

The Long Story of an Indigenous Health Research Project

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Abstract

Indigenous health inequities represent a significant challenge for health research and programming. The research seeking to address these inequities also faces significant challenges. To guide researchers through these challenges, several resources exist. That said, the real world of Indigenous research is complex and contains much that, as experience suggests, is not accounted for by the existing resources. Therefore, this article tells the full and honest story of conducting research within largely Western systems and the barriers they present to Indigenous community-based health research that respects self-determination, OCAP, CARE and FAIR principles, and culture. When relevant to discussion, examples are provided from a recently completed COVID-19 vaccine promotion research project. In telling this story, many questions are posed, some of these are tentatively answered, and many are left for contemplation and future work. When answers are provided, they often stem from personal experience, and so, conclusions should be approached cautiously. Regardless, prioritizing respectful and authentic relationships appears to be a universal compass that can guide researchers to *the good way*. Still, more consistent and honest reporting of barriers, failures, and opportunities may be needed to truly reflect the challenging realities of ethical Indigenous research.

Keywords: Health equity; Indigenous health research

Self-Location (Acknowledgements)

This article is written, at times, from my own experience as a non-Indigenous person working in the broad realm of Indigenous health research. At other times, the perspectives of Indigenous colleagues are presented. Throughout most of my education, I learned very little about Indigenous Peoples, colonization, or Indigenous health. Before learning of the contemporary state of Indigenous health and the tremendous injustice and lost potential that emerge from inequalities of social determinants, an interest in health

equity and global health had emerged for me. During my undergraduate education, one lecture concluded with a brief comment on boil water advisories in Canada. These two or three brief sentences, only just making their way into the lecture before the class ended, spurred me to look further, truly hoping that they were an exaggeration. The search for more context was eye-opening, making it clear that the same issues driving me toward global health also exist in the country that I call home. As I continued to learn of the inequities in my own backyard, pursuing a career in global health felt increasingly hypocritical. With new

understanding, I immediately followed my undergraduate degree with a Master of Public Health, specializing in Indigenous Peoples' Health.

During my master's degree studies, considerable time and energy was spent searching for answers to how, as a non-Indigenous person, I could support Indigenous health research. I believed that I wanted to help, but felt there was too much I was not—and never would be—able to comment on. When describing this to a mentor and asking what it is that I could contribute, I was given advice that inspired this article. Specifically, I was told that all I could do was write and work from who I am. Therefore, this article discusses the challenges and opportunities that come from my non-Indigenous perspective. I have spent more than 20 years in a Western education system that provides rewards, through grades and scholarships, for adopting Western ways of knowing and doing. This undoubtably influences what is written in this article, and the reader should proceed with that understanding.

I must take this time to thank all those who have supported me throughout my education and career. There was so much I did not know or understand when I began down this road. My learning has relied on patience and guidance from many Indigenous and non-Indigenous teachers, within and outside academia. I have much left to do to reciprocate the valuable knowledge that has been shared with me. I hope that this article holds benefits that can begin to repay that debt. For inexperienced, non-Indigenous researchers, I hope this article can provide understanding around the nature of ethically engaged and community-driven research with Indigenous communities. Perhaps with this understanding, interest in conducting research of a similar nature will emerge. Beyond that, we (the authors) believe that barriers are not lifted until they are named—and we hope this article can initiate conversations about some of the barriers to conducting ethical research with Indigenous communities.

Introduction

This article's intention is to shed light on the complexity and requirement for flexibility that remain present within the rarely linear reality of Indigenous community-based health research. This endeavor will be pursued by discussing the full story of Indigenous community-based research and providing examples of some challenges and opportunities that one may encounter. Specific examples will be given from a recently completed Indigenous community-based vaccine promotion project (see Sullivan et al., 2023), when relevant to the discussion. At other times, academic literature and lessons learned from experience will be presented. The story of research will be discussed in three phases: Relationships, Proposal Writing, and Research and Reporting. As this story unfolds, questions will be discussed—for example, what are the effects of the lag between proposal writing and REB approval? Or what does operational funding mean to relationship building? Before delving into these questions or the complexities of Indigenous community-based health research, this article will briefly discuss some of the history that influences current guidelines, and what these guidelines have to say about ethical research with Indigenous Peoples.

In close harmony with the land, the Indigenous Peoples of Turtle Island (North America) accumulated considerable flexible, fluid, and adaptive wisdom (Battiste & Henderson, 2000; Kimmerer, 2014; Little Bear, 2009). The survival of early European settlers relied heavily on the generous and open sharing of this wisdom (Lemke, 2016). Today, Indigenous Elders and Knowledge Keepers are sharing wisdom on climate solutions, Indigenous agricultural advancements help feed the world, and many are kept healthy with a variety of well-known medicines discovered by Indigenous Peoples (Ansari & Inamdar, 2010; Cameron et al., 2021; Lemke, 2016). Still, Indigenous discoveries and knowledges have been largely appropriated throughout colonization, leaving many of us unaware of the tremendous scientific and philosophical

contributions Indigenous Peoples have made (Lemke, 2016).

While the advances made by Indigenous Peoples may not fit within the Western definition of “research,” the underlying process of observing, hypothesizing, gathering knowledge, and drawing conclusions certainly does. Unfortunately, the dismissal of Indigenous Knowledges as research appears to extend into much of the research that has occurred on Indigenous Peoples. Despite Indigenous Peoples having “been researched to death,” many of the inequalities this research should have lessened still remain today (Goodman et al., 2018, p. 1; Public Health Agency of Canada, 2018). There are many reasons for the failure to address colonially rooted inequalities—with helicopter research being among the most discussed (Ferreira & Gendron, 2011).

Helicopter research occurs when researchers enter Indigenous communities, conduct research, and then leave, never to be heard from again (Ferreira & Gendron, 2011). Absent from this approach are the voices of the Indigenous Peoples the research is concerned with. This marginalization of Indigenous voices parallels the treatment of traditional Indigenous Knowledges that, while emerging from a clearly “scientific” process, are typically only recognized by Western academia once appropriated by Western approaches. Helicopter research is entirely one-sided, excluding local knowledge and benefiting researchers while rarely, if ever, benefiting communities (Ferreira & Gendron, 2011). In fact, this misguided practice can misinterpret the Indigenous communities’ lived realities and perpetuate negative stereotypes about Indigenous Peoples that have been used to justify systemic racism (First Nations Information Governance Centre [FNIGC], 2019). Negative stereotypes may be an expected outcome when research focuses on documenting deficits or needs rather than strengths or solutions (Chambers, 1983).

More than 30 years ago, Kirkness and Barnhardt (1991) called for changes to how higher education interacts with Indigenous students. From their work, the five R’s of

Indigenous research eventually emerged to include respect, relevance, reciprocity, responsibility, and relationships (Kirkness & Barnhardt, 1991; Wilson, 2008). Still, more than three decades later, the challenges detailed by Kirkness and Barnhardt remain, as evident by the expansion of research discussing what changes are needed to close inequalities in health, education, and employment for Indigenous Peoples (Absolon, 2011; Canadian Institutes of Health Research [CIHR] et al., 2018; Carroll et al., 2020). Needless to say, progress has been slow and is ongoing. Today, there are numerous evolving guidelines, statements, and training courses directing researchers on ethical conduct regarding Indigenous Peoples. Among these resources, the 2018 *Tri-Council Policy Statement 2 (TCPS-2), Ethical Conduct for Research Involving Humans* remains highly relevant to Indigenous research in Canada (CIHR et al., 2018). With an entire chapter and 22 articles dedicated specifically to ethical research with Indigenous Peoples, this resource remains a fairly comprehensive guide to the unique considerations that come with this work (CIHR et al., 2018).

With the caveat of “when / if appropriate,” the TCPS-2 stresses that research with Indigenous Peoples must engage those Peoples, including their leaders, throughout research—from establishing recruitment criteria to analyzing data and mobilizing knowledge (CIHR et al., 2018, articles 9.1, 9.3, & 9.17). The nature of engagement can vary depending on the research, but should be determined jointly by researchers and the involved community/communities (CIHR et al., 2018, article 9.2). Still, it is recommended that researchers and communities consider applying a collaborative and participatory approach (CIHR et al., 2018, article 9.12). Additionally, research should benefit the participating community, and research contexts should determine whether this benefit be through hiring and training locally, enhancing the skills (capacity) of community personnel, or via some other avenue (CIHR et al., 2018, articles 9.13 & 9.14). Finally, the TCPS-2 highlights Indigenous-specific considerations to the treatment of data

or materials gathered, including their potential secondary use (CIHR et al., 2018, articles 9.18–9.20).

