Exploring the Meaningful Partnership of Elders in Indigenous STBBI Research

Dedicated to my Mom, Patricia Bridget Walsh thank you for your endless love, encouragement, and support. And to my sisters Nicole Smith and Teresa Marsdin for your love, patience, and belief in me.

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By Bridget Marie Marsdin, BSW and Elder coauthors:

Sheila Nyman, Sharp Dopler, Catherine Martin, Sandra Laframboise, Pitsulala Lyta, Elizabeth Benson, Linda Barkman, Lucy Barney, Debra Paris Perry, Sipporah Enuaraq & Qánügvá Günus

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AUTHORS: Bridget Marie Marsdin, B.S.W

With Elder coauthors,

Sheila Nyman, Sharp Dopler, Catherine Martin, Sandra Laframboise, Pitsulala Lyta, Elizabeth Benson, Linda Barkman, Lucy Barney, Debra Paris Perry, Sipporah Enuaraq & Qánügvá Günus

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Abstract

Indigenous Elders are highly regarded as community leaders, traditional healers, and experts of Indigenous cultures and knowledges (Clark & Wylie 2021; Hadjipavlou et al., 2018; Lessard et al., 2021). The meaningful partnership of Elders in Indigenous STBBI (sexually transmitted and/or bloodborne infections) research has become increasingly recognized as an integral part of developing decolonial research processes, ensuring the implementation of Indigenous methods in STBBI research, and increasing the sexual health and wellbeing of Inuit, Métis, and First Nations communities through the development of culturally and ethically responsive research (Flicker et al., 2015; Hillier 2020; O'Brien et al., 2020). This study sought to expand upon and connect current literature with the expertise and guidance of Indigenous Elders who have been involved in STBBI research. Thirteen Elders were recruited nationwide to participate in three virtual Talking Circles to explore their meaningful partnership in Indigenous STBBI research and to offer guidance to researchers on how to strengthen these research partnerships in the future. Five overarching themes emerged from the thematic analysis of these Talking Circles: (1) Understanding the historical and ongoing impacts of colonialism and the need to decolonize STBBI research; (2) Prioritizing the knowledge and lived experience of Elders and Indigenous people living with STBBI throughout the research process; (3) Centering spirituality and ceremony in Indigenous STBBI research; (4) The importance of implementing Indigenous methodologies in STBBI research; and (5) Foregrounding Indigenous ways of being, knowing, and doing in STBBI research. This study offers future Indigenous STBBI researchers a robust foundation to build meaningful research partnerships with Elders to improve STBBI research and benefit the sexual health and wellbeing of Métis, Inuit, and First Nations communities.

Keywords: *Indigenous, Métis, Inuit, First Nations, Elders, STBBI, HIV/AIDS research, engagement, partnership, collaboration, Indigenous and decolonizing methodologies, Indigenous ways of being, knowing, and doing, qualitative research*

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Table of Contents

Chapter One: Introduction

There is a growing understanding among Indigenous and allied researchers for the need to foreground Indigenous ways of being, doing, and knowing in research to serve the health and wellbeing of Inuit, First Nations, and Métis communities (Barlett et al 2007; Blair et al., 2022; Busija 2020; Drost 2019; Hart, 2010; Held, 2019). It is apparent that conventional research approaches often do not serve the best interests of Indigenous Peoples because Western research does not offer adequate information to address colonial health disparities. This is evidenced by the continued increase of STBBI (sexually transmitted and blood borne infections) in Indigenous communities (Jackson & Tremblay, 2019; PHAC, 2018). Indigenous Elders are knowledge keepers who are held in high regard by their communities as traditional leaders because they embody and exemplify Indigenous ways of being, doing, and knowing and they are experts of cultural, traditional, and ancestral teachings (Rowe et al., 2020; Varcoe et al., 2010; Viscogliosi 2017; Wilson 1996). Indigenous ways of being, doing, and knowing have provided a longstanding foundation of indomitable strength to First Nations, Inuit, and Métis communities to survive, thrive, and revitalize under centuries of genocidal policies (Clark & Wylie, 2021; Quayle & Sonn, 2019; Rand, 2016). Elders are intergenerational transmitters of cultural and traditional teachings in Indigenous communities, and they are honoured as spiritual leaders and healers (Flicker et al., 2015; Rowe et al., 2020; Viscogliosi et al., 2020). The centering of Indigenous knowledges in STBBI research highlights the integral role that Elders offer as research partners who can ensure that the unique worldviews, cultures, and traditions of their communities are prioritized throughout the research process (Flicker et al., 2015). It is vital that Elders are meaningful partners in STBBI research from inception until completion to verify that Indigenous ethics, principles, and protocols are adhered to throughout the research process and

the needs of the community are prioritized (Flicker et al., 2015). Indigenous STBBI research should serve the unique needs of Métis, First Nations, and Inuit communities and Elders are highly attuned to these needs and hold a profound understanding of how best to address the issues facing their communities (Rowe et al., 2020; Viscogliosi et al., 2020). Elders have been scientists and researchers since time immemorial and they offer profound insight into wholistic healing practices that attend to the physical, mental, emotional, and spiritual needs of their communities (Abolson, 2010). The meaningful partnership of Elders in STBBI research can transform research processes to reflect the distinct cultures, worldviews, and traditions of their communities by avoiding the pan-Indigenizing of research approaches and processes (Flicker et al., 2015). Moreover, there is a great need for research to shift from deficits-based approaches that pathologize Indigenous communities to strengths-based approaches that draw upon robust and sophisticated scientific, spiritual, ceremonial, and healing practices that are central to the health and wellbeing of Indigenous individuals, families, and communities (Kelm, 2010).

Rationale for this Study

This research study seeks to illuminate the importance of engaging Elders as meaningful partners in Indigenous STBBI research. Indigenous Elders play a valuable role in research by culturally and ceremonially guiding the project, thereby boosting cultural congruence in research study designs (Flicker et al., 2015). It is integral that Indigenous Elders are meaningful partners in research because they are leaders and healers who are deeply respected for promoting well-being and social cohesion within their communities (Viscogliosi et al., 2017). It is crucial that researchers center the values of the community, and the wisdom of Elders reflects Indigenous values, ways of doing, and ways of being (Tuhiwai Smith, 2012). This signifies the importance of integrating Indigenous wisdom into STBBI (sexually transmitted infections and blood borne

infections) research through meaningful partnerships with Elders, who offer robust research skills as interpreters, transmitters and distillers of Indigenous knowledges, ceremonies, and ancestral teachings (Datta, 2018). Conventional STBBI research often neglects to address the profound health disparities Indigenous peoples experience from colonial, structural barriers, lack of access to social determinants of health, and increased rates of STBBI (PHAC, 2018). This highlights the need for the integration of Indigenous worldviews, knowledges, and values in STBBI research (Flicker et al., 2015; Hillier et al., 2020). This study is significant because it will promote awareness and insight into the meaningful partnership of Elders and will highlight how the wisdom of Elders must be prioritized in research to shape social and health strategies in Indigenous STBBI prevention, support, and care. In their role as research partners, Elders can ensure that research is culturally safe, ethical, and in the best interest of their communities (Flicker et al., 2015). The purpose of this study is to explore Elders research experiences, expertise, and wise practices to guide researchers in how best to develop meaningful research partnerships that center Indigenous ways of knowing, doing, and being. The aim of this study is to increase the quality of STBBI research in the future to benefit Indigenous communities.

Positioning myself in this Research

I am a white settler woman of Irish ancestry, living with chronic pain illnesses, from a background of intergenerational poverty, trauma, abuse, and addiction. Arising out of this legacy of trauma, I sought out social justice movements related to issues of sexual violence, sexual health, and HIV/AIDS with a focus on bodily integrity, autonomy, and healing from an anti-oppressive framework. My entry into social services was through volunteerism as a sexual violence crisis-line worker and a youth street outreach worker. I flourished in these volunteer positions which influenced my decision to pursue a career in social services. I was soon hired on

as the Community Services Outreach worker for Planned Parenthood where I offered outreach, health promotion groups, counselling, and advocacy. My next position was at The AIDS Network where I worked for several years in counselling, community education, and harm reduction. This offered me the opportunity to work with and learn from Indigenous people living with HIV and AIDS and allies working in the community and in research. It was during this time that I sought out HIV/AIDS research which led me to read the prolific work of researchers such as Dr. Randy Jackson (Associate Professor in the School of Social Work and the department of Health and Aging at McMaster University and my thesis supervisor), Dr. Saara Greene (Director and Professor in the School of Social Work), Ms. Renée Masching, (Director of Research at Communities, Allies, and Networks, CAAN- formerly known as the Canadian Aboriginal AIDS Network) and Ms. Doris Peltier, (National Coordinator of Visioning Health, a community-based, participatory research project for Indigenous women living with HIV and Community Engagement Coordinator, Feast Centre for Indigenous STBBI Research).

In my service and support of IPLWH (Indigenous people living with HIV and AIDS) as a white woman and settler, I was critically aware of my inability to offer culturally relevant support and services. This led me to connect with local Indigenous agencies to support folks in accessing Indigenous healing practices, spiritual teachings. and ceremonies. These Indigenous agencies offered IPLWHA the opportunity to build relationships with Elders and become re-connected to their culture, partake in ceremony, and receive spiritual counselling from Elders. I was invited by several clients into Sharing Circles in honour of the relationships we had built with each other. These Sharing Circles provided me the opportunity to bear witness to the powerful healing benefits offered by the Elders through traditional healing practices, spirituality, and ceremonies. It was evident that the clients made a remarkable shift towards increased health

and well-being, and they expressed how this reconnection to their identity and culture transformed their lives, with an emphasis on the strong bonds they had developed with the Elders. The immutable power of returning to Indigenous ways of being, doing and knowing was illuminated by these personal transformations.

I returned to McMaster University as a mature student a few years later to seek an undergraduate degree in social work. Dr. Randy Jackson taught one of my favourite courses, Social Work and Sexualities. It was in this classroom that I built a connection with Dr. Randy Jackson, and this opened up the pathway for a research assistantship with the Feast Centre for Indigenous STBBI Research. The Feast Center is co-led by Indigenous researchers Dr. Randy Jackson, Principal Investigator and Ms. Renée Masching, Principal Knowledge User. The research and activities of the Feast Centre are guided by a diverse Council of Elders who are from Inuit, First Nations, and Métis communities who also inspired the topic of this study.

My positionality as a white settler woman and social worker who has chosen to focus my research on the centering of Indigenous knowledges in STBBI (sexually transmitted and blood borne infections) through meaningful partnerships with Elders in research, it is imperative that I practice, according to D'Arcangelis (2017) "radical reflexivity" that looks beyond the self to consistently examine the ever-present role of oppressive structures and systems that maintain my power and privilege despite my efforts of introspection. Moreover, this act of reflexivity can serve to re-center whiteness and offer me a false notion of innocence through continuous confession (D'Arcangelis, 2017). There is no route to innocence, and it is impossible to extricate myself from the ubiquitous privilege that is bestowed upon me because of my identity. Thus, I remain aware that self-reflexivity can be used to "reinscribe the power relations it seeks to mitigate" by centering the white/liberal, advantaged subject through "individual confession at the

expense of collective action" (D'Arcangelis, 2017, p.4). D'Arcangelis (2017) offers an alternative to the "confessional" and suggests that white researchers adopt Pillow's (2003) concept of "reflexivities of discomfort" whereby, white researchers are continuously implicated in colonialism and emphasizes the need to "disrupt the liberal imaginings of a subject who can equalize structural power inequities" (p. 4). D'Arcangelis (2017) supports Ahmed's (2004) concept of the "double turn" whereby white researchers "stay implicated in what you critique" and how it is necessary that we continue "turning towards roles and responsibilities in racism" (p.5) rather than continuously seeking innocence through confession. This study reminds us how much the researcher's identity shapes the research, which gives the researcher control over the production of new knowledge. This control over new knowledge production can be used as just another tool of colonialism even when the motives are emancipatory (Rossiter, 2001). D'Arcangelis (2017) offers valuable insights into how "colonial power relations are reproduced at the micro-level of intersubjective relations" (p. 10) within qualitative research. Moreover, this author highlights how white researchers are often "yearning to transcend colonialism and seek redemption in research" and the necessity for us to "look beyond the self into the collective aspects of our own subjectivities" (p. 2). D'Arcangelis offers profound insights into the need for white researchers to adopt a practice of "radical reflexivity" in research. This approach contributed to my ethical decision-making throughout this collaborative study with the Elders.

Research Question and Objectives

This study explores the meaningful partnership of Elders in STBBI research by engaging Elders in Talking Circles to identify: (1) What have been the challenges and/or successes they have encountered during your involvement in STBBI research as Elders? (2) Were Indigenous teachings and practices used in this research? A) If yes, how so? B) If no, what barriers stopped

this from happening? (3) Why is it important for Elders to partner in Indigenous STBBI research? (4) Which wise practices, including ethics, values, methods etc. need to be used throughout the research process? (5) What guidance would you give Indigenous STBBI researchers to strengthen meaningful research partnerships with Elders in the future? The objective of this study is to guide researchers in developing meaningful partnerships with Elders in Indigenous STBBI research to improve research for Indigenous communities.

Methodology and Methods

This study is guided by decolonizing and Indigenous methodologies. These approaches in research "can be defined as research by and for Indigenous peoples, using techniques and methods drawn from the traditions and knowledges of those peoples" (Evans et al., 2009 p. 894). The Indigenous research method used in this study was three virtual Talking Circles where Elders were asked to contemplate guiding research questions and to share their narratives concerning their involvement in STBBI research and how best to strengthen their partnerships as co-researchers.

Overview of Thesis

In Chapter Two, the Critical Literature Review will explore Indigenous-related research studies that involve Elders in various roles along a spectrum of engagement. Chapter Three will examine decolonizing and Indigenous methodologies that have guided the ethics, development, implementation, method, processes, and analysis throughout this study. This section will also demonstrate how these methodologies have arisen from Indigenous ways of being and knowing and serve as the foundation for an Indigenous research paradigm. Chapter Four is the Methods section which provides detailed information about the use of the Indigenous method of Talking Circles. This chapter also reviews the ethics process and considerations. Moreover, this section

outlines the processes of thematic analysis and participatory members' checking sessions. Chapter Five is the Findings section which provides the analysis, opinions, experiences, and discussion offered by the Elders during the Talking Circles. These findings are presented under five overarching themes. Chapter Six, the Discussion section will connect the findings of the Elders with pertinent literature through the lens of decolonizing and Indigenous methodologies. Moreover, this chapter will discuss the limitations of this research, and implications of this study for policy and practice.

Chapter Two: Literature Review

There is a growing body of community and academic research that emphasizes the need to implement Indigenous strengths-based approaches under the leadership of Elders in research, policies, and programming that impacts the lives of Indigenous Peoples. One of the reasons for this call is because it recognizes Elders as community leaders, traditional healers, and intergenerational transmitters of knowledge (Flicker et al., 2015; Hadjipavlou et al., 2018; Rowe et al., 2019; Varcoe et al., 2010; Viscogliosi et al., 2017; Viscogliosi et al., 2022). Indigenous strengths-based approaches must centre the expertise of Elders as they carry ancestral teachings that have ensured the survival of their communities and cultures even under genocidal policies that have sought their erasure (Clark & Wylie, 2021). Kelm (2010) highlights how conventional HIV/AIDS research has pathologized Indigenous communities based on historical assumptions of "vulnerability, health disparities, and definitions of risk … through colonial discourse that repeatedly pathologizes and sexualizes Indigenous Peoples" (p.194). Health researchers anticipated that HIV/AIDS would rise to epidemic proportions in Indigenous communities based on historical epidemics such as smallpox and tuberculosis (Kelm, 2010, p. 196). This was not the case as it took over two decades for HIV/AIDS to emerge in Indigenous communities in significant numbers (Kelm, 2010). To decolonize research processes, it is crucial to disrupt these faulty pathological assumptions and explore the profound and immutable strengths and protective factors that are inherent to Indigenous cultures in tandem with wholistic approaches to health and wellbeing. McGregor and colleagues (2010) signify how alternative Indigenous research can serve to further Indigenous governance and they note that "Indigenous Peoples have always engaged in research processes, "to keep the land alive" and how researchers must recognize the experience and contributions of Elders (p.102). Indigenous Peoples, particularly

Elders, have always enacted research processes of hypotheses, observations, and experiential knowledges to develop new understandings about their people and the environment. These practices have ensured the vibrancy and sustainability of their peoples and the lands and animals around them, to maintain the creation of life and to serve future generations. Canada has a long history of enacting exploitative research practices on Indigenous communities which has resulted in a deep mistrust of settler-researchers and westernized research practices (Macklin et al., 2021). Elders are attuned to the needs of their communities and can ensure that research is ethically and culturally sound and that it provides substantive benefits to Inuit, Métis, and First Nations communities. Moreover, Elders play an integral role in the health and wellbeing of their communities as they are experts in Indigenous healing practices that provide a vast array of holistic healing benefits, such as sweat lodge ceremonies (Hadjipavlou et al., 2018; Varcoe et al., 2010; Viscogliosi et al., 2017; Viscogliosi et al., 2022). This study asserts the need for the meaningful partnership of Elders in Indigenous STBBI research because Elders are community-based researchers and experts of Indigenous knowledges and their leadership can serve to shape STBBI research to reflect the distinct cultures, values, and needs of Indigenous communities. Further to this, Elders play a significant role in supporting the developmental needs of younger generations, and sexual health is integral to holistic health (Landy & Worthington, 2021; Rand, 2016). Traditionally, sexuality was not seen as shameful in Indigenous communities, however, this shifted through the enforcement of colonial, westernized discourses steeped in sexual stigma. Sexual stigma and shame contribute to higher rates of STBBI, and lower testing rates which results in lower rates of STBBI support and care (Burns, 2020; Flicker et al.,2015). Elders are well positioned to Indigenize teachings about sexuality and to offer traditional teachings about sex that reflect Indigenous ways of being and knowing that promote “an expansive and multi-

dimensional understanding of sexuality… and encourages the reclamation of sexuality" (Burns, 2020, p.34). Morgensen (2012) further highlights how one of the ways that "colonial power came into being was by mobilizing gendered and sexual power" (p.5). This colonial usurpation of Indigenous sexuality and gender paved the way for sexual violence and shame and Elders are well positioned to transform this colonial mindset through the intergenerational transmission of ancestral teachings that promote Indigenous ways of being and knowing in sexuality and STBBI.

