For Whose Benefit?

A Review of Indigenous Health Research Policies, Systems, and Practice in Canada

Authors

The Forum for Indigenous Implementation Research and Evaluation ("FIIRE") Network was established in 2014 as part of the Applied Public Health Chair in Indigenous Health and Information and Knowledge Systems (2015-2020) and funded through the Canadian Institutes of Health Research (CIHR) initiative, "Clearing the Pathways to Health Equity for Aboriginal Peoples" ("Pathways"). Led by Dr. Janet Smylie, the initiative brought Indigenous peoples and allies together to share knowledge and improve collective well-being. The FIIRE Network was a national knowledge network dedicated to Indigenizing public health intervention research and evaluation and as such, formed an integral part of Pathways. Core to the membership of FIIRE were the national and regional Indigenous governing bodies and organizations with mandates to represent the interests of specific Indigenous populations. The FIIRE Network's goal was to enhance the benefits of applied Indigenous public health intervention research for Indigenous populations.

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We acknowledge Christi Belcourt who has generously shared her artwork entitled: Honouring my Spirit Helpers – Baagitchigaway Manitouon. A mirrored pattern showcasing Indigenous plants including sunflowers, strawberry plants, and lily pads. In the middle, there are roots that expand to the bottom half of the canvas, which encompasses what is below water. Otters, fish, and plants can be seen underneath the water.

Preamble

From 2016-2019, the FIIRE Network collectively drafted the report *'For Whose Benefit? A Review of Indigenous Health Research Policies, Systems, and Practice in Canada'* through a process of consensus. The report captures the expertise, perspectives and experiences of network members regarding Indigenous health research policy and practice in Canada that were generously shared through interviews and focus groups held in 2015 as part of an internal baseline evaluation of the network.

The report has since served as an internal reference document for members of the network and in 2017, sections of the report informed Canada's Fundamental Science Review. As a network, we recognize the social value and the generative nature of the collective expertise and analyses contained within this report and in view of that, we have made the report available to the public with some caveats.

The details of the report reflect the state of Indigenous health research policy and practice in Canada at the time of its writing and as such, should be read and referred to with this in mind. As with all things, Indigenous health research policy and practice in Canada has not stood still – federal and provincial investments in the space have increased and opportunities for Indigenous agencies and organizations to access said funding has also made some advances. However, in practice, systemic biases and a general lack of accountability to the Indigenous peoples and communities who are intended to benefit, remain. As such, we think the recommendations summarized throughout the report continue to be relevant to the field of Indigenous health research in Canada.

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EXECUTIVE SUMMARY

Indigenous health research in Canada can help improve the health and wellness of Indigenous peoples. In practice, research policies and systems should promote Indigenous health equity. However, these policies and systems are diminished by inconsistencies, systemic biases, and poor transparency and accountability to the Indigenous peoples and communities they are intended to benefit. From the perspective of these communities, health research can often feel extractive, racist, unhelpful, and in many ways, a harm in-and-of itself. Indigenous health research is particularly problematic when it concerns Indigenous populations but is led or conducted by outsiders; when it is disconnected from the Indigenous contexts in which data is collected or which findings are to be applied; and when it perpetuates the structured political and social advantaging of non-Indigenous settler populations at the expense of Indigenous peoples.

Initiated collectively, this report is an act of harm reduction: a concept that Indigenous peoples have unfortunately had to rely on for over 500 years. In this report, we describe the overall failure of the health research community in Indigenous health research to establish, support, and maintain diverse, accountable relationships between government agencies, research sponsors, researchers, national and regional Indigenous governance bodies, and Indigenous communities. We provide an analysis of key barriers to good relationships in Indigenous health research. We also recommend that:

1) Research policies and guidelines be consistently initiated, implemented, and governed so that, at their core, they faithfully reflect community interests and priorities.

2) Concrete policy mechanisms be initiated to improve transparency and accountability in research practice.

3) Education, training, and mentorship programs be instituted to improve non-Indigenous peoples' awareness of systemic and attitudinal biases and their influence and impacts.

These recommendations are intended to inform and provide constructive guidance to the broader health research community, including government agencies, institutions, and research sponsors with interests in Indigenous health research. We contend that research relationships be structured as complex relational networks supported by a fluid network of resources, where Indigenous communities form the core, as depicted in Figure 2 (Page 54).

Throughout this report, we draw upon the experiences and expert knowledge of FIIRE Network members. While the majority are also members of Indigenous communities, at the FIIRE they sit as representatives of national, regional, and local Indigenous governing bodies and organizations. It is our hope that by sharing this report with diverse Indigenous communities we will encourage additional Indigenous voices to contribute to the dialogue, demand accountability in Indigenous health research from government agencies, research sponsors and researchers to Indigenous communities, and expand upon the recommendations we provide.

It is our intention that this report will encourage concrete improvements in research relationships, including the prioritizing of Indigenous communities in research that affects them. Collective action is required to address the significant gaps and challenges between existing Canadian research policies and systems that guide Indigenous health research, and what is actually occurring in practice.

Summary of Recommendations

1 Recommendations To Address Funding Limitations In Indigenous Health Research

We recommend evaluating and modifying existing funding priorities and protocols in Indigenous health research in Canada, including the following actions:

- **Increase funding for Indigenous health research so that it is proportional to the size of the Indigenous population in Canada and reflects the high degree of health and social inequity this population experiences. Funding must also recognize the need to strengthen Indigenous capacity toward self-sustainability. For example, as per the AHRSC (Aboriginal Health Research Steering Committee) recommendation, the goal should be 9.2% of CIHR's total budget.**

- **Collaborate with regional and national Indigenous governance and advocacy bodies, and Indigenous communities, to develop an evidence-based, mandated policy that allocates and makes available the necessary financial resources to meet the requirements of community consultation and engagement as well as knowledge translation (e.g., clearly allocate line items for these activities in research budgets).**

- **Review indirect funding policies at research institutions so that all research partners have access to indirect funds.**

- **Ensure that community interests are reflected in compliance mechanisms and in metrics for obtaining and maintaining research funds. Funding agencies should work with Indigenous communities to identify and prioritize these oversight tools (e.g. quarterly community assessments of research projects).**

- **Revise existing federal funding policies to recognize regional and national Indigenous governance and advocacy bodies and community-based programs as eligible applicants for health research granting programs.**

- **Expand funding criteria for applicants to include alternate metrics for success beyond classic classic academic metrics such as publications (e.g. community engagement, mentorship, advocacy)**

Summary of Recommendations

2

Recommendations To Improve Governance and Oversight Of Indigenious Health Research

We recommend that the following governance and oversight policies be initiated in Indigenous health research in Canada, with the overall goal of creating Indigenous self-governed or partnered mechanisms:

- **Establish an independent Indigenous health research ombudsman tasked with responding to submitted complaints as well as conducting social audits of provincially and federally funded research programs.**
- **Mandate universities (and other research centres) to be more coordinated and responsible for research-community partnerships.**
- **Mandate community-academic research agreements that clearly outline roles and responsibilities; ownership and control of data; and financial support and funding allocations.**
- **Establish reporting guidelines with peer-reviewed journals that require researchers who submit their research for publication to include a description of how they consulted, engaged, and partnered with Indigenous community**
- **Incentivize collaborators to support Indigenous leaders and -led organizations to develop Indigenous 'community bills of rights' that incorporate principles of respect, reciprocity, and self-governance, but ensure that the resulting document(s) are customized and relevant to local contexts.**
- **Initiate sustainable programming—in partnership with Indigenous leadership—that encourages and enables Indigenous communities to strengthen community-based research capacity and expertise.**
- **Partner with Indigenous organizations and community leaders in order to establish core funding for permanent community-based (or regionally based) knowledge partners. Develop a national or regional brokering mechanism for Indigenous communities and researchers to initiate partnerships in research. (i.e. NaNaandawewigamig[2])**
  .
- **Establish a social-auditing program to oversee federal and provincial research programs. A social audit that is conducted collaboratively with members from government agencies, sponsors, and Indigenous-led organizations, at the community level, would provide an oversight tool to monitor research practice and establish accountability.**

Summary of Recommendations

3

Recommendations to Address the Power Imbalances Present in the Indigenous Health Research Ecosystem

- **Establish efforts to address policy shortfalls regarding the setting of Indigenous health research priorities and strategies (e.g., co-design, research registries)**
    - **Focus on approaches that are strengths-based rather than deficit-based**
- **Facilitate and resource knowledge sharing through mandated research agreements**
    - **Support Indigenous communities and organizations to develop and implement community-level practices of knowing and doing (e.g., horizontal sharing), building on existing Indigenous methods**
    - **Knowledge translation conducted by those external to Indigenous community should be communicated through face-to-face interactions; accessible, relevant, and safe; and have knowledge champions located within communities**
    - **Allocate resources to communities so they are able to staff research projects with local knowledge keepers and brokers**

- **Facilitate and resource knowledge governance through mandated research agreements.**
    - **E.g., legal research agreements and contracts between communities and the research community**

- **Facilitate and resource reciprocal relationship building**

Summary of Recommendations

4

Recommendations to Address Structural and Lateral Violence in Indigenous Health Research

- **Cultural safety certification as a pre-requisite for non-Indigenous researchers and non-Indigenous staff at federal and provincial health research institutes and agencies**

- **In partnership, develop Indigenous health components for secondary and post-secondary schools to raise awareness**

- **Establish training and mentorship programs to develop non-Indigenous research partners' skill sets in Indigenous worldviews, ethical space, and other skills related to lived experiences of Indigenous peoples.**

INTRODUCTION

Scope and Purpose of the Consensus Document

Widespread health and social inequities persist between First Nations (status and non-status persons living both on and off reserve, across nations, and in urban, rural, and remote geographies) Inuit, and Métis people—collectively referred to as Indigenous peoples—and non-Indigenous peoples in Canada. These inequities are often illustrated through statistics that reveal disparities such as consistently higher rates of chronic disease and non-communicable diseases in Indigenous populations (Anderson et al., 2016; King, 2011; Smylie & Firestone, 2016).

Health research alone will not resolve health inequities. Political commitments and action are necessary to redress the serious, intractable issues associated with colonization (Smylie & Firestone, 2016). The Truth and Reconciliation Commission of Canada (TRC, 2015a) documented the link between colonial governmental policies—such as residential schools, forced community relocations, the outlawing of Indigenous cultural practices, and child welfare apprehensions—and Indigenous and non-Indigenous health inequities. Historically, these policies were part of an explicit federal goal to assimilate Indigenous people into European settler society. This approach failed. While its legacy is apparent, Indigenous peoples in Canada not only persist as distinct nations, they continue to maintain a strong sense of identity and a rich diversity of knowledge and practices.

Health research can contribute to the reduction of existing health inequities by establishing an informed evidence base. Indigenous health research differs from mainstream health research. It requires that additional attention be paid to issues of equitable access to health care resources, unique social determinants of health, and acknowledgement and awareness of the intergenerational impacts of dispossession and colonialism (Kolahdooz et al., 2015; Smylie & Firestone, 2016).

This consensus report forms the FIIRE Network's commentary on Canadian health research policies and systems as they apply to Indigenous health research. It makes direct reference throughout to policies and systems at federal, provincial, territorial, and institutional levels. For example, Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, "Research Involving the First Nations, Inuit and Métis Peoples of Canada" ("TCPS 2–9") and the Canadian Institutes of Health Research (CIHR).

In Canada, the policies and systems that guide and support health research with and about Indigenous people place a significant emphasis on establishing and maintaining relationships with Indigenous communities.[1] Despite this relational emphasis, in practice, Indigenous peoples and their communities continue to experience exploitation and harms due to research. One of the legacies of these harms is a persistent lack of trust between Indigenous peoples and the various non-Indigenous organizations, agencies, and individuals with interests in Indigenous health research.

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[1] We draw on the United Nations description of Indigenous communities, peoples, and nations as those "having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them" noting that in Canada, inherent, treaty, and land claim rights of Indigenous peoples have been asserted and recognized. For a full definition see "1981: Martínez Cobo Study": https://www.un.org/development/desa/indigenouspeoples/about-us.html

For example, two national commissions, the Royal Commission of Canada on Aboriginal Peoples (Canada, 1996) and the Truth and Reconciliation Commission (TRC, 2015) as well as infamous examples of bad research (Mosby, 2013; Wiwchar, 2004), characterize ongoing breaches in trust between Indigenous peoples and non-Indigenous governments and institutions within the context of health research (see also Aboriginal Health Research Steering Committee [AHRSC], 2015; Eggertson, 2015a, 2015b, 2016; Webster, 2012, 2015). Although engagement with Indigenous peoples has at times informed these research policies and processes, many government and institutional policies remain non-Indigenous: they are neither initiated nor governed by Indigenous peoples, and as such, often fail to acknowledge Indigenous peoples' systems of knowledge.

The commitment by the federal government to improve the lives of Indigenous peoples living in Canada through reconciliation – renewing its relationships with Indigenous peoples in Canada, through respect, cooperation, and partnership – provides a unique opportunity to share the FIIRE Network's expertise and initiate further dialogue to improve existing policies and systems that guide and support health research with, and about, Indigenous peoples. This exercise is essential given the climate of dissonance between members of federal, provincial and territorial government agencies, the health research community, and Indigenous communities.

Throughout this report we focus on relationships, particularly those with Indigenous communities, as we believe them to be key to the wise practice of Indigenous health research **(see Textbox A).** Relationships are fundamental to the truth and reconciliation process. The TRC defines reconciliation as "an ongoing process of establishing and maintaining respectful relationships" (2015, p. 16). We understand that respectful health research relationships are premised on the equitable sharing of power and resources—a state not yet achieved by research systems in Canada.

In order to realize this equitable state, we support Indigenous community control of Indigenous health resources, including health research resources. We view Indigenous community control over all Indigenous research in Indigenous communities as a necessary end to achieve the ultimate goal of self-determination, and believe that all research policies should recognize and support this goal (TRC, 2015).

The analysis in this report is based on a series of interviews, focus groups, and meetings with—and between—FIIRE Network members, and is supported by a directed review of peer-reviewed literature. Through our analysis, we identify critical barriers to good research relationships in Indigenous health research, including the limitations of research funding, gaps in governance, the presence of power imbalances, and systemic racism.

Throughout the analysis, wise and promising practices feature along with recommendations. A discussion outlining why we believe relationships are critical to the success of Indigenous health research follows the analysis. We assert that in practice, research relationships should always have Indigenous communities at their core. We contend that this is a reality not presently occurring. Our intention is that this report will further the dialogue toward action—not rhetoric—that will prioritize Indigenous communities and address significant gaps and challenges between what is envisioned in existing Canadian policies and systems that guide Indigenous health research, and what is actually occurring in practice.

The FIIRE Network agrees that wise practices in Indigenous health research include:

Recognizing, respecting, and supporting the rights of Indigenous communities to self-determination in research, including:

- **Prioritizing, establishing, and facilitating engagement and partnerships with communities throughout the research cycle.**
- **Recognizing and addressing the limited resources and inequities (e.g., power imbalances between communities and research or funding institutions) faced by community partners, and facilitating capacity strengthening[3] and the systems-change necessary to redress them.**
- **Recognizing, respecting, and supporting Indigenous- and community-led research and data oversight policies (e.g., Ownership, Control, Access and Possession [OCAP®] and Indigenous research ethics protocols and committees (e.g., community research ethics guidelines).**
- **Recognizing and respecting cultural safety.[4]**
- **Facilitating knowledge translation in a respectful, reciprocal, and meaningful manner; that is, communities must derive social and concrete value from the research that they choose to partner on.**

Textbox A | Wise[2] and Promising Practices for Initiating, Establishing, and Maintaining Good Relationships in Indigenous Health Research

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[2] The term 'wise' is used here in place of 'best' or 'evidence-based' so that Indigenous knowledge and practice, which often rely on experiential proofs, are included as core sources of information in addition to evidence emerging from universities and non-Indigenous sources (Well Living House, 2017).

[3] We agree with Potter and Brough (2004) that 'capacity building' is too often reduced to "little more than training" (p. 336). Instead, they argue that capacity building should be examined through a systems-lens and include: "(1) structures, systems and roles, (2) staff and facilities, (3) skills, and (4) tools" (p. 336). However, we prefer capacity 'strengthening' to 'building' as 'strengthening' acknowledges the skills, expertise and knowledge that communities bring to a new research relationship.

[4] In this report, we define cultural safety as the relationships and spaces where Indigenous people feel comfortable, respected, and able to be themselves. Using this definition, cultural safety can be self-determined and context dependent. For example, Native Youth Sexual Health Network (NYSHN) defines cultural safety as follows: "To us this means that it is our birthright to feel safe and be our whole selves when we're in any space(s). Indigenous nations are not all the same. We have the right to talk and share about our different cultures, spiritualities, teachings and the realities of our own communities when we talk about our bodies. It also means that reclamation and restoration of this includes addressing how colonization has impacted the cultures around our bodies": https://www.nativeyouthsexualhealth.com/what-we-believe-in

Methods

This report was initiated, developed, and finalized through a process of consensus. Input and participation on data sources, analysis, and writing was sought from all FIIRE Network members. We tell of our own experiences with health research policies, systems, and practices that guide research with and about Indigenous peoples and communities. We engaged members both collectively and independently—repeatedly—and in a respectful manner. We used a mixed methods approach.

First, we included a thematic analysis of 18 semi-structured qualitative interviews held with 19 FIIRE Network members. These interviews were transcribed verbatim and subsequently edited and approved by the participants. We also included an analysis of a focus group held with members.

Second, we included a synthesis of workshops, meetings, and discussions with FIIRE Network members. In our thematic analysis, we employed a critical, decolonizing analytic lens (see Attride-Stirling, 2001; Smylie et al., 2009 for more detail) to represent the concepts and ideas as they were understood by the FIIRE Network members who shared them.

Third, we carried out a directed review of relevant, scholarly peer-reviewed literature on Indigenous health research in Canada generated from 2010 to 2016 (201 marked the release of TCPS–9, widely perceived as one of the more influential standards for Indigenous health research in Canada). See Appendix A for more detail.

The recommendations in this report are intended to inform and provide constructive guidance to the broader health research community, including government agencies, institutions, and sponsors with interests in Indigenous health research.