All these elements, and many more that were omitted for brevity's sake, are to be accounted for with a research agreement that is secured with community leadership, through community processes (CIHR et al., 2018, article 9.5). This agreement should be specific in detailing the terms and undertakings of both the researcher and the community (CIHR et al., 2018, article 9.11).

Research involving Indigenous Peoples in Canada has been primarily conducted by non-Indigenous Peoples (CIHR et al., 2018). Through practices such as helicopter research, the result has been research that can do more harm than good (Ferreira & Gendron, 2011; FNIGC, 2019). Therefore, the guidance offered by resources such as the TCPS-2 is much needed, and it should be no surprise that the TCPS-2 is just one of many resources available to guide researchers toward work that is meaningful and ethical for both universities and Indigenous communities (Global Indigenous Data Alliance [GIDA], 2019; Gower, 2012; McIlduff et al., 2020; Riddell et al., 2017). That said, these resources are guidelines, not instruction manuals, implying that justified deviations are possible. The TCPS-2 makes clear that it provides guidance only, and revisions will be required as research is implemented (CIHR et al., 2018). Further, Indigenous research methodologies are not static (Walter & Andersen, 2013, Chapters 3–5), and as they continue to evolve, it is essential that the institutions, funders, regulations, and guidelines they operate within evolve as well.

In this complex and ever-changing environment, satisfying obligations to community, university, and funders can present a significant challenge—especially when these obligations are in conflict. The creativity and flexibility needed to navigate conflicting demands remains an area where, in my experience, guidelines are insufficient. Further, informal conversations with experienced researchers confirms that my own experience is not particularly unique. Therefore, this article seeks to tell the honest story of research as it

engages with largely Western systems and seeks to overcome the barriers they present to Indigenous community-based health research that respects self-determination, sovereignty, and culture.

The full and complex picture of Indigenous health research includes many perspectives, such as those of Indigenous and non-Indigenous researchers, Indigenous community members, university administrators, and funders. At this time, it would be unfeasible for the authors to present all these perspectives, for many reasons. Everyone likely has different experiences with this kind of work. For university administrators and funders, their experience is likely very different from that of researchers in the field. Perhaps a separate article written from the perspective of funders and administrators would be better suited than inclusion in this discussion. For the research team, fulfilling obligations to community and maintaining ethical relationships is always top priority. These obligations prevented the inclusion of perspectives from much of the research team. For partnered Indigenous community members, their time is prioritized for community obligations, which are many and prevent detailed inclusion of their perspectives here. For these reasons, this article paints a partial picture of Indigenous health research that occasionally focuses on a very personal, Western, experience-based perspective. Readers who have not done so are urged to read the earlier Self-Location section before proceeding further.

Phase One: Relationships

There are many explanations for why relationships are crucial for ethical research with Indigenous Peoples. Oster and Lightning (2022) provide excellent discussion, including the following:

Given the history of mistrust, exploitation and even unethical research practices with Indigenous populations, collaborative research partnerships necessitate good relationships. For our long-standing community-based

participatory research partnership, trust in our relationships has been foundational. (p. 56)

Oster and Lightning (2022) provide detailed, valuable, and compelling discussion. This section, however, will primarily present the rationale that comes most naturally to the lead author as an individual, non-Indigenous, Western thinker. This is not at all to say that other arguments are less valid. Instead, the following rationale may serve to demonstrate some of the multiple pathways through which different world views can come to similar conclusions. Following this rationale will be a more detailed discussion of some considerations for building the authentic relationships with Indigenous communities that are needed for ethical community-based Indigenous health research.

The fact that health inequities introduced in the early days of colonization continue to exist today is evidence enough that what has been common research practice for decades has not been particularly effective (Ferreira & Gendron, 2011; Goodman et al., 2018, Public Health Agency of Canada, 2018). What has been relatively common, however, is helicopter research that silences Indigenous voices and limits self-determination (Ferreira & Gendron, 2011). Putting it mildly, this is troubling given that self-determination is considered by many as among the most important social determinants of Indigenous health (Greenwood et al., 2018; Nesdole et al., 2014; Reading & Wien, 2009) and is internationally recognized as a right of Indigenous Peoples (United Nations, 2007). Today, the importance of self-determination is reflected in ethical guidelines calling on research to involve Indigenous Peoples, as much and as early as possible, in any research that may affect their lives (CIHR et al., 2018; FNIGC, 2019; GIDA, 2019).

Self-determined, Indigenous-led solutions have a wide base of academic support (Fehring et al., 2019; Hart et al., 2021; Kipp et al., 2019; Muhunthan et al., 2017). Furthermore, cultural continuity is an important Indigenous determinant of health (Auger, 2016), yet “the

intergenerational effects of colonization continue to impact the culture, which undermines the sense of self-determination” (Oster et al., 2014, p. 1). As a result, it is possible, and has been observed by the author, that individuals with cultural expertise may already be stretched thin by community commitments. There are historical examples of unethical research done *on* Indigenous communities, such as nutritional studies on Indigenous communities and residential schools (Mosby, 2013). Given this history, researchers cannot expect to simply enter a community and have their demands for guidance met. Therefore, a requirement that is inherent to conducting ethical, self-determined research *with* Indigenous communities is the formation of strong, trusting, reciprocal, and authentic relationships between researchers and potential co-researchers or participants (Kirkness & Barnhardt, 1991; Wilson, 2008).

1.1 Introduction to Relationship Building—The “R’s”

Given that trusting and ethical relationships should be a prerequisite to research with Indigenous communities, the story of ethical Indigenous research begins with relationship building. For the relationships that allowed the vaccine project used as examples throughout this paper to occur, efforts to build trust began long before proposal writing. In fact, the lab has been conducting research *with* this community for several years and has built trusting relationships through previous work. To uphold this trust, new lab hires are mentored in cultural safety, and lab leadership only introduces potential collaborators to community if they will uphold the respectful nature of existing relationships. Often, potential collaborators and new hires will shadow lab leadership within communities so the lab’s experienced staff have the opportunity to provide mentorship on culturally safe practices within those communities. Potential collaborators will also be provided with template research and partnership agreements to support their understanding of what the lab’s partnering communities have come to expect.

Having community members trust that the lab will adhere to this practice ultimately expedites the formation of relationships between community members and new members of the lab's team and collaborators.

Relationships are built personally between individuals and families—rejecting guidelines of universality. Still, both academic literature and our experience at this lab highlight several seemingly ubiquitous aspects of relationship building.

Research with Indigenous communities must follow the five R's, meaning that it must be done in relationship and be respectful, reciprocal, relevant, and responsible (McGregor et al., 2018). By following the R's, the research team at the lab forms authentic relationships with Indigenous partners. Transparency and open discussion are used both throughout and before any conducted research, in an intentional effort to build trust and organic collaboration. To ensure authenticity, relationships extend far beyond the boundaries that typically define the researcher-participant relationship. In practice, this often means that researchers provide in-kind services whenever possible and requested. At the lab, this has included, but is not limited to, cooking and serving food at community events, supporting cultural events, and putting community's interests above those of funders or universities.

1.2 An Ethical Space

Researchers at the lab engage in cultural practices and acknowledge multiple ways of knowing, being, and doing. Engaging in cultural activities can range from smaller tasks, such as providing tobacco to an Elder for opening and closing meetings in prayer, to more time-consuming activities such as attending, upon invitation, Ceremony. When engaging in cultural practices, researchers directly experience multiple ways of being and doing. Because the doing is purposeful, it denotes a way of knowing that may be novel to non-Indigenous researchers like myself. These purposeful and authentic actions contribute to the creation of a safe and ethical space where multiple ways of knowing, being, and doing coexist on equal

ground. This space is especially important for researchers who have emerged from a Western education system and, as a result, are influenced by Western ways of knowing and doing.

Western and Indigenous world views evolved to be different and unique in response to their distinct histories, traditions, and realities (Ermine, 2007). A safe and ethical space exists when two societies with different world views are positioned to engage each other, and it is believed that such engagement creates new directions for thought (Ermine, 2007)—something that the failure of academic research to bridge the research-to-practice gap, especially with Indigenous communities, suggests is needed.