Varcoe and colleagues (2010) highlight the need for engaging Elders in healthcare programs and research through the development of reciprocal relationships by honouring local culture, traditions, and protocols because Elders hold profound influence in Indigenous communities (p.158). Rowe and colleagues (2019) also assert the need for Elders to be engaged in healthcare strategies because they offer traditional knowledge that exists within the context of a particular community and their relationship to the land (p.3). Moreover, Elders wisdom should be captured in health research, however, settler researchers "must avoid [the] co-opting of Elder's voices" (p.3). The initiation of settler-researchers' work often begins in academic institutions, and it is crucial to avoid the "epistemic racism of the academy…because it marginalizes Indigenous knowledges that have supported the wellness of Indigenous Peoples for a millennia" (Matthews, 2017; Royal Commission on Aboriginal Peoples, 1996). This reinforces the need for Elders to take a leadership role in research and for settler-researchers (such as myself) to be continuously mindful that we do not claim ownership of and/or divert the wisdom of Elders for any purposes other than that which is the expressed intent of the Elders.

Viscogliosi and colleagues (2017) developed a scoping review protocol that highlights the integral, leadership roles that Elders play in their communities. Their findings support the need for the engagement of Elders in research because it illuminates how Elders play multiple

roles in their communities to maintain social cohesion and community well-being. In addition, this scoping review articulates how Elders play an influential role in strengthening the social cohesion of their communities by promoting social participation through "activities that encourage social interaction" and by advancing intergenerational solidarity which "involves mutual help in which each generation gives to and receives from following and preceding generations" (Viscogliosi et al., p.2). This offers Indigenous community members the opportunity to engage and give back to their community and provides spaces for building mutually supportive relationships with Elders. Further to this, Viscogliosi and colleagues (2017) signify that government healthcare programs are ineffective for Indigenous communities and how healthcare can benefit from the leadership of Elders in participatory research because Elders are experts of cultural values, ceremonies, and traditional healing practices which serves to enhance culturally responsive research. The findings of this scoping review support the aims of this study because it offers a structured protocol to ethically engage Elders in research. Moreover, it provides a multi-variable synopsis of the unique and integral roles that Elders play in their communities which can deepen my understanding as a settler-researcher. It is imperative for all settler-researchers who collaborate with Indigenous communities to understand the myriad roles Elders play in their communities to enhance the development of meaningful partnerships in research.

The focus of this study is specific to Elder involvement in Indigenous STBBI research to address a lack of research that focuses primarily on STBBI research and Elder engagement. Thus, this study will also explore academic and community literature that involves the engagement of Elders in research that contributes to cultural continuity, and the health and wellness of Indigenous communities. This offers a more expansive overview of the research

literature which contributes to a broader understanding of how Elders are engaged in guiding research processes. This literature review explores Elders engagement in STBBI research, cultural continuity research, and health and wellbeing research by exploring how researchers conceptualize the need for Elders to be engaged in research, key research engagement strategies with the Elders, and how Elder engagement shaped research outcomes. Moreover, this literature review will identify gaps in the research and signify how this study attempts to fill these gaps.

Engaging Elders in Indigenous STBBI Community-Based Research

Indigenous community-based HIV research has prioritized the meaningful engagement of Elders in research for decades. This is highlighted in the study conducted by Flicker and colleagues (2015) "*Research Done in a Good Way*": *The Importance of Indigenous Elder Involvement in HIV Community-Based Research,* which highlights how Elders ensure that community-based research (CBR) is conducted ethically. The findings of this research identify key themes that emerged from the qualitative interviews of fifty-one academic and community researchers. Themes that emerged from this study identify key reasons why researchers engage Elders in Indigenous HIV-CBR: "Elders are keepers of Indigenous knowledge, dynamic ethical consultants, community protectors, and credible sources of information" (p.1149). Moreover, Elders can offer support, such as "counselling, mediate conflict, offer historical context, and conduct ceremonial roles" (p.1149). Flicker and colleagues (2015) offer a strong foundational context for this study because their findings demonstrate the need to engage Elders in Indigenous HIV-CBR by illuminating the voices of researchers. In addition, the qualitative feedback from the researchers demonstrates the need for this study to explore the role of Elders engagement in research from the viewpoint of the Elders. Hence, this study's focus will be grounded in the various standpoints of the Elders. Similar themes may emerge from this study however, the

Elders have shaped the focus, the methodology, and the outcomes of this study in their roles as collaborators, co-authors, and participants. This study's approach foregrounds the Elders Indigenous ways of being and knowing, which will provide further benefits to Indigenous STBBI research.

Within Wilson and colleagues' (2016) study engaging Indigenous youth in HIV prevention, there is a strong emphasis on the need for youth to learn from the traditional cultural teachings of their Elders, with a focus on land-based learning and cultivating strength from ancestral spiritual teachings. This study further emphasizes the need for Elders to act as meaningful partners in STBBI research because they are recognized by Indigenous youth as sources of strength and cultural guidance. Rand's (2016) study on STBBI prevention and sexual health promotion for Inuit women emphasizes that Elders have a significant role in community sexual health because Elders connect the elements of "community-wide, family focused, and youth-centred approaches together" (p.4). Moreover, this study demonstrates how the engagement of Elders is crucial for encouraging the development of reciprocal relationships and "ensuring respect, cultural safety and Indigenous ways of knowing are upheld throughout the research process" (Rand, 2016, p.4). Landy and Worthington's (2021) study engages Indigenous youth and Elders in an arts-based sexual health promotion and STBBI prevention workshop because they identify the traditional role of Elders as leaders in "cross-generational health promotion and education" and this role has been disrupted by colonialism (p.1). This study emphasizes the need for Elders to be involved in community-based, participatory research processes to "reclaim traditional roles in sexual health education and health promotion with youth" (p.1). An Advisory Committee guided this research where an Elder played an integral role of inviting other Elders to participate in this art-based, film project (p.3). The Elders in this

study expressed a theme of "comfort" participating in this project because they had "ownership/control" over the filmmaking process, they worked in partnership with youth, and there was an inclusion of traditional cultural items which were integrated into the Elders teachings (p.6). Landy and Worthington (2021) contributes to this study, because it centers the voices of the Elders as they signify specific elements of research processes that increases their comfort level. The development of meaningful partnerships with Elders in research not only requires that Elders comfort levels be met, but they are engaged throughout the research process in ways that uphold their cultural values, principles, and ethics.

Engaging Elders in Indigenous Cultural Research

There is a spectrum of Elder engagement found in research with Indigenous communities. This engagement ranges from Elders acting only as consultants before the research begins without any further involvement in the research process, to the opposite end of the spectrum, where Elders are meaningful partners in research studies in their roles as co-researchers and co-authors on the research team. These research partnerships often involve the meaningful engagement of the Elders throughout the entire research process, from the shaping of the research question to the dissemination of the results through knowledge translation activities. These various levels of engagement shape the research findings and the depth and breadth of Indigenous knowledges and cultural specificity found in the research ethics, methodologies, and methods. Increased levels of Elder engagement in research leads to a greater level of cultural resonance and foregrounds Indigenous ways of being and knowing throughout the research process because Elders exemplify these qualities.

In their study on the importance of cultural continuity in Métis communities, Auger (2021) consulted with four Elders on multiple occasions leading up to the research interviews

and following traditional protocols, they offered the Elders "tobacco, small gifts, and a meal to share" during these research visits (p.74). This study emphasizes how Métis people look to trusted Elders within their communities, as they hold significant roles in sharing cultural knowledge and the intergenerational transmission of Métis culture (p.73). Using a similar approach, Busija and colleagues (2020) conduct an Australian study that focuses on the contemporary role of Elders in Indigenous communities and how their roles may be eroding, due to the "progressive loss of traditional ways of life" (p. 513). This study seeks to strengthen the role of the Elders through the development of a conceptual model that illuminates their roles using a community-based, participatory research approach. Before the onset of this study, the researchers held a traditional Yarning Circle attended by twelve Aboriginal and Torres Strait Islander Elders who were strongly in support of this project, and they offered their input on the research process. The Yarning Circle is a traditional conversational process that involves the sharing of stories and the development of shared knowledge (Walker et al., 2014). According to Walker and colleagues (2014) the Yarning Circle "prioritizes Indigenous ways of communicating in that it is culturally prescribed, cooperative and respectful" (p.1216). These studies focus on the significant roles of Elders in maintaining cultural continuity. Moreover, the researchers consulted with Elders preceding the enactment of this research to ensure they were approaching this research in culturally ethical ways. The privileging of Indigenous protocols is integral in these studies, as it demonstrates cultural safety in consultation with the Elders. However, if these studies sustained the guidance of Elders throughout the entire research process, it would have increased the benefits to the Indigenous communities.

Quayle and Sonn (2019) promote the use of critical community psychology and decolonizing methodologies in research practices. This study explores an arts-based, storytelling

and portrait project with Noongar Elders, an Aboriginal community in western Australia. The purpose of this project was to develop an archive of healing and reclamation stories to share with future generations to highlight cultural continuity and survival despite ongoing racialized oppression. The authors visited with and consulted Elders several times before they initiated this study. Quayle & Sonn (2019) articulate how psychology must practice within the context of historical and ongoing oppression, and through the affirmation of "Indigenous expertise, self determination, and authority" (p.56). Parallels exist with this study because we recognize the need for Elder research collaborators to create meaning from their past experiences in research and offer guidance to researchers to avoid future harm through the replication of oppressive research practices. Moreover, it is imperative that Elders reclaim their rights as the researchers of their communities.

Clark and Wylie (2021) conducted an ethnographic study to explore how Blackfoot Elders perceive traditional values and how they contributed to their community's ability to overcome cultural genocide. This study features Portraiture, which is a story-telling method used to capture detailed stories of the intersection between human experiences and sacred beliefs. Stories were gathered at three traditional Indigenous ceremonies and during personal visits, where Elders shared stories of resistance and resilience. Clark and Wylie (2021) highlight the significance of building reciprocal relationships with the Elders as co-researchers by participating in smudging, gift giving, personal visits and larger traditional ceremonies as an integral part of the research process. This Clark and Wylie (2021) resonates with this study because it promotes research collaboration that foregrounds Indigenous traditional teachings, ceremonies, and knowledges, while emphasizing the cultivation of reciprocity and relationship building throughout the research process. This study is also shaped by decolonizing and

Indigenous methodologies that stresses the importance of ceremony, collaborative processes, and the co-creation of knowledge, within an ethical space that upholds Indigenous values. In the preceding research there is also a strong emphasis on the need to integrate cultural protocols, ceremonies, and the Indigenous knowledges of the Elders because of their unique roles in cultural continuity and the intergenerational transmission of Indigenous cultures, thus Elders were engaged as consultants and participants throughout the research process. However, this study asserts the need for Elders to be meaningful research partners throughout all stages of the research process.

Engaging Elders in Indigenous Health and Wellness Research

In a health program study led by Blair and colleagues (2022), they collaborated with Elders to develop a Community Kidney Health Program in Saskatchewan, called *Nîsohkamâtowak*, the Cree word for *Helping Each Other*, to improve health care for First Nations and Métis patients by integrating "culturally sensitive models of care" (p.2). Several study events were held, and they were guided by a holistic participatory framework honoring "Indigenous protocols, traditions, culture, and spirituality" (p.4) This research uses storytelling and engages in a "collaborative co-designed process to develop *Calls to Action* in kidney care" (p.2). The researchers identify a noticeable increase in benefit to care and plan to continue partnerships with the Elders in the design of clinical protocols and the use of traditional medicines (p.7). Blair and colleagues (2022) demonstrate how the meaningful engagement of Elders in research can be taken up by healthcare programs to increase health benefits for Indigenous communities which resonates with this study because it is our hope that our research benefits future Indigenous STBBI research to be taken up in STBBI policy and programming for Indigenous communities.

Inuit communities have largely been excluded from health planning, research, and services (Cameron, 2011). Dion and colleagues (2021) promote health approaches that center Inuit self-determination. This research team features an Inuit Elder as a co-researcher and co-author who offers her expertise in traditional cultural practices and approaches throughout this study. This research seeks to capture Inuit approaches, and the underlying principles and practices in relation to self-determination. Dion et al. (2021) signifies how Inuit cultural approaches support community wellbeing, particularly in "the ways of being together and of taking care of each other" (p.1). The Elder co-author takes a leading role in this study to ensure that it is ethically and culturally sound. One of the main findings highlights how mentorship and consultation with Elders is essential to individual and community wellness. Inuit approaches focus on Elders intergenerational transmission of knowledge and their role of guiding individuals and families to ensure their resilience and wellbeing. Dion and colleagues (2021) align with this study because it demonstrates the meaningful partnership of an Elder as a co-researcher and co-author. Moreover, there is a strong emphasis on the beneficial contributions of Inuit cultural approaches and self-determination in health research, planning and programming, while prioritizing the significant roles that Elders play in community wellbeing.

Drost and colleagues' (2019) seeks to expand traditional Indigenous healing practices in Alberta Health Services to reduce healthcare disparities. This study includes the engagement of two Elders and a cultural helper who offer guidance and expertise on traditional healing practices, such as sweat lodge ceremonies. The outcomes of interviews and focus groups highlight the need for: (1) enhancing cultural competency and safety training among leadership and employees; (2) Adhering to tradition and protocol; and (3) Establishing meaningful partnerships between institutional stakeholders and Indigenous community leaders. In addition,

this study recommends that community Elders support the development of community partnerships and ensure adherence to unique local traditions and protocols because this collaboration with the Elders can establish "an ethical space of engagement" (Drost et al., 2019, p.75). Drost and colleagues (2019) research about the inclusion of Indigenous healing practices in healthcare resonates on several levels with this study about the meaningful partnership of Elders in Indigenous STBBI research because their study was initiated with the understanding that Indigenous healing practices will increase healthcare access and benefits for Indigenous communities. Moreover, it stresses the significance of meaningful research and healthcare partnerships with Elders because they recognize the powerful, multi-faceted roles that Elders play in their communities.

Crier and colleagues (2021) oversee a transformative health and research cluster that features the partnership of Indigenous Elders, and this study highlights the need for participatory action research for people with "lived experience of the carceral state" that is grounded in the "wisdom of Indigenous Elders" and this team has been formed to "disrupt status quo research practices" (p.30). The goal of this study is to educate, inspire, and shift the political will of policymakers, the general public, academics, and community members. Indigenous Elders, community members, and Knowledge Keepers take a leadership role in this work. Elders are Knowledge Keepers, however, not all Knowledge Keepers are Elders. Knowledge Keepers, "hold traditional knowledges and teachings and they have been taught to care for those teachings by senior Knowledge Holders or Elders" (Queen's University, 2022, Whereas, Elders are also traditional Knowledge Holders, "who have been bestowed with this title, by their community because of the spiritual and cultural knowledges they hold" (Queen's University, Office of Indigenous Initiatives, 2022, Linking Ways of Knowing, paragraph, 4). Jardine and colleagues

(2021) hold similar aims and emphasize the need for Indigenous models of addiction treatment in Saskatchewan. This study seeks to identify areas of community resilience and empowerment to center in models of addiction recovery. This research team features two Elders as co-researchers, and they implement storytelling as the Indigenous method of gathering data. Co-researchers identified several areas of resilience and empowerment among Indigenous Peoples in addiction recovery, including the support of Elders in spirituality, connection to culture, and traditional healing practices. Jardine and colleagues (2021) recommend the development of addiction treatment models that consider the impact of colonization on substance use and integrate strengths-based approaches to care with the guidance of Elders. The outcomes of these studies demonstrate a positive shift in recognizing the holistic benefits of culturally appropriate care and Indigenous healing practices, through the meaningful partnership of Elders in health research. These results could not have been achieved through a westernized approach to research that positions the researcher as the expert. In these studies, it is clearly recognized that the Elders are experts of Indigenous knowledges and cultural protocols and are best equipped to understand and respond to the needs of their communities. This research resonates with our study because we support the powerful role that Elders play in the health and wellbeing of their communities.

Elders Encourage Ethical and Reflexive Research Practices

Lessard and colleagues (2021) reflect on several years of working as a research team by exploring research encounters that privileged the Elders knowledges using Indigenous methods. The authors identify integral considerations regarding the influence of Elders on research, such as continuous relationship building, and meaningful acts of reciprocity and mutuality. Moreover, Lessard and colleagues (2021) reflect on the ways that the Elders transformed the research, and they emphasize the significance of building these relationships over time. The Elders on their

research team signify the importance of being together in “kindness and relationality” not just as a matter of process (p.29). Lessard and colleagues (2021) stress the importance of understanding “how we shape the research and how the research shapes us” (p.29). This calls for continuous critical self-reflexivity for settler-researchers. Moreover, they signify that community must shape narrative inquiry to ensure that it is “grounded in ethical relationships” (p.29). They also indicate the importance of partaking in ceremony, of slowing down relationships and paying attention to language. Lessard and colleagues (2021) articulate how working with Elders has been a journey of reconciliation that has opened stories of healing, community building, and new worlds. This article resonates with our study because we seek to foreground Elders knowledge through meaningful leadership and collaboration. This article illuminates the significance of building relationships over time that are grounded in kindness-not process. I have had the privilege of building relationships with the Council of Elders at the Feast Centre for Indigenous STBBI Research over a significant period of time. These relationships have been built on mutuality, reciprocity and within ceremony. As a student investigator this research team offers me insight, guidance, and context to continue to build these relationships with “a good mind” that is not preoccupied with outcomes and deadlines. This study will address gaps in the research by centering the voices of the Elder coauthors and collaborators because Elders have guided this research throughout the life of this study and their contributions in the Talking Circles are the focal data contained in the findings of this research. Moreover, this study will guide future researchers in developing meaningful research partnerships with Elders and in turn improve research for Indigenous communities.