This report draws on the experiences and expert knowledge of FIIRE Network members. While the majority are also members of Indigenous communities, at the FIIRE they sit as representatives of national, regional, and local Indigenous governing bodies and organizations. It is our hope that by sharing this report with diverse Indigenous communities we will encourage additional Indigenous voices to contribute to the dialogue, demand accountability, and expand upon the recommendations we provide here. In health research with or about Indigenous peoples, Indigenous communities are the least empowered and are rarely treated fairly as partners. Yet, these very communities have the most to lose and gain through health research.

UNDERSTANDING AND ADDRESSING BARRIERS TO GOOD RELATIONSHIPS IN INDIGENOUS HEALTH RESEARCH

In Canada, Indigenous health research relationships between Indigenous communities, national and regional Indigenous governing bodies and organizations, researchers, government agencies, institutions, and research sponsors are strained. This concern surfaced in interviews held with FIIRE Network members and is further supported in public discourse (see AHRSC, 2014; Eggertson, 2015a, 2015b, 2016; Webster, 2012, 2015) and peer-reviewed literature (Castleden et al., 2015; Flicker et al., 2015; Moore, 2015; Steigman & Castleden, 2015). Drawing on these expert observations and experiences, we highlight the issues that are contributing to this strain and how they result in the breakdown of relationships between various institutions and individuals involved in Indigenous health research.

Here, we identify four interrelated and interconnected themes that form critical barriers to developing and sustaining the complex relational networks and fluid resources essential to wise practices in Indigenous health research. These four themes are:

- funding constraints that have increased tensions among those with interests
- lack of adequate governance and poor adherence to policies and guidelines
- power imbalances that marginalize Indigenous organizations and communities
- systemic racism and the lack of cultural safety in research and health settings

As a collective, we consider these themes to be among the most pressing concerns in Indigenous health research policy and practice. Throughout this report, we reference case studies and provide recommendations based on our own expertise as well as existing wise and promising practices. We hope that our analysis will serve as a starting point for dialogue between the many stakeholders in Indigenous health research and move the dialogue toward actionable change.

Funding Constraints in Indigenous Health Research

Funding constraints exacerbate strains in the Indigenous health research ecosystem in Canada. As voiced by one FIIRE Network member, “there isn’t enough time or space to … continually build and strengthen our relationships and our partnerships. Because I think we’re always under these strains of time pressures and funding pressures, and whether we like it or not, competition around a small pot of resources and funding that only comes from a few places now.”

Efforts to improve the quantity and quality of funding, while commendable, have been moderate. Federal, provincial and territorial funding policies[5] for Indigenous health research are inconsistent, lack transparency and can be controversial (e.g., where required to match funds, specifically with extractive industries). Together, these properties undermine the quality of research, creating barriers to establishing the necessary infrastructure and systems—including complex relational networks and fluid resources—required to initiate, establish, and sustain relationships.

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[5] The vast majority of funding for Indigenous health research in Canada is distributed by three federal funding agencies: the Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council (SSHRC), and the Natural Sciences and Engineering Research Council (NSERC). To a lesser degree, funding is also distributed through Health Canada, some provincial and territorial agencies, and private foundations.

For example, a rash of funding cuts in recent years to national and regional Indigenous governing bodies have limited these organizations' capacity to facilitate relationships and advocate on behalf of communities. They have also placed Indigenous scholars at a disadvantage compared to their non-Indigenous counterparts and increased the risk of tokenism[6] in research programs and institutions. At times, federal and provincial funding policies contradict research policies that guide practice in Indigenous health research (e.g., TCPS 2–9).

Efforts to improve the quantity and quality of funding have been moderate. In 2006, CIHR created the Institute of Aboriginal Peoples' Health (IAPH) to investigate "factors that will improve the health and well-being of Aboriginal people living in Canada through supporting development of Aboriginal health research and ensuring that research undertaken is relevant to meeting the needs of Aboriginal communities"[7] (CIHR, 2006, "Introduction"). From 2008 to 2016, IAPH invested $85,825,478 CAD[8] in Indigenous health research—a large amount overall, yet when spread across nine years it amounts to less than $10 million per year. In contrast, the CIHR budget is approximately $1 billion per year. The bulk of this (approximately 70%) is spent on highly competitive, investigator-led research. The remaining 30% is referred to as priority-led research and is shared across the CIHR Institutes.[9]

Statistics Canada puts the Indigenous population within Canada at 4% (2015),[10] an underestimate considering that urban Indigenous populations have been undercounted (Rotondi et al., 2016; Seventh Generation Midwives Toronto & Well Living House, 2016). If CIHR expenditures on Indigenous health research were reflective of the population, expenditures would be roughly $40 million per year: a minimum of $12 million invested in priority-led research and an additional $28 million in investigator-led.

Given the significant health inequities between Indigenous and non-Indigenous populations in Canada, CIHR's allocation toward Indigenous health research should, using an equity lens, be higher. The Aboriginal Health Research Steering Committee (AHRSC) has estimated that altogether, Indigenous health research accounts for just over 3% of CIHR's total expenditures (Webster, 2015). CIHR has also been investing less in Indigenous health research over time: from 2007 to 2008, they invested $34 million; from 2014 to 2015, it was $31 million (Eggertson, 2016).

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[6] Alycia Fridken (2016) provides a nuanced take on tokenism in her work on meaningful involvement in health policy decision-making – she argues that it may serve as a positive starting point, if the effort is reflexive in nature but will require ground rules to "mitigate silencing and racism". (Fridken, 2016).

[7] For more information about IAPH, see: http://www.cihr-irsc.gc.ca/e/9188.html

[8] For IAPH's breakdown, see: http://webapps.cihr-irsc.gc.ca/cfdd/db_results_submit; the invested amount was calculated by selecting IAPH (now IPH) from the Institute/Theme drop box and calculating the total number of grants distributed during the timeline.

[9] For more detail about CIHR budgetary estimates and strategic plans see: http://cihr-irsc.gc.ca/e/49658.html

[10] For more detail about these Indigenous population estimates in Canada see the archived Aboriginal Peoples: Fact Sheet for Canada at: http://www.statcan.gc.ca/pub/89-656-x/89-656-x2015001-eng.htm

Indigenous researchers, governing bodies, and communities have expressed serious concerns about these funding cuts and their effect on Indigenous health research (AHRSC, 2014). In response, the federal government has committed to increasing the level of funding to 4.6% of CIHR's expenditures (AHRSC, 2016). However, in a 2016 briefing note regarding CIHR addressed to the Indigenous research community from the AHRSC, the authors recommended, "that the 4.6% grow to 9.2% in recognition of the additional burden faced by Indigenous communities to achieve comparable levels of health and well-being" (AHRSC, 2016)**.**

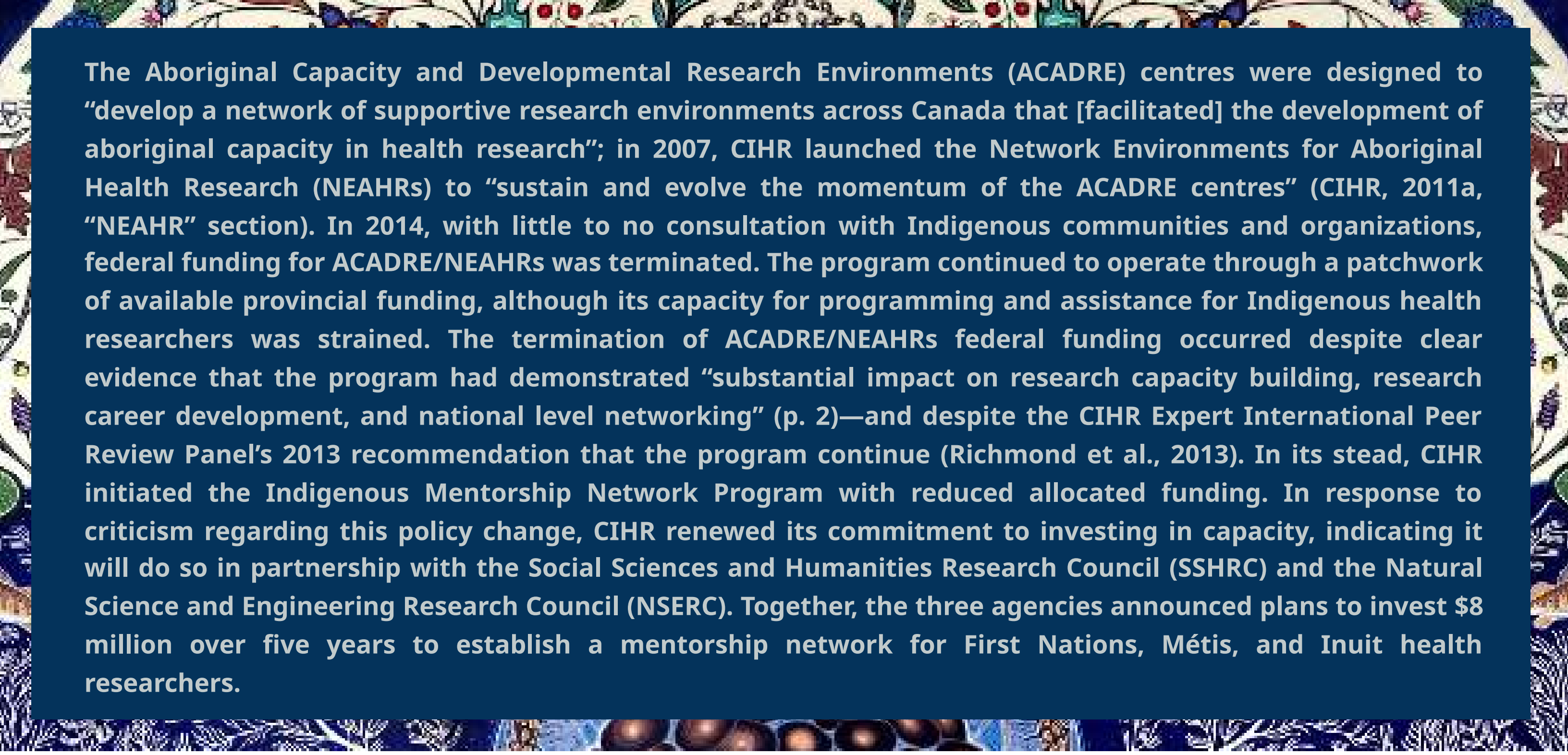
Federal and provincial funding policies for Indigenous health research are inconsistent, and inconsistent policies undermine the quality of research. For example, they impact the sustainability of programs and create barriers to establishing and maintaining infrastructure and systems, including the complex relational networks and fluid resources needed in Indigenous health research. To quote a FIIRE Network member who is an active public health researcher, "there isn't a lot of consistent funding. You know, it's year-to-year. Nobody knows what is happening next, and [if] they're going to just pull the carpet out from under [our] feet and then … and then what?"

The logical conclusion is that research partnerships and resulting networks that were years in the making are lost. In addition, where there is funding, it is limited. A FIIRE Network member from a national Indigenous governance and advocacy body said, "I don't know whether they just give you barely enough to … make you stand up, but not enough to let you propel yourself forward, or … nobody ends up getting enough money to move anything forward."

Under these conditions, relationships become fragmented, in effect erasing the gains in social capital (e.g., trustworthiness between actors) that can contribute to growth and innovation in a given field or sector (Adler & Kwon, 2002). As explained by a FIIRE Network member who works in government, it is, "very difficult to restart something. It just takes time to re-build, you know. Those kinds of networks. Once a network or group [loses] its funding … if they [lose] the funding then they have no resources or cease to exist. They can't help improve the health of Indigenous peoples and communities through that network anymore."

David Newhouse put it best in his 2014 open letter to the Governing Council of CIHR: "This is not the time to change course or emphasis or dilute the effort…. While gains have been made, these are fragile and still require nurturing and support. Without it, the research capacity that has been carefully nurtured will begin to dissipate and within another decade we will be launching another program to rebuild it" (AHRSC, 2014, p. 31).

Federal and provincial funding policies for Indigenous health research lack transparency. *At one point, global experts assessed CIHR's Indigenous health research programs as being progressive and necessary to positively transform the field (Robertson et al., 2013). For example, the Aboriginal Capacity and Developmental Research Environments (ACADRE) centres and Network Environments for Aboriginal Health Research (NEAHRs)* ***(see Textbox B)****. Despite the global experts' assessment, p*rograms were initially slated to be cut with little to no consultation with national and regional Indigenous governing bodies or communities. As one FIIRE Network member remarked, "and so they're [IAPH] doing great and they are told don't change anything and … so changing something that's working well doesn't really make a lot of sense. So [it is] understandable that members of the community are really frustrated."



The Aboriginal Capacity and Developmental Research Environments (ACADRE) centres were designed to "develop a network of supportive research environments across Canada that [facilitated] the development of aboriginal capacity in health research"; in 2007, CIHR launched the Network Environments for Aboriginal Health Research (NEAHRs) to "sustain and evolve the momentum of the ACADRE centres" (CIHR, 2011a, "NEAHR" section). In 2014, with little to no consultation with Indigenous communities and organizations, federal funding for ACADRE/NEAHRs was terminated. The program continued to operate through a patchwork of available provincial funding, although its capacity for programming and assistance for Indigenous health researchers was strained. The termination of ACADRE/NEAHRs federal funding occurred despite clear evidence that the program had demonstrated "substantial impact on research capacity building, research career development, and national level networking" (p. 2)—and despite the CIHR Expert International Peer Review Panel's 2013 recommendation that the program continue (Richmond et al., 2013). In its stead, CIHR initiated the Indigenous Mentorship Network Program with reduced allocated funding. In response to criticism regarding this policy change, CIHR renewed its commitment to investing in capacity, indicating it will do so in partnership with the Social Sciences and Humanities Research Council (SSHRC) and the Natural Science and Engineering Research Council (NSERC). Together, the three agencies announced plans to invest $8 million over five years to establish a mentorship network for First Nations, Métis, and Inuit health researchers.

Textbox B | Aboriginal Capacity and Developmental Research Environments Centres and Network Environments for Aboriginal Health Research

In response to criticism from the Indigenous research community (AHRSC, 2014), CIHR committed to meeting annually with leaders from the Assembly of First Nations, Métis National Council, and Inuit Tapiriit Kanatami. In addition, AHRSC recommended that Indigenous peoples be better represented in CIHR's decisions. One possible solution is to appoint Indigenous members to CIHR's governing council (AHRSC, 2016). These first steps are necessary but not sufficient. Indigenous communities are not homogenous and have diverse needs; as such, they will need to be included in a more direct way in these processes.

Controversial government research funding policies have undermined Indigenous communities' needs and interests. For example, CIHR has a 'matching funds' policy for some of its research grants. Grantees are thus required to source external funds from additional sponsors— private and not-for-profit sectors, for example—or reduce costs through in-kind contributions (Eggertson, 2015a). In Indigenous health research, this policy creates two primary barriers to achieving health equity while also harming the interests of Indigenous communities.

First, eliciting matching funds for Indigenous health research from the private sector can be difficult to impossible, as the research mainly focuses on issues of health disparity. These are complex and systemic issues where research translation is considered difficult, reducing financial incentives for private sector investment. This area is chronically underfunded, as we have already argued, so having to seek out matching funds increases the burden of research when the goal should be to reduce or avoid burden altogether. Thus, if grantees are unable to obtain matching funds, it may have the effect of reducing available funding opportunities, further marginalizing an already marginalized population (Eggertson, 2015a; AHRSC, 2014).

Second, the matching funds requirement can impede Indigenous communities' right to self-determine as partners in research. Researchers may not be required to disclose their funding to their community partners, potentially compromising the interests of Indigenous communities if that funding is sourced from companies or foundations whose interests are in conflict with those communities. For example, oil and mining industries, with whom many Indigenous communities are in dispute.

More general federal funding cuts to national and regional Indigenous governing bodies and organizations limit their capacity to facilitate relationships and advocate on behalf of communities. Since 2012, many have seen their funding cut. In some cases, this has resulted in organizations deprioritizing or eliminating available programs and services, including health research platforms such as the Native Women's Association of Canada and Pauktuutit Inuit Women of Canada (Eggertson, 2015a; Webster, 2012).

In a few instances, some organizations, such as the Canadian Indigenous Nurses Association (CINA), have rallied support through advocacy campaigns to request sustainable funding. CINA's effort resulted in a small increase in funds that prevented it from closing its doors, but also attached new project deliverables. Other organizations, like the Canadian Aboriginal AIDS Network (CAAN), who had 70% of their funding from the Public Health Agency of Canada (PHAC) cut, have secured short-term reprieves in response to public criticism **(see Textbox C)** (PHAC, 2016). Still, some organizations—for example, the National Aboriginal Health Organization and the Aboriginal Healing Foundation—have been forced to close their doors and cease operations altogether, resulting in a loss of valuable, tacit knowledge bases, expertise, capacities, and partnerships that were many years in the making (AHRSC, 2014; Eggertson, 2015a; Webster, 2012).

The widespread decline in funding available to national and regional Indigenous governing bodies and organizations that provide leadership in Indigenous health research risks reversing the gains made over the past decade to strengthen the voice of Indigenous communities. It does so, in part, by de-legitimizing and marginalizing these organizations. As one member aptly put it, "the government is not sympathetic to [Indigenous-led] organizations … we're professionals, you know, we should be more visible. We should have more staff to help us do the work we do; [to] do research, do recruitment, inspire others, you know, and [teach] others.... We want to support communities. You know, how can we do that when our organizations [are not] able to advocate?"

The Canadian Aboriginal AIDS Network (CAAN), a not-for-profit coalition founded in 1997, provides leadership, support, and advocacy for Indigenous people living with and affected by HIV/AIDS. In 2016, their annual funding was cut from $750,000 to $250,000 (CBC, 2016). In response, their sponsor, the Public Health Agency of Canada (PHAC), stated that they had increased investments in Indigenous organizations (from 19 to 24 total organizations funded with a net increase of $1.8 Million), pointing out that their priority was to invest more in local versus national programs (CBC, 2016). CAAN has since launched an advocacy campaign, arguing that the funds they received were necessary to "initiate national programs and partnerships which provide the critical Indigenous connection, perspective, and capacity required for equitable health solutions and wise investment strategies that are beyond the reach of governments alone and require Indigenous, private sector and other supports as well" (CAAN, 2016). PHAC's decision, they wrote, "decimates the leading voice of First Nations, Métis and Inuit peoples living with HIV or AIDS and organizations that are members of CAAN and will have far-reaching consequences on both Indigenous health and reconciliation" (CAAN, 2016). It may be reasonable to expect that regionally led initiatives should have priority over national programs; however, according to those involved the eligibility for funding changed and CAAN was placed in direct competition for resources with non-Indigenous organizations. Alternatively, PHAC could have held public consultations with Indigenous communities and leaders prior to changing their funding policy, especially given the overall impact these cuts may have had on capacity and sustainability of services and programs. The federal Ministry of Health has since intervened and requested that all organizations focused on HIV and hepatitis C and slated to lose their funding be extended through to March 31, 2018, providing CAAN with a 1-year reprieve (PHAC, 2016).

