RELATIONAL AND REFLEXIVE RESEARCH:
PEOPLES, POLICIES, AND PRIORITIES AT PLAY IN ETHICALLY APPROVING
RESEARCH WITH INDIGENOUS PEOPLES

by

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Abstract

The paradigm is shifting in research involving Indigenous Peoples: research with Indigenous Peoples at a meeting place of multiple worldviews—the ethical space—instead of research on or about them. The emergent paradigm is an invitation for researchers to think, know and act differently—to do research with Indigenous Peoples leading. This story is just one example of doing differently while answering the question, “What are the perspectives and practises of Research Ethics Boards (REB) members, chairs, and administrators regarding the review and approval of protocols for research with Indigenous Peoples?” The conceptual framework of this study integrates disciplines, theoretical models, methods, and complementary story-generating and story-gathering methods to support decolonizing and Indigenizing of the research simultaneously. An interdisciplinary methodological framework informed by decolonizing methodologies, autoethnography, and narrative inquiry guided this research process with 18 participant contributors (including myself) from nine provinces and territories in Canada. Data were collected and re/assembled through digital stories, interviews, and artifacts to share stories and insights about practical innovations with participants’ REBs. They suggested ways to improve the theory, application, and practice of ethics for research with Indigenous Peoples including office hours dedicated to Indigenous research ethics, asking the ‘right’ questions in protocols and forms, and having Indigenous Peoples sit on the institutional REB. All participant contributors called on researchers, REBs, institutions, and funding agencies to improve how we do research/review with Indigenous Peoples.
Dedication

To all the Indigenous scholars taking and making space in academic institutions
Prologue

For those who are well versed in this topic, there is likely very little that will be new or surprising to you in this dissertation. Perhaps some of things you already know will be validated from the participant contributors in this study; perhaps you will be glad to see so many other people who are innovating in their institutions; perhaps you will find comfort in some stories that people have so graciously shared with me. For those of you who are intermediate in your understanding, I hope you will have some ‘Ah ha! Moments’ as you experience the stories in this dissertation. I know that I have been inspired by every person who participated in this research and I am attempting to tell these individual and collective stories in a way that will inspire action. That will remind us that we are not alone in this journey.

At its very core, ethics – in all senses of the word – are about what is right and what is wrong. And because making ethical decisions involves humans and the diversity of all of our experiences, there is rarely consensus on what constitutes what is right and what is wrong. Even when some agreement is made on a policy or a principle of ethics, the practice of ethics – our moral actions or how we behave in the world given what we know – do not necessary follow. There are many examples of this incongruence in research ethics and it is particularly evident in the practice of research/review with Indigenous Peoples.

For the last 20 years, a parallel process emerged in Canada: on one side from government/academic initiatives with the development of policies and guidance for research with Indigenous Peoples, and on the other side from First Nations, Inuit, and Métis Nations and communities themselves on the governance of research with their people and on their lands. The *Tri-Council Policy Statement for the Ethical Conduct of*
Research with Humans, Chapter 9: Research with First Nations, Inuit, and Métis

Peoples, released in 2010, reflects the dual and iterative relationships to be built between Research Ethics Boards (REBs) and Indigenous Peoples, and now, nine years later researchers and REBs continue to grapple with the practice of applying these principles.

In this story, I am both the protagonist and the practitioner, the researcher and the participant, the student and the teacher, the insider and the outsider. I have studied, observed, examined, and enacted Indigenous research ethics for more than a dozen years and I have experienced firsthand the black box of research ethics review. That is, people can relatively easily identify the strategies and processes as they relate to research ethics and ethics review but are left in the dark as to how these strategies and processes interact with each other behind the closed doors of the REB. This dissertation will illuminate the inside of the black box for a moment and provide a snapshot of the inner workings of REBs with respect to research with Indigenous Peoples.

When delivering presentations or facilitating training, I often talk about the importance and necessity for researchers and REBs to operate outside their comfort zones in research/review with Indigenous Peoples. This dissertation is my demonstration of doing that very thing: to step outside my own comfort zone. Some of my friends are genuinely shocked to hear that I have used autoethnography as one of my methodologies because they cannot imagine that I would be comfortable sharing personal parts of myself in a PhD dissertation. They are not entirely wrong. I am not comfortable. And I am doing it anyway.

I purposefully guide you through storytelling, using different voices – spirit, personal, poetic, and academic – as an exercise in bringing multiple worldviews together in interdisciplinary ways. For the avid academic, the less formal voices may be
distracting or even uncomfortable. That will mean you are learning. The ‘less scientific’ voices throughout are equally wise and offer a different view or lens on the topic. This is my integration, my rendering, of multiple complex knowledge systems into an intellectual adaptation as a means to decolonize research/ethics – in lay terms, this dissertation format, language, stylistics, and multi-media are also about actively challenging ideas of what is ‘academic’ and creating research contributions from which all people can take and learn something.

I did not separate the different styles that comprise my voice, nor did I delineate among individual stories when they are part of the collective. These parts of me are impossible for me to separate and to artificially compartmentalize them to meet academic requirements is not only counter-intuitive, it is counter-ethical in the context of this research. So, you may find yourself oscillating between being fully engaged in what you are reading to being fully confused or fully uncomfortable. Welcome to my ethical world! Feeling uncomfortable is when you know you are straddling multiple world views, and I encounter these daily. As I steeped myself in my practise, I learned these tensions (of multiple worldviews) live within me and throughout me and I cannot escape or dismiss them.

My Master’s research (2006-2008) demonstrated a need for authentic relationships in research with Indigenous Peoples. I was just starting to learn what that meant then (2008) but I did not really know how to do it (Julie of PhD 1.0 was only 25 years old and still had a few things to learn). Over the years, others have helped me to understand those relationships and to face my fears by helping me write my circles into lines. I have been true to myself for the entirety of PhD 2.0 (not to say that there were not some bumps along the way, there were). I have been my authentic self and I have
incorporated (some of) my voices in this dissertation to articulate and expose those parts of myself to you. In doing so, I inadvertently invited others to do the same. And they did when they joined as participant contributors.

My intention in conducting this research is to not to call people *out*; rather, it is to call people *in*. To call people into dialogue and intentional action in our attempts to become able humans and able institutions – to *do* thorough and ethical research/review with Indigenous People. As evidenced by the current regulatory system in Canada, we are just beginning to discuss the ‘how’ of applying *TCPS* Chapter 9: Research with First Nations, Inuit, and Métis peoples. It is time to bring together the culmination of the teachings I have received on this subject since I was an undergraduate student. It is important to share what I have learned in a good way, built on the intention to *do* things differently, in my journey of becoming an able human (that is, to practice and embody the principles of Inuit Qaujimajatuqangit (IQ) to be discussed further later).
Acknowledgements: (Some of) my relations

There is no particular order to the people I am introducing you to here. The relationships I introduce here are not a decorative addition or side bar story, a peripheral entity that exists separately or independently from me and my research; I am connected with my “ethics family”, and the following relations were/are instrumental in making this work (and me) come to life. I also want to honour their contributions in context. I have so much love and gratitude for all of these people.

Mudder and Gussy. By far my biggest fans (though I’m not sure Gussy could tell you what I do for living, which is why I even quoted Yoda in this dissertation so there would be something in it that resonates with him). There are not enough words in the world to describe the support and love that my parents have shown me throughout my wavering ideas of whether or not I would finish this PhD. Thank you for always believing in me and supporting me (even when I kept changing my mind).

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Kyle, Kevin, Yvonne, Ben, and all other readers who took time to read this dissertation in part or in full. Knowing that non-academic audiences can find something useful in this dissertation is so very important to me and I am glad to hear there were even parts that made you laugh!

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To those who I inevitably and inadvertently left out – nakummek, thank you.
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CHAPTER 1: RESEARCH IS REFLEXIVE AND RELATIONAL

This is a story about the perspectives and practises of how research ethics board (REB) members, chairs, administrators, and policy-makers review and approve research with Indigenous Peoples, including whether and how they apply Chapter 9 of the *Tri Council Policy Statement 2* (TCPS2) (Canadian Institutes of Health Research (CIHR), 2007; Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC), 2014). My intention in undertaking this degree of research was to address the policy-to-practice gaps I identified regarding research/review with Indigenous Peoples. I observed and articulated this gap, not only through previous research and in earlier publications (Bull, 2010; Bull, 2016; Bull & Juutilainen, 2014; Brunger & Bull 2011; Brunger, Bull, & Wall, 2015; Brunger, Schiff, Bull, & Morton-Ninomiya, 2014; Martin, Valcour, Bull, Wall, Paul, & Graham, 2012), but also through sharing personal experiences and teachings at ethics meetings and conferences such as the Canadian Bioethics Society (2008, 2010), the Ethics Rupture Summit (2012), the Ethics in Practice International Conference (2015), and the Canadian Association of Research Ethics Boards Annual Conference (2012, 2017, 2018). My goal was to develop and demonstrate meaningful and straightforward methods of implementation to bridge the policy-to-practice gap—the *ethical space*—by helping others discover and explore that space. As Caine, Estefan, and Clandinin (2013) affirm, “experience in our world is grounded in a relational in-between space where we attend to the multiple dimensions of looking backward and forward, inward and outward, and pay attention to places simultaneously as spaces of being, becoming, and possibility” (p. 582). The ethical space is the relationship.
A paradigm shift is occurring in health research involving Indigenous Peoples\textsuperscript{1}: research with Indigenous Peoples instead of research on them (Riddell et al., 2017; Fitzpatrick et al., 2016)\textsuperscript{2}. Both Indigenous communities and academia have influenced and reshaped the movement to development ethics policy for research with Indigenous Peoples. (CIHR et al., 2014). While the notion of doing research with people sounds simple, simplicity does not follow in practise. Numerous detailed policies have led to apprehensions and misinterpretations between institutional research ethics review and Indigenous community research review. This dissertation highlights foundational considerations in negotiating the ethical space\textsuperscript{3} in research with Indigenous Peoples by offering insight for researchers and Research Ethics Boards (REBs) on how to practice from Etuaptmumk (Two-eyed Seeing)\textsuperscript{4} during research/review – one that not only acknowledges, but also encourages and enhances research itself through elevating Indigenous research authority – by implementing Indigenous governance structure within the REB system.

This dissertation is a story woven together using the mediums of storytelling and spoken-word poetry, with multiple data sets. It is a parallel practice of examining my own thinking about “the state of Indigenous research/review in Canada” alongside

\textsuperscript{1} In this paper, I refer collectively to First Nations, Inuit, and Métis Peoples of Canada as \textit{Indigenous Peoples} and to specific nations or groups where applicable. The term “Aboriginal Peoples” or “Aboriginal” are used only when quoted from other sources and should be considered interchangeable with the term \textit{Indigenous Peoples}.

\textsuperscript{2} See, for example, Mosby (2013).

\textsuperscript{3} This ethical space has been articulated by Cree Elder and scholar, Willie Ermine (2007), to denote this space of engagement that is essential in health research involving Indigenous Peoples (2007). This builds on work from Roger Poole (1972) which examined the space between two opposing societies when they are required to work together to address an issue. Essentially, it is a framework for human dialogue that Ermine adapted to conceptualize the relationship between Indigenous and non-Indigenous Peoples, highlighting the necessity of integration. Ethical Space is discussed in more detail in the conclusion of this paper.

\textsuperscript{4} Mi’kmaw Elders, Albert and Murdena Marshall, articulated \textit{Etuaptmumk (Two-eyed Seeing)} to refer to integrating both Western and Indigenous Science in a co-learning model (Bartlett, Marshall, and Marshall, 2012).
examining the commentaries of current REB members, chairs, and research administrators from a variety of academic institutions across Canada, along with key invited policy makers, which I collected through recording consensual conversations. All of the participant contributors passionately and enthusiastically joined me in this journey to share their insights with me. The collective interest and investment demonstrated by those who participated in this study is overwhelming; it was my honour to sit with these committed innovators, most of whom see the value of doing differently and who seek to be the change in their own institutions. What a privilege.

The articles, artifacts, articulations (and alliterations!) represent my contributions to the ongoing conversation and action regarding research/review with Indigenous Peoples. To borrow from a concept of my Cree cousins in the South, this collection of things that I have been gathering is like a sacred bundle of items; sacred bundles provide direction (Ironstar, 1993). As you will see, I have been building my sacred bundle of research ethics for a long time.

This dissertation is not about me, it is me.

It is not about ethics, it is ethics.

Fundamental to my (and most) qualitative research practice is the belief that truth and reality are collaboratively constructed, informed, and reshaped in relationship to, and through the interactions we have with people and the environments in which we live (Silverman, 2000). In most Indigenous contexts, the first thing we do when we meet each other is to introduce ourselves. Not just ‘Hi, I’m Julie’; we introduce ourselves in-relationship to our familial and territorial connections. So, in an effort to demonstrate that practise, this first chapter is an introduction to me and my relations. First, I discuss
the importance of reflexivity in research/review with Indigenous Peoples by locating myself – my many parts – in this research.

I am a Southern Inuk (NunatuKavut) woman with familial ties to Paradise River in Sandwich Bay on the Southeast Coast of Labrador. I have a complex family tree and will save some of those details for one of the books I hope to write post-PhD, when I am further along in my healing and understanding. I grew up partially on the island of Newfoundland and partially in Central Labrador primarily with my young single mother (most of my immediate and extended family still lives in central and southern Labrador). When I was 15 years old, I had the fortune to welcome a step-father into my life and am grateful for the role he plays for me and my mother. My great-grandmother passed to the spirit world in 2015 and she had 13 children, 27 grandchildren, 43 great-grandchildren (of which I was one), and 10 great-great grandchildren (with a couple more on the way). We are a mixed family with connections to many parts of the world, with roots firmly planted in Labrador. Even though I have lived away since going to university in 2001, there is a sensation of peace and tranquility that comes over me every time I am in my home territory. This feeling, this connection cannot be replicated in any other place that I have lived or visited. It is the feeling of home, of where I belong.

Now that I live in Southern Ontario, I often joke that I am a displaced polar bear (because of my love of cold and disdain for hot humid summer days). My connection to the ice and snow-covered land is genuine. Like most people, I did not realize the magnitude of beauty and magic in the lands where I grew up, taking for granted that such delight exists everywhere. It is no wonder that I was curious about the universes early on – one cannot help but imagine what is possible when being enveloped by the Aurora Borealis dancing in the sky, reflecting on and from the glistening snow.
Research is Reflexive

Despite dominantly accepted (though not necessarily dominantly practised) models of research that insist researchers can and must be objective and removed from their work, an important part of the movement for ethical conduct and review of research with Indigenous Peoples is teaching the importance of locating oneself in the research (Absolon, 2011; Moore, 2015). Many scholars dispute the objectivity paradigm. They see researcher subjectivity as integral to the work and authentic engagement in the research which requires researchers locate themselves in the context of their research. This vital reflexive exercise is an ethical imperative in research that is iterative and dynamic, and ought to be revisited in all stages of the research, as our locations (and relations) can shift and evolve over time (Riddell et al., 2017). This is not to say that reflexive practice only exists in Indigenous research. There are, of course, other disciplines (such as Social Work and Education) and methods (such as ethnography and narrative inquiry) that include reflexive practise. However, reflexivity is a requirement in Indigenous research, regardless of the discipline or subject matter because Indigenous research is relational.

One of the first questions I always get when working with Indigenous communities is “who owns you?” or “who do you belong to?” as a way of asking who I come from and what my relationships are (which is why I declared my territorial and familial relations earlier). Locating self is always necessary in research with Indigenous Peoples, no matter the context – whether we are at home welcoming others to our territory, visiting another Indigenous territory, or meeting on non-Indigenous territories

5 Though these specific phrases are mostly geographically-dependent, the intention to learn ‘where are you from’ knows no bounds and is embedded within Indigenous Peoples’ relational understanding of the world.
or with non-Indigenous people. Relationality is integral, and we need to be able to articulate our location to others (Smith, 1999). For me, as Southern Inuk and as an academic, my research practice does not allow me to artificially separate myself from my research; I cannot be objective because all of my research is all of my relations. This relational, intersectional understanding of reality can be examined through autoethnographic methods that provide researchers the time to dynamically and intentionally practice reflexivity. The following illustrates this understanding.

One of my comprehensive exams included the creation of a digital story⁶ (Where I’m From, November 2017) about my position and social location in my research with an accompanying paper exploring autoethnography as a methodological framework. The narration for that story is written in poetic form and excerpts from it are woven throughout this dissertation to reflect and to (re)introduce myself-in-relationship to the people and places that have shaped me, and to name the dynamics between researchers and communities, even when we are Indigenous and working within our communities.

**My reflexive practice**

My reflexive practice took on many forms: conversations with friends, peers, colleagues, mentors; writing poetry, journal reflections, responses to current events, tweeting; observing my colleagues through my job as a Research Methods Specialist and through my study as a PhD candidate; through an expanding wall of Post-it notes; through painting; through meditation; through ongoing conversations with myself; and through ceremony. I would like to introduce you to the characters or voices in my ongoing, internal conversations: spirit, poetic, personal, academic.

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⁶ The full digital story can be viewed online: [https://www.youtube.com/watch?v=BXbVq5v6UaA&t=387s](https://www.youtube.com/watch?v=BXbVq5v6UaA&t=387s)
**Spirit Voice.** [Depicted as Spiritual Signposts] Spirit voice speaks when there are relevant stories of challenge, discomfort, guidance, validation, confirmation, and direction that I have had the pleasure and privilege of noticing. To spiritually engage with the work means to be present. To be brave. To be humble. To be grateful. It is to learn to sit in discomfort. To learn to trust. It is to make the assertion that “I have to believe it to see it” rather than “I have to see it to believe it”. Though I am earning a PhD in academic work, I may well only be in spiritual kindergarten as I learn to connect to my intention: to become an able human. As you will see throughout this dissertation, I learned a lot about myself and take the time to reflect on where I have come from in the journey. Part of my reflexive practice was deeply spiritual, and I purposefully integrate some spiritual signposts throughout the story. There are too many synergies and serendipities. I know I am supposed to be exactly here, doing this specific work, at this precise time. These interactions/observations/sensations are not separate from my research and they are not separate from me. They are me and they are my research. These spiritually significant moments of personal growth are me and manifest in and of the choices I make and the actions I take.

**Personal Voice.** [Depicted as Personal Reflection]. This entire dissertation is really one major self-reflection on some levels, but in places where I have inserted my most personal stories – the way I talk, my personal voice, is fairly informal, contractions and all, to complement the relevant academic (voice) content I am narrating. For all of these short reflections, there are typically several pages of field text that the excerpt or summary comes from. There is a lot
of data in #TheJuliestPhD so this is an attempt to reveal some ongoing conversations I was having with myself throughout the study (i.e., doing and demonstrating autoethnography).

**Poetic Voice.** [Depicted with differently justified margins].
I have integrated poetic voices throughout the story (primarily my own [justified to the right of the page] with a couple significant pieces from others [centre justified]) that are instrumental in my becoming an able human (and in writing this dissertation).
I explain further my decision to include poetry throughout this story in Chapter 3: Research Design.

**Academic Voice.** [Depicted by conventional APA style]. This is where academics will feel most at ease, in their natural environment. In this dissertation, it may not be the dominant voice; it is one of the voices and it is an important one, but it is not the only one. I eviscerate the culture of academia by superfluous articulations and alliterations, using voluminous libretti to describe my perspectives and those of participant contributors in this study.

**Where I’m from: Privileging my poetic voice.**

While preparing to write my second comprehensive exam on autoethnography (November 2017), I read examples of autoethnographies (e.g. on topics like depression (Jago, 2002); eating disorders (Holmes, 2016); and abuse (Olson, 2004)), and I found myself deeply entangled in the emotional journeys that the authors took me on as a reader. This emotion was especially prevalent in Indigenous scholars’ autoethnographies because it was the “familiar sites of personal pain and dislocation, land struggle, historical erasure, and the many other violences inflicted by global coloniality” (Sium &
Ritskes, 2013, p. III). I was compelled to find ways to tell my story in a way that worked for me – in a way that would reveal hidden parts of myself but through a medium/voice that I was comfortable sharing (i.e., no bar stool, open-mic confessions for me).

I am glad I have a friend who I can talk to about these academic acrobatics and how to achieve the requirements of the degree while exploring the boundlessness of doing differently that can unfold and what might manifest by challenging the status quo. We often talk about meta-analysis which sometimes turn into meta-meta-analysis and before we know it, we are analyzing our analysis of an analysis. We joke about wondering ‘how meta can we go’ while simultaneously reflecting on our own positions and assumptions. It was validating to read Jones, Adams, and Ellis (2013) who described autoethnography this way:

Autoethnography requires that we observe ourselves observing, that we interrogate what we think and believe, and that we challenge our own assumptions, asking over and over if we have penetrated as many layers of our defenses, fears, and insecurities as our project requires. It asks that we rethink and revise our lives, making conscious decisions about who and how we want to be. And in the process, it seeks a story that is hopeful, where authors ultimately write themselves as survivors of the story they are living. (p.10)

After some good conversations, lots of reading and viewing of others’ autoethnographies, I started to lean in (Snyder, 2015). I was deliberately and intentionally expanding my comfort zone to move toward a deeper understanding of myself and my research. As I read more stories, I focused my awareness on the analysis and interpretation elements that intertwine to create me and my stories. This does not
mean that I dismissed the academic components or ‘science’ of the method; on the contrary, I am doing both simultaneously. I began to weave together the art and science of autoethnography.

Where I’m From

From contemplating a moral imperative
To engaging with my own narrative
From second guesses to life's lessons
The integration of me and life
to illustrate the complexity
it’s not perplex to me
for me to be the social justice freedom fighter
not just for me but for anyone who needs me to be
I use the voice that's been given to me
To challenge the dominate view
contributing to the danger of a single story
(Excerpt, Digital Story, November 2017)

Spiritual Signpost: On the second day, I encountered autoethnographic anxiety – the feeling in my stomach that overwhelmed me in the moment I went from the academic conceptualization of spending this time reflecting with myself to realizing I would have to share deep and personal parts of myself with others. Then I remembered that “maybe stories are just data with a soul” (B. Brown, 2010).

The first weekend I was struggling with where to start and what to do. I watched videos and read papers, but nothing resonated with me: I did not find a style or voice that was going to work for me. I turned to old faithful – the pen and the paper – and I spent several hours just writing. Allowing myself to write freestyle with no goal other than documenting some random parts of my life that seemed like might be important, I ended up writing 30 pages by hand. Over the next few days I transcribed that writing into nearly a dozen typed pages. Despite
having all this content, it didn't seem quite right. It wasn't sitting well, and I knew that wasn't the way I wanted to tell my story. When the next weekend came, I spent Friday evening watching YouTube videos and TED talks (grateful for unlimited streaming!). And then I found it. After many hours of listening to obscure stories from people all over the world through dance, song, spoken word, and film, I was inspired greatly by George Ellis Lyon’s work on ‘where I'm from’. I was captivated by the simplicity and creativity that went into that form(ul)ation and I knew immediately that I would write the narration of my digital story in a similar way.

I channeled my inner beat poet/hip hop MC/spoken-wordist (who is slowly creeping out of me). Writing in this voice I produced a draft script in a couple of hours (see Appendix A for full narration script); literally, a couple of hours which might sound ridiculous, but it poured out of me. It was easy; I realized that I could write an entire documentary in this style (or perhaps an entire dissertation?!). There are things I can say so succinctly in my poetic voice that would take pages in my academic narrative – and it still might not read the way I want to say it. My poetic voice gives me the space to say it without borders, expectations, APA format.

I now realize that how the words come on the page is unimportant: the process of writing is healing, it is helpful, it is humbling. It is a beautifully liberating place to be in when we start to reconcile the pieces of ourselves that may be out of balance through the simple act of shaping our life stories with words that make sense to us alone.
Though I had read about the purported therapeutic benefits of autoethnography, I did not really consider what my experience of writing my personal story would feel like, or how it may or may not be an emotional and/or spiritual experience. I practice reflexivity in all kinds of ways on a regular basis, but to engage in a deep retrospective of myself in relationship to my research is a very personal, passionate, and long-term relationship I have with Indigenous Peoples’ research ethics and it had more emotional impact than I anticipated. The creation of that digital story for my comprehensive exam was my first time doing this kind of work within my academic practise; I am a private person and it is not my nature or my preference to share personal parts of my life experiences publicly. I could be immobilized by the idea of making myself vulnerable by sharing my story (B. Brown, 2010), or I could take a risk, and stand in knowing that the power of sharing these stories is contributing meaningfully to ongoing dialogue and action. Autoethnography “emerges from the researcher’s bodily standpoint as she is continually recognizing and interpreting the residual traces of culture inscribed upon her hide from interacting with others in contexts” (Spry, 2001, p. 711). This practise, this position, is not always comfortable, but it is one worth pursuing for the rich learning and complex understandings that can emerge.

Our identities are in constant flux and are impacted by the relationships we have with the people and social worlds around us and our relationships with the wider world shape these identities. Critical self-reflection in the pursuit of deep understanding is centered in the work I do and reflects a tenet of Indigenous research practises globally; this approach ensures I take time to evaluate myself in relationship to the research I do (Martin, 2012; Sium & Ritskes, 2013). Essential to ethically doing research/review with Indigenous Peoples, as Méndez (2013) notes, “the richness of autoethnography is in
those realities [or deep understandings] that emerge from the interaction between the self and its own experiences that reflect the cultural and social context in which those events took place” (p. 284). This intentional integration of my experiences throughout this dissertation serves to re-imagine what is possible when multiple worldviews overlap and honours all of me – the greatest influence and greatest limitation in all of this.

Speaking openly about personal parts of my life helps me grow and confront my discomfort of sharing deeply personal stories and requires an ongoing practice of the sacred teachings of honesty and bravery. Doing this part of the work – critical self-reflection and exploration of the essence of my relationality in my research and revealing it to the people I am working with – is essential to working-in-relationship with Indigenous Peoples (or anyone for that matter). However, researchers often ignore this practice because they do not see how it could inform the doing of their research or because it is discouraged from their institutional or disciplinary positioning (i.e., makes it hard to keep timelines, more red tape) or because it is not considered ‘academic’ work that needs to be noted or documented in any meaningful way.

Just as I am required to write this dissertation as evidence of my knowledge conducting a research study to meet the requirements of doing the academic portion of a PhD program, so, too, am I required to examine my own life and my positioning within my research and be able to articulate it to the people and communities I work with. By fully explaining my own position within my research, research participants can fully understand and can provide free, prior, and informed consent to meet the requirements of doing ethical research with Indigenous Peoples. There remains a balancing act of fulfilling my academic duties while maintaining my responsibility to the community. This dissertation is a demonstration of ‘the dance’ that many Indigenous scholars find
themselves in as they navigate meeting everyone’s expectations (in communities and at institutions) to be responsible researchers. This dissertation is my contribution as I lead by example and show a different way of doing/demonstrating/living robust, academic research.

**Research is Relational**

My collegial and overlapping networks related to Indigenous Peoples’ research ethics are broad, include many Indigenous scholars, span disciplines, and includes non-Indigenous researchers working with Indigenous communities on a variety of locally relevant issues. Despite the university’s best attempts to compartmentalize every aspect separately, to assert these processes, Indigenous Peoples rarely find themselves in scenarios where black-and-white thinking is useful or practical; Indigenous scholars often hold several spaces and places simultaneously, and rarely can fit their entire selves in the artificial insider-outsider binary ‘box’ where objectivity supposedly lives (Tuck & McKenzie, 2015).

I draw energy and wisdom from these networks and I amplify our voices – our collective learning and commentaries – and use them to inform the foundation of my research in a way that is grounded in respect, relevance, reciprocity, and responsibility (Kirkness & Barnhardt, 1991). I recognize those who have come before me, acknowledge whom I have learned from, and work collaboratively across disciplines, communities, and nations. These are some of the ways I honour the sacredness of the relationships within my networks and show my gratitude for the many blessings and teachings I have received from them. They are all part of this story of me, this autoethnographic story I am sharing. As Riddell et al. (2017) explain:
The strongest theme in the literature on Indigenous research ethics is that every stage of the research relies on relational processes – from the researchers’ own intentions in seeking particular knowledge, through the design and implementation of methodologies and gathering of consent, to the analysis and dissemination of knowledge. (p. 8)

**The Power and Strength of Relational Medicine**

There is an Indigenous academic movement that propelled an increase in Indigenous faculty, students, curriculum, research, and conversations about ethics over the past couple of decades. In the academic realm and in life, the successes we (Indigenous scholars) have are contingent on our relationships with ourselves and with each other. Indigenous Peoples inherently (though not exclusively) work in-relationship. We created workarounds and solutions with each other even when governments and others did not support our initiatives (and even overtly discouraged) our doing so. For example, efforts to dismiss or dismantle Indigenous health research initiatives were/are countered with an increase in Indigenous academics and community participation. There is strength in these relationships and our collective resistance has not wavered.

