Title: Research and Reconciliation: Exploring the approaches of non-Indigenous researchers to Indigenous research

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Abstract

Rationale: Given the history of unethical research in Indigenous communities, there is often apprehension among Indigenous communities towards research carried out by non-Indigenous researchers. We examined the approaches, experiences, and motivations among non-Indigenous researchers at one research-intensive Canadian university conducting research with Indigenous communities to identify facilitators and barriers to ethical research with Indigenous peoples.

Methods: We conducted, transcribed, and thematically analysed eight semi-structured interviews using an iterative process within a critical constructivist framework informed by Indigenous research methodologies. Shared experiences among non-Indigenous researchers were arranged into primary themes.

Results: We identified four primary themes related to non-Indigenous researchers conducting Indigenous research: 1) relationships with communities are foundational to the research process; 2) non-Indigenous researchers experience a personal self-reflective journey grounded in reconciliation, allyship, and privilege; 3) accepted knowledge frameworks in Indigenous research are familiar to most, but inconsistently applied; and 4) institutions act as barriers to and facilitators of ethical conduct of Indigenous research. Four core principles – relationships, trust, humility, and accountability – unified the primary themes.

Conclusion: Our data demonstrates that current approaches to Indigenous research at this university have elements that are congruent and incongruent with accepted policies, such as the Tri-Council Policy Statement 2 (TCPS2). Congruently, non-Indigenous researchers value relationships and research is informed by Indigenous knowledges. Incongruently, the TCPS2 lacks applicability to secondary data analysis, for some non-Indigenous researchers. Additionally, institutional barriers to implementing accepted processes, such as partnership agreements, exist. We identify strengths and areas for improvement of current policies and practices in Indigenous research.

Words: 250

Introduction

Historically, non-Indigenous researchers carried out the majority of research in Indigenous communities in Canada (1). Furthermore, health-related research rarely had direct benefits for the communities being studied, was rarely translated to meaningful action, and sometimes led to direct harms (1-6). As a result, there often continues to be a sense of apprehension and mistrust among Indigenous communities towards research carried out by non-Indigenous researchers (1). Colonial approaches to research with Indigenous communities also occurred in other countries around the world, including the United States of America and Australia (7). We use the term Indigenous to represent the First Nations, Inuit and Métis Peoples in Canada.

In our Canadian context, there are several policy documents which guide research in Indigenous communities, including the First Nations Principles of Ownership, Control, Access and Possession (OCAP®[i]) and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS2). The OCAP® principles, established in 1998, make it clear that First Nations' communities have the right to control data collection processes occurring in their communities. Communities have ownership of their collective data, have continued access to it throughout the research process, including controlling how data are interpreted and disseminated (8, 9). The TCPS2 is a joint policy of Canada's three federal research agencies: the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC). The TCPS2, Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada**,** aims to inform and promote respectful, reciprocal, and collaborative research with Indigenous communities (1). Developed in collaboration with Indigenous leaders and communities, the TCPS2 details the appropriate consultation processes, documentation, and approvals necessary for ethical community engagement (1). For example, articles 9.13 and 9.14 indicate that research should reflect community needs and priorities, and should have benefit to the communities, through capacity-building initiatives such as training, local hiring, recognition of contributors, and the return of results. Moreover, in accordance with article 9.15 and 9.17, researchers should engage Elders and community researchers in the design and execution of research. These community members should play a role in ensuring data analysis considers contextual factors, including cultural norms and traditional knowledge (1).

Conducting research in accordance with the TCPS2 guidelines is a requirement for receiving funding through any Canadian federal research agency. Moreover, many Research Ethics Boards at academic institutions, including at the University of Toronto (UofT), have adopted the TCPS2 principles as requirements for approval (1, 2). However, because some of the principles are abstract, several logistical and ethical challenges for research with Indigenous communities have been described (4, 10-14). Additionally, there is limited evidence regarding current practices at Canadian universities and their congruence with the TCPS2 and other guidelines. In response to this knowledge gap, we explored the understandings, motivations, and levels of relevant

knowledge of non-Indigenous researchers at one large, research-intensive Canadian university (UofT) whose research scope includes Indigenous health.