Chapter Three: Methodology, Methods, and Analysis

Methodology

This study explores the meaningful partnership of Elders in STBBI research and foregrounds the Elders knowledges as pivotal to the research process as they enact roles as both research collaborators and/or participants. This study is grounded in decolonizing and Indigenous theories and methodologies which are illuminated by the contributions, ethics, and principles provided by the Elders, as experts of Indigenous knowledges. Moreover, Elders are leaders and healers who are deeply respected for promoting well-being and social cohesion within their communities (Viscogliosi et al., 2017) and they exemplify Indigenous ways of being and knowing and it is essential to center the values of the community in Indigenous STBBI research (Tuhiwai Smith, 2012). Further to this, Elders offer robust research skills as interpreters, transmitters, and distillers of Indigenous knowledges, ceremonies, and ancestral teachings (Datta, 2018). According to Flicker, et al. (2015, p. 1149) "Elders often provide the wisdom, knowledge, and ceremonial guidance to assist with research processes that respect Indigenous worldviews." Additionally, Elders are attuned to the needs of their communities, and they can bridge the Indigenous knowledges gap in STBBI research, policy, and programming through partnerships in research that highlights the need for "culturally based healing treatment for Indigenous People living with [STBBI]" (Hillier et al., 2020). This gap is demonstrated by a dearth of Indigenous specific services in STBBI prevention, support, and care (Hillier et al., 2020). Elders are in a unique position to transform research that will be used to inform STBBI policy and programming for Indigenous Peoples through the development of research partnerships that respond directly to the unique needs of their communities. Elders embody their communities' distinct cultures, knowledges, and ways of being, which serves to Indigenize STBBI research processes to benefit

the health of Métis, Inuit, and First Nations communities as their needs are brought to the forefront of STBBI research (Flicker et al., 2015).

Indigenous Ways of Being and Knowing

Decolonizing and Indigenous theories are rooted in Indigenous ways of being (ontologies) and knowing (epistemologies). Indigenous ontologies (ways of being) are not meaningfully captured in the western sense of the word because according to Hunt (2013) "they are bounded in ways that limit their ability to fully account for Indigenous worldviews" (p. 1). According to Kramm (2021) "ontologies cannot be reduced to ontological assumptions or commitments but are always embedded as a way of life" (p. 3). Hunt (2013) emphasizes how "stories and storytelling are widely acknowledged as culturally nuanced ways of knowing produced within networks of relational meaning-making" (p.1). Indigenous ways of being and knowing, are intergenerationally transmitted by Elders to younger generations through stories and parables that offer complex and sophisticated teachings during various developmental stages of life and arise from land-based knowledges. Wildcat et al. (2014, p.2) describes land-based knowledge as "forms of governance, ethics, and philosophies that arise from relationships to the land." These knowledges are cultivated by the Elders through their own relationships to the land and their connection to ancestral knowledges. Indigenous ways of being are often "consensus-based and group focused" (Kramm, 2021, p. 4) which emphasizes the need to understand the intersubjectivities within the relational network of the community. Elders are theorists of traditional Indigenous knowledges and according to Bruhac (2014, p.2) "can be defined as a network of knowledges, beliefs, and traditions intended to preserve, communicate, and contextualize Indigenous relationships with culture and land over time." It is integral that diverse Indigenous knowledges are centered in STBBI research because these approaches support the

holistic health needs of Inuit, Métis, and First Nations communities (Abolson, 2010). Moreover, the centering of Indigenous knowledges in STBBI research encourages the use of Indigenous methods, principles, and ethics in the research process from inception to application. Indigenous ways of knowing and being are grounded in community traditions, worldviews, and experiences. Although there are a multiplicity of Indigenous knowledges and significant differences, Indigenous scholars agree there are overlapping, shared, and key foundational tenets. According to Hart (2010, p. 3):

> First, knowledge is holistic, cyclic, and dependent upon relationships and connections to living and non-living beings and entities. Second, there are many truths, and these are dependent upon individual experience. Third, everything is alive. Fourth, all things are equal. Fifth, the land is sacred. Sixth, the relationship between people and the spiritual world is important. Seventh, human beings are least important in the world.

The centering of Indigenous worldviews and conceptualization of the self, kinship and community are crucial to Indigenous STBBI research because it positions research in the community and provides meaningful outcomes for Indigenous researchers and participants living with and/or affected by STBBI. According to Cochran et al (2008, p.23) "...how we go about acquiring knowledge in Indigenous communities is just as critical for the elimination of health disparities—if not more so—as the actual knowledge that is gained about a particular health problem." Indigenous knowing emphasizes the continuous process of relationship building and there is an onus on the researcher to build ethical relationships and research processes that reflect the needs of the community (Stewart, 2009). Indigenous ways of being and knowing can be taken up using community-based participatory research methodologies that according to Koster et al. (2012) "...respects and values the community as a full partner in the co-creation of the

research question and process, and shares in the acquisition, analysis, and dissemination of knowledge" (p. 195). This approach promotes ethical research by fostering an environment where settler researchers can locate themselves as researchers and practice a reflexive approach that "...demands aggressive inquiry into the very possibilities of [their] unreflective knowledge and practices" (Macbeth, 2001 p. 37 in Koster et al., 2012 p. 197). Ferreira and Gendra (2011) indicate how community-based participatory research allows community members to participate as "full collaborators" and researchers, "are not just objective investigators but are active learners throughout the research process" (p.153). Several Elders in this study have functioned as meaningful collaborators throughout this research and I have positioned myself as a student-learner-researcher who is privileging the knowledges and wise practices of the Elders to enrich STBBI research.

Indigenous ways of being, doing and knowing connect to the research questions of this study because they are the foundation for wise practices, Indigenous worldviews, ethics and values, and key to the development of meaningful relationships with Elders in research (and beyond). Indigenous ways of being and knowing are grounded in this study because the purpose of this research is to explore the cruciality of developing meaningful partnerships with Elders in STBBI research, to understand the colonial barriers to privileging Indigenous knowledges in research, and to gather wise practices from the Elders to strengthen research partnerships and processes. This research is guided by privileging the Elders' knowledges throughout the research process, and following Indigenous ethics, such as the emphasis on building strong relationships between researchers and participants, which is often seen as a conflict of interest under westernized research approaches. Indigenous ways of being and knowing influence the nature of the questions in this study by providing open-ended questions that offer Elders an opportunity to

share their expertise using their own holistic narratives to illuminate their experiences and offer cultural teachings. For instance, the first question that Elders were asked to respond to in the Talking Circles was: - What were the successes and challenges that you encountered during your involvement in STBBI research? This question allows the Elder to choose what they define as "successes or challenges" without being influenced. Moreover, the Talking Circle method offers a space for the Elders to share what they determine to be the most poignant information, experiences, stories etc. based on their ethics and principles. Further to this, at the beginning of each Talking Circle I encouraged the Elders to consider the questions only as a guide and to move in whatever direction or topic that they were compelled to share. The qualities and features of Indigenous ways of being, doing and knowing are boundless, however, this study endeavors to privilege these ways by honouring them through the sacred integration of prayer and ceremony into the research processes and by supporting meaningful relationships with the Elders- before, during, and after this study. The data that is collected from this study exemplifies Indigenous ways of being, doing, and knowing because it has been provided by Elders who embody these values and worldviews. Attention is given to the holistic and egalitarian features of this data that illuminate relational, spiritual, ceremonial, and land-based knowledges that connect to all living and non-living beings.

Indigenous Paradigm

Decolonizing and Indigenous methodologies are rooted in an Indigenous paradigm which according to Kuokkanen (2000, p.412) is centered in, "self-determination…and the right to maintain and develop cultural manifestations of cultural practices including the restitution of their spiritual and intellectual properties." Moreover, Kuokkanen (2000, p. 413) emphasizes that an Indigenous paradigm is "a culturally specific discourse based on Indigenous peoples'

premises, values and worldviews" that "can raise questions of relevant research regarding Indigenous communities" (Kuokkanen, 2000, p.214). An Indigenous paradigm offers a foundation to build Indigenous "intellectual self-determination and sovereignty" which is crucial in research because it directly impacts the health and well-being of Indigenous communities. Kuokkanen (2000, p. 417) elaborates how an Indigenous paradigm, "maintains a critical stand towards Western metaphysical dualism which still informs much of current patterns of thinking and research practices." This reinforces the need for an Indigenous research paradigm and Wilson (2001) asserts, "We now need to move beyond an "Indigenous perspective" in research to researching from an "Indigenous paradigm" that includes Indigenous ontology, epistemology, methodology and axiology" (p.175). Moreover, Wilson (2001) emphasizes that the axiology of an Indigenous research paradigm contains a set of "morals and ethics and must set out to do something beneficial in this world" (p.175). Elders are known for their understanding, honour and commitment to Indigenous morals and ethics, and they can transform westernized research ethics to reflect the values of Indigenous peoples, such as the ethical emphasis on relationship building which is fundamental to Indigenous research. Hart (2010) further promotes the development of an Indigenous research paradigm that encourages research that is rooted in "radical Indigenism" coined by Eva Marie Garrotte (2003) that encourages "…the reassertion and rebuilding of traditional knowledge from its roots, its fundamental principles" (p.101). Radical Indigenist scholars resist academic discourses that "strip Indigenous intellectual traditions of their spiritual and sacred elements" (p. 6). Hart (2010) signifies that if these elements are sacrificed, so is all meaning. Elders, as the carriers of ancestral knowledges are experts of these fundamental principles and are in the utmost position to further an Indigenous research paradigm. Moreover, Elders are spiritual leaders who prioritize the integration of prayer

and ceremony throughout the research process and as meaningful research partners they can ensure the research upholds sacred ways. Hart (2010) highlights this divergence between euro-western ontologies and Indigenous ontologies signifying the need for an Indigenous research paradigm that recognizes the inherent connection between the physical and spiritual realms with worldly actions, which must be sanctioned by the sacred (p.6).

This study recognizes Elders as experts of Indigenous epistemologies and acknowledges they are in an exemplary position to lead research that focuses on the health and well-being of their communities because they have been healers and researchers since time immemorial. The leadership and partnership of Elders in STBBI research ensures the use of an Indigenous paradigm that centers the wholistic connection of the sacred, the land, sexual health, and traditional healing practices. This wholistic approach to STBBI challenges conventional scientific and clinical approaches that focus almost solely on the pathophysiology and how it impacts the physical bodies of people living with STBBI (Hillier et al., 2020). Elders bring the power of spirituality, ceremony and the sacred to reframe STBBI as a natural part of life that needs to be responded to with loving energy, acceptance, and care not shame and stigma. Spirituality and ceremony are protective factors that connect Indigenous people living with STBBI to the Creator, their Elders and ancestors, and their community. The strengthening of these healing relationships encourages the envisioning of self as a spiritual being who is sacred and deserving of wholistic healing (Abolson, 2010). Elders hold a profound and sacred connection to the land which can be used to guide traditional healing practices in STBBI. For instance, CAAN has been undertaking a multi-year, multi-stakeholder initiative entitled, *Weaving our Wisdoms: Using a Land-Based Approach to Optimize Whole-istic Health among Indigenous People living with HIV* which connects “HIV Olders” who are long term survivors

who carry land-based knowledges that they share with younger generations who are impacted by HIV. This study offers land-based learning and healing opportunities because reconnection to the land is recognized as a vital pathway towards health and healing for Indigenous Peoples. This initiative implements land-based wellness programs that focus on the benefits of land-based approaches and research methods to support Indigenous people living with HIV and AIDS. An Indigenous research paradigm is compelling to this study because it underlines the need for research that goes beyond tokenistic involvement of Elders to establishing meaningful partnerships as a form of research reclamation. This study also contributes to an Indigenous research paradigm that is reflective of First Nations, Inuit, and Métis communities because it foregrounds the wise practices of the Elders who are the leaders, traditional healers, and knowledge holders of these communities. Moreover, this study supports Elders as meaningful research partners who are positioned to shift STBBI research into the leadership and self-determination of Indigenous communities.

Decolonizing and Indigenous Theories and Methodologies

Decolonizing theories seek to deconstruct colonial ideologies that are upheld by the structural power of westernized thought and research approaches (Held, 2019). Moreover, decolonizing theories question Western discourses that seek to delegitimize Indigenous ways of being and knowing through the re-centering of Indigenous knowledges in research and education. According to Sium et al. (2012) “decolonization does not exist without a framework that centers and privileges Indigenous life, community, and epistemology” (p.1). This study seeks the reclamation of research processes under the leadership of Elders using Indigenous methodologies to support self-determination and promote healing and recognition in their communities. According to Kovach (2005) “Gaining control of the research process has been

pivotal for Indigenous peoples in decolonization…and gaining control over research findings has been critical in pushing forward community-based goals of self-determination" (p.4). Decolonizing and Indigenous theories are critical of the dominance of euro-western ideologies, and theoretical frameworks in research that focus more on outcomes, whereas Indigenous methodologies are more concerned with the process. Decolonizing and Indigenous theories have individual characteristics, however they are highly interrelated as they are both rooted in Indigenous ways of knowing that value relationality, and the interconnectedness of the sacred and worldly realms, with an emphasis on wholism that values the emotional, spiritual, cognitive, and physical dimensions of knowledge (Abolson, 2010). Sexuality is intimately connected to all of our dimensions, senses, and sense of self and this increases the significance of following decolonizing and Indigenous theories in STBBI research. This wholistic approach is vital to STBBI research because when Indigenous methodologies are implemented the process is paramount and the research is person-centred, relationship based and includes IPLWH and Elders on the research team (Flicker et al., 2015). The combination of these characteristics creates a research process that is spiritual, healing, and empowering, and serves to destigmatize STBBI because it attends to wholeness and healing, not isolated pathology. Moreover, it offers a platform for non-Indigenous researchers to witness the wholistic transformation that can occur within the research process.

Held (2019) emphasizes that Indigenous methodologies must arise from an Indigenous paradigm and new research paradigms need to be developed in partnership between Indigenous and non-Indigenous researchers to address settler colonialism and contribute to Indigenous sovereignty over land, infrastructure, and resources. This study is a collaboration between Elders as the experts and a settler-student-researcher. The Elders have guided the Indigenous

methodology, method, and ethics throughout the life of this study. Moreover, they have shared wise practices to inform future researchers how to build capacity in strengthening meaningful research partnerships in STBBI. This commitment to Indigenizing research in collaboration with the academy, despite generations of colonial trauma highlights the dedication and compassion that Elders have for their communities. Held (2010) maintains that to genuinely decolonize research paradigms we must privilege Indigenous ways of knowing through continuous application of Indigenous methodologies in research. This study features Talking Circles as an Indigenous method of gathering data. Baskin (2005) encourages the use of a Storytelling Circle as an Indigenous method which is conceptually aligned and involves "the direct involvement of participants and community; the reciprocal relationship between researcher and participant; the goals of self-determination, decolonization, and direct benefit to the community; and the potential for learning and healing" (p.171). Lavallée (2009) elucidates the unique characteristics of using Sharing Circles, another similar method, through "the sacred meaning they have in many Indigenous cultures and in the growth and transformation bases for the participants" and the "acts of sharing all aspects of the individual—heart, mind, body, and spirit" (p. 29). This method also rebalances the power dynamics in the researcher–participant relationship whereby the Elders share rich dialogue generated in the Circle for research purposes (Lavallée, 2009). Kovach (2005, p.10) emphasizes how Indigenous theory is "inextricable from methodology" because it will guide which issues are important to study, the chosen participants and their role in the study, the validation of subjective knowledges and how the study is presented. This study is grounded in Indigenous theory and methodology and this is evident through the choice of research question, the decision to collaborate with Elders from the inception of this study to receive guidance, the decision to use the Indigenous method of Talking Circles (recommended

by coauthor Elder Sheila Nyman), the Elders contributions are foregrounded as the key findings of this study, we participated in two members checking sessions where the Elders provided their feedback and input on the thematic analysis, and the Elders were offered the choice to sign on as coauthors to recognize their significant contributions to this study. Held (2019, p.5) offers four core beliefs inherent to an Indigenous research paradigm: "a relative and relational ontology, an intersubjective and relational epistemology, an axiology that promotes respectful representation, and a liberatory, participatory methodology." These core beliefs align with this research because this study grew out of a relational ontology that is exemplified by the Elders in how they respond to others with profound compassion and humanity. Moreover, the Elders accentuated the paramount importance of relationship building in research and how the dynamics of relationality are fundamental to the research process, and this was evident in the relational behaviour of the Elders during the Talking Circles. This study also strongly supports respectful representation because the meaningful partnership of Elders is rooted in this philosophy. Further to this, the Elders have been collaborators and coauthors throughout this study which is bolstered by the use of Talking Circles as the Indigenous method which is grounded in a liberatory and participatory methodology. These core beliefs have also shaped the data analysis in this study as I have been guided by a relational approach that examines the intersubjectivities in the relationships between the Elders and researchers; explores how they have been represented in these research settings; and ensures the Elders contributions are analyzed using the criteria they deem as most significant.

The meaningful collaboration of the Elders has provided an ethical and principled framework throughout all processes of this study from inception to outcome. This study seeks to follow an Indigenous research paradigm that is rooted in relationality, positions the Elders as

researchers and privileges the Elders' knowledges and experiences. Indigenous and decolonizing methodologies have risen out of Indigenous ways of being, doing, and knowing and their application in research demands the leadership of Elders who are highly skilled and knowledgeable experts. This study seeks to demonstrate that it is crucial for Elders to be meaningful partners in Indigenous STBBI research because their power, knowledges, influence, and insight are necessary to make substantive decolonizing and Indigenizing shifts in STBBI research to benefit their communities.

