The Changing Tide: Indigenizing Re-Search with Indigenous Women Living with HIV to Explore, Understand, and Support their Health and Well-Being

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Abstract

The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study – Positive Aboriginal Women (CHIWOS-PAW) actively Indigenizes and honours re-search by, with, and for Indigenous communities. In this study, as Indigenous and non-Indigenous researchers, we weave our ways of knowing and doing together on the Ancestral, Traditional, and stolen lands of the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh Úxwumixw (Squamish), səl̓ílwətaʔɬ təməxʷ (Tsleil-Waututh), S’ólh Télméxw (Stó:lō), and the Kwantlen Territories. We conceptualize ‘re-search’ as a cyclical journey that is not about ‘discovering’ new knowledge but designing a process to search for what is known, existing, and embodied by Mother Earth and our Ancestors. In this paper, we describe our process of using strengths-based approaches grounded in our connections with the Lands and Waters to explore how Indigenous Women living with HIV support their health and well-being by drawing upon Indigenous teachings and healing. Over the course of multiple gatherings conducted over 1 year with the same group of women, we utilized arts-based research methods, Indigenous teachings and ceremony, and Sharing Circles to collect and analyze women’s perspectives and experiences of their health and healthcare. The Wise Women were living in the Coast Salish Territories, yet came from different Communities, including Coast Salish, Cree, Blackfoot, and Navajo Nation. Our Indigenized re-search process was healing for the Wise Women who participated in the study and for us as the re-search team, which promoted re-connection to self, nature, and culture. We share insights on our learnings to support other community-based research teams to engage in re-search by, with, and for Indigenous Women that prioritizes safety, healing, and benefit for those who participate. Such insights include the importance of centering Indigenous Ways of Knowing, Ceremony, and Cultural Practices; changing re-search jargon to more inclusive and honouring language; and reaffirming commitment to Indigenous Communities.

Keywords

Community-based research, arts-based methods, focus groups, emancipatory research, social justice

Acknowledgement and Gratitude

We begin with an acknowledgement and gratitude for the Ancestral, Traditional, and stolen lands of the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh Úxwumixw (Squamish), səl̓ílwətaʔɬ təməxʷ (Tsleil-Waututh), S’ólh Télméxw (Stó:lō), and the Kwantlen Territories on which we are privileged to live, work, play, love, and especially learn from. We recognize the privileges that we hold as re-searchers, as uninvited settlers who occupy this land, and as Indigenous

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Peoples (Peters, 2020). We acknowledge a responsibility to do our work in a Good Way, and to honour the experiences of those who walked the land before us. In walking this road together, we must practice Allyship. ‘Allyship’ is not a title: Allyship is a gift that is given. Allyship is within our spirits, practiced every day, as we are ever learning and growing. In Allyship we honour each other’s cultures, worldviews, and have the courage to stand together. When we practice Allyship we build relationships with a foundation of respect and wisdom.

Coast Salish Lands, Waters, and Peoples have been here since the beginning of Time. We honour the Coast Salish for being the caretakers, knowledge gatherers, and keepers of medicines: medicines that were hidden from colonizers to keep them safe and protected. Today these medicines and knowledges are being remembered by Indigenous Peoples with the guidance and teachings of our Ancestors, Elders (past, present, and emerging), and children. We honour our teachers.

To honour this way of life is to go back to our first teachers: the Land, the Waters, and all of Nature including the four-legged, the finned ones, the winged ones, the slitherers and crawlers, the wind, rocks, mountains, and the Rooted Family (trees, plants, medicines, grasses). These are All Our Relations. We are all connected. Take time and sit with these first teachers and listen. Take time to re-connect and learn. Take time to understand that without the Lands, Waters, and All Our Relations, we would not be here. As our re-search team took the time to connect and re-connect with these first teachers, we opened the stranglehold that colonization had on our ways of learning and healing.

Through this paper we offer a history-telling of our journey in re-search together as Indigenous and settler researchers, as we work with an Indigenous Community of Women living with HIV in the Coast Salish Territories to support their health. From the beginning of our search for knowledge we worked, learned, grew, and un-learned together. We challenged the assumption that truth can only be found through Western positivist methodologies, and we wove our wisdoms and teachings together to create an Indigenous re-search process to explore and celebrate the strength of Indigenous Women living with HIV (The Feast Centre, 2021; Weaving Our Wisdoms, 2021). We have immeasurable gratitude to the Indigenous Women living with HIV who participated in the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study – Positive Aboriginal Women (CHIWOS-PAW): Wise Women who gifted us their teachings, histories, and learnings to share bravely and widely.

**Purpose:** Our purpose with this paper is to describe our approach to developing and implementing our Indigenized re-search process. In keeping with Indigenous protocol, we begin by identifying and introducing ourselves. This is our journey, and how our worldviews and perspectives shaped our research question and approaches. We begin by describing how Water Teachings informed the process of our re-search, and how sitting with this knowledge and these teachings created a foundation for a unique, safer, engaging, and healing process for Indigenous Women living with HIV. By connecting with the Lands, Waters, Traditional Medicines, and Cultural Teachings we developed an arts-based Indigenized re-search approach to recognize and honour the strength that flows from Indigenous Women living with HIV when connected with their Traditional Ways of Knowing. Guided by a connection to the Land, Waters, Medicines, and Teachings, and held in Ceremony with an Elder, Indigenous Leaders invited Indigenous Women living with HIV to participate in three Gatherings over the course of 1 year to connect, create collective and personal art, share reflections in Sharing Circles, and explore key learnings and teachings. We will take you on a journey of discussions on the successes, tensions, and challenges navigated by the re-search team: sharing our teachings for all those committed to Indigenizing re-search.

