



RADY FACULTY OF HEALTH SCIENCES

ONGOMIIZWIN –
INDIGENOUS INSTITUTE OF
HEALTH AND HEALING

The Urban Indigenous Health Research Gathering

A report documenting a gathering hosted in Winnipeg, Manitoba on urban
Indigenous research engagement

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**ONGOMIIZWIN –
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EXECUTIVE SUMMARY

Vision for the Urban Indigenous Health Research Gathering: The *Urban Indigenous Health Research Gathering* (UIHRG) was hosted in Winnipeg, Manitoba in 2018 to engage urban Indigenous people with a variety of perspectives and experiences to learn about engaging urban Indigenous communities in health research. The gathering was a result of ongoing discussions among Indigenous leadership at an institutional and community level that identified the lack of standards or frameworks guiding ethical engagement in health research with urban Indigenous communities in Manitoba. Several people were invited to establish an ongoing dialogue and participate in shared learning about urban Indigenous research engagement with a focus on Winnipeg as a source of wise practices. More importantly, the gathering was able to mobilize urban Indigenous perspectives on research engagement through the notion of the *Village*. The *Village* provides a promising opportunity for urban Indigenous communities to enact collective notions of Indigenous self-determination, sovereignty and community empowerment through health research.

Key Themes: Considering the voices, knowledge and wisdom of UIHRG attendees, five key themes were extracted and interpreted through locally developed or accepted frameworks. Themes include: 1) *relationship-building and relationship-strengthening*; 2) *community control and shared decision-making around meaningful outcomes*; 3) *respecting difference through centering Indigenous and local paradigms and voices*, 4) *intergenerational and interdisciplinary mentorship and capacity building*, and 5) *human-centered engagement*. The themes are elaborated further through a case study showcasing how Indigenous communities in Winnipeg have been meaningfully and successfully engaged in health research. While many pathways may be pursued to articulate guidelines supporting urban Indigenous health research engagement, two options are worthwhile to explore based on the UIHRG. These options involve organizing guidelines for urban Indigenous health research engagement either as part of a larger framework (such as the University of Manitoba Framework for Research Engagement with First Nations, Metis and Inuit Peoples) or as a separate framework existing on its own.

Conclusion: Through a review of the relevant knowledge-base on Indigenous research engagement and key themes from the UIHRG, a one-size-fits-all approach does not work nor is it relevant and acceptable. Rather, health research engagement among urban Indigenous communities must encourage that researchers walk alongside communities with one simple instruction: *nothing about us, without us*.

BACKGROUND & CONTEXT

A Vision for the Urban Indigenous Health Research Gathering

This report was written to understand and document *The Urban Indigenous Health Research Gathering* (UIHRG), which was a gathering hosted in Winnipeg, Manitoba in October, 2018.

The UIHRG was intended to engage researchers, organizations, knowledge keepers, elders, youth and funding agencies in discussions related to research ethics and engagement within urban Indigenous health research. It was born through ongoing discussions among Indigenous leadership at an institutional and community level about the lack of understanding on how to engage outsider and non-Indigenous university researchers in urban Indigenous health research. The report has been written for academic, organizational, and government audiences to understand and further engage in ongoing dialogue about urban Indigenous health research in Manitoba and the advancement of guidelines to support ethical, culturally safe and equity-promoting research engagement.

Given the recent establishment of *Ongomiizwin – Indigenous Institute of Health and Healing* – a leading institute focusing on Indigenous health research, education and service – it was recognized that while First Nations, Metis and Inuit health research engagement have been articulated by institutions and communities, no clear guidelines exist describing pathways for urban Indigenous communities in Manitoba. This absence is not reflective of a growing urban Indigenous population identifying urban centres as “*home*,” and increasing interest in urban Indigenous health research to close knowledge, policy and service gaps. Moreover, over the last 3 decades much work and wisdom under the leadership of Indigenous women, youth and elders in Winnipeg have facilitated a highly networked organizational environment with increasing levels of decision-making capacity to represent and oversee partnership-based research involving urban Indigenous communities.

This foundational work in Winnipeg has been carried out by what is known colloquially as the *Village*. The Village is a “*place where everything belongs, loves, and supports each other*” (described by Althea Guiboche of Got Bannock.¹ In the heart of Winnipeg, this imagined community is re-constructing a sense of cultural and political identity allowing Indigenous communities a means to assume local control and revitalize Indigenous lifeways in an urban centre. We hope readers approach perspectives shared in this report through the lens of the Village to understand how research engagement can be better conceptualized and understood based on an urban Manitoba perspective, with a focus on Winnipeg as a rich source of wise practices and lessons learned.

¹ Available at: available at: <https://www.youtube.com/watch?v=4LsH3sb0Vbc>

As recent recommendations to improve the health of First Nations, Inuit, Métis, and urban Indigenous communities are detailed by the Truth and Reconciliation Commission of Canada's (TRC) Calls to Action, they have stimulated discussions and actions across Canada including the development of regional and community specific engagement protocols. Accordingly, the UIHRG builds on previously developed health research engagement frameworks (*Framework for Research Engagement with First Nations, Metis and Inuit Peoples* available at:

https://umanitoba.ca/faculties/health_sciences/medicine/media/UofM_Framework_Report_web.pdf)

and relationships in Manitoba to progress the TRC Calls to Action in urban contexts.

Critical Indigenous Perspectives on Research Ethics

Research ethics generally refers to a collection of philosophies, theories, laws, concepts, procedures and practices used to govern the conduct and transmission of research involving human subjects. They constitute the moral and legal valuation of research to define what is right and wrong, good and bad, fair and unjust, and so on. Research ethics seek to ensure that processes of knowledge generation minimize harms and maximize benefits; respect human rights, dignity, privacy and autonomy; and encourage the fair distribution of benefits and risks [1]. The development and application of contemporary research ethics has predominantly taken place within an institutionalized context of Eurocentric² knowledge validation [2] often resulting in the marginalization of research ethics rooted in Indigenous values, ways of knowing and ways of being in relationship . The advancement of Indigenous research and science has in fact occurred for hundreds of generations. The institutional processes of marginalization have undervalued and delegitimized Indigenous knowledge systems, and thus have contributed to the historical and ongoing harm of Indigenous Peoples [3-7].

Globally, Indigenous perspectives on research ethics are rooted in diverse natural, social, cultural, spiritual and legal orders that are fundamentally different from dominant Eurocentric approaches (e.g. Kantianism, utilitarianism, biomedical ethics, etc.). Despite the diversity of Indigenous paradigms³, many share similar principles that prioritize relationality, wholism and equity [3-8]. In contrast to rule-based, procedural and top-down approaches informing contemporary research ethics, which are often carried out through university-based institutional research ethics boards (IREB) [9-11], relationship-

² *Eurocentrism* refers to a worldview centered on or biased towards European civilization, history, knowledge and ethics to the exclusion of non-Euro-American worldviews.

³ *Paradigms* refer to the different ways we understand, see, act and value the world. A research paradigm may include worldviews, perspectives, methodologies, methods, practices, and ethics through which knowledge is generated and interpreted.

based approaches position research ethics as an emergent process of negotiated and shifting relationships between people, institutions, nations, laws, and the natural and spiritual world. In other words, research ethics cannot be predetermined by institutional authorities based solely on universal standardized protocols and procedures that value “good” research. Rather, research ethics must be defined in practice through situational processes of relationship-building and relationship-strengthening with all our relations, both human and non-human, such as land, communities, animals, nature, sacred objects and sites, traditional knowledges, and past and future generations [6].