Methods

This study has been guided by the Feast Centre Council of Elders since its inception. This Council is comprised of Elders who carry Indigenous and cultural knowledges across several nations and territories. The Council of Elders guided the development of the research question and design, the decision to use Talking Circles as an Indigenous research method, and the emphasis on prioritizing Indigenous ethics and principles of research such as relationship building, responsibility, and reciprocity with the Elders recruited to this study. I have had the honour of building relationships with the Elders on this Council in my role as an Elder's helper which has also offered me an ideal opportunity to learn from the Elders during their Council Gatherings and this profound learning has helped to shape this study. There are three Elders from this Council who have signed on as the original coauthors on this study, Sheila Nyman, Sharp Dopler, and Catherine Martin. This was indicated in my McMaster Research Ethics Board (MREB) application, so they were advised by the MREB during the ethics process. I developed an in-depth ethics application for this study and submitted it to the MREB. The initial response from the MREB took an exceptionally long time so I contacted a representative, and I was advised that my application had to be sent out externally for review to someone with experience

in Indigenous research. The initial MREB response contained several requests for revisions and once I completed these revisions and resubmitted the ethics application it was officially approved in a short period of time.

To initiate the recruitment process I sent electronic research study packages containing the recruitment email script, recruitment posters, social media posts, and consent-letter of information to representatives from the Feast Centre and CAAN to promote this study throughout their networks. Elders who were interested in participating contacted me through email or telephone and I set up telephone follow up meetings with each potential participant. I began each of these meetings by asking the eligibility screening questions. These screening questions were: (1) Do you self-identify as an Elder? (2) What Indigenous community are you connected to? (3) Do you have experience participating in STBBI research? If the Elder did not meet this criteria, I offered an explanation to the Elder and expressed my gratitude for their interest in this study. If the Elder met this criteria, I reviewed the study details and answered any questions. If they were still interested in participating in this study, we followed the informed verbal consent process where I asked a set of study questions about how they would like to receive study results, preferred contact, if the Elder would like to be named as a coauthor, if I could contact them by telephone for a follow up check in after the Talking Circle, and if they were interested in participating in a members checking session to offer feedback, and I obtained verbal consent from each Elder. After our telephone call was complete, I emailed each Elder the Consent-Letter of Information to ensure they had it available to review and I thanked them for signing up for this study.

I scheduled three Talking Circles on three separate days during the afternoon to accommodate the various time zones. Several days before each Talking Circle, I emailed the Elders the Talking Circle Guide [see Appendix A] and a list of Indigenous supportive counselling services in case the Talking Circle triggered emotional distress for any of the Elders. The Talking Circle Guide offered guiding questions to assist in stimulating discussion about the inclusion of Elders as meaningful partners in Indigenous STBBI (sexually transmitted and blood borne infections) research. The Talking Circle questions were: (1) What have been the challenges and/or successes you have encountered during your involvement in STBBI research as Elders? (2) Were Indigenous teachings and practices used in this research? A) If yes, how so? B) If no, what barriers stopped this from happening? (3) Why is it important for Elders to partner in Indigenous STBBI research? (4) Which wise practices, including ethics, values, methods etc. need to be used throughout the research process? (5) What guidance would you give Indigenous STBBI researchers to strengthen meaningful research partnerships with Elders in the future? These questions elicited in-depth responses from the Elders as they shared detailed personal stories and drew on examples from their involvement in STBBI-related research, advocacy, and community work. I ensured to communicate with the Elders that the questions were only intended as a guide and the intent of these Talking Circles was to offer the Elders a space to contribute in the way they were most compelled to share because I did not want to constrain how they chose to contribute.

Modelled on the Indigenous Talking Circle (Baskin, 2005; Lavallée, 2009; Poff, 2006; Rothe, Ozegovic, & Carroll, 2009), my use of a Talking Circle is inspired and reflected by the central importance of oral tradition and storytelling for Indigenous Peoples (Poff, 2006; Rothe, Ozegovic, & Carroll, 2009). This format structures the gathering of stories about the meaningful

partnership of Elders in research by providing a cultural signal to participants that this consultation is premised on egalitarian, supportive, non-confrontational values meant to solicit collective identification of problems and solutions (Rothe, Ozegovic, & Carroll, 2009). In adopting this approach, the central goal is to create a "mutually respectful, win-win relationship —a relationship in which the Elders are pleased to participate in research and the community at large regards the research as constructive" (Poff, 2006, p. 28).

At the beginning of each Talking Circle, I reviewed the informed consent process for this study and reminded the Elders that our Talking Circle would be audio and video recorded and I would be using the Zoom live transcription feature to capture everything that the Elders shared in the Talking Circle except the verbal consent process, opening and closing prayers and personal introductions. I received verbal consent from each Elder and entered it into the Oral Consent Log before we began each Talking Circle. There are added benefits that the Zoom platform offers to the participants and the research. According to Olliffe et al. (2021, p.1) these added benefits are: "1) Rich therapeutic value 2) There's no place like home 3) Reduced costs to extend recruitment and reach inclusivity." Zoom can inspire the gathering of rich data from participants in the comfort of their own homes and allows for multi-site data collection (Oliffe et al., 2021).

The Talking Circles were opened and closed in prayer, song, and ceremony by individual Elders. I virtually shared sweetgrass that offers healing and therapeutic benefits, and it is one of the main medicines for First Nations and Métis Peoples. I discussed my role with the Elders, as one of facilitator, where I would offer guiding questions and keep track of the speaking order of the Talking Circle. I emphasized the importance of the Elders freedom to share whatever they chose to in the Talking Circle without any pressure. We explored the Elders' past experiences in STBBI research and the successes and challenges they experienced. After this, the Elders shared

the importance of their meaningful partnership in STBBI research and offered future researchers' critical guidance and wise practices on how best to strengthen these research partnerships. After the completion of each Talking Circle, I sent bank e-transfers or mailed cheques for the one-hundred-dollar incentive to each Elder based on our previously agreed upon method pf payment. In addition, I contacted each Elder after the Talking Circle by telephone to follow up and see how they were doing and to request their feedback about how they thought and felt it went. Immediately after each Talking Circle was complete, I downloaded the video recording and closed captioning transcript to my personal computer. I then downloaded these items to my password protected MacDrive into an encrypted folder. Next, I edited the Zoom live transcription closed captioning documents by carefully following the video/audio recordings and correcting any errors. I ensured that I took the necessary time to watch and listen to the recordings so that I could see, hear, and feel the nuance, expression, emotion, and energy shared by the Elders throughout the Talking Circles. This consisted of watching and listening to the recordings several times. (Once the transcripts were revised for accuracy, I permanently deleted the Zoom videos from my computer).

Analysis

Once the transcripts were complete, I hand coded the data to develop a draft thematic analysis through the development of overarching themes that emerged across the three Talking Circles. This coding method is consistent with recommendations offered by Onwuegbuzie and colleagues (2009) for analyzing focus group data, I used constant comparison to weave the Elders contributions together. Following processes similar to those developed by Strauss and Glazer (1990), Onwuegbuzie and colleagues (2009) described three stages of analysis to be

followed. In the first stage, I used open coding that refers to "the part of analysis that pertains specifically to the naming or categorizing of phenomena through close examination of data" (Strauss & Glazer, 1990, p. 62). In this first step, I grouped smaller units of the data that expressed similar properties and assigned it a code. This was a data driven exploratory process where I identified common concepts across all three Talking Circles and identified them using codes. These codes were: building research relationships, representation in research, community benefits from research, ceremony and spirituality, Indigenous research methods and methodologies, colonialism and intergenerational trauma, meaningful engagement of Elders, traditional healing practices and medicines, inclusion of Elders and IPLWH (Indigenous people living with HIV), Elders are ancestral knowledge holders, importance of language, use of land-based knowledges, oral tradition and storytelling, cultural traditions, and Elders supporting youth. In the second stage of coding—axial coding- I grouped the codes "back together in new ways *by making connections between a category and its subcategories*" (Strauss & Glazer, 1990, p. 97; italics in original). This process allowed for the overarching themes to begin to emerge by connecting subcategories with similar characteristics into larger categories. In the final stage, using selective coding, I developed the overarching themes that best captured the content of the Talking Circles. Selective coding is the process of "selecting the core category, relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (Strauss & Glazer, 1990, p. 116). Validity was established by linking the codes and categories with direct quotes from the Elders. To further ensure the trustworthiness of the findings, the Elders reviewed this thematic analysis to ensure that it was a genuine reflection of their contributions during the Talking Circles. Once the first draft of this study was complete, the Elders were invited to attend volunteer virtual members checking

sessions via Zoom for an opportunity to review this thematic analysis to ensure that it resonated with them. Before these sessions, I emailed the Elders a copy of the study overview along with the complete Findings Chapter containing the thematic analysis supported by their contributions. During these sessions, I presented this overview and thematic analysis of the Talking Circles, and the Elders offered their feedback, input, and suggestions for minor revisions. We also discussed potential ways of bringing our study forward, such as the development of a publication, resources for researchers, and conference presentations. After these sessions were complete, I sent the Elders traditional gifts of gratitude and thank you cards to their mailing addresses.

Chapter Four: Findings

The following section will explore five overarching themes that emerged from this study's three virtual Talking Circles with the Elders. This study used the Indigenous method of Talking Circles as opposed to focus groups because they are commonly used to gather information within Indigenous contexts as this method encourages storytelling and collective listening, while providing a culturally safe and appropriate setting (Tremblay et al., 2018). According to McGregor et al. (2010) in the Talking Circle, the facilitator is also a participant in the process and can share knowledge and experiences with the participants and this process helps alleviate the power imbalances often found in research as it ensures that the contributions of all participants are equally recognized. Although I provided guiding questions and supported the flow of the Talking Circles, I presented myself as a student/learner of the Elders and I also shared personal information about myself to contribute to our relationship building. Moreover, the spirit of the Talking Circle encourages Elders to use personal narratives to deepen and expand upon the research subtopics of inquiry. There were thirteen Elders who each participated in one of three two-hour Talking Circles. A majority of the Elders identified as women, and four Elders identified as Two Spirit. Two Elders identified as Inuit, two Elders as identified as Métis, with Anishinaabeg and European ancestry, one Elder identified as Cree and Black and eight Elders identified as First Nations: one Elder from a Gitxsan Nation, one Elder from a Kwakiutl Nation, two Elders from Tlingit Nations, one Elder from a Haudenosaunee Nation, and four Elders from Anishinaabeg Nations. The Talking Circles were opened and closed in ceremony by Elders who offered traditional prayers, smudging, words of blessing, and spiritual song. One of the Elders, Aggie, was making Bannock during the Talking Circle because creating this traditional food for others brings her peace and contentment. Another Elder, Bone Collector

found a tuft of an eagle feather during the beginning of a Talking Circle in which he said was a blessing from the Creator. The following thematic analysis aims to capture the highlights of the Elders' rich and illuminating contributions during these Talking Circles.

This thematic analysis of Elders as meaningful partners in Indigenous STBBI research, produced five overarching themes: (1) Understanding the historical and ongoing impacts of colonialism and the need to decolonize STBBI research; (2) Prioritizing the knowledge and lived experience of Elders and Indigenous people living with STBBI throughout the research process; (3) Centering spirituality and ceremony in Indigenous STBBI research; (4) The importance of implementing Indigenous methodologies in STBBI research; and (5) Foregrounding Indigenous ways of being, knowing, and doing in STBBI research. These themes are supported throughout this section using the in-depth and powerful contributions of the Elders.

Understanding the historical and ongoing impacts of Colonialism and the need to Decolonize STBBI Research

One overarching theme that emerged from the Talking Circles was the need for non-Indigenous researchers to make concerted efforts to understand the historical and ongoing impacts of colonial policies and systemic violence on Métis, First Nations, and Inuit communities, such as, the Residential School system, the Indian Act, and Missing and Murdered Indigenous Women and Girls. This knowledge and understanding are a necessary precursor to shape research processes that serve the best interests of Indigenous communities as opposed to only serving the interests of academic or other government funded institutions. Without a decolonial theoretical framework researchers will lack capacity to shift their colonial mindset or transform research processes to strengthen relationships with Indigenous communities to serve their needs. Paula discusses the impacts of forced Christianity in Residential Schools and how it

instilled stigma about certain behaviours such as substance use, and how this creates barriers to healing the multi-generational trauma experienced by Indigenous communities.

> I really find that the stigma that the Elders [who went to] Residential School… carry [are] those Christian values of shaming and blaming and I don't know how we get around that. I accept everyone and we are all on a path for a reason, and I really believe that if they are drinking or drugging excessively it's because they're crying out for help, and we need to help them. I find that I've been really thinking about what [Residential School] really took from us as a people, and…they took the community out of our families. I conduct myself in a way where I try to have compassion, to have acceptance.

Sandra also shares how there is intergenerational trauma and stigma connected to sex caused by the legacy of shame and sexual abuse experienced in Residential and day schools. Moreover, she shares how this shame contributes to worsening health outcomes because many people do not want to discuss sexual health issues, and this is compounded by the lack of funding for sexual health services in Indigenous communities:

> There's a trauma about sex, they won't speak up on it. Some just live with the disease they are carrying before it's too late and a lot of them, they don't give enough credit to the communities, or funding the communities for any of this like the STDs or anything like that. Because a lot of things are kept under hush hush all time. This all generates back to the Residential Schools, the day schools. And the way our people were just told to be quiet.

Moreover, Deidre shares the shame her mother used to carry concerning her Indigeneity because of her experiences in Residential school and the trauma of having her language and culture stolen

from her as a young child. She also discusses how her Mom used to hide her Indigeneity when people asked about her ancestry:

> My mother was raised in Residential school in [name of Province]. So, they took her language they took all kinds of things, so my mother became Italian. If anybody asked her, they said look at you- you must have a little something in you and she said yeah, I'm Italian she wouldn't even admit that she was Indigenous at all, because she knew that being Indigenous was very negative. But she's funny because my Mom is still with us and she's in her nineties, and one of the things she always says is "I was Indian before it was cool."

Leanne also discusses the impacts of colonialism and forced Christianity on Indigenous Peoples and how traditional cultural beliefs were perverted and demonized under this system. She used the powerful illustration of how left-handed Indigenous children were physically abused in Residential school for using their left hands and how the left hand is considered the sacred hand in many Indigenous cultures because it connects to the heart. This sharing triggered deep emotions and precipitated healing for one of the Elders in the Talking Circle who had experienced this specific abuse as a child and had not understood until that moment the faulty reasoning behind this childhood abuse.

> It's just like the left hand was taken away from us, because it was the devil's hand. They were strapped when they were in Residential School if they used their left hand. For Indigenous people, our left hand is sacred because it goes from the heart down to your hand. So, when you're offering somebody something you use your left hand. It's the sacred hand because it comes from the heart… so you hand them the tobacco or the gift with the left hand because that just means so much to the person that accepts it.

Louise demonstrates how the intergenerational trauma caused by colonial policies, such as the Residential School system and the Indian Act have instilled a deep-seated fear of western medicine and has also led to an increase in the use of unhealthy coping behaviours. The combination of these factors contributes to the increased rates of chronic illness in Indigenous communities.

> Why our people don't comply with Western medicine, why our people are living with diseases like HIV, diabetes, lung disease? It's because of everything that affects us in our minds, and that is our experiences and the intergenerational trauma from Residential school, the Indian Act impositions, changing our matriarchal system to a patriarchal system. The discrimination that we experience in our daily life, therefore, turning to unhealthy behaviors such as alcohol, drugs, cigarette smoking, weed smoking, gambling, and such. If researchers could understand our lived experience from being healthy and thriving, to what happened to us with the imposition of the Indian Act and trying to survive in today's society, it's important for them to understand. When they understand, then they can treat us from a trauma-informed, harm reduction place and with the love that we keep talking about for each other.

Red Sky demonstrates her experiences of overt racism and discrimination in our colonial healthcare system and how this contributes to the trauma and systemic oppression that Indigenous Peoples face on a large scale. She emphasizes the need for Elders to be given the opportunity to share these stories of systemic oppression in research to contribute to substantive change that centers Indigenous values.

> I think about some of the experiences I've had in going to the emergency at the hospital, and how I was so easily dismissed as an alcoholic or mentally crazy or blamed and

> shamed, as a drunk or a drug user and I'm just there to look for drugs…I realize now how deeply hurt you are and traumatized. My childhood experiences brought me into today, how they impacted my physical and mental health and the importance that Elders need to tell these stories…to make some changes. So that we could stop being invisible, and our voice is heard in all of these mechanisms, especially within our health system. It needs to be reviewed and how there's so much loss of our values and that it's all about money and it's not about tender loving care, or it's not about nurturing. You know how we gathered around them, and we took care of them. That's what it was like growing up as a child and seeing it. I know it's there, but…it's, almost all gone.

Paula describes highly discriminatory hiring practices in a non-profit organization where she was employed as she was the only Indigenous women who had ever been hired. This left a gap in culturally relevant care and Elder Paula was a lone voice calling for services that were grounded in Indigenous culture and values:

> I was the only First Nations woman that was ever hired at that agency, and the place just celebrated their 35th anniversary. So that was a real challenge trying to explain to them the culture and how we care for each other and how we should support each other, and it was hard.

Aggie highlights the lack of action on the calls to justice from the National Inquiry into Indigenous Missing and Murdered Women and Girls and how this is another example of Indigenous Peoples being treated as "disposable." In addition, she draws a connection between the sexual objectification of Indigenous people and the increased risk of STBBI. Aggie calls out the failure of the government and police to protect Indigenous women and men from disease and

violence and how this neglect has contributed to an ongoing crisis situation for Indigenous communities:

> I'm still fighting for the safety of women because every day there's more than one person going missing. I have spoken to reporters on the importance of the implementation of the recommendations in the National Inquiry of the Missing and Murdered Indigenous Women. All this is tied together with STDs…because this wouldn't have happened if our people weren't being treated as sexual objects…we are seen as a disposable people, where we're just disregarded and the lack of support from governments and police shows that they are still treating us as disposable people. The fight continues until we have these safe places for women to be safe and for men to be safe…it involves men too, a lot of men go missing as well…We're living in a crisis, where people are not safe, they're not safe from disease, they're not safe from being murdered, they're not safe from dying. And this is something that we have to keep doing.