**Identifying ourselves:** “Everyone belongs to a tribe. And this is our tribe.” – Elder Sheila Nyman

We all have unique experiences, worldviews, and teachings that shape the way we understand and move through the world. Reflecting on our own worldviews throughout the re-search process is critical to ensure that re-search priorities are not being driven by purely academic pursuits and interests (Smith, 2012), but are driven by the interests and priorities of Indigenous Women living with HIV. Following Karina Walter’s Indigenist re-search principles, we start with a reflection on the privileges we carry to do this work (Walters et al., 2008), and how our interests and worldviews shape the re-search undertaken (Kovach, 2009).

The co-authorship team has been working for many years, on various re-search projects focused on the sexual and reproductive health and rights of women living with HIV (The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study [CHIWOS: www.chiwos.ca]; Women, ART, and the Criminalization of HIV Non-disclosure [WATCH: watchHIV.ca]; and the British Columbia CARMA CHIWOS Collaboration [BCC3: www.HIVEarMe.ca]). Coming to this project, we were familiar with each other, our working styles, and our strengths which guided our roles and responsibilities.

Valerie Nicholson is our Gatherer of Wisdoms. Kwe (hello). Talusi (my name is) Valerie. The name given to me 4 days after my birth is The One the Eagles Watch Over. I was gifted the name NoDe WenDa which means Wolf Eyes from a Dene family and have been gifted the name Auntie from the Torres Straight Islanders. I am Mi’kmaq, Haida, Roma, and UK Islander descent. I am a Mother and a Grandmother. I live with HIV.

Rebecca (Becky) Gormley was gifted the title Keeper of Wisdoms. Becky is the research coordinator of the CHIWOS PAW project and graduated from a Master of Public Health program at Simon Fraser University. She is a settler and uninvited guest on the Lands of the Coasts Salish, who constantly works to practice allyship in a Good Way.
Debbie Cardinal is our Gatherer of Wisdoms and Facilitator. Debbie is a Cree woman living with HIV. As an Indigenous Woman, Debbie is deeply invested in creating better programming, policies, care, and lives for other Indigenous Women.

Elder Sheila Nyman is our Protector and Guide. Elder Sheila is a Syilx Metis woman from the Lower Similkameen in the Okanagan Valley, who began her work with women living with HIV as the former Executive Director of New Dawn, New Day, and New Way Recovery homes during the mid-90s. She continues to use her skills as an Elder with traditional healing training and as a Master’s level Clinical Social Worker, providing support to women living with HIV. She integrates western and Indigenous models of healing strategies and the wisdom she learned over many years of working with women, Indigenous People, and HIV research projects. She held us together in ceremony and safety, and grounds us throughout the research journey.

Angela Kaida was gifted the title of Gatherer of Wisdoms. She is an immigrant settler from East Africa who now resides on unceded Coast Salish territories. Angela is an epidemiologist by training and holds a Canada Research Chair at Simon Fraser University. Her global research program centers on unceded Coast Salish territories. Angela is an epidemiologist by training and holds a Canada Research Chair at Simon Fraser University. Her global research program centers on a rights-based, evidence-informed, and community-driven approach to sexual and reproductive health among women and youth affected by HIV. Angela practices active allyship with women living with HIV.

The Teachings that Came Before Us

We begin with the words of a Wise Woman, an Indigenous Woman living with HIV who participated in the CHIWOSSPAW study:

“Trying to get proper treatment as an Aboriginal Woman, it’s an uphill struggle. It’s a constant, constant. But if you fall down, or if you give up, you fall down, you hit rock bottom. I’ve been there. So, it’s a constant uphill battle.”

Indigenous People have been the focus of Western research for decades; and not necessarily to their benefit. Much of this research has been done “on” rather than “with” or “for” Indigenous Communities across the Land Between the Coast Waters known as North America (MacDonald et al., 2014; Mosby, 2013; Ninomiya & Pollock, 2017; Pacheco et al., 2013), driven by priorities and methods of academics seeking to extract and own knowledge (Smith, 2012). In Western research, Indigenous Knowledge and Experiences are considered to be an abstract idea: something to study, rather than recognized as a way of life (Harris, 2002). Much of this research highlights disparities among Indigenous Communities without contributing to substantial change in these inequities. Indigenous People continue to be under-served in the Canadian healthcare system (Fontaine, 2005; Peiris et al., 2008) due to a lack of culturally safe and appropriate programming (Fontaine, 2005), a paternalistic “patient-provider” relationship (Browne & Fiske, 2001; Browne, 2007; Bucharski et al., 2006; Wang et al., 2012), and mistrust in the healthcare system rooted in experiences of colonialism, discrimination, and racism (McCall et al., 2009).

