Evaluating a Métis Community Pilot of Dried Blood Spot Testing within a Métis-Specific Cultural Response for Those Living With/Affected by HIV and Other STBBI

By

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B.A., University of Victoria, 2016

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF PUBLIC HEALTH

in the School of Public Health and Social Policy

Supervisory Committee

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Abstract

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There is a shortage of literature on culturally grounded Métis approaches to addressing human immunodeficiency virus (HIV) and sexually transmitted and blood-borne infections (STBBI). The goals of this research were two-fold: to document and explore the development of an emerging Métis model of health and wellness for people living with or impacted by HIV and STBBI, and to conduct an evaluation of a dried blood spot testing (DBST) pilot for HIV and STBBI in Alberta drawing strongly on perspectives of Métis community members. This study utilized community-based and Indigenous research approaches in partnership with Shining Mountains Living Community Services (Shining Mountains) to address these goals. The first research goal (documenting and exploring a Métis model of health and wellness for people living with/impacted by HIV/STBBI) involved three gathering circles comprised of eight diverse Métis community members and stakeholders, which was supplemented by a community mapping exercise, and resulted in the development of the Red River Cart Model. The second research goal (evaluating a pilot of DBST for HIV/STBBI) involved the analysis of 26 survey responses and four gathering circles comprised of 19 participants who were self-identifying Métis individuals who received DBST at one of two events in the Métis community; semi-structured interviews with three DBST providers; and the document analysis of minutes from meetings with stakeholders held throughout the planning process of the DBST pilot. Results include the Red River Cart Model (a service tool and multi-level conceptual model describing a Métis understanding of health within an HIV/STBBI context) and suggest that DBST is an acceptable community-led testing intervention for Métis people. This research builds on limited existing literature by articulating a Métis model to health and wellness which can be used by service providers, policy makers, and Métis communities, and provides evidence in support of a testing intervention implemented by Métis Peoples for Métis Peoples.

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ACRA: Aboriginal Community Resilience to HIV/AIDS

AHS: Alberta Health Services

AIDS: Acquired Immunodeficiency Syndrome

CAAN: Canadian Aboriginal AIDS Network

CATIE: Canada's Source for HIV and Hepatitis C Information

CFIR: Consolidated Framework for Implementation Research

CIET Canada: Community Information and Epidemiological Technologies Canada

CIHR: Canadian Institutes of Health Research

DBST: Dried blood spot testing

D&S: DRUM & SASH

ELISA: Enzyme-linked Immunosorbent Assay

HBV: Hepatitis B Virus

HCV: Hepatitis C Virus

HIV: Human Immunodeficiency Virus

IS: Implementation Science

KT: Knowledge Translation

LGBTQ2S+: Lesbian, Gay, Bisexual, Transgender, Queer, and Two-Spirited (and other associated identities, represented by the + symbol)

MNA: Métis Nation of Alberta

MRP: Most Responsible Person

NAHO: National Aboriginal Health Organization

NLHRS: National Laboratory for HIV Reference Services

PARIHS: Promoting Action on Research Implementation in Health Services Framework

PHAC: Public Health Agency of Canada

POC: Point of Care

PPH: Population and Public Health

RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance

SES: Socioeconomic Status

Shining Mountains: Shining Mountains Living Community Services

STBBI: Sexually Transmitted and Blood Borne Infections

STI: Sexually Transmitted Infections

Acknowledgements

I would like to acknowledge and thank the Métis people who have generously given their time to this research and shared their experiences with me. I am also incredibly grateful to Raye St. Denys and Kandace Ogilvie, and the work of Shining Mountains Living Community Services; without them I could not have done this research. I was warmly welcomed into the community, and I am honored to have been involved with this Métis-specific work of DRUM & SASH. It was a privilege to meet so many amazing Métis people throughout this journey, which has further fueled my passion about Métis health and communities. I would also like to thank the DRUM & SASH team for supporting my learning throughout my MPH.

I am deeply grateful to my supervisory committee for the guidance and encouragement given to me throughout this process. To Dr. Cathy Worthington: I appreciate your tireless devotion and dedication to community-based research and working with Indigenous communities. Your enthusiasm is evident, particularly when it comes to the mentorship of future Indigenous researchers. To Dr. Rachel Landy: I always appreciate our 'debriefs', and your openness and advice regarding my thesis, my life, and everything in-between. You have shared a wealth of knowledge with me and being able to talk ideas through with you has increased my confidence. To Dr. Renée Monchalin: thank you for joining my supervisory committee and adding a Métis voice and lens to my writing. Your feedback has opened my eyes to Métis research and perspectives I was not aware of, and your work in the field of Métis health and HIV research is inspirational to me. Each of you has contributed something incredibly valuable to me and my work. I could not have selected a better, or more supportive, supervisory committee.

I am thankful for the financial support provided to me by the Universities Without Walls, and the BC SUPPORT Unit Vancouver Island Centre, which allowed me to conduct this research.

To those whom I have worked with and collaborated in my Métis community in Victoria, or through the Métis Nation of BC, I thank for having an impact on my life. Especially the strong Métis women and Elders, who inspire me and encourage me to be the best person I can be.

I also want to thank my family (both mine and Mike's side) for their love and support. I owe my dad a special thank you for driving me to the airport so many times, often with short notice, so I could conduct this research. And I am endlessly thankful to my fur family (my husky Mara and two rescue cats Missy and Hurley) for their love and cuddles when I was stressed.

Finally, and most importantly, I thank my husband Michael, who has tirelessly supported me throughout this degree. Words cannot express how grateful I am to have you in my life.

Chapter 1: Introduction

"*...it is extremely rare and unusual when Indigenous accounts are accepted and acknowledged as valid interpretations of what has taken place. And yet, the need to tell our stories remains the powerful imperative of a powerful form of resistance.*" (Smith, 2012, p. 36)

This thesis is a sub-study which was conducted within a larger five-year Canadian Institutes of Health Research (CIHR) Implementation Science team grant that aims to scale up, implement and evaluate shared care models for HIV/STBBI in several Indigenous communities in Alberta (DRUM & SASH, 2020). This thesis research was conducted using community-based research approaches, and as such, is strongly grounded in the Métis community, Métis knowledge, and Métis approaches to research and health. The goals of this thesis research are twofold: to document and explore the development of an emerging Métis model of health and wellness for people living with or impacted by HIV (human immunodeficiency virus) and sexually transmitted and blood borne infections (STBBI), and to conduct an evaluation of a dried blood spot testing (DBST) pilot for HIV and STBBI in Alberta drawing strongly on perspectives of Métis community members. To facilitate this research, two research questions were developed:

1. What could a Métis-specific cultural response to HIV and STBBI look like?
2. Is DBST an acceptable testing method for Métis communities?

These research goals were developed through consultation with Shining Mountains Living Community Services (Shining Mountains) based on Métis community member interest in a Métis-specific model of health for people living with HIV or impacted by STBBI, and community requests for testing at events. By utilizing Métis knowledge and approaches, Indigenous methodologies and Implementation Science (IS), I promote Métis voices in order to allow Métis Peoples and communities to speak about their experiences and opinions regarding their health and wellbeing as they relate to HIV and STBBI. As the quote from Linda Tuhiwai Smith above discusses, the stories of Indigenous Peoples form an important act of resistance (Smith, 2012). Métis Peoples, like many other Indigenous Peoples across the globe, have survived many past and current attempts to eliminate them through assimilation, disempowerment, oppression, and colonization (Dyck, 2009). Despite these setbacks, Métis Peoples remain strong. Throughout this thesis, my aim is to highlight the strength, wisdom, and resilience of Métis Peoples and communities when it comes to their health and wellbeing.

This thesis is structured to allow the reader to follow the entire process of the research. The introductory chapter introduces the reader to core concepts and context which are important for understanding this research. The literature review discusses relevant research and findings for Métis Peoples, including HIV/STBBI statistics, barriers to testing, shared care models, IS, and Indigenous approaches to evaluation. The methodology chapter explains the theoretical underpinnings of my approach to research, how the research was conducted, and the rationale for the methods that were used. The results chapter provides the outcomes of data collection and the analysis processes. The discussion chapter interprets the findings in the context of what is known already within the literature and provides recommendations for future research and programming.

Some sources referenced in this thesis refer to First Nations, Métis and Inuit as Aboriginal Peoples. The term Indigenous has largely replaced Aboriginal and is the preferred language of many Indigenous Peoples. Therefore, I only use the term Aboriginal when the referenced materials do so. Additionally, I include the accent on the term Métis simply because many Métis governments and communities do so as well. My intention is not to privilege French

Métis ancestry, although I acknowledge that this is an important conversation that needs to take place among Métis Peoples (Macdougall, 2017).

Who are the Métis?

I preface this section by highlighting the challenges and difficulties that arise when discussing identity. The debate around the definition of Métis identity is considered controversial to many (Richardson, 2016). In my opinion, attempts to reduce Indigenous identity to one of three categories (First Nation, Inuit or Métis) are reductionist, and do not do justice to the unique nature of individual communities, kinships, identities, and ancestries. My intention here is not to take any particular side with respect to who is or is not Métis, but to provide a balanced perspective using what other prominent Métis scholars and researchers have written.

It is important to note that the Métis are a distinct people that arose from the marriage of European settlers (typically fur traders) with First Nations women, as early as the 17th century according to some sources (Standing Senate Committee on Aboriginal Peoples, 2013). Their offspring, who were half Indigenous and half European, were often excluded from their First Nation and European settler communities, and became reliant on themselves, forming their own communities. Subsequently, these communities developed unique and distinct cultures and traditions which formed the beginning of what we now know as the Métis Nation (Métis National Council, n.d.). Depending on their originating First Nation and European identities, Métis Peoples were referred to as 'Half-Breeds', 'Bois-brule', 'li Michif', 'Otipimisiwak' ("the people who own themselves" in Cree), 'Mixed-bloods' or 'Bungi'. The introduction of the term "Métis" to represent these communities came much later, and was controversial at the time (Macdougall, 2017).

The term Métis did not appear on Canadian census form until the year 1986, approximately one year after the census began to officially gather data on Indigenous Peoples, and after the identification of Métis as Aboriginal people within s.35 of the Constitution Act in 1982 (Andersen, 2016). Today, the majority of Métis Peoples live in what is considered the "Métis homeland", which extends from Western Ontario, across the prairies and into North-Eastern British Columbia (Gaudry, 2018b). The Métis homeland also extends into the Northwest Territories, as well as into the Northern United States (Métis National Council, n.d.). Today, 84.9% of Métis Peoples in Canada reside in either in British Columbia (BC), the Prairie provinces, or Ontario (Statistics Canada, 2011). Communities across the homeland developed along routes of the historic fur trade in order to facilitate trading and the semi-nomadic lifestyle of Métis fur-trappers, traders and buffalo hunters.

There are multiple opinions voiced by many authors and scholars on who should be able to call themselves Métis. The Métis National Council defines "Métis" as a person who self-identifies as Métis, is accepted by the Métis Nation, is of historic Métis Nation Ancestry, and is distinct from other Aboriginal Peoples (Métis National Council, 2011). This definition was adopted by the Métis National Council in 2002, and was subsequently adopted by the other provincial Métis governing bodies within the Métis National Council (Métis National Council, 2011). This definition was affirmed by the Supreme Court of Canada in 2013 during a case which was brought into the court system by the Powley family of Sault St. Marie in Ontario, who were charged with unlawfully hunting a bull moose without a valid license and species tag (Supreme Court of Canada, 2003). In *R v Powley*, the Powley family claimed they had rights as Aboriginal peoples to hunt on their homeland. This historic Supreme Court Case decision ruled that Métis identity as it pertains to s.35 rights in the Constitution Act must meet three distinct criteria: that the individual in question self-identifies as being Métis, that they can prove an ancestral connection to a historic Métis community, and that a modern-day Métis community accepts them as being Métis (Supreme Court of Canada, 2003). This is now referred to as the ‘Powley test’; individuals who do not meet the criteria within the Powley test cannot register as citizens of the Métis Nation, and cannot participate within the government, or vote, within the Métis Nation.

Differences in opinion have arisen regarding what constates a “historic Métis community” as well as what can be considered “proof of ancestry”. Unlike the Indian Registry, there is no federally-managed historic registry of Métis Peoples (Métis National Council, 2011). This places the burden of proof on the Métis citizenship applicant. Proof is usually considered the record of a direct ancestor as “Half-breed” or “Métis” in the 1901 Canadian census, or a documented Manitoba land claim or Métis scrip (Métis National Council, 2011). This becomes more challenging if one’s Métis ancestors resided outside of areas where scrip was historically issued, such as areas outside of the prairies (Métis National Council, 2011). Scrip was a federal policy to extinguish Métis rights and title in exchange for tickets for parcels of land (Gaudry, 2018a).

The Métis Nation of Ontario has conducted and commissioned historical research regarding Métis communities within its province, some of which fall outside of the “historic Métis homeland” map (2020). The Métis Nation of Ontario has published the findings of this research on their website. However, this has caused controversy within the Métis National Council. A report written by the President of the Métis National Council titled, *Addressing the Integrity of the Historic Métis Nation Homeland,* states that the Métis Nation of Ontario joined the Métis National Council in 1994 with a clear understanding and expectation that they would uphold the national definition of the Métis Nation and its Homeland (Chartier, 2018). The report argues that the territorial and socio-cultural bounds of the Homeland map are what make Métis Peoples citizens of the Métis Nation, and distinguish them from persons of mixed-Aboriginal ancestry who do not meet the requirements of Métis identity. This report also states that the Métis Nation of Ontario has attempted to extend the boundaries of the Métis Homeland map by including six new historic communities within Ontario, of which only one has been accepted by the other governing bodies within the Métis National Council as constituting a historic Métis community (Chartier, 2018). This shows that disagreements exist among the governing members of the Métis Nation on what constitutes a "historic Métis community".

One perspective on Métis identity is centered around ancestry which is rooted in the Red River Settlement, now Winnipeg. Métis scholars have argued that mixed-blooded Aboriginal people have arisen throughout Canada, but the Métis are those who emerged as a distinct national group from the unique customs and cultures from the Red River Valley specifically (Chartier, 2018). They argue that the Red River Settlement was the birthplace of Métis Nationalism and is therefore the heart of the Métis Nation (Chartier, 2018). For these scholars, being Métis is rooted in the political will, cultural identity, and struggle for rights of a smaller group from Western Canada (Chartier, 2018). Researcher Chris Andersen (2014) corroborates this view; he writes that the term "Métis" should not be a catch-all term for individuals of mixed Indigenous ancestry who have been disenfranchised by various mechanisms of the Canadian state. Métis lawyer and writer Chelsea Vowel holds a similar view, and writes the following about Métis Peoples and identity: "We aren't just found in the Red River (though almost all of us have kinship links to it), we are a diaspora that came out of a specific history to form our own communities….a history of settlement, movement, intermarriage, cultural growth, roots dug deep” (2011, p. 1). Although Vowel believes most Métis to have ancestral links to the Red River Settlement, she recognizes that diaspora has led to distinct Métis communities across the homeland.

Others have questioned whether historic Red River ancestry is a requirement for Métis identity. Métis legal scholar Kerry Sloan, whose doctoral thesis focused on Métis understandings of community and territory with a focus on Métis Peoples in BC, writes of evidence that historic Métis communities were established in the north even before the Red River Settlement (2017). Sloan (2017) writes of the Powley test for a Métis community, which is defined as a group of Métis with a distinctive collective identity, living together in the same geographic area (both historically and currently) and sharing a common way of life. She challenges this definition, stating that this definition of a historic Métis community is too restrictive and is incongruent with Métis understandings of community (Sloan, 2017).

Others offer definitions of Métis identity which are less focused on the Red River but are still prairie centric. Métis Scholar Adam Gaudry, who writes about Métis identity, history and political thought, claims that there are two uses of the term “Métis”, one grounded in history (“Métis Peoples”), and one which has emerged more recently (“New Métis”) (2018b). Gaudry (2018b) states the following about a historical identification of Métis identity:

> The first is the oldest form of Métis identity, grounded in collective Métis action, cultural practice, and political assertions from at least 1816. This identity is grounded in a common culture, common historical experience, and a common sense of self that emerged in the historic "North-West," the prairies and parkland in what are now Manitoba, Saskatchewan, and Alberta and whose diaspora put Métis farther afield. Thus,

> the Métis are both a people and an Indigenous Peoples in the fullest sense of those terms, leading to the common use of the collective name "Métis Nation" among Métis.
>
> (p. 166)

According to Gaudry (2018b), “new Métis” are self-identifying Métis who have recently discovered their mixed Indigenous ancestry, and have created their own communities, rather than connect with historical communities. Examples of the “new Métis” according to Gaudry (2018b) include Métis communities from Eastern Ontario, Quebec, and the Maritimes. He suggests that “new Métis” take on Métis identity due to enduring confusion around the definition of Métis identity, the pervasive definition being one grounded in mixed race rather than a distinct Indigenous culture (Gaudry, 2018b). Although Gaudry’s definition is more open than ones that are Red River centric, this still places the onus on communities to prove that they meet Powley ruling requirements of a historic Métis community.

On the other end of the spectrum are authors and scholars with more inclusive definitions of Métis identity. Métis social work scholar Catherine Richardson (2016) says the following about Métis identity: “I understand Métis as someone who has both European and First Nations ancestry, who defines themselves as Métis, and who experiences some connection to a Métis community” (p. 11). Richardson (2016) also states that the current political debate around Métis identity implies that some Métis are more “authentic” than others (p. 14). Other authors such as Monique Auger (2017) have written about the role that self-identification plays in Métis identity. Auger (2017) writes about Harry Daniels, a Métis advocate for the inclusion of Métis Peoples in the Constitution, who advocated for an inclusive definition of Métis nationhood that accepted those who self-identified as Métis (Standing Senate Committee on Aboriginal Peoples, 2013). Métis health researcher Carrie Bourassa also acknowledges the existence of Métis communities in Eastern Canada in her doctoral thesis, and highlights that some of these communities, as well as some in central Canada, reject the Métis National Council definition of Métis, and assert their own definitions (Bourassa, 2008).

Despite disagreements in Métis identity politics, there is a fundamental link to self-identification and a Métis culture that remains consistent: Métis Peoples are much more than a “mixed” peoples derived solely from two identities. Métis Peoples have rich and distinct culture and way of life which should be equally respected and honored as othered Indigenous groups. (Métis culture and worldview will be discussed in the Methodology chapter).

Métis Governance Across Canada

In order to better represent the distinct needs of the Métis at the federal level, the Métis Nation separated from the Native Council of Canada and formed the Métis National Council in 1983 (Métis National Council, n.d.). The Métis National Council is composed of five provincial governments; the Métis Nation of Ontario, the Manitoba Métis Federation, Métis Nation – Saskatchewan, the Métis Nation of Alberta, and the Métis Nation British Columbia (Saunders & Dubois, 2019). The Métis Nation of the Northwest Territories is not represented at the national level by the Métis National Council. The Métis National Council’s leadership is composed of leadership from each provincial Métis Government (Saunders & Dubois, 2019). Each provincial Métis government is guided by its own constitution, which also dictates the structure of its government system (Saunders & Dubois, 2019). Typically, each province within the Métis homeland that is currently a member government of Métis National Council is divided into Regions, and each Region is formed by individual chartered communities or locals (Saunders & Dubois, 2019).

Métis Nation of Alberta

The Métis Nation of Alberta, which was founded in 1928, is the federally and provincially recognized government of Métis Peoples residing in Alberta (Métis Nation of Alberta, 2019b). Its governance structure is composed of an elected Provincial Council, which is comprised of a president, vice-president, and six regional presidents and vice-presidents (Métis Nation of Alberta, 2019b). The Métis Nation of Alberta's self-described mandate is to be a representative voice on behalf of Métis Peoples in Alberta, to provide Métis Peoples with opportunities to participate in policy and decision making processes, and to promote the advancement of Métis Peoples through the pursuit of self-reliance, self-determination and self-management (Métis Nation of Alberta, 2019b). Each elected official also holds a portfolio of responsibilities (i.e., health, education, culture, etc.).

The Métis Nation of Alberta provides several programs and services to Métis Peoples that focus on the areas of health, children and families, and youth programs and supports. The health-focused services listed on the Métis Nation of Alberta website are: a cancer transportation pilot program, a fetal alcohol spectrum disorder program, and opioid navigation services (Métis Nation of Alberta, 2019a).

Métis Peoples in Alberta

The 2017-2018 Annual Report from the Métis Nation of Alberta states that there are 36,011 total Métis citizens registered with the Métis Nation of Alberta (Métis Nation of Alberta, 2018). The 2016 census identified 258,640 individuals with an Aboriginal identity in Alberta, representing 6.5% of the total population of Alberta (Statistics Canada, 2017). Of these, 114,375 individuals reported Métis single identity, and 2,905 individuals reported multiple Aboriginal identities. These multiple Aboriginal identities were not further described or broken down by Statistics Canada (Statistics Canada, 2017). The number of Métis individuals according to the

2016 census represents almost half of all Aboriginal-identifying individuals in the province, and about 2.9% of the entire province (Statistics Canada, 2017). The most commonly reported Aboriginal language spoken in Alberta is Cree, with 14,160 speakers who reported an ability to carry a conversation in Cree (Statistics Canada, 2017). The 2016 census identified 155 native (i.e., first language/mother tongue) Michif speakers living in Alberta, although Michif is not the sole language of the Métis Peoples and there are many dialects spoken among Métis Peoples (Statistics Canada, 2017). However, there can be much overlap between languages and some Cree speakers could be considered Michif speakers as well (and vice versa), as the Michif language intertwines the Cree and French languages (Neuhaus, 2010).

Alberta is home to the only Métis-specific land base in Canada. There are eight Metis settlements in Alberta (note the absence of the accent, which is the preferred spelling by the Metis Settlements General Council), which were established in 1938 by the passing of the Métis Betterment Act (Martin, 1988). The Settlement areas totals 1.25 million acres of land, all located in the northern part of Alberta, with a combined population of just over 5,000 residents (Alberta Government, 2020). Each settlement has its own elected government in the form of a council. In order to be registered as a Metis Settlement member, individuals must meet the following requirements: be of Aboriginal ancestry, identify with Métis history and culture, be at least 18 years of age, have lived in Alberta for the previous five years, have been approved for membership by the local Settlement council, must reside on the Settlement, and must not be in debt to the Settlement without a repayment agreement (Alberta Government, 2020).

Métis Peoples in Canada Today: The “Third Space”

Many Métis Peoples describe themselves as “walking in two worlds” (Bourassa, 2008, p. 20), referring to the difficulties and challenges of navigating and balancing competing priorities from the broader, Eurocentric society, as well as their own Métis lives, families and communities. Catherine Richardson (2016) writes about the ‘third space’ occupied by Métis Peoples in modern day Canada. She describes the “first space”, which is occupied by dominant culture which is typically Eurocentric, in which Métis Peoples will often deny their identity or experience challenges (Richardson, 2016, p. 52). The “second space” is the space occupied by First Nations, where Métis Peoples often spend their time but may have their European heritage de-emphasized (Richardson, 2016, p. 52). This space is often dominated by discussions of colonization and is governed by First Nations worldview, stories, and cultures (Richardson, 2016). Then there is the “third space”, the Métis space, where the “predominant cultural story is about hybridity and the integration of various ancestries for the purposes of survival and wellness” (Richardson, 2016, p. 53). It is within this ‘third space’ with other Métis, that Métis Peoples tend to feel the most comfortable (Richardson, 2016).

This occupation of the ‘third space’, and its corresponding consequences for identity, has formed the story and experience of Métis Peoples since our ethnogenesis. Métis Peoples are often considered too white for the ‘second space’ and too Indigenous for the ‘first space’. This is highlighted here because understanding the ‘third space’ that Métis occupy is essential to understanding the contexts in which this research, and its interpretation, take place. It also provides context for the large number of frameworks and ideologies that are drawn upon to form the methodological framework of this research.

Positioning Myself in this Research

As a Métis student undertaking this research in partnership with Shining Mountains, an Indigenous social services agency in Red Deer, I begin by self-locating myself within this work. Qualitative and Indigenous methods understand that objectivity within a research setting does not exist (Absolon & Willett, 2005). Self-location is important so that the reader can better understand the lenses and contexts through which the author and researcher has interpreted their work (Absolon & Willett, 2005). It is also a way for researchers to ground themselves in the work they are doing and explain their relationship with the research. Self-reflection upon one's role and obligations to the work is an important aspect of working within an Indigenous research paradigm (Wilson, 2001).

I am a Métis woman who was born and raised on the traditional territory of the Lekwungen peoples in Victoria, British Columbia. My Métis-side of the family is Scottish and Cree Métis and has roots in the Red River Settlement (now Winnipeg) and Duck Lake Saskatchewan. My non-Métis side is of primarily Scottish and mixed Western European Canadian settler heritage. I was raised knowing my Métis heritage and I became involved in community gatherings as a pre-teen. It is through my involvement with the community and my relationships with several Métis mentors and Elders that I have learned what I know about Métis culture. Community involvement has been an important element in my life.

I have spent the past ten or so years discovering who I am as an individual and what it means to be a Métis woman living in an urban centre outside of the Métis homeland. Becoming involved in the administration of our local chartered community, the Métis Nation of Greater Victoria, paved the way for my political involvement within the Métis Nation BC as a regional youth representative. Being involved in Métis politics has shaped my understanding of the relationship between Métis Peoples, particularly outside of the homeland, with the provincial and federal governments. During my time as a youth representative, I have seen dismissal and resistance about engaging with Métis Peoples from the BC government, particularly from the health and social ministries. I have come to understand and identify this dismissal and refusal to engage in a respectful relationship as an act of ongoing oppression and colonization of Métis Peoples within the province of BC.

Witnessing and experiencing a poor relationship between Métis Nation BC and the BC provincial government has highlighted to me the importance of health advocacy for and by Métis Peoples. As I understand from my work experience in policy as well as my Master's coursework, high-quality research, usually quantitative research, is needed as "evidence" to implement change in policy arenas. The burden of producing this proof is almost always placed on Indigenous communities. Although I disagree with that "evidence" should be limited to these methods, I also recognize that we operate within a colonial system which currently demands that Indigenous Peoples conform to the demands of the system in order to advocate for themselves. I write this not only to emphasize the ongoing injustices and barriers for Indigenous Peoples to advocate for themselves, but to allow the reader to understand my passion for Indigenous-led research done in an ethical way. When done well, I think Indigenous-led research can meet the demands of the government, and the needs of our Indigenous Peoples and create policy changes to better the wellness of our people. This is what I aim to do in my work.

I was first introduced to HIV and STBBI research by Dr. Catherine Worthington several years ago. Although I do not have lived experience with HIV or HCV, I have seen the consequences of living with HCV for decades in a family member. I have also witnessed the effects of stigma on our Métis communities which span not only HIV, HCV and STBBIs, but also mental health, substance use, and violence. The effects of stigma within my Métis community, and within the broader Métis Nation fuel my desire to better understand and address it. This desire is one of the reasons why I became involved with the DRUM & SASH Project.

The DRUM & SASH Project Overview

The DRUM & SASH (D&S) project is a Canadian Institutes of Health Research (CIHR) funded team grant which aims to develop, implement and evaluate shared care models to increase care and prevention of HIV, Hepatitis C, other sexually transmitted and blood-borne infections (STBBI) and related mental health issues in Indigenous communities in Alberta (DRUM & SASH, 2020). The D&S research team has partnered with Tallcree First Nation, Driftpile First Nation, Sucker Creek First Nation, Stoney Nation, Blood Tribe, and the Métis Nation of Alberta through Shining Mountains for five years to implement and evaluate shared care models for HIV/STBBI (DRUM & SASH, 2020). The goals of the D&S project are fourfold: 1) to scale up and adapt shared care models to the community contexts, 2) to strengthen capacity for all team members using a co-learning format which is grounded in Indigenous context-based knowledge and guided by an Elders council, 3) to assess the implementation and co-learning aspects of the shared care models, and 4) to foster community to community knowledge sharing and mentorship through the creation of an online resource (DRUM & SASH, 2020).

The history of the D&S project, its work, and its partnership with Tallcree First Nation, Driftpile First Nation and Sucker Creek First Nation goes back approximately fifteen years to a project called Aboriginal Community Resilience to HIV/AIDS (ACRA) (C. Lund, personal communication, January 8 2020). ACRA was supported by Community Information and Epidemiological Technologies (CIET) Canada, a group of non-profit research-focused organizations that has worked with Indigenous Peoples in Canada and across the globe (C. Lund, personal communication, January 8 2020). The aim of ACRA was to identify resilience-based protective factors against HIV among youth ages 12-30 (C.

Lund, personal communication, January 8 2020). One outcome of this project was community interest in developing a shared care model.

The desire to further explore shared care models led to a CIHR Implementation Science Component 1 grant application, which was successful in obtaining eighteen months of funding to study and implement shared care models within the communities of Sucker Creek First Nation, Driftpile First Nation, and Tallcree First Nation. This project was titled **D**evelopment of a **Ru**ral **M**odel for Integrated Shared Care in First Nation and Métis Communities (DRUM) (C. Lund, personal communication, January 8 2020). Based on continued community interest, as well as interest from the Stoney Nation, Blood Tribe, and the Métis Nation of Alberta, the team secured funding through the CIHR's Implementation Science HIV/AIDS Component 2 funding stream. The project was renamed to DRUM & SASH to represent the inclusion of the Métis Nation as a project partner (C. Lund, personal communication, January 8 2020). Further funding and in-kind support has been secured from the CIHR Canadian HIV Trials Network (DRUM & SASH, 2020).

About Shining Mountains Living Community Services

As a partner in the D&S project, the Métis Nation of Alberta delegated authority to Shining Mountains to lead the development of the Métis-specific portion of the shared care model. Shining Mountains is described on its website as an "Aboriginal owned, staffed and operated" agency located in Central Alberta (Shining Mountains Living Community Services, n.d.). The organization was originally named Waskasoo Community Homes and was renamed Shining Mountains in 1997 (R. St. Denys, personal communication, January 15 2020). Shining Mountains is operated by Executive Director Raye St. Denys who is Métis. Although the Shining

Mountains office is in Red Deer, the organization is provincial in scope (R. St. Denys, personal communication, January 15 2020).

According to their website, the mission statement of Shining Mountains is “to provide services for Aboriginal People on a Status-Blind basis that build capacity for increased physical, mental, emotional, and spiritual health within marginalized and under-served populations who are, or are at risk of being affected by HIV/AIDS and/or HCV infection, regardless of where they reside” (Shining Mountains Living Community Services, n.d.). Shining Mountains offers a diverse range of programs and services to individuals, regardless of Aboriginal status or identity. For example, Shining Mountains owns and operates housing, and provides support services for individuals at risk of HIV or STBBI, or individuals at risk of experiencing homelessness, intimate partner violence, addictions, or other challenges related to self-sufficiency (Shining Mountains Living Community Services, n.d.). These services include harm reduction services, transportation, and service navigation (R. St. Denys, personal communication, January 15, 2020).

Shining Mountains is continually adapting to the needs of the community. Recently, they have begun to offer onsite rapid HCV testing, and are looking at potentially become certified as a half-way house for Indigenous clients (R. St. Denys, personal communication, January 15 2020). Shining Mountains has developed Métis-specific HIV and STBBI pamphlets and educational materials for distribution in their office, online, and in other communities (Shining Mountains Living Community Services, n.d.). Shining Mountains worked with D&S through a process of community readiness and assessment surrounding HIV and STBBI, and based upon feedback from the Métis Nation of Alberta (MNA) and community members, decided to focus their work on the development of a Métis-specific model to support individuals living with HIV or impacted by STBBI, and the pilot of DBST. These projects, and my conversations with Shining Mountains staff, informed the development of the research goals for this thesis.

Holistic Perspectives of Health

Indigenous Peoples in Canada conceptualize health holistically, crossing many domains of one's life. The term holistic refers to holism, a concept which in medical contexts, refers to the care of an entire patient in all aspects of well-being ("Holism", 2020). Indigenous perspectives on health and wellness understand that health reflects multiple components such as physical, mental, emotional, and spiritual dimensions (Loppie Reading & Wien, 2009). This is important to highlight because the modern medical system takes a siloed approach to health and prevention, which fails to address complexities of interrelated factors of health and wellbeing, whereas Indigenous Peoples understand these dimensions to be highly inter-related (Loppie Reading & Wien, 2009).

Métis Peoples share a similar understanding of health with other Indigenous Peoples. Métis Peoples conceptualize health holistically (Dyck, 2009). Métis writer Miranda Dyck (2009) defines Métis health as not being solely dependent on the individual; health is a concept which includes the family, community, and Métis Nation across many life stages (i.e., Elder, adult, youth, infant). Research conducted with Métis women in Saskatchewan corroborated a holistic understanding of health among participants (McCallum-McLeod, Willson, Northwest Metis Women's Health Research Committee, & Prairie Women's Health Centre of Excellence, 2004). Participants defined health as "more than the absence of disease or defect" and described all aspects of the body, mind, and spirit as core components of one's health (McCallum-McLeod et al., 2004, p. 4). Participants also said they felt that the mainstream health system focuses too much on physical health (McCallum-McLeod et al., 2004). Healing was defined by the participants in this study as a way of life that involves not only individuals, but the spiritual and cultural support and strength of families and communities (McCallum-McLeod et al., 2004). Métis lawyer Yvonne Boyer (2019) writes that Métis healing practices are distinct from those of First Nations and Inuit, as they draw heavily upon Métis cultural practices. More about Métis worldviews is included in the Methodology chapter.

Locating this Research in an Indigenous Social Determinants of Health Framework

There are a multitude of factors which influence the health of people, many of which lie outside of the realm of the healthcare system (Loppie Reading & Wien, 2009). These are referred to as the social determinants of health (Loppie Reading & Wien, 2009). For Indigenous Peoples, many of the social determinants of health relate to the socio-political context under which Indigenous communities have lived, both historically, and currently (Loppie Reading & Wien, 2009). The Government of Canada recognizes 12 main determinants of health: income and social status, employment and working conditions, education and literacy, childhood experiences, physical environments, social supports and coping skills, healthy behaviours, access to health services, biology and genetic endowment, gender, culture, and race/racism (Government of Canada, 2019). These personal and social determinants of health affect the health and wellbeing of Indigenous Peoples, in addition to determinants that are distinct to Indigenous Peoples in Canada (Government of Canada, 2019). Indigenous health researchers Charlotte Loppie Reading and Fred Wien categorize the determinants of Indigenous health as distal, intermediate, and proximal (2009). These determinants are intertwined. In the following sections, I will provide an overview of the Loppie Reading and Wien's Indigenous social determinants of health framework.

Proximal determinants of health.

The proximal determinants of health identified by Loppie Reading and Wien (2009) are: health behaviours, physical environments, employment and income, education, and food insecurity. These determinants are defined as proximal because they include conditions that have direct impacts on physical, emotional, mental and/or spiritual health (Loppie Reading & Wien, 2009). Loppie Reading and Wien (2009) state that the exact mechanisms through which health is impacted by proximal determinants is not well articulated within the literature. However, the authors emphasize the role that stress plays in health, particularly in individuals and families who struggle to have their basic needs met. For example, overcrowded housing can have impacts in many other areas of one's life, creating a stress response, which in children increases likelihood of behavioural and learning difficulties, and is associated with increased substance use in adults (Loppie Reading & Wien, 2009). This is just one example of how interconnected the determinants of health are (Loppie Reading & Wien, 2009).

Health behaviours. Health behaviours are a well researched determinant of health. According to Loppie Reading and Wien (2009), the most relevant health behaviours for Indigenous Peoples are: alcohol use, cigarette smoking, inadequate prenatal care, exercise, and diet (2009). Indigenous adults are twice as likely as non-Indigenous adult Canadians to smoke cigarettes, which leads to higher rates of lung cancers and breathing problems, than those of non-Indigenous Peoples in Canada (Loppie Reading & Wien, 2009). Type 2 diabetes has been labelled by some an epidemic among Indigenous communities, and is a fairly well researched illness which has been associated with poor diet and reduced exercise (Loppie Reading & Wien, 2009). A study on Métis health in Manitoba which used data from the Canadian Community Health Survey found that when compared to all other Manitobans, Métis Peoples were: less likely to report consuming fruits and vegetables five times per day, more likely to report the consumption of five or more alcoholic drinks on one or more occasions per month, and had a smoking rate of 53% higher than the provincial average (Martens et al., 2010). As evidenced by these statistics, Métis Peoples engage in health behaviours differently than non-Indigenous Canadians.

Physical environments and housing. In terms of physical environments, Indigenous Peoples have been the subject of forced dispossession of lands, and in some cases, imposed reserve structures for First Nations, and forced relocations for Inuit families and communities (Loppie Reading & Wien, 2009). Many reserves and communities suffer from poor housing quality and housing shortages (Loppie Reading & Wien, 2009). Mold is a pervasive issue among poorly constructed houses, resulting from a lack of appropriate ventilation and overcrowding (Loppie Reading & Wien, 2009). For Métis Peoples, housing challenges manifest as an equal likelihood to live in crowded dwellings (compared to non-Indigenous Canadians) (Loppie Reading & Wien, 2009). However, Métis Peoples are twice as likely to live in housing which needs major repairs (14% of all Métis) compared to non-Indigenous Canadians (7% of all Canadians) (Loppie Reading & Wien, 2009). Poor housing quality has been linked to reduced health outcomes by increased rates of infectious diseases, lower respiratory tract infections, injuries, and mental health problems among Indigenous Peoples (Loppie Reading & Wien, 2009).

Socioeconomic status. Employment, income, and education, which together compose socioeconomic status (SES), are well researched social determinants of health. Colonization, colonialism, and systemic racism have resulted for many Indigenous Peoples in denied access to resources and conditions necessary to achieve a comfortable SES (Loppie Reading & Wien, 2009). Colonization, colonialism, and systematic racism manifest as increased rates of poverty resulting from higher rates of unemployment amongst Métis Peoples when compared to non-Indigenous Peoples in Canada, as well as wage disparities among those Métis Peoples who do work full-time (Loppie Reading & Wien, 2009). The average income for full-time Métis employees in Canada was 32,176 in the 2001 Census, compared to 43,486 for non-Indigenous employees in Canada (Loppie Reading & Wien, 2009). Poverty is associated with increased involvement in crime, social exclusion, reduced social cohesion, and a lack of control over one's life, resulting in anxiety, insecurity, and feelings of hopelessness (Loppie Reading & Wien, 2009). These may lead to increased rates of diabetes and mental health issues (Loppie Reading & Wien, 2009). Education is a component of SES that determines health in many ways, such as through poor health literacy, which impacts the ability to find reliable health information, and reduced job-related skills (Loppie Reading & Wien, 2009).

Food insecurity. Many Indigenous Peoples were forced by the government to change their lifestyles from harvesting and a trade/gifting economy to one that relied on mainstream society for food sources (Loppie Reading & Wien, 2009). This has complicated issues of food insecurity. Transporting food to northern and rural/remote communities is expensive, making healthy foods unaffordable for many Indigenous families. Additionally, the cost of hunting can be prohibitive for families as well, reducing access to traditional foods (Loppie Reading & Wien, 2009).

Authors Loppie Reading and Wien (2009) conclude the section on proximal factors by acknowledging that they are mainly comprised of individual level factors, like poverty, which lead to poor health outcomes such as stress and obesity. They highlight that some work has been done to examine community-level proximal determinants of health by constructing community-level wellness scores, but do not discuss that work within their model. In conclusion, the proximal determinants of health are those that closely affect the day-to-day lives of individuals, and thus are identified as ‘proximal’ determinants.

Intermediate determinants of health.

Loppie Reading and Wien (2009) describe the intermediate determinants of health as those which arise from the proximal determinants; however, the intermediate determinant effects are also intertwined and affect each other as well as the proximal determinants of health(2009). The proximal determinants are: health care systems, educational systems, community infrastructure, resources and capacities, environmental stewardship, and cultural continuity (Loppie Reading & Wien, 2009).

Health care. Benefiting from the health care system means that individuals must be able to access its services; this ability to access services is not always the case for Indigenous Peoples and communities (Loppie Reading & Wien, 2009). There are many issues which compound a lack of access as well as the lack of suitability of services for Indigenous Peoples. Research has shown that systemic barriers affecting Indigenous Peoples in Canada include long waitlists, lack of coverage by insurance, transportation challenges, difficulty finding childcare in order to attend appointments, and a lack of services in communities (Loppie Reading & Wien, 2009). Racism is another institutional barrier which prevents engagement with the healthcare system; this is further discussed below. Racism and discrimination have been identified as barriers which reduce the likelihood of Métis Peoples accessing health and social services (Monchalin, Smylie, & Nowgesic, 2020), and affect the overall health of Métis Peoples (Macdougall, 2017).

Education systems. Although education was discussed as a component of SES in the proximal determinants of health, it is mentioned as an intermediate determinant also (Loppie Reading & Wien, 2009). This component highlights some of the policy challenges which have resulted in reduced educational outcomes and a lack of community control over education systems (Loppie Reading & Wien, 2009). Research has shown that education impacts one's income, employment, as well as living conditions (Loppie Reading & Wien, 2009). Individuals who have achieved higher levels of education tend to earn more, and tend to emphasise the importance of education to their children and family members (Loppie Reading & Wien, 2009). Métis Peoples, as well as First Nations and Inuit, are more likely to leave high school before completion (48.0% have not completed high school, from 2001 Census) compared to non-Indigenous Canadians (30.1%) (Loppie Reading & Wien, 2009). Preschool programs are associated with better health outcomes and good return on investment, yet Indigenous focused programs for preschools like Aboriginal Head Start are underfunded (Loppie Reading & Wien, 2009). Programs like the underfunded Aboriginal Head Start are a good example of how community infrastructure, resources, and capacities affect health.

Community infrastructure, resources and capacities. Loppie Reading and Wien (2009) state that the health of individuals and their family is greatly affected by the community in which they live. Having economic development opportunities has been identified as an important determinant of health at the community and individual level (Loppie Reading & Wien, 2009). Limited opportunities to develop social and health programs and services keep Indigenous communities marginalized by maintaining economic insecurity, demonstrating the close relationships between community infrastructure, social programs, and economic prosperity (Loppie Reading & Wien, 2009). This is compounded by a lack of funding for social services, and difficulty obtaining qualified individuals from within communities to work in key social and health sector jobs (Loppie Reading & Wien, 2009). Dealing with underfunded social programs increases bureaucracy (i.e., applying for additional funding) which leads to increased stress at the community level (Loppie Reading & Wien, 2009).

This determinant manifests within Métis communities in different ways compared to First Nations or Inuit communities. Regarding healthcare specifically, Evans and colleagues (2012) write:

> In comparison to status First Nation and the Inuit, the Métis receive significantly fewer local, provincial and national resources for health care. In general, Métis Peoples receive health care supports and services from non-Aboriginal health care providers. Unlike Inuit and First Nations communities, Métis communities rarely have their own health centres (p.57).

The authors continue by highlighting the geographic and jurisdictional barriers that reduce access to health care, which are often a result of not having Indian Status, and restrict Métis communities in obtaining resources to employ a health director (Evans et al., 2012). Evans and colleagues (2012) say that, “at all levels of organization, the Métis are under-resourced,” which manifests as an over-reliance on volunteers to keep Métis communities running (p.57).

Environmental stewardship. Environmental stewardship has been another widely recognized determinant of Indigenous health. Indigenous Peoples hold a close relationship with the land and its environment (Loppie Reading & Wien, 2009). Close ties to the environment is a major reason why Indigenous Peoples enjoyed strong health prior to European colonization (Loppie Reading & Wien, 2009). Dispossession of lands has resulted in reduced land-based activities, including healing and harvesting activities (Loppie Reading & Wien, 2009). Contamination of water and food sources has become a serious issue for many communities, and has forced many Indigenous Peoples to rely on other food sources (Loppie Reading & Wien, 2009). The dispossession and contamination of lands have forced Indigenous Peoples to live further away from their environment, resulting in poorer health (Loppie Reading & Wien, 2009). This is particularly true for the Métis, who have struggled as a result of the dispossession of lands through the scrip system and as a result of encroachment by European homesteaders, which prevented Métis Peoples from living in accordance with their traditional ways (Macdougall, 2017).

Cultural continuity. Culture is recognized by many as a strong determinant and protective factor of health, especially for Indigenous Peoples. Cultural continuity is a term which was developed by Chandler and Lalonde (1998) in their landmark study, which showed that First Nations people in BC experienced reduced rates of suicide when they had increased social and cultural cohesion, as well as intergenerational connectedness through engagement of Elders, within their communities (Chandler & Lalonde, 1998; Loppie Reading & Wien, 2009). These are related to factors such as land title, self-government and involvement of women in self-government, control of education, security and cultural facilities, and control over health and social programs in the community (Chandler & Lalonde, 1998; Loppie Reading & Wien, 2009). A lack of access to traditional and cultural healing activities has been found to have a direct and profound experience on the mental health of young Métis Peoples (Auger, 2019).

In comparison to the proximal factors, which directly influence and contribute to ill health, the intermediate factors are characterized by Loppie Reading and Wien (2009) as those which arise from the proximal determinants. Most of the intermediate factors exist at systems or community levels (Loppie Reading & Wien, 2009). The distal determinants, discussed below, are those determinants from which both the proximal and intermediate determinants arise (Loppie Reading & Wien, 2009).

Distal determinants of health.

The distal determinants of health are described by Loppie Reading and Wien (2009) as the ones with the "most profound" impacts on the health of Indigenous Peoples, as they are related to the political and socio-economic contexts in which Indigenous Peoples live their lives (p. 22). They are also the determinants which are furthest from the individual and the most difficult to change, hence the term 'distal'. These include colonialism, racism and social exclusion, and self-determination.

Colonialism. Colonization is a process where an outside group establishes external control over another group, resulting in economic dispossession, poor social services, and the imposition of an ideological foundation which places one race and skin colour in a position of power (Loppie Reading & Wien, 2009). Colonialism, which is a policy of enacting colonization through the establishment of settlers, still impacts Indigenous Peoples today through neo-colonialist policies (Loppie Reading & Wien, 2009). There were many tools used within colonialism which have had detrimental health impacts on Indigenous Peoples, including residential and day schools, Indian hospitals, restrictions on subsistence activities like hunting and fishing, forced relocations, and the dispossession of lands. These have resulted in the disengagement of Indigenous Peoples from their cultures, affecting cultural continuity, and created intergenerational and intercommunity traumas (Loppie Reading & Wien, 2009). For Métis Peoples, colonialism has manifested in the ways described above, but also includes the scrip system (which was used to remove Indigenous rights and title amongst Métis), disparities in funding and resources at provincial and community levels, exclusion from the Indian Act and individual health benefits offered to status First Nations (i.e., Non-Insured Health Benefits), and exclusion from the Federal Government's apology and settlement related to residential schools (Macdougall, 2017).

Racism. The social stratification of individuals along racial lines has dramatically impacted the way Indigenous Peoples can access services, participate in the economy, gain education, and acquire resources (Loppie Reading & Wien, 2009). Policies such as the Indian Act have been used as methods of control through systemic racism (Loppie Reading & Wien, 2009). Additionally, racist experiences within everyday interactions produces stress responses among many Indigenous Peoples, impacting their self-esteem, and has been shown to increase alcohol and drug use among youth (Loppie Reading & Wien, 2009).

Self-determination. Self-determination is the level of control individuals and communities have over their lives. It influences all other determinants of health. Loppie Reading and Wien (2009) state that in order for individuals to experience favorable intermediate determinants of health,

> Aboriginal peoples must participate equally in political decision-making, as well as possess control over their lands, economies, education systems, and social and health services. Unfortunately, this is not the case; rather, the colonial agenda has enforced unequal access to and control over property, economic assets, and health services. In many ways, this restrictive structure has actually encouraged Aboriginal social, political and economic development that is not self-determined (p. 24).

Research has shown that a lack of self-determination is associated with feelings of depression (Loppie Reading & Wien, 2009).

Bringing the Determinants Together.

Loppie Reading and Wien (2009) combine their discussion of the Indigenous-specific determinants of health with a life course approach and call their model the “Integrated Life Course and Social Determinants Model of Aboriginal Health” (Loppie Reading & Wien, p. 26). The authors say this allows for researchers to consider how life stages interact with the various distal, intermediate, and proximal determinants of health and unique socio-political contexts of health which can differ across First Nations, Métis and Inuit communities. It also allows for a more complex analysis of how these factors are interrelated and interact with one another to create vulnerabilities and capacities for health (Loppie Reading & Wien, 2009).

A Life Course Perspective on Health

Public health interventions have historically targeted adult risk factors, which have failed to adequately address risk factors experienced by children, youth, and the elderly (Reading, 2009). The majority of education and interventions have targeted health behaviours such as smoking, diet, and exercise (Reading, 2009). These interventions have been linked to declining chronic disease rates in certain populations, but not among Indigenous communities and other communities characterized as vulnerable (Reading, 2009).

Reading (2009) writes in his report to the Senate Sub-Committee on Population Health that while these health behaviours may be passed on to the next generation, the circumstances in which chronic diseases have arisen will remain unchanged because the core determinants of these illnesses will have been left unaddressed. In addition to a social determinants of health framework, an understanding of the life course perspective can improve the effectiveness of public health interventions (Reading, 2009). Reading (2009) writes that “life course epidemiology offers a way to conceptualize how underlying biological and socio-environmental determinants of health, experienced at different life course stages, can differentially influence the development of chronic diseases" (pp. A-53). A life course perspective acknowledges that a life-long trajectory of health begins with gestation; the way individuals experience health and illness will differ with age (Loppie Reading & Wien, 2009).

Life course approaches are holistic in nature, complementing the holistic nature of Indigenous perspectives on health and wellness (Reading, 2009). A life course approach provides researchers with the tools to integrate scientific, cultural, and sociological knowledge in a meaningful way (Reading, 2009). This integration of biologic and social risk factors can facilitate deeper understandings of differences between community-level outcomes (Reading, 2009).

Métis Social Determinants of Health

Some work has been done articulating Métis-specific social determinants of health; this work was undertaken by Miranda Dyck and Métis Centre at the National Aboriginal Health Organization (NAHO) (2009). Dyck writes that a social determinants of health approach resonates with Métis perspectives and worldviews as it aims to understand the "causes of the causes" of health (2009, p. 3). She articulates the Métis social determinants of health and wellbeing on a continuum of past to future. Dyck (2009) writes that the Métis social determinants of health are strongly linked to the historical, socio-political, and economic contexts in which Métis Peoples arose and have experienced through colonialism. This includes marginalization, a lack of recognition of Métis Peoples, their rights, and the removal of their land base, compounded by the loss of culture, Métis knowledge, language, and spirituality. Much of this corroborates what has been written by Loppie Reading and Wien (2009) regarding the Indigenous social determinants of health. However, unique to the model developed by Dyck

(2009) is the inclusion of factors such as resiliency, healing and resurgency, placing a strengths-based lens or perspective into the framework.

Other Indigenous Social Determinants of Health Frameworks

There are other Indigenous social determinants of health frameworks developed by public health and Indigenous health researchers and scholars. For example, Greenwood and de Leeuw (2012) developed a model titled, *Web of Being: Social Determinants of Aboriginal Peoples' Health*. Their model also categorizes determinants as proximal, intermediate, and distal, and the web aspect of the model underscores the interrelated nature of determinants. One strength of Greenwood and de Leeuw's (2012) model is the inclusion of gender as its own determinant, whereas it is only briefly mentioned within Loppie Reading and Wien's (2009) model. Interestingly, Greenwood and de Leeuw's (2012) model includes residential schools as an explicit determinant, but not other harmful policy interventions such as day schools, forced community relocations, 60's scoop, Indian day hospitals, or the millennium scoop. Greenwood and de Leeuw's (2012) model contains more determinants, making it very comprehensive but possibly overwhelming to users outside of public health. It also lacks a life course perspective, which is one reason why Loppie Reading and Wien's model was selected for this research (Greenwood & de Leeuw, 2012).

Another conceptual model of Indigenous health is the Xpey' Relational Environments framework developed by several Indigenous health researchers at the University of Victoria (Kent, Loppie, Carriere, MacDonald, & Pauly, 2017). This model was developed specifically to be applied as an analytic framework to conceptualize the physical, interpersonal, and institutional settings influencing Indigenous health equity (Kent et al., 2017). The World Health Organization defines health equity as:

> …the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. "Health equity" or "equity in health" implies that ideally everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential. (World Health Organization, n.d., p. 1)

Using a tree as a symbol, the determinants are categorized as root environments (social, political, historical, cultural), core environments at the trunk of the tree (communities, systems, and institutions), and the stem environment at the crown of the tree (non-human, human and symbolic) (Kent et al., 2017). The roots represent many of the consequences of colonial histories and intergenerational trauma. The core connects the root and stem environments, and include systems of authorities, policies, bureaucracies, and leadership and management within relevant institutions. The stem environments represent those which affect the health of individuals in the "most obvious and direct ways" like interpersonal environments, the natural and built environments, identities and cultures (Kent et al., 2017, p. 277). While the symbology of the framework is holistic and easy to understand, and its grounding in equity and social justice is a clear strength, the model lacks a life course perspective. The authors also state that the framework is grounded in a First Nations perspective of health; the framework's application to other cultural groups like Métis Peoples would need to carefully consider their unique experiences. However, it is a good framework to apply when the goal is to better understand the determinants of health equity (Kent et al., 2017).

Locating HIV and STBBI in a Social Determinants of Indigenous Health Perspective

Based on the literature on Indigenous determinants of health, underpinning this thesis research is the understanding that health and wellness are holistic concepts within Indigenous communities, and many complex interrelated and interacting determinants of health exist which influence individuals and communities differently through the life course. Also recognized are the inherent differences between First Nations, Métis and Inuit communities, and the understanding that Métis communities have experienced some of the socio-political, historic, and economic contexts differently than First Nations and Métis communities, resulting in slightly differing health outcomes.