Bone Collector shares how colonialism caused profound cultural erasure in Indigenous communities and how it is the process of "remembering" that brings one into the role of being an Elder because it is not dependent on age. Moreover, he illuminates the need for Elders to dispel the myths around STBBI through the dismantling of colonial language and thought and the re-centering of spirituality:

> We're all born Elders and we just forget. So much erasure in our life that we have to go through the whole process of remembering everything and when we remember everything that's when we become an Elder. A barrier can be misperceptions about who is considered an Elder because it is not about age- this is a colonized way of thinking- we live in a very colonized world. We want to speak in a way that allows our voices to be

> heard as they are meant to be and not misinterpreted by colonized thinking. So, this is the importance I believe in having Elders within this whole system and dispelling the myths around blood borne infections and disease and looking at them for what they truly are, they're divine and holy messages from our Creator, dismantle the messages…dismantle the colonization, and then the messages come through in here (pointing to head) and more importantly in the heart (pointing to heart).

Samizi discusses the importance of decolonizing STBBI research, but also recognizes how much of the research is directly linked to universities which are colonial institutions. She emphasizes the need for each of us to decolonize ourselves first, or we will be unsuccessful in transforming research:

> Decolonizing STBBI research, yes, but we, we have to do it through the university, and the university is a colonial institution and as a colonial institution it's got all of these structures that just fuck us up to no end. We can talk about how important it is to decolonize and everything else and it starts with each one of us. If we don't do that work, then we don't have a hope in hell of doing it anywhere else. If we don't do it inside ourselves.

Sandy Leo declares how most research is conducted using a westernized model that does not serve Indigenous communities because it is founded on a colonial approach that objectifies Indigenous Peoples as "priority communities." She asserts the need for Indigenous Peoples to be treated as sovereign peoples and nations who are entitled to autonomy and self-determination

> So, there's a lot of successes that I've seen and a lot of failures that I've seen and one of the failures that I see constantly is we use a Western traditional model to do research. I

> am tired of fighting that way…it needs to be done, but it is draining. It is so important at every level of research and research has got to get this together, they all work to get their degrees…even our own Indigenous community, but they come back using this freaking western traditional model. One of the real ethical issues I find is that we're not being met for who we are and how we are. We're being met from a colonial point of view, by the researchers and we're being treated that way and we always have, you heard the clapping, we always have to do this and say, hold on, even in our Indigenous communities. So, I'm tired of things like priority communities because I'm a human being, I'm not a priority community, I'm not a number. I'm Indigenous, the priority in this country is that I am a sovereign being on a sovereign land and therefore I should not be a priority community. I'm a sovereign being on my sovereign land, and therefore as a sovereign entity, you need to treat me that way.

Prioritizing the Knowledge and Lived Experience of Elders and Indigenous People living with STBBI throughout the Research Process

Each of the Elders discussed the need for researchers to prioritize the knowledge and lived experience of Elders and/or Indigenous people living with STBBI from Inuit, Métis, and First Nations communities. There are several references using the acronym IPLWHA (Indigenous people living with HIV and AIDS) throughout this section, as it is commonly used in HIV and AIDS research. The Elders offered poignant discussion highlighting how Indigenous Elders have always been researchers because they have developed complex and sophisticated scientific knowledge since time immemorial using keen observation and close relationships with the environment around them. Widely supported by other participants, Louise asserts the following:

> We talk about research, scientific research, but Indigenous people have had research for generations and generations, we know where the best fishing hole is, we know how to preserve our food, we know where the best food places are.

This dichotomization of Elders from science and research is a colonial construct that only envisions research through the lens of western academia. Elders have always been researchers as they have collectively developed complex Indigenous sciences over thousands of years that kept their communities safe and healthy and informed sustainable environmental practices that also protects animal life, land, and water. Samizi describes the importance of nurturing a mutually beneficial relationship between Elders and IPLWHA in HIV and AIDS research and advocacy:

> We need to be honouring lived experience, with the Indigenous HIV community holding us up as Elders with nurturing and support, so that we can offer that back to them as healing, by coming together with love and joy, grief, and healing.

This idea upholds the collective Indigenous values of mutual aid and support that are inherent to Indigenous cultures, and as Samizi asserts, must also extend to the HIV and AIDS community. Moreover, they signify the responsibility of the community to care for Elders in their work on research teams because these nurturing relationships empower the Elders to bring the needs of the community to the forefront of STBBI research. There is great mention of the care that Elders bring to the community, however, Samizi reminds us that Elders also need support and care from the community to fulfill their roles as leaders, healers, and researchers and how it must be a relationship of reciprocity and mutuality. Evelyn highlights the need for Indigenous people living with STBBI and Elders to be involved in research because, "Involvement in research helps to highlight the genuine issues that IPLWHA [Indigenous people living with HIV and AIDS] and Indigenous communities are experiencing and bring these issues

to the forefront." Evelyn further emphasizes how IPLWHA and Elders involvement in research contributes to ethical research processes that are aligned with Indigenous principles of research, such as the inclusion of prayer and ceremony throughout the research process "And that was wonderful what became of us, we started going into research and making sure issues were addressed in a good way." This expression, "in a good way" is an Indigenous expression and it is a commonly used expression amongst Elders, as it denotes "participation that honours tradition and spirit" (Flicker et al., 2015, p.1149).

There was also a common thread throughout the Talking Circles about how Elders are able, through their position on research teams, to amplify the voices of their community members in STBBI research. Evelyn emphasizes how Elder involvement in research promotes the sharing of stories and voices that often go unheard, "We are supporting people who don't have a voice and sharing stories of lived experience and this is very impactful and helps to make changes." This highlights the role of Elders as advocates who are often entrusted with the deeply personal stories of their community members along with the power to represent the needs of their community. Moreover, there was an emphasis on how Elders can use their positions of power and respect to advocate for change by disrupting the status quo. Samizi highlights the need for "Understanding that if we aren't upsetting some people in our advocacy surrounding HIV, mental health, and harm reduction, - we aren't doing our jobs." This reinforces how Elders viewed themselves as strong community leaders who are well positioned to advocate for change. Evelyn contributed a similar sentiment by illuminating the role that Elders and IPLWHA can play in research by levelling the power dynamics on research teams by challenging academics and clinical practitioners:

> I was always, truly amazed that, you know, the people that I worked with in research, the academics, the doctors that I worked with… I had to bring them down from their pedestals. I asked them to meet me halfway and sure enough, everything just started coming out and we made sure that we had our prayer ceremony, it was something that was never there before.

Here, Evelyn demonstrated her ability to advocate for the integration of prayer ceremonies into research processes and this would never have materialized without the meaningful involvement of Elders and IPLWHA on these research teams.

The unique insight, cultural knowledges, and lived experiences of Indigenous Elders were also discussed as key assets in STBBI research to ensure that it is relevant to their communities, as many Elders had witnessed researchers repeating errors and their research added little benefit to the health and wellbeing of their communities. Ticasuk describes how Elders carry deep experiential knowledges that can transform research processes to serve the genuine needs of their communities:

> Why is it important to be partners in research as Elders? I think it's really important, because we've been around the world a million times metaphorically, and we've seen a lot of things that have progressed and a lot of things that have not. We've seen what works and does not work. And we've always been left outside of the table, so now we're there. We have firsthand knowledge of how we have been ignored, so that we can help the next generation when they're speaking their truth, we can say, they are speaking their truth, because I've been there, done that and I know what went on. So, in order for our voice to be a part of it we need to make sure that we're actually heard, it's important that our voices are there so that we can help guide our research in terms of what worked, what

> were the best practices, and how we can engage other people based on what we have seen, also based on the things that have changed over the years and our own personal lived experiences.

Several of the Elders expressed frustration because they had experienced tokenism in STBBI research, and they emphasized the need for researchers to build relationships with Elders before the research begins to ensure that Elders are engaged as research partners from the inception to the application of the research. Sandy Leo shares how there has been an emphasis in HIV and AIDS research on the meaningful involvement of IPLWHA, however, Elders are often tokenized in research. In addition, she asserts the need for reciprocity in research partnerships with Elders through the provision of research training in recognition of the valuable knowledges they bring to the research team.

> We talk a lot about ways of doing things we talk a lot about how our ways are unique and we line up to add principles of GIPA, [Greater Involvement of People living with HIV and AIDS] MIPA [Meaningful Involvement of People living with HIV and AIDS], "Nothing About Us Without Us" and we consult our Elders at the end of a project to bring them in to do the prayers, or at the beginning of a project to do the prayers, but they're not involved from the get go in developing the research, and we're not receiving training for research, I'm lucky enough and mouthy enough and pushy enough to say, "Hey, I'm here, I'm here to unlock that door, you better let me in or I'll break it down." And I speak about it all the time and I challenge the white systemic ways of doing things. You have to have the Elders from the get-go, because the Elders have access to community, traditional knowledge, to ways of doing things, to ways of being, and their input is important, because they can guide how to reach out.

Louise also shares how she has been tokenized by researchers who invited her into research studies near the completion of the study, so they would be recognized for consulting an Elder:

> I participated in research, sometimes from the very beginning, which was awesome. But there are research projects that only welcomed me and asked me to participate when they were about to publish their article, so they could get recognition that they have ambitious people on the research team. I did comply with them because I felt it was important that they start inviting us more. And so, I was always gentle and nice to them, I said, sure.

Sandy Leo stresses the importance of working with Elders from the beginning of the research process, from the inception of the study, even before the research question is developed to ensure that it resonates with the genuine needs of the community. Moreover, it is crucial that researchers choose Elders directly from the community they are seeking to engage in the study. She also encourages researchers to ensure that Elders understand and support your research, or they will refrain from promoting it, because Elders will not promote research that does not bring benefits to their community:

> There is a failure of not involving Elders from the get-go, and not just your Elders that talk the academic language, not just the Elders that will understand the university, but the actual Elders from the community where you want to go into in-depth research with… and if they don't speak, and if they don't reach out to the communities that's because there's something wrong, not from their part, from the part of the researcher and the research. Right, because they need to understand it, in order to promote it. We need to understand it before we can promote, we need to believe in it.

Sophie also illuminates the need for researchers to build relationships with the Elders before the research process has begun. She emphasizes the need for researchers to learn about the community by understanding the history and the culture and through personal experiences that are gained through relationship building by engaging in traditional activities.

> Researchers should look into each community climate as much as they can before they go into that community. What is the language? Be open and get to know the community first before you go… learning and working aren't just from nine to five. Get to know the community, look into what type of evening gatherings are held in that community. If there are Elders groups, ask if you can attend those Elders groups. If there is a sewing group, ask if you can attend those. If there are beading groups, ask if you're welcome. They have to know our history; they have to be well informed. When you're going to be talking about sexual health you have to know the community structure, the political structure within the communities, and also the knowledge of the regional ethics protocols.

Another challenge that Elders often face in STBBI research is the pan-Indigenization of research that responds to the needs of Indigenous Peoples as one monolithic group. Sandy Leo stresses how researchers must remember that Indigenous communities are individual sovereign nations and communities with unique cultures, languages, and needs. Sandy Leo laments the use of a pan-Indigenous approach in STBBI research and offers guidance for researchers about the authentic representation of Elders in research and how that must include taking immediate and substantive action when Elders have concerns about the research:

> You are pan-Indigenizing research, you're pan-Indigenizing everything. And yet we fail to recognize from the get-go, that each region of this beautiful expansive land that we're sovereign on, each region is its own country, its own nation, its own territory, with its

> own language and its own ways of doing things and being. And so, to write national research… is a failure on the part of those who funded and the failure on the part of those who do it. You continue to perpetuate the system, and you don't do meaningful engagements. You know, because true representation is nothing if you only invite me to your table and I have to eat with your fork and your spoon in your ways and talk their language, that's not true representation, I'm not free at that moment. Free, full representation means that, if there's a red flag in your research and at our advisory meeting, then you stop everything. And you take the time to work out that red flag. That's how important that is.

This is a powerful invocation for researchers to treat Inuit, Métis, and First Nations communities as individual and sovereign nations and to respect their research needs as identified by the Elders and the community members. This offers a strong reminder of how the meaningful partnership of Elders in research can contribute to the self-determination of Indigenous nations. Moreover, these powerful insights demonstrate the need for Elders to represent themselves in their own cultural authenticity as partners in STBBI research and not be weighed down by institutional dictates and demands.

The Importance of Ceremony and Spirituality in STBBI Research

Bone Collector stresses the importance of Elders as co-researchers in STBBI research because they can reframe sex and sexuality as sacred and carry the knowledges necessary to integrate ceremony into this research. He further stresses the need for Elders to use their "lifetime of experience" to reframe the current stigma around STBBI by sharing the sacredness of blood and the body. Bone Collector connects this transmission of knowledge with the Potlach

ceremony where Elders share their gifts, wealth, and holy knowledge. The true sign of wealth in the Potlach ceremony was the amount of wealth that a Chief or an Elder could give away:

> Why do we need Elders to be part of this, especially around the blood borne diseases… sexually transmitted diseases in today's society? We are taking something as sacred and holy as sexuality and the act of sex and…made into a filthy thing, even if it's between two consenting adults and we don't talk about it. But back in the day, the Potlatch was the sharing of true wealth and knowledge… This is where I'm at right now is understanding different ways that we can not just consider it, but gather the sacred and holy knowledge, that was only held within our blood, and within our flesh. This knowledge that we've ingested during our lifetime, and to reactivate the sacred and holy ceremony…because everything changes, language evolves, culture evolves.

Samizi recounts how one of the barriers in the past in recruiting Elders to STBBI research was how some of these "Knowledge Carriers" were judgemental and closed off about STBBI. This can be linked to colonial discourses on sexuality, STBBI, and substance use that connect it to shame, stigma, and blame. In addition, it is likely that many of these Elders were indoctrinated by Christianity in Residential schools which distorted their worldviews. However, Samizi has observed a substantial shift as many Elders are now participating in STBBI research and advocacy from a harm reduction, barrier free approach and offering ceremony to everyone, including people who are actively using substances:

> Listening to the community and the spirits is so important. One barrier was encountering Knowledge Carriers who are judgemental and closed off to IPLWHA [Indigenous people living with HIV and AIDS]. Since then, however, I have encountered many Elders who

> are coming into all of this from a harm reduction approach, from a barrier free approach, to make ceremony accessible to all the people. And that's a beautiful thing.

Bone Collector emphasizes the need to heal the spirit before the healing of the mind and body can occur. He also focuses on how the spirit has been neglected due to the myriad affects of colonization, however, he also asserts that nothing has the power to colonize the spirit, and Elders are healers who can support others on their healing journeys:

> I have seven teachings…to describe these truly healing techniques, and it begins not by healing the body, or the mind, but it begins with healing the spirit. The spirit is the easiest thing to heal, all you got to do is acknowledge it and it comes springing back to life, but we don't acknowledge our spiritual selves in the way that we have the ability to. We're healers, brilliant, beyond all understanding and colonization…Residential School and colonization has distracted from this so much. The one thing we cannot colonize no matter what, is our spirit, our spirit remains pure, unapproachable, you can't do anything to it to damage or distract from it, but once you forget about it, that's when everything else can take its place.

Moreover, Leanne describes the power of spirituality and ceremony in her sharing of smudging, and she shares this gift even if that person is in a state of intoxication. Moreover, she describes the spiritual transformation that she witnesses in people after she shares this ceremony. Leanne emphasizes how smudging allows IPLWHA to "let go of everything that they don't need" such as stigma and judgement and they emerge as their strong, spiritual selves and are often able to move towards healing:

> When I have people coming here to smudge, they will come up to me and they'll say, [first name] can I smudge? Even though they're weaving back and forth, even though they're not in a good place at that time, but when I smudge them the look on their faces how they feel, they're not walking out of here hunched over, they're walking out with their head held high because they have taken off everything that they don't need… okay, this person is stigmatizing me, that's not me, just take that right off because that's the person who needs a lesson- not me. And he told me, he said that when I smudged him that night and he woke up two weeks later, he was a different person because I let him smudge and he said that the Creator, was with me all that time. He said I could feel it on that second week when I woke up…I was sick as a dog and I wanted to go for another drink, but I didn't, I came here instead.

Louise also shares the power of ceremony and how it keeps Indigenous Peoples "safe and strong" and needs to be prioritized in research and education. For instance, she explains the "spirit strand" which is a wholistic theory of healing that "braids" the mind, body, and spirit together. Further to this, Louise emphasizes how ceremonies celebrate rites of passage and offers people a sense of self-respect, love, and responsibility for others and how these ceremonies are an essential part of Indigenous communities moving forward in their healing:

> We know how to take care of our children; we have ceremonies that have kept our people safe and strong. That's the research I'm interested in because it works, and it works for our people. It was because of the imposition of the Indian Act and the Residential Schools that our people became unhealthy living without these, and therefore the spirit strand. Look at the mind, body, and spirit, braiding all of these three together and I did this throughout my whole career in diabetes and HIV- STI education, and now perinatal

> health. Our research is that we know what works for us. We know that we're overrepresented in these new diseases that we need modern medicine for, but we also know that it's our ceremonies, and our way of being, that will help us move forward. These are the things that we need to weave into our education and our research to ensure that ceremony is part of the work that everyone does with Indigenous people because that's what kept us strong and that's what gave us a sense of belonging and the sense of being loved. Ceremonies are what taught us to be responsible for ourselves and others. For example, when we brought a baby into the world, we welcome that baby with ceremony, we give it a name we drum the baby into the community, grandmother gives the first kiss. Each community has their own ceremony, but that baby is welcomed. Then that baby will be looked after by not only just the family, but the whole community and that's what those ceremonies taught us. It's the same with the coming-of-age ceremony. When you taught a young girl transitioning from girlhood to womanhood, boys from boyhood to manhood. They learned their responsibility of respecting themselves first before they can respect others.