**Structure of this Dissertation**

I have a long way to go and a lot to learn as I am just getting started now that all of these people have helped me build a solid foundation. In all my academic pursuits, my motivation and commitment has always been to the communities I serve. I have worked hard and learned many lessons to earn my “credentials from the community” to become an able human. Now, with the collective wisdom and tenacious spirit that comes
with those community credentials, I am ready to earn and appropriately use my academic credentials as I demonstrate that I am an able scholar.

The next chapter, Chapter Two is an introduction to #TheJuliestPhD, describing the autoethnographic components of this study. Since this study is ethics-led, not methods-led, this description of my autoethnography practice is an important context to understand Chapter Three, which chronicles the entire research design. It is important to discuss the methodological and ethical dimensions of this study before diving any deeper into the contextual and collaborative components that follow. Chapter Four can be likened to a literature review; it is a record of past events (Oqaluttuarisaaneq) that is divided into two parts. Section I examines myself and the journey and Section II identifies key considerations in research, regulations, governance, including the development of research ethics oversight in Canada. Both these sections together serve to provide context and background to me and my relationship to ethics, and to the regulatory systems and structures as they currently exist.

Chapter Five is divided into three parts. Part I: Theorizing Ethics, outlines some of the key ethical theories as it relates to this study. Then in Part II: Applying Ethics, I discuss some of the key challenges and considerations brought forth by participant contributors. Finally, in Part III: Practicing Ethics, I offer a collective approach to addressing those challenges. Chapter Six is called Becoming able humans and able institutions. Here I describe the ways in which everyone involved in the research system is responsible to decolonize their minds (becoming able humans) and decolonizing the systems (becoming able institutions) by offering insight and innovations from participant contributors. The chapter ends with my research ethics utopia – a creative piece that describes what an ethics gathering place/space (Mawi’omi) could look like.
Finally, Chapter Seven briefly summarizes some key messages from this study along with some closing remarks.

The order, titles, and numbers of the chapters in this dissertation may seem strange; it is probably just the start of what you will notice is different about this dissertation. I tried to write it more conventionally, but it was not working. This work is not linear, and I think about it in a circular fashion – Spoiler Alert: I do not resolve all the issues! – which meant figuring out how to write these circles in a straight line as much as possible to demonstrate interconnections. This is my best attempt. The road map looks like spaghetti because sometimes the circles in straight lines overlap. The all-encompassing circle is the autoethnography; this is ultimately a story about me and the other data collections and methodological choices are all a reflection of what I wanted/needed to accompany on my autoethnographic journey. So, the autoethnography really started before I had finalized my actual research design. This is why I started with talking about myself and situating my research before I really get into the design – this is the order of events and so this is the place to begin the story.
CHAPTER TWO: INTRODUCING #THEJULIESTPHD AND DOING AUTOETHNOGRAPHY

I started out on this journey wanting to understand the perspectives and practises of research ethics board (REB) members, chairs, and administrators, and policy-makers pertaining to how REBs review and approve research with Indigenous Peoples, including whether and how they apply Chapter 9 of the TCPS2. More specifically, I wanted to learn how REB members determine their level of authority/jurisdiction when assessing research protocols for review and issuing approvals for research with Indigenous Peoples. I wanted to do what very few others dare to do: willing to invite myself inside to engage with the people inside the ‘black box’\(^7\) that is the REB to many. Until now, I had many assumptions and insights based on experiential and anecdotal insights – some positive, some negative; some accurate, some fabricated – but I did not have a chance to have a deep conversation with myself or other people about it until now.

Part of figuring out the ‘how-to’ lies in seeking better answers to the broad ethical questions REBs must vigorously satisfy to protect researchers, the university, and most importantly, participants. In 2015, Nicholls et al. conducted *A Scoping Review of Empirical Research Relating to Quality and Effectiveness of Research Ethics Review* where they identified that most literature on this topic was quantitative (surveys and reviewing administrative data) and focused primarily on procedural and structural aspects (i.e., how processes behave) of REBs. They clearly noted that there is a shortage of qualitative and longitudinal research regarding the quality and effectiveness (i.e., how people behave) of research ethics review (see van den Hoonaard, 2008; 2011; 2016 for

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\(^7\) A black box is typically a complex system with the contents and inner workings being a mystery to those outside the system. In research, the REB is a black box – researchers and others can partially see the technical composition of the board but the process and practice that happens behind closed doors remains unknown.
some examples that do). My research is about voicing, exploring, and navigating the decision-making, determining new ways forward, satisfying ethical questions on all fronts, and resolving tensions without undermining any authority, and being in-relationship.

I draw on several disciplines to frame my research orientation, which when combined, can support advancing an Indigenous research ethics commentary at the institutional REB level and the mainstream/community level. Indigenous Peoples and communities see the value in what can be learned through research but often resist the way that it is typically conducted. It is the responsibility of researchers to appropriately address this reality, this resistance to how researchers typically conduct their work. I am responsive/ble when I conduct my research in a new way, in a way that others can learn from and adapt for their own work; I am responsible when I influence how others think (whether or not I even know I am aware of this influence).

Autoethnography is one of a few research methods that purposefully and explicitly requires researchers to engage in ongoing self-reflection and to acknowledge and mitigate their own biases, and to story these into their research writing. Holt (2003) considers that, “by writing themselves into their work as major characters, autoethnographers have challenged accepted views about silent authorship, where the researcher’s voice is not included in the presentation of findings” (p. 2). Writing ourselves into our research, as well as building on the conversations we have with others, is part of the iterative and fluid process of autoethnography (Wall, 2008). This approach to my study serves a dual purpose: (a) to reflect on myself – my positions, privileges, and powers – as it relates to my research, and (b) to demonstrate the use of digital story (and story-weaving) as a means to decolonize research practise.
**Personal Reflection:** When I decided to resume my PhD studies for the Fall 2017, I intended to work with the REB at the hospital I work at to co-design and co-deliver training on TCPS Chapter 9. One day in discussing my big plan with my friend, Jann, I was carrying on about how active the alerts were on my 2010 article (and Youtube and all the social media as a result!) and how it was motivating me. In this conversation, she commented on all the data I inadvertently collected over the years – noting my papers, presentations, book chapters, keynotes, course syllabi and so on – on this topic. And then suggested I integrate all of my work since I last attempted to do a PhD (2012) and do autoethnography. And I immediately replied, “No!” (that would mean talking about myself!). And she said, “okay”, and we left it alone for a while and I continued plotting my way forward along with my hospital REB.

Despite my best efforts to do something different for my doctoral research (i.e., *not* do autoethnography), the idea of autoethnography kept haunting me.

As I worked at my Fall coursework and focused on aligning with the hospital REB, the plan and timeline started to fail; they were moving quicker than I could move my research given I was not yet done my comprehensive exams, and my thinking was shifting. I took some time to really look at how much data I had from myself – if I was really going to consider centering on autoethnography, would I have what I need to do so? I don’t keep much in the way of personal items (I have moved too much to enjoy collecting much of anything), but I do keep my filled notebooks/agendas and old presentations, as well as all kinds of documents. I giggled as I reviewed the print copies of key
pieces of literature (with my notations and post-it notes still included!) I had used over the years. I had a gold mine of data. I also realized I was a key contributor in the conversations in the literature I would be referencing in any review I would do because over the time I was not in school, I was still contributing. I would be integrating and reviewing a lot of my own work, regardless of methodology. It just made sense to make it about me and supplement my story with the stories of REB members, no matter (and because of) how uncomfortable I feel to do/share personal stories.

The further I engaged with idea of making my PhD autoethnography research, the easier it became to fully indulge in critical self-reflection, muse about my new understandings, and to share those reflections with others. Writing about myself in a real, authentic way within an academic setting is still a challenge, but I am getting more comfortable being uncomfortable which is often a learning for anyone engaged in this kind of work. It is not always easy or comfortable to write this way. But we cannot walk away when it is hard or uncomfortable; when we show ourselves, the collective learning is amplified. For me, this is a way to tell a counter-narrative, and it got easier as I kept doing it (with coaching from #TeamJulie, of course). Vivienne and Burgess (2012) discuss counter-narratives at length, providing examples from research with refugees where there is critical need to share stories that reflect peoples’ living experience, not only stories that reflect media and societal assumptions and biases.

Choosing autoethnography as a methodology, and specifically to use digital storytelling as a method, is an explicit one. I intend to “disrupt Western imagination of ‘theory’ through Indigenous knowledge production and storytelling” (Sium & Ritskes, 2013, p. II) to create new possibilities that emerge when we are not bound artificially by
disciplinary boundaries or political borders. As the first in my family to graduate from high school, the first to get a university degree, the first to travel outside of Canada, the first to do so many things – I am the counter-na(rra)tive. To wonder how I have overcome is to overlook the careful placement of gifts from my ancestors – through them, with them, of them – how do we thoroughly measure that?

*Where I’m From*

Exploratory

To find the power of love
Instead of the love of power
It’s my superpower to be empowered
To learn to let go. To absolve.
To dissolve the single story
To evolve in all my glory

The theory and practice of social change to rearrange the action of exchange
From the first to graduate high school to breaking the cycle
From moving away yet not leaving it behind to finding mine.
From 'you can do it if you put your mind to it'
and to do it you just have to go through it
Empathy, breathlessly, conscious
To walk a mile. To think a while
I shoot for the moon but sometimes I’m too busy gazing at stars from afar
My strength through resiliency from the communities that entrust in me
The legacy I want to see that came before me
My ancestors were investors in me.
My identity
So much to question and so much to learn
The fire inside burns, with no limitation
My foundation is *All My Relations.*
(Excerpt, Digital Story, November 2017)

Writing this poem is a relational method that privileges my relationships with myself and the world around me, rather than trying to separate myself from my research. In the practice of acknowledging and honoring ourselves – our *whole* selves – and telling and sharing our stories, we open ourselves up to possibilities that otherwise lay
dormant (Wall, 2008). My decision to use multi-methods by weaving autoethnography and empirical research demonstrates that which I seek to describe: to enact and practice the tenants of doing differently.

“To Thine Own Self Be True”8: Autoethnography in Practice

Méndez (2013) suggests the most common criticism of autoethnography is the emphasis on the self: critics refer to it as narcissistic, self-indulgent, and subjective (which sounds like all research to me). Ellis et al (2011) note that “[a]utoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or assuming they don’t exist” (para. 3). There is a level of skepticism about autoethnography that suggests it is merely a personal therapeutic exercise, rather than an analytical system with explicit processes of investigation (Fine et al., 2003). There may be therapeutic benefits of this approach. However, to reduce autoethnography to merely a self-indulgent exercise of introspection as an end in and of itself is inaccurate. “It is only through systemic, ongoing reflexivity, however – including a continuing examination of personal subjectivity – that we can avoid self-indulgence” (Bishop and Shepherd, 2011, p. 1284).

It is through the process and product of analytical autoethnography that deep understandings of our self as an actor in the world can be undertaken to inform and advance conceptual approaches to complex problems, and to generate solutions grounded in shared lived experiences (in community) and personal growth and

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8 Shakespeare (1603)
development (in self). I have seen this in myself and in my work as I moved from descriptive autoethnography during my comprehensive exams in the Fall 2017 term to analytical autoethnography during the research itself in 2018.

**Autoethnography: A Process of Decolonizing through Relational Ethics**

As Ellis (2007) describes, applying relational ethics is integral in autoethnography as it asserts that we, as researchers, have ties and responsibilities to those we work with in research. For me, I am responsible for decolonizing my work, always. For me, decolonization means challenging the dominant paradigm and using the gifts that my voice as has given to me to imagine, practise, and embody a different way of doing things. Autoethnography provides a process and method for me to explore myself-in-relationship: (a) to the work I do in the university (i.e., in a colonial context, practicing colonial cultural research traditions and rites of *knowing* and *doing*, like writing this dissertation and orally defending it), and (b) to my goals of health and healing for myself and the communities I work alongside (i.e., in an Indigenous context, practicing Indigenous research in Indigenous ways of *knowing* and *doing*, such as participating in experiential learning and relationship building through ceremony, traditional activities, and community). I am learning to make space for my story in the work I do; this is an honest act of self-determination and this PhD work is my greatest attempt thus far. Though criticized by skeptics (Holt, 2003; Davies, 1999) as identity politics, all research is personal and political, and I take the responsibility of being

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9 The digital story can be viewed online: [https://www.youtube.com/watch?v=BXbVq5v6UaA](https://www.youtube.com/watch?v=BXbVq5v6UaA)  
A forthcoming book chapter describes the analytical components of the autoethnography that I refer to in this section. Stay tuned at [www.juliebull.net](http://www.juliebull.net)
explicit in my intentions as part of decolonizing research practises seriously. Sium and Ritskes (2013) articulate some of the reasons why I have chosen autoethnography:

While dominant scholarship might push aside…autoethnography or traditional storytelling as not rigorous enough or as ‘identity politics’, the experiences of those who live out decolonization are integral to the integrity of the movement, grounding it to the material realities of the people whose lives bear the scars of colonialism and the long histories of resistance and triumph. (p. II)

I’m from traditions and technologies
Blank stares and apologies
My existence is resistance
I tried to keep my distance
but my persistence is optimistic
The probability of my success, “statistically significant”
The predicament is not definitive
My willingness is no coincidence
It’s serendipitous that the impetus from my imagination
is the acceleration of exploration.
It was in the instant that I went against it
(Excerpt, Digital Story, November 2017)

Like many other Indigenous people who are learning, studying, and working in academia, I quickly came to see that “decolonization, despite its relatively new entry into academic vocabulary, has been practised and engaged and theorized in Indigenous communities in ways that have already yielded rich, complex layers of thought” and for some time (Sium & Ritskes, 2013, p. II). Even though Fanon wrote about decolonization in *Wretched of the Earth* (1961), it was not widely accepted or acknowledged by academics for decades to come (arguably it is still not widely accepted, though it is increasingly being acknowledged).
Fanon asserted that humans have an ethical commitment to the rights of all humans. This is the principle core of Fanon’s decolonization theory: that all people are entitled to moral kindness and no one is dispensable. Not surprisingly, Fanon’s work continues to underpin scholars who work in social justice and human rights. Like Freire (1970) in *Pedagogy of the Oppressed*, Fanon understood that part of the colonial and oppressive culture is such that violences are inflicted by the oppressor and at some point, the oppressed themselves become the oppressor – on themselves, on each other, and in retaliation to the oppressors. I align with Fanon in that my commitment is in choosing the content of our character and the substance of our actions rather than engaging in revenge or reproach. I take responsibility for the positions I find myself in and choose not to occupy space of oppression and violence against others. This is decolonization; it is about how people mobilize themselves into a revolution.

It is frustrating and disheartening for Indigenous researchers (like me) who are intimately aware of (and experiencing) colonization (and ongoing colonial influence) to witness the inertia of change. In efforts to decolonize research, some non-Indigenous researchers – whether intentionally or not – continue to privilege their own voices in the work, rather than the voices of participants, which is the point of the research in the first place: “…who does the storytelling, remains an important question in decolonization work. While Indigenous Peoples have been the subjects of ‘objectivity’, colonial-settlers are in the positions of power to wield [objectivity] with impunity” (Sium & Ritskes, 2013, p. IV).
Peeling Back the Onion: Storying Me, Myself, and All My Relations

My intention is to challenge you, emotionally and critically, through the telling of this story. “Stories in Indigenous epistemologies are disruptive, sustaining, knowledge producing, and theory-in-action. Stories are decolonization theory in its most natural form” (Sium & Ritskes, 2013, p. II). Over time, my efforts to decolonize scholarly work are becoming more explicit. I tend to challenge the status quo (just ask my PhD committee!) and prefer exploring and proposing “alternative” ways to address complex problems. Where I was timid or shy before, I am now intentional and explicit and aim to influence systems and policies to positively impact the lives of Indigenous Peoples, specifically. Maybe it is my age, or my incoming/increasing gray hair, or my growing confidence, or the support I have from the helpers all around me that brought me to this liberation. Sium and Ritskes (2013) say that “[s]tories become mediums to unmake colonial borders” (p. VI) and I am committed to telling these stories, using written word, spoken word, songs, poetry, and so on to disseminate in ways that are widely accessible and privilege Indigenous voices.

Where I’m From

From statistical analysis to individual variance
From philosophical debate to examining my own self
From skirting sickness to weaving wellness and asking for help
From imaginary friends to a visionary end
From 'just do your best' and 'forget all the rest'
From ethical theory to the way we actually act
not a question of fact but a matter of fact.
To look back from humble beginnings to nine round innings
A nomadic life not tamed by the skyscrapers that tower over the city
My own standing committee on how to do me
From simplicity to complexity and to weave them together
A proud carrier of my eagle feather
(Excerpt, Digital Story, November 2017)
**Personal Reflection:** As I fully immersed myself in old notebooks, I noticed an interesting trend. My inward-facing commentary did not match my outward-facing dialogue for many years. I would contemplate and write about racial and systemic issues, but I would censor myself in my publications and presentations. Now I am unapologetically explicit that these core issues of colonization cannot be glazed over or taken lightly. These are the roots and we must expose them. Part of what is different now compared to then is that I found/was finding a way to talk about these things that did not leave me feeling misunderstood and/or attacked by my audiences. I know that there are people attending my presentations who are not choosing to be there. Yet, generally, people receive my messages in good ways, as they were intended. Perhaps over time what became clearer is that it was really about inviting non-Indigenous researchers and research administrators to #justsuckless\(^{10}\).

While I am now in my latest or last attempt at my PhD (for a variety of reasons), my burning interests for my PhD research did not change over time: it has always been about the ethical space – how we are in it, how we embody it, how we challenge it, how we resist it, how we become it. But the world around me sure is different now than it was in 2008. More people are engaged in and talking about/through Indigenous research ethics, and more people are ready to listen than ever before. I witnessed the slow acclimatization of these communities of practice over the last decade – Indigenous communities too. And now, I could turn my gaze toward academic institutions and

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\(^{10}\) This phrase, ‘just suck less’ was first said to me by a research participant when I was working on a research project in Southern Labrador (2009) in response to the question of what individuals and institutions could do to improve their service to communities. Since then, I have found the poignant and pertinent nature of this quote to resonate with people, so I continue to use it all these years later.
internal operations of REBs – unpacking/unboxing the black box – to see what was happening in practice vis-à-vis policy. It was time to begin the difficult conversations about power and privilege, together. And to really talk about what it means to value Indigenous Peoples and the knowledge systems and sciences we come with, means to talk about the talking about it. How we organize, facilitate, participate, and deliberate these discussions is everything in terms of protecting Indigenous Peoples from research harms.

**Being Responsible: Standing in My Truth**

I carry much responsibility in doing this work as “a testament to what it means to value the personal as political, to value Indigenous communities as the loci of decolonizing theory” (Sium & Ritskes, 2013, p. II) in my journey to becoming an able human. I am responsible when I do research in a way that amplifies the voices of the communities who invite me to work with them. For Indigenous students and scholars, challenging dominant modes of defining and transmitting knowledge, and conducting research using Indigenous methods, informed by Indigenous epistemologies and ontologies, can lead to academic and/or professional difficulties, especially when we assert our Indigenous ways within colonial frameworks, like universities.

Indigenous Peoples are also doing their part on many fronts at the community level and at the academic level to respond to research(ers) coming into their communities. More Indigenous scholars than ever are shifting and re-aligning the ways in which they conduct research. Discovering and following in the footsteps of others who came before me (Brant-Castellano, 2004; Kovach, 2009; Sinclair, 2003; Smith, 1999; Wilson, 2008), I find a solid place to stand within the concepts and realities of ‘the ways of being’ in academic culture. I have more confidence in articulating and
positioning myself and my research. The ground is less shaky now. I am responsible when I approach my research as an Indigenous person first and overlay this worldview with academic frameworks to piece together a way forward that honours community directives and satisfies the academic requirements.

When I first started my practice as an autoethnographer, I did some looking at what I could see about my publications’ activity online – tools like Google Scholar are helpful (not perfect) for monitoring this. I first started talking about watching my Google Analytics in October 2017 in one of my comprehensive exams (see autoethnography digital story). Around this time there started to be more regular notifications for my publications, especially the 2010 journal article (Bull, 2010). I continue to expand my sense of where my commentaries are travelling as I tune into Google’s analysis every few weeks.

Figure 1. Google Scholar Analytics October 2018 shows the scholarly activity as captured through Google Scholar over the course of the past eight years. The analytics data (i.e. number of citations) for this article provide valuable insights that I continued to monitor, reflect on, and include as part of this dissertation research data set.
These two components: (a) reflexivity practice to support the ongoing (re)positioning of myself as “researcher”, and (b) discovering/(re)examining emerging data and discourses linked to my previous publications are reflected (or not) in current Indigenous Peoples’ research ethics conversations – together provide a rich, in-depth data set to support a robust autoethnography about my relationship with research ethics. This dissertation synthesizes key segments/strings/threads of this ongoing conversation with myself, integrated with the voices of others as they confirm or challenge my positions because developing a deeper ethical, theoretical, and methodological understanding of my practice requires connecting with myself, where I come from, and where I am now, here in this place, at this time in the story.

*Where I’m From*

I’m from pedagogies and philosophies  
From paradoxes and curiosities  
I’m an interdisciplinarian, a contractarian and a humanitarian  
I’m from consent and confidentiality  
From thinking about it critically  
From the practicality of morality  
I’m from conflicts of interest, I know that I’m different  
I’m from justice and autonomy  
Mutual exclusivity is not for me; It’s all a false dichotomy  
It’s the space between when we feed the machine  
The *ethical space* that we find in that place  
(Excerpt, Digital Story, November 2017)

Now that I have introduced myself in relationship (to my familial ties and to research ethics) and have sufficiently stepped far enough outside my comfort zone, it is time to describe the research design in more detail. The following chapter explains all aspects of the research design from conceptualization to dissemination.
CHAPTER THREE: RESEARCH DESIGN

Humans are storytelling organisms who, individually and collectively, lead storied lives. Thus, the study of narrative is the study of the ways humans experience the world. (Connelly & Clandinin, 1990, p. 2)

This entire dissertation is a demonstration of doing autoethnography and doing narrative inquiry. It is (about) stories. This chapter specifically chronicles the complete research design. I start by situating this study as interdisciplinary research in action and describing the research question and intentions that frame it. Then I discuss its qualitative research orientation, and the conceptual and theoretical thinking that inform it. I explain the methodologies that frame the study and the ethics that underpin my research practice. Then I introduce the participant contributors who graciously shared their knowledge and experiences, and I describe the methods I used to gather and analyze the data. Finally, this chapter ends with a description of dissemination and knowledge translation ideas and a short discussion of limitations and reflections.

Interdisciplinary Research in Action

This exploratory interdisciplinary qualitative research draws primarily from four major disciplines: Philosophy, Education, Anthropology, and Health Science(s). Within each discipline lives ontologies, epistemologies, methodologies, methods and so on, and each discipline is unique. However, the collection of disciplines in this research overlaps in various ways. To me, this is the ‘inter’ in interdisciplinary, the space created where the circles all overlap. My academic background in Philosophy and Psychology (BA) and Applied Health Services and Policy Research (MAHSR) coupled with practical
experience as an REB member, an Indigenous Research Advisory Committee member and Chair, investigator, participant, and knowledge user, provides a solid foundation in both theoretical and applied skills relating to my research topic.

My life experiences as a white-passing Southern Inuk woman, a learner, a storyteller, a poet, a writer, a not-so-good moccasin-maker, a cousin, a daughter, a granddaughter, an orator, a traveler, a scholar, an educator, an ethicist, and a leader, all overlap and position me as an expert in myself. As a young person, I never really felt like I fit into specific boxes and would always find myself oscillating in the spaces between defined norms or the idea of being one thing or picking one way to define myself (which we see in the university all the time when people identify with their degree/faculty/orientation but share nothing else about what influences how they see, understand, and describe the world(s) they are researching). It was uncomfortable for me, trying to narrow my sense of self to ‘fit’ in these dynamics. But as I get older it is increasingly more liberating to expand within/among and appreciate the distinctive value of operating outside the boxes and in the spaces between.

During the first year of my PhD I already knew I was interdisciplinary by nature and this was where I belonged because I naturally and inherently operated in the space between prescribed disciplinary boundaries. But I also felt like I was on the outside looking in because I had not yet found my voice. I could then see how I may fit; and now I know that at the time I could not yet fully feel or articulate my belonging and as a result it often felt feel like me and my work did not really fit anywhere. Now, with more teachings, more experiences, and more integrations (i.e., literally, more time to think about all of it), I can see that my work and me fit everywhere. I am also now even more sure that I do not have to pick one box. I am grateful that I allowed the learning to come
naturally instead of suppressing or narrowing or diminishing myself into boxes to satisfy the requirements of a degree and potentially losing my sense of self along the way. Being true to myself through the research process is an integral component of how I practice ethical research. It is the embodiment and expression of authenticity.

*Where I'm From*

I’m from ‘throw salt over your shoulder’
and ‘if you’ve got nothing nice to say, don’t say anything at all’
From a free-for-all to protocol
I’m from ‘an eye for an eye makes the whole world blind’. Leave no one behind
The forget-me-not from the one you forgot
I'm from the land and the sea, the animosity of atrocities
From a preoccupation of being mismatched, the outcast
From the devastation of domination
From the aftermath of backlash to fighting back.
From 'whatever doesn't kill you makes you stronger'
and ‘laughter makes you live longer’
It makes me a fighter and the load feels lighter
It's my grit that bit that you can’t describe
a heartbeat deep inside
(Excerpt, Digital Story, November 2017)

My capacity to see interconnectedness and to operate relatively unscathed in the spaces-between lies in my living experiences. It is through living that I am able to understand and articulate the nuances of research ethics (in theory, application, and practise; in the books and in the field). It is the intersection of life and research and the natural ability I have to seamlessly overlap multiple moving parts, integrating through iterations, adjusting and adapting as necessary, and continuously striving for ethical excellence, that positions me to do this work and to tell my story.
Research Questions and Intentions

This dissertation reflects the stories of those associated with REBs (members, chairs, research administrators, policy makers, and me) related to the ethics review and approval for research with Indigenous Peoples. The question(s) guiding this research are:

What are the perspectives and practises of people connected to REBs (including me) regarding the review and approval of protocols for research with Indigenous Peoples?

- How are REBs implementing Chapter 9 of the TCPS 2?;
- What is the current landscape of research/review with Indigenous Peoples?;
- How do REBs currently approach protocols involving Indigenous Peoples?;
- How do the policies and the practices mis/align?;
- What are possibilities and opportunities for advancement in the future?; and
- What REB innovations of review with Indigenous Peoples currently exist?

How does someone navigate being “Indigenous in the academy”?

- What is it like to be an Indigenous ethicist within an academic setting?
- How can Indigenous philosophies and epistemologies be intertwined in academic performance?

The intentions behind this research are to:

- Ground my research spiritually, through ceremony and engaging with Inuit Qaujimajatuqangit (IQ Principles) throughout my PhD research journey;
- Systematically and comprehensively examine, synthesize, and analyze literatures to depict the complexities in governance of Indigenous research;
- Interview those associated with REBs to collect stories about research/review with Indigenous Peoples;
- Co-create a model of guiding questions and considerations for researchers and REBs to inform evaluating ethics protocols’ alignment with TCPS2: Chapter 9; and
- Create an autoethnographic digital story about my relationship to research ethics.
Though my recruitment materials listed health research with Indigenous Peoples, the interviews were not confined to speaking solely about biomedical models of research/review. Heath ethics is an important aspect of this research and has been the catalyst for the development of robust Indigenous community research governance. However, I decided to remove the word ‘health’ from my research question since the conversations with participant contributors existed far beyond concepts of health in research/review. The insights and experience offered by the people in this study transcend disciplinary boundaries and can apply in any research setting.