HIV, HCV, HBV, and syphilis are health issues that need to be analyzed and understood within a social determinants of Indigenous health and life course perspective. There are many challenges related to STBBI diagnoses and care which can be better understood by applying a social determinants of Indigenous health and life course perspective, such as access to health care, access to testing, geographic location, sociopolitical contexts, which may influence stigma and awareness, and reduced health literacy resulting from reduced access to education. It is important to position health behaviours as the consequences of the distal determinants of health, which are colonialism and self-determination, racism, and social exclusion. It is also important to understand compounding determinants such as mistrust of the health system, social relationships, childhood and domestic violence and substance abuse, rather than defining these as risky or amoral behaviours (Negin, Aspin, Gadsden, & Reading, 2015).

It is important to recognize that much of the focus of the literature and previous research on Indigenous Peoples and HIV/STBBI has been deficit focused (Negin et al., 2015). While the process of writing a thesis necessitates demonstrating an understanding of the health challenges experienced by Indigenous Peoples, and exploration of HIV and STBBI rates specific to Métis populations, research should be solutions focused, examining wise practices in communities and leadership, strategies for improving communication around STBBI and risk, and protective factors that can be strengthened through community-based and driven programming (Negin et al., 2015). As such, this research will be solutions focused, and highlight the inherent strength and resilience of Métis Peoples.

Chapter 2: Literature Review

It is well understood that there is a paucity of Métis-specific health research and health data in the literature (Andersen, 2016; Evans et al., 2012; Kumar, Wesche, & McGuire, 2012). This is true for information relating to the impacts of HIV and STBBI amongst Métis as well. In this chapter, I outline the information which is currently available regarding HIV and STBBI in Indigenous and Métis populations in Canada and Alberta, and provide relevant information about testing modalities for HIV and STBBI. I then provide the reader with a brief overview of the field of IS in order to contextualize the purpose and methodology of this study, which is provided in the chapter following this one.

HIV in the Indigenous Population of Canada and Alberta

HIV is a virus which is passed through blood and bodily fluids, and leads to a compromised immune system (BC Centre for Disease Control, 2019). HIV can be passed through sexual (vaginal and anal) contact where exchange of bodily fluids may occur, or via vertical transmission from mother to child through the placenta, during childbirth, or after birth via breastmilk (BC Centre for Disease Control, 2019). HIV can also be passed through shared drug use equipment such as needles (BC Centre for Disease Control, 2019). Without treatment with antiretroviral medication, HIV will cause serious symptoms and eventually lead to acquired immunodeficiency syndrome (AIDS) (BC Centre for Disease Control, 2019). It is important to note that, with treatment, individuals living with HIV can live long and fulfilling lives. Treatment is also important from a prevention standpoint, as research has consistently shown that viral load, which can be reduced to undetectable rates via treatment, is the greatest risk factor involved in the transmission of HIV (Montaner et al., 2006).

Indigenous Peoples continue to be overrepresented in HIV statistics (Public Health Agency of Canada, 2010b). In 2017, information on race/ethnicity was available for 49.3% of provincial/territorial (including Alberta) reported HIV cases to the Public Health Agency of Canada, for a total of 1,184 cases with identifiable ethnicity (Haddad, Li, Totten, & McGuire, 2018). In 2017, of the reported HIV cases with a known race/ethnicity, 34.5% were reported as Caucasian, 25.3% were reported as Black and 20.1% were reported as Indigenous (Haddad et al., 2018). The Indigenous race/ethnicity category was further subdivided into the following subgroups: First Nations (17.4%); Métis (2.3%); Inuit (0.2%); and Indigenous unspecified (0.3%) (Haddad et al., 2018). An estimated one in ten people living with HIV in Canada are Indigenous (Haddad et al., 2018); as of 2016, an estimated 63,110 individuals in Canada were living with HIV (both diagnosed and undiagnosed) (Public Health Agency of Canada, 2018). An important limitation of these data is the lack of historic ethnic identifiers used and reported by Quebec and Ontario, and a lack of ethnic identifiers from British Columbia for recent data. Both are due to provincial differences in reporting practices (Haddad et al., 2018).

There is a concentration of HIV in Alberta among people who engage in heterosexual sex, representing 42.8% of people with HIV (Public Health Agency of Canada, 2014). In 2018, a total of 24,178 STI cases were reported, of which 249 cases were of HIV (Government of Alberta, 2019a). This represents a reduction of HIV incidence of 13.2% compared to 2017; in total there were 38 new cases of HIV reported in 2018 (Government of Alberta, 2019a). As of 2019, statistics are unavailable regarding the specific incidence or prevalence of HIV within the Métis population nationally or in Alberta, except for those provided above.

HCV in the Indigenous Population of Canada and Alberta

The Hepatitis C virus (HCV) is the causal agent of Hepatitis C. HCV infects liver cells and can manifest as an acute or chronic infection (Public Health Agency of Canada, 2019). The transmission of HCV is predominantly blood-borne, and chronic HCV infection is the leading cause of liver transplants in Canada. Direct acting antiviral treatments, which were approved for use in Canada in 2014, offer a cure for HCV (Public Health Agency of Canada, 2019). The course of treatment takes between 8 and 12 weeks and is taken orally, and offers fewer side effects than older treatments for HCV (Public Health Agency of Canada, 2019).

An estimated 220,697 to 245,987 persons live with HCV in Canada, of whom approximately 44% are undiagnosed (Trubnikov, Yan, & Archibald, 2014). People born between 1945 and 1975 account for over 60% of HCV infections in Canada (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019; Trubnikov, Yan, Njihia, & Archibald, 2014). Although a cure exists for HCV, the number of reported cases of HCV across Canada within the general population has been on the rise since 2013 (Public Health Agency of Canada, 2019). Nationally, prevalence of HCV has increased the most in ages 25-29 and 30-39 (Public Health Agency of Canada, 2019). In Canada, national surveillance data are insufficient for determining the number of cases of hepatitis C among Indigenous populations, largely because many provinces do not collect ethnicity data (Uhanova, Tate, Tataryn, & Minuk, 2013). However, in 2010 the Public Health Agency of Canada performed an analysis on three data sources (I-Track, Enhanced Hepatitis Strain Surveillance System, and Enhanced Street-Youth Surveillance) to gain more insight into the epidemiology of HCV in Indigenous Peoples in Canada (Public Health Agency of Canada, 2010a). This analysis showed that in 2008, the rate of reported HCV was almost five times higher among Indigenous Peoples in Canada compared to non-Indigenous Peoples in Canada (Public Health Agency of Canada, 2010a).

During 2005 to 2016, rates of HCV diagnoses for First Nations individuals in the Edmonton Zone of Alberta Health Services (AHS) were consistently higher than other Zones (Government of Alberta, 2019b). The rate of HCV diagnoses in First Nations people in most Alberta Zones remained relatively stable between 2005 and 2016 (Government of Alberta, 2019b). However, for First Nations people living in the South Zone, the rate of diagnoses per 100,000 population increased 12 times from 53 in 2015 to 631 in 2018 (Government of Alberta, 2019b). This overall increase in HCV diagnosis among First Nations occurred roughly equally for both men and women, and occurred in both acute (n=39) and chronic (n=57) infections (Government of Alberta, 2019b).

Injection drug use is the most commonly reported risk factor for new cases of HCV across the general population of Canada (Public Health Agency of Canada, 2019). The Public Health Agency of Canada (2019) attributes the rising rates of HCV to be mainly related to increased injection drug use which is compounded by challenges related to the opioid epidemic, and to a lesser extent, improved case detection.

HBV in the Indigenous Population of Canada and Alberta

The Hepatitis B virus (HBV) is the causal agent of Hepatitis B. Like HCV, HBV infects liver cells. Although they are from two separate viral families, both HBV and HCV can cause symptoms such as jaundice, fatigue and abdominal pain (Public Health Agency of Canada, 2019). HBV is transmitted through bodily fluids during sexual contact, close contact with another individual with HBV, shared use of contaminated drug-use equipment, or through mother-to-child transmission (Public Health Agency of Canada, 2019). An HBV vaccine has been available since the 1980s; no cure is available for HBV, but treatment can reduce viral replication in the body (Public Health Agency of Canada, 2019).

Like HCV, specific rates of HBV in the Indigenous, and specifically the Métis populations, are unknown. Overall prevalence of HBV across Canada has remained fairly steady since 2012 (Public Health Agency of Canada, 2019). In 2017, a total of 4,905 cases of Hepatitis B were reported in Canada: 192 cases of acute infection (corresponding to a rate of 0.5 infections per 100,000 population), 4,086 cases of chronic infection (corresponding to a rate of 11.4 infections per 100,000 population), and 627 cases of unspecified Hepatitis B infection (Public Health Agency of Canada, 2019). In Alberta in 2017, the rates of chronic HBV infection were 12.6 per 100,000, which is slightly above the national average of 11.4 per 100,000 (Public Health Agency of Canada, 2019). The national burden of HBV is thought to have stayed steady due to spread between and by unvaccinated, isolated, or vulnerable populations complicated by migration from endemic countries (Public Health Agency of Canada, 2019).

Syphilis in the Indigenous Population of Canada and Alberta

Syphilis is an infectious bacterium that is transmitted via sexual contact. Syphilis often does not cause symptoms during early infection, meaning an individual can unknowingly pass on the infection to others (Government of Alberta, 2010). Without treatment, syphilis can cause damage to bones, the brain, and the cardiovascular system, and can be transmitted from a mother to her unborn child resulting in congenital syphilis (Government of Alberta, 2010). There is an estimated two-to-five times increase in risk of acquiring HIV when someone has a syphilis infection (Government of Alberta, 2010). Syphilis is curable with antibiotics when identified early (Health Canada, 2013).

From 2010 to 2015, the rate of infectious syphilis in Canada increased by 85.6%, from 5.0 to 9.3 cases per 100,000 population (Choudhri, Miller, Sandhu, Leon & Aho, 2018).

In the general population of Alberta, there was a 187% increase in the number of cases of infectious syphilis between 2017 and 2018 (Government of Alberta, 2019a). A syphilis outbreak in Alberta has been declared in the media, making accessible testing and awareness even more important ("Infectious syphilis outbreak declared in Alberta," 2019). The highest infectious syphilis rates among AHS Zones in 2018 were the Edmonton Zone (70 cases per 100,000 population) and the North Zone (43.5 cases per 100,000 population) (Government of Alberta, 2019a).

In 2010 a report by the Office of the Chief Medical Officer of Health of Alberta claimed that syphilis infection rates were 18.6 times higher among young Aboriginal women and 2.8 times higher in Aboriginal men compared to Caucasian Albertans (Government of Alberta, 2010). Among the on-reserve First Nations population in Alberta, combined rates of chlamydia, gonorrhea, and syphilis have increased by 38% in the last five years (2007–2011) (Health Canada, 2013). Incidence and prevalence rates for infectious syphilis within the Métis population are unavailable either provincially or federally.

Métis-specific Health Data.

As described in the previous sections on STBBI, finding high quality data on Indigenous-specific rates of STBBIs can be challenging. This is particularly the case when one tries to identify statistics by Indigenous identity (i.e. First Nation, Inuit, or Métis). A large amount of Métis-specific health data comes from national and provincial surveys, which unfortunately limits the generalizability and scope of the data (Métis Centre of the National Aboriginal Health Organization, 2011). In some cases, statistics cannot be disaggregated by Indigenous group due to an inadequate sample size, as is the case in the Canadian Community Health Survey (Métis Centre of the National Aboriginal Health Organization, 2011). Additionally, Statistics Canada only began collecting Métis data in a targeted way since 1996, which limits the longitudinal data available on Métis Peoples (Macdougall, 2017; Monchalin, 2019).

When it comes to administrative health data, jurisdictions often have differing and inconsistent practices with regards to Indigenous ethnic identifiers, and many do not collect identifiers by Indigenous group (Andersen, 2016; Métis Centre of the National Aboriginal Health Organization, 2011). Additionally, individuals may not feel comfortable identifying as Métis at the point of care, due to fear of discrimination (Monchalin et al., 2020; Wesche, 2013). This limits ethnic-specific data that can be collected by hospitals and physicians. Distilling Métis-specific data from administrative data involves linking citizen registry data with administrative health data, a very time-consuming and lengthy process, which may be difficult for inadequately resourced Métis groups to achieve (Métis Centre of the National Aboriginal Health Organization, 2011). This process limits data to Métis registered citizens, which represents a smaller subset of the larger Métis population.

Additionally, there is a severe underrepresentation of Métis-specific research within academia (Métis Centre of the National Aboriginal Health Organization, 2011). Eighty (80) peer-reviewed articles inclusive of Métis health and wellness were identified in a systematic review examining academic journals between 1980 and 2009, of which only 12% were specific to Métis health and wellbeing (Kumar et al., 2012; Métis Centre of the National Aboriginal Health Organization, 2011). Some of the difficulties surrounding this include a lack a Métis representation in academia, difficulty or controversy in the definition of a Métis community (or even Métis identity), and a lack of articulated Métis-specific research guidelines (Métis Centre of the National Aboriginal Health Organization, 2011). A large amount of the research that is published on Indigenous health provides pan-Indigenous statistics which are not disaggregated by identity. Typical challenges experienced by those attempting to conduct Métis-specific research include a lack of health infrastructure, limited human resources, community reliance upon volunteers, and political instability (Evans et al., 2012; Monchalin, 2019). Overall these challenges with accurate data and the conduct of Métis-specific research have resulted in a lack of services for Métis Peoples (Monchalin, 2019).

Testing for HIV and STBBI

Various methods of testing and testing technologies for HIV and STBBI currently exist in Canada, however the majority involve a venous blood draw by a health care practitioner (Knowles & Wilton, 2018). This process usually involves requesting or being offered a test by a health care practitioner, a requisition form which is filled out for the test and given to the individual, and pretest counselling. Pretest counselling involves the healthcare practitioner offering information on HIV and STBBI, their modes of transmission, and risk behaviours (Knowles & Wilton, 2018). In the majority of instances, an individual must take the lab requisition to a facility where dedicated health care practitioners will draw the blood sample and send the sample to the lab for testing (Knowles & Wilton, 2018). Then the individual must wait for a test result to be communicated to them through a post-test counselling process (Knowles & Wilton, 2018).

Testing for HIV and STBBI is a complex interaction with the health care system, which is often anxiety provoking for individuals (Worthington et al., 2010; Worthington & Myers, 2003). Getting tested involves engaging with health care practitioners, which places the person at risk of feeling potentially stigmatized for their risk/health behaviours or identity, or a lack of cultural responsiveness (Worthington et al., 2010). Fear and anxiety are common responses to being tested for HIV. Some individuals choose to get tested to reduce this fear or anxiety, or because of a sense of responsibility for the health of oneself and others (Worthington & Myers, 2003). Physician guidelines for testing of HIV viral load with the goal of achieving and maintaining viral suppression are: testing at the beginning of care, upon initiation of antiretroviral treatment, whenever treatment is modified, and repeated every 4-8 weeks until viral suppression is achieved, then repeated every 3 to 4 months for long-term monitoring (Eisinger, Dieffenbach, & Fauci, 2019). This represents many repeated healthcare interactions for individuals living with HIV.

Linkage to care occurs when an individual who tests positive for either HIV or another STBBI is connected to a health care practitioner who can provide them with treatment and ongoing care (Johnston, 2017). Linkage to care is an extremely important process because the individual can be linked to other supportive services, such as harm reduction, housing, and/or disability services (Johnston, 2017). Linkage to care is also important because there is some evidence that early linkage to care is associated with decreased HIV-associated morbidity and mortality (Tso et al., 2016). Some interventions, such as community-based mobile outreach testing, have been associated with improved linkage to care for HIV (Tso et al., 2016). Qualitative research has shown that men are more likely to experience poorer or reduced linkage to care compared to women (Tso et al., 2016).

HIV treatment is arguably one of the most important pieces of a coordinated HIV response (UNAIDS, 2017). By treating individuals and achieving viral suppression among those who live with HIV, transmission of the virus can be effectively prevented (Eisinger et al., 2019). This is known as “Undetectable Equals Untransmittable” or “U=U” and has been the subject of HIV anti-stigma and awareness campaigns (Eisinger et al., 2019). The science behind U=U is strong; however, its validity depends on the individual maintaining an undetectable viral load at all times (Eisinger et al., 2019).

Although venous blood draw conducted by a health care professional are still the most used form of HIV and other STBBI testing, technical innovations have led to the development of newer types of testing, such as rapid testing/point of care testing, DBST for HIV and STBBI, and at home testing, all of which are in various stages of implementation and use across Canada (Knowles & Wilton, 2018). Methods of testing include nominal, non-nominal, and anonymous.

Venous blood draw.

The majority of HIV and STBBI testing in Canada occurs within laboratories and requires a venous blood draw by a trained individual such as a lab technician or phlebotomist (Knowles & Wilton, 2018). Most testing requires a two-step process: first the sample is screened, and if a positive result is given, confirmatory testing is performed (Fish, 2017; Government of Alberta, 2018). For HIV, the sample is screened using a fourth-generation HIV testing technology such as an enzyme-linked immunosorbent assay (ELISA) (Government of Alberta, 2018; Knowles & Wilton, 2018). If the screening test indicates a negative result, no further action is taken. If the screening test indicates a positive result, a confirmatory test is conducted on the sample, typically using a Western Blot or a polymerase chain reaction test (Government of Alberta, 2018). According to the Government of Alberta website for citizens on HIV and testing, the ELISA test takes most test facilities 2-4 days to produce (Government of Alberta, 2018). If a Western Blot is used as a confirmatory test, results take 1 to 2 weeks to produce (Government of Alberta, 2018).

There are barriers to regular venous testing for HIV and STBBIs. Typical logistical barriers include a lack of time to test, and a lack of transportation to testing locations (Fish, 2017). Individual-level barriers include a lack of knowledge of STBBI, modes of transmission, or testing methods, misperception of one's own risk, and fear of results (Fish, 2017). The typical two-step testing process (screening and confirmatory testing) creates barriers due to the requirement for multiple visits (ordering the test and then receiving results) (Fish, 2017).

Rapid (point of care) testing.

Rapid testing, also called point-of-care (POC) testing, is a type of screening test for HIV which produces results immediately, using only a couple of drops of blood (Knowles & Wilton, 2018). If a reactive (i.e., positive) result is given through the POC test, a confirmatory test via a venous blood draw must be completed (Knowles & Wilton, 2018). Research on the feasibility and acceptability of rapid HIV testing has shown that immediate results are often preferred to waiting for results (Tuysuzoglu, Corliss, Fitzgerald, Abascal, & Samples, 2011). Additional positive factors such as the non-invasiveness of rapid testing, confidentiality, improved accessibility, reduced loss-to-follow-up, and the ability to discuss results with a healthcare practitioner immediately have been cited as reasons why rapid testing is sometimes preferred to venous blood draws (Gahagan et al., 2018; Tuysuzoglu et al., 2011). A benefit to POC testing is that non-healthcare workers can be trained to offer the testing (Ruffinen et al., 2015). System-level challenges may include the implementation process, human resource requirements such as ongoing training, a sustainable supply-chain for the production of HIV rapid tests, and an appropriate reimbursement model for physicians, nurses and/or clinics (Stevens, Gous, Ford, & Scott, 2014). Individual barriers to POC testing include not knowing where to access POC testing, and a fear of being recognized at a testing site (Gahagan et al., 2018). The exact sensitivity and specificity of POC tests depends on the particular assay used by the testing product, however, POC tests generally have a slightly higher false-positive rate than venous tests (Dalcin & Bogoch, 2018).

Between 2011 and 2012, syphilis and HIV POC testing was piloted in the Edmonton Sexually Transmitted Infections (STI) clinic by the AHS' Edmonton STI Clinic Public Health Outreach Team (Bergman, Anderson, Singh, & Poetz, 2013). This pilot study found that testing for syphilis at POC was challenging because it takes 20 minutes to confirm a negative syphilis test, which is a concern for high-volume sites (Bergman et al., 2013). Other concerns included the amount of supplies required to accommodate testing (Bergman et al., 2013). Ultimately, HIV POC testing was continued at the Edmonton STI clinic, and others, but syphilis rapid testing was not because it was not yet licensed for use in Canada (Bergman et al., 2013).

It is possible to screen individuals for HCV with an oral swab (Drobnik et al., 2011); however, information on the availability of HCV oral swab tests in Canada is limited. HCV POC testing is licensed in Canada and involves a finger-prick to sample; results take approximately 20 minutes (Fish, 2017).

Self-testing and at-home testing.

Self-testing kits, which allow individuals to collect their own samples and mail the samples to a lab for analysis, are not currently licensed in the Canadian market, although there are unlicensed kits being sold over the internet (The Canadian Press, 2019). Self-testing kits have been approved in other jurisdictions, and evidence from studies in these jurisdictions has revealed many benefits, as well as challenges, posed by self-testing modalities. These studies have shown that self-testing is an acceptable way to test for HIV and STBBI, particularly among groups considered to be higher risk, and the majority of users can perform the self-testing process accurately (Krause, Subklew-Sehume, Kenyon, & Colebunders, 2013; MacGowan et al., 2018; Tuysuzoglu et al., 2011). Self-testing offers the opportunity for users to feel empowered and reduces the likelihood of experiencing stigma since sample collection can be conducted in privacy (Tuysuzoglu et al., 2011). Self-testing also promotes mutual partner testing (Tuysuzoglu et al., 2011).

There are also challenges of self-testing. The window-period for self-testing kits are often longer than lab-based tests, and there is a risk of false-negatives and a sense of false reassurance during acute infection if the window period is not strictly observed (Tuysuzoglu et al., 2011). A prohibitive cost can reduce access to self-testing, and there is a risk that individuals may not receive timely pre- and post-test counselling along with the opportunity to screen for other STBBI (Tuysuzoglu et al., 2011). A Google search on January 9th 2020 for "at home HIV test kit Canada" resulted in products ranging from a $99 urine test for gonorrhea and chlamydia, to a $379 urine and finger prick blood test which tested for the presence of 10 STBBI including HIV (LetsGetChecked, 2020).

Anonymous, nominal, and non-nominal testing methods for HIV.

Anonymous, nominal, and non-nominal forms of testing are not specific to any one type of testing technology, but are approaches to testing based on levels of privacy. Anonymous testing is a method of testing which means that no identifiable information is put on the blood sample, test results, or clinic/lab paperwork, preventing the identification of the individual being tested. A positive test result must always be reported to a local public health unit; however, in the case of anonymous testing, no name is provided (Johnston, 2017). Anonymous HIV is only offered at select clinics and sites (Johnston, 2017).

Nominal testing occurs when an individual's name is attached to their test. In the case of a positive test result, the individual's name as well as their positive result is forwarded to the local public health unit (Johnston, 2017). Non-nominal testing involves using a code as a patient identifier to protect the individual's privacy, but in the event a result is positive the individual's full name is provided to the local public health unit (Johnston, 2017).

HIV is a reportable illness in all Canadian provinces and territories with the exception of Quebec, meaning a confirmed HIV diagnosis is reported to the relevant provincial health body, and the Public Health Agency of Canada (PHAC) (O'Byrne & Bryan, 2013). When a positive diagnosis of HIV is received, the individual is asked to provide the health care practitioner or a public health nurse with contact information for all sexual partners and drug-sharing partners since their last HIV test (Johnston, 2017). This process is called contact tracing and it is conducted to notify previous sexual and drug-sharing partners of their potential exposure to HIV (Johnston, 2017). Although names of the individual are not used, in certain cases it may be possible for individuals to discern the individual's identity (Johnston, 2017). Some provinces legally require that partner notification be carried out, others like Alberta allow it to be conducted with the patient's permission (meaning it is not required but highly recommended) (Johnston, 2017).

Anonymous HIV testing is controversial within public health (O'Byrne & Bryan, 2013). One perspective is that nominal testing should be used to allow for better surveillance and contact tracing. The other is that nominal testing may prevent individuals from being tested willingly and interacting with the health system, which subsequently may deter them from receiving care and therefore preventing the potential spread of HIV (O'Byrne & Bryan, 2013). While anonymous or non-nominal testing may reassure individuals of confidentiality, one study identified difficulty in linking individuals to care after receiving anonymous testing services (O'Byrne & Bryan, 2013). According to HIV Community Link, an HIV service organization in

Calgary, anonymous testing is available at two locations in Calgary (HIV Community Link, n.d.).

DBST Overview

DBST is a method of testing blood for the presence of HIV, HCV, HBV, and syphilis antibodies. The use of DBST has improved the detection of HIV, HCV, and other STBBI in many contexts, including developing and developed countries, and provides an effective alternative to venous blood sampling (Girardin et al., 2019; Radley et al., 2017). The concept of DBST itself is not novel, as heel-prick DBST has been the main method in many countries for the screening of newborn metabolic disorders since the 1960s (Parker & Cubitt, 1999). The process of DBST for HIV, HCV, and STBBI involves using a lancet to prick the skin, usually on the finger-tip, which is blotted onto a filter paper (called a Guthrie card), and the papers are then dried and shipped to a lab where they are processed for testing (Parker & Cubitt, 1999).

Benefits and challenges associated with DBST.

DBST has recently been identified as an alternative approach to screening for STBBIs within the context of developed countries such as Canada and the United Kingdom (Ashworth, Douthwaite, Mullender, Cunningham, & O'Shea, 2015). DBST has shown to be useful in resource limited settings, such as rural and remote locations which may have limited access to laboratory services (Chevaliez & Pawlotsky, 2018). Dried blood spot analysis has been shown to be cost-effective, and can be used to screen a large number of individuals at any time (Chevaliez & Pawlotsky, 2018; Martin et al., 2013). DBST is also portable and can be performed in environments that may be unsuitable for venous blood collection (Tait, Stephens, McIntyre, Evans, & Dillon, 2013).

Test results take time to process and require a system of patient notification to be in place. When test results are not immediate, there is a risk that the patient will be lost to follow up (Tait et al., 2013). Patients receiving testing through this pilot needed to be followed up with verbally over the phone. This task requires human resources, which may be challenging for underserved and under resourced areas. However, there is some evidence that verbally following up with individuals to provide their results and immediately connect them with care increases patient retention (Stevens et al., 2014). Waiting for test results can be an anxiety-provoking experience for those receiving testing (Worthington et al., 2010).

DBST in Canada.

DBST for HIV and STBBI has been implemented in other provinces in Canada. In February of 2019, a CBC article covered the launch of DBST for HIV and HCV in Prince Edward Island (Spencer, 2019). In July 2017, Public Health Ontario announced they would accept properly and appropriately collected dried blood spot tests at their labs for the testing of HCV (Public Health Ontario, 2017). DBST has also been piloted in in Manitoba for HIV, unspecified hepatitis and syphilis (Lodge & Klinic Community Health, 2019), and in BC for HIV, HCV, and syphilis within the Sex Now Survey Research Project (Lachowsky, 2019). DBST for HIV was also launched in several First Nation communities in Saskatchewan in 2017 through partnerships with PHAC (Government of Saskatchewan, 2017).

DBST in other countries.

As early as 1992, one of the first instances of DBST being used to test for HIV was in East Africa (Nyambi et al., 1994). There is evidence of DBST being used, in epidemiological studies, to test for HBV in the early 1980s, for HCV in 1987, and for syphilis in 1998, all within

European countries (Parker & Cubitt, 1999). DBST has a long history in other countries as a testing modality.

DBST has been highlighted as an alternative form of testing for HIV and HCV that has the potential to reduce barriers, particularly for individuals residing in rural or remote communities (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). DBST has a demonstrated track record in improving testing rates for HIV and STBBI; it has been used in other countries as a part of efforts to address and eliminate HCV and reach 90-90-90 targets for HIV. One example is the use of DBST as a core initiative in Scotland's Action Plan on Hepatitis C (McLeod et al., 2014). It has also been used to diagnose HIV and HCV among incarcerated individuals in the UK (Craine et al., 2015). DBST can be used to monitor HIV viral loads among those receiving HIV care in many diverse settings (Smit et al., 2014), and to diagnose HIV in infancy in resource-limited settings (Patton et al., 2007).

Barriers to HIV and STBBI Testing for Indigenous Peoples

In order to reach viral suppression, individuals must know they have HIV, and must be able to initiate and continue ongoing care within the HIV care cascade. This care cascade includes linkage to medical care, the initiation of antiretroviral therapy, and continued adherence to a treatment plan, which optimally leads to viral suppression of HIV (Jongbloed et al., 2019). Treatment as prevention is the basis for the planned elimination of HIV, according to the UNAIDS 90-90-90 plan (Jongbloed et al., 2019; UNAIDS, 2017). However, there are many barriers facing Indigenous Peoples with HIV and other STBBI to accessing testing and care, and achieving viral suppression of HIV. Many of the barriers that face Indigenous Peoples for getting tested for HIV and STBBI overlap or are similar to the barriers experienced by Indigenous

Peoples seeking care for HIV/STBBI. These can be categorized according to psychosocial and geographic barriers, and are described in the following sections.

Psychosocial barriers to testing.

Psychosocial barriers effect an individual's willingness to be tested for HIV and STBBI in various ways. A few major barriers are a sense or feeling of fear (i.e. anxiety), and anticipated discrimination or stigma (Traversy, Austin, Ha, Timmerman, & Gale-Rowe, 2015; Worthington et al., 2010). An individual may fear receiving a positive HIV result (Worthington et al., 2010), or may fear being judged unfairly by health care professionals when accessing testing or seeing someone they know when they are getting tested (Traversy et al., 2015). Individuals may feel they are unable to cope with results or the possibility of testing positive (Traversy et al., 2015). Individuals may perceive themselves to be lower risk or misjudge their risk level or risk behaviours or behaviours they believe to safeguard themselves against HIV (Traversy et al., 2015). This is also an issue from the healthcare provider standpoint, as many healthcare providers may misjudge their patient's risk level or believe that HIV is not an issue within their patient population (Traversy et al., 2015).

Comfort levels of both the patient and the healthcare provider are barriers to testing as well. In many cases patients may not feel comfortable talking to their healthcare provider (Traversy et al., 2015). They may also not have access to information about HIV, or where know where they can get tested (Traversy et al., 2015). Healthcare providers may feel uncomfortable asking their patients about risk behaviours and the need to get tested (Traversy et al., 2015). Time may also be an issue; healthcare providers may feel that they lack adequate time to address HIV risk, behaviours, or testing with patients (Traversy et al., 2015).

Physical and geographic barriers to testing.

Physical barriers to testing can prevent individuals from getting for HIV and STBBI. These barriers include living in a rural or remote town with limited access to health services, having to arrange for transportation and other logistics to access health services, testing service hours of operation, language barriers, as well as a lack of anonymous testing methods in smaller areas (Traversy et al., 2015).

Barriers to HIV and STBBI Treatment for Indigenous Peoples.

In order to receive treatment for HIV and STBBI, an individual needs to access testing services and be connected to healthcare for treatment. Similar to other healthcare services, there are barriers that prevent many from accessing the care and treatment needed. Two commonly referenced barriers are geographic barriers and psychosocial barriers.

Geographic barriers to treatment

Geography also plays a role as a barrier in accessing treatment. For those individuals diagnosed with HIV in Alberta, there are two HIV clinics to serve them: one in Edmonton (the Kaye Edmonton Clinic) and the other in Calgary (the Southern Alberta Clinic) (HIV Community Link, 2017). This presents an obvious geographical barrier for those living in northern and/or remote areas (Government of Alberta, 2015). For First Nations living on reserve, medical transportation can be arranged (Indigenous Services Canada, 2019) but is made challenging by the distances. Transportation supports are unavailable for Métis or non-status First Nation individuals because they do not qualify for non-insured health benefits to assist with coordination of medical transportation (Indigenous Services Canada, 2019), unless they are able to secure access to medical transportation through a service agency. The challenges for many Indigenous individuals residing in their community or reserve may include arranging time away from work, child care, time away from family, lack of support, not having someone there to attend clinic with them, fear of someone finding out the reason for trips to the city, feeling too tired to travel these distances, and the need for other supportive services that requires more trips (Canadian Aboriginal AIDS Network, 2008; Government of Alberta, 2015).

Psychosocial and other barriers to treatment.

Colonization has resulted in racism, which is entrenched within all governmental and service systems, including the healthcare system. Racism and discrimination continue to negatively impact the health and wellbeing of Indigenous individuals and communities (Allan & Smylie, 2015). This results in many Indigenous individuals planning or strategizing their healthcare related visits around anticipated racism, or even results in refusal to seek treatment (Allan & Smylie, 2015). As noted previously, racism and colonization, which are interrelated and intertwined, are important social determinants of Indigenous Peoples' health (Loppie Reading & Wien, 2009).

Cultural safety is a concept that arose in the field of nursing in New Zealand. It was originally defined as "the effective nursing of a person/family from another culture by a nurse who has undertaken a process of reflection on own cultural identity and recognises the impact of the nurses' culture on own nursing practice" (Papps & Ramsden, 1996, p. 491). However, the concept of cultural safety has been broadened to include the practices of all healthcare practitioners. The BC First Nations Health Authority defines cultural safety as "an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care" (First Nations Health Authority, n.d., p. 10).

Research has uncovered many promising practices in regard to improving the cultural safety of healthcare service delivery to Indigenous Peoples and communities (Allan & Smylie, 2015). These include: cultural-safety training for non-Indigenous healthcare professionals, which are rooted in educating individuals about social justice issues and the historical and current experiences of Indigenous Peoples in Canada; the implementation of trauma-informed care; efforts to increase the number of Indigenous healthcare workers; facilitating the transition of healthcare administration to Indigenous communities; the employment of Indigenous patient navigators or support workers; and interventions to address implicit bias within healthcare practitioners (Allan & Smylie, 2015).

Fear of stigmatisation related to the cause or concern of one's medical visit and fear of breach of confidentiality result in low testing rates and service usage among high-risk groups (Krause et al., 2013). Privacy and confidentiality are serious concerns for individuals living either on reserve or in small communities who wish to be tested for HIV or other STBBI, due to the close-knit nature of family and friend relationships in smaller towns (Canadian Aboriginal AIDS Network, 2008). Other stigma-related obstacles to accessing care include fear of discrimination or judgement over one's sexual and/or gender identities, drug use, or lifestyle, during a healthcare visit (Canadian Aboriginal AIDS Network, 2008).

One study on Indigenous youth experiences of HIV care identified fear about one's health status, dread, and denial as major reasons why Indigenous youth delayed receiving care for their HIV (Prentice et al., 2011). Encouragement and support from friends and family can help alleviate these barriers (Prentice et al., 2011). Indigenous youth reported other barriers to care including lifestyle, not needing HIV medication, not wanting to take pills, intolerance of side effects, or believing that the medication is bad for them (Prentice et al., 2011).

Many Indigenous Peoples have definitions or understandings of health and wellbeing that differ from mainstream biomedical understandings, which can influence the way they engage with the medical system (or choose not to) (Jongbloed et al., 2019). Many Indigenous Peoples who have been diagnosed and are living with HIV or affected by other STBBI prefer holistic services, whose first aim might not be antiretroviral treatment (Jongbloed et al., 2019). Importantly, while the absence of holistic services currently may be considered barriers to receiving care, they should be used to improve the way health and social services are offered to Indigenous Peoples living with HIV or affected by STBBI.

Shared Care Models

Shared care models are a model of care where a specialist physician, usually affiliated with an urban clinic, and a primary health care practitioner, typically working within a community, agree to share certain aspects of care (Hutchinson, Sutcliffe, Williams, & Estcourt, 2015; Mapp, Hutchinson, & Estcourt, 2015). Shared care models can be coordinated to address many complex health concerns or the unmet needs of specific patient populations. A shared care agreement can be either a formal written agreement, or an informal verbal agreement between practitioners about the shared activities and level of responsibility of care for each health care provider (Hutchinson et al., 2015). Shared care models have been successfully applied to Indigenous, rural, remote, and urban settings to work toward improving the diagnosis, treatment and ongoing care of individuals living with mental health or substance use concerns, HIV and/or HCV (Bouis et al., 2007; Byng, Norman, Redfern, & Jones, 2008; Haggarty, Klein, Chaudhuri, Boudreau, & McKinnon, 2008; Hoang et al., 2009; Lobo, Mascarenhas, Worthington, Bevan, & Mak, 2015).

Shared care is an appropriate model of care for increasing access to care in rural and remote contexts because it can be used to provide both timely and relevant health care (Anderson & Larke, 2009; Byng et al., 2008; Lobo et al., 2015; Samy, Hall, Rounsevell, & Carr, 2007). It is also a cost-effective way to improve health care access in rural and remote contexts (Kelly, Perkins, Fuller, & Parker, 2011; Lobo et al., 2015). Shared care provides opportunities for holistic, wrap-around supportive services based on the needs of a community (Lobo et al., 2015). Within a Métis context, a shared care model can be used to structure holistic, culturally-relevant care, which may include the use of Métis Elders, peer-navigators or support workers, case management/support, and counselling services (Tu et al., 2013). The aim of D&S is to scale-up and evaluate the implementation of holistic, Indigenous shared care models, of which prevention and wellness promotion are two key aspects. Testing for HIV and STBBI in innovative ways, such as DBST, is a very important aspect of reaching the undiagnosed, and encouraging awareness and prevention within communities (Chevaliez & Pawlotsky, 2018; Gahagan et al., 2018; Wainberg, Hull, Girard, & Montaner, 2016).

The typical programming elements of shared care depend on the distinct needs of the community being served, and the specific health issue that is the focus of the service. Shared care models written about in the literature are usually developed with input from the patient population, community members and leaders, patient and healthcare practitioner feedback, and integrate practical considerations around funding, the environment and context, community readiness, and organizational capacity (Kelly et al., 2011). In addition to the basic shared care agreement, the typical programming elements of shared care models include:

- Peer wellness coaches and peer navigators (Bouis et al., 2007; Mooss, Hartman, & Ibañez, 2015; Swarbrick, Murphy, Zechner, Spagnolo, & Gill, 2011; Swarbrick, 2013; Tu et al., 2013),
- Case management, usually provided by a registered nurse or social worker (Askew et al., 2016; Byng et al., 2008; Haggarty, Ryan-Nicholls, & Jarva, 2010; Kroon et al., 2008; Lombard, Proescholdbell, Cooper, Musselwhite, & Quinlivan, 2009; McGuire, Gelberg,

Blue-Howells, & Rosenheck, 2009; Sullivan & McCabe, 2015; Tu et al., 2013; Veinot, 2006),

- Counselling services (Haggarty et al., 2010; Lobo et al., 2015; Mooss et al., 2015; Tu et al., 2013; Wong, Luk, & Kidd, 2012),
- And in Indigenous communities, Elder support (Tu et al., 2013).

In some specific contexts, additional elements may include drive-in and out or fly-in and out services from a specialist physician (Hussain, Maple, Hunter, Mapedzahama, & Reddy, 2015), or technology based interventions such as telehealth via a telephone or teleconference appointments for patients with health care providers (Cheng, Nazareth, & Flexman, 2015; Pyne et al., 2010). These shared care models span the entire continuum of care from diagnosis to initial treatment as well as ongoing care and can include prevention. Therefore, testing forms the “beginning” of the shared care model continuum, which spans from identification of those at risk, to diagnosis, treatment, ongoing care and wellness promotion, to prevention (Stevens et al., 2014).

Shared care models in Indigenous communities.

There is evidence in the academic literature of shared care models being implemented within Indigenous communities to meet an unmet health need (Maar et al., 2009). Findings from these shared care models emphasize the importance of utilizing Indigenous staff and healthcare practitioners to help ensure culturally competent care; this can also result in more receptive patients due to an increased sense of safety (Askew et al., 2016; Haggarty et al., 2010). Research identifying best practices of shared care models identified the importance of being grounded in a social justice perspective (Haggarty et al., 2010). Peer support workers are a common programming element that contribute to the cultural safety and relevance of shared care model programs (Bouis et al., 2007; Maar et al., 2009; Mooss et al., 2015). Traditional healing activities can be integrated into the shared care model to provide more holistic, relevant and integrative health services (Maar et al., 2009).

Testing within a shared care model.

Shared care models are interventions which span the entire HIV continuum of care for an individual living with, or at risk of HIV, HCV and STBBI – and testing is an important part, as it is the mechanism through which people are informed of their HIV status (Stevens et al., 2014). In the instance of a negative test result, this provides a valuable opportunity to educate the individual on prevention (Mykhalovskiy, Patten, Sanders, Bailey, & Taylor, 2009). In the case of a positive result, the follow-up fosters an opportunity to connect individuals to the cascade of care.

Although this research project is nested within the work of D&S, as its focus is on testing and its evaluation, it is a distinct sub-study within the work of D&S. In the case of this sub-study, and the implementation of the DBST pilot within the Métis community in Red Deer, D&S has acted in a facilitation and support role. For shared care models to be truly effective, reaching the undiagnosed through testing cannot be overlooked, and therefore this project forms an important aspect of D&S work within the Métis community of Red Deer.

Implementation Science (IS)

IS is defined as the "scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services and care" (Eccles & Mittman, 2006, p. 1). IS is a field of research which cuts across many fields of health sciences, healthcare delivery, as well as theoretical and methodological domains (Norton, Lungeanu, Chambers, & Contractor, 2017). The field of IS is relatively new and was created to address challenges in implementing evidence into practice across and within diverse fields of health care (Nilsen, 2015). IS not only focuses on the empirical evidence but examines the contexts of health care implementation through the investigation and application of theories, models and frameworks which often draw upon the fields of individual and organizational psychology and sociology, in addition to those developed through IS (Nilsen, 2015). For IS to work well, there must be an effective partnership between researchers, community, and policy makers (Blanchard & Aral, 2011).

The field of IS overlaps with the field of quality improvement to a significant degree, as both share the ultimate goal of improving health care (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015). However, quality improvement usually begins with the identification of a quality problem or issue within healthcare, whereas IS begins with an under-utilized evidence-based practice (Bauer et al., 2015). A large part of the work of IS is in creating knowledge that is easy to digest and can be generalized to many contexts and systems, particularly outside of the ones being studied (Bauer et al., 2015). Therefore, knowledge translation forms a core important aspect of IS as a field.

IS is also distinct from clinical research, which typically focuses on the health outcomes and impacts of an evidence-based practice intervention. IS typically studies factors such as rate of uptake and quality related to use of evidence-based practice interventions, rather than clinical outcomes, with the aim of discovering facilitators and barriers of implementation and system change (Bauer et al., 2015). The main focus is to evaluate the process of implementation rather than outcomes (Bauer et al., 2015).

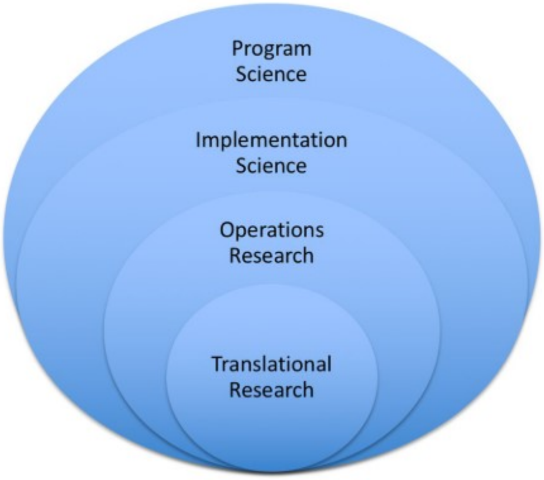
Program science.

Program science is a field of research concerned with the systematic application of knowledge to optimize the scale, impact and quality of health programs (Becker et al., 2018).

Program science arose to specifically address the disconnect between advances in research, the priorities of policy makers, and those responsible for implementing HIV and STBBI services (Becker et al., 2018). Becker et al. situate IS as a sub-field within the greater field of program science, as pictured below in Figure 1.

Figure 1

Program Science and its Relationship with Other Research Frameworks by Becker et al. 2018



The goal of program science is to better connect the work of researchers, policy makers, and service providers (Becker et al., 2018). Nested within program science is the area of IS, which focuses on the uptake of evidence by knowledge users. Within IS is operations research. Operations research is focused on the "identification, implementation and assessment of strategies to improve program operations in real-world settings" (Herbst et al., 2012, p. 531). And finally, nested within operations research is the field of translational research. Rubio and colleagues (2010) offer the following definition for translation research: "translational research fosters the multidirectional integration of basic research, patient-oriented research, and population-based research, with the long term aim of improving the health of the public" (p. 471). This means promoting the movement and evolution of research findings from basic science into clinical research trials and population-based studies. Translational research is nested within operations research, which is nested within IS, which is nested within program science (Becker et al., 2018). These spheres of program science work together to connect seemingly disparate forms of research to improve the overall effectiveness of programs and services.

Becker et al. (2018) describe three "spheres" of a program science approach: strategic planning, program implementation, and program management and evaluation. Strategic planning involves the local epidemiology of the population served by the program, and what the context-specific issues to that population are (Becker et al., 2018). This sphere of program science can be somewhat technical and may include research into geographical aspects of health issues, creating spatial-distribution maps of hot-spots within epidemics or outbreaks, research into modes of infectious transmission, or mathematical or economic models of transmission (Becker et al., 2018). Program implementation requires the decision to define which programs to implement and how best to implement them (Becker et al., 2018). This sphere includes research in community engagement and community mobilization strategies (Becker et al., 2018). Program management and evaluation involves designing evaluations of programs to determine whether gaps in services or outcomes are being improved (Becker et al., 2018). This sphere includes work around tools which help program managers to conduct evaluations (Becker et al., 2018).

Context and complexity.

Implementation of any evidence-based intervention is usually very complex, typically because interventions are multi-pronged, and must adapt to local contexts (Bauer et al., 2015). These local contexts are themselves considered complex, given the range of diverse health care practitioners, patients, policies, and settings, which interact to increase complexity (Bauer et al., 2015). Attempting to "optimize" the natural context in which an adoption is being studied poses a threat to the validity of an IS study (Bauer et al., 2015, p. 7). Many studies, particularly clinical ones, aim to remove contextual confounders. However, aiming to remove contextual confounders does a great disservice to those attempting to integrate evidence-based interventions into any system, as these confounders represent the "normal conditions into which interventions must be integrated if they are to be workable in practice" (May, Johnson, & Finch, 2016, p. 1). In order for research to be applicable and workable in practice, close attention must be paid to the context in order to better understand barriers and facilitators to uptake of evidence-based practice (May et al., 2016). This is because studies do not take place in vacuums; all interventions are negotiated within complex spaces (May et al., 2016).

Context is so complex because attempts to describe the context of intervention studies are lengthy and time-consuming, and may also vary widely by author and field (May et al., 2016). The number of potential contextual confounders are endless, as one can even consider the broader political, social, historical, economic, cultural, and psychosocial factors at increasingly larger levels (e.g. municipal, regional, provincial, federal) which influence contexts (May et al., 2016). To reduce the scope and size of context, many IS frameworks focus on *place* as context, which describes and focuses on more of the physical environment and related boundaries and structures that influence health-related practice (May et al., 2016). However, one must wonder if this attempt to narrow context into a description of *place* is doing a disservice to the research or will limit our understanding of the barriers and facilitators of these programs being implemented (May et al., 2016).

Fidelity versus adaptation.

As with any field of research that has existed for some time, disagreements and debates have arisen within the field of IS about the best way to approach the scale-up of existing programs in other geographical areas and contexts. Some advocate for maintaining fidelity to the original program's intervention as closely as possible, and others argue that adaptations are required when implementing programs in other areas in order to ensure success. This disagreement is referred to as the fidelity versus adaptation debate, also known as fidelity versus fit or integrity versus adaptation (Carroll et al., 2007).

Implementation fidelity (or integrity) is defined as the degree to which a program is implemented in accordance with the way it was defined and intended by the original program developers. Carroll and colleagues (2007) argue that, "Only by understanding and measuring whether an intervention has been implemented with fidelity can researchers and practitioners gain a better understanding of how and why an intervention works, and the extent to which outcomes can be improved" (p. 1). Strict proponents of implementation fidelity may argue that a high degree of fidelity is the only way to ensure programmatic success (Parekh et al., 2019).

Properly assessing fidelity can be challenging due to the lack of data that is typically reported within studies (Carroll et al., 2007). Achieving a high level of fidelity comes with many challenges for those responsible for implementing and managing programs (Carroll et al., 2007). The more specific and simpler the intervention, the more likely it can be implemented with a high degree of fidelity (Carroll et al., 2007). This means that it is difficult to achieve a high degree of fidelity for complex interventions. Ensuring a high degree of fidelity requires significant time and resources are dedicated towards education, training, and support for those providing the service to ensure they remain as close to the intervention as possible (Carroll et al., 2007). The tight prescriptive nature of a program may be at odds with the aims or desires of the new intervention site (Dane & Schneider, 1998). It also requires a high level of ongoing evaluation and feedback to ensure that fidelity to the original program is maintained (Carroll et al., 2007), which requires human resources and a focus on data collection. Complex interventions are interventions which usually have multiple interacting components (Craig et al., 2008). Rigid insistence of maintaining fidelity can cause disagreement or discord among program administrators (Dane & Schneider, 1998).

Adaptation is defined as any change to the original program during the course of implementation or ongoing management that make the program more suitable for its context or facilitate the completion of a particular activity (Parekh et al., 2019). Some authors argue that a level of adaptation is necessary for most program success (Parekh et al., 2019).

A middle ground has arisen within this debate which acknowledges both arguments and identifies that program adaptation is appropriate if “core components” are not changed (Parekh et al., 2019). Ideally, adaptations in programs should be planned in advance in order to be able to predict how/if the adaptations will affect core components (Parekh et al., 2019). It is also important in implementation to clearly identify what the core components of a program are (Parekh et al., 2019). Some researchers have shown that, in their experience, adaptation has facilitated more success within programs as it allows for programs to better meet the needs of the local context and population (Parekh et al., 2019).

Shortcomings of IS.

One deficit of IS is its narrow focus on the implementation of programs and its lack of focus on how knowledge is created within its field (Ellison, 2014). Ellison states, “Implementation science questions the route knowledge takes to reach individuals and populations for whom a benefit is sought, but not how that knowledge is generated” (2014, p. 11). Ellison follows this statement with a suggestion that scientists and researchers need to rethink scientific rigor in favor of the knowledge that can be gained from both qualitative research and real-world research trials (Ellison, 2014). This recalls back to the disagreement within IS about context, and whether or not researchers should aim to remove all potential confounders in order to aid in the identification of efficacy, and whether or not homogeneity within research participants and contexts creates evidence which is ineffective for use within the real world (Ellison, 2014). In conclusion, this disagreement suggests we should thoughtfully consider what constitutes good evidence in the field of public health (Ellison, 2014), particularly when we are doing research with Indigenous Peoples and communities. This is important to consider because Indigenous knowledge systems and methodologists do not construct concepts such as biases and objectivity in the same way that Western scientists do (Ellison, 2014).

Frameworks in IS.

There are many published frameworks and models within the field of IS. A framework is a broad set of organized constructs that, without specifying causal relationships, can provide a series of steps to guide the implementation of an evidence-based intervention (Bauer et al., 2015). This section will provide an overview and analysis of a few of the most prominent frameworks within the literature and will discuss why the RE-AIM (Reach, Effectiveness, Adoption, Implementation and Maintenance) framework was chosen to help guide the evaluation of this research.

Consolidated Framework for Implementation Research (CFIR). The Consolidated Framework for Implementation Research (CFIR) classifies 39 implementation constructs over five domains (Bauer et al., 2015; Damschroder et al., 2009). These domains are considered influential moderators or mediators of implementation outcomes. The CFIR, like other models, provides a process to allow for the structured and systematic review of the context in which implementations are occurring (Bauer et al., 2015).

CFIR was first published in 2009 in the Journal of IS (Damschroder et al., 2009). It was developed by the authors with the intention of providing more detail and clarity on the many constructs and domains identified within other IS frameworks, many of which had no clear definition in the literature (Damschroder et al., 2009). Through a snowball sampling method, the authors identified existing frameworks within the literature and distilled their constructs/domains into the five domains contained within CFIR. A systematic review conducted in 2016 identified 26 unique articles which used CFIR to guide the data collection, analysis, and/or reporting of IS studies (Kirk et al., 2016).

CFIR domains. The first domain of CFIR covers characteristics of the intervention being implemented (Kirk et al., 2016). The authors state that most interventions will be unsuited to their contexts without some level of adaptation taking place before implementation (Kirk et al., 2016). Interventions may be identified in terms of core aspects and "adaptable periphery" (adaptable elements, structures, and systems related to the intervention and organization into which it is being implemented) (Kirk et al., 2016). Damschroder and colleagues (2009) recommend that adaptable periphery are altered in a "co-adapting, co-evolving" way (p.5). Aspects to consider under domain one include: the source of the intervention (whether it is perceived to be internally or externally driven), the strength and quality of evidence in support of the intervention, whether stakeholders perceive the intervention to be advantageous as an alternative to status quo, the adaptability of the intervention, trialability, complexity, design packaging (i.e., how the intervention is pitched and presented to stakeholders), and costs associated with implementation (Kirk et al., 2016).

The second and third domains are the inner and outer setting (Kirk et al., 2016). The outer setting includes political, economic, and social factors that influence the way interventions are implemented (Kirk et al., 2016). For the outer setting, aspects that should be considered include: patient needs and resources (and whether barriers to patient participation in the intervention are addressed), "cosmopolitanism" (the degree to which the organization has networked with corresponding organizations, representing social capital), peer pressure, and external policies and incentives (Kirk et al., 2016). For the inner setting, consideration should include: the social characteristics of the organization (e.g., age, maturity, and size), networks and communication, organizational culture, and implementation climate (Kirk et al., 2016). Implementation climate includes several sub-categories to consider:

- Tension for change (whether or not stakeholders consider the current situation intolerable);
- Compatibility of the intervention (meaning and values ascribed to the intervention and whether these fit the values of the organization, perceived risks and needs, and whether or not the intervention fits well into the workflow of the day-to-day operations);
- Relative priority (shared perception of the implementation's importance within the organization);
- Organizational awards and incentives (whether tangible, such as incentivized billing, or intangible, such as prestige or appreciation within workplace);
- Goals and feedback (the degree to which goals are adequately communicated, acted upon, and fed back to staff through alignment of feedback with the goals of the organization);
- Learning climate (acceptability of failure within the organization) (Kirk et al., 2016).