Textbox C | The Canadian Aboriginal AIDS Network Case Study

Research has shown that “incorporating research into the policy and advocacy work of community-representative bodies means they are better placed to promote policy reform long after traditional research institutions would have moved on to different themes and contexts” (Lea et al., 2005, p. 106). These federal cuts to Indigenous organizations will reduce their capacity to promote policy reform while also limiting their ability “to partner with researchers and to fully actualize the Aboriginal health-care agenda in Canada” (Gregory & Harrowing, 2012, p. 16).

Dual criticisms arise from this funding context. Most obviously, there is an important gap between available funding for Indigenous health research and the funding necessary to meet the health needs of a large and growing percentage of the Canadian population. However, perhaps more importantly, there has been a failure to recognize that these necessary funds are part of a larger fiduciary responsibility held by the federal government to promote and assist Indigenous peoples toward self-determination. Overall, these funding programs are often poorly matched for the growth and resource needs of regional and national Indigenous governance and advocacy bodies. This undermines the eventual self-sustainability of these bodies.

In recent years, the federal government’s approach has improved. In 2016, the federal government announced its proposal to invest $96 million over five years and an ongoing $10 million “to support the capacity of Aboriginal Representative Organizations to engage with the Government” (Indigenous and Northern Affairs Canada, 2016, “Engaging with Indigenous Peoples”). Additionally, in 2017, the federal government proposed a $13.7 million investment over two years for “permanent bilateral mechanisms” to establish nation-to-nation capacity between the federal government and the Assembly of First Nations, Inuit Tapiriit Kanatami and self-governing Inuit groups, and the Métis National Council and its governing members (Department of Finance, 2017, p. 165). These investments, although beneficial, will neither immediately nor fully address the damage inflicted by the 2012 cuts. As we have highlighted, these resulted in the loss of valuable, tacit knowledge bases, expertise, capacities, and partnerships that were many years in the making. These disruptions will take many years to rebuild and will require that the federal relationship with Indigenous peoples is consistent. As the CAAN case study **(Textbox C)** demonstrates, policy inconsistencies and shifting mandates continue to be a problem, regardless of proposed federal budget commitments.

Funding cuts place Indigenous scholars, organizations, and communities at a disadvantage and increase the risk of tokenism in research programs. CIHR, for instance, earmarks most of its open funding calls for “established and ‘star’ scholars,” placing less established Indigenous scholars at a disadvantage (Eggertson, 2015a, p. 97).

Attempts to unpack this problem and develop alternative metrics for evaluating scholarly success and career advancement more generally have begun in earnest across various academic disciplines.[11] However, Castleden et al. (2015) note that “simply reforming tenure and promotion processes to encompass a broader array of metrics to assess merit fails to address the reality that some things (such as the authenticity of relationships) defy conventional forms of measurement, and attempting to do so is merely a return to the sort of post-positive Eurocentrism we have been critiquing” (p. 16). Indeed, one FIIRE Network member stated that they would “like to see more First Nations researchers involved. Whether they’re credentialed by the academy or not, they’re recognized by their own community.”

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[11] For more detail on alternative metrics see: https://www.cwauthors.com/article/Understanding-alternative-research-metrics

These quotes hint at relational accountability as a more meaningful measure to assess merit than academically recognized metrics that denote a scholar as established. They also highlight the need to develop promising alternatives to alleviate the disadvantages faced by Indigenous scholars when they attempt to access funding.

Academics also point to the constraints of a university-based system that incentivizes research. For example, the bias of tenure and promotion committees who make decisions based on number of peer-reviewed publications, citation indices, and acquired research funds. Scholars highlight how this system fails to capture the needs of relationship-based and community-focused heath research, such as relational accountability (Castleden et al., 2015). The effect, they argue has, “the potential to create conflict between researchers’ relational accountability to Indigenous community partners, and their academic accountability to their disciplines and peers” (Castleden et al., 2015, p. 2).

Government funding opportunities are biased toward institutions. In addition to marginalizing Indigenous scholars, the current system also limits access to funding for Indigenous-led organizations, programs, and communities. For example, CINA is frequently invited to attend national and provincial dialogues on Indigenous health research in an advisory role **(to learn more about CINA, see Textbox D).** This role pushes them to give advice but requires them to negotiate the system to meet their own research needs. FIIRE Network members who represent regional and national Indigenous governance and advocacy bodies described the invitation to act as advisors, provide insight, or review draft grant applications as exploitation. They remarked how they were limited to these roles because their lack of resources and credentials make them ineligible for many grants. One member summarized their advisory experiences as “very undermining, very marginalized … we [our organization] heavily informed the process and content and we did not get full credit … we need to get out of that advisory capacity and we need to develop a strong partnership.” In response to this growing concern, CINA developed a partnership accord with their sister organization, the Canadian Nurses Association, in 2016.

The Canadian Indigenous Nurses Association (CINA) is the first and longest running not-for-profit Indigenous health professionals’ organization. CINA was established in 1975 out of the recognition that Indigenous health professionals can best meet Indigenous peoples’ health needs. Their mandate is to improve the health of Indigenous peoples by supporting Indigenous nurses through the development of Indigenous health nursing. CINA’s strategic activities in Indigenous health research and education have resulted in a memorandum of understanding with CIHR-IAPH (2009) and, most recently, a partnership accord with the Canadian Nurses Association, signed in 2016. These partnerships outline ways of ‘working together’ that support Indigenous nurses to reclaim their own Indigenous knowledge, languages, and laws, and support reclaimative processes through program and research practices that recognize unique expertise.

Textbox D |The Canadian Indigenous Nurses Association (CINA)

The same FIIRE Network member specified that one of the reasons partnership must be encouraged is also one of the main reasons why it is avoided: the sharing of resources. “Nobody’s named it yet but that’s what I see as the underlying issue. Because, once we sign that partnership accord, then we have to open up a discussion on sharing resources, right? So, if they apply for a million-dollar grant, are they willing to share some of those resources with [our organization] so that we could work together on that?”

Nearly all funding opportunities in Indigenous health research require the applicant to have an academic appointment with a university or medical institution in order to receive funding. There are some instances, although limited, where communities registered as not-for-profit entities can apply for funding. However, in these instances, the process of applying for institutional eligibility has been described as “so burdensome as to be prohibitive” (Brunger & Wall, 2016, p. 1873).

These examples illustrate how government-funding policies can increase incidences of tokenism, particularly when there is little accountability in place. Researchers are known to engage or collaborate with Indigenous communities merely to ‘check a box,’ failing to account for Indigenous communities’ interests and priorities. There continue to be many examples of how this plays out in the Indigenous health research ecosystem.

“There [were] a few people who [had] reached out to us [an Indigenous agency] for support in doing research where it was really clear that the community hadn’t been engaged at all before the research methodology was structured, and they were basically signed on near the end so that there was a community partner.”

“In order for them [the researchers] to get the funding, they needed the token Indian to participate and … you’ve signed [onto] supporting their research. You’ve, you know, they got their letter of support. They’ve listed you as a co-[applicant] and then all of the sudden everything they’ve said they were going to do, the methodology, they didn’t do. And then they would take some of the data after and publish it as … like a secondary publication which wasn’t allowed. That data was not given permission by the community to use … so you have this rising tension between the communities and the workers … so if you have an Aboriginal person who is bridging these non-Aboriginal researchers with communities, you’re [the Indigenous researcher] stuck in the middle. You’ve just helped them exploit this community, but you didn’t even mean to do that.”

Government funding policies in Canada are not aligned with, and may even contradict, Indigenous health research guidelines. For example, TCPS 2–9 requires that researchers consult and engage with Indigenous communities as part of the research process. Brunger & Wall (2016), Castleden et al. (2012), and Moore (2015) all note that the associated costs for these processes are rarely accounted for as line items in research budgets.

Boffa et al. (2011) describe the stress of meeting funding agency timelines as a key challenge in research, noting the difficulty around relationship building and the gradual (i.e., slow) process of trust development. Likewise, communities who may wish to participate in a research project are frequently under-resourced and overburdened. These competing pressures are compounded by poor policy mechanisms, that permit researchers to account for contributions from Indigenous communities or organizations as ‘in kind’[12]- a process that both devalues and overtaxes communities and organizations as partners.

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[12] 'in kind’ contributions on grants account for equipment, services and/or labour rather than money.

One FIIRE Network member aptly summarized these experiences: “It’s usually the Indigenous people that are doing the bulk of the work and not getting paid for it.” Another member commented on the need to resource Indigenous communities so that they can adequately partner in research activities: “Well having the resources to do it. And not just the financial but the human resources. Right. Having the right people around the table. Having the … knowledge keepers, the youth, the right people.”

One way to better support Indigenous communities to partner with researchers would be to require that core-funding mechanisms be targeted at initiating and sustaining resource needs, such as staffing and facilities, or to require a percentage of all grants to be allocated specifically to community partners to administer funds. For example, the National Institutes of Health (NIH) in the United States distributes grants to eligible Native American tribes with the aim of building research capacity and establishing partnerships; 30% of these grants are allocated specifically to the Native American Research Centers for Health (NARCH) (Department of Health and Human Services, 2015). Brunger and Wall (2016) have written about how similar funding mechanisms in Canada, such as the ACADRE/NEAHRs’ seed-funding activities, have begun to disappear.

Alternatively, governments and sponsors could deliver a proportional percentage of indirect funds[13] directly to Indigenous communities and regional and national governance bodies. Currently, universities, colleges, and their affiliated health research institutes and research hospitals receive not only Tri-Council[14] grants but also additional funding to support ‘indirect’ costs, such as investigator salaries and research administration and facility costs from the Health Research Fund (HRF) (Research Support Funds, 2016). The amount of indirect funding received by each institution is based on the total amount of grant funding received. For smaller institutions that generate less than $100,000 in annual grant funding, indirect funding can range as high as 80% in additional funds (Research Support Funds, 2016). For larger institutions like the University of Toronto, which is awarded hundreds of millions in Tri-Council grant funding each year, an additional 17.7% can be received (Research Support Funds, 2017). Indirect funding and the essential research support it provides is only accessible to universities and colleges and their affiliated health research institutes and hospitals, which is disturbing given the structural fiscal and resource inequities we have already described. Strikingly, Indigenous governing bodies and organizations, even if they have met the rigorous criteria required to be an “eligible institution” for Tri-Council research grants,[15] are not eligible to receive HRF monies, which are structurally monopolized by universities, colleges, and their affiliates. Furthermore, the majority of the CIHR Pathways grants are on the list of grants ineligible for HRF awards.[16]

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[13] Indirect funds are typically the 15–40% of grant funds funneled to the institutions administering them, such as academic institutions and research centres.

[14] The Tri-Council is composed of the three federal Canadian research-funding institutions: CIHR, SSHRC, and NSERC.

[15] The requirements for “eligible institutions” can be found at: http://science.gc.ca/eic/site/063.nsf/eng/h_3D5FA603.html?OpenDocument

[16] The list of grants that are ineligible for HRF awards can be found at: http://www.rsf-fsr.gc.ca/apply-demande/calculations-eng.aspx

These funding limitations and barriers have increased tensions between Indigenous communities, national and regional Indigenous governing bodies, researchers, academic institutions, and the government agencies and sponsors involved in Indigenous health research. Funding policies for Indigenous health research and the Indigenous agencies that support it continue to perpetuate many of the inequities present in both Indigenous health research and health generally. Inequities in funding perpetuate a patronizing and fiscally unfair relationship between government sponsors and Indigenous peoples. This chronic and crosscutting underfinancing critically undermines efforts before they even start. Some of the wise and promising practices we have described can provide a start for addressing these concerns. There have been a handful of successful programs that have had their funding cut, or significantly reduced, from which important lessons can be drawn. Table 1 summarizes our recommendations when evaluating existing funding policies.

Table 1

Recommendations To Address Funding Limitations In Indigenous Health Research

We recommend evaluating and modifying existing funding priorities and protocols in Indigenous health research in Canada, including the following actions:

- **Increase funding for Indigenous health research so that it is proportional to the size of the Indigenous population in Canada and reflects the high degree of health and social inequity this population experiences. Funding must also recognize the need to strengthen Indigenous capacity toward self-sustainability. For example, as per the AHRSC recommendation, the goal should be 9.2% of CIHR's total budget (AHRSC, 2016).**

- **Collaborate with regional and national Indigenous governance and advocacy bodies, and Indigenous communities, to develop evidence-based, mandated federal and/or provincial policies that allocates and makes available the necessary financial resources to meet the requirements of community consultation and engagement as well as knowledge translation (e.g., clearly allocate line items for these activities in research budgets).**

- **Review indirect funding policies at research institutions so that all research partners have access to indirect funds.**

- **Ensure that community interests are reflected in compliance mechanisms and in metrics for obtaining and maintaining research funds. Funding agencies should work with Indigenous communities to identify and prioritize these oversight tools (e.g. quarterly community assessments of research projects).**

- **Revise existing federal funding policies to recognize regional and national Indigenous governance and advocacy bodies and community-based programs as eligible applicants for health research granting programs.**

- **Expand the funding criteria for applicants to include alternative metrics for success beyond those linked to academics, such as publications (e.g., relationship metrics developed in partnership with Indigenous communities).**

Inadequate Governance Results in Poor Adherence to Mandates and Policies

The effects of inadequate governance[17] manifest in many ways. One such way is the failure by government agencies, sponsors, and the wider research community to adequately engage and partner with Indigenous communities and national and regional Indigenous organizations. The problem is systemic: it starts with the failure to engage and partner when setting government and institutional priorities for Indigenous health research. It endures when the broader research community fails to engage and partner with Indigenous communities throughout the research cycle. Such failures are driven partly by the systemic inconsistencies and contradictions in the policies that set, guide, and sponsor Indigenous health research priorities (Castleden, 2012; 2015; Brunger & Wall, 2016; Moore, 2015; Morton-Nimoya et al., 2017).

These failures are also the consequence of Indigenous communities having insufficient human resources, finances, infrastructure, and time to engage and partner with the research community. The problem is further exacerbated by variable and limited accountabilities between the research community, Indigenous communities and organizations, government agencies, and sponsors. Combined with poor research oversight, there are few mechanisms in place to measure accountability to Indigenous communities. The mechanisms that do exist are mostly governed by sponsors, universities, and hospitals who, in practice, prioritize accountability to their own institutional policies over the concerns of Indigenous communities. The inevitable impact of these failures is research that fails to benefit communities and lacks social value.[18] There is also a persistent lack of trust and a breakdown in communication on all sides when roles, rights, responsibilities, and accountabilities are not clear. Compounding these concerns is the potential unwillingness by Indigenous communities to partake in health research due to an ongoing legacy of harmful research, a choice that will continue to worsen existing health inequities.

Government agencies, sponsors, and institutions often fail to engage and partner with Indigenous communities and organizations when setting federal, provincial, and institutional mandates and priorities for Indigenous health research. One FIIRE Network member expressed their disappointment with CIHR' ability to engage with respect to mentorship programing, as, "mentorship has to be something that's conceptualized with both the community and the academy. If we just focus on the academy, we're missing the purpose and the picture, and we're going back on everything we've learned in the last decade." As highlighted in Textbox B, ACADRE/NEAHRs lost its federal funding. In its stead, CIHR is implementing the Indigenous Mentorship Network Program with a fraction of the funding that was available to ACADRE/NEAHRs. Another example of the failure to engage and partner with Indigenous communities and organizations when setting mandates, detailed in **Textbox E,** is the consultation process for the CIHR Guidelines for Health Research Involving Aboriginal People, which was superseded by the TCPS 2–9 in 2010.

"So, I think that there needs to be more listening … on the part of the funder, [on] how things need to work, and I think that the value of the expertise of the people who are working [at] the community-level needs to be heard … when things are developed in [the] isolation of community and, you know, despite the best efforts even of those people that are involved in the relationship as individuals, despite the best efforts of everybody, it can be really difficult to … move forward."

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[17] By governance, we mean governance that explicitly recognizes and lays out the roles, responsibilities, rights, and accountabilities of those individuals, communities, agencies, and organizations that have vested interests in Indigenous health research in Canada.

[18] Social value is the expectation that research is, at its core, the "evaluation of a treatment, intervention, or theory that will improve health and well-being or increase knowledge" (Ezekiel etal., 2000, p. 2703). We contend that in Indigenous health research, social value amounts to tangible benefits, knowledge, and tools that are useful and relevant to Indigenous communities.

In 2007, CIHR released their Guidelines for Research Involving Aboriginal Peoples (CIHR, 2007). They were in effect until 2010, when the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2nd edition) (TCPS 2) was released and took precedence. TCPS 2 features a specific chapter, Chapter 9, on Research Involving the First Nations, Inuit and Métis Peoples of Canada. However, TCPS 2–9 was not as widely regarded as the 2007 guidelines, which were respected by Indigenous communities, organizations, and the wider research community for being grounded in collaboration thus robustly rooted in Indigenous values. The 2007 guidelines were developed by the Aboriginal Ethics Working Group in consultation with ACADRE centres, Indigenous communities, and scholars in Indigenous studies, anthropology, ethics, law, medicine, public health, and the natural and social sciences. In contrast, although the 2007 guidelines informed TCPS–9, it was not similarly grounded in collaboration. For this reason, critics contend that TCPS–9, and its subsequent version, TCPS2-9, does not have the same rigour, and in practice, Indigenous communities have been known to use the 2007 guidelines instead.

