

Table of Contents

Introduction.....1

Section 1: Commentaries

Quilting allyship in a time of COVID-19.....3
Andrea Mellor

Making Allyship Work: Allyship Perspectives in a Community-Based Research Study.....14
Katsistohkwí:io Jacco, Madeline Gallard, Joanna Mendell, Darren Lauscher, Deb Schmitz, Michelle Stewart, Catherine Worthington, Nancy Clark, Janice Duddy, & Sherri Pooyak

Section 2: Stories

Let the Fires Unite: Our journey of allyship.....33
Claudette Cardinal, Niloufar Aran

Welcoming and Navigating Allyship in Indigenous Communities.....52
Mikayla Hagel, Miranda Keewatin, & Dr. Carrie Bourassa

Allyship: Braiding Our Wisdom, Our Hearts and Our Spirits.....58
Denise Jaworsky and Valerie Nicholson

Section 3: Student paper

Student Placement at the AHA Centre, a project of CAAN.....67
Michael Parsons

Section 4: Research development and findings

Creating change using two-eyed seeing, believing and doing; responding to the journey of northern First Nations people with HIV.....76
Linda Larcombe, Elizabeth Hydesmith, Gayle Restall, Laurie Ringaert, Matthew Singer, Rusty Souleymanov, Yoav Keynan, Michael Payne, Kelly Macdonald, Pamela Orr, Albert McLeod

Drivers of Sexual Health Knowledge for Two-Spirit, Gay, Bi and/or Indigenous Men Who Have Sex with Men (gbMSM).....	93
<i>Harlan Pruden, Travis Salway, Theodora Consolacion, and Jannie Wing-Sea Leung, Aidan Ablona, Ryan Stillwagon</i>	
Indigenous Resilience and Allyship in the Context of HIV Non-Disclosure Criminalization: Conversations with Indigenous People Living with HIV and Allies Working in Support of Community.....	114
<i>Emily Snyder and Margaret Kísikâw Piyêsîs</i>	
miyo-pimâtisiwin iyiniw-iskwênâhk (Good Health/Living Among Indigenous Women): Using Photovoice as a tool for Visioning Women-Centred Health Services of Indigenous Women Living with HIV.....	130
<i>Carrie Bourassa, Miranda Keewatin, Jen Billan, Betty McKenna, Meghan Chapados, Mikayla Hagel, Marlin Legare, Heather O'Watch, and Sebastien Lefebvre</i>	
Reflections on Acts of Allyship from a Collaborative Pilot of Dried Blood Spot Testing.....	153
<i>Danielle Atkinson, Rachel Landy, Raye St. Denys, Kandace Ogilvie, Carrielynn Lund, and Catherine Worthington on behalf of the DRUM & SASH team</i>	
Towards <i>Amaamawi'izing</i> (Collaborating) in Interdisciplinary Allyship: An Example from the Feast Centre for Indigenous STBBI Research.....	170
<i>Randy Jackson, Renée Masching, William Gooding, Aaron Li, Bridget Marsdin & Doris Peltier</i>	
Working together: Allies in researching gender and combination antiretroviral therapy treatment change.....	187
<i>Claudette Cardinal, Carly Marshall, Alison R. McClean, Niloufar Aran, Katherine W. Kooij, Jason Trigg, Erin Ding, Kate Salters, Robert S. Hogg on behalf of the CANOC Collaboration</i>	

Creating change using two-eyed seeing, believing and doing; responding to the journey of northern First Nations people with HIV

Linda Larcombe, Elizabeth Hydesmith, Gayle Restall, Laurie Ringaert, Matthew Singer, Rusty Souleymanov, Yoav Keynan, Michael Payne, Kelly Macdonald, Pamela Orr, Albert McLeod

ABSTRACT

In Manitoba, Canada there is a critical need to understand the journey that northern First Nation people living with Human Immunodeficiency Virus (HIV) experience and navigate. Unique factors make the northern journey different from that of all other Manitobans. These include geographic isolation in small reserve communities with limited health care services, difficulties in maintaining confidentiality, stigma, and a lack of culturally appropriate programs and health interventions. In contrast, connection to family and community, access to the land and traditional foods, ceremony and medicine are factors that might create resiliencies among northern First Nation people living with HIV.

Here, we describe the methods that we are using to harvest and analyze narratives from people with lived HIV experience from northern Manitoba, and from health care providers who have knowledge about the health care processes. Our methods are focused on foraging an allyship. To do that, we are committed to explicitly developing ethical space using two-eyed seeing, believing, and doing. We understand that allyship is an important ethical approach to engaging with, and developing actionable recommendations relevant to northern First Nation people in Manitoba.

We anticipate that through this process we will learn from First Nation individuals living with HIV how practices for HIV health care delivery need to be changed. With this knowledge we can then move from knowledge to action to reduce stigma and promote well-being.

AUTHOR CONTACT

Linda Larcombe (MA, PhD.)
Associate Professor, Department of Internal Medicine, Rady Faculty of Health Sciences,
University of Manitoba
Room 531A Basic Medical Sciences Building 745 Bannatyne Ave.
Winnipeg, MB Canada R3E 0J9.
larcombe@umanitoba.ca Ph. (204) 975-7726

INTRODUCTION

In Manitoba, over fifty percent of new clients in care for Human Immunodeficiency Virus (HIV) in 2018 self-identified as Indigenous (First Nation, Inuit or Métis) (Manitoba HIV Program, 2019). In addition, treatment outcomes expressed as the proportion attaining viral suppression, is lower among self-identified Indigenous individuals (Manitoba HIV Program, 2019). The 2018 Manitoba HIV Program report suggested that HIV rates among Indigenous peoples “reflect long-standing systemic racism in Manitoba’s health care system” (Manitoba HIV Program, 2019). There is a critical need to understand the journey that First Nation people (Dene, Cree, Oji-Cree and Ojibwe) navigate in living with HIV in northern Manitoba. Barriers to obtaining appropriate HIV care for Indigenous peoples have been described in the literature, but there has been little study of the ways that historical, personal, community, cultural, organizational, health system and policy factors interact in the construction and maintenance of these barriers (Manitoba Health Seniors and Active Living, 2016a, 2018a; Manitoba HIV Program, 2016a; Plitt et al., 2009).