**Qualitative Research Orientation**

While at one time, we, as Indigenous Peoples, were faced with leaving our Indigeneity at the door when we entered the academic world, several of us are now actively working to ensure our research is not only respectful, or ‘culturally sensitive’, but is also based in approaches and processes that are part of our cultures. (Hart, 2010, p. 1)

It has been a liberating and motivating experience to engage with work by Indigenous Peoples. During my first years of my doctoral studies, there was far less written by Indigenous scholars and now I have a growing collection (i.e., stacks) of books and articles by Indigenous scholars from around the globe. I read a lot of this literature during this doctoral research and have a mountain of “tangential” literature (i.e. those pieces less relevant to my research, but that I am interested to explore when I can read for pleasure) that I will read post-PhD. Regardless of the topical relevance, it motivates me to see increasingly more Indigenous authors.

Fundamental to qualitative research practice is that truth and reality are collaboratively constructed, informed, and reshaped in relationship to and through
interactions with people and the environments in which we live, as these are understood subjectively (Denzin & Lincoln, 2005). As Fine, Weis, Weseen, and Wong (2003) note, “[m]ethods are not passive strategies…they produce, reveal, and enable the display of different kinds of identities” (p. 187). There are multiple realities, epistemologies, ontologies, and pedagogies and they all exist simultaneously, not separately. There is no objective truth; rather, multiple, sometimes conflicting or colliding truths are evident and exist concurrently. Though this assumption of co-existing worldviews underpins a lot of qualitative research, it is an imperative of all Indigenous research and integral to most Indigenous worldviews (Little Bear, 2000). This worldview challenges ideas of objectivity, considering them an illusion since we can only ever know things through our individual interpretations and representations (Denzin and Lincoln, 2005). The qualitative research orientation was most suitable for this research as it best captures the nuances that my study aimed to illuminate.

It is not enough to merely describe the multiple parts, it is about the integration of them toward action, including integrating ourselves, our values, our assumptions, into our research understanding and practise. As part of doing qualitative research, socially/relationally locating ourselves—identifying our relationship to our research in a number of ways—also aligns with the underlying values of Indigenous research. As Indigenous researchers, it is essential to critically and continually re-locate ourselves when doing qualitative research. Autoethnography is an ongoing practice of positioning oneself at the center of the research and at the same time always re-locating oneself within the dynamics at play in the space(s) of intersections one traverse (Méndez, 2013).
Philosophical Assumptions and Paradigmatic Collisions

As an Indigenous learner and teacher, I find myself constantly straddling (at least) two divergent worlds. Given the illusion of knowledge acquisition and production that are inherent in doing academic work, I cannot really imagine a time that this tension or duality will not be part of my practise/life. So long as academic institutions hang on to their colonial foundations, it is unlikely that we will actually see a major shift in practice any time soon. Rather, others like me will continue to chip away at the foundation to demonstrate that it too can be dismantled in such a way that the entire structure becomes shaky, opening space for us to lead from the future as it unfolds.

My Praxis: Research is Action

Aristotle described three basic human activities: theoria (thinking), poiesis (making), and praxis (doing). My interest/focal point/passion is in the doing. In that regard, this entire dissertation – the process and the product(s) – is my praxis.

My Ontological Position: Research is Relational

The foundation of this dissertation is a relational one and it is demonstrated in my relationship with myself, my relationship with others, and my relationship to research ethics. At times, you may find yourself unsure which relationships I am talking about and may be confused by the unfolding parallel stories. My hope is that these connections and the overlapping of relationships will become increasingly clear as you move through the dissertation.

As Caine, Estefan, and Clandinin (2013) note, “[a] relational and transactional ontology precedes narrative inquiry research, because stories are about what happens to
and between people” (p. 583). The inter-connectedness of all things—natural, physical, emotional, and spiritual worlds—reflects an Indigenous worldview. Some Western models of science and research insist the requirement of objectivity. However, this is only ever achieved through an egocentric way of understanding or implicit bias or subjectivity. Physicist Teman Cooke delivered a TEDx Talk called *The Scientific Method is Crap*\(^\text{11}\) where he argues for a new way of understanding science that is more examination than experimentation.

**Spiritual Signpost.** (June 15, 2018) As expected, I found myself on many emotionally and spiritually difficult journeys throughout my PhD research. This was especially evident during my six-week immersion sprint when existential crisis’ and confusions were commonplace. I had the great pleasure to spend a day learning from Diane Hill and it was the best medicine I could have asked for during those times of questioning and uncertainty. She talked about the interconnectedness of all of the universes, the ways in which quantum physics is helping build a bridge toward Indigenous spirituality and understandings of the world. She described so powerfully that everything is narrative. I realized as I sat listening to her that my attempts to decolonize myself is evidenced as I shift from the academic structures of ‘science’ and lean on the integration of quantum physics toward Indigenous science. She reminded me that humans reflect the earth and the earth reflects back. Everything is necessarily and naturally interconnected. Diane’s intellectual, emotional, and spiritual intelligence and her articulations of their interconnectedness was just the fuel I needed to carry on

\(^{11}\) [https://www.youtube.com/watch?v=j12BBcKSgEQ](https://www.youtube.com/watch?v=j12BBcKSgEQ)
with my dissertation writing. She reminded me and reinforced for me that the work I am doing is contributing to a larger conversation that is grounded in generations of understanding how the universes operate together.

**My Epistemological Position: Research is Reflexive**

My worldview is both critical and constructivist. I base my research on the notion that we (humans) have individually and collectively constructed the society in which we live and that a critical perspective on such constructions are required to understand how we can *do* differently in research/review with Indigenous Peoples. I draw on Mi’kmaq Elders, Albert and Murdena Marshall’s teaching of *Etuaptmumk* (Two-Eyed Seeing) to find a way out of the confusion that has consumed the research regulatory system, specifically as it relates to the governance of research with Indigenous Peoples (Bartlett, Marshall, and Marshall, 2012).

For Indigenous science and research, it is important to locate ourselves in our work – declare our subjectivity through articulating how we understand and examine our own positioning in the research (Kovach, 2009; Moore, 2015; Smith, 2005; Wilson, 2008). Challenging ideas of objectivity, this vital exercise of reflexivity is practicing relational ethics, is imperative to *doing* Indigenous research, and is part of a research practice that is iterative and dynamic. Re-locating ought to be part of the practise, that is revisiting our location (re-locating ourselves) in all stages of the research, as our locations can shift and evolve over time (Riddell et al, 2017). This conversation about our location in research includes naming the inevitable power dynamics that exist between researchers and communities (Absolon, 2011). There is great importance for researchers—Indigenous or not—to engage fully in reflexive practice for the entire
duration of their research projects (Absolon, 2011). Even though this is not standard practise, it is wise practise. We need to reflect on our own positions of privilege and power, examine our assumptions and motivations, be clear in our intentions, and respectful in our actions (Kovach, 2009). According to Indigenous epistemologies, the idea that we can separate our self from society/nature/one another/the universe is a fallacy that requires dismantling. Everything is interconnected like we see in Figure 2. This acknowledgement of our place in the world and everything we bring with us in our research orientation(s) is necessary in decolonizing research. It is necessary for us to reflect, individually and collectively, on how our positions impact us and the people around us.

I use the concept of Zooming-In-and-Out (Figure 2) to ensure my reflexive practice is iterative in a way that is purposeful and intentional (and to help reel me in when I go too far in one direction or another). I reflected on the processes and products
of my research (past and present) and built on the key components in Figure 2 throughout the duration of my doctoral research. I did not make stringent to-do lists or demand a specific amount of productivity-by-product; I was always working on it – whether it was randomly percolating on the day’s news about a data breech or an injustice for an Indigenous person or community, or it was reading literature on ethics or watching videos of teachings, or it was actively writing. To use the analogy in Figure 2. Zooming in and out (created in November 2017 to illustrate the concepts in my study), I do not even know yet what lies above the surface (let alone underneath), despite being engaged in this work since the early 2000s. The many related components all require their own individual examination of their combined parts before even being able to start the conversations about the integration between the different circles and how they overlap. I confirmed many things during this research; I also learned of many further areas of examination to be pursued and questions to be asked (as should happen with any good research process) and zooming in and zooming out was essential in the process.

**My Axiological Position: Research is Spiritual**

I am a pragmatic person, driven by justice, and I see wisdom as greater than knowledge. Being kind is better than being right. We all place value – whether consciously and intentionally or not – on people, places, and things. Within the context of this research, the value-laden understanding and application of ethics is important as it illuminates a conflictual or contentious starting point. The collision of Western and Indigenous notions of ethics are fraught with varied interpretations and (mis)understandings and result in confusion in the practice of research/review with
Indigenous Peoples. Some of this comes down to how these things are negotiated/understood in the different knowledge systems; Indigenous knowledge systems center on interconnectedness and spirit. Research has spirit and we cannot artificially separate different parts of ourselves and the world from the research we are doing or creating.

The interpretive nature of this study, my axiology, is such that I am not separate from the research. I clearly articulate throughout this dissertation what some of my own values and assumptions are and how they influence this study. I am a herd animal spiritually, so it makes sense that I am doing the work for and with the herd. I cannot separate the different components of me from my research because they are inherently and necessarily interwoven. My spiritual intentions impact what I am doing, and I cannot separate myself or my research from that. This relates to IQ in that Inuit also operate with a herd mentality. It is all about survival, even research.

I undertook my research with a spiritual intent and with ceremonial guidance. I attempt to share some of these experiences with you to demonstrate how it is all connected. Through this interpretive positioning – straddling, acknowledging, and working across realms – I am well situated to examine the stories that individuals have shared with me as they relate to the collective conversation and action on research/review with Indigenous Peoples.

**Conceptual Framework: It is all Connected**

My conceptual theoretical framework is layered and multi-faceted, like me, and is my best attempt at articulating an integration of my thoughts and sensations related to working in my area of research focus (that includes me, research ethics theory,
application, and practise) for more than a dozen years. As part of my PhD course work, I was assigned the task of proposing a conceptual framework that reflected how I was thinking about my research at the time (four classes into the Fall term). The assignment was to create a concept map (Novak & Cañas, 2006) of our thinking about our research, and I did not know when I created it that I would refer back to it throughout the term and while preparing my research proposal, and again during the analysis and writing of this dissertation. In an effort to capture my thinking in a two-dimensional form, I created a slide and presented it in class as part of the course assignment on October 1, 2017. This framework has guided the research and I found myself returning to it on several occasions throughout the data collection and analysis stages. Figure 3 is my best articulation (in two-dimensional form) of how I presently understand the world in relation to this research:

*Figure 3: Conceptual framework*
My research question is at the center and though I will attempt to describe the whole figure, keep in mind that it is the interconnectedness of all the parts that I am most interested in relaying through the imagery and description. This means there is less ‘a then b’ and more ‘a influences, and is influenced by, b’; it is where they overlap. This figure is a two-dimensional attempt at illustrating a three-dimensional concept – it is not a circle, it is a sphere.

The blue circle around the research question illustrates the four primary disciplines (Philosophy, Education, Anthropology, Health Science) I draw on for this research (though other disciplines have found their way into my thinking, e.g., business management and leadership applied-components and processes of doing). Then, each major discipline is further described to indicate the branches of each that I am drawing on (Philosophy [ethics, epistemology, meta-physics], Education [leadership, adult education, pedagogy], Anthropology [critical theory, autoethnography, cross-cultural], and Health Science [bioethics, health policy, health education]).

The visual images between each core discipline represent underlying assumptions of my research and perspectives that I come with, personally as a learner/participant in my research, and professionally as a researcher/learner in my study. Etuaptmumk (Two-Eyed Seeing) is at the top to illustrate the integration of my Western and Indigenous epistemologies, which is not just foundational to this research, it is my way of life, my way of thinking: I am of two worlds. Moving clockwise, the image of continual improvement through ‘plan, act, check, do’ depicts the agile and iterative approaches I take throughout all of the research, regardless of which discipline or method I am drawing on. On the bottom, the scales of justice represent the underlying and inherent goal of all the work I do: justice for Indigenous Peoples—research ethics is
where I practice my resistance and change-making. Finally, the image to the left side of the blue circle is a model of ‘good governance’. Again, this is an underlying premise of my work: good governance that is participatory, responsive, and transparent is required for Indigenous Peoples’ health research.

Along the outer edges of the blue circle, there are four embedded approaches I use: Indigenous sciences, agile and iterative approaches, reflexive practises, and decolonizing methodologies. These operate alongside pieces of literature in the framework (The Ethics Rupture (van den Hoonoord and Hamilton, 2016), Research is Ceremony (Wilson, 2008), Research as Resistance (Strega and Brown, 2015), Decolonizing Methodologies (Smith, 1999), and Ethical Space of Engagement (Ermine, 2007) that significantly influence my thinking on, and action toward, a greater understanding of research/review with Indigenous Peoples. Finally, to illustrate the major contributors to my theoretical foundations, the Theory of Diffusion of Innovations and the Theory of Reflexivity are noted on the right and the Theory U is depicted on the left. Together, all of these moving, evolving, and interconnected parts combine as a backdrop to this research. Though Figure 3 is my best attempt to visually represent my conceptual framework, to fully imagine how all of this works in practise, we need to consider it as a shifting and evolving 3D model – a sphere or orb with a dynamic outer membrane that is always moving and shifting around the core, perhaps.

**Theoretical Trifecta**

This interdisciplinary, qualitative study is built with an interdependent theoretical framework that draws on three primary theories:

1. *Theory of Reflexivity* (Soros, 1987);
2. *Theory of Diffusion of Innovations* (Rogers, 2003); and


These theoretically support this research and are illustrated and integrated into the conceptual framework described earlier. The *Theory of Reflexivity* underpins the autoethnographic component of my research, while the *Theory of Diffusion of Innovations* and *Theory U* represent a way to understand the *doing* of something, in this case, research/review with Indigenous Peoples. All theories together overlap, and my interest is in examining the points of convergence to understand the space-between and to identify ways that REBs can enhance their processes to ensure ethically sound research review and approval.

*Theory of Reflexivity*

We are all actors and observers (Soros, 1987). Both participatory and descriptive theories are necessary to understand an experience according to Soros, which aligns with social sciences that aim to both observe and participate (unlike the natural sciences that observe without participation). I am an *active* participant in this research while I worked alongside participant contributors (those associated with REBs in academic institutions across Canada. Soros’ analysis of social systems is far more comprehensive than other models because it accounts for events, groups, ideas, and variables – many models only reflect two elements (Umpleby, 2007). This model (Figure 4) provides a feedback loop/process of comprehensive analysis and ongoing

*Figure 4: Theory of Reflexivity* (Soros, 1987)
critical self-reflection and bias-checking; this is to mitigate how our thinking influences our actions. It is at this meeting place of contemplation and concrete action that reflexivity occurs. As an autoethnographer and narrative inquirer, the theory of reflexivity is perhaps the easiest theory to articulate given the reflective nature required to perform autoethnography and narrative inquiry. The intentional weaving of autoethnography and empirical research allows several ways/levels of reflections like I am doing (and is described/demonstrated throughout this dissertation).

**Theory of Diffusion of Innovations**

Everett Rogers’ (2003) *Theory of Diffusion of Innovations* (Figure 5) is about a process of how innovations are communicated, comprehended, and applied. There are a few people in society who are innovators (when it comes to research ethics, I hope I am one of them), and there is a larger group of early adopters (several of whom participated in this study), but academic culture/most institutions are in the early or late majority to change—someone has to go first and upgrade the institution’s operating system, as it

![Figure 5: Diffusion of Innovations Theory (Rogers, 1995)](source: Everett Rogers' Diffusion of Innovations model)

were. I wanted to understand the perspectives and practises of people associated with research ethics board (REB) pertaining to how REBs review and approve research with
Indigenous Peoples, including whether and how they apply Chapter 9 of the *TCPS2*. More specifically, I wanted to learn how REB members determine their level of authority/jurisdiction when assessing research protocols for review and issuing approvals for research with Indigenous Peoples. I wanted to learn so many things about what the current REB practice looked like regarding the implementation of *TCPS2* Chapter 9. In my effort to do this, I sought to find and build relationships with the early adopters I encountered on my journey, and worked to support them in leveraging their networks, colleagues, and peers to recruit/build the early majority. The plan is to recruit enough people to the innovation bandwagon that the late majority will join in. Finally, the very last to catch on are the laggards; their lives become more complicated the longer they resist, and eventually they join in. The innovators are ready to get to the doing and the early adopters are ready to learn more. I believed it would be relatively easy for me to find enough people who wanted to share stories about Indigenous research ethics in action (Spoiler Alert: it was!).

Rogers (2003) outlines a five-step process that people use to make decisions about which of those innovator stages they fall into:

1. Knowledge – when we become aware that an innovation exists and understand its basic purpose(s);
2. Persuasion – when we form an attitude toward the innovation;
3. Decision – when we engage in activities to learn more so we can decide whether to accept or reject the innovation;
4. Implementation – when we put the innovation into action; and
5. Confirmation – when we assess and reiterate our innovation decision in practice.
“People will adapt an innovation if they believe that it will, all things considered, enhance their utility” (Orr, 2003, p. 2). The *Theory of Diffusion of Innovations* (Rogers, 2003) provides guidance on how to introduce personal engagement as integral to any successful innovation and the participant contributors who joined me shared stories of how REBs can do the innovating.

For me, this theory helps articulate what I have come to see in the past dozen years of doing this work. When I first started my PhD in 2008, few people were even in the first stage – knowledge; it was just beginning. There was limited writing on the subject at that time. There were parallel processes of inquiry occurring with institutional ethics and Indigenous ethics and for the first decade of that, they were parallel processes that existed independently from each other yet they both substantially influenced and shaped each other simultaneously. Now, the worldviews are colliding, and many people find themselves (together, unsure, and confused) in the ethical space.

The cultures of institutions and organizations are often so busy with general operations that they rely on opinion leaders’ perspectives to inform their decision-making (Orr, 2003). So, an influential way to impact change through innovation is to affect the opinions of opinion leaders. For Orr, it is this detail alone that can make-or-break the early adoption of an innovation: “whether or not opinion leaders vouch for it” (p. 3). According to Rogers, I am trying to reach the 16% and together we will awaken the next 34%!

While in some ways it feels closer than ever, as is evidenced by my entire PhD journey, getting to the Indigenous research ethics tipping point—the point when ideas or fads outlive their trendiness in compartmentalized sectors or cultures and spread exponentially throughout the entire society—is about timing, not time (Orr, 2003).
When I was publishing on Indigenous research ethics in 2010, there were few other Indigenous scholars writing on the topic. Professors often told me that my work and my ideas were ‘ahead of my time’ and that is increasingly clear since resuming my doctoral studies in September 2017 and re-immersing myself in the literature. I am sometimes surprised to see how little certain things have changed (e.g. the same contentious issues of jurisdiction, governance, collective consent, conflicts of interest, ownership, still bewilder researchers and research ethics boards in their efforts to conduct ethical research/reviews with Indigenous Peoples). While the collective Indigenous research ethics ‘tipping point’ is not yet arrived, we are much closer than we were a decade ago. The momentum continues; the energies are gathering; and a critical mass is building. The participant contributors in this study and who you will hear from in subsequent chapters, demonstrate the mobilization that is happening across Canada; they are mostly innovators and early adopters who are keen to stay engaged in helping enlist the early majority.

As an innovator, it can be really difficult when people around me are laggards and late adopters, which is how it felt when I was doing PhD 1.0. In the decade since I originally started my PhD studies, more innovators and early adapters have emerged so instead of just having the 2.5% to work with, I now have the 16%. One of my most hopeful moments throughout this research process was in speaking to other innovators at institutions across Canada who are already doing differently. The 2.5% have encouraged/engaged the 13.5% (early adopters) and we are now 16% strong. After spending so much time in isolation with very few innovators and surrounded by laggards, it feels like I have won a lottery in having so many incredible people walking this journey with me. Some of the people who participated in this study are characters in
my story previously and some people are brand new friends, colleagues, and co(i)nspirers. A movement has been happening for the past decade and I am doing the enjoyable job of bringing these different pieces together and connecting the community as I go.

Theory U

*Theory U* is a change management method articulated by Otto Scharmer (2009). It asserts that the quality of changes in systems or organizations is a function of the awareness, autonomy, and adaptability of the participants. Since it emerged, *Theory U* has come to be understood in three primary ways: as a framework, as a method, and as a way of being. It is meant to be a method in pursuit of profound change and as a way of being to connect us to our authentic and higher selves. I particularly appreciate the ways that *Theory U* embodies my understanding of becoming an able human and allows me to genuinely overlap the personal and professional.

Before finding this theory, I had a similar way of articulating my understanding of how an innovation can actually be implemented – how to *do* innovating. In using *Theory U* (Figure 6) as both a method and way of being I have been ‘diffusing my innovation’ and bringing others along to get to the tipping point, together! *Theory U* is

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*Figure 6: Theory U (Scharmer, 2009)*
built on a collaborative platform of co-initiating, co-sensing, co-inspiring, co-creating, and co-evolving (Scharmer, 2009). The point is that the doing is only possible and sustainable if the decisions about and implementation of the innovation are done collaboratively. Figure 6 provides a simple conceptualization of Theory U to understand the five connected components. Additionally, Scharmer discusses a counter-narrative to the Theory U which is illustrated as an upside-down U. The upside-down U represents how counter-narrative is a reality in this work where people are stuck in themselves, one truth or one perspective. Scharmer describes presencing as leading from the future as it emerges in collaborative ways and absencing as a worldview where the source of problems is exterior, not interior: where we are stuck in one self (the non-reflective and non-evolving self). Absencing is the social space of destruction and presencing is the social space of emergence and creation. While we will always have the space of destruction operating alongside creation, we need not let it defeat us for this balance is an aspect of nature.

**Transforming Theory into Practice**

As I spoke with participant contributors, read and re-read their transcripts, and listened back to the interviews, I was experiencing these theories come to life in practise. The dual application of narrative inquiry throughout my approach (i.e., personal storying through autoethnography and participant stories through interviews), framed within an interdisciplinary structure underpins this research and mirrors this duality. The first two theories (*Theory of Diffusion of Innovation* (Rogers, 1995) and *Theory of Reflexivity* (Soros, 1987) are interconnected with the overall premise that those individuals in leadership positions with specific characteristics (e.g., persistence,
tenacity, determination, risk-takers) are innovators who, when collaborating with others in a co-design fashion (*Theory U*) and are opportunistic/aware of the tipping point, can actually make change. I predicted that the level of implementation is highly dependent on individuals being tasked to do so and can be held up for a variety of reasons, including but not limited to, institutional barriers (Miller, Baird, Littlefield, Kofinas, Chapin, & Redman, 2008), intellectual obstacles (MacLeod, 2016), and inter-personal conflict (Kline, 2008). The 17 participant contributors who joined me in this study corroborated that prediction.

**Methodologies**

In this section, I explore and explain the overlapping methodologies that are interwoven in this study. An interdisciplinary methodological framework informed by Decolonizing Methodologies, Autoethnography, and Narrative Inquiry guided this research multi-method study. Since storytelling is an integral component in this research, I briefly describe the importance and necessity of stories and my choice to integrate story throughout my dissertation in this section.

**Decolonizing Methodologies**

To implement decolonizing methodologies is to tell a counter-story to the dominant perspectives of knowledge production (Smith, 1999) and it seems counter-intuitive to write about decolonizing methodologies as a stand-alone category since it is actually the foundation of this entire dissertation – in both process and product. There is no set criteria or checklist that automatically makes one’s research decolonizing or to assess the colonial bias of one’s methodologies. Decolonizing methodologies is an exercise of researching back, drawing on Indigenous epistemologies and ontologies
through a critical lens, about topics that are useful and meaningful to Indigenous Peoples. Smith’s seminal 1999 work was not only an Indigenous articulation of how to do research in an ethical way, it was also a call to action. I reiterate this call here in this dissertation, 20 years after Smith’s book was first published.

There is immediate need for “cultural adaptation of the theoretical framework and methodologies” in research and we must include Indigenous epistemologies, thereby “ensure[ing] research is inclusive of [Indigenous] cultural values, such as collectivity and storytelling” (Mark & Boulton, 2017, p. 1). This research is my best attempt at responding to Smith’s call to action. Even though this research did not specifically seek to work with Indigenous Peoples, it is Indigenous research because I am doing it and it is all shaped by me and I am Indigenous. I am fortunate that some of the participant contributors were also Indigenous and we shared in visions together of how research/review could look for Indigenous Peoples. I am done with the idea that applying and integrating Indigenous ways of knowing is only applicable and relevant to research with Indigenous Peoples: I know that Indigenous epistemologies, methodologies, and pedagogies can greatly improve the structures of research and education for everyone and can critically inform innovations in the governance of research with all people.

My own relationship with academia and research informs and fuels my quest to both decolonize and Indigenize simultaneously as I embody roles of both dismantler and rebuilder. I distinguish between decolonizing (the action of addressing colonial influence) and Indigenizing (the action of re-asserting Indigenous ways of knowing and being to stimulate change). While the notion of Indigenizing is valuable and appealing, I do not think it is possible without simultaneously decolonizing. How can colonial
structures be Indigenized if they are not also being decolonized? I am not terribly fond of these words anymore; they have become part of the mainstream vernacular, settlers’ attempts to ‘reconcile’ through ‘Indigenization’ and ‘decolonization’ that merely perpetuate the systemic and institutional barriers that prevent Indigenous Peoples from leading Indigenization efforts.

There is a line in one of my poems: ‘Indigenization is in your imagination’ and it plays in my mind often as I observe institutions and agencies put a dream catcher on the wall or designating a specific outdoor space for smudging, for example, and then patting-themselves-on-the-back for their leadership, believing that they have now decolonized their institution and that reconciliation is achieved. Yet, there is unlikely an example where a single action elicits a renewed relationship, though it is a good start. Reconciliation is a journey, not a destination; it is for each of us as individuals to reflect upon and act on, not a wall-hanging or well-sponsored corporate event; it is our challenge to take up new behaviours and attitudes grounded in our collective truths, not about “keeping up an appearance” or meeting colonial expectations. This is not meant to be defeatist or disrespectful; it is a truth that I am compelled to tell. “Getting woke” is a process of personal and critical self-reflection, not likely to be accomplished in an afternoon workshop; while it can end up feeling good, the journey is often shocking, emotional, provocative and personally challenging to get there, and everyone is on their own timeline.

**Storytelling: The Oldest Knowledge Translation Strategy**

Storytelling is the oldest mode of knowledge exchange and was the first pedagogy or way of teaching (Whiteduck, 2013). Indigenous Peoples still practice the
tradition of oral storytelling, and families keep and protect stories, passing them down from generation to generation. We learn that “[s]torytelling is also a powerful and essential component of any Indigenous-based research and should be respected as a way of sharing lived experiences, exploring personal beliefs and values, and discovering place-based wisdom” (Cunsolo Willox, Harper, & Edge, the ‘My Word’ Lab, & the Rigolet Inuit Community Government, 2012, p. 133). Oral stories continue to be a means of sustaining and protecting Indigenous knowledge (Lee, 2009). These are some reasons why I choose to integrate storytelling at all stages of my research and weave together various storytelling approaches in this dissertation.

Previous attempts by non-Indigenous researchers to tell stories that do not belong to them, namely to record, capture, or write them out without permission, stirred resistance in communities who believed they were being exploited (Smith, 1999). The extraction of these stories is not unlike other resource extraction and is not only a research indiscretion, it is also a spiritual and cultural transgression, and a modern example of ongoing colonial entitlement and an exertion of privilege to determine and exert control over Indigenous narratives. “By telling our stories we’re at the same time disrupting dominant notions of intellectual rigor and legitimacy, while also redefining scholarship as a process that begins with the self” (Sium and Ritskes, 2013, p. IV). My use of story is a decolonial exertion in honour of my ancestors, who have instilled in me a capacity to use the power of words (in many forms) to influence others and initiate change. My right to perform the rite of storytelling about my research experiences is granted to me by the communities I work with; my obligation to situate myself deeply in my process and interpretation of my research is my obligation as an Indigenous woman practicing Indigenous science. As Clandinin, Cave, and Berendonk (2017) describe,
“Stories are lived, and told, not separated from each person’s living and telling in time, place and relationships, not seen as texts to be separated from the living and telling and analyzed and dissected (p. 91).

Autoethnography

There are varying degrees to which researchers emphasize and engage the different components of autoethnography: auto- (self), -ethno- (sociocultural connection), and -graphy (application by way of research process) (Reed-Danahay, 1997). Some people use autoethnography to align with autobiographical and literary studies (Ellis & Bochner, 2006) while others focus on linking the position of self within the literature (Holt, 2003).