Textbox E |CIHR Guidelines for Health Research Involving Aboriginal People

Efforts by the research community to engage and partner with Indigenous communities and national and regional Indigenous governing bodies are inconsistent and often inadequate. Yet, these relationship-based activities are essential to research conducted with and about Indigenous communities. Engagement is a building block to realizing the inherent right to Indigenous self-determination. As such, it should result in full partnerships and the goal of self-sustainability and self-determination in health research. We strongly recommend that these activities precede all others and that they are reflexive, repetitive, and continue throughout— and beyond—a given research project.

“I don’t believe you should enter a community with even a research agreement completed or a methodology completed and ask them to sign onto it.”

“Communities have to be involved in the planning, the … implementation and evaluation, and it has to be meaningful.”

“Have them [engagement with Indigenous community] be staged … there’s the first stage of gathering, the second stage of checking back, and the third stage of dissemination and acknowledgement of the work that’s been done.”

The recommendation to engage is present in policies that govern research with Indigenous peoples in Canada. TCPS 2–9 (2014) describes community engagement as “a process that establishes interaction between a researcher or research team, and the Aboriginal community relevant to the research project. It signifies a collaborative relationship between researchers and communities” (CIHR, NSERC, SSHRC, 2014, p. 112). Nonetheless, the inconsistent nature of the research community’s engagement with Indigenous communities continues to be one of the more persistent criticisms raised by Indigenous communities, as well as national and regional Indigenous organizations.

“We see it [failure to engage and/or partner] every day. Like in our communities and in our institutions, that we all work in and what that actually looks like. How can we actually have a voice and say, “Okay, this isn’t acceptable?””

“They weren’t being upfront and truthful … the intention wasn’t honourable from the get-go. It was just to get the funding. It was just to get the dollars to do their research. So, I’ve got a lot of examples of crappy research that happened.”

The problem is pervasive throughout the research cycle. As noted by one FIIRE Network member who described an example where priorities and methodologies were set without community input: *"There [were] a few people who [had] reached out to us for support in doing research where it was really clear that the community hadn't been engaged at all before the research methodology was structured, and they were basically signed on near the end so that there was a community partner."*

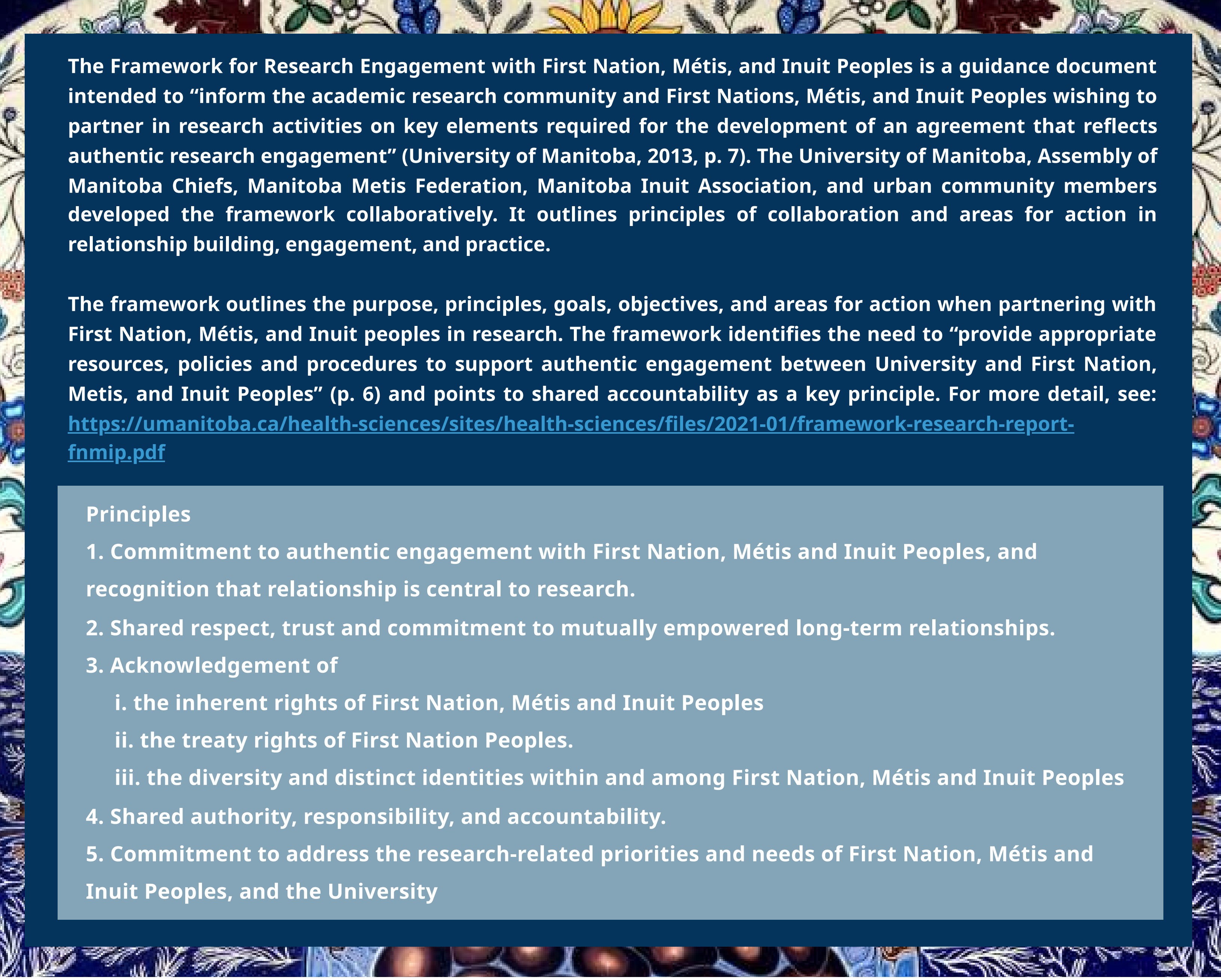
Another FIIRE Network member cautioned that the failure to engage and partner with communities reduces the utility of research outcomes. In particular, Western methodologies often do not reflect Indigenous approaches to knowing and doing—for example, the development of measurement tools. "The measurements themselves don't reflect Indigenous ways of knowing and doing … the way that we measure things just doesn't get at what wellness really means to communities. So, I think that … redefining things, developing measures that make sense to communities, that like, reflect their priorities and their values."

Finally, non-Indigenous researchers do not consistently work with Indigenous communities to share and report knowledge back in ways that matter to communities. "Anything that they do collect, one of the things that I'm seeing that doesn't happen in any … research is that there isn't … there isn't going back and providing it to them in usable formats."

These examples provide further evidence of inadequacies in the mandates and policies guiding and sponsoring Indigenous health research (Brunger & Wall, 2016; Castleden, 2012; 2015; Moore, 2015; Morton-Nimoya, 2017). However, they are also the result of researchers and institutions underestimating, and quite simply, failing to respect:

- Indigenous-community knowledge and skills;
- the time and investment necessary to build relationships that bridge historic and existing attitudinal and systemic discrimination;
- the complexity of Indigenous community knowledge systems and protocols; and,
- the importance of context to health services.

The prevalence of these poor practices signifies weak oversight over the broader research community and illustrates the pervasive systemic racism that results in Indigenous peoples in Canada being treated as 'lesser than' (Lux, 2001; McCallum, 2005). They are also evidence of poor accountability on behalf of government agencies, sponsors, universities, and institutions—who are tasked with overseeing these policies—to communities. Universities, for instance, must be more proactive and take guidance from Indigenous communities and organizations. Implementing TCPS 2–9 and the TRC, for example, requires an investment of resources from universities, a more coordinated approach, and an active responsibility for research-community partnerships **(see Textbox F).**



The Framework for Research Engagement with First Nation, Métis, and Inuit Peoples is a guidance document intended to “inform the academic research community and First Nations, Métis, and Inuit Peoples wishing to partner in research activities on key elements required for the development of an agreement that reflects authentic research engagement” (University of Manitoba, 2013, p. 7). The University of Manitoba, Assembly of Manitoba Chiefs, Manitoba Metis Federation, Manitoba Inuit Association, and urban community members developed the framework collaboratively. It outlines principles of collaboration and areas for action in relationship building, engagement, and practice.

The framework outlines the purpose, principles, goals, objectives, and areas for action when partnering with First Nation, Métis, and Inuit peoples in research. The framework identifies the need to “provide appropriate resources, policies and procedures to support authentic engagement between University and First Nation, Metis, and Inuit Peoples” (p. 6) and points to shared accountability as a key principle. For more detail, see: https://umanitoba.ca/health-sciences/sites/health-sciences/files/2021-01/framework-research-report-fnmip.pdf

Principles

1. **Commitment to authentic engagement with First Nation, Métis and Inuit Peoples, and recognition that relationship is central to research.**
2. **Shared respect, trust and commitment to mutually empowered long-term relationships.**
3. **Acknowledgement of**
    - **i. the inherent rights of First Nation, Métis and Inuit Peoples**
    - **ii. the treaty rights of First Nation Peoples.**
    - **iii. the diversity and distinct identities within and among First Nation, Métis and Inuit Peoples**
4. **Shared authority, responsibility, and accountability.**
5. **Commitment to address the research-related priorities and needs of First Nation, Métis and Inuit Peoples, and the University**

Textbox F | University of Manitoba Faculty of Health Sciences: Framework for Research Engagement with First Nations, Métis, and Inuit Peoples

Peer-reviewed journals present another avenue that can encourage appropriate engagement and partnering with Indigenous communities and organizations, as they require evidence of ethics approval and oversight. For example, the *British Medical Journal* (BMJ) requires “every research article submitted to include a statement that the study obtained ethics approval (or a statement that it was not required and why), including the name of the ethics committee(s) or institutional review board(s), the number/ID of the approval(s), and a statement that the participants gave informed consent before taking part” (BMJ, 2020, “Statement of Ethics Approval”).

Peer-reviewed journals could require researchers to include descriptions in their submissions of how they engaged with community, since Indigenous community engagement is a TCPS 2–9 criterion. This requirement would ensure a linkage between researchers’ interests and sponsors, who require publication as a research product, and the communities who partner in research that concerns them.

The Counsel of Grandparents at the Well Living House was established as a governance mechanism to improve accountability to the Indigenous community. The members are Elders with "extremely high credibility and influence within and beyond Indigenous communities across Canada" (Well Living House, n.d., "Counsel of Grandparents"). The Grandparents act as "role models, strategists, teachers, knowledge keepers, advocates and supports" and ground Well Living House in Indigenous ways of knowing and doing. In this way, Well Living House is accountable to both the institution under which it is housed, St. Michael's Hospital, and to the Indigenous communities it aims to serve. This co-governance relationship is formalized through a signed memorandum of understanding between the Grandparents and St. Michael's Hospital outlining objectives, governing principles, and purpose. For more detail, see: http://www.welllivinghouse.com/wp-content/uploads/2014/04/WLH-MOU-Signed.pdf.

Textbox G |Counsel of Grandparents at the Well Living House

Finally, **Textbox G** describes another promising oversight practice: the Counsel of Grandparents at Well Living House, formalized in 2012. Well Living House is an action research centre for Indigenous infant, child, and family health and well-being.

The resources, finances, infrastructure, and time available to Indigenous communities and their academic partners are not sufficient to meet the needs of adequate engagement and partnership. One of the limitations Indigenous communities face when attempting to engage and partner in research is an overall lack of available capacity, such as available resources, finances, infrastructure, time, and human resources.

"*People are dealing with like huge crises in [their] communities, let alone having to think about like, research on, you know, whatever it is that we're doing in the community. So, I think that that just like, really makes it tough to ... they're already so overworked, overstretched, have like very little resources and are dealing with like all kinds of challenges at the community level, and so I think that just like makes the environment tough.*"

Researchers have highlighted the irony of the TCPS 2–9 requirements and the burden they place on Indigenous communities (Maar et al., 2011; Moore, 2015). Through their mandates, the Tri-Council ensures research compliance with TCPS 2. However, there is no explicit funding in place for the guidelines, and activities required for the ethical conduct of research are often not reflected in research budget line items, increasing barriers to implementation (Moore, 2015). Efforts to utilize the ethical guidelines requires training and understanding by financial services located at the universities and institutions responsible for approving research budgets (Moore, 2015).

However, raising the awareness of staff members in financial service departments will not alleviate the burden placed on community members who are tasked with research responsibilities, often with little or no compensation for their services[19](Brunger & Russell, 2015; Maar et al., 2011; Moore, 2015). Brunger & Russell (2015) suggest that even “the process of reviewing and approving research can be highly demanding on a community’s resources” (p. 373), but also point out that these processes are the very spirit of TCPS 2–9. Such policies, they posit, create a Catch-22 for Indigenous communities: for example, Brunger & Wall (2016) argue that, when practised uncritically, processes like community engagement “can cause harm by leading to community fatigue, undermining the community’s ability to be effectively involved in research, and restricting the community’s ability to have oversight and control over research” (p. 2). Brunger and Wall (2016) also note that TCPS 2–9 does not resolve inadequate engagement through its recommendations, such as encouraging community members to volunteer (e.g., in-kind contributions), as these recommendations can both burden community members and devalue their contributions. The authors conclude: “research ethics guidelines that speak of partnerships and relationships but promote contract-style consents and volunteer obligations, these are connected not (just) by metaphors of power, but by the immediacy of ongoing colonialism” p. 1874). Many provincial and federal funding agencies fail to account for these capacity constraints. Moreover, researchers will typically prioritize funding to meet their research obligations and interests, such as operations, publications, and attending conferences—all of which are tied to metrics for their own careers. As one FIIRE Network member pointed out, for the CIHR-funded Partners for Engagement and Knowledge Exchange (PEKE) grants, “none of the financial resources trickle down to [the] community.” As another FIIRE Network member shared from their discussion with an Indigenous Chief, instead, if there was available capacity in communities, there could be, “research entities within First Nation communities.” These entities would in turn have the capacity to negotiate and moderate the complex relationship-building endeavour that is so critical.

Brunger & Wall (2016) recommend that communities be provided with sustainable funding to train and compensate community staff to support researchers conducting research in their communities. These relationships, however, should be framed as partnerships and not merely as research support. Increasingly, there are promising practices for how this can be achieved, both at the level of individual research projects and more systemically. For example, Well Living House aims for at least 50% of the budget of each community-partnered research project to be transferred directly to community partners **(see Textbox H).** This is above and beyond the salary support provided to non-community-situated research staff that support community-based research implementation and community liaising. **Textbox I** then describes the Labrador Aboriginal Health Research Committee and its process for supporting the strengthening of community-level research capacity and competencies systemically.

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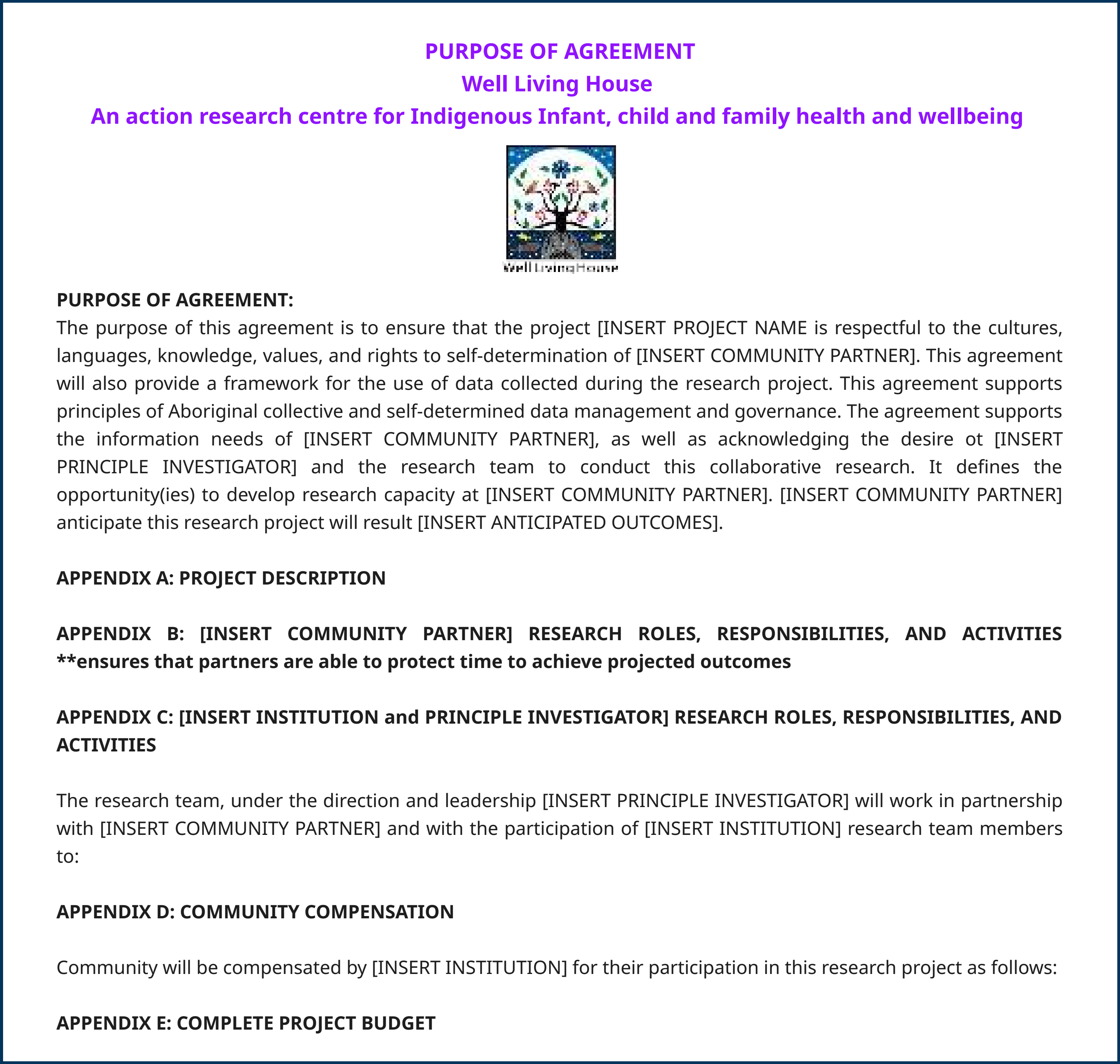
[19] This is how ‘in-kind’ contributions to research grants manifest in practice.