Hearing and sharing narratives about the barriers to HIV testing, treatment and care and the resilient ways in which northern First Nation people navigate these barriers is a critical health priority for a number of reasons: 1) the rates of HIV infection and disease in First Nation peoples of Manitoba are increasing (Manitoba Health Seniors and Active Living, 2016b, 2018b; Manitoba HIV Program, 2016b); 2) HIV testing and care is a complex process (Plitt et al., 2009; Thompson et al., 2012); 3) the communities are remote and there is a lack of access to health services and social supports (Allec, 2005); 4) there are limited strategies to address barriers and enhance enablers for implementing current best practices of HIV testing and care for northern Manitoban First Nation people; 5) there is a perceived lack of integration of First Nation cultural ways of knowing and healing practices with western medicine practices (Fayed et al., 2018); and 6) a lack of Indigenous cultural safety that has been identified in health care in Canada (Allan & Smylie, 2015; Brooks-Cleator, Phillipps, & Giles, 2018; Gracey & King, 2009; King et al., 2019).

The goal of the project is to develop culturally-safer, geographically-responsive supports for northern First Nation Manitobans living with HIV. In 2018 a multi-stakeholder group of researchers from the Manitoba HIV/STBBI Collective Impact Network (MB HIV CIN) came together to explore the lived HIV experiences, assumptions and realities of First Nation people in the north of the province. MB HIV CIN is a group of people from First Nation communities, academia, community-based organizations, people with lived experience, and from First Nation-led and provincial and federal health organizations. All have a common vision to eradicate HIV transmission and other sexually transmitted blood borne infections (STBBIs) from the Canadian province of Manitoba by 2030 and to ensure the well-being of those living with HIV.

Our team is collecting and documenting the experiences of First Nation people in the HIV care cascade¹ using journey mapping, story-telling, and oral narration to compare and contrast the

¹ The HIV Cascade of Care (also known as Care Continuum) provides a framework for service providers and policymakers to measure progress according to steps in the delivery of HIV treatment and care. It allows us to assess development towards HIV prevention and care goals, identifying gaps in sustained patient care. <http://cfenet.ubc.ca/hiv-cascade-care-british-columbia>

northern experience with First Nation people in Winnipeg. Our research investigates what changes need to occur so that individuals can live well with HIV in the far north. To accomplish this, we need to build relationships among the allies (and the organizations they work with) to facilitate and create systems change.

The process by which the lived knowledge and experiences are collected, shared, understood and integrated into systems change requires consideration of the profoundly deep cultural, economic, and geographic differences that exist between northern First Nations and people who strive to be allies. In this project, the role of researchers is to actively engage in learning from the communities and First Nation people how to best work toward decolonizing the HIV journey so that First Nation people from the north can maximize well-being and make choices about their lives that are not restricted because of a colonial and centralized health care system. Our methodology involves two-eyed seeing, believing and doing to hear and learn how northern First Nation people negotiate the HIV care cascade as they look after their own health (Bartlett, Marshall, & Marshall, 2012; Iwama, Marshall, Marshall, & Bartlett, 2009; King, 2011; Marshall & Bartlett, 2007). We recognize that northern First Nation people living with HIV are experts with lived experience in navigating a health system designed and administered within a western bio-medical framework dominated by non-Indigenous people and ideologies. We propose that this participatory-action research can contribute to systems change in HIV health care by seeing, hearing, understanding, and communicating the barriers, facilitators and resiliencies that people encounter while navigating their lived journeys.

LAYING THE FOUNDATION

Relationships of trust and mutual care underlie the foundations of allyship. Some of the research team members (Larcombe, Singer and Orr) have a long-standing research collaboration with Manitoba Dene First Nation communities originally focusing on social, environmental and biological factors influencing their experience with endemic and epidemic tuberculosis (Larcombe et al., 2012a; Larcombe & Orr, 2007; Larcombe et al., 2008; Larcombe et al., 2012b; Larcombe et al., 2005).

In 2016, we held a research meeting funded by the Canadian Institutes of Health Research (CIHR is a national funding agency for health research) to introduce the Chief and Council from Northlands Denesuline First Nation to a network of researchers at the University of Manitoba. The purpose of the meeting was to foster relationships between First Nation leadership and potential academic collaborators. Through that discussion, a gap in knowledge was identified regarding STBBIs, such as HIV in northern Manitoba. The research team became aware that the community had taken an active lead in HIV awareness in the past and that they were concerned about the current trends in HIV transmission. For example, in 1994 the community hosted a forum on HIV to provide information about the disease. They had invited First Nation people knowledgeable about HIV and people living with HIV to raise awareness and address information gaps. Since that time educational programs have been limited except as part of the junior high and high school health curriculum (Canadian AIDS Society, 2010).

In response to these concerns, Dr. Larcombe and the team were recipients of a grant from REACH 2.0 to pilot the Canadian Aboriginal AIDS Network's Community (CAAN) Readiness assessment tool with Northlands Denesuline (Canadian Aboriginal AIDS Network, 2012; Larcombe et al., 2019). Learnings from that pilot study led to the development of this current project, *Mapping the Journey: developing culturally appropriate, geographically-responsive HIV care for northern Manitoba First Nations people* with funding for a 3-year CIHR Operating grant (University of Manitoba Human Research Ethics Board #HS20496). The study team includes academics, provincial, federal and First Nation organizations, clinicians and HIV activists. Over the past several years, many on the research team have been growing relationships with multiple stakeholders including policy-makers, community-based organizations, First Nation organizations and communities. Thus, the foundation was set for this current project to further enhance its work on allyship and building research capacity within an ethical space.