Without creating a space for multiple ways of knowing, being, and doing to equally coexist, one may risk continuing colonial research practices where Western science extracts, misinterprets, and claims ownership over Indigenous Knowledges (Ferreira & Gendron, 2011). As Indigenous and Western world views are unique (Ermine, 2007), a space for multiple world views is required for the inclusion of Indigenous ways of knowing, being, and doing. It is within this ethical space that an iterative and equal synthesis of community expertise, Indigenous Knowledges, and Western research occurs.

This crucial ethical space is supported by the lab's mentorship model, which rejects the hierarchical relationships typically seen within research (Karnieli-Miller et al., 2009). This model recognizes that everyone has something valuable to bring to the table, regardless of age, experience, training, or any other factor. In employing a mentorship model and respecting and recognizing community expertise, the lab is admitting the need for co-learning, mutual capacity building, and organic reciprocity.

1.3 Respect

Researchers undoubtedly bring valuable skills to the table; however, as evident from history (helicopter research), these skills can be misdirected and are limited by lack of shared lived experiences. The antidote to misdirection is accurate direction. In the context of

community-driven research, Indigenous or otherwise, accurate direction is found in community expertise (del Pino et al., 2016), because, after all, “you don’t know what you don’t know” (Absolon, 2011, p. 10). If we assess the value of contributions by the scarcity of individuals possessing the necessary expertise, community experts are far more valuable than researchers. As a result, a hierarchical researcher-participant relationship is entirely inappropriate when conducting community-based research.

When recognizing that the community member you are engaging with may be one of only a few individuals with their local cultural knowledge, respect or even reverence is an appropriate and rational response. Among the R’s, respect is particularly relevant, given the others may organically follow its presence. For example, if you respect the community, it is imperative that you ensure research is reciprocal, relevant, and responsible. The effort of ensuring these R’s are present varies and is dependent on the colonial systems you work within, as well as the understanding of colleagues and leadership of the R’s and the necessity of sovereignty.

The typical label of “participant” suggests a passive role in research and reflects a hierarchical power dynamic within the researcher-participant relationship (Karnieli-Miller et al., 2009) that, as has been argued, is completely inappropriate. Recognizing this, the lab refers to participants as “co-researchers,” and that terminology will continue throughout the remainder of this paper.

1.4 Cultural Safety

Ultimately, research at the lab strives to be conducted *in a good way*, meaning that research respects and benefits the community, while relationship building is intentional, strength-based, and acknowledges the lived experiences and expertise of co-researchers (AHA Centre, 2018). The formation of these relationships relies on staff who are self-reflexive in their pursuit of cultural safety (Gopal et al., 2022) while simultaneously holding one another accountable in their own efforts toward

cultural safety. The lab’s research projects are strengthened by the relationship-dependent union of academic competencies and co-researcher expertise and contributions relating to cultural safety and cultural appropriateness, as well as the local context. This union would not be possible without researchers and co-researchers being mutually respectful and accountable.

Beyond the limits of academia, I have heard the process of approaching cultural safety described as walking down a road, only to realize how much further is left to walk. I have had many experiences where I felt I could finally see the distance I had left to walk, only to later realize that there is so much further to go. Therefore, discussion into what cultural safety looks like will be brief. Cultural safety involves one’s reflection on power imbalance among relationships and is determined by the Indigenous person being engaged—and it is believed that the aspects of engagement described to this point contribute to cultural safety and can help prevent harm (Curtis et al., 2019).

1.5 Relationships and Operational Funds

Building the trusting relationships needed for meaningful engagement and self-determination can take significant time—perhaps many days, but potentially years. To bring trust and authenticity into these relationships, researchers at the lab go far beyond typically-funded research activities. Further, these relationships likely need to be in place before research begins, meaning that the potentially lengthy task of building these relationships typically precedes even the research funding applications process. Therefore, a lab seeking to engage in ethical research with Indigenous Peoples relies on an operating grant with enough size and flexibility to support this relationship work. In the absence of such operational funds, a lab may require its researchers to perform an unsustainable amount of unfunded and unpaid work. This represents a significant barrier to ethical research with Indigenous Peoples. For the operating grants that do exist, experience

suggests they are typically too narrow in scope to support the diverse priorities of communities. Having to refuse supporting a community priority because “that’s not what we are funded for” does not exactly communicate authenticity in relationship building. Without operating grants that are sufficiently flexible and funded, the field may be missing the potential of any future work that emerges from strong, trusting, and authentic researcher-community relationships.

1.6 Summary

Ethical research with Indigenous populations must promote self-determination, and this requires it to be conducted with, not on, Indigenous Peoples. As a result, relationship-building and maintenance are the first steps in any research work. In building relationships, pursue authenticity. At the lab, this is achieved through open and transparent discussion and the R’s (respect, reciprocity, relevance, and responsibility). To support relationships, researchers, especially those who are Western, must acknowledge and appreciate multiple ways of knowing, being, and doing without hierarchy. Furthermore, self-reflexive researchers can help promote cultural safety and support relationship building. That said, relationships exist between individuals, making them resistant to any universal guideline, especially given the heterogeneity of Indigenous Peoples. Next, the ways in which relationships are most present within research at the lab will be discussed.

1.7 Relationships in Action—The Community-Chosen Advisory Committee

Self-determination requires engagement, which requires relationships. That said, the degree to which a project is truly self-determined by a community and the degree to which a project is feasible may be correlated in a negative manner. On one extreme, you could complete community-wide surveys every time a research decision is required. The other extreme is represented by the widely criticized practice of helicopter research (Carroll et al., 2020). It seems that the highest degree of self-

determination is almost always beyond the limits of feasibility. Given that many Indigenous health inequities interact and can compound (Reading & Wien, 2009), inaction from those who are positioned to support a solution may also be inappropriate. Often, some degree of self-determination is sacrificed to ensure projects are feasible, funded, and implemented. In the lab’s experience, the most feasible research approach allowing community direction that is meaningful and accepted by community is to support the formation of community-chosen advisory committees (ACs).

ACs are the primary avenue through which the voices of co-researchers are highlighted and brought into the lab’s research. Once established, AC members ideally become active directors of research design, implementation, and mobilization. ACs are paramount to all research undertaken by the lab, and this is no accident. Providing a huge benefit to feasibility, ACs can act as a proxy of community-wide surveys and serve in an ethics-exempt advisory role. This allows for research decisions to receive community input without excessive delays or engagement-related budget increases (although AC members are compensated for their time spent advising the lab). However, there is diversity within Indigenous communities, just as there is diversity between communities. There will almost certainly be voices and perspectives within a community that are not accounted for in any given AC.

Unless an Indigenous community has access to funding and the capacity to navigate academia and complete their own research, the lab’s experience is that establishing ACs is a good approach to ensuring community direction is meaningful and feasible. In particular, if capacity-building is included in a research project, ACs can serve as an intermediate step in the road to full Indigenous self-determination in academia. While the TCPS-2 does not require research to include capacity-building, it does stress that communities must benefit, and one avenue through which this benefit can come is through the additional building of skills (CIHR et al., 2018).

Establishing an AC requires answering the important question of which community members are most capable of reflecting the community's voice. Apart from researchers working in their own communities, one should not expect to walk into a community health centre and be immediately directed toward AC-eligible community members. ACs typically include local Elders, Knowledge Keepers, community research assistants (CRAs), and people with lived experience. If you do not have a community's trust, they likely will hesitate to connect you with these individuals.

When the researcher has trusting relationships formed within a community, the question of who qualifies for an AC appointment can be raised. The community, typically leadership such as Chief and Council or Health Services Directors, needs to be asked who qualifies for an AC appointment. The AC helps bring their community's voice into research, and having anyone beyond the community determine who can represent their voice is a clear violation of their internationally recognized right to self-determination (United Nations, 2007). Therefore, it is the community who nominates individuals to guide research through their membership on an AC. Membership for the AC may also occur more organically as existing AC members identify the need for additional community members to be consistently involved in the decision-making processes.

As mentioned, the lab's experience is that establishing ACs is a good approach to ensuring community direction is meaningful and feasible. Community acceptance of this approach is inferred from the community partner's continued interest in conducting research alongside the lab. Further, and in adherence with TCPS-2 articles 9.3 and 9.11, community leaders are engaged and formally enter a research agreement with the lab before every research project. Project-specific research agreements are accompanied by partnership agreements between the lab and all its partnering communities.