The third domain of outer setting also includes consideration for implementation readiness, which includes: leadership engagement, available resources, and access to information and knowledge (Kirk et al., 2016).

The fourth domain, characteristics of individuals, includes consideration of: knowledge and beliefs of the intervention, self-efficacy, individual stage of change (how the individual has accepted the intervention and integrated its use into their practice), individual identification with the organization (the degree of an individual's commitment to an organization), and other attributes such as tolerance of ambiguity, values, capacity, innovation, tenure and learning styles (Kirk et al., 2016).

There are four essential activities of implementation process, which are: planning, engagement (opinion leaders who are both experts and peers, formally appointed implementation leaders, champions, and external change agents), execution, and the process of reflection and evaluation (Damschroder et al., 2009).

In their discussion of IS, Damschroder and colleagues (2009) discuss some potential reasons why evidence-based interventions fail to result in health outcomes. Barriers to achieving health outcome changes can arise at any level, including patient, administrator, health care practitioner, and policy maker levels (Damschroder et al., 2009). As a process theory, CFIR is designed to be used to facilitate the planning, organization and scheduling of a new intervention. The authors present the components of each of the five domains as a method for understanding implementation, or for use in formative evaluation (Damschroder et al., 2009). CFIR is a helpful framework as it provides a comprehensive list of explicitly defined constructs to guide data collection (Damschroder et al., 2009). CFIR can also be used to guide exploration into identifying factors which influenced performance of the intervention (Damschroder et al., 2009).

It can also be used to organize, format, and present implementation research findings. Based on the number of domains and criteria, CFIR is a comprehensive tool which may assist in identifying stumbling blocks and facilitators for interventions. However, its detailed nature may prove challenging to researchers and program administrators, as many data elements need to be collected (Kirk et al., 2016). There may also be challenges in collecting accurate data to evaluate certain elements such as employee receptivity and engagement. Other challenges include recording unanticipated influences during the implementation process, and accounting for these influences in the evaluation (Damschroder et al., 2009).

Promoting Action on Research Implementation in Health Services (PARIHS) Framework. The PARIHS framework posits that there are identifiable, interacting factors that strongly influence whether the implementation of an evidence-based intervention is successful (Kitson, Harvey, & McCormack, 1998). The PARIHS framework was originally published as an unnamed framework to support implementation in 1998. The PARIHS framework identified three core components: evidence, context, and facilitation, which the authors described as interacting and interrelating with each other to determine the effectiveness of an implemented evidence-based practice (Kitson et al., 1998). The authors state that current research is inconclusive regarding which of these three factors is most important, and therefore, they should be considered equally important within the framework (Kitson et al., 1998). The PARIHS framework was developed to provide an alternative explanation for implementation successes and failures, in contrast to frameworks of the time which focused on unidimensional implementation factors (Kitson et al., 1998).

The category of evidence within the PARIHS framework is broad and includes evidence from studies and clinical practice guidelines through formal experiments, clinical experience or professional knowledge, patient preferences, and locally-derived data through projects like project evaluations or quality improvement initiatives (Kitson et al., 1998). The PARIHS framework gives equal weight to these diverse evidence forms, but does provide some details as to what is considered high-quality and low-quality evidence. For the research category, randomized controlled trials, systematic reviews, and evidence-based guidelines are considered high-quality (Kitson et al., 1998). Clinical experience should be based on high-levels of consensus which provide consistent views; evidence where expert opinion is divided, or several "camps" exist should be avoided (Kitson et al., 1998). Patient preferences should be integrated through partnerships and this should be reflected within the evidence used (Kitson et al., 1998).

Context is defined by the PARIHS framework as "the environment of setting in which the proposed change is to be implemented" (Kitson et al., 1998, p. 150). The category of context includes receptivity, organizational culture, leadership, and evaluation (Kitson et al., 1998). An environment which would rank high within the PARIHS framework's context category would be characterised as: a patient-centred, learning organization which values people and continuing education; roles which are clearly defined and have clear leadership, with effective teams and organizational structures; and values internal measures, audits, feedbacks, peer reviews, and external measures to drive improvement.

Facilitation is defined by the authors of the PARIHS framework as "a technique by which one person makes things easier for others" (Kitson et al., 1998, p. 152). A facilitator is someone whose job is to help people understand the change which is being implemented and how the desired outcomes will be achieved (Kitson et al., 1998). Facilitation includes many sub-elements and mechanisms which influence implementation, including purpose, holistic-oriented (does the implementation allow teams to reflect on and change attitudes and ways of working), roles, skills and attributes. A facilitator which would rank high within the PARIHS framework's facilitation category would be characterised as an individual who is respected and respects others, is empathetic, authentic and credible; is accessible, and facilitates access to knowledge, has authority, and has successfully negotiated a change agenda; their style is identified as flexible, and consistent, with an appropriate presence and supportive (Kitson et al., 1998).

Some improvements to the original PARIHS framework have been suggested within the literature, and identified by the original authors of PARIHS themselves, who have played an active role in revisiting, improving, and publishing improvements to the original PARIHS framework (Stetler, Damschroder, Helfrich, & Hagedorn, 2011). Recommendations based on identified limitations of the framework include the need to consider addressing the underlying motivation for change, such as change tension (a factor considered in the CFIR framework) (Kitson et al., 2008). The PARIHS framework was designed to be used in the beginning of the implementation, however most of the literature applies the PARIHS framework retroactively during the process of evaluation (Kitson et al., 2008). The framework fails to provide details on how data should be collected within each category (Kitson et al., 2008). The lack of conceptual clarity of each sub-element within the PARIHS has been noted as a limitation within the existing literature (Kitson et al., 2008). There is also ambiguity about how one determines or identifies a "successful implementation" (Kitson et al., 2008). One major benefit of the PARIHS framework is more flexible in what it considers to be evidence (Kitson et al., 2008). Its clear preference for patient inclusion within evidence generation makes the PARIHS framework desirable for patient-oriented research and patient-centered care models/interventions.

RE-AIM Framework. The RE-AIM framework was designed specifically as an evaluative framework for public health interventions. The authors cite the prevalence of a reductionist approach (that is, attempting to oversimplify context in an effort to eliminate potential confounding variables) as a major flaw within IS and public health research

Abrams and colleagues (1996) working within the context of a tobacco-use reduction program, originally posited that the impact of a public health intervention is the product of a program's reach (the percentage of population receiving the intervention) and its efficacy (I = R x E). Glasgow and colleagues (1999) built on the I = R x E model be adding three additional (AIM) domains (adoption, implementation, and maintenance) to create the RE-AIM framework. In the RE-AIM framework, each domain is represented from 0% to 100% (or 0 to 1 on a scale).

Reach. Reach represents the individual level of participation in the intervention, whether that might be employee or patient participation. This includes the percentage of individuals reached by the intervention, as identified by Abrams and colleagues (1996), as well as risk characteristics. This is completed by comparing records of program participants and complete sample or "census' information for a defined population. This type of data collection would likely be easier for a clinic or hospital, which have access to detailed records on the population which is receiving the intervention. Reach also requires researchers to consider the characteristics of the participants (those whom the intervention targets).

Efficacy. Glasgow and colleagues (1999) identify two key issues within efficacy: the importance of addressing both the positive and negative outcomes of a program, as well as the need to include behavioural, quality of life, and participant satisfaction outcomes. While the majority of public health interventions focus on the positive outcomes of interventions, there can be serious negative consequences associated with these interventions. One example identified by Glasgow and colleagues(1999) is the psychological and social consequences experienced by individuals who have received a serious diagnosis. One should also consider the net positive and negative impacts to society and the health system at large, particularly when it comes to misplaced or ill-placed resources within the health system. Glasgow and colleagues (1999) encourage researchers to measure outcomes outside of the typical focus on biological outcomes and risk factors of medical researchers to include behavioural outcomes, cost assessments, quality of life, mental health, and even consumer satisfaction.

Adoption. Adoption refers to the representativeness of the settings which adopt interventions. Adoption can be assessed through observation or via surveys and interviews. It is also critical to examine barriers to adoption through the observation of non-participating settings.

Implementation. Implementation is often referred to as effectiveness; this refers to the extent to which a program is delivered as it is intended. Implementation interacts with efficacy to determine the effectiveness of a program, at both an individual-level and program-level. At the individual level, factors such as patient adherence or compliance with medical advice may be considered.

Maintenance. Maintenance should be considered at both the individual level and organization or community-level. For the individual, maintenance refers to how long an individual can sustain a desired change within their behaviours. At the community level, assessment of how well an intervention becomes routine is important. This is sometimes referred to as the extent to which an intervention is institutionalized. Evidence of maintenance at the community-level could be legislation (e.g., tobacco control legislation) or integration into local policy (e.g., no-smoking policy).

Combining the RE-AIM Dimensions.

The authors argue that combining the component dimensions according to their formula provides the best overall representation of quality. The authors do not discuss any preference for methods to measure efficacy, but discuss the need to use quantifiable, reliable and valid measures. Data should be collected over a minimum time frame of 6 to 12 months for implementation evaluation, and 1-2 years or longer for maintenance evaluation. The RE-AIM framework can be used to assess an intervention’s overall public health impact, compare its impact across organizational units or over a period of time, directly compare the two or more interventions using the RE-AIM score, or to better inform decisions about the redistribution of program resources (Glasgow, Vogt, & Boles, 1999).

Strengths.

The RE-AIM framework has been in existence for 20 years, making it one of the older and more utilized models in IS alongside the PARIHS framework (Gaglio, Shoup, & Glasgow, 2013). A 2013 systematic review identified 73 peer-reviewed publications which utilized the RE-AIM framework (Gaglio et al., 2013), which shows it has been well utilized since initially published in 1999. RE-AIM focused on providing an alternative to evaluative models which emphasized a reduction in confounding factors, emphasizing the need to evaluate public health interventions in real-world settings. It values external validity, which is the degree to which intervention results can be generalized across populations, interventions, and settings, making it highly pragmatic (Ory et al., 2015). The RE-AIM factors are easy to understand and follow a logical sequence, beginning with adoption and ending with maintenance (Gaglio et al., 2013). This easy to understand nature makes the RE-AIM approach to evaluation more suitable for community-based partners.

The framework has evolved over time to include more diverse content areas (Gaglio et al., 2013). It has also been used not only for evaluation, but for planning, reporting, and policy decision making as well as complex, multi-level community-based interventions (Gaglio et al., 2013). The framework has grown to include the use of, and recognize the importance of, qualitative data and research (Gaglio et al., 2013).

Limitations.

The authors identify the fact that the exact relationship between each factor, and how they work together to determine the overall public health impact, is unknown (Glasgow, Vogt, & Boles, 1999). Confusing definitions of reach and adoption have been highlighted by some authors as a flaw of the framework (Gaglio et al., 2013).

Integrating IS with Indigenous participatory evaluation approaches.

As this thesis research is nested within the broader D&S IS study, which utilizes RE-AIM, this research will draw upon the IS RE-AIM framework as an evaluation heuristic, combined with a Participatory Indigenous Evaluation approach, to evaluate the implementation of DBST (Glasgow, Klesges, Dzewaltowski, Estabrooks, & Vogt, 2006). IS will facilitate the process of examining influences, including barriers and facilitators at individual, organizational and structural levels, and evaluate outcomes through the RE-AIM framework (Blanchard & Aral, 2011; Glasgow et al., 2006; Lobb & Colditz, 2013).

Indigenous evaluation approaches incorporate traditional Indigenous knowledges and Indigenous participatory research methodologies into the evaluation approach (Grover, 2008; Kawakami, Aton, Cram, Lai, & Porima, 2008). In keeping with wise practices within the field of Indigenous evaluation, potential outcomes to measure and evaluate (e.g., acceptability) were identified in partnership with Métis community stakeholders from Shining Mountains.

Indigenous participatory evaluation approaches place emphasis on the importance of the researcher relinquishing power imbalance and building strong relationships with community partners and members (Chandna et al., 2019). Many Indigenous evaluation approaches utilize surveys, interviews, and focus groups (Chandna et al., 2019). Additionally, consultation plays a large role in evaluative activities and research (Chandna et al., 2019). For evaluations within Métis communities, areas of assessment could examine acceptability, feasibility, and the cultural safety in the provision of services, and could draw upon or integrate multiple forms of Métis knowledge.

Indigenous knowledge.

The term Indigenous knowledge is sometimes used interchangeably with traditional knowledge. There is overlap between traditional knowledge, knowledge systems, and Indigenous worldviews, as many of the themes are similar and include the importance of connection, relationality with other humans, the earth, animals, and spirits, and energy (Nyman, 2014). There does not appear to be a consensus in the literature on a definition of traditional or Indigenous knowledge, as it seems to be a difficult concept to define, as it means different things to different people. However, many have described it by its aspects and characteristics (Ellison, 2014). Author Bruchac (2014) has provided one definition of traditional Indigenous knowledge: “Traditional Indigenous knowledge can be defined as a network of knowledges, beliefs, and traditions intended to preserve, communicate, and contextualize Indigenous relationships with culture and landscape over time” (p. 1). Here, I will write about recurring themes within Indigenous knowledge and summarize what has been written in the academic literature about Métis traditional knowledge.

Characteristics of Indigenous knowledge. Aikenhead and Ogawa (2007) write that the term “knowledge” is a difficult one to translate into most Indigenous languages, as Indigenous languages tend to be verb-based and action oriented, whereas English considers knowledge to be a thing (a noun) to be possessed. The closest translation tends to be something similar to the concept of “ways of being” or “ways of living” (Aikenhead & Ogawa, 2007). This speaks to the inseparable nature of Indigenous knowledge (as a verb) and Indigenous worldviews. Within Indigenous epistemologies, knowledge cannot be separated from the knower (Aikenhead & Ogawa, 2007). In Cree culture, the term “coming to know” refers to an individual’s quest to become wiser through an exploration of how to live in better harmony with their community and nature (Aikenhead & Ogawa, 2007).

Holistic. Indigenous knowledge is holistic (Aikenhead & Ogawa, 2007). All the aspects of knowledge, which include (but are not limited to) spiritual knowledge, physical knowledge, artistic knowledge, and philosophy, cannot be separated from one-another (Aikenhead & Ogawa, 2007). To attempt to isolate one specific field of knowledge from others is to disrupt the holistic balance that exists within Indigenous epistemologies and knowledge systems (Aikenhead & Ogawa, 2007).

Boyer (2019) writes about the many types of healing practitioners that have existed within Indigenous communities since pre-contact. Most communities draw upon a wide array of resources to assist them in healing others. For example, Boyer (2019) talks about how specialized healers may combine the use of medicinal herbs with spiritual assistance of supernatural forces. Boyer (2019) talks about the many healing practices which healers have drawn upon within Indigenous societies, including sweat lodges, the calling of spirit helpers, cupping, botany, and shaking tent ceremonies.

Rational. Indigenous knowledge is empirical in nature and is grounded in natural observation and rationality, which ties it to Western knowledge (Ellison, 2014). However, Indigenous concepts of rationality are culturally-based and developed, and are grounded in common understandings discussed in this section (e.g., holistic, place-based, etc.) (Aikenhead &

Ogawa, 2007). It is also intergenerational, participatory in nature, and locally-based but also systematic (Ellison, 2014).

Place-based. Much of Indigenous knowledge is place-based and is tied to the environment (Aikenhead & Ogawa, 2007; Maldonado et al., 2016); this is true for Métis Peoples also (Adese, 2014). As people who lived within, and depended on the landscape to survive, Indigenous Peoples had to be incredibly adaptive (Maldonado et al., 2016). Indigenous knowledge is reflective of this, so in one sense it is also portable, as it was taken from place to place as communities moved (Bruchac, 2014). Oral stories often contain knowledge about adaptation and landscape management strategies used by communities which were critical for survival and wellbeing (Maldonado et al., 2016). As such, storytelling forms a core aspect of traditional knowledge as most communities transmitted knowledge orally from one generation to the next (Maldonado et al., 2016). Knowledge is also transmitted from one generation to the next through modeling behaviours, singing songs, reciting prayers, learning and performing dances, and learning spiritual ceremonies (Aikenhead & Ogawa, 2007).

Knowledge keepers. Some forms and types of traditional knowledge are shared by all members of a community as they are informed by the experience of being Indigenous (Bruchac, 2014). Some Indigenous knowledge is more specialized, which is gained by an individual through a deliberate and conscious action and desire to gain knowledge in a certain area, often through a spiritual calling (e.g. medicine person, Chiefs, community leaders) (Bruchac, 2014). These people often focus on acquiring knowledge through an in-depth process which often takes many years. Individuals who have undertaken this particular path, or special training, are referred to as "knowledge keepers" (Bruchac, 2014). This is why many, but not all, knowledge keepers are Elders (Bruchac, 2014). The Canadian Aboriginal AIDS Network's (2005) resource on supporting Métis individuals with HIV states the following about traditional knowledge:

> Teaching and learning the complexities of traditional cultural values and practices takes a lifetime. It is a never-ending process of living to achieve different levels and layers of understanding. One acquires spiritual and intellectual growth through dynamic interaction with other beings sharing the same environment, often by repetitive experience." (p. 11)

Métis Indigenous/traditional knowledge. Métis ways of knowing, like Indigenous ways of knowing, are diverse because Métis Peoples come from a variety of Indigenous and European backgrounds, traditions, and practices (Adese, 2014). Therefore, there are some differences among stories and practices, however most communities share many themes within their traditional knowledge systems (Adese, 2014).

Identity. Métis traditional knowledge is grounded in who the Métis Peoples are as a unit of identity, and is closely tied to our cultural practices (Edge & McCallum, 2006). It is related very closely to Métis traditional health knowledge and healing practices. Cultural protocols constitute a significant part of traditional knowledge because they offer us guidance in the way we operate within everyday life (Edge & McCallum, 2006). These cultural protocols are inextricably linked to our traditional languages (Edge & McCallum, 2006). Michif is one of the most recognized Métis languages, although it is not the sole Métis language, as many Métis spoke dialects of mixed European and Native languages, which often differed by region (Saunders & Dubois, 2019). This example also serves to highlight the locality of traditional knowledge (Edge & McCallum, 2006). Michif is a very descriptive language with its roots in both Cree and French; it contains within itself principles of Métis governance and laws, kinship, genealogy, and teachings regarding relationships with ourselves and with the Earth (Edge & McCallum, 2006).

Métis healing knowledge and practices. Boyer (2019) writes about Métis healing practices as being holistic and unique to Métis Peoples. Métis healers relied on medicinal herbs to alleviate physical and other ailments (Boyer, 2019). Gathering herbs and medicines according to Métis protocol is strongly emphasized within Métis knowledge (Boyer, 2019). Showing respect for the plant is important, this requires one to recognize that the life of a plant or animal, no matter their size, is equally as powerful as the life of a human (Boyer, 2019).

Métis healing knowledge was (and is) also closely tied to place. Kermoal (2016) writes about the historic and present relationship between Métis and land, saying “the ontological relationship that Métis Peoples have with the land is very much at the centre of their political and collective aspirations” (p.117). She highlights how the encroachment of settlers meant that Métis way of life had to change from semi-nomadic to non-mobile, which changed the way Métis healers gathered and relied upon herbs. Medicinal recipes had to be changed due to changes in location (Kermoal, 2016).

Kermoal (2016) also writes about the pivotal role played by women in developing, holding and sharing Métis healing knowledge. Much of Métis healing knowledge was held and passed down by Métis women to their daughters and granddaughters, particularly through the guidance of First Nation grandmothers (Boyer, 2019; Kermoal, 2016). Métis women held extensive obstetrical knowledge which benefited local settlers, especially those who could not afford a male physician to attend their birth (Kermoal, 2016). Women had a system of studying and experimenting with plants, such that they understood all the qualities and potential uses of each plant (Kermoal, 2016). Kermoal writes that Métis women were repositories of Indigenous medicinal knowledge (2016).

Wahkohtowin. Wahkohtowin is a Cree term that represents our relationships, specifically our kinships, but also describes our interrelationships with all living beings and the Earth's ecosystem (Adese, 2014). Wahkohtowin emphasises a holistic worldview and perspective, and its teachings are re-iterated in many Métis stories and ceremonies (Adese, 2014). This also includes a sense of being responsible to one's ancestors.

Métis academic Brenda Macdougall (2017) has written about the role of Wahkohtowin in Métis ways of life. Wahkohtowin itself is described as a way of life for many Métis Peoples which reiterated the importance of sharing with each other and caring for one another (Macdougall, 2017). Macdougall (2017) describes Wahkohtowin as being synonymous with the term "all my relations", a concept which is common amongst many Indigenous Peoples (p.9). Wahkohtowin ensured a collectivist nature amongst Métis Peoples, as it promoted a shared sense of responsibility (Macdougall, 2017). It also guided peoples actions through the creation of Métis societal expectations (Macdougall, 2017). Thus, relationality and collectivism, as demonstrated through the concept of Wahkohtowin, formed an integral part of Métis worldviews.

Storytelling. Just as with Indigenous traditional knowledges, storytelling is an important form of knowledge translation within the Métis traditional knowledge system. Storytelling includes stories of mythological origins, like the creation story, as well as historical and present-day life narratives, either in oral, written, or artistic forms. Adese (2014) writes the following about Métis storytelling:

> Each of the authors remembers, re-knows, and re-claims, through their storytelling, what outsider narratives on Métis Peoples have often obscured. In doing so the authors form

> relationships with their readership, entrusting their stories to them. They enable a re-knowing, re-claiming of Métisness, an act that is, even if it does not directly intend to be, a rejection of race thinking and of efforts to assimilate Métis (Adese, p. 50).

Clearly, storytelling forms an important part of our traditional knowledges and ways of knowing, and is an act of resistance against assimilation and a reclamation of one's identity as a Métis.

Conclusion

Based on the available data and evidence discussed within this chapter, there is a clear lack of Métis-specific research and evidence, particularly around HIV and STBBI, and community-based, Métis-grounded approaches toward HIV and STBBI. The literature discussed in this chapter also serves to provide context into why community-based testing pilots are important and shows the need for Métis specific research to address HIV and STBBI testing and approaches to care for Métis individuals affected by HIV/STBBI. This thesis research is uniquely situated to help develop two community-based interventions to address HIV and STBBI using a Métis approach to research and evaluation. These interventions are a model of Métis-specific health and wellness for people living with or impacted by HIV and/or STBBI, and DBST for HIV and STBBI in the community. As such, the goals of this thesis research are: to document and explore the development of an emerging Métis model of health and wellness for people living with or impacted by HIV/STBBI, and to conduct an evaluation of a DBST pilot for HIV and STBBI in Alberta by drawing strongly on perspectives of Métis community members. To facilitate this work, two research questions were developed:

1) What could a Métis-specific cultural response to HIV and STBBI look like? And,
2) Is DBST an acceptable testing method for Métis communities?

As mentioned briefly above, a Métis approach to research is a complex methodology that has yet to be fully articulated. Some aspects of a potential methodology were introduced in this chapter and will be further discussed in the next chapter.

Chapter 3: Methodology

Indigenous researcher Shawn Wilson writes about an Indigenous research methodology in his book *Research is Ceremony* (Wilson, 2008). Wilson writes: “Methodology refers to the theory of how knowledge is gained, or in other words, the science of finding things out” (2008, p. 34). A methodology will typically outline both the knowledge system relied on, as well as the methods used to gather data (Kovach, 2009). This research has relied on multiple methodologies, as no one system perfectly fits the methodological needs of Métis-specific, community-based research. This chapter will define and describe the methodologies which guided this research, and describe the study design, methods, informed consent process, ethical considerations, and knowledge translation aims of this study.

Goals of the Research Project

In partnership with Métis stakeholders through Shining Mountains, the goals of this thesis research are twofold. The first is to document and explore the development of an emerging Métis model of health and wellness for people living with or impacted by HIV and STBBI. This model will be used to guide future Métis-specific supports and shared care developments within the D&S project, and was designed primarily for use as an intake assessment tool at Shining Mountains. Métis stakeholders hope this model will be adopted by other Métis and Indigenous service agencies or communities in the future. This Métis-specific response is grounded in the symbolism of the Red River cart and uses its various parts to situate and contextualize components of community-based interventions and supports for individuals living with/affected by HIV and/or STBBI. Therefore, I will use the term “Red River Cart Model” to refer to this Métis-specific model of health and wellness for individuals living with or impacted by HIV and/or STBBI. The documentation and exploration of the Red River Cart Model through thematic analysis will also provide a guide for the implementation of future interventions and/or shared care models that may be used to support individuals living with/affected by HIV, HCV and/or STBBI in other Métis communities. The second goal of this thesis research is to conduct an evaluation of a DBST pilot for HIV and STBBI in Alberta drawing strongly on perspectives of Métis community members. In keeping with the second goal, lessons learned will be documented and shared in order to improve the implementation of DBST in other Métis communities, either in Alberta or across Canada.

Research Questions

Following the goals of this project, two specific research questions were created to guide the development of this thesis research. The first research question **(RQ1) is: what could a Métis-specific cultural response to HIV and STBBIs look like?** This was also the question posed to gathering circle participants during the data collection phase of the research. To answer this research question, I worked closely with Shining Mountains and supported their work to develop the Red River Cart Model of a Métis-specific response for supporting individuals living with/affected by HIV and/or STBBI. This took place through focus group sessions comprised of Métis stakeholders and cultural advisors identified and recruited by Shining Mountains. Supplementary data from a community mapping exercise was included in the analysis.

The second research question **(RQ2): is DBST an acceptable testing method for Métis communities?** RQ2 has allowed for the use of a voices and perspectives in keeping with an Indigenous participatory evaluation approach. The use of a Métis lens (discussed later) will help to explore potential acceptability and feasibility in other Métis communities, both within Alberta and in other provinces. RQ2 will also assess the feasibility of implementing DBST in Métis communities, with the assistance of the RE-AIM framework of evaluation. RQ2 was addressed by a survey and gathering circles with Métis participants who received DBST at one of two Métis events, and semi-structured interviews with test providers. Supplementary data included minutes from planning meetings and observational notes from the testing events.

Conceptual Approach (Methodological Foundations and Frameworks)

A comprehensive Métis research paradigm or methodological framework has yet to be fully articulated and discussed within academic literature. Recent work by Métis health researchers Monchalin and Bourassa (2019) has laid the groundwork for a Métis-specific methodology for HIV-specific research. Many Indigenous researchers have done significant work in developing Indigenous research paradigms and methodologies, which form the foundational building blocks of this research. Other methodologies have played large parts in this research, particularly community-based research and Indigenous participatory evaluation theory. As this work is nested within a larger scale IS project, IS has played a role in the development of the research, data collection tools, and the analysis. IS has also played a role in the application of the RE-AIM framework for evaluating DBST (RQ2). Weaving these distinct and diverse methodologies and theoretical frameworks together forms my Métis lens, which informs and guides my actions as both a researcher and community member.

Indigenous methodologies and research paradigms.

A research paradigm is a broad set of beliefs and underlying principles upon which research is based (Wilson, 2008). Cree researcher Shawn Wilson (2008) describes an Indigenous research paradigm as being composed of an ontology (a set of beliefs regarding reality), epistemology (knowledge system or way of thinking), methodology (theory of knowledge development), and an axiology (the ethics or morals that guide the search for knowledge). This paradigm goes beyond the mere discussion of methodology to consider more important questions surrounding research, such as which methods allow for the conduct of research in an ethical way, how our worldviews influence us as researchers, and what knowledge can and should be researched, and the consequences of conducting such research. The book *Research is Ceremony* (Wilson, 2008) is the first book I read which described and discussed an Indigenous research paradigm or methodology, and it contributed significantly to my understanding of both Indigenous methodologies and conducting Indigenous-focused research within academia. Given that my Métis roots are Scottish and Cree, and many Métis individuals have Cree heritage, I found Wilson's writings to be very relevant to my approach to this study. Wilson also describes his understanding of an Indigenous research paradigm in a way that is easy for the reader to understand and follow. Therefore, I reflected upon Wilson's descriptions of ontology, epistemology, axiology, and methodology as I developed this thesis research and worked with the Métis community on this research project.

Ontology. Indigenous knowledge systems generally accept that there are multiple realities, and therefore multiple truths (Wilson, 2008). Similar to a constructivist paradigm, Indigenous ontologies do not accept a positivist paradigm which asserts there is one reality and therefore one singular truth that can be uncovered through a research process (Wilson, 2008). Wilson (2008) draws on aspects of his traditional Cree knowledge system, and the concept of relationality, to describe and contextualize the ontology of an Indigenous research paradigm. Not only is our relationship with the environment, other humans, animals and creatures important to an Indigenous worldview and research paradigm, but our relationships with the theories and methods we are using is equally important. Knowledge itself is relational, and as we are researching we are developing relationships with the knowledge we are co-creating and discovering (Wilson, 2001).

Epistemology. Epistemology refers to our ways of knowing, our knowledge systems, and our worldviews, which are, of course, built upon relationships and relationality (Wilson, 2008). An Indigenous epistemology includes our cultures, stories, traditions, and worldviews (Hart, 2010; Wilson, 2008). Researcher Anthony Hart (2010) describes worldviews as “cognitive, perceptual, and affective maps that people continuously use to make sense of the social landscape and to find their ways to whatever goals they seek” (p. 2). Our worldviews can be subconscious, meaning they are not something people are necessarily aware of, needing active reflection to bring them to the surface. Indigenous knowledge systems are subjective, and often rely heavily on the wisdom of Elders to interpret and develop knowledge (Hart, 2010).

Wilson (2008) positions Indigenous epistemology as a way of creating relational accountability, which allows the researcher to fulfill their obligation to the world around them. Through their methodology, researchers affirm a commitment not only to themselves and the work, but to their community, the community they are working with, their ancestors, their nation, and the cosmos itself. This positions the collective at the forefront of the epistemology, and consequently the research work itself, rather than the researcher.

Indigenous Knowledges. Indigenous knowledges form an integral part of an Indigenous epistemology, and therefore are important aspects of an Indigenous research paradigm. ‘Traditional Indigenous knowledges are typically described as holistic, cyclic, and dependent upon relationships, including those with living and non-living beings and entities (Hart, 2010). Hart (2010) also describes the truth as being subjective and unique to the individual, acknowledging that there are many truths (and also many realities) in Indigenous ways of knowing, as discussed earlier. Hart (2010) emphasizes the importance of positioning oneself as a human within the greater context of the world, acknowledging the equality of all living beings and the sacredness of the world. This research values Indigenous knowledges as being truthful, equally valid, experiential, and holistic, and gives respect to the many forms in which knowledge is translated, including experiences, storytelling, gathering circles, prayers, and ceremony (Hart, 2010).

Authors Robbins and Dewar (2011) write about the strong link between Indigenous knowledges and traditional healing approaches. They argue that traditional knowledges must be actively practiced in order to be maintained, and that the act of practicing 'traditional' knowledges through our ceremonies and healing approaches relies on the use of the community's traditional land base (Robbins & Dewar, 2011). It is the land which links Indigenous knowledge and healing, meaning the three are closely interrelated. Robins and Dewar (2011) also highlight the challenges of referring to Indigenous knowledges as 'traditional' knowledges, citing the fact that the concept of 'traditional' is one rooted in British colonialism and is not an Indigenous concept, as well as the inherent challenges that exist when one attempts to write about knowledges rooted in oral-history. Thus, I use the term Indigenous knowledge in this thesis, wherever possible and relevant.

Axiology. An axiology is the ethics or morals which guide the pursuit of knowledge through research (Wilson, 2008). Wilson's (2008) description of an axiology, and accompanying questions to guide researchers, are built upon the "Three R's" of Indigenous research (respect, reciprocity, and responsibility) (p. 77). When we adopt these Three R's, and allow them to guide our processes throughout the research journey, we are adopting an Indigenous axiology (Wilson, 2008). Wilson (2008) describes an axiology as being built upon the concept of relational accountability. Research must be respectful and should aim to help those who the researcher has been building a relationship with through the research process (i.e., the community) (Wilson, 2008). This includes ensuring the integrity of the research methodology (i.e., respect), and the usefulness of the results (i.e., reciprocity) (Wilson, 2008, p. 77).

Methodology. As described in the introduction to this chapter, a methodology is the theoretical foundations which guide the approach to research and inform the specific methods used to gather, analyze and discuss data. Authors Walter (Trawlwoolway, Tasmania) and Andersen (Michif/Métis) (2013) describe a methodology as “the theoretical lens or worldview through which research is understood, designed, and conducted” (Walter & Andersen, 2013, p. 42). Walter and Anderson (2013) distinguish the complexities of methodologies from the simplicity of “methods”, which they define as any “technique for gathering and analyzing information” (2013, p. 41).

A large portion of what Wilson (2001) describes as a methodology is enacting the concept of relationality (2001). He describes research as a process of being accountable to *all our relations*, obligations, and gaining knowledge to fulfill our responsibilities within a certain relationship (Wilson, 2001). This is a very similar concept to axiology, but with more of an emphasis on how these relationships are fulfilled. Wilson weaves relationality within all four aspects of his Indigenous research paradigm, as all aspects of the paradigm are connected closely to each other (Wilson, 2008).

Using Two-Eyed Seeing to bridge cultures.

The concept of Two-Eyed Seeing suggests that individuals who are familiar with both Indigenous systems of knowing/doing and Western ways of knowing can appreciate and utilize aspects of both in order to address complex contexts or challenges (Bartlett, Marshall, & Marshall, 2012). Two-Eyed Seeing was developed by two Mikmaq Elders (Albert and Murdena Marshall) and thus is grounded in Mikmaq worldview. Despite the differences in worldview between Métis and Mikmaq cultures and knowledges, Two-Eyed Seeing is a tool or approach that can be used to bridge two very different knowledge systems. It is a way of respecting and integrating what is considered good and effective of both systems of knowledge (Bartlett et al., 2012). Métis Peoples were initially of two cultures; many Métis Peoples still draw upon both their European cultures and First Nations cultures. Both are important aspects of who Métis people are as individuals, communities, and a collective Nation. I believe the concept of Two-Eyed Seeing fits well with a Métis approach to research because it honours the strength of both knowledge systems (Martin, 2012). It is also one way of accepting and embracing diversity within the Métis community, which is an important principle of ethical Métis research (NAHO: Métis Centre, 2010). This thesis research accepts both knowledge systems as equally valid, and both were used to provide insight into cultural and practice differences between team members and contributors to the study. Neither knowledge system has been or will be described or positioned as dominant or superior to the other.

Given that many Métis Peoples acknowledge and celebrate both their European and Indigenous ancestries, I believe a Métis ontology and epistemology could be reflective of both Western and Indigenous approaches to research. As such, this research project is grounded in the understanding that HIV interventions, like any health intervention, need to fit within a Métis (and therefore Indigenous) way of knowing, being and doing (Bourassa, 2018). In this sense, Two-Eyed Seeing helps bridge Indigenous and Western paradigms to better acknowledge and integrate aspects of both paradigms within the research.

Métis worldviews.

Métis worldviews, as discussed earlier, are distinct, and draw upon both European and First Nations cultures and worldviews from which the individual, family, clan, or community draws their ancestry (Monchalin & Bourassa, 2019). Métis worldviews are also highly individualized as they are impacted by the experiences of Métis Peoples and their relationship with their culture and Métis identity (Monchalin & Bourassa, 2019). For example, many Métis Peoples adopt strategies to walk in our world, which include, silence, "passing" for white, or the utilization of culture "underground" or away from the public (Monchalin & Bourassa, 2019). It is important to understand that culture is not stagnant, it is something that continues to evolve over time (Monchalin & Bourassa, 2019).

Religion can, and often does, play a part in the worldview of Métis Peoples. Many first-generation Métis Peoples were Catholic, particularly if their European parent came from France or Ireland, or Anglican or Protestant if the European parent were English or Scottish (Hogue, 2015). Métis descendants may choose to engage in either organized religion, traditional Indigenous forms of spirituality, a mixture of both, or neither. As such, their worldviews will be informed by their personal practices and beliefs (Monchalin & Bourassa, 2019).

Language plays a role in Métis worldviews as well. Many think the "official" language of the Métis is Michif, which is a creole language that uses aspects of both Cree and French (Saunders & Dubois, 2019). However, there are many dialects of Michif. Despite the wide variety of languages and differences in spelling and pronunciation, many Michif terms are used in Métis literature and research to give greater context to Métis worldviews. Some discuss the Cree/Michif languages as being integral to Métis knowledge and worldviews (Edge & McCallum, 2006).

Monchalin and Bourassa (2019) write of the important contributions of Cree and Dené women to Métis worldviews. As these women married European men, they brought with them their practices, attitudes, values, and beliefs, and raised their children in a fusion of these two identities, creating a worldview and way of living from two distinct cultures (Monchalin & Bourassa, 2019). These values included the importance of women in shaping the Métis way of life, akin to a matriarchal style of living. Unfortunately, the valuing of women was at odds with the European patriarchal and colonial ways, which resulted in the silencing of matrilineal narratives (Monchalin & Bourassa, 2019). This silencing has also impacted the worldviews of Métis Peoples (Monchalin & Bourassa, 2019). Hence, I believe that recognizing the inherent strength and resilience of Métis women should be considered or recognized within Métis-specific research. The leadership of Métis women was reflected in the high participation of Métis women within my thesis research, which will be reflected on in the Discussion Chapter.

Métis Approaches to Research

Monchalin and Bourassa (2019) have written about a potential Métis-specific methodology for conducting HIV research. Their work is not intended to be a strict methodology but rather to illustrate what a potential methodology for HIV research could look like, which can be further informed and guided by the Métis community using the methodology in their research. The authors discuss several important aspects to conducting research with Métis communities, including: understanding the complexity of Métis identity, honoring the resiliency of Métis Peoples, recognition of how a lack of Métis-specific data has contributed to reduced programming for Métis Peoples in health and social areas, Métis worldviews, and wise practices and methods for working with Métis communities (Monchalin & Bourassa, 2019). Many wise practises identified by Monchalin and Bourassa (2019) were considered or integrated into the design of this research and guided the analysis and development of recommendations; a discussion of how their wise practices were considered follows.

Wise practices in Métis research.

Monchalin and Bourassa (2019) write that a Métis worldview will directly inform a Métis methodology. Both the methodologies and the methods should be given priority in the research process, as the methodology ensures that the methods are undertaken appropriately (Monchalin & Bourassa, 2019). Some wise practices for research involving Métis people identified by Monchalin and Bourassa (2019) include:

- Community involvement, such as an Elder, or community representative,
- Recruitment facilitated by relationship building and a reflection of Métis Peoples within recruitment materials,
- Creating a safe space by accepting diversity of identity and withholding judgement,
- Acknowledging local Métis protocol in the conduct of research.

Monchalin and Bourassa (2019) provide a well-rounded approach to a Métis-specific methodology that blends well with community-based research. How these wise practices were integrated into the research process is discussed further below in the methods section. These wise practices were integrated into my research project in the following ways:

- Involvement from Métis community members including the Executive Director of Shining Mountains, the Métis-specific D&S Coordinator, the D&S National Coordinator (who is Métis) and community members invited by these individuals, including a Métis Elder;
- Participant recruitment was either undertaken by these individuals, or facilitated/supported by them in the case of the DBST experience evaluation; and
- Several efforts were taken to ensure a safe space was created, which included having an the Elder in the gathering circles, ensuring emotional supports were

> available for participants if needed, asking Elders if they accepted tobacco according to their personal and local protocol, discussing confidentiality before gathering circles took place, asking the Elder to begin Red River Cart Model development circles and the following language circle with a prayer, and the making of a spirit plate (food offering to ancestors and spirits) before the meal alongside the prayer.

As discussed earlier, Métis worldviews and cultural practices take many forms. Considering and integrating Métis worldviews and practices into my research served to legitimize my research work within the Métis community, and establish myself as a trustworthy individual within the community who was committed to doing community work the right way. Grounding the research within a Métis process and an Indigenous research paradigm were two ways I attempted to ensure the research process was respectful of Métis ways of doing and being. In addition to this Métis process, I used other research methodologies including community-based research, to ensure that the research was socially just and community driven. I also worked to ensure this research was grounded in the Principles of Ethical Research articulated by the National Aboriginal Health Organization (2010).

Ethical approaches to Métis research.

In 2010, the National Aboriginal Health Organization (NAHO) worked with Métis stakeholders to identify principles of ethical Métis research. These can be summarized in six principles or overarching themes: reciprocal relationships, respect, safe and inclusive environments, recognition of diversity, “research should”, and Métis context (NAHO: Métis Centre, 2010). These principles were integrated throughout the research project in multiple ways. “Research should” was a category/theme identified in document by the NAHO Métis Centre and it includes the need for research to: be relevant, benefit all, be accurate, accountable, and responsible, acknowledge contribution, and protect Métis cultural knowledge (NAHO: Métis Centre, 2010). These concerns were in the forefront of my considerations during research planning and data collection tool development. In keeping with community-based research principles (discussed below), the topic and methods of this thesis research were ensured to be relevant to the needs of all Métis Peoples, as it was based on interventions requested by community (i.e., development of the Red River Cart Model and DBST) and were accountable and responsible to the Métis community. Accuracy as well as the protection of Métis cultural knowledge was highlighted during the data collection and analysis and will be emphasized during the knowledge translation phases of the project by obtaining permission and approval from key community members, and if possible, an Elder, with particular attention paid to ensuring that protocols regarding the sharing of community-specific information or traditional knowledges are followed. The contribution of individuals was recognized through honoraria, and in the case of RQ1, small gifts, and will be recognized in the future through shared authorship of knowledge translation pieces.

Using a Métis lens.

The use of a Métis lens (or perspective) is integral to the evaluation of DBST from a Métis perspective. In addition to data collected from Métis recipients of DBS testing through the survey and gathering circle, as well as testing provider perspectives (discussed further below), I used my own lens as a Métis person to gain insight into the experience of testing recipients and to assess findings which are related to, or to comment on, the potential cultural-safety of DBST as an intervention for Métis communities. Since writing on Métis methodologies and approaches to research and/or analysis within academia is sparse (LaVallee, 2014), I outline here what I have identified from the literature, as well as what I personally consider as constituting aspects of a Métis lens.

What constitutes a Métis lens.

Métis researcher Amanda LaVallee's PhD thesis (2014) focused on adapting a Western methodology (System Dynamics and Group Model Building) into a Métis methodology for the purpose of addressing TB related issues in the Métis community in Saskatchewan. Her work utilizes a multiple framework approach to enhance her understanding of performing research in a good way, as well as ensuring her work is considered credible, of high-quality, and understandable to a wide audience (LaVallee, 2014). She uses the infinity symbol, which represents Métis Peoples and is depicted on the Métis flag, to depict the balance between Western and Indigenous knowledge systems used within a Métis approach to research. She also emphasizes the importance of understanding Indigenous concepts of health as a core aspect of a Métis approach. Her writings, as well as my education in public health, helped me to identify an Indigenous and Métis understanding of health and wellness and a core element of my Métis lens in this work.

Indigenous understandings of health. An Indigenous understanding of health and wellness is an integral aspect of a Métis lens within a health and wellness context. LaVallee (2014) discusses an Indigenous health paradigm as being an important aspect of a Métis research methodology and doing research with Métis communities. An Indigenous health and wellness paradigm is closely related to typical Indigenous worldviews which are holistic and relational in nature (LaVallee, 2014). Emphasized components of an Indigenous model of health include the idea that physical and spiritual health are not separate; health includes a focus on the land and community, harmony, balance, respect and reverence for all life (two-leggeds, four-leggeds, winged, and finned), and reciprocity and interdependence with each other and nature (LaVallee, 2014). Two models are drawn upon to add a greater context to this understanding of holistic health. These are the medicine wheel, which is grounded in First Nations teachings, and the Red River Cart Wheel, which is a model of holistic wellness developed and used by the Métis Nation Saskatchewan (LaVallee, 2014). Although the medicine wheel is considered by some to be more grounded in First Nations teachings, the medicine wheel is used by many Métis Peoples (LaVallee, 2014). The Red River Cart Wheel developed by the Métis Nation Saskatchewan provides more of a community-level focus to health, touching on aspects which include health priorities, communication, data collection and research, and community engagement (LaVallee, 2014). Lavallee (2014) notes that Indigenous, and hence Métis, models of health and wellness include an emphasis on the spiritual that is often disregarded by Western models of health. Examples include the importance of dreams and their meanings, prayer to the Creator and ancestors for healing, smudging as an act of healing and self-care, as well as participation in ceremony to address physical and mental health issues (e.g., sweat lodges, drumming, etc.). This is important because all aspects of the self are considered inseparable to Indigenous Peoples and form a core aspect of Indigenous identity, and therefore form a core aspect of health and wellness (LaVallee, 2014). Therefore, a Métis lens includes an Indigenous understanding of health and wellness which includes holism, relationality, and recognizes the important role played by spirituality.

Self-location and personal perspective. My personal experience as a Métis woman informs the way I apply a Métis lens. As a Métis person, I have been involved in Métis politics in BC, as well as the Métis community in Victoria, for six years. My attendance at provincial Métis annual general meetings, governance assemblies, youth gatherings, and my contributions to specific working groups have given me an insider’s understanding into political issues at the provincial, regional, and local levels that affect the lives and rights of Métis Peoples. Through this work I have gained immense respect for the resilience of Métis Peoples, but also gained a better understanding of the loss we have experienced over decades and centuries of living and surviving within a colonial system. This loss refers to the loss of our ways of life, our traditions, and for many, the loss of Indigenous knowledges, our languages, and our ways of existing in better harmony with nature and with each other. I have also witnessed the strength of our Métis women who have had a large hand in ensuring our cultures and traditions are not lost completely, and who have dedicated their lives to the reclamation of our culture and the prosperity of our people.

Qualitative research acknowledges the concept that we as humans cannot be entirely objective in our pursuit of knowledge through research (Ouellette, 2011). Within Indigenous methodologies we consider our perspectives that we bring to be a strength, but also one that we must account for and attempt to explain to the reader. This is recognized as an important piece of Indigenous methodology, but I think it is very important to include this in a Métis lens. I do not feel my analysis and evaluation would be the same had I not had several years of experience working within my own Métis community. And while the experience of Métis Peoples in BC is not the same of Métis in Alberta, many Métis Peoples in BC have roots in the prairies through kinship ties which connect us (Saunders & Dubois, 2019). This aspect of myself, which is similar to self-location, can be considered contextual knowledge which is used within the process of research (LaVallee, 2014).

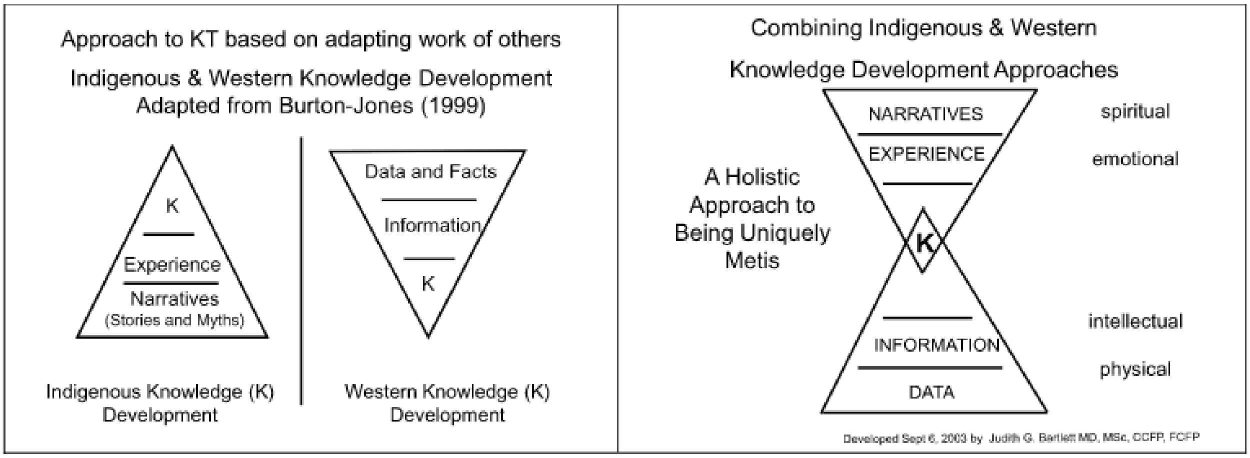
Understanding the history of Métis Peoples. Understanding the history of the Métis Peoples is an important aspect of using a Métis lens or approach to research (Martens et al., 2010). As discussed in the introductory chapter, the Métis arose as a distinct people in the late 17th/early 18th centuries during the fur trade (Métis National Council, n.d.). Distinct Métis communities along routes of the fur trade developed across Ontario, Manitoba, Saskatchewan, Northwest Territories, Alberta, BC, and the Northern US (Hogue, 2015; Métis National Council, n.d.). The Métis were semi-nomadic peoples, whose unique governance structure was created around the communal subsistence buffalo hunt (Hogue, 2015). A consistent theme throughout the history of the Métis Peoples has been political activism with a goal of protecting Métis rights, lands, and ways of living (Métis National Council, n.d.). Understanding the socio-political, historical, and economic contexts in which Métis Peoples have experienced colonialism, oppression, and neo-colonial policies is key to using a Métis lens.

A Métis wellness lens and approach to research. A study performed by the Manitoba Métis Federation (MMF) on the health status of Métis Peoples in Manitoba described what they consider to constitute a Métis wellness lens. This lens is based on Margaret Kovach's definition of Indigenous methodologies being grounded in Indigenous epistemologies and aligned methods (Kovach, 2009). The MMF states that the historical context of Métis Peoples is an important aspect of the Métis lens (Martens et al., 2010). A Métis lens combines both Indigenous and Western knowledge development approaches to create a holistic approach which is more in line with ancestral ways of knowing. It combines myths and stories (spiritual) and experiences (emotional) from Indigenous ways, with the Western "data and facts (physical) and information (intellectual)" to create a Métis lens (2010, p. 77). The MMF describes the Western knowledge system as relying on quantitative research, and the Indigenous knowledge system as relying on qualitative research; both, together, provide a more complete picture than one on its own (Martens et al., 2010).

A figure depicting a Métis lens or approach to knowledge development through research is included below in Figure 2.

Figure 2.

Métis Framework for Knowledge Translation and Development Developed by Bartlett (2010)



This model, while it has not been formally researched, has been used by the MMF in their health-related work with communities (Martens et al., 2010). It shows the differences between a Western approach to knowledge development, where data, facts, and information are distilled into knowledge. This is compared to an Indigenous approach to knowledge development, where knowledge is acknowledged as already existing, and being informed by the experience of individuals and communities, which are informed by our narratives. Both are combined, equally, to form a uniquely Métis approach to knowledge creation (research) (Martens et al., 2010). This is just one example of the way Métis research has been conceptualized in the literature. Although there are some elements of this model which do not resonate with me, I thought it important to include given that discussion of Métis-specific approaches to research within literature are very limited to date.

To summarize, a Métis lens with a focus on evaluation is grounded in my personal experience as a Métis person (self-location and personal perspective), a thorough understanding of Métis history, and an Indigenous or Métis understanding and perspective of health and wellness. In the absence of a Métis-specific approach or methodology to evaluation, I felt it important to describe how I would use my personal perspective to inform the evaluation (that is, by utilizing what I call a Métis lens). Some aspects of this Métis lens have been articulated by others, particularly the history of the Métis, and a Métis understanding of health and wellness are acknowledged by Monchalin and Bourassa (2019) in their methodology for Métis HIV-specific research. The wellness lens developed by the MMF includes a holistic understanding of health and an approach which includes both Western and Indigenous knowledge approaches (Martens et al., 2010). While I think both Western and Indigenous approaches to research and knowledge development can be used within Métis research contexts (particularly in the absence of Métis methodologies or evaluation approaches), I am hesitant to describe a Métis lens as one which attempts to combine the two approaches to knowledge development (Martens et al., 2010). Furthermore, my experience in government and academia has shown that Western knowledge systems can and do utilize qualitative research approaches which draw upon experiences and stories shared by research participants. In my opinion, the visual representation of the Métis wellness lens produced by Bartlett and used by the MMF may reinforce a narrative that Métis people are simply a combination of European and Indigenous, rather than distinct Indigenous Peoples with our own approaches to research and evaluation. As such, I think further articulating a Métis lens or Métis approaches to research and evaluation are worthwhile endeavours, but are unfortunately beyond the scope of this Masters' thesis research.

Community-based and Participatory Action Research.

Community-based and community-driven research has informed the development of this thesis project as well as the broader work of D&S. Community based research, particularly within public health, is a collaborative approach to research which aims to equitably involve community members, organizational representatives, as well as researchers, in the research process (Israel, Schulz, Parker, & Becker, 1998). Participatory action research is similar to community based research; it combines education and social action into the action of research (George, Daniel, & Green, 2006). Wallerstein and Duran (2006) emphasize that community-based research and community-based participatory research are not methods, but rather approaches to research. Community-based participatory research emphasizes the participation of community members within a community-based research process (Minkler & Wallerstein, 2008). There are eight generally recognized principles of community-based research:

1. Recognizes community as a unit of identity,
2. Builds on strengths and resources within the community,
3. Facilitates collaborative partnerships in all phases of the research,
4. Integrates knowledge and action for the mutual benefit of all partners within the research,
5. Promotes a co-learning and empowering process that attends to social inequalities,
6. Involves and cyclical and iterative process,
7. Addresses health from both positive and ecological perspective,
8. Disseminates findings and knowledge gained to all partners (Israel et al., 1998).

These principles distinguish community-based research from other forms of research which are less community-centered in nature (Israel et al., 1998). These principles have informed both this thesis research and the work of D&S.