Further to this, Red Sky draws a parallel between her work in trauma in somatic healing and the healing affects of ceremony. She refers to the science behind somatic healing and how Indigenous ceremonies have always provided this form of healing through a reconnection to the spirit:

> I work in trauma, and we have weeklong programs…where we introduce the subject, and in others introduce a process of how to connect physically in our being with the feeling…not to re-experience the trauma, but to connect with that feeling. There's so much science around somatic healing, but it's just a process that we use and there's all

> kinds of descriptions of it. But…it does what our ceremonies do, it helps us to reconnect with our spirit. We connect to who we really are that word spirit. First, we are a spirit on a human journey.

Samizi shares how Elders hold a place of closeness to the spirit world which positions them as "helpers" because they are attuned to ancestral knowledges that existed before colonization and how these Indigenous ways of being, doing, and knowing are critical to decolonizing STBBI research:

> I think that closeness to the spirit world positions us as helpers, to be able to hear from them, the ones who are in the spirit world. The ones who lived before colonization interfered with our ways of being, doing, and knowing, I think that's why it's important. Because the reality is that unless we're listening to them, we don't have a friggin hope in hell of decolonizing anything, because there isn't a single person living on this Earth right now, who has lived in a world that is not colonized, not one of us.

The Importance of Implementing Indigenous Methodologies in STBBI Research

Paula describes her mother's skill in transmitting cultural knowledge to Indigenous youth in the form of sewing and birch bark basket making, and she stresses the deep meaning of sharing these traditional skills:

> My mom, she's an Elder, she's 84 years old, and she teaches she's very good at sewing and giving youth and other people direction…in how to instill our natural ways, our sewing and our needs and she enjoys teaching others to make birch bark baskets which she didn't get a chance to before when she was taken to Mission [Residential] School.

Sophie emphasizes the use of storytelling as a crucial way to learn about Indigenous cultures in research. Through her own storytelling she articulates the positive impact of the traditionally close relationship she had with her grandparents and how she learned from their wisdom as Elders. Moreover, she asserts the important role that Elders play in sexual health by sharing their wisdom with younger generations:

> I think storytelling has a big, important part of learning from each other. I'm my father's oldest child and in our traditions the oldest child is typically adopted by the grandparents, but because I was my father's oldest child, he felt that he couldn't give me up to, to be adopted by my grandparents. So, I learned from a young age that I had two sets of parents two mothers and two fathers, one of them being my biological parents, and one of them being my grandparents. I learned that living with my second set of parents which were my grandparents that they have so much wisdom they can share as Elders who also learned from their Elders. I think it's very important that Elders continue talking about issues such as sexual health.

Sandy Leo strongly supports the use of Indigenous methodologies in STBBI research and shares her experience as a co-researcher using cedar bark basket weaving and the medicine wheel in an HIV and AIDS study. Sandy Leo emphasizes the meaningful impacts of this research and shares how well received it was compared to other studies using western methodologies. Moreover, she demonstrates the power of including Elders as meaningful research partners and how it Indigenizes and transforms the research process.

> We weave with cedar bark here in the West and we've just published a paper through the [name of university]. Every one of us is a strand on the basket weaving our stories and that's how we conducted the research using our medicine wheel. Using the basket

> metaphor and holding the stories of the people and each one of us is a strand of that weave, and we're connected to the tree of life, to the earth, to the medicines. We published that paper in the [name of journal] and it was selected for the article of the year. We got a cash award and our conference fees covered for whoever wants to go to the conference [name of location] to present this research paper. When we use our methodologies, and we use our creation stories and our ways of being together. When we use them to explain who we are and how to do research we come out as the best, the best of the best in an academic, white environment. Like weaving the birch bark basket, like peeling that bark off the tree you know it's done in a ceremonial way with old knowledge, there on the land, right. It's the same thing with our beading, we bead patterns we bead our flowers as Métis, we do all these things. These are skills that can be used to explain our research… like weaving the sweet grass, building the drum. It's all our methodology, and…we've been around for thousands of years and who taught academia what to do? We did. The first thing we do that we're taught from the get-go, is observation, and relationship. We observe the cycles of Mother Earth, we observed the patterns of our birds, the pattern of our growing seasons, the patterns of what we observe, and we then incorporate that and use that. And that is research methodology in Indigenous ways.

Louise highlights the need to use relevant cultural teachings and methodologies in HIV and AIDS research and resources for Indigenous communities. She also illuminates the cruciality of featuring resources that resonate with Indigenous values and worldviews such as using an Indigenous approach to healing that features collective love, protection, and nurturance from the entire community:

> I know in HIV/AIDS because of the shame and guilt…of sexuality and of the abuse that still continues in our communities that we needed to create resources that were relevant to our people, for example, one poster we created was for women who believed in Grandmother Moon and how strong the moon is for our cycles as women and…we work to follow those beliefs and practices to keep ourselves strong. What we did for another one of the projects we hired an Indigenous writer and an illustrator, and we created [title of book]. This book talks about bringing our community together to learn about…HIV and why our people are being overrepresented in HIV and STI. To help people understand this gathering tree…about how we as Indigenous people wrap around people as a family and community when someone is sick, not to shun them, but to come together for them. It talks about…welcoming someone home to the community and it's such an amazing thing to do and our communities liked it, they finally started understanding our own plight not knowing why our people are the way that we are.

The Importance of Centering Indigenous Ways of Being, Knowing, and Doing

Red Sky asserts the need to re-center Indigenous ways of being and knowing in sexuality and gender because colonial discourses have attempted to erase the teachings and spiritual beliefs that have arisen from a matricentric worldview which envisions the world around us in connection and association with the mother:

> When we talk about sexuality and gender and being… [and] how we've been traumatized over the years and it's social conditioning- the roles that we're taught in education, and… that a woman has to submit to a man. We lost the Divine Mother, which is our culture… the core of Mother Earth teachings…that divine heart, the Divine Mother.

Sophie highlights the importance of integrating Indigenous languages, such as Inuktitut into research and conversations around sex and sexuality. Moreover, she warns STBBI researchers about terminology that often does not have a literal translation. This demonstrates the need for sexual health terminology that is grounded in Indigenous languages and ways of being instead of imposing westernized concepts and approaches to sexuality on Indigenous communities:

> The type of language that we use when we talk about sexuality and sexual health it needs to be understood by the target group that you want to reach, as you have heard…English is not our first language. We have our first languages that we still know, and are very strong, but some of the languages, the clinical language in English does not always have translations. So, the language that is being used has to be very understandable and when you have interpreters working with you…literal translations do not work. I remember when I was in one of the communities…in regard to language we don't have certain words in Inuktitut, like for oral sex. So, we are very descriptive…we had to sit with an Elder and ask them a question. Okay, we're going to talk about oral sex, and we don't have a word for oral sex. So, we had to give a description of oral sex and at first the Elder was a little bit embarrassed. But it's important that we know the language that we're using.

Ticasuk shares how Inuit ways of being, knowing, and doing, such as rites of passage rituals, teaching children about sexuality, and land-based programming can strengthen the health and wellbeing of Inuit youth. Moreover, Elder Ticasuk highlights the Inuit Qaujimajatuqangit Principles which is a cultural framework that can be used to guide non-Inuk researchers in building meaningful partnerships with Inuit communities and use it to guide research processes:

> In [name of territory] our children are taught at home by our parents…we teach our children. We had our rituals. So, for example, these are representative of me becoming a woman, with my first period, and then this is me becoming a mother, and that's me as a grandmother. (pointing to a traditional chin tattoo with three vertical black lines). So, our worldviews are very much cemented in our lives…our children are taught at home, and we begin discussing sexuality at home when children reach puberty. We need more opportunities for STBBI research to be done in the north [name of territory]- the needs are not being met. I'm in the research department, we do a lot of research on sexual health as well as activities for youth and young adults. They have on the land programming, which is very important to our culture, our worldview is one with the land. And we are guided by…a set of principles, values, and beliefs, our worldview is one of connectedness. I absolutely love how we were able to as Elders in the Inuit world come up with the concept of the guiding principles, [Inuit Qaujimajatuqangit] …which are, of being of service to others, consensus in decision making, which is inclusive of everyone. We also have knowledge acquisition, working together for a common purpose, which is extremely important because in the North we're very different in terms of climate, so we face very different challenges up North.

Samizi recounts how her most profound learnings came from teachings grounded in Indigenous ways of being, knowing, and doing and how these learnings were more transformative, compassionate, and "life changing" than anything she had learned from people who were "formally trained" to work in HIV and AIDS. This demonstrates the profound value of privileging these teachings in STBBI research:

> That teaching was the thing that changed my life, right. I work with so many social workers and other formally qualified people who would get frustrated, angry, and burned out with the street involved, people with addictions, people living with mental health issues. And when I got that teaching about sitting with G'Chi Manidoo [Ojibwe word meaning the Creator or the Great Mystery] and deciding what we needed to do to help others and to help ourselves learn changed everything for me because I no longer looked at the people I served with pity. I no longer thought that what I thought was important to them. Instead, what I understood was how much courage it takes to choose a life of pain and that I need to honor that by listening and paying attention, because all of those people…the street involved people, the people who are incarcerated, people living with HIV, drug users, mental health patients, all of those people who are marginalized and discriminated against and [made invisible] by the rest of the world taught me more about love and generosity and compassion and kindness and truthfulness and courage and all of those teachings that we talk about, than any professional ever did.

Bone Collector illuminates the benefits of growing up with Elders in the home. He also highlights how Elders have gathered and contemplated a lifetime of spiritual knowledge and how this knowledge can be accessible to anyone who chooses to take the time to remember what has been forgotten. Further to this, Bone Collector emphasizes how the teachings of Elders can help Indigenous communities reconnect to their ways of being, knowing, and doing that have been obfuscated by outside distractions.

> In the past we always lived together, and we had Elders within the home. We had grandmas and grandpas, and we could crawl into their arms and just feel some comfort and love. This is what this planet really needs is comfort and love…and nowadays…our

> Elders speak the words of knowledge that they've gathered over their whole life as [they] had their time to be depressed or removed from society and sit in a cave somewhere. I went and lived out in the bush and just contemplated, I sat in this big deep rest to be able to remember, because we don't forget anything, our culture, our history. I hear so many of our people saying, oh we've lost that, it's gone- no it's just forgotten and all we need to do is…remember. It's the distractions-the distraction of fear, the distraction of religion, the distraction of illness, that has caused us not to even begin to contemplate such a lifestyle based on a spiritual, not religious, a spiritual base.

Sandy Leo shares her anger and frustration about how Indigenous ways of being, knowing, and doing such as, land-based learning, traditional medicines, and ceremony are not prioritized in research with Indigenous communities. Further to this, she calls out researchers to transform their research models because the health of Indigenous communities continues to suffer:

> We think in imagery we think in hieroglyphics, being on the land, touching the medicines, we are ceremonial people. Our connections to our traditional medicines and our ways needs to happen from the get-go in research, from the very first meeting. At every meeting I've told doctors to shut up and to listen to us, at every meeting, I said to the doctors, well that's fine and dandy you think your system works and your model works. Why are we still doing this 30 years later? Why are you fighting against us that long? Don't you know?

Deidre shares how she comes from an Indigenous and Black background that offers her two resilient cultures to draw from. However, in the past she carried internalized shame because she did not feel a sense of belonging with either community. Now, she uses her experiences to teach

her own children and other youth about the power of finding self-worth through pride in one's culture and she centers these teachings in her work in sexual health:

> I feel very blessed, you know, I have one foot in my Black community, one foot in my Indigenous community. I've always taught my children who came in three different shades of brown about both of their very proud and very resilient cultures, and I think learning that as young as you can, learning your background…because I was always ashamed, I never fit anywhere. I was to too light to be black and I was too Black to be Native, so I never fit anywhere, so when I went out on the streets, I just was trying to find someplace to fit- just needed to fit somewhere. That's all I thought I was worth…and my biggest challenge is teaching our young people about their self worth. You know, like, you deserve to be protected, you deserve to [use] a condom and you don't have to worry because you can go have sex with someone else.

Leanne stresses the importance of Elders sharing the power of traditional medicines and the seven Grandfather teachings from the Ojibwe culture that have been passed down for generations. These life teachings are represented by: Minwaadendamowin (respect), Zaagidiwin (love), Debwewin (truth), Akodewewin (bravery), Nibwaakawin (wisdom), Miigwe'aadiziwin (generosity), and Dibaadendiziwen (humility). Elder Leanne emphasizes the need to ground our service to others and our research processes by using these traditional medicines and teachings to support IPLWHA on a journey to genuine healing.

> I put our five medicines in…I put the sweet grass, I put the tobacco, and I put the cedar, but I also put the male and the female sage in there so that way I have everybody. I'm not going to miss anybody…[because] the Creator doesn't give you four days, and doesn't give you 10 days, he gives to you now, at that second. I'll go up to him and I'll tell him

> about the seven Grandfather teachings because that's one of the things that I promote here is that no matter what condition you are in or where you are at that moment you are still living one of the Grandfather teachings…subconsciously you are doing what you need to do, so don't stop. We sat because we're closer to Mother Earth and that's where some of our stuff goes to is to the ground because Mother Earth is taking care of us, and she'll get rid of whatever you need away from you. This is a way of life. The seven grandfather teachings, they're not commandments- thou shalt not. We have respect, respect yourself, and respect everybody else, respect the moon, respect the sun, respect the trees, respect the water. Those are not commandments our Creator is not like that. We can learn the seven grandfather teachings, the thirteen moon teachings, the totem pole teachings, and all the other teachings…because it's free. There's quite a few of them that come in now and I might even be proud to say that there are quite a few non-Indigenous people that are coming in here too now that want to learn all that stuff. Then when we start talking about what we do here about HIV and AIDS and how we're trying to incorporate the seven Grandfather teachings into how to live with what you have because no matter what you're going to be walking down that journey together and you have the seven grandfather teachings because you got respect, you got love, you got humility, you got all of them. So don't let anybody take that away from you, because if they do, they need the ten commandments.

Sophie reinforces the need to include land-based experiences when working in sexual health and STBBI research because they offer a culturally based, safe place for Elders to share their perspectives and teachings about sexuality:

> Someone touched upon land-based experiences, I know that as Indigenous people it's very important for programs, such as land-based camps to connect, because they connect back to their heart, their soul and their body and it's a welcoming, learning environment. The Elders that are talking about sensitive subjects such as sexual health if they are in a welcoming environment, then it's going to translate into a welcoming environment for other people.

Further to this, Red Sky stresses the importance of Indigenous ways of being, knowing, and doing by discussing an inherent connection to the land, and a deep acceptance of the "humanness" of others. She also highlights the richness of Indigenous cultures and the teachings from the Elders. Moreover, Red Sky shares how Indigenous Peoples have been forced to "walk in two worlds" and the effort and tension of navigating these worldviews:

> As you know we are connected to the land and…allowing nature to run its course and to be accepted into each other's humaneness. We taught each other and we allowed others to learn by their own experience, to learn by their own errors, and we never admonished them or beat them, it was not punitive, but they learned but this was seen by the newcomers as a weakness, but our Elders have taught us what we know. I hear all the time, Mano [Ojibwe word] like just let it be, allow it to take its course. There was of course, control and power which changes all those dynamics. When we talk about healing it's kind of a term that acknowledges that there's something wrong with us. I try to look at it as human goodness, this human goodness you know this is our richness…how we're not broken, and we don't need to be fixed. We just need to be allowed to connect in the way we always have, and this can become teachable and not rejecting, this constant conflict, because we have to live in two different worlds- we're in that constant conflict.

Sandra laments the lack of Indigenous healthcare workers even in Indigenous specific healthcare centres because they have not been trained in culturally relevant care which negatively impacts her community. She also discusses her position as an Elder and a member of the 7th Generation with her responsibility for teaching the younger generations about integral topics such as STBBI. Further to this, Sandra describes the need for younger generations to learn Indigenous ways of being, knowing, and doing, such as the Longhouse ways and ceremonies from her community that reflect their cultural values such as, "the clan-based system, matrilineal descent, cooperation, respectfulness, and peacefulness" (Hill, 2015).

> Even when you go into your Aboriginal health centers it's not Aboriginal nurses, it's not Aboriginal doctors in there. So, you have to explain to them why you're in there and they're not trained culturally to deal with stuff like that and there's a lot of us even my age, who don't like going to the doctors and talking about this stuff. I am the Seventh Generation from where I am from, so we have to try to teach the younger generation, not because they're going to listen but hopefully, they do. I know it's my experience a lot of them don't want to hear it, but one day they will listen. They don't go to ceremonies much and if they do go, they're going to the Longhouse that's what we have here and different ceremonies… I wasn't taught Longhouse ways because my great grandfather was Christian, my grandfather went but, he never took my mom and her siblings because they were all too busy working. She tells stories we call her grandmother and I listened to her when I was younger…because she would do a Talking Circle around a fire. I'd go sit and listen to her stories, and she didn't have the perfect life when she grew up either.

Aggie reinforces the importance of deeply listening to Elders because they gained their profound wisdom through oral tradition, which has been passed from generation to generation over

thousands of years. She also emphasizes the sacredness of Indigenous ways of being, knowing, and doing because it took great courage to preserve this knowledge under the ravages of colonialism. Moreover, Aggie highlights the need for Elders and Indigenous youth to listen and learn from each other by sharing traditional knowledges with future generations and in turn these teachings will contribute to the health and wellbeing of the youth.

> The best advice I can give is to listen, listen to what they have to say because they know. They know the experiences, they know what they have seen, it's not anything you can find in a book, in the mind of an Elder. A long time ago we didn't have written knowledge, it was an oral tradition and that's how knowledge was passed down from generation to generation. And then again with the Residential School system that changed our lives, our way of life was taken away and if it wasn't for those few people that hid in the bush- the culture was kept alive and here we are in 2022 and younger people are willing to listen, if you're there to offer them the guidance. Listen, you know, just simple listening, and act on the knowledge that you're being taught. Don't just sit there, go out and act on that knowledge, because that's how you're going to get somewhere, how you are going to heal yourself, because it's not only Indigenous people that were taught the wrong things, it's the whole society because you were taught the wrong things too. We know what we're talking about because we lived it, we are the ones that are teaching you and look at us sitting here, you're listening, which is good. We can't give up on our youth, we got to keep trying to teach them, because if they don't learn the ways, then it's going to die with our generation, and we can't let that happen. Let them come in, make them feel comfortable and we don't judge each other, that's not our teachings. So just let them come and be open to everything, you know, but listen to them, maybe they have

> something to say because we haven't always been listened to in our lives, and they're just as important as an Elder. They're our future.