Well Living House negotiates Research, Publication, and Data-Sharing Agreements with its community research partners with the aim of recognizing and respecting Indigenous communities' right to self-governance. The agreements are legally binding and define project purpose and principles; research partners' roles and responsibilities; and community compensation. Complete project budgets detailing funding allocations for both the researchers and communities are attached as an appendix as part of an effort to improve transparency.



PURPOSE OF AGREEMENT
Well Living House
An action research centre for Indigenous Infant, child and family health and wellbeing

Well Living House

PURPOSE OF AGREEMENT:
The purpose of this agreement is to ensure that the project [INSERT PROJECT NAME is respectful to the cultures, languages, knowledge, values, and rights to self-determination of [INSERT COMMUNITY PARTNER]. This agreement will also provide a framework for the use of data collected during the research project. This agreement supports principles of Aboriginal collective and self-determined data management and governance. The agreement supports the information needs of [INSERT COMMUNITY PARTNER], as well as acknowledging the desire ot [INSERT PRINCIPLE INVESTIGATOR] and the research team to conduct this collaborative research. It defines the opportunity(ies) to develop research capacity at [INSERT COMMUNITY PARTNER]. [INSERT COMMUNITY PARTNER] anticipate this research project will result [INSERT ANTICIPATED OUTCOMES].

APPENDIX A: PROJECT DESCRIPTION

APPENDIX B: [INSERT COMMUNITY PARTNER] RESEARCH ROLES, RESPONSIBILITIES, AND ACTIVITIES **ensures that partners are able to protect time to achieve projected outcomes

APPENDIX C: [INSERT INSTITUTION and PRINCIPLE INVESTIGATOR] RESEARCH ROLES, RESPONSIBILITIES, AND ACTIVITIES

The research team, under the direction and leadership [INSERT PRINCIPLE INVESTIGATOR] will work in partnership with [INSERT COMMUNITY PARTNER] and with the participation of [INSERT INSTITUTION] research team members to:

APPENDIX D: COMMUNITY COMPENSATION

Community will be compensated by [INSERT INSTITUTION] for their participation in this research project as follows:

APPENDIX E: COMPLETE PROJECT BUDGET

Community compensation obligations outlined in data agreements are one mechanism that academic investigators can use to channel a percentage of research funding to their community partners. Well Living House sets benchmarks with respect to the proportion of total research operating funds that are transferred to community research partners. For the period of 2012 to 2015, 45% of the nearly $4 million dollars of research operating funds that were generated by Well Living House were spent supporting Indigenous community research partners .

Textbox H | Well Living House Academic–Community Funding Protocols

Established in 2004, the Labrador Aboriginal Health Research Committee (LAHRC) was mandated to "support research activities designed to assist Labrador Indigenous communities and organizations in their efforts to promote healing and wellness and to improve health services in their communities" (Brunger et al., 2014, p. 7). Between 2004 and 2011, LAHRC initiated and hosted a series of workshops designed to strengthen capacity and competencies in community in order to support community members in their roles as partners in community-based health research. For the first two years following its inception, LAHRC and the communities it worked with suspended research and prioritized capacity strengthening. This was described as helping communities build up a knowledge and language base regarding health research (J. Graham, personal communication, April 11, 2017). In 2006, LAHRC hosted a workshop where researchers were invited to meet with community members to identify research priorities. In 2011, they hosted a workshop focused on establishing "viable procedures for governance of health research involving Indigenous communities in rural and remote areas in the province" (Brunger et al., 2014, p. 8). With the termination of funding for ACADRE/NEAHRs, LAHRC funding has ceased and the program has since been terminated. However, LAHRC provides a promising example for how capacity strengthening can be carried out. Its success is evident in that many of the communities in the region have established research offices with policies (e.g., ethics, research approval and evaluation) that are also, in some cases, fully resourced (J. Graham, personal communication, April 11, 2017).

Textbox I |The Labrador Aboriginal Health Research Committee

The LARHC example demonstrates that strengthening research capacity in communities cannot be reduced to financial support. Instead, it shows that communities must be empowered through investments in a variety of capacities, including education and staffing in order to participate in research relationships in an equitable and sustainable manner.

One FIIRE Network member suggested that it should be Indigenous communities reaching out to researchers, and not the reverse. In reality, however, this may not always be possible for Indigenous communities who have limited capacity and are already strained due to traumas and competing interests. Multiple FIIRE Network members recommended relationship brokering as a promising practice and tool for initiating relationships between parties with shared needs and interests. This tool can provide a framework so that Indigenous communities' priorities are met while also recognizing their respective capacity constraints. A brokering service can also assist researchers in locating communities who share their research interests. As one FIIRE Network member pointed out, researchers "could come to us saying, 'Listen, there's money for suicide prevention. What would you like to see done?' Well, we are here as researchers to assist that process in navigating the academic side of it and assisting with methodologies. But what, from your perspective, in the community should be done and how should it be done? What would you like to see change? What would you like to see come out of this and [how can] it be a meaningful partnership and engagement?"

Others have proposed similar programs (McNall, 2009). Governance tools like these should, however, be developed and managed by Indigenous communities and organizations (TRC, 2015). The CIHR-funded Partners for Engagement and Knowledge Exchange (PEKE) program was envisioned as a way to deliver this service. One example of how this program is working toward this effort is the First Nations Health and Social Secretariat of Manitoba PEKE, which has created a website for sharing and knowledge exchange.[20] All of the PEKEs are working toward implementing similar tools but are limited by CIHR and IAPH mandates.

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[20] For more detail on the First Nations Health and Social Secretariat of Manitoba's PEKE project, see: https://pekemanitoba.wixsite.com/mysite

"So, we're trying to broker relationships between researchers, whether they be Aboriginal [or] non-Aboriginal, and communities … We've got a survey that's going to be going out specifically only to communities asking them what the priorities are, what their needs are. Are they interested in engaging? Are they interested in engaging with private sector? Are they interested in scaling up any health intervention … if their priority isn't oral health or diabetes or [tuberculosis] or mental health, maybe their priorities are cancer, you know, which isn't part of the Pathways PEKE Program."

Ultimately, the value behind brokering should be to expand research mandates, beyond those prioritized by funding agencies, to meet the needs of Indigenous communities. However, brokering on its own will not address similar capacity gaps in the research community. Capacity and readiness as terms are frequently applied to Indigenous communities, but less so to the research community, who require highly specialized skillsets to engage in advanced conversation and build on strong foundational understandings of Indigenous ways of knowing and doing.

There is weak oversight of research practice in Indigenous health research. What does exist is mostly governed by government, sponsors, universities, and hospitals who are responsive to their own institutions rather than the concerns of communities. Indigenous communities have difficulty accessing and are mostly unaware of existing non-Indigenous policies governing research oversight. FIIRE Network members noted that many communities might hesitate to employ existing policies, citing systemic biases and a consistent failure to listen to Indigenous community. Accordingly, Indigenous communities are not properly empowered to report weak adherence by researchers to comply with existing mandates and policies that govern Indigenous health research.

Some FIIRE Network members recommended that an Indigenous health research ombudsman be created as a practical and immediate way to address the lack of oversight, like "[someone] who looks after the rights of all the partners and players." This approach could have the effect of "creating a watchdog for us as Indigenous people to protect us against unethical research practices."

Other members recommended creating a research-rating registry, similar to a Better Business Bureau model, which would allow communities to report research violations or issue report cards on research projects. Still other FIIRE Network members are developing a 'community bill of rights' as a starting point of engagement that prioritizes and supports the communities approached by researchers. Members were careful to note that efforts to improve accountability to Indigenous community must be mindful not to add to the already complex government bureaucracy that limits a community's authority.

Accountability mechanisms should be shared between Indigenous and non-Indigenous partners. Where possible, the priority should be capacity strengthening in community or Indigenous-led institutions to empower them to initiate, implement, and manage these mechanisms. One way to achieve this goal is to use community-academic research agreements. Earlier, we outlined how such agreements can be used to establish ground rules for sharing research funds to establish capacity at the community level **(Textbox H)**. TCPS2-9 does recommend the use of research agreements, and the previous CIHR Guidelines for Health Research Involving Aboriginal People **(Textbox E)** include a sample agreement as a template for the research community to refer to (CIHR, 2007).

Indigenous communities should be empowered to initiate and establish research contracts with researchers and institutions. Universities, hospitals, and other funded institutions could be tasked with the responsibility of supporting Indigenous communities and organizations to initiate these contracts because, as we have highlighted, these institutions often receive significant indirect funds—15–40% of any given grant.

FIIRE Network members also discussed the value of licensing research as an oversight mechanism. This is the approach taken in the Northwest Territories (NWT), where researchers are required to obtain a license **(Textbox J)**.

The Government of the Northwest Territories (GNWT) requires that all those seeking to conduct research in the Northwest Territories apply for and secure a license. The license enables the GNWT to track research projects in its territory in order to share them with other researchers and residents, as well as communicate to the proper community organizations. The licensing office provides links and information to Indigenous communities regarding their respective research priorities. The requirement for licensure may assist territorial governments in developing an inventory of the research that is taking place across regions while also encouraging "community participation" in research processes (George, 2011:p. 361). In addition, licensing fees help recoup the costs necessary to resource community governance. For more detail on research licensure in the Northwest Territories, see: https://nwtresearch.com/licensing/scientific-research-license.

Textbox J | Northwest Territories Research Licensing

As part of a policy toolbox, licensing can be a useful governance tool. However, in the longer term, community self-governance should be the priority rather than oversight by a government agency. FIIRE Network members emphasized the importance of assisting Indigenous communities to develop sustainable capacity to oversee their own governance mechanisms. The Mi'kmaw Ethics Watch **(Textbox K)** is an example of community self-governance and a good model for how research ethics oversight can be effectively governed by an Indigenous community.

There are several examples of ethical guidelines that have been developed and are self-governed by Indigenous communities in Canada; we list a few of the better known examples below. Community-based codes of ethics have been one of the areas where Indigenous communities have been able to resist the systemic oppression that is present in health research.

In the mid-1990s, the Health Information Research Governance Committee was mandated by the Association of Manitoba Chiefs to oversee the Regional Health Survey, review academic proposals for research concerning First Nations, and “promote First Nations benefits through research, including partnerships based on: (i) Free, Prior [and] Informed consent (on collective and individual basis); (ii) First Nations OCAP[®] principles that First Nations have Ownership, Control, Access, and Possession of their own data; (iii) First Nations ethical standards (as per AMC Chiefs Resolution Jan.07-01)” (First Nations Health and Social Secretariat of Manitoba, n.d., “Health Information Research Governance Committee”).

The Manitoulin Anishinaabek Research Review Committee, which serves seven First Nations, was initiated in 2001 in the face of “community frustrations” with the “lack of free and informed consent of research participants, unauthorized linking of collected interview data with patient health information, potential psychological harm to research participants, culturally inappropriate research methods, a lack of community consultation, and the lack of a strategy for knowledge uptake” (p. 60)—even where institutional research ethics had been obtained (Maar, 2007). The committee represents a “shared vision for Aboriginal research on Manitoulin Island” (Maar, 2007, p. 61).

In 1999, a Mi’kmaw Ethics Watch Review Committee was initiated to “study and develop principles and protocols that will protect the integrity and cultural knowledge of the Mi’kmaw people” (see: https://www.cbu.ca/indigenous-affairs/mikmaw-ethics-watch/). The guidelines outline the authority of the Mi’kmaw over research conducted with or about their people, the roles and responsibilities of researchers, and the responsibilities and obligations of the Mi’kmaw Ethics Watch, which is an oversight committee appointed by the Sante’ Mawio’mi that reviews all proposed research involving Mi’kmaw people.

In 2003, the Nuu-chah-nulth Tribal Council opted to form a Research Ethics Committee, largely in response to a particularly contentious case of research exploitation. Starting in the 1980s, a researcher obtained blood samples from community members to conduct research on arthritis, but proceeded to use the samples for numerous unrelated studies, as well as loaning the samples to other researchers—all without permission from the community (Dalton, 2002; Schmidt, 2001; Wiwchar, 2004). In an article by Wiwchar (2004), a member of the community is quoted as saying, “So now we’ll know who’s coming into our communities, and we’ll have the ability to make sure they follow our protocols and rules” (p. 4). This statement speaks to the power of self-governed oversight over research. The Nuu-chah-nulth Tribal Council Research Ethics Committee monitors all research that takes place within its member communities (Kovach, 2015).

Textbox K | Self-Governing Ethics Practices in Indigenous Communities

“Though infrequent, there are also promising examples of Indigenous leadership addressing weak or missing governance in Indigenous health research.

The First Nations principles of ownership, control, access, and possession (OCAP)®, initially known as OCA, were adopted in 1998 by the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey. OCAP® provides the basis for Indigenous governance and management of all First Nations on-reserve data through a set of principles that support First Nations data sovereignty (First Nations Centre, 2007). Many of the members of the FIIRE Network referred to OCAP® as a wise practice in Indigenous-led governance and management of data. As stated by one member, these examples provide value, “because oftentimes we know the power dynamics of research and communities, they haven’t always been balanced and … the First Nation principles of OCAP® create the opportunity to balance that, to ensure that both parties are sitting at the table equally in terms of having … proper engagement. They’re fully informed. They’re fully engaged.”

The First Nations Information Governance Centre (FNIGC) is an incorporated not-for-profit with a mandate from the Assembly of First Nations’ Special Chiefs in Assembly; FNIGC is tasked with upholding the OCAP® principles. Rather uniquely, FNIGC has registered a trademark for OCAP® as an oversight mechanism for their data governance tool. Currently, FNIGC offers the Fundamentals of OCAP® course for researchers and others to learn more about how it applies to research and information governance. In the future, researchers will be able to submit their proposals for review and certification.

As one FIIRE Network member pointed out, one of the problems with Indigenous health information and data is that when researchers approach communities they often do it on a community-by-community basis, reducing the opportunity for effective, crosscutting governance.

“There’s no streamlined process currently…. So there were discussions at one point to have like, a national body to do … to govern … Indigenous health information … but there’s not any core funding for it in the same way there is for First Nations.”

“The province gathers surveillance information and then they roll it up to Ottawa and Ottawa doesn’t necessarily share that information back to people. So that’s information that I think belongs to people and not the government, and they make it challenging to, you know, access that information and they kind of hold onto it with an iron fist and, yeah, I don’t know to what extent they can own patient-population data, but they claim to.”

This problem is compounded when it comes to secondary data, where a lack of guidance allow access to Indigenous population-health data sets without requiring Indigenous-led data governance or research agreements. This approach differs from the 2007 CIHR guidelines **(see Textbox E),** where an agreement was required. The problem has been identified by Smylie and Firestone (2015), who write that, “While the persons conducting secondary data analysis may be initially more distanced from the Indigenous communities whose data is being used, compared to study involving primary data, secondary data analysis is not exempt from potentially harming Indigenous individuals and communities, particularly if we consider the issues raised earlier regarding the potential harms of deficit based reporting” (Smylie & Firestone, 2015, p. 73). The First Nations Health and Social Secretariat of Manitoba is working to address this gap by using information-sharing agreements, established between First Nations communities and the Province, which govern health information.

There continue to be attempts to undermine efforts by Indigenous communities to establish Indigenous governance and data management. Some members of the research community have stressed that the OCAP® principles are too restrictive, creating barriers to research. For example, Campbell (2014) has argued that TCPS 2‒9 can provide sufficient guidance. This is an argument we do not support.

Another tool to improve transparency and accountability in Indigenous health research is social auditing. This method works well in spaces where there is little to no trustworthiness between actors (O'Neill, 2002) **(see Textbox L).** When employed long-term, social audits have been shown to improve trustworthiness (Ebrahim, 2003; Gao et al., 2006; O'Dwyer, 2005; Zadek & Raynard, 1995).

The social audit tool is based on the principles of a financial audit. It aims to establish an accountability mechanism that improves management practices within a relationship and an independent and transparent channel for communication of stakeholders' views (Ebrahim, 2003; Gao et al., 2006; O'Dwyer, 2005; Zadek & Raynard, 1995). Social audits can be undertaken regularly or in response to a complaint. Where there is evidence of poor practice, sponsors could amend, reduce, or terminate grant funding.

Textbox L | Social Audit Tool

A collaborative social audit conducted with members from government agencies, sponsors, and Indigenous-led organizations at the community level would provide an oversight- monitoring tool for research practice and would encourage adherence to existing guidelines as well as Indigenous community and organization expectations. This social audit could take the form of research reviews in each community where Tri-Council-funded research is taking place, prior to funding renewal.

Table 2 summarizes recommendations that can help prevent and resolve poor practices in Indigenous health research. We believe efforts to establish oversight of Indigenous health research, particularly that are self-governed by Indigenous communities and organizations, can improve relationships and lead to effective engagement and partnerships between those interested in Indigenous health research.

Table 2

Recommendations to Improve Governance and Oversight of Indigenous Health Research

We recommend that the following governance and oversight policies be initiated in Indigenous health research in Canada, with the overall goal of creating Indigenous self-governed or partnered mechanisms:

- Establish an independent Indigenous health research ombudsman tasked with responding to submitted complaints as well as conducting social audits of provincially and federally funded research programs.

- Mandate universities (and other research centres) to be more coordinated and responsible for research-community partnerships - See Textbox F.

- Mandate community-academic research agreements that clearly outline roles and responsibilities; ownership and control of data; and financial support and funding allocations.

- Establish reporting guidelines with peer-reviewed journals that require researchers who submit their research for publication to include a description of how they consulted, engaged, and partnered with Indigenous community.

- Incentivize collaborators to support Indigenous leaders and -led organizations to develop Indigenous ‘community bills of rights’ that incorporate principles of respect, reciprocity, and self-governance, but ensure that the resulting document(s) are customized and relevant to local contexts.

- Initiate sustainable programming—in partnership with Indigenous leadership—that encourages and enables Indigenous communities to strengthen community-based research capacity and expertise.

- Partner with Indigenous organizations and community leaders in order to establish core funding for permanent community-based (or regionally based) knowledge partners. Develop a national or regional brokering mechanism for Indigenous communities and researchers to initiate partnerships in research.

- Establish a social-auditing program to oversee federal and provincial research programs. A social audit that is conducted collaboratively with members from government agencies, sponsors, and Indigenous-led organizations, at the community level, would provide an oversight tool to monitor research practice and establish accountability.