Improved access to testing has been the expressed desire of many communities participating in D&S; several communities have specifically requested for the D&S team to facilitate training for DBST in their communities. In this sense, the intervention of DBST arose from the expressed desires of the Métis community, and its evaluation to ensure it was culturally appropriate and acceptable to Métis Peoples made sense from an ethical standpoint. To ensure this research was reflective of community-based and participatory approaches to research, the methods and design of this thesis research are heavily influenced by Métis stakeholders at Shining Mountains. The process of piloting DBST, from training Métis staff at Shining Mountains to provide the testing, to implementing the testing, as well as training staff to provide pre- and post-test counselling, has served to increase the capacity and skills of staff at Shining Mountains. Métis stakeholders and team members were consulted and requested to guide the development of data collection tools; final approval for data collection tools (e.g., post-testing survey, interview, and gatherings circle questions), as well as research processes and recruitment rests with them, thereby ensuring that the relationship is collaborative throughout the research process. Additional collaborative relationships with researchers at the University of Victoria, and policy makers at AHS and the Public Health Agency of Canada (PHAC) have been facilitated through this work, which reflects the third principle of community-based research. In this way, this thesis research respects the will and desire of Métis stakeholders and community members to control how research is conducted in partnership with their members which is an important aspect of community-based research (Fitzpatrick et al., 2016).

Co-learning is an important aspect of this thesis research as well as the D&S process. Team meetings and debriefs will ideally result in lessons learned for all members, which can be carried forward and shared to inform and improve future testing events. In the D&S model, communities are encouraged to act as mentors to other communities, and researchers learn as much about the needs of communities and community members can strengthen their research and programming skills related to HIV and STBBI. A cyclical process to knowledge generation and improvement is utilized within all aspects of D&S, and all work, particularly the development of shared care models (and future development of a Métis-specific response to HIV and STBBI) draws on a strengths-based approach that recognizes resilience within communities. This is reflected in the strengths-based (instead of deficit-focused) approach and understanding that embeds both the Red River Cart Model and the evaluation of DBST. Knowledge translation is an important aspect of both the D&S study and this sub-study which has already been given significant thought; the type of knowledge translation products will be influenced and directed by the Métis community. As a part of this community-based research approach, a community-based knowledge translation plan was created (more below).

Indigenous Participatory Evaluation Research.

Both the D&S project and this thesis research value Indigenous participatory evaluation techniques as methods for evaluating interventions from a community perspective. Participatory evaluation methods typically involve both stakeholders and evaluators, in a collaborative relationship, to ensure that the evaluation is practical and useful to those working within these programs or interventions, and for those who typically use the interventions (Grover, 2008). Indigenous participatory evaluation involves community from the outset and focuses on honoring and including the community's culture and practices (Grover, 2008). The process involves having community members identify what meaningful and successful outcomes would look like, and empowering the team to use culturally-relevant indicators to measure (Grover, 2008; Jordan, Stocek, Mark, & Matches, 2009).

Bringing these methodologies together.

All of the methodologies discussed, including Shawn Wilson's work on an Indigenous research paradigm, Métis approaches to research from the academic literature, and Two-eyed

Seeing, to Western community-based research, and the RE-AIM framework, have informed this study equally. However, I see the use of a Métis lens as being a key ingredient in this work, especially my perspective as a Métis woman studying public health. Existing Métis research has relied on many different methodologies. Each methodology has strengths and weaknesses, and it is important to acknowledge that no one methodology or knowledge system is better than the other, although some are more appropriate to certain contexts than others. The selected methodologies discussed above were influenced by Métis partners at Shining Mountains, and were determining factors in deciding upon the study design in partnership with Shining Mountains.

Study Design

This thesis study design is qualitatively-dominant using sequential mixed methods (Padgett, 2012). **RQ1** (What could a Métis-specific cultural response to HIV and STBBI look like?) is addressed through the use of gathering circles which are thematically analyzed. To supplement, data from the community mapping exercise were also considered in the thematic analysis. **RQ2** (is DBST an acceptable testing method for Métis communities?) is addressed through the use of a survey, which provides quantitative and qualitative information, gathering circles, semi-structured interviews with test providers, and document analysis. For clarity, methods of data collection, analysis, and techniques to enhance trustworthiness and rigor are discussed separately for each of the two distinct research questions.

Methods.

Research question 1 (RQ1): What could a Métis-specific cultural response to HIV and STBBI look like? Métis stakeholders within the D&S project identified the need to develop a Métis-specific response to HIV and STBBI based on the distinct needs of Métis Peoples rather than adapting a First Nations model to a Métis community. This research question (RQ1) was addressed through gathering circles and supplementary data from a community mapping exercise which took place at the Métis community launch of the D&S project. Gathering circles involved discussing the research question directly. Gathering circle participants were asked to consider "What could a Métis-specific cultural response to HIV and STBBI look like"? and an open-ended discussion about the Red River Cart Model and its components took place, facilitated by myself and the National D&S Coordinator.

Tool foundations. This Red River Cart Model has its roots in a tool which was developed by Shining Mountains (2011) called the 'Red River Forks' tool. The purpose of this tool is to allow individuals to self-reflect on the gifts (i.e., values, teachings, habits) given to them by their parents (Shining Mountains Living Community Services, 2011). The tool recognizes that some of what we have learned from our parents or guardians may affect individuals subconsciously and requires active reflection to observe more objectively (Shining Mountains Living Community Services, 2011). The tool also recognizes that some of what we are taught by parents or parental figures may no longer be helpful in an individual's life; these could be negative coping skills or a negative self-image (Shining Mountains Living Community Services, 2011). The tool allows the user to reflect on both their resiliency and their challenges or burdens (Shining Mountains Living Community Services, 2011).

The Red River Forks tool contains two Red River cart wheels, one representing the user's father or father figure, and the other representing the mother or mother figure (Shining Mountains Living Community Services, 2011). Both the wheels are identical, and contain the elements of the medicine wheel (i.e., physical, spiritual, emotional, mental components) around the rim of each wheel (Shining Mountains Living Community Services, 2011). Each spoke in each wheel refers to an aspect of life which we may have received teachings from our parents about, which are: health, employment, nutrition and fitness, home responsibility, family roles, environment, recreation, commitments, relationships, history and ancestry, values and beliefs, and spiritual connection (Shining Mountains Living Community Services, 2011). For each wheel, the user reflects on and can draw between the spokes symbols or aspects which represent what they learned about each component from their respective parent, paying particular attention to the culture in which their parents were raised (Shining Mountains Living Community Services, 2011).

The Red River Forks tool also contains an image of an empty Red River cart (Shining Mountains Living Community Services, 2011). The Red River cart represents what the user potentially carries from parents, extended family, community, and/or society (Shining Mountains Living Community Services, 2011). The user of the tool is encouraged to reflect about and represent four items within the cart: a symbol or image that reflects themselves, an important life lesson, resiliency, and the user’s heaviest burden that they carry (Shining Mountains Living Community Services, 2011). The user of the tool can draw or cut and paste magazine clippings to best represent this (Shining Mountains Living Community Services, 2011). Between the forks of the cart the person is encouraged to draw a symbol of what the person wants to strive for most in their future (Shining Mountains Living Community Services, 2011). By completing this process, the individual can reflect upon their strengths and challenges, and relate this to how they might achieve their future goals.

During early discussions about the development of the Métis-specific shared care model under D&S, there was discussion amongst Métis team members about developing a tool which was grounded in Métis symbology, particularly the Red River cart. Raye St. Denys, the

Executive Director of Shining Mountains, suggested building upon the Red River Forks tool and customizing it to reflect a holistic approach to health and wellness in an HIV and/or STBBI context. Métis team members of D&S agreed that the Red River cart was a symbol of Métis culture that would not be mistaken for First Nations or Inuit culture, and therefore made a good choice for the development of the Métis-specific model of health and wellness for those living with or affected by HIV and/or STBBI.

Gathering circle instrument development. As noted, the idea of using the symbol of a Red River Cart Model to situate and contextualize the aspect of the Métis-specific response was proposed by the Raye St. Denys and was based on previous work she had done creating a tool for individuals to identify what they learned from their parents (the Red River Forks tool). Discussion between the D&S National Coordinator, the D&S Métis Coordinator, myself, and the Executive Director of Shining Mountains resulted in the identification of the main gathering circle question: "What would a Métis-specific cultural response for those affected by HIV/STBBI look like"? Which is also RQ1. Those involved in developing this question felt it was open enough to encourage discussion on the distinct needs of Métis Peoples living with HIV, HCV and/or impacted by STBBI and related mental health. Based upon this idea, I drafted several more discussion questions to assist in the gathering circle discussions (Appendix A).

Participants, sampling and recruitment. In keeping with community based and Indigenous research methods, gathering circle participants were primarily identified and recruited by the Métis D&S Coordinator in partnership with Shining Mountains (Laveaux & Christopher, 2009). Participants self-identified as Métis and were known to Métis staff at Shining Mountains. They also had an intimate knowledge of the Métis community, and either lived experience with, or were service providers for, people living with HIV and/or STBBI.

Potential participants were contacted by email or phone (the decision on how to contact was made by the Métis coordinator) and were recruited based on their knowledge of Métis culture and knowledge of, or involvement in sexual health services. Community knowledge keepers including an Elder, a Métis individual with lived experience, Métis community leaders and those working in the field of sexual health were recruited to participate in the gathering circles. As a Métis-identifying individual, I was invited by members of the first gathering circle to have my voice included, as a participant, in this portion of the research. A total of eight different participants were involved in the gathering circles. Not every participant was able to attend all three circles; thus, participation levels fluctuated between the various circles.

Gathering circle process. During the gathering circles, participants were asked to think of the question "what would a Métis-specific response to HIV and STBBI look like?" During the first gathering circle participants were briefly introduced to the Red River Forks tool, and how the idea of the Métis-specific model for those affected by HIV and/or STBBI arose from the Red River Forks tool. Participants were encouraged to imagine that they had an empty Red River cart which they were packing with items that they would need on their journey towards health and wellness. The gathering circle discussions were further contextualized by providing an in-depth presentation on D&S in order for participants to understand the potential uses of the tool to develop further interventions within D&S. I was also given the opportunity to introduce myself to the participants, talk about my role within D&S, my experience working within my home Métis community, and my thesis research. I spoke a bit about the lack of Métis-specific HIV and STBBI research, and the reasons for conducting this thesis research. This helped in building a comfortable space for the gathering circles to take place, and also served to further establish my relationship with participants.

Gathering circles were audio recorded, transcribed and analyzed using a process of holistic coding and thematic analysis. Data from the community mapping exercise at the Métis community launch of the D&S project was used as supplementary data. Pictures documenting the community mapping results were considered in the context of the themes and subthemes identified from the transcripts; where applicable, notes from the community mapping exercise has been included to support the identification of themes.

Informed consent was obtained by participants prior to beginning each gathering circle. The National D&S Coordinator spoke to participants about the importance of maintaining confidentiality. Participants were informed that their identity would be kept confidential, and that their names would not be used within this thesis, or any community reports, or publications developed from this research. Verbal/oral consent was obtained from each participant of the gathering circles. I explained to participants that they could withdraw consent at any time and/or ask for any information or statements to not be recorded (in that case I would pause the recorder to ensure that information was not captured by the recording process). Oral consent was decided to be an appropriate form of consent given the nature of these gathering circles, which were grounded in a Métis process that involved Métis culture. The Tri Council Policy Statement 2 Chapter 3 allows for verbal consent to be obtained instead of written consent, particularly when certain cultures (such as Indigenous cultures) prefer oral consent to written consent, or the process of obtaining written consent may be interpreted as distrusting on the part of the researcher (Government of Canada, 2018).

Data collection. Data were collected from gathering circle (focus group discussions with integrated Métis practices) participants. Participants came together three times to discuss the development of the Red River Cart Model. The questions, which are outlined in Appendix A, were used as a guide for the gathering circle discussions. The first two gathering circles took place in a semi-private area in the HIV Edmonton office, and food and refreshments were provided for participants. The final language-focused gathering circle took place in a private meeting room of the MNA office in Edmonton. An Elder who is supporting the work of the gathering circle was approached by the D&S National Coordinator and Métis D&S Coordinator, and asked to guide the process, according to local Métis custom. The D&S National Coordinator assisted with the facilitation of the gathering circles and asked the Métis Elder to open and close each gathering circle with a prayer and/or ceremony. Based on feedback from the local Métis community, the Elder was gifted tobacco in accordance with local protocol. A small thank-you gift of tea and soap (a monetary value of $5 or less each) was given to participants who attended the final gathering circle. Additionally, those contributing to the work of the Métis cart model were provided with an honorarium for attending gathering circles, from Shining Mountains, in accordance with their organizational policy and practices. Further information on the Metis approach to the gathering circles for RQ1 is included in the beginning of the fourth (Results) chapter.

Supplemental data. Additionally, data from the Métis community mapping exercise was gathered to assist in answering this research question. The community mapping is a large group exercise that takes place as an aspect of each community's community readiness assessment and shared care model development as a part of the D&S project. During community mapping, members of a community and other stakeholders come together to identify what health and social resources are available to clients living with/impacted by HIV, HCV and STBBI (Jakes, Hardison-Moody, Bowen, & Blevins, 2015). Community mapping can assist with identifying under-utilized resources, unrecognized assets, as well as potential gaps in services (Jakes et al., 2015).

As an information gathering activity, the community mapping exercise was conducted following the launch of DBST during the Métis D&S community launch. The Métis D&S community launch was a community event which took place in Red Deer, AB, at the Bower Ponds venue from 10am to 4pm on September 19th and 20th, 2019. Métis community members of Red Deer, and Shining Mountains employees, as well as partners involved with the implementation of DBST (employees from Alberta Health Services, Public Health Agency of Canada, the Red Deer Street Clinic, and D&S research team members), and representation from the MNA were invited to attend. The purpose of the Métis D&S community launch was to inform community members and stakeholders about D&S, celebrate work accomplished by D&S and Shining Mountains to date, and hold group discussions related to HIV, HCV and STBBI in the Métis community.

The community mapping exercise involves placing large flip-chart paper around various parts of the room and labeling them with service categories (e.g. harm reduction resources, cultural resources, employment resources, etc.). Each participant is provided with pen and a sticky note; they will write down a resource available in their community on their sticky note (e.g. needle exchange services at a local pharmacy) and place it under the relevant service category. This method is very similar to the Participatory Community Engagement Mapping method, but does not involve a geographic map (Burns, Dagmar, Paz, & Advancement Project, 2012). Photos were taken of each flip chart paper to record identified resources and transcribed. Data collected from the community mapping exercise was used as an additional data source to give context to the Métis-specific model. As the primary researcher on this thesis research, I also kept a journal to record personal reflections on the research process, but this journal was not included in the data analysis.

Data analysis. Gathering circles were audio recorded and transcribed by myself after consent was obtained. All data were uploaded into NVivo software to assist with coding. Thematic analysis was used, which is a process that begins with achieving familiarity with the data through open-minded reading, then progressing into a search for meanings and themes and finally, organizing those themes into meaningful text (Padgett, 2012; Sundler, Lindberg, Nilsson, & Palmér, 2019). As described in sections above, I analyzed these data with a Métis lens. For coding I relied heavily on a holistic coding approach, described below, which is based on the work of Saldaña (2013).

A code is a word or short phrase and represents a "summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldaña, 2013, p. 3). Coding, or the process of attributing a code to represent a word or short phrase, can be used on many forms of data including interview transcripts, observational notes, journals, documents, literature, videos, websites, and email-correspondence (Saldaña, 2013). Several codes can be used repeatedly throughout the process. The act of coding requires that the researcher use their analytic lens in order to perceive and interpret what is happening within the data. This analytic lens is often influenced by what Saldaña calls "filters", which affect the way we analyze the data and are influenced by our methodological perspectives (Saldaña, 2013). One example of a filter is the RE-AIM framework, which I used as a filter, alongside my Métis lens (another filter), to evaluate the acceptability and feasibility of DBST.

After the data has been coded the researcher then undertakes a process of codifying the data (Saldaña, 2013). This involves arranging codes in a systematic order in order to categorize them. Grouping codes in this way allows for the emergence of categories and patterns during analysis, which subsequently allow for the identification of themes and concepts (Saldaña, 2013). Themes are distinct from codes in that they are an outcome of the process of coding, codifying, and analytic reflection (Saldaña, 2013).

Holistic coding is distinct from other methods of coding as it is more of an exploratory method of coding (Saldaña, 2013). Exploratory methods allow for the preliminary assigmnent of codes and future refinement of the coding system, letting the researcher review the codes multiple times (Saldaña, 2013). As a method, it allows the researcher to attribute codes to large pieces of data, rather than approaching and coding the data line-by-line (Saldaña, 2013). Therefore, it facilitates looking at the data from the "bigger picture". Saldana recommends following up holistic coding with a process that further analyzes the data, such as thematic analysis (Saldaña, 2013).

Analytic memos were kept throughout the process in order to document the process of inquiry as well as emergent patterns, categories, and subcategories (Saldaña, 2013). Analytic memos can be used to document decision making particularly in instances where data may be ambiguous. They can also be used to map links between codes or themes and reflect on challenges within the study as well as directions for future research (Saldaña, 2013).

Techniques to enhance trustworthiness and rigor. Several strategies to enhance the trustworthiness and rigor of research were used during the analysis stage. Trustworthiness is the degree to which we can trust the findings to be as close to the experiences of the participants as possible within a study (Padgett, 2012). Techniques to ensure rigor were developed by Guba (1981) to evaluate the potential credibility, transferability, dependability and trustworthiness of completed research (Morse, 2015).

Padgett (2012) describes three main threats to trustworthiness: reactivity, researcher bias, and respondent bias. Padgett (2012) states that trustworthiness in research must be earned by demonstrating it throughout the research process. Reactivity is defined as the potentially distorting effects of the researcher's presence on participants' beliefs and behaviours. I attempted to reduce reactivity throughout the data collection process by remaining non-judgemental, open, and welcoming at all times during gathering circles. The presence of an Elder also likely contributed to the psychosocial and cultural safety of the gathering circles. Researcher bias occurs when observations and interpretations are clouded by preconceptions and personal opinions of the researcher. An example of this is when a researcher asks leading questions. To avoid researcher bias I kept the gathering circle and interview questions broad for both research questions (RQ1 and RQ2). Padgett (2012) discusses debriefing and support as an important method for reducing researcher bias. I also kept a journal and checked in with my research support system (supervisory committee) regularly to ensure that I remained aware of my biases and/or preconceptions throughout the entire research process. Respondent bias occurs when participants may conceal the truth or withhold information in order to protect their privacy (Padgett, 2012). In order to address respondent bias, I included both an anonymous survey and a confidential gathering circle, to accommodate differing levels of comfort with sharing information.

Data triangulation, the use of multiple data sources, was used as a strategy to strengthen trustworthiness (Padgett, 2012). Supplemental data from the community mapping exercise were used to confirm/corroborate data from the gathering circles.

For the gathering circle, member checking was employed as an appropriate strategy for enhancing rigor, since members have indicated interest in continuing with the work. Member checking involves bringing a transcript and/or analysis back to the study participants to allow them to confirm that the findings are representative of their experience (Padgett, 2012). I invited participants to member check a community report of the findings which summarized the prominent themes; however, they were not involved in member checking the transcripts in order to reduce the time requirements and workload of participants. I sent a draft of the community report (Atkinson et al., 2020) to participants via email to offer an opportunity for participants to read, and make comments or suggestions to ensure the analysis accurately reflected what was discussed by participants.

In addition to using data triangulation, peer debriefing, and member checking to enhance the trustworthiness of this research, I utilized elements of an audit trail during my analysis. An audit trail enhances the transparency and reproducibility of a study (Padgett, 2012). I incorporated the audit trail into my research journal which also contained my reflections on the data and research process. The audit trail also assisted me in maintaining organization during the process of thematic analysis, as it recorded decisions I made regarding the data and reasons for decisions, which was helpful considering the large number of themes discovered through this research.

Research question 2 (RQ2): Is DBST an acceptable testing method for Métis communities?

The second goal of this research was to conduct an evaluation of a dried blood spot testing pilot for HIV and STBBI in Alberta, drawing strongly on the perspectives of Métis community members. To facilitate this evaluation process, research question 2 (**RQ2**) was developed, which asks: is DBST an acceptable testing method for Métis communities? RQ2 was addressed through the use of surveys, gathering circles with DBST recipients, and semi-structured interviews with DBST providers, and supplemented with document analysis of meetings between Shining Mountains, AHS, NLHRS, and D&S.

Participants, sampling and recruitment.

Dried blood spot test recipients. Addressing RQ2 involved several types of participants and methods of data collection. To understand the acceptability of DBST from the perspective of those who received dried blood spot (DBS) testing, testing recipients were invited to complete a (pen and paper) survey as well as participate in a gathering circle. DBS test recipients were visually identified and verbally recruited by myself, and the test providers (using the introductory statement in the letter of implied consent contained in Appendix B) during two DBST (pilot) events including the Métis launch (described above) on September 19th 2019 in Red Deer at the Bower Ponds venue and a Métis health forum held in Edmonton on November 30th 2019. In order to understand who may have been recruited to participate in this study at these events,, it is necessary to provide an overview of these two community events. Page 114 provides a brief description of the community launch of the D&S project in Red Deer, where select members of the Métis community and partnered organizations were invited to attend. The Métis health forum is an annual event put on by the Métis Nation of Alberta which features a corresponding health fair. The health fair holds several dozen booths which feature information on training programs, resources, and services geared towards Métis people. Corresponding activities took place at the Métis health forum which included presentations and group discussions on select topics determined by the MNA. The Health forum drew a broad audience comprised of Métis people either working in the field of health, or interested in health, from Edmonton and surrounding areas.

All self-identifying Métis recipients of DBS testing were invited to complete the survey by either myself or individuals providing the testing. Additionally, I verbally recruited test recipients to participate in my gathering circles. Gathering circle participants were offered a $25 VISA gift card as a token of appreciation for participation in the gathering circle. $25 was determined to be an appropriate amount as it is very commonly used as an amount for honoraria for interviews or focus groups of 1 hour or less and is equal to what an individual might receive for an hour of work in the informal economy (Collins et al., 2017; Guta et al., 2014). No compensation was offered to those who only completed the survey because it was so brief. Participants had to self-identify as Métis to be eligible to participate in either the survey or the gathering circle.

Dried blood spot test providers. To understand the perspectives of dried blood spot test providers, employees at Shining Mountains who were trained to administer the DBST were invited to participate in a telephone interview (questions in Appendix D). Understanding the perspective of DBST providers was necessary to assess the feasibility of implementing DBST in other Métis communities. I recruited these participants following the written recruitment script via email (see Appendix E). Due to the limited number of staff trained to offer DBST, three individuals were targeted for recruitment. The Métis D&S Coordinator confirmed the individuals who received training in DBST. The only requirement for interview participants was that they had received training in the administration of DBST. Interview participants were offered a $25 VISA gift card as a token of appreciation. DBST provider interviews occurred via telephone after the completion of both testing events.

Supplementary data. In addition to survey, gathering circle, and semi-structured interview data, additional data included meeting minutes and notes takes during meetings between policy makers, research team members, and the Métis community/Shining Mountains. These notes included details about the process of working with government bodies and stakeholders leading up to the implementation of DBST, challenges experienced, and wise practices utilized. I also took observational notes during the September 19/20th Métis community event where DBST was launched, as well as at the Métis health fair on November 30th. No personally identifying data was collected in observational notes to protect the privacy of those receiving testing. My research journal detailing reflections on the process of implementation and evaluation was also be used as a confirmatory data source.

*RQ2: Instrument development***.** All data collection instruments were developed in partnership with stakeholders from Shining Mountains and the Métis D&S Coordinator. The data collection instruments to address RQ2 include: the survey (see Appendix C), gathering circle questions for Métis testing recipients (see Appendix F), and interview questions for DBST providers (see Appendix D). The survey was co-developed with input from the D&S research team, with strong direction and final approval given by the Executive Director of Shining Mountains and the Métis D&S Coordinator. Factors such as limiting the length and number of questions in order to reduce the amount of time needed to hold the circle were considered in the approval process.

Data collection. Surveys were handed out to DBS test participants and collected on September 19th during the launch of DBST in the Métis community and on November 30th to coincide with the DBST offered at the Métis health forum. One gathering circle occurred on September 20th in the afternoon, and three occurred on November 30th in the afternoon. Observational notes were taken during both events, as well as for all meetings held regarding the planning and implementation of DBST before the launch on September 19th, and any debriefs and reflections afterward.

Data analysis. Survey data were transcribed and compiled into an Excel document. Data from the survey were analyzed using descriptive tables. The gathering circle, as well as interviews were audio recorded, transcribed, and uploaded to NVivo 12 to facilitate the thematic analysis of data (Padgett, 2012). The same approach described above for the analysis data related to RQ1 was used to analyse the qualitative data collected to address RQ2, which included holistic coding of the data as described by Saldaña (2013), and thematic analysis as described by Padgett (2012).

Applying the RE-AIM Framework.

As discussed in the previous chapter, IS helped guide the development of the research approach, data collection tools, and analysis. Here, I discuss why the RE-AIM framework was selected as an analytic framework to assist with RQ2, and how it was applied to the data analysis process. The RE-AIM framework was selected to assist with the evaluation of DBST for several reasons. One of the strengths of the RE-AIM framework is the fact that it was developed specifically for assessing the implementation of public health interventions (Glasgow et al., 1999), and as such it acknowledges the complexity of such interventions and the contexts in which they are implemented. The RE-AIM framework is comprehensive as it covers the factors of reach, efficacy, adoption, implementation and maintenance; yet, it is simple and clear enough for individuals outside of public health and policy to understand and potentially apply it to their work. The RE-AIM framework is also one of the older evaluative frameworks, having been applied to public health interventions for the past 20 years (Gaglio et al., 2013).

After the transcription, coding, and thematic analysis of data were conducted, the RE-AIM framework was applied to the themes identified. The coded data from the gathering circles, document analysis, and the survey results were re-analyzed using the RE-AIM framework as a lens. Themes were then categorized according to where they fit within the RE-AIM framework. I used outcomes typically measured and reported from the literature from each component of the RE-AIM framework to assist in this process of categorizing and analyzing evaluative components and themes, and reported on the evaluation findings using the RE-AIM categories themselves (Gaglio et al., 2013; Harden et al., 2018). The questions used to guide the RE-AIM analysis are included below in Table 1. I compiled this guide to the RE-AIM framework based on the work of Gaglio and colleagues (2013), who undertook a systematic review on the use of the RE-AIM framework to identify the most commonly reported outcomes within the RE-AIM framework.

Table 1

Commonly Reported Outcomes According to RE-AIM Categories to Guide Analysis

Category	Commonly Reported Outcomes to Guide Analysis
Reach	Exclusion criteria, percentage of individuals who participate based on a valid denominator, characteristics of participants compared with nonparticipants, use of qualitative methods to understand recruitment (Gaglio et al., 2013).
Effectiveness	Measures of: primary outcome, primary outcome relative to public health goal, broader outcomes or use of multiple criteria (e.g. quality of life), of robustness across subgroups, short term attrition, qualitative methods and data to understand outcomes (Gaglio et al., 2013).
Adoption	At setting level: setting exclusions, percentage of settings approached that participated, characteristics of settings participating, use of qualitative methods to understand setting level adoption (Gaglio et al., 2013). At staff level: staff exclusions, percent of staff that participated, characteristics of staff participants, use of qualitative methods to understand staff participation (Gaglio et al., 2013).
Implementation	Fidelity, adaptations, cost of intervention in terms of time and money, consistency of implementation, use of qualitative methods to understand implementation (Gaglio et al., 2013).

Maintenance	At individual level: measure of primary outcome after treatment, measure of broader outcomes, robustness data, long-term attrition, use of qualitative methods and data to understand long-term effects (Gaglio et al., 2013). At setting level: is program still operating 6mo after implementation, if and how program was adapted long term, discussion of sustainability, use of qualitative methods to understand setting level institutionalization (Gaglio et al., 2013).

Techniques to enhance trustworthiness and rigor. Many of the same strategies used enhance the trustworthiness and rigor of the analysis for RQ1 were employed for the analysis for RQ2. Data triangulation was used to strengthen trustworthiness (Padgett, 2012). Data from meeting minutes, and field notes from the Métis launch were used to confirm/corroborate data from the gathering circles. I used members of the research team and my supervisory committee as resources for debriefing, support, feedback, and to stimulate new ideas during thematic analysis of the data. An audit trail was included in my research journal which enhanced the transparency and reproducibility of the study (Padgett, 2012). Data from the gathering circle were not member checked in order to reduce the burden required for participation on behalf of participants, protect their anonymity, and reduce challenges associated with follow up.

Informed Consent Process (RQ2)

Informed consent was obtained from each research participant each time they engaged in the research process. I started the gathering circles by paraphrasing the information from the consent form (Appendix H) and emphasized the importance of confidentiality. I made sure to address any questions from the participants before the gathering circles began. Prior to beginning the gathering circles, participants signed the informed consent forms and were given a copy to take home. Contact information for myself as well as my supervisor was included on the informed consent form. For semi-structured interviews with testing providers, verbal consent was obtained, and I signed the assent form (Appendix I) on behalf of each participant. I chose to obtain verbal consent and sign an assent form on behalf of interview participants because the interviews took place over the phone during a period of extreme cold weather in Alberta. Some participants were completing the interviews from their home and I did not know if they had access to a printer and scanner, so to make it easier for them to participate, I obtained consent verbally. For survey participants, the letter of informed consent was paraphrased verbally, and once informed consent was received, a copy of the letter was given to the participants.

Ethical Considerations

Ethics approval through the University of Victoria's Human Research Ethics board for this sub-study was obtained on September 18th, 2019 as an amendment to the D&S ethics application (certificate # 18-1179). In keeping with wise practices in the field of Indigenous community-based research, this sub-study fostered a process where the Métis community and partners directed the research agenda and helped shape, and give approval, to all data collection tools concerning Métis participants. Using a shared decision-making process, engagement with Métis stakeholders was an ongoing process, as several Métis individuals as well as representatives from Shining Mountains are involved with the Guidance and Management Committee of D&S, of which this project is a sub-study.

All aspects of this sub-study followed the guidelines set out in the Tri Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2, with a specific focus on Chapter 9: Research involving the First Nations, Inuit and Métis Peoples of Canada (Government of Canada, 2018). Additionally, the Principles of Ethical Métis Research as described by the National Aboriginal Health Organization's Métis Centre (2010) were considered throughout the study.

Protecting the identity of all participants was a priority for all research conducted during this thesis research. No names or personally identifying information were collected during any interviews, observations, or surveys, except for on signed consent forms, and names were not attached to the interview/gathering circle data or quotes used within this thesis. All responses were kept confidential.

Effort was made to keep the survey and group/interview questions emotionally non-intrusive in order to keep risks associated with participation low. In case participation became emotionally upsetting for an individual, a Métis Elder was present at all data collection events. I also had information on local supports available, if a situation arose where an individual felt they needed further support. All data collected was kept in either a locked cabinet or in a password protected laptop in a secure location.

Strengths and Limitations

There are some recognized limitations to research conducted in a group setting (Padgett, 2012). These include having one participant dominate the conversation which can result in others not speaking up (Padgett, 2012). In this instance a skilled facilitator is necessary in order to create a space where all are comfortable to speak (Padgett, 2012). I am fortunate to have received group facilitation training in the past year, and I felt comfortable facilitating the gathering circle processes.

Limitations. The logistics of holding group data collection opportunities (gathering circles) can be difficult to overcome, and this is one challenge associated with community-based research in Indigenous communities. These can include challenges around transportation, obtaining childcare, and obtaining time off of work. Another concern was that a participant may breach confidentiality, so it was important to warn individuals about this in the consent process before the gathering circles began (Padgett, 2012). The group nature of this form of data collection may prevent participants from sharing information of a personal nature (Padgett, 2012). To address this, the comfort of the gathering circle participants was made a priority and the importance of confidentiality was emphasized at the beginning of each gathering circle within my sub-study.

Strategies to address methodological rigour were engaged in this sub-study to enhance the trustworthiness of the research. Important knowledge (lessons learned) have been gained regarding the experience of self-identifying Métis in Alberta who have received DBST, as well as the Red Deer Métis community in leading the DBST pilot, that can be used to inform and guide future DBST initiatives within other Métis communities. Similarly, the Red River Cart Model may not resonate with every Métis person; however, the intention is for it to be customizable and adaptable, and even optional, for current and future Métis individuals living with or impacted by HIV/STBBI.

Strengths. As a Métis student and researcher, I always self-identified to potential research participants as a Métis individual and student. I think my identity as a Métis person, as well as the relationships I worked to build with the sub-study's partners, were a strength to this research. For instance, although the number of eligible (potential) participants was small, participation in the research was high. Further discussion around the strengths and limitations of this research are included in the final section of the discussion chapter.

Knowledge Translation Progress and Future Plans

Knowledge translation (KT) is a key aspect of any research project, and successful and meaningful KT requires thoughtful consideration from the very beginning of a research project. Knowledge translation is a term that describes the process which facilitates the synthesis, dissemination, exchange, and ethical application of knowledge in order to improve health (Straus, Tetroe, & Graham, 2009). KT in Indigenous communities and most communities outside of academia, is very different from the styles of KT which have dominated academic institutions up until recently (Smylie et al., 2004). Traditionally, manuscripts and conference presentations have formed most knowledge translation activities for many Western academics for a long time and this serves to mainly share knowledge with those who are involved with research in an academic setting, and other experts within the field such as policy makers.

Research has identified that KT strategies which actively work with and identify the needs of Indigenous communities are effective (Smylie et al., 2004). Moving forward, I will be working with Shining Mountains and Métis stakeholders involved with the sub-study to develop Métis-specific and appropriate KT materials based on the findings of this study. The exact format, type, and included messaging will depend on the expressed needs and desires of Métis stakeholders. To date, those who participated in the Red River Cart Model gathering circles (RQ1) have requested a brief, community-friendly report to share with other Métis organizations, communities, and Indigenous service agencies. This community report on the process and findings of RQ1 has been drafted and sent to gathering circle participants for feedback.

Ethical KT considers who has ownership of knowledge and who stands to benefit from this knowledge. In the context of this study, the Métis community is considered the caretakers of knowledge arising from this project, and any information shared on it will be subject to approval of the community in keeping with identified ethical KT principles from the literature (Cochran et al., 2008; Ellison, 2014; NAHO: Métis Centre, 2010). This sub-study's approach to KT will also consider the ethics of sharing any information which might be considered to be traditional in nature, by asking for permission from the Métis community prior to sharing, in order to conform to the Principles of Ethical Métis Research (NAHO: Métis Centre, 2010). All findings shared from the project will emphasize a strengths-based perspective and highlight the resiliency of the community and those involved in the study (Cooper & Driedger, 2018). Additionally, in recognition of the inherent power imbalance that exists between academic institutions, researchers, and Indigenous communities, and to acknowledge the work done by Métis community members and Shining Mountains staff, community members will be reflected in the authorship of any manuscripts which result from this study. Ensuring that community is reflected in co-authorship is one way to ensure that the benefits of community-based research is shared more equitably across members of the team (Jull, Giles, & Graham, 2017).

To date, two abstracts based on the findings of this sub-study have been submitted to and accepted for oral presentation at the Canadian Association for HIV Research’s annual conference in 2020. The titles of these abstracts are: Evaluating DBST from a Métis Community Perspective, and Creating a Métis-specific Model of Culturally-Relevant Shared Care for Métis Individuals living with or affected by HIV/STBBI. Unfortunately the in-person conference was cancelled to prevent the spread of COVID-19; findings were shared through two e-posters (of the same titles) for an online version of the conference. An additional abstract was submitted to the AIDS 2020 conference in San Francisco based on the application of the RE-AIM framework to the evaluation of DBST in the Métis community. The D&S team, Shining Mountains and other Métis stakeholders (e.g., participants, MNA) felt that it is important and useful to share information on the process, findings, and lessons learned from creating a culturally-specific evaluative process of DBST, and an assessment tool designed to support individuals living with/impacted by HIV and STBBI with international Indigenous communities through these conference presentations. Future opportunities to share findings in conferences will be explored in partnership with Shining Mountains and the D&S team.

Conclusion

Although the approach to this sub-study's research required an approach which combined several methodologies and theories, I focused on actively weaving together these important approaches to research with the use of a Métis lens. Using a Métis lens provided me with an opportunity, similar to Two-Eyed Seeing, to bridge different approaches and worldviews in a way that made the most sense for the Métis community with whom I was working. By focusing on qualitative approaches to data collection, I was able to build key relationships to conduct this important research within the community, a process that cannot be overlooked within Indigenous and community-based research methods. I was also able to use multiple data sources and approaches to gain a nuanced understanding of people's experiences with DBST, as well as a Métis understanding of health and wellness in an HIV and/or STBBI context.

Chapter 4: Results

I conducted a thematic analysis of the data through the use of a holistic coding process which was described in the methodology chapter. Resultant themes from the analysis are presented under the corresponding research question. My intention in the structure and presentation of this chapter is to use quotes from participants as often as possible, in order to allow Métis Peoples to speak for themselves and facilitate a better connection with the data and topic at hand for the reader. Many of these themes and subthemes are overlapping and interrelated, but they will be discussed individually for the sake of clarity and organization. All names associated with quotes in this chapter are pseudonyms.

RQ1: What could a Métis-specific cultural response to HIV and STBBI look like?

The first research question (RQ1) was: what does a Métis-specific cultural response for those affected by HIV and other STBBI look like? This was also the question posed to gathering circle participants during the development of the Red River Cart Model. From the gathering circles and community mapping exercise data, I supported the creation of a model of Métis-specific health and wellness for individuals living with/affected with HIV and/or STBBI. The model development was led by Raye St. Denys, Executive Director of Shining Mountains, the National D&S Coordinator, and the Métis-specific D&S coordinator. This model is owned by members of the Métis community and Shining Mountains, and it will continue to be shaped over time. My role in the model's development was that of a participant observer, where I supported and provided context to each component of the model through the data analysis. The themes that are part of the model are arranged in a way that improves the flow of this section for the reader but does not conform to the clockwise order in which model components were discussed by the participants (or are represented within the visual model). The model in its current state of development (as of spring 2020) is provided in Appendix J. This version of the model was also described in the community report which was developed in March 2020 and shared with RQ1 gathering circle participants (Atkinson et al., 2020).

Participants and Process

A total of Eight Métis individuals participated in the three gathering circles. Some participants could only attend a single gathering circle, others attended all three. Between 5 and 7 Métis individuals participated in the first two gathering circles which focused on the open discussion of model components and how they related to health and wellness in an HIV or STBBI context. A third, smaller gathering circle was held with three Cree-Michif language holders and two additional participants, to add terms and labels in Cree-Michif. Participants of the first two gathering circles were a diverse group of self-identifying Métis Peoples who were identified and recruited through Shining Mountains and the Métis-specific D&S coordinator. These participants had experience working in HIV and STBBI services, or were connected to or familiar with the work of Shining Mountains. Participants of the first two gathering circles included a Métis Elder, a two-spirited identifying Métis individual, and Métis individuals with lived experience with HIV or STBBI. There was an equal gender balance amongst all participants, whose ages ranged from mid-30's to late 70's.

The gathering circle processes were grounded in a Métis way of doing things. To begin each gathering circle, an Elder was gifted tobacco by either myself or the National D&S Coordinator and asked to open the process in a way they felt was appropriate (i.e., prayer). Some participants brought their children for the day. Lunch and refreshments were provided, and the Elder was asked to pray over the meal. During the first gathering one of the children brought his fiddle and played a song, which led to a jig amongst the members of the group. On the second gathering circle day, the children were invited by the Elder to help make a spirit plate, and in return received teachings about the spirit plate. Prayers were offered by the Elder at the end of each day for safe travels home. For participating in each gathering circle, participants were provided with honoraria by Shining Mountains in accordance with their organizational policies. At the final gathering circle I gave small gifts of soap and herbal tea to participants in accordance with the local Métis customs of gift-giving.

While there were a wide variety of diverse participants in the gathering circles and participants were actively engaged, the voices of professionals working in the field of HIV and STBBI were particularly strong within these gathering circles as they had intimate knowledge of the D&S project and the context of the model's development. At times, there were differing perspectives raised by gathering circle participants, particularly around whether or not components should be strongly defined or left more non-specific (e.g., the role of community and distinguishing community from social aspects of health). Both of these factors influenced the current model. Participating in and assisting with the facilitation of the gathering circles was a learning process, and I shall reflect further on the process and the impact of the process on the resulting model in the Discussion chapter.

What is the Red River Cart Model?

The Red River Cart Model is a multi-level tool which was primarily designed to help clients plan health and wellness related goals by identifying areas of their health and wellness which could use additional support and services. Although the Red River Cart Model was developed as an intake assessment tool to be used at Shining Mountains, it could be used for existing clients as well, and by other service agencies. The Red River Cart Model can be used by individuals with assistance from a support or social worker. Participants of the gathering circles recognized that the model could be adapted for other health contexts, such as Elder abuse prevention or chronic diseases like diabetes and heart disease. Thematic analysis identified program, community, and system level interventions under the components which can form aspects of a Métis-specific cultural response to HIV and STBBI. These will be discussed alongside the individual-level analysis, where appropriate. Prior to discussing the core themes, several overarching contextual and process themes will be addressed.

Overarching Contextual and Process Themes for RQ1

Several themes were identified which pertain to the application or use of the Red River Cart Model itself, or the context or process through which the Red River Cart Model itself was developed. These themes are: beginning the journey, an individualized approach, and community and member engagement. These themes are important contextual themes for the Red River Cart components, and are overarching themes of the entire process.

Beginning the journey.

Gathering group participants emphasized that developing, using and applying the Red River Cart Model within practice was a process or a journey that the gathering participants were on together. As one participant said, “We’re beginning. And that’s an important word there. We’re beginning to build a Métis-specific response to STBBIs.” They indicated that the work of coming together as a group to build this model represented the beginning of this journey, of which the goal was not to reach a particular destination, but to begin a small part of what they (and myself) hope will become a larger initiative to address HIV and STBBI at a larger level within the Métis Nation across Canada. This was further illustrated by the participant who said “the objective today is to come to the beginning, to begin this process”.

Individualized approach.

Discussions around the application of the model with participants emphasized the importance of using an individualized, client-centered process. Participants indicated it was also very important that the model be flexible for other communities as well as individuals to adapt through a similar process of discussion, reflection and refinement that our group undertook. Participants used the term "living document" many times to emphasize that the model represented a guide, which was not written in stone, and was something to be offered to clients receiving HIV or STBBI care or supports (but not mandatory). Participants were concerned that the model may be implemented in other communities by individuals not as knowledgeable about Métis culture, and wanted to avoid imposing definitions of components when applying the model. One participant reflected on this using the community as an example:

> *So, when I look at community and what my understanding of it is, it's going to be completely different from my clients. And that's why I was saying like you can't… it has to be written in there somewhere that this is just guideline information it can't be finite.*
>
> (Stephanie, a Métis social worker)

In this quote, Stephanie is explaining how the different aspects of the model will mean different things to different people. "Community" is one aspect of the model (discussed later) which may have overlapping meanings with other components such as "social" to model users. She used this as an example of why it is important to allow the clients to define what the components of the model mean to themselves, rather than attempting to impose a rigid definition of each component.

Participants were adamant that the application of the model with new clients had to be a flexible and individualized process. Using the model with a client meant that a support worker or health care worker had to show a “compassionate response” (Eleanor) in order to connect with that individual and identify with them their wellness priorities. One participant referred to it as the “individual’s hierarchy of needs”, implying that needs are unique to the individual. Another participant emphasized “meeting the client where they are at”, fostering a relationship with the client where they felt comfortable self-identifying their own personal needs in that moment, rather than having someone else’s assessment of needs or priorities placed upon them. This means that the individual’s self-identified needs may not be the same ones we would identify in the same situation. What is defined as a person’s most important needs will likely differ from individual to individual. In this sense, the Red River Cart Model supports to a holistic process of self-assessment.

Community and member engagement.

There was some disappointment in the smaller turnout at the first gathering circle. In preparation for the first gathering circle, many potential participants were identified and recruited by the Métis-specific D&S coordinator. This included Métis individuals and representatives from Métis health and service organizations. However, the Métis-specific coordinator said it was challenging to get participants to commit to attending a full day gathering circle. This caused some participants to feel (understandably) disappointed. One individual used this as evidence of the important work that was being done that day, as the lack of attendance could have been reflective of stigma or the lack of importance that HIV and STBBI are shown within health and social organizations and Métis communities.

Eleanor reflected on the composition of the gathering circle at this “beginning” stage, stating:

> *Who is at the table for this stage, for this time, is who is here, and who should be here. And if somebody else is not here it is because it's not their time. Otherwise, what motivates us to show up and do things would have been in their heart as well.* (Eleanor)

This quote emphasized the ability of participants to see the bigger picture of the work being done through D&S. It is also reflective of a Métis perspective; events or processes that are 'meant to happen' will happen when they are intended to, underpinning a spiritual concept or understanding that there may be forces greater than us that influence our work.

More individuals attended the second gathering circle than the first, which allowed for a wider variety of experiences and stories to be shared to inform the development of the model. However, one individual noted that someone who had previously committed to attending the second gathering circle was no longer able to do so because that individual's employer said their other projects were more important and required urgent attention. This was disappointing to some because the individual referred to held some traditional teachings around Métis understandings of gender. This highlights that the lack of engagement could be due to the perceived unimportance of HIV/STBBI in the Métis community.

This theme was reflected differently for the final gathering circle. The number of invitees for the third circle was limited to three language holders in addition to myself and Raye St. Denys. The willingness of language holders to be engaged in this work may be representative of the respect and value placed upon language work in the Alberta Métis community.

Themes According to Components of the Métis-specific Cultural Response for Those Living With or Affected by HIV/STBBI (Red River Cart Model)

The Red River Cart Model has the cart's driver at the centre, with 12 corresponding images of components relating to a holistic Métis view of health and wellness (see Appendix J). These images are: The cart itself (container for the journey), the grub box (resources), toolbox (education, skills and training), stove (housing), weapons (harm reduction), fiddle (social), sash (community), cart tarp (spirituality and culture), medicine bag (clinicians and treatment), Métis flag (politics), capote coat (family), York boat (goals), and moccasins (connection to land). Not pictured within the model are the rawhide and spokes, which are discussed as sub-themes of the cart itself (the container for the journey). Some components have overlapping themes, so themes and subthemes (where applicable) are organized to help the reader understand the flow of concepts. The components, and what each component represents within a wellness context, was decided using a consensus-based process of discussion and decision making among gathering circle participants. The aspects of the cart itself are described first below, followed by the components and their corresponding themes.

Red River cart – container for the journey.

The Red River cart was also referred to as a wagon interchangeably during the gathering circles. The cart's role within the model is to hold the 'items' which the individual would pack for their health and wellness journey. Participants discussed how integral the Red River cart was to the survival of Métis Peoples, as indicated in the following dialogue excerpt:

Eleanor: *It [doesn't get] much more Métis than the carts. That speaks a whole ocean of things to us and reminds us of our roots and our history and our travel here from the East and all sorts of things like that. It was also like whatever was in the cart was whatever we needed to survive.*

Roseanne: *And that's why we as Métis Peoples survived because we packed our cart thoughtfully and carefully.*

Eleanor and Roseanne are referring to the understanding that Métis families had to pack the cart with thought and intention for each journey. Only the most important items would be put in the Red River cart, as its limited space would contain everything needed to survive in difficult environments.

The idea of the Red River cart being packed for a journey towards health and wellness, thoughtfully and intentionally, grounded the model. This is explained in this excerpt here:

> *So, if you think of the cart being empty. And I go into Shining Mountains and I say I've just been diagnosed with Hepatitis C, I don't know what to do, I don't know where to go…So, this cart [model] that will be used as an assessment tool for Shining Mountains and whoever else that uses it, it will be a way to build my own care plan. With the available resources that…. I get to pick and choose what I want in the wagon for my journey.* (Eleanor)

When the Red River Cart Model is being used with a client, the client will need to think carefully about what they would 'pack' on their metaphorical journey towards health and wellness while living with or receiving treatment for an STBBI. The items packed should be considered carefully to ensure that they are playing a helpful role in the individual achieving their health or wellness goal.

Spokes of the wheels – our roles as individuals, family and community members.

Participants suggested that the spokes of the wheels of the Red River cart should be used to represent the roles we as individuals and as Métis Peoples play in our lives. There are many different roles we play, such as youth, father or mother, man or woman, two-spirited, grandfather or grandmother, brother or sister, auntie or uncle, and Elder. Often, we play more than one role in our family and our community. Within Métis culture, each role comes with corresponding responsibilities to one's family and community. Below is a dialogue excerpt that shows how participants discussed the spokes of the wheels:

Roseanne: *I think one of the things that what's in our wagon and I don't see…is responsibilities. Like we had responsibilities to each other. Yes, we had rights. But we also had responsibilities.*

Stephanie: *But what would represent those rights and responsibilities? Because I've been drawing pictures here, and …*

Mark: *Like our roles and responsibilities… So maybe the spokes would be like that? Because without the spokes the cart can't go anywhere.*

Roseanne: *Without the spokes the wheels would collapse.*

In the preceding dialogue the reader can see the integral role of the spokes in keeping the cart and the wheels together. This is reflective of Métis understandings of family, that individuals needed to be able to fulfill the responsibilities associated with their roles within the family. This was integral to the survival of the Métis. One participant talked about the importance of roles within family, and how ideally family helps and supports each other when needed:

Pat: *The spokes also represent the family. Because if there's one broken spoke, you all come together as a family to see how you can help that person. Like you're all trying to fix that spoke.*

Mark: *Otherwise the cart wobbles.*

In the above dialogue, Mark compares the wobbling of the cart to a Métis family encountering challenges with a member who might need help. When a member of the family is hurting, others gather together to help support the individual (as discussed by Pat) because otherwise, the family cannot operate properly.

The fact that every individual within Métis society had responsibilities to themselves and to others was an important talking piece amongst participants in the gathering circles. This reflected the fact that everyone, no matter their age or ability, were valued within the community and within the family for what they contributed. Some roles were gender-based, such as childbearing, or two-spirited roles. Many were age-based, such as older children caring for younger children.

The question of how roles pertaining to lesbian, gay, bisexual, transgender, queer/questioning and two-spirited (LGBTQ2S+) identities would be reflected within the model was also discussed:

Eleanor: *Okay, so let me make a point of this. So, my understanding of this… is that how the person identifies as far as gender goes should not affect anything around the circle.*

Blake: *No, but if you look at two-spirit, and they [Elders] have teachings about it. There is a whole spiritual element that doesn't get out there, and if that is important to them it may come to the fact that they want to connect to another two-spirit Elder…*

Here, one participant who identified as two-spirited stressed the importance of acknowledging the inherent spiritual element of a two-spirited identity. Two-spirited identity was closely related to spiritual topics and was identified by the participants as a distinct spiritual role, whereas the other identities relating to sexual orientation were applicable to each role and therefore each spoke of the wheel. Participants also emphasized the fact that the term or concept of two-spirited identity was not the Indigenous "paintbrush" over LGBTQ2S+, that in the past it represented a specific role that an individual would play within their community. It was (and is) not considered by the gathering circle participants to indicate any particular sexual orientation.

Rawhide – resilience. Rawhide was commonly used to lash together pieces of the Red River cart. The rawhide was wrapped over the wooden pieces of the cart while wet, so when the rawhide dried, the strips contracted to form a very hard and tightly lashed leather rope. The rawhide was spoken of as the element that kept the entire cart held together. When discussing the future use of the cart model within the larger D&S goals, participants were asked what they felt kept the D&S project together. Eleanor rephrased the question to directly ask the participants what they felt contributes to the sustainability of community interventions such as D&S. Roseanne discussed the resilience of Métis Peoples and how this relates to the sustainability of interventions such as the Red River Cart Model and D&S:

Eleanor: *Well, let's think about this when we bring the scope in a little bit, if we think just project, if were just thinking a response to STBBI in a Métis cultural way. What is it that's going to keep that cart together so that when that [CIHR] funding ends what's going to keep that going?*

Roseanne: *I think it is resilience. And survival. We have survived on nothing.*

The concept of survival and resilience were discussed together by multiple participants:

Victoria: *I would say it* [resilience] *threads into everything. Because it was every piece of, it was the resilience, it was being able to laugh at oneself, it was the jigging, the comradery, the community and all those types of features that kept the Métis strong regardless of what was done to them, and they would just say "fine" and move along.*

Eleanor: *Okay then, we need to unpack the rawhide and we need to give it some role in what we're doing. So, what is it that keeps everything together?*

Victoria: *Resilience.*

Pat: *And survival. Because we did find a way to survive, wherever we were.*

This extended quote shows that community and culture played important roles in the resilience and corresponding survival of Métis Peoples. Culture and community are both discussed as important elements of the model later in this section.

The Contents of the Red River Cart Model – Themes Related to the Components of the Model

After discussing the aspects of the Red River cart itself (the cart, rawhide, and spokes) participants began to discuss the various elements of the cart's components (i.e., what would be packed in the cart on a health and wellness journey). First, they identified typical objects that would be packed into the cart, and then established the meanings of each packed item as it pertained to wellness and health in an HIV/STBBI context. These are described sequentially below, beginning with the grub box.

Grub box - resources.

The grub box was described as a large, handmade, wooden box that would contain dried goods and foodstuffs for journeys. Participants indicated that the grub box could represent resources within an HIV or STBBI care context, and that this made sense with the metaphor of the cart being packed for a journey. At the *individual* level, this corresponded to the use of social supports such as transportation subsidies or food banks, as discussed below:

Nicole: *If someone was food insecure, if they had issues paying for their food or getting enough to eat, would that go under resources or somewhere else? Like using a resource like a food bank?*

Mark: *Sounds like something that would be put under resources, like if we think about all the resources a person might use.*

Blake: *Yeah and there would be bus tickets and stuff under there too.*

The discussion centered mainly around supports individuals could access through health and social programs and services. One participant acknowledged this could include information resources that an individual might need for themselves, such as resource pamphlets or websites on where to find services. At the *program* or *community* level, this could look like the resources that organizations work to provide to their clients, such as developing pamphlets to meet a specific information need for clients like where to access testing. Participants also saw it as a reminder for programs and communities that member participation in programs and services can require supports for individuals and families, such as childcare and transportation subsidies.