There is ongoing debate about the dichotomous distinction between evocative (art) and analytic (science) models of autoethnography (Chang, 2008; Ellis & Bochner, 2006; Holt, 2003; Richardson, 2000). While most researchers choose one or the other and do not explore the meeting place – my favourite space! – using both viewpoints, it is possible to illuminate the inevitable dualistic interplay by critically examining ourselves and our positioning in-relationship. Though most attempts to do autoethnography include some discussion of power and privilege, the imperative to practice this is much more explicit in Indigenous Peoples’ research method(ologie)s (Smith, 1999) and was integral in the production of this dissertation.

This meeting of science and art can be uncomfortable or confusing to others who criticize autoethnography as either being too scientific and not artful enough, or too artful and not scientifically rigorous enough (Ellis, Adams, & Bochner, 2011). One of the necessary components of autoethnography is “to recreate the researcher’s experience
in a reflective way, aiming at making a connection to the reader which can help [them] to think and reflect about [their] own experiences” (Méndez, 2013, p. 284). For me, in PhD 2.0, there is no room for artificial attempts to delineate the art and the science of autoethnography— it is the integration of the two, between and within: the space where they overlap. As evidenced by this dissertation, I am no longer interested in choosing between the binaries that can feel imposed by other academics (and accept I do not have to); rather, I am primarily interested and strongly invested in deeply understanding the space between them.

**Narrative Inquiry**

Indigenous Peoples still actively practice the tradition of oral storytelling, and stories are kept and protected under the stewardship of families who the stories were gifted to, and who are responsible to pass the stories from generation to generation as part of their obligation that comes with the gift. These stories continue to be a means of sustaining and protecting Indigenous knowledge (Lee, 2009). In academic settings, a methodological approach to storytelling is called narrative inquiry. In this sense, stories become ways of collecting and analyzing research participants’ knowledge. Fundamentally, it is hard to gather deep, meaningful stories through over-structured interviews that can discourage collecting fulsome chronologies of events that support tying a person’s individual story with the collective one.

The essence of narrative inquiry is to listen to participants’ stories (and in my research that includes me), especially in relation to the events and entities that connect us (individually) with the communities and systems around us (collectively) (Creswell, 2014). In this meeting place of connection (the ethical space), researchers examine the
relationships between all of the events and entities, and do not attempt to compartmentalize a participant’s personal experience in isolation to the collective story. I attempt to enact this in how I am doing this dissertation. This will be more obvious to you in subsequent chapters where the stories of participant contributors come to life in a more substantial way.

Stories are relatable and get to the essence of our identities and how we make sense of our environments; Indigenous knowledge keepers and Elders understand this and practice Indigenous science from this place (Ermine, 2007). This is a fluid and agile method of investigation that is locally- and context-specific (Chan, 2010). Since people use events in time to substantiate or frame their personal narratives, it is important to use this methodology in my research as I build on existing knowledge that illustrates the duality between participants’ personal experiences and those of the collective.

Applying this methodology, a very small sample can yield a lot of data for the researcher and participant to synthesize and analyze together. Participants are purposefully chosen because of their personal relationship to the question under investigation; that is what the “inclusion criteria” is framed around. The process follows that participants tell their stories and undertake an ongoing process of re-storying through iterations between the researcher and the participant (this is especially intriguing—and entertaining—in the autoethnographic portions of my research where I am explicitly both the researcher and the participant simultaneously).

As Caine, Estefan, and Clandinin (2013) assert, “our thinking as narrative inquirers grows out of being-in-relation” (p. 580). Importantly, they go on to articulate an experience of relational consideration that resonates with me and the experiences I had/have throughout this research:
The narrative nature of experience, viewed from within narrative inquiry, necessitates considerations of relational being and knowing, attention to the artistry of and within experience, and sensitivity to the nested and overlapping stories that bring people together in research relationships” (Caine, Estefan, and Clandinin, 2013, p. 584).

This collaboration continues, and a mutual decision is made about how the story will be written/told and to what extent it discusses the interconnectedness with the collective experiences. Finally, a co-determined process of trustworthiness-checking occurs that may involve participants reviewing transcripts, responding to a presentation of collective research findings, or some other participant-driven process that meets the rigour of establishing validity (Creswell, 2014).

**Ethics**

Though I am ‘performing the antics’ of doing academic work in this chapter as I present the research design, I am mixing up the order (some might say) and will talk about the ethics (both the process and practise) before the methods. I am doing this for two reasons: first, to demonstrate that ethics needs to come before methods in our research practise, and, second, because I want to document this ethics process before introducing the participants. Simon (2012) say that this kind of work is “ethics-led as opposed to method-led” (p. 40) and maybe all research should have this orientation (it does in #TheJuliestPhD Utopia, Chapter 6).

It seems a little insincere and incomplete to have a section called ‘ethics’ when this entire dissertation is ethics. Nonetheless, it also seems many people cannot imagine how I prepared my ethics research plan (and subsequently prepared institutionally
specific paperwork to have it reviewed by eight other institutions in a timely fashion – this is now my most peer-reviewed piece of work). I know they cannot imagine because every time I share the story of my research ethics experience for this study, people are shocked and say they “cannot imagine going through that”. It is necessary to devote this section to explaining how I presented the ethical considerations in this research, and my experience of the process of ethics review and approval.

**Ethical Considerations**

Autoethnography brings its own specific ethical considerations: the privacy, autonomy, and consent of non-participatory actors in my own story; perceived conflicts of interests; and ownership and stewardship of data and resultant stories to name a few issues needing resolution. Further, principles of relational ethics are a key consideration in narrative inquiry and inform my ethical approach to this project and nestle well under the overarching framework of Indigenous research ethics that I apply in all my work. To address some of these ethical considerations, I was very clear with people over the past several months that I am working on this research and that everything is data. I sometimes say that data may get tossed into the mix (in a de-identified or aggregate way). Also, the people who have played large roles (those who I introduced yoat the start) were in this research with me and engaged in ongoing conversations about how they are represented in my story.

Risks-to-self for individual participants in this research are minimal, for this audience of REB Chairs and affiliates, in particular. I suspect (and hope!) that people involved in influencing research ethics review in any capacity understand and are able to surmise the potential risks to themselves if they choose to voluntarily participate in
research, though I was still explicit in how I framed participation in the information letter and consent form. I intended for participants to be in charge of their level of participation and the stewardship of their contributions. That being said, it is possible that some particularly difficult experiences of conflict with colleagues or examples of unethical research practices could have emerged in conversations, and so there was a discussion about a variety of ways we could navigate this situation should it arise.

Privacy and confidentiality are often two of the central tenants in procedural and/or prospective research ethics. While these are important considerations, it does not account for the possibilities that emerge in participatory or engaged research projects. Participants ought to have a choice as to whether or not (and how) they will be named. In this research, I set up the process in such a way that participant contributors decided for themselves the level and extent to which they wanted their data to be kept private. I am grateful that almost everyone who contributed (all but one) did so openly and agreed to be named as a participant contributor in the study.

This group is/was very responsive throughout the research process; most reviewed their transcripts and made clear requests with respect to what needed to be deleted and/or corrected for confidentiality and accuracy, which I have honoured. Some stories that were shared in our conversation were not intended for you readers, they were to provide context in the moment. The shared understanding of this nuance between me and the participant contributors was a key element in our collaborative approach to doing this research relationally and ethically. The relationship I have with the participant contributors in this study and the way that we negotiated consent throughout illustrates the range of options available for confidentiality of research participants. I am glad to be
able to write about this in a continued effort to “develop understanding of the relational 
ethics that underlie narrative inquiry” (Clandinin, Cave, and Berendonk, 2017, p.94).

Finally, an essential premise of relational and Indigenous research ethics is that 
decisions are made within the context of a relationship; this is the foundation of my 
research. Pollard (2015) believes that, “Understanding our relationships with others, and 
the ethical actions to be taken, requires knowledge of traditions, universal principles, 
rationality, our subjectivity, and our interconnectedness” (p. 364). My consent checklist 
(and the conversations it provoked) is an example of a way I practised making decisions
in relationship with participant contributors, through dialogue.

**Ethics Review and Approval**

The idiosyncratic and inconsistent processes of REBs was evident for me as I 
recruited participant contributors for this study. There was no standard approach to 
people’s responses to my research – research ethics boards at different institutions had 
different policies and procedures to follow. Though I will discuss my experience of the 
REB protocol process here, there is further detail and contextual integration of my 
experience included in subsequent chapters. In this section I am simply describing ‘what 
happened’ during the REB review and approval process; later, I will describe “my 
thoughts about” the REB review and approval process.

**Personal Reflection:** I am, of course, curious about the conversations that my 
REB protocol provoked – why did it go to full review at some institutions? Why 
did no one have any questions or comments for me during or after their reviews? 
Why was it approved outright with no further commentary or questioning?
Initially, some people expressed concern about a possible lack of participation – suggesting that I may not get enough participants for my project (I proposed 5-10). I received REB approval from my institution and I sent my first invitation to participate later that day. I received an email reply within 10 minutes; the person was keen to participate. We scheduled our conversation for a few days later; however, when we met to talk, the participant contributor informed me that their institutional REB needed to review and approve my study before they could participate.

For a brief moment, I found myself second-guessing my recruitment strategy and thought the concerns about participation raised earlier might be right and I may need to alter my strategy/research plan. Then, I immediately started to wonder how many of those studies that I read about where they interviewed researchers about the REB process actually intended to profile REB members themselves but were discouraged because of the regulatory structure. I did not fall down when I learned that I would need this additional REB review, though it did trip me up for a second.

**Spiritual Signpost:** (February 16, 2018) That same night fox came to visit me in Prince Edward Island, at my friend’s place where I was staying for a few days, and while I was on the phone with another friend enjoying the fresh night air; fox winked at me from the tree line. I quickly saw the opportunity that was presenting itself and fox reminded me to perform the antics of the culture at hand (in order to get into the hen house or the black box in this case), without losing sight of the prize (getting into the hen house or black box). I wanted to talk to those associated with REBs and so I had to ‘do the dance’ and ‘jump through the hoops’ of the academy to do so, whether I believed my research deserved or required or benefited from further reviews or not. Since I am a #dorklete, it was
a good opportunity for me to demonstrate my prowess to others and show them
that the REB is perhaps not the monster that it’s made out to be AND that it is
possible to undergo multi-jurisdictional review in a (relatively) efficient way.

Of course, as it turns out, fox was wise, and I quickly realized that the
data arising from documenting the process of obtaining eight REB approvals is
super robust and one of the richest collections of information included in this
study. I just had to remember that my PhD was/is a performance of sorts and I
just had to learn the variations in the steps and dance my way through.

I received my first REB approval from my home institution (Appendix B) University of
New Brunswick (February 13, 2018). The others, in chronological order of date
approval were issued:

University of Prince Edward Island (March 14, 2018)
Simon Fraser University (March 23, 2018)
St. Thomas University (April 10, 2018)
Ryerson University (April 20, 2018)
University of Regina (April 20, 2018)
University of Victoria (April 20, 2018)
Northwest Territories Research Licensing (September 7, 2018)

It is important to note (especially for the sake of Dr. Anonymous’ anonymity,
whose institution is not listed above) that not every institution who reviewed this
protocol had an individual who participated. Likewise, several participant contributors
did not require additional ethics review of the study prior to their participation. As I
spoke to peers and colleagues about some of things that Dr. Anonymous said, everyone
thought that they could identify her. This is because Dr. Anonymous, though an
individual human in this study, represents a mass amount of people who share in her
perspectives and beliefs. Everyone knows at least one Dr. Anonymous and many will
think they know who she is.

At this particular time when my support network would check in, my experience
of relaying my “how’s the research going?” updates was its own amazing thing – the
looks on peoples’ faces (or silence on the phone) when I told them I was preparing REB
protocols for numerous (more than five) institutions. The responses were indicative of
the culture of fear that is associated with REBs – why would anyone bother to do that
instead of adapting the research to make the REB process easier/smooth/er/clearer?
These reactions came from various researchers at various levels (graduate students,
PhDs, and seasoned researchers alike) and came from good places of wanting me to
succeed and not suffer and all good things, yet, it was and is concerning for a #dorklete
like me to relate to these responses for this research reality was far too interesting to get
upset about (after my momentary ‘uh-oh’). It makes me wonder how much time, if any,
researchers are actually spending reflecting on the ethical conduct of their research or
the rigour of their method, or the quality of their question(s). Have they just become
robots who are trained to produce a standard response to standard questions on the REB
protocol, absent of actually thinking about the ethics of what they are proposing to do?
And measuring their research skills by how efficiently they can ‘clear’ the REB and get
moving on their projects, regardless of how well thought out it is?
Participant Contributors

Over the past dozen years, I have built far more than a network; it is a family. There are many relationships at play in this project but the most central one is the relationship I have to the study of ethics. This relationship I continue to build on, has taken me around the world, introduced me to amazing, bright, and thoughtful people, and it has played a key role in my becoming an able human. Everything is relational. This area of work is specific, and so it cannot be surprising that some of the participant contributors are people I had relationships with prior to conducting this research. I knew eight people beforehand and nine people who joined are newcomers to my ethics family.

Participant contributors are predominately innovators and early adopters. They came forward to join me in telling a collective story and I am grateful for the contributions they have all made to this work. I am also grateful that one participant contributor came with an entirely different story to tell, one that is still deeply entrenched in academia and is common discourse (i.e. Indigenous research process is onerous and time consuming and we should not have to do it if we have approval from our academic institution). This person, Dr. Anonymous, was the only participant who asked to be unnamed and they provided a critical counter narrative. Everyone else (all 16) consented to be named (#ethicsendorsement!) and joined me in-relationship to share these stories. I am honoured to have spent time learning with them and compiling our collective understandings, innovations, suggestions, and visions in this story. I am thankful for all the #ethicsgeeks and #dorkletes who have joined me in this process and I want to introduce them all to you, so you can get to know them a little bit too (a more fulsome description of recruitment is included later in this chapter).
- Suzy Basile, REB Member at Université du Québec en Abitibi-Témiscamingue
- Danielle Connell, REB Coordinator at St. Thomas University
- Genevieve Dubois, Manager at CIHR Ethics Office
- Brenda Gagne, Research Ethics Coordinator at Mount Saint Vincent University
- Gwen Healey, Executive Director and REB Member Qaujigiartiit Health Research Centre
- Karen Henderson, REB Coordinator at Mohawk College
- Joy Knight, Research Compliance Coordinator at University of Prince Edward Island
- Riley Kucheran, REB Member at Ryerson University
- Johanne McCarthy, REB Member at Mohawk College
- Kenna Miskelly, Research Administrator at University of Victoria
- William McKellin, REB Chair at University of British Columbia
- Catherine Paquet, President Canadian Association of Research Ethics Boards
- Amanda Sheppard, Research Scientist at Cancer Care Ontario
- Raven Sinclair, REB Chair at University of Regina
- Chris Turner, Research Ethics Officer at Vancouver Island University

12 https://uqat.ca/recherche/laboratoire-de-recherche-sur-les-enjeux-relatifs-aux-femmes-autochtones-mikwatisiw/
13 http://w3.stu.ca/stu/research/ethics
14 http://www.cihr-irsc.gc.ca/e/2891.html
16 https://www.qhrc.ca/community-research-ethics
17 http://reb.mohawkcollege.ca/
18 https://www.upei.ca/research/research-services/research-certifications/research-ethics-board
19 https://www.ryerson.ca/research/resources/ethics/
20 https://www.uvic.ca/research/conduct/home/regapproval/humanethics/index.php
21 https://ethics.research.ubc.ca/about-human-research-ethics/ethics-boards
22 https://www.care-accre.org/
24 https://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/index.html
25 https://research.viu.ca/research-ethics-board/forms-guides-and-examples
- Susan Zimmerman, Executive Director, Secretariat on Responsible Conduct of Research\textsuperscript{26}
- Dr. Anonymous, REB Member at small Canadian University

\textit{Karen & Johanne (Mohawk College) participated together in a virtual group interview}

\textbf{Consent is a Conversation}

I did my best to embody and enact the principles and values of ethical research in the most inspiring researcher-participant relationships. I was motivated by the innovators who openly and honestly shared their innovations in the spirit of reciprocity and generosity. They freely shared their knowledge and wisdom – complete with their missteps and mistakes – in an effort to give early adapters a starting place. I was moved by the bravery that participant contributors showed as they shared deeply challenging stories with me. I am grateful that the people whose voices are woven throughout this dissertation trusted me with their stories. I am not in the business of attempting to represent anyone. Rather, I re-present a collection of individual and collective stories. I am re-presenting a series of individual stories and conversations, insights and confusions, missteps and successes, in a collective story. It is meant to be reflective not representative. It is a snapshot at this time, in this place in an evolving story.

\textbf{Methods: Processes and Practices}

The research is grounded in and informed by extensive literature (i.e., academic, archival, and grey literatures) and policy reviews to substantiate and complement the multi-methodological (autoethnographic and empirical) data collection. I used

\textsuperscript{26} \url{http://www.rcr.ethics.gc.ca/eng/srcr-scrr/tor-cdr/}
complementary story-generating and story-gathering methods, and I assembled data through autoethnography, interviews, artifacts, and to a lesser extent, observation.

While taking the PhD “scenic route”, my research shifted and evolved alongside some substantial policy and practice changes in the governance of research in Canada. Even since rebooting for PhD (September 2017), I invoked methodological modifications (not all chronicled here) in response to a few of these shifts where they underpin both the contextual and methodological complexities in doing research on research ethics.

During the proposal development for this research, I created (Figure 7), a visual representation of my research model, which draws on multiple models to illustrate the dynamic, iterative, and agile approaches that informed my research practise. This overlapping of multiple related components of the research (i.e., the methods, methodologies, ethics, theories, epistemologies) illustrates a model with no beginning and no end—necessarily and intentionally. It is not a linear process and I have found

Figure 7: Research model
myself anywhere on the spectrum at any moment during research, but my goal was to find myself working from the *ethical space*. Figure 7 contains many elements, and that is the point. This research undertaking was not one that could be simply reduced to a linear model. Caine, Estefan, and Clandinin (2013) show that “[i]nterdependence is not threatening, but rather is the spark for creativity” (p. 580).

This research is inherently interdisciplinary (including inter-methodological, inter-epistemological perspectives) and throughout this study, I was primarily concerned with the integration of those in-between spaces. I continue on my quest to identify, define, and negotiate the *ethical space*. In an effort to assert decolonizing practices in my research, challenging dominant views of what is and is not knowledge, valid, or legitimate, I intentionally chose digital storytelling and poetry as a focal point for this study because it is an excellent method for making the unseen, seen, like illuminating the dynamic energy and particulars of ethical spaces. It is my honour to share the stories graciously offered (and permitted for sharing) with you, in their voices.

**Digital Storytelling**

Though there are many ways research data can be ‘produced’, I was drawn especially to digital storytelling because it “uses digital tools to help diverse people create powerfully compelling and emotionally engaging personal narratives …provid[ing] alternative views and perspectives helpful to demystifying stereotyped representations about Indigenous Peoples” (Mark & Boulton, 2017, p. 3). As Powell et al. (2007) describe, Indigenous digital storytelling, in particular, has “the potential to integrate Indigenous artifacts, sacred places, and stories in innovative new ways undreamt of between the margins of the white page” (p.19). This is not to dismiss the
power of the written word, rather, it is to acknowledge non-written modes of communication and knowledge exchange as similarly valid and valuable. Digital storytelling is used in many settings where conventional research techniques are mismatched or where a clear preference to do research differently is identified. Though REB members and administrators are conditioned to and complicit in documents-as-knowledge, many of the participant-contributors in this study recommended that videos and other visual arts be used to mobilize and translate knowledges as it relates to the ethics of research with Indigenous Peoples (yes, even REB members and Chairs would like a break from reading from time to time).

There are several key components cited about digital storytelling: therapeutic benefits; knowledge translation potential; preservation of cultural heritage, education, training, or professional development; and community development (Cunsolo et al., 2012; Sloan-Morgan, Castleden, & Huu-ay-aht First Nation, 2015). Digital stories are typically 3-5 minutes and use mixed media (voice-over narration, music, and other audio, set to photos and visual artifacts). Often used in a workshop setting, participants create individual stories through collective exercises, sharing experiences, and building skills. Digital stories used for research or for other purposes provide a space for counter-narratives to emerge.

Digital storytelling quickly gained popularity among Indigenous communities: In North America, there are examples of digital storytelling research from the United States (Powell et al., 2007), New Brunswick (St-Denis & Walsh, 2016), Newfoundland and Labrador (Cunsolo Willox et al., 2012), Alaska (Wexler et al., 2013), and British Columbia (Sloan et al., 2015). Globally, Indigenous researchers in Australia (Shay & Wickes, 2017) and New Zealand (Lee, 2009) are also engaging with digital storytelling.
as a research method. Digital storytelling is now widely adapted in many research areas with research partners and participants who otherwise and often have their voices dominated and silenced by others. Globally, there are many examples in HIV research (Willis, Frewin, Miller, Dziwa, Mavhu, & Cowan, 2014), mental health research (LaMarre & Rice, 2016), and disability research (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015). Digital storytelling is also gaining momentum in professional development as pedagogy in disciplines like nursing (Stacey & Hardy, 2011), education (Gachago, 2014), leadership (Wijnen & Wildschut, 2015), and environment (Gearty, 2015). The possibilities of this method in interdisciplinary settings are endless.

**Spoken Word Poetry**

Poetry is the human language that can try to say what a tree or a rock or a river is, that is, to speak humanly for it, in both senses of the word “for.” A poem can do so by relating the quality of an individual human relationship to a thing, a rock or river or tree, or simply by describing the thing as truthfully as possible. Science describes accurately from outside, poetry describes accurately from inside. Science explicates, poetry implicates. Both celebrate what they describe. We need the languages of both science and poetry to save us from merely stockpiling endless “information” that fails to inform our ignorance or our irresponsibility. (Le Guin, 2016, p.2)

My decision to include poetry throughout this dissertation is both organic and deliberate. It is accidental in that I have written poetry since I was around 10 years old, so I have a 25-year data set of poetry to draw from. It is deliberate for all the reasons that Le Guin describes in the opening quote: I do not separate poetry and science, or art
and analysis, or thinking and doing. While I know that the presentation in multiple styles (poetry, digital stories, text) may be daunting to those who are disciplinary and methodologically trained to do one very specific thing, I am primarily speaking to the 16% (innovators and early adopters under the diffusion of innovations curve) who are waiting for a more fulsome discussion and who will understand both the significance and necessity of this approach.

By replacing unfounded, willful opinion, science can increase moral sensitivity; by demonstrating and performing aesthetic order or beauty, poetry can move minds to the sense of fellowship that prevents careless usage and exploitation of our fellow beings, waste and cruelty. (Le Guin, 2016, p. 2)

The spirits of our stories live in the telling so digital storytelling and spoken word provides me an alternative voice in this dissertation and my life that both challenges and balances my academic mind/voice.

Where I’m From
Force fed a single story
Pain and poverty in all its glory
Though a chapter, it's not the book
I found my hook from the way you look when I speak my truths
I'm from the aurora borealis
I'm from the chaos and the balance
I'm from the mountains and the land
To understand a dreamland where the ocean meets the sand
I personify darkness to light
stars in the night
I know I'm alright and I'm not afraid to fight
The power of my ancestors in me
Power and love in equal proportions
Life's distortions
I’m from unnamed dirt roads to the 401
Why am I the one?
Leaving the midnight sun
Doing what I can with that which is undone.
From everyone in my business to anonymity
The proximity of creativity
From strong Bull women,
from generation to generation
From the formation of my own creation
(Excerpt, Digital Story, November 2017)

Data Collection

I described my autoethnographic data set more fully earlier on, but briefly, I have deeply immersed myself in my old note books (from conferences, classes, and conversations) and writings (reflections, responses, and reactions), papers that got started but never finished, random thoughts and scribbles along the margins of influential books and articles, the analytic data from Google Scholar and Twitter – to examine more closely the trends and themes in my own work over the years and in an attempt to map the trajectory of my thinking. There is so much published and unpublished data to support the autoethnographic component of my study.

In addition to over a dozen years of my own archival data through my participation in the conversation and action on research/review with Indigenous Peoples (the autoethnography part of #TheJuliestPhD), I also conducted conversational interviews with participant contributors to gain a better understanding (from multiple perspectives) of what the landscape currently looks like and what we can all do differently to advance the ethical conduct/review of research with Indigenous Peoples.
Conversational Interviews

In conceptualizing this project, my plan was to conduct a national survey of researchers and REB members/chairs but instead I thought a qualitative approach more appropriate to the question under study. It allowed me to stay true to my strengths (and roots) as a qualitative researcher, and led to a ‘storied’ data collection, which is an excellent way to elicit the meaningful conversation and thick, rich description of lived experiences and personal reflections essential to this study.

Informed by Narrative Inquiry, I facilitated one-to-one conversations with a semi-structured question guide (Appendix C) to understand the experiences of REB members and Chairs, and other affiliated, relevant, appropriate people, like REB administrators. Questions were related to their experience facilitating and participating in the review and approval of health research with Indigenous Peoples, and how they are/not applying TCPS2 Chapter 9 with their local REB and in their work. I originally called these ‘interviews’ in my dissertation proposal but found myself cringing when I re-read that proposed methods section, so I have changed the language to more accurately reflect what I actually did – recorded a conversation conducted in-relationship with the participant contributors in this study.

Recruitment for conversational interviews.

It is because of my relationships that the ethics and recruitment stage of this research went so smoothly. My experiences and opportunities in the past dozen years have resulted in numerous relationships with people working to advance the ethical conduct and review of research with humans generally, and with Indigenous Peoples specifically. Some of those relations joined as participant contributors in this study, though I did not have a pre-existing relationship with more than half of the participant
contributors. I did not need to go to a second phase recruitment iteration or strategy. Because of my existing relationships and peoples’ genuine and passionate interest to participate, it took 12 weeks to schedule and conduct 16 interviews. The biggest challenge was negotiating busy schedules.

My recruitment strategy was purposive, selective, and relational. I was already engaged in international, national, provincial, and local Indigenous research ethics on many levels and for a number of years. My network is diverse and robust. I gather relations as I journey and am able to draw on this support system as well as contribute to broader ethics conversations; this was all happening well before September 2017 when I re-engaged with my PhD research. My ‘little black book’ of ethics contacts had grown in a way I would not have imagined in 2008 when I technically then embarked on my PhD research. Now, in 2019, I have a stronger sense of who is doing the work related to research/review with Indigenous Peoples. I was open to all points-of-view and was especially keen to speak with the ‘innovators’ in Indigenous research ethics in Canada. I sent invitations to existing relations – people I knew closely, some acquaintances, and some who were recommended by others (Appendix D).

There were 18 people who participated in this study (six REB members, two REB chairs, five research administrators, one provincial health agency employee, one national REB organization representative, and two policy makers, and me, all connected to research ethics in Canada). This diverse and interrelated network of individuals who participated indicate the interest and commitment at the REB and policy level regarding improving the ways in which institutional REBs review research with Indigenous Peoples. Having conversations with the CIHR Ethics Office and the Secretariat on the Responsible Conduct of Research helps solidify and reinforce the current landscape in
Canada and assists in visioning a collaborative way forward where all the players in research ethics review are dedicated to doing differently. While everyone was invited to, no participants created or submitted an independent digital story. However, 16 out of 17 participant contributors agreed to have their audio used in the reporting of the research and dissemination, and overall more than 20 artifacts consisting of published and unpublished papers, websites, templates, checklists, and videos were contributed by 12 participants (Appendix E: Additional Resources).

Data gathering for conversational interviews.

Most conversations happened virtually using GoTo Meeting and two were conducted face-to-face. I created the detailed consent form and checklist (Appendix F) for participant contributors in such a way that it was clear they were in the driver’s seat when it came to how they and their data were presented in this study. Many participant contributors also provided suggestions of resources they found helpful and thought others might too when seeking to gain a greater understanding of research/review with Indigenous Peoples. My goal was to interview 5-10 people and after more than a dozen interviews, other people were still reaching out to participate. As much as it was hard to do so, I no longer encouraged people to participate in the research after I completed 13 conversational interviews. The final three interviews (policy makers and national REB organization made for a total of 16 interviews, with 17 participants, plus me) served to enhance the conversation and to demonstrate the relationality involved in bringing our innovations to life. Those people who wanted to participate after I finished data gathering were invited to stay connected for subsequent work on this subject, to follow #TheJuliestPhD on Twitter for updates, and to be involved in further discussions about
how we can do differently as we lead from the future as it emerges. All things considered, data collection was a fairly short timeframe for this study. The first conversation was on March 20, 2018 and the last one was on June 25, 2018. The 16 interviews resulted in 922 pages of transcripts and 25 hours of audio files.

