally appropriate information (e.g., how traditional medicines would interact with prescribed medications),[39, 41, 42, 46, 47, 52] information on options for cultural resources/support/practices in their community,[44, 50, 52, 54] and respect traditional Indigenous medicine place in health and healing [47, 52]
Health System: charged for going to a walk-in clinic;[52, 55] cost of medications [41, 42]	Culture, language and heritage incorporated into educational programming [51]
Limited access to phone, computers; unreliable internet or phone service [41, 42]	Offer opportunities to families to connect with someone they can identify with (e.g., similar cultural background):[56] Education programs delivered by Indigenous peers and health professionals;[42] Access to Indigenous health staff and Elders [39, 40, 46, 51, 54]

Lack of child care [42]	HCP demonstrate culturally secure practices [56] and have knowledge on creating safe-spaces:[48] HCP use strengths-based approaches,[47] ask about parents' community, cultural and spiritual needs and how they can help in addressing them,[54] offer support that considers how contextual factors (historical trauma, social inequities) impact health behavior [53, 54]
Work schedule conflicts with accessing health care [42]	Welcoming health care environment [42, 52] (e.g., display art work and languages of different cultures in clinic space)[52]

CHAPTER 4.

Paper 3: We're here too: Findings from a qualitative study of the experiences and preferences of Red River Métis families looking for health information when their child is sick

Paper 3 is under review as:

Knisley, L., Driedger, S. M., Hartling, L., Chartrand, F., Sanguins, J., & Scott, S. D. (2023). We're here too: Findings from a qualitative study of the experiences and preferences of Red River Métis families looking for health information when their child is sick. *International Journal for Equity in Health.*

Abstract

Background: Red River Métis families need access to meaningful and appropriate resources when their children are sick. At the invitation of the Manitoba Métis Federation (MMF) to partner in this research, our aim was to understand Red River Métis parents' experiences and preferences for seeking child health information when their child is acutely ill, to inform the adaptation of existing parent resources.

Methods: A qualitative descriptive approach underpinned by a participatory paradigm guided this study. Semi-structured interviews were conducted with 19 Red River Métis parents and Elders via Zoom or telephone. An inductive thematic analysis approach was used to explore patterns and themes across the data.

Results: Analysis generated four themes: 1) We're here too; 2) We are not all the same; 3)

Finding trustworthy information; and 4) Information needs to be widely available. Red River Métis pride was prominent in the results. Parents provided tangible ways to modify existing parent resources, including adding information on how to access Elders, healers and/or traditional medicines and showing different family structures, transport, living situations, Métis names, and incorporating Métis languages. While most parents reported looking for child health information online, they also stressed the need to provide multiple options, including information sheets, recognizing that parents seek information in different contexts. Parents also emphasized the importance of accessible, safe spaces to find child health information, including local schools, community centres, healthcare organizations and the MMF.

Conclusion: There is a lack of child health information created specifically for Red River Métis families. The development of this information can support their information needs and preferences and the ongoing efforts to revitalize Red River Métis culture and language. Study findings will inform the adaptation and dissemination of existing child health resources to ensure they reflect Red River Métis parents' information needs and preferences. This research is a critical step in addressing an identified need for Red River Métis families to have culturally relevant and meaningful child health resources, and in the pursuit of equitable care for all children in Canada.

Trial Registration: N/A

Keywords

pediatrics, information, knowledge translation, knowledge mobilization, child health, Indigenous, Métis, Red River Métis

Background

Worried families often look for health information to help decide how to care for their sick child (1-5), and what they find can have a crucial impact on a child's health status.(2) Understanding and prioritizing families' child health information needs can support their decision-making, healthcare access, and appropriate healthcare service delivery.(6-10) It is also a critical step in developing information that is accessible, useful and meaningful.

Knowledge translation (KT) "is the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system".(11) Members of our research team have created successful KT tools (e.g., videos, infographics) with parents that merge evidence, personal narratives/stories and art to share information on common childhood conditions. (12-17) These resources were created to have broad accessibility and fit with the Canadian population. However, further research is needed on whether these resources are relevant for specific cultural groups and contexts.(18-21)

This project arose from a need identified by the Manitoba Métis Federation (MMF; the national government of the Red River Métis) for Red River Métis families to have access to meaningful and appropriate resources when their children are sick. The MMF saw existing parent tools developed by Translating Emergency Research for Kids (TREKK; trekk.ca), a knowledge mobilization network for children's emergency care, and came to TREKK to fund the adaptation of these tools for Red River Métis families.(22) At the invitation of the MMF to partner in this research, our aim was to understand Red River Métis parents' experiences and preferences for seeking child health information when their child is acutely ill. The research team consists of MMF staff (JS), a Red River Métis scholar (SMD) and allied academics from

TREKK (LK, LH, SS).

The MMF represents Red River Métis in the Canadian province of Manitoba, as well as Citizens living outside of the province with historical connections to the Red River Settlement. In 2021, the number of self-identifying Métis living in Manitoba was 96,730 with 46.7% living in Winnipeg.(23) It is important to note that although individuals self-identify it does not mean they are recognized as Red River Métis citizens by the MMF. The MMF governance structure divides the province into seven regions, and within each region there are 135 smaller divisions referred to as Locals. Approximately half of the Red River Métis population live within the city of Winnipeg, Manitoba's capital city, with the rest living diffusely throughout the rest of the province.

Red River Métis have expressed a need for reliable health information and that health systems have left much of their information needs unmet.(24) Métis parents have recognized culture and a positive sense of Métis identity as essential elements of raising children and as key components that are missing from health services.(25) Yet, Métis are underrepresented within research,(26, 27) and there is a silence in the literature about Métis health and well-being.(28) Furthermore, Red River Métis are rarely included in a distinctions-based approach. Most research that includes Red River Métis tend to be pan-Indigenous, grouping them with First Nations and Inuit Peoples,(29) which can diminish their unique and diverse experiences.

Red River Métis and First Nations Peoples often live side-by-side within Manitoba, yet have unequal access to health services and supports due to different fiduciary responsibilities between the federal and provincial governments, which can increase health inequities and challenge the uptake of research, policies, programming, and services.(30) Red River Métis access health services through the province; they do not have access to federally supported health services available to on-reserve First Nations or Inuit Peoples.

Findings from this study will inform the adaptation (31, 32) and dissemination of existing child health resources to ensure they reflect Red River Métis parents' information needs and preferences. Furthermore, understanding the barriers that prevent parents from getting the information they need can help expose and challenge existing colonial processes perpetuating inequitable care.

Red River Métis

The Canadian Constitution recognizes Métis, First Nations, and Inuit Peoples as the three Indigenous groups and first peoples of Canada.(33) As a people, the Métis were the initial off-spring of mixed First Nations and European ancestry in the 17th and 18th centuries with historical ties to the Red River Valley and westward expansion during the fur trade.(34) The Métis developed a united and unique nation in North America's northwest, forming its own language, traditions, and culture.(29, 33, 35) Manitoba is widely recognized as the birthplace of the Red River Métis Nation.(28, 35) Although some Métis might adopt more Indigenous or more Western ways of knowing, Red River Métis remain in an interstitial space – as being neither First Nations nor European settler populations.(36) Like other Indigenous Peoples, Métis have experienced and continue to experience the legacy of colonial policies that disrupt their ways of knowing and being,(28) including historical dispossession of lands and even outright war.(24, 37) It took until 2013 for the Supreme Court of Canada to conclude the Canadian government failed its constitutional obligations towards the Métis following the creation of Manitoba, in 1870.(38)

Methods

A qualitative descriptive approach,(39, 40) underpinned by a participatory paradigm,(41,

42) guided this study. A decolonizing research framework(43) guided the use of ethical, iterative, culturally-based, and process-oriented methods that were relational, respectful, relevant, reciprocal and responsible.(44) The Consolidated Criteria for Reporting Qualitative Research checklist was used.(45) Meetings took place with MMF leadership to explore the adaptation of existing parent resources. Tri-Council Policy Statement(46) of ethical guidelines, and Ownership, Control, Access and Stewardship (OCAS) principles of the MMF(47) were followed. Ethics approval was obtained from the MMF and University of Alberta Health Research Ethics Board [#Pro00111866].

Recruitment

Parents were invited to participate in a Zoom or telephone interview to increase feasibility of data collection during the COVID-19 pandemic. A recruitment poster and standardized email messages were developed and shared using established communication channels through the MMF. Recruiting took place from July 2021 to April 2022 via word-of-mouth or emails from the MMF and snowball sampling methods.(48) Parents were purposefully selected to aim for a breadth of age, gender and geographic representation.(49) Interested parents were instructed to contact the lead author (LK) via email or phone who then provided them with a study information sheet and determined eligibility: a) self-identification as a Red River Métis citizen in Manitoba; b) a parent (or guardian) of a child of any age; c) fluent in English (speaking, hearing) to allow for meaningful participation in the interview. Elders, who are people that hold respected position within Red River Métis communities to provide guidance, share wisdom and pass knowledge of cultural importance from one generation to the next, were invited to participate through the MMF.(50) Participating Elders were also parents and grandparents.

Data Collection

To maintain consistency, LK coordinated and conducted each interview using a semi-structured interview guide developed in consultation with the research team. Interview topics included child health information needs and preferences, necessary changes to existing resources, trusted sources for health information, preferred topics and formats, and experiences finding the information. Eligible parents were contacted to schedule an interview via phone or Zoom(51) based on their preference. Parents were given the option to provide written or verbal consent. Consent forms (and the digital recordings for verbal consents) were stored, along with the transcription of the audio file, on a password protected secure, Canadian server.

Parents were asked to look at one or two resources available on trekk.ca in advance of the interview. Two parents did not review the web page due to lack of internet access. In these instances, the resources were described to the participant by LK. All interviews were digitally recorded through Zoom and professionally transcribed. Parents were asked to complete a demographic questionnaire (Table 1) at the end of the interview and given a gift card in recognition of the time, following MMF guidelines ($50 for parents; $250 for Elders).

Data Analysis

We used an inductive thematic analysis approach(52) to explore patterns and themes across the data. Analysis was conducted by LK and comprehensively reviewed and confirmed by the research team. Interviews were professionally transcribed then audio verified to ensure accuracy and familiarity with the data.(52) Transcripts were uploaded to NVivo,(53) an advanced storage-code-and-retrieval software program, to facilitate the organization and analysis of the data. Inductive analysis was performed in three phases: coding, categorizing and developing themes. We used a combination of inductive coding(54) and thematic analysis(52) to allow the generation of new codes and categories. Codes were operationally defined to ensure consistent application to all data, clustered according to commonality and placed into categories(54), which were then grouped into initial themes. Field notes were used to document observations and decisions. Data collection and analysis were done concurrently to attain reliability and validity,(55) allowing the monitoring of progress of the interviews and to permit follow-up of ideas emerging from the data.(56) This process was done until no new information was generated from the interviews, suggesting data saturation.(57) Descriptive statistics were used to summarize demographic data.

Rigour

Rigor was enhanced through thick description, and comprehensive review and critique of findings and interpretations by the research team.(58) To help achieve reliability in the data, member checking was conducted during the data collection process by seeking confirmation or clarification of any uncertain comments during the interview(59) and checking data between interview participants.(58) Additionally, preliminary findings were shared with parents via a handout and discussion at a booth set up during the MMF Annual General Assembly (March 25-27, 2022; approximately 3,000 attendees) to check findings. Detailed field notes and reflective journaling were used during data collection and analysis to document contextual details, assist with pattern and theme recognition, build an audit trail and examine potential biases.(56)

Results

Thirty-three parents contacted LK about participating in the study. One parent did not meet the inclusion criteria and 13 could not be reached for follow-up after two additional attempts to contact them. A total of 19 semi-structured interviews(56) were conducted by LK (3 of which were Elders). Most parents lived in rural communities (n=14), with the remainder living in an urban area. Demographic characteristics are in Table 1.