Research agreements allow for both the community partner and the lab to

collaboratively establish the roles of each party with each new research project they take on together. Partnership agreements are overall agreements establishing how the lab and community partner will work together in response to community-determined needs, ensuring self-determination and sovereignty of the community partner at all levels of work done between the lab and the community partner.

Prior to the vaccine project, the lab had already established an AC within the partnered community, and it is this AC that brought their community's voice into this research, actively directed the lab on key decisions, and promoted their community's self-determination. This AC continues to guide the research throughout knowledge mobilization, and the included vaccine project examples in this paper are only being made public after their feedback, approval, and encouragement. In the vaccine project, funds were reserved for capacity building in the form of hiring and mentoring a new CRA to support the community's existing CRA. Through AC guidance, this budget item was adapted to support two younger, part-time CRAs as the AC identified a need to increase the engagement of younger members of the community. The research agreement for the vaccine project outlined the project clearly, with special focus on the roles of the researcher, roles of the AC and community, and collaborative roles. Data ownership and reporting requirements were clearly outlined, and the agreement was presented to, and signed by, the community's Chief before research commenced.

Phase Two: Proposal Writing

As has been argued, relationships are a prerequisite to ethical research with Indigenous Peoples. It is hypothetically possible that a proposal could be written before relationships are formed; however, relationship building is not formulaic, and it would be near impossible to develop a proposal that accounts for relationship building with any acceptable degree of accuracy in terms of activities, timelines, or funds required. This is a barrier to ethical research with Indigenous Peoples, as the

task of relationship building likely cannot be addressed by securing research funds and instead needs to be achieved before research funds can be applied for, particularly to allow for self-determination in this space.

At the lab, this barrier was overcome as partnering communities were engaged through mutual trusted contacts or through word of mouth, with other communities becoming interested in the type of work their friends' or family's communities were engaged in. Previously established relationships and reputation through word of mouth are both essential when establishing partnerships with Indigenous communities.

In the absence of previously established relationships, perhaps sufficiently flexible operational funding can alleviate the mentioned barrier to ethical research with Indigenous communities. Regardless, the assumption that you have existing relationships with an Indigenous community does not mean the complexity of Indigenous health research is simplified. In this phase, some considerations relating to barriers, opportunities, and lessons from proposal writing that seeks to uphold self-determination will be shared.

2.1 Funding Frenzy and Degrees of Engagement

Academia is fast paced and highly competitive. Within this space, success and survival depend on, quite literally, competing with peers for access to funding. In academia, competition exists for funding, prestige, and career advancement. Whether or not the benefits outweigh the costs of competition is certainly beyond the scope of this paper.

Competition does infer hierarchy, and this comes into conflict with the lab's non-hierarchical mentorship model. The lab can work to change the realities of academia but certainly cannot control them. That said, the lab has quite a bit of autonomy in how it operates and, as much as possible, applies for funding, publishes, and operates as a cohesive unit. Success at the lab is shared and largely measured by positive community impact, not necessarily fund application acceptance or

publications. While both of the latter are important, the positive community impact is essential to ethical research with Indigenous communities.

Regardless of how the lab operates, competition is a reality of academia—with academic worth tied to productivity. As Brené Brown explains, “when worthiness is a function of productivity, we lose the ability to pump the brakes: The idea of doing something that doesn't add to the bottom line provokes stress and anxiety” (Brown, 2018, p. 128). When the bottom line is research, letting an opportunity for funding slip by is not exactly encouraged. After all, for the individual lab, it would be better to secure funding and alter a proposal or, at worst, return funding, than to lose out on those future options. The competitive academic environment compels researchers to apply for anything they may be able to secure and, if so fortunate, figure out remaining details later.

As funding proposals reflect intended research, then the highest degree of self-determination is realized when communities are engaged throughout proposal writing: from priority identification, throughout research methods and methodologies, and all the way to knowledge mobilization plans. Fortunately, there are funders who go beyond recognizing this to offering concrete financial support. The Saskatchewan Health Research Foundation (SHRF) offers the START Award, which “supports engagement activities aimed at building research teams and the collaborative development of research questions and approaches” (SHRF, 2022, p. 5). My personal experience of this award was overwhelmingly positive, as the program called for proposals detailing how Indigenous communities would be engaged in the writing of collaborative research proposals. At the lab, we were approved for a proposal describing how we would engage two of our partnering communities. With that funding, we were able to engage those communities and develop an Indigenous self-determined research proposal, which has since been approved and is currently being implemented.

I am certainly no expert on the many

funding organizations and opportunities that exist. That said, I have been made aware of another organization with a similar program. The Michael Smith Health Research BC organization describes their Convening and Collaborating Program as follows: “Co-developing research by engaging with stakeholders helps ensure the research is relevant, and can increase the likelihood of leveraging the award into additional funding from national and international sources” (Michael Smith Health Research BC, n.d., para 2).

When it comes to self-determination in research, I believe that SHRF and Michael Smith Health Research BC are providing strong examples of how funders can offer their support. Unfortunately, my experience is that the programs offered by these two organizations are not the academic norm. Without programs like these, it is not uncommon for proposal deadlines to arrive before a proposal can be written that is truly collaborative, from priority identification to knowledge mobilization plans. The community members you engage are community members first, with many community priorities at times taking precedence to research. These non-research priorities must be honoured for the relationship to be authentic and respectful.

As mentioned, inaction can be inappropriate—especially when an opportunity for funding that could benefit the community is presented. At times, it may be necessary that a proposal is written with little more than the community’s priority, consent, and knowledge of their preferred research methods. This is not ideal, but also not necessarily a reason to abandon a potential project. The following section will describe how the lab responds to this challenge and will conclude with examples from the vaccine project.

2.2 Dynamic Communities, Dynamic Priorities

In the event that upcoming deadlines and barriers to engagement prevent a fully collaborative proposal, the dynamic nature of communities becomes an important consideration. This dynamic nature means that

an issue identified as a priority during one month, week, or even day may not remain so in the next. There are a variety of causes for a community’s shifting priorities, including the priority being sufficiently addressed without external support or perhaps the emergence of other priorities of higher importance. Resources permitted, communities will be implementing a solution to whatever priority a proposal seeks to address.

The presence of a problem, and that problem being a community priority, does warrant investigating potential solutions. However, any such investigation must include any community-driven solutions that are currently being implemented or are planned for the future. In testing hypothesized solutions, conversations must occur to determine what the community has been doing or intends to do, as these interventions are self-determined, community-based solutions, and there is ample evidence of their effectiveness (Fehring et al., 2019; Hart et al., 2021; Kipp et al., 2019; Muhunthan et al., 2017). If academic pressures prevent such conversations from occurring, a proposal must have built-in flexibility to shift its investigation to any community-driven solutions, once identified.

In summary, the demands of academia occasionally mean that researchers must choose between inaction and the development of proposals with less-than-ideal levels of community engagement. If a truly collaborative proposal cannot be developed, flexibility is required to respond to community direction when later engagement occurs.

2.3 Proposal Writing—Lessons From Experience

When full engagement is limited, proposals should be developed with the flexibility required to adjust to the community’s preference when later engagement occurs. While researchers at the lab are accustomed to the need for flexibility, funders and universities may not be. Therefore, to minimize disruptions to research, it is in one’s best interests to reduce the need for flexibility to the greatest degree possible, without infringing on Indigenous

communities' right to self-determination.

For the vaccine project, competing researcher and community commitments meant the proposal was developed without full collaboration. While the proposal was structured to allow significant flexibility, previous experience with the proposed community partners reduced the amount of flexibility required. From this experience, methods and methodologies that have been preferred in the past were proposed, reducing the risk that major methodological alterations would be required when further engagement occurred. However, not everyone has years of experience with a given community. In the absence of this experience, academic literature can certainly be consulted and, perhaps, the experience of this lab can provide support. Therefore, before discussing the vaccine project, proposal writing lessons from academic literature and the lab's experience will be shared. That said, anything proposed that is not the direct result of engagement and collaboration should be done so with caution. Further, no two communities are exactly the same, and what is typically preferred by the lab's community partners may differ significantly from the preferences of other communities.

2.3.1 Methodology

Through its focus on involving community members as much as possible in any research affecting their lives, community-based participatory research (CBPR) has been considered a valid means to promote self-determination (Castleden et al., 2008; Dudgeon et al., 2017). CBPR frameworks equalize power imbalances within research, build trust between researchers and communities, and foster a sense of ownership over research (Castleden et al., 2008). Building trust is especially imperative considering the dishonesty that characterizes the historical experiences of Indigenous Peoples with the academic research community. Consequently, CBPR is generally considered a strong methodological footing for working with Indigenous Peoples and is often the methodology employed by the lab.