Methods

To meet the above objective, we undertook a critical constructivist qualitative study. While this study was not designed using Indigenous research methods, it was informed by our team's knowledge of the common guiding principles of Indigenous research, includng collaboration and a respect for diverse forms of knowledge and expertise (10, 12, 15, 16). We conducted semi-structured interviews (17) to gather information about researchers' general level of knowledge of current guidelines related to Indigenous health research and the ways in which the researchers operationalize this knowledge. Our team consisted of Indigenous and non-Indigenous medical students, an Indigenous resident physician, and Indigenous and non-Indigenous physician-researchers.

Study design and sampling

The inclusion criteria for identifying potential interviewees included [1] academic affiliation with UofT and [2] research focus/interest related to Indigenous health. We identified potential participants through UofT faculty and departmental websites (the Faculty of Medicine, the Faculty of Dentistry, the Lawrence S. Bloomberg Faculty of Nursing, the Factor-Intewash Faculty of Social Work, the Leslie Dan Faculty of Pharmacy, the Dalla Lana School of Public Health, the Institute for Health Policy, Management and Evaluation, and departments within the School of Graduate Studies). We also searched academic websites related to Indigenous Health: the National Network for Aboriginal Mental Health Research, the Indigenous Health Research Development Program, and the National Collaborating Center for Aboriginal Health. Where possible, we employed the Boolean filters of 'Indigenous' and 'Aboriginal.' To maximize our sample size, we also identified additional potential participants by searching the author lists of publications by faculty members identified through our original search of faculty websites and databases.

We contacted 32 potential participants by email to schedule an interview at a time and place convenient for the participant. Eight participants respectfully declined, and there was no response from 14 participants. In the end, while we had 10 accepted invitations for participation, adequate information power was achieved with eight completed interviews. Information power, as described by Malterud et al. (18), indicates that fewer participants are required in settings where the sample holds more relevant information. Elements such as a narrow study aim, a highly specific participant selection, strong interview dialogue, an analysis supported by accepted theory, and a nuanced exploration of details increase the information power contained within a sample, thus decreasing the number of participants required (18). Our sample size of 8 participants is supported by several characteristics of our data. Firstly, the nuanced and deeply

descriptive nature of the participant's responses resulted in a very rich data set. This was complemented by a narrow study aim, a sample population specific to location, academic position, and interest, as well as the use of established critical constructivist theory to guide our analysis.

Data collection & Validity

Four members of the research team (AK(a), AK(b), CRW, LR) developed an interview guide. The interview guide was not piloted. The primary investigator (AK(a)) conducted, recorded, transcribed verbatim and anonymized eight semi-structured interviews. There were no repeat interviews. There were no non-participants present at the interviews and no field notes were made during the interviews.

Analysis

All authors manually coded the transcripts using a bottom up approach to derive themes directly using an iterative process within a critical constructivist framework (19). We refined the identified themes through discussions that included all authors (who represent Indigenous and non-Indigenous critical, decolonizing perspectives) (7). These discussions aimed to mitigate any assumptions that might have gone unquestioned by an individual investigator or a homogeneous group of investigators. Finally, we created a framework to integrate and graphically represent themes and subthemes (Figure 1).

Results

In total, we conducted eight semi-structured interviews between August and October 2017. No participants dropped out or withdrew consent. The mean interview length was 29 (range 15-58) minutes. Our sample included participants from six different disciplines including medicine, other health professions, and primary research disciplines.