Table 4.1: Parent Demographics (n=19)

Characteristic	n (%)
Age (Years)	
18 - 30 years old	5 (26)
31 - 45 years old	8 (42)
46 - 55 years old	2 (11)
Over 55 years old	3 (16)
Prefer not to answer	0 (0)
Missing Data	1 (5)
Gender	
Woman / female	15 (79)
Man / male	3 (16)
Gender that does not align with your sex assigned at birth	0 (0)
Transgender	0 (0)
Two-Spirit	0 (0)
Gender-fluid	0 (0)
Non-binary	0 (0)
Woman/ female and Genderfluid	1 (5)
Not sure/ Questioning	0 (0)
Prefer not to answer	0 (0)
Missing Data	0 (0)
Highest level of formal education completed:	
Less than Grade 5	0 (0)
Grade 5-10	0 (0)
Grade 11-12	3 (16)
Some University or College	4 (21)
University of College Degree	8 (42)
Post Graduate Degree such as Masters or PhD	0 (0)
Prefer not to answer	0 (0)
Missing Data	4 (21)

Relationship support: Do you have a supportive adult in your everyday life (e.g., spouse, common-law partner, other partner/relationship)?	
Yes	11 (58)
No	4 (21)
Prefer not to answer	1 (5)
Missing Data	3 (16)
Yearly Household Income: (i.e. total sum of income from all adults living in house hold)	
Less than 10,000	0 (0)
10,001 – 30,000	1 (5)
30,001 – 50,000	5 (26)
50,001 – 70,000	2 (11)
70,001 – 100,000	1 (5)
Greater than 100,000	4 (21)
Prefer not to answer	2 (11)
Missing Data	4 (21)
Occupational Status	
Unemployed	0 (0)
Household worker	0 (0)
Casually Employed (Less than 10 hours per week)	0 (0)
Employed: Part-time (Less than 35 hours, more than 10)	3 (16)
Employed: Full-time (35 hours per week or more)	11 (58)
Retired	0 (0)
Prefer not to answer	1 (5)
Missing Data	4 (21)
Number of Children in the Family	
0	0 (0)
1	1 (5)
2	4 (21)
3	5 (26)
4	3 (16)
5	3 (16)
Prefer not to answer	0 (0)
Missing Data	3 (16)
Primary Language Spoken in the Household	
English	14 (74)
English and French	1 (5)
English and Saulteaux	1 (5)
Missing Data	3 (16)
Have you used Emergency Department Services for your Child?	
Yes	11 (58)
No	3 (16)
Missing Data	5 (26)

Interviews ranged from 40 to 80 minutes (M=52.47). Analysis generated four themes: 1) We're here too; 2) We are not all the same; 3) Finding trustworthy information; and 4) Information needs to be widely available.

Theme 1: We're here too

Parents shared their personal experiences and reflections on being Red River Métis and their relationship with Métis culture. They spoke of their pride and strength in being Red River Métis and the cultural values passed down through family or other ways. However, the generational impact of colonial oppression and racism are reflected in some parents' experiences of family disconnection from Red River Métis identity and culture, and fear of healthcare providers. Additionally, the divisions between Indigenous groups that were created by colonization can be heard in parents' reports of Red River Métis getting lost among the description of Indigenous Peoples and not having access to the same federally funded health programs as First Nations and Inuit Peoples. (Table 2)

Being Red River Métis

Four parents spoke of their pride in being Red River Métis, seeing Red River Métis succeed and seeing Red River Métis culture in books or on TV. Three parents also spoke about efforts to define and celebrate Red River Métis culture, such as programs offered by the MMF (e.g., beading classes, parent groups). However, parents highlighted how scarce Red River Métis-specific resources are: **"***There's a lot of great resources that they put out targeting specifically First Nations stuff or Inuit. But we're kind of here too. We're more urban usually. We kind of blend in a little bit. But visible too… we fall in that gap because yes, we're seen as Indigenous people, but we don't have access to the same programming". [Mother, 006]*

One parent talked about being disconnected from her Métis identity as a child: *"we just grew up in that generation where it's just like, you pass for a white person…So it's all new to me too." [Mother, 010]* An Elder commented on their childhood experiences of racism in rural Manitoba: *"The Métis family were treated like second class citizens… there was no one that I* *would have trusted to go and talk to, none at all. But I don't think that's the case these days."[Elder, 017]* Another parent shared the generational impact of racism on her own healthcare experiences, including feeling scared when health professionals would visit her home: *"Generationally it's engrained. Whether we know it or not… And right now, my people have no reason to respect the medical field or the government. It's got to be earned now.*"*[Mother, 006]*

Cultural values

During discussions on how resources could be culturally adapted, many parents reflected on their Red River Métis cultural values, including personal connection, humour/laughing together, working together, and gathering over food. As one parent described: *"That personal connection is key. It's important. We come from a background where culturally we work together."[Mother, 006]* Similarly, another parent shared the importance of food in bringing people together: "*…with the Métis everything is about food… Anytime I go to an event we always have the snacks, the lunch, the supper… even when I go visiting around, it's always about the food." [Mother, 020]*

Theme 2: We are not all the same

Red River Métis parents have unique and diverse experiences within different regions of Manitoba. Parents shared ways the existing resources could be changed to reflect Red River Métis families and culture better. They described changes to the artwork or graphics that might help to capture their attention, without appearing tokenistic, and making information about traditional medicines, healers and Elders more accessible. Additionally, parents discussed the need for resources to be available in languages other than English, the loss of Indigenous languages, and their interest in reconnecting with these languages.

Reflecting Red River Métis culture

Five parents did not think any changes were needed to the existing resources' artwork or graphics. Some felt the artwork was fine as it was, the skin and hair colours represented were diverse, and that parents would not need to see Métis artwork to look at a child health resource: *"I love our craftwork but I'm not the person that needs to see like a beading pattern on my pamphlet from the doctor…I want you to tell me the facts and I want you to tell me them in as clear a language as possible." [Mother, 006]* Two parents warned that attempts to represent cultural groups can appear tokenistic and end up othering a group or individual and seeing them as different from the 'norm': *"If we're talking specifically Métis. There's a rainbow of us, right. Not all the same. And I think we try to do better with representation but sometimes it feels really just a little bit too tokenistic…why do they always have to be about like the seven teachings or Bannock or hunting? Like one of my favourite ones is just a book about a family setting up for Christmas. They just happen to be Brown. Like, why can't that exist?" [Mother, 006]*

Six parents spoke about how seeing Red River Métis culture within a child health resource could help families connect with it. For example, seeing themselves or their culture included in a resource may feel more trustworthy or welcoming, and it may catch their interest because it is not something they see very often. Five parents suggested including artwork that would represent Red River Métis culture, such as flower drawings, beadwork, traditional clothing and the Métis sash. Other suggestions included using Métis names, showing families from different cultural groups to acknowledge that people can identify with multiple groups, and avoiding gender and family stereotypes: *"… I think you could use more variety in like the ages of the caregivers taking care of the children. Especially for like the Métis and all Indigenous communities, we have lots of blended families and aunties and uncles taking care of the kids too". [Mother, 002]*

Another parent wanted to see a variety of homes and foods: *"… my kids, they like a lot of wildlife, like, moose and bears and deer…Like that's kind of what we eat and kind of what we're raised on". [Mother, 011]* This parent also highlighted the importance of including different transport options. For example, limited taxi services, and other transport barriers, particularly within rural areas, may result in families staying in a hotel once discharged from the hospital. Showing ways other than driving a car to the hospital could better represent diverse family situations.

Acknowledging traditional medicines

Parents spoke of using traditional medicines or knowing Métis families who do and wanted child health information that acknowledged this use. As one mother described: *"…sometimes the health information can end up being very Westernized and not always the way that Métis people would necessarily start dealing with an illness." [Mother, 002]* Another parent suggested: *"something like that, if you want some traditional medicine, contact your local healer, this is their name….but like to even include some holistic stuff in there, like, from an Elder, that would be awesome." [Mother, 007*] However, parents spoke of doctors' reluctance to discuss traditional medicine. As one parent said: *"It's a touchy subject. Doctors don't even touch it." [Mother, 004]* Similarly, parents did not feel comfortable bringing the subject up with doctors. An Elder shared her mother's reluctance to tell doctors about their use of herbal medicines: *"my mom used to say, Is that legal to do that, to give herbal medicines? She used to say don't tell the doctor I gave you that. And yet it's natural medicine…And you could see the benefits right away…we survived all these years…The only time I think somebody went to the [hospital], is if they had like problems breathing". [Elder, 012]*

Language

Parents were asked if the existing resources should be available in languages other than English. The most frequently cited language was French (n=13); reasons included to represent Canada's two national languages and because many Red River Métis speak French. The next most cited languages were Michif (n=8) and Cree (n=8), followed by Ojibway (n=6), Saulteaux (n=5), and Swampy Cree (n=1). Thirteen of the parents reported that English was the primary language spoken in their home, with one parent reporting English and Saulteaux were spoken (Table 1). None of the parents indicated they themselves were fluent in an Indigenous language. One parent understood but could not speak Saulteaux.

An Elder shared their experience of forced assimilation within the education system: *"We couldn't use our language. We had to speak English." [Elder, 012]* Another Elder explained that "*..most people are the same with me. They're older people, it [Indigenous language] kind of stopped with them. The youngest… It's all a foreign language to them now." [Elder, 019]* Four parents spoke about the loss of Indigenous languages and questioned whether a resource in another language would be useful to families whose main language was English. Some parents spoke of interest in reconnecting with Indigenous languages: *"…if you were trying to encourage Métis community, to do it in Michif... I mean medical terms are complicated, but that might be a fun way to encourage people to read it. There's lots of people who are trying to reconnect to language that way." [Mother, 002]* Additionally*,* one parent suggested having an auditory resource, to reach people who may speak a language but not be able to read it.

Theme 3: Finding trustworthy information

This theme focuses on the relationships and places that are trusted for accessing child health information. Learning about the information sources that Red River Métis families trust can help inform the processes of developing and disseminating this information. Parents shared the people, organizations and places they trust to get child health resources but also emphasized the importance of accessible, safe spaces to find this information. (Table 3)

Communicating with healthcare professionals

Of the 13 parents that reported turning to family and friends for health information when their child is sick, 11 stated that their family or friends worked in health care. Parents wanted to get health information from healthcare professionals, in particular when they did not know where to look for this information or were not comfortable looking up information online. However, the *way* healthcare professionals share this information is important. While most parents wanted to access trusted information from healthcare professionals, they also highlighted the difficulties they can face when engaging those healthcare professional sources. Two parents reported witnessing discrimination from healthcare professionals, which can deter people from trusting and reaching out to them: *"racial discrimination deters people from calling [for medical help]…if I'm going to something and I feel unwanted…., I'm definitely not gonna be going back." [Mother, 010]* Parents also spoke about difficulties getting clear answers to their questions. For example, they described turning to social media when doctors use medical jargon, and feeling "*small because they don't understand what they're talking about." [Mother, 018]* Five parents wanted access to one trusted place, whether in-person or online, to find information and also help when they feel overwhelmed about how best to navigate their child's health care.

Sharing information

Parents commented they would trust information from an Indigenous source, and if it was from organizations (i.e., not an online forum or a personal opinion), such as a government body or a university that shares research and cites sources. Suggested places to share child health information included schools, daycares, community centres, baby clinics, babysitting courses, social workers, doctor's office, provincial health department, public health offices, early childhood programs and the MMF. For example, it was suggested child health information could be included within an organization's website, emails/newsletters, and existing resource kits (e.g., MMF's Little Métis Box [https://www.mmf.mb.ca/early-learning-child-care], an activity kit offered to families with children aged zero to six to explore Red River Métis culture and history together). Parenting groups/classes were also suggested: *" ... come in and talk about stuff and talk about the website and talk about things that are in the website, ... give them pamphlets... just include the parents in stuff like that so they know that it's out there, because maybe some people don't have access to a computer or access to a phone and access to anything." [Mother, 018]*

Theme 4: Information needs to be widely available

This theme describes parents' accounts of the information formats (i.e., the way information is presented) they use or would prefer to access. While most parents reported looking for child health information online, they also stressed the continued need to provide multiple options, including information sheets. Parents seek information in different contexts. Widely available information may help worried families decide whether to travel long distances and/or incur the costs of seeking medical care for their child. For example, one parent reported: *"information needs to be put out widely, not just, like, oh, go to the hospital…For me to take my children to the hospital it's an hour drive. To go to [city/town], is just about two hours from where I live. And then if we have to call in an ambulance, that costs us like $500 something. Sometimes it is what it is, but that's why I say, information anywhere would be great." [Mother, 018]*

Digital formats

Searching online for child health information was reported by 17 parents. Google was the most cited online source (n=12) but its limitations were acknowledged: *"... you Google for your splinter, and you're dying of cancer next week in your head. And when it's your child, that's dangerous thinking." [Mother, 006]* Social media was the next most cited online source (n=8). Parents described preferring the succinct and instant format of social media and being able to connect with community groups and other families. Two parents wanted easy access to an online assessment that could help them make decisions on when and where to seek medical care for their sick child: "*just in one location…Because it's that step before having to make that decision whether to call your family doctor or to go to the urgent care versus the emergency". [Mother, 003]* Online information sessions were suggested by two parents. For example, a class to *"go through some of these things that are on the website and how to react." [Mother, 005]*. Three parents mentioned getting information via email would be helpful and six parents liked videos. While videos were described as being quick to watch, web pages were suggested when parents have more time: *"... scrolling through is really nice. If you're sitting in a waiting room and you've got the time then it's something that you can read to expect what's going to happen next for treatment versus what you're going to do at home for treatment." [Mother, 003]*

Paper formats

Parents stressed the importance of having multiple ways to access child health information. For example, some families cannot access the internet, cell phone or landline to find information. While most parents went online, many valued having a hard copy format that would direct them or remind them of this online information: *"an information sheet with, oh, if you want to look on YouTube, you can watch this video. If you want to look on the website, go to Google, search for* *this….I'd rather grab a pamphlet and read it like that or talk to somebody who has experienced it…" [Mother, 007]*

Discussion

Parents provided tangible ways to modify existing KT tools for Red River Métis families, including adding information on how to access Elders, healers and/or traditional medicines and showing different family structures, transport, living situations, Métis names and social gatherings with food. While modifying the appearance of a resource can be part of the cultural adaptation process, (60) there must also be an explicit focus on decolonizing and anti-racist approaches (61) during the KT process, including recognizing the generational impact of colonial oppression and racism on the healthcare experiences and information preferences of Red River Métis families. We focus our discussion on key considerations for developing and/or adapting child health information for Red River Métis families: 1) supporting the revitalization of Métis language and culture: 2) building relationships; and 3) context.