While procedural ethics differ in several ways compared to relational ethics, the latter focuses on the dynamic relationship between individual (e.g. participant) and communal rights (e.g. tribe or nation) underpinning many Indigenous paradigms and geopolitical jurisdictions where research is conducted and transmitted. Dominant Eurocentric paradigms typically favour individual rights and safeguards in the absence of communal rights. Consequently, an emphasis on individual rights has made discussions over research governance and decision-making, data stewardship, and intellectual property rights invisible at a communal level. This lack of attention toward communal rights has privileged non-Indigenous research investigators sponsored by institutions at the expense of community and tribal authorities [12, 13]. Accordingly, they have undermined the needs and aspirations of Indigenous Peoples to enact notions of self-determination, sovereignty and empowerment through research.

Furthermore, the historical and ongoing legacies of colonization, racism and marginalization have disempowered Indigenous knowledge systems and harmed Indigenous Peoples. Oftentimes harm has been reproduced by the very research itself [3-7, 12]. Those harmful research practices are captured with the well-known maxim among many Indigenous communities that is both figurative and literal: *“we’ve been researched to death”* [14]. Therefore, in light of Indigenous-led advocacy and decolonization efforts across settler nations, research ethics have sought to centre and engage with distinct yet converging processes beyond knowledge and evidence generation, including cultural revitalization, healing, restorative justice and reconciliation, collective empowerment, sovereignty, and self-determination [3-8]. Research ethics cannot be separated or removed from existing relationships and structures governing ethical conduct in communities and societies, such as individual, social, cultural, professional, spiritual and political ethics [15].

Despite the seemingly incommensurable aims of Indigenous and Eurocentric ways of knowing when

applied to research ethics, the possibility of creating an *ethical space*⁴ that brings different paradigms together has been proposed or proven useful in various contexts [16-24]. Although many case examples have successfully blended different ways of knowing when the continuity of trusting and reciprocal research relationships are achieved at an individual level, they are not immune to the bureaucratic and systemic challenges institutions create. As institutional processes and structures are founded on dominant Eurocentric ways of knowing, the existence of unequal power relations may unintentionally disempower and further marginalize Indigenous paradigms, even in the name of inclusion and empowerment [25-27]. Thus, research institutions that typically enforce guidelines and provide oversight must approach the inclusion of and partnership with Indigenous paradigms and communities respectfully and intentionally to neutralize institutional power imbalances.

First Nations, Inuit & Métis⁵ Health Research Ethics in Manitoba, Canada

In Canada, the past 40 years of Indigenous health research has witnessed a transformative shift through the development and application of national ethical guidelines. Changes are a result of harmful research practices that have served to exploit, misrepresent, pathologize and exotify First Nations, Inuit and Métis communities, thus causing a culture of mistrust toward research [28-30]. Alternative solutions have since been proposed at a national level through sustained advocacy to reconcile the unjust relationship between Canada and Indigenous Peoples. They have been mobilized through several initiatives including the *Royal Commission on Aboriginal Peoples* (1991-96); *First Nations and Inuit Regional Longitudinal Health Survey* (1997), which informed the development of the First Nations *Ownership, Control, Access and Possession (OCAP)* framework; *CIHR Guidelines for Health Research Involving Aboriginal People* (2007), and a number of various regional strategies and voices advising the development of national ethical guidelines [30-33].

By 2010, the second edition of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*⁶ introduced a new chapter titled “*Research Involving First Nations, Inuit and Métis Peoples of*

⁴ *Ethical Space* is a concept proposed by Roger Poole (1972) and applied to Indigenous research contexts by Willie Ermine to describe the in-between space where opposing and contradictory paradigms co-exist momentarily at a specific place and time. This space enables the management of cultural difference through the negotiation, refinement and mobilization of hybrid ways of knowing and doing research.

⁵ The report uses “*First Nations, Inuit and Métis*” to describe the Indigenous Peoples of Canada at a national level. They are 3 major constitutionally recognized Indigenous groups in Canada with diverse worldviews, knowledges, histories, cultures, languages, territories, and nationalities. In reference to Manitoba, “*First Nations, Metis and Inuit*” will be used to reflect the higher regional proportion and distinct history of *Metis* (without an acute accent).

⁶ A policy shared between three Canadian federal research funding agencies including the *Natural Sciences and Engineering Research Council of Canada* (NSERC), *Canadian Institutes of Health Research* (CIHR) and *Social Sciences and Humanities Research Council* (SSHRC). In 2014 the TCPS2 underwent minor revisions.

Canada.” Drawing from Indigenous, community-based and participatory research principles (see Figure 1 illustrating a *Continuum of community-based research*), the chapter understands ethical research engagement as more than respect for human subjects, concerns for welfare and justice, and informing participants about their rights during consent-seeking processes. The chapter encourages reciprocity throughout the research process to advance the priorities of Indigenous communities, produce knowledge that is beneficial to communities, encourage sufficient time for community participation and knowledge sharing, and offer mutual capacity building opportunities. These overarching yet open-ended guidelines are outlined to inform the implementation of research ethics protocols and procedures at a regional and community level across various provinces and territories [1, 34].

Regionally, Manitoba has been a leader in First Nations, Metis and Inuit health research. Manitoba’s involvement and contributions to Indigenous health research in Canada preceded national efforts to mobilize ethical guidelines based on relationships between medical doctors, health researchers, and Indigenous leadership. During the period between the late 1970s to early 1990s, medical doctors and health researchers through the *Northern Medical Unit* and *Northern Health Research Unit*⁷ observed cross-cultural challenges during the delivery of healthcare and use of questionable research approaches among Inuit and First Nations communities in Northern Manitoba and the Kivalliq Region⁸. These observed challenges included researchers imposing research agendas; intrusively entering communities without consent and interfering with everyday community life; withholding and misinterpreting findings; and the misuse and theft of data, traditional knowledge, and genetic and biological samples [35-37]. Their encounters with communities also occurred at a time when an increasing strength in political and grassroots Indigenous leadership emerged to advocate for and progressively mobilize models of self-governance across communities, including governance over healthcare and health research [35, 38].

Since the late 2000s, First Nations, Metis and Inuit bodies representing various communities across Manitoba have established formal institutional and community mechanisms to provide ethical review and oversight for researchers and organizations engaged in partnership-based health research with communities, advancing research practices across a continuum highlighted in Figure 1. National and

⁷ The *Northern Medical Unit* and *Northern Health Research Unit* are now positioned under *Ongomiizwin – Indigenous Institute of Health and Healing* at the University of Manitoba, and are referred to as *Ongomiizwin – Health Services* and *Ongomiizwin – Research*, respectively.

⁸ Metis groups were often excluded or made invisible through health research for various reasons including not self-identifying as Metis, limited capacities for Metis communities and organizations to assume research responsibilities, and erasure through ethical guidelines, funding envelopes and community engagement strategies that did not recognize or conflated Metis communities with First Nations.

regional efforts over the past 40 years have culminated in the development of Nanaandawewigamig's *First Nations Information Governance Centre*, Manitoba Metis Federation's *Health and Wellness Department*, Manitoba Inuit Association's *Health and Wellbeing Department*, and the University of Manitoba's *Framework for Research Engagement with First Nations, Metis and Inuit* [39].