CREATING ETHICAL SPACE TO ENHANCE ALLYSHIP

The study team (some of whom are First Nation) understand the need for First Nation HIV research to be conducted using an intentional decolonizing approach, with cultural humility, as allies strive to be allies and build relationships of allyship with First Nation team members (Jaworsky, 2019; Kluttz, Walker, & Walter, 2020; Jackson Smith, Puckett, & Simon). Decolonizing is a process through which non-First Nation research partners commit to thinking, feeling, understanding and creating actions in solidarity (allyship) with First Nation people and communities (J. G. Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Krusz, Davey, Wigginton, & Hall, 2020; McGibbon, 2018). This decolonizing work and allyship is based on the values of justice, equity, caring and respect. Understanding the broad context (social, biologic, economic, and political) of how First Nation people in the remote northern sectors of Manitoba come to be tested for HIV and how they negotiate treatment and care is essential knowledge. It is required for planning and implementing interventions that are culturally appropriate and have the potential for safely engaging northern marginalized populations in HIV care.

Allyship is a way that people with privilege and power can support those in non-dominant groups to rectify inequities by establishing bonds, creating relationships, breaking barriers, and by fostering communication, action and accountability (Nixon, 2019; J Smith, Puckett, & Simon, 2016). Becoming an ally is a journey without a destination. In practice, a person cannot *become an ally* because of any action or deed. Instead, an individual or group consistently works at being an ally by learning and behaving in de-colonizing ways, and by sustaining equitable relationships with Indigenous people (Jaworsky, 2019; Kluttz et al., 2020; Smith et al., 2016). There is always the danger of reproducing the subordination of marginalized people regardless of intentions. The work of allyship, therefore, must be explicit and have accountability to the non-dominant group – in this case northern First Nation people including those living with HIV. In this project the work of allyship involves creating and nurturing ethical space in our research methods, building our own capacity for understanding ethical space (Ermine, 2007), and using two-eyed seeing (Marshall & Bartlett, 2007), believing and doing to highlight the structural oppressions in the health system that go unrecognized by non-First Nation researchers (Nixon, 2019).

Ethical space

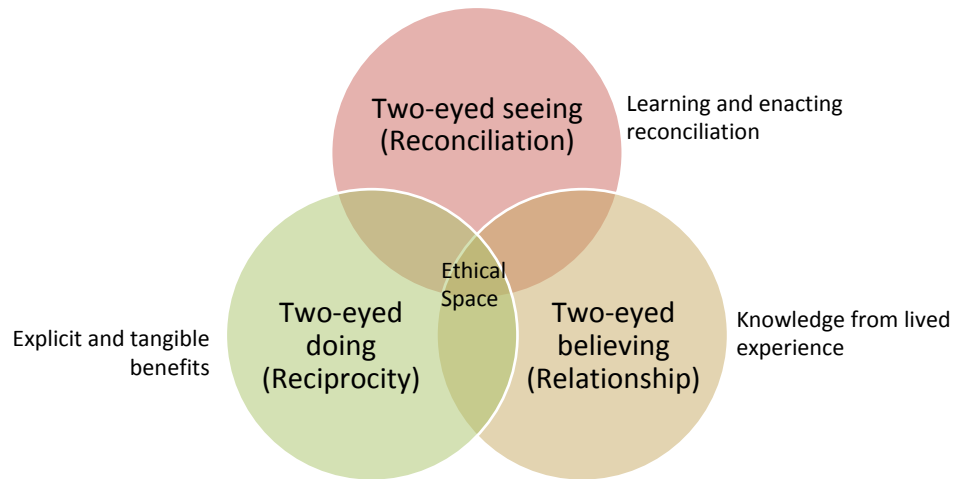
Our methodology requires the building of ethical space within which research participants, partners, communities and organizations are respected, heard, and understood. Elder Willie Ermine (from Sturgeon Lake First Nation in the north central part of Saskatchewan) says that “ethical space is formed when two societies, with disparate worldviews, are poised to engage each other” (Ermine, 2007). He explains that ethical space requires a culture in which feedback is received in ways that resonate and are useful for multiple contexts (Ermine, 2007). Ermine describes the space as an area between knowledge systems that helps to create opportunities for dialogue and ideas (Ermine, 2007). It is a space where each group must step out of their own ideologies and systems for common grounding and to interact as human beings (Ermine, 2010). The differences between cultural safety, cultural competence, cultural humility must be understood, along with the importance of a de-colonializing approach (Ermine, 2007; Hyett, Marjerrison, & Gabel, 2018; McEldowy & Connor, 2011; Sherwood & Edwards, 2006; Tervalon & Murray-Garcia, 1998). Engagement within the ethical space triggers dialogues that can bridge diversity of knowledge and create openings for developing deep appreciation for multiple ways of knowing. The ethical space is an imperative framework within which the researchers are actively engaged in learning and using methods formulated to inform culturally relevant systems change.

Two-eyed seeing

Two-eyed seeing / Etuaptmumk is a concept that was coined by Mi’kmaq Elder Albert Marshall (who lives in the community of Eskasoni, Nova Scotia, in the Traditional Territory of Mi’kma’ki). It is a guiding principle for inter-cultural collaboration in research and has been recommended for policy and program development in Manitoba (Martin, Thompson, Ballard, & Linton, 2017). Two-Eyed Seeing encourages the realization that beneficial outcomes are much more likely in any given situation if we are willing to bring two or more perspectives into play (Institute for Integrative Science and Health). In Marshall’s words, Two-Eyed Seeing is: “To see from one eye with the strengths of Indigenous ways of knowing, and to see from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together” (Bartlett et al., 2012).

Our research therefore combines ethical space and two-eyed seeing and uses the concepts of 1) Two-eyed seeing to learn about and enact reconciliation, 2) Two-eyed believing with knowledge from the lived experiences of northern First Nation people living with HIV, and 3) Two-eyed doing through reciprocity that explicitly and tangibly creates benefits for First Nation people (Figure 1). These are concepts and principles that Dr. McLeod, a First Nation Knowledge Keeper and a Principal Investigator, presented to the research team in a series workshops designed to build our understanding of two-eyed seeing, ethical space and allyship. As well, we apply these principles in our on-going dialogues between the Indigenous and non-Indigenous partners in the project.