The conversations were digitally recorded and then transcribed verbatim by a non-Indigenous transcriptionist – a transcriptionist who was enthralled (yes, that is the word!) with the stories she was hearing as she typed up the interviews. I consider it bonus points that the transcriptionist was so engaged with the topic and the depth of knowledge in the interviews that she created her own follow-up list of resources to check out on the topic! #reconciliACTION

Artifact Collection

I invited everyone who participated in a conversational interview to share any artifacts that they felt were pertinent to their understanding of research/review for research with Indigenous Peoples. This information was also included on the invitation letter, so people could submit artifacts and not participate in an interview (this happened on three occasions where people submitted some documents and links to resources but did not participate in an interview). Appendix E demonstrates some of the key resources that participant contributors offered to this study. I have contributed a number of personal artifacts to this data collection, too (some included in the appendix and several that have contributed to my understanding but are not explicitly listed here).
Observations

I did not subscribe to any strict mode of observational analysis in my study. However, since I work and study in and around academic institutions, it is impossible to separate my daily encounters from my understanding of research/review with Indigenous Peoples. This also includes my observations of government initiatives and media outputs. The general impressions I get when I see comments posted on a racist article online or the comments I hear in passing as I walk through the city. As a white-passing Inuk, I get to hear a lot of ‘what people really think’ about Indigenous Peoples because for some reason people think it is okay to say those things to someone if they do not think they are Indigenous. I have also observed how the funding agencies (namely CIHR and SSHRC) have attached themselves to the reconciliation rhetoric and are advancing their calls for funding to include more targeted research with Indigenous Peoples.

Data Analysis

Throughout the study, I continued to be involved in the conversations and actions regarding research/review with Indigenous Peoples. As much as I sometimes felt that I was living in a snow globe of post-it notes, I was not living in a vacuum. I stayed engaged by delivering guest lectures at both undergraduate and graduate classes on Indigenous research ethics and methods, I presented at the University of Toronto Indigenous Health Conference (May 2018), I attended CAREB in April 2018, I was a keynote speaker at York University Indigenous Research Ethics Workshop (March, 2018), and I continue to build relationships with others who are working in this field.

Though it was not the intention to elicit generalizable data in this study, it is important to reiterate what Igor (Gontcharov, 2016) and others have explained: it is
difficult to find generalizable data on the practice of REBs because of their dynamic and diverse structures. For this reason and others outlined earlier, I used iterative, agile, and reflective means of content and thematic analysis for all data of this narrative inquiry. I employed both descriptive and interpretive analysis as I made constant connections between and among categories and subcategories. I decided not to use software to support this analysis stage of the work and focused on pen-and-paper methods. My home office/dining room with floor to ceiling windows turned into a massive Post-it note repository/gallery and I continuously added reflections, interpretations, and analysis to it from the moment I started PhD 2.0. The amount of Post-it notes grew exponentially as I got to the data gathering and analysis stages and in the height of analysis, about 70% of my living space was full of/decorated by post-it notes. My Post-it note practise, as shown in Figure 8, served many functional purposes, not the least of

Figure 8: Post-It Note progression
which to demonstrate a literal and physical overlapping of key concepts, intentions, worldviews, and perspectives from different people and places.

During the analysis I also learned a name for something I knew I wanted to do in my dissertation – mash up my own writing. *Found poems* are poems that are purposefully created using fragments from different sources. In my case, I used some of my own poetry lines and intertwined them with my academic or prose writing and overlaid them with participant contributor voices. This intentional weaving of a variety of texts from different people in different times and places allow for an integration across boundaries that otherwise lays dormant.

It helps illuminate the fact that these complexities and solutions regarding research/review with Indigenous Peoples is one that is fluid and dynamic and is not bound artificially by the borders and boundaries of institutional constructions.

Through this research process, I had the privilege to co-compose a series of individual narratives and a collective story which is featured in this dissertation. As Clandinin and Connelly (2000) note, narrative inquiry researchers are accountable to the participants and have an ethical responsibility to examine the relationships among us. There was an ongoing negotiation between me and participant contributors. With the exception of Dr. Anonymous, all other participant contributors wanted to have an active role and we engaged in an ongoing dialogue to varying degrees.

**Transcripts**

Participant contributors received an electronic file of their full text transcript to review any sections they wanted to keep confidential, additional comments or suggestions, and identify any errors or omissions. For those who commented on their
transcript, the most common changes were editorial and for accuracy. For example, a word or a name may have been misheard on the audio file so they fixed it in the transcript. Since most of the people in this study agreed to be named, I made sure to include them in an ongoing consent process to ensure that I was presenting their stories in a way that was acceptable to them. It was at this stage of participant review where they also reminded me which of their stories they wanted to be kept confidential and which ones they wanted me to share. My thinking is aligned with Caine, Estefan, and Clandinin (2013) in that “we understand the inquiry as a negotiated research practise” (p. 576). The iterative back-and-forth with the participant contributors improved the transcripts and contextualized stories; it also enriched the analysis as will be discussed more fully in the analysis section.

**Field Texts and Observations**

In narrative inquiry, there are field texts (called field notes in other forms of study). These field texts can be field notes, transcripts, conversations as the researchers sees them as an opportunity to reflect. For this study, I used all of these things and more. My field texts included: a notebook in every bag and room so I could easily jot things down as they came up; a document on my laptop called ‘random reflections’ where I would often write several pages at a time; a note file on my iPhone where I often dropped poetry lines or random ponderings as I was in transit or away from my computer; a hard copy agenda where I took daily and weekly notes of contextual and technical components of my study; a file on my computer called ‘media dump’ where I put all the news reports and articles about what is happening in Canada as it relates to the relationship Canada has with Indigenous Peoples; an email folder with over 500
messages in it from conversations with participant contributors; the random notes people would send me; and all the documents and resources that participant contributors sent.

Data Freak-out

There is plenty evidence that supports the idea that there is a point in time in most PhD candidates’ trajectories where there is a freak-out. It is not uncommon for it to happen after data collection is ‘complete’. The plan is usually pretty straight forward until then. But after you have the data you have got to do something (ground-breaking, innovative, original, world-changing, etc.) with it. There were times when I found myself questioning my own methods, falling victim to the dominant inner critic’s narrative that my data were not “enough”, that somehow this PhD process was all too easy, or I was going to get questioned about doing too little at my defence or any number of ridiculous scenarios. In these moments I would take myself back into the literature that helped shape my methods-thinking and orientation. I re-read Clandinin and Connelly’s earlier work and found solace in the writings of other narrative inquirers.

In Park, Caine, McConnell, and Minaker (2016), Park illustrated the tension that I was feeling:

I had been taught to organize and collate in order to make sense of the research findings. I wanted to keep the messiness and multiplicity that were true to the individual participants and their experiences, but I was concerned that the reader would interpret such narratives as lacking purpose or consequence (p. 10).
Quality and Trustworthiness

My self-appointed ethics-police-certification (and ethics police hat that was gifted to me!) does not preclude me from discussing the importance of the trustworthiness of my research. I discuss triangulation, member-checking, trustworthiness, limitations, restrictions, restraints and all the concepts that mean verification. I have integrated these together in this section rather than describing each element separately because the practice of how I am assuring the quality of the data includes and responds to all those components. The greatest #ethicsendorsement and measure of trustworthiness of the data in this study is that participant contributors are named, and that I am willing to name them. This demonstrates the reciprocal trust in our relationship and enhances the legitimacy and validity of the data through this act of transparency.

Starting on May 1, 2018, I created #TheJuliestPhD on Twitter and used it as an online repository of documents, videos, and other artifacts and dynamic elements that contribute to this study. My agile practice includes the constant (re)questioning of ‘is this ethical?’ as I do my research, and as other narrative inquirers have noted, the sharing of stories and the co-composing of research texts and experiences can be a catalyst for taking/making action. I am documenting my musings on Twitter (i.e., in writing, photos, print, story, etc.) and I am watching the momentum grow in the #TheJuliestPhD community; creating a collection of artifacts (i.e., data) and dialogue as part of being transparent in my work, my influences, and my thinking. This transparency is about my explicit intention to decolonize my research practises and processes in the ways that I can and to demonstrate the possibilities—the very real and rich research—that emerges when we work in these ways; it is not more difficult to do ethical research.
Almost all of the participant contributors were actively engaged throughout the analysis and writing stages of this research. They received the transcripts of their interviews for accuracy and as a means of ongoing consent. This act of member-checking ensured that I was re-presenting the stories and insights from participants in ways that they were comfortable with me sharing. There were no substantial comments on the transcripts. Most of those who responded did so with edits for grammar or clarity or to add an additional example to illuminate a point they discussed in the interview. I continuously engaged in my own reflective practice throughout the entire duration of the study, asking questions to and of myself in the process to ensure the ethical conduct of this study was sound.

Though it was not my intention to generate generalizable information in this study, this lack of interest in generalizability is a criticism of qualitative research despite that not being the purpose or intention behind the practise. Given Nicholls et al. (2015) findings that research examining REBs through engaging the REB members themselves is usually quantitative and has not addressed the contextually-specific nuances and the idiosyncratic nature of the REB within a fluid system of governance, it is preferable that a qualitative study examines and exposes them. Specifically, they maintain that “[q]ualitative studies that include ethnographic methods could help to elucidate decision making models or objects of concern that are not easily or readily accessible through structured quantitative approaches” (p. 12). There are some publications that used qualitative methods to describe researchers’ perspectives of the REB (such as Moore et al., 2017; Sylvester et al., 2018; Sloan-Morgan et al., 2015), but there is an absence of research that describes the perspectives of the REB members themselves.
Knowledge Translation and Exchange

The Knowledge Translation and Exchange (KTE) for my PhD research started long before the PhD 2.0 reboot. Then, in my final course for my doctoral studies (September 2017), I started explicitly discussing this research interest. My data between PhD 1.0 (2008) and PhD 2.0 (2018) provide evidence of my constant commitment to knowledge translation and exchange. In my research, this is not a separate or end point, it is ongoing. Like many, my 2010 publication (Bull, 2010) shows that slow uptake does not mean no uptake. Those seeds I have been planting in my ongoing KTE efforts through publications, presentations, trainings, and teachings continue to flourish.

I have many ideas for my continued efforts in KTE for this work and will continue collaborating with participant contributors to find ways to meaningfully disseminate and mobilize the knowledge-into-action from #TheJuliestPhD. Some of the ideas we have discussed so far include podcasts, digital stories, online training modules, flip books, interactive training guides, webinars, and infographics. To continue my efforts to fulfill academic obligations and to share the information from this study to academic audiences, I will keep presenting and publishing this work. This study was presented at the 17th International Congress on Circumpolar Health in Copenhagen, Denmark in August 2018; a keynote address delivered at Holland Bloorview Research Institute REB Retreat in Toronto in November, 2018; the 4th Seminar of the Ethics of Research with Indigenous Peoples in Val d’Or, Quebec in November 2018; in my lecture for the 2018 Dr. Peggy Hill Memorial Lecture in Indigenous Health at the University of Toronto in December 2018; the Research Atlantic Annual meeting in Halifax, Nova Scotia in December 2018; and in three guest lectures to university classes. It is all about timing, not time. I was reminded of this again as I was nearing the
completion of the writing for this dissertation when I received an invitation from New Zealand to contribute a chapter to a book on Indigenous Research Ethics, by Indigenous Peoples across the globe. I look forward to sharing the wisdom and guidance from participant contributors in that context in the months to come.

**From Research Design to the Collective Story**

I am thankful for the gracious involvement of the participant contributors, their enthusiasm, and their willingness to come along on the journey. Their contributions, coupled with my knowledges and experiences, and the unwavering support of the cast of characters in my journey, have brought me to this point. Now it is time to tell the collective story.

Part of what I hope to demonstrate is how integration in our work can come from unlikely places. It is the integration, the delicate dance, between science and art; the analytical and the evocative; the bringing together of seemingly dichotomous ways of understanding. The space between these disciplines (are there spaces, really?), the places where they overlap, the places where they repel. This space between is complex, challenging, and provocative. And when we start to pay attention, it becomes a space of liberation and a space of possibilities. It becomes a means by which we can do it (whatever it is).

The following chapters may read or seem unconventional because there is an intentional overlapping of results and discussion with a literature review and analysis. This is how I have thought about my research and it is how my research revealed itself. It is my best description of the overlapping I articulated earlier where I explained my theoretical framework. At times, participant contributors’ commentaries are also woven
into the discussion as in other sections. This is about the putting the ‘inter’ in
‘interdisciplinary’ and demonstrating the integration of the viewpoints and voices influencing and involved in my research. It is the explicit overlapping that is essential in
this study.
CHAPTER FOUR: OQALUTTUARISAANEQ (A RECORD OF PAST EVENTS)

Section I: Examining Myself and Storying the Journey

In this section, I highlight parts of my journey in becoming an able human and those moments that are touchstones in my life – experiences, conversations, diversions, detours – that I reflect on and refer back to and that I believe are part of shaping me.

Where I Belong

My heart belongs to Labrador, a connection I cannot explain
a feeling from within, nothing to take in vain
though miles away, my heart is here in this beautiful Land
a sense of community, always a helping hand
We have adopted and adjusted to modern-day life
through years of struggle, challenge and strife
on our pathway to change, we will fight
we continue to move forward, we will unite
Governments come, and governments go. promises broken, make friend over foe
despite circumstance and because of them we grow
…as proud, strong, Southern Inuk Peoples
We will not be silenced, we will not be forgotten
Right here is where I belong
I will continue to sing the song, my home, my life, my Labrador
it is the air I breathe, my life forever more
Constantly and continually, securing my identity
Generations before me, fighting for my liberty
I know where I came from and I know where I am going
My roots firmly planted, continuously growing
Though miles away, my heart is here to stay
The road not taken – we’re creating our own
“We’ve always been here – this is our home”
(October, 2007)

“You will because you can”

Not unlike many people, I experienced countless struggles throughout my childhood. My home life was difficult, and my story is one of growing up remote, poor, Indigenous, with a young single mother. My young mother did her best to insulate me
and guide me through the complex and chaotic reality of my young childhood. School was a place where there was some stability. My mother recalls stories from my childhood where I was so inquisitive and curious and would question everything. It is typical for most children to go through the stage of asking “why” for everything. For me, that was not a stage but was (and still is) a state of mind. Looking back now, I was a philosopher from the beginning. I typically did well at school, and when things got challenging, as they often did, my mother always said, “you will because you can.” She was right. This was/is a mantra for me; her encouragement was/is instrumental in my becoming an able human. She instilled in me a deep commitment to social justice.

“And that has made all the difference”

One of the moments that stands out in my becoming was when I was 12 years old and in Grade Seven. My English class was studying a poem, The Road Not Taken by Robert Frost. I remember most of my classmates staring blankly into space as we read the poem; meanwhile, I was memorizing it as it was read aloud. It really stuck with me.

_The Road Not Taken_ by Robert Frost (1916)

Two roads diverged in a yellow wood, And sorry I could not travel both
And be one traveler, long I stood, And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair, And having perhaps the better claim
Because it was grassy and wanted wear, Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay in leaves no step had trodden black.
Oh, I marked the first for another day! Yet knowing how way leads on to way
I doubted if I should ever come back.

I shall be telling this with a sigh Somewhere ages and ages hence:
Two roads diverged in a wood, and I, I took the one less traveled by,
And that has made all the difference.
I would find myself reciting it over and over again…to myself and to anyone else who would listen. It resonated with me before I knew what ‘resonated with me’ meant. The last line grounds me and runs through my mind when deliberating over decisions: “and I, I took the one less travelled by, and that has made all the difference”. It reminds me that there are lots of choices along the way, and adventures to be had on either road; it forces me to consider the ‘roads less travelled by’ that I have taken and all the difference they made.

“Do the thing which you think you cannot do”

Living out particularly dark moments in my mid-teens, I stopped attending school, even though school was the only place I really found solace at that point. I could be a good student – it was not the school work I was rejecting – I was disenchanted with my current situations and my future prospects. My hiatus only lasted about three months
and I returned to school. When I met with the Principal to explore my options and to determine a way for me to complete my grade “on-time”, he did not think it was possible for me to complete the work in time to complete with my class (#challenge accepted).

**Personal Reflection:** Early into taking on the Principal’s challenge, I doubted myself and worried I had grabbed the bull by the horns too hard on this one. And that is when Eleanor Roosevelt would echo in my mind and I would recite to myself (and sometimes to others…I would also often find myself having to explain to my classmates who Eleanor Roosevelt was): *You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You must do the thing which you think you cannot do.*

I buckled down, I worked hard, and I did pass that year with reasonably high marks. I went on to finish high school, apply for university, apply for bursaries and scholarships, and worked as many hours as I could (often working more than one job) to save up enough cash to pay for tuition (all while still contributing to the household because Mom could not do it alone). I did what I thought I could not and, in 2001, I was off to the “City” – Charlottetown, Prince Edward Island (PEI) and the University of PEI (UPEI). I am certain I made Eleanor proud. However, when I got there I was once again confronted with doing things I thought I could not do. I did not know anyone – not a single person in my life to that point – who ever went to university. Everything was brand new and mostly frightening to my 18-year old self. All I had to guide my way was me as I chose an untrodden path. #foreshadowing
Asiggupâk (Takes Another Path, Goes by Another Way)

I started my undergraduate degree at UPEI in 2001 with my eyes on becoming an ophthalmologist (a dream I had since aged seven when I first got glasses and had some rapid degeneration that the specialists could not figure out or name. Like every determined little girl, I decided that I would figure it out for myself when I got older when I became the specialist!). In my first semester of my undergraduate degree, my required courses were Chemistry, Biology, Math, and Physics. I had the option to choose one elective in that first semester: I choose Philosophy. I had a quirky professor, much like the one you probably imagined in your head when I said I was taking a Philosophy class.

Like many other Indigenous students who have to leave their home to attend university, I found myself struggling to connect in my new “home” and it was not feeling very welcoming at that point. The “City” was a big adjustment; university was also really different than I expected although I am not sure how else I thought it should have been. It seemed I was in over my head and that I questioned my suitability for university. It was easy to let those critics in my head – some of my own inner critics and many of the criticisms from other people that I had internalized – deflate me. Thanks to my mother and her unwavering ability to pick me up when things go astray, she encouraged me to try a different approach in my second semester: namely to pick courses that sounded interesting! Novel concept, right? She reminded me that just because I had my eyes on being an ophthalmologist since age seven did not mean that I had to do that. I could explore different options, and that I did.

With my mother’s encouragement ringing in my ears, I remember lining up to register for the second semester courses. (Yes, there was a time in the not-so-distant past
before everything related to university registration and course selection was electronic). I vividly remember the feelings of fear and excitement as we waited in line, hoping that that person in front of us would not get the last spot in that class we really wanted to take because the only way to get registered was to stand in the line for the class you wanted and hope there was enough room in it for you, too. I was excited to broaden my horizons and I chose a variety of classes solely on what sounded interesting in the social sciences and humanities that semester. I did not really know what social sciences and humanities even was at that point, but I was eager to find out. I enrolled in English, Psychology, Women’s Studies, Philosophy, and something else that I can’t readily recall. It was that Philosophy class – *Contemporary Moral Issues* – that catalyzed the expansion of the brain of Julie Bull.

In that class, we discussed ethical and moral dilemmas related to controversial topics like war, capital punishment, abortion, euthanasia, affirmative action, and pornography. I was enthralled by the discussions and felt like I was picking up everything that quirky professor, Dr. Malcolm Murray was laying down. I attribute so much of my Philosophical foundation to him. He was an exceptional teacher and is a brilliant thinker of ethical theory. I feel privileged to have learned from him in both my undergraduate and master’s degrees.

It did not take long into that second semester for me to know that I wanted to switch my major to Philosophy. My 18-year old self was so excited with this choice. I enthusiastically told everyone I cared about, my friends, peers, mentors, professors, and anyone else who would listen that I was going to major in Philosophy. The only people who shared my enthusiasm were my Philosophy professors. Everyone else questioned my decision and most tried to discourage me from making that choice. “But Julie, what
kind of job will you get with a Philosophy degree?” “How does Philosophy apply to the real world?” “What the hell are you gonna do with a degree in Philosophy?”

I rarely had a satisfactory answer to people who questioned my decision back then because I honestly had no clue what I was going to do, but I never wavered on my choice because what I did know was that it was right for me; I am also stubborn. I was fueled to follow this passion, even though I had no idea what would come next or where it would lead. I have always struggled with the artificial separation of theory and practice that permeates many academic institutions and research practises because this conceptualization of ‘how things are’ never aligned with my worldview. While I was unable to eloquently articulate that back then, I knew that I was starting to find my way, roaming on the road less travelled.

Two roads diverged in a wood, and I,  
I took the one less traveled by,  
And that has made all the difference.27

As I got to the upper year courses for my Philosophy degree, I found myself especially drawn to ethics and ethical theory. Of course, all Philosophy students are required to take at least one or two classes in ethics. It is a major branch of Philosophy, after all, and all the great thinkers discussed ethics at one time or another. I took every ethics class that was offered during my degree. I was obsessed, energized, “lit”, discovering, and learning voraciously. My friends wondered if I had transcended to a different place and time because my thinking seemed different to them as my perspectives were widening and my insights growing. All the while, they would be sure to remind me that “no one pays people to just think about stuff” or “philosophizing about these problems won’t solve them” and #insertyourtropehere.

27 Excerpt from The Road Not Taken by Robert Frost (1916).
I kept doing it anyway. I followed my passion. I followed my gut. I followed my heart. No one recommended this path to me and most people tried their hardest to deter me from choosing it. I am so glad I did not listen to them. I am grateful to my 18-year old self for continuing to take the road less traveled, even against the odds (and against popular opinion) and to my mother for encouraging me to give university one more semester before I threw in the towel in my first year. The spark in me was ignited in that Contemporary Moral Issues class in 2002 and though it has dimmed and flickered in the 16 years since then, the light has never fully gone out. No matter what I was studying, where I was working, or what I was doing, it was all always about ethics. Everything is about ethics; ethics is about everything.

Sunnguvuk (Becomes Strong)

You may write me down in history
   With your bitter, twisted lies,
You may trod me in the very dirt
   But still, like dust, I'll rise.

You may shoot me with your words,
   You may cut me with your eyes,
You may kill me with your hatefulness,
   But still, like air, I'll rise.²⁸

In the summer of 2004, after being unable to secure a seasonal job despite my efforts and employability, I was recruited to apply for a research assistant position. I had some knowledge of the research issue from my studies, and had some research experience too, so I decided to apply. Surprising myself, I got the job and this change in my life course became the new ground from which I grew for the next six years of my

²⁸ Excerpt from Still I Rise by Maya Angelou (1978).
education and employment. That work experience impacted me far beyond technical skills and research methods – it was a catalyst and it nourished me. In doing Indigenous research, I started to be more comfortable in my own skin, as an Indigenous person – as an Indigenous person who is often assumed to be white. This work experience helped me realize how I could (and did) veil myself in the white privilege that my light skin permitted me to have and I was ready to do something differently.

*Where I’m From*

Compassion through interaction
Satisfaction with my own expansion
Extraction, just a fraction of my own distraction
It’s relational not sensational
I take personal responsibility
It’s my own self-advocacy
I have the right to be myself, to love myself. To honor me
It’s all about hope, a slippery slope to learn to cope
My resiliency, my legacy
Reclaiming my identity
(Excerpt, Digital Story, November, 2017)

I am a persistent and passionate person. During my undergraduate studies I attempted many times to bring Indigenous issues, affairs, worldviews into the classroom discussions but it was usually futile. A young 18-20 year-old can only endure hearing so many times: “that’s not scientific” and “that doesn’t really apply here” and “I don’t know anything about that so let’s stick to the topic” before you just stop bothering. I will leave the racist comments out but be sure that I got lots of those, too. Even well-intentioned faculty members have said things like “there are no Aboriginal people here” and “but you’re not like them”.

**Personal Reflection:** With light skin and little of my own cultural knowledge, I struggled with my identity for a long time. I didn’t hide my Indigeneity from
everyone, but it wasn’t something I wore on my sleeve until 2004. A big shift happened for me during that 2004 research assistant job – I was no longer as afraid – the community loved me into being brave. The community members who I worked with gave me the greatest gift: they believed in me, encouraged me, and authenticated for me that I was part of the community. I was not only willing to speak up after that role, I knew I had to. I knew that part of what I was put here to do is to speak up. I had the power and strength of the community by my side and that is invaluable. This was exactly the medicine I needed to be able to continue on my journey to becoming a better researcher, and more importantly, an able human. It was also during 2004 that I had the great privilege to learn from (Dr.) Colleen (MacQuarrie). She was my professor in advanced qualitative research methods and became my undergraduate Honours supervisor. Her encouragement and support to study what and how I wanted was instrumental in my becoming. She helped build a solid foundation for me and my community-based research within an academic setting. We have since become friends and this dissertation has benefited from her review and commentary.

**NâmmaKik (Come at the Right Time)**

In 2005, when I was nearing the end of my undergraduate degree, the Canadian Institutes of Health Research (CIHR) consulted with Indigenous communities and researchers across Canada as part of their process in developing the *CIHR Guidelines for Health Research with Aboriginal Peoples* (2007) and they were in Moncton which was close enough for me to get to. At this consultation, sitting with many Elders and teachers, I had my first experience with applied ethics. I was seeing how ethical theory
was played out (or not) in the development of ethics policies. I was hooked from that meeting alone – seeing how the interweaving of theory and practice was unfolding with the *CIHR Guidelines*. I learned so much, from both the policy and the practical side of things. There were more questions than answers and the complexities of ethics took on a whole new meaning when we started talking about governance of research and the application of research ethics policy. I had no idea as I sat in those 2005 meetings that I would still be thinking, writing, and working on this topic 14 years later. Those years of studying ethical theory as an undergraduate student despite the disdain, disappointment, and discouragement of others, provided the foundation for my future, namely the application of ethics in practice.

In May of 2006, I was just about to graduate with my bachelor’s degree, and I had an abstract accepted for a research conference in Labrador in my hometown of Happy Valley-Goose Bay. That is a rare occurrence when your hometown is in the North. I eagerly jumped at the opportunity to attend the conference, but this choice meant missing my undergraduate convocation. Knowing there is no going back on some decisions, I did not hesitate in choosing the conference over the convocation; I was way more interested in moving into the next phase and learning from the future as it emerged, so to speak, as I felt I was choosing to keep growing instead of behaving as though I had “finished” because I had an undergraduate degree – more like I was just getting started. At the conference, community members and leaders spoke about research ethics and research governance as a key research priority for Indigenous Peoples in Labrador.

**Personal Reflection:** Everything started to align for me – I could see how my Philosophy background was already coming in handy and how the emerging
field of research ethics policy for research with Indigenous Peoples was providing a unique opportunity for me to be engaged in that work. I couldn’t have planned it any better if I tried. As it turns out, I also met Fern (Dr. Brunger) at that conference, who became my Master’s supervisor and remains an amazing colleague, friend, and mentor. I consider myself lucky to have met her and we still work together. What felt like a simple decision to skip my last day as an undergrad and looking fancy in a gown for some pictures started something bigger that I never could have predicted.

Though I did not have much of an answer during my undergraduate days when people would question my choice of a Philosophy degree and do everything in their power to convince me to make a different choice, I knew it was what I was supposed to be doing. And I was right. It laid the groundwork for what I would do in graduate school and is the foundation for all the work I have done since. Now that more than a dozen years have passed, and I look back at the series of events that occurred in the early parts of my career, it makes me wonder if I really had much say in any of it. It all just aligned so well.

**All Ethics, All the Time**

While finding a Master’s program was not easy and I was feeling hopeless at the time I was looking, I now know I won the graduate school “lottery” when I found my program (Applied Health Services Research, 2006-2008, Atlantic Regional Training Centre, University of Prince Edward Island) and the people that I met there. I was most excited back then about the fact that my Master’s degree had the word ‘applied’ right in the title (it has become slightly more common in the dozen years since then but was still
rare in 2006). I was confident that this meant I would be able to do more than theorize about something, I could actually *do* something. I started to put those theoretical teachings into practical application. I worked with Indigenous Peoples in Labrador to discuss the implications for their communities from the implementation of the *CIHR Guidelines for Health Research involving Aboriginal People* (2007).