Although health research ethical guidelines and oversight bodies in Manitoba have provided clarity on how researchers, organizations, funders and IREB can engage First Nations, Metis and Inuit, research engagement with urban communities has remained underdeveloped [40]. Research institutions and communities are unequipped to fully realize standards due to a lack of guidelines to deal with ever-changing geopolitical and cultural boundaries demarcating urban Indigenous communities. Consequently, ethical guidelines and review processes are not clearly articulated for communities with multiple authorities, unclear or absent political or representative bodies, and ambiguous jurisdictional boundaries. Challenges are further exacerbated by the general tendency of IREB to focus on risk and liability, thus treat research ethics and consent-seeking as discrete procedural practices separate from the research process itself to protect not only individuals, but more importantly, research institutions. In so doing, IREB are subject to privilege the data gathering phase of research unintentionally, where individual consent is typically obtained, without much emphasis across other phases (e.g. analysis and representation, knowledge translation, research aftercare, capacity building, etc.) [15].

Figure 1. *Continuum of community-based research (adapted)**

	Research in a community	Community-Based Research	Community-Based Participatory Research	
Defining the problem	Researcher identifies problem	Researcher identifies and aligns problem with community	Community works with researcher to identify problem	Community identifies problem
Degree of community engagement	Research <i>in</i> the community	Research <i>with/in</i> community as partial partner in some phases	Research <i>with</i> community as full partner in some phases	Research <i>with</i> community as full partner in all phases
Role of researcher	Collaborator with control over all decisions	Collaborator with control over most decisions	Collaborator and makes mutually agreeable decisions	Equal partner and equal decision- making power
Role of community leadership/organizer	Community organizers may assist; identify participants	Community organizers may assist; identify participants; serve in advisory capacity	Community organizers may assist, identify participants; serve in advisory capacity	Community leadership/ organizations are full partners with researchers
Role of community member	Community members as participants	Community members as participants	Community members as participants and researchers	Community members as participants and researchers
Capacity building & mentorship	Researchers gain skills	Researchers gain skills and some awareness of helping community develop skills	Researchers gain skills; work with the community to help build community capacity, particularly for data collection	Researcher and community work together to help build community capacity/ infrastructure toward research independence
Ownership, control, access & possession/ stewardship of data	Researcher owns data, controls research, and decides about use and dissemination of research results	Researcher owns data, controls research, and decide about use and dissemination of research results; community may help make minor decisions	Researcher owns raw data, but shares and verifies clean data with community; use and dissemination of data based on mutual decision	Researcher and community equally own, control, share, use and disseminate data and results

*Adapted from “*Practicing Community Engaged Research*” by Mary Anne McDonald (2009). Retrieved from <https://www.citiprogram.org/citidocuments/Duke%20Med/Practicing/comm-engaged-research-4.pdf>

Challenges & Opportunities within Urban Indigenous Research Contexts

Many policy reforms have been successful to ensure Indigenous Peoples’ rights are respected and honoured during research engagement. However, gaps in knowledge continue to persist. They are especially apparent in relation to communities that do not have clearly bounded jurisdictions or mechanisms to enforce ethical guidelines, such as urban, off-reserve and non-status communities in Canada [40]. Yet communities in urban contexts – more so than traditionally bounded Indigenous jurisdictions that have developed research and administrative capacities – are still expected to partner with researchers sponsored by universities or organizations to access funding through government

agencies. With a growing population of culturally diverse Indigenous people residing in urban contexts without any land-based or means of local control, researchers, communities, and institutional research bodies are left to navigate an ethically ambiguous landscape lacking much needed guidance and recourse to uphold individual and communal rights. However, 2 frameworks successfully adopted in various Canadian regions offer unique insights on urban Indigenous research engagement. They include the Ontario Federation of Indian Friendship Centres' (OFIFC) *USAI Research Framework* (2012) and the Urban Aboriginal Knowledge Network's (UAKN) *Urban Aboriginal Research Charter Template: A Guide to Building Research Relationships* (2016).

The USAI Research Framework highlights 4 principles including: *utility, self-voicing, access* and *inter-relationship* [41]. Drawing from the OFIFC's framework, the UAKN elaborated on those 4 principles to detail a total of 8 principles, including: *community-driven research, protection, ongoing consent, ownership and intellectual property rights, fairness, respect, honesty* and *community relevance and practicality* [42, 43]. These principles have been proposed to ensure ethical partnership-based and community-driven research occurs despite multiple authorities and ambiguous jurisdictional boundaries. Notwithstanding other rare examples of formalized urban Indigenous research engagement frameworks and initiatives (e.g. *Manitoba Research Alliance/Canadian Centre for Policy Alternatives*, which is an urban Indigenous funding partnership), a paucity of ethical guidelines and review bodies beyond one-time individual case examples are unavailable across settler countries witnessing increasing engagement in urban Indigenous research. With an emphasis on Canadian contexts, 10 overlapping areas that remain underexplored during urban Indigenous research engagement are detailed below.

1) Consultation, community access & decision-making

The point-of-access into many urban Indigenous communities may be difficult without clear boundaries on who represents the community of interest and who to consult when creating research agreements and agendas once a community is identified. No longer can we rely on essentializing pan-Indigenous assumptions to obscure the complexity of *community* during cross-cultural engagement. Rather, urban Indigenous communities of interest are often defined based on flexible membership or affiliation with *associational communities* focusing on the development or administration of specific health, social, cultural, educational and economic goods and services [44, 45]. In Canada, these may

include Friendship Centres⁹, service and advocacy organizations, community and cultural centres, clinics and hospitals, activist networks, collectives and families, elders' and health councils, or coalitions with specialized training and expertise. Among various associational communities, representation and decision-making authority may be more formalized and structured than in other cases [19, 41, 46-48]. However, the boundaries that constitute *community* should not be conflated with *community organizations*.

Nonetheless, boundaries of urban Indigenous communities appear more precise when understood as horizontal networks held together by multiple and shifting relationships across different places to enact collective identity, agency and empowerment. This understanding differs from fixed unitary structures from which the desires of homogenous communities are governed from the top-down over a geographically bounded area [49, 50]. But depending on the nature of the research (e.g. investigator-driven, policy or service-driven, community-driven), consultation with multiple authorities may hold varying and conflicting cultural, organizational and legal definitions of consultation, participation, communication, consent, accountability, and decision-making. However, successful research engagement with Indigenous communities has consistently demonstrated relationship-building with adequate time as a precursor to gaining community access, acceptance, and forging authentic research relationships based on co-learning, respect, trust, reciprocity, transparency and responsiveness to Indigenous values and community needs [51].

Additionally, research with urban Indigenous communities offers opportunities to deal with challenges to reconcile individual and communal rights, which may be experienced with culturally and geopolitically bounded communities, such as First Nations, where Indigenous political leadership and representation (i.e. communal rights) may not align with community membership or interests (i.e. individual rights) [52]. Indigenous groups such as women, youth, elders, people with disabilities, people who use drugs, and LGBTQAI2S, whose voices are often silenced by structures within and external to Indigenous communities, may seek alternative and unique mechanisms to secure leadership and representation in urban settings. These specific mechanisms would require an intersectionality-

⁹ Friendship Centres across Canada have become a default mechanism to engage urban Indigenous communities in research. They were developed in the 1950s to fill service gaps for Indigenous communities (primarily First Nations and Metis) migrating from traditional territories as a result of displacement, enfranchisement, and socioeconomic opportunities. However, in many instances Friendship Centres may not be the appropriate representative or may not reflect the needs of urban Indigenous communities. Due to organizational priorities and challenges, the *Indian and Metis Friendship Centre* in Winnipeg is no longer central to meeting the needs of urban Indigenous communities. Rather, they work alongside a number of other Indigenous-led organizations engaged with various federal, provincial, municipal, First Nations and Metis jurisdictions.

based approach to address multiple forms of oppression at the level of inclusion, representation and decision-making.