Indigenous People are over-represented among people living with HIV in Canada. According to 2018 national HIV estimates, 14% of all new HIV diagnoses are among Indigenous Peoples, despite comprising only 4.9% of the total Canadian population (Public Health Agency of Canada, 2020). There is significant variation of race or ethnicity among people living with HIV by sex – among males, 16.3% are Indigenous; and among females 30.9% are Indigenous (Public Health Agency of Canada, 2020). These patterns are profoundly important, as the experience of living with HIV differs by sex and gender, and is shaped by experiences of racism, sexism, criminalization, violence, poverty, stigma, and discrimination.

In Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls, testimony from survivors of violence and their family members highlighted how intergenerational trauma shapes experiences of structural and societal marginalization in the form of “poverty, insecure housing or houselessness, and barriers to education, employment, healthcare, and cultural support” (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). Importantly, attempts at forced assimilation including residential schools and the Sixties Scoop, and ongoing impacts of intergenerational trauma work to deny Indigenous Women their traditional roles in community (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). In British Columbia, the racism and discrimination within the provincial healthcare system was highlighted in a report commissioned by the Ministry of Health. In Plain Sight highlighted unique impacts on Indigenous Women, who carry the burden of Indigenous-specific racism as life-givers (i.e., assumptions of being a ‘bad parent’ and having to navigate the child welfare system), taking care of communities and families who experience racism, and reporting frequent feelings of unsafety (Turpel-Lafond, 2020). These feelings of unsafety, of receiving inappropriate and at times harmful care, translate into poorer health outcomes.

A health equity approach calls for enhanced understanding of the needs and priorities of women living with HIV, in all their diversity, and in all their strengths. This begins with listening to Indigenous Women living with HIV to explore how they understand health, and their experiences accessing healthcare. As another Wise Woman shared:

“I understand what residential[school], adoption, Sixties Scoop [are]. I really have closure now. And to me my past, for me my life now is to walk it with cedar. To walk the lands, and teach, and heal, and vision, and write. I know what my future is.”
Our team was aware of the deficit-based approach commonly used to examine health outcomes of Indigenous Women living with HIV, and knew that we had to do something different.

It is with this understanding that we began the CHIWOS-PAW study. CHIWOS-PAW is a sub-study of CHIWOS: Canada’s largest community-based cohort study of self-identified women living with HIV (transgender and cisgender inclusive) (Loutfy et al., 2016, 2017). PAW stands for Positive Aboriginal Women and is a term gifted to us by Kecia Larkin. In British Columbia, CHIWOS-PAW is led by, with, and for Indigenous Women living with HIV, under the guidance of Valerie Nicholson and her Ancestors, and in Ceremony and safety with Elder Sheila Nyman. We aimed to understand how Indigenous Women living with HIV understand and experience their health through traditional ways of knowing through an Indigenousized approach, rooted in positivity.

Re-Finding Our Foundations

The Beaver Teaches Us Wisdoms

The beaver teaches wisdom. As great builders, they change their environment to build their lodge. The beaver teaches us to honour our knowledges and teachings of All Our Relations and to use them wisely and respectfully. This is wisdom.

As we began this work, we reflected on the recent “mad rush” to Indigenize re-search (Canada Research Coordinating Committee, 2019; Gaudry & Lorenz, 2018; Peters, 2020; Schmidt, 2019), which sits in conflict with the deep, deliberate, and difficult process of loosening the stranglehold of colonialism to authentically engage with other ways of knowing. The work of reforming, re-growing, and finding re-connection in Indigenous Ways of Knowing is not easy, fast, or obvious. Much learning, unlearning, and growing is needed to sit in this space by both Indigenous and non-Indigenous team members. Only once we re-connected with the Land and Waters and engaged in Ceremony did we have an opening to receive knowledge from the Ancestors, and through our bodies it moved downward like a root from our spirit to the Waters and Mother Earth. This connection with the Land, Waters, Ancestors, and medicines was pivotal to the foundation of this re-search project. To Indigenize our strengths-based re-search project, we embraced four Indigenous teachings: Teachings from Water, Art as Communication, Indigenizing Language, and Connection With the Land, On the Land, With the Waters.

Teachings from Water

Water connects us all: water is a living thing, a spiritual entity with life giving forces. The first relationship that we have is that with our life giver. We come from water. We were in water approximately eight to 10 months. Women are especially strong in spirit during their moon time as the moon cycles the waters. Water is one of the first medicines given to us by the Creator. Water is living, water is sacred, water is medicine.

Many Nations across the Land Between the Coast Waters believe the Earth to be their mother and the waters to be like the blood that runs in our veins. The oceans, streams, rivers, lakes, ponds, and seas provide life to everything on Mother Earth. The Assembly of First Nations honours water with the Spiritual Water Teaching that we can have great strength to transform even the tallest mountain while being soft, pliable, and flexible (Assembly of First Nations, n.d). A teaching from Valerie’s Grandfather was of the relationship between water and all living things. Creator made the water so all could have life. Creator also knew that some would not be able to find water, so Creator gave water movement. Water would find its own journey, take on different forms, have memory, and spirit. Thank you, Grandfather:

Art as Communication

Our first form of communication was drawing on cave walls, in the sand, or dirt. When we didn’t know someone else’s language, we used pictures. Art can offer an opportunity for people to share thoughts and perspectives that are difficult to express in words (Darley et al., 2007; Snyder, 1997), and at the same time enhance well-being by focusing on strengths (Puig et al., 2006). Many Indigenous Cultures rely on art to understand and conceptualize the world and oneself (Archibald & Dewar, 2010; Herring, 1997), and as a source of healing (Coholic et al., 2012; Wright et al., 2016).