Figure 1. Systems change with two-eyed seeing, believing and doing (McLeod & Larcombe 2020).



Our research process is designed to hear, share, and learn from the lived experiences of First Nation people living with HIV. From these insights the health care system can respond and develop culturally safe actions and interventions for HIV care. Approaching our research with two-eyes will facilitate the goal of supporting First Nation people living with HIV with interventions and programs that are culturally relevant and sustainable.

TWO-EYED SEEING – LEARNING ABOUT AND ENACTING RECONCILIATION

Our research approach considers that *two-eyed seeing* is necessary in order to understand that for people living in northern Manitoba, the journey with HIV is potentially different from those living with HIV in the Winnipeg southern urban environment. Our research methods seek to build ethical space by including and respecting the unique perspectives of northern and urban First Nation individuals living with HIV. We will also interview First Nation and non-First Nation health care providers who deliver HIV services in the urban and First Nation community health centres.

Two-eyed seeing, like critical feminist theory challenges the assumption that there is a single objective truth (Inhorn & Whittle, 2001; Jaworsky, 2019). Truth and reality are socially, culturally, historically, and politically constructed and until recently, the western biomedical perspectives have dominated the HIV health care system (Becker et al., 2012; McClarty et al., 2020). Two-eyed seeing means that First Nation epistemologies (ways of thinking), research frameworks (ways of questioning), and methodologies (ways of doing) are prioritized over Western methodology and interpretations in our research in order for the outcomes reflect First Nation knowledge, traditional teachings, and culturally derived revelations (Adelsen, 2000; Steinhauer & Lamouche, 2015). The voices of those with lived experience and those specifically impacted by geographic remoteness have a perspective that has not yet been fully heard in HIV care.

CREATING SPACE FOR TWO-EYED SEEING AND ETHICAL SPACE BUILDING IN THE PROJECT

There are several ways that we have created the space for two-eyed seeing and ethical space to be built into the research project: 1) designing the research team to involve First Nation investigators; 2) building the capacity of the research team on two-eyed seeing and ethical space; 3) incorporating Two-eyed believing – hearing and understanding the journeys; 4) incorporating Two-eyed seeing - seeing data collection; 5) creating space for dialogue between Northern partners (First Nation and non-First Nation) with Winnipeg centric partners; and 6) incorporating Two-eyed doing - changing systems to be more geographically, culturally safe, and responsive together with all partners.

1) Designing the Research Team to Involve First Nation Investigators

The research project was structured from the outset to involve First Nation investigators as equal research partners with academics. Typically, Principal Investigators do not draw a salary from the research project because they are affiliated and paid by their university. Our research team requested that the funders (CIHR) allow a budget line for paying Co-Principal Investigator Dr. McLeod for the duration of the project in recognition of his participation, skills and expertise equal to the other two academic Principal Investigators. He is not affiliated with a University but recognition of his expertise as an Elder and Knowledge Keeper is key in his role as a CIHR Principal Investigator and a way of enacting reconciliation. Elders are sometimes considered “research participants” or “collaborators” in First Nation research projects and are paid an honorarium for their contributions. In this project the Elder Knowledge Keeper has a vital role in leading, teaching, monitoring our efforts to develop and maintain ethical space, engaging with First Nation individuals and community partners using suitable protocols and methods, and ensuring that the research is relevant and culturally appropriate. We also involved the Keewatin Tribal Council (KTC) from the inception of the research proposal and involved one of their staff as a co-investigator.

2) Building the capacity of the research team on Two-Eyed Seeing and Ethical Space

As a method for learning and enacting reconciliation, the research team’s Elder/Knowledge Keeper held a preliminary workshop “Exploring Ethical Space and Indigenous Cultural Imperatives in Community-Based Research” (2019) at the Ma Mawi Wi Chi Itata Centre. He also held a four-part workshop/webinar series “Ethical Space and Research with Indigenous Populations” (2020) to build ethical space capacity and ultimately increase allyship. Through the lens of two-eyed seeing, two-eyed believing and two-eyed doing, the workshops focused on ethical space building. In response to COVID-19 public health protocols, Dr. McLeod created these four virtual workshop/webinars for the research team to enhance existing relationships and build of new ones so that we are in a position to identify explicit and tangible benefits of our research for First Nation and non-First Nation research partners, and to enact reconciliation. In Dr. McLeod’s ethical space series, he challenged participants to move out of their comfort zone by recognizing ongoing negotiations of ethical spaces (Bergen, 2020) and by demonstrative actions such as finding and visiting local First Nation and Métis spaces such as Winnipeg’s

Circle of Life Thunderbird House, the Manitoba Métis Federation Inc. and the Ma Mawi Wi Chi Itata Centre.

3) Two-eyed believing – hearing and understanding the journeys

Manitoba First Nation experiences with navigating the health system while living with HIV have received little attention to date. Important and relevant knowledge from First Nation peoples who navigate life with HIV needs to be heard, believed and valued (UNAIDS, 2016; White, 2005). The role of a research ally is to learn from First Nation people using methods that resonate with their ways of decision-making policies, programs and interventions.

First Nation people have always asked questions, assembled knowledge, made observations and generated informed decisions to guide their practices of living and staying well (Kovach, 2012). First Nation practices of assembling knowledge by hearing peoples' experiences and narratives about HIV can form the basis of information from which change can occur. Our research is guided by a First Nation research framework that has the qualities of wholistic epistemology, story, purpose, the experiential, ethics, ways of gaining knowledge, and an overall consideration of the colonial relationship (Kovach, 2012). This embodies the non-linear conceptual framework Kovach describes as research which 'follows more of an in and out, back and forth, and up and down pathway' [49].