1. Child health resources can support revitalization of Métis language and culture

Red River Métis pride was prominent in the results. While the results highlight mixed messages around the relative value and benefit in providing Red River Métis specific resources, it cannot be understated that this is a function of colonization.(62) Métis lived under a reign of terror in being Métis(63) and subsequently learned to hide their identity, language, deemphasize their First Nations or Métis heritage and emphasize Euro-Canadian heritage to reduce exposure to racism, social injustices and health inequalities.(26) Métis history has been denied or silenced for centuries and colonization continues to impact the relationship Métis have with their identity and culture, including connection to language, key people (e.g., Elders), cultural teachings and traditional medicines.(26, 62) Generations of people who may not have formally identified as

Métis have come forward with increased pride and desire to identify as Métis, in part due to the formal development of Métis government structures and increased recognition of Métis in Canadian court cases.(26, 29, 43, 62)

Cultural health, which is defined as expressing and celebrating one's identity and place in the world, is important for health and well-being.(64) There is a gap in research focusing on the distinct experiences of Métis families.(65) Resources can help to counter a legacy of colonization by: 1) focusing on the strengths of Métis (i.e., traditions, ways people support each other in community, community-driven solutions); 2) promoting the understanding that Métis people, organizations, and communities have the knowledge and expertise to identify and address their own concerns; and 3) supporting the cultural identity of Métis through knowledge sharing and documenting these important teachings for future generations.(66)

There is a resurgence towards language revitalization, and information resources in Michif or another of the Métis languages could support such an initiative. The Michif language was once common in Métis communities and is now considered endangered, with fewer than 1000 people speaking it. Language revitalization efforts promote individual and community healing(62, 64, 68) and there was interest among the parents to learn an Indigenous language. The MMF is promoting Michif through access to language resources and lessons at the Louis Riel Institute.(67, 69) Inserting Michif, and/or another language alongside English text in a child health resource could be a favorable way to integrate language that would help both adults and children learn together in a more fun and engaging way. Working with language experts will be important to ensure content is interpreted and translated correctly, for example, dialect and associated nuances in the messaging are not lost.(66)

Parents wanted information on how to connect with Elders, Indigenous healers and traditional medicines, and this has also been reported in other studies with Indigenous families looking for child health information.(70-78) Resources can acknowledge and respect the use of these services by including clear signposting to more information, advice and support available. Healthcare providers who may not be able to incorporate traditional medicines and healing practices into treatment plans could share the resources to demonstrate their respect and support of Métis cultural resources and their roles in health and healing.(65, 74, 76) However, challenges in accessing these supports, such as not being available in local communities, (79) must also be considered in any resource development.

2. *Relationships are key for sharing trusted information*

Information is just one part of a health communication process that can also involve interactions with healthcare professionals, family and friends.(80) Relationships are key for information sharing and tied to trust. Kinship and social networks are sources of information and comfort for parents in this study and these can be effective approaches for knowledge translation.(81) However, Red River Métis families also want child health information and advice from healthcare professionals, which is in line with extant literature.(65, 82, 83) The tension that some parents experienced racism in the health system and therefore distrust health professionals is not incongruent with trusting health professionals to provide accurate health information. Parents who are worried about their sick child will do whatever they can to help them, including turning to a health provider for advice. The relationship with these health providers matters, and studies have reported Indigenous families are less likely to trust healthcare providers' advice(76, 77) and will seek care elsewhere(76) if they feel their perspectives and unique knowledge about their child is being dismissed. Culturally appropriate health care, of which clear information is a vital component, offered in an environment free of racism and stereotypes, can improve health outcomes and quality of care; unfortunately, this type of care is not available to everyone.(84) Many healthcare providers lack training in culturally appropriate approaches.(85) We recently conducted a scoping review that highlighted actions individual healthcare providers can take to improve Indigenous families' access to meaningful child health information: listening to patients/families, including them in decision-making, giving honest information, and sharing information within families' communities.(65) Additionally, Métis health professionals are trusted for health information and an important component of cultural safety.(28, 64)

Red River Métis parents in this study emphasized the importance of accessible, safe spaces to find child health information, including local schools, community centres, healthcare organizations and the MMF. A 2020 guide to producing health information highlighted schools and teachers as reliable sources of health information for families.(80) Additionally, accessing information closer to home has been a preference for Indigenous families in other studies.(70) Investing time to build relationships with these healthcare, educational and community organizations is critical to the dissemination of accessible and trusted child health resources.(86-89)

3. Context matters

Findings demonstrate a variety of sources and formats (e.g., via healthcare providers vs. social connections; online vs. paper-based) that can make it challenging to know where to begin with the resource development process. Different people have different experiences and opportunities, which shape their needs, concerns, challenges, interests and preferences for accessing health information. Effective health communication is not generic and the variety in preferences is reflective of the different contexts in which Red River Métis live. We can try to serve these varied needs with layered approaches to communication and sharing of child health information. For example, printed information can signpost to more online details. Information on web pages can be supported by replicating the information on a printable PDF. Healthcare settings, such as waiting rooms, could have computers with internet for families to access health information before or after their visit. These low-cost, simple-to-implement ideas can be practical ways to share knowledge and also have also been suggested in other studies.(90, 91) Additionally, incorporating an intersectionality lens within the KT process can promote the understanding that people are shaped by different social locations or categories (e.g., gender, race, Indigeneity, class).(49, 92, 93) Intersectionality-informed research can help to advance the understanding of the commonalities and differences among Red River Métis parents seeking health information, as well as highlight the similar and different experiences of parents across social categories.

Contextualization is key to successfully utilize approaches according to the specific health information or decision-making needs; for example, making a decision to seek care; receiving information after a diagnosis or about a treatment; looking for emotional support versus specific information. Recognition of contexts is also an essential part of KT.(94) However, KT efforts within health research are deeply embedded in Western science approaches.(95) A scoping review of promising and wise KT practices in the Indigenous health field reported meaningful involvement of families and other users of the health information is an effective KT method.(81) It is also fundamental to decolonization.(96) Co-creation of child health resources *with* Red River Métis families and communities can ensure the KT process is planned and implemented in context, and that the shared knowledges will reflect the local protocols, conditions, history, culture, languages and worldviews of the community. (81)

Strengths and limitations

To the best of our knowledge, this is among the first studies that aims to understand Red River Métis parents' experiences and preferences for seeking child health information when their child is acutely ill. It was conducted in partnership with the MMF to help address the lack of child health information for Red River Métis families. Additionally, we shared and verified study findings with Red River Métis citizens attending the MMF annual general assembly. However, the study does have some limitations. It was conducted during the COVID-19 pandemic, which restricted the ability to conduct in-person interviews or focus groups, which may have impacted the engagement of parents who preferred this option. Lastly, parents were not asked to demonstrate Red River Métis status (e.g., showing a citizenship cards) and it is therefore possible that study participants may not fall under the official definition of Red River Métis citizenship. However, as recruitment was done through the MMF, it is assumed that all participants had some level of involvement in the Red River Métis Nation.

Conclusion

Gaining a better understanding of the information-seeking experiences and preferences of Red River Métis families can expose and challenge existing colonial processes perpetuating inequitable access to child health information. There is a lack of child health information aimed at Red River Métis families, and the development of this information can support their information needs and preferences and the revitalization of Red River Métis culture and language. Investment of time to build relationships with the MMF, Red River Métis organizations and communities is needed to co-create child health resources with Red River Métis families and disseminate these resources effectively. This research is a critical step in addressing an identified need by the MMF for Red River Métis families to have culturally relevant and meaningful resources available when their children are sick, and in the pursuit of equitable care for all children in Canada.

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Table 4. 2: Red River Métis pride and experiences

Theme	Parent/Elder	Quotes	Category
We're here too	Father, 001	“Métis people are proud people, we’re proud to be – especially Manitoba Métis people. I’m pretty proud to be Métis”	Being Métis
	Mother,020	“you get this feeling inside like, right on, you're representing the Métis culture, kind of a thing.”	Being Métis
	Mother,002	“we’re kind of in the process of redefining or further defining what it means to be Métis and the differences than what the other two Indigenous groups of Canada”	Being Métis
	Mother,003	“Métis people in general always kind of fall into the same thing under, just full aboriginal, whereas they kind of get lost in things. They always feel separated from stuff, and nothing is solely for them”	Being Métis
	Mother,006	That personal connection is key. It’s important. We come from a background where culturally we work together. We’re more communal. At least that’s how it was in my upbringing.”	Cultural values
	Mother,020	“…with the Métis everything is about food… Anytime I go to an event we always have the snacks, the lunch, the supper, whatever it may be…when I go visiting around, it's always about the food at people's houses...I think us Métis people love our food.”	Cultural values
We are not all the same	Mother,004	“it’s hard to find that trustworthy source, right, and most people, being Métis, you want to see some Indigenous in a pamphlet before you give it any attention.”	Reflecting Métis culture
	Mother,020	“Anything to do with our Métis culture, I think would catch my attention. Or, like, the beading…the drawing of the flowers and stuff like that. If I was flipping through a page and all of a sudden, I came across that, I definitely would stop…you don't see it very often. And I think if we seen it more often then I probably wouldn't think like that, as often.”	Reflecting Métis culture
	Mother,016	“Just from like online books that were written by Métis people. I was looking at a cookbook and they have a lot of Métis beadwork and artwork and sashes...It’s like the artwork would really help in terms of like getting someone interested in it, especially from the Métis community.”	Reflecting Métis culture
	Mother,018	“… I don’t represent myself as one person…It doesn’t matter the colour of your skin, it’s who we are, but we have to go beyond the thought of that. We have to include, because if we include other nationalities and then it will look better upon everyone else, because maybe this family of a different culture/nationality will want to use it, because hey, it includes us. We don’t feel left out or, like that’s how I view it anyways.” “if I came upon a thing like that and I only seen say Caucasians, I would feel so, like, that’s not for me because I don’t see anyone of my skin colour or of my, like, my kids don’t have blue eyes, blond hair and things like that.”	Reflecting Métis culture
	Mother,011	“not everyone has a vehicle to go to the hospital, so, maybe creating that, like, I went with my mom on our health authority bus. Like, that would be something that’s more of a norm.”	Reflecting Métis culture
	Mother,003	“…if you’re doing videos for Métis families, Métis names and something that they can relate to and that they’re like, oh look, that’s my daughter’s name or that’s my family members name in there.”	Reflecting Métis culture
	Elder,012	“it is going to be lost because we’re getting old…I’m trying to teach my [relatives] but it’s like they’re not interested…There are some that will come to see me; they want to learn…I just take them to the patch, right, where I get the medicine from…I’m not hiding it or anything if somebody wants to…To pass it on because it could save a person’s life or make their life better.”	Acknowledging traditional medicines
	Mother,006	“many of our Indigenous languages are oral …an auditory resource that would be amazing…you might know all the words and being able to carry on a full conversation in your traditional language, but not know how to read a pamphlet about medical problems.”	Language
	Mother,012	“they [Métis] all speak English. We might as well say we lost our language already.”	Language