Symbols, teachings, and colours, along with the seven sacred teachings of humility, courage, respect, love, wisdom, truth, and honesty informed our work in a Good Way. The visions and teachings gifted to Valerie Nicholson, the project lead, were carefully recorded using colours and symbols (see Figure 1), building over the course of a year.

Indigenizing Language

We began with de-constructing the word ‘research.’ In Western settings, research involves discovering ‘new’ knowledge: knowledge that can be observed, collected, and analyzed in an objective manner. The teachings Valerie received from Elder Sean from the Musqueam Lands is that we do not have ideas, concepts, or answers: they have always been there, put down by our Ancestors for us to pick up when needed. When we are ready, we search for them. That is why we call it re-search; we are re-searching for the knowledge as something that already exists and is laid down by Ancestors for us to discover (Absolon, 2011). This is captured by a teaching from Valerie’s Grandfather: Old knowledge, is new knowledge, to new people. Through processes of re-searching for this knowledge, we are guided by our Ancestors to look to Mother Earth and within ourselves, our Blood Memories, to
do our work in a meaningful way (Smith, 2012). Blood Memories speak to the teaching that histories and Ancestral Knowledge are present within each of us, connecting us to the teachings of our Ancestors (Lavallee, 2009). We all have the ability to tap into our Blood Memories and our Traditional Ways of Knowing, when we can go deep within ourselves and connect to Mother Earth and all that She holds.

Language connects us to Mother Earth through our work. We Indigenized our words to align with an Indigenous worldview (shown in Table 1). Language plays an important part in knowing how to unpack our own experiences, and research jargon can act as a ‘gatekeeper’, excluding people outside of the academy, as terms are often not intuitive (Chambers et al., 2018). Our team found that select terms also de-personalized the people from the research. For example, we chose not to call the women who participated in CHIWOS-PAW ‘participants.’ We found that referring to ‘participants’ stripped each woman of her complex and various social roles and identities. Instead, by embracing the language of ‘Wise Woman’, we centre her as a unique individual who is gifting us her knowledge.

**Connection With the Land, On the Land, With the Waters**

Re-search is ceremony (Wilson, 2008). When taking an Indigenized approach, the process itself is as important as the teachings that come from the re-search (Bartlett et al., 2007; Baskin, 2005; Kovach, 2009). To facilitate a deeper connection with Indigenous Ways of Knowing and Blood Memories, we did not aim to merely incorporate Indigenous Ways of Knowing into an existing re-search framework. We sought to create an Indigenized re-search process founded on Indigenous Protocols, Ways of Knowing, Doing, and Being (Bartlett et al., 2007; Smith, 2012).

Prioritizing activities to connect us with the Land, Waters, and all of our relational connections (Martin & Mirraboopa, 2003) was essential for both the re-search team and the Wise Women. The re-search process was grounded in Ceremony, building trusting relationships, and providing opportunities to connect with the Land and Waters, so women could reconnect their bond with Mother Earth, grounding us in Blood Memories and Ancestral Teachings. This also bonded us as a group, in a circle with healing energies and the power of Mother Earth. Being close to Traditional Medicines, Water, and having ample opportunity to be on the Land was especially important, as the main re-search questions were focused on Traditional Ways of Knowing, which are generally connected to the Land (Barwin et al., 2013; Robbins & Dewar, 2011).

**Conducting Re-Search on the Land, With the Land**

Our responsibility is to build the roads so others can travel them. In this section, we describe how we developed the CHIWOS-PAW study design and the facilitator’s guide in ceremony with our Elder, guided by community-based research principles, Water Teachings, and the teaching of interconnectedness and All My Relations, to honour the many teachings carried by the women invited to participate. We honour and understand that Survivors of the Sixties Scoop, residential schools, and attempts by the Canadian government to deny Indigenous Peoples their culture may not recognize
their ability to tap into Blood Memories and the Ancestral Teachings they carry. Our Ancestors guided us to incorporate teachings throughout our time together, and to create space for self-exploration and description of their own teachings and ways of knowing and doing.

Our CHIWOS-PAW Journey

Between December 2019 – March 2020, we aimed to gather four different times: (1) Introductory Gathering; (2) Sharing Circle Gathering; (3) Heart-to-Heart Gathering; 4) Community Gathering. Women were invited to participate in CHIWOS-PAW if they were Indigenous, self-identified as women (inclusive of cisgender, transgender, and gender diverse women), were living with HIV, and were living on the Coast Salish Territories. We circulated flyers and other recruitment material through online and personal and professional networks. Women who were interested in participating in the study connected with either the re-search coordinator or the Indigenous team lead to learn more. This initial conversation was used to determine eligibility to participate, to answer questions about the re-search process and what was expected, and for the re-search team to be able to prepare any supports needed to make women’s participation a good and comfortable experience. We received research ethics board approval from Simon Fraser University and the University of British Columbia/Providence Health (certificate number: H19-01682).