2.3.2 Methods

When selecting methods, the lab's

experience is that qualitative approaches are generally preferred. Among the many options, sharing circles have been well received, proposed by the lab in the absence of sufficient engagement, and typically proposed by the community when engaged. Sharing circles are similar to focus groups, as researchers and community members gather information through group discussion (Berg, 2001). While protocols may vary between communities, sharing circles consistently differ from focus groups in the sacred meaning they hold for many Indigenous cultures (Lavallée, 2009). Generally, sharing circles are used as a healing method where information, spirituality, and emotionality are shared in an environment that is respectful, supportive, and free of judgment (Restoule, 2004). Through trusting and authentic researcher-community relationships, community-specific protocols can, and should, be gathered and followed. At the lab, methods are chosen to respect, support, and work toward healing with co-researchers to the greatest extent achievable. The healing nature of the circle, its atmosphere of respect and support, and the preference of partnering communities make it the most frequently selected method.

A tremendous value of sharing circles is that, according to partnering communities' protocols, the facilitator's role is passive. Academic failures to promote Indigenous health and equity may suggest that academic interpretations of what is happening within Indigenous communities—and what solutions are needed—have been inaccurate and ineffective (FNIGC, 2019). If this is the case, it follows that methods chosen that reduce the influence of researchers could increase the relevance of results. Sharing circles are a great method to address this possibility.

Generally, qualitative methods have been seen by Indigenous researchers as more appropriate for use with Indigenous communities than quantitative alternatives (Walter & Andersen, 2013, Chapters 3–5). In part, this is due to the observation that qualitative methods typically align more closely with community interests and agendas than quantitative methods (Walter & Andersen,

2013, Chapters 3–5). The lab’s experience does not stray from this literature, with its work generally being guided by communities to gather more qualitative data than quantitative. Still, quantitative data holds tremendous value too. Statistics are the language of the state and, in being such, are well equipped to inspire transformational change (Walter & Andersen, 2013, Chapters 3–5). Walter and Andersen provide far more detailed and valuable discussion than will be included here, and curious readers are urged to review their work. The authors explain that quantitative statistics that are Indigenous-led, from the questions asked to the analysis performed, are likely to provide answers to questions that others never thought to ask. This could work to balance the current statistical landscape where non-Indigenous-led statistical analyses of Indigenous-specific data are inaccurately accepted as exhaustive descriptions of who Indigenous Peoples are (Walter & Andersen, 2013, Chapters 3–5).

2.3.3 Data Analysis

How data or knowledge is collected is certainly relevant for research with Indigenous communities; however, so too is how data is analyzed (Castleden et al., 2008). We all carry biases, and these biases are often influenced by our experience and training, yet are also resistant to training (Ballard, 2019). In 2019, it was found that 80% of Canadian universities have, or are developing, some form of strategic plan relating to reconciliation and the success of Indigenous students (Universities Canada, n.d.). That said, my experience is that Canadian education can, and should, still be considered largely Western. Therefore, there are likely Western biases that are common in researchers trained through academia.

At the lab, researcher bias in data analysis has been addressed by utilizing the Nanâtawihowin Âcimowina Kika-Môshahkinikêhk Papiskîci-Itascikêwin Astâcikowina (NAKPA) procedure. NAKPA, Cree for “Medicine/Healing Stories Picked, Sorted, Stored,” is an Indigenous qualitative analysis approach adapted from the Collective Consensual Data Analytic Procedure (CCDAP;

Starblanket et al., 2019). The CCDAP was developed to address the lack of community involvement in data analysis, and holds the additional benefit of reducing the risk of bias that any single person could bring into analysis (Bartlett et al., 2007).

NAKPA relies on group consensus and community input to organize data into themes (Starblanket et al., 2019). Following NAKPA protocol, researchers and co-researchers collaboratively organize anonymized sharing circle responses thematically by question. Following this, each theme is given a name and considered a minor theme. Once this process has occurred for each question, the resulting minor themes are, again, combined thematically through panel consensus, resulting in major themes (Starblanket et al., 2019). It takes little experience with the NAKPA procedure to see clearly the potential pervasiveness of researcher bias in qualitative analysis sans panel format. Important considerations for the NAKPA process will be revisited in Phase 3.3, Making Sense.

Regarding quantitative analysis, the lab’s relatively limited experience with collection also extends to analysis, although any interpretations from quantitative analysis that the lab performs is always run by the appropriate AC to ensure accuracy and relevance. That said, Walter and Anderson’s (2013) words remain relevant—Indigenous-led analysis is likely to prove valuable in balancing the statistical landscape with Indigenous-led answers to questions Western researchers may never think to ask.

2.3.4 Data Ownership

Once data is analyzed, the question of how it is stored requires consideration. Regarding storage, the literature is clear: the data belongs to the community, and it is they who determine how it is treated (CIHR et al., 2018; FNIGC, 2019; GIDA, 2019). Regardless of how the community determines the data should be treated, the data will always belong to them. It is, therefore, the community who must be consulted on any potential change to the agreed-upon treatment, whether this be changing storage location or protocol or considering

subsequent use of the data (CIHR et al., 2018).

The lab's team is knowledgeable and trained in the First Nations principles of OCAP (ownership, control, access, and possession), the TCPS-2 articles, and the CARE (collective benefit, authority to control, responsibility, and ethics) and FAIR (findable, accessible, interoperable, and reusable) principles (CIHR et al., 2018; FNIGC, 2019; GIDA, 2019). These principles have been developed to help guide researchers in overcoming the damaging practices of the past and promoting self-determination among Indigenous Peoples in research processes and data stewardship (Castellano, 2004). In Indigenous community-driven research, there is much that is beyond the control of researchers. That said, familiarizing yourself with these guidelines is something one can control and is certainly a requirement when working with Indigenous communities.

2.3.5 Knowledge Mobilization

Given that the knowledge (data) informing any learnings belongs to the community, how these learnings are shared also needs to be determined by the community (CIHR et al., 2018). Again, there may be many degrees of community involvement in knowledge mobilization. Because research agreements outline the expectations of researchers and community members, communities are aware of final reporting or publications requirements. Depending on the knowledge being mobilized, the community may have little interest in involving themselves in the process, but the lab recommends, at the very least, receiving approval from community members before mobilizing any knowledge. However, when preferred by the community, more active community involvement brings new interpretations and discussion to any published work, along with often innovative ways of mobilizing the knowledge beyond academia. When Indigenous community partners are actively involved in knowledge mobilization, which often occurs throughout the project when ethical and collaborative work is being done (Hutchinson et al., 2023), innovative and effective ways of sharing are inevitable outcomes. Previously, community partners have

guided the lab to develop government briefs, storybooks, information pamphlets, resources to support culturally safe services, and more.

2.3.6 General Insights

Beyond methodologies, methods, data analysis, data storage, or knowledge mobilization, the lab has found there are certain practices that are generally beneficial when writing proposals in the absence of full engagement. For example, any methods recommended to funders are done so with caution. In nearly every funding proposal, the lab integrates some variation of the following: "While overly detailed methods and methodologies ultimately infringe upon Indigenous Peoples' right to self-determination, previous experience suggests that the following will be preferred. That said, methods must be responsive to community direction." The inclusion of these two sentences is a concrete and easy-to-implement example of integrating flexibility into a research proposal.

Research must benefit community (CIHR et al., 2018). At the lab, this benefit often comes through addressing a community priority and, ideally, implementing a community solution. That said, some community-identified priorities may provide less tangible community benefit than others. Still, integrating capacity building into all research proposals provides concrete community benefit. As mentioned, establishing ACs is a good approach to ensure meaningful community direction. Some communities have capacity and experience navigating funding and implementation of programs and projects, but for those who do not, building this capacity is often a priority. Building community capacity to navigate funding bodies, research implementation, and academia moves various fields toward self-determination. At the lab, proposals will near-universally include funding for CRAs, and the vaccine project followed this trend. CRAs mentor researchers on cultural and community factors, while researchers mentor CRAs in the world of research. The benefits of this mutual capacity building are numerous and justify its integration into nearly any research.