Table 4.3: Preferences for child health information

Theme	Parent/Elder	Quotes	Category
Finding trustworthy information	Mother,007	“I just don’t have the time or the patience to search through the internet and read up on stuff… they [health professionals] say Google it. Well, no, I’m coming to you because I want your opinion on it.”	Communicating with healthcare professionals
	Mother,003	“Something written by professionals, like, a pediatrician or not just a pediatrician but like specialists…. where you can connect to them because they’re from Canada… they practice the same medicine where you live because around the world obviously, they practice it differently and they have different techniques for different things.”	Communicating with healthcare professionals
		“it gets confusing where one person will say one thing and another. It seems in general it’s just very difficult to find what answer is right, what one is wrong”	
	Elder, 017	“A lot of people are not computer savvy or they don’t know anybody that might be able to help them. So, they’re in the dark, who do they go to? So, if they’re really sick, they go to emerg. Or urgent care.“	Communicating with healthcare professionals
	Mother,006	“I would want it to be curated and monitored by people who have medical training or at least knowledge… I don’t want Wikipedia where everybody can go and edit it…Or at least an actual registered organization that it is, is not spewing rhetoric or false studies.”	Communicating with healthcare professionals
		“…I think if you have a person that you can communicate with that you can form a trusting connection with, even if they’re just helping you navigate and talk to this person and talk to that person...I think culturally speaking is, is very important, especially in the climate we’re in right now. Right. We want reconciliation. We have to acknowledge that there’s a problem in our healthcare system. And it’s a lack of understanding and respect that creates and promotes fear along with the past"	
	Mother,004	“hearing doctors who, like all these high words of vocabulary ask you of things you have no idea what they’re saying or anything. So, it’s no comfort. Knowing they’re trying to explain to you but you don’t even understand what they’re saying. So, a lot of times I would reach out to social media for this feedback.”	Communicating with healthcare professionals
	Mother,007	“our professionals are busy and they’ve got to see their patients and get through the day, but, the one’s that take the time to listen, that makes you feel really important and that what’s going on with you matters.”	Communicating with healthcare professionals
	Mother,006	“…most people have smartphones, but there is something said about holding something in your hand. About physically being handed something that has words on it or a number or a website that oh, this can help…It's comforting to touch it.”	Digital formats
	Mother, 009	“I like how when you go onto social media, it’s there right when you need it.”	Digital formats
	Mother,018	“Facebook for parents, because I like to have that interaction with an actual parent…then you don’t feel so alone…There’s a lot of people like me that have kids that deal with things like that…it’s the connection.”	Digital formats
Information needs to be widely available	Mother,009	“I really like videos. I’m just more of a visual learner that way.”	Digital formats
	Mother, 004	“when my son was heavy breathing, I didn’t understand what was going on so going on social media and just looking it over or even just making a post on Facebook and asking has anyone experienced this and then you get feedback immediately”.	Digital formats
	Mother,003	“… a video would be fast, so they could be like, okay, the kid is sick, this is what we should do instead of panicking and running to an urgent care or an emergency.”	Digital formats
	Mother, 011	“… videos are helpful and kind of easy snippets to watch. I like reading stuff and holding it actually and referring back to it too though.”	Paper formats

CHAPTER 5.

Paper 4: Engaging Red River Métis families in Manitoba in the development of child health resources: Findings from a qualitative study

Paper 4 is ready to submit to *Research Involvement and Engagement* as:

Knisley, L., Driedger, S. M., Hartling, L., Chartrand, F., Sanguins, J., & Scott, S. D. (2023). Engaging Red River Métis families in Manitoba in the development of child health resources: Findings from a qualitative study.

Abstract

Background: Most research that includes Red River Métis tends to be pan-Indigenous. Grouping Métis with First Nations and Inuit can diminish their unique and diverse experiences. Taking a step toward addressing this problem, the Manitoba Métis Federation (MMF; the national government of the Red River Métis) invited us to partner in this research, which focuses on understanding engagement strategies that can help expose Red River Métis parents to child health research opportunities and build trust and transparency amongst research partners and participants.

Methods: A qualitative descriptive approach underpinned by a participatory paradigm guided this study. Semi-structured interviews were conducted with 19 Red River Métis parents and Elders via Zoom or telephone. An inductive thematic analysis approach was used to explore patterns and themes across the data.

Results: Analysis generated four themes: (a) show me why you are here; (b) make it easier for me to take part; (c) create welcoming spaces; and (d) it should be a give and take experience. Parents emphasized the importance of kinship and personal connections, and said they want to hear about child health study opportunities from trusted organizations. They want researchers to be transparent about their research motivations and to offer multiple ways to participate to help them fit research into their busy lives. Relational approaches within the research process (e.g., creating informal/welcoming environments, gathering over food, fostering shared learning/creative opportunities) are prominent in the findings.

Conclusion: There is a dearth of research focused on the distinct experiences of Red River Métis families. Engaging Red River Métis parents early in the research process will help incorporate their preferences and perspectives into the design of a larger project to adapt child health resources. More training is needed to help researchers improve their abilities to engage in self-reflection, listen, recognize power relationships, and demonstrate trust and transparency in each research interaction. It is only through respectful and successful engagement that child health research can be relevant, applicable and positively impact Red River Métis children, families and communities.

Background

It is internationally recognized that engaging patients (i.e., individuals with personal experience of a health issue and informal caregivers, including family and friends) (CIHR, 2014) is a key factor in improving health service delivery, quality and patient experiences (Barello et al., 2012; CIHR, 2014; Esmail et al., 2015; NIHR, n.d.). In child health research, engaging parents/families is fundamental (Esmail et al., 2015). However, there is a gap in research on the best strategies to engage parents; little is known about families' preferences with regard to research engagement or appropriate preparation, training and feedback practices required (Bombak & Hanson, 2017; Domecq et al., 2014; Flynn et al., 2019; IAP2, 2018; Srugo et al., 2023). For Indigenous families, barriers to research participation are heightened by harm inflicted on Indigenous patients and communities in health care and research generally, discriminatory practices, and tokenistic engagement approaches that give patients and families little control over how research is conducted (Curtis et al., 2023; Rolfe et al., 2018). Additionally, most research that includes Red River Métis tends to be pan-Indigenous, grouping them with First Nations and Inuit, which diminishes their unique and diverse experiences (Logan, 2007; Mashford-Pringle et al., 2023).

Taking a step toward addressing these issues, the Manitoba Métis Federation (MMF; the national government of the Red River Métis) invited us to partner in this qualitative study focused on identifying engagement strategies that can help expose Red River Métis parents to child health research opportunities and build trust and transparency amongst research partners and participants. Meaningful engagement of families and other users of health information has been identified as an effective knowledge translation (KT) practice in the Indigenous health field (Morton Ninomiya et al., 2022). KT is the synthesis, dissemination, exchange, and ethically sound use of knowledge to improve health, deliver successful health services and products, and strengthen healthcare systems (Straus et al., 2013). Findings from this study will inform the engagement strategies for a KT project that will help address an identified need from the MMF for Red River Métis families to be able to easily access meaningful and appropriate health information when their children are sick. Members of our research team have created KT tools (e.g., videos, infographics) with parents which merge evidence, stories and art to share information on common childhood conditions (Archibald et al., 2018; Hartling et al., 2010, 2013, 2021; Knisley et al., 2022; Scott et al., 2012, 2013). At the invitation of the MMF, the project will adapt (Aarons et al., 2017; Barrera et al., 2017) these existing child health tools to ensure they are meaningful and useful to Red River Métis parents. The research team consists of the MMF (FC, JS), a Red River Métis scholar (SMD), and allied academics (LK, LH, SS).

Red River Métis

The Canadian Constitution recognizes Métis, First Nations, and Inuit as the three Indigenous groups and first peoples of Canada (Government of Canada, 1982). As a people, the Métis have historical ties to the Red River Valley dating back to westward expansion and the fur trade in the 17th and 18th centuries, and were the initial off-spring of mixed First Nations and European ancestry (Shore, 2017). The Métis created a united and unique nation, with its own traditions, language and culture in North America's northwest (Government of Canada, 1982; Logan, 2007; MMF, n.d.). Like other Indigenous Peoples, Métis experience the legacy of colonial policies that disrupt their ways of knowing and being (Cooper et al., 2020). Métis historically lived under a reign of terror (MMF, n.d.) and subsequently learned to hide their Métis identity, language, and heritage to try to decrease exposure to racism, social injustice and health inequalities (Fiola, 2015). Métis history has been denied or silenced for centuries, and colonization continues to impact the relationships Métis have with their identity and culture (Fiola, 2015, 2021). Additionally, a small fraction of research in Canada is Métis-specific; Métis experiences and preferences are underrepresented, hidden and ignored in research, programming, and policy (Cooper et al., 2020; Furgal et al., 2010). Understanding Red River Métis parents' preferred engagement strategies can strengthen research approaches and practices to respectfully engage Red River Métis families in child health research. Only *with* parents and families can we generate evidence to effectively inform policy changes, and contribute to equitable child health care.

Methods

A qualitative descriptive approach (Sandelowski, 2000, 2010), underpinned by a participatory paradigm (Heron & Reason, 1997; Reason, 1994), was used to interview Red River Métis parents and Elders who: (a) self-identified as Red River Métis citizens in Manitoba; (b) were parents (or guardians) of children of any age; and (c) fluent in English (speaking, listening) to allow for meaningful participation in interviews. Principles of community-based participatory research and integrated KT (iKT) (Straus et al., 2013) guided the respectful and mutually beneficial partnership with the MMF and the engagement of Red River Métis parents (Christopher et al., 2011; Lin et al., 2020). The MMF (JS, FC) guided the research design and process, including the development of study materials, explaining and overseeing recruitment strategies and engagement protocols that were culturally appropriate and respectful. The Métis Life Promotion Framework (MLPF), a Métis framework for knowledge translation and development created by Red River Métis physician and researcher Dr. Judith Bartlett, moves beyond the individual and physical body to remind us that Métis values, culture, community and strengths intersect with one's health and well-being. (Martens, Bartlett et al., 2010). The MLPF is a decolonizing framework (Bartlett et al., 2007; Martens, Bartlett et al., 2010) and was used along with guidelines for research involving Indigenous peoples in Canada (CIHR, NSERC & SSHRC, 2022), and Ownership, Control, Access and Stewardship (OCAS) principles of the MMF (University of Manitoba, n.d.) to guide the use of ethical, iterative, culturally-based, and process-oriented methods that were relational, respectful, relevant, reciprocal and responsible (Chilisa, 2020). The Consolidated Criteria for Reporting Qualitative Research checklist was also used (Tong et al., 2007). This study received ethics approval from the MMF and University of Alberta Health Research Ethics Board [#Pro00111866].

Recruitment

Parents were invited to take part in a Zoom (Archibald et al., 2019) or telephone interview to increase feasibility of data collection and follow public health requirements during the COVID-19 pandemic. Standardized email messages and a recruitment poster were developed and shared via MMF communication channels. Recruitment took place from July 2021 to April 2022 through word-of-mouth, emails from the MMF and snowball sampling methods (Barbour, 2014). Parents were purposefully selected to achieve diverse age, gender and geographic representation (Hankivsky, 2014). Upon being contacted by interested parents via email or phone, the lead author (LK) shared the study information sheet and determined eligibility. Elders, who hold respected positions within a community and share wisdom, guidance, and knowledge of cultural importance, were invited to participate through the MMF (Dodgson & Struthers, 2003).

Data Collection

Each interview was coordinated and conducted by LK using a semi-structured interview guide developed in consultation with the research team. Interview topics included ways to make it easier for Red River Métis families to be involved in research, recruitment strategies and creating safe spaces in research. Parents could provide written or verbal consent. Interviews were recorded, professionally transcribed, then audio verified to ensure accuracy and familiarity with the data (Braun & Clarke, 2022). Consent forms, digital recordings for verbal consent and transcribed audio files were stored on a password-protected, secure Canadian server. Transcripts were uploaded to NVivo, an advanced software program used for qualitative data analysis. Demographic characteristics (Table 5.1) were collected via a questionnaire at the end of each interview. Gift cards were given to parents ($50) and Elders ($250) in appreciation of their time, following MMF guidelines.