Our foundational strength was the trust and relationships that our Indigenous Team Members have in community. It was equally important for the settler study team members, who did not have many of these existing relationships, to prioritize establishing a safer space, building relationships with the Wise Women, and earning their trust. Therefore, we held the first Introductory Gathering to allow for brief introductions, share the different roles and responsibilities of the re-search team, what to expect at the Sharing Circle Gathering, and what to bring.

Next, six Indigenous Women living with HIV participating in CHIWOS-PAW and the re-search team attended a 4-day Sharing Circle Gathering at a retreat centre on Kwantlen and S’ólh Téméxw (Stó:lō) Lands (December 2019). During the Sharing Circle Gathering we conducted arts-based and qualitative data collection to answer the guiding CHIWOS-PAW question on how Indigenous Women living with HIV in the Coast Salish territories understand and support their health through Traditional Ways of Knowing. Each day started with Ceremony with all members of the Tribe, where eagles watched over us. Everyone stayed overnight, feasted together, and the Indigenous Team Leads led women through a series of arts-based activities, activities that connected us to the Land and Waters, and Sharing Circles. A medicine table was set up, which helped support our health, wellbeing, Ceremony, and connected with teachings that were being shared and explored (see Figure 2). The medicine table became a place of Gathering for women, who would share teachings of traditional medicines and how it supported their healing. Women were honoured for their expertise with $200 CAD.

The Sharing Circle Gathering focused on connecting with the Land and Waters, seeing oneself with Mother Earth, and reflected on how, as Indigenous Women living with HIV, they understood and experienced their health through Traditional Ways of Knowing. During this gathering, the Wise Women reflected on the following six questions using symbols, colours, imagery, and words to add their reflections to six prepared canvases representing different aspects of their health. Figure 3 shows the backgrounds of the six collective canvases upon which women added their Wisdoms. The numbers on each canvas correspond with the question that was asked (ie. canvas 1 represents question 1; canvas 2 represents question 2; etc).

1. How do you use Indigenous medicines and ceremony in your health and healing? The significance of Indigenous medicines was displayed as Earth Medicines, rooted in the teaching of the seven colours.3
2. How would you love to vision your healthcare? Women’s vision for Indigenous Women living with HIV’s health was conceptualized as a fluid, healing, Water Medicine Wheel.
3. What bumps and falls did you experience in your healthcare? A waterfall represented challenges that women faced accessing healthcare.
4. What supported you to get through these bumps and falls? Canoes in a calm reflection pool represented supports that helped women navigate through their challenges.
5. Think of a symbol that represents your inner strength. Bear paw prints traversing a landscape represented how women drew upon their inner strengths and the courage of the bear to transform their healthcare.
6. Think of a message that you would like to share with healthcare providers. Using rivers as a symbol for
knowledge dissemination, women wrote messages to healthcare providers.

We came together in Sharing Circles throughout each of the four gathering days. Women were invited to share what they added to the canvas and take us through their journey and reflections. We audio-recorded each Sharing Circle with consent.

The last full day of the Sharing Circle Gathering was dedicated to each woman’s personal journey. Each woman was given her own blank canvas to reflect on four over-arching questions:

1. Think about your own health and healing: when you feel good, when you feel healthy, what does that look like? What supported you to feel like that?
2. How have your traditional or spiritual beliefs or cultural practices played a role in your health and healing?
3. What are you already doing that supports you? What do you need to support your traditional health and healing?
4. Creating a personal slogan: what do I tell myself to remind me of my strengths, my culture, and my traditions?

Old knowledge teaches us that when something is put down on paper, we don’t carry it anymore. We know that the paper and wood of the canvas came from a living tree: the paper is still living but in a different form and can take the burden of our negative experiences. Therefore, while women had these four questions to reflect on, it was up to them to decide if they wanted to respond to the questions. The women put their feelings, wisdoms, and histories onto their canvas, which became an extension of their hands and spirit. At the end of the day, women shared their personal journeys by walking us through their personal canvas in a Sharing Circle and were supported by an Indigenous Elder and the Indigenous Leads to take that deep journey and reflection within themselves. Women were also asked to reflect throughout the Sharing Circle Gathering on how different items in nature reflected their self, health, culture, and healthcare transformation.

The Sharing Circle Gathering ended with a closing celebration of the women. The re-search team organized a gallery of all the completed collective and individual canvases woven together to show the strength and community that was enriched over the Gathering (see Figure 4). Women were invited into the gallery with the sound of the drums, and sat in stillness taking in the art, imagery, symbols, and colours of the canvases; the emotional connection of the heart and spirit in the room; and the strength that they would take away from the
Gathering and the work that they had done. Each Tribe Member shared words to describe their journey and to reflect on the collective gallery. Our reflections transitioned into Safe Journeys Forward, and how to keep care going home after the retreat. Everyone shared a desire to reconnect, and to continue the healing work. The Tribe left with hope for the future, knowing that we would be meeting again.