Métis toolbox – education, skills and training.

Participants discussed the importance that tools held in our traditional semi-nomadic Métis culture. Families would have carried a wide variety of tools including hammers, saws, knives, woodworking tools, and tools for hide tanning, as a few examples. Through discussion, the participants established that the Métis tools would represent education, skills, employment and training within a modern HIV or STBBI context. A wide range of training was discussed within this category, including formal and informal training and education. Data from the community mapping exercise emphasized the role of the MNA to provide supports at the *individual* level and partnered organizations like CAAN and CATIE to provide resources at the *program* level.

At the *individual* level, participants referred to this component as supports which enable clients to access education, skills, employment or training which is relevant to their goals. A wide range of supports were discussed, including funding such as scholarships and bursaries for academic and trades-based programs, and community-led training such as first aid, which would allow individuals to become certified for certain types of jobs.

At the *program* level, this referred to specific training and education around HIV and STBBI. Training offered by CATIE and other organizations were referred to as examples for improving awareness and capacity among service providers, and were also identified through the community mapping exercise. Another example discussed was the DBST administration training received by Shining Mountains staff. At the *institutional* level, this could refer to cultural safety training and presentations given to Métis local leadership and/or MNA leadership about HIV and STBBI and their impact on Métis Peoples and communities.

Métis stove - housing.

The Métis stove was described as a heavy cast-iron stove, similar to a wood stove used to heat a modern house, but was transportable and used both for heating and cooking. Participants identified the stove as corresponding to housing, as it provided warmth, comfort, and a way to prepare food, which were aspects associated with housing. Within the model, housing refers specifically to housing supports and interventions such as HIV supportive housing, affordable housing, Indigenous community housing, and other housing programs. Thereafter, the discussion focused mainly on housing supports available to individuals in Red Deer. Participants described challenges and barriers to obtaining housing supports, as evidenced by this discussion about a local Indigenous housing non-profit:

Mark: *I mean it's [Indigenous housing] not impossible to get into, but very, very difficult.*

Stephanie: *Yeah, like I wouldn't even be able to get into it, because I don't make enough money.*

Mark: *And see right off the bat there that's an issue.*

Stephanie: *I'm employed full time and I wouldn't be able to…*

Mark: *I mean that's what I'm getting at, you're working full time.*

Stephanie: *You also have to get them to like you, I think.*

Roseanne: *And you also have to get 70 hours of volunteering and putting up sweat lodges or whatever, but if you're not meeting it [requirements] in that way…*

Eleanor: *They have very specific requirements for living there. You have to be willing to take part in Native spirituality whether you want to or not, you have to make a certain amount of money to be admitted because they want to make sure you make your rent.*

Nicole: *So, if you're making minimum wage it's not realistic.*

Stephanie: *I think it was you had to make over 35k a year.*

Roseanne: *So, if you're just on a senior's pension you don't qualify.*

This dialogue shows how challenging it can be for individuals to meet the requirements for housing supports. Fortunately, Shining Mountains provides some housing, and there are several organizations which focus on providing housing and supports for those who are "difficult to house":

Eleanor: *So, in the city you've got Hope Mission that finds people housing, the only thing is that there's two populations that are hard to house, one of them is those actively using drugs and alcohol, and the others are mental health.*

Stephanie: *Yeah, the Schizophrenia Society does housing for individuals with mental health issues and then I know that there is Housing First and Safe Harbour.*

Roseanne: *And Canadian Mental Health has a housing piece as well.*

Participants were also able to identify specific organizations that provided some type of housing support for seniors, youth, and transition housing for survivors of domestic violence. As discussed by some participants, housing was identified as one of the most important elements of health and wellness. They described insurmountable challenges experienced by friends who slept rough, particularly in the winter, commenting that it is almost impossible to survive let alone attend to one's health in those scenarios. Thus, lack of housing created an absence of warmth and comfort, and related back to the notion of a stove as shelter and housing.

Weapons – harm reduction and protection.

Participants immediately identified weapons and tools for self-protection as one of the first items that would be packed within the Red River cart for any type of travel. This included rifles, traps and snares, as discussed by Mark and Eleanor:

Mark: *I was going to mention that one of the things I haven't heard is weapons and protection, because back in the day they'd be going into the forest, so they'd need protection, so they would have like an arsenal of different types of weapons and traps, and like snares and what not.*

Eleanor: *So, what would you call that if you were going to group it all together?*

Mark: *I wouldn't use weapons, but [something] along the lines of protection.*

Eleanor: *Protection?*

Mark: *So, it's kind of like protecting yourself, your mind and your body.*

Participants discussed issues with using the term "weapons" and indicated that it was not ideal to represent this theme of protecting oneself, but the group struggled to come up with an alternative name or category. One participant felt concerned that individuals may feel triggered using the term "weapons" or the image of a rifle, but felt it was suitable to use as long as the emphasis of the component was on protection of oneself and not on violence. Although snares and traps were mentioned in the discussion as well, these were later differentiated by participants, who reflected upon the fact that snares and traps corresponded to provisions instead of protection.

Participants communicated the importance of including a harm reduction approach within the Red River Cart Model, and gave the analogy of bringing a rifle into a forest to protect oneself from wildlife, the concept of harm reduction could be well-represented by weapons. Participants brainstormed various harm reduction services and initiatives they felt would fit well within the model:

Eleanor: *That can be the condoms, and this and that, you know.*

Mark: *As well as like, reaching out type of thing right, like protecting yourself and avoiding used needles right,*

Eleanor: *like harm reduction. Needle exchanges, that sort of thing.*

Supervised drug consumption sites were mentioned, as well as needle disposal services, drug testing for fentanyl, and a new product obtained by Shining Mountains, which is a drink coaster that can be used to test for Rohypnol/GHB (colloquially known as the "Date Rape Drug"). At the *individual* level, this Red River Cart Model component involves accessing harm reduction supplies, whereas at the *program* level, this component can involve provision of harm reduction supplies and services, and integration of a harm reduction philosophy and approach to an organization or community. At the *policy maker* level, policy makers and governments can consider how their policies support Indigenous approaches to harm reduction, and within *Métis governments*, Métis leaders can advocate for increased harm reduction focus in Métis policy as well as through partnerships with other organizations.

Métis fiddle - social.

The group decided that the Métis fiddle best represented the "social" component of an individual's overall wellness. However, the fiddle itself had a lot of meaning to the participants, as did the definition of "social" as a component of one's health. The fiddle was closely linked to Métis social activities such as jigging, singing, as well as Métis culture and Métis spirit. Within this theme of "social", two subthemes were identified, which are: Métis spirit and healing.

Participants also recognized that the concepts of social, spiritual, and cultural were closely related. In Métis culture, many social events are culturally and/or spiritually based. There was quite a bit of discussion about the distinction between social and community as well. This is because community, especially Métis community, can be a strong source of social supports and wellness by fulfilling an individual's need for friendship, support and human interaction. This overlapping nature of these components was demonstrated by the overlapping nature of programs and supports identified through the community mapping exercise. The gathering circle participants came to the consensus that because these concepts are closely linked, it was important for the client using the tool to reflect upon and define these components for themselves, although examples from their discussion are given below.

Within an HIV or STBBI context, social aspects of health related to gathering with other individuals with lived experience or who are understanding of HIV/STBBI challenges, although it was acknowledged by participants that community could play this role as well. At the *program* level, communities and organizations can create opportunities to support social connections amongst individuals with lived experience by creating safe spaces for these connections to take place. This might look like having an Elder or social worker lead a support circle, or offering drop in programs. *Policy makers* and governments can consider how existing policies support the social wellbeing of Métis individuals living with or affected by HIV/STBBI, and whether or not social isolation among individuals living with or affected by HIV/STBBI is a concern which is reflected through policy and programs across communities. *Métis governments* can consider how communities can be supported to create and implement low-cost interventions such as support circles, which integrate Métis culture and traditions, in order to support the social wellbeing of Métis individuals living with/affected by HIV/STBBI.

Métis spirit.

Some participants also equated the fiddle with the spirit of the Métis Peoples. For example:

Eleanor: *Did you add the fiddle? We talked about the fiddle.*

Pat: *Yeah, our spirit.*

Eleanor: *So, we need the fiddle.*

Mark: *I like that. Because it definitely gets spiritual when that fiddle gets going. I don't think I can hear one without starting a half jig at least.*

Things that typically reflect the Métis spirit include elements like laughter, comradery, community, positivity, and resilience. These concepts were discussed by participants in conjunction with the term "Métis spirit". One participant shared how important music was in her volunteer work with Elders in long-term care. Eleanor said “It’s just amazing, the power of music” in reference to the way the Red River jig (Métis fiddle song) brings energy and laughter to the Elders she plays for. The fiddle was also identified as something that “brings laughter along with it” (Stephanie), and was “ever present” in Métis houses and communities (Eleanor). This sub-theme links the component of social closely to community, and was discussed in close conjunction with the concept of healing.

Healing.

The fiddle itself was identified as something that was inherently powerful, especially during difficult times, as evidenced in this story shared by a participant:

Eleanor: *I remember when . . . . I couldn’t pray anymore, but I could play music, so I just told God I can’t even talk to you right now… but I’ll play, and that was my prayer until I could get the words out again, so I think that when we’re looking at Métis specific stuff, um, that when we look at what we need in our cart, tools of healing, that we want to remember music and the power that it carries with it.*

Here, music is described a tool of healing, but also as something that is powerful and can connect people with their spirituality, which can help people to find strength, solace and during difficult times (hence its healing nature). Participants also described the fiddle, and music in general, as being “good for the soul” (Eleanor) and something that always brought laughter around. One participant highlighted the link between music and memory:

> *Cause music is like scent. And that’s what brings back that that feeling. If you remember when you were little and you remember that music or that song, the fiddle music just brings you back.* (Victoria)

Another participant added that "music can be healing" (Eleanor) and it was one reason why she is often asked to play music for community members during wakes or memorials. Ultimately, participants saw the fiddle as a representation of the social nature of Métis community and identity, but also as a representation of the Métis spirit, as well as a powerful tool for healing.

Métis sash - community.

The Métis sash was a traditionally finger-woven sash made of many strands of different colours of wool. Sashes were historically worn by men around their waist and were considered a tool that had many different purposes. Voyageurs wore the sash tied tightly around their waist to prevent hernias when hauling heavy loads. The threads could be pulled out of the end and used to repair clothes. The sash could be used as a rope to haul goods, or as a belt to tie capotes closed. After the buffalo hunt, the men would drape their sash over their buffalo so when the women came to process the buffalo meat, they could identify which buffalo belonged to their family. The sash has always been a very visual representation of Métis identity. The different colours of the sash have different meanings and corresponding teachings, some of these meanings and teachings may differ by community.

Participants identified the sash as representing community; this could either be the Métis community specifically, or however the individual defines their own community. This was described by a couple participants in the following dialogue excerpt:

Roseanne: *And like for me when I think of community, like in Red Deer, and as far as I know anywhere else, we have different communities. Like we have our Métis community in the community of Red Deer, but we have our street involved people, they're all their own community… They all have their own community…*

Pat: *So, there's like different levels of community. Yeah.*

One participant shared a lovely metaphor for community as it pertains to the sash:

> *Because it's [the sash] made of individual little strands that we can pull them out and break them easy enough. But when we start weaving them together in a braid, or bringing them together, in our family, each time we add to that we're stronger. Until we have our sash [community] and nothing breaks that. It needs to be strong enough to haul massive loads. And save peoples lives, and I think it still does that.* (Roseanne).

As shown in this quote, the concept of community, and in particular the Métis community, is closely related to community, nationhood and strength. Another participant described community as "what makes you strong outside of your family".

There was significant overlap between this component (the sash as representing community) and the social component (fiddle). One participant distinguished community from social by emphasizing the role that each individual plays within their community. This role could range from volunteer, employee, business owner, or mentor. Participants recognized that although the components of social and community were distinct, community can often overlap with social and an individual may feel as though they get their social needs met through various aspects of community.

Métis cart tarp – spirituality and culture.

The Métis cart tarp was a canvas (or sometimes hide) tarp that was placed over the contents of the Red River cart and tied down to the cart rails. It would protect the contents of the cart from the harsh winter weather of the Prairies, and it also prevented items from falling out of the cart. In some instances, willow branches were used to create arches over which the canvas tarp would be draped, which added height for increased storage in the cart under the tarp. Participants discussed the protective nature of the cart tarp, which refers to spirituality and culture in the model, and how this corresponded to “protection” in a modern-day sense of having to protect oneself:

Roseanne: *It provides protection from the rain, elements, the outside…*

Victoria: *Outside negative forces.*

As phrased by one participant: “the tarp that is over it, is the spiritual covering that keeps everything from falling out” (Eleanor).

In Métis contexts, spiritual protection is often requested during prayer, whether the prayer is religious or spiritual in nature:

> *When in my circles, when we talk about “covering,” we’re usually referring to prayer and the spirituality part of it, that we need that protection from the Creator, God, and that you know before we start on the journey or before we do anything*. (Eleanor)

It is important to note that spirituality can mean a lot of different things for a lot of different people. Some may feel more drawn towards organized religion, and some may feel more drawn towards traditional Indigenous spiritual practices, or a combination of both, or neither. Most participants felt strongly that culture and spirituality should be together within the same component, as evidenced by this discussion:

Eleanor: *Does culture belong up in the top with spirituality or does it belong down with the social? Is it more of a social thing or is it a covering that should stay with the tarp?*

Blake: *I would say it should stay. Spirituality and culture and so intertwined.*

Mark: *Culture is spirituality and spirituality is culture.*

And as discussed earlier, the discussion of culture and spirituality often overlapped with social (the fiddle). This is because the majority of ceremonies take place surrounded by others from our community, and ceremonies link us to our culture and spirituality. The theme of spiritual and cultural covering, which was represented by the cart tarp was firmly established by the group. A subtheme around the role of Elders in spirituality and culture was identified.

Elders in spirituality and culture.

All participants recognized that Elders play an important role within spirituality and culture within Métis communities. It was also recognized that Elders, just like potential clients or model users, may follow a very individualized path regarding their spirituality. They may have been brought up in a Christian environment and may have more knowledge about Christian customs than Métis or Cree-based spirituality. Some may choose to actively practice a Christian or Catholic doctrine. Some may practice both, or prefer to practice only Indigenous spirituality. Additionally, Elders may have a special calling to perform a particular practice or service, such as keeping a sweat lodge. Elders were discussed as an important resource and were identified as knowledge keepers and individuals who were well equipped to guide others and provide support during difficult times.

A significant portion of the discussion focused on the importance of ensuring that appropriate Elders were identified for people who identify as two-spirited or as members of the LGBTQ2S+ community. Some indicated that there are Elders who perform ceremonies who do not allow individuals who identify as a member of the LGBTQ2S+ community to attend their ceremonies. Individual preference regarding the gender identity of the Elder was discussed as well, as some individuals may feel more comfortable being with an Elder who shares the same gender as the client. There were some questions and discussion around how this conversation should be navigated with clients:

Blake: *You know I'm wondering if it might be easier to ask the question you know, if you were like, if someone says, okay. I'm a spiritual person of some sort, we don't know what that is right, and then they want to see an Elder and they want to go to a sweat, would it be easier to say, "Okay, would you be more comfortable with a, you know a female Elder, a male Elder, or a two-spirit Elder?" and just leave it at that and then they don't have to divulge, they're comfortable right.*

Eleanor: *Good idea.*

It was also mentioned that, in some instances, the individual might want support or benefit from having a social or support worker present when they first meet an Elder or spiritual advisor, particularly if the individual has a history of trauma. This was pointed out by Eleanor, who said that while some may feel empowered to reach out to Elders on their own, others "may not feel safe enough to just bring a stranger into their lives without having some safety around them" (Eleanor).

Participants indicated that many individuals who seek out their culture for the first time can be very nervous and fearful around breaking protocol. Elders were acknowledged as the most important resource regarding protocol in cultural and spiritual ceremonies. Participants thought that preparing information sheets about protocol of ceremonies, which are edited and reviewed by an Elder, would be one option to address this fear. A second option would be coaching individuals through asking Elders for guidance about protocol, as shown in this quote:

> *I always tell people to check with the Elder that is running it. Again when it comes to smudging, what is a smudge, why is a smudge, who goes to a smudge, but again people have said I'm really not comfortable and I'm afraid to go outside of the room during a smudge without offending people, what do I do, and I said before the meeting you just*

> *need to go to the Elder and say, "How can I respectfully decline from participating?" and each Elder may have a different thing, "Well if you're comfortable staying in the room put your hand on your heart and I'll give you a blessing. You know, there's always a way around it and the person running it is your safeguard.* (Eleanor).

Typical anxieties around protocol that were discussed by participants included how to respectfully decline, what type of clothing to wear, what to bring, what types of food to share, and when to speak. The importance of respecting time when anything cultural or spiritual was taking place was emphasized. Ultimately, Elders were seen by participants as one of the best resources for guidance regarding culture, spirituality and protocol. Within the model, for the *individual*, this means having access to Elders can be a key component of engaging in spirituality and culture. *Program* implications include the importance of knowing the Elders beforehand, as well as potentially developing an educational tool such as a Q&A about participating in ceremony, or being prepared to spend time introducing a client and an Elder. At the *policy maker* level, consideration can be given to how policies can be used to support the integration of Elders into health and wellness service provision in an HIV or STBBI programming context.

Medicine bag – clinicians and treatment.

The medicine bag is a distinct part of Métis culture; it provided an opportunity to showcase our unique Métis floral beadwork or embroidery on the leather or cloth of the bag. The participants reflected upon the fact that as Métis Peoples we had our own system of health that drew upon both our Indigenous and European knowledges and practices. This is similar to the beadwork of Métis medicine bags which were influenced by European floral embroidery motifs taught by missionaries. Representing the clinical aspects of HIV and STBBI care with the Medicine Bag seemed natural and intuitive to the group of participants. However, from a Métis perspective, clinical care of HIV and STBBI through medication and ongoing specialist care forms only one aspect of an individual's physical health. Traditional medicine was also recognized as an important aspect of healing for some Métis Peoples. Therefore, it is appropriate that the medicine bag be considered an inclusive theme representing all treatment aspects related to health in an HIV/STBBI context, which can include primary care, specialist care, and traditional Indigenous or Métis healing approaches. This interpretation of the meaning of the medicine bag is respectful of the holistic understanding of Métis health and wellbeing as well as the holistic and individualized nature of using this model. Two subthemes arose from the data analysis: stigma in healthcare and laughter as medicine.

Stigma in healthcare.

Discussions regarding clinicians and treatment naturally gravitated towards the stigmatizing experiences of those who have accessed health care whilst living with HIV or an STBBI. One participant shared stories of health care workers not using any universal precautions around them despite the healthcare worker showing signs of illness, which made them extremely uncomfortable. Another person shared a story about having nurses approach them with gloves, gowns and a mask because of their status: "God help you if there's something on your file [about HIV], 'cause they're coming in to see you with a hazmat suit on" (Blake).

There was a shared sense of frustration amongst participants around the lack of knowledge and awareness from healthcare practitioners regarding transmission modes and risks and the types of universal precautions needed for patients with HIV or an STBBI. This frustration with lack of knowledge and awareness about HIV, HCV and the proper use of universal precautions (e.g., gloves, gowns) also pertained to stigmatizing attitudes by healthcare workers. One participant shared a particularly shocking story of confidentiality being breached within a long-term care facility:

> *I told some of you people here, in my work in long term care, well, I walked into a room one time with this man there sitting on the edge of his bed, and he was crying, and he turned and he said, "Oh my God, oh my God, come in, please. Please." And I said, "What's wrong?" And he says, "I haven't seen anybody for two days," he was sobbing that way. I said [to myself], "Okay he's on the dementia floor, this may be his truth, but it may not be the truth." So I went to the desk and I said to the lady, I said, um, "So and so in this room is saying that nobody has come and seen him for two days," and she said, "Oh God, he's the one with HIV." And I went, "WHAT?", and she goes, "Yeah, isn't it terrible?"* (Eleanor)

In this example, a healthcare worker breached patient confidentiality with a volunteer by informing the volunteer of the patient's HIV status. The lack of confidentiality could be interpreted as the nurse misunderstanding one or more of the following: the risk or causes of transmission of HIV, the potential impact that stigma could have on this patient, or the potential impacts of breaching patient confidentiality. Ultimately this experience highlights the importance of educating healthcare workers about HIV, STBBI, and stigma, with an emphasis on transmission and risk.

One participant who had lived experience with HCV also spoke about feeling the need to hide their status from healthcare practitioners so they would not be stigmatized. Although there were many stories shared of difficult experiences, it was used as a talking point to emphasize the importance of awareness and stigma reduction within healthcare and society in general. The takeaway for the model is that at the *individual* level, stigma can impact the way people interact with healthcare practitioners, potentially hiding their status when it may be important to disclose. At the *program* level, this means ensuring that program and service providers of all level are educated about HIV, HCV, STBBI and stigma, and the role that stigma plays in impacting how individuals access the health system. At the *system* level, this highlights the importance of training and awareness regarding HIV and STBBI, and ensuring that the importance of these types of training are emphasized at the policy and government levels. For *Métis governments*, Métis leaders can consider how stigma can best be addressed within Métis communities, and how Métis governments can partner with organizations to provide stigma awareness training.

Laughter as medicine.

Laughter as a topic often repeated throughout both gathering circles. It was identified as an ingredient placed within the medicine bag: "And what else is in the medicine bag? You forgot humour!" (Eleanor). It was described as one of the most powerful healers we Métis Peoples have in our culture:

> *We'll just remind us of the different things in here and this will help with. We've mentioned the fiddle, and we mentioned humor are two of the strongest medicines the Métis have. That the music, I was telling them that I play the Red River Jig for the seniors in long term care, even the ones in lock down dementia sit up like that, it's just amazing, the power of music, but also of the humor.* (Eleanor).

Similar to resilience and rawhide, laughter was considered to be woven in throughout everything:

Stephanie: *Do you honestly, like…I mean just thinking about this, I would think that humour goes throughout everything.*

Victoria: *It's the main thread.*

Laughter is almost always present in Métis events, including these gathering circles. It was described as something that, like resilience, weaves throughout everything Métis Peoples do. Stigma in healthcare, and laughter as medicine are two important sub-themes which are reflective of the discussions that took place in the gathering circles. Treatment by both Western and Indigenous healers is an important component of the model.

Métis flag - politics.

Participants who were involved with D&S or who had knowledge of the work being done by D&S reflected upon the importance of political support for HIV and STBBI initiatives and research in Métis communities. Participants said that without support from leadership, whether that was at the community level, provincial level, or federal level, community health interventions were incredibly difficult to sustain. As described by one participant, "We need our political leaders in the wagon with us to support the work we are doing, to help in that. And to honour them." Honoring political leadership is an important part of Métis culture, because to work as a leader is often considered as working in service to Métis Peoples, communities, and the Métis Nation itself.

Participants agreed that within the model, the flag should represent political support, as the flag has represented the Métis nation and Métis politics within Métis communities for centuries. One participant reflected on the fact that at the individual level, clients may not immediately understand what this category means to them, or have any knowledge of the political structure of Métis governance, but that particularly motivated individuals and service workers could use political support to fill service gaps: "That's probably what I would go to leadership for, for creating some kind of change within a community and even going and talking to my leadership and then going to the City Council of Red Deer because I've seen something that needs to change within our community" (Stephanie).

Advocacy and bringing issues to political leaders were identified as important interventions to create change. Aside from the political aspect of the flag and the use of advocacy to create change, aspects of the flag and its meaning to Métis Peoples were discussed. Participants identified Métis Peoples as having a very political background. As one participant stated: "The [Métis] flag … honours the importance of our political leaders" (Eleanor).

Métis capote coat – family.

The Métis capote is a coat, typically sewn from Hudson's Bay Company point blankets or other 100% wool blankets, such as those made by the North West Company. Because they were made of wool, the coats repelled water and were warm. The coats were long, often down to the knees, and were tied closed at the waist with a belt made from a strip of the blanket, or a Métis sash or leather belt. They had a hood and sometimes decorative fringe made from leftover pieces of the blanket was added.

Participants decided that the capote would be a great representation of family and kinship. The capote was identified as something that had values of warmth and compassion and represented family members caring for one another*:* **"**It represents a kinship, the non judgemental, the warm, and compassionate services, the care of each other, taking care of each other" (Eleanor).

It was very important to participants that the definition of family was open to interpretation. Family could be those who you were related to or those who you chose to keep in your life, as articulated by participant Blake who said, "Especially with the AIDS crisis in there [the LGBTQ2S+ community]. We didn't have family often that really accepted us, you know, they basically totally rejected us out of their lives, and so we made family out of that [shared circumstance]". Some participants also recognized that biological family members are not always healthy to be around, or supportive.

Participants recognized that biological family members may not play an active role in the individual's life. They discussed how family could look very different for many people:

> *For me family doesn't necessarily mean I'm related to them by blood, and I have family of creation, I have family that's picked, that I've pulled close because they support me and I support them umm… and I think that that's one of the biggest things when you have a client coming in. That, uh, to make that distinction for them and to say like 'family isn't just the people that you're born to'.* (Stephanie)

Participants emphasized that family can look very different from one person to another; it could be one particular foster parent a former child in care connected with, it could be their street family, or it could be a gang that they are a member of.

Participants identified some common qualities of family, regardless of how family was defined: that they were individuals they could turn to for support, and people they felt comfortable talking to or confiding in. When assessing the "family" component of the model with a client, Stephanie said she would take the following approach:

> *First, you would have to have a larger discussion about the family and how they function. Do they have resources, do they have supports built in place? Like are they supportive of you? So, just some of the really basic ones that I think of: do they have the ability to help with transportation? Do they have the ability to help with childcare when you need to go for doctors' appointments? Are they safe to be around? Are they going to be non-*

judgemental - and then going through those discussions as well, like what does non-judgemental mean? (Stephanie).

Family can be those who the individual is related to, or those who the individual choses to have in their life to play a supporting role. It is important that the individual examine who they consider to be their family, whether or not they are related to them. As a support system, family plays an important role in the lives of individuals living with or affected by HIV/STBBI. Family may be more relevant to the *individual* than at the *program* or *policy maker* level. At the *program* level, organizations and community can consider how they might be able to provide supports for families, embracing a holistic definition of the term ‘family’. This may look like supportive spaces for families to debrief, or accessible family counselling. *Policy makers* and *Métis governments* can consider how definitions of family may restrict access to program and services, as consider adopting a holistic definition of the term in order to increase access to services.

Métis York boat - goals.

Métis Peoples were, and are, very resourceful people, and have been known to adapt tools used by both European and Indigenous ancestors. One instance of this is the Métis York boat. The York boat was adapted from fishing boats that were used in the Orkney Islands of Scotland. A York boat was very large, but could still be portaged by a large group, allowing Métis Peoples to cover large areas of both water and land. Reflecting on the fact that the York boat allowed people to travel from one point to another, participants decided that the York boat would be a good representation of an individual’s goals.

Participants reflected on the role that goals may or may not play in the life of an individual, particularly when someone has just received a new diagnosis such as HIV or another

STBBI. Portaging, like working towards a goal, is not an easy task. Participants discussed this difficulty, as shown in the following dialogue excerpt:

Blake: *Well, we portaged, right, and that's a hard road! It was not an easy thing to do because you had to carry all of your crap with you and carry this boat across land. You were going to do what? You were going to trade your knowledge and information and supplies down the river right.*

Another participant referred to this process as "getting around obstacles" to reach your destination.

Travelling with the York boat to your destination involved navigating challenges and was a difficult process. This is similar to the journey a person might take when living with HIV or an STBBI. However, sometimes it can be difficult to get to place in life where dreaming of a different future is possible. Dreaming of a different future can even be scary for some people, as Blake discusses here:

> *Using your boat and the whole portage [metaphor], one of the most difficult things for them to do is to get out of the river they're in and go across a strange land and even imagine themselves floating their boat in another river.* (Blake).

Regardless of how challenging it can be, the participants reflected on how important it was to identify personal goals, regardless of how "big" or "small" they were. Participants reflected on the importance of having dreams as a method of motivating oneself to create change in their life.

For some people, identifying a dream might mean thinking about what they used to dream about when they were younger. And participants recognized that it can take many years for people to get to a place where they can work towards their goals. Mark, Blake and Eleanor speak about this in the following dialogue:

Mark: *You know that sounds along the lines. When I was there, I've been out in the [oil] patch pretty much my whole life, that's what I know, that's my community, and I still feel connected to my community. And then that portage, it took me years to get me from there to school, because that was my original dream. I wanted school.*

Blake: *And you had to build those York boats too from scratch, it's not easy.*

Mark: *It won't happen tomorrow. This is a process.*

The York boat was a heavy, large boat designed to help the Métis travel great distances across water and land. It took a lot of time and work to make and use a York boat, but they were tools which got the Métis Peoples to their desired locations. Thus, a York boat is symbolic of working towards one's goal or dream, whatever they might be. For people living with HIV or an STBBI, this could look like working to maintain their current treatment plan, establishing stable housing, or returning to school to work towards a dream career. At the *program* level, communities and organizations can consider how they can support clients to create SMART goals (specific, measurable, achievable, relevant and timebound goals), and what supports might be needed by individuals working towards achieving their goal(s).

Métis moccasins – connection to land.

Moccasins are shoes or slippers made out of hide. Métis Peoples often beaded the tops (vamps) of moccasins in characteristic floral beadwork, and sometimes adorned them with fur cuffs, ribbon bows or wrapped horsehair. Quillwork or floral embroidery may have been used to decorate the vamps instead of beadwork. There were a few different styles and shapes of moccasins that Métis used, such as round toe or pointed toe moccasins. Moccasins were selected as a representation of our relationship with the land, because moccasins help us to walk and dance and connect our feet to the Earth. There was emphasis on connection to the land and the healing nature of being on the land, which the participants felt it warranted its own component within the model because it did not quite fit within the "medicine bag" component. The meaning of connection to land for wellness was negotiated in the following dialogue excerpt:

Eleanor: *So, what would be the natural, connection to land?*

Nicole: *Well I thought moccasins because it's what connects you to land, it's in between your feet and the land. That could be one way.*

Blake: *Hmmmm, yeah.*

Nicole: *It's like walking softly on the Earth you know. And your relationship to the Earth and the land.*

Mark: *Right, and then all of this stuff helps you to tread softly.*

Stephanie: *It does make sense, because you can't have moccasins without having gone hunting or having an animal hide and having to put that work into creating them.*

Each participant was able to connect with this theme and share a bit about how meaningful their connection to the Earth was. For some, it was as simple as having a fire going, or sitting down in the grass and focusing on feeling connected to the Earth. For one person, seeking connection with the land helped them cope when they felt overwhelmed. For an individual living with or affected by HIV or STBBI, having a relationship with the land can strengthen all aspects of health such as physical (e.g., getting out on to the land), mental and emotional (e.g., stress reduction), and spiritual (e.g., feeling connected to Creator/God, Earth, or their culture). At the *program* level, organizations and communities can think about how they can promote land-based healing activities for clients. Both *policy makers* and *Métis governments* can consider how policies and funding streams support communities to implement land-based healing programs and activities in Métis communities.

Concluding the Red River Cart Model development.

The Red River Cart Model is intended to be used in an individualized process; it can be used by an individual living with or affected by HIV/STBBI to self-reflect and assess their own health and wellness, and create goals towards improving their overall health and wellbeing. The main components of the model are: the cart (container for the journey) with its spokes and rawhide, the grub box (resources), toolbox (education, skills and training), stove (housing), weapons (harm reduction), fiddle (social), sash (community), cart tarp (spirituality and culture), medicine bag (clinicians and treatment), Métis flag (politics), capote coat (family), the York boat (goals), and moccasins (connection to land). The meaning of each component is flexible and can be customized by the user depending on their particular diagnosis or lived experience with HIV or STBBI.

As mentioned earlier, the model is meant to be adaptable to each individual and to different communities as well. Participants acknowledged that this model could be adapted and potentially used for other health concerns, such as Elder abuse, or managing other chronic diseases like heart disease or diabetes. It was important to participants that the model be flexible and possibly changed based on future feedback; therefore, the model as written above represents its state after early development, and will likely be changed in the future to better meet the needs of Métis Peoples and communities.

Relationship Between RQ1 and RQ2

At the outset of this research project, I anticipated that the two research questions would be closely aligned. I envisioned using the Red River Cart Model as a framework through which the evaluation of DBST (as an example of a community-level Métis response to HIV/STBBI) could take place. As the research progressed, the use of the Red River Cart Model as an intake assessment tool made the most sense to those involved in the research. As a result, it is more appropriate for me to reflect, and further contextualize the evaluation of DBST from what was learned through the development of the Red River Cart Model, in the discussion chapter. Thus, for the sake of this Results chapter, RQ1 and RQ2 are treated as distinct research questions and findings.

Context and Processes Leading to the Alberta Métis Pilot of DBST

The pilot of DBST in the Métis community of Alberta required much planning and preparation from program leads at Shining Mountains, the D&S National Coordinator, AHS and the National HIV Laboratory Referencing Services (NHLRS). The initial connection between Raye St. Denys at Shining Mountains and Dr. John Kim at the NHLRS led to a signed research agreement between the two organizations with the express goal of providing training and DBST to screen for HIV, HCV, HBV and syphilis amongst members of the Alberta Métis community.

AHS had public health-related concerns about not being able to track the positive results within the provincial system, so they requested to be a part of the process of planning and implementing the pilot. This required AHS to create an internal process for handling the dried blood spot samples within their systems, as well as a modified test requisition form. The process of piloting DBST required the Métis community to identify a qualified Most Responsible Person (MRP) to sign the requisition forms. The MRP is the health care practitioner who is required to ensure that positive test results are communicated to the patient, and that they are connected to care. The MRP's scope of practice must include the ability to order tests.

During the process of planning for the pilot of DBST, there were differences in perspective about a number of issues. These policy-related disagreements were around the use of a nurse practitioner as the MRP; whether or not Shining Mountains could or should collect dried blood spot test samples through their office; and whether or not venous blood tests for STBBIs were “better” than DBST for pregnant individuals. These policy issues were navigated, and the pilot successfully took place at two Métis community events. After the two events, AHS requested that Shining Mountains agree to pause the collection of DBST while AHS created an internal policy process for DBST and conducted a cost-benefit analysis.

In this pilot, the actual testing of dried blood spot samples took place at the NHLRS in Winnipeg, requiring samples to be sent via courier after they were dropped off at an agreed-upon AHS laboratory services location. All test results (including positive and negative results) were communicated by the MRP or their designate to the individual who received testing via telephone. While this was not AHS policy, those involved in the pilot from D&S and Shining Mountains felt it was important for all DBST recipients to be notified of their results (both positive and negative) by the MRP, as in the case of negative results, this provided an opportunity to educate individuals about how to protect themselves from HIV and STBBI in the future.

RQ2: Is dried blood spot testing an acceptable testing method for Métis communities? RQ2 is: is DBST an acceptable testing method for Métis communities? In this section, the findings from the evaluation of DBST are organized into separate categories: survey results and thematic results. The application and analysis of the DBST using the RE-AIM framework are presented in the Discussion chapter.

Participants and process. Potential participants were identified and/or recruited by either myself or a testing provider at the time they received DBST during the two pilot events. Some participants completed both the survey and gathering circles. Gathering circles were held in an area separated from the other events taking place, and began with an introduction of myself and the purpose of the research and the process of obtaining informed consent after reviewing the recruitment form with the group as well as the importance of confidentiality. Gathering circle participants were given a $25 VISA gift card as token of appreciation. Three employees of Shining Mountains who were trained to offer DBST completed a semi-structured interview with myself over the phone; they were each mailed a $25 VISA gift card as a token of appreciation. An Elder was on-site and available if a participant indicated they wanted emotional support after the gathering circles, however none indicated so. Thirty individuals received DBST at one of the two events where it was offered; 26 participated in the survey and 19 participated in one of four gathering circles for DBST recipients.

Survey results.

There were 26 individuals who participated in the study by completing a survey about their DBS testing experience. The majority (73%) were female. Broken down by sex, the survey results are presented according to demographic information (Table 2), previous testing experience (Table 3), and experience with DBST and acceptability (Table 4).sex.

Key results. The survey asked questions about respondents' year of birth, ancestry, spoken languages, place of residence, and sex and sexual identities (e.g., two-spirited, gay, or lesbian, etc.). Of note, over half of respondents did not indicate a sexual identity or preference, so results were not presented for that question. Of the 26 survey responses, two selected "prefer not to answer" when asked their year of birth. Birth year ranged from 1943 (oldest reported respondent) to 1997 (youngest reported respondent), as shown below in Table 2. The average reported year of birth was 1965, making the average respondent around 56 years of age.

Table 2.

Demographic characteristics by sex

Characteristic	**Female (n=19)**		**Male(n=7)**		**Total (n=26)**	
	n	% (of female respondents)	n	% (of male respondents)	n	% (of total respondents)
Year of birth (mean)	1963		1970		1965	
Year of birth (range)	1943 (min) – 1997 (max)		1961(min) - 1982 (max)		1943 (min) – 1997 (max)	
Place of residence (city)	15	78.9	5	71.4	20	76.9
Place of residence (rural, isolated or Métis settlement)	4	21.1	1	14.2	5	19.2
Identity (in addition to Métis) – First Nation or other	1	5.3	3	42.9	4	15.4
Language spoken – English	19	100	7	100	26	100
Language spoken – Indigenous (Cree or Michif)	2	19.5	2	28.6	4	15.4
Language spoken – French	2	10.5	2	28.6	4	15.4

All respondents indicated that they had Métis ancestry. Two indicated that they had First Nations ancestry in addition to Métis ancestry. All participants indicated they spoke English, and seven respondents indicated they spoke more than one language, including four respondents (15.4%) who indicated they could speak an Indigenous language (Cree or Michif). The majority of respondents (76.9%) indicated they lived in the city. Two individuals indicated they lived on a Métis settlement in Alberta, and two indicated they lived in a rural or isolated area.

Previous testing experiences.

Participants were asked about any previous testing experience with HIV, HCV, HBV and syphilis. If participants indicated they had received a test before, they were asked to report how long ago the test was (see Table 2).

Table 3.

Previous testing experiences by sex

Question	**Response**	**Female (n=19)**		**Male (n=7)**		**Total (n=26)**	
		n	%	n	%	n	%
Have you ever been tested for HIV?	Yes	7	36.8	4	57.1	11	42.3
	No	11	57.9	2	28.6	13	50.0
	Unsure	1	5.3	1	14.3	2	7.7
If yes, when was your last HIV test?*	In the past 3 months	1	5.3	0	0.0	1	3.8
	7-12 months ago	1	5.3	0	0.0	1	3.8
	Longer than a year ago	5	26.3	4	57.1	9	34.6
Have you ever been tested for HCV?	Yes	6	31.6	3	42.8	9	34.6
	No	9	47.4	3	42.8	12	46.2
	Unsure	4	21.1	1	14.3	5	19.2
If yes, when was your last HCV test?*†	In the past 3 months	1	5.3	0	0.0	1	3.8
	Longer than a year ago	5	26.3	3	42.8	8	30.8
Have you ever been tested for HBV?	Yes	3	15.8	2	28.6	5	19.2
	No	10	52.6	4	57.1	14	53.8
	Unsure	6	31.6	1	14.3	7	26.9
If yes, when was your last HBV test?* †	In the past 3 months	1	5.3	0	0.0	1	3.8
	Longer than a year ago	2	10.5	2	28.6	4	15.4
Have you ever been tested for syphilis?	Yes	3	15.8	1	14.3	4	15.4
	No	13	68.4	5	83.3	18	69.2
	Unsure	3	15.8	1	14.3	4	15.4
If yes, when was your last syphilis test?* †	In the past 3 months	1	5.3	0	0.0	1	3.8
	Longer than a year ago	2	10.5	1	14.3	3	11.5

* For the table, the category '3-6 months ago' is omitted as there were no responses in this category.

† For the table, the category ‘7-12 months ago’ is omitted, as there were no responses in this category.

Previous test experiences. Thirteen of 26 participants (50.0 %) indicated they had never been tested for HIV previously. Of those who had previously been tested for HIV, nine respondents (34.6% of all respondents) indicated their last test had taken place over a year ago.

Previous HCV tests. Twelve out of 26 participants (46.2%) indicated they had never been tested for HCV previously. Five participants (19.2%) indicated they were unsure if they had previously been tested. Eight participants (30.8%) indicated they had been tested for HCV longer than a year ago.

Previous HBV tests. Fourteen out of 26 participants (53.8%) indicated they had never been previously tested for HBV. Seven respondents (26.9%) indicated that they were unsure if they had ever received an HBV test. Four participants (15.4%) indicated they had received their HBV test longer than a year ago.

Previous syphilis tests. Four participants (15.4%) indicated they had previously been tested for syphilis, and four (15.4%) were unsure if they had previously been tested. Of the four that indicated they had previously been tested for syphilis, three indicated their test was over a year ago, and one was in the last three months. The majority of respondents (69.2%) indicated they had never received a test for syphilis.

Experience with DBST and acceptability.

Participants were presented with some statements regarding their experience with DBST and asked if they thought others would be open to receiving DBST as a type of testing for HIV and STBBIs. Participants were asked to select the response that best aligned with their opinion and experience of DBST, ranging from strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree (Likert scales).

Table 4.

Acceptability of DBST by sex

Question and Responses	Female (n=19)		Male (n=7)		Both (n=26)	
	n	%	n	%	n	%
I would recommend this testing method to friends or family *(Strongly Agree or Agree)*	19	100.0	7	100.0	26	100.0
I thought this type of testing was easy *(Strongly Agree or Agree)*	18	94.7	7	100.0	25	96.2
I would use this type of testing again *(Strongly Agree or Agree)*	17	89.5	7	100.0	24	92.3
I received enough information today about HIV/HCV/HBV/ syphilis *(Strongly Agree or Agree)*	18	94.7	7	100.0	25	96.2
I will encourage family and friends to get tested *(Strongly Agree or Agree)*	16	84.2	6	85.7	22	84.6
Overall my testing experience was positive *(Strongly Agree or Agree)*	18	94.7	7	100.0	25	96.2

When asked if respondents would recommend this type of testing method to family or friends, all respondents (100.0%) indicated that they strongly agreed or agreed. Twenty-five of 26 respondents (96.2%) indicated they strongly agreed or agreed that DBST was “easy”. Twenty-four of 26 (92.3%) respondents indicated that they strongly agreed or agreed that they would receive DBST again. Twenty-five of 26 respondents (96.2%) indicated they strongly agreed or agreed that they received enough information about HIV, HCV, HBV and syphilis during their testing experience. Twenty-two of 26 respondents (84.6%) indicated they would encourage their family and friends to get tested using any method. Twenty-five of 26 respondents (96.2%) indicated they strongly agreed or agreed that their overall experience with DBST was positive. One individual (3.8%) selected “neither agree nor disagree” as a response to questions about ease of testing, using the testing again, and an overall positive experience with testing. Although almost every respondent agreed or strongly agreed with most questions, o17 of the 19 indicated that they would recommend others in their life to be tested.

Thematic analysis of testing recipient gathering circles and test provider interviews.

Nineteen self-identified Métis Peoples who received DBST at one of the two events participated in gathering circles. In addition, three employees of Shining Mountains who had been trained to offer DBST at the events were interviewed individually. These data sources were thematically analyzed together using the approach described in the third chapter.

The majority of gathering circle participants were Métis women; all test provider interviewees were self-identifying Métis women and employees of Shining Mountains, who had experience in providing HIV/STBBI and/or housing supports. The holistic coding and thematic analysis of transcripts from testing recipient gathering circles and test provider interviews revealed seven broad themes: ease of testing process, challenges with existing testing processes, lack of Métis-specific services, potential to improve access to testing, stigma and awareness, information, and health role models. As mentioned in the beginning of this chapter, some of these themes are closely related and may overlap, but are discussed individually here.

Ease of testing process. Many participants used positive adjectives to describe their experience with DBST, such as “easy”, “fast”, “quick”, “simple”, and “comfortable”. Some participants compared the process of DBST to the way they monitored their blood glucose if they were diabetic. Participants specifically indicated that there was minimal pain or discomfort involved with receiving DBST. Service providers who were trained to perform the DBST indicated that the process of offering testing (and the process of being trained) was fairly easy and straightforward as well.

The testing providers were described by those who received testing as personable and likeable, and helped to increase the comfort of those who were receiving testing. One example of this is a comment which a participant made:

> *She talked to you which was nice, compared to when you go into the other place and they're like, "What's your name? What's your number?" She talked and it was nice and it was actually more relaxing than doing the diabetic test because when you have to do those all the time on your fingers you're always tense because you need to know what it is, this was like the same type, like getting the same puncture, but it was relaxing and I wasn't used to that because it was just, you know, natural, more natural, there was no tension around it.* (Alice, test recipient).

Another participant shared his surprise at how easy the process was, "Well they can test for 4 or 5 different diseases all at once within 60 seconds, man, and no pain. None. Done. Wow." (Ellis). This was further corroborated by another participant who said, "Easy. That's the key word right there, it's so easy, you just go in and you go out. Done." (Dave) As evidenced by these quotes, "easy" was frequently used to describe the process of being tested.

Many participants specifically spoke about the atmosphere in which testing took place. Testing recipients thought that events were a good opportunity to offer DBST. The fact that others were receiving testing served to normalize the testing process; this is further discussed under the *stigma and awareness* theme later.

Challenges associated with existing testing processes. Within the gathering circles with test recipients and semi-structured interviews with test providers, participants often compared their experience with DBST to previous experiences with venous testing. Two prominent challenges or barriers to "regular" venous testing were logistics, and geographical access. One example of this comparison is provided here by a test recipient:

> *Personally I think it was a really good experience in comparison, like I did get blood testing about a year ago, and it's kind of a gong show, you go in first your family doctor, then a couple of weeks later the blood testing at the lab, waiting at the lab, getting blood sucked out of you, and then waiting maybe a month or two before you hear anything, right?* (John, test recipient)

As shown in the above quote, the process of obtaining a requisition requires an appointment with a physician and attendance at a lab facility where the blood sample can be taken. Some participants spoke about how this process required them to find a way to take time off work so they could travel to the doctor and lab appointments. Some participants described the overall process of getting blood work done in the current health care system as stressful, time-consuming and somewhat challenging to navigate in terms of logistics.

Participants who indicated they were from a smaller community discussed the challenges associated with getting regular blood work done including time required for travel, having to wait for appointments, and scheduling follow up visits to discuss results with their health care provider. This was described by one participant:

> *You know, like, right now you have to go to the lab, drive, like us rural people, we have to drive to Vermillion or Lloydminster, go to the lab, wait there for an hour, get your test, go home, then you have to drive back, then oh you have to make an appointment with your doctor to get your results read … like, you know, I have to drive like 40 miles every 3 months to meet those two appointments/trips, you know, and it's costly.* (Clara, dried blood spot test recipient).

As shown in the above quote, rural patients face time and transportation costs associated with receiving testing.

Some people reported feeling anxious, especially regarding the notification process for venous testing, as demonstrated in this dialogue excerpt from a gathering circle:

Interviewer: *You mentioned something about having to make a doctor's appointment, would your doctor's office take your blood or would you have to go somewhere else to have that done?*

Mark: *So I go to my doctor, I tell my doctor that look I wanna get tested for everything right, just like 4 vials, walking out of there like….but then ah he gives you the paper, that you take to a lab, and then the lab takes your paper, right? Two weeks from now, three weeks from now, whenever they can fit you in, whereas this you come in (noise) drip, drip, drip, done. Still gotta wait, but you're not waiting four months from asking the doctor from actually getting your results, can be anywhere up to six months, took them I think 4.5 months before I just got any results back, and it was just like, "If it's negative you won't hear from us," it's positive if they call. Then they freaked me out by calling me by saying it was, you know, high cholesterol, that was my negative I guess, that was why they were calling me, but it was panic inducing for me!*

The notification process was highlighted as a challenging aspect of the regular venous testing process due to confusion around whether or not they would be notified of results. Similarly, others mentioned feeling anxious or confused about whether or not they should expect a call regarding their results. Some felt worried that they had a positive test result but had somehow missed their notification call due to a change in contact information. Many indicated that they would prefer to receive a phone call with results, even if all their test results were negative. One participant who was a cancer survivor felt it was very important to her to know for certain:

> *But if you're a cancer survivor, which I am, you get a letter, you get tested periodically, and you get a letter one way or another always. And that's reassuring. So, this would be very reassuring to get an answer one way or another.* (Amber, dried blood spot test recipient).

Another participant shared their experience with notification anxiety:

> *Yeah, it's always nice to get that phone call that yeah, everything came back negative. Yeah, compared to, "I haven't heard anything." Are they still testing it, is it caught in the mail, is this going on, etc.? Do I need to worry? But with the calling you they will let you know when the test is completed. So, you won't be left guessing, thinking, "Did they get my number wrong, did they lose it?"* (Nancy, dried blood spot test recipient).

Testing providers believed that the ideal way to notify people of their test results was in person, especially if someone had a positive result. In a "perfect world" (Sarah, test provider), the health care provider would be able to come and meet the test recipient wherever they were, such as their home, to provide them with their results. Although they recognized it would be sometimes challenging, when individuals received a negative result it still provided a valuable opportunity to meet in person and provide further education around harm reduction/safer sex practices.

Overall, many frustrations and challenges with the current testing process was shared in the gathering circles. Ultimately, test recipients thought DBST could offer solutions to some of these challenges; this is further discussed in the *potential to improve access to testing* theme below.

Lack of Métis-specific services. Participants discussed a lack of Métis-specific services as one reason why Métis people had a low awareness of STBBI, and was identified by participants as a barrier or challenge for Métis individuals accessing STBBI testing and treatment. This sentiment was described by one of the testing providers in her interview, who spoke to the desire for Métis-specific services regarding HIV, STBBI and sexual health in general:

> *I would love to be able to see more being developed. Because obviously there's a need out there for Métis Peoples to have Métis-specific services. Um. I think that even with just the few dried blood spot events that we've had it shows that Métis Peoples are willing to try something like that when it is being offered by their own community. And I think that you know especially in the bigger [city] centres Métis stuff would be fantastic. I think a lot of people if they know about it, they would be more than willing to access it.* (Sarah, a Métis social worker and DBST provider).

This was corroborated by another test provider. When asked if any other organizations in the province offered Métis-specific services, aside from Shining Mountains, she said "…not to my knowledge. We're [Shining Mountains] the only ones that do what we do [in Alberta]" (Christine, DBST provider). This highlights both the scarcity of Métis services in Alberta, and also the value of the Métis-specific services that are provided by staff at Shining Mountains.

The Métis identity of the test provider, as well as the environment in which the testing service was offered, seemed to have some impact on the comfort level of test recipients. As discussed earlier in this section, many participants thought that holding the testing in a public, Métis-specific space contributed to the comfort and ease of the testing process as well as improved the acceptability of the testing process by allowing individuals to see that others were accessing the testing. All test providers commented on the lack of Métis-specific services for

Métis people and how this prevented or reduced engagement with the health system in terms of HIV and STBBI testing.

When test providers were asked what could be improved about the current process of notification for Métis Peoples, one test provider thought that having a Métis Elder present to support people alongside the healthcare professional would be one way of creating a more supportive and culturally safe atmosphere, especially if a positive result needed to be communicated to an individual. The inclusion or integration of Métis Elders to increase the relevance and safety of services was an important suggestion which will be discussed further in the results section. The importance of notifying individuals face-to-face in the case of a positive result was emphasized. Another test provider mentioned that, in the case of DBST, being able to connect with the person who administrated their test if they needed services afterwards was a benefit:

> *But I like the fact that they could come to somebody who actually did their testing for them. So, say myself and [another test provider], we were there right from the very beginning, so now we can also help them with the rest of what they need. Bring them to different services help them you know get to say their appointments with Dr. X [the HIV specialist] or whatever doctor they may need to get to. Connect them with, say, myself for counselling. So there's lot of that kind of stuff. I'm really happy with that.* (Sarah, test provider).

The above quote shows that test providers felt that having Métis Peoples providing the testing and follow up added an element of continuity of care to the process; this sentiment was echoed by test recipients. Test providers also spoke about how the administration of testing facilitated the relationship building process with those they were offering services to, which ultimately helped them to provide better and more holistic services in a way that is congruent with Métis approaches to health and wellness.

Potential to improve access to testing. Many gathering circle and interview participants spoke about potential future uses of DBST. Participants shared thoughts around the acceptability of offering DBST at events; one individual said, "I think something like this can be very accessible to people, not just to Métis but to other people at events like this" (Jake, test recipient). Many people explicitly said they thought other Métis community members would feel comfortable receiving DBST at a Métis event. Additionally, most participants said that if DBST was offered at a future Métis event they would likely get tested again.

When participants were asked what they thought friends and family might think of DBST, one person indicated that their friends or family were not likely to get tested outside of something like DBST offered at an event "because they have to go to a lab to get it done" (Joan, test recipient). Another participant agreed, and when asked to speak further about this, the individual responded that they thought DBST would have to come to their community (a Métis settlement) in order to get family, friends, or others Métis Peoples tested for HIV or STBBI. This shows that geographic and other barriers need to be reduced or addressed in order to improve testing amongst Métis Peoples.

DBST could have the potential to increase the cultural safety of the testing process by making people feel more comfortable and less likely to experience judgement by the person administering the test. One of the test providers said, "The ones that I chatted about it with said they felt more comfortable, especially knowing that it was a Métis person doing their testing" (Sarah, test provider). This shows that having Métis-identifying test providers can help Métis test recipients feel more at ease with the testing process.