Power Imbalances

"Many obstacles to establishing good research relationships are rooted in power imbalances between Indigenous peoples of Canada and the non-Indigenous institutions and researchers that govern, sponsor, and conduct Indigenous health research. Although Indigenous peoples, communities, and organizations are increasingly consulted on research projects, they are rarely included as full partners. More often than not, they are treated as research subject, participant, beneficiary of—or consultant to—research.

"It's offensive—and so these are [the] people that are funding. I mean, this entity is funding us and they want the Elders involved but they have no idea, and how disrespectful that is as long as you're…"We'll pay your flight and your means and that's it." And they [the Elders] work their butts off every single day for our communities and so that is their job. And so not to be acknowledged in that, in an equal way … knowledge keepers or community have to be treated as equals. They have to be treated as though they're the co-authors, they're the writers, they're the co-presenters, they're equal across the board—not just participants. So, it's like we can talk about having all of these involvements but really when it's, when they do have it in black and white or if it ever is in black and white, it actually has to be practised."

Indigenous peoples are also often subject to tokenism, a practice rooted in institutional racism that only serves to devalue Indigenous contributions.

Systemic power imbalances reflect the colonial nature of Indigenous peoples' relationships with Canadian institutions, which have supported exploitative and morally reprehensible research. For example, the 'nutrition studies' carried out at residential schools in the 1950s (Mosby, 2013) and the more recent incidence of the Nuu-chah-nulth blood samples being taken and used inappropriately in the 1980s and 1990s (Wiwchar, 2004).

This section shares perspectives and personal experiences of these systemic biases and their resulting inequities. We describe how they inform Indigenous health research priorities and how they can limit Indigenous ways of knowing and doing to tokenistic actions. We also look at implementation science **(see Textbox Q)**, an emerging methodological framework in public health intervention, and how it can exacerbate existing power dynamics. We recognize that these are experiences rooted in racism, a topic we will specifically address in the next section.

Individuals and agencies that are external to Indigenous communities often set indigenous health research priorities. For example, research priorities are predominantly set by government agencies (e.g., CIHR, Health Canada) and the broader non-Indigenous research community. This practice contravenes the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and reflects the systemic power imbalances at play in the Indigenous health research ecosystem. CIHR's Pathways to Health Equity for Aboriginal Peoples program, for example, has four priorities: suicide prevention, diabetes/obesity, tuberculosis, and oral health. Although these are relevant health concerns in many Indigenous communities, FIIRE Network members were disappointed by the focus on deficit-based priorities and the lack of transparency around Pathways' priority-setting process. This concern is shared by others.

In his open letter to CIHR, included in kahwa:tsire*, Rod McCormick of Thompson Rivers University wrote that, "Instead of Aboriginal communities and researchers deciding upon the priorities as has become our practice, some mysterious source decided upon 4 priority themes to address Aboriginal health" (AHRSC, 2014, p. 29). This process demonstrates how research priorities often fail to reflect Indigenous communities' actual interests and needs: a mismatch that Brunger and Wall (2016) suggest, "may mean the research is 'unethical' from the community point of view" (p. 7), even if it meets the ethical requirements of an institutional Research Ethics Board.

“Notably, CIHR’s own internal policies also support this criticism: “CIHR-IAPH will continue building an advanced research agenda and pursuing its strategic directions in partnership with many stakeholder groups including Aboriginal communities and organizations” (CIHR, 2008, p. 5). This disconnect is concerning because Indigenous health research is mainly funded by CIHR. By setting Indigenous health research priorities without deliberate and transparent input from Indigenous communities, CIHR is setting an institutional precedent that is in tension with its own internal policies. As such, CIHR fails to live up to its mandate.

Indigenous communities’ interests and needs are integral to Indigenous health research priority-setting processes. Capturing these requires building sustainable relationships and partnerships with communities and organizations that embody respect and reciprocity as part of the ongoing effort of reconciliation (TRC, 2015).

“External stakeholders, government people, program people, have to make a place at the table that is equal for the community and their input has to be weighed as equally important as everything else we do in that community.”

“I think having community at the table. Otherwise we’re … trying to do something on behalf of community, so the more, I don’t know, closer to the ground it is, the more relevant and the more … that the process manages power relationship, the more likely it is to be relevant and accurate.”

This approach is also in line with Article 23 in UNDRIP, which states, “Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions” (UNDRIP, 2008, p. 9).

The federal government, as part of its commitment to UNDRIP and its principles, should establish concrete efforts to address policy shortfalls regarding the setting of Indigenous health research priorities and strategies.

An equally important concern is how imposed priorities frame Indigenous health as deficit-based, an approach that repeatedly stigmatizes Indigenous populations (Reading et al., 2016). As stressed by one FIIRE Network member, “We’re not deficit White peoples made to be less than who we are. And often times, like we’re shamed into that in terms of, “This is how your health … you’re doing so poorly.”

In their work on community engagement, Baydala et al. (2013) reflect on how a deficit-based approach can be self-perpetuating. They write that “as researchers, we have become especially adept at documenting ‘problems’ in Aboriginal communities but are less skilled at identifying community strengths, resources and cultural relevant solutions” (p. 8). Instead of focusing on disease or deficit-based health research in Indigenous communities, we recommend prioritizing strength-based approaches to research with Indigenous peoples **(see Textbox N)**. Shifting to a more holistic approach to wellness or well-being is in keeping with Indigenous ways of conceptualizing health (King et al., 2009).

Native Youth Sexual Health Network (NYSHN) youth facilitator Alexa Lesperance worked with her community, Naotkamegwanning First Nation, to create the Sexy Health Carnival. "The carnival works to break the barriers of fear, stigma and shame relating to issues that we face in our communities. It has creating safer practices content [*sic*] that makes learning information about issues that affect our bodies more accessible and most importantly more fun to learn about for inspiring youth, community members and Elders! Various booths range from topics such as suicide, harm reduction, consent, sexual violence prevention, STI's, birth control and masturbation" (Native Youth Sexual Health Network, n.d., "Sexy Health Carnival"). The carnival also features interactive games, prizes, and safer sex supplies, as well as content- and age-appropriate activities for younger children so that their parents, siblings, or other caretakers can participate in the carnival. The Carnival has become one of NYSHN's most popular outreach tools, with many requests each year from Indigenous communities and events for the Carnival to visit their community. Indigenous youth leaders conducted an evaluation of the program in 2014 with funding from the Ontario HIV Treatment Network (OHTN) and received the OHTN Community-Based Research Award. They have also received a CIHR award to expand implementation and evaluation across additional communities. See https://www.nativeyouthsexualhealth.com/sexy-health-carnival for more detail.

Textbox N | Native Youth Sexual Health Network and the Sexy Health Carnival

"Most research is still initiated by non-Indigenous researchers, so policy mechanisms that elicit and employ Indigenous community priorities are essential. Resource constraints have left Indigenous communities under-resourced and there are few processes in place to enable communities to proactively set research priorities and attract funding and researchers. A good example of how an Indigenous community has been able to set priorities and attract researchers is the Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre) **(see Textbox O).**

Several promising examples provide insight on how to address this critical deficit. Co-design has been proposed as a promising Indigenous research approach because it shifts the relationship of researchers and Indigenous communities from a patriarchal and colonial relationship to one that embodies the principles of respect and reciprocity (Goodyear et al., 2015). New Zealand research guidelines, for example, empower Māori "to take a governance role in the 'planning, development and execution of research as well as monitoring the project through its life cycle'" (Goodyear et al., 2015, p. 4). This contrasts with the current CIHR model, where seed funding is required to develop partnerships. However, in this model, the research priorities are already set by CIHR. In her work on partnerships, Bhardwaj (2014) provides a framework for involving Indigenous communities in research. This framework encourages researchers to initiate a research forum with communities early on to discuss common interests and establish ethical space **(see Textbox P)**, "where research ideas are shared, developed, modified and implemented." (p. 20).

The Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre) supports community-based research development across the country. The AHA Centre “emphasizes regional work with national coordination” (CAAN, 2017, “AHA Centre”) and is tasked by communities with establishing academic partnerships to initiate and implement community research priorities (S. Pooyak, personal communication, April 7, 2017). The AHA Centre requires that research teams include “Indigenous Knowledge frameworks and ways of knowing the world” (CAAN, n.d., “AHA Centre) and provides communities with capacity tools, such as assistance with research proposal development and grant writing. However, as with many similar initiatives, the AHA Centre struggles with financial uncertainty. In 2017 they were renewed for $1.5 million, but the renewal does not account for inflation or the increase in workload given their success. Moreover, because the program is housed under CAAN, it is not clear how CAAN’s recent funding uncertainty will impact the AHA Centre, which relies on CAAN’s infrastructure and partners to achieve their goals (S. Pooyak, personal communication, April 7, 2017). See https://caan.ca/en/aha-centre/ for more detail.

Textbox O | Aboriginal HIV & AIDS Community-Based Research Collaborative Centre

Ethical space is a concept initially developed by Roger Poole (1972) and later expanded on from an Indigenous perspective by Willie Ermine. Ermine (2007) writes that ethical space is “formed when two societies, with disparate worldviews, are poised to engage each other” (p. 193); Brunger et al. (2014) describe it as “an abstract space in which there is a meeting of entities with different intentions (p. 5). Brunger et al. (2014) describe how they brought “community members, community research review administrators, research ethics board administrators, and health board research administrators” into an “*ethical space* and worked together to critically interrogate the bureaucratic structure of the government, health, and university-based ethics review processes” (p. 3) in Newfoundland and Labrador. These actions resulted in changes in how Indigenous health research is governed in Newfoundland and Labrador—specifically, it resulted in “community-led reforms to the provincial research ethics boards” (Brunger et al., 2014, p. 3).

Textbox P | Ethical Space

“Brunger et al. (2016) promote the creation of research registries that can document past research to prevent redundancies, along with a database of research priorities identified by Indigenous communities. The database of priorities bears similarities to our earlier recommendation to establish a brokering tool, one that is culturally safe, to match researchers with Indigenous communities and organizations. Policies that bundle these mechanisms and tools would provide a starting point for establishing sustainable research partnerships.

Harvard Business School academics have demonstrated how community-level priority setting and partnering might look on a smaller scale. As part of their field-based research course, Native Americans in the 21st Century: Nation Building II, they offer a pro bono service through which Native leaders and communities can partner with student interns to bring about “*tribally* driven agendas and perspectives” (Norman & Kalt, 2015, p. viii). Examples such as this provide a starting point for conceptualizing and dialoguing on how to better facilitate and resource reciprocal relationship building that can redress power imbalances and improve Indigenous health research practices, such as community-led priority setting.

“Power imbalances and structural inequities can result in spaces in which Indigenous ways of knowing and doing are merely integrated into the Western paradigm (Cameron et al., 2010; Dyck & Kearns, 1995). These spaces are where appropriation and co-option of Indigenous knowledge are regularly practised. Brunger et al. (2016) illustrate these concerns in their examination of community engagement, where they question whether and how “research ethics guidelines and associated assumptions about the value of community engagement may be grounded in, and inadvertently reinforce, ongoing colonialist relations of power” (p. 1862). They conclude that community engagement, “if done uncritically and in service to ethics guidelines rather than in service to ethical research—can itself cause harm by leading to community fatigue, undermining the community’s ability to be effectively involved in the research, and restricting the community’s ability to have oversight and control over research” (p. 1862).

Indeed, Nowrouzi et al. (2016) point out that, with respect to biological sampling research in Indigenous communities in Canada, “although TCPS2 provides the minimum standard of protection for Aboriginal peoples in research, particularly biological sampling, it does not allow Aboriginal peoples much autonomy in how a study is carried out” (p. 23).

TCPS 2‒9 was never intended to be prescriptive; however, its co-option is a reflection of “ongoing colonialist relations of power” (Brunger et al., 2016, p. 1862). Any uncritical implementation of “ethics” by non-Indigenous operators who are not critically reflexive moves away from Indigenous self-determination to co-option, in the same way a swimmer may get pulled downstream by a powerful current. In this setting, the powerful currents are epistemic racism, differential power, privilege, financing, and decision-making.

Implementation science is an emerging framework gaining favour in public health-intervention research and policy circles. It provides an illustration of existing power dynamics in Indigenous health research and the imposition of externally developed research strategies and methodologies. As a tool, implementation science is used to critically analyze public health interventions prior to their implementation, exploring how and why they will work and under what conditions. The CIHR Pathways program is funding several implementation research programs under the four Indigenous health priority areas (suicide prevention, diabetes/obesity, tuberculosis, oral health) in order to “understand factors that facilitate or hinder scale-up” (CIHR, 2015, p. 13). Pathways promotes the use of implementation science, and its funding cycle is phased to support the eventual scaling up of Indigenous health interventions in communities. However, without the agreement of the very communities in which implementation science methodologies are to be applied, the Pathways program has failed to involve Indigenous communities and organizations in the planning and implementation of research. By adapting this non-Indigenous research paradigm, CIHR missed an opportunity to build upon Indigenous research paradigms. As a result, Indigenous communities are left scrambling to understand this new externally imposed methodology and address some of its critical theoretical and practical failings, including but not limited to the concept of ‘scaling up,’ which is considered by some in Indigenous health research to be antithetical. CIHR’s $25 million investment in implementation research programs is at risk of failing to produce research of social benefit to Indigenous communities.

“The danger here is creating something that’s like pan-Indigenous, pan-Aboriginal … we can’t just make concepts that have worked and use generic English language and say, here you go. Now go and improve your health status over here. It’s not going to work, right. We’ve said that for decades.”

Textbox Q | Implementation Science

“It’s a mainstream concept and it’s something that appeals to national and federal funders for obvious reasons. It’s a very dangerous concept in Indigenous health because it doesn’t take into account what people have been saying forever, and that’s that you have to start with whatever population you’re working with. That could be a culturally based population. It could be a population that defines itself in some way, but they’re an Indigenous population that’s self-defined. And everyone knows implicitly whether it’s like peppered through the literature or not, that what works for one community is just not necessarily going to work for another—and the health issues vary across communities. That’s a given as well.”

These statements of FIIRE Network members illustrate the overall frustration with funders efforts to haphazardly apply general research approaches across diverse Indigenous communities. Instead of looking at implementing evidence-based research in Indigenous communities, funders must first partner with communities to understand promising practices at the community level.

“We’ve seen some really wonderful examples, for example, with mental wellness teams around how community-to-community sharing, as opposed to community-to-somebody-else, to community sharing, kind of up and back down again. The community-to-community sharing, that horizontality, removes some of those power imbalances and can be really compelling for one community to say, “Oh, we’ve heard that such and such works. We want to take your manual or your approach and then make it relevant to us,” but that it’s done direct without some kind of interceder. That also seems important.... There’s ... if communities don’t have a say in that process, there’s just a lot more risks for ... the intervention not to be effective. So, it’s that engagement and participation, which would be really important, and mindfulness of ... even within, you know, the diversity of cultures and even within a nation that of course has differences and one can’t make assumptions and it’s up to the community to decide what will fit and what won’t fit.”

Implementation science risks ignoring the health knowledge and practices that are intrinsic to Indigenous communities. Even with good intentions, the uncritical imposition of external research theories, methods, and practices in Indigenous communities results in the perpetuating of colonial practices that undermine Indigenous community self-determination.

A number of FIIRE Network members recommended providing resources for community-level and horizontal sharing. “[It would] be very helpful to have an economical way to actually share horizontally—share best practices using every means possible.” Empowering horizontal sharing, as well as other community-level practices of knowing and doing, builds on existing Indigenous methods of cross-community knowledge sharing, and promotes the contextual knowledge sharing that is necessary for adaptation. Horizontal knowledge sharing also respects the Indigenous public health-intervention research goal of Indigenous self-determination, a goal many FIIRE Network members consider a priority.

“I think what hinders [knowledge exchange] is the fact that we don’t engage community at the onset. It’s not just about getting ... helping them ... or getting community to help apply and share knowledge. It’s about getting them to figure out what’s important and.... It’s about giving them the opportunity to define this and do it on their own. Like I mean supporting them to do these things rather than doing it for them.

Textbox Q | Implementation Science (cont'd)

> ***"Many people may say, ‘Oh, yeah, you can just publish it in a journal or put it on the website.’ It’s only one of the means of sharing information, but, as we all know, many of the lived experiences and the best practices never get into [the Canadian Medical Association Journal] or other journals. And so, there has to be, in addition to academic journals, there have to be other ways to facilitate communications among all the different communities. The reason why I say [this is] very often we know of success stories in one community but, because that information is disseminated only in a limited fashion, so many other places don’t know, ‘Oh, such a community uses a particular approach.’ If they don’t know, they can’t even consider for their own community, ‘well, might it be useful or not?’”***

Textbox Q | Implementation Science (cont'd)

Inconsistent and poor knowledge translation and data-sharing practices create barriers to community-level ways of knowing and doing—critical components to ensuring research benefit is realized at the community level. There is rich peer-reviewed literature on Indigenous knowledge sharing and translation that provides key learnings and wise practices in this area (see Estey et al., 2008; Estey et al., 2010; Estey et al., 2014; Jardine & Furgal, 2010; Smylie et al., 2004; Smylie et al., 2009; Smylie, 2011; Smylie et al., 2014). For example, one key focus is on knowledge translation in which external researchers report back or return knowledge to a community.[21] However, in this instance, one of the main criticisms has been that not all knowledge is shared back with communities.

The return of knowledge differs from mainstream knowledge translation, as research is embedded within communities, mitigating many of the criticisms of mainstream knowledge translation. Smylie (2011) provides an analysis of the different contexts under which Indigenous knowledge translation can occur.

One FIIRE Network member pointed out how this creates a loss for community: “And then those reports which … have the potential to generate good information, I don’t know where they go. It doesn’t go through any kind of scrutiny really. It just goes to the funder and they read it or don’t. They shelve it or don’t. They archive it or don’t, like we don’t really know. So, we have so many years of health knowledge based on like community-based interventions, and I don’t know what’s happening with that. I don’ know if anyone wants to do anything with it. I feel like it’s knowledge lost. It’s community knowledge. Like they’re putting time and energy and effort into it, into doing these evaluations because they have to, to get more money for their programs to sustain them, but then, you know, who holds that? Where do they share it? You know, what is important out of it? Could we look at a picture over time? You know what I mean. Like there’s just nothing that happens with it currently and it’s too bad. You know, it’s a loss. I’m really into like knowledge preservation. So, it’s a loss for that.”