Table 5.1: Parent Demographics (n = 19)

Characteristic	n (%)
Age (Years)	
18 - 30 years old	5 (26)
31 - 45 years old	8 (42)
46 - 55 years old	2 (11)
Over 55 years old	3 (16)
Prefer not to answer	0 (0)
Missing data	1 (5)
Gender	
Woman/female	15 (79)
Man/male	3 (16)
Gender that does not align with your sex assigned at birth	0 (0)
Transgender	0 (0)
Two-spirit	0 (0)
Gender-fluid	0 (0)
Non-binary	0 (0)
Woman/female and genderfluid	1 (5)
Not sure/questioning	0 (0)
Prefer not to answer	0 (0)
Missing data	0 (0)
Highest level of formal education completed:	
Less than Grade 5	0 (0)
Grades 5-10	0 (0)
Grades 11-12	3 (16)
Some university or college	4 (21)
University or college degree	8 (42)
Post-graduate degree such as Masters or PhD	0 (0)
Prefer not to answer	0 (0)

Missing data	4 (21)
Relationship support: Do you have a supportive adult in your everyday life (e.g., spouse, common-law partner, other partner/relationship)?	
Yes	11 (58)
No	4 (21)
Prefer not to answer	1 (5)
Missing data	3 (16)
Annual household income: (i.e., total income earned by all adults living in household)	
Less than 10,000	
10,001 – 30,000	0 (0)
30,001 – 50,000	1 (5)
50,001 – 70,000	5 (26)
70,001 – 100,000	2 (11)
Over 100,000	1 (5)
Prefer not to answer	4 (21)
Missing data	2 (11)
	4 (21)
Occupational status	
Unemployed	0 (0)
Household worker	0 (0)
Casually employed (Less than 10 hours per week)	0 (0)
Employed: Part-time (Less than 35 hours, more than 10)	3 (16)
Employed: Full-time (35 hours per week or more)	11 (58)
Retired	0 (0)
Prefer not to answer	1 (5)
Missing data	4 (21)
Number of children in the family	
0	0 (0)
1	1 (5)
2	4 (21)
3	5 (26)
4	3 (16)
5	3 (16)
Prefer not to answer	0 (0)
Missing data	3 (16)
Primary language spoken in the household	
English	14 (74)
English and French	1 (5)
English and Saulteaux	1 (5)
Missing data	3 (16)
Have you used emergency department services for your child?	
Yes	11 (58)
No	3 (16)
Missing data	5 (26)

Data Analysis

We adopted an inductive thematic analysis approach (Braun & Clarke, 2022) to explore patterns and themes across the data. Codes were operationally defined and placed into categories (Saldaña, 2021), and then grouped into initial themes. Observations and decisions were documented using field notes. Data collection and analysis were performed concurrently to monitor interview progress, follow up on ideas generated from the data (Morse & Field, 1995) and ensure reliability and validity (Morse et al., 2002). This process continued until no new information was collected from the interviews, suggesting data saturation (Mayan, 2016). Demographic data were summarized using descriptive statistics.

Rigour

Dense description, comprehensive review and critique of findings, and interpretations by the research team enhanced rigor (Morse, 2015; Rolfe et al., 2018). Member checking was conducted to ensure reliability by seeking confirmation or clarification of any uncertain comments during the interviews (Kidd & Parshall, 2000) and verifying data between interview participants (Morse, 2015). Discussions and a handout were used to share and check preliminary findings with parents at a booth during the MMF Annual General Assembly (March 25-27, 2022; approximately 3,000 attendees). Field notes and reflective journaling were used to record contextual details, assist with pattern and theme recognition, build an audit trail and explore possible biases (Morse & Field, 1995).

Results

In total, 33 parents contacted LK about participating in the study. Inclusion criteria were not met by one parent, and despite two attempts to make contact, 13 parents could not be reached for follow-up. Semi-structured, qualitative interviews (Morse & Field, 1995) were conducted by

LK with 19 parents (3 of which were Elders), ranging from 40 to 80 minutes (M = 52.47). The majority of parents lived in rural communities (n = 14), and the others lived in an urban setting (n = 5). Four themes were generated during the analysis: (a) show me why you are here; (b) make it easier for me to take part; (c) create welcoming spaces; and (d) it should be a give and take experience.

Theme 1: Show Me Why You Are Here

Red River Métis parents want to know more about the research team: Who are the researchers? Why are they are doing the research? Who are they working with? How will they use the findings? They want researchers to be upfront and transparent about their Métis or non-Métis identities, their roles in the research and how Métis researchers are involved. However, as one parent stated: “It needs to be more than words” (006, Mother). Parents shared the importance of kinship and personal connections. Investing time to build relationships with Métis groups/organizations and community members is critical to finding research partners, champions and collaborators who are willing to share information, and building trust among parents so they feel more comfortable taking part in the research.

Who Are You?

Parents wanted researchers to disclose where they are from, the communities they belong to, their motivations for doing the research and who they are accountable to. One mother expressed the importance of researchers being transparent about their (non-)Métis status and/or collaborations with Métis researchers:

> I just wanted to know … It’s a proud thing to be proud of our own people … To engage people into conversating, it’s good that the person you’re talking to or if you have on your team a member who is Métis … It kind of opens up another warm welcoming of,

> "Okay, I'm the same as you and I know your struggles or your experiences." It kind of seals that deal of comfort for a lot of people ... [if researchers] come from Métis background and it's like, wow, they're so proud. They want this program to be successful. They're going to do anything to help. (004, Mother)

Other parents wanted researchers to share why they believe in the project and find ways to create a research atmosphere that is not too formal and scripted. One parent described researchers' typical approaches as:

> Almost "showman-y," almost like gimmicky. It almost seems like it's not really something I believe in what they're saying—more of like "We're doing this because this is something we're paid to do, not something we believe in," type of thing. (008, Father)

When researchers talk about their motivation for doing the research it can: "show them [parents] that there's people out there that actually want to, like, help them know … that there's help, there's information. … I love that" (018, Mother).

Who Are You Working With?

Parents were asked to identify potential research team members and collaborators to develop/adapt child health resources. Six parents wanted the MMF to be included in research with Red River Métis parents: "We are more helpful to you, you know, like when you're putting it out there that you're teaming up with MMF to do this; and it only makes sense to have a Métis person in it" (004, Mother). Five parents mentioned the importance of including Elders and medicine keepers in the research to ensure the inclusion of knowledge beyond Western health approaches: "Sometimes the health information can end up being very Westernized and not always the way that Métis people would necessarily start with dealing with an illness" (002, Mother). Collectively, these preferences highlight the importance of adequate resources within the MMF to facilitate these connections, review research requests and oversee approved research processes.

Trust was highlighted as a key part of engagement. One parent stated:

> I've found in Métis culture is people like to be invited specifically and to be invited by someone that they know to do something and then they're more willing to do it … People like word of mouth, and kinship is so important. (002, Mother)

Similarly, another parent added:

> That personal connection is key. It's important … If we look at historically, there's a mistrust of authority … There's a mistrust of doctors and medical professionals, and for good reason ... I don't have that personal experience because I was born with very pale skin. But I've seen it, and I've watched it in my family members and my friends and my loved ones. And it is very real. And so, there's a reluctance to trust and to reach out. (006, Mother)

Four parents noted that involving healthcare professionals could help build trust in the research project: "If my doctor would have given me this, I would have been like, 'Sure, I'll take part in this,' versus trying to find it through the MMF" (003, Mother). Four parents also suggested involving social service employees to help connect with families that may not typically be involved in research, but could benefit from the child health resource: "maybe another avenue to let parents know, like 'We're here to help you … Would you be interested in how you could learn more? What would have helped you?'" (011, Mother). Moreover, eight parents emphasized the importance of including diverse parent experiences within the research project. More specifically, parents wanted foster parents, lower income families, rural/remote community representation, and extended family members (e.g., grandparents, aunts, uncles) involved, recognizing there are many different family types and situations. One parent explained:

> We're the ones who know exactly what's going on with our children. We see it. We don't read it in a book. We see it every day. And us explaining this to you as a researcher will give more parents an opportunity to have information and to feel not so alone in this fight, whatever they're fighting against, whatever they're dealing with, with their kids, themselves. (018, Mother)

Theme 2: Make It Easier for Me to Take Part

Parents lead busy and demanding lives: "We're tired. Most of us are barely hanging on" (006, Mother). Parents highlighted multiple factors that influence whether they can participate in research, including their time, energy, competing priorities, childcare and costs. They shared practical ways to communicate study opportunities, such as including study information in existing communications and posting study information in frequently visited places. Parents said they want to be offered multiple options to participate in research (e.g., surveys, interviews, focus groups) and emphasized that their comfort with using virtual platforms (e.g., Zoom) increased during the COVID-19 pandemic.

Sharing Study Opportunities

Six parents suggested sharing study opportunities with families through the MMF by incorporating study information into existing communications or channels: "The pharmacy at the MMF is very well utilized and some of the programs are already in place. They were giving food boxes to Elders and families … you could slip in your research invitation that way" (002, Mother). Seven parents also suggested advertising study opportunities in frequently visited places, such as restaurant bulletin boards, post offices, community centres, and kids' entertainment centres (e.g., trampoline parks). Five parents mentioned schools and Métis daycares as relevant places for outreach because of their shared focus on child health: “Schools should be getting involved, especially elementary schools and stuff. This would be a fantastic thing to be presenting at assemblies or putting in like newsletters in schools so that parents can have access and know about this” (005, Mother). Three parents reported they would trust study information that was shared by trusted sources on social media sites, such as: “Facebook pages in the community … the trustworthy admins of that page. For me, like it would be our public health nurse or it could be someone really trustworthy that’s designated to operate that site” (004, Mother).

Accessible Ways to Participate

Nine parents said that the option to participate virtually is important. They emphasized the convenience of using Zoom, particularly during the COVID-19 pandemic and when their children are sick. However, others favored in-person sessions or surveys: “I definitely prefer in face, but I think Zoom is kind of the next best thing.” (011, Mother); “Those [in-person sessions] are nice. More of a casual setting. Yeah, those would be better. Like in groups” (015, Mother). Two parents explained that multiple options are needed, particularly for people without access to necessary technology:

> I think the easiest is this, the Zoom. And I think the only thing that would stop somebody is if they didn’t have Internet. I mean, I don’t know how much more easier it could be when we can do it over the computer like this. (020, Mother)

This study was conducted during the COVID-19 pandemic when in-person interactions were limited and parents seemed to be more comfortable using a virtual platform:

> Zoom is good. I enjoy Zoom actually. Since I've gotten to use it more, I do enjoy it because it is personal, too … I can see you … [It's] easy to use. You send me a link and I just click it and there I am. (001, Father)

Four parents wanted research opportunities to be made available as part of existing local events to make participation easier. One parent suggested "coming into the communities and doing group sessions with parents who want to, who are comfortable with it, and then they can do questionnaires if they don't want to talk personally" (018, Mother). Parents highlighted time as another factor affecting participation, and suggested that offering multiple options could help. For example, one parent preferred the convenience of a survey: "that I could just fill out… on my own time, if the kids went to bed and I could fill out a survey and send it in, that would be easier for me than doing a Zoom call" (013, Mother). One parent explained: "60 minutes for a lot of people is outside of their capacity … In the scheme of people's priorities, when they're not even managing their own care, 60 to 90 minutes is a highly long time" (002, Mother).

Incentives/Compensation

Parents suggested incentives such as free parking, food/snacks, gift cards or other types of gifts (e.g., water bottles), and flexible meeting times as ways to encourage participation: "You're going to get a lot more people sign up if they know that there's free food … I signed up to go get my vaccines at the community centre because I heard that they were giving away a water bottle and a donut" (005, Mother). Four parents highlighted that compensation for transport costs (e.g., mileage, bus ticket, taxi slip) can impact whether a family is able to participate. One parent shared:

> If you have a family coming from [city/town]—one of our Métis communities that's like about an hour and 15 minutes away—well that's a good $20 in gas there and back. And

> usually people from there don't really have the resources and the money and the income to be doing stuff like that … a mileage check could be an incentive, too. (020, Mother)

Four parents highlighted the importance of childcare support, including clear communication about whether childcare is provided on-site, for what ages, and whether snacks are available. "Childcare, that would be great. I would sign up right away" (013, Mother).