There were a few other key events that happened during my first year of graduate school. It is when I first sat on a Research Ethics Board (REB) at the University of Prince Edward Island in 2006. I also delivered my first published presentation\(^{29}\) outside of the classroom setting with my peers on research ethics for research with Indigenous Peoples. I was invited to speak at a national gathering of graduate students in Indigenous health; this was to be the first of a few of these events (and presentations) I was able to attend (as per my university requirement, my full CV is attached at the end of this dissertation).

My Master’s program was two years and it was a jam-packed time with so much happening, both in my small circle, and in the broader circles around me. The midpoint, 2007, was particularly notable. I went to Winnipeg to attend the 7th Annual National Gathering of Graduate Students in Aboriginal Health Research: Our Seven Teachings: What We Have Learned, an CIHR-Institute of Aboriginal Peoples’ Health (IAPH) hosted event, and it felt like home. Not the city or the campus or the landscape, all of that was quite unfamiliar to me actually. I felt like home with the students and faculty that I met there and knew I was on the right track. I heard then IAPH Scientific Director,

Dr. Jeff Reading, talk about the advancements being made at the CIHR-IAPH and the commitment being made in research ethics. I was honored that year to receive the Scientific Director’s Award of Excellence for my proposed research examining the 

*CIHR Guidelines for Research Involving Aboriginal Peoples* which I called “Defining Our 'Ethical Space': Labrador Innu, Inuit and Inuit-Métis Perspectives on the Governance of Health Research”. I did not fully understand the magnitude of the work that I was doing.

At that same gathering in Winnipeg, I presented a new paper on the *TCPS* and Indigenous research. Indigenous research ethics was a hot topic in and around Indigenous communities and Indigenous-led initiatives during that year and I had a couple of opportunities to present on it. At this point, in 2007, there was little happening at institutional levels regarding the review and approval of research with Indigenous Peoples. Interestingly, at this time, there were consultations being done on the draft second edition of the TCPS, which now includes a full chapter on “Research with First Nations, Inuit, and Métis Peoples”. It is well beyond the scope of my dissertation to speculate why there was a loss in the knowledge and integration in the transition from the *CIHR Guidelines* to the *TCPS2*. It is important to note that this was happening simultaneously.

Over the years, people I met at student gatherings became colleagues and remained friends. Even all these years later and some of us still work together, sometimes over great distances. I am particularly grateful for the mentorship and peer

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support that these gatherings provided. In retrospect, knowing now what I know about my colleagues’ graduate school experiences, I was fortunate to be among the small group of people doing Indigenous research. I got to meet well-known people before I even knew they were famous. I got to learn from some of the most brilliant minds in Indigenous health research and have become part of a scholarly, spirited, and spiritual family that spans across Canada.

I went on to complete my Master’s degree in the summer of 2008. At that same time, I was working at the University of Prince Edward (UPEI) as a research coordinator and mentoring some of the Indigenous students on campus through a Mi’kmaq health research project. As the project and the summer was coming to an end, they received funding from Health Canada’s Aboriginal Health Human Resources Initiative (AHHRI) for an Aboriginal Welcome Centre, and I was offered the position of Director, just as I was about to move to Halifax and start my doctoral studies at Dalhousie University. A conundrum indeed.
Section II: The 10-Year PhD

Personal Reflection: It all started with that difficult decision: Do I take the job at UPEI or do I commit to a Halifax-based PhD program? I was obviously keen to take on the role at UPEI because I helped build what was starting and had relationships throughout the university and Indigenous communities there. However, I was also accepted to start my PhD in September (2008) and already had a U-Haul rented to drive my things to Halifax and had rented an apartment. I knew I had to pick one or the other – the job in Charlottetown or the school in Halifax.

PhD 1.0: Agguk (Go Against a Head Wind)

After a lot of consideration, I decided to move to Halifax and solely concentrate on my studies. During all my years in university I worked and volunteered (and in high school and even now!) while I was attempting to complete and excel at my studies. It was difficult to manage such hectic schedules and I was ready to make a commitment to myself and my research so moving to Halifax seemed like a nice way to reboot. There was a myriad of factors that led me to that decision but even after I got to Halifax, I thought about the position at the UPEI all the time. During that fall semester in 2008, I was still in contact with several of the Indigenous students at UPEI and I would assist them in any way I could, virtually. Essentially, I was providing some of the supports that students need on campus without actually being on campus. My heart was still in Charlottetown and the work that we started there.
During that first semester at Dalhousie University, I also had the opportunity to guest lecture\(^{31}\). I had just completed my Master’s thesis a couple months prior and people were hungry to discuss Indigenous perspectives on research ethics and I was glad to have the opportunity to engage in those conversations. I was working under the supervision of an internationally known bioethicist and it seemed that the world was my oyster. Yet something did not feel right. It just did not fit. As days and weeks went on and the position at UPEI still was not filled, I went from wondering, to looking over my shoulder, to spending more time thinking about working with UPEI students than I was on my studies at Dalhousie. I decided that perhaps I could find a way to continue working on my PhD AND do the position at UPEI. Surely it could not be any harder than trying to provide support “off the books” while I was in a different province than to actually do it as a paid role.

Many people, including my doctoral supervisor at the time, encouraged me not to take the position. They said it would be “ruining my academic career” and that “those service type” jobs are not looked on highly by “the great scholars” (whoever they are). I was told that I should pick one or the other – working at UPEI OR PhD. I did not know how exactly, but I was determined to make it work and was convinced that I could do both things. It is not unheard of for people to do such a thing. Against the wind I went.

Unfortunately, that determination was not enough to make things work out for me at Dalhousie. I had not planned to be working at UPEI while I was attending Dalhousie and had not organized my PhD studies in such a way as to accommodate working away; the situation was far from ideal to the point I was ready to give up trying

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\(^{31}\) Defining our Ethical Space: Labrador Innu, Inuit, and Métis Perspectives on the Governance of Health Research. (Invited lecturer) Presented to Cross Cultural Health Promotion Research and Policy class at Dalhousie University, September 30, 2008.
to do both simultaneously. I moved back to Charlottetown in January 2009 which meant putting the PhD on the back burner. My academic-self felt deflated, but I was not defeated.

Did you want to see me broken?
Bowed head and lowered eyes?
Shoulders falling down like teardrops,
Weakened by my soulful cries?

Just like moons and like suns,
With the certainty of tides,
Just like hopes springing high,
Still I'll rise.\(^{32}\)

As though to show me that a pathway toward my PhD studies still existed, I was invited to give a special presentation to the UPEI REB in 2009 on the forthcoming TCPS2 chapter on research with First Nations, Inuit, and Métis\(^{33}\) Peoples. This, looking back, was my first formal attempt at sorting through TCPS2 Chapter 9 with an institutional REB. I also was asked to provide a guest lecture in a Sociology class\(^{34}\). These were a couple of signposts along my journey – little occurrences that I could interpret to mean I was on my path, even if it was less travelled – because I thought I was “giving up” or “putting on hiatus” my academic work related to Indigenous research ethics when I took the directorship at UPEI. I know now that it is all related and all connected.

**Spiritual Signpost**: Before the official opening of the Mawi’omi Aboriginal Student Resource Centre, I was gifted an eagle feather by David Varis. He sat

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\(^{32}\) *Still I Rise* by Mayo Angelou


\(^{34}\) *Aboriginal Research Ethics and Engaging the Communities*. (Invited lecturer) Presented to Contemporary Aboriginal Issues Sociology Class at the University of Prince Edward Island, May 19, 2009.
with me and told me of the visions and dreams he had for students at the university and how inspired he was by the work that I was doing. He reminded me that I was on the right path, even if/when it didn’t feel like it. He reminded me of the gifts I have and the importance of sharing them with others. He reminded me that I am not alone, even though it can feel that way as a pioneer and a leader. He reminded me that I was a leader and that I had the power of many ancestors and helpers with me in my journey.

PhD 1.1: “Do or do not, there is no try” 35

After a few months back in Charlottetown, my colleagues supported me in finding a suitable university in Atlantic Canada to resume my doctoral studies. Not quite as smoothly as I am making it sound, everything lined up once again over the summer months. I met a potential new doctoral supervisor through other research work I was doing in the region; all my credits from Dalhousie were transferable; and I finally felt like I could start making headway with my PhD in the fall of 2009 at the University of New Brunswick (UNB). The best part was that I could stay in PEI to work while completing my studies at UNB which meant I could also resume my role on the UPEI REB!

As soon as the September 2009 research funding competition was announced, my new supervisor told me she wanted to nominate me for the Vanier Graduate Scholarship, known as Canada’s most prestigious doctoral award. I hesitantly went along with the idea and did what was required of me for the application process, but I

35 This quote from Yoda in Star Wars: Episode V – The Empire Strikes Back (Lucas, 1980) will likely be the only part of this dissertation that my step-dad reads.
could not imagine for a minute that I would receive this award. Imposter syndrome is pervasive in academia and I was not immune to its effects.

**Personal Reflection:** I was hesitant because I didn’t believe in myself the way that others did. As I was finalizing all documentation at a meeting in Fredericton with my supervisor and the Deans, I laughed on the inside as I thought to myself ‘who do these people think I am? I’m not that stellar of a student and they are going to find out…I think we all just wasted a lot of time on this nomination package…but thank you for the vote of confidence!’ Turns out I actually was considered in that competition and won! I was a recipient of the Vanier Graduate Scholarship in 2010.

During my early days at UNB, I had the great fortune to be introduced to (Dr.) Will van den Hoonaard. When I met him in 2009, he was preparing a manuscript for his forthcoming book, *The Seduction of Ethics*. I remember how inspired I was by him and how much I knew I had to learn from him. I was so excited that I got to read the pre-published manuscript of *The Seduction of Ethics*. As Gontcharov (2016) says, “*The Seduction of Ethics* is a critical study of the current system of ethics review, the system that is based on the biomedical understanding of research” (p. 126). Interestingly, he says, “it is also a self-critical study as it comes from one of the architects of this system” (p.126).

Now that I was running the Mawi’omi Aboriginal Student Centre at UPEI, I got to bring a couple other Indigenous students with me to Halifax in the summer for the 9th *Annual Graduate Student Gathering: In the Spirit of Growing Knowledge* where I confirmed and initiated long-term collegial relationships. This was the beginning of my presentations on the notions of authenticity in research relationships. During my time at
Mawi’omi, I had parallel processes happening: on the one side, I was working to support Indigenous students at university and on the other I was examining research practices. I learned a lot in this work and wanted to share my understanding. This work was also popular in and around Indigenous academic circles and resulted in a series of presentations in 2009.

There was increasing attention being paid to Indigenous research ethics, and initiatives were happening all over Canada to address some of the challenges. I was privileged to have had the opportunity be involved in some of these early conversations and contribute much of my learning on the subject from the Indigenous Peoples I met during that time. I was a member of the Pan Northern Ethics Group with the Arctic Health Research Network and a member of the Ethics Working Group for the Aboriginal Health Research Network. I was all-in on all-things-ethics from 2008 to 2012. I worked on a variety of research projects in multiple roles. Most notably, I had

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the opportunity to work with my home community on the NunatuKavut Community Health Needs Assessment and was a co-investigator on a CIHR grant with Fern (Brunger, 2010-2013). I was excited to continue conducting research on research ethics and we published a couple articles together to share what we were learning in Labrador. I also continued to present work on collaborative research, research ethics, and research partnerships.

Notably, in 2010, I published some of the commentary from my Master’s research in The Journal of Empirical Research on Human Research Ethics (JERHRE). This article – Research with Aboriginal Peoples: Authentic Relationships as a Precursor to Ethical Research – did not receive much attention in that first year or so. In that same year, I also published some of these ideas in other places.

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increasingly involved in research ethics in a variety of ways: I was an education committee member for the Secretariat on Research Ethics where I helped co-develop training materials for Chapter 9 of the TCPS and I became a member of the NunatuKavut Research Advisory Committee.

**Movin’ on up…to Toronto.**

Moving to Toronto at the end of 2010 was the beginning of new adventures, including with my health. I joke that I must have been allergic to Toronto because it was around the same time that I moved here that I fell ill. It would take a few years to diagnose and treat, and dealing with recurrent infections took a toll on my body, mind, and spirit. I stubbornly stumbled through 2011 as I attempted to work on my PhD while my body was screaming at me to take a break. I finally officially did so in 2012 when I took a medical leave from my doctoral studies. However, as I look back now, it turns out that 2012 held some really important moments and events that are central in this story. Despite being sick I was in/on the scene.

In the spring of 2012, I attended the Canadian Association of Research Ethics Board (CAREB) annual meeting where I represented the research team I was working with examining our research ethics processes in NunatuKavut with a poster presentation (Appendix G). I remember being particularly struck with the words that people were using to describe our research as I stood nervously by our poster. They were describing our work as innovative, outstanding, ground-breaking, exceptional,

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*IPY Legacy: From Research to Action*. July 11-16, 2009 Yellowknife in Canada Circumpolar Health Supplements (7), 410-413.

novel. I felt an honest confusion at first, wondering how it was possible for all of these highly educated people who work in research ethics to think what we were doing was so exceptional. As I observed the audiences over the next days and listened to presentations, my confusion turned to contemplation and by the end of the conference, I had a newfound insight into the realities of research oversight and I started to see why others thought our work with NunatuKavut was so innovative: we worked together as a team on a shared priority. Novel concept.

In September 2012, (Dr.) Fern (Brunger) (and others) hosted the Aboriginal Health Research Ethics Workshop in my hometown of Happy Valley-Goose Bay. I was delighted to be invited as a keynote speaker for that event alongside Doris Cook. At this point, the provincial legislation on research ethics in Newfoundland and Labrador was brand new and we were still working out how to apply it in practise, so we convened a workshop to talk about it.

As was/is often the case in the workshop, the other presenters talked about some of the challenges and difficulties, while I took the time to talk about the possibilities and opportunities. I am forever the grand optimist and despite all the challenges and obstacles and the reasons why something might not work, I am always keen to talk about and find the thing(s) that will. We will never have it all figured out and when we think we have figured most of it out, something new comes along for us to address. It is the ability to adapt to this that I feel has been one of my greatest strengths and I extend gratitude that I have been able to refine that skill, especially in the face of adversity and even when it means standing alone. In fact, this may be the only way change is ever

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initiated and I can see how my ancestors persevered so that I could be here to do this important work now.

From the Happy Valley – Goose Bay meeting, several of us collaborated to write an article called *Animating the Concept of Ethical Space: The Labrador Aboriginal Health Research Committee Ethics Workshop*. I am so fortunate to work with people who are the *doers*. Though many of us also like to indulge in a good old-fashioned think-tank (myself included), it is the actions that follow that really mean the most. I learn so much from watching other people negotiate that and am glad that I am able to contribute to action-oriented work that is being picked up, imitated, and integrated in lots of places and spaces and for lots of reasons.

Perhaps one of the most influential meetings that I attended in 2012 was the International Ethics Rupture Summit: Exploring Alternatives to Research Ethics Review at UNB. Will van den Hoonard (the one who seduced us with his ethics book) was the principal organizer of the event and I had the great privilege to be invited to this international summit. I presented on our ongoing work with NunatuKavut and discussed some of our emerging solutions to common challenges as the Health Research Ethics Authority was well underway in my home province. I offered some of our key learnings as a way out of the muddle and was the only presenter who spoke specifically to research with Indigenous Peoples. It was a captive audience and I met some brilliant people there. I met people from several countries who were as into #dorksports as I was,

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and specifically about research ethics! And despite the great variance in our disciplinary backgrounds and research interests, we all had one thing in common: a desire to ensure research ethics review for non-biomedical research aligns with the ethics and the methods of those non-biomedical research paradigms.

I remember being picked up at the Fredericton airport for the Ethics Rupture (2012) by a lovely grad student who was fanboying over my 2010 paper. That never happened to me before. I was not aware that people were actually reading my work. I had no expectations for that first publication, and I thought my paper would be treated like most Master’s level papers, as a building block but not academically valued much more than that. I remember struggling a bit with the idea that people were starting to know me, when I did not know them. People would recognize me, but I wouldn’t recognize them.

Though I met many people at the Ethics Rupture who I learned from and who helped shape my thinking and understanding, one in particular was Dr. Igor Gontcharov (a doctoral student at the time) and someone whose recent PhD work I highlight in several sections in this dissertation. At that time, he presented on the shift of language in the TCPS 2 from ‘research subject’ to ‘research participant’ and I was enthralled with the discussions that followed.

I also attended the International Polar Year (IPY) in 2012 which is where I learned more about the Association of Polar Early Career Scientists (APECS) and where I delivered both oral and poster presentations45 to a wide-ranging audience. I remember

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• Martin, D., Bull, J., Graham, J., Moore, C., Baikie, G., Reading, C., Wien, F. (2012). Teachings from our Learners: Graduate students’ experience with funding support from the Atlantic Aboriginal Health Research Program. Poster Presented at the International Polar Year Conference, Palais de
being overwhelmed by the size of this conference and simultaneously intrigued that I was meeting people from all over the world who were conducting research in the polar regions. Suddenly the magnitude of the importance of the work that I was doing was evident to me. I was sitting at IPY with predominately natural and physical scientists from mostly non-Arctic countries. I learned of so many researchers who had conducted research in the Arctic for decades and never built relationships with the local people. I started to see firsthand some of the international politics at play regarding Arctic sovereignty and resource extraction. I could hear people talking about the role they all thought they played in what happened to the Arctic. None of those people were actually from the Arctic.

My optimistic self was brought down a notch or two as I was making these important connections; however, I did not let that be the conquest. Instead, since I had all this free time on my hands now that I was on sick leave (I probably should have just rested constantly perhaps, but I believe staying engaged helped me during that time) and volunteered with APECS, so I could learn more about how the international scene operated and to meet like-minded people who are engaged in research in the Arctic.

Avalappuk (Boat is driven off course).

In January 2013, while still managing a chronic undiagnosed health issue and being on medical leave from my PhD, I started working at an Indigenous-led research and policy organization in Toronto, the Toronto Aboriginal Support Services Council (TASSC). It was an interesting experience for me to take what I learned in university and in doing community-based research, and to be able to work with the Toronto Congres, Montreal, QU, Canada. April 22-27, 2012
Indigenous community to apply all of it in practice. There was a lot of reciprocal
learning happening (and my learning curve was steep because it was my first time
working in an Indigenous context in Toronto. I was also learning the histories and the
cultures and the politics of the local nations while also trying to get a handle on my new
role).

**Personal Reflection:** By now, I had spent almost three years being sick and still
there was no diagnosis. No prognosis. No anything. It was early days in 2013
when I was called back to see another specialist for results. I remember sitting in
the waiting room and I hoped and prayed for an answer. At this point, I didn’t
care what the answer was. I knew that I could deal with whatever the diagnosis
was. I was less sure that I could handle another ‘we don’t know, but it’s not
<insert weird random disease>’. I was relieved to learn that day they finally,
after nearly three years of being sick, found the issue and they could solve it – it
just required getting a nephrectomy – I literally had to make a flesh sacrifice to
continue on my journey. Everyone says they give their blood, sweat, and tears to
their PhD and I just took that to a whole other level. I was going to have a kidney
removed and I needed ânniasiuutik (medicine) to help me heal.

This was a particularly difficult time in my life – of course, when we are in these
moments we carry on and can only reflect on the extent of the difficulty when they have
passed. But now I can see I needed healing of all kinds. The old ones always remind me
that there are some lessons that keep repeating themselves until we learn them. “There
are many symptoms to the broken life syndrome and if the reasons for these are not
addressed, they re-cycle and keep coming back, even though we thought they were
resolved” (Akpaliapik Karetak, 2017, p. 204). I have come to see (with love) the impacts
of some of my life events and the impressions and scars and lessons and blessings they offered me on my journey to becoming an able human.

As One

Philosophical discussions with the plants and the trees
some people call this a chronic disease
it’s the gentle breeze from the seven seas
that keeps me where I want to be
the rain is penetrating
and you’re speculating
for me it’s resonating
and now I’m celebrating
The wind speaks to me, it’s lover’s delight
I’ve become the moon on a cloudy night
Don’t put traffic lights on my human rights
I can re-write the black and the white
Nature’s spirit is everywhere
you’re unaware that it’s a love affair
life in solitaire, the electric chair
they can repair some of that despair
As one with the ocean, the sky, and the earth
it’s a re-birth of my own self-worth
Virtual reality is my morality
it’s the mentality of neutrality
The universal laws are probable cause
to believe in a higher power
(September 2015)

PhD 1.2: Finish or bust…or not

After returning to my PhD from medical leave in Fall 2013, one kidney lighter, my earlier supervisor before I went on my leave had retired, and I was left to sort out the logistics of my doctoral committee on my own. Despite my best efforts and having two leading Indigenous health researchers willing to work with me at two different institutions, nothing panned out. After a year and a half of valiant attempts to make my PhD dreams come true (and paying tuition for three semesters and not making any
progress on the degree), I decided to stop being so stubborn and I officially withdrew from my PhD program at the end of summer 2014 because I had not advanced and it was costing me money (my Vanier funding had ended and being a recipient of this award made me ineligible to apply for most other funds).

Even though I officially withdrew from my PhD studies, the universe clearly did not get the memo and I was still finding myself doing all kinds of academic work. There was no formal data collection or active research activities nor was there any deliberate or intentional methods in my approach. I decided to focus on other (related) areas of inquiry and spent the next few years working on various projects and initiatives, all related to research and ethics, but in a less direct way. These experiences enhanced my understanding of ethics-in-practise.

I was invited to give three talks in 2014\textsuperscript{46} and the one that really stands out to me is the 3\textsuperscript{rd} Seminar on the Ethics of Research with Aboriginal Peoples at Université du Québec en Abitibi-Témiscamingue in Val d’Or, QC. If memory serves, this was the first time that I was an invited keynote speaker at an event where I did not know the organizers (or know someone who knew someone who had recommended me). It was now through word-of-mouth and my publications that people were coming to know me; this was new and something I had to adjust to random strangers coming up to talk to me about my work, even fangirl/boying on occasion. So weird then, and still weird now.


I continued and ramped up my level of volunteering with APECS and travelled to Helsinki for the Arctic Science Summit Week (ASSW) in 2014 where I co-hosted a full day workshop connecting Indigenous Peoples in the Arctic with Early Career Researchers. My colleague (Dr.) Sandra Juutilainen, and I published a short commentary\textsuperscript{47} after the meeting. It was also in that year that a collaborative article I was part of was published in the \textit{Canadian Journal of Native Studies}\textsuperscript{48}. Even though it has a 2014 publishing date, it was written several years prior, so it was a bit funny to read bits of my own story in there that already seemed so distant after a couple of years had passed; my autoethnography is about attempting to name some of my shifts, adaptations and reiterations throughout this PhD journey.

\textbf{Maujagak (Jump from ice-pan to ice-pan).}

I have fond memories of looking out the living room window in my childhood home, out into the Atlantic Ocean. Spring was always my favorite view because there were ice bergs and ice pans\textsuperscript{49} as far as the eye could see. I remember the fun of jumping from ice-pan to ice-pan, carefully calculating each move so as not to make a mistake and fall. Never certain of what step is next and always ready to jump and land safely in any direction. There is a sense of freedom. Of autonomy. Of being centred with nature. “No one ever tried to stop us [despite what you read in the media about this, it is a contemporary rite of passage in the regions I grew up]. Instead, we were encouraged to learn the techniques and then to improve by practising” (Uluadluak, 2017, p.158).

\textsuperscript{49} Ice pans are pieces of ice that have broken up from the larger ice and float independently
Becoming an able human meant and required practical and experiential learning. It was not to be like an egg or a stone but rather to be sensitive and strong, simultaneously. I had not yet received any of the teachings of IQ so it took time to (un)learn.

**Personal Reflection:** In the summer of 2015, I found myself between jobs with no immediate prospects on the horizon. Normally such uncertainty provoked anxiety for me, but something was different this time. I felt calm, liberated, and eager for new adventures. My friends weren’t sure if I was in denial or delusional, but I knew that I was right where I was supposed to be. I had no great prophecy of what was to come, I didn’t know what my next job would be, I didn’t even know if I’d stay in Toronto. All I knew was that everything was going to work out and I just needed to trust that my journey was unfolding just as it should.

Only a few weeks passed before I was offered a sessional teaching position at the University of Toronto in the Indigenous Studies Department to teach Indigenous Health Systems (ABS 350). I was excited to get this opportunity to be in the classroom and found myself settling into the role quite naturally. I realized that some of the same things I loved about being a student were also the same things I loved about being the professor. This was especially evident in my passion for challenging perspectives and pushing boundaries/innovating.

Clearly my efforts to distance myself from academic work were not effective as I found myself immersed in academic endeavors in ways I never imagined possible without a university affiliation. I was engaged in projects on evaluation, governance, community-wellness, and was designing and delivering training on engagement and relationship-building. I guess it makes sense why it is increasingly common for people
to assume I am already Dr. Bull, which I have been introduced as (and had to correct) for a few years now. Who else in their right mind would spend so much time and energy working on academic initiatives if it is not actively contributing to a degree or to a paying job? Me, that’s who. #dorklete. I guess some (quiet, sensible) part of me knew I would find myself back in my doctoral studies and that I was just taking my own path to get there. That (much wiser) part of me was definitely not in my conscious thought; it was not on my active ‘to-do list’.

TaKuatsaK (What is to be a provision for a journey).

Remember Fern Brunger from that first conference I attended and presented at instead of going to my undergrad convocation back in 2006? We collaborated together a lot in the years since then on various community-based projects in Labrador. From our collaborations and shared reflections together, Fern and I worked with NunatuKavut to co-author a paper in 2015 for the Toolbox of Principles for Research in Indigenous Contexts: Ethics, Respect, Equity, Reciprocity, Cooperation and Culture. This particular publication coincided with the Ethics Seminar at UQAT where I delivered a keynote at the end of 2014. I was grateful for that invitation and was keen to contribute to the toolkit as a means to share from the experiences that I had been having working in research/review with Indigenous Peoples. I was finding ways that I could ensure that I was giving back to the communities and people I serve as opportunities presented themselves to me.

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One of the people I met at the *Ethics Rupture* in 2012 (Martin Tolich) invited me to deliver a keynote presentation at the *Ethics in Practice Conference* at the University of Otago in Dunedin, New Zealand in 2015\(^5\). This was another of those pivotal moments in my understanding of the ethics of research with Indigenous Peoples and it was an exceptional experience to see how it was playing out on the global stage. It was also a moment of knowing I was on the right track when someone was inviting me (on their expense) to visit New Zealand to give a talk! Suddenly the work that seemed so isolating as I sat by myself in Canada was making international connections and my relationships started to bloom. I remember having dinner with Martin and the other keynote speakers when I arrived in Dunedin and one of them mentioned being at a meeting the previous month with Jeff Reading and he asked if I knew him. I was pleased to say that I did. I was reminded that the vast geography that spans Canada does not preclude the closeness of the Indigenous Health Research community that crosses all boundaries.

My excitement for travel and opportunities for relationship building and delivering conference presentations continued in 2015 and I attended two important international meetings\(^5\). It was the third time I attended the International Congress on Circumpolar Health (ICCH) and the second time I attended the Arctic Science Summit.

\(^{51}\) *When Two Worlds Collide: Ethical Quirks and Quandaries in Research Involving Indigenous People.* Presented at Ethics in Practice Conference, University of Otago, Dunedin, New Zealand, May 22–24, 2015.


Week (ASSW). There was always a marked difference in the two events and while I was grateful for all the opportunities and the learning that came from both, my preference was, and still is, with the ICCH. In that same year, 2015, efforts from the collaborations of nearly a decade between NunatuKavut and Dr. Fern Brunger garnered attention from Memorial University of Newfoundland when we received the President’s Award for Excellence in Community Engagement\textsuperscript{53}.