Here, we highlight FIIRE Network members’ valuable expert opinions and recommendations on knowledge translation, shared during our series of interviews and meetings. One FIIRE Network member recommended that in knowledge translation, face-to-face interactions (gatherings, for example) be prioritized. “The face-to-face interaction is more meaningful and there’s a lot of things in … there’s differences in the language, in the way things are said. How things are said can be more important than the way things are said, and the words that are used might not translate and wouldn’t make their way into certain types of publications. [….] it depends how they use that [word/idea] in context. And so, you wouldn’t … you know, it could be a higher power, it could be Creator, it could be god, it could be sky.

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[21] The return of knowledge differs from mainstream knowledge translation, as research is embedded within communities, mitigating many of the criticisms of mainstream knowledge translation. Smylie (2011) provides an analysis of the different contexts under which Indigenous knowledge translation can occur.

And then by … it can mean something much bigger but just in publication you would narrow that down to one thing and it would lose some meaning."

Another FIIRE Network member advised that the process of knowledge translation should be accessible, relevant, and safe. "Really good communication and using appropriate language and definitions. When I mention appropriate language, I mean highly technical terms don't produce a user-friendly document and should be avoided. But by using the term 'language' I also mean to ask if there is an Indigenous word that can inform the knowledge exchange better than an English word? I think people gravitate to the use of Indigenous languages because they bring them home, if you will. It is a cathartic way of communicating. But it's also the messenger who makes a difference. Involving strong, recognizable, reliable, highly-thought-of voices is therefore key. And I'm not saying this in an elitist sense. I'm saying these kinds of voices usually come from the ground up, and it's these well-informed voices that are extremely important to hear. Creating safe spaces and places is absolutely critical because if indeed we're going to discuss, debate, and decide on sensitive issues, then we don't want our conversations to dissolve into conflicts that end in abusive situations. I think the friendlier approach is to hold conversations and dialogue sessions but always with ground rules and intent. And I think Elders really can be very helpful in situating the dialogue and locating it in a happy healthy nexus."

Another key requirement in knowledge translation is the presence of information champions. Another FIIRE Network member stated, "Having champions of that information, that's why I think data governance is really … something that really needs to be talked about. Academics can get pretty dry and it's, it can be fairly lofty and detached sometimes, and I guess that goes back to the beginning where I was saying show up in the community. So, I guess that's another way of showing up in people's everyday lives, is showing them how that information will directly benefit them or what's directly to be learned and used from that information. And utilizing communication channels and networks."

One way to realize this request is to allocate resources to communities so they are able to staff research projects with local knowledge keepers and brokers.

"I've heard from many communities that one person doesn't hold our knowledge and cannot consent to have our knowledge being taken or used or reported on. It needs to [be] a community decision. And so, what is recognized is someone who has a PhD and can speak in research methodologies. And that person should have beside them a community member that is respected as a knowledge holder or a knowledge keeper or a spiritual practitioner to lend that voice to it as well. And to have, in that way, if they're brought to that forum, that stage the Indigenous knowledge and ways of knowing would be recognized or it would be … that would be part of it being recognized as having the same value as Western teachings."

Overall, communities should always have the final word regarding research data and findings; this key principle can be implemented via research agreements. "So I think, you know, I think it's up to the community. So I think that if a community feels comfortable with it, and that's what they want to do, then they should be able to have control over their information. I don't know that it's up to us to say you have to have control over it. I think it's up to us to support whatever decision they make."

Research agreements can support knowledge translation and data sharing. Although knowledge translation and data sharing are encouraged in multiple types of research guidelines (government, institutional, and Indigenous), as we described earlier, researchers do not always engage in these practices. Contracts that work toward bridging Indigenous and non-Indigenous understandings during the negotiation of research partnerships is one way to achieve this goal; an approach like this would require facilitation from experienced Indigenous health researchers. One wise practice, described earlier in Textbox H, is the research agreement between Indigenous communities, organizations and researchers as recommended in TCPS 2.-9 Well Living House has also been structuring their research, data, and publication agreements based on the Indigenous teaching of the 'Dish With One Spoon' inter-nation treaty, which establishes parameters for those with similar interests and different expectations.[22]

Another excellent example is the jointly developed code of ethics for the Kahnawake Schools Diabetes Prevention Project between researchers at McGill University and the Mohawk community of Kahnawake. The code sets out policies for knowledge translation and data sharing as well as tools to address disagreements and conflicts. (Geary et al., 2013).

Overwhelmingly, the barrier to achieving goals that support partnering with Indigenous communities and organizations as well as facilitating knowledge translation and exchange to and within Indigenous communities is the lack of available resources, including infrastructure, time, and funding. This lack of resources reveals the colonial platform of unequal distribution of health and social resources—a reality that continues to this day.

It is key that policies be implemented to facilitate and resource knowledge translation and data sharing. However, regardless of whether there are research policies in place to guide and improve research practices, as long as institutions and researchers retain the power and legitimacy in the research process through funding mechanisms and institutional privilege, there will be little improvement.

Systematic, deliberate, and transparently quantified efforts that are proportional to need and disparity are necessary to rebalance and redistribute power and privilege. We have emphasized repeatedly that funding availability, timelines, and institutional metrics continue to undermine efforts to improve relationships between researchers and Indigenous communities. (See also: Brunger & Wall, 2016; Castleden et al., 2012; Castleden et al., 2015; Steigman & Castleden, 2015).

Schnarch (2004) provides some examples of how to improve funding to Indigenous community partners and organizations, such as the American Indian Health Service, which funds North American Research Centers for Health and "unambiguously defines American Indian organizations as research organizations and their staff as researchers" (p. 86). Another example is the Health Board for the Inuit region of Nunavik, which only funds local and regional organizations (Schnarch, 2004). One FIIRE Network member recommended that Indigenous partners and collaborators always be listed as co-authors on knowledge outputs (e.g., presentations, publications and reports).

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[22] To learn more, see the Well Living House statement of governance, which refers to the 'Dish With One Spoon' as a useful model for considering how Indigenous and non-Indigenous parties can enter into agreements to set the boundaries of interests, expectations, and outcomes in Indigenous health research. See: http://www.welllivinghouse.com/about-us/research-ethics-well-living-house-governance/

There has ultimately been little effort to address the power dynamics that continue to reinforce barriers to improving funding availability, institutional timelines, and metrics. These efforts must incorporate and embed decolonization as a core principle.

Respecting the principle of decolonization in research does not mean discarding Western approaches to research (Louis, 2007, pp. 131–132). Instead, it requires “asserting [Indigenous methodologies] as legitimate” (Ledman, 2015, p. 161). Table 3 summarizes our recommendations to begin to address the power imbalances inherent in the Indigenous health research ecosystem.

Table 3

Recommendations to Address the Power Imbalances Present in the Indigenous Health Research Ecosystem

- Establish efforts to address policy shortfalls regarding the setting of Indigenous health research priorities and strategies (e.g., co-design, research registries)
  - Focus on approaches that are strengths-based rather than deficit-based

- Facilitate and resource knowledge sharing through mandated research agreements
  - Support Indigenous communities and organizations to develop and implement community-level practices of knowing and doing (e.g., horizontal sharing), building on existing Indigenous methods
  - Knowledge translation conducted by those external to Indigenous community should be communicated through face-to-face interactions; accessible, relevant, and safe; and have knowledge champions located within communities
  - Allocate resources to communities so they are able to staff research projects with local knowledge keepers and brokers

- Facilitate and resource knowledge governance through mandated research agreements.
  - E.g., legal research agreements and contracts between communities and the research community

- Facilitate and resource reciprocal relationship building

Systemic Racism

Racism is a major unaddressed barrier to Indigenous health equity. Inequitable access to health services and differential treatment have been documented and linked to poor health outcomes for Indigenous peoples (Allan & Smylie, 2015; Sinclair Working Group, 2017). It is thus not surprising that racism lies at the root of most of the ethical tensions and inequities in Indigenous health research policies, systems, and practice described in this report.

As stated by one FIIRE Network member: "I think racism is one of the top, like two to three determinants of Indigenous health, if we look at it in all its systemic and attitudinal and epistemological forms. And, I think there's a huge problem in that there's a denial and a lack of acknowledgement and assessment and response to this problem."

The effects of systemic racism can manifest in individual research projects and at a systems level—for example, the undertow towards appropriation. Colonialism and its manifestations continue to influence Indigenous health research policies, systems, and practice. This section discusses how a lack of cultural safety is present in the relationship between government agencies, institutes, sponsors, the wider research community and Indigenous communities and organizations. This has contributed to systemic biases and structural inequities in research practice.

Colonialism and its manifestations continue to influence Indigenous health research policies, systems, and practice. For instance, it underlies many of the structural biases that limit Indigenous leadership. One FIIRE Network member reflected on this, saying, "I think the history of colonization and intergenerational trauma and the fact that so much of the racism has been systematized in terms of policies and programs and assumptions prevents voices from being brought to the table."

Systemic issues, such as racism, require long-term incentives to address them, like access to ongoing improvement through training and mentorship to raise awareness of First Nations, Métis, and Inuit peoples' histories and their concerns regarding health research processes in their communities.

There continues to be a lack of cultural safety in Indigenous health research in Canada. In this report cultural safety is defined as the relationships and spaces where Indigenous people feel comfortable, respected, and able to be themselves (see page 10 for a definition). This lack of cultural safety demonstrates an overall lack of respect in Indigenous health research, which in turn directly influences incidences of racism and tokenism. For example, as highlighted by the quotes below, researchers' engagement with community members, such as knowledge keepers and Elders, lacks respect; contributions have been undervalued, marginalized, and poorly understood.

"So having that involvement is one thing, but actually treating and … or being respectful and knowing and having the knowledge of how when you have an Elder involved, or a knowledge keeper, that you know whatever territory they're from and what the process is and procedure for interacting with that Elder, that it's practice. That it's not just, "Oh we have our Elder, we're good now." Or, "We have our community, we're good now." Or, "We have our youth, we're good now." There is actually work to be … like they need to know. CIHR needs to know what those steps are because it is so … it's offensive."

"A lot of other researchers have never worked with communities before, and they don't even know what's an Elder: 'How do we find an Elder? Well, who is the Elder?' 'Is it an old person? Is it [someone] supposed to have gray hair?' … something so simple as who's an Elder and how do we get one? I remember one researcher, 'Well, I like that feather, how do I get a feather? I want the feather.'"

Such systemic biases can be partially addressed through cultural safety training, mentorship, and learning that actively creates an environment “that is free of racism and stereotypes where Aboriginal people are treated with empathy, dignity, and respect” (Health Council of Canada, 2012, p. 5).

In many respects, the aim should be to remove the burden from those impacted by the lack of cultural safety and instead place it upon those responsible for creating culturally unsafe spaces. Addressing implicit bias[23] and improving cultural competencies have been demonstrated as appropriate first steps toward any effort to improve cultural safety (Allan & Smylie, 2015).

Ideally, these interventions would start at the primary education level in Canada with required courses at the post-secondary level. In the interim, Well Living House has identified programs such as San’yas Indigenous Cultural Safety Training Program (Textbox R) as possible gold standards (Churchill et al., 2017). This program also provides cultural safety training for policy-makers. Programs like these need to incorporate local and regional realities, as was recently done by the Southwest Ontario Aboriginal Health Access Centre, who developed the Ontario Indigenous Cultural Safety Program for Ontario health professionals.[24]

The San’yas Indigenous Cultural Safety Program[25] originated in British Columbia (BC), Canada where it was initiated by the Provincial Health Services Authority – Aboriginal Health Program. The program was developed in response to The Transformative Change Accord: First Nations Health Plan, which tasked First Nations and the Province of BC with increasing cultural competency within health authorities through curriculum development (https://sanyas.ca/). San’yas offers facilitated, online Indigenous cultural safety training in BC and Ontario that is “designed to increase knowledge, enhance self-awareness, and strengthen the skills of those who work both directly and indirectly with Aboriginal people” (San’yas Indigenous Cultural Safety Training, n.d., “Frequently Asked Questions”).

Textbox R | San’yas Indigenous Cultural Safety Training Program

Government funded researchers should be required to obtain cultural safety training and certification from an agreed upon provider. Cultural safety programs should be designed in partnership with Indigenous communities and organizations and should reflect local and regional issues and concerns where possible. Textbox S provides a list of wise and promising practices for cultural safety training.

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[23] Implicit bias are those individually held attitudes, beliefs and stereotypes that present unconsciously and inform our thinking and behaviours (Staats, 2014).

[24] For more detail about the Ontario Indigenous Cultural Safety Program, see: http://soahac.on.ca/ics-training/

[25] For more detail about the San’yas Indigenous Cultural Safety Training Program, see: http://www.sanyas.ca

- Cultural safety training should focus on topics like racism, White supremacy, power and privilege, and settler colonialism, rather than “culture” (i.e., where culture is understood only as foods, dress, ceremonies, traditional teachings, etc.). Participants need to be reflexive and critically self-aware before they can begin the process of unlearning myths and assumptions they may hold about Canada and Indigenous peoples

- Cultural safety training must take place in a safe learning environment. Even though it can be uncomfortable for non-Indigenous participants to learn about racism, the evidence shows that learning can stem from discomfort. Strategies to prevent disengagement include the use of self-compassion activities and normalizing participants’ stereotyping and assumption-making, but also sharing tips to challenge them.

- Cultural safety training should be developed using adult education and transformative education principles so the educator or facilitator can reach adult learners and so the program itself is oriented toward achieving health equity and can effectively advance the goals of the TRC. In practice, this may include reconsidering the TRC. It may also include reconsidering the use of didactic, lecture-style methods and perhaps using interactive, multi-faceted approaches.

- Indigenous peoples and non-Indigenous allies (both White people and People of Colour) should be included in the development, implementation, and evaluation of cultural safety training.

- Scholars and educators need to develop, test, and implement standards and assessment tools that make it easier to measure program effectiveness.

- Training programs must be complemented by changes implemented at policy and organizational levels and be supported by executives and senior leaders in order to maximize uptake and impact.

Textbox S | Wise and Promising Practices for Cultural Safety and Competency Training (Adapted from Churchill et al., 2017)

The recommendations in Textbox S are in keeping with the calls to action made by the TRC, including the following:

Call to Action 23: “We call upon all levels of government to: … Provide cultural competency training for all health-care professionals” (TRC, 2015b, p. 3).

Call to Action 24: “We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the *United Nations Declaration of the Rights of Indigenous Peoples*, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism” (p. 3).

Establishing professional training and mentorship programs as a pre-requisite to participating in Indigenous health research is imperative. FIIRE Network members had a number of recommendations for what these programs should include and prioritize.

“There’s got to be a better way for peoples to understand, you know, and the only thing you can, that’s very basic to start with is to give them a lecture on cultural safety and health status and all that, specific to our region.”

"[What] I'd really like to see in terms of research and health in general is education on local traditions, I mean at least local to the province, and knowledge around why health disparities exist and knowledge around strengths and resiliency in First Nations become a standardized part of education—in that it's even required for licensing for accreditation purposes for professional development and like, re-certification."

"Cultural safety needs to be like the basis and the centre and not what people are striving to do. It needs to already be there, otherwise they shouldn't even start."

Ultimately, improving cultural safety is critical to developing research relationships and creating safe spaces that promote respect and enhance equal footing. As one FIIRE member so aptly put:

"I think it has to be done in a safe way, all parties have to feel safe. We trouble terms like cultural competency and cultural safety a lot because we recognize them as good guiding frameworks in our encounters with one another and they remind us of the unequal power relations that challenge Indigenous people, persons, groups who come from a very different history than outsiders would."

FIIRE Network members also pointed out that cultural safety training can help improve relationships with members of Indigenous communities and organizations. "And so, I think what helped me become more aware that I had blind spots, and become more aware of possibilities on how I could be more effective in relationships, was to be mentored by the two of them [Elders], and they were very generous with me and helped me."

Cultural safety training is only a preliminary stage. Those individuals and organizations who propose heath research with and about Indigenous peoples should work to acquire the knowledge and skills necessary to partner with Indigenous community. Cultural safety training is analogous to first-aid training for a physician: critical, but not enough on its own.

The risk with institutionalizing cultural safety training is that non-Indigenous organizations and institutions can appropriate the process and institutionalize it; as a result, the training can become less meaningful and a box to check in the same way that TCPS 2–9 has for many academic researchers. In addition to cultural safety, training and mentorship should be provided for partners wishing to engage with Indigenous community on Indigenous worldviews, ethical space, and other skills related to lived experiences of Indigenous peoples. With these supports in place, health research can be practised in a culturally safe way, interpreted with cultural relevance, and have meaningful social value at its end. These suggestions build on the findings of Bull (2010), who writes that research relationships should be stratified and researchers' entrance into Indigenous community be based on experience. One possible way to achieve this would be to require universities to establish mentorship programs with placements for researchers-in-training at various levels, including in Indigenous research centres (e.g., Well Living House, Blue Quills University, Waakebiness Institute for Indigenous Health), Indigenous-led governance bodies and organizations, and in Indigenous community itself.

Training and mentorship programs for researchers should be informed by Indigenous communities and organizations that are empowered and enabled to do so, in line with some of our earlier recommendations—for example, providing sustainable core funding for Indigenous communities and organizations that support health research in Canada. However, it should not be the burden of Indigenous peoples and communities to ensure that governments, institutions, and researchers are conducting themselves in a culturally safe manner: This burden belongs to them and should be addressed by them. Table 4 summarizes our recommendations for addressing systemic racism present in Indigenous health research.

Table 4

Recommendations to Address Structural and Lateral Violence in Indigenous Health Research

- Cultural safety certification as a pre-requisite for non-Indigenous researchers and non-Indigenous staff at federal and provincial health research institutes and agencies

- In partnership, develop Indigenous health components for secondary and post-secondary schools to raise awareness

- Establish training and mentorship programs to develop non-Indigenous research partners' skill sets in Indigenous worldviews, ethical space, and other skills related to lived experiences of Indigenous peoples.