From our data, we identified four primary themes related to conducting Indigenous research as a non-Indigenous researcher. For the purposes of graphic representation, each theme has been named in square brackets. The four primary themes are: 1) Relationships with communities are foundational to the conduct of Indigenous research [*community*]; 2) Non-Indigenous researchers experience a personal journey related to reconciliation, allyship, and privilege [*personal journey*]; 3) Accepted knowledge frameworks in Indigenous research are familiar to most, but inconsistently applied [*knowledges*]; and 4) Institutional structures can act as both barriers and facilitators to the ethical conduction of Indigenous research [*structures*]. Each of these primary themes included several subthemes, which are expanded upon below. In addition, we identified four core principles discussed by all of the interviewees that linked the primary themes: relationships, trust, humility, and accountability. We represent these relationships between main themes, their subthemes, and the core principles graphically in **Figure 1.**

[Insert Figure 1: Conceptual model of themes, subthemes, and core principles]

[Caption: The four primary themes and their subthemes occupy each quarter of the inner circle. The outer circle holds the core principles that link each of the subthemes. Subthemes are underlined in the text.]

Relationships with Indigenous communities are foundational to the research process [*Community*]

The perspective that relationships with Indigenous communities are foundational to the research process was a prevalent theme in our analysis. Study participants described a 'bottom-up' approach, which ensured that the research question was relevant to and generated by the community:

> [We] involved input from the community right from the day one, both in terms of what are the research questions that we should be asking, what are the focuses we should be looking at, and also when we've got the results, how do we interpret the data, what do we do with these data, what's the context that these data should be interpreted in. (P03)

Within the primary theme of community, there were prevalent subthemes of partnership and Indigenous leadership. In some projects, community input was sought through the creation of an official advisory council. Other projects leveraged partnerships and relationships with individuals in the community to seek input on the project, data, and/or methodology. Importantly, mutual respect was identified as a subtheme, as it was considered an essential foundation for building relationships with communities. Participant 7 expressed the importance of mutual respect by saying, "Don't rush into things with assumptions. Be respectful and pay attention to group norms." (P07)

The final subtheme within this the primary theme of community was that the reciprocal exchange of knowledge, skills, and resources also helped to strengthen the relationship between the researcher and the community:

> I have the research background and […] I bring a certain skill set, but I recognize that my skill set is not [enough]. […] I was not trained as an Indigenous researcher or a researcher of Indigenous health. So, I've tried to partner with people who have that expertise and bring my expertise and learn, but I don't want to assume things. (P08)

Indigenous research is a personal journey for non-Indigenous researchers [*Personal Journey*]

There were three main motivators for pursuing Indigenous health research: relevance, health equity, and necessity. Most participants felt that there were elements of their research scope with direct relevance for Indigenous health. This included a higher burden of various diagnoses in Indigenous communities, and/or specific needs with regards to social service delivery. Secondly, many participants were explicitly motivated by their interest in health equity. Finally, several

participants referred to the concept of "happenstance"; their involvement was unintentional, but a series of circumstances prompted engagement in Indigenous research. For example, some researchers were approached directly by communities, or invited onto an existing project by a colleague, with permission from Indigenous stakeholders.

Regardless of motivating factors, all participants, either implicitly or explicitly, alluded to a personal journey of growth and reconciliation associated with their research work in Indigenous communities. This primary theme included subthemes of learning the meaning of allyship, recognizing the privilege associated with a non-Indigenous identity, and developing resilience based on challenges related to the research process. One participant described the tensions of allyship by saying, "You're going to have people that are uncomfortable with a non-Indigenous person […] and you have to just go with it. People have varying levels of comfort about having an ally" (P05).

Participants recognized that historical context and past historical injustices have strained the relationship of Indigenous communities with researchers. In response to this understanding, some participants reframed their role through the lens of reconciliation. Participant 2 said, "I do Indigenous health research cautiously and I do it in the spirit of reconciliation" (P02). Reconciliation became an important subtheme within the theme of the personal journey experienced by the non-Indigenous researcher.