Some participants commented on the potential uses for DBST beyond HIV and STBBI. One person commented that "If they can start doing this [DBST], you know, they can start doing so much more! Like if this takes off, like oh they can do so much more without having to deal without having to deal with what [name] is saying [regarding challenges with typical testing processes]" (Alice, test recipient). This quote indicates interest among participants about future applications of the testing modality to screen for other health conditions in a way that is accessible for Métis Peoples.

Stigma and awareness. The topic of stigma was a very prominent theme within both the testing recipient gathering circles as well as the test provider semi-structured interviews. Quite a few participants felt that the high level of stigma amongst the Métis community was due, partly, to the lack of awareness about HIV and STBBI. This was emphasized by one participant:

> *Like there's a lot of people that I know are still in the stigma of "It's a death sentence", you know. Even I find myself looking down at these people, and I shouldn't because I know it's not, but they're not seeking the treatment that they need so it is more or less a death sentence sooner or later if they don't seek the treatment. So, it's just that awareness, and uh the word of mouth.* (Deborah, test recipient)

This quote shows that although some people know that treatment has improved for HIV and STBBI, many are still unaware of these improvements, and this has resulted in some people choosing to abstain from treatment.

Word-of-mouth was acknowledged by several participants as being a particularly strong contributor to the spread of information (or misinformation) in the Métis community. Although many participants thought that society and their community were becoming more open and less judgemental, participants felt that there was still a sense of taboo and shame surrounding being tested for HIV or STBBI. One woman of an older generation shared about her experience growing up as a Métis woman in a conservative family regarding stigma and shame around sex and sexual health:

Clara: *No, I don't think there's enough awareness.*

Interviewer: *Why do you think that is?*

Clara: *Well, it's just never been mentioned in any discussion or anything sexual…it usually comes up at some point in time you know. Yeah. Sexual conversations are kind of taboo for a lot of people.*

Alice: *It's true.*

Clara: *Because you were raised that way.*

Alice: *Well, not amongst my friends! (Laughter)*

Clara: *But I mean your mom or dad, like your family.*

Alice: *Oh yeah, yeah.*

Clara: *Like your parents never talked about it. But it should be talked about. It needs to be talked about.*

Alice: *Well yeah!*

Clara: *Like a norm. Everything…it's like there, it's not going to go hide in a corner. Like if you just didn't talk about it, it would just go away.*

This dialogue highlights several important points. Some Métis communities and families, in the past, did not talk about or educate their children about safer sex practices. Interestingly, Alice points out that her friends talked about sex, implying that the topic was less taboo amongst her peers. Others corroborated these stories, pointing out that there was a lot of judgement 'back in the day' if a woman asked about sexual health or STBBI, and said, "God forbid you know you asked about one, or if you even got one, 'cause then you've really become a bad woman" (Deborah, test recipient). Participants noted that although the stigma around testing, sexual health, and sex as topics of conversation have somewhat improved, they still perceive stigma as a pervasive issue within Métis families and communities.

Stigma was described as an element that prevented individuals from getting tested through a family physician or clinic, and is closely related to the themes of *lack of Métis-specific services* and *increasing access to testing*.

In a couple of cases, individuals who had a history of intravenous drug use came to the Shining Mountains office to request DBST because the lab technicians were unable to get a venous blood sample due to collapsed veins. For these individuals, DBST would offer one way to provide screening services with less difficulty of obtaining a sample and would circumvent the fear and anxiety of using a laboratory service. This was described by one of the test providers:

> *We had a couple people that have come into the office that regular testing wouldn't work on because they've had some you know previous history and being able to do a regular blood draw was not… it wouldn't work for them. So, I found that particularly helpful because at least they're getting it, they may not be getting it the quote-unquote normal way or usual way is perhaps the better terminology, but still able to get the testing and feeling comfortable in coming in and getting tested here.* (Sarah, Métis social worker and dried blood spot test provider).

For these individuals, DBST offered a way to access HIV and STBBI screening in a psychologically safer environment. It also provided a way to get tested when other methods failed, particularly among a population whom face a lot of stigma and may be at higher risk of HIV or STBBI due to drug use. One of the test providers mentioned that the Shining Mountains office is in a house, which helps to further put potential clients at ease.

Health role models. Another theme that arose from gathering circles was the concept of being a 'health role model'. Participants contextualized DBST as an activity that supported their health. There was an understanding amongst participants that it was important to take care of their health, as evidenced in this dialogue excerpt:

Sally: *I can see it in like gatherings like this where we're all together, we're not being singled out, like we're all Métis Peoples, we're all doing the testing, we're looking after our health.*

Marie: *And that's it. We're being role models in the sense of yes, I've taken the time to look after my health or to see if there's something more to take care of.*

Participants thought that seeing other people getting tested was encouragement for others to do so as well. Recipients also commented that offering testing at Métis events normalized the process of getting tested and reduced stigma associated with testing.

Based on participant feedback in the gathering circles, it was clear that other types of screening interventions have been operating within the context of Métis events, which have served to normalize the act of attending to one's health by receiving these services. Testing recipients talked about DBST as one part of health and wellness-related interventions that were event-based within the Métis nation. As one participant said, "Because we also do the uh, we have the bus that comes out where the women did the mammograms and the pap smears, they do all that, they could bring this out to the assembly. So yes, it would be wonderful" (Bob, test recipient). It is possible that the previous inclusion of health-related screening services at large Métis events has served to normalize accessing health services and reduced potential stigma associated with their use.

Information. Information and awareness regarding HIV and STBBI was a theme reiterated throughout the gathering circles and interviews. The majority of participants believed that the general level of awareness within their Métis community was low or very low, as discussed above under the *stigma and awareness* theme. Many thought this was a result of a lack of information. One person said “I think there needs to be more [information] shared about it [HIV/STBBI]” (Joanna, test recipient), in response to why awareness about HIV/STBBI was low in the Métis community.

Some individuals recounted experiences with others, who believed that HIV was not an issue in Métis communities because it wasn’t talked about very much. Participants saw ‘talking about it’ (i.e., starting a conversation around HIV/STBBI) as the biggest thing that Métis Peoples could do to raise awareness and reduce stigma. One participant added a comment about how the lack of talking about HIV and STBBI and related topics contributed to fear around HIV/STBBI and topics, saying “some people are very scared just of the idea of talking about AIDS or HIV or syphilis” (Clara, test recipient). Clara further explained that this fear of talking about HIV and STBBI has led to people like her to not get tested, and specifically mentioned never being offered an HIV or STBBI test by a health care provider, and being unaware of the need to ask for a test. Participants thought that having visible and accessible testing available at events was a great way to share information about HIV and STBBI and raise general awareness about it.

Although the theme of *information* was closely linked to the theme of *stigma and awareness*, participants distinguished the two by emphasizing that a lack of information contributed to a high level of stigma and a lack of awareness in Métis communities. Thus, information will play a key role in improving awareness and reducing stigma in future Métis HIV/STBBI interventions.

Conclusion

The purpose of this chapter was to present the results of this thesis research according to each research question. Wherever possible, I drew directly upon the words of the participants in order to promote Métis voices. The process of answering RQ1 has resulted in the creation of a new model of Métis health and wellness for individuals living with or impacted by HIV/STBBI, which contributes to the limited literature regarding Métis specific understandings of health and wellness in HIV and STBBI contexts. The process of responding to RQ2 has highlighted perspectives of Métis test providers and recipients in order to provide an evaluation of the feasibility and acceptability of DBST within Métis contexts. In the next chapter, I will discuss the findings in the context of the existing literature.

Chapter 5: Discussion

The goals of this thesis research were two-fold: to document and explore an emerging Métis model of health and wellness for people living with or impacted by HIV/STBBI, and to conduct an evaluation of a dried blood spot testing pilot for HIV/STBBI in Alberta drawing strongly on the perspectives of Métis community members. To facilitate this research, two research questions were developed:

1. What could a Métis-specific cultural response to HIV and STBBI look like?
2. Is DBST an acceptable testing method for Métis communities?

Answering these questions involved two distinct (but related) approaches. The first question was answered through the use of three gathering circles with diverse members of the Métis community in Alberta who had experience with HIV/STBBI services and/or lived experience: gathering circle members came together to discuss the development of a Métis-specific model of care for individuals affected by HIV and STBBI (the Red River Cart Model). These sessions were audio recorded, transcribed and thematically analyzed to provide further context and details to the model. Data from the community mapping exercise was also considered during the thematic analysis. The second research question was answered by synthesizing and analyzing information from four gathering circles with 19 self-identified Métis individuals, survey responses from 26 Métis individuals who received dried blood spot testing at one of two Métis community events, and three semi-structured interviews with Métis dried blood spot testing providers. The surveys provided information on the demographics of participants as well as feedback on the acceptability of dried blood spot testing. Two sources of additional data were included: minutes from meetings with stakeholders held to plan the pilot of dried blood spot testing, and observational notes from the testing events. Surveys were used to assess DBS acceptability. Thematic analysis was conducted on the transcripts of gathering circles, semi-structured interviews, observational notes from testing events, and meeting minutes. Identified themes and subthemes provide valuable information to not only answer these research questions but offer insights into approaches to improve HIV and STBBI testing and care for Métis individuals living with or affected by HIV/STBBI.

The purpose of the previous chapter was to provide the reader with an in-depth understanding of the data and results from both research questions. This purpose of the discussion chapter is to analyze the findings within the context of the literature in order to draw conclusions, and it is divided into three sections. The first section will discuss major findings from the research results to provide responses to the research questions, and interpret these findings within the context of the literature regarding Métis health, HIV and STBBI. The second section will apply the RE-AIM framework to the pilot of dried blood spot testing. The third section will discuss implications of the findings and provide recommendations for various levels of interventions (e.g., D&S project, Métis communities, government policy makers, healthcare practitioners), discuss the limitations and strengths of this research, and identify areas of future research.

Research Question 1: Integrating Results with the Literature

As stated above, the first research question (RQ1) was: *What could a Métis-specific cultural response to HIV and STBBI look like?* As summarized below in Table 2, thematic analysis identified three overarching/process related themes (beginning the journey, an individualized approach, and community and member engagement), as well as themes and sub-themes related to each component of the Red River Cart Model. These components are: the cart itself (container for the journey) with its spokes and rawhide, the grub box (resources), toolbox (education, skills and training), stove (housing), weapons (harm reduction), fiddle (social), sash (community), cart tarp (spirituality and culture), medicine bag (clinicians and treatment), Métis flag (politics), capote coat (family), York boat (goals), and moccasins (connection to land). Table 5 below outlines each component, with corresponding recommendations for considerations (or interventions) for each level:

Table 5.

Suggested Implications and Areas for Consideration According to Individual, Program Level, Policy Makers, and Métis Governments.

Model Component	Suggested Implications, Considerations and Recommendations According to Level			
	Individual	Program level (i.e., community organizations, health service providers)	Policy makers	Métis governments
Grub box - resources	Use of social supports (e.g., transportation subsidies).	Information, and/or resources provided to clients, particularly to reduce barriers to participation in programs or education.	Do policies support community-based organizations to provide supports to clients (e.g., food supports, transportation subsidies)?	Are existing programs or information meeting the resource (e.g., social support) needs of Métis individuals living with HIV/STBBI? How can advocacy or partnerships be used to strengthen social support programs for Métis individuals living with HIV/STBBI?
Métis toolbox – education, skills and training	Supports which enable clients to access education, training, and/or skills development which are relevant to their goals.	Training and education regarding HIV, STBBI and stigma should be provided to community-based organization staff and health service providers.	Do policies support the training and education needs of health and social service providers? Are government workers and policy makers education about stigma, HIV and STBBI in Métis communities?	Are existing educational supports meeting the needs of Métis people living with HIV/STBBI? Are there opportunities for advocacy to play a role, such as through the development of scholarship and bursary funds for Métis people living with/affected by HIV and STBBI? Have Métis-specific educational supports been developed

				for communities to implement their own interventions regarding HIV and STBBI?
Métis stove – housing	Housing supports and interventions (e.g., Indigenous housing, affordable housing, supportive housing for people living with HIV).	Are housing supports welcoming and accessible to Métis people living with/impacted by HIV/STBBI? What barriers exist to Métis people living with HIV/STBBI trying to access housing services, and can these be resolved or reduced?	Can changes be made to funding streams and policies to better support Métis-specific housing services?	What partnerships can be leveraged in order to fund or support Métis housing organizations across Canada? Can research partnerships be formed in order to better understand how Métis people experience homelessness and barriers to housing, and identify rates of homelessness amongst Métis people?
Weapons – harm reduction and protection	Harm reduction services (e.g., condoms, needle exchange, supervised consumption sites).	Have community organizations adopted a harm-reduction perspective or mandate, and included harm-reduction education for health and support workers? Explore opportunities to offer Indigenous approaches to harm-reduction.	Does local, provincial and/or federal policy support the provision of harm-reduction services, or use a harm-reduction informed lens or perspective to policy development?	Métis leaders can consider advocating for a harm-reduction approach amongst Métis communities. Métis governments can develop harm-reduction educational materials for Métis communities and individuals.
Métis fiddle – social	Social supports or events accessed by Métis individuals living or impacted by with HIV/STBBI (e.g., support circle).	Are there opportunities to provide support to Métis individuals living with HIV/STBBI, such as through drop in social services (e.g. support circle, mentorship).	Do policies or funding streams support or create space for community organizations to offer these types of support services (e.g., support circle, mentorship, meeting space for social activities)	Métis governments can examine how they can support Métis communities and organizations to implement low-cost interventions such as support circles to improve the social health and wellbeing (and reduce social isolation) amongst Métis individuals living with HIV/STBBI?
Métis cart tarp – spirituality and culture	Connections to cultural, spiritual or religious leaders	How can organizations and programs connect Métis individuals living with/affected by	Do existing policies and funding streams allow communities and organizations	Where applicable and possible, provide Métis communities with funding for traditional healing activities, particularly for

	in the Métis community.	HIV/STBBI with Elders? Are Indigenous support workers (e.g. Indigenous nurse navigators) aware of Métis Elders in the community to refer clients to?	to utilize funding for traditional healing activities?	those living with or affected by HIV/STBBI
Medicine bag – clinicians and treatment	Connection to physician, specialist and/or traditional healers.	Explore partnerships and/or shared care models or integrative care models to increase access to both HIV/STBBI treatment and care, and traditional healing. Consider providing Métis-specific or Métis-informed services.	Consider existing research and recommendations on the barriers to HIV/STBBI care for Indigenous Peoples. Resolve jurisdictional disagreements and gaps which have led to inequities in health service provision between Métis and First Nation communities.	Advocate for the resolution of policy gaps resulting in inequitable health service funding for Métis organizations. In the absence of sufficient funding for Métis-specific services, consider partnering with First Nations communities and/or Indigenous service organizations to offer more or better Métis-informed services. Advocate for cultural safety training among health and social workers.
Métis flag – politics	Advocacy for a certain cause (or involvement in Métis politics) may be important aspects of health and wellness to some people.	Community-level interventions are challenging to sustain in Métis communities without the support of Métis politicians. Is there an opportunity to partner with a Métis community or Métis government for a project related to HIV/STBBI among Métis people?	How has your corresponding level of government engaged Métis governments and leaders in the development of health or social policy or programs related to HIV/STBBI?	Adopt HIV/STBBI as a priority area within health policy and programming.
Métis capote coat – family	Family as a support system.	Can your organization adopt a broad definition of family in order to improve access to services for Métis people living with/affected by	Do existing policies allow for organizations and service providers to adopt a holistic or broad definition of family?	Advocate for widespread adoption and use of a Métis understanding of family and kinship systems within Métis programs and services, particular for

		HIV/STBBI and their family members?		individuals living with or affected by HIV/STBBI.
Métis York boat – goals	What resources can an individual access to support the development and achievement of goals?	How can health and social/support workers assist Métis people living with/affected by HIV/STBBI to develop their own goals, and identify corresponding resources to support them in achieving those goals?	How can existing health and social services be leveraged to support Métis people living with/affected by HIV/STBBI in reaching their self-identified goals (e.g., specific funding or bursaries for Métis people with HIV)?	How can existing Métis services and supports be leveraged to help Métis people living with/affected by HIV/STBBI meet their goals? Can alternative criteria for programs, services and benefits be developed for individuals with lived experience, in order to improve access (i.e., affirmative action)?
Métis moccasins – connection to land	Connection to land can support all aspects of health and wellness.	Can existing wellness programs include an on the land element or aspect?	Are policies reflective of holistic health interventions for Métis communities which include land based activities?	Advocate for the creation of stable and flexible funding streams which support land based activities for Métis individuals living with/affected by HIV and STBBI.

In response to the research question, it is important to note there are many ways a potential Métis-specific cultural response to HIV and STBBI might look. Particularly in Indigenous communities, there is no one ‘right way’ to provide a Métis-specific cultural response to HIV and STBBI. Within the context of the D&S project, and based on the findings of this research, I propose that any potential Métis-specific cultural response to HIV/STBBI would contain the following eight features:

1. Involves the use of a Métis model of health and wellness, grounded in a social determinants and life course perspective (such as the Red River Cart Model);
2. Is strongly grounded in Métis community engagement;
3. Provides Métis-specific approaches and services that reflect the needs of Métis people;

4. Allows for a flexible and individualized approach for clients;
5. Values process over outcome (is congruent with Métis ways of doing);
6. Involves a multi-level approach;
7. Focuses on stigma reduction and increased awareness of HIV and STBBI; and
8. Integrates event-based interventions in the community, such as dried blood spot testing.

These aspects are each discussed further below.

1. Involves the use of a Métis model of health and wellness. The Red River Cart Model could be described as 'comprehensive' because it acknowledges many social determinants of health (including housing, connection to land, resources, education and training, housing, harm reduction, social, community, family, spirituality and culture, clinicians and treatment) as well as a life course perspective. These two elements (social determinants of health and life course perspective) were identified as very important elements of a Métis understanding of health, and were therefore important aspects of the Métis Red River Cart Model. This social determinants of health and life course perspective was demonstrated by participants throughout the discussion; the interrelatedness of health and social elements of one's life across life stages and roles, and how these interacted with each other to promote health, were emphasized. Not every Indigenous health model directly acknowledges or refers to the social determinants of health, such as the Medicine Wheel. The Red River Cart Model was designed to be flexible in its application, thus being able to meet the individualized and holistic needs of client. The Red River Cart Model also allows users to self-identify meanings of components and determine the level of importance of the model's components. For example, some clients may feel that culture and spirituality are less important aspects of their own health and wellness, or may chose to meet their cultural and spiritual needs in different ways (e.g., connection to nature, advocacy). As such, the Red River

Cart Model is grounded in a holistic, Métis understanding of health and wellness, as it reflects a holistic understanding of wellness that is grounded in Métis cultures and worldviews, and can be applied or used flexibly.

Many of the components of the Red River Cart Model reflect an understanding of the proximal and intermediate social determinants of health, as described by Loppie Reading and Wien (2009). The fact that life stages were reflected in the roles and responsibilities (the spokes of the wheels) within the model can also be interpreted as a reflection of a life-course perspective regarding health and wellness, as the model acknowledges that health related experiences and one's relationships with the various components of the model will change according to life stage and role (Loppie Reading & Wien, 2009; Reading, 2009). This means that the Red River Cart Model well reflects the Integrated Life Course and Social Determinants Model of Aboriginal Health developed by Loppie Reading and Wien (2009), which was discussed in the introductory chapter.

Métis-specific models of health and wellbeing are somewhat rare in the literature. As discussed in the methodology chapter, LaVallee (2014) discusses a Red River Cart Wheel Model of health in her doctoral thesis, which informed work done by the Métis Nation – Saskatchewan health department. This model is represented by one Red River cart wheel, which contains eight spokes, and each represent a different aspect of health or wellness (data collection and research, relationship and partnerships, community engagement, Elders and youth, health priorities, prevention and health promotion, suicide prevention, and communication) (LaVallee, 2014). At the centre of the wheel is Métis health and wellbeing, and the hub contains four additional components (individuals, communities, stakeholders, and partners) (LaVallee, 2014).

There are several similarities and differences between the Red River Cart Wheel Model discussed by LaVallee (2014) and the Red River Cart Model developed and described in this thesis. LaVallee describes the model as a “framework for understanding health” (2014, p.58). The model discussed by LaVallee highlights a multi-level approach which emphasizes interventions at the community and policy levels (e.g., data collection and research, relationships and partnerships, community engagement, etc.) and is grounded in a social determinants of health approach (2014). The model’s acknowledgement of youth and Elders as life-stages indicates a partial consideration of a life course perspective or consideration for traditional and contemporary roles held within Métis communities and families (LaVallee, 2014). Another strength of the model discussed by LaVallee (2014) is its explicit inclusion of prevention and health promotion, one aspect which is missing from the Red River Cart Model discussed in this thesis. The Red River Cart Model also reflects aspects of health promotion, as it highlights the individual’s journey to wellness. However, it is less clear how or if the model discussed by LaVallee (2014) can be utilized by individuals; its strengths may lie in its ability to be applied at community and policy levels to understand how health is impacted by Métis interventions.

In comparison, the Red River Cart Model described in the previous chapter – which was developed by members of the Métis community in partnership with Shining Mountains – can be clearly applied to both individual as well as at other levels, as demonstrated in Table 5 (program level (community organizations), policy makers, and Métis governments). The Red River Cart Model acknowledges all the stages of life (e.g., infant, youth, Elder, and adulthood) and roles that individuals play within families and community both traditionally and contemporarily (e.g., father, Elder, sister, etc.). It is strongly rooted in a social determinants of health perspective as it acknowledges the link between health and other social aspects such as housing and community.

The Red River Cart Model was also developed with an HIV and STBBI context in mind; to my knowledge no other Métis models of health and wellness related specifically to HIV/STBBI exist in the literature currently. An HIV/STBBI contextualized model of health, such as the Red River Cart Model, is reflective of Indigenous understandings of health within an HIV/STBBI context that have been presented in the literature. This includes aspects like: the role of culture in health and HIV prevention (Wilson et al., 2016), the role of politics and leadership in health (Monchalin et al., 2016a), how stigma can affect access to testing and treatment (and thus health outcomes) (Worthington et al., 2010), and the strong role played by one's family, home, and peer group on one's health (Woodgate et al., 2017). These contexts are reflected in the recommendations and considerations contained in Table 2 The Red River Cart Model developed and documented within this research adds an additional strong model of Métis-specific wellness to the sparse literature surrounding Métis-specific models of health in an HIV/STBBI context, and should be used in partnership with community engagement (#2, below) to help identify potential Métis-specific or informed interventions (#3).

2. Métis community engagement. Despite the challenges involved with engaging individuals in the process of developing the Red River Cart Model, the importance of engaging communities was emphasized during the model development. Participants felt that if other communities wanted to utilize the Red River Cart Model, it would be wise to go through a process of consultation to ensure that the model is reflective of the needs of the community and those with lived experience. Community and member engagement, which was an overarching theme of RQ1, is at the heart of both community-based research and Indigenous research approaches. In order to effectively meet the needs of Métis people living with HIV or affected by STBBI, programs, services, and policies should be grounded firmly in an understanding of what

Métis people say they need. Indigenous approaches acknowledge that communities are best positioned to decide for themselves the approaches, or services that they need. This serves as a good reminder that communities themselves, even across a single identity (i.e., Métis), are diverse, and therefore will likely have different needs compared to other communities. Based on this understanding, Métis communities hoping to use the model defined through the first research question should undertake a process of community engagement to adjust the model if necessary. This will ensure that the Red River Cart Model, and any interventions implemented as an aspect of a Métis-specific response to HIV/STBBI, are truly reflective of the self-identified needs of Métis community members, particularly those with lived experience of HIV and STBBI.

Communities are generally acknowledged as a cornerstone of health-related interventions in Indigenous contexts. For example, the Canadian Blueprint to Inform Hepatitis C Elimination Efforts in Canada (The Blueprint) (2019) provides specific recommendations for Indigenous populations. The Blueprint recommends the use of community readiness and awareness interventions in Indigenous communities in partnership with Indigenous leadership as a core community-level intervention in the fight to eliminate HCV (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). Dr. Andrew Lodge, Medical Director of Klinic Community Health in Winnipeg has written about the importance of asking what the communities that they serve need (Lodge & Klinic Community Health, 2019). The Klinic Community Health centre has been selected as a pilot site for the Manitoba Mino Pimatisiwin Model of STBBI Care, which aims to increase the ability of non-Indigenous organizations to offer culturally safe health services (2019). Lodge writes, “At Klinic, we are committed to asking the question, what do the communities that we serve need? Sometimes this begins with humility and acknowledging that, though we are doing amazing work every day, we can likely still do better for some people" (2019, p.1). Thus, working with Indigenous communities to identify their preferred approaches is an important element of community-based HIV and STBBI interventions.

Métis community engagement is an aspect of the Red River Wheel Model of Métis health discussed by LaVallee (2014), but she offers little discussion around this point within the model. From a research perspective, Monchalin and Bourassa (2019) have written about the role of Métis community involvement within Métis-specific HIV research. In accordance with community-based research and Indigenous research methods, they encourage researchers to take engagement one step further by including Métis people in the research process. They say:

> When doing research that is meant to benefit a Métis community, who better to partner with than the community themselves? For example, involving local Métis Elders in the beginning stages of the research will ensure it is carried out in a good way, and that it is fulfilling a Métis methodological process that is relevant. While the researcher may want to explore questions surrounding HIV, the community may steer the research process towards understanding social determinants that impact the rates of HIV (Monchalin & Bourassa, 2019, p.11).

Monchalin and Bourassa (2019) identify the involvement of Elders in the research process as a wise practice within research; this is likely to be true for any health intervention. CAAN has also written about the need for community engagement and consultation to take place with Métis communities, in order to give a voice to Métis with lived experience (Canadian Aboriginal AIDS Network, 2005). Ideally, community-based intervention for Métis people would be grounded in Métis community engagement.

3. Provides Métis-specific approaches and services that reflect the needs of Métis people. The three overarching themes (which were beginning the journey, individualized approach, and community engagement) identified in the analysis of the first research question are also relevant for any Métis-specific response to addressing HIV/STBBI, whether it be at the level of the individual, program, policy, or Métis government. Based on the data and thematic analysis, especially from research question two where participants indicated there was a lack of Métis-specific services, and a lack of culturally-safe services, it is clear that Métis people want Métis-specific approaches to programs and services related to health, particularly regarding HIV and STBBI.

Beginning the journey was an overarching theme identified through RQ1, which refers to the currents stage of developing an HIV/STBBI response within and across the Métis Nation. Métis-specific health and wellness services are not widely offered and are not available to meet the needs of Métis Peoples, resulting in Métis Peoples relying on mainstream health services which fail to acknowledge the holistic needs of Métis Peoples (Auger, 2019). However, Métis people are (slowly) gaining more recognition and consideration at multiple levels of governments. I am hopeful that in the future, Métis governments and communities will be able to administer Métis health services for their peoples. Métis governments, provincial/federal governments, and health authorities should be considering how future Métis health services can consider the needs of Métis people living with/impacted by HIV/STBBI.

Connected to this is the theme *an individualized approach*. In the third (Methodology) chapter, I discussed some prominent elements of Métis worldview which include a holistic view around health and wellness. This holistic view was emphasized in the findings from the first research question also. It was particularly prominent when discussing certain components of the model such as “social”, “community”, and “connection to land”; participants emphasized the importance of allowing individuals to determine the meaning and priority of the various components for themselves. This aspect is closely related to the second overarching theme (Métis *community engagement*) in that engaging the community is a necessary step in determining the community’s needs. Therefore, any Métis-specific response to HIV and STBBI needs to be grounded in a holistic perspective of Métis wellness, and allow for aspects which can be individualized in order to best meet the distinct and potentially differing needs of individual clients.

In addition to being holistic, a Métis-specific cultural response to HIV and STBBI needs to be grounded in language and culture. Holism, culture and language are very closely linked for Métis, and all Indigenous Peoples (Dyck, 2009). Connecting each component within the model to items which are reflective of Métis culture served to fulfill this aspect. This corroborates work done on the social determinants of Métis health by the Métis Centre of the National Aboriginal Health Organization, which states that holism should be a principle of a Métis health approach (Dyck, 2009). Dyck states that programs must be culturally and contextually relevant to Métis people (2009). She goes on to say that “culturally and contextually relevant is a common sense principle. Any determinants used must be deemed relevant to Métis and be in keeping with the needs and priorities of Métis” (Dyck, 2009, p. 9).

Although now 15 years old, the Canadian Aboriginal AIDS Network (CAAN) developed a document titled *Supporting Métis Needs: Creating Healthy Individuals and Communities in the Context of HIV/AIDS* (2005); this document advocates for a Métis-specific approach to HIV which is grounded in community engagement, approaches, and interventions. The research findings in this thesis support and corroborate what is written in CAAN’s document: that culturally-safe and accessible Métis-specific health services related to HIV and STBBI need to be developed and provided for Métis people. These services need to be strongly grounded in the cultural context and values of Métis Peoples, and supported by community development, capacity building, and training opportunities (Canadian Aboriginal AIDS Network, 2005). CAAN's document also emphasizes the importance of solving issues around a lack of Métis-specific services regarding health and wellness in general.

4. Allows for a flexible and individualized approach for clients. The importance of an individualized approach was highlighted as an overarching theme in the analysis of research question one. Participants were adamant that applying and using the Red River Cart Model needs to allow for individuals to self-determine what each component means to their unique situation. The participants felt that the descriptions of each component should be guidelines only, and that the intention of the model is to be flexible and not so rigid that some clients might find it not useful or inapplicable to their situations. Based on the prominence of this theme within the analysis, it is logical that a Métis-specific cultural response to HIV and STBBI also allow for a flexible, and adaptable individualized approach. This could include offering a variety of programming and supports for individuals to opt in or out as they see fit. In this way, the Métis cultural response to HIV and STBBI can empower individuals to self-determine their own needs and desired resources and services. The importance of building flexible and adaptable approaches to address HCV is also highlighted in *The Blueprint* (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019).

These findings are reflective of what others have written about the diversity of Métis Peoples within the Métis nation or Métis identity. Because Métis people were born from a wide variety of European and First Nation ancestries, individual practices, beliefs and worldviews, which varied greatly according to kinship networks and ties, vary widely between contemporary Métis individuals and families still. Dyck (2009) writes that Métis are a highly diverse peoples, this is corroborated by Monchalin and Bourassa (2019) who write that "a Métis worldview is as unique from one Métis person to the next" (p. 8). Just as individuals within a Métis identity are unique, so will their needs be regarding HIV and STBBI programming.

5. Values process over outcome (is congruent with Métis ways of doing). The first overarching theme of the analysis of research question one was *beginning the journey*. This theme is reflective of what I, as a graduate student and Métis person, have come to understand as an emphasis on 'process over outcome' within Metis ways of doing things. The concept of 'process over outcome' highlights the importance of doing things the right way, in a way that is congruent with our values, approaches and worldviews as Métis Peoples. Based on my experience working in government, mainstream approaches emphasize meeting the 'finish line' at any cost, emphasizing the outcome over how the work is done (i.e., the process). In my experience, the value of outcome over process encouraged the cutting of corners or taking of shortcuts that resulted in reduced work quality; this often resulted in not engaging the public or communities when it was appropriate to do so. Therefore, valuing process over outcome is relevant to a Métis-specific response to HIV and STBBI because the response will need to be grounded in a way of doing things which is congruent with Métis Peoples and worldviews. To clarify, this does not mean that reaching goals or improved outcomes regarding HIV and STBBI interventions are not important. It means that it should be done carefully, with attention given to the process, and may take longer than expected.

Métis researcher Janice Cindy Gaudet (2019) writes about a Métis methodology which emphasizes process and draws on Métis relational ways of knowing, being, and doing. She calls this methodology “Keeoukaywin” which in English roughly translates to “the Visiting Way” (Gaudet, 2019, p. 47). The Visiting Way emphasizes the importance of gathering Métis women in their/our homes (typically around the kitchen table) and on the land as a research method (Flaminio, Gaudet, & Dorion, 2020). However, Gaudet writes that the Visiting Way is much more than a method; it is a way of being that is based on a process which is “caring, respectful, and grounded in self, place, land and family”(Gaudet, 2019, p. 53). I interpret Gaudet’s writings on the Visiting Way to show that a Métis methodology is not solely a means to an end (that is, to gather data to answer a question), but that the process of the Visiting Way is an end in itself. It attempts to shift the focus of Métis research from being goal oriented into one which is process oriented and reflective of Métis ways of knowing, being, and doing. Although the Visiting Way is a methodology, it is grounded in Métis worldviews and as such, can inform the way Métis people develop and implement health interventions.

6. Involves a multi-level approach. The analysis of research question one in chapter four (Results) discusses multi-level aspects of the components of the Red River Cart Model. These levels are broken down into: individual, program level, policy makers, and Métis governments. For example, the Métis stove (housing) is one aspect of the Red River Cart Model (see Appendix J for the visual of the model in its current state of development; Table 2 above contains suggested implications for each component of the model). When an individual is applying the Red River Cart Model to their life, they can assess their housing stability and quality. When applying the model at other levels, it can help us to identify and examine policy and program gaps for supporting Métis individuals with HIV and STBBI to address their housing needs, as well as possible actions that Métis governments (such as the Métis National Council, or MNA) can take also. This process of applying the Red River Cart Model at different levels can highlight the need for organizational partnerships and areas for potential advocacy, whether these are at Métis governance levels, among programs and services, or municipal, provincial or federal government levels.

A multi-level approach to Métis health is discussed by other Métis writers, namely Dyck (2009) and LaVallee (2014). Dyck, who writes about the social determinants of Métis health, discusses some elements of Métis health which are more removed from the individual. These refer to the systemic determinants of health including colonialism, racism, and a lack of Métis rights, which Dyck says can be addressed through programs and services to Métis people (2009). This multi-level perspective is also reflective of the Integrated Life Course and Social Determinants Model of Aboriginal Health developed by Loppie Reading and Wein (2009). Loppie Reading and Wein discuss 'layers' of health, describing them as proximal, intermediate, and distal, of which each can be targeted at different levels to create change (2009). In the model discussed by LaVallee, the levels are reflected by the outside rim of the wheel (individuals, communities, stakeholders and partners), which identify potential levels of society/governments to target for change.

CAAN's Métis guideline to *Creating Healthy Individuals and Communities in the Context of HIV/AIDS* also suggests a multi-tiered approach to health (2005). The document advocates for development and advancement in select strategic areas which span several levels, including Métis-specific healthcare and testing services, community development, partnerships and collaboration, and research and evaluation (Canadian Aboriginal AIDS Network, 2005). Their work highlights many policy issues which have contributed to inequities in health and social services, particularly around identity and membership, jurisdictional disputes and barriers, inequitable resource allocation and funding, scarcity of Métis health research, and the policy void at provincial and federal levels with respect to urban Aboriginal and Métis Peoples (Canadian Aboriginal AIDS Network, 2005). Many of these areas correspond to community, organization/programming, or government/policy levels, reflecting a multi-tiered or multi-level approach to addressing Métis health in an HIV/STBBI context.

7. Focuses on stigma reduction and increased awareness of HIV/STBBI. Stigma was one element related to many aspects of the model and was also a prominent theme in the evaluation of the acceptability and feasibility of DBST (RQ2). Stigma was acknowledged as one potential factor that prevented individuals from attending the gathering circles for the development of research question one. *Stigma in healthcare* was its own subtheme contained within the medicine bag (clinicians and treatment) of the Red River Cart Model.

Stigma has been identified as having many impacts on individuals living with HIV. Stigma is a key area for intervention as it has been linked to a reduced ability for individuals to adhere to antiretroviral therapy and can prevent individuals with HIV from accessing care (Jongbloed et al., 2019; Katz et al., 2013). Stigma can act as a barrier to education and preventative measures, and can prevent individuals from accessing accurate health information following diagnosis (Woodgate et al., 2017). It also contributes to psychological distress and a reduced sense of wellbeing (Woodgate et al., 2017).

The Blueprint recommends that Indigenous communities create programs to address stigma, particularly around increasing community awareness regarding harm-reduction and care cascades (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). Peer-reviewed literature also recommends that stigma interventions target multiple levels of influence (i.e., intrapersonal, interpersonal, and structural) for the greatest impact on improving treatment adherence within individuals living with HIV (Katz et al., 2013).

8. Event-based testing as a component of a Métis-specific cultural response to HIV and STBBI. The very positive response from members of the Métis community regarding dried blood spot testing indicates that event-based based testing interventions like dried blood spot testing could form a part of a Métis-specific response to HIV and STBBI.

Some research and evaluation work has been done on event-based testing in Indigenous communities as a response to HIV and STBBI. Albert McLeod, a two-spirited Indigenous researcher and HIV advocate presented on event-based STBBI testing at Indigenous events in Manitoba at the 28th Annual Canadian Conference on HIV/AIDS Research in Saskatoon in 2019. McLeod shared his experience working with community to implement point of care testing and dried blood spot testing at the Annual International Two-Spirit Gathering in Manitoba and at Manitoba's Aboriginal AIDS Awareness Week event in Winnipeg, both in 2018 (McLeod et al., 2019). His research drew several useful and meaningful conclusions: that the Annual International Two-Spirit Gathering is a culturally-safe response to the HIV pandemic in Indigenous communities; that some Indigenous communities are ready to offer POCT and dried blood spot testing; POCT and dried blood spot testing were acceptable to two-spirited participants and were acceptable when offered both indoors and outdoors (McLeod et al., 2019). He also recommended that the province of Manitoba create a standardized process for event-based testing (McLeod et al., 2019).

Other research shows that event-based outreach can provide acceptable opportunities for the promotion of HIV awareness within Indigenous contexts. The 'Sexy Health Carnival' is an intervention by and for Indigenous youth, where the goal was to reduce barriers such as fear, stigma and shame around sexual health, and promote safer practices using information booths and interactive games (Monchalin, Lesperance, Flicker, Logie, & Network, 2016b). The Sexy

Health Carnival was offered at four powwows in Ontario in 2014 (Monchalin et al., 2016b). Using a community based research methodology, an evaluation of the Sexy Health Carnival showed that Indigenous youth participants: preferred the Sexy Health Carnival to school-based sexual education interventions, appreciated the positive focus of the intervention, valued the free condoms offered as a part of the intervention, and felt that the Sexy Health Carnival was important to have at powwows (Monchalin et al., 2016b). The authors conclude that the Sexy Health Carnival was positively received by youth participants, which supports the need to develop peer-led interventions addressing stigma and awareness (Monchalin et al., 2016b).

The eight proposed features of any Métis-specific cultural response to HIV and STBBI are grounded in the findings of this Métis community-based research study, and are congruent with the existing literature. The strengths of these findings include: the community-based nature of this research, and the inclusion of Métis approaches, culture, and worldviews into the research and analysis. A weakness of this study is the small number of participants, which emphasizes the need for the model findings to be shared further with more Métis communities and Métis individuals with lived experience. While there may be other features that emerge from future work, particularly adaptations of the model to different community contexts and health concerns, these eight proposed features of a Métis-specific cultural response (and the Red River Cart Model) provide a starting point for Métis communities and agencies interested in developing their own Métis specific response to HIV/STBBI.

Research Question 2: Integrating Results with the Literature

To recap, RQ2 was: is DBST an acceptable testing method for Métis communities? Answering this question involved the thematic analysis of survey results, gathering circle transcripts, interview transcripts, and document analysis of meeting minutes and observational notes from both DBST events. Analysis revealed key themes and information around who received dried blood spot testing, the acceptability of dried blood spot testing, as well as seven distinct themes: ease of testing process, challenging with existing testing processes, lack of Métis specific services, potential to improve access to testing, stigma and awareness, information, and health role models. While the majority of participants were female, and more work needs to be done to understand opinions of Métis men, two-spirited Métis, and LGBTQ2S+ identifying Métis about DBST, these findings suggest that DBST is an acceptable testing intervention for Métis communities.

Survey responses: Demographics. The demographic information from survey respondents provided valuable information about who received DBST. Out of 30 individuals who received testing at one of two events, 26 completed a survey, which is 87% of those who received DBS testing at the events. Those who participated in the survey were most likely to identify as female (73.1%), potentially suggesting that dried blood spot testing was more likely to reach women than men. However, this must be understood within the context of the events in which dried blood spot testing was offered. The first was an invitation only event where select members of the Métis community, Shining Mountains and partnered organizations were invited to participate in the community launch of the D&S project which was held in Red Deer. The second was a provincial Métis health forum held in Edmonton. Therefore, those who received dried blood spot testing were either individuals invited to the first event (community launch of D&S), or those who were attending the second event (Métis health forum). Individuals who attended the Métis health forum are those who are likely to be: engaged either with their local Métis community or the MNA, residing in Edmonton or the surrounding area, or those who have received supports or who have the personal resources (i.e., money for travel, or access to a vehicle and fuel) to travel to the event, or are working in a health related capacity either in a partnered organization or are a healthcare provider. Because test recipients were drawn from these audiences, those who could receive testing were limited to the pool of attendees from either event. Based on my observations, there were more female attendees at the second event (Métis health forum); this may be due to the gender imbalance that exists in many health occupations (e.g., nursing). It is possible that the presence of more women at the second event can explain the gender differences in those that received testing. Outside of the events, a couple of individuals approached staff at the Shining Mountains office to request DBS testing. These individuals indicated that venous testing was extremely difficult due to extensive collapsed veins. Potential use of DBS amongst those with collapsed veins should be explored further.

Other participant characteristics should also be understood within the context of who attended the events. The average year of birth for survey respondents was 1965 (1963 for women, 1970 for men), and so the average survey respondent was approximately 55 years of age. The majority of survey respondents also lived in the city (76.9%). Four respondents indicated they spoke an Indigenous language. The average age, as well as the prevalence of urban residents, could be indicative of the type of individual likely to attend one of the two events. The majority of respondents did not indicate a sexual preference, so it is difficult to understand the extent to which the survey and gathering circle responses were reflective of LGBTQ2S+ perspectives and experiences. Preliminary research by others supports the acceptability of DBST amongst two-spirited Indigenous Peoples within the context of testing taking place at two-spirited events in Manitoba (McLeod et al., 2019).

Previous testing experience. Survey responses indicated that the majority of the respondents had not received testing for HIV, HCV, HBV and/or syphilis before, or were unsure if they previously had. For HIV, 50.0% had not received HIV testing previously. For HCV, 46.2% of all respondents indicated they had never received testing and 19.2% indicated they were unsure if they had. For HBV, 53.8% of all respondents indicated that they had not received previous testing, however 26.9% indicated they were unsure if they had; men were slightly more likely to indicate previous testing. For syphilis, 69.2% of all respondents indicated they had never received testing and 15.4% indicated they were unsure if they had; this was similar across sex (15.8% of women indicated they had been tested previously compared to 14.3% of men). Of those who responded, men were more likely to indicate they had previously received testing for HIV, HCV, HBV or syphilis. Respondents indicated they were least likely to have previously been tested for syphilis, which is important to highlight given the current outbreak of syphilis within the province of Alberta ("Infectious syphilis outbreak declared in Alberta," 2019).

Acceptability. Most participants indicated that dried blood spot testing was an acceptable testing method; this was demonstrated through the following responses: the majority strongly agreed or agreed (100.0%) that dried blood spot testing was easy, and that they would receive dried blood spot testing again if offered (92.3%). Most participants (96.2%) indicated that their overall DBST experience was positive. These findings were corroborated by feedback given in the gathering circles, where people used terms such as “easy” and “simple” to describe their testing experience, and said they would encourage others to also get tested. The majority of survey participants agreed or strongly agreed (96.2%) that they received sufficient information about HIV, HCV, HBV and syphilis from their DBST provider. When asked if they would encourage family and friends to get tested, 84.6% of agreed or strongly agreed. This is slightly lower than the other response averages, and while speculative, this could be due to the STBBI stigma levels within the Métis community (Woodgate et al., 2017). Research on the acceptability of DBST within Indigenous contexts, aside from work done by McLeod and colleagues (2019), is limited.

Thematic analysis. Themes identified from transcripts of the four gathering circles and three semi-structured interviews support the conclusion that dried blood spot testing is an acceptable type of testing for Métis communities. The first theme, *ease of testing process,* summarized the views of both those who received dried blood spot testing and those who were trained to provide dried blood spot testing at the events. Many compared dried blood spot testing to venous testing, describing dried blood spot testing as much easier and simpler, which was described as a strength of DBST. Other research has shown that DBS is straightforward enough for individuals to provide self-collected samples, which reflects the findings around ease and simplicity of process identified in this research (van Loo, Dukers-Muijrers, Heuts, van der Sande, & Hoebe, 2017).

The second theme was around *challenges associated with existing testing processes*, which were typically described by participants as a complicated process requiring access to a physician to order the test, traveling to a laboratory facility (and the corresponding logistic challenges around working, childcare, and cost and time involved in traveling), undergoing the sampling process, and then waiting for results. For some people, these represent barriers which can prevent them from engaging in the testing process and looking after their health. Many barriers to HIV and STBBI testing have been studied and reported in the literature. A 2015 review conducted by Bolsewicz, Valley, Debattistia, Whittaker and Fitzgerald focused on Canadian, Australian and UK generated evidence regarding barriers to HIV testing (2015). This review showed barriers and challenges which prevent individuals from engaging in HIV and STBBI testing, and include: internalized stigma and negative perceptions of HIV, not being recommended by a physician or healthcare practitioner to get tested, poor quality of testing services, lack of cultural safety of testing services, a poor understanding of HIV, geographic distance, the need to return for results, and a lack of time, among others (Bolsewicz et al., 2015). Their review highlights the socio-structural aspects and barriers of testing, and acknowledges a lack of studies regarding testing barriers and behaviours from non-urban and culturally diverse communities (Bolsewicz et al., 2015). Other research has focused on the role of risk and perception of risk as contributing factors to testing behaviours among Indigenous youth in Canada. One mixed methods study showed that a misperception of risk and feelings of invulnerability were prominent reasons for youth not getting tested for HIV (Mill et al., 2008). However, our research did not attempt to examine risk or behaviours associated with getting tested, and instead focused on acceptability of dried blood spot testing in the community.

Lack of Métis-specific services was another theme identified within the analysis. A *lack of Métis-specific services* is discussed above under RQ1 also; here I will focus on the implications of a lack of Métis-specific services on HIV/STBBI testing. Test providers indicated in their interviews that to their knowledge, Shining Mountains was the only organization that provided Métis-specific social services and supports to those living with or impacted by HIV/STBBI. Test providers highlighted the importance of Métis people offering DBST to Métis community members. The test providers, based upon feedback they received from community members and test recipients, felt this contributed to an improved sense of comfort among test recipients, which enhanced the ease of the testing process. They highlighted that Métis-specific provision of testing reducing apprehension and lessened fears around the potential of experiencing judgement during the testing process.

Participants saw the provision of dried blood spot testing as opportunities to provide Métis-specific testing services, which could be accompanied with pre- and post- testing counseling by a Métis individual, and followed up with Métis specific services through Shining Mountains. Participants felt that having the testing present and visible in community events also contributed to its acceptability, as individuals could see others waiting in line for testing. Others spoke of the lack of Métis-specific services within a stigma context, which supports the acceptability of dried blood spot testing in Métis communities, as it is one way to offer a Métis-specific testing service in a way that increases comfort and thereby has the potential to increase access to testing as well.

A lack of Métis-specific health services has been identified as an issue by many researchers and community organizations (Dyck, 2009; Kumar et al., 2012; Monchalin & Bourassa, 2019). Others have acknowledged that a lack of culturally-safe services impact the way Métis Peoples access healthcare services (Monchalin, Smylie, Bourgeois, & Firestone, 2019; Monchalin et al., 2020; Wesche, 2013), some citing jurisdictional and policy issues as contributing factors (Auger, 2019; The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). In the context of Indigenous HCV interventions, Indigenous-led, culturally safe and responsive care has been identified as being more effective than mainstream care, but is constrained by a lack of resources and Indigenous or allied health care practitioners (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). Other research has shown that peer-led HIV prevention and sexual health interventions are acceptable and even desirable to young Indigenous community members (Monchalin et al., 2016b).

The theme of *potential to improve access to testing* is closely related to themes *challenges associated with existing testing processes*, and *lack of Métis-specific health services*. Dried blood spot testing was identified and described by participants as one way that barriers to HIV and STBBI testing could be reduced. Citing its portability, many thought that dried blood spot testing should be brought to their own communities as a way of increasing testing for HIV and STBBI. The challenges experienced with typical testing procedures, combined with the high levels of stigma and unawareness of HIV and STBBI in Métis communities, were identified as reasons why Métis individuals do not engage in testing. By bringing DBST to their communities, participants thought that the reduced barriers in testing could (i.e., geography, cost to travel) lead to increase testing within their communities.

Research has shown that dried blood spot testing can increase the accessibility of testing for HIV (Craine, Parry, O'Toole, D'Arcy, & Lyons, 2009), and Hepatitis B and C (Chevaliez & Pawlotsky, 2018). For viral hepatitis and HIV, dried blood spot testing can be used for multiple stages across the cascade of care, including screening, diagnosis, treatment decision making and monitoring (Chevaliez & Pawlotsky, 2018). Dried blood spot testing also provides opportunities to screen a very large number of individuals at a single point in time and can be used in situations where phlebotomy is challenging (i.e., infants, people who inject drugs) (Chevaliez & Pawlotsky, 2018; McLeod et al., 2014). In the UK, dried blood spot testing has been shown to be successful at increasing testing within 'difficult to reach' populations (Tait et al., 2013). Non-healthcare practitioners can be trained to offer dried blood spot testing, meaning it can be offered in low-resource contexts (Chevaliez & Pawlotsky, 2018). An additional benefit is that confirmatory testing can be conducted on the same test strip, eliminating the need for the individual to return to a testing centre for a venous test (Chevaliez & Pawlotsky, 2018).

Therefore, these research findings corroborate the existing research that states that dried blood spot testing offers a valuable opportunity to increase testing in rural, remote and resource-limited settings.

Stigma and awareness was another theme identified from the thematic analysis, which was closely tied to the theme of *information*. Stigma and a lack of awareness were identified by participants as factors which discouraged testing within Métis communities, which was thought to be a result of a lack of information within communities. Participants thought that holding the dried blood spot testing at Métis events was a great way of reducing stigma and increasing knowledge and awareness regarding HIV and STBBI. Although I am not aware of existing research which has shown that event-based dried blood spot testing can impact stigma and awareness, peer-led awareness interventions have shown to be successful in breaking down stigma in Indigenous contexts (Monchalin et al., 2016b). Some participants spoke of their lack of awareness about improved HIV treatments, believing that HIV was "still a death sentence" (Joanna, test recipient). Others were surprised to hear that HCV is effectively curable now. The lack of conversation surrounding STBBI within communities was discussed as one reason why there are high levels of stigma and reduced awareness which have resulted in a lack of information about HIV/STBBI within Métis communities. DBST at community events was mentioned by participants as one way of starting the conversation about HIV and STBBI in Métis communities. In conclusion, participants felt the nature of DBST and having DBST available at community events allowed for open conversations around HIV and STBBI, which demonstrates the acceptability of dried blood spot testing in Métis communities.

One interesting theme that arose from the analysis was the idea of *health role models.* Some participants felt that by getting tested, particularly in a public environment, they were role modeling healthy behaviours to others within their families and communities. Modeling healthy behaviours was discussed in a positive light, which was further contextualized by participants speaking about other screening services which have been offered in the past at Métis events (e.g., mammograms in buses, etc.). Offering services which allow Métis individuals to act as health role models serves to increase the acceptability of caring for one's health.

These findings are similar to those in the literature regarding role modeling health as an aspect of leadership among youth. One study examining Indigenous models of youth leadership in HIV contexts identified acting as a health role model as one aspect of youth leadership (Monchalin et al., 2016a). In this study, being a health role model was further identified as behaviours someone used to strive to be physically, mentally, emotionally and spiritually healthy which were also associated with leadership (Monchalin et al., 2016a). Role modeling health behaviour has also been identified as one aspect of youth leadership across cultures and ethnicities in the US (Kahn, Hewes, & Ali, 2009).

In conclusion, findings from the thematic analysis support the idea that dried blood spot testing is an acceptable intervention from the perspective of Métis community members. In order to understand and evaluate the feasibility of piloting or implementing dried blood spot testing in Métis communities, I will next discuss the application of the RE-AIM framework so the reader may understand some of the barriers and facilitators encountered during the planning and implementation stages of the pilot.

Section 2: Applying the RE-AIM Framework

The RE-AIM framework (Reach, Efficacy/Effectiveness, Adoption, Implementation, Maintenance) is a heuristic used to evaluate health interventions (Gaglio et al., 2013). Data and corresponding findings to support each of the five components of the RE-AIM framework will be discussed here according to each component.

Reach.

Reach is defined by the original authors of the RE-AIM framework as an individual-level measure of participation (Gaglio et al., 2013). This is most commonly reported as a percentage of participation in a program or service based on a valid denominator (number of total eligible participants) (Gaglio et al., 2013). Other commonly reported aspects of the reach component include the exclusion criteria, characteristics of participants, and use of qualitative methods to understand recruitment (Gaglio et al., 2013).

Based on the structure of the service that was offered (event-based testing), it is not possible to determine the number of total eligible participants who could have received dried blood spot testing at the two events in which it was offered. However, based on observational notes and meeting minutes, as well as survey and gathering circle/interview results, some evidence has been identified to support the assessment of the reach of dried blood spot testing. 30 Métis individuals received testing in total; of those, 26 participated in surveys and 19 participated in gathering circles. Fifty percent (50.0%) of survey participants indicated they had never received HIV testing previously, indicating that the service has the potential to reach those who do not know their HIV status. The majority of survey respondents were female; however, it may be that event attendants were more likely to be female. Most participants were middle-aged, with the average reported year of birth being 1964 making the average age of participants around 56. Only three participants were born in the year 1980 or later, meaning the testing mainly reached middle-to-older-aged adults. This may be due to the average age and characteristics of individuals who were drawn to attend one of the two events where dried blood spot testing was offered.