**To PhD or not to PhD, That was the Question**

There were several valiant attempts on my part to make the PhD undertaking work for me again during 2015 and 2016. Meanwhile I was also working, including teaching distance courses through the University of Victoria School of Public Health and Social Policy\textsuperscript{54} and doing consulting work on training, evaluation, board governance, and ethics oversight. In the fall of 2016, I even visited Harvard as part of my effort to find a PhD program that was best suited to me, enjoying a short holiday to Boston and Cape Cod only to learn that the PhD in Health Policy with a focus on research ethics that I was so excited about at Harvard was not accepting applications for the upcoming academic year. Well, there you have it. I tried. I tried so many things and I finally realized that it was time to put that PhD thing back to bed for the time being...again.

If you really want to do something, you should not give up until you reach your goal...and you cannot learn enough just by words. You also must experience and practise. (Uluadluak, 2017, p. 163)

\textsuperscript{53} https://www.youtube.com/watch?v=IvKq4SI_DvI
\textsuperscript{54} Inter-professional Practice (HLTH 404); Engaging in International and Global Health Development Work (INTS 461); Indigenous Health Research Methods (INGH 522); Wise Practises in Indigenous Community Health (INGH 453)
Later in 2016, a fruit of my labour was born when a chapter I authored was included in the publication of the _The Ethics Rupture: Exploring Alternatives to formal Research Ethics Review_ with Will (remember him?). I was reminded of all the time that Will had given to me by way of encouragement and editorials. I was reminded how powerful mentorship is. I was reminded how important it is for all of us to have someone like Will on our side. He was tirelessly patient with me as I struggled to write that book chapter in 2013/2014 while I was sick and had my nephrectomy. He believed in me when I did not/could not really believe in myself and he stood alongside me and held my hand every step of the way to ensure that I was included in that book. Though I am sure that everyone’s first book chapter is special to them, I do feel that this one for me holds an even more important place. It reminded me that I have people on #TeamJulie and that is invaluable during those moments when we do not really have it in ourselves to be our own cheerleaders.

At the same time, 2016 (post-Truth and Reconciliation Commission (TRC) era) was characterized by increased attention on all-thing-Indigenous. There was also an increased frequency and diversity of speaking/training requests that I received. Specifically, the _invitations_ for me to speak about research ethics began to substantially increase in 2016 and 2017. Ah, finally, people were ready to talk about it!


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My intention with the lists of talks here (and in footnotes) is to show the depth and breadth of my experiences and the variety/types of conferences/meetings invitations I receive, highlighting the ones I agreed to attend/deliver. This is not meant to sound arrogant or boastful. Along with all of the invited talks, I delivered a number of peer reviewed presentations in 2016/17 as well56. I also started actively collaborating more

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with international colleagues during this time. I needed to do something to contribute and to help elevate Indigenous voices in these venues even though I was not working at a university or leading research; I could not stay away, and they kept inviting me!

**Spiritual (re)Direction**

Then, at the end of 2016, I got an unexpected call to work with Dr. Renee Linklater at the Centre for Addiction and Mental Health (CAMH) as a Research Methods Specialist, specifically to work on systems-level strategies to enhance the policy and practice of research with First Nations, Inuit, and Métis with researchers across the CAMH hospital. She whispered sweet ethics everything in my ear and I could not say no. I was already committed to a few small contracts and negotiated working part time at CAMH until I was able to finish up my consulting projects and commit to

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- Bull, J. (2016). *Natural extension to self-governance: Regulating research through relationships*. Presented at Inuit Studies 20th biennial conference, Memorial University of Newfoundland, St. John’s, Newfoundland & Labrador, October 7-10.
- Zaika, Y., Fugmann, G., Vlakhov, A., Bull, J. (2016). *Gaining a better understanding and awareness of the Arctic through education and outreach*. Session convened at the University Arctic Congress, St. Petersburg State University, St. Petersburg, Russia, September 12-16, 2016.
working there full-time. It did not take long for me to see the possibilities to impact large institutions like CAMH, and I was up for the challenge.

Remember that I had put the PhD completion to bed just a few short months before as I was done trying. Then my position at CAMH, coupled with the encouragement from my leadership team, made me reconsider taking that PhD back out for a spin. Again, I spent substantial time investigating my options – what programs are best suited for me? Who will supervise me? Will I need to move? Should I find the program that is best for me instead of trying to fit myself in other program’s boxes? Will the program of my choice even accept my previously completed coursework?

**Personal Reflection:** One day in spring of 2017, fewer than six months after I started working at CAMH, walking with Renee to get lunch on a cool rainy day, I recounted to her the perils of finding a suitable program, institution, and supervisor to complete my doctoral studies. Then she said the most profoundly simple thing: ‘can you finish it where you started?’ This felt like a lightning bolt. What an innovative concept, right? We laughed together. And I started really thinking about the possibility of picking up where I left off in the program that I started in. I was filled with a new cautious optimism – a little breeze caressed the coals of my PhD fire – and I felt that things would work out this time as I heard Mom echo in my mind: ‘third time’s a charm’.

**PhD 2.0: Ommak (Come alive)**

I reunited with my doctoral research in September 2017 and while it took us a little while to get reacquainted, it has been one heck of a ride since. For people who have only known me in the past couple of years, they think that I am doing the world’s fastest
PhD. Then I remind them that I started this whole thing in 2008 and it is now 2019.
There is nothing fast about this 10-year PhD. It is both fast and slow and I would not have it any other way. Some may view my PhD journey as “rocket-speed” and “way too easy”; it is/was neither of those things. This does not acknowledge my ongoing work and engagement in my research area while I was not formally enrolled in a PhD program, nor does it reflect an understanding of how actively and deeply I engage with my relationship with myself through my reflexive practise, and that I never stopped doing this even though I stopped paying tuition.

When I re-enrolled for September 2017, I was committed to my study and determined to complete degree requirements in that semester which would allow me to begin my research in January 2018. That meant that I had to take a course, write and defend two comprehensive exams, and write and defend my research proposal, all while working full time. No problem. On December 15, 2017, I spent a day in Fredericton on the UNB campus where I successfully defended two comprehensive exams in the morning and my research proposal in the afternoon. It was a marathon semester with a marathon defence day and I had enough people on #TeamJulie to make it all possible.

I sometimes question the applicability of my academic work to my family and my community. Then, in November 2017, I was honored to receive the acknowledgement as a Labradorian of Distinction (given based on nominations from fellow Labradorians) reminding me that the way I approach my academic pursuits is raised up by my family and community and it is because of their unwavering support that I am able to do the important work that I do.
Akunngani (Between them, amid them, among them).

I am still a Research Methods Specialist at the Centre for Addiction and Mental Health, Canada’s largest mental health and addiction hospital; I worked full-time for the duration of PhD 2.0 and managed to squeeze out a few contributions along the way. In March 2018, I received an Emerging Research Scholar Change Maker Award\textsuperscript{58} from the Ontario Ministry of Education. I published two papers, both open access and readily available online\textsuperscript{59}. And even though I could not attend in person, I was also the lead convener on a session\textsuperscript{60} at Polar 2018 in Davos, Switzerland. I decided to focus my ‘extra’ energy on my doctoral studies in 2018 so I have forgone these international meetings.

Mapiatilippâ (Put on so that it overlaps).

I learned two things very early on in my Philosophy days: 1) the more I know, the more I know I do not know; and 2) everything to be known is already known; it is only in the integration or the matching or the collisions of that which already exists that we can create something new. For many of the early years in my academic career, I held strongly to my imposter syndrome. It did not help that it seemed what I was doing and saying was such common sense and yet the messages I was receiving was that it was innovative and ground-breaking. I can see now that it is actually both those things – old

\textsuperscript{58} https://event-wizard.com/OERSCORE2018/0/pages/107392/
sense and innovation – simultaneously. I am simply overlaying key components of what I’ve learned in a way that makes sense to me in the practice of research ethics. The key is in the overlapping of existing ideas.

So, when I write and talk about research ethics for research with Indigenous Peoples, it comes from more than a superficial or cursory description of the complexities. It comes from more than a dozen years of thinking, talking, writing, analyzing, observing, participating, and practicing it in all the ways mentioned so far. My passion for human protection in research and specifically the governance of research involving Indigenous Peoples fuels my desire to learn as much as I can about the topic, from as many perspectives as I can, through the stories and insights from as many enthusiasts as I can. We must turn the gaze inward, individually and institutionally. This dissertation is my attempt to synthesize some of the complexities in research/review with Indigenous Peoples and share some of the collective teachings from the participant contributors who have joined #TheJuliestPhD.

Now that I have shared a record of past events as it relates to me and my relationship to research ethics, I will describe the record of past events as it relates to the development of research oversight in Canada. The following section explains both the general research ethics policy development and the specific Indigenous research ethics development that has been happening simultaneously.
Section III: Research, Regulations, Governance: Development of Research Ethics Oversight in Canada

The regulatory space of research involving humans is a highly dynamic field, and a place of significant tensions caused by the challenging political economy of the globalizing – postcolonial and post-industrial – world, process in biomedical technologies, interdisciplinary structure of science, corporate interests, and the changing character of risk. (Gontcharov, 2016, p. ii)\(^{61}\)

As this entire research project is about the operation of research ethics regulation(s) in Canada, we must reflect on the history of research ethics and how we got where we are, today. In this section I present a record of the development of ethics policies in Canada, highlight key events and factors, and bring it all together to contextualize where we are in the conversation in 2018/2019. The participant contributors in #TheJuliestPhD reflected on this history during our conversations and I include their voices alongside my commentary to further validate what is well-documented in the literature, and to demonstrate how these long-standing challenges, issues, tensions, and barriers remain unresolved.

The landscape of research ethics in Canada developed significantly from the 1970s to the late 2000s, but prior to the late 1970s there was very little discussion about the regulation of research involving humans. In 1978, in the wake of the release of the Belmont Report in the United States (which was in response to the infamous Tuskegee

\(^{61}\) I recommend reading Igor’s dissertation, specifically Chapter 1 for the key conceptual limitations of perspective ethics review as a means to inform revision of TCPS2 and the practice of ethics review more generally: [http://digitalcommons.osgoode.yorku.ca/phd/30/](http://digitalcommons.osgoode.yorku.ca/phd/30/)
Syphilis Study), both the Medical Research Council of Canada (MRC), which is now CIHR, and Social Sciences and Humanities Research Council (SSHRC), issued the first ethics guidelines as an attempt to introduce standards of research ethics in Canada.

The MRC revised its Guidelines in 1987 (Interagency Advisory Panel on Research Ethics [PRE], 2002), and shortly after, in 1989, the National Council of Bioethics in Human Research (NCBHR) began to conduct site visits of Research Ethics Boards (REBs) across Canada to gain an understanding of the level of compliance with the MRC Guidelines (Kinsella, 1997). In 1995, NCBHR published the results of those visits and demonstrated that the MRC Guidelines were not being utilized as intended and that there was a lack of consistency in REB procedures and processes. It was concluded that there was need for greater regulation of REBs and research ethics in Canada in general. Further, the emergence of genetic research practices and possibilities (i.e., “designer” medicine, anyone?) increased dialogue on the ethics of genetic research, specifically as they relate to socially identifiable populations (Kinsella, 1997), including Indigenous Peoples.

In 1994 the Tri-Council Working Group (TCWG), with members from CIHR, SSHRC, and NSERC, was formed to review and revise ethics guidelines for research involving humans. They produced and published four seminal documents: an issues paper in 1994, a discussion draft in 1996, a final report in 1997 (PRE, 2005), and a final policy published in 1998, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al., 2014), which, since then (and with some revisions over time), is the ethics framework for all research conducted in Canadian public institutions or supported by public funding agencies.
While the NCBHR and TCWG did their reviews and revisions in the early/mid 1990s, the parallel process of the *Royal Commission on Aboriginal Peoples* was underway where over 350 research projects were commissioned (Indian and Northern Affairs Canada [INAC], 1996), including research on the ethics of research involving Indigenous Peoples. They proposed guidelines for research with Indigenous Peoples, which included respect for the culture, language, knowledge, and values of Indigenous Peoples. The Royal Commission stated that “Aboriginal peoples have distinctive perspectives and understandings deriving from their cultures and histories and embodied in Aboriginal languages [and therefore] research that has Aboriginal experience as its subject matter must reflect these perspectives and understandings” (RCAP, p. 2). The important contribution of RCAP with respect to research with Indigenous Peoples, then, was the caveat that a blanket approach to research ethics and health research in general was insufficient and that specific guidelines for research with Indigenous Peoples had to be co-created by researchers and communities in a respectful, relevant, reciprocal, and relational way. I emphasize this section because we are still, in 2018, advocating that a blanket approach to research ethics in general, and in Indigenous research in particular, is not sufficient. Participant Amanda Sheppard has been working in research with Indigenous Peoples for many years and is currently a Lead Scientist in the Aboriginal Cancer Care Unit at Cancer Care Ontario. When we spoke, she reiterated the necessity to tailor research/review to the specific community and to be aware of the implications that our approaches take.

First, I need to recognize that there are different groups with different priorities, so a research question may not be relevant for one group or another, or they may

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62 This is not to say that every research project is required to incorporate spiritual or cultural components. For example, a study designed to identify the prevalence of a chronic disease may not explicitly refer to the spirit world. However, Indigenous Peoples are connected to spirit, and it will become part of the research whether the researcher anticipates it or not.
not be in a position to act on any findings, so it might not be the best timing. So, I just always be considerate and try to be as inclusive as possible, but make sure it's relevant. So, for instance…when we're tailoring [a project], we're tailoring it with Inuit, and then we're tailoring it again with First Nations, and then we're tailoring it again with Métis because those groups have very different experiences in the healthcare system. (Amanda Sheppard)

The first edition of the TCPS (CIHR et al., 1998) provided no specific guidance on the ethics of research with Indigenous Peoples, rather, a placeholder (Section 6) noted insufficient consultation had occurred with Indigenous Peoples, and the authors felt it was pre-mature to write policy without appropriate consultation. This acknowledgement was reflective of recommendations outlined the release of the RCAP final reports with four volumes (INAC, 1996). The placeholder mirrored the emerging dialogue on research with First Nations, Inuit, and Métis and was meant to be the beginning of a conversation about how to work through the complexities in practise.

While all of these government-led initiatives were rolling out, Indigenous communities were also mobilizing to assert their inherent right to self-determination in relation to research. The movements toward Indigenous Peoples’ self-determination in Canada and elsewhere around the world (Sium & Ritskes, 2013; Smith, 1999) provided a roadmap for Indigenous communities to develop their own research/ethics review processes and procedures. Two of the longest standing Indigenous community-based ethics review systems in Canada can be found in Kahnawá:ke (Code of Ethics, 1996) and Manitoulin Island (Guidelines for Ethical Aboriginal Research, 2001) (Appendix H shows an example from Qaugiartiit Health Research Centre Reviewer Health Research Ethics Checklist). As well, a significant contribution of the Steering Committee of the First Nations Regional Longitudinal Health Survey was developing OCAP®: the principles of ownership, control, access, and possession as “an expression of self-determination in research” in 1998 (Schnarch, 2004, p. 81). This was explicitly “a
political response to tenacious colonial approaches to research and information management” (Schnarch, p. 80). They argued and framed OCAP® on principles that overtly exerted self-determination and directed researchers from outside Indigenous communities to become aware of and practice these principles in their research as they offer “a way out of the muddle of contemporary Indigenous research and the ethical dilemmas that characterize it” (Schnarch, 2004, p. 80).

From the territory of Nunavut, Gwen Healey shared stories of her active involvement in research ethics since the early 2000s and how they are working to ensure ethical research with people of Nunavut. She noted the importance of researcher humility and the role she plays in educating researchers coming to Nunavut from outside the Territory, the South in particular. This willingness of researchers to be mentored and community to educate is still required because examples of (attempted) unethical research with Indigenous Peoples continue to happen now, in 2018.

[The project] broke so many rules of ethical conduct and this person, I believe was quite unaware of the historical context of our territory. But they had REB approval from their university, and I was flabbergasted because nobody in their right mind would have approved this in any ethical context that I have ever worked in at a university. The experience that I have to date tells me that this is not a good project, and this is violating a number of ethical principles. I feel personally like I just cannot live with turning a blind eye to this kind of work anymore. That’s been allowed to persist for so long, I'm not mean or negative, I think that probably there's a role for the topic [the researcher] wanted to study but the methods were wrong and disrespectful to our community, and I feel like we really have a role to educate people. (Gwen Healey)

For researchers who operate outside of the biomedical model or the positivist paradigm, there is growing skepticism that our voices will ever be heard in the regulation of research. As Igor (Gontcharov, 2016) explains “This skepticism is an outcome of documenting 1) the ongoing methodological pauperization of the social sciences, and 2) privatization of the research ethics infrastructure by positivist
researchers” (p. 12). I was glad to have found his 2016 doctoral dissertation, “Mandated Ethics: Regulatory Innovation and its Limits in the Governance of Research Involving Humans” (2016) while I was doing research for my dissertation. His summary of the landscape of research oversight in Canada is excellent, and I strongly encourage anyone seeking to learn more about that to read his work. As I will not rewrite his dissertation here, let me share that he highlights and articulates the clash of ideas that can happen at the REB level (and that I would argue are even more evident and contentious in Indigenous research because of an additional layer in multi-jurisdictional review that warrants considerations to both individual and collective interests and is governed by Indigenous Peoples).

The institution of prospective ethics review by research ethics boards has itself become a source of risk to researchers and participants, meanwhile policymakers and REB professionals still lack the capacity to critically engage in self-reflective analysis of its contribution to the governance of research involving humans. (Gontcharov, 2016, p. 5)

In “Leashes and Lies: Navigating the colonial tensions of institutional ethics of research involving Indigenous Peoples in Canada”, Stiegman and Castleden (2015) summarize the reality in practice for researchers attempting to work in relationship with Indigenous Peoples within the limitations of the existing REB structure: “the length of leash the university affords Indigenous peoples to determine research with their people, and on their territory, is highly problematic” (p. 4). They go on to describe a specific incident where their research was delayed, despite community approval and readiness to participate, because of the REB process: “In total, it required three rounds of revisions with the university REB over 100 days, which resulted in our project, centered on land-
based activities that were entirely dependent on seasonality and guide availability, being postponed for a full year” (Stiegman and Castleden, 2015, p. 3).

The bureaucratic nature of REBs and the limited knowledges they hold can inhibit appropriate review for research with Indigenous Peoples, as evidenced by the example above. Furthermore, in research involving humans generally, the pendulum has swung to this place of moral panic, “when ‘ethics’ acquired a derogatory meaning (Gontcharov, 2016, p. 70). Fifteen years earlier, Will van den Hoonaaard (2001) discussed this very notion in “Is Research Ethics Review a Moral Panic?” Will and Igor have both joined me in my ethics journey and they have articulated some of our shared concerns. We (along with many others) are challenging the ways in which research ethics review is conducted.

What emerges in the process of bureaucratization of research ethics is a new definition of ethics, which is often far removed from the idea of actual ethical challenges arising in ethnographic work, as well as academic knowledge production in general. The antagonistic understandings of ethics are the source of ‘ethics rupture’, of growing tensions between ethics on the books and ethics in action, REB ethics and ethics of the studied situations. (Gontcharov, 2016, p. 9)

Gontcharov echoes sentiments also found in The Ethics Rupture (van den Hoonaaard and Hamilton, 2012) and subsequent New Brunswick Declaration (van den Hoonaaard, 2014): there is a “growing gap between formal research ethics review and actual ethical challenges in research practise” (p. 12). This gap is evident in any research with humans that is outside the purview of the biomedical model from which REB are built and is especially apparent in research with Indigenous Peoples.
The Impetus for the Regulation of Research with Indigenous Peoples

From the mid ‘80s to the ‘90s, was really sort of the ‘insider research era’. I think it’s because of increasing Indigenous people going into graduate and doctoral studies. And a heightened awareness of what was happening and the research that was going on and some of the horror stories that had come out. (Raven Sinclair)

Though there were some Indigenous scholars beginning the dialogue in the 1970s (Red Horse et al., 1989), it was not until the early 2000s that a significant number began writing about the complexities of research involving their communities (Tuhiwai Smith, 1999; Brant-Castellano, 2004; Kovach, 2009; Bull, 2010; Martin, 2012; Moore, 2015; Bird-Naytwhow et al., 2017). At the same time, there was an increase in attention to issues of research involving collectivities, specifically in genetic research, leading to discussion of the collective impacts (i.e., risks and benefits) of research, not just the effects to those who individually participate.

By 2002, the ethical questions with respect to collective impacts were a particularly hot issue in Indigenous health research in Canada after revelations were made nearly two decades after blood samples were taken from members of the Nuu-chah-nulth tribe in British Columbia (Atkins et al., 1988) who consented to research examining genetic causes of rheumatoid arthritis discovered that these biological samples, with a clear and specific research purpose, were used for other research that the

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63 ‘Collectivities’ refers to any sum of people who are identifiable by the sum of the group, or collective. This can be used synonymously with ‘community’ but because the conversation in genetic research stemmed from discussions of collectivities, I use that language as a means of staying true to the conventional language as it evolved over time. To learn more about studies involving collectivities and the impetus they had in starting the dialogue about the collective impacts of research, see: Greely (2001); Weijer et al. (1999).

64 See, for example, a Newfoundland and Labrador Example dubbed The Texas Vampires (Cummings, 2012).

65 The contemporary academic dialogue regarding Indigenous research ethics was greatly influenced by health research so some of the common language is shared (e.g. consent, protocol, autonomy).
community did not consent to (Dalton, 2002). Like many other Indigenous communities since, Nuu-chah-nulth went on to develop their own ethics committee in 2008. Increased dialogue and policy development on Indigenous research ethics emerged alongside this significant and publicly reported/known ethical breach – while the work toward an Indigenous ethical framework had already been underway, this incident further illustrated research participant exposures and research practices that undermine individuals’ authority over their person (even down to the DNA).

The process of establishing research governance for health research with Indigenous Peoples is a hot and long-debated challenge of academics and community members alike; the conclusion is always the same: community engagement is required (for example: Kovach, 2009; Martin, 2012; Moore, 2015). The process of “how to” is about what actions researchers need to demonstrate to REBs to show meaningful engagement is initiated with the community to satisfy the ongoing research governance issues that will roll-out during the course of a research project, as outlined in the TCPS2 in general and Chapter 9 in particular (CIHR, NSERC, and SSHRC, 2014). Igor Gontcharov (2016) emphasizes that “[c]urrently, we do not have a system of research ethics oversight, but rather a system of research protocol/project oversight” (p. 88).

Substantial literature on this topic emerged over the last few decades from the perspectives of both researchers and communities. However, scant evidence is available that names what facilitates and what challenges REBs to fully implement the TCPS2, and Chapter 9, in particular. There are increasing calls in the research literature, both making the argument for and outlining policies to guide, more ethical review and approval processes for research with Indigenous Peoples (Fitzpatrick et al., 2016; Martin, 2012; Moore, 2015; Riddell et al., 2017). However, for the uninitiated and
uninformed, there is no clear direction (e.g., template) or criteria to facilitate a robust understanding and interpretation of TCPS2 Chapter 9 in practise. Despite increasing literature on the topic of research ethics and REBs from researcher and community perspectives, very limited scholarly literature exists on the perspectives of the REB members themselves.

The questions of community consent versus individual consent. Like, if the community doesn't want, but some individual would like to participate in the research, what should I do? Should I still go ahead with it or not? The policies are clear about that. You need both consent, and this is for a reason. I think we can trust the Indigenous institutions that we have right now if we don't get the consent, they can also give you the reasons why, or they should any way. And if they do, then it makes their research project acceptable or well-known and we can trust the Indigenous institutions that deal with that on a daily basis. So, if they say no to the project it might be for a good reason. It can't be for a personal reason but still researchers are afraid of that. It's like one more step to go through for them. It's like a pain in the neck. And I'm like “well, no, it will be a very good tool after all because the day when they ask you if you have your community consent and we will be able to show it, then this is the key, not the paradise, but it's the key to go ahead with your work”. I know some communities that will never let you walk in if you don't have this piece of paper. (Suzy Basile)

Interrupting Indigenous Peoples’ research sovereignty is part of ongoing colonization. There are four key false assumptions that continue to be evident/reinforced in/by government policies and demonstrate the ongoing nature of colonization. First, Indigenous Peoples are inferior and are not capable of self-governing; second, treaties are “a form of bureaucratic memorandum of understanding, to be acknowledged frequently, but ignored often” (Royal Commission on Aboriginal Peoples [RCAP], 1993, p. 4); third, actions deemed to be of potential benefit to communities according to the government do not require consent or consultation; and finally, that non-Indigenous people could/would make decisions on behalf of and for Indigenous Peoples without including Indigenous values in that decision-making. These deceptions are described by
many (Tuhiwai Smith, 1999; Battiste & Henderson, 2000; Howitt & Stevens, 2005; Ermine, 1995; Louis, 2007), and summarized well in Part II of the *Royal Commission*. Though these false assumptions may be less explicit in contemporary contexts, they continue to “significantly underpin the institutions that drive and constrain the federal Aboriginal policy process” (RCAP, 1993, p. 4).

The critique of this mindset, however, instigated the formation of guidelines for health research involving Indigenous Peoples, primarily through the work of the RCAP, which resulted in the creation of the CIHR’s Institute for Aboriginal Peoples Health and culminated in the creation of the *CIHR Guidelines* mentioned previously. The *CIHR Guidelines* were in formal effect from 2007-2010, at which time the provisions in the 2010 second edition of the *TCPS* (Chapter 9) were meant to guide researchers working in Indigenous communities. Though the CIHR Guidelines’ formal run was brief, some research ethics enthusiasts across Canada still seek guidance from and use them (e.g., the Newfoundland and Labrador Health Research Ethics Authority, 2011). Despite the *CIHR Guidelines* no longer being formal or funding policy, many Indigenous researchers and communities still advocate for their application in research projects.

Geneviève Dubois-Flynn, Manager of CIHR Ethics Office tells the story of how the original *CIHR Guidelines for Health Research with Aboriginal Peoples* came to be.

When CIHR was created in 2000, this was a bold vision of having 13 virtual institutes, form the Canadian Institutes of Health Research, as a successor to the Medical Research Council, so it became a new organization and each of these institutes were led -- are led by highly recognized experts in their field.

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66 After the creation of the CIHR-IAPH, came the development of its Aboriginal Capacity and Development Research Environments (ACADRE) centers, which was later redesigned into the Network Environments of Aboriginal Health Research (NEAHR Centres). Today, a new mentorship program at IAHP exists to serve Indigenous health researchers in the country. To read more about the evolution of these initiatives, see [http://www.cihr-irsc.gc.ca/e/27071.html](http://www.cihr-irsc.gc.ca/e/27071.html) and [http://www.cihr-irsc.gc.ca/e/49453.html](http://www.cihr-irsc.gc.ca/e/49453.html). There is a current (2018) call underway for the development of new Network Environments for Indigenous Health Research (NEIHR).
Regarding the Institute of Aboriginal People's Health - what it was called until very recently - it was headed by Dr. Jeff Reading. Institutes each had a budget to fund research in their particular area. I remember very clearly Jeff Reading going to Science Council -- Science Council is a place where all scientific directors get together once a month to discuss priorities for CIHR and of course sharing what they do within their own institute so that they can eventually develop collaboration among themselves, among institutes. So, Jeff Reading went to Science Council, a particular meeting in the year 2001 or 2002, and he said to his counterparts, the scientific directors and to the President and Vice Presidents: we were given a substantive budget -- I'm thrilled that the Institute of Aboriginal People's Health has that amount of money to fund research in health and improve health outcomes of Indigenous peoples, because there are considerable gaps.

But we are in an untenable position he said because, "But we don't have proper protections." Not saying protection, but protections to ensure that the research that's going to be conducted with Indigenous population is going to be ethical. So, he said we need to develop some guidelines, ethics guidelines to make sure the research is properly conducted, because the Tri-Council policy statement does not include at this point a chapter on Indigenous research ethics. So, Jeff Reading convinced Science Council that CIHR needed to invest time and resources in developing guidelines for research involving Aboriginal peoples.

So, the Ethics Office at CIHR was the obvious structure best positioned to undertake that work. I was senior advisor at the time, and then I became Acting Director for three years. So, I was there when all these discussions took place and when the guidelines were finalized. We hired Doris Cook, who is a Mohawk and who worked with us for a couple of years and who was the project lead on the development of these guidelines. So we -- the way she started was of course trying to get as much as possible, you know, any academic literature on research ethics and Indigenous research - from Canada, but there was not much at the time even though there were some pockets of academics who had already written on this, but also from Australia and New Zealand, which had been written and then the guidelines that existed in their country and see, you know, what were these principles and what were these key issues that they were dealing with in their own guidelines. So that's how it started and I think we commissioned a paper as well, a White Paper to identify what were these issues.