4) Two-eyed seeing - seeing data collection

Our research will integrate northern First Nation's ways of knowing, coping and wellness strategies, and understanding of lived experiences into HIV health care services. Here we explain two of our data collection methods that will allow for two-eyed seeing to understand the differences, common themes, and the strengths of First Nation people living with HIV journey. The first method is the use of semi-structured, open-ended interviews to elicit stories and narratives that will enhance the breadth and depth of knowledge about individual HIV journeys. Unlike closed interviews where participants are meant to respond to specific questions, open-ended interviews that evoke stories places control of the narrative into the hands of the storyteller (Garrouette & Westcoot, 2013; Thomas, 2005; Wilson, 2008).

A deep level of listening and meaningful exchange comes from a developed relationship between co-learners through storytelling (Wilson, 2008). Creating space in a qualitative interview that allows for stories and narratives acknowledges the truth, wisdom and reality experienced by the person living with HIV and acknowledges that researchers value and believe their experiences. Storytelling is an Indigenous way of sharing information about relationships, resilience, insights, revelations and/or reflections (Garrouette & Westcoot, 2013; Thomas, 2005). Ojibwe and Oji-Cree philosophy considers the story to be a living being that can exist outside of time and space; it might change shape over time and it has its own purpose (Garrouette & Westcoot, 2013). Stories train and nurture the listener and they allow the storyteller to use their own voice to convey knowledge in a wholistic way (Thomas, 2005). A story might be a portion of or a complete narrative. A story might provide important context for why an individual was unable to get an HIV test or why inadequate housing might have contributed to an individual's inability to remain linked to care. Narratives are a compilation of stories—either oral or written—that may

include gestures, pictures, history or myths, all organized within the author's response to a particular context.

A second technique our research uses for two-eyed believing is journey mapping. Journey mapping was developed from process mapping that was first used by industry and was adapted by healthcare as a clinical auditing tool to examine how patients are managed in hospital or health care settings (Trebbele, Hansi, Hydes, Smith, & Baker, 2010). Mapping peoples' health journeys has been used to provide data to optimize care, create systems efficiencies in clinical and hospital settings, and to identify barriers and facilitators for safe reliable health care (Johnson et al., 2012; Jones, Shakhder, & Singh, 2017; Kelly et al., 2003; Kim, Spahlinger, Kin, & Billi, 2006; Layton, Moss, & Morgan, 1998; Sevaldons, 2011; Trebble et al., 2010).

Documenting how a patient navigates the healthcare system in general or with a specific disease (i.e. Parkinson's, rheumatoid arthritis, cancer) has been used to understand and "see" a patient's experience (Del Rio, Baudet, Fernandez, Morales, & Socas Mdel, 2007; Helsing, 2007; Jones et al., 2017; Oliver et al., 2008). Journey mapping peoples' experiences through the HIV cascade of care is a method that can document the potential uniqueness of the paths. Journey mapping in health care systems can benefit from input from multiple perspectives and by using a variety of techniques to gather and represent data (Jones et al., 2017; Kelly et al., 2003; Sevaldons, 2011). Journey mapping and documenting experiences peoples have in the HIV cascade of care is a method that can document the potential uniqueness of the paths.

As we conduct our interviews, specific questions will elicit understanding of barriers, facilitators and resiliencies that individuals face or use along the HIV cascade of care journey (Jongbloed et al., 2019). During the time of the interview, we ask the participant to illustrate through words and images the steps, barriers, and facilitators along the journey of care. A comparison between the journeys of northern First Nation people living with HIV compared to First Nation peoples living with HIV who have always resided in an urban centre is meant to identify potential similarities and differences in their journeys. We will develop a composite experience journey map of those First Nation people living in northern Manitoba and a composite process journey map from interviews with health care providers.

5) Creating space for dialogue between Northern partners (First Nation and non-First Nation) with Winnipeg centric partners

As part of our research design, we have incorporated quarterly meetings of our research team that includes both Northern and Winnipeg-centric First Nation and Non-First Nation partners. During these times, we bring together viewpoints on the design, progress and outcomes of the research. We also have incorporated points in the research design where we have intentional gatherings with expanded circles of Northern and Winnipeg-centric First Nation and non-First Nation partners especially as we make sense of the data and work together to make systems changes.

This research project also operates within the MB HIV/STBBI Collective Impact Network which brings together many of these same partners from time to time throughout the year. For instance, some of the research team and partners came together for a gathering of First Nation and Non-First Nation partners at the Circle of Life Thunderbird House in November 2019: A Gathering to

Discuss the Pathways to Care Project: establishing a two-eyed seeing stakeholder engagement table bringing together Indigenous leaders, rural and remote leaders and STBBI-prevention-testing-care leaders. The Network also hosts two large gatherings per year on a variety of topics plus has a focused action group on Truth and Reconciliation which Dr. Larcombe and Dr. McLeod are co-leading and includes many of this research team. On-going relationship building, overtime and through these various opportunities, all contributes to the building of allyship.

TWO-EYED DOING – EXPECTED OUTCOMES (CHANGING SYSTEMS TO BE MORE GEOGRAPHICALLY ORIENTED AND CULTURALLY RESPONSIVE)

The purpose of this research is to use the resulting knowledge to inform health care interventions, practices and programs locally and provincially to create systems change (C. Bartlett et al., 2012; Iwama et al., 2009). This research is meant to lead to action. The essential third phase of this project will involve synthesizing the findings and bringing together research partners (First Nation and non-First Nation) and communities to effectively discuss and co-create systems changes that are needed. An effective research ally is “willing to learn how to ‘stand with’ a community” (Tallbear, 2014).

We are opening up our academic methods to 1) include paradigms, theory and other ways of collecting, synthesizing and sharing of information, and 2) to use our skills and networks of collaborators to explore new methods and approaches for research proposed by First Nation people. A possible limitation of our work is that the lived experience and knowledge of northern First Nation people living with HIV may not be fully appreciated by others. Despite our best efforts there will always be gaps in our understanding. Our role as allies however is to recognize and voice these limitations but not back away from the work of creating change.