For some, the personal journey also included an element of emotional burden and burnout. Participant 2 reflected on this by saying, "There are not a lot of Indigenous researchers – […] what's hard is that it's always the same people, everyone is burnt out" (P02). Burnout was more common among those doing community-based research, rather than secondary data analysis. However, for some discomfort promoted reflection, a final subtheme within the primary theme of personal journey. This relationship between discomfort and reflection was articulated by Participant 6, who said, "My hope would be that as non-Indigenous researchers, we can live in a place of distress. […] I am a little bit worried that if I don't remain distressed then I'm not paying attention." (P06)

Accepted knowledge frameworks in Indigenous research are familiar to most, but inconsistently applied [*Knowledges*]

Various knowledges are essential to doing Indigenous research "in a good way". This a phrase commonly used in many Indigenous communities with regards to "participation that honours tradition and spirit", and is respectful (20). Indigenous knowledge keepers and community members facilitate the incorporation of historical and current contexts and Indigenous knowledge into the analysis. Participant 3 illustrated the ways by which community engagement positively supported the analysis by saying, "If anything [community engagement has] provided some context [or] validation of what we thought would be the context." (P03)

Indigenous knowledge played a role in facilitating collaborative and respectful data analysis. In our data set, this included the incorporation of ceremony into research meetings and the research process, respect for the land, the 'adoption' of an Indigenous worldview, and the involvement of Elders. As one participant said, "You always have to have an Elder involved from the beginning and at every meeting preferably. They ground the project. They ground the people. Ceremony is important, as much as possible." (P02)

With regards to western knowledge frameworks, there are several Canadian policy documents that exist to guide research in Indigenous communities. While all participants were familiar with the OCAP® principles and the TCPS2, OCAP® emerged as the more commonly applied tool in practice. Additionally, the Truth and Reconciliation Commission (TRC) report and the United Nations Declarations of Human Rights (UNDHR) emerged as a guiding document for several of our participants; these aforementioned documents are not required readings to inform research with Indigenous communities, but certainly have cross applicability.

Institutional structures as barriers and facilitators to the ethical conduction of Indigenous research [*Structures*]

Our data demonstrate that institutions, including universities, faculties, departments, or research institutes, have the potential to facilitate or impair the ethical conduction of Indigenous research, depending on their leadership, structural organization, and values. Within these institutions, structural facilitators of ethical Indigenous research include precedents for advisory groups, partnership agreements, and Indigenous Affairs Units. Integrating Indigenous research principles, including those outlined in the TCPS2 and OCAP® documents, into the culture and identity of the institution was an important subtheme. This was done through institutional mandates and mission statements, thus ensuring continuity and sustainability of the work. A participant described the impact of formalized agreements, saying "We have signed relationship protocols with a promise to work with [communities] and continue to engage with them to try our best to answer their research questions. The director here has really formalized that process." (P07)

In contrast, participants affiliated with institutions without such structures experienced barriers and institutional resistance to conducting their research in accordance with TCPS2 and/or OCAP® principles. For example, some institutions had no precedent for the establishment of partnership agreements or memoranda of understanding (MoUs), as required by the TCPS2. One participant described their experience saying, "I went to my research institute and said that we want a partnering agreement and [they] said, 'we don't do that'." (P02)

Core Principles

In addition to the four primary themes and their subthemes, we identified four core principles discussed by all of the interviewees that linked the primary themes: *relationships, trust, humility*, and *accountability.*

Every participant spoke about the importance of building *relationships* and establishing *trust* with the community and individuals. Our data supports the finding that trust must be mutual; it must be gained and given by both parties. Upon agreeing to engage in research, particularly research led by a non-Indigenous researcher, an Indigenous community must trust that the researcher will honour any agreements and welcome community engagement at the level deemed suitable by the community, and that the research will align with community priorities and be used to benefit the community. Trust in these aforementioned principles permits Indigenous communities to share their data and their stories, which are, in all senses of the word, sacred. Similarly, non-Indigenous researchers must reciprocate this trust by efficiently and optimally conducting research in congruence with community values and by respecting Indigenous ownership of the data. Trust is both the foundation for and a facilitator of relationship building. As such, it often requires a significant time investment. Participant 5 articulated this by saying; "It requires two years of a kind of process for people to be comfortable with that you are going to analyze this data in a very respectful way." (P05)