2) Institutional & community ethical review

Many urban Indigenous jurisdictions do not have community-based ethical review bodies to enforce ethical guidelines and provide ethical oversight. Community and local ethics review bodies are able to ensure community values, needs and methodologies are prioritized, and they offer another level of cultural safety to uphold communal and individual rights. As a result, partnership-based research projects must rely on university IREB or other mainstream institutional review bodies without Indigenous or local community representation [53]. These review bodies typically do not have the capacity or knowledge to interpret agreements, plans and study designs reflecting the complex relationships that exist among Indigenous communities [46]. However, a variety of structures and processes are developed on a project-by-project basis to fill this ethical review gap whereby community partners play the dual role of reviewing research ethics proposal for institutional review and providing ongoing research oversight and decision-making to support daily research activities. These may include steering or advisory committees and boards; research councils, panels and juries; and culture-based structures and processes (e.g. elders, kinship networks, ceremonies and rituals, etc.) [17, 22, 46, 54-58].

3) Intellectual property rights & data management

It is widely understood that principles respecting community ownership and stewardship over data are essential within Indigenous research contexts, such as OCAP/S (Ownership, Control, Access, Possession/Stewardship) in Canada [59]. Although individual participant rights are often prioritized by IREB, the role of communal rights is becoming more recognized by ethical review bodies. However, the mechanisms to operationalize these principles among urban Indigenous communities become progressively difficult when multiple authorities are involved without clear guidelines; research protocols are culturally heterogeneous; individual and communal rights conflict; and the stewardship or possession over data requires ongoing managerial capacities and resources [40, 46, 52, 53, 58].

Furthermore, these challenges vary between quantitative (e.g. survey data, administrative data, etc.) and qualitative approaches (e.g. interview/focus group data, field notes, photovoice, etc.). Analyzing disaggregated data from quantitative datasets may require multiple authorities to govern access. In many cases, it remains unclear whether data collected on urban Indigenous residents at a provincial, municipal and academic level in metropolitan jurisdictions is owned by government agencies, tribal

authorities of origin, or other research institutions [40, 58]. Data derived from qualitative datasets may be silenced or misinterpreted at a communal level, thus undermining individual participant rights [60]. Moreover, these challenges using quantitative and qualitative approaches may become progressively complex with methodologies that incorporate online data sources, interventions and evaluations, or traditional and sacred knowledge [60-63].

Regarding traditional or sacred knowledge (e.g. stories, teachings, ceremonies, medicinal knowledge, etc.), they may require alternative authorities to guide decisions over ownership and stewardship separate from political leadership. Intellectual property rights may be vested individually or communally among elders, knowledge keepers, traditional healers or other cultural authorities [60]. Such processes may be difficult to interpret in urban contexts given the dispersion of culturally heterogeneous authorities and protocols.

4) Data gathering, storytelling & consent-seeking

The ethics of data and information gathering, which are pointedly emphasized through IREB consent-seeking procedures and approvals, can be difficult to interpret as multiple cultural and institutional definitions of collective and individual consent, anonymity, confidentiality, and even what constitutes data exist. While free, prior and informed consent at an individual and communal level are becoming considered a standard research practice when engaging Indigenous communities in partnership-based research, interpretations may differ across various cultural contexts. Interpretations may include: research agreements vs. ceremonies and rituals; written consent vs. oral consent; one-time consent-seeking guided by procedural approaches vs. ongoing consent-seeking guided by relational approaches; use of consent forms vs. exchange of gifts or ceremonial offerings (e.g. tobacco among many First Nations and Metis); and considerations on what constitutes accessible language and meaningful information sharing during consent-seeking processes [22, 60, 64-67]. However, obtaining informed consent from individuals and communities ultimately requires community direction and negotiation in many cases to respond to and respect unique cultural protocols [67]. Consent-seeking processes are further complicated by storytelling and oral traditions found in many Indigenous communities, which may require additional protocols to ensure participants are safeguarded from emotional distress, data is collected and interpreted by appropriate facilitators, and whether to record and document stories in written form [20, 68].

5) Analysis & representation

Although the ethics of data analysis and representation are not given as much attention as the data

gathering phase during ethical review, they have unique implications for urban Indigenous communities. In addition to deficit-based representations through research and news media that have stereotyped and historically justified marginalizing practices of state-sponsored intervention and interference into Indigenous communities, research on urban Indigenous identities has problematically positioned urban communities as 'out of place,' homogenous, or invisible within larger cosmopolitan communities living in urban centres [69, 70]. Exclusion from research or practices of pan-indigenizing urban communities has failed to produce positive strength-based conceptions of urban Indigenous identities. Positive conceptions are able to adequately interrogate systemic challenges creating service and policy gaps while showcasing the distinctive ways urban communities are revitalizing cultural lifeways to support health and wellbeing [70].

6) Knowledge sharing & translation

Knowledge sharing and translation among research partners is a vital stage of the research process when knowledge is translated into the development and evaluation of policies and service provisions, and the scaling up of interventions [71, 72]. Knowledge sharing within Indigenous contexts prioritizes integrated knowledge translation throughout research processes; diverse and accessible knowledges; multi-directional knowledge exchange that equally privileges expert and local voices; and the translation of useful evidence into real-time responses and actions [72, 73] Ultimately, knowledge generation cannot be separated from the application of knowledge. Although similar challenges involving knowledge translation, exchange and action are shared between urban and other Indigenous jurisdictions, partnership-based research in urban contexts may need to take extra precautions to allow for the translation of knowledge given ambiguous boundaries defining community, community-based authorities, and shifting organizational structures and processes described elsewhere in this section (see *Capacity building & mentorship; Research aftercare & nurturing partnerships*). However, with the closer proximity between urban communities and institutions engaged in policy and service development, the uptake of research in urban contexts may be better leveraged in a timely manner.

7) Capacity building & mentorship

Capacity building and mentorship are important community-based research principles widely adopted within Indigenous research contexts. They support insider-focused methodologies¹⁰, ongoing consent-

¹⁰ Insider-focused methodologies are approaches to research that privilege the voices and involvement of researchers originally from or situated in research communities of interest with specialized forms of explicit and implicit local knowledge on a specific topic or issue. Ideally, they are able to generate valid, unbiased and authentic knowledge that is contextualized, relevant, reflexive and sensitive to communities [3].

seeking practices, employment opportunities, and self-determination through research. Practices of capacity building and mentorship centre on training community-based research assistant to carry out day-to-day research and knowledge translation activities; enhancing community-based decision-making structures, processes, and administrative capacities; adapting institutional structures and processes to align with community values and protocols; incorporating commitments to healing and cultural revitalization directly through research capacity building; and encouraging shared learning and mentorship at an institutional (e.g. ethical review bodies, funding agencies), community (e.g. leadership, community members, community-based researchers), and individual level (e.g. youth, students, independent research investigators) [53, 74, 75]. These efforts to build capacity may be hampered by challenges based on organizational retention and turnover; availability of community and human resources to assume research responsibilities; allowing institutions to govern the conduct of community-based research assistants; lack of Indigenous representation and tokenism; inadequate project timelines and resources to engage in training, mentorship and reflective practices; and institutional resistance to recognize and incorporate community protocols [76-79].