Honouring Voices (Thematic Data Analysis)

After the Sharing Circle Gathering, the CHIWOS-PAW Tribe connected to honour the women’s voices (through data analysis) embedded in ceremony. Thematic analysis (Braun & Clarke, 2006) was led by the Indigenous Team Lead, the Peer Indigenous Research Associate, and the re-search coordinator. We met in person weekly, opening with a grounding and Indigenous songs to centre ourselves. Our analysis processes modelled the DEPICT model (Flicker & Nixon, 2015) and was framed with Karina Walters’ Indigenist Research Principles (Evans-Campbell et al., 2009). We immersed ourselves in the art and words of the Wise Women: reading each transcript out loud, we noted the wisdom and teachings that spoke to us, which were collected into streams and creeks of knowledge. We connected individual histories to the images on the collective and personal canvases. At the close of each day, we had a deep reflection on what we learned from the Wise Women and from each other. To leave the words and emotions of this work on the page, we held Ceremony which helped us to go home with a clear heart, spirit, mind, and body. The CHIWOS-PAW BC team came together periodically to review the streams of knowledge and reflect on the lessons learned together.

We planned to hold a Third Gathering with the Wise Women to come together and revisit their teachings and to close the first steps of this journey with ceremony and a feast. Due to COVID-19 public health advisories established in British Columbia in March 2020, we were not allowed to gather in person. We tried to adapt and hold this Gathering virtually but it was not to be. We were shown that a virtual gathering through technology was not our journey. Our Ancestors showed that this work must be done from the heart.

The Protection of the Land

Colonization actively strives to disenfranchise the voices and knowledge of Indigenous people. From study inception, we committed to centering what the women needed, most importantly their safety as they navigated complex topics around understanding and experiencing health. We grounded with the Land and Water as the foundation of our safety. All study processes and activities were rooted in Ceremony. The Kwantlen and S’ólh Téémxw (Stó:lō) Territories welcomed us, as visitors, to do our work on this Land. We opened each day with a smudge outside, connecting and reaffirming our knowledge of the relationship between the Land, Water, ourselves, our work, and each other: in reflection that we are all connected. Eagles were present and watching over the group throughout each smudge, which was a sign that we were doing this re-search in a Good Way.

Each morning, our Elder opened with All My Relations – the teaching that everything is connected, and we are all one. This teaching reminds us of our relationship with the Lands and Waters and everything on Mother Earth: the protection and medicine that it gifts us, and her strength and knowledge. It provides a space for us to connect with our Ancestors, and to gain strength and trust in ourselves – it prepares us for our work, and to share Knowledge and Teachings. It restores our weariness when we are depleted or unsure (Martin & Mirraboopa, 2003).

The importance of gathering and connecting as women was highlighted throughout our re-search. Space was intentionally created to encourage women’s safety, healing, and well-being,
including feasting together for every meal; taking breaks to dance; going for walks out in nature together; and holding movie nights at the end of a long day. It was important to gather and connect as women, and to honour and recognize the expertise of each Tribe member.

Heart-to-Heart Gathering

Like streams adapt to their environment, we adapted to host a series of individual ‘Heart-to-Heart Gathering’ conversations between each Wise Woman, the re-search coordinator, the Indigenous Team Lead, and the Indigenous Peer Research Associate. Heart-to-Hearts were held virtually in September 2020. Prior to each Heart-to-Heart, we mailed a package of medicines, tea, and study information to each woman to honour her knowledge. This individual connection, rooted in ceremony, provided a space for us to check in with each other, catch up on our lives, and reflect on our journey together at the Sharing Circle Gathering with a guided visual meditation. With each Wise Woman we reviewed the major streams of knowledge (themes) identified from the analysis to ensure that we captured their teachings appropriately and had a discussion to understand who needed to hear these teachings, to inform how to share the knowledge the women shared with us around the fire (knowledge translation).

Future Gatherings Around the Fire

We are changing the tide of re-search and have a responsibility to share our learnings with others so that they may join us on this journey. We have shared our process and Indigenized methodology through several virtual presentations (Nicholson et al., 2019), each rooted in Ceremony and Indigenous practice, to share what it means to be engaged in and experience Indigenous re-search. We developed an interactive methodology, as at the heart of Indigenized re-search is action and reflection. Presentation attendees were asked to reflect on the same questions that the Wise Women of CHIWOS-PAW reflected on at the Sharing Circle Gathering – sharing firsthand the importance of reflection on what you are asking the people participating in your study to do, and the importance of asking questions that matter. This built a connection between people who may not understand Indigenous medicines and Ceremony and seeing how it may fit in their own lives, practices, and ways of thinking. To date, we have shared this presentation with over 450 people. In May 2021, we held an arts-based, interactive, virtual presentation. This event, ‘The Tide Comes In’; Indigenizing Re-search to Explore How Indigenous Women living with HIV Understand and Support their Health focused on Indigenizing methodologies and processes, using art and the power of art-first and visual communication. Two Wise Women led virtual groups through the same questions that they once reflected on. This is Indigenized research in action, and by inviting the women to lead, we are widening the circle.

Teaching of the Trees: (A Discussion on what We Learned)

In many cultures, we make an offering to Mother Earth to honour her before we pick or take anything. This offering can be done in many ways: it can be a thank you prayer, putting down tobacco or hair, or medicines. Each culture carries their own traditions.

| The Trees are the Elders of the Earth.  
| Go to the forest or to the mountains and find a young tree.  
| Then find an old tree.  
| Spend time with each.  
| Sit by the young tree and listen to your thoughts.  
| Then move to an old tree and listen to your thoughts again.  
| Just being in the presence of an old tree, you will feel more calm.  
| Your thoughts will contain wisdom and your answers will be deeper.  
| Why is this so?  
| These old trees know more, have heard more, and are the Elders of the Earth.  
| We must ensure these trees live so we can learn from them.  
| My Creator, help me to protect the trees and listen to them.  