2.4 Proposal Writing and the Vaccine Project

For the vaccine project, a last-minute proposal was developed with the knowledge that two partnering communities had expressed COVID-19 vaccination as a challenge and priority. That said, barriers such as those described in Phase 2.1 prevented a truly collaborative proposal from being submitted. Rather, knowledge of community priorities, awareness of funder preference, and experience working with both communities drove the proposal's development. Flexibility was built into the proposal to allow for community guidance when further engagement did occur; however, this section will highlight an easily avoidable and costly mistake that stemmed from an insufficiently flexible proposal.

The vaccine project had three related aims: bring an Indigenous voice into the conversation around COVID-19 vaccines, understand Indigenous vaccine hesitancy and confidence within partnered communities, and identify effective strategies for promoting Indigenous vaccine confidence. To pursue these objectives, the project intended to pilot social media interventions (posts) in the two communities, comparing different messaging techniques. The project hoped to gain a better understanding of how historical and contemporary forces influence the landscape of Indigenous vaccine hesitancy. After an informal literature review, the messaging techniques employed by conspiracy theories and behavioural insights were selected for piloting. The proposal planned for one community to receive behavioural insights, while the other would receive the conspiracy theory arm to allow for comparison. However, the choice of which community received which strategy was not defined. We had planned to present both options to both communities and, if they requested to receive the same strategy, we would adapt the approach as required.

The first draft of each post would be developed from literature pertaining to the different techniques as well as academic- and AC-identified sources of COVID-19 vaccine hesitancy. Next, ACs for each community would be engaged to provide feedback and edits. Edits

would be taken to the lab and addressed, and then new posts would be presented, with this process continuing until all posts received AC approval. It was in engaging the AC that the research hoped relevant historical and cultural factors would be reflected in the posts. That said, AC feedback was not to be limited to cultural or historical factors, as this would infer that those factors are the only ones where AC knowledge holds value. After piloting the posts, researchers were to gather social media analytics, compare techniques, and conclude the project with a sharing circle.

As Hutchinson et al. (2023) explain, combining researcher skills with community expertise requires continuous and multidirectional knowledge mobilization throughout the research process. For the vaccine project proposal, the lab's universal inclusion of multidirectional knowledge mobilization through authentic relationship-based research was employed. Further, it was predicted that co-researchers and CRAs, through their community presence, would mobilize relevant knowledge to their community. This sharing of information from trusted members of the community can help bridge the research-to-practice gap (Hutchinson et al., 2023). Additionally, the vaccine project proposal dictated that any knowledge mobilization activities would require the approval and, if interested, involvement of the community.

As you can see from this description of the project's proposal, flexibility was allowed in relation to which messaging techniques each community received, as well as the form and content of piloted posts. Furthermore, sharing circles and NAKPA analysis were proposed, given that this is often preferred by the communities. While this project did propose some quantitative data collection and analysis, social media analytics referred to the performance of the different piloted posts. Therefore, the proposed quantitative approach could not be seen as a description of Indigenous Peoples, their communities, or their lived or living experiences. However, as will become clear, deviations from this proposal were

required.

The vaccine project was identified as a priority in the summer of 2021 through routine engagement and relationship work in two communities; however, the project was not approved until several months following this engagement. For one of these communities, the vaccination priority identified in the summer was no longer a top priority when funding was approved. As mentioned, communities are dynamic and so are their priorities. Despite this setback, the other engaged community remained interested in the project and, most specifically, in bringing Indigenous voices into the controversial space surrounding COVID-19 vaccines (Priebe et al., 2022; Verd et al., 2022). As a result, the lab scrambled to convert a project conceived for two communities into work that could feasibly be completed within one. This change required no shortage of flexibility from researchers, university, community, and funders.

In moving a two-community project into a single community effort, some sacrifices to the initial plan were made. The number of posts representing each messaging strategy (conspiracy theories and behavioural insights) needed to be reduced. Further, increased engagement was required to approve social media posts, as now a single AC was required to familiarize themselves with the strategies relating to conspiracy theories as well as those employed by behavioural insights. A research agreement was drafted and signed reflecting these changes, as well as detailed descriptions of the responsibilities of community, the AC, and researchers, along with shared responsibilities.

At the lab, researchers are accustomed to the near-constant need for flexibility, and the community members we work with are often equally, or more, accustomed to this requirement. Funders and universities, however, are more accustomed to detailed timelines and work plans. For this project, the University of Saskatchewan—specifically their Behavioural Research Ethics Board—and the fund administrators at Global Impact deserve to be recognized and commended for their support and flexibility through these changes.

While the project was able to proceed with some changes, there was one entirely avoidable error in the initial proposal that could not be overcome. A major aim of the project was to identify effective strategies for promoting Indigenous vaccine confidence. To do this, the project looked to the literature for promising, if somewhat subjectively determined, messaging strategies (potential solutions). The intention was to pilot these strategies to see which were most effective.

Academic literature is well established on heightened vaccine hesitancy among Indigenous Peoples due to experiences of racism and unethical research (Mosby & Swidrovich, 2021). Therefore, this project was conceived with the assumption that vaccine hesitancy would be, and remain, high within the partnered communities. While this idea was supported by conversations with community members who indicated that achieving high vaccination rates was a community challenge and priority, the proposal incorrectly assumed that this priority would remain present months after proposal writing. Subconsciously, this error included the deficit-based assumption that vaccine hesitancy would not be overcome without external intervention.

The research, especially the sharing circle, provided valuable understanding to the nature of Indigenous vaccine hesitancy and how it can be overcome. That said, this understanding could have been much stronger. The proposal recognized the importance of community's involvement in solutions, and community feedback was a significant influence on the piloted posts initial drafts and final forms; however, insufficient attention was given to the solutions conceived and implemented entirely by community members. The proposal, unfortunately and avoidably, lacked the flexibility to shift from investigating the academically "promising" solutions to investigating the community-driven and -implemented solutions. The piloting of external solutions is only an appropriate way to understand what can be done to support vaccine confidence if what is currently being done is not effective. If what is currently in place is effective,

our pursuit of understanding should shift to understanding what Indigenous communities are currently doing to successfully promote vaccine confidence.

Throughout the project, conversations with community members repeatedly made clear the success of the local Pandemic Response Team. Embarrassingly, the consultation of literature that determined which solutions were “promising” had overlooked the golden rule of Indigenous health: self-determination is best (Greenwood et al., 2018; Nesdole et al., 2014; Reading & Wien, 2009). By piloting interventions that included community feedback only as a component, we unintentionally inferred that the knowledge reflected in community feedback was insufficient to stand on its own and to stand worthy of investigation or piloting. If the project’s testing of potential solutions had included a closer look at the community’s efforts, we would better understand how to replicate their success.

2.5 Proposal Writing Conclusions

Truly collaborative research proposals are highly valuable, but not particularly common or supported. While this certainly risks research moving toward helicopter approaches, there are actions researchers can take to hold space for self-determination within minimally engaged proposals. Generally, limited engagement during proposal writing means more flexibility will be required for the proposal writing or research implementation. This flexibility is required by all those involved in research. Proposals should be as flexible as communities are dynamic. Proposals looking to investigate potential solutions to a community-identified priority must be sufficiently flexible to avoid the unintentional, deficit-based, and costly mistake of the vaccine project. Self-determined solutions are effective (Greenwood et al., 2018; Nesdole et al., 2014; Reading & Wien, 2009), and proposals need to reflect this by, at the very least, investigating community-driven solutions alongside external solutions. Even if the researcher is unaware of any solution the community is implementing, a proposal should

still be written to allow investigational focus to shift over to anything the community may end up deciding to implement.

In the lab’s experience, the requirement for flexibility can be reduced by consulting relevant literature and previous experience. Also from the lab’s experience, CBPR approaches, qualitative methods such as sharing circles, and panel data analysis are preferred research approaches. It has been briefly argued here that approaches that limit the influence of researcher bias may hold significant value. Further, there may be much to gain from quantitative measures, as long as they are Indigenous-led. As research concludes, data must be treated according to community guidance—and this guidance remains imperative as knowledge is mobilized, especially in how the data is shared externally or academically. By integrating research capacity building and cultural capacity mentoring into proposals, community research capacity increases while researchers’ cultural capacity also increases.

Phase Three: Research and Reporting

With relationships formed and a truly collaborative—or sufficiently flexible—funding proposal approved, research can finally begin. However, researching in a good way with Indigenous Peoples is complex. Some of these complexities have been discussed previously, such as the dynamic nature of communities or the pressures of Western/colonial academia. Still, complexities remain as research is implemented, and these will be the focus of Phase Three: Research and Reporting. This phase will provide general discussions of REB writing (3.1), data collection (3.2), data analysis (3.3), and knowledge mobilization (3.4). Specific examples from the vaccine project will follow each general discussion.