Trust was further facilitated by formal structures such as partnership agreements, strategy documents, and MoUs. These elements were also a tool to maintain *accountability*. The principle of accountability ensures that the trust that supports the integral relationship between a researcher and the community is not broken. For example:

> The big emphasis of our strategy document over the last few years is formalizing these relationships. To […] keep [our organization] and our team liable, we have items in the […] scorecard to ensure that we are doing our work. (P07)

Finally, *humility* emerged as a prominent principle. Humility facilitates relationship building by decreasing the influence of power imbalances. Moreover, the personal journeys experienced by researchers often included acknowledging one's limitations and learning that one's role includes contributing a specific knowledge and skill set, which requires conscious humility. This is emphasized by the following quotation:

> I see myself as almost like a guest that has been invited in. […] I've been invited in because I have some skills that those folks think would be useful and so I try to be really careful in understanding what might be some expertise I have to offer and humble about the fact that I don't have much else and just try to be really cautious. (P06)

Interpretation

Little is known about how frameworks for ethical engagement and research with Indigenous communities are applied in practice, particularly by non-Indigenous researchers. Our data, collected and analysed by a diverse research team consisting of Indigenous and non-Indigenous researchers, demonstrates that approaches to Indigenous research at UofT have elements that are both congruent and incongruent with accepted policies, such as the TCPS2 and OCAP®.

The TCPS2 and OCAP® principles were familiar to all participants and were generally regarded as a minimum standard for research. However, while participants were all individually aware of current policy statements and best practices in the field, there was a gap with regards to the implementation of research-related policy statements at the institutional level. Some institutions did not have precedents for and/or opposed the implementation of accepted elements, such as data sharing agreements. In these settings, it was the researchers' responsibility to advocate for and create systems by which they could carry out their research in an ethical manner. This represented an additional burden that predisposed participants to burn out.

Additionally, participants involved in the analysis of secondary data felt that the TCPS2 was less applicable to their work as it was more focused on guiding community-based research and direct community engagement. This is concerning, given that there is still an important role for community engagement and collaboration in the context of secondary data analysis. Specifically, the ownership of the data still lies with the community and there is still an important role for community consultation to inform data storage, interpretation, and dissemination.

Despite these gaps in the conduct of Indigenous research, there are several strengths of the current approach, which form a solid foundation for continued improvement and growth. For example, the literature on Indigenous research methodology almost universally acknowledges the importance of relationship building and community engagement in the research process (1, 4, 15); our data was congruent with this finding. In our data set, the relationship-building process described by interviewees allowed all non-Indigenous researchers and Indigenous community members to recognize each other's value and collaborate effectively. This diminished the tendency to make assumptions, encouraged active listening and learning, and induced an appreciation for Indigenous knowledge among the non-Indigenous researchers in our sample. Recent literature indicates that the data analysis stage of a collaborative research project is often a challenging period due to disagreement with regards to interpretation (4, 13). However, this was not a concern expressed by participants in our sample. While the community-based analysis rarely differed significantly from that of the non-Indigenous research teams to which participants in our study belonged, our participants and their research teams deferred to community-driven interpretations in cases of incongruence.

Our study describes the impact on non-Indigenous researchers of engaging in Indigenous research. Many participants acknowledged that they existed in a privileged space in society and that entering Indigenous communities was simultaneously humbling and challenging. For many, it was the first time they had had to prove that they were trustworthy, had to justify and substantiate their intentions, and consistently had to have their identity and intentions challenged. As well, researchers had to trust the community knowledge guiding the process. Gaining and granting trust was an element of the personal journey experienced slightly differently by each researcher.