The methods used for this research will build and maintain a respectful relationship between the research partners to model and apply to best practices. The knowledge can be shared and reified by provincial and federal HIV health care systems, First Nation and non-First Nation health organizations, communities and individuals. These groups are, to some extent, already engaged in the research either as team members or as members of MB HIV CIN. Thus, they are engaged or are witnesses to two-eyed seeing, believing, and doing. The groups involved in the MB HIV CIN have variable levels of involvement in the study, but all have been invited to have an active role in the study design, methods, interventions and evaluations. Ultimately, we envision knowledge sharing and the development of HIV interventions that are consistent with and reflect First Nation worldviews and ways of being.

CONCLUSION

This paper describes how we are attempting to grow allyship in our research project through various approaches including building relationships, creating ethical space dialogues and using a two-eyed seeing framework. We endeavor to move beyond two-eyed seeing to consider two-eyed believing and doing. In doing so, we are building ethical space dialogue and fostering allyship to create more geographically and culturally responsive HIV systems of care for remote First Nation people in partnership with northern First Nation and non-First Nation partners. This

methodology guides our research team to see and acknowledge worldviews and ways of knowing outside of the western biomedical context and challenges us to use First Nation methods for hearing and believing lived HIV experiences and responding by direct action. By growing relationship, allyship and partnership through this approach, we believe we can move toward greater transformational change in the system.

Acknowledgements: This research is funded with an operating grant from the Canadian Institutes of Health Research (Grant Number CBA-164022). Health Research Ethics Board (HREB) certificate # HS20496.

REFERENCES

- Adelsen, N. (2000). *Being Alive Well: Health and the Politics of Cree Well-Being*. Toronto, ON: University of Toronto Press Inc.
- Allan, B., & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada*. In Toronto, ON: The Wellesley Institute.
- Allec, Robert (Producer). (2005). *First Nations Health and Wellness in Manitoba*. Retrieved from www.gov.mb.ca/imr/ir/publications/pubs/1st_nations_health_final2005.pdf
- Bartlett, C, Marshall, M, & Marshall, A. (2012). Two-Eyed Seeing and other lessons learned within a co-learning journey of bringing together indigenous and mainstream knowledges and ways of knowing. In *J Environ Stud Sci* (Vol. 3, pp. 331–340).
- Bartlett, J. G., Iwasaki, Y., Gottlieb, B., Hall, D., & Mannell, R. (2007). Framework for Aboriginal-guided decolonizing research involving Metis and First Nations persons with diabetes. *Social Science & Medicine*, 65(11), 2371-2382. doi:10.1016/j.socscimed.2007.06.011
- Becker, ML, Kasper, K, Pindera, C, Cheang, M, Rodger, D, Sanche, S, . . . Gill, MJ. (2012). Characterizing the HIV epidemic in the prairie provinces. In *Canadian Journal of Infectious Diseases and Medical Microbiology* (2013/03/02 ed., Vol. 23, pp. 19-22).
- Bergen, Rachel (Producer). (2020). *Manitoba Hydro pulls majority of workers from Keeyask project amid blockades*. Retrieved from <https://www.cbc.ca/news/canada/manitoba/keeyask-blockade-manitoba-hydro-maintenance-mode-1.5580933>
- Brooks-Cleator, L., Phillipps, B., & Giles, A. (2018). *Culturally Safe Health Initiatives for Indigenous Peoples in Canada: A Scoping Review*. *The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmieres*, 50(4), 202-213. doi:10.1177/0844562118770334
- Canadian Aboriginal AIDS Network. (2012). *Assessing community Readiness and Implementing Risk Reduction Strategies*. Retrieved from <http://caan.ca/wp-content/uploads/2012/05/CR-manual-eng.pdf>
- Canadian AIDS Society. (2010). *Knowledge is Our Best Defence: An HIV/AIDS Education Resource for Canadian Schools*. Retrieved from Ottawa, ON.: <http://www.cdnaids.ca/wp-content/uploads/Knowledge-is-our-best-defence-HIV-curriculum-2010.pdf>
- Del Rio, A. S., Baudet, J. S., Fernandez, O. A., Morales, I., & Socas Mdel, R. (2007). Evaluation of patient satisfaction in gastrointestinal endoscopy. *Eur J Gastroenterol Hepatol*, 19(10), 896-900. doi:10.1097/MEG.0b013e3281532bae

- Ermine, W. (2007). The Ethical Space of Engagement. *Indigenous Law Journal*, 6(1).
- Ermine, W. (2010). What is ethical Space? In *The Different Knowings Speakers' Series*. McMaster University, .
- Fayed, S.T, King, A, King, M, Macklin, C , Demeria, J, Rabbitskin, N, . . . Gonzales (Sempulyan), S. (2018). In the eyes of Indigenous people in Canada: exposing the underlying colonial etiology of hepatitis c and the imperative for trauma-informed care. *Canadian Liver Journal*. doi:doi: 10.3138/canlivj.2018-0009
- Garrouette, E, & Westcoot, K. (2013). The Story Is a Living Being: Companionship with Stories in Anishinabeg Studies. In J Doerfler, N. J Sinclair, & H. K Stark (Eds.), *Centering Anishinaabeg Studies: Understanding the World through Stories*. Winnipeg: University of Manitoba Press.
- Gracey, M., & King, M. (2009). Indigenous health part 1: determinants and disease patterns. *Lancet*, 374(9683), 65-75. doi:10.1016/S0140-6736(09)60914-4
- Helsing, E. (2007). A patient's journey - The reluctant patient: Parkinson's disease. *British Medical Journal*, 335(7627), 989-990. doi:10.1136/bmj.39329.606840.AD
- Hyett, S., Marjerrison, S., & Gabel, C. (2018). Improving health research among Indigenous Peoples in Canada. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 190(20), E616-E621. doi:10.1503/cmaj.171538
- Inhorn, M. C., & Whittle, K. L. (2001). Feminism meets the "new" epidemiologies: toward an appraisal of antifeminist biases in epidemiological research on women's health. *Social Science & Medicine*, 53(5), 553-567. doi:10.1016/s0277-9536(00)00360-9
- Institute for Integrative Science and Health. Two-eyed Seeing. In.
- Iwama, M, Marshall, M, Marshall, A, & Bartlett, C. (2009). Two-eyed seeing and the language of healing in community-based research. *Canadian Journal of Native Education*,, 32(2), 3.
- Jaworsky, D. (2019). An allied research paradigm for epidemiology research with Indigenous peoples. *Arch Public Health*, 77, 22. doi:10.1186/s13690-019-0353-1
- Johnson, J. K., Farnan, J. M., Barach, P., Hesselink, G., Wollersheim, H., Pijnenborg, L., . . . Collaborative, HANDOVER Res. (2012). Searching for the missing pieces between the hospital and primary care: mapping the patient process during care transitions. *Bmj Quality & Safety*, 21, 97-105. doi:10.1136/bmjqs-2012-001215
- Jones, P. H., Shakhder, S., & Singh, P. (2017). Synthesis maps: visual knowledge translation for the CanIMPACT clinical system and patient cancer journeys. *Curr Oncol*, 24(2), 129-134. doi:10.3747/co.24.3452