8) Research aftercare & nurturing partnerships

The appropriate closure of studies following research agreements or maintenance of relationships beyond a single research project is critical to ensure the research processes foster authentic research relationships. These relationships may take shape in a variety of ways through knowledge sharing, friendships, volunteering, advocacy, research consultancy, and building ongoing research programs or developing new partnerships. In urban Indigenous research contexts, they may be more difficult to achieve through formal organizational structures due to shifting priorities and limited mandates; funding constraints; changing community membership; and organizational turnover of leadership and staff that may not have a prior relationship with community members and/or existing research partners [78, 79]. Thus, nurturing sustainable relationships and partnerships become increasingly challenging to support research and capacity building opportunities. Yet there is a mounting need to generate evidence-based research among urban Indigenous communities that supports organizational program evaluations and decision-making, grant applications, and political claims and policy interventions. Long-term research engagement also presents an opportunity to complement employment and research-driven community involvement within community organizations in the face of cost containment interfering with the day-to-day delivery of organizational initiatives, programs and services [79].

9) Multi-sited & multi-jurisdictional research

The harmonization of ethical review processes across multi-sited and multi-jurisdictional research projects poses a number of logistical, administrative and cross-cultural challenges in Indigenous research contexts. Harmonized ethical review processes aims to streamline review processes to ensure efficiency, reduce costs, and prevent duplication. While the logical step has been to centralize ethical review structures and processes, centralization does not respect the diverse values and protocols of Indigenous communities that may be better interpreted through local and site-specific ethical review bodies. Across settler nations where national ethical guidelines exist to ensure community-specific research engagement with Indigenous communities, tensions may arise when attempting to harmonize multi-sited and multi-jurisdictional ethical review [80]. For urban Indigenous communities, these challenges may be particularly pronounced due to fluid definitions of community and the complexity of multiple partnerships despite close physical proximity [81].

10) Self-determination, sovereignty & community empowerment

The role research plays to enact collective understandings of Indigenous self-determination, sovereignty and empowerment are widely documented across settler nations whereby Indigenous communities are engaged in processes to decolonize communities and institutions [3, 8, 12, 18, 82]. These principles promote non-interference, autonomy and control over decisions, and bottom-up approaches. They honour urban Indigenous rights, voices, knowledges and histories, and provide a space to safely put culture-based methodologies into research practice. Yet without a land-base and perhaps a means of local control, insights and wise practices generated through urban research engagement become a vital part of wider societal actions to reconcile and transform historically unjust relationships between Indigenous Peoples and settler nations.

However, research engagement with Indigenous communities should not be uncritically applied to various contexts without considering how it may disempower communities. Research may off-load unexpected burdens onto communities while disproportionately benefitting non-Indigenous research partners sponsored by institutions such as universities and other organizations. The continued flow of these benefits may sustain the dominance of Eurocentric approaches regarding knowledge generation and validation. In turn, efforts toward Indigenous self-determination, sovereignty and empowerment can become displaced and threatened [83-85].

THE GATHERING

The Urban Indigenous Health Research Gathering

The Urban Indigenous Health Research Gathering (UIHRG) was hosted on October 19, 2018 in partnership with the *Ongomiizwin – Institute of Indigenous Health and Healing* and *Aboriginal Youth Opportunities (AYO)*. The UIHRG took place at the Indigenous Family Centre (IFC) located in the North End neighbourhood of Winnipeg, Manitoba. IFC is a non-profit, spiritual-based organization that primarily supports Indigenous families residing in the North End through various programs, initiatives and collaborations that honour and respect Indigenous histories, cultures and spiritualities. Invitations were sent to a number of researchers, organizations, knowledge keepers, elders and youth resulting in the attendance of 20 people. The UIHRG also provided a space for community members to drop-in and contribute their voices. The gathering was designed to hear the voices and gather wise practices of people involved in First Nations, Metis, Inuit and urban Indigenous health research, and engage in dialogue with the Scientific Director of the Institute of Indigenous Peoples Health at the Canadian Institutes of Health Research. The gathering opened and closed with a prayer and wisdom shared by Ongomiizwin elder-in-residence, Margaret Lavallee. The gathering was carried out through talking circles to encourage shared dialogue, from which key themes related to urban Indigenous research engagement were extracted.

What did we learn?

“I invited him just to walk with me and see what life is like for me.”

–Jenna Wirch, community youth leader

The key themes from the UIHRG honour the knowledges, voices and wisdom of urban Indigenous communities in Winnipeg, past, present and future. The report interprets key themes and subthemes about urban Indigenous research engagement through three promising frameworks identified at the UIHRG, including 1) the *Circle of Courage*, 2) the *Merchant’s Corner Project Charter*, and 3) AYO’s *ARROWS Youth Engagement Strategy* (see Appendix A for more details). Below are five key themes detailing what we learned about urban Indigenous research engagement with UIHRG attendees.

1) Relationship-building and relationship-strengthening

We cannot begin research without a relationship!

An unequivocal response among attendees was that relationship-building prior to any undertaking in

research is essential. Building and strengthening relationships supports the creation of trust and accountability, which has been historically broken by outsider and non-Indigenous researchers, and mitigates research practices that could result in intrusion instead of collaboration and partnership. Attendees identified that relationship-building can take on many forms from volunteering, helping out, learning together, attending community gatherings, feasting, and doing fun activities. Relationships were not considered one-time events driven by institutional expectations to secure funding and generate evidence. It was pointed out that securing funding is not a strong determinant of gaining community access and shaping the success of a research project. Relationships are ongoing and genuine interactions grounded in shared interests, empathy and allyship¹¹. Relationships may last a life time beyond a research project or working relationship. In this sense, the process of building strong and trusting relationships is the most important outcome of any research engagement.

Absolute integrity and spiritual guidance

Through building and strengthening relationships to support research engagement, research was equated to ceremony by attendees. Before consultations, research agreements, research plans, and ethical protocols and reviews are fully realized, research must begin and continue to be a place of ceremony that requires collaborators to understand their intentions and respect the sacredness of relationships to living and non-living things, including people, laws, sacred medicines and places, and the natural and spiritual world. With absolute integrity devoid of insincerity and hypocrisy, both personally and professionally, outsider researchers should be able to maintain and honour the coherence of Indigenous and community values, and work in service to communities. Examples on how to ensure absolute integrity and seek spiritual guidance may include learning about the cultures, histories and struggles of Indigenous Peoples; receiving mentorship; participating in cultural safety training; and engaging in ceremonies guided by community partners (e.g. sweat lodges, pipe ceremonies, project naming ceremonies, and prayers).

2) Community control and shared decision-making around meaningful outcomes

Equitable research governance, community definition and representation

Community control over research and the research process was highlighted among attendees and demonstrated that communal rights are legitimate rights in urban centres. While notions of communal rights are not necessarily intended to govern the conduct of entire urban indigenous populations, their

¹¹ Allyship is an “active, consistent and arduous practice of unlearning and re-evaluating, in which a person in a position of privilege and power seeks to operate in solidarity with a marginalized group” (The Anti-Oppression Network: <https://theantioppressionnetwork.com/allyship/>).

recognition were part of efforts to ensure urban Indigenous people and communities are honoured and protected through research in urban settings.

Different definitions were shared on what community control over research meant ranging from advisory roles to developing sustainable decision-making capacities through partnership. Community authorities representing Indigenous leadership should be able to determine the level of their participation without interference, coercion and external expectations. Aspects of the research process that were emphasized included involvement in the identification of research topics, objectives and outcomes; study design development; ownership and stewardship over data, stories and traditional knowledge through OCAP/S principles; data and information gathering; and knowledge translation and sharing. It was identified that community involvement must also look beyond community advisory committee models to operationalize mechanisms for meaningful partnership and shared decision-making. These concerns were raised based on community authorities or representatives becoming burdened by advisory roles they already assume on many other boards and committees related and unrelated to research.