Theme 3: Create Welcoming Spaces

Red River Métis parents in this study said they want to participate in research spaces that are informal, welcoming and familiar to them. Formal spaces, such as churches and hospitals, were described as settings that are not comfortable. Parents explained that it is the people within a space who predominantly make a welcoming place. Gathering in a group and offering food can also create a more relaxed atmosphere and the opportunity to socialize beyond the research process itself. Additionally, parents said that it was important to ensure public safety measures especially during the COVID-19 pandemic.

Physical Spaces

This study took place during the pandemic, and many parents discussed safety in the context of COVID-19 precautions. For example, parents described a safe space as one that did not have too many people, allowed for social distancing, and was not located in a hospital setting: "Everybody now is concerned about COVID, so just to put it out there that people are double vaccinated … masks provided, sanitizer provided" (016, Mother).

Five parents said they prefer research spaces that are informal and relaxing. For example, some parents described not feeling comfortable in churches or medical facilities. Less formal settings and places with windows, daylight and a social atmosphere, such as coffee shops are preferred:

> Not medical facilities. You know, more relaxed atmospheres... in [my community] it's like the Friendship Centre. That's a safer space. You know, walking into public health, no, not really. Because there's a stigma attached with that, right. Government offices. No. It needs to be somewhere more relaxed, casual. (006, Mother)

Some parents living within or near the city of Winnipeg described not feeling comfortable going to the downtown area or certain areas of the city: "That's a really triggering location for a lot of people who won't go into places in the north end [of the city], because it's connected to their past or they don't feel safe there" (002, Mother). However, another parent cautioned that places some people may avoid could actually be places where parents have the most need.

Nine parents living in rural areas described their local community centres as safe spaces for research because they feel familiar and are welcoming to everybody. Four participants specifically mentioned places connected to Red River Métis such as MMF offices and Métis centres: "a Métis building here in the community … It's quiet and it's not so public because it's for Métis people, so it would be comforting to know that like what you're saying there is all confidential, and people would understand that " (004, Mother). Community centres were described as: "not fancy" (010, Mother), "spacious" (018, Mother), "always a safe place for everybody to go and meet" (016, Mother), where "everybody is happy to see you. They know you. If they don't know you, then they get to know you" (009, Mother). One participant explained: "it's the people there and the things they do … It's just very inviting and you could go once and then wait 5 years and go again and you wouldn't be treated any differently or anything like that" (010, Mother).

A Welcoming Feeling

In addition to the physical space, parents described how to make them feel comfortable and welcomed, such as having opportunities to interact (e.g., "ice breakers"), clearly stating that discussions should be kept confidential, and wearing informal clothing:

> You don't want to have to go somewhere where you feel like you need to dress up … I think sometimes when we start doing research projects or asking opinions or hosting information sessions, we want to make our best impression, and that's alienating … Don't show up in a three-piece suit … show up in a way that makes people comfortable … Put on the Batman mask and the Olaf mask [for the kids] and dress for the clients. (006, Mother).

Food was the most commonly reported way to welcome Red River Métis families, mentioned by nine parents: "People love luncheons. And it kind of puts it out there that you're having a friendly welcoming … People love to visit" (004, Mother). Additionally, parents emphasized the importance of offering food: "with the Métis everything is about food … that's just like a cultural expectation to open a dialogue with food and like tea or water" (002, Mother).

Similarly, six parents shared a preference for gathering in a group setting to participate in research: "a group conference or a group meeting is really good … you like to hear other people's opinions and you're all from the same the community. It's good" (004, Mother). One parent described a relative's reaction to information about the study: "She was like, 'I honestly don't know how I would contribute. Like, I don't know how to answer those questions [in an interview]. That's a lot of pressure on me, one person'" (006, Mother). She continued:

I think if you could have smaller, more … coffee house-style meetings and discussions where it's not so much pressure for me to like ask you a question and you answer, where you can just kind

> of chat and spitball, and those things just naturally start to flow. … Culturally speaking, that would be awesome, because we have, again, a tendency to mistrust that one-on-one and people in authority. So, if we're just gathering for an event and then we're, you know, chatting about some other stuff, I think that would probably be more honest. They'd be more forthcoming … because they'd be more comfortable. (006, Mother)

Theme 4: It Should Be a Give and Take Experience

Research should be an opportunity for both the research team and participants to share and learn together. Seven parents emphasized that the research experience should be reciprocal, that information sharing between researchers and participants should be mutual and create a beneficial experience for everyone. One mother described how it felt to be talked at in the past: "Yeah, it feels like being more of like, 'This is a presentation,' not so much of, 'This is information for you to need' type of thing" (008, Mother). In contrast, another parent described the collaborative approach taken in the current research: "Even doing this with you, I appreciate the time you took out of your life … and I feel like me and you doing this is even helping everyone. It's like I'm getting information from you, you're getting information from me. So, it's a give and take" (018, Mother).

Some parents suggested building fun activities into the research process to help researchers and participants learn something new, including cultural activities. One mother lamented the loss of Red River Métis languages, art, and baking and cooking techniques, and suggested events such as a "bake with granny day" or "going to an activity centre or a camp" as part of the research process (015, Mother). Another mother explained how fun activities can help us learn about culture without even realizing it. For example, she described her children enjoying watching the "Métis Minute" on TV:

> They kind of recognize the music and they'll ask more questions about a cart they see because like we don't have any carts in [city/town]. So, just seeing that and like, "Oh, that's what they used to drive a long time ago," and "Oh, they made that." It's like they got information on there that they're appreciating. I don't know if they're realizing that they're learning so much about their culture at that time. (011, Mother)

One mother expanded on the idea to conduct the study while doing an activity:

> Maybe while they're participating, doing—making something, an activity … [like] dot painting as you guys were doing the research … [or] someone is going to demonstrate or at the end give little packages on how to make Bannock … I've done the beading circles and they're talking about everything there … It's kind of relaxing." (015, Mother)

A parent offered another idea based on a recent experience:

> I've had a woman come and explain about all these different medicines … when it helps more, and stuff like that …if it was written, or there was pictures, diagrams—something to know what this is good for, what this root is good for. (020, Mother)

Discussion

Researchers have a responsibility to protect research participants from harm. Lack of respect and understanding can undermine trust, and research interactions should be viewed as opportunities to build cultural safety. Cultural safety refers to environments, relationships and systems that help people feel safe, valued and able to participate in research, and that respect their cultural, spiritual and belief systems (Williams, 1999). Key learnings from this study include the importance of establishing trusting and respectful relationships, having flexible options to participate (e.g., survey, online, in-person group), creating a welcoming/informal environment, and offering mutual learning opportunities within the research process.

The MMF has clear guidelines for providing compensation, reimbursements, gifts and food to show appreciation for parents' and Elders' time and knowledge (Kyoon-Achan et al., 2021; MMF, n.d.). Additionally, frameworks and policies exist that set expectations and guidelines for ethical healthcare research with Indigenous peoples (CIHR, NSERC & SSHRC, 2022; NAHO, n.d.; United Nations, 2007; University of Manitoba, n.d.). However, these documents do not capture the practical steps for engagement, such as routine interactions with partners and participants, that are essential for successful iKT and CBPR (Jull et al., 2018). Research training often does not fully prepare researchers to engage and interact with research partners/participants (Datta, 2018) and issues related to power in research relationships persist (Crosschild et al., 2021; Reimer-Kirkham et al., 2009). Our interactions can build or break research partnerships and relationships, and exploring these engagement details can help prevent tokenistic involvement (Liabo et al., 2020). We focus our discussion on these interactions and their impacts on cultural safety.

The concept of cultural safety was developed in Aotearoa, New Zealand by Māori nurse leaders, and requires healthcare providers and researchers to self-reflect on their preconceived assumptions, stereotypes, beliefs, personal and institutional positions of power, and the historical and ongoing impacts of colonial relationships underlying imbalances in power and privilege (Browne et al., 2009; Ramsden 2002, 2015). Cultural safety can only be judged by the Indigenous person receiving the care, and trust is paramount (Bull, 2010; Papps & Ramsden, 1996; Ramsden 2002, 2015). Parents in this study suggested practical ways to demonstrate respect and create welcoming spaces for parents to share their experiences, preferences and recommendations with researchers, all of which contribute to cultural safety. For example, parents wanted to understand researchers' motivations and connections to projects.

Communicating answers in a study information sheet is not enough. Such explanations must become part of each introduction to build transparency and trust (Plamondon & Neufeld, 2022). Researchers can show respect by sharing who they are, their connections with the Red River Métis Nation (i.e., as a Red River Métis citizen and/or via a working relationship with the MMF), their motivations for doing the research and their role in the project. These interactions foster getting to know each other as people beyond roles and titles (Robins, 2021). Researchers must also learn about the Red River Métis communities they are working with before and during the study (Blodgett et al., 2011; Dieter et al., 2018; Kyoon-Achan et al., 2021). Rix et al. (2014) used journaling to reflect on communication style, gauge community support for the project, examine philosophical beliefs and generate insights into how life experiences shape and influence how research is conducted. Understanding one's position within a study supports awareness of power and privilege and intersecting systems, such as racism, ableism and classism, which impact each interaction (Crosschild et al., 2021; Smith, 2006).

Parents in this study wanted to learn about child health study opportunities from trusted organizations, including the MMF, schools, daycares and health providers— approaches that have been supported in other studies (Cruz et al., 2014; Harrigan et al., 2014; Knisley et al., 2021, 2023; Kyoon-Achun et al., 2021; Peay et al., 2018; Schroth et al., 2015; Tracey et al., 2020; Williams et al., 2018). A trusted messenger is just as important as the message itself, and establishing collaborations with trusted organizations is essential for accurate data collection and uptake of findings (Nunan, 2020). Trust can and should be built during every interaction with Red River Métis families, community members and organizations (Kyoon-Achun et al., 2021). To that end, parents in this study said they want researchers to spend time in their communities. We organized informal meetings with the MMF and attended MMF events during this research project, which are strategies supported in the literature (Crosschild et al., 2021) Becoming known and earning acceptance through this process can help to build trust (NAHO, n.d.). The time and effort researchers invest in each interaction and establishing collaborative partnerships can be critical when tackling expected and unexpected barriers in the research process (Brett et al., 2014; Wilson et al., 2015). Our partnership with the MMF was essential to the successful engagement of parents and Elders in this study. Partnering with MMF staff as trusted messengers for sharing study materials made recruitment possible, even during the COVID-19 pandemic.

Our findings show that personal connections are important, as reported in other studies (Kyoon-Achun et al., 2021). In a systematic review of culturally safe communication, Jennings et al. (2018) argued that something as simple as "good, caring talk" can alter power dynamics in healthcare interactions. Words matter because they can sustain relationships and keep us connected (Kovach, 2018), but they also have the power to conceal and perpetuate injustices (Shaheen-Hussain, 2020). In Western/European research training, we are often taught to use sterile language and methodologies; however, personal anecdotes and stories are powerful communication tools (Curtis et al., 2023; Kovach, 2018). Sharing stories can also decolonize research (Kovach, 2018) and support cultural safety (Moller, 2016). In one study, researchers spent time with participating mothers over tea to get to know each other before data collection began (Butten, 2021). They shared information about themselves, discussed why they were doing the research and how they related as mothers. During the data collection phase, the researchers and participating mothers shared information and asked each other questions, creating a balance of sharing. In other studies, researchers used relational approaches, such as humour, storytelling and sharing meals, to keep the research atmosphere friendly and conversational, and to help decrease tensions and research-related anxiety (Hewer et al., 2019; Kyoon-Achan et al., 2021).

When conversations happen organically, such as over a meal, it supports more open and relaxed interactions within research, which can help build relationships and generate rich discussions and meaningful data (Bessarab & Ng'andu, 2010). Red River Métis parents in this study expressed a preference for relational approaches within the research process, including informal environments, gathering over food/refreshments, and providing opportunities to learn or be creative while participating in research. They suggested incorporating joint learning activities for researchers and participants, like beading circles and lessons about traditional medicines. Games, neighbourhood walks, crafts and shared meals have created safe spaces in research with First Nations and Métis women and girls (Cooper et al., 2019). These activities also provide opportunities to decolonize research and support reconciliation (Gerlach, Browne, & Greenwood, 2017; NAHO, n.d.).

Most parents felt comfortable using online formats during the COVID-19 pandemic, however, many looked forward to the return of informal group settings. Parents said offering multiple ways to participate in research is critical. Listening to parents' preferences and offering multiple ways to participate can shift the distribution of power, helping to promote equitable interactions and relationships between parents and researchers (Gerlach et al., 2017; Rolfe et al., 2018). Embracing an attitude of learning rather than knowing can move researchers from a position of authority over others towards a position of solidarity, curiosity, and openness (Plamondon & Neufeld, 2022). It also opens up opportunities for valuable learning beyond Western/European literature and scientific methods through listening, observing and interacting with research participants/partners (Loppie, 2007).