The second [step] was of course to establish what we called the AEWG, Aboriginal Ethics Working Group, and -- so these -- I mean this is -- the information is in the previous CIHR guidelines. I believe there were 12 and probably 10 of them were Indigenous people themselves-- and they actually, they drafted the guidelines. So that was the second step.
And the other step was of course, and I have to tell you that from the very beginning, Indigenous communities were consulted. So, they were consulted from the get-go. And it was not towards the end that they were, but they were really involved from the very beginning. And I think that was -- it was, from what I understand it was a sign of credibility of the process and one of the reasons our past guidelines continue to be highly praised and highly recognized. So -- and the process of consulting with Indigenous communities was continuous. I mean there were -- not only were some specific communities identified, but there were a number of workshops that were held from east to west as well as in the North.

So at the time, what made it easy was that we had in Canada the National Council on Ethics in Human Research (that no longer exists), it used to be funded actually by the funding agencies and Health Canada, but then with changes in funding et cetera it no longer became possible for us to support what we called NCEHR and they are the body that organized all these visits and workshops, and they actually had a lot of credibility in the country because they -- their role was to conduct site evaluations on research ethics. So that's what the goal of NCEHR was to promote better understanding of research ethics and making recommendations on how to improve their current practises. NCEHR played a key role. So, after that -- the guidelines were developed and they became CIHR funding policy. But in December, in the year 2010, the Panel on Research Ethics released [TCPS] Chapter 9. (Geneviève Dubois-Flynn)

Raven Sinclair shared some stories with me about her being involved in the creation of those CIHR Guidelines and the integral role they still play today.

I think all researchers, all research ethics boards, everyone should be reading the CIHR policy for sure -- Chapter 9 [TCPS] and the CIHR policy as well. It's just much more robust…it's got the philosophical background and historical piece, and it's very detailed. But I don't think you can really understand Indigenous research ethical criteria or protocol unless you really have done a bit of homework. For academics, that might be the best critique because I don't know any of them who don’t take that really, really hard. And then do their homework. (Raven Sinclair)

Meanwhile, in that time between the mid-1990s and mid-2000s when federal funding and other agencies were wrestling with their own roles and responsibilities,
communities were very busy too. Community research policies were created\(^{67}\), guidance documents published\(^{68}\), and local research review protocols\(^{69}\) put in place to support both researchers and REBs in understanding the processes and protocols of engagement, governance, and collective consent required to conduct research on the territory of Indigenous Nations. Spoiler alert – it starts with asking permission\(^{70}\) (which is easier when you have a relationship). And despite the growing number of guidance documents available, researchers and REBs are still grappling with how to assess the application of them in practice and what it would look like to do research in the ways the guidelines promote. Riddell et al. (2017, p.8) assert that, “[a]lthough such guidelines provide a strong foundation, conducting ethical, culturally respectful, and effective research with Indigenous communities remains challenging” because of the constraints from funding agencies and REBs on researchers who attempt to work in relationship with Indigenous Peoples.

In 2007, the United Nations adopted the Declaration on the Rights of Indigenous Peoples (UNDRIP); Canada rejected adopting it at the time, as did the United States, New Zealand, and Australia. Nearly a decade later, in May 2016, Canada announced that it would adopt and fully implement the UNDRIP but quickly asserted in June of that year that the Declaration was not workable within current Canadian Law (Ivision, 2016). There is a notable intersection of ethics and law in the governance of health research by way of consent\(^{71}\). “Controversy over the interpretation of free, prior, and informed

\(^{67}\) TCPS2, Chapter 9: Research Involving First Nations, Inuit, & Métis.

\(^{68}\) CIHR Guidelines for Research Involving Aboriginal People, 2007

\(^{69}\) See, for example: Kahnawá:ke Schools Diabetes Prevention Project, 1996; Guidelines for Ethical Aboriginal Research, 2003; NunatuKavut Community Council Research Advisory Committee, 2006.

\(^{70}\) There is global dialogue on this issue: Australian Institute of Aboriginal and Torres Strait Islanders, 2012; Health Research Council: Guidelines for Researchers on Health Research Involving Maori, 2010; Lowitja Institute, 2013; Laycock et al., 2011; Putaora Writing Group, 2010; Drugge, 2016.

\(^{71}\) For more on the intersection of research ethics and law, see Rath et al., 2014.
consent as a ‘veto’ is a major roadblock to Canada’s implementation of the [UNDRIP]’” (Papillon & Rodon, 2017, p. 1). This is one of the many issues that underpin the complex landscape for the governance of health research with Indigenous Peoples and leads to many practical complications in implementation72.

The laws versus cultural norms are sometimes very different. That's why we only give conditional [approval], because we're trying to maintain the spirit of acknowledging that these Indigenous communities or Indigenous people have the right to say yes or no and determine how this research is going to move forward. (Brenda Gagne)

In Canada in 2008, then Prime Minister, Steven Harper, gave a public apology73 to residential school survivors which was followed by the appointment of the Truth and Reconciliation Commission (TRC) who were tasked with investigating and providing Canada with a way to heal from the residential school era. After more than five years of hearings and reviewing documents, the TRC (2015) published 94 Calls to Action for Canadians to address through reconciliation and to heal the relationship between Indigenous and non-Indigenous people in Canada. The TRC reiterates the necessity of Indigenous Governance and autonomy, and asserts that Canada must adopt, and fully implement, the UNDRIP before any true reconciliation can occur (TRC). This larger discussion on governance cannot be separated from the governance of research; therefore, researchers and REBs are required to know the ethical and legal dimensions of research with Indigenous Peoples, which may appear to be beyond the scope of their work but is an integral component to working ethically.

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72 For more information about the political landscape on this issue, see AANDC, 2010; Government of Canada, 2011.
73 Since Newfoundland and Labrador did not join confederation until 1949, former students of the residential schools in that province were not included in Steven Harper’s apology (and subsequent compensation) in 2008. On November 24, 2017, Prime Minister Justin Trudeau met with former students of residential schools in Happy Valley-Goose Bay to deliver an apology.
It's interesting to see that the TRC has gotten a tremendous amount of publicity and it's acknowledged in institutional strategic documents. Basically, there's at least the appearance of an attempt to implement the recommendations, the calls to action that apply to the institution. (Chris Turner)

Addressing the TRC Calls to Action does not play a central role in this dissertation; however, the insights and innovations shared from participant contributors in this study provide recommendations for academic institutions and government funding agencies (both of whom are explicitly implicated in the Calls to Action 7, 11, 16, 18, 19, 20, 62, 63, 65, and 77).

Despite the reconciliation rhetoric in federal politics for the past few years regarding a nation-to-nation relationship, little has been done to actually implement the Calls to Action (TRC, 2015) or the UNDRIP (2007)74. “This gap in effective governance created by retreating or neutered centralized government agencies provide opportunities for the resurgence of Indigenous communities and their own governments” (Adams et al., 2014, p. 2). There is variance across the country with respect to the levels of sovereignty that Indigenous Peoples have over their communities and their lands: Some have fully formed governments that communicate and negotiate directly with the Federal Government; others have tri-lateral agreements between themselves, the provincial jurisdiction in which they reside, and the Federal Government; and others are in ongoing land-claim negotiations (i.e., modern treaties) or in legal battles to fulfill agreements made in the original treaties (Harding et al., 2012; Aboriginal Affairs and Northern Development Canada, 2010; Government of Canada, 2011). Regardless of the relationship between specific Indigenous Nations and other governments, researchers

74 In March 2018, CBC launched a website called “Beyond 94: Truth and Reconciliation in Canada”. This interactive and living website chronicles the progress in Canada in addressing the 94 Calls to Action from the TRC.
and REBs have an ethical imperative to conduct themselves, and their research (Guta et al., 2010), in ways that not only acknowledge, but also adhere to Indigenous models of governance (Fitzpatrick, 2016).

I find that regulations, when they're so prescriptive can miss the purpose. What is the purpose? The purpose of Chapter 9 is to facilitate research in a culturally appropriate way. Is what the REB is doing culturally appropriate? Is the Board stepping in where they shouldn't? Is the Board requiring things that the community is directing? Is the Board now making really culturally awkward requests of the researcher? I mean this would not be appropriate. So, I personally am more into principle-based understanding and application. What is the principle? What is the purpose behind this? Are we being consistent with that? (Kenna Miskelly)

From ‘Human Subject’ to ‘Human Participant’

When the TCPS2 was released in 2010, I was glad to see that there was a shift in language that removed ‘subject’ and replaced it with ‘participant’. Though a small change on the surface, this shift in language has implications for the ways in which we understand governance in research. “[T]he task of the word participant is to change the mindset of both researchers and the researched, and to empower humans involved in research” (Gontcharov, 2016, p. 160).

I often contemplate what this means in the context of research with Indigenous Peoples because we are not just considering ‘participant’ to mean an individual. It is both individual and collective participation. What changes in practice have arisen since this shift in language more than eight years ago? Has it empowered Indigenous Peoples and communities to be active participants rather than passive subjects? Have the systems and structures of research oversight and the practice of research shifted to encourage and allow such participation? Is the shift in language merely rhetoric or is there an
actionable change that followed? Can people and communities actually assert their self-determined participation within the current regulatory and research systems?

Unless we change our actions to reflect this change in language in the TCPS2, we are simply playing soccer with semantics. Igor has described some of the nuances entailed in this language shift, so I will not reiterate what he has already so eloquently articulated but I am drawing attention to this notion of language and the implied notion of active participation because of its relevance to the discussion of relational research.

**Blazing Trails and Growing Pains**

As more guiding documents and policies emerged, Indigenous academics started writing about the increasing ethical tensions and dilemmas they encountered (Brant-Castellano, 2004; Kovach, 2009; Martin, 2012; Moore, 2015). The emphasis was no longer on the tensions of working in communities, but rather the tensions of doing community research in academic institutions. And doing Indigenous research in academic (read: colonial) institutions is hard intellectually, emotionally, and spiritually (Bird-Naytowhow, Hatala, Pearl, Judge, & Sjoblom, 2017; M. Brown, 2005; Wilson, 2008).

Participant contributors – Suzy, Johanne, Riley, and Raven – all corroborated these challenges during our conversations and they all told stories of their experiences of ‘being Indigenous’ in academia. In particular, Johanne conveyed the deeply emotional and spiritual toll that it takes to do the work we do.

I get exhausted seeing the same mistakes over and over again. And it's emotionally difficult because you have to recognize that these people don't talk to each other, so we all see the same mistakes. That's why it's good to have some great team members to pick you up and stand behind you and support you in some of the things that you’re seeing happening. The key piece that we need
to see to overcome some of these challenges is just basic education on the relationship of Indigenous people with research and with institutions that are doing the research. We have a painful history and not investing in caring about that by educating yourself is harmful even to the people on research ethics boards. We had talked about maybe having more than one person on the ethics board so that I would have somebody who I didn't have to explain things to and they just got it and we could kind of support each other. I feel strongly about that. I think those are some of the biggest challenges for me. It's beyond just the pen and paper, it's about the historical trauma. And I think that is for me, being on a research ethics board that’s the biggest challenge, as some nights I go home and I'm like “ahhh -- not again”. And I think that's why having these discussions in a group with my friends on the research ethics board has been important to have that relationship. (Johanne McCarthy)

These evolving commentaries reflect frustration with the cultural rigidity of the structures of academic institutions, REBs, and research funding mechanisms. The institutional REB system and the entire research regulatory structure in Canada is not set up in a way that Indigenous research(ers) can operate seamlessly. Raven shared many stories of her own experiences on the tension that exists when Indigenous researchers are operating within Western systems.

That we're doing this methodology because it came through ceremony. The elder told us we should do this, and we just did it. But I think in other instances it's like in my own application in 2015, some of the questions they're asking because they don't understand what I'm saying or the implications, sort of the philosophy, protocol behind it. One of them was something sort of standard are you going to have a research agreement with the community and then explaining that this was a national community so no, but I was going to have an advisory board in town that would have constant input and oversight of the project and that's what I've done. And then some other questions that again easy to answer wasn't a huge barrier but made me realize that there's a lack of understanding of Indigenous research. (Raven Sinclair)

Everyone can remember those moments when enough was enough. The time when we learned about an ethics breech in an Indigenous community that opened our
eyes. For Brenda, she recalls that moment being when she learned that a researcher copyrighted songs that were collected.

I think the turning point might have been when I heard of the researcher in Labrador that copyrighted a number of songs and never gave credit to the community from which he gathered these historical songs of and by-the-community. And it's like how can you do that? That's not even right in everyday copyright let alone not giving a community -- apparently, they made money from this as well, so I'm just, I'm floored that things like that can happen and still happen, so it's something that since I've started here has become something that I've trying to fight for. It's something that I believe in and making sure that participants have a say in what's happening and what's happening to their information, to their data and of course, ethics is never black and white. (Brenda Gagne)

These collective stories name how the cultural values framing the processes at the university, scholarly work, and REBs inherently contradict what is needed for ethical research with Indigenous Peoples in most contexts because these systems are built on, and maintained by, colonial culture and influences (Stiegman & Castleden, 2015). They are not centred on Indigenous ways and, in fact, often exclude these ways by policy (i.e., the permissible or prohibited binaries that come with systems) rather than focusing on integrating Indigenous epistemologies, sciences, and values into ethics discourses, research practises, and knowledge-making. However, once Indigenous scholars named the problem, they could begin challenging it (Brown, 2005). And Indigenous Peoples need to keep taking up space. I am so grateful that there are/were Indigenous people participating in this study who join me in the spaces between, straddling multiple worlds. I am hopeful like Johanne who shares my eternal optimism and can see, with me, the shifts happening before our very eyes.

I love that there's this beautiful wonderful community of Indigenous academics who are now starting to articulate our past, our history, our relationships, our world-view in a way that the institution can hear it. So that's what I try to focus on is learning how to talk in the way that the institution can actually hear me and
I'm learning through all of these other Indigenous academics that are writing about research and research methodology, research ethics and how to get the message across to non-Indigenous researchers that the way we are doing things is just as valid and using their lingo to explain how we do things, because sometimes I think that it's hard to explain because we don't talk the same language when it comes to research and so knowing how to speak in a way that other people can hear me, I think that's important. (Johanne McCarthy)

As Johanne spoke, I found myself nodding along because I was relating to her experiences. I have worked hard to find ways to integrate my multiple ways of knowing and being in my scholarly work. I have learned how to use my academic voice in a way that does not dismiss or detract from my messages from the community. As evidenced in this chapter, there are many overlapping and intertwined stories that are operating simultaneously regarding ethical research/review with Indigenous Peoples. There has not been one clear path nor has there been one clear process or policy in this evolving area of study. There have been and continue to be multiple worldviews colliding where Indigenous Peoples and Nations have been asserting their self-determination in research and academic institutions are left wondering how to apply the current policies into practice.

It was my privilege to listen to and learn from the participant contributors in this study and the following chapter describes some of the key learning and messages from them as we explore the ethical space. The chapter is comprised of three sections: theorizing ethics, applying ethics, and practicing ethics. These three interrelated and independent categories serve to articulate the varied conversations I had with participant contributors and to demonstrate the complex interrelationships at play when discussing research ethics.
CHAPTER 5: DETERMINING AND NEGOTIATING THE ETHICAL SPACE

I come to this doctoral research as the ethical space. I navigate that space by practicing Etuaptmumk, namely integrating how I understand through both my Western and Indigenous ways of theorizing, applying and practicing ethics. Part I: Theorizing Ethics in this chapter, introduces some ethics theories, drawing on both my personal and cultural understanding of ethics from Inuit Qaujimajatuqangit (IQ) and other Indigenous orientations, and my professional and scholarly understandings of ethics from a hybrid of relational ethics and applied ethics. In Part II: Applying Ethics, discusses how these theoretical foundations have/not been applied in the creation of research ethics policy in Canada and subsequently in the application of the policy by REBs themselves. The final section, Part III: Practicing Ethics chronicles some of the participant contributors’ experiences in their practice of applying TCPS2 Chapter 9 and illustrates common research complexities and possible solutions for researchers and REB members (and communities!) involved in research/review with Indigenous Peoples. Here I attempt to share some of the ways in which Etuaptmumk has helped me navigate (and become) an ethical space as I learned to theorize, apply, and practice ethics.
Section I: Theorizing Ethics

It is not my intention to separate the major branches of Western ethics theory (of which there are many) or to delve deeply into any number of Indigenous ethical theories (of which there are even more), nor do I wish to assert that any one theory in particular is dominant or preferred. Rather, what I want to draw your attention to in this section is the theoretical interconnectedness, and to engage with the space between them – the ethical space – the examination of the structures, systems, and individuals that reinforce ethical action. We cannot separate theory from practise, a meeting place where applied ethics lives (and where #TheJuliestPhD finds a comfortable home). Again, it is about the connectedness, not the separateness. It is also about the humanness. Ethics cannot be reduced to specific moral codes or religious doctrines; it encompasses the whole of all the moral ideas, philosophical thought, and unique epistemologies.

Ethics is really just based on the values of your community so if we're operating in alignment with those values, then we can't help but be ethical when you get right down to it. (Gwen Healey)

I completed a Philosophy degree and was never once introduced to (never mind studied) an Indigenous philosopher/thinker or philosophical system as a class requirement. Many participant contributors discussed the foundational difference and Riley summed it up in the following way:

Starting from a place where Indigenous ethics are different from Western ethics. There is Western ethics and there's Indigenous ethics, and I think that is just a good place to start. It gets people thinking, “Oh, everything that I've been thinking about ethics actually only applies to Western ethics and that there's this whole other world of ethics”. (Riley Kucheran)

Ethical Space

Elder and scholar, Willie Ermine, articulated the concept of ethical space to denote a space of engagement that is essential in research involving Indigenous Peoples
Ermine is Néhiyaw (Cree) from a family line with ties to the ancestral knowledge and lands of Sturgeon Lake First Nation, Treaty Six Territory, in Saskatchewan. He builds on the work of Roger Poole (1972), who examined the space between two opposing societies when they are required to work together to address an issue. Ermine adapted Poole’s framework for human dialogue to conceptualize the relationship between Indigenous and non-Indigenous Peoples, highlighting the necessity of integration (of worldviews, methods, perspectives).

Willie [Ermine] wrote the book on Indigenous ethics, The ethical space. And he's one of our foremost living philosophers in Indigenous country and he's an Elder. Just being on Elder isn't that he can say whatever he wants and get away with it, but what he says and when he says it is very intentful and very purposeful. And he doesn't speak without a lot of thought behind it. He taught me there's a Cree word for ‘speaking with very deliberate thought’. I wouldn't have to worry that anything that he's going be engaged in is unethical. He lives Indigenous knowledge. He lives Indigenous ethics. (Raven Sinclair)

**Personal Reflection:** My undergraduate attempts to embody ethical space was hard. I was doing it alone and had no guidance or support from others in my efforts navigating the abyss. I’m sure I could have learned from Willie in an afternoon what it took me five years to figure out on my own in my early 20s. As Willie describes, it is about finding the humanity in it all. It’s not a grand theory of equality. We have to see each other as human first. Some people say that I am idealist and that I have a romantic version of an illusion to think that it is all about humanity. Maybe. It is *all* an illusion though since we have constructed and created the society in which we live. In my version of the illusion, it is all about humanity.

This notion of ethical space provides a foundation for positioning myself as of and in two worlds—that I am *in* the ethical space and I *am* the ethical space—and the
ideal candidate to take on up the challenge of applying *Etuaptmumk* from here. This is also a place of invitation, for Indigenous and non-Indigenous researchers and REB members to come together in the ethical space to enact the spirit of the ethics they purport to portray and practice.

**Etuaptmumk**

Mi’kmaq Elders, Albert and Murdena Marshall, share the teaching of *Etuaptmumk* (Two-Eyed Seeing) to refer to integrating both Western and Indigenous science in a co-learning model with shared benefits (Bartlett, Marshall, & Marshall, 2012). Some of Albert’s talks and teachings can be found online. A YouTube video, “Two-eyed Seeing: Knowledge for Environmental Decisions”. *Etuaptmumk* is applied widely (e.g., CIHR-IAPH even issued a priority funding program oriented to it in 2012) and is increasingly used by Indigenous Peoples and partners across Canada as a way to solve complex problems while examining phenomenon that affects Indigenous Peoples. Southern Inuk scholar, Debbie Martin clarifies that,

In upholding Indigenous worldviews, the motive is not to diminish or dismiss the important work of Western health research but, rather, to critically examine the lens through which health research is interpreted and understood and to offer, in place of this dominant view, an alternative lens through which health research can embed Indigenous perspectives and realities. (Martin, 2012, p. 24)

I want to be clear and reiterate that I think the solutions we seek are in the bringing together, the space between. It is not about convincing or converting anyone. We must be critical and diligent in (and delighted to undertake) our efforts to apply and
embodiment of Etuaptmumk} because the existing dominant colonial structures make it difficult for Indigenous perspectives to find equal footing.

So, trying to find a way to bring these two worlds together, to make sure that we see if from both sides I think would have an incredible impact on everyone. I don't know how that's going to look or how we're going to do it, but I have a dream. (Brenda Gagne)

One of the ways that researchers and REBs can approach Etuaptmumk is to ensure that their efforts are Indigenous-informed, Indigenous-driven, and Indigenous-led. For me, that is to study and embody the values, philosophies, and ideologies of Inuit Qaujimajatuqangit (IQ) alongside all of the other Indigenous teachings/values/responsibilities I receive in my journey.

**Inuit Qaujimajatuqangit or IQ**

IQ refers to that which Inuit have always known to be true. Just because Inuit (or other Indigenous Peoples for that matter) prepared their governing laws in non-paper formats does not mean we lived without rules and regulations that governed our people, our societies, and our territories. “Times have changed but the values for holding things together for a happy and purposeful life are still as true today as they were yesterday” (Kalluak, 2017, p. 56). IQ is ethics, as it is guidance on how to live the good life. It is both a philosophy and a practise; it is both ancient and contemporary.

IQ is the wisdom gleaned from experiences and passed down from one generation to the next; it is “the truth through which we live a good life in our world. It provides purpose and meaning for us and is the way of being in the world that our ancestors set down for us to ensure our survival and well-being. It is our traditional knowledge” (Kalluak, 2017, p. 41). This knowledge is understood as iliqqusiq (our
patterns of behavior and being) and *silatuniq* (our abilities to think and behave wisely), which is really what research is all about.

The blueprint embedded within *IQ* entails treating everything as living, not wishing ill will on others, not thinking bad thoughts, and demonstrating respect, harmony, kindness, sharing, wisdom, humility, and patience. This is not to be confused with the Western reference of IQ (intelligence quotient) which measures specific, culturally based/biased knowledge; this *IQ* – Inuit Qaujimajatuqangit – is about how to live in the world (how to be an able human). We, Inuit, are taught to always offer a helping hand instead of being a by-stander. To always pitch in, regardless of how much or little we have. We learn by listening, observing, and practising. We are taught not to keep that which is not rightfully ours; if we find something, we locate its owner instead of keeping it for ourselves. There are eight interconnected principles of *IQ* and in my ongoing learning in each principle, I have weaved and integrated teachings from each one of them throughout my doctoral research and in this dissertation:

- *Inuuqatigiitsiarniq* (respecting others, relationships and caring for people);
- *Tunnganarniq* (fostering good spirit by being open, welcoming and inclusive);
- *Pijitsirniq* (serving and providing for family or community, or both);
- *Aajiiqatigiinniq* (decision making through discussion and consensus);
- *Pilimmaksarniq* or *Pijariuqsarniq* (skill development through practise, effort, action);
- *Piliriqatigiinniq* or *Ikajuqtigiinniq* (working together for a common cause);
- *Qanuqtuurniq* (being innovative and resourceful); and
- *Avatittinnik Kamatsiarniq* (respect and care for the land, animals and environment).

It's really about the relational piece of our community. We're all connected in some way and so we all have a collective responsibility to look out for each other. And that's really kind of the founding value of the Katimajit. We're just going from a values-approach, not the, ‘I have five years of research
experience, I have a Master's degree in that’, that just doesn't matter. It’s an *a priori* first-principle approach. (Gwen Healey)

As Gwen said above, it is our collective responsibility to respond to and address the ethical dilemmas and paradoxes that persist in Indigenous research/review. It is about working together and being able to have the foresight to plan according to the dynamic nature of Indigenous ways of knowing and balance this foresight with the pressures/realities/needs of contemporary society. “Being able to plan conscientiously enables you to live well, to be successful and then to be able to share with others and serve the common good. This is how to live a good life as an Inuk” (Attangalaaq, 2017, p. 111). This is how to be a human in Inuit society. This is how to be Inuit. We learn that “it was of utmost importance to create an able human being who would possess wisdom, innovativeness, make wise decisions to benefit everyone and act for the well-being of the community by being resourceful and diligent in helping others” (Akittiq & Akpaliapik Karetak, 2017, p. 139). Even though many of the traditional ways have been taken away, displaced or misplaced, “the core principles do not change or diminish in value” (Aupilaarjuq, 2017, p.174). They are about how to live a good life. They are about how to become an able human.

**Personal Reflection:** Sometimes I grapple with the guilt that comes from making a better life for myself, although, to be clear, many of my immediate and extended family members feel sorry for me that I live in Toronto (“it’s so big and busy!”) and do what I do (“whas dat you do again, Julie?”); they often just shake their heads because clearly I am failing at life: I don’t own a house or even a snowmobile. I’ve often felt to be the outsider, even when I’m at home. Always living on the edge on the periphery of multiple worlds, balancing the best I can
(which sometimes meant hanging on by my pinky toenail), and always collaborating across boundaries.

Through ongoing examination of myself and my culture, I am (re)learning some of the traditional teachings that were displaced and dislocated. We can draw strength and wisdom from these teachings and carry them with us through the uncertainty and contention.

IQ offers not only a holistic way to understand and relate to the world that is much needed in our era of human-caused ecological disequilibrium, but it also provides a sophisticated and highly intelligent blueprint for raising children to understand and embody these values. (Greenwood, 2017, p. 220)

Though I am a novice learner in the study of IQ, it certainly comes naturally to me to see this interconnectedness as a key element and helps explain my natural (ancestral) inclination toward interdisciplinary studies. It is in my blood! I am reminded of the gifts and skills and lessons from my Mother. I always thought she showed incredible strength and resilience, even more so as I get older. Norman Attangalaaq says that “it was through [the] difficult[ies] that I became aware of my parents’ amazing way of doing conscientious planning” (p. 102). The old ones were always looking and thinking ahead, preparing and planning for the future. “She taught us about insects and the smallest of creatures because they teach us to never be proud, and we will never think that we are better than anyone else around us” (Uluadluak, 2017, p.171). I can relate to Norman’s stories and am grateful for these important lessons that I received in my childhood that have helped me on my journey to become an able human. These are the teachings of humility; I still carry these lessons everywhere I go.
The impacts and effects of the disruption and dislocation endured by my great, great, grandparents trickled down to their children’s children, and while our connection to the land and to each other remained relatively unscathed, there was significant loss of language and culture over generations. My family is young (until 2015 my great-grandmother was still alive and could tell us of her experiences) so the effects and impressions are not ancient history, long to be forgotten – it is clear and present in our contemporary reality. My mother started the heavy lifting to reclaim our culture and I have learned from her (and many others) that there is an immediate and crucial need for us to work collaboratively to become able humans (and as I contend, able institutions).

**Piliriqatigiingniq (Working Collaboratively)**

No society can act properly if you take away its foundational values and beliefs, make people feel they were completely wrong to live the way they did, and tell them to leave all of this behind. (Akpaliapik Karetak, 2017, p. 205).

Inuit are not under any illusion that only Inuit are becoming human. We are well aware that Qallunaat (non-Inuit) are also in the business of making humans. This is why it is so important for all of us to seriously contemplate the impacts and influences we have on ourselves, each other, and the environment – our **interrelationships**, the **interconnectedness** of all of creation. We must work together. “Our struggles will only make sense when Western society also comes to understand this history, because we do not want to continue to repeat the past wrongs of both Inuit and Qallunaat” (Akpaliapik Karetak, 2017, p. 206). It is not only Indigenous Peoples who will benefit when we work together collaboratively.
Naalak (To Listen/Pay Attention)

One of the