DISCUSSION

Research Relationships That Prioritize and Privilege Indigenous Communities Result in Health Research With Social Value

Reconciliation has been defined by the TRC as the "ongoing process of establishing and maintaining respectful relationships" (2015a, p. 190). Non-Indigenous individuals, institutions, and organizations invested in Indigenous health research must practice reconciliation in order to address the historical and ongoing harms of colonial policies that continue to inform health research and to establish and sustain long-term research relationships with Indigenous communities. Diverse Indigenous communities across geographic regions are essential to the conceiving, planning, and carrying out of health research with and about Indigenous peoples in Canada. Without their active involvement—through relationship, embedded engagement, and collaborative partnership—health research will not benefit Indigenous communities, nor will it generate any social value. As Smylie (2015) notes, this task will not be easy: "The complexity of entrenching this [respect for different ways of understanding and living] into action in all that we do should not be underestimated. We must challenge and transform the foundational disrespect for Indigenous ways of knowing and doing that was used to justify colonial policies and is persistently embedded in our laws, schools, health systems and unconscious minds" (p. e261). This task will require mindful reflexivity—it will be necessary to "engage in self-reflection" and "listen, learn and locate" (p. e262). In many ways, relationships are the perfect measurement tool, as sustainable, fair and reciprocal relationships are evidence of success.

Relationships between the researcher and the researched should be authentic in their collaboration, and should "enable the researcher … to understand the concerns that these populations bring to the experience of being researched, and to be able to respond respectfully and appropriately to the peoples studied and their community" (Bull, 2010, p. 16). In 2016, CINA developed a Collaborative Indigenous Partnership Framework (see Textbox T), where "values are grounded in diverse Indigenous philosophies that centre relationality, respect and reciprocity at the core of self-determination" (p. 7).

Relationships should also be guided by Indigenous research principles, such as the four R's: respect, reciprocity, responsibility, and relevance (Kirkness & Barnhardt, 1991). Throughout this report we have highlighted how some of these principles might manifest in equitable research practice. For instance, Indigenous ways of knowing, doing, imagining, and visioning must be observed, respected, and valued throughout the research process so that the information that is collected is interpreted accurately and the outcomes are relevant to Indigenous communities. As summarized by one FIIRE network member, "You have to really draw upon community knowledge to get the best, to make whatever they're researching better. It only makes it [the research] more valuable".

Researchers' relationships with Indigenous communities must be established early on and research priorities should be determined and developed collaboratively. "Sometimes even though the intention is good, an entity involves the communities or the Aboriginal organizations too late … I think that is not good for a relationship … It's brainstorming together to actually come up with the project and plans and so on and so forth."

Relationships must also be sustainable, drawing on the wise practices of Indigenous kinship. Indigenous kinship systems are referred to in the TCPS 2–9 guidelines, where they are described as multi-generational networks with responsibilities and obligations to relations, including ancestors and future generations (CIHR, NSERC, & SSHRC, 2010).

As the Canadian Indigenous Nurses Association (CINA) says: "Nothing for us – without us."

It's a new era—CINA recently released its Collaborative Indigenous Partnership Framework: Supporting Our Unique Expertise - Indigenous Nursing Knowledge. CINA is recognized as the longest standing Indigenous health professional association in Canada. This makes CINA a significant collaborator with Indigenous health and leadership organizations, mainstream nursing organizations, educational institutions, governments (federal, provincial, territorial), and local Indigenous governments. Its key aims are to support political action for the true recognition of treaty rights, self-determination, and sovereignty approaches to health, education and justice. Early on, Indigenous nurses developed an Indigenous nurse identity, which combined a strong belief in social and cultural responsibility with a professionalizing nursing ethic.

CINA believes in authentic Indigenous partnerships with Indigenous rights-holders and non-Indigenous stakeholders that are inclusive of values grounded in diverse Indigenous philosophies that centre relationality, respect, and reciprocity at the core of self-determination.

CINA's Authentic Indigenous Partnership Strategy identifies Indigenous relational values and protocols to maintain CINA's established recognition as a leader in Indigenous health and Aboriginal health nursing. CINA identifies partners that will maintain and advance ongoing nursing policy, research, practice, and education goals, and these partnerships may yield funding sources that further support Indigenous self-determination. The framework implementation protocol will ensure that CINA's leadership and expertise is upheld in the spirit of an 'Indigenous-ally' relationship.

UNDRIP calls for participation of Indigenous peoples on issues that affect them. In the context of CINA's work, partners must understand spiritual ties to the land, collective and individual rights and identities, and the worldviews, traditions, languages, and cultures of Indigenous nurses. A rights-based partnership—"Nothing for us – without us" requires mainstream nursing leadership organizations, policy makers, educators, and researchers to understand the structural barriers and challenges that Indigenous nurses encounter. This style of partnership requires co-created strategies as a key feature of an environment that enables and ensures the full and effective participation of CINA. To uphold CINA's leadership and maintain the integrity of its partnerships, its collaborative mechanisms will include a conflict resolution protocol and increased focus on mentorship. (Reproduced from CINA, 2016.)

Textbox T | Canadian Indigenous Nurses Association Collaborative Indigenous Partnership Framework

Finally, research relationships should be structured to consciously redress existing power inequities and encourage respect for diversity. Two FIIRE members spoke of diversity, saying:

"No one particular person dominates the conversation. I think it's a very respectful dialogue and no matter how many degrees a participant has, that's not relevant. I think it's all the lived experience that's important for all, everybody involved. It's like building a barn together."

"We all bring knowledges which some might disagree with because they think it absurd and odd and downright non-fitting … there [has] to be an openness to different voices at the table and a strong appetite for welcoming them in a respectful way."

When researchers' relationships with Indigenous communities are strained research findings can be decontextualized and misrepresented. This is more likely when relationships are non-Indigenous and colonized, rooted in limited engagement, lack sustainability, and occur outside of participatory action research. Non-Indigenous researchers may miss or undervalue Indigenous community knowledge and skills, and the complexity of Indigenous community-knowledge systems and protocols. This context is key to research that leads to effective health services.

Government agencies, institutions, and sponsors underestimate the investments that are necessary for building relationships—particularly given the historic and existing attitudinal and systemic discrimination experienced by Indigenous peoples. When research is not rooted in relationships, research that is poorly developed and implemented can result and produce outcomes that fail to benefit community members. Such research is more likely to cause harm by reinforcing and exacerbating racist stereotypes and can result in what one network member has described as "reduced storytelling."

Relationships in Indigenous Health Research are Fragmented and Misaligned

Many of the policies that provide guidance and inform research with Indigenous peoples in Canada (e.g., TCPS2–9), require researchers to engage and partner with Indigenous communities. Policies also emphasize the need to recognize diverse interests within Indigenous communities. These policies came about largely in response to multiple concerns from Indigenous communities regarding exploitation and harm resulting from research. There was a clear need to improve accountability, co-operation, and mutual respect (Castleden et al., 2012). In many respects these policies have been welcomed and prompted positive changes to practice. "More and more, researchers and grant holders and ethics boards in different areas of research … are coming to us for assistance on how to approach First Nations communities or First Nations issues in a respectful way. And that, again, is an achievement in and of itself."

Still, as we have highlighted throughout this report, concerns remain regarding the degree to which Indigenous communities are involved in health research. Concerns also remain about the overall accountability of researchers, institutions, and sponsors to Indigenous communities. Although policies and systems do address the relationship interface between researchers and Indigenous communities, in practice, there are various levels of researcher-to-Indigenous-community engagement and accountability. Better alignment among all of the diverse institutions, agencies, and individuals involved in Indigenous health research (i.e., government agencies, sponsors, Indigenous institutions and advocates, and academic researchers) is needed. Every party needs to be clearly accountable to Indigenous communities. The criteria requires a more complex and relational network (Figure 2) that is in keeping with the "nation-to-nation" recommendations of the Royal Commission on Aboriginal Peoples (1996), UNDRIP (2008), and the TRC (2015a).

However, in practice, Indigenous communities are not always as involved as they should be. True partnerships between communities and researchers are rare. Engagement activities are frequently relegated to specific time-points during research projects and do not adequately account for priority setting, knowledge translation, and sustainable implementation.

Through a series of memes (Figure 1), NYSHN outlines their key concerns when it comes to partnering with researchers on issues of Indigenous youth and their health and wellbeing.

Figure 1 | NYSHN Recommendation Memes Addressing Research With Indigenous Youth

There has been a failure to recognize that Indigenous communities may not have the necessary time, resources, finances, and infrastructure to meaningfully partner in research. Moreover, and disturbingly so, many of the Indigenous governing bodies—whose mandates are to advocate for community interests—are systematically marginalized by the government agencies, institutions, and sponsors of health research through funding constraints and policies that remove them from priority setting activities and other formal roles in research.

Figure 2 illustrates how relationships between academic researchers, government agencies, institutions, sponsors, Indigenous governing bodies, and Indigenous communities are fragmented and misaligned. It also presents an alternative and improved model of how complex relational networks and fluid networks of resources should be structured in Indigenous health research.

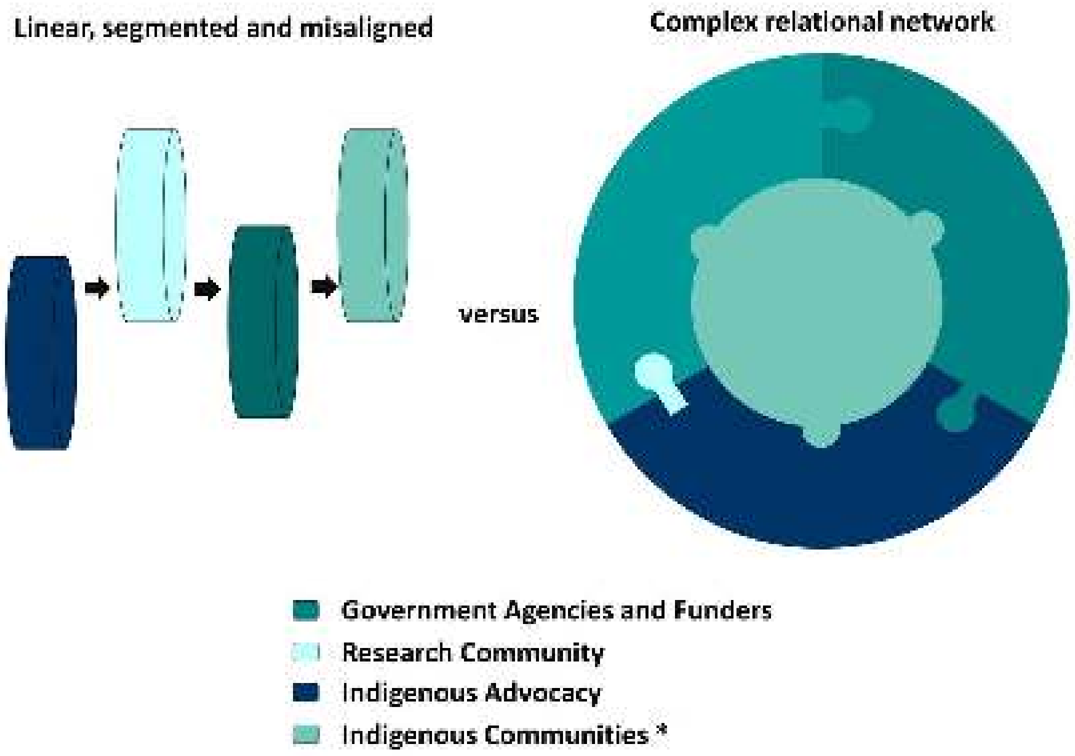

Figure 2 | Relationships Between Academic Researchers, Government Agencies, Institutions and Sponsors, National and Regional Indigenous Governing Bodies, and Indigenous communities

Systemic Limitations of Canada’s Indigenous Health Research Policies

This report identifies failings inherent in the policies guiding Indigenous health research in Canada. These failings are not necessarily the product of any single individual or institution, but more so the result of systemic failures. For example, contradictions in guidelines, inadequate accountability mechanisms, and institutionalized and systemic racism. These types of failings are hard to redress.

“It’s not the people but it’s the structure. So it’s the internal policies they have that prevent the people from doing … I think perhaps what some of them know they need to be doing.”

Carla Moore shares this view in her work analyzing TCPS 2-9. She writes, “how these policies are operationalized and understood by peer-review committees and financial services employees is critical to achieving those ethical requirements” (2015, p. 101). The concern is expressed more directly by Steigman and Castleden (2015), who write that “our frustrations—which echo those of many colleagues struggling to do research ‘in a good way’ (see, for example, Ball & Janyst 2008 and Bull, 2008) within this framework [TCPS 2]—highlight the urgent work that remains to be done if university-based researchers are to be enabled by establishment channels to do ‘ethical’ research with Aboriginal peoples” (p.2).

In general, systemic failings are insidious in their manifestations and require complex solutions; yet, the time and financial constraints described earlier are commonly addressed on an ad hoc basis. There are few mechanisms to tackle the complex systemic causes detailed earlier and emphasized by Steigman and Castelden (2015), who write that, “we seem to have been able to do research in a good way, and at times this has been *despite*, not *because of*, the TCPS2” (p. 2).

Government Policies Must Address the Lack of Transparency and Accountability in Indigenous Health Research

Many FIIRE Network members specifically referenced or intimated the importance of accountability in research relationships. Members reflected on relational accountability, illustrating how it can be informed by the structure and proximity of relationships. For instance, in interviews some members expressed how their accountability was primarily to their communities, as opposed to government agencies or researchers.

“We’re just accountable to a lot of people … we hold that like position very humbly, and like very carefully … all of the youth leaders and community partners inform all of the work that we do, so nothing is without them. Everything is with them.”

“I do things in a way that is from love and compassion and is tied into Elders and communities as a part of that project, as well as through ceremony…”

Some members highlighted the complete lack of accountability in relationships between the different parties involved. “You know, so there’s a real disconnection between the federal government and these communities."

Others questioned where accountabilities lie: “[I] feel like there’s like a lot of secretive hiding where accountability comes from, but like we actually need to know, otherwise it’s like the space is compromised. Like, it’s not safe.”

In Indigenous health research, everyone is accountable to participating Indigenous communities, which can only be realized through well-developed and established relationships (Figure 4). One of the key failures in the current relationship structure is the weak or complete loss of accountability to Indigenous communities. Figure 4 outlines how this loss of accountability manifests in research. We note that it is often those with mandates to advocate for community interests (i.e., national and regional Indigenous governing bodies) who are most often marginalized through systemic failures of financial and capacity constraints.

Figure 4 | Accountability in Indigenous Health Research is, in Part, Informed by the Structure and Proximity of Relationships

Steigman & Castleden (2015) write about the lack of accountability between Indigenous communities and researchers, suggesting that researcher compliance to TCPS 2–9 supersedes any ethical directives given by Indigenous peoples themselves. If a researcher opts to comply with the ethical directives issued by Indigenous communities, and it contravenes with their university-based REB’s implementation of TCPS 2–9, the researcher is at risk of losing their project funding and potentially their career in the academy. As a result, Indigenous partners are also at risk of losing the potential benefits of the research processes and outcomes that would have taken place in their communities. It is very clear that one of the impacts of this breakdown is diminished trust and harm. Ultimately, investments are wasted when there is a lack of Indigenous community-level leadership and suboptimal outcomes.

These concerns reflect the need to cultivate and advance research relationships between Indigenous communities, Indigenous governance bodies, researchers, government agencies, institutions, and sponsors through appropriate and applied policy measures that enable rather than impede. Going forward, these polices must include mechanisms that hold all concerned parties to account, particularly to Indigenous communities.

Achieving Self-Determination in Indigenous Health Research

Self-determination in research oversight is in line with UNDRIP, RCAP, and the TRC of Canada. For instance, UNDRIP highlights the minimum standards for the rights of Indigenous peoples to improvement of health and self-determination of the mechanisms to achieve it:

Article 21:
1. “Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including, inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.”
2. “States shall take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions. Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities” (2008, p. 17).

Article 23: “Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions” (2008, p. 18).

The TRC of Canada also recommends sustainable capacity strengthening and self-determination in Indigenous health:

Call to Action 18: “We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties” (2015b, p. 2).

Call to Action 19: “We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services” (2015b, pp. 2–3).

CONCLUDING REMARKS

This report makes clear the importance of relationships in health research conducted with and about Indigenous peoples in Canada. This is largely because Indigenous ways of knowing, doing, imagining, and visioning must be acknowledged, respected, and valued in research processes so that the information collected is interpreted accurately and research outcomes are applicable to, and benefit, Indigenous communities. Research done in this way benefits Indigenous communities and generates social value.

Disturbingly, in practice, this is not happening. We believe that, in part, these relationships are not in place due to the lack of trust between Indigenous communities, government agencies, research sponsors, Indigenous institutions, Indigenous advocates, and academic researchers. This reality reflects historic and ongoing colonial and harmful practices in health research with and about Indigenous peoples. We suggest that these realities persist regardless of the existing research standards and systems intended to respect and empower Indigenous communities in research processes. We argue that the goal of good research relationships in Indigenous health research have not been achieved because, in practice, systemic factors such as financial constraints, contradictory policies, inadequate oversight mechanisms, and deeply embedded power imbalances, along with systemic racism, have stymied these relationships, creating barriers to wise research practices.

The TRC describes reconciliation as “an ongoing process of establishing and maintaining respectful relationships” (2015a, p. 16). We recognize the core importance of relationship in research and the need to establish respectful relationships as a priority. Respectful relationships in Indigenous health research must incorporate all of the principles we have outlined regarding wise and promising research practice, and the recommendations we provide in this report are a starting point toward improving these critical relationships. For instance, the guiding principle of recognizing and respecting cultural safety is an expectation of UNDRIP and the TRC, yet for research partners in Canada to truly do so in an authentic manner would require significant resourcing efforts. These efforts would include developing and disseminating best practices, mentoring and educating the research community, and establishing oversight mechanisms so that efforts are translated from policy to practice.

It is critical to note that Indigenous communities across Canada are heterogeneous in nature; implementing these practices with a broad brush would be a mistake. Instead, we need to learn from and support existing models and wise practices. Some examples include the First Nations Information Governance Centre, the Aboriginal HIV & AIDS Community-Based Research Collaborative Centre, and the Native Youth Sexual Health Network. We recognize that the realization of Indigenous self-determination in health research, policy, and practice will be as rich and diverse as the Indigenous communities in which this work is situated.

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