3.1 Ethics Application Writing

Research Ethics Board (REB) application writing is generally straightforward; however, there are certain complexities and opportunities that are unique to research with Indigenous

Peoples. Indigenous research methods and methodologies may differ considerably from the Western approaches that are likely more familiar to an institution's REB. This can lead to research delays as lab members are required to provide lengthy explanations for the inclusion, or exclusion, of certain elements of their REB applications. For example, institutions may have clear rules for data storage that conflict with Indigenous data ownership. As researchers spend time justifying their REB application, the dynamic nature of communities remains, potentially limiting the responsiveness of the planned research. Few proposals are written to budget for unexpected delays in REB writing and approval. Therefore, as researchers attend to the concerns of the REB, operational funds are used that are needed to maintain relationship authenticity and build new relationships.

Barriers do exist at the REB stage of research; however, these barriers may present opportunities. As mentioned, including capacity building within research proposals is a good approach to moving a community closer to true self-determined research. These increases in community research capacity, however, may require accompanying increases in academia's cultural understanding and safety. Discussions with REB members provide researchers who have front line experience the opportunity to share their experiences and knowledge. This dialogue can ultimately serve to increase the cultural understanding of administrators who may otherwise not have the opportunity. Every new administrator who understands the importance of tobacco offerings as an Indigenous protocol or sharing circles is a benefit to the field.

3.1.1 REB Writing and the Vaccine Project

In the vaccine project, a drawn-out REB process provided the opportunity to engage an REB member in lengthy discussion about some of the lab's commonly employed methods. The lead author's experience was that the individual engaged was eager to understand the role of the AC and the nuances of a sharing circle. What ensued was mutual knowledge-sharing, where the author gained a deeper understanding of what is required for the REB while the REB

member gained a deeper understanding of the realities of research with Indigenous Peoples.

The vaccine project included funding for a CRA that was intended to increase the community's research capacity. In addressing REB concerns, there was also a small but important increase in the cultural understanding within the university's REB. This opportunity for mutual knowledge sharing is only possible when both parties are willing and open to have a conversation outside of their acknowledged sphere of understanding—humility and transparency here are imperative.

3.2 Gathering Knowledge

When researching with Indigenous Peoples, knowledge is gathered in many ways and at many times. Of course, there is knowledge gathered when implementing research methods, such as sharing circles. Occasionally, research methods will have community-specific protocols. When these exist, they must be followed. For example, the vaccine project engaged a CRA to gather community-specific sharing circle protocol. In implementing methods, seek guidance from community on protocols and continue to ensure you are respecting the relationships underpinning the research. Formal research methods are fairly straightforward and will not be the focus of this section. Instead, the knowledge that is shared while engaging community will be discussed.

Indigenous research is engagement heavy, and this engagement is purposeful. Generally, engagement occurs to promote self-determination, to ensure the voice of co-researchers is present and meaningfully reflected in research and that space is created for mutual knowledge mobilization throughout the research process (Hutchinson et al., 2023). This suggests that engagement brings some knowledge or understanding to research that was not present beforehand. Therefore, phone calls, informal interviews, and ethics-exempt advisory meetings with Indigenous co-researchers all represent valuable, and necessary, opportunities to gather and share knowledge. A separate publication on the vaccine project presents outcomes of AC

engagement and informal community interviews alongside sharing circle results and social media analytics in the results and discussion sections.

Regarding informal interviews, barriers to engagement may force a rather expansive definition of “informal.” One can never be certain when valuable sharing will occur. This is especially true when so much of the research process is dedicated to authentic relationship building. Therefore, information that ultimately proves invaluable to research may be shared in the most unlikely circumstances—for example, following highly competitive games of minigolf, go-kart races, or when eating a meal together or walking/driving together to a destination.

Within any opportunity to engage community, relationships come first. In these exchanges, community members and researchers may joke, catch up through chatting, cry, pray, and support each other. While this is always indirectly important to the research, as it maintains relationships, much of these interactions are informal and not directly relevant to research results. Of course, researchers have the community’s consent to take notes and gather knowledge shared during engagement. Further, any data sharing is always done so with community involvement and consent. That said, researchers may still need to draw some line in the sand of what “data” they attend to and consider. In making these decisions, the risk of introducing researcher bias is high. From the perspective of a non-Indigenous academic, what qualifies as data worth gathering is an important question—and one I grapple with frequently.

3.2.1 Defining Knowledge

No amount of cultural safety training will ever leave me truly understanding the experiences of Indigenous Peoples. Further, Indigenous and Western world views and ways of knowing are distinct (Ermine, 2007). In determining what is and is not data, these differences are imperative. If I use my own, largely Western-influenced assessments of importance, I am subjugating everything else that has been shared to Western definitions of importance—an idea that is clearly colonial.

Therefore, in considering the vast knowledge that is shared throughout the engagement needed for Indigenous research, self-reflexive researchers are a requirement.

As a non-Indigenous person, my experience with Indigenous Peoples, their Knowledges, and, thankfully, no shortage of their patience has repeatedly shown me how cautiously I should approach my initial reactions to information that does not align with my world view. Given that we understand ideas through our world view, I still do require some kind of Western explanation to truly understand what is shared with me. In the absence of these explanations, however, respect is present, and ideas are accepted on the basis that an inability for Western science to produce an explanation does not mean one does not exist or that the ideas are invaluable. Now I lean heavily on the saying, “you don’t know what you don’t know” (Absolon, 2011, p. 10). Of course, I feel confident that I truly do know that comments on the quality (or lack) of my mustache are not directly relevant to vaccine promotion. On the other hand, there are clear examples of comments that are directly relevant to the research—for example, what a co-researcher is hearing from their community about vaccine concerns. That said, a grey area exists, and I imagine that the width of this area, while decreasing with experience, may never disappear. Within my grey area, there are also comments that I strongly believe are relevant but do not quite understand.

The grey area exists because I am not fully capable of understanding all that is shared with me or how it may be relevant to the research project at hand. Clearly clarification is needed. Ideally, this clarification arises by simply asking for further explanation during the engagement where the comments were offered. However, admitting you do not understand or are not following the conversation can be difficult, and interrupting a rapidly expanding conversation can be inappropriate and awkward. Sometimes, grey area comments must sit in a temporary space for future reflection and exploration. At the next appropriate opportunity, guidance can be sought on the

meaning of these comments from community members, co-workers, and mentors. Other times, the importance of a teaching or comment changes over time as more teachings are offered.

With researchers receiving community guidance, input, and approval throughout the project, it is assumed that the community will ensure relevant grey area comments are reflected in research. That said, this grey area is very real and relevant for me as a non-Indigenous researcher. Given its presence risks bringing bias and colonial practices into research, it was brought into this section and out of the wide grey area of importance informing this paper.

3.2.2 Gathering Knowledge—the Vaccine Project

I have little doubt that, throughout all the vaccine project's engagement, there was some knowledge that I failed to understand the importance of. Still, a separate publication concerning the project's results has been approved by the AC guiding the project. Here is one example of a comment that was offered, the importance of which grew considerably with time. While we were collaboratively developing the social media interventions with the AC, a co-researcher commented that anything we say must be respectful. It was easy to accept this, given that we are always guided by community and respect is one of the R's required for research with Indigenous Peoples. As more literature was read and sharing circle results emerged, however, the importance of respectful messaging grew. It is important to note that the co-researcher who shared this knowledge, from their world view, may still define the importance of respect differently here. As mentioned, being Western, my own understanding emerges from Western explanations. However, the importance of respect in this research context, as I understand it, is that people have legitimate concerns around vaccines, and the online anti-vaccine community has been shown to recruit undecided individuals far quicker than the pro-vaccine community (Johnson et al., 2020). In part, this is because anti-vaccine online groups (clusters) are more dispersed throughout online spaces and provide a larger number of sites for

engagement than pro-vaccine communities (Johnson et al., 2020). The result is that anti-vaccine clusters entangle themselves within the network of the vaccine hesitant in a manner that pro-vaccine clusters do not (Johnson et al., 2020). Therefore, if we fail to respect an individual's concerns around vaccines, the anti-vaccine community is present and ready to give people they respect they require.