Attendees did not offer any rigid definitions of urban Indigenous communities that could provide clarity on who constitutes a community and who to consult. Rather, they approached community through an understanding of unity in diversity. The concept of the *Village* was used to describe the ever-changing boundaries of urban Indigenous communities that can facilitate research engagement in practical ways. The Village is a word used to describe an existing and diverse network of kinship and organizational ties between Indigenous-led service organizations, advocacy groups, collectives, families and residents in Winnipeg. It represents the historical and ongoing cultural presence of Indigenous people in Winnipeg's North End, and by extension, the inner city. The meanings attached to the Village (though not exclusively) are grounded in and mobilized through the Cree/Anishinaabe philosophy and teaching of *mino-pimatisiwin/mino-bimaadiziwin*, which generally translates to the *good life*. Through a networked understanding of community as flexible and multiplicitous, attendees were able to conceptualize representation with urban Indigenous people in more dispersed ways. Furthermore, drawing on an understanding of the Village can make outsider research engagement in urban centres easier to navigate and more accessible when determining the appropriate authorities to consult and make decisions.

Reciprocity & mutual benefit

There was an overall acceptance that research has often failed to mutually benefit communities and has

primarily served the interests of outsider researchers. Reciprocity and mutual benefit were identified as principles to support the similar and divergent needs and aspirations of urban Indigenous communities in relation to outsider researchers. It should be enacted throughout the research process by remaining responsible and accountable to the roles, duties and rights that communities and outsider researchers agree upon. Reciprocity can be enabled in many ways that may include gift-giving; acknowledging; celebrating; sharing results, data and stories; and providing equal employment and decision-making opportunities. However, reciprocity cannot be achieved simply by giving back based on what is expected at the outset, but reciprocity must be relevant and meaningful to emerging challenges and opportunities of those involved during the research process and beyond. This form of responsibility-based engagement to go above and beyond what is expected is vital to account for uncertainty and change leading to mutual benefit.

Knowledge must lead to meaningful action

Attendees pointed out that producing good evidence-based knowledge was not enough. They shared how processes of knowledge translation should be embedded throughout the research process to ensure research was transformed into tangible and meaningful actions and outcomes. Knowledge products should be produced in a variety of mediums that are accessible to diverse audiences. Many of the concerns facing urban Indigenous communities cannot rely on evidence that is generated once research projects are complete. They require real-time responses to deal with immediate challenges. They can be used to support policy and service development, community development, and the preservation of stories and traditional knowledge. In fact, attendees viewed research without action or producing no new knowledge within the community as unethical, and only serving the interests of outsider researchers. These insights shift how we think about the relationship between evidence and action from that of evidence-based practice to practice-based evidence. Knowledge is generated by ways of doing (i.e. practice-based) as opposed to ways of thinking (theory-based).

3) Respecting differences through centring Indigenous and local paradigms and voices

Avoid pan-Indigenizing and stereotyping

Through the stories shared by attendees it was apparent that urban Indigenous research engagement cannot be understood through the convenience of using a pan-Indigenous lens that obscures cultural diversity and leads to stereotyping. These practices were viewed as an impediment to progressing research relationships as they are unable to capture the complexity of community dynamics, and the unique needs and aspirations within urban Indigenous communities, and between non-Indigenous and Indigenous communities. Genuine cross-cultural collaboration will require the ability to respect

cultural differences and negotiating power relationships so that spaces of research and ceremony can be shared and cultural differences can co-exist. This twofold action can build new linkages and relationships within and across Indigenous and non-Indigenous communities that are collaborative and equitable.

Centring community-oriented worldviews, methodologies and ceremonies

It was widely acknowledged that all research should provide opportunities to centre local Indigenous worldviews, methodologies and ceremonies, if communities choose. The degree of their inclusion should be directed by elders, knowledge keepers or the relevant community authorities. Many attendees identified the general tendency for health research to privilege scientific and biomedical knowledge while delegitimizing and tokenizing Indigenous ways of knowing and lived experience. Scientific, biomedical, and even to an extent other Eurocentric social justice approaches may be irrelevant, damaging, inaccessible and alienating. While Medicine Wheel teachings, tobacco teachings and the concept of *mino-pimatisiwin/mino-bimaadiziwin* were generally acknowledged by attendees as widely acceptable and relevant to urban Indigenous communities, their utility may not reflect the diversity of Indigenous cultures, worldviews, methodologies and values. Furthermore, an emphasis on drawing from various concepts and values within Indigenous languages was highlighted as means to guide ethical research engagement.

Focusing on strengths, gifts and community assets

Many attendees reinforced the idea that health research should focus on individual and community strengths, gifts and assets when engaging with and representing communities. Many of the deficit-based narratives about urban Indigenous communities that are pervasive in health research may stigmatize and blame communities, and are often empirically inaccurate depictions. Urban communities were considered home for many attendees and negative portrayals served to be a sign of disrespect. They suggested that research would require researchers to shift their lens to measuring the positive and what is working instead of measuring the negative and what is not working. However, a strength-based shift on what is valued as “good” evidence is not intended to circumvent research revealing forms of structural and systemic oppression that create health inequities. Rather, health research should identify underlying sources of poor health and structural disadvantage while at the same time elevating the strengths and agency of communities.

4) Intergenerational and interdisciplinary mentorship and capacity building

Interdisciplinary research on health and wellness

Promoting health equity among urban Indigenous communities was broadly understood to encompass more than the clinical treatment of disease and behaviour change. Health research would necessitate a focus on the social determinants of health, health promotion and prevention, biomedicine, and especially important, Indigenous and traditional health knowledge. Attendees explained how Indigenous and traditional health knowledges have often been marginalized by the dominance of biomedical approaches. Thus, research should bring together interdisciplinary research teams and approaches with the capacity to undertake different forms of health and wellness research necessary to respond to complex health needs.

Training, employment & non-exploitation of intellectual labour

Building the capacity of urban Indigenous communities to fully undertake research in a meaningful way will require research training, skills development and mentorship, and investing in community members with lived experience and valuable gifts or skillsets. Given a context of extreme poverty, unemployment and social exclusion experienced among urban Indigenous communities, research was not simply viewed as an intellectual endeavour by attendees, but an economic one that can provide employment. Like outsider researchers who secure their careers and benefit financially from engaging in Indigenous research, attendees mentioned how these employment opportunities should be redistributed to value the intellectual labour and contributions of urban Indigenous communities. In so doing, research can refrain from reproducing economically exploitive community-researcher relationships.

The place of youth and elders

The involvement of youth and elders was identified as an essential component of research in urban Indigenous communities to foster intergenerational relationships leading to the transmission of knowledge. It was suggested that the roles and responsibilities of youth and elders should not be marginalized or tokenized, but meaningfully embedded and supported throughout research projects. On the one hand, the importance of elders as keepers of knowledge should be elevated through research to validate and transmit knowledge to the community at large. On the other hand, it was recognized that many youth do not understand their own culture, history and identity. They should be given the opportunity through research to learn about themselves instead of having research conducted by outsiders to define who they are. From this perspective, research becomes a site for healing, self-determination, and reclaiming a sense of self, family and culture through belonging and co-learning.

5) Human-centred engagement

Engaging as a human first

The nature of engagement was viewed by attendees not as a transactional event, but an evolving relationship where communities and researchers engage as humans first before the establishment of professional boundaries that may create emotional distance. Engagement should not come from a place of paternalism, humanitarianism and/ or elitism. In such instances engagement may appear disingenuous, suspicious or dehumanizing to communities. Rather, engagement on a human level should come from a place of genuine interest and shared understanding. For example, attendees identified the use of humour as one important way to facilitate human-centred engagement within Indigenous contexts. In light of historical and ongoing colonial violence experienced by Indigenous communities, humour can offer a shared position for communities and researchers to critique this violence (and that perpetuated through research processes) while lifting up each other's spirits. Humour is not intended to cause offence or undermine community hardships, but when deployed in the appropriate situations during engagement, can elevate our understanding of one another and ease tensions that may be intensified within the racist contexts health research often operate.