Exclusion criteria for participation in the study were not self-identifying as Métis and children/youth under the age of 18. Although not eligible to participate in the study, DBST was offered to individuals who had an Alberta Health number; identifying as Métis was not a requirement to receive DBST at these events. At the second (larger) community event where dried blood spot testing was offered, venous testing for HIV and STBBI was offered concurrently in a different room. If women receiving the testing indicated they were pregnant (or possibly pregnant), the testing providers counselled them on the differences between venous testing and dried blood spot testing so individuals could make an informed decision on which type of testing to select. Although more invasive, venous blood testing can provide quicker results, whereas DBST results through this pilot took two weeks to receive.

During the first testing event, which was held during the Métis community launch of the D&S event, fewer individuals were tested because there were fewer attendees at the event compared to the second event. At the second testing event, which was held during the MNA's annual health forum, many community members were present and there were many concurrent activities taking place. Three test providers offered dried blood spot testing in a separate room in the conference area. The three test providers were occupied performing testing for almost the entire day, and there was a line up out the door of individuals waiting to receive testing. It is possible that with more trained test providers on site, and more space to offer the testing, that more individuals could have received testing that day. It is also possible that the topic of the two events (D&S community launch and Métis health forum) drew in participants who were more open to receive testing than other Métis community members. Gathering circle and interview participants spoke about the potential for dried blood spot testing to reach rural and remote communities in Alberta. Many saw dried blood spot testing as a solution to policy and service gaps that exist around HIV and STBBI testing in rural and remote communities as it would address issues and barriers related to geography. One individual commented on the possibility for dried blood spot testing to be used outside of an HIV/STBBI context to test for other illnesses (e.g., diabetes) in rural and remote communities as well.

Efficacy.

Many studies have been conducted on the efficacy of dried blood spot testing methods in screening for infections. A recent systematic review and meta-analysis examined the diagnostic efficacy of dried blood spot testing for HBV and HCV (Lange et al., 2017). The meta-analysis in this study found that the pooled sensitivity and specificity of dried blood spot testing for HBV-DNA was 95% (95% CI:83-99) and 99% (95% CI: 53-100) respectively (Lange et al., 2017). For HCV-RNA detection, pooled sensitivity and specificity was 98% (95% CI: 95-99) and 98% (95% CI: 95-99) respectively (Lange et al., 2017). However, this study also acknowledged that the overall quality of some of the studies was low, and risk to bias was moderate. These sensitivity and specificity rates mean that the majority of individuals with HBV or HCV will be identified through dried blood spot testing (Lange et al., 2017). This makes dried blood spot testing of HBV and HCV a viable alternative to venous blood tests (Lange et al., 2017).

A 2017 validation study for syphilis identified the sensitivity and specificity of dried blood spot for detecting *T. pallidum Ig* (syphilis Ig antibodies) as 90% (95% CI: 72-97%) and 99% (95% CI: 95-100%) respectively (van Loo et al., 2017). Sensitivity and specificity for venous syphilis testing depends on the type of test of test conducted. For example, an enzyme-linked immunosorbent assay to detect IgG antitreponemal antibodies has a sensitivity of 98.4%

and a specificity of 99.3% (Seña, White, & Sparling, 2010). This means dried blood spot testing for syphilis less sensitive but has a similar specificity to a venous *T. pallidum Ig* test (Seña et al., 2010).

The sensitivity and specificity of dried blood spot testing for HIV Ag/Ab (HIV antigen and antibodies) is 100% (95%CI: 81-100%) and 99% (95% CI: 95-100%), making dried blood spot testing for HIV very accurate and comparable to venous testing (van Loo et al., 2017). Advancements in HIV testing has increased the sensitivity and specificity of testing while narrowing the window period after exposure. 4th generation tests, which have been available since 1997 and are performed on venous blood samples, have a specificity of 99.5% and a sensitivity of >99.8% (Alexander, 2016). 5th generation tests, available since 2015,and also performed on venous blood samples have a sensitivity of 100% and a specificity of 99.5% (Alexander, 2016).

Overall, dried blood spot testing for HIV, HCV, HBV and syphilis has comparable sensitivity and specificity rates to many types of venous tests for the same infections. This means that dried blood spot testing can be confidently offered as an alternative form of testing in communities.

Adoption.

Adoption can refer to the degree to which an individual changes or adopts a health behaviour; it may also refer to the ability for health care workers or settings to adopt changes (Gaglio et al., 2013). 92.3% of survey respondents indicated that they would get tested with dried blood spot testing again if it was offered. In gathering circles, many participants mentioned that they had learned about potential modes of transmission that they were unaware of during the pre-test counselling (e.g., sharing toothbrushes, inadequately sanitized nail salon tools) and would change their behaviours going forward to reduce their risk. Many also said they would share what they learned with their family and friends and encourage them to get tested as well. Although it is difficulty to measure adoption without long-term monitoring, most participants indicated that they learned something new or would take something away with them after they had received dried blood spot testing.

Implementation.

DBST has yet to be adopted or fully implemented in Alberta, so it is difficult to make conclusions yet about implementation (i.e., extent to which the program is delivered as intended). However, some implications and recommendations for future implementation can be identified from this work. This thesis research describes a pilot between Shining Mountains, the National Laboratory for HIV Reference Service (NLHRS), and Alberta Health Services (AHS). Upon the request of AHS, Shining Mountains and NLHRS have ceased DBST (at the time of writing) to allow AHS to conduct a cost-benefit study of DBST within the Alberta context. AHS also indicated they needed time to create an official policy process through which DBST would be tracked between their laboratory system and the NLHRS. Once this policy process is in place, it will be possible to implement DBST more broadly. Recommendations for implementation are discussed further below.

Maintenance.

Maintenance can refer to the maintenance of health behaviours at the individual level, or the maintenance of the program at the setting level (Gaglio et al., 2013). In the context of this sub-study, it is not possible to evaluate the extent to which any health behaviour changes have been sustained. Although the testing itself has not been implemented and maintained during the timeframe of this sub-study, this research has helped to identify some factors that should be considered going forward to support the long-term maintenance of dried blood spot testing. These factors are: respect for the Métis community, Métis ways/valuing Indigenous self-determination, training refreshers for testing administrators, support from policy-makers, and identifying the most responsible person (MRP). These will be discussed individually in the final section of this chapter.

Assessing the feasibility of dried blood spot testing in other Métis communities.

There were challenges in piloting DBST which may be reflective of the fact that it has yet to be adopted in the province of Alberta, and therefore does not have an existing approved policy and process surrounding its use. Piloting DBST in the Métis community required time and dedication from representatives of Shining Mountains as well as support from the D&S National Coordinator. It also required time and dedication from employees of the partnered organizations (AHS and NLHRS). As most Métis communities rely on volunteers to administer programs (Evans et al., 2012), the feasibility of piloting dried blood spot testing without the support of an Indigenous services agency such as Shining Mountains is significantly reduced. It is possible that by adopting an official policy and process for dried blood spot testing within AHS, feasibility for communities would be increased because it would reduce the amount of planning meetings required between partners and the community or organization aiming to use dried blood spot testing. The supplies necessary for offering dried blood spot testing (e.g., gloves, band aids), as well as a training refresher were offered by AHS, which increased feasibility from a community or organization perspective. It is not clear who would be responsible for paying for these supplies, should DBST be adopted provincially in the future. Results from the semi-structured interviews showed that learning to administer DBST was easy, making it feasible for non-health staff and volunteers to learn how to provide dried blood spot testing in community settings.

Another challenge identified was the fact that event-based testing was operating across several jurisdictions, making linkage to care with an appropriate care provider difficult. Requiring the community to secure an MRP is a potential barrier to other communities hoping to offer DBST. Although DBST itself is portable, the process requires sufficient space to store the cards while they are drying, which is not convenient for offering testing in smaller venues.

In the Literature Review chapter, I provided a brief overview of the CFIR and PARIHS frameworks, in addition to the RE-AIM framework. Ultimately the RE-AIM framework was selected for its public-health perspective, widespread adoption and use within the literature, and the fact its heuristic is easy to understand and apply, making it appropriate for use with community organizations. However, there are aspects of the CFIR and PARIHS frameworks that could be considered in this context to supplement the analysis of DBST, such as quality of available evidence, the underlying need for change (and the role this need played in the success of the intervention), and the role of leadership and change makers in the context of interventions. It is also important to note that DBST is not widely available in Canada; DBST for HIV and STBBI is largely provided through PHAC as a part of their study on DBST.

As discussed earlier, the majority of existing research on DBST is focused on the laboratory validation of its screening applications; little evidence exists on the use of DBST from a programmatic perspective and subsequent evaluations. This could be interpreted as a limitation or barrier to implementation. However, PARIHS (another IS framework) explicitly values research which is patient-oriented. Although patient-oriented research methodology did not inform this thesis research, some have described patient-oriented research as building upon the work of community-based research, which explicitly informed this research work (Bell et al., 2019). PARIHS also emphasizes the consideration of the underlying need for change. In this context, it was Shining Mountains that understood the underlying need for change: that Métis people need accessible HIV/STBBI testing opportunities which are held in psychosocially supportive and culturally safe environments. Thus, Shining Mountains provided the change leadership necessary to pilot DBST (while supported by the AHS, NLHRS, and D&S). The process of reflecting upon the pilot of DBST from an IS perspective, through the use of the RE-AIM framework, has highlighted several lessons learned, which are discussed below.

Lessons Learned from RE-AIM Framework Analysis: Recommendations

Applying the RE-AIM evaluative framework revealed several important lessons learned form piloting dried blood spot testing in the Métis community. These lessons learned include the *importance of research agreements, training refreshers for testing administrators, support from policy makers, and identifying the most responsible person* (MRP).

Importance of research agreements. During the planning for the pilot of dried blood spot testing, there were some tensions due to cultural differences between the various agents (Shining Mountains, AHS, NLHRS), differing priorities, and possibly a lack of experience with working in partnership with Métis communities. Shining Mountains' goal was to offer dried blood spot as an option to Métis people in order to address the lack of Métis-specific and culturally safe testing options available in Alberta. The community was ready for this as evidenced by the fact that multiple people from the Métis Nation of Alberta requested that testing be offered at their events, and in particular at their Annual General Assembly, which draws hundreds of Métis people together annually and presented an opportunity to reach a broad Métis audience. Shining Mountains and the NLHRS were ready to implement dried blood spot testing, but AHS had public-health concerns related to their mandate to monitor positive test results of reportable infections, as well as logistical concerns around their software and the transfer of DBST cards between community groups and the laboratories.

Shining Mountains signed a research agreement with the NLHRS, which specifically outlined the principles of ethical collaboration that would be used by the NLHRS, which acknowledge and respect for the Métis right to self-determination, including the right to decide about testing in their communities. This also included an agreement that no community findings outside of the federal or provincial STBBI reporting systems would be published without written community consent. This agreement served several purposes: to begin a professional relationship in a good way by recognizing the shared history and effects of researchers and governments on the health and wellbeing of Indigenous communities, to provide guidance to the long-term relationship by outlining responsibilities and agreed upon actions by the signatories (e.g., the disposal of dried blood spot test strips after testing to ensure no future research is conducted without an agreement in place), and served to acknowledge the inherent rights of the Métis community to self-determination. Although a research agreement may seem trivial to some, it can be an important first step in establishing a positive relationship between a government agency and an Indigenous community.

Training refreshers for testing administrators. Semi-structured interviews with three Métis dried blood spot testing providers showed that both providing the testing, and the corresponding training, was easy. Two of the test providers stated that the training refresher that was given to them in between the two events was very helpful in reminding them about the process of dried blood spot testing and ensuring that the blood spot sample was large enough. This was also because several samples from the first event did not yield enough blood to complete the necessary tests, which emphasizes the importance of effective and ongoing training. This was relevant as a few months had passed between the two events. Should dried blood spot testing be offered provincially, communities may benefit from having community-friendly and specific training materials developed on dried blood spot testing, which would allow test providers to refresh their skills on their own.

Support from policy makers. Support (i.e., financial, communication, human resources) from policy makers and staff within the AHS and NLHRS was key to the success of the pilot of dried blood spot testing. AHS staff communicated regularly with Shining Mountains and D&S, provided medical supplies for the testing which reduced the cost to Shining Mountains, provided the training refresher for test providers, and identified an MRP for the second testing event. Without support from AHS and NLHRS, piloting dried blood spot testing in the community would have been extremely challenging. Hopefully, the NLHRS, policy makers and AHS staff will be able to continue to provide support to new and existing Métis and First Nation communities in Alberta who wish to use dried blood spot testing to improve access to testing for HIV and STBBI.

Section 3: Implications of Findings and Recommendations

For this section, I will separate the implications of the findings and recommendations according to level, beginning with individual, then community-based organizations, policy makers, and concluding with implications for Métis governance systems and leadership.

Individual:

Much of the Red River Cart Model itself is applicable directly to individuals, as evidenced by Table 5. By applying the Red River Cart Model, Métis individuals can self-assess broad areas of their own health and wellness, and identify potential areas to strengthen and develop with community-based supports. Additionally, the Red River Cart Model is flexible and adaptable to the needs of individuals.

Community-based organizations and policy makers:

Here, the program level and policy maker levels from Table 5 have been combined, as many of the recommendations are similar or overlap.

Improve cultural safety of existing health services. The first recommendation based on these research findings is for community-based service and health care organizations to increase cultural safety by educating their staff on Métis history, people, and their health. As participants indicated, there is a lack of Métis-informed services, and accessing mainstream services, particularly those related to HIV/STBBI, can provoke anxiety. Therefore, all staff and health care practitioners should be educated on cultural safety, including phlebotomists and those working in lab setting. Based on their research with urban Métis women in Toronto, Monchalin, Smylie, Bourgeois and Firestone (2019) identified five recommendations to increase the cultural safety of services for Métis people. These recommendations are: ensuring there is a Métis presence (e.g., Métis employees, Métis symbols or signage on doors so clients can identify workers who can offer support to Métis clients), a holistic interior design that also reflects Métis imagery, Métis specific or informed service spaces, a welcoming and friendly reception/front desk, and culturally informed service providers (Monchalin et al., 2019). The authors highlight that artwork is not a quick solution to increasing cultural safety, as improving cultural safety requires deeper work involving education and self-reflection (Monchalin et al., 2019). It is also important that policy, administrative, and support staff receive cultural safety training, not just front line workers (Monchalin et al., 2019). These strategies identified by Monchalin and colleagues (2019) are an excellent starting point for community organizations and health service providers to improve the cultural safety of their service provision.

Support Metis-led interventions for Métis people. Within the literature, peer-led interventions have been shown to have a positive impact in Indigenous contexts (Monchalin et al., 2016). In this study, this was reflected in the way that both the Métis-specific Red River Cart Model and dried blood spot testing were interventions either designed or implemented by Métis people for Métis people. Métis communities are often under-resourced, which means that communities often struggle to implement their own programs and services. Indigenous and non-Indigenous service organizations and policy makers should consider how they can support Métis-specific or Métis-informed services for Métis people which utilize peer-led interventions.

Adequately resource Métis communities and Métis service organizations to offer Métis-specific health services and interventions. As discussed earlier, a lack of Métis-specific services was a strong theme in RQ2. This was particularly emphasized in the interviews with test providers, and was identified as a barrier to engaging in HIV/STBBI testing and services. The need for responsive and holistic Métis-services was also discussed in the context of a Métis-specific cultural response to HIV/STBBI (RQ1). Métis communities are often under-funded and lack capacity, despite the desire and demand for Métis health and social services (Evans et al., 2012). Federal and provincial policy issues have resulted in gaps in funding and services between Métis and Status First Nations (The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019). Resolving these policy gaps and creating stable, multi-year Métis-specific funding streams for HIV and STBBI work can help resolve these inequities (Canadian Aboriginal AIDS Network, 2005; The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups, 2019).

Implement a provincial DBST program in Alberta, and create a standardized process for DBST within the health system. These research findings have shown that the Métis community may find dried blood spot testing to be an acceptable testing intervention for HIV and STBBI in the community and could thus potentially improve testing within the Métis population of Alberta. However, implementing dried blood spot testing may be difficult for under-resourced Métis communities. One challenging aspect of arranging for dried blood spot testing was finding an appropriate MRP for the test requisitions. Compared to First Nation communities, which often have a health centre with a dedicated nurse, nurse practitioner and/or partnered physician, Métis communities often lack centralized community or regional health services, which can make referrals and follow-up for patients challenging (Evans et al., 2012). The health system should consider how it can support Métis communities in finding an appropriate MRP in order to offer dried blood spot testing to its membership. Finding an appropriate MRP is particularly important when planning for event-based testing opportunities, as Métis events can often draw individuals from a wide geographic area, which can make linkage to care and services challenging. Creating and adopting a standardized policy and streamlined process for dried blood spot testing may help to reduce the workload involved in DBST for the community, should it be adopted in the province outside of a research setting.

Métis governance systems and Métis leaders.

Make HIV and STBBI a priority within Métis policy and programming. Test recipients and providers both identified a lack of a policy and program focus on HIV and STBBI information and awareness among Métis communities, which contributed to increased stigma in communities and a lack of knowledge about testing. While Métis communities are often under-resourced, some provincial Métis governments have health departments and Ministers of Health which are responsible for health policy and programming (Métis Nation of Alberta, 2019a). In these instances, Métis governments and health departments should consider how they can prioritize

HIV and STBBI within existing and future policy, programming, and collaborative work. Part of this work should include partnering with relevant provincial and territorial governments to identify Métis data on HIV and STBBI incidence and prevalence in order to gain a better understanding of the effect of HIV and STBBI on Métis people and communities. The Métis National Council should explore how it can support provincial Métis governments to implement a Métis response to HIV and STBBI, including supporting Métis communities to offer their own HIV and STBBI interventions around awareness, stigma, and testing.

Areas of Future Research/Collaboration

The knowledge generated from this study highlights several areas for future research. Firstly, Métis approaches to research and knowledge development should continue to be developed by Métis academics in partnership with Métis communities and Elders, and should be published in community accessible formats. Recent work has filled some of this gap by authors such as Monchalin and Bourassa (2019) who have written about a Métis-specific methodology for HIV research, and Gaudet (2020) who has written about the Visiting Way methodology. However, the evaluative work in answering research question two sparks the question: what could a Métis approach to evaluation look like? This could be an opportunity to provide a Métis approach or commentary to existing Indigenous Participatory Evaluation Approaches. Additionally, the process of researching and writing the literature review and methodology section have highlighted potential opportunities to work on developing a Métis perspective on Two-Eyed Seeing, as well as an opportunity to continue to develop a Métis lens for use in community-based research or to support health equity analyses.

Regarding RQ1 (what could a Métis-specific cultural response to HIV and STBBI look like?), future work could involve sharing the Red River Cart Model with more Métis individuals with lived experience to gain further feedback. I believe this will serve to strengthen the model and make it more applicable and useful to people who may be using it or implementing it into their social work or healthcare practice. As noted earlier, the work done to date is preliminary, and adjustments will likely be made as the model is implemented at Shining Mountains. I also recommend that the Red River Cart Model be evaluated with input from the Métis individuals who have used the model. Knowledge translation of the model should be emphasized, particularly utilizing a community-to-community or organization-to-organization mentorship model, which will allow Shining Mountains to share their experience in implementing and using the model with other communities and service organizations. The development of the model has also raised the question about its application to other health contexts, which should be explored in partnership with the MNA and other Métis communities.

Regarding RQ2 (is DBST an acceptable testing method for Métis communities?) my recommendations are that the feasibility and acceptability of DBST continue to be evaluated by the Métis community in more contexts. This research did not sufficiently capture the dried blood spot testing experiences of young Métis adults under 30, two-spirited individuals, and Métis members of the LGBTQ2S+ community. It would also be beneficial to capture more male voices in order to better understand how men perceive and experience dried blood spot testing. This further research or evaluation should be done so that Shining Mountains, and other Métis service organizations or communities, can understand the testing experiences of individuals across genders and sexual identities in order to better meet their testing needs. Areas of further work around dried blood spot testing could include evaluation of the linkage to care process and experience, and risk/behaviours and current levels of knowledge regarding HIV and STBBI among Métis community members. Another much needed area of research would be to examine the impact of a lack of Métis health and social services among Alberta Métis, with a focus on comparing urban and rural contexts across Métis communities.

The pilot of dried blood spot testing offered a unique opportunity to build a new relationship between Métis people, the AHS, and the NLHRS. Some individuals involved with the pilot acknowledged a lack of relationship between AHS and Métis Peoples. This pilot has demonstrated a willingness and interest by some AHS staff to partner with, and develop a relationship with, Métis Peoples and service providers in Alberta. This research has shown that Métis people are keen to develop and administer health interventions to Métis people, particularly around HIV and STBBI. This interest has opened new opportunities for collaborative relationships between Métis Peoples and the AHS, which I hope will continue.

Implications for Population and Public Health

As this Master's thesis is being undertaken within a Master's of Public Health degree, it is important to tie the findings of this thesis research to the field of population and public health (PPH). There are several important findings from this research study that are relevant to PPH practitioners and policy makers. The first is the importance of acknowledging the distinct identity and health care needs of Métis Peoples. It is important to understand that policy actions rooted in colonialism have affected Métis Peoples differently than other Indigenous groups, such as exclusion from the Indian Act, a lack of a formal land-base across much of Canada for Métis people via the script system, and a denial of rights at all levels of governments (Dyck, 2009; Evans et al., 2012; Macdougall, 2017). Jurisdictional limitations have resulted in inequities in health care funding and service provision between First Nations, Inuit and Métis Peoples, leaving Métis Peoples without Métis-specific services and therefore requiring them to access mainstream health services (Evans et al., 2012). All levels of Métis-governments are under resourced (Evans et al., 2012). PPH practitioners and policy makers can advocate for the resolution of policy gaps and collaborate with Métis communities to address the lack of useful and relevant Métis health data to create systemic changes. PPH practitioners, researchers, and policy makers can use Métis-specific data and research to advocate for the adequate funding of Métis communities and to support the creation of Métis-specific health services. Those working in the PPH field can consider how to best advocate for Métis people from a policy perspective. In my opinion, one weakness of some PPH departments within governments is their hesitancy to use advocacy to create change within government.

The findings of this research have several implications for prevention of HIV and STBBI. Firstly, findings corroborate the literature, which show that Métis Peoples, like other Indigenous Peoples, experience stigma when accessing health care services and testing. This can result in: lack of information about HIV/STBBI leading to stigma and a lack of awareness, which reduces the likelihood that people talk about HIV/STBBI in the Métis community. PPH practitioners and policy makers can use this as an opportunity to champion stigma reduction, in partnership with communities, and address cultural safety amongst health care workers and social service providers. PPH practitioners and policy makers can also support Métis communities to develop and implement community-identified interventions, like DBST, to address HIV and STBBI in a way that is congruent with Métis approaches.

Strengths and Limitations

Some of the strengths of this research are its community-based nature with an emphasis on a strengths-based approach to research. The research topics were indicated to be of importance to the Métis partners involved in this research. This research showed that Métis people are eager and willing to participate in Métis research when offered the opportunity. I also attempted to use the voices of Métis participants as much as possible, as in my experience, Métis voices and perspectives can sometimes be overshadowed by the perspectives of others within pan-Indigenous research or community work. Offering Métis individuals the opportunity to participate in the research at the same time as the development of the model was taking place, or in the same venue as the dried blood spot testing, reduced some barriers to participation as it removed the need to coordinate travel to an additional venue and arrange further time away from work. This research was also grounded in Métis approaches, which utilized Elders as supports and integrated practices such as prayer and gift giving. This ensured the research was culturally relevant and respectful to participants. The research was also grounded in an understanding of the Métis Principles of Ethical Research, and offered by a Métis person, in partnership with Métis people, for Métis people.

As a relatively small thesis research study, results should be informative to other communities and contexts, but are only a starting point for further inquiry. Because the participants were either recruited specifically for the development of the model (RQ1) or were recruited from one of two community events (RQ2), the participants cannot be considered reflective of all Métis people in Alberta, or even Métis people in Red Deer. However, this thesis does provide the foundation for a Métis-specific perspective on an HIV/STBBI cultural response and also explores the acceptability of a testing modality offered in a community setting, which is a unique addition to the research and literature on Métis experiences and corresponding factors influencing HIV and STBBI testing.

Researcher Reflection

The process of undertaking this research and writing this thesis helped me learn much as a Master's student and a Métis person. I feel very blessed to have been mentored through this experience by my supervisory committee, and the D&S team, and to have been welcomed into the Métis community in Edmonton and Red Deer to conduct this research. I am especially thankful to Raye St. Denys, Kandace Ogilvie, and Carrielynn Lund for being open to working with me on these important research goals. The process of conducting this research has re-affirmed, to me, the strength and resilience of Métis Peoples.

Conducting a Master's thesis of a moderate size within a large team grant did not always feel like an easy task, although I was well supported throughout my experience. This experience has reminded me of the importance and power of words. Stories and experiences can be useful in creating change. I am also taking away an improved ability to trust myself, and my decisions and choices. As Métis people, we are the best suited to determine for ourselves our needs, particularly around health and wellness. I hope I have demonstrated this through this research.

During the process of working on this research I learned about different ways of approaching and doing Métis research, from the literature, and from Métis researchers, as well as from community. Working within a large team grant has provided me with the opportunity to work with communities I never would have had the chance to work with otherwise, and has opened my eyes to new approaches to community-led and community-driven health interventions. It has also made me reflect on the role of women in our Métis communities, both historically and contemporarily. I have often heard Elders of both genders acknowledge the important role of women in our Métis communities, who have kept our Indigenous knowledges alive; it is the women we must thank for being life givers, knowledge keepers, and sources of strength, and leadership, for our communities. The strengths of Métis women were re-iterated throughout this project, from the fearless leaders and advocates for Métis people working at Shining Mountains, to the women working on D&S, and on my supervisory committee, to the women who shared their voices and experiences with me as research participants. I hope that I can one day be as fearless as these strong women.

Conclusion

Through this thesis research, I have attempted to highlight the strength of Métis community members’ voices and their ability to speak for themselves on issues related to HIV/STBBI care and testing. Grounded in an approach to research which utilized community-based and Indigenous research methodologies, this work highlighted the need for Métis community-identified and implemented services that were grounded in a cultural understanding of Métis Peoples today. Métis Peoples, despite decades of oppression across Canada, continue to assert their right to self-determination by identifying holistic ways to address health and wellness topics in their communities.

References

"Holism". (Ed.) (2020) Random House Unabridged Dictionary Random House.

Abrams, D. B., Orleans, C. T., Niaura, R. S., Goldstein, M. G., Prochaska, J. O., & Velicer, W. (1996). Integrating individual and public health perspectives for treatment of tobacco dependence under managed health care: a combined stepped-care and matching model. *Annals of Behavioral Medicine, 18*(4), 290-304.

Absolon, K., & Willett, C. (2005). Putting Ourselves Forward: Location in Aboriginal Research In L. Brown & S. Strega (Eds.), *Research as Resistance: Critical, Indigenous and Anti-oppressive Approaches* (1 ed., pp. 97-126). Toronto, ON: Canadian Scholars' Press

Adese, J. (2014). Spirit gifting: Ecological knowing in Métis life narratives. *Decolonization: Indigeneity, Education & Society, 3*(3).

Aikenhead, G. S., & Ogawa, M. (2007). Indigenous knowledge and science revisited. *Cultural Studies of Science Education, 2*(3), 539-620. doi:10.1007/s11422-007-9067-8

Alberta Government. (2020). *Metis Settlements and First Nations in Alberta: Community Profiles*. Retrieved from indigenous.alberta.ca

Alexander, T. S. (2016). Human Immunodeficiency Virus Diagnostic Testing: 30 Years of Evolution. *Clinical and Vaccine Immunology, 23*(4), 249-253. doi:10.1128/cvi.00053-16

Allan, B., & Smylie, J. (2015). *First peoples, second class treatment: the role of racism in the health and well-being of Indigenous Peoples in Canada*. Toronto, ON: The Wellesley Institute Retrieved from https://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf

Andersen, C. (2014). *Metis: Race, Recognition and the Struggle for Indigenous Peopleshood* Vancouver, BC: UBC Press.

Andersen, C. (2016). The colonialism of Canada's Metis health population dynamics: caught between bad data and no data at all. *Journal of Population Research, 33*(1), 67. doi:10.1007/s12546-016-9161-4

Anderson, J. E., & Larke, S. C. (2009). Navigating the mental health and addictions maze: a community-based pilot project of a new role in primary mental health care. *Mental Health in Family Medicine, 6*(1), 15-19. Retrieved from

Ashworth, K., Douthwaite, S., Mullender, C., Cunningham, E., & O'Shea, S. (2015). Dried Blood Spot (DBS) testing; An alternative approach to screening. *Journal of Clinical Virology, 70*, S106-S106. doi:10.1016/j.jcv.2015.07.246

Askew, D. A., Togni, S. J., Schluter, P. J., Rogers, L., Egert, S., Potter, N., . . . Brown, A. D. H. (2016). Investigating the feasibility, acceptability and appropriateness of outreach case management in an urban Aboriginal and Torres Strait Islander primary health care service: a mixed methods exploratory study. *BMC Health Services Research, 16*(1), 178-178. doi:10.1186/s12913-016-1428-0

Atkinson, D., St. Denys, R., Ogilvie, K., Lund, C., Shining Mountains Living Community Services, & DRUM & SASH. (2020). *Community Report and User Guide: The Red River Cart Model for Metis People Living with or Affected by HIV and Other Sexually Transmitted and Blood Borne Infections* Retrieved from

Auger, M. D. (2019). 'We need to not be footnotes anymore': understanding Métis people's experiences with mental health and wellness in British Columbia, Canada. *Public Health*. doi:10.1016/j.puhe.2018.12.001

Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-Eyed Seeing and other lessons learned within a co-learning journey of bringing together indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences, 2*(4), 331-340. doi:10.1007/s13412-012-0086-8

Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. *BMC Psychology, 3*(1). doi:10.1186/s40359-015-0089-9

BC Centre for Disease Control. (2019). HIV/AIDS. Retrieved from http://www.bccdc.ca/health-info/diseases-conditions/hiv-aids

Becker, M., Mishra, S., Aral, S., Bhattacharjee, P., Lorway, R., Green, K., . . . Blanchard, J. F. (2018). The contributions and future direction of Program Science in HIV/STI prevention. *Emerging themes in epidemiology, 15*(1), 7-7. doi:10.1186/s12982-018-0076-8

Bell, T., Vat, L. E., McGavin, C., Keller, M., Getchell, L., Rychtera, A., & Fernandez, N. (2019). Co-building a patient-oriented research curriculum in Canada. *Research Involvement and Engagement, 5*(1), 7-13. doi:10.1186/s40900-019-0141-7

Bergman, J., Anderson, B., Singh, A., & Poetz, A. (2013). *Syphilis and HIV Point-of-Care Testing Pilot Project: Alberta Health Services' Edmonton STI CLinic Public Health Outreach Team* Winnepeg, Manitoba: National Collaborating Centre for Infectious Diseases

Blanchard, J. F., & Aral, S. O. (2011). Program Science: an initiative to improve the planning, implementation and evaluation of HIV/sexually transmitted infection prevention programmes. *Sex Transm Infect, 87*(1).

Bolsewicz, K., Vallely, A., Debattista, J., Whittaker, A., & Fitzgerald, L. (2015). Factors impacting HIV testing: a review - perspectives from Australia, Canada, and the UK. *AIDS Care, 27*(5), 570-580. doi:10.1080/09540121.2014.986050

Bouis, S., Reif, S., Whetten, K., Scovil, J., Murray, A., & Swartz, M. (2007). An Integrated, Multidimensional Treatment Model for Individuals Living with HIV, Mental Illness, and Substance Abuse. *Health & Social Work, 32*(4), 268-278.

Bourassa, C. (2008). *Destruction of the Métis Nation: Health consequences.* ProQuest Dissertations Publishing, (Dissertation/Thesis)

Bourassa, C. (2018). Addressing the Duality of Access to Healthcare for Indigenous Communities: Racism and Geographical Barriers to Safe Care. *HealthcarePapers, 17*(3), 6-10. doi:10.12927/hcpap.2018.25507

Boyer, Y. (2019). Aboriginal Society and Good Health In *Moving Aboriginal Health Forward: Discarding Canada's Legal Barriers* Purich Publishing

Bruchac, M. M. (2014). Indigenous knowledge and traditional knowledge. *Encyclopedia of Global Archaeology*, 3814-3824.

Burns, J., Dagmar, P., Paz, S., & Advancement Project. (2012). Participatory Asset Mapping: A Community Research Lab Toolkit 43. Retrieved from http://www.communityscience.com/knowledge4equity/AssetMappingToolkit.pdf

Byng, R., Norman, I., Redfern, S., & Jones, R. (2008). Exposing the key functions of a complex intervention for shared care in mental health: case study of a process evaluation. *BMC Health Services Research, 8*(1), 274-274. doi:10.1186/1472-6963-8-274

Canadian Aboriginal AIDS Network. (2005). *Supporting Metis Needs: Creating Healthy Individuals and Communities in the Context of HIV/AIDS*. 602-251 Bank Street

Ottawa, Ontario, K2P 1X3: Canadian Aboriginal AIDS Network

Canadian Aboriginal AIDS Network. (2008). *Relational care: A guide to health care and support for Aboriginal people living with HIV/AIDS.*

Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science, 2*(1), 40. doi:10.1186/1748-5908-2-40

Chandler, M. J., & Lalonde, C. (1998). Cultural Continuity as a Hedge against Suicide in Canada's First Nations. *Transcultural Psychiatry, 35*(2), 191-219. doi:10.1177/136346159803500202

Chandna, K., Vine, M. M., Snelling, S., Harris, R., Smylie, J., & Manson, H. (2019). Principles, Approaches, and Methods for Evaluation in Indigenous Contexts: A Grey Literature Scoping Review. *Canadian Journal of Program Evaluation, 34*(1). doi:10.3138/cjpe.43050

Chartier, C. (2018). *"Addressing the Integrity of the Historic Metis Nation Homeland"* Retrieved from https://www.metisnation.ca/wp-content/uploads/2018/11/MNO-Nov-2018-Report-Recommendations-appendices-final.pdf

Cheng, W., Nazareth, S., & Flexman, J. P. (2015). Statewide hepatitis C model of care for rural and remote regions. *Journal Of Gastroenterology And Hepatology, 30 Suppl 2*, 1-5. doi:10.1111/jgh.12863

Chevaliez, S., & Pawlotsky, J.-M. (2018). New virological tools for screening, diagnosis and monitoring of hepatitis B and C in resource-limited settings. *Journal of Hepatology, 69*(4), 916-926. doi:10.1016/j.jhep.2018.05.017

Cochran, P. A. L., Marshall, C. A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., & Gover, R. M. S. (2008). Indigenous Ways of Knowing: Implications for Participatory Research and Community. *American Journal of Public Health, 98*(1), 22-27. doi:10.2105/AJPH.2006.093641

Collins, A. B., Strike, C., Guta, A., Baltzer Turje, R., McDougall, P., Parashar, S., & McNeil, R. (2017). "We're giving you something so we get something in return": Perspectives on research participation and compensation among people living with HIV who use drugs. *The International journal on drug policy, 39*, 92. doi:10.1016/j.drugpo.2016.09.004

Cooper, E. J., & Driedger, S. M. (2018). Creative, strengths-based approaches to knowledge translation within indigenous health research. *Public Health, 163*, 61-66. doi:10.1016/j.puhe.2018.06.020

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ, 337*, a1655. doi:10.1136/bmj.a1655

Craine, N., Parry, J., O'Toole, J., D'Arcy, S., & Lyons, M. (2009). Improvingblood-borne viral diagnosis; clinical audit of the uptake of dried blood spot testing offered by a substance misuse service. *Journal of Viral Hepatitis, 16*(3), 219-222. doi:10.1111/j.1365-2893.2008.01061.x

Craine, N., Whitaker, R., Perrett, S., Zou, L., Hickman, M., & Lyons, M. (2015). A stepped wedge cluster randomized control trial of dried blood spot testing to improve the uptake of hepatitis C antibody testing within UK prisons. *European journal of public health, 25*(2), 351-357. doi:10.1093/eurpub/cku096

Dalcin, D., & Bogoch, I. I. (2018). Point-of-care testing for HIV. *Canadian Medical Association Journal, 190*(18), E569-E569. doi:10.1503/cmaj.180068

Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation science : IS, 4*(1), 50-50. doi:10.1186/1748-5908-4-50

Dane, A. V., & Schneider, B. H. (1998). PROGRAM INTEGRITY IN PRIMARY AND EARLY SECONDARY PREVENTION: ARE IMPLEMENTATION EFFECTS OUT OF CONTROL? *Clinical Psychology Review, 18*(1), 23-45. doi:10.1016/S0272-7358(97)00043-3

Drobnik, A., Judd, C., Banach, D., Egger, J., Konty, K., & Rude, E. (2011). Public health implications of rapid hepatitis C screening with an oral swab for community-based organizations serving high-risk populations. *American Journal of Public Health, 101*(11), 2151-2155. doi:10.2105/AJPH.2011.300251

DRUM & SASH. (2020). The DRUM & SASH Project Retrieved from https://www.drumandsash.ca/

Dyck, M. (2009). *Social Determinants of Metis Health*. Ottawa, Ontario: National Aboriginal Health Organization

Edge, L., & McCallum, T. (2006). MÉTIS IDENTITY: SHARING TRADITIONAL KNOWLEDGE AND HEALING PRACTICES AT MÉTIS ELDERS'GATHERINGS. *Pimatisiwin: A Journal of Aboriginal & Indigenous Community Health, 4*(2).

Eisinger, R. W., Dieffenbach, C. W., & Fauci, A. S. (2019). HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable. *JAMA, 321*(5), 451. doi:10.1001/jama.2018.21167

Ellison, C. (2014). Indigenous knowledge and knowledge synthesis translation and exchange. Retrieved from Ellison, C. (2014). Indigenous Knowledge and Knowledge Synthesis Translation and Exchange (KTSE). Prince George, BC: National Collaborating Centre for Aboriginal Health

Evans, M., Anderson, C., Dietrich, D., Bourassa, C., Logan, T., Berg, L., & Devolder, E. (2012). Funding and Ethics in Métis Community Based Research. *International Journal of Critical Indigenous Studies, 5*, 54-66. doi:10.5204/ijcis.v5i1.94

First Nations Health Authority. (n.d.). *FNHA's Policy Statement on Cultural Safety and Humility* Retrieved from https://www.fnha.ca/Documents/FNHA-Policy-Statement-Cultural-Safety-and-Humility.pdf

Fish, S. (2017). Hepatitis C point of care testing: What is its impact on testing and linkage to care? Retrieved from https://www.catie.ca/en/pif/spring-2017/hepatitis-c-point-care-testing-what-its-impact-testing-and-linkage-care#footnote6_auybdbs

Fitzpatrick, E. F. M., Martiniuk, A. L. C., D'Antoine, H., Oscar, J., Carter, M., & Elliott, E. J. (2016). Seeking consent for research with indigenous communities: a systematic review. *BMC medical ethics 17*(1), 65.

Flaminio, A. C., Gaudet, J. C., & Dorion, L. M. (2020). Métis women gathering: visiting together and voicing wellness for ourselves. *AlterNative: An International Journal of Indigenous Peoples, 0*(0), 1177180120903499. doi:10.1177/1177180120903499

Gaglio, B., Shoup, J. A., & Glasgow, R. E. (2013). The RE-AIM framework: a systematic review of use over time. *American Journal of Public Health, 103*(6), e38-e46. doi:10.2105/AJPH.2013.301299

Gahagan, J., Minichiello, A., Swab, M., Marshall, Z., Hodge, K., Gaudry, S., . . . Schwandt, M. (2018). HIV point-of-care testing in non-urban settings: A scoping review. *The Canadian Journal of Human Sexuality, 27*(1), 12-20. doi:10.3138/cjhs.2017-0034

Gaudet, J. C. (2019). Keeoukaywin: The Visiting Way - Fostering an Indigenous Research Methodology. *aboriginal policy studies, 7*(2). doi:10.5663/aps.v7i2.29336

Gaudry, A. (2018a). *Better late than never? Canada's reluctant recognition of Metis rights and self-government*. Yellowhead Institute Retrieved from https://yellowheadinstitute.org/2018/08/21/better-late-than-never-canadas-reluctant-recognition-of-metis-rights-and-self-government/

Gaudry, A. (2018b). Communing with the Dead: The "New Métis," Métis Identity Appropriation, and the Displacement of Living Métis Culture. *American Indian Quarterly, 42*(2), 162-190. doi:10.5250/amerindiquar.42.2.0162

George, M. A., Daniel, M., & Green, L. W. (2006). Appraising and Funding Participatory Research in Health Promotion. *International Quarterly of Community Health Education, 26*(2), 171-187. doi:10.2190/R031-N661-H762-7015

Girardin, F., Hearmon, N., Negro, F., Eddowes, L., Bruggmann, P., & Castro, E. (2019). Increasing hepatitis C virus screening in people who inject drugs in Switzerland using rapid antibody saliva and dried blood spot testing: A cost-effectiveness analysis. *Journal of Viral Hepatitis, 26*(2), 236-245. doi:10.1111/jvh.13023

Glasgow, R. E., Klesges, L. M., Dzewaltowski, D. A., Estabrooks, P. A., & Vogt, T. M. (2006). Evaluating the impact of health promotion programs: using the RE-AIM framework to form summary measures for decision making involving complex issues. *Health education research, 21*(5), 688-694. doi:10.1093/her/cyl081

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *American Journal of Public Health, 89*(9), 1322-1327. doi:10.2105/AJPH.89.9.1322

Government of Alberta. (2010). *The Syphilis Outbreak in Alberta* Edmonton, AB Retrieved from https://open.alberta.ca/publications/6959825

Government of Alberta. (2015). *HIV-Positive Individuals Who are Unwilling or Unable to Prevent the Spread of HIV in Alberta* Edmonton, Alberta: Office of the Chief Medical Officer of Health Retrieved from http://www.health.alberta.ca/about/OCMOH-reports.html

Government of Alberta. (2018). HIV Testing: Should I Get Tested for Human Immunodeficiency Virus? Retrieved from https://myhealth.alberta.ca/Health/Pages/conditions.aspx?hwid=abl4059&lang=en-ca

Government of Alberta. (2019a). *Alberta Sexually Transmitted Infections and HIV 2018*. Edmonton, AB

Government of Alberta. (2019b). *First Nations - Health Trends in Alberta: Rates of hepatitis C diagnoses among First Nations people by Zone, both sexes, Alberta, 2005-2018* Retrieved from http://www.afnigc.ca/main/includes/media/pdf/fnhta/HTAFN-2019-03-05-HepC%20by%20Zone%20FN.pdf

Government of Canada. (2018). *Tri Council Policy Statement 2 Chapter 3 - The Consent Process* Retrieved from https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter3-chapitre3.html#d

Government of Canada. (2019). Social determinants of health and health inequalities. Retrieved from https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health.html

Government of Saskatchewan. (2017). *HIV Prevention and Control Report* Saskatoon Retrieved from http://publications.gov.sk.ca/documents/13/108029-2017-Saskatchewan-HIV-Prevention-and-Control-Report.pdf

Greenwood, M. L., & de Leeuw, S. N. (2012). Social determinants of health and the future well-being of Aboriginal children in Canada. *Paediatrics & child health, 17*(7), 381-384. Retrieved from https://pubmed.ncbi.nlm.nih.gov/23904782
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3448539/

Grover, J. G. (2008). CHALLENGES IN APPLYING INDIGENOUS EVALUATION PRACTICES IN MAINSTREAM GRANT PROGRAMS TO INDIGENOUS COMMUNITIES. *The Canadian Journal of Program Evaluation, 23*(2), 33.

Guta, A., Flicker, S., Travers, R., Switzer, S., Bungay, V., Husbands, W., . . . Worthington, C. (2014). *HIV CBR Ethics: Ethical Issues Related to Compensation* Retrieved from http://www.hivethicscbr.com/documents/HIVCBREthics_FactSheet01.pdf

Haddad, N., Li, J., Totten, S., & McGuire, M. (2018). HIV in Canada - Surveillance Report, 2017. *Can Commun Dis Rep, 44*, 9. doi: https://doi.org/10.14745/ccdr.v44i12a03

Haggarty, J., Klein, R., Chaudhuri, B., Boudreau, D., & McKinnon, T. (2008). After Shared Care: Patients' Symptoms and Functioning 3 to 6 Months Following Care at A Rural Shared Mental Health Care Clinic. *Canadian Journal of Community Mental Health, 27*(2), 47-54. doi:10.7870/cjcmh-2008-0017

Haggarty, J., Ryan-Nicholls, K., & Jarva, J. (2010). Mental health collaborative care: a synopsis of the Rural and Isolated Toolkit. *Rural and remote health 10*(3), 1314.

Harden, S. M., Smith, M. L., Ory, M. G., Smith-Ray, R. L., Estabrooks, P. A., & Glasgow, R. E. (2018). RE-AIM in Clinical, Community, and Corporate Settings: Perspectives, Strategies, and Recommendations to Enhance Public Health Impact. *Frontiers in public health, 6*, 71. doi:10.3389/fpubh.2018.00071

Hart, M. A. (2010). Indigenous worldviews, knowledge, and research: the development of an indigenous research paradigm *Journal of Indigenous Voices in Social Work, 1*(1).

Health Canada. (2013). *First Nations Health Status Report - Alberta Region 2011-12*. Retrieved from http://publications.gc.ca/collections/collection_2013/sc-hc/H26-4-2012-eng.pdf

Herbst, J. H., Glassman, M., Carey, J. W., Painter, T. M., Gelaude, D. J., Fasula, A. M., . . . Purcell, D. W. (2012). Operational Research to Improve HIV Prevention in the United States. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 59*(5), 530-536. doi:10.1097/QAI.0b013e3182479077

HIV Community Link. (2017). *New to Alberta: What You Need to Know*. Calgary, AB: HIV Community Link

HIV Community Link. (n.d.). Where to Go. Retrieved from https://hivcl.org/where-to-go/

Hoang, T., Goetz, M. B., Yano, E. M., Rossman, B., Anaya, H. D., Knapp, H., . . . Asch, S. M. (2009). The Impact of Integrated HIV Care on Patient Health Outcomes. *Medical Care, 47*(5), 560-567. doi:10.1097/MLR.0b013e31819432a0

Hogue, M. (2015). *Metis and the medicine line: creating a border and dividing a people*. Regina, Saskatchewan, Canada: University of Regina Press.

Hussain, R., Maple, M., Hunter, S. V., Mapedzahama, V., & Reddy, P. (2015). The Fly-in Fly-out and Drive-in Drive-out model of health care service provision for rural and remote

Australia: benefits and disadvantages. *Rural And Remote Health, 15*(3), 3068-3068. Retrieved from http://ezproxy.library.uvic.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=mnh&AN=26190237&site=ehost-live&scope=site

Hutchinson, J., Sutcliffe, L. J., Williams, A. J., & Estcourt, C. S. (2015). Developing new models of shared primary and specialist HIV care in the UK: a survey of current practice. *International Journal Of STD & AIDS*. Retrieved from http://ezproxy.library.uvic.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=mnh&AN=26113516&site=ehost-live&scope=site

Indigenous Services Canada. (2019). *Non-Insured Health Benefits (NIHB) Medical Transportation Policy Framework (Interim)* Retrieved from https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/reports-publications/non-insured-health-benefits.html

Infectious syphilis outbreak declared in Alberta. (2019). *Edmonton Journal*. Retrieved from https://edmontonjournal.com/

Israel, B., Schulz, A., Parker, E., & Becker, A. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annual review of public health, 19*(1), 173-202. doi:10.1146/annurev.publhealth.19.1.173

Jakes, S., Hardison-Moody, A., Bowen, S., & Blevins, J. (2015). Engaging community change: the critical role of values in asset mapping. *Community Development, 46*(4), 392-406. doi:10.1080/15575330.2015.1064146

Johnston, C. (2017). The HIV Testing Process. Retrieved from https://www.catie.ca/en/fact-sheets/testing/hiv-testing-process

Jongbloed, K., Pooyak, S., Sharma, R., Mackie, J., Pearce, M. E., Laliberte, N., . . . For the Cedar Project, P. (2019). Experiences of the HIV Cascade of Care Among Indigenous Peoples: A Systematic Review. *AIDS and Behavior, 23*(4), 984-1003. doi:10.1007/s10461-018-2372-2

Jordan, S., Stocek, C., Mark, R., & Matches, S. (2009). Doing Participatory Evaluation: from "Jagged World Views" to Indigenous Methodology. *The Australian Journal of Indigenous Education, 38*(1), 74-82. doi:10.1375/S1326011100000612

Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation science : IS, 12*(1), 150-159. doi:10.1186/s13012-017-0696-3

Kahn, L., Hewes, S., & Ali, R. (2009). *Taking the lead: Youth leadership in theory and practice*. Retrieved from https://youngfoundation.org/wp-content/uploads/2012/10/Taking-the-Lead-October-2009.pdf

Katz, I. T., Ryu, A. E., Onuegbu, A. G., Psaros, C., Weiser, S. D., Bangsberg, D. R., & Tsai, A. C. (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society, 16*(3 Suppl 2), 18640-n/a. doi:10.7448/IAS.16.3.18640

Kawakami, A. J., Aton, K., Cram, F., Lai, M., & Porima, L. (2008). Improving the practice of evaluation through indigenous values and methods. *Fundamental issues in evaluation*, 219-242.

Kelly, B. J., Perkins, D. A., Fuller, J. D., & Parker, S. M. (2011). Shared care in mental illness: A rapid review to inform implementation. *International Journal Of Mental Health Systems, 5*(1), 31.

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

Kermoal, N. (2016). Metis Women's Environmental Knowledge and the Recognition of Metis Rights In N. Kermoal & I. Altamirano-Kimenez (Eds.), *Living on the Land: Indigenous Women's Understanding of Place* AU Press, Athabasca University

Kirk, M. A., Kelley, C., Yankey, N., Birken, S. A., Abadie, B., & Damschroder, L. (2016). A systematic review of the use of the Consolidated Framework for Implementation Research. *Implementation science : IS, 11*(1), 72. doi:10.1186/s13012-016-0437-z

Kitson, A., Harvey, G., & McCormack, B. (1998). Enabling the implementation of evidence based practice: a conceptual framework. *Quality in Health Care, 7*(3), 149-158. doi:10.1136/qshc.7.3.149

Kitson, A., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. *Implementation science : IS, 3*(1), 1-1. doi:10.1186/1748-5908-3-1

Knowles, Z., & Wilton, J. (2018). *HIV Testing Technologies*. CATIE: Canada's Source for HIV and Hepatitis C Information Retrieved from https://www.catie.ca/en/fact-sheets/testing/hiv-testing-technologies

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

Krause, J., Subklew-Sehume, F., Kenyon, C., & Colebunders, R. (2013). Acceptability of HIV self-testing: a systematic literature review. *BMC public health, 13*(1), 735-735. doi:10.1186/1471-2458-13-735

Kroon, H., Ke, R., Wensing, M. J. P., Grol, R. P. T. M., Franx, G., & Grimshaw, J. (2008). Organizational change to transfer knowledge and improve quality and outcomes of care for patients with severe mental illness: a systematic overview of reviews. *Canadian Journal of Psychiatry-Revue Canadienne de Psychiatrie, 53*(5), 294-305.

Kumar, M. B., Wesche, S., & McGuire, C. (2012). Trends in Métis-related Health Research (1980-2009): Identification of Research Gaps. *Canadian Journal of Public Health / Revue Canadienne de Sante'e Publique, 103*(1), 23-28. doi:10.1007/BF03404064

Lachowsky, N. (2019). Sex Now 2019 Dried Blood Spot Collection in BC.

Lange, B., Roberts, T., Cohn, J., Greenman, J., Camp, J., Ishizaki, A., . . . Easterbrook, P. (2017). Diagnostic accuracy of detection and quantification of HBV-DNA and HCV-RNA using dried blood spot (DBS) samples – a systematic review and meta-analysis. *BMC infectious diseases, 17*(1), 693. doi:10.1186/s12879-017-2776-z

LaVallee, A. (2014). *Converging Methods and Tools: A Métis Group Model Building Project on Tuberculosis.* University of Saskatchewan,

Laveaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key Principles of CBPR meet the Indigenous research context. *Pimatisiwin, 7*(1), 1-1.

LetsGetChecked. (2020). Reach your resolution with LetsGetChecked. Retrieved from https://www.letsgetchecked.com/ca/en/

Lobb, R., & Colditz, G. A. (2013). Implementation science and its application to population health. *Annual review of public health, 34*(1), 235-251. doi:10.1146/annurev-publhealth-031912-114444

Lobo, R., Mascarenhas, L., Worthington, D., Bevan, J., & Mak, D. B. (2015). Evaluation of the regional nurse-supported hepatitis C shared care program in Western Australia: a mixed methods study. *BMC Health Services Research, 15*, 399-399. doi:10.1186/s12913-015-1055-1

Lodge, A., & Klinic Community Health. (2019). The importance of asking: what do the communities that we serve need? Retrieved from http://klinic.mb.ca/2019/07/the-importance-of-asking-what-do-the-communities-we-serve-need/

Lombard, F., Proescholdbell, R. J., Cooper, K., Musselwhite, L., & Quinlivan, E. B. (2009). Adaptations across clinical sites of an integrated treatment model for persons with HIV and substance abuse. *AIDS patient care and STDs, 23*(8), 631-638. doi:10.1089/apc.2008.0260

Loppie Reading, C., & Wien, F. (2009). *Health Inequalities and the Social Determinants of Aboriginal Peoples' Health*: National Collaborating Centre for Aboriginal Health

Maar, M. A., Erskine, B., McGregor, L., Larose, T. L., Sutherland, M. E., Graham, D., . . . Gordon, T. (2009). Innovations on a shoestring: a study of a collaborative community-based Aboriginal mental health service model in rural Canada. *International Journal Of Mental Health Systems, 3*, 27-27. doi:10.1186/1752-4458-3-27

Macdougall, B. (2017). *Land,family and Identity: Contextualizing Metis Health and Well Being*. S.l.: National Collaborating Centre for Determinants of Health.