- Jongbloed, K., Pooyak, S., Sharma, R., Mackie, J., Pearce, M. E., Laliberte, N., . . . Cedar Project, Partnership. (2019). Experiences of the HIV Cascade of Care Among Indigenous Peoples: A Systematic Review. *AIDS and behavior*, 23(4), 984-1003. doi:10.1007/s10461-018-2372-2
- Kelly, M. J., Lloyd, T. D., Marshall, D., Garcea, G., Sutton, C. D., & Beach, M. (2003). A snapshot of MDT working and patient mapping in the UK colorectal cancer centres in 2002. *Colorectal Dis*, 5(6), 577-581.
- Kim, C. S., Spahlinger, D. A., Kin, J. M., & Billi, J. E. (2006). Lean health care: what can hospitals learn from a world-class automaker? *J Hosp Med*, 1(3), 191-199. doi:10.1002/jhm.68
- King, A, Lavand, D, Nicholson, V, Ryan, C, St Denys, R , Thomas, J, . . . Alexander, K. (2019). Indigenous Harm Reduction = Reducing the Harms of Colonialism: Policy Brief. In: Canadian Aboriginal Aids Network (CAAN) & Interagency Coalition on AIDS and Development.
- King, M. (2011). Importance of “Two-Eyed Seeing”. Retrieved from
- Kluttz, Jenalee, Walker, Jude, & Walter, Pierre. (2020). Unsettling allyship, unlearning and learning towards decolonising solidarity In (Vol. 52, pp. 49-66): *Studies in the Education of Adults*.
- Kovach, M. (2012). *Indigenous Methodologies: Characteristics, Conversations, and Contexts*. Toronto: Universtiy of Toronto Press.
- Krusz, E, Davey, T, Wigginton, B, & Hall, N. (2020). What Contributions, if Any, Can Non-Indigenous Researchers Offer Toward Decolonizing Health Research? *Qualitative health research*, 30(2), 205-216.
- Larcombe, L, Mookherjee, N, Slater, J, Slivinski, C, Singer, M, Whaley, C, . . . Orr, P. (2012a). Vitamin D in a northern Canadian First Nation population: dietary intake, serum concentrations and functional gene polymorphisms. *PloSOne*, 7(11), e49872. doi:10.1371/journal.pone.0049872
- Larcombe, L, & Orr, P. (2007). Housing conditions which serve as risk factors for tuberculosis infection and disease. *Canadian Communicable Diseases Report*, 33.
- Larcombe, L, Orr, P, Lodge, A, Brown, J, Dembinski, I, Milligan, L, . . . Nickerson, P. (2008). Functional gene polymorphisms in Canadian Aboriginal populations with high rates of tuberculosis. *Journal of infectious Disease*, 198, 1175-1179.
- Larcombe, L., McLeod, A., Samuel, S., Samuel, J., Payne, M., Van Haute, S., . . . Orr, P. (2019). A Dene First Nation's community readiness assessment to take action against HIV/AIDS:

- a pilot project. *Int J Circumpolar Health*, 78(1), 1588092.
doi:10.1080/22423982.2019.1588092
- Larcombe, L., Orr, P., Turner-Brannen, E., Slivinski, C. R., Nickerson, P. W., & Mookherjee, N. (2012b). Effect of vitamin D supplementation on *Mycobacterium tuberculosis*-induced innate immune responses in a Canadian Dene First Nations cohort. *PloS one*, 7(7), e40692. doi:10.1371/journal.pone.0040692
- Larcombe, L., Rempel, J. D., Dembinski, I., Tinckam, K., Rigatto, C., & Nickerson, P. (2005). Differential cytokine genotype frequencies among Canadian Aboriginal and Caucasian populations. *Genes and immunity*, 6(2), 140-144. doi:DOI: 10.1038/sj.gene.6364157
- Layton, A., Moss, F., & Morgan, G. (1998). Mapping out the patient's journey: experiences of developing pathways of care. *Quality in Health Care*, 7 Suppl, S30-36.
- Manitoba Health Seniors and Active Living. (2016a). Annual Statistical Update: HIV and AIDS 2015. Retrieved from Winnipeg, MB:
<http://www.gov.mb.ca/health/publichealth/surveillance/hiv aids/docs/dec2015.pdf>
- Manitoba Health Seniors and Active Living. (2016b). Annual Statistical Update: HIV and AIDS 2015. In *Epidemiology & Surveillance Public Health Branch Public Health and Primary Health Care Division* (Ed.), *EpiReport*. Winnipeg, MB.
- Manitoba Health Seniors and Active Living. (2018a). 2016 Annual Statistical Update: HIV and AIDS. Retrieved from Winnipeg, Manitoba:
<https://www.gov.mb.ca/health/publichealth/surveillance/hiv aids/docs/dec2016.pdf>
- Manitoba Health Seniors and Active Living. (2018b). 2016 Annual Statistical Update: HIV and AIDS. In. Winnipeg, Manitoba.
- Manitoba HIV Program. (2016a). 2016 Manitoba HIV Program Update (May 2016). Retrieved from http://ninecircles.ca/wp-content/uploads/2017/07/2016-MHP-Update_FINAL_full2.pdf
- Manitoba HIV Program. (2016b). 2016 Manitoba HIV Program Update (May 2016). In.
- Manitoba HIV Program. (2019). 2018 Manitoba HIV Program Update. Retrieved from Winnipeg: https://ninecircles.ca/wp-content/uploads/2019/10/2018-Manitoba-HIV-Program-Report_final_opt.pdf
- Marshall, Albert, & Bartlett, Cheryl (2007). Two-Eyed Seeing.
<http://www.integrativescience.ca/uploads/articles/2010September-Marshall-Bartlett-Integrative-Science-Two-Eyed-Seeing-environment-sustainability-Aboriginal.pdf>
- Martin, Donna, Thompson, Shirley, Ballard, Myrle, & Linton, Janice. (2017). Two-eyed seeing in research and its absence in policy: Little Saskatchewan First Nation Elders'