Humility and reflexive practices

The teaching of humility was expressed by attendees to describe researcher engagement with communities. Humility referred to a practice of self-reflection ensuring outsider researchers are comfortable with not knowing or being experts, and unlearning ones taken-for-granted role as an outsider researcher. It requires researchers to be modest, patient and welcoming to the realities and knowledge of communities engaged in research. Humility allows us to maintain equality with all life and ways of knowing. However, attendees explained that it is not enough to be a well-intentioned or even a thoughtful and sensitive researcher. They understood humility as something non-Indigenous researchers, especially, must act on once they have re-learned with communities. These responsibilities are part of larger efforts to reconcile unequal relationships between Indigenous Peoples and Settler Canada. Humility can mean working toward changing institutional policies and practices to better reflect communities; helping communities take up space in research institutions if they choose; nurturing long-term partnerships to ensure actions and positive health outcomes are realized; directing resources to and building neighbourhood and organizational capacity; or continuing to volunteer with and mentor communities.

Welcoming outsiders into communities

Following the previous theme, attendees highlighted the ways in which communities can be very

welcoming and accommodating to outsider researchers. It was understood that in order for outsider researchers to build strong and trusting relationships that require researcher presence in communities and collaboration, communities had to be welcoming. They pointed out how many urban Indigenous communities are actively ensuring community needs are met through require research. Many culturally diverse urban communities have to share public spaces in cities regardless if research is involved, thus the act of welcoming through research can foster positive Indigenous and non-Indigenous relations. Attendees explained how they have welcomed researchers into their community gatherings, initiatives, organizations, neighbourhoods, territories, and even their homes and ceremonies. Although human-centred engagement will have to be negotiated in various contexts to define personal and professional boundaries, human-centred engagement can only be truly successful if a strong relationship is established through friendship, allyship and empathy.

Case Study

Case Study: Aboriginal Youth Opportunities

Research Context: Case study 1 describes a community-based research project between a University of Manitoba graduate student and Aboriginal Youth Opportunities (AYO). The project investigated urban Indigenous youth engagement in health and wellness policy and programming decision-making processes. Although the research was student-driven, the project integrated Indigenous, community and participatory principles throughout the research process. As the project would only receive limited funding at the outset, partners did not prioritize funding as a precursor to engage in the research project but instead the strength of the relationship and a shared vision between partners. Yet sufficient funding was eventually secured through a community-based funding partner after the development of a research plan and agreement. Funders allowed for flexibility, community participation and co-learning, and entrusted research partners with the ability to allocate funds in culturally appropriate and community-relevant ways.

Organizational Profile: AYO is a self-defined and self-determining urban Indigenous-led youth collective of community volunteers and organizers that are unaffiliated with any First Nations, Metis, Inuit, or urban Indigenous-led organizations. AYO exists as a loose network of several initiatives, gatherings, groups, and programs through which participation and representation of Winnipeg's Indigenous inner city residents (primarily First Nations and Métis) are achieved in porous and relational ways. Community engagement processes extend beyond AYO to include the Village, which is an organizing concept to describe existing relationships between Indigenous-led collectives, organizations and residents working in Winnipeg's inner-city. AYO does not rely on fixed bureaucratic structures for participation, representation and administration, such as quorum, vetoing, boards of directors, administrative capacities and bank accounts, and organizational membership. Rather, through rotational leadership that centres Indigenous youth voices AYO prioritizes active participation and relevance over consensus. These flexible relationship-based approaches allowed for research partners to better negotiate emerging challenges that arose when balancing individual and collective consent, autonomy, degrees of participation and decision-making authority, and non-interference.

Community engagement: Relationship-building with AYO began after attending a community gathering. The student researcher continued to volunteer with other initiatives and community partners reciprocally contributed to class presentations of the student. During this time the possibility of conducting research became an ongoing discussion until a research partnership agreement was drafted and signed 11 months later. The research agreement outlined a research governance structure showing three parties: 1) Community Advisory Group, 2) Knowledge Exchange Network (KEN), and 3) university researchers. Despite the necessary steps to respect research agreements and institutional guidelines, over time more ambiguous forms of consent came to guide research engagement between the student and community partners based on the structure of the collective and research practicalities. However, ambiguous consent required more than the establishment of research agreements. It required exceptionally strong relationships based on friendship, high levels of participation and trust, and dedicated service to community beyond research activities.

Data gathering, analysis & knowledge translation: The research project involved a multi-method approach over 1 year of fieldwork (4 years of engagement in total) including semi-structured interviews, participant-observation, private document reviews, and news and social media analyses. These methods were defined and interpreted through a community lens and allowed for flexibility with Indigenous and local methodologies. Data required participant transcript reviews and final approval from community-based partners to release knowledge products. Knowledge translation activities included ongoing engagement and knowledge sharing with community partners, community presentations and feasts, organizational presentations, social media and online resources, and multimedia knowledge products contributing to the day-to-day community organizing of AYO. Alternatively, an agreement was made to share authorship through academic conferences, publications and reports. Throughout these processes the community was respected and honoured.

Capacity building & mentorship: Capacity building and mentorship occurred between the student, thesis committee supervisors, funders, administrative staff, and community partners and members. During the research process the student and community partners engaged in informal and formal mentorship to learn about research ethics, institutional review processes, research methods, community organizing, and knowledge translation. The research project also involved the creation of a KEN to build on the skills and gifts of young people. The KEN was involved in graphic design, video-making, and community and social media engagement to translate knowledge. Throughout the research process community partners and helpers were compensated through employment and honoraria. Shared learning also occurred among administrative and academic staff that were responsible for student oversight and the administration of funds when working with AYO's unique organizational structures and processes.

Research aftercare & nurturing partnerships: Nurturing relationships after the research project ended occurred in the form of co-presenting at community gatherings, conferences, and organizations; volunteering and contributing to community initiatives and gatherings through AYO; and establishing new working relationships and partnerships with university professors and faculties.

Advancing Urban Indigenous Research Engagement Guidelines

It appears that no single approach can be used to understand or carry out research with urban Indigenous communities. Despite the diversity of perspectives and experiences during the UIHRG,

several key themes capture shared concerns and guiding principles that might be used to advance the development of guidelines on urban Indigenous health research engagement in Manitoba, and Winnipeg more specifically. These themes relate to and elaborate on those found in the literature exploring Indigenous research engagement. Attendees did not explicitly refer to all the challenges and opportunities reviewed in this report, such as community and institutional ethical review, multi-sited and multi-jurisdictional research, and challenges working in organizational contexts that create inadequate conditions to foster sustainable partnerships. However, their voices enrich debates going on in various jurisdictions where urban Indigenous health research is being undertaken. Granted that research engagement guidelines may be mobilized in a number of ways, two options may be worthwhile to explore. Presently, these options involve organizing urban Indigenous health research engagement either as part of a larger framework (e.g. University of Manitoba's *Framework for Research Engagement with First Nations, Metis, and Inuit Peoples*) or as a separate framework existing on its own. Either way these options will have to operate within the larger context of health research in Manitoba.