The complexity of existing in a place of discomfort and distress for non-Indigenous researchers is important. By promoting reflexivity, it may mitigate unconscious bias in relationships, the research process, and/or analysis. Experiencing resistance from the community may also prompt non-Indigenous researchers to think critically about their methodologies, invest more effort into the relationship-building process, and/or seek out help from Indigenous community members in order to facilitate the research process. However, these experiences may also contribute to an emotional burden among some non-Indigenous researchers. In this group, it can eventually lead to burnout and an exit from Indigenous research.

Community-based research was more strongly associated with burnout, as the requirement for in-person presence and personal relationship-building sets the stage for increased emotional tensions. Feelings of burnout prompted participants to question their roles in and suitability for Indigenous research. To develop resilience, some participants spoke about depersonalizing the work. Specifically, while the work and the associated relationships require a personal investment, they could not consider challenges to be personal failures. Other participants reframed their work in the spirit of reconciliation. This reaffirmed their role in Indigenous research as a responsibility. Moreover, this prompted researchers to use historical context to frame challenges experienced while working within Indigenous communities.

Our data presents several powerful calls to action for policies and programs to improve the operationalization of ethical Indigenous research principles. Firstly, to mitigate the impact of institutional barriers to Indigenous research, there is a need for institutions to undertake internal reviews of relevant structures and processes and their congruence with accepted knowledge frameworks such as the OCAP® and TCPS2 principles. An internal review process will allow institutions to identify and address gaps. Additionally, work to increase applicability and relevance of accepted principles for researchers engaged in secondary data analysis is required. This may come in the form of community-developed guidelines, new policy statements, and/or amendments or addendums to existing documents. Practical training regarding the implementation of accepted principles, regardless of research type, may be beneficial. Furthermore, while all participants supported the mentoring of Indigenous researchers, very few projects employed Indigenous community members in a meaningful way. Indigenous community members were more likely to be employed in a more peripheral capacity such as data collection. Future studies may benefit from exploring potential barriers to and implementing supports for Indigenous capacity building, including funding, academic structures, and community structures. This data also demonstrates a need for programs to support non-Indigenous researchers, to prevent burn out. This includes support both technically and logistically, as well as through some of the emotional challenges of this work. This may include resource-sharing programs, dedicated staff members on institutional ethics boards, and teaching sessions to promote the implementation of elements such as partnership agreements. To address the burden of some systemic barriers on both Indigenous and non-Indigenous researchers, establishing a supportive

network between the two parties may have the potential to build Indigenous research capacity and promote learning and relationship.

Limitations

The results of this study may not be generalizable to all non-Indigenous researchers involved in Indigenous health research, given that the research was limited to one university in an urban center. Each academic institution has a unique culture and structures which inform approaches to research. Likewise, the geographic location of an academic institution determines, to some extent, associated Indigenous community research settings. Additionally, our sampling strategy selected for participants with a publically identified interest. This may favour participants who were currently involved in Indigenous health work in accordance with accepted principles. As such, our sample may not represent the experiences of those who struggled to apply accepted principles, or who have ceased prior involvement in Indigenous research due to burnout, institutional barriers, or other challenges.

Conclusion

This work presents the perspectives of non-Indigenous researchers at one Canadian university about their experiences with and approach to Indigenous health research. Most pressingly, we reveal that while knowledge of the accepted knowledge frameworks, including OCAP® and the TCPS2, is prevalent among non-Indigenous researchers, institutional barriers and resistance can make it difficult for some researchers to actually operationalize relevant principles. This finding is a powerful call to action for institutions to consciously align their institutional research protocols with Indigenous and post-colonial knowledge frameworks. Institutional alignment with accepted frameworks is a meaningful commitment to reconciliation that has the potential to facilitate the ethical conduct of Indigenous research. Additionally, it appears that certain policy statements (e.g., TCPS2) are felt to have limited applicability in certain contexts where they should be operationalized, such as secondary data analysis.