More work is needed within KT scholarship to acknowledge and respond to barriers that deter Red River Métis families' participation in research, and transform processes that reinforce racism and discrimination (Durey & Thompson, 2012; Lavallee et al., 2014). Red River Métis parents in this study said they want to participate in research and are willing to be contacted for future project phases. Relational approaches to research interactions challenge positions of power traditionally held by many academic researchers (Crosschild et al., 2021). Such approaches require valuing reciprocity, acknowledging parental expertise, and taking time to create opportunities to share knowledge and learn together (Crosschild et al., 2021; NAHO, n.d.).

Strengths and Limitations

This study was conducted in partnership with the MMF to understand how to engage Red River Métis citizens in Manitoba in the development/adaptation of child health resources. Due to the COVID-19 pandemic, we could not travel to Red River Métis communities and conduct in-person interviews or focus groups, which may have impacted the engagement of parents who preferred this option. Parents were not asked to demonstrate Red River Métis status (e.g., by showing a citizenship card) and it is possible that study participants were not official Red River Métis citizens. Nevertheless, because recruitment was done through the MMF, we can assume that all participants had some level of involvement in the Red River Métis Nation.

Conclusion

Very little research has focused on the distinct experiences of Red River Métis families. Parents in this study expressed a desire to participate in research that can improve child health. We cannot understand Red River Métis families' healthcare experiences without creating culturally safe spaces to share food, stories and knowledge, and to listen and learn together. Meaningful engagement in KT research can build—rather than break—trusting relationships and foster ways to implement research that respect and align with parents' preferences. Our engagement of Red River Métis parents early in the research process will help us incorporate their preferences and perspectives into the design of a larger project to adapt child health resources. More training is needed to improve researchers' abilities to engage in self-reflection, listen, recognize power relationships and demonstrate trust and transparency in each research interactions. Only through respectful and successful engagement can child health research be relevant, applicable and positively impact Red River Métis children, families and communities.

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CHAPTER 6.

Concluding Chapter

Overview of Findings

The cumulative results from this dissertation make a substantive contribution to advancing KT knowledge on the adaptation of child health tools for Red River Métis families and the role of KT science in reconciliation. In this concluding chapter, I provide an overview of the knowledge developed from the four dissertation papers to address gaps in the literature and the relevance of this dissertation to nursing, KT and patient engagement. I discuss the strengths and limitations of the work and conclude with directions for future research.

Effective strategies to improve child health information available to Red River Métis families cannot be developed without understanding their information needs and preferences. Findings from this dissertation reveal a critical gap in the child health information available to Red River Métis families and highlight a lack of research focused on their distinct experiences. This dissertation contributes critical new insights with the potential to support the adaptation and dissemination of child health information. Key learnings include the importance of establishing trusting and respectful research relationships; providing a creative and welcoming research environment; recognizing and responding to the unique and diverse experiences of Red River Métis parents; and the role of KT tools in countering a legacy of colonization (e.g., by supporting language revitalization). This dissertation builds on available knowledge to develop culturally safe and effective health information messaging and dissemination strategies.

Addressing an Identified Need

This dissertation takes a substantive step toward addressing a need identified by the MMF: Red River Métis families currently lack access to appropriate and meaningful child health resources when their children are sick. Having recognized this need, the MMF invited TREKK researchers to partner with them to adapt existing TREKK child health resources for the Red River Métis community. TREKK was established through the Government of Canada's Networks of Centres of Excellence Knowledge Mobilization initiative to accelerate sharing the latest evidence in pediatric emergency care with emergency healthcare providers and families. Background information on TREKK's creation and mandate (Chapter 2) helped set the stage for this dissertation and the need to culturally adapt KT tools.

Scoping Review

The scoping review in Chapter 3 mapped literature on Indigenous families' experiences seeking child health information and identified barriers and facilitators to information access. Like other Indigenous groups, Métis continue to experience the legacy of colonial policies that disrupt their ways of knowing and being (Clarke et al., 2016; Driedger et al., 2015; Tough & McGregor, 2007). This scoping review was not limited to Métis to allow exploration of findings in a broader Indigenous context.

Scoping review findings identified that Indigenous families do not have access to necessary health information to care for their sick children, which can lead to insensitive, ineffective and unsafe health care. There is a critical gap in understanding the information needs and preferences of Indigenous families who must make decisions about their children's health. Additionally, research on the distinct information-seeking experiences of Métis families is scarce. The findings highlight the broad networks families use to access child health information. Family and friends are vital sources of advice and support when children are sick; healthcare professionals are also sources of health information, reassurance, and advice regarding the best course of treatment. Parents reported turning to other sources (e.g., the Internet) if they did not receive health education during healthcare visits. Overall, we identified three barriers (*racism and discrimination during healthcare visits*, *ineffective communication with healthcare providers*, and *structural barriers)* and three facilitators (*easily accessible information*, *improved communication and relationships with healthcare providers*, and *culturally safe healthcare)* affecting Indigenous families' access to child health information. Our scoping review shares actions that healthcare providers, organizations, and researchers can take to improve Indigenous families' access to meaningful child health information, which includes providing the necessary infrastructure, training and resources to support health literacy and culturally safe health care.

Qualitative Study

Stage two of this dissertation included a qualitative study. The Métis Life Promotion Framework helped me to reflect on how information-seeking experiences and preferences affect Red River Métis parents': 1) sense of who they are a person/caregiver (Nature); 2) experiences of how others see themselves or how they want others to see them (Identity); 3) ability to express their information needs as a parent (Development); 4) ability to care for their sick child (Relationship); 5) ability to interact with others, such as healthcare providers (Network); 6) ability to be involved in their child's health care (Support); 7) social and cultural influences (Environment); and 8) ability to have a choice over their child's care (Governance) (Martens, Bartlett et al., 2010). These experiences and preferences are interrelated and influenced by community and cultural factors. As such, they should inform the cultural adaptation process.

Paper 3 (Chapter 4) shared the findings of Red River Métis parents' experiences and preferences for seeking health information when their children are acutely ill. Four themes were generated from the analysis: (a) *we're here too;* (b) *we are not all the same;* (c) *finding trustworthy information;* and (d) *information needs to be widely available.* Participants identified several tangible ways to modify existing parent resources, including: adding information on how to access Elders, healers and/or traditional medicines; showing different family structures, social gatherings, food, transport, and living situations; using Métis names; and incorporating Métis languages. Additionally, the findings demonstrate that developing culturally-appropriate tools that include this information can support Red River Métis families' information needs and preferences and ongoing efforts to revitalize Red River Métis culture and language. Drawing on our findings, we identified three key considerations for developing and/or adapting child health information: supporting Métis language and culture revitalizing, building relationships, and ensuring fit with the context. Culturally appropriate child health resources can help to counter a legacy of colonization by: focusing on the strengths of Métis communities (i.e., traditions, social support structures, community-driven solutions); promoting the understanding that Métis people, organizations, and communities have the knowledge and expertise to identify and address their concerns; and supporting the cultural identity of Métis by sharing knowledge and documenting these essential teachings for future generations (Task Group on Healthy Living Messaging, 2020).

Another aim in Stage 2 was to increase our understanding of the engagement strategies that can help expose Red River Métis parents to child health research opportunities and build trust and transparency amongst research partners and participants (Paper 4; Chapter 5). Only through respectful and successful engagement can child health research be relevant, applicable and positively impact Red River Métis children, families and communities. Four themes were generated from the analysis: (a) *show me why you are here;* (b) *make it easier for me to take part;* (c) *create welcoming spaces;* and (d) *it should be a give and take experience.* Findings show that a lack of respect and understanding can diminish safety in research. Research interactions provide opportunities to build cultural safety. This study identifies practical ways to demonstrate respect and create welcoming spaces for Red River Métis parents to share their experiences, preferences and recommendations with the research team. Additionally, study findings highlight how each interaction is an opportunity to build transparency and trust, and to reduce power imbalances. Researchers can show respect by sharing who they are, how they are connected with the Red River Métis Nation, their research motivations and their roles in the project. These interactions help researchers and participants get to know each other as people beyond formal roles and titles. We cannot understand Red River Métis families' healthcare experiences without creating culturally safe spaces within research—spaces to share food, stories and knowledge, and to listen and learn together. Through meaningful engagement in KT research, we can begin to build—–rather than break—trusting relationships, and implement research in ways that respect and align with parents' preferences.

This dissertation contributes to the scarce academic literature available on the child health information needs of Red River Métis families. There is also a lack of child health information created for Red River Métis families. Developing culturally appropriate informational tools can satisfy their information needs and preferences and support the revitalization of Red River Métis culture and language. This body of work makes substantial contributions to KT and patient engagement science by identifying tangible ways to engage Red River Métis families in research and to culturally adapt child health resources to meet their information needs and preferences. However, it also highlights the need to link this work with organizational and funding structures in health care to facilitate necessary system changes and long-term impacts on child health outcomes.

Relevance to Nursing

Exploring the experiences and preferences of Red River Métis seeking child health information and identifying barriers and facilitators affecting information access is very relevant to nursing. Findings from this dissertation show that healthcare providers are key sources of health information for Red River Métis families. Nurses can play a critical role in closing the gap of health inequities by improving access to this information. Nurses are in an ideal position to educate and support families during healthcare encounters, and the uptake of these findings can help nurses and other healthcare providers implement culturally safe care.

Many of the barriers identified in this dissertation (e.g., lack of culturally appropriate health information, stereotypical assumptions during healthcare encounters) contribute to the perpetuation of unsafe spaces that limit access to child health information, further reinforcing racism (Coombes et al., 2020; Durey & Thompson, 2012). Social justice and health equity are core values within the nursing profession, and nursing has an obligation to dismantle racism (Bell, 2021; Louie-Poon et al., 2022; Thorne, 2014; Zappas et al., 2021). Uptake of our findings requires nurses to be open to lifelong (un)learning, including critical self-reflection on their professional role and institutional power in contributing to culturally (un)safe care (Leyland et al., 2016). Establishing cultural safety involves moving beyond understanding Red River Métis cultural traditions and values to acknowledge how colonization and generational trauma have shaped current social determinants of health that breed health inequalities (Yeung, 2016). Additionally, as healthcare providers, researchers, community advocates, leaders, educators and citizens, nurses must remain open-minded and learn how to recognize and change oppressive and/or privileged behaviours (Bell, 2021; Zappas et al., 2021). However, direction on incorporating these values and learnings in practice is lacking (Horrill et al., 2021; Varcoe et al., 2014), and the nursing profession as a whole needs to support nurses with the necessary training, education and resources to provide anti-racist, culturally safe care and disrupt "practice as usual" (Gerlach, 2016).

Relevance to Knowledge Translation Science

This research makes a unique contribution to the process of culturally adapting KT tools by: (a) supporting ongoing calls for more distinction-based research that recognizes and celebrates the diverse and unique cultures of Red River Métis; (b) contributing to the knowledge base on how culturally adapting KT tools can support reconciliation; and (c) offering tangible ways to modify child health tools to meet Red River Métis families' information needs and preferences. Co-creation of child health resources must be done *with* Red River Métis families and communities and is essential for effective KT (Morton Ninomiya et al., 2022) and fundamental to decolonization (Smylie et al., 2014). This dissertation shares how KT methods can support revitalizing Red River Métis language and culture (e.g., by incorporating Red River Métis language into KT tools and incorporating baking, cooking or other cultural practices into the research process). Parents suggested tangible ways to modify existing KT tools for Red River Métis families, including adding information on how to access Elders, healers and/or traditional medicines, depicting different family structures, transport, and living situations, using Métis names, and depicting social gatherings with food. The findings demonstrate that while modifying the appearance of a resource can be part of the cultural adaptation process (Resnicow, 2000), there must also be an explicit focus on decolonizing (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007) and anti-racist approaches (Louie-Poon et al., 2022) during the KT process, including recognizing the generational impacts of colonial oppression and racism on the healthcare experiences and information preferences of Red River Métis families. These approaches require researchers to: (a) develop a better understanding of the problems that Red River Métis parents may face within the healthcare system, such as how some stories remain dominant and others marginal; (b) be aware of power in research relationships and actions to equalize power dynamics; and (c) incorporate reflexivity and reciprocity within research practices (Aranda, 2006).