MacGowan, R. J., Chavez, P. R., Gravens, L., Wesolowski, L. G., Sharma, A., McNaghten, A. D., . . . Group, f. t. e. S. (2018). Pilot Evaluation of the Ability of Men Who Have Sex with Men to Self-Administer Rapid HIV Tests, Prepare Dried Blood Spot Cards, and Interpret Test Results, Atlanta, Georgia, 2013. *AIDS and Behavior, 22*(1), 117-126. doi:10.1007/s10461-017-1932-1

Maldonado, J., Bennett, T. M. B., Chief, K., Cochran, P., Cozzetto, K., Gough, B., . . . Voggesser, G. (2016). Engagement with Indigenous Peoples and honoring traditional knowledge systems. *Climatic Change, 135*(1), 111-126. doi:10.1007/s10584-015-1535-7

Mapp, F., Hutchinson, J., & Estcourt, C. (2015). A systematic review of contemporary models of shared HIV care and HIV in primary care in high-income settings. *International Journal Of STD & AIDS, 26*(14), 991-997. doi:10.1177/0956462415577496

Martens, P., Bartlett, J. G., Burland, E., Prior, H., Burchill, C., Huq, S., . . . Bailly, A. (2010). *Profile of Métis health status and healthcare utilization in Manitoba: a population-based study*. Winnipeg, Man: Manitoba Centre for Health Policy.

Martin, D. (2012). Two-eyed seeing: a framework for understanding indigenous and non-indigenous approaches to indigenous health research. *The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres, 44*(2), 20-42.

Martin, F. (1988). *Federal and provincial responsibility in the Metis settlements of Alberta* Retrieved from http://publications.gc.ca/collections/collection_2018/aanc-inac/R32-425-1988-eng.pdf

Martin, N., Hickman, M., Miners, A., Hutchinson, S., Taylor, A., & Vickerman, P. (2013). Cost-effectiveness of HCV case-finding for people who inject drugs via dried blood spot testing in specialist addiction services and prisons. *BMJ Open, 3*(8), e003153. doi:10.1136/bmjopen-2013-003153

May, C. R., Johnson, M., & Finch, T. (2016). Implementation, context and complexity. *Implementation science : IS, 11*(1), 141. doi:10.1186/s13012-016-0506-3

McCallum-McLeod, L., Willson, K., Northwest Metis Women's Health Research Committee, & Prairie Women's Health Centre of Excellence. (2004). *Northwest Saskatchewan Metis women's health: research discussion paper for the Northwest Metis Women's Health Research Committee*. Winnipeg, Man: Prairie Women's Health Centre of Excellence.

McGuire, J., Gelberg, L., Blue-Howells, J., & Rosenheck, R. A. (2009). Access to primary care for homeless veterans with serious mental illness or substance abuse: a follow-up evaluation of co-located primary care and homeless social services. *Administration and policy in mental health, 36*(4), 255-264. doi:10.1007/s10488-009-0210-6

McLeod, A., Gervais, L., Van Haute, S., Cyr, M., Nenakawekapo, P., Witges, K., . . . Magwood, B. (2019). *Enhanced STBBI Testing at Indigenous Events in Manitoba.* Paper presented at the The 28th Annual Conference on HIV/AIDS Research Saskatoon, Saskatchewan

McLeod, A., Weir, A., Aitken, C., Gunson, R., Templeton, K., Molyneaux, P., . . . Hutchinson, S. (2014). Rise in testing and diagnosis associated with Scotland's Action Plan on Hepatitis C and introduction of dried blood spot testing. *Journal of Epidemiology and Community Health, 68*(12), 1182-1188. doi:10.1136/jech-2014-204451

Métis Centre of the National Aboriginal Health Organization. (2011). *Paucity of Metis-Specific Health and Well-being Data and Information: Underlying Factors*.

Métis Nation of Alberta. (2018). *Annual Report 2017-2018.* Retrieved from http://albertametis.com/wp-content/uploads/2018/12/AGA-Report-2018.2-ilovepdf-compressed-1.pdf

Métis Nation of Alberta. (2019a). Health. Retrieved from http://albertametis.com/programs-services/health/

Métis Nation of Alberta. (2019b). History Retrieved from http://albertametis.com/about/history/

Métis Nation of Ontario. (2020). Historic Research. Retrieved from http://www.metisnation.org/registry/citizenship/historic-research/

Métis National Council. (2011). *Metis Registration Guide* Ottawa, Ontario Retrieved from https://www.metisnation.ca/wp-content/uploads/2011/04/M%C3%A9tis-Registration-Guide.pdf

Métis National Council. (n.d.). The Metis Nation. Retrieved from https://www.metisnation.ca/index.php/who-are-the-metis

Mill, J. E., Jackson, R. C., Worthington, C. A., Archibald, C. P., Wong, T., Myers, T., . . . Sommerfeldt, S. (2008). HIV testing and care in Canadian Aboriginal youth: a community based mixed methods study. *BMC infectious diseases, 8*(1), 132-132. doi:10.1186/1471-2334-8-132

Minkler, M., & Wallerstein, N. (2008). *Community-based participatory research for health: from process to outcomes* (2nd;2. Aufl.; ed.). San Francisco, CA: Jossey-Bass.

Monchalin, R. (2019). *Digging up the Medicines: Urban Metis Women's Identity and Experiences with Health and Social Services in Toronto, Ontario.* University of Toronto, Retrieved from https://tspace.library.utoronto.ca/handle/1807/97587

Monchalin, R., & Bourassa, C. (2019). A Culturally Specific Approach: Developing a Metis Methodology for HIV Research. *Journal of Indigenous HIV Research, 10*.

Monchalin, R., Flicker, S., Wilson, C., Prentice, T., Oliver, V., Jackson, R., . . . Network, N. Y. S. H. (2016a). "When you follow your heart, you provide that path for others": Indigenous Models of Youth Leadership in HIV Prevention. *International Journal of Indigenous Health, 11*(1), 135. doi:10.18357/ijih111201616012

Monchalin, R., Lesperance, A., Flicker, S., Logie, C., & Network, N. Y. S. H. (2016b). Sexy Health Carnival on the Powwow Trail: HIV Prevention by and for Indigenous Youth. *International Journal of Indigenous Health, 11*(1), 159. doi:10.18357/ijih111201616011

Monchalin, R., Smylie, J., Bourgeois, C., & Firestone, M. (2019). "I would prefer to have my health care provided over a cup of tea any day": Recommendations by urban metis women to improve access to health and social services in toronto for the metis community. *AlterNative: An International Journal of Indigenous Peoples, 15*(3), 217-225. doi:10.1177/1177180119866515

Monchalin, R., Smylie, J., & Nowgesic, E. (2020). "I Guess I Shouldn't Come Back Here": Racism and Discrimination as a Barrier to Accessing Health and Social Services for Urban Métis Women in Toronto, Canada. *Journal of racial and ethnic health disparities 7*(2), 251.

Montaner, J. S. G., Hogg, R., Wood, E., Kerr, T., Tyndall, M., Levy, A. R., & Harrigan, P. R. (2006). The case for expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic. *The Lancet, 368*(9534), 531-536. doi:10.1016/S0140-6736(06)69162-9

Mooss, A., Hartman, M., & Ibañez, G. (2015). Manual development: A strategy for identifying core components of integrated health programs. *Evaluation and Program Planning, 53*, 57-64. doi:10.1016/j.evalprogplan.2015.08.004

Morse, J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research, 25*(9), 1212-1222. doi:10.1177/1049732315588501

Mykhalovskiy, E., Patten, S., Sanders, C., Bailey, M., & Taylor, D. (2009). Beyond buzzwords: toward a community-based model of the integration of HIV treatment and prevention. *AIDS Care, 21*(1), 25-30. doi:10.1080/09540120802068753

NAHO: Métis Centre. (2010). Principles of Ethical Metis Research

Negin, J., Aspin, C., Gadsden, T., & Reading, C. (2015). HIV Among Indigenous Peoples: A Review of the Literature on HIV-Related Behaviour Since the Beginning of the Epidemic. *AIDS and Behavior, 19*(9), 1720-1734. doi:10.1007/s10461-015-1023-0

Neuhaus, M. (2010). The Marriage of Mother and Father: Michif Influences as Expressions of Métis Intellectual Sovereignty in Stories of the Road Allowance People. *Studies in American Indian Literatures, 22*(1), 20-48. doi:10.1353/ail.0.0114

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science, 10*(53).

Norton, W. E., Lungeanu, A., Chambers, D. A., & Contractor, N. (2017). Mapping the growing discipline of dissemination and implementation science in health. *Scientometrics, 112*(3), 1367-1390. doi:10.1007/s11192-017-2455-2

Nyambi, P. N., Fransen, K., Beenhouwer, H. D., Chomba, E. N., Temmerman, M., Ndinya-Achola, J. O., . . . Groen, G. v. d. (1994). Detection of human immunodeficiency virus type 1 (HIV-1) in heel prick blood on filter paper from children born to HIV-1-seropositive mothers. *Journal of Clinical Microbiology, 32*(11), 2858-2860.

Nyman, S. A. (2014). *Indigenous Ceremony and Traditional Knowledge: Exploring their use as models for healing the impacts of traumatic experiences*. Victoria, British Columbia University of Victoria.

O'Byrne, P., & Bryan, A. (2013). Resisting Public Health Surveillance: Anonymous HIV Testing and the Imperative of Health. *Surveillance & Society, 11*(1/2), 35-54. doi:10.24908/ss.v11i1/2.4326

Ory, M. G., Altpeter, M., Belza, B., Helduser, J., Zhang, C., & Smith, M. L. (2015). Perceived Utility of the RE-AIM Framework for Health Promotion/Disease Prevention Initiatives for Older Adults: A Case Study from the U.S. Evidence-Based Disease Prevention Initiative. *Frontiers in public health, 2*(143). doi:10.3389/fpubh.2014.00143

Ouellette, R. (2011). *Evaluating Aboriginal Curricula using a Cree-Metis Perspective with a Regard Towards Indigenous Knowledge.* Laval University,

Padgett, D. (2012). *Qualitative and mixed methods in public health*. Thousand Oaks, Calif: SAGE.

Papps, E., & Ramsden, I. (1996). Cultural safety in nursing: the New Zealand experience. *International journal for quality in health care : journal of the International Society for Quality in Health Care, 8*(5), 491-497. doi:10.1093/intqhc/8.5.491

Parekh, J., Stuart, E., Blum, R., Caldas, V., Whitfield, B., & Jennings, J. M. (2019). Addressing the Adherence-Adaptation Debate: Lessons from the Replication of an Evidence-Based Sexual Health Program in School Settings. *Prevention Science, 20*(7), 1074-1088. doi:10.1007/s11121-019-01032-2

Parker, S. P., & Cubitt, W. D. (1999). The use of the dried blood spot sample in epidemiological studies. *Journal of clinical pathology, 52*(9), 633-639. doi:10.1136/jcp.52.9.633

Patton, J. C., Akkers, E., Coovadia, A. H., Meyers, T. M., Stevens, W. S., & Sherman, G. G. (2007). Evaluation of Dried Whole Blood Spots Obtained by Heel or Finger Stick as an Alternative to Venous Blood for Diagnosis of Human Immunodeficiency Virus Type 1 Infection in Vertically Exposed Infants in the Routine Diagnostic Laboratory. *Clinical and Vaccine Immunology, 14*(2), 201-203. doi:10.1128/cvi.00223-06

Prentice, T., Mill, J., Archibald, C. P., Sommerfeldt, S., Worthington, C., Jackson, R., & Wong, T. (2011). Aboriginal Youth Experiences of Accessing HIV Care and Treatment. *Journal of HIV/AIDS & Social Services, 10*(4), 395-413. doi:10.1080/15381501.2011.623903

Public Health Agency of Canada. (2010a). Epi-Update: Hepatitis C virus (HCV) among Aboriginal People Surveyed by Three National Enhanced Surveillance Systems in Canada.

Public Health Agency of Canada. (2010b). *HIV/AIDS Among Aboriginal People in Canada*.

Public Health Agency of Canada. (2014). *HIV/AIDS Epi Updates Chapter 1: National HIV Prevalence and Incidence Estimates for 2011*. Centre for Communicable Diseases and Infection Control

Public Health Agency of Canada. (2018). *Summary: Measuring Canada's Progress on the 90-90-90 HIV Targets, 2016*.

Public Health Agency of Canada. (2019). Report on Hepatitis B and C in Canada: 2017

Public Health Ontario. (2017). *Hepatitis C Virus (HCV) RNA detection using dried blood spots*. Public Health Ontario Retrieved from https://www.publichealthontario.ca/-/media/documents/lab/lab-sd-123-hcv-rna-detection-dbs.pdf?la=en

Pyne, J. M., Fortney, J. C., Tripathi, S. P., Maciejewski, M. L., Edlund, M. J., & Williams, D. K. (2010). Cost-effectiveness Analysis of a Rural Telemedicine Collaborative Care Intervention for Depression. *Archives of General Psychiatry, 67*(8), 812-821. doi:10.1001/archgenpsychiatry.2010.82

Radley, A., Melville, K., Tait, J., Stephens, B., Evans, J. M. M., & Dillon, J. F. (2017). A quasi-experimental evaluation of dried blood spot testing through community pharmacies in the Tayside region of Scotland. *Frontline gastroenterology, 8*(3), 221-228. doi:10.1136/flgastro-2016-100776

Reading, J. (2009). *A Life Course Approach to the Social Determinants of Health for Aboriginal Peoples'*. Retrieved from https://sencanada.ca/content/sen/Committee/402/popu/rep/appendixAjun09-e.pdf

Richardson, C. L. (2016). *Belonging Métis*. Vernon, British Columbia: JCharlton Publishing Ltd.

Robbins, J. A., & Dewar, J. (2011). Traditional Indigenous Approaches to Healing and the modern welfare of Traditional Knowledge, Spirituality and Lands: A critical reflection on practices and policies taken from the Canadian Indigenous Example. *International Indigenous Policy Journal, 2*(4), 2. doi:10.18584/iipj.2011.2.4.2

Rubio, D. M., Schoenbaum, E. E., Lee, L. S., Schteingart, D. E., Marantz, P. R., Anderson, K. E., . . . Esposito, K. (2010). Defining translational research: implications for training. *Academic medicine : journal of the Association of American Medical Colleges, 85*(3), 470-475. doi:10.1097/ACM.0b013e3181ccd618

Ruffinen, C. Z., Sabidó, M., Díaz-Bermúdez, X. P., Lacerda, M., Mabey, D., Peeling, R. W., & Benzaken, A. S. (2015). Point-of-care screening for syphilis and HIV in the borderlands: challenges in implementation in the Brazilian Amazon. *BMC Health Services Research, 15*(1), 495. doi:10.1186/s12913-015-1155-y

Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). Los Angeles: SAGE.

Samy, D. C., Hall, P., Rounsevell, J., & Carr, R. (2007). 'Shared Care - Shared Dream': Model of shared care in rural Australia between mental health services and general practitioners. *The Australian Journal Of Rural Health, 15*(1), 35-40. Retrieved from http://ezproxy.library.uvic.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=mnh&AN=17257297&site=ehost-live&scope=site

Saunders, K., & Dubois, J. (2019). *Métis politics and governance in Canada*. Vancouver;Toronto;: UBC Press.

Seña, A. C., White, B. L., & Sparling, P. F. (2010). Novel Treponema pallidum Serologic Tests: A Paradigm Shift in Syphilis Screening for the 21st Century. *Clinical Infectious Diseases, 51*(6), 700-708. doi:10.1086/655832

Shining Mountains Living Community Services. (2011). Red River Forks Tool Retrieved from http://www.smlcs.ca/resources.html

Shining Mountains Living Community Services. (n.d.). Welcome to Shining Mountains Aboriginal Owned, Staffed, and Operated in Central Alberta. Retrieved from http://www.smlcs.ca/

Sloan, K. (2017). ALWAYS COMING HOME: METIS LEGAL UNDERSTANDINGS OF COMMUNITY AND TERRITORY. *Windsor Yearbook of Access to Justice, 33*(1), 125-147. doi:10.22329/wyaj.v33i1.4814

Smit, P. W., Sollis, K. A., Fiscus, S., Ford, N., Vitoria, M., Essajee, S., . . . Peeling, R. W. (2014). Systematic review of the use of dried blood spots for monitoring HIV viral load and for early infant diagnosis. *PloS one, 9*(3), e86461. doi:10.1371/journal.pone.0086461

Smith, L. T. (2012). *Decolonizing methodologies: research and Indigenous Peoples* (2nd;Second; ed.). London;New York;: Zed Books.

Smylie, J., Martin, C. M., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2004). Knowledge translation and indigenous knowledge. *63*(0). doi:10.3402/ijch.v63i0.17877

Spencer, B. (2019, Feb 19, 2019). Health PEI offers first blood spot testing clinic for HIV and Hepatitis C, Web *CBC*. Retrieved from https://www.cbc.ca/news/canada/prince-edward-island/pei-dry-blood-spot-testing-1.5024372

Standing Senate Committee on Aboriginal Peoples. (2013). *The people who own themselves: Recognition of Metis identity in Canada*. Parliament of Canada Retrieved from https://sencanada.ca/content/sen/Committee/411/appa/rep/rep12jun13-e.pdf

Statistics Canada. (2017). *Focus on Geography Series, 2016 Census* Ottawa, Ontario Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/as-sa/fogs-spg/Facts-PR-Eng.cfm?TOPIC=9&LANG=Eng&GK=PR&GC=48

Stetler, C. B., Damschroder, L. J., Helfrich, C. D., & Hagedorn, H. J. (2011). A Guide for applying a revised version of the PARIHS framework for implementation. *Implementation science : IS, 6*, 99-99. doi:10.1186/1748-5908-6-99

Stevens, W., Gous, N., Ford, N., & Scott, L. E. (2014). Feasibility of HIV point-of-care tests for resource-limited settings: challenges and solutions. *BMC medicine, 12*(1), 173-173. doi:10.1186/s12916-014-0173-7

Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *Canadian Medical Association Journal, 181*(3-4), 165-168. doi:10.1503/cmaj.081229

Sullivan, P. W., & McCabe, H. A. (2015). Reprise: Case Management in Substance Use Services in the Age of the Affordable Care Act. *Journal of Social Work Practice in the Addictions, 15*(2), 185-199. doi:10.1080/1533256X.2015.1027447

Sundler, A. J., Lindberg, E., Nilsson, C., & Palmér, L. (2019). Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open, 6*(3), 733-739. doi:10.1002/nop2.275

R v Powley, (2003).

Swarbrick, M., Murphy, A. A., Zechner, M., Spagnolo, A. B., & Gill, K. J. (2011). Wellness coaching: a new role for peers. *Psychiatric rehabilitation journal, 34*(4), 328-331. doi:10.2975/34.4.2011.328.331

Swarbrick, M. A. (2013). Integrated care: wellness-oriented peer approaches: a key ingredient for integrated care. *Psychiatric services (Washington, D.C.), 64*(8), 723-726. doi:10.1176/appi.ps.201300144

Tait, J. M., Stephens, B. P., McIntyre, P. G., Evans, M., & Dillon, J. F. (2013). Dry blood spot testing for hepatitis C in people who injected drugs: reaching the populations other tests cannot reach. *Frontline gastroenterology, 4*(4), 255-262. doi:10.1136/flgastro-2013-100308

The Canadian Network on Hepatitis C *Blueprint* Writing Committee and Working Groups. (2019). *Blueprint to Inform Hepatitis C Elimination Efforts in Canada*. Montreal, QC Retrieved from canhepc.ca/sites/default/
files/media/documents/blueprint_hcv_2019_05.pdf

The Canadian Press. (2019, August 8, 2019). HIV self-testing kits for blood examined for licensing in Canada. *CBC*. Retrieved from https://www.cbc.ca/news/health/hiv-self-test-1.5240284

Traversy, G., Austin, T., Ha, S., Timmerman, K., & Gale-Rowe, M. (2015). Good news on HIV: An overview of recent evidence on barriers and facilitators to HIV testing. *Canada Communicable Disease Report, 41*(12), 302.

Trubnikov, M., Yan, P., & Archibald, C. (2014). Hepatitis C Virus Infection in Canada: 2011. *Centre for Communicable Diseases and Infection Control, 40*(19). doi:https://doi.org/10.14745/ccdr.v40i19a02

Trubnikov, M., Yan, P., Njihia, J., & Archibald, C. (2014). Identifying and describing a cohort effect in the national database of reported cases of hepatitis C virus infection in Canada

(1991−2010): an age-period-cohort analysis. *CMAJ Open, 2*(4), E281-E287. doi:10.9778/cmajo.20140041

Tso, L. S., Best, J., Beanland, R., Doherty, M., Lackey, M., Ma, Q., . . . Tucker, J. D. (2016). Facilitators and barriers in HIV linkage to care interventions: a qualitative evidence review. *AIDS, 30*(10), 1639-1653. doi:10.1097/QAD.0000000000001101

Tu, D., Belda, P., Littlejohn, D., Pedersen, J. S., Valle-Rivera, J., & Tyndall, M. (2013). Adoption of the chronic care model to improve HIV care In a marginalized, largely aboriginal population. *Canadian Family Physician, 59*(6), 650.

Tuysuzoglu, S., Corliss, H., Fitzgerald, S., Abascal, B., & Samples, C. (2011). Acceptability and Feasibility of Rapid HIV Testing in an Adolescent Clinic Setting: Youth Testing Attitudes, Knowledge, and Behaviors. *Journal of Adolescent Health, 49*(6), 609-614. doi:10.1016/j.jadohealth.2011.03.007

Uhanova, J., Tate, R. B., Tataryn, D. J., & Minuk, G. Y. (2013). The epidemiology of hepatitis C in a Canadian Indigenous population. *Canadian journal of gastroenterology = Journal canadien de gastroenterologie, 27*(6), 336-340. doi:10.1155/2013/380963

UNAIDS. (2017). *90-90-90: An ambitious treatment taret to help end the AIDS epidemic*. Retrieved from https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf

van Loo, I., Dukers-Muijrers, N., Heuts, R., van der Sande, M., & Hoebe, C. (2017). Screening for HIV, hepatitis B and syphilis on dried blood spots: A promising method to better reach hidden high-risk populations with self-collected sampling. *PloS one, 12*(10), e0186722. doi:10.1371/journal.pone.0186722

Veinot, T. C. (2006). The Case for an Integrated Approach to HIV/AIDS Prevention: Support and Treatment Services in Canada. *Journal of HIV/AIDS & Social Services, 5*(3), 181-199. doi:10.1300/J187v05n03_12

Vowel, C. (2011). You're Metis? So which of your parents is an Indian? Retrieved from https://apihtawikosisan.com/2011/12/youre-metis-so-which-of-your-parents-is-an-indian/

Wainberg, M. A., Hull, M. W., Girard, P.-M., & Montaner, J. S. G. (2016). Achieving the 90–90–90 target: incentives for HIV testing. *Lancet Infectious Diseases, The, 16*(11), 1215-1216. doi:10.1016/S1473-3099(16)30383-8

Wallerstein, N. B., & Duran, B. (2006). Using Community-Based Participatory Research to Address Health Disparities. *Health Promotion Practice, 7*(3), 312-323. doi:10.1177/1524839906289376

Walter, M., & Andersen, C. (2013). *Indigenous statistics: a quantitative research methodology*. Walnut Creek, CA: Left Coast Press.

Wesche, S. D. (2013). MÉTIS WOMEN AT RISK: HEALTH AND SERVICE PROVISION IN URBAN BRITISH COLUMBIA. *Pimatisiwin: A Journal of Aboriginal & Indigenous Community Health, 11*(2).

Wilson, C., Oliver, V., Flicker, S., Prentice, T., Jackson, R., Larkin, J., . . . Mitchel, C. (2016). 'Culture' as HIV Prevention: Indigenous youth speak up. *Gateways: International Journal of Community Research and Engagement, 9*(1), 74-88. doi:10.5130/ijcre.v9i1.4802

Wilson, S. (2001). What Is an Indigenous Research Methodology? *Canadian Journal of Native Education, 25*(2), 175.

Wilson, S. (2008). *Research is ceremony: indigenous research methods*. Black Point, N.S: Fernwood Pub.

Wong, W., Luk, C., & Kidd, M. (2012). IS THERE A ROLE FOR PRIMARY CARE CLINICIANS IN PROVIDING SHARED CARE IN HIV TREATMENT? A

SYSTEMATIC LITERATURE REVIEW. *Sexually Transmitted Infections 88*(2), 125-131.

Woodgate, R. L., Zurba, M., Tennent, P., Cochrane, C., Payne, M., & Mignone, J. (2017). “People try and label me as someone I'm not”: The social ecology of Indigenous Peoples living with HIV, stigma, and discrimination in Manitoba, Canada. *Social Science & Medicine, 194*, 17-24. doi:10.1016/j.socscimed.2017.10.002

World Health Organization. (n.d.). Health Equity.

Worthington, C., Jackson, R., Mill, J., Prentice, T., Myers, T., & Sommerfeldt, S. (2010). HIV testing experiences of Aboriginal youth in Canada: service implications. *AIDS Care, 22*(10), 1269-1276. doi:10.1080/09540121003692201

Worthington, C., & Myers, T. (2003). Factors Underlying Anxiety in HIV Testing: Risk Perceptions, Stigma, and the Patient-Provider Power Dynamic. *Qualitative Health Research, 13*(5), 636-655. doi:10.1177/1049732303013005004

Appendix A: Gathering Circle Outline for Métis Community Members to Develop a Métis-specific Response to HIV, HCV and STBBI

Prior to Gathering Circle:
Coordinator or graduate student will hand out the consent forms and read them out loud. An opportunity to ask questions will be provided and all questions will be answered. Potential participants will be assured they are under no pressure to participate and may go at any time without anything negative happening to them and that they may leave at any time during the circle should they wish to.

The individuals who choose to participate will be asked to sign an oath of confidentiality and it will be explained by the Elder what this also means in Aboriginal cultural practice. It will be explained that even with the signed confidentiality agreements we cannot guarantee someone in the circle will not share something from the circle. We will also explain that, in the event they wish to leave the circle and do not want their comments used, we will not include their comments in the research.

The participants will be told of the support available to them should they feel they would like to speak to someone during or after the gathering circle. The Elder and other local support services will be on hand to provide this support if needed.

Opening

Opening welcome ceremony will conducted by a local Elder including local traditions and offerings, sharing of food – refreshments provided by local caterer will be provided

Introduction

Coordinator and graduate student introduces the research project. [*We are part of a project that is developing and assessing a shared care model for HIV and other health concerns in your community and other First Nation and Métis communities in Alberta. We want to understand your experience of dried blood spot testing, and what we could do to improve it.*]

Gathering Circle

Gathering circles are similar in format to focus groups, but they are grounded in Metis ceremony and mutuality. The Elder may chose to present a traditional circle sacred item (feather, sharing stick, rock, etc.) and passes it in their traditional direction indicating that this person has the right to speak. The person holding the sacred object has the right to speak and be heard, and when he or she is finished, passes the sacred object on. If a person does not wish to speak, he or she does not have to do so, but may pass the sacred object on.

Circle Questions for Métis Participants:

What would a Métis cultural response to HIV and/or HCV and STBBI look like?
What are the necessary components of a program or model designed to support Métis people living with HIV or HCV?
What programs or supports currently exist for Métis people in Alberta (or in your region/community) living with HIV or HCV?
What are the gaps (or barriers) in these supports or services for Métis people in Alberta living with HIV? HCV? Other STBBI?

What are the unique challenges of Métis people living with HIV, HCV, and/or STBBI?
Is there anything else you would like to share with us?

Closing

The Coordinator and graduate student will thank the participants for their participation and explain the next steps and what the reporting back to the community process will be. The closing ceremony will be led by a local Elder following local traditions and offerings.

Appendix B: DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences

You are invited to participate in a study entitled **DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences** that is being conducted by Danielle Atkinson.

Danielle Atkinson is a graduate student in the department of Public Health and Social Policy at the University of Victoria and you may contact her if you have further questions by emailing dbruce@uvic.ca or calling 250-920-9038.

As a graduate student, I am required to conduct research as part of the requirements for a degree in public health. It is being conducted under the supervision of Catherine Worthington. You may contact my supervisor at worthing@uvic.ca or 250-472-4709.

This research is being funded by the Canadian Institutes for Health Research and the CIHR Canadian HIV Trials Network.

Purpose and Objectives

The purpose of this research project is to understand the experiences of those who are have used dried blood spot testing, and evaluate dried blood spot testing from a Metis perspective.

Inclusion Criteria: Participants are eligible to participate if they have received dried blood spot testing.

Importance of this Research

Research of this type is important because it will help us to improve the way we offer programs and services for Metis people regarding HIV, sexually transmitted and blood borne infections, and testing.

Participants Selection

You are being asked to participate in this study because you have been tested for either HIV, Hepatitis C, Hepatitis B or Syphilis through dried blood spot testing.

What is involved

If you consent to voluntarily participate in this research, your participation will include the completion of a paper survey which will take approximately 5 minutes of your time. You may be asked if you would like to participate further in a private interview or group talking circle.

Inconvenience

Participation in this study may cause some inconvenience to you including time away from work, family, etc. and/or arranging for childcare and transportation.

Risks

We do not expect this study to cause you or others any harm. However, you may experience some unexpected emotions in the process of the interview. If you feel upset during the interview or at any phase in the research, we will provide you with support. An Elder or social worker will be available to speak with you privately about your experience. We will also give you information on support services in your area.

Benefits
The potential benefits of your participation in this research include your contribution to the development of future programs and services, to ensuring that testing for HIV and sexually transmitted and blood borne infections are culturally safe and appropriate for Metis people.

Voluntary Participation
Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your survey data will not be used.

Anonymity
In terms of protecting your anonymity, your name will not be connected to your survey answers.

Confidentiality
Your confidentiality and the confidentiality of the data will be protected. Data will not be connected to your name. All paper surveys will be kept in a locked filing cabinet in a secured location.

Dissemination of Results
It is anticipated that the results of this study will be shared with others through the DRUM & SASH website and Shining Mountains Living Community Services through plain-language reports.

Disposal of Data
Data from this study will be disposed of at the end of the DRUM & SASH study. Electronic data will be erased and paper copies of the survey will be shredded.

Contacts
Individuals that may be contacted regarding this study include:
Catherine Worthington, University of Victoria, Nominated Principal: (250) 472-4709
Renée Masching, CAAN, Principal Knowledge User: 902-433-0900 (collect)
Carrielynn Lund, DRUM & SASH National Coordinator: 780-450-1711 (collect)

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

By completing and submitting the questionnaire, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Appendix C: Post DBST Survey
DRUM & SASH Sub-study:
Experience of partnering communities using Dry Blood Spot (DBS) testing

Dried blood spot (DBS) testing has been used to screen newborn babies for specific diseases for over 50 years. Recently, it has been used to test adults for HIV, Hepatitis B & C and Syphilis, and there are plans to include Tuberculosis (TB) and pre-diabetes in DBS testing.

We are interested in understanding more about what people think about this type of testing, and the characteristics of people who choose to take the DBS test. You can leave any question blank if you do not wish to answer, or choose "I prefer not to answer". Your name or any other identifying information will not be attached to this survey.

About You:

1. **Year of your birth: __________**

☐ I prefer not to answer

2. **Ancestry: (Please choose ONE answer)**

☐ Métis
☐ First Nation, non-status
☐ Other:____________________________
☐ First Nation, status
☐ Inuit
☐ I prefer not to answer

3. **What languages do you speak? (Check all that apply)**

☐ Indigenous language(s) (please specify):
____
☐ Other language (please specify):
____
☐ French
☐ English
☐ I prefer not to answer

4. **Where do you live? (Please choose ONE answer)**

☐ City (more than 10,000 people)
☐ Rural/isolated (camp, farm, etc.)
☐ On Reserve
☐ Other: ______________
☐ Town, Village or Hamlet (less than 10,000 people)
☐ On Métis Settlement
☐ I prefer not to answer

5. **What is the first half of your postal code? ______________________________**

Format: Letter-Number-Letter (e.g. V2N, M3N, L4M). These locate your response to a region, not a specific address

☐ I prefer not to answer

6. **I identify as: (Please choose <u>all that apply</u>)**

☐ Male
☐ Two-spirit
☐ Straight
☐ Female
☐ Transgender
☐ Intersex (Born with traits of both male and female)

☐ Lesbian
☐ Bisexual
☐ Other: ______________________
☐ I prefer not to answer
☐ Gay
☐ Asexual
☐ Unsure

Previous Testing:

7. Have you ever been tested for HIV?

☐ No
☐ Unsure
☐ Yes
☐ I prefer not to answer

8. If you answered "yes" to Question 7, when was your last test for HIV?

☐ in the past 3 months
☐ 7-12 months ago
☐ I have <u>never</u> been tested for HIV
☐ 4-6 months ago
☐ longer than a year ago

9. Have you ever been tested for Hepatitis C?

☐ No
☐ Unsure
☐ Yes
☐ I prefer not to answer

10. If you answered "yes" to Question 9, when was your last test for Hepatitis C?

☐ in the past 3 months
☐ 7-12 months ago
☐ I have <u>never</u> been tested for Hepatitis C
☐ 4-6 months ago
☐ longer than a year ago

11. Have you ever been tested for Hepatitis B?

☐ No
☐ Unsure
☐ Yes
☐ I prefer not to answer

12. If you answered "yes" to Question 11, when was your last test for Hepatitis B?

☐ in the past 3 months
☐ 7-12 months ago
☐ I have <u>never</u> been tested for Hepatitis B
☐ 4-6 months ago
☐ longer than a year ago

13. Have you ever been tested for Syphilis?

☐ No
☐ Unsure
☐ Yes
☐ I prefer not to answer

14. If you answered "yes" to Question 13, when was your last test for Syphilis?

☐ in the past 3 months
☐ 4-6 months ago

☐ 7-12 months ago ☐ longer than a year ago
☐ I have never been tested for Syphilis

Your DBS Experience Today:

Please circle the number that most closely reflects your opinion for each statement:

	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
15. I would recommend this testing method to friends or family	1	2	3	4	5
16. I thought this type of testing was easy	1	2	3	4	5
17. I would use this type of testing again	1	2	3	4	5
18. I received enough information today about HIV, Hepatitis C, Hepatitis B, Syphilis, and testing	1	2	3	4	5
19. I will encourage family and friends to get tested	1	2	3	4	5
20. Overall, my testing experience today was positive	1	2	3	4	5

21. Do you have any additional comments about DBS or others types of testing?

____

Thank you very much for your time!

Appendix D: Semi-Structured Interview Questions for Dried Blood Spot Testing Providers

Prior to Interview
Coordinator and/or graduate student will provide the consent forms and read them out loud. An opportunity to ask questions will be provided and all questions will be answered. Potential participants will be assured they are under no pressure to participate and may cancel the interview at any time. Participants and potential participants will be given a $25 visa gift card as a token of appreciation.
The participants will be told of the resources available locally should they feel they would like to speak to someone after the interview.

Introduction
Coordinator and/or graduate student introduces the research project. [*We are part of a project that is developing and assessing a shared care model for HIV and other health concerns in your community and other First Nation and Métis communities in Alberta. We want to understand your experience with administering dried blood spot testing, and what we could do to improve it, so it can be used in other Métis and First Nations communities.*]

Guiding questions for service providers who have administered dried blood spot testing:

1. How was administering dried blood spot testing? Was there anything challenging about it? Was there anything easy about it? What, if anything, would you change about the testing process?
2. What do you think of dried blood spot testing in comparison to other forms of testing? What are the pros and cons to dried blood spot testing from the community's perspective?
3. What do you think of the linkage to care process for Metis people who receive a positive result on their dried blood spot test? What would be the ideal way to notify Metis people of their test results? Who should be doing the notifying? What is missing from the process?
4. The following questions pertain to the Metis community specifically. Do you think that dried blood spot testing is a culturally safe way for Metis people to get tested for HIV and STBBI? Please explain. Are there enough Metis-specific supports or programs regarding the testing, treatment and care of individuals with HIV and STBBI? What are some of the strengths of these programs? What is missing? Do you think HIV and STBBI are considered important issues by Metis community leaders or politicians?
5. What would you like to see improve with regards to the testing, treatment and care of Metis people living with HIV and STBBI?
6. What would a Métis-led, national or province wide response to HIV and STBBI look like for Métis people? For example, if national and/or provincial Métis leadership decided to make the elimination of HCV a priority for Métis people, what would be the necessary components of such an initiative or response? Would culture play a role in this, and if so, how?
7. There are new forms of testing that will soon be available, like self-testing at home (similar to a pregnancy test, except using blood instead of urine). What would you think of this form of testing? Do you think this form of testing might be accepted or used by the Metis community?

Closing

The Coordinator and graduate student will thank the individual for their participation and explain what the end of study reporting will look like.

Appendix E: Recruitment Script for DBS Testing Providers

(Standard greeting and then the following):
You are invited to participate in a private interview exploring experiences of administering Dried Blood Spot Testing. Dried Blood Spot Testing is a new way to test for HIV, Hepatitis B, Hepatitis C, and syphilis. The Metis Nation of Alberta (MNA), with leadership from Shining Mountains Living Community Services (Red Deer, AB), is interested in assessing the implementation of dried spot blood testing in collaboration with the DRUM & SASH team. Information from these interviews will be used to help evaluate dried blood spot testing, and make improvements to future testing initiatives in the Metis community. You have specifically been invited to participate because you have provided/administered dried blood spot testing for HIV/HCV/HBV/syphilis to members of the Metis community, or have contributed to the development and implementation of dried blood spot testing in partnership with Shining Mountains Living Community Services.

Participating in the interview will take approximately 60 minutes. You will be offered a gift card in the amount of $25.00 to help compensate for your time. You are under no obligation to participate and, should you choose not to participate, your decision will not affect your relationships or employment with MNA, Shining Mountains, Alberta Health Services, or any of the DRUM and SASH team members.

This research is being done as part of the DRUM & SASH project in which we are working in partnership with 5 First Nation communities in Alberta and the Métis Nation of Alberta to develop, implement, and evaluate shared care models for STBBI and related mental health issues. For more information on DRUM & SASH, please visit our website: www.drumandsash.ca

Should you agree to participate, you will be contacted by Danielle Atkinson to set up a date and time for an interview. The interview may be conducted in person, over the telephone, or via an electronic teleconferencing system (e.g. Skype or Zoom).

Individuals that may be contacted regarding this study include:
Danielle Atkinson, graduate student, University of Victoria. Email: dbruce@uvic.ca, 250-920-9038
Catherine Worthington, University of Victoria, Nominated Principal: email: worthing@uvic.ca, (250) 472-4709
Renée Masching, CAAN, Principal Knowledge User: 902-433-0900 (collect)
Carrielynn Lund, DRUM & SASH National Coordinator: 780-450-1711 (collect)

Shining Mountains Living Community Services
4925 46Street
Red Deer, AB T4N 1N2
Phone: 403-346-9794
Fax: 403-346-9380

Appendix F: Gathering Circle Questions for DBS Participants (Recipients)

Gathering Circle Outline
Prior to Gathering Circle
Coordinator and graduate student will hand out the consent forms and read them out loud. An opportunity to ask questions will be provided and all questions will be answered. Potential participants will be assured they are under no pressure to participate and may go at any time without anything negative happening to them and that they may leave at any time during the circle should they wish to. Participants and potential participants will be given a $25 visa gift card as a token of appreciation.

The individuals who choose to participate will be asked to sign an oath of confidentiality and it will be explained by the Elder what this also means in cultural practice. It will be explained that even with the signed confidentiality agreements we cannot guarantee someone in the circle will not share something from the circle. We will also explain that, in the event they wish to leave the circle and do not want their comments used that we will do our best to remove them from the tape. This cannot however be guaranteed.

The participants will be told of the support available to them should they feel they would like to speak to someone during or after the Gathering circle. The Elder and other local support services will be on hand to provide this support if needed.

Opening
Opening welcome ceremony will conducted by a local Elder including local traditions and offerings, and refreshments will be provided.

Introduction
Coordinator and/or graduate student introduces the research project. [*We are part of a project that is developing and assessing a shared care model for HIV and other health concerns in your community and other First Nation and Métis communities in Alberta. We want to understand your experience with dried blood spot testing, and what we could do to improve it, so it can be used in other Métis and First Nations communities.*]

Gathering Circle
Gathering circles are similar in format to focus groups, but they are grounded in Metis ceremony and mutuality. The Metis Elder may choose to use a traditional circle sacred item (feather, gathering stick, rock, etc.) and passes it in their traditional direction indicating that this person has the right to speak. The person holding the sacred object has the right to speak and be heard, and when he or she is finished, passes the sacred object on. If a person does not wish to speak, he or she does not have to do so, but may pass the sacred object on.

Guiding questions for those who have received dried blood spot testing:
How was your experience with dried blood spot testing? If you have ever received other types of HIV or STBBI testing (e.g. blood draw at the lab), how does dried blood spot testing compare with these other types of testing? Would you be open to trying other types of testing, like at home testing kits?

The following questions pertain to dried blood spot testing from a Metis perspective. Do you think that dried blood spot testing is a way of testing that Metis people would be comfortable with? Please explain. Do you think dried blood spot testing should be offered at future Metis events? Why or why not?

Were you provided with adequate information about HIV, Hepatitis B& C and Syphilis before, during or after your test? Did anything surprise you?

As a result of getting tested today, will you do anything differently in the future? This could mean changing behaviours like getting tested again in the future, or telling family members to get tested.

There are new forms of testing that will soon be available, like self-testing at home (similar to a pregnancy test, except using blood instead of urine). What would you think of this form of testing? Or other forms of testing where you could get the results back quickly?

Closing

The Coordinator and graduate student will thank the participants for their participation and explain the next steps and what the reporting back to the community process will be. The closing ceremony will be led by a local Elder following local traditions and offerings.

Appendix G: Recruitment Script for DBS Gathering Circle

(Standard greeting and then the following)

You are invited to participate in a gathering circle exploring experiences of Dried Blood Spot Testing. Dried Blood Spot Testing is a new way to test for HIV, Hepatitis B, Hepatitis C, and syphilis. The Metis Nation of Alberta (MNA), with leadership from Shining Mountains Living Community Services (Red Deer, AB), is interested in assessing the implementation of dried spot blood testing in collaboration with the DRUM & SASH team. Information from these gathering circles will be used to help evaluate dried blood spot testing, and improve future testing initiatives in the Metis community. You are being invited to participate because you have received dried blood spot testing and self-identify as a member of the Métis community.

Participating in the talking circle will take approximately 60 minutes. You will be offered a gift card in the amount of $25.00 to help compensate for your time. You are under no obligation to participate and, should you chose not to participate, your decision will not affect your access to services or relationships with MNA, Shining Mountains, or any of the DRUM and SASH team members.

This research is being done as part of the DRUM & SASH project in which we are working in partnership with 5 First Nation communities in Alberta and the Métis Nation of Alberta to develop, implement, and evaluate shared care models for STBBI and related mental health issues. For more information on DRUM & SASH, please visit our website: www.drumandsash.ca

Should you agree to participate, the gathering circle will be held on the 19th of September in the afternoon. Thank you so much for considering this.

Individuals that may be contacted regarding this study include:
Danielle Atkinson, graduate student, University of Victoria. Email: dbruce@uvic.ca, 250-920-9038
Catherine Worthington, University of Victoria, Nominated Principal: email: worthing@uvic.ca, (250) 472-4709
Renée Masching, CAAN, Principal Knowledge User: 902-433-0900 (collect)
Carrielynn Lund, DRUM & SASH National Coordinator: 780-450-1711 (collect)

Shining Mountains Living Community Services
4925 46Street
Red Deer, AB T4N 1N2
Phone: 403-346-9794
Fax: 403-346-9380

Appendix H: Consent Form for Gathering Circles

Interview Participant Consent Form (Gathering Circle)

DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences

You are invited to participate in a study entitled "**DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences**", a sub-study of the DRUM & SASH study (www.drumandsash.ca) , that is being conducted by Danielle Atkinson (graduate student) in partnership with a collaborative research team made up of researchers and Aboriginal community representatives.

Danielle Atkinson is a graduate student in the department of Public Health and Social Policy at the University of Victoria and you may contact her if you have further questions by emailing dbruce@uvic.ca or calling 250-920-9038. As a graduate student, Danielle Atkinson is required to conduct research as part of the requirements for a degree in public health. It is being conducted under the supervision of Catherine Worthington (Nominated Principal Investigator for DRUM & SASH). You may contact her supervisor at worthing@uvic.ca or 250-472-4709. You may also contact the project coordinator, Carrielynn Lund, at carriel@caan.ca or call 780-450-1711.

This research is being funded by the Canadian Institutes for Health Research and the CIHR Canadian HIV Trials Network.

Purpose and Objectives
The purpose of this research project is to understand the experiences of those who are have used dried blood spot testing, and evaluate dried blood spot testing from a Metis perspective.

Importance of this Research
Research of this type is important because it will help us to improve the way we offer programs and services for Metis people regarding HIV, sexually transmitted and blood borne infections, and testing.

Participants Selection
You are being asked to participate in this study because you have been tested for either HIV, Hepatitis C, Hepatitis B or Syphilis through dried blood spot testing.
Inclusion Criteria: Self-identified Metis individuals who have participated in dried blood spot testing.

What is Involved
If you consent to voluntarily participate in this research, you will be asked to participate in a gathering circle (like a focus group but with Metis cultural elements) approximately 60 minutes long.

What will happen in the Interview

You will be asked a series of questions about your experience with dried blood spot testing. You will be asked for permission to tape the conversations so we don't miss anything you say. Notes will also be taken to record information about the circle.

What will happen after the Interview session?

Your response will be combined with the other interview responses and analyzed to determine the acceptability of dried blood spot testing in Metis communities. Future reports of the findings of the study will be made public.

Inconvenience

Participation in this study may cause some inconvenience to you, including time away from work, family, etc. and arranging for childcare and transportation.

Risks

We do not expect this study to cause you or others any harm. However, you may experience some unexpected emotions in the process of the interview. If you feel upset during the interview or at any phase in the research, we will provide you with support. An Elder will be available to speak with you privately about your experience. We will also give you information on support services in your area.

Benefits

You may find it helpful to share your knowledge and experience. We hope you feel good about your participation which will help us improve the services in your community and to develop a national shared care model to be available across Canada for other First Nation, Metis and Inuit communities to access.

Compensation

As a way to compensate you for any inconvenience related to your participation, you will be given a $25.00 gift card. If you consent to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation was not offered, then you should decline.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be deleted.

Confidentiality

We will keep your personal identity in this study confidential. You do not have to provide any information that will identify you. We will also keep your personal sharing confidential, except in situations where we are required by law to release the information (e.g., if we hear information that a child has been or is being abused; if we hear that you may harm yourself or another person, that is, there is reason to believe that you are at risk to commit suicide or hurt someone else, etc.).

During the Interview, we will make notes and record the discussion on audiotape. This is only to make sure that we do not miss any of your valuable stories and opinions. We will transcribe tape recordings into writing and will remove all the information that identifies you. We will store all the tapes, notes and paper research data in a locked cabinet in a secured office. We will protect the data in our computer using passwords and save the data on a secured computer system.

The study reports will never show your name or any information that identifies you. Only the research team members will listen to the audiotapes and read the transcripts of this study. We will destroy all the audiotapes when we complete this study. We will also destroy all the written and electronic data five years after we complete this study.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: community meeting(s), focus groups, plain language written report, workshops, and presentations.

Disposal of Data

Paper and audio data from this study will be shredded and electronic data will be erased from the hard drive.

Contacts

Catherine Worthington, University of Victoria, Nominated Principal: (250) 472-4709
Renée Masching, CAAN, Principal Knowledge User: 902-433-0900 (collect)
Carrielynn Lund, DRUM Coordinator: 780-450-1711 (collect)

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the consent form read to you, have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

CONSENT

Name of Participant	*Signature*	*Date*

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix I: Assent Form for Interviews with Test Providers

University of Victoria

Interview Participant Assent Form (Testing Providers)

DRUM & SASH: First Nation and Métis Communities Working in Partnership to Develop Shared Care Models for HIV and other STBBI

DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences

You are invited to participate in a study entitled "**DRUM & SASH Sub-Study: Evaluation of Dried Blood Spot Testing Experiences**", a sub-study of the DRUM & SASH study (www.drumandsash.ca) , that is being conducted by Danielle Atkinson (graduate student) in partnership with a collaborative research team made up of researchers and Aboriginal community representatives.

Danielle Atkinson is a graduate student in the department of Public Health and Social Policy at the University of Victoria and you may contact her if you have further questions by emailing dbruce@uvic.ca or calling 250-920-9038. As a graduate student, Danielle Atkinson is required to conduct research as part of the requirements for a degree in public health. It is being conducted under the supervision of Catherine Worthington (Nominated Principal Investigator for DRUM & SASH). You may contact her supervisor at worthing@uvic.ca or 250-472-4709. You may also contact the project coordinator, Carrielynn Lund, at carriel@caan.ca or call 780-450-1711.

This research is being funded by the Canadian Institutes for Health Research and the CIHR Canadian HIV Trials Network.

Purpose and Objectives

The purpose of this research project is to understand the experiences of those who are have administered dried blood spot testing, and evaluate dried blood spot testing from a Metis perspective.

Importance of this Research

Research of this type is important because it will help us to improve the way we offer programs and services for Metis people regarding HIV, sexually transmitted and blood borne infections, and testing.

Participants Selection

You are being asked to participate in this study because you have administered testing for either HIV, Hepatitis C, Hepatitis B or Syphilis through dried blood spot testing for members of the Metis community.

Inclusion Criteria: You are eligible to participate if you have provided/administered dried blood spot testing for HIV/HCV/HBV/syphilis to members of the Metis community, or have contributed to the development and implementation of dried blood spot testing in partnership with Shining Mountains Living Community Services.

What is Involved

If you consent to voluntarily participate in this research, you will be asked to participate in semi-structured private interview, either in person, on the telephone, or using a videoconferencing system (e.g. Skype or Zoom).

What will happen in the Interview

You will be asked a series of questions about your experience with providing dried blood spot testing. You will be asked for permission to tape the conversations so we don't miss anything you say. Notes will also be taken to record information important information.

What will happen after the Interview session?

Your response will be combined with the other interview responses and analyzed to determine the acceptability of dried blood spot testing in Metis communities, and in particular, the experiences of those who have provided the testing. Future reports of the findings of the study will be made public.

Inconvenience

Participation in this study may cause some inconvenience to you, including time away from work, family, etc. and arranging for childcare and transportation.

Risks

We do not expect this study to cause you or others any harm. However, you may experience some unexpected emotions in the process of the interview. If you feel upset during the interview or at any phase in the research, we can provide you with a list of local resources for you to access.

Benefits

You may find it helpful to share your knowledge and experience. We hope you feel good about your participation which will help us improve the testing and services for Metis people.

Compensation

As a way to compensate you for any inconvenience related to your participation, you will be given a $25.00 gift card. If you consent to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation was not offered, then you should decline.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be deleted.

Confidentiality

We will keep your personal identity in this study confidential. You do not have to provide any information that will identify you. We will also keep your personal sharing confidential, except in situations where we are required by law to release the information (e.g., if we hear information that a child has been or is being abused; if we hear that you may harm yourself or another person, that is, there is reason to believe that you are at risk to commit suicide or hurt someone else, etc.).

During the Interview, we will make notes and record the discussion on audiotape. This is only to make sure that we do not miss any of your valuable stories and opinions. We will transcribe tape recordings into writing and will remove all the information that identifies you. We will store all the tapes, notes and paper research data in a locked cabinet in a secured office. We will protect the data in our computer using passwords and save the data on a secured computer system.

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Contacts

Danielle Atkinson, University of Victoria graduate student, dbruce@uvic.ca, (250) 920-9038
Catherine Worthington, University of Victoria, Nominated Principal: (250) 472-4709
Renée Masching, CAAN, Principal Knowledge User: 902-433-0900 (collect)
Carrielynn Lund, DRUM Coordinator: 780-450-1711 (collect)

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the consent form read to you, have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

ASSENT

______________________	______________________	____________
Name of graduate student or researcher obtaining assent	*Signature*	*Date*

____
Location where assent was obtained (building, community, province)

A copy of this form will be left with you, and a copy will be taken by the researcher.

Appendix J: Red River Cart Model

Name: ______________________________

Shining Mountains Métis Care Assessment

Email: ______________________________

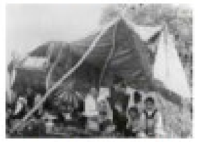
Phone: ______________________________

Date: ______________________________

Métis flag
(leadership)

Ukotāson

Métis cart tarp
(spirituality and Culture)



Pahkwanehikan

Métis Capote coat
(family)

Li capote

Métis sash
(community)

Le ceinture
fléchée

Métis York boat
(goals)

Misti awota osi

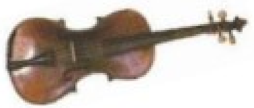
Métis medicine bag
(clinicians & treatment)

Maskihkî maskimut

Métis moccasins
(connection to land)

Pahpekin muskisinah

Métis fiddle
(social)



Li vialon

Métis grub box
(resources)

Nemawiwut

Métis weapons
(harm reduction)

Nîmaskwana

Métis stove
(housing)

Kotawanapisk

Métis tools
(education & training)

Apuchichikuna

Strong 🟥
Medium 🟩
Weak 🟦
Broken ⬛