NEW DIRECTIONS & EMERGING QUESTIONS

Based on a review of the relevant knowledge-base on Indigenous research engagement and themes from the UIHRG, there is an unequivocal and salient point to be made about engaging urban Indigenous communities in health research: there is no such thing as a one-size-fits-all approach. As Fast and Kovach (2009, p. 28) explain, "*the community-researcher relationship within urban Canadian Indigenous landscapes is complex and there is not necessarily agreement upon how best to approach questions of representation, voice and enactment of relationship in research*" [86] However, opportunities may exist to build on community strengths, innovation, collaboration and empowerment, such as the Village, which was born out of a cultural and political resurgence of urban Indigenous grassroots activism since Idle No More. It demonstrated how urban centres have become "*home*" to many individuals and families, and are intimately tied to the protection of land, water and culture, from which health and wellness flow [87].

Therefore closing research engagement gaps for Manitoba-based urban Indigenous communities should, at a minimum, facilitate partnership-based approaches; centre Indigenous and local paradigms and voices; enhance community capacity through training, employment, decision-making and administration; and promote social justice work supporting anti-colonial institutional engagement and structural change through healing and justice. This transformative shift may fundamentally rest on a paradoxical move to respect and honour cultural differences while simultaneously sharing ethical

spaces of interdependency and relational accountability that allow for co-existence and change [88].

Nonetheless, critics have cautioned us about the taken-for-granted and unquestionable good of health research engagement with Indigenous communities, which can in fact burden, disrupt and disable strategies to ensure self-determination and health equity among Indigenous Peoples [49, 79, 83-85, 89-92]. Such circumstances may create and re-inscribe inequitable power relations that disempower and threaten communities in material and experiential ways through the popular rhetoric of inclusion, empowerment and reconciliation. But as the Village reminded us during the UIHRG, when engaging urban Indigenous communities in health research, there is “*nothing about us, without us.*” Thus, in the final section, ethical questions are adapted from various sources in light of the UIHRG to begin reflecting on the challenges and opportunities of engaging urban Indigenous communities in health research in Manitoba [40, 42, 47]. We suggest that a starting point for ethical research engagement among urban Indigenous peoples and communities would entail individual researchers or research teams reflecting on the following questions.

Ethical Questions for Indigenous Health Research in Urban Contexts

1. What constitutes *research* in urban settings (e.g. investigator-driven, policy or service-driven, community-driven, etc.)?
2. What constitutes *health research* in urban setting (e.g. genetics, biomedicine, health promotion, health services, health policy, social determinants of health, etc.)?
3. Who constitutes the *community* in urban settings and specific to the research project in question?
4. How are individual and collective rights at the interface of urban, rural, remote, First Nations reserve and/or Metis jurisdictions negotiated in urban settings for the project in question? Do urban Indigenous people and/or organizations require consent from First Nations, Metis and Inuit authorities in *home communities* or communities associated with tribal membership or citizenship?
5. What are reasonable levels of trust, co-operation and accountability within urban Indigenous communities, and between urban non-Indigenous and Indigenous communities?
6. How is the cultural diversity of Indigenous people in urban settings accounted for in relation to *community consent*, and how do typically under-represented or disadvantaged groups ensure representation and involvement (e.g. women, youth, elders, people with disabilities, LGBTQAI2S, etc.)?

7. What do community consent and knowledge validation mean in urban contexts? Is it possible? How does it function?
8. What constitutes relevant and effective communication, knowledge translation, exchange and action in urban settings?
9. How are community or individual ownership and possession of data addressed when diverse communities of people, leadership, organizations and government agencies are involved?
10. Who can reasonably be involved in community reviews and evaluations of research protocols in urban settings?
11. Once community is defined, how are the relevant authorities within the community to be determined when multiple authorities may be involved?
12. What are the appropriate funding agencies that allocate funding to urban Indigenous health research, and how can these be established if none exist?
13. How do we conduct community-based training, mentorship and grant administration to build individual and collective research capacity in communities?
14. How do we build the capacity of research institutions (e.g. IREB, researchers, non-Indigenous urban organizations, health authorities) to understand and manage urban Indigenous research engagement?
15. What funding and engagement mechanisms are in place to establish ongoing community participation beyond on-time research projects, and how do we maintain sustainable working relationships with community leadership and representation given shifting authorities, priorities and staff turnover in urban settings?

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APPENDICES

Appendix A: Conceptual Frameworks to Guide the Interpretation of Key Themes

	DESCRIPTION	SOURCE
CIRCLE OF COURAGE MODEL	The <i>Circle of Courage Model</i> was developed by Martin Brokenleg and Larry Brendtro. The Circle of Courage is a model conceptualized through Indigenous philosophies and western psychology to support positive youth development and child rearing. The model critiques Eurocentric notions that understand positive development through coercion and discipline. Although the model applies to children and youth, it is grounded in fundamental principles that respect and nurture relationships with all humans as sacred beings. It has 4 principles including: 1) <i>the Spirit of Belonging</i> , the universal longing for human bonds is cultivated by relationships of trust so that the child can say, "I am loved;" 2) <i>the Spirit of Mastery</i> , the inborn thirst for learning is cultivated; by learning to cope with the world, the child can say, "I can succeed;" 3) <i>the Spirit of Independence</i> , free will is cultivated by responsibility so that the child can say, "I have power to make decisions;" and 4) <i>the Spirit of Generosity</i> , character is cultivated by concern for others so that the child can say, "I have a purpose for my life."	Brendtro, L. and Brokenleg, M. (2009). <i>Reclaiming youth at risk: Our hope for the future</i> . Bloomington: Solution Tree Press.
MERCHANTS CORNER PROJECT CHARTER	The <i>Merchants Corner Project Charter</i> was developed to guide the community redevelopment of the <i>Merchants Corner</i> in Winnipeg's North End. The building was constructed in 1913 and eventually became the <i>Merchant's Hotel</i> , which was a source of violence and pain for the North End community. The redevelopment began in 2012 when the hotel closed and opened in 2018. The charter outlines six principles including: 1) <i>co-operative connection</i> between groups and facilities in the community, and encourages collaborative partnerships that build on strengths and wellbeing of the community, 2) <i>mixed use</i> including residential, educational, retail and community components; 3) <i>sustainability</i> on all levels including economic, environmental, social and cultural; mindful of community wellness and spiritual wholeness toward the Seventh Generation; 4) <i>Community Economic Development</i> principles including developing local resources, an inclusive process, holism, collaboration and sustainability; 5) <i>intergenerational</i> opportunities for people of all ages and stages of life including elders, youth, adults, children and families; 6) <i>universally accessible</i> ensuring all facilities are universally accessible to all citizens.	Merchants Corner Inc. (2015). <i>Merchants Corner Update Report Back to the Stakeholders</i> . Winnipeg: Merchants Corner Inc.
ARROW YOUTH ENGAGEMENT STRATEGY	The <i>ARROWS Youth Engagement Strategy</i> was developed by community leaders Michael Champagne and Jenna Wirch in 2008, two years prior to the creation of AYO. With the voices and experiences of urban Indigenous youth living in Winnipeg, the relationship-based strategy primarily supports service provider to engage youth through service and program development. It was founded on the principles of the Winnipeg Urban Aboriginal Youth Strategy, <i>Oshki Annishinabe Nigaaniwak</i> (2007). The ARROWS strategy incorporates six principles to foster meaningful engagement beyond young people to include: 1) <i>accessibility</i> , 2) <i>resources</i> , 3) <i>relationships</i> , 4) <i>opportunities</i> , 5) <i>welcoming</i> , and 6) <i>support</i> . The most important principle holding processes of engagement together are the <i>relationships</i> people forge.	Champagne, M. & Wirch, J. (2010) <i>ARROWS Youth Engagement Strategy (Revised)</i> . Retrieved from https://www.ayomovement.com/arrows.html