Relevance to Patient Engagement Research

The MMF invited TREKK to partner in adapting child health resources to make them meaningful and useful to Red River Métis parents. The need for this research was identified by the MMF, which is a crucial component for successful KT and patient engagement research. The engagement of Red River Métis families in this research will undoubtedly play a central role in successfully adapting child health resources for this community. The findings contribute to the importance of relational approaches within patient engagement. Although parents are busy and live with many competing demands, participants in this research expressed a desire to be involved in future studies, particularly if the research environment continues to be welcoming and values reciprocity. Personal connections are prominent in our findings, as has been reported in other studies (Kyoon-Achun et al., 2021). Parents identified tangible ways for researchers to build trust and create welcoming environments to engage families in research: spend time in communities, meet in informal spaces, gather over food/refreshments, be clear about who you are and your motivation for doing the research, and provide opportunities to learn or create something together during the research process. Relational approaches require investments of time and resources. This dissertation contributes knowledge on strategies within patient engagement research that can build trust, create opportunities to share knowledge and learn together (Crosschild et al., 2021; NAHO, n.d.), as well as respectfully and meaningfully equalize relationships (Crosschild et al., 2021) to co-create useful child health resources.

Overall Implications for Research and Practice

Integrating major findings from the scoping review and the qualitative study with central perspectives from the research literature exposed key areas with the potential to improve the process of culturally adapting child health resources for Red River Métis families. Several key elements recur in our findings and are supported by related research:

1. Distinctions-based approaches are needed in healthcare and research (Task Group on Healthy Living Messaging, 2020), yet there is a lack of studies focused on the distinct experiences of Métis families in Canada (Cooper et al., 2020; Fiola, 2015; Furgal et al., 2010; Hayward et al., 2020; Logan, 2007). Determinants of effective health communication differ from context to context, and the variety of parent preferences shared in this dissertation is reflective of the different contexts in which Red River Métis live. We can serve these varied needs with layered approaches to communication and sharing child health information.
2. Access to culturally appropriate health information is vital to Indigenous families (Coombes et al., 2020; Eni & Rowe, 2011; Rose & Garwick, 2003; Stewart et al., 2013). Although the qualitative study findings highlight mixed messages around the relative value and benefit of providing Red River Métis-specific resources, it cannot be understated that this is a function of colonization (Fiola, 2021).
3. Cultural adaptation must move beyond changes to the surface structure (i.e., appearance, language translation) to complete the transformation of KT tools by addressing the particular group's core values, beliefs, and norms (Resnikow et al., 2000). This process must also be culturally safe, which requires research teams to understand, respect, and

engage with Indigenous families' beliefs and experiences of health, healing, and illness, as well as recognize the detrimental effects of colonization, racism, and prejudice on healthcare behaviours and experiences (Amgarth-Duff et al., 2019; Coombes et al., 2020; Eni & Rowe, 2011; Hendrickx et al., 2020; Henry, 2007; Latimer et al., 2020; Rose & Garwick, 2003; Stewart et al., 2013; Wright et al., 2019a, 2019b).

4. The co-creation/adaptation of child health resources can support revitalizing Red River Métis language and culture. Resources can acknowledge and respect the need for connecting with Elders, Indigenous healers and traditional medicines by including clear signposting to additional sources of information, advice and support (Amgarth-Duff et al., 2019; Butten et al., 2021; Coombes et al., 2020; Kealoha & Kataoka-Yahiro, 2017; Rose & Garwick, 2003; Stewart et al., 2013; Wright et al., 2019a, 2019b, 2020). They can also support the cultural identity of Métis by sharing knowledge and documenting important teachings for future generations (Task Group on Healthy Living Messaging, 2020). Parents in our qualitative study expressed interest in learning an Indigenous language. Placing Michif and/or another language alongside English text in a child health resource could be an effective, fun and engaging way to integrate language to help adults and children learn together.
5. Relationships are key for information sharing and are tied to trust. Kinship and social networks are sources of information and comfort for parents, and these can be effective approaches for KT (Morton Ninomiya et al., 2022). However, healthcare providers are key sources of health information for Indigenous families and must also be considered in KT plans (Butten et al, 2021; Henry, 2008; Neill, 2008; Neill et al., 2015). Investments

also must be made to increase the representation of Indigenous clinicians and provide anti-racist training for all healthcare providers (Williams et al., 2022).

Strengths and Limitations

Scoping Review

Given the complex nature of accessing health information and the various ways this access is defined or understood, it is possible that studies relevant to the scoping review may have been missed. However, a strength is the involvement of an academic librarian with significant expertise in creating robust search strategies for Indigenous-focused research. Another strength is that multiple reviewers were involved in screening and data extraction (Arksey & O'Malley, 2005; Levac, Colquhoun & O'Brien, 2010). Literature that was not published in English was excluded due to dissertation budget and time restrictions, which may impact comprehensiveness and generalizability.

Qualitative Study

To the best of my knowledge, the qualitative study of this dissertation research is among the first aimed at understanding Red River Métis parents' experiences and preferences regarding access to child health information when their children are acutely ill. It was conducted in partnership with the MMF to help address the lack of child health information for Red River Métis families. Although the study was focused on Red River Métis parents, findings such as incorporating relational approaches and efforts to revitalize Red River Métis culture and language within the KT process, may be transferable to different Indigenous Nations in Canada who share similar experiences with systemic racism in the healthcare system.

Study findings were shared and verified with Red River Métis citizens who attended the MMF annual general assembly. However, there are some limitations. First, data collection occurred during the COVID-19 pandemic, which restricted the ability to travel to rural communities and conduct in-person interviews or discussion/focus groups. The original study design needed to be modified to virtual interviews. This may have impacted the engagement of parents and Elders who preferred more relational approaches. Second, to maintain the feasibility of this dissertation research, non-English speaking populations were excluded. Although research has been successfully conducted with Red River Métis using English-only focus groups and interviews (Cooper et al., 2020), this limitation may have created barriers to participation for parents and Elders who are more comfortable speaking another language (e.g., French, Cree-Michif, French-Michif, Cree, Oji-Cree, Saulteaux). Third, because parents were not asked to validate their Red River Métis status (e.g., show a citizenship card) it is possible that some study participants may not fall under the official definition of Red River Métis citizens. However, as participants were recruited through the MMF, it is assumed that all participants had some level of involvement in the Red River Métis Nation. Finally, although this research was conducted in close collaboration with both the MMF and my supervisory committee member, Dr. Michelle Driedger, who is a Red River Métis citizen and scholar with extensive experience conducting research with the MMF, I am not a Red River Métis citizen. Thus, it is possible that some participants did not feel comfortable disclosing their experiences and preferences to a white researcher.

Future Directions

Findings from this research will inform the adaptation and dissemination of existing child health resources in partnership with the MMF to ensure they reflect Red River Métis families' information needs and preferences. Red River Métis families will be engaged to provide their feedback on the adapted resources': (a) content; (b) usability (e.g., usefulness, relevance, simplicity, length, aesthetics, future use, influence on health decisions and recommendations to others; Hornbæk, 2006); and (c) responsiveness to cultural and language needs. Research to evaluate the resource can help to increase knowledge uptake and use by Métis families, its utility in supporting the efficient use of health services (e.g., prevent readmission, shorten length of stay) (DeWalt & Hink, 2009), and how to improve healthcare experiences. In future research, scholars should also pay attention to structural barriers to health (McCallum & Perry, 2018; Nutbeam, 2000) and larger, more holistic responses (Ali et al., 2019) that identify healthcare providers' and community organizations' use of child health information resources and their views on how these resources could be developed, implemented within clinical care and shared with Red River Métis families. For example, researchers could explore barriers and facilitators that shape the extent to which healthcare professionals share information. Additionally, it is important to identify factors that influence health and community organizations to invest in developing and disseminating evidence-based information to ensure the sustainability of resource adaptation within the healthcare system.

Conclusion

This dissertation takes a pivotal step toward addressing a need identified by the MMF for Red River Métis families to have access to culturally relevant and meaningful resources when their children are acutely ill. It also supports equitable health care for all children in Canada. I conducted a multi-phase, multi-method study guided by ethical, iterative, culturally based and process-oriented methods that were relational, respectful, relevant, reciprocal and responsible. Study findings have implications for clinical practice communications, KT, and patient engagement science.

Using scoping review methods, I mapped literature on Indigenous families' experiences seeking child health information and identified barriers and facilitators that affect information access. The findings indicate that Indigenous families do not have access to the necessary information to care for sick children, which can lead to insensitive, ineffective and unsafe healthcare. Additionally, there is a critical gap in understanding Indigenous families' information needs and preferences when making decisions about children's health. Strategies to improve information available to Indigenous families cannot be developed without learning from families' experiences, and the responsibility for finding this information should not rest solely with Indigenous families.

The scoping review and qualitative study findings showed a lack of child health information for Red River Métis families. The qualitative study surfaced themes from Red River Métis parents' and Elders' information-seeking experiences and preferences that increase our understanding of culturally safe healthcare communication and adaptation of child health resources. Developing culturally appropriate child health resources can support families' information needs and preferences and support the revitalization of Red River Métis culture and language. Findings from this dissertation provide essential insights for parents, healthcare providers, policy makers, and service providers about how to help worried Red River Métis families find child health information and make healthcare decisions for their sick children. Investments of time and resources are necessary to build relationships with the MMF, organizations, communities and Red River Métis citizens. Moreover, increasing the number of Red River Métis researchers and clinicians is vital to co-create these resources and disseminate them effectively.

Health information is a fundamental component of high-quality health care. We must partner with Red River Métis families and other stakeholders to identify their healthcare priorities and how they fit within healthcare programming, policies, and procedures (Cooper & Driedger, 2015). This dissertation has generated new knowledge on the information-seeking experiences and preferences of Red River Métis families and informed the cultural adaptation of existing child health resources. The findings contribute to future research planning that can continue to expose and challenge the colonial processes perpetuating inequitable access to child health information.

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Appendix A.

Interview Guide (Discussion Group or one-to-one interview)

Title of Project: Engaging Metis citizens in Manitoba in the development of child health resources

Good morning/afternoon. Thank you for taking the time to meet with us. We would like to ask you some questions about children's health that you might like more information about, as well as the best way to get this information. For example, other people have said they like to get child health information as videos or in a storybook. We would also like to explore ways to make it easier for Metis citizens to be involved in research about their children's health. We are going to tape while we talk to make sure that we catch everything that we talk about. All the information we collect will be anonymous. Any names or identifying information will be removed. If you provided verbal consent, then your name will be kept on that audio recording only. You may refuse to answer any questions or leave the discussion at any time. Do you have any questions before we begin? Please feel free to ask questions at any time during the interview.

To start, we thought it would be good to do an 'ice breaker'. There are lots of pictures in the middle of the table. Please choose one picture. Then each of you will be asked why you chose that particular photo. If you don't want to take part, simply say "pass" when I come to you. *[The group facilitator will start, in order to demonstrate the action - this would only be done during an in-person group session]*

Ok, let's get started:

You have been given some examples of information that have been created to help parents when your child is sick. We want to change some of these tools so they better meet the information needs of you and your family.

1. Do you think the information that you were shown should be changed in any way to be more helpful for Metis families?
    - How should the resources be changed/adapted?

        a) Different topics needed?
        b) Format preference (e.g. information sheet, video, infographic)?
        c) Do they need to be in a different language?
        d) Different art work?

2. Where do you look for health information when your child is sick or injured?

    a) Who do you go to?
    b) Where would you look?
    c) How satisfied are you with the information you get? Does it usually answer your questions? Why/why not?
    d) Are you able to get the information when you need it?

3. Where should we look to find the necessary information to help us adapt the resource?

4. Who should be involved in this research in addition to parents?

5. How can we make it easier for Metis parents to be involved in the research project?

    a) As a participant - i.e., focus group/interview
    b) As a member of the research team - i.e., Advisory Committee

6. How should we recruit parents who may be interested in participating in the research project?

7. How can we make sure that everyone's perspectives are included in the research project?

8. What are some of the ways in which we can make sure everyone feels safe when working together on this research project? For example:

    a) What meeting space(s) should be used for focus groups, advisory group meetings?
    b) What types of things should we think about to make sure the environment and physical space is considered safe by everyone participating in the research?
    c) Are there any spaces that should be avoided?

Thank you for your thoughtful responses to our questions. Is there anything else that you think we should know about the things that are available for parents regarding their child's health?