Louise recounts a story about a Chief who offers a relational lesson in Indigenous values and ways of being, juxtaposed against Western ways of relating to each other and identifying ourselves using institutional accreditation. This story illuminates the need for non-Indigenous researchers to learn from Elders and how they approach relationships, research, and community.

> We believe in the land, we believe in Mother Earth, that is always there to nurture us. Therefore, a lot of my career was educating the non-Indigenous world of the importance of our culture, our beliefs, and our practices. I was at an Indigenous nursing conference, and we always ask the local chief to welcome us to their territory. After everyone was introduced, he introduced himself and you know how doctors and nurses have all these initials beside their names? RN, BSC, MD, FRCP and so on. Well, he said, "hi I'm Chief [name] and my initials are FCSGFB, I'm a Chief, I'm a father, I'm a son, I'm a brother, I'm a grandfather" and those are his initials. This says all the things about our lived experience and the experiences we bring to the circle. So, that was why I shared that story because we do have lived experience with lots of good knowledge, and we should be treated as equals, in the research world, as well.

Chapter Five: Discussion

This chapter will outline the overarching themes that emerged from the contributions of the Elders during the Talking Circles, about their meaningful partnership in STBBI research by connecting these findings to relevant literature and decolonizing and Indigenous theory. These themes are: (1) Understanding the historical and ongoing impacts of colonialism and the need to decolonize STBBI research (2) Prioritizing the knowledge and lived experience of Elders and Indigenous people living with STBBI throughout the research process (3) Centering spirituality and ceremony in Indigenous STBBI research (4) The importance of implementing Indigenous methodologies in STBBI research (5) Foregrounding Indigenous ways of being, knowing, and doing in STBBI research. In addition, I will examine potential limitations of this study along with relevant critical reflections. Further to this, I will explore the potential contributions and implications of this study on future Indigenous STBBI research, policy, and social work practice.

Understanding the historical and ongoing impacts of colonialism and the need to Decolonize STBBI research

The Elders stressed the need for researchers (particularly non-Indigenous researchers) to develop an understanding of the historical and ongoing impacts of colonialism on Indigenous communities because this knowledge is a crucial foundation and is necessary to inform the decolonization of STBBI research processes and outcomes. The meaningful partnership of Elders plays a significant role in the decolonization of STBBI research because it positions them as equitable decision-makers who can enact decolonial research processes and Indigenous research principles throughout the entirety of the study. The Elders in this study emphasized their deep connections to ancestral knowledges that pre-existed colonization and how they carry specialized ancestral knowledges acquired through oral tradition from their Elders and their powerful

connection to the ancestors from the spirit world. Moreover, the Elders stressed that before we can enact change to decolonize STBBI research and sexual healthcare responses we must learn how to "decolonize our minds and decolonize ourselves" as a necessary first step.

Narasimhan & Chandanabhumma (2021) conducted a scoping review on the decolonization of Public Health systems using Indigenous health-focused literature and they found "a lack of clarity in the conceptualizations of decolonial processes" (p.306). There is a great need for decolonial processes to contribute to the substantive goals of decolonization and Elders are in the utmost position to discern both short-term and long-term goals on behalf of their communities. We can draw from Tuhiwai Smith (2012) conceptualization of decolonization, "Decolonization can be seen as a solution that draws on 'colonized time' and 'pre-colonized time' addressing the legacy of colonialism and drawing on knowledge and practices from pre-colonial times" (p. 55). Tuhiwai Smith's conceptualization strongly resounds with the findings of this study, as the Elders shared in multiple ways the need to tear down colonial systems that are oppressing their communities and to build these systems back up using precolonial knowledges from the ancestors that have been gifted to the Elders so that they can transmit this knowledges to their communities. Moreover, precolonial- Indigenous Knowledges have evolved over thousands of years and were used to keep their communities safe and healthy before the colonial genocide that sought the erasure of Indigenous Peoples. Quayle and Sonn (2019) study focused on the collection and archival of Aboriginal Noongar stories shared by the Elders, that featured historical and current colonial injustices as an act of reclamation and healing. From partaking in this experience, the researchers conceptualize decolonization in research as the continuous foregrounding of Indigenous knowledges and experiences in all research environments and this would ethically prioritize the leadership of Elders.

Narasimhan & Chandanabhumma (2021) scoping review thematically analyzes conceptualizations of decolonial processes in research under three key themes, "reflection of self and systems, planning for decolonizing action, and decolonization as action" (p.313). These themes align with many of the contributions of the Elders in our study as demonstrated in the "reflection of self and systems" which requires a critical awareness of the legacy of colonialism and the first step according to Fanon 1963 is the "decolonizing of the mind." (Tuck & Yang, 2012, p.19) this was also highly emphasized by the Elders in our study. Moreover, Narasimhan & Chandanabhumma (2021) highlights the need to question the "legitimacy of colonial structures and worldviews" and to critique those who "uphold dominant structures and institutions" (p.313). These guiding recommendations were also echoed by the Elders throughout this study as they asserted the need to confront researchers and clinicians about the failings of Western research methods and healthcare approaches for Indigenous communities. Several Elders in our study were placed in untenable situations when they were guiding research processes where they were forced to constantly advocate for the inclusion of prayer and ceremony as non-Indigenous researchers were more concerned with following Western positivist methodologies. Fortunately, these Elders were steadfast in their approaches, and they continue to transform research processes in a good way.

Another key theme that emerged from Narasimhan & Chandanabhumma (2021, p.315) was the need for the "planning of decolonizing action" which entails engaging "the marginalized group as intrinsic to decolonization and…the need to centre and reclaim localized knowledge as the critical lens of inquiry rather than the subject of the critique." The Elders echoed similar calls to action by stressing the need to uphold Elders, IPLWHA, and community members in research as experts with lived experience and as cultural knowledge carriers, and as one of the Elders

asserts, we are "sovereign beings," not passive members of "priority communities" to enact research upon. The final overarching theme identifies "decolonization as action" which deeply resonates with Tuck and Yang's (2012) seminal work *Decolonization is not a Metaphor* as it illustrates how the fundamental objective of decolonization is the active liberation, sovereignty, and self-determination of Indigenous Peoples. Genuine acts of decolonization include repatriation of land and resources, development of Indigenous specific governance systems and infrastructure, and the transformation of policy that reflects the sovereignty of Indigenous communities (Narasimhan & Chandanabhumma, 2021, p.315). The Elders shared similar ideas about the need to work with Indigenous communities and according to Sandy Leo, to treat them as "sovereign nations on sovereign lands," who know best what their communities need with the understanding that colonial systems and policies continue to degrade the very cultural traditions that keep their peoples safe and healthy. The Elders articulated this ongoing struggle with researchers who continue to neglect the guidance of Elders and continue to use Western research methods that have failed the sexual health needs of Indigenous communities for several decades.

Prioritizing the knowledge and lived experience of Elders and Indigenous People living with STBBI throughout the research process

The Elders were in agreement on the importance of prioritizing the knowledge and lived experience of Elders and IPLWHA (Indigenous people living with HIV and AIDS) throughout the research process as it is an integral part of decolonizing STBBI research. The Elders recognized that many people inhabit both of these roles because there are many Elders who also have lived experience of STBBI. Moreover, this theme resonates with the long-time goals of the AIDS movement such as "Nothing About Us Without Us" which arose from the Denver Principles developed in 1983 by the advisory committee from the People with AIDS Coalition

who initiated the PWA self-empowerment movement which promotes people who live with HIV/AIDS to be at the forefront of activism, advocacy, and research and reinforces the right to live with dignity, and without stigma (The Body, 2001). This also includes GIPA and MIPA (Greater and Meaningful Involvement of people living with HIV/AIDS) because the success of HIV/AIDS activism and research has rested on the advocacy, expertise and efforts of people living with HIV and AIDS for several decades and this continues to be a fundamental part of the successes that emerge from HIV/AIDS research (Closson et al., 2016; Katz et al., 2019; Kendall et al., 2017; Oliveras et al., 2018).

Further to this, the Elders stressed the need to implement Indigenous principles of research, such as authentic relationship building and true representation that offers IPLWHA and Elders the opportunity to engage in research practices and processes that genuinely reflect Métis, First Nations, and Inuit cultures, values, and worldviews. Katsistohki:io and colleagues (2021) discuss their "Making it Work" community-based research project that highlights key learnings from their approach to culturally relevant research that is grounded in an Indigenous worldview and contributes to strong allyships between Indigenous and non-Indigenous allies. The authors underline the need to build authentic relationships that include taking the time to get to know one another on a personal level through the cultivation of these relationships. One of the key learnings encourages research teams to "share ten cups of tea" and the authors emphasized it was this relationship building and personal sharing that led to the ultimate success of their community-based research project because it encouraged the research team to build trust and authentic allyship (p.18).

In addition, STBBI research must respond to the needs identified by the community as most prescient and beneficial. It is essential that research teams proactively respond when Elders

and/or IPLWHA researchers express concerns over any facet of the research process. This response should occur in an effective, substantive, and timely manner because the failure to address these concerns is an act of bad faith as research teams cannot claim meaningful research partnerships with Elders and IPLWHA if they neglect their concerns about the research. Several Elders shared their experiences of tokenization on research teams where they were only tasked with opening and closing prayers and/or invited onto the research team once the study was near completion to seek the Elder's late-stage approval. This signifies weak efforts on the part of the researchers who are only seeking superficial engagement from the Elders to build their own reputations. When Elders are engaged as meaningful partners in STBBI research, culturally relevant STBBI prevention, support, and care are prioritized and thus more likely to be taken up in policy (Flicker et al., 2015). This uptake of research to policy can increase the integration of Indigenous knowledges in individual, community, and systemic responses to STBBI.

This study clearly demonstrates the need for Elders to play a meaningful role as research partners in STBBI research because of the myriad benefits they bring to the sexual health and wellbeing of Métis, Inuit, and First Nations communities by grounding STBBI research in cultural teachings, ceremony, and Indigenous healing practices. These meaningful research partnerships would also ensure that Elders are in a position of power to bring the unique needs of their communities to the forefront of STBBI research. They would also be involved in the development of STBBI research from its inception to application to verify that the research is relevant, beneficial, and ethically sound. Moreover, Elders would strive to attend to specific gaps in sexual healthcare and social determinants of health that contribute to increased rates of STBBI in Indigenous communities (Flicker et al., 2015; Viscogliosi et al., 2017).

Centering spirituality and ceremony in Indigenous STBBI research

"When we bring ceremony into our research, we bring our people home" Doris Peltier, National Coordinator, Visioning Health study for Indigenous Women Living with HIV and Community Engagement Coordinator, the Feast Centre (personal communication, September 6, 2022).

The Elders affirmed the need to center Indigenous spiritualities and ceremonies in STBBI research because they exemplify traditional culture and offer profound healing benefits. As we have emphasized throughout this study, many Elders shared their experiences of frustration during their involvement in research and the need to consistently advocate for the inclusion of ceremony and prayer. When the research teams eventually heeded their requests and included prayer and ceremony in the research process, they felt a sense of empowerment because this transformation invited the inclusion of strengths-based, Indigenous models of care, such as the Medicine Wheel, which promotes the holistic healing of the body, mind, emotions, and spirit symbolized by the quadrants of the wheel that represent all directions and all peoples (Abolson, 2010). Iseke (2013) asserts that Indigenous research and ceremony are "inextricably linked…and central to both the politics and acts of decolonizing in the academy" (p.37). The Elders on this study highlighted this through a powerful mantra that is supported by many Indigenous scholars, such as Cree scholar Shawn Wilson's (2008, p.89) "research is ceremony." Wilson (2008) explains this connection further by emphasizing, "there is a lot of work, dedication, and time spent in building up relationships with the cosmos that allows the visible ceremony to happen" (p.89-90). The Elders offered similar thoughts about their profound relational connection to the spirit world that has been refined over thousands of years in the creation of ceremonies that connect Indigenous Peoples to the realm of the Creator. In connection to this, Iseke (2013)

accentuates how the centering of spirituality and ceremony in research is decolonizing through the sacred act of immersing the researchers in spiritual prayers, traditional ceremonies, and Indigenous healing practices. The Elders articulated how this centering of spirituality and ceremony in STBBI research can increase the uptake of these practices in healthcare practice and policy, while simultaneously offering valuable teachings for non-Indigenous researchers and academia. Further to this, Iseke (2013) honours spirituality and ceremony as a way of life, "we live life in the Creator's world and whether we walk in the forests or on the city streets, we can live life in ceremony and in relation to the spirit world" (p.38). This omnipresent spiritual connection to the Creator was articulated in various ways by all of the Elders on this study. The Elders have shared the profound meaning and the power of healing that spirituality and ceremony hold in their lives and how it must be centered in STBBI research to transform research processes to reflect their spiritual values and Indigenous healing practices.

The Importance of Implementing Indigenous Methodologies in STBBI Research

Many of the Elders stressed the importance of implementing Indigenous methodologies in STBBI research because they are rooted in Indigenous cultural practices that offer holistic healing benefits to Indigenous Peoples and create a safe environment to share personal stories. O'Brien and colleagues (2021) from CHIWOS (Canadian HIV Women's Sexual and Reproductive Health Cohort Study) strongly support the implementation of Indigenous methodologies in research because this was a major contributor to the success of this project in conjunction with the CBPR (community-based participatory research) approach. O'Brien and colleagues (2021) found these combined research approaches offered space for Indigenous women living with HIV to safely share their experiences and priorities regarding "health, well being and HIV prevention and care" (p. 173). Moreover, CHIWOS was led by Indigenous

researchers, supported by Elders, and employed the use of Sharing Circles, an Indigenous healing method that provided the women with a culturally appropriate safe space to share openly and freely. In addition, O'Brien and colleagues (2021) offered poignant reflections to inform future research, for instance, the need for "the research to take place in a culturally relevant place… [featuring] culturally adapted methods…and ceremony, validating the findings with the participants to ensure that the knowledge, priorities and experiences of Indigenous women were respected…and leveraging relationships with Elders, artists, Indigenous and non-Indigenous researchers" (p.176). These findings also strongly resonate with the research recommendations provided by the Elders in our study. In our study we use the Talking Circle method which is grounded in the Elders knowledges and experiences, and we also held two members' checking sessions where the Elders had the opportunity to validate, critique, and offer feedback on the thematic analysis of the findings.

Heidebrecht and colleagues (2022) research, *"Every One of Us is a Strand in that Basket" Weaving Together Stories of Indigenous Wellness and Resilience From the Perspective of those with Lived and Living Experience With HIV/Hepatitis C Virus* implemented the Indigenous method of weaving cedar bark baskets to represent, "the story of the weaving together of an Indigenous approach to research" (p.189). This "basket highlights the ways that settler-colonialism in Canada has produced a system of healthcare that has neglected the Indigenous experience" (p.189). Heidebrecht and colleagues (2022) features the voices of Indigenous women who attended the "Awakening our Wisdom" retreat that focused on Indigenous methodologies and strengths-based methods in HIV research (p. 191). These women identified several key values inherent to Indigenous methodologies such as, the paramount importance of relationality above all else, using integrous approaches in gathering data, and

weaving stories of connection that have been disconnected by colonialism. The findings of their study align with the contributions of the Elders on our study, as they also underlined the need to develop strong relationships, the importance of using Indigenous methods to gather data "in a good way" and the revitalization of culturally, collective care that has been disrupted by colonial systems and policy.

Foregrounding Indigenous Ways of Being, Knowing, and Doing in STBBI Research

There is an urgent need to foreground Indigenous ways of being, knowing, and doing in STBBI policy, research, and practice. This paradigmatic shift requires investment in Indigenous governance, infrastructure, and sovereign healthcare systems to develop services that centre Indigenous approaches in STBBI prevention, support, and care. The Elders in this study stressed the need for this Indigenous paradigmatic shift so responses to STBBI genuinely resonate with the unique experiences, values, and worldviews of Indigenous communities. For instance, Red Sky shared her experience developing a sexual health program for Indigenous women that featured the Anishinaabe Grandmother Moon and Moon time teachings that illuminates the sacred connection between the lunar cycle and women's reproductive cycles (Anishnaabe Health Toronto, 2000). These teachings were developed over centuries and often shared through intergenerational oral tradition from Elders to youth. Moreover, these teachings follow Indigenous science and wholistic theory as they are grounded in Indigenous ways of being and knowing (Abolson, 2010). Red Sky also shared with us how these teachings encouraged women to open up and engage in discussions around women's reproductive and sexual health because Grandmother Moon and Moon time teachings resonate with their values and worldviews around sex, as opposed to the imposition of disconnected Westernized ideologies on women's sexuality and reproduction. Further to this, Aggie signified how Indigenous ways of being, knowing, and

doing can also benefit the lives of non-Indigenous people and she emphasized how non-Indigenous peoples also suffer under the oppressive weight of colonialism. Louise shared with us a success story about the taking up Indigenous ways of being, knowing, and doing in an illustrated children's book dedicated to connecting with Indigenous communities about HIV and AIDS, "The Gathering Tree" (Loyie, Brissenden & Holmlund, 2005). This book was developed to teach children poignant lessons of how Indigenous communities have always gathered around their loved ones offering them love and support, particularly during times of illness. This book received a powerful response from Indigenous parents and children because it was a reminder of their profound strength in collective caring, compassion, and healing in their communities. This book also served as a protective force against stigma and the erosion of their collective goodness and humanity in the face of HIV and AIDS.