- A teaching from the Traditional Circle of Elders from Haida Gwaii, a lesson from the trees.

One morning during the Sharing Circle Gathering, we asked the women to go outside and find one old tree and one young tree to talk to in their own ceremony. After talking with the trees, the women were asked to find an item in nature that reflected their culture and their selves. As women learned from the trees, we reflect on what we learned from the Wise Women and Indigenizing the re-search process.

Indigenizing Re-Search is a Strengths-Based Approach

Indigenized re-search comes from a body of positivity and strength. It requires a shift away from deficit-focused re-search into the inner strength and power of each individual’s history, and a focus on being proud of who they are, their histories, and their culture (Chilisa et al., 2017). This does not mean that we can forget or neglect to explain the Canadian context of colonialism, and the ongoing traumas and violence that Indigenous Women and Indigenous Peoples experience; but calls us to recognize the strengths and
wisdoms of Indigenous Peoples who came before us, and those that are thriving and reclaiming their culture. One Wise Woman reflected on her journey:

“This is my world, and this is what keeps my foundation of all my journeys, of everything that has happened. Would I go back and change anything? No. Because that’s who I am today. All my teachings I would not have gotten if I changed one little thing.”

**Indigenizing Re-Search Requires Learning and Unlearning**

Water teaches us movement, relationships, and the importance of being adaptable to where we need to go. Just like water, we must adapt and change our approaches to re-search. We are all re-searchers coming from different backgrounds and experiences. Some of us are trained in Western-academic institutions. Much of this training teaches a particular format or method of approaching research questions, with a belief that knowledge is to be created, and that researchers stay somehow objective.

Doing re-search in a new way is not a straightforward process. It takes time, discussion, and a humbling reflection on the assumptions that you hold, and at times moving through spaces of discomfort before emerging with new ideas. It requires courage: courage to change engrained approaches and assumptions to what constitutes knowledge, and courage to stand up and question the practices of your colleagues. As others have noted, critiquing Western methodologies as the current standard is necessary - but not without its challenges. There are academic gatekeepers that will privilege Euro-Western methodologies and epistemologies, with certain underlying assumptions of what is “valid research” (Chambers et al., 2018). However, to Indigenize the re-search process and truly center Indigenous Worldviews, we must have new learnings on how re-search is to be done.

As outlined, we undertook a process of un-privileging traditional academic research paradigms to prioritize connection with the Lands and Waters, and to support the women participating in the re-search to guide the questions. Indigenizing re-search requires a legitimatization and recognition of all forms of knowledge – including Indigenous Knowledge, Blood Memories, and Ways of Knowing. There must be opportunities for Indigenous and non-Indigenous re-searchers to come together and work to create something new together (Chilisa et al., 2017; Datta, 2017). As we continue our work, we honour the Indigenous re-searchers who laid a foundation in Indigenizing re-search, creating and encouraging spaces for growth and collaboration (Absolon, 2011; Cajete, 2000; Kovach, 2009; Smith, 2012; Wilson, 2008).

**Indigenizing re-search takes time and care**

Building trusting and meaningful relationships take time and work. In many traditions, baskets are used to hold offerings and to collect from the land. During the Sharing Circle Gathering, each Wise Woman was gifted a basket woven by an Indigenous Elder by the Principal Investigator Angela at the beginning of the Gathering to gather and give thanks in a Good Way. This ceremony was guided by our Ancestors: it connected us, and we witnessed trust building.

The CHIWOS-PAW BC re-search team had worked together for several years on various projects before coming together for the CHIWOS-PAW project. This allowed for a deep trust to build, understanding each other’s strengths, communication styles, viewpoints, and histories: which created an environment whereby we could be open and honest with each other, voicing our concerns, and having frank and difficult conversations as we worked to challenge assumptions and create a new re-search methodology.

An Indigenist approach requires the attention, time, and effort to find ways that honour and support those who are participating. The re-search team had to prioritize earning the trust of the women who participated in the study, which was partly facilitated by having a series of Gatherings, and creating time to meet all together, feast together, learn from each other, and to create meaningful activities for all of us to engage in, and reflect on.

**Prioritize the safety of the women participating by intentionally building in the time needed to connect with the Land, Waters, and each other**

By prioritizing safety and wellbeing, women were unafraid to speak their histories and truths, and shared deeply with the re-search team. Our meaningful connections to the Land, Waters, Elders, Traditional Medicines, and respect for the wholistic and interconnected relationships provided a safe and loving experience for women to share deep experiences, and access memories, Blood Memories, and teachings to share their living experiences. We would not have had the same level of depth and commitment had we conducted a focus group within a Western, book-learned academic setting. In one of the Heart-to-Heart chats approximately 10 months after participating in CHIWOS-PAW, one woman shared how her participation continued shaping her life. Before, she was reluctant to share her name and story with others, including some family members. She noted that taking the time to connect with Mother Earth, and finding strength in medicines and ceremony, she was proud to be an Indigenous Woman living with HIV. She not only disclosed her HIV status to her family members, but requested that her real name, instead of her pseudonym, be attached to her artwork whenever shown. Research, when done as ceremony, can be healing.