- experiences of the 2011 flood and forced displacement. *The International Indigenous Policy Journal*, 8(4).
- McClarty, L. M., Cheuk, E., Ireland, L., Kendall, C., Bibeau, C., Loeppky, C., . . . Becker, M. (2020). Cohort profile: the LHIV-Manitoba clinical cohort of people living with HIV in Manitoba, Canada. *BMJ open*, 10(5), e034259. doi:10.1136/bmjopen-2019-034259
- McEldowry, R., & Connor, M. J. . (2011). Cultural safety as an ethic of care: A praxiological process. *Journal of Transcultural Nursing*, 22(4), 342–349.
- McGibbon, Elizabeth. (2018). Decolonizing health care: reconciliation roles and responsibilities for white settlers. *Women’s Health and Urban Life* 13(4).
- Nixon, S. A. (2019). The coin model of privilege and critical allyship: implications for health. *BMC public health*, 19(1), 1637. doi:10.1186/s12889-019-7884-9
- Oliver, S., Bosworth, A., Airoidi, M., Bunyan, H., Callum, A., Dixon, J., . . . Tanner, L. (2008). Exploring the healthcare journey of patients with rheumatoid arthritis: a mapping project - implications for practice. *Musculoskeletal Care*, 6(4), 247-266. doi:10.1002/msc.139
- Plitt, S. S., Mihalicz, D., Singh, A. E., Jayaraman, G., Houston, S., & Lee, B. E. (2009). Time to testing and accessing care among a population of newly diagnosed patients with HIV with a high proportion of Canadian Aboriginals, 1998-2003. *AIDS patient care and STDs*, 23(2), 93-99. doi:10.1089/apc.2007.0238
- Sevaldons, B. (2011). Giga-mapping: visualisation for complexity and systems thinking in design. Paper presented at the Nordic Design Research Conference, Helsinki.
- Sherwood, J., & Edwards, T. . (2006). Decolonization: A critical step for improving aboriginal health. *Contemporary Nurse*, 22(2), 178 – 190.
- Smith, J, Puckett, C, & Simon, W. (2016). Indigenous Allyship: an overview. Retrieved from http://www.wellbeingwaterloo.ca/blog/wp-content/uploads/2019/10/Indigenous_Allyship_Toolkit_inside_pages_10_5x8_5_PRINT.pdf
- Smith, Jackson, Puckett, Cassandra, & Simon, Wendy. Indigenous Allyship: An Overview. In: Office of Aboriginal Initiatives, Wilfrid Laurier University.
- Steinhauer, D , & Lamouche, J. (2015). Miyo-pimatisiwin “A Good Path” Indigenous knowledges, languages, and traditions in education and health. . In M Greenwood, S de Leeuw, N Lindsay, & C Reading (Eds.), *Determinants of Indigenous Peoples Health in Canada Beyond the Social* (pp. 152-168). Toronto Canadian Scholars Press.
- Tallbear, K. (2014). Standing with and speaking as faith: a feminist-indigenous approach to inquiry. . In (Vol. 10, pp. N17). *Journal of Research Practice*.

- Tervalon, Melanie, & Murray-Garcia, Jann. (1998). Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. In (Vol. 9, pp. 117): *Journal of Health Care for the Poor and Underserved*.
- Thomas, R.A. (2005). Honouring the oral traditions of my ancestors through storytelling. In LA Brown & S Strega (Eds.), *Research as resistance: critical, Indigenous and anti-oppressive approaches*. Toronto: Canadian Scholar's Press.
- Thompson, L. H., Sochocki, M., Friesen, T., Bresler, K., Keynan, Y., Kasper, K., & Becker, M. (2012). Medical ward admissions among HIV-positive patients in Winnipeg, Canada, 2003-10. *Int J STD AIDS*, 23(4), 287-288. doi:10.1258/ijsa.2011.011309
- Treble, T. M., Hansi, N., Hydes, T., Smith, M. A., & Baker, M. (2010). Process mapping the patient journey: an introduction. *BMJ*, 341, c4078. doi:10.1136/bmj.c4078
- UNAIDS. (2016). 90-90-90 Treatment for All. Retrieved from <http://www.unaids.org/en/resources/909090>
- White, Bird D. . (2005). Foreword-Grand Chief Dennis White Bird. *Canadian journal of public health. Revue canadienne de sante publique*, 96(1), 5-6.
- Wilson, Shawn. (2008). *Research is ceremony: Indigenous research methods*. Halifax, N.S.: Fernwood Publishing.