In agreeance with the Elders, Althaus (2020) promotes the use of Indigenous ways of being and knowing to inform policymaking for Indigenous and non-Indigenous peoples in Australia because "Indigenous approaches offer new exciting ways forward for engagement, sustainability, and policy innovation" (p.187). Moreover, Althaus (2020) reminds us that when Indigenous knowledges are taken up in policy, it is crucial that this is carried out "within the context of self-determination and appropriate recognition" (p.188) and to ensure these Indigenous Knowledges are not coopted or commodified which is "endemic to Western knowledge systems" (p.198). Similar to this study, Althaus (2020, p.188) encourages the development of "genuine partnerships" between Indigenous and non-Indigenous peoples to enable the movement towards the "authentic and respectful privileging of Indigenous ways of being and knowing" because this shift can begin to address longstanding policy failures. This

transformative movement towards the privileging of Indigenous ways of being, doing, and knowing would be best served under the leadership of Elders.

Limitations and Reflections

The limitations of this study are primarily located in my positionality as a white-settler-student- researcher who has been inculcated with Euro-Western ways of being and knowing. My social location as a white-settler-student from the academy offers me a place of privilege and power because I have access to resources that do not exist outside of institutions, such as, funding opportunities and training. Moreover, my positionality as a white settler combined with my lack of research experience caused me to grapple with ethical tensions about my legitimacy as a researcher working with Indigenous communities. This feeling of illegitimacy was heightened during this study in collaboration with the Elders because they are held in high esteem as Knowledge Holders and traditional healers. This instilled in me a hyper-awareness of how I interacted and communicated with the Elders because I feared that I may behave offensively at times because of my settler ignorance. Moreover, it is crucial to acknowledge how this study arose out of a neoliberal, colonial institution that limits the potentiality of Elders as research partners because of the Westernized, academic routinization of scholarly research. These critical reflections further illuminate the need for Elders to be meaningful partners in research because within their positionality as Indigenous community leaders and teachers they offer a clear and robust critique of colonial research processes. This demonstrates the need to disrupt settler colonialism in myself and the research process by privileging the teachings and wise practices of the Elders. It was crucial as an ally-in-progress that I envision myself as the student of the Elders because their knowledges and teachings are the foundation of this study. It was vital that I practiced according to D'Arcangelis (2017) "radical reflexivity" to look beyond

myself to consistently examine the ever-present role of the oppressive structures and systems that maintain my power and privilege despite my efforts of introspection and reflection. It was imperative, according to McGuire-Adams (2021, p.763) "to unsettle my settler consciousness" by embarking on a journey towards settler allyship, through the "de-centering of whiteness and the disruption of privilege." This study foregrounds the knowledges of the Elders and promotes their meaningful research partnerships as paramount to the Indigenization of STBBI research to best serve the needs of Inuit, Métis, and First Nations communities.

Moreover, it is significant to note that my presence in the Talking Circles as a white settler undoubtedly impacted the Elders level of comfort. Although, the Elders were generous and open in their sharing, my presence contributed to the dynamics of the Talking Circles as the only white woman. Regardless of my presence, the Elders were highly supportive and emphasized the need for non-Indigenous researchers to learn Indigenous Knowledges from Elders and to centre these learnings in STBBI research. As a white-settler-woman in the Elders space of sharing I made a concerted effort to communicate with honour and humility. During all three Talking Circles the Elders shared deeply personal stories and it was clear that we had cultivated a safe and ethical space where each of us could share with vulnerability. I did my best to contribute to this environment through attuned listening and demonstrating my utmost respect for the Elders during this data gathering stage, the members' checking sessions, and throughout all of our interactions. Moreover, I communicated with the Elders with vulnerability, and I shared sensitive details about myself and my background. The Elders exuded profound wisdom, spirituality, and compassion during the Talking Circles and throughout this study. At the end of the Talking Circles when we were checking out with each other before the closing prayer the

Elders identified that they felt a deeper sense of wellbeing after sharing this experience together which further highlights their capacity to heal others, particularly, when they are a collective.

Another limitation of this study was the tension of drawing on overarching themes from all of the Elders who are from different communities as this is a pan-Indigenous approach to research because this study does not contrast the nuances and distinctions between Indigenous nations, communities and/or identities, such as Haudenosaunee vs. Anishnaabe vs. Métis vs. Inuit. Sandy Leo vehemently expressed her disdain for the use of a pan-Indigenous approach in research because it fails to recognize the sovereignty of Indigenous nations and neglects the unique cultures of these communities. This study is limited by a pan-Indigenous approach however, the purpose of this study was to focus on "Elder specific" contributions to Indigenous STBBI research which is a specialized field and only a limited number of Elders have this experience. Thus, it would have proven difficult to engage Elders with this research experience from only one Métis, Inuit, or First Nations community. In addition, the time limitation and length of this study hindered our ability to compare the responses of the Elders based on their nations and/or communities.

A significant limitation of this study, which was discussed by many of the Elders is "the tension of navigating two worlds" (Indigenous vs Western worlds). This tension resonates with this study because we were beholden to the Master of Social Work timeline and framework and required to meet the criteria set by the McMaster Research Ethics Board (MREB). The ethics review took exceptionally long because they had to recruit an external ethics reviewer because the MREB lacked expertise in Indigenous research. Their need to recruit externally exposes an alarming gap in Indigenous research expertise on the MREB. Moreover, the standard thesis writing process often felt constraining and reinforced the need to decolonize writing so that it

displays Indigenous Knowledges in a way that reflects their richness, strengths, and meaning, as they are boundless, timeless, and continuously evolving- making it difficult to contain them in a Westernized, linear, structure. Further to this, the use of English when engaging in research with Indigenous communities is highly problematic and was noted by several Elders on this study because many English words do not translate in Indigenous languages and often lose their meaning. To move towards decolonial writing that supports Indigenous autonomy and self-determination, it is crucial that research teams with Elders as partners (who often carry their languages) feature the use of Indigenous languages throughout the research process to deepen cultural resonance and meaning and to engage Indigenous communities in study outcomes that align with their worldviews.

Implications for Policy and Research Practice

The current conventional approach to STBBI policy and practice does not often include Indigenous traditional healing practices and wholistic approaches to healthcare (Absolon, 2010; Allen et al., 2020). Despite centuries of the attempted colonial erasure of traditional healing practices, medicines, and ceremonies, these practices continue to thrive in Indigenous communities because they provide profound healing and therapeutic benefits (Allen et al., 2020). Indigenous healing practices offer wholistic care that supports physical, mental, emotional, and spiritual healing (Abolson, 2010) and it is essential to offer an integrated model of STBBI care that includes both Indigenous healing practices and biomedical care (Hillier et al., 2020). When Indigenous Elders are researchers who are shaping the research questions, methodologies, and ethics they can transform STBBI policy, programming, and practices to reflect the unique needs of their communities and promote autonomy and self-determination (Flicker et al., 2015). These potential outcomes align with the UNDRIP Act (United Nations Declaration on the Rights of

Indigenous Peoples) which guarantees the right of Indigenous Peoples to autonomy and self-determination which is identified in Article Four, "Indigenous Peoples in exercising their right to self-determination have the right to autonomy or self-government in matters relating to their internal and local affairs…" (p.8). This includes the self-determination and autonomy of Indigenous communities in deciding how best to culturally respond to STBBI through prevention, support, and care. The establishment of robust partnerships with Elders can help shape research outcomes that can be used to inform policies to support Indigenous peoples affected by STBBI through sustainable funding for traditional healing practices and culturally distinct STBBI programs in First Nations, Inuit, and Métis communities.

According to Morgensen (2009, p.47) Indigenous activists recognize how the narrative of HIV is shaped "[by] colonial governmentality in sexual cultures and public health" and how there must be "intellectual sovereignty" over Indigenous Peoples relationship to HIV/AIDS, policy, and social change. This intellectual sovereignty shifts research and theory back into the rightful foray of Indigenous Elders, theorists and researchers. Tuhiwai Smith (2012, p.77) examines how Indigenous research and activism have the capacity to work together to increase the wellbeing of Indigenous peoples as "... the two activities of research and activism connect with the visions, aspirations and needs of Indigenous communities and how the activities of research and activism assist Indigenous communities to live as Indigenous communities that experience cultural sustainability as well as social, economic and political well-being." Indigenous STBBI research can play a significant role in foregrounding Indigenous intellectual sovereignty in STBBI-related policies by privileging the voices of Indigenous Elders who have a profound understanding of the needs of their communities.

Elders in this study are calling out decision-makers for the lack of culturally safe, clinical services and harmful health practices that are systemically entrenched in our current healthcare systems (Hickey et al., 2021). Elders must be involved in the design and implementation of healthcare services that include cultural healing practices and medicines because biomedical and epidemiological approaches to health are failing Indigenous Peoples. According to Hickey et al. (2021, p.303) "we use research to support Indigenous peoples to determine their own transformative change. We affirm Indigenous knowledges as foundational and relational to health research, policy, and service delivery." According to Askew et al. (2020, p.103) it is necessary "to return our gaze to Indigenous conceptualizations of a strengths-based approach and [re]consider its application for a public health committed to closing the gap in health outcomes for Indigenous peoples." This decolonial research approach is well positioned to advocate against institutional policies that counter Indigenous ways of being and knowing because they can be embedded throughout the research process using Indigenous methodologies and methods (Tuhiwai Smith, 2012). Moreover, it has the potential to dismantle colonial harms that are often perpetuated through research by privileging the expertise of the Métis, Inuit, or First Nations communities. Ball and Jaynst (2008) emphasizes the need for research partnerships with Indigenous communities "to be conceived through broader social agendas of restorative justice and self-determination and guided by principles of community relevance, community benefit, and mutual capacity building" (p.33). Lewis (2012) highlights how community-based-participatory research with Indigenous communities can contribute to decolonizing research by using a holistic framework that considers continuous colonial relations and centers Indigenous methodologies. Indigenous STBBI research that follows a community-led participatory model that harnesses cultural strengths and healing practices can support Indigenous self-determination

in healthcare policies, programs, and practices to serve distinct First Nations, Métis, and Inuit communities.

In partnership with Elders, STBBI research is motivated by social justice and the self-determination of Indigenous communities and is better positioned to inform culturally relevant policies. The Elders have highlighted the intersection of culture, place, and health, particularly for Indigenous Peoples who uphold and honour land-based knowledges. Lamouch (2010) notes that "the break with land is the single most important factor in health problems among Indigenous peoples." This emphasizes how programs should promote reconnection to the land to improve the health of Indigenous people living with STBBI. Land-based learning is taught intergenerationally from the Elders to the youth, and it is based on the experiential, embodied, spiritual, and ancestral connections to the land and the wildlife (Wildcat et al., 2014).

There are also implications for social work practice because according to DeCorte and Roose (2020) it is crucial that social workers understand "each phase of the policy cycle" so they can intervene throughout these processes to serve a social justice agenda, otherwise social workers are merely practicing under the "status quo" (p.227). In addition, McCave et al. (2014) emphasizes how sexual wellbeing is often neglected in social work which "contributes to the continued oppression of marginalized populations" (p.409). It is vital for social workers to understand the impacts of colonial trauma and systemic oppression on the physical, spiritual, emotional, and mental health of Indigenous Peoples and how these factors contribute to an increased risk of STBBI. It is imperative that we recognize how sexual wellbeing is intimately related to our entire sense of self, health, and wellbeing, and must be prioritized in social work practice to avoid reproducing the taboos and stigmata that surround sexuality. Social workers can play an integral role as allies and advocates if we maintain a critical, anti-colonial analysis of the

systemic oppression that Indigenous Peoples experience and how it relates to sexual health outcomes (Hillier et al., 2020). Spiegel et al. (2015) emphasizes the need to move away from the "biomedical paradigm," however if we focus too closely on social determinants health, we may focus too much on "risk factors" and lose sight of "systemic factors that drive these health disparities" (p.1). Social workers are uniquely positioned to respond to both systemic factors and the ways in which Elders and Indigenous communities hold the power and knowledge to amplify emancipatory theories and methodologies in STBBI research and policy.

Conclusion

This study explored the meaningful partnership of Elders in Indigenous STBBI research in three virtual Talking Circles with thirteen Elders from across Turtle Island. In these Talking Circles, the Elders shared: the successes and barriers they experienced in STBBI research, how Indigenous teachings and practices were implemented in this research and if they were not, what prevented this from happening, the importance of Elders as STBBI research partners, and important wise practices, Indigenous methods, ethics, and principles that should be implemented in STBBI research, and guidance on how to strengthen these research partnerships for future researchers. Through the thematic analysis of the Talking Circles five overarching themes emerged: (1) Understanding the historical and ongoing impacts of colonialism and the need to decolonize STBBI research; (2) Prioritizing the knowledge and lived experience of Elders and Indigenous people living with STBBI throughout the research process; (3) Centering spirituality and ceremony in Indigenous STBBI research; (4) The importance of implementing Indigenous methodologies in STBBI research; and (5) Foregrounding Indigenous ways of being, knowing, and doing in STBBI research. This study was grounded in decolonizing and Indigenous theories and methodologies that strongly align with the contributions of the Elders in this study.

Moreover, this study has been shaped and guided by Elder collaborators/coauthors since its inception to emulate the purpose of this study with authenticity. This study has illuminated the myriad cultural teachings, Indigenous Knowledges, and traditional healing practices that Elders bring to Indigenous STBBI research and how these meaningful partnerships can serve to heal Inuit, Métis, and First Nations communities. Sandy Leo illuminates the power of Elders to heal through their teachings “this shows the other beauty of when we come together like this, and we share. We can give teachings, we receive teachings, and we get and give healing with our words.”

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Appendix A

TALKING CIRCLE GUIDE

Exploring the Meaningful Partnership of Elders in Indigenous STBBI Research

With Bridget

NOTE: *TEXT WRITTEN IN INTALICZED BOLD CAPITAL LETTERS CONSTITUTES ADDITIONAL REMINDERS MEANT TO GUIDE THE TALKING CIRCLE FACILITATOR ONLY.*

[THE COMPLETION OF THE INTRODUCTORY SECTION OF THE FOCUS GROUP SHOULD TAKE APPROXIMATELY 10-15 MINUTES]

I) INTRODUCTION AND INSTRUCTIONS:

Hello, my name is Bridget. Thank you for agreeing to participate in this Talking Circle. Just to remind everyone, we are exploring the meaningful partnership of Elders in Indigenous STBBI (sexually transmitted and blood borne infections) research today.

In a minute, we will all introduce ourselves. But first, I would like to discuss confidentiality and obtain your oral consent.

[FOR FACILITATOR: REVIEW INFORMED CONSENT FORM AND ANSWER ANY QUESTIONS ABOUT IT]

Confidentiality: **[*READ ALOUD] -*** *Before* we begin our Talking Circle, I want to spend a few moments talking about confidentiality.

- Everyone's views are welcomed and important.
- The information which we will collect today will be attributable *(connected or associated)* to you as a group.
- We will not identify quotes or ideas with *any one person* of this group. Because of the nature of small communities or groups, it is possible that people could link participants in this room to quotes in the report. This is why we need to talk about confidentiality.
- We *are* assuming that when we learn about one another's views, they remain confidential. In a small group like this, people are identifiable to some degree by their views and opinions.
- Having said this, and having made these requests, you know that we cannot guarantee that the request will be honoured by everyone in the room.

- So, we are asking you to make only those comments that you would be comfortable making in a public setting; and to hold back making comments that you would not say publicly.
- If you want to stop being in the Talking Circle you can leave or stay and simply stop talking, but it will not be possible for you to pull out your data from the flow of the conversation because of the interconnected nature of the group discussion where one person's comments can stimulate the sharing of comments made by others in the group.
- To ensure that everyone is feeling safe and comfortable, I will check in with everyone throughout the Talking Circle.

Talking Circle: The Talking Circle is an honoured Indigenous tradition, where you are free to share your contributions and to express yourself without question or interruption. This Talking Circle belongs to all of you, I will offer guiding questions, however you will decide the many directions this Talking Circle takes.

Purpose: Elders are teachers, healers, and researchers in their communities, and it is crucial that they are meaningful partners in research initiatives that impact their communities because they are best attuned to the needs of their peoples. This Talking Circle offers you, as Elders, the opportunity to discuss the successes and challenges you have experienced participating in research (and related community work) to offer guidance and wise practices to Indigenous STBBI researchers to encourage more meaningful partnerships in the future by centering Indigenous ways of being and knowing.

Consent: All sharing must be completely voluntary, you are NOT obligated to answer any question that you are uncomfortable with, and you may withdraw consent at any time. If you share something personal with the group that you would like left out of the transcription, please let me know. I can also start and stop the recording based on your instructions.

Recording: Our Talking Circle will be recorded to capture everyone's contributions in their entirety. I will save this recording to an encrypted folder in my password protected MacDrive. Once I have ensured that the transcription is accurate and complete, I will permanently delete and electronically shred this recording. Likewise, once I complete the thematic analysis, I will permanently delete and electronically shred the transcription. This guide offers an outline of questions to follow that are related to this research initiative, however, all of you will ultimately guide this Talking Circle in the direction it needs to take.

Talking Circle:

1. We will begin with introductions for those who are comfortable in introducing themselves.

2. An Elder will open the ceremony of our Talking Circle with prayer.

3. We will revisit the agreement and consent process with each other to confirm that each Elder is participating with informed consent, so we are ethically grounded.

4. We will review the intention and purpose of our Talking Circle to ensure we have a shared understanding.

5. You (the Elders) will respond to the Talking Circle questions using your Indigenous experiential, cultural, and traditional knowledges.

6. When you (the Elders) have expressed that you are finished speaking we will move towards closing the Talking Circle.

7. An Elder will close the Talking Circle ceremony with prayer.

Guiding Talking Circle Questions:

1. What have been the challenges and/or successes you have encountered during your involvement in research/community work as Elders?

2. Were Indigenous teachings and practices used in this research? A) If yes, how so? B) If no, what barriers stopped this from happening?

3. Why is it important for Elders to partner in Indigenous STBBI research?

4. Which wise practices, including ethics, values, methods etc. need to be used throughout the research process?

5. What guidance would you give Indigenous STBBI researchers to strengthen meaningful research partnerships with Elders in the future?