In addition to notable institutional considerations, our data also highlights that Indigenous research is a deeply personal experience. Non-Indigenous researchers involved in Indigenous research experience a profound personal self-reflective journey where they are challenged in the spheres of reconciliation, allyship, and privilege. In order to mitigate burnout, participants are often required develop a sense of resilience, depersonalize the work, and acquire an understanding of the historical context that informs many of the current relationships in Indigenous communities. Finally, our research confirms that relationships with individuals and communities are foundational to the conduction of research in Indigenous communities. These relationships are built on mutual respect and trust, and strengthened by continued commitment, accountability, and humility.

This paper moves beyond a theoretical understanding of the guiding principles of Indigenous and community-based research to examine their implementation in practice. Under the mandate of reconciliation, Canadian institutions have a responsibility to better understand the factors unique

to Indigenous research and to create and implement structures to facilitate this work. This study characterizes these structures and their roles in the research process in order to strengthen future research partnerships between non-Indigenous researchers and Indigenous communities.

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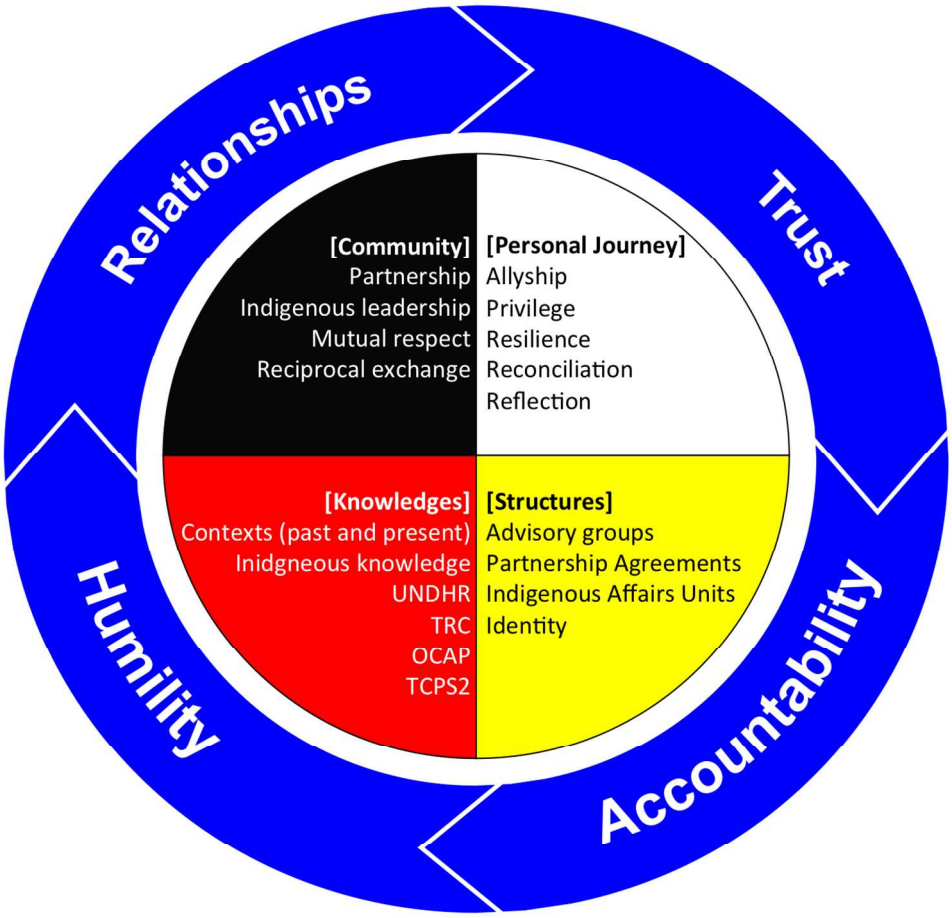

Figure 1: The four primary themes and their subthemes occupy each quarter of the inner circle. The outer circle holds the core principles that link each of the subthemes. Subthemes are underlined in the text.