**Indigenizing Re-Search is Action-Oriented**

As is central to principles of community-based re-search, action must be at the heart; and the women who participated and shared so intimately of themselves are first to guide the action and who needs to hear these histories.
Our Heart-to-Heart Chats provided the next steps of bringing teachings from CHIWOS-PAW home to community. Wise Women validated our findings, ensuring that we are sharing their priorities, and guiding us to who needed to hear these teachings, including their own healthcare providers and communities to know that they are not alone. As one Wise Woman shared: “We Will BE the Voice of Change” (see Figure 5).

This allowed us to direct our efforts in disseminating the knowledge at hand. As other re-searchers have noted, “data sets alone do not generate solutions” (Duarte et al., 2020). Indigenized Methodologies require that re-search is conducted according to Indigenous Protocols, and that the relationship between the Indigenous Communities and the re-search team does not end at the creation of a dataset or after “analysis.” It is not enough to describe the racism, discrimination, and oppression that Indigenous Women face; but to honour the voices there must be an active sharing back of the re-search teachings in a way that reaches and serves community by addressing priority issues (Held, 2019). Engaging women who participated in the study in the dissemination of the results not only provides paid opportunities for Indigenous Communities and the re-search team does not end at the creation of a dataset or after “analysis.” It is not enough to describe the racism, discrimination, and oppression that Indigenous Women face; but to honour the voices there must be an active sharing back of the re-search teachings in a way that reaches and serves community by addressing priority issues (Held, 2019).

Engaging women who participated in the study in the dissemination of the results not only provides paid opportunities for Indigenous Women living with HIV, but ensures that their voices are being heard in the manner they need it to be heard.

**Prioritize Indigenous Ways of Knowing and Knowledge**

Re-search must be guided by the ancient content of our Ancestral Teachings. Throughout this paper, we have described how we built re-search around an Indigenous Worldview. Rather than extracting data from ‘willing participants’ to create a universal truth or system of knowledge, the search for existing knowledge given by our Ancestors is focused on first connecting the self to family, Ancestors, community, and Mother Earth (Martin & Mirraboopa, 2003). This celebrated connection will then show us the knowledge that we are looking for.

Indigenous re-search must be led by Indigenous People. Everyone can Indigenize their re-search by acting in allyship with Indigenous Re-searchers, with Indigenous Re-searchers making decisions about the study process, methods, inviting Elders, and non-Indigenous re-searchers supporting in appropriate ways, bringing their knowledge. All members involved in re-search can immerse themselves in the teachings of Elders and Ceremony of the Lands, and interconnected.

This is our tribe. All my relations.

**Continuing to Learn and Grow: Limitations**

We undertook this re-search project as a small team with the learnings that we carried from our Ancestors, with the six Wise Women who participated in the study. The idea of a ‘pan-Indigenous’ reflection and teaching is not feasible – nor should generalizability be strived for. There cannot be a ‘unified’ story in the sense that different nations will have different teachings and truths. However, by naming and honoring the fact that there are many truths and teachings, we were able to take an approach of sharing wisdoms and building relationships rather than one of competing views or perceptions. We see this limitation as a strength in our study.

**Conclusion: Old Knowledge, is New Knowledge, to New People**

As water teaches us to be fluid and ever-changing, so must re-search shift to highlight the strength of Indigenous communities. Under Indigenous leadership, with the support of re-searchers practicing allyship, re-search can be transformative. This requires flexibility, adaptability, and reflexivity of all re-searchers to decolonize the re-search; and an embracing of Indigenous worldviews and full grounding of ceremony to Indigenize it. The Land and Waters has held and protected Ancestral teachings for so long, holding old knowledge to be shared with new people.

Water always balances itself, at any angle (see Figure 6). We came together as a balanced group of women; we were balanced in trust, respect, and value added to the team. We started as a group of re-searchers, some trained through academia, others trained through life experiences; but with equal weight given to all the knowledges we were bringing forward. As our circle grew and we embraced new team members and community, we changed like the ripple from a rock entering the water - yet with our new additions, we remained balanced and interconnected.

This is our tribe. All my relations.

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Notes
1. Throughout our project and this paper, we intentionally capitalize terms that are related to Indigenous Identity, Institutions, or Rights. For example, Indigenous Women living with HIV. This teaching is to show respect and to honour Indigenous Identity, Institutions, or Rights that, throughout Canadian history, were actively disrespected and denied.
2. A teaching received from Elders and Ancestors that Turtle Island isn’t recognized by all Indigenous Communities, and going back to our traditional ways we identify the Lands we live on as the Land Between the Coast Waters.
3. The teachings of the colours vary across our Indigenous Lands. These are from Elder Fred John from the Salish Lands. White represents Winter Seasons; Red represents New Beginnings and New Starts; Yellow represents Grandfather Sun and the Warmth of Summer; Black represents the Night, Stars, and Rest; Blue represents Water and Skies; Green represents the Trees and Grasses; and the Brown represents Earth.

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