Most knowledge informing the project was gathered while implementing research methods and during AC meetings. That said, there were instances in which far more informal engagement was needed to gather the knowledge and perspectives the project required. For example, one of the project's co-researchers was approached after a game of mini-putt for insights for final reporting. In this example, activities that help maintain the authentic relationships required for research also provided opportunities to gather knowledge. Engaging co-researchers at games such as mini-putt is far from the norm at the lab, as most engagement occurs during regularly scheduled AC meetings. However, when researching a broad topic like vaccination, it is quite possible that perspectives will be needed that do not exist within a previously formed AC. By continuing to rely on AC guidance to determine if additional perspectives are needed and, if necessary, in identifying those people with needed perspectives, research continues to respect AC knowledge and adhere to the TCPS-2 (CIHR et al., 2018, article 9.15).

In the vaccine project, one of the social media posts included a vaccination-promoting meme. While there are certainly Elders who are familiar with the meme format, the Elders on this project's AC were not, as was made abundantly clear by the awkward silence that followed attempts to get feedback. Thankfully, the AC interrupted my embarrassment by quickly making it clear that a younger perspective was needed. After the AC identified community youth who could be engaged, and then provided an introduction, research was able to proceed with the perspectives it required.

3.2.3 Gathering Knowledge Conclusions

Gathering knowledge, in the engagement-heavy reality of Indigenous research, extends far beyond that which occurs when performing typical data collection methods. Crucial data is gathered in the engagement that precedes research, occurs throughout it, and follows later analysis. Non-Indigenous researchers need to practise caution while weeding through all that is shared during authentic engagement. Further, just as community is engaged initially to identify who should be involved throughout a project, those identified may also recommend additional individuals to be engaged.

3.3 Making Sense

In the previous section, the treatment of knowledge (data) gathered during engagement was discussed. Here, experiences and observations will be shared relating to making sense of data gathered through formal data collection methods. During my time at the lab there has been limited use of quantitative data, making my experience with quantitative analysis with community members limited. Still, the general approach of including community members as much as preferred and possible remains relevant. Beyond that, the author is in no position to provide discussion. This subsection will focus on qualitative data, given that it is often the data preferred by the communities we work alongside.

As mentioned, the lab has relied almost exclusively on the NAKPA analysis procedure for qualitative data. The NAKPA process was described previously (2.3.3), but its reliance on community input, a panel format, and consensus should be reiterated. Firstly, community input is required by ethical guidelines. Further, as will be argued, the differences between Western and Indigenous world views can cause problems when qualitative data stemming from one world view is analyzed solely from the other. In Phase 2.3.3, it was mentioned that little experience is needed with the NAKPA procedure to see the potential pervasiveness of researcher bias in qualitative analysis without a panel format. This

idea will be expanded upon through discussing the experiences of the vaccine project.

3.3.1 Making Sense in the Vaccine Project

During the vaccine project's sharing circle, there were several complex quotes offered. While sorting these quotes with the NAKPA procedure, I was amazed at how many different ways any given quote could be sorted. After the first reading, I often had what I thought was a clear idea of where a quote should be thematically placed. As co-workers and community members offered their perspectives, however, it became clear that the analysis would look very different without the panel. Further, even between people with similar academic backgrounds, there are many ways to interpret qualitative data.

There was a wide diversity of opinions presented over the course of applying the NAKPA procedure to the vaccination project data. This appears to suggest that, depending on the composition of one's panel, the results of the following analysis could look very different. One purpose of the methodologies employed by the lab is to respectfully bring the voice of community into research. Given that the voice of the analyzers is certainly present when analyzing qualitative data, community inclusion in this process remains crucial.

Ultimately, the panel format introduced by CCDAP and NAKPA reduces the influence of any single person's biases over analysis. However, the composition of one's panel appears to also affect its results, meaning the panel cannot completely eliminate bias. Indigenous societies evolve—and as they do, it is reasonable for Indigenous methodologies to follow suit (Walter & Andersen, 2013, Chapters 3–5). Perhaps future evolutions of methods will be able to eliminate bias; however, given the current reality, it may be beneficial for those who participate in NAKPA analysis to provide self-location posts, similar in purpose and content to the one found at the start of this article. There are many benefits to qualitative data, and many benefits to analyzing it with NAKPA, but there may remain opportunities for improvement.

3.4 Sharing

After gathering knowledge and, with community's guidance, making sense of it, we are ready to begin considering how we will share the findings of our research. Given that the data informing these findings belongs to the community, how we interpret the data and report our interpretations requires community oversight, approval, and recognition (CIHR et al., 2018).

The question of how we share is inevitably influenced by academic pressures (Anderson & Cidro, 2019). Still, one should want to share in a manner that allows the greatest transmission of knowledge. If academic pressures limit sharing, creativity may be required. The Uncle Paul and Auntie Doris principle suggests that results should be meaningful to the Uncles and Aunties of a community and communicated understandably (Kovach, 2018). Indigenous scholars have described storytelling as a highly effective and accessible manner to convey meaning (Cidro, 2012). However, some may view storytelling as an oversimplification of data for the purpose of accessibility (Cidro, 2012).

The three-act structure is widely observable in the stories we read and watch (Field, 2005). The three acts are the set-up, the confrontation, and the resolution (Field, 2005). The academic contributions of a journal article are the resolutions to the confrontation presented by a previous gap in knowledge. The set-up is found in the introduction and background sections. Therefore, traditional Western academic knowledge translation contains elements of storytelling. The difference between academic knowledge translation and Western storytelling, therefore, is not necessarily in their underlying structural elements.

As I consider this section, I realize the hypocrisy of stressing accessible sharing while writing in a manner that is, subjectively, inaccessible to many. That said, the intended audience is relevant in determining how we share. This article's audience is not necessarily the Uncles or Aunties of any given community, unless they happen to work in academia...

Regardless of how sharing occurs, the question of whether publishing is appropriate is also relevant. As mentioned, the lab is driven by community—and the lab's experience is that the community's priorities rarely lie with academic publishing. When one project is completed, a new priority often becomes the community's focus. This presents a barrier to community participation in the writing of research articles. Furthermore, it can significantly limit the number of publications produced by principal investigators doing this kind of work. Therefore, the recognition that publishing quantity may not correlate with the quantity or quality of research done with Indigenous communities is imperative, especially for career advancement. When career advancement, and the influence that comes with the territory, relies largely on publications, those who do ethical work with Indigenous communities may be doing this important work at the sacrifice of their career's long-term trajectory within academia. Furthermore, with limited publications, securing the operating grants needed to support ethical research with Indigenous Peoples may be significantly affected. If the purpose of research with Indigenous Peoples is to provide meaningful and desired community benefit, publications do not appear a suitable manner to determine advancement in the field.

3.4.1 Sharing the Vaccine Project

This article has focused much on frequently experienced but rarely discussed challenges and barriers that are unique to ethical Indigenous health research. The vaccine project provided many examples of the rarely linear reality of Indigenous research. However, rarely linear does not mean never linear. When no threat to confidentiality was present, results were presented to the AC and confirmed over the course of research. Permission to prepare a publication was granted, and the early drafts were well received. Multiple community members were included as authors in the publication, and two in particular were heavily involved. This involvement brought new observations, confirmed interpretations, and added depth and relevance to the work. It can be difficult to include community members in the

lengthy process of publishing a research article, as described in 3.4. That said, when community involvement can occur, the work truly benefits.

Conclusion

Much exists to guide researchers toward ethical, self-determined research with Indigenous Peoples. Despite the tremendous value of these resources, researchers are still faced with barriers that guidelines don't fully address. Waiting until all barriers are lifted is not appropriate, and so, this article shares experience-derived approaches that can mitigate some risks. Describing anything as universally relevant to Indigenous Peoples risks pan-Indigenizing; however, prioritizing respectful and authentic relationships appears to be a universal compass that can guide researchers to a good way of doing research. Still, more consistent and honest reporting of barriers, failures, opportunities, and innovative community-led solutions may be needed to truly reflect the challenging realities of responsive, self-determined and ethical Indigenous research within colonial systems that do not always support the flexibility required. It is by sharing these experiences and barriers that colonial systems can be challenged by those who are working to straddle two world views and ways of knowing and doing while still meeting expectations in both. These systems require dynamic, understanding, and flexible processes in order to be responsive to the dynamic and complex requirements of ethical, responsive, and self-determined research, in order for their commitment to truth and reconciliation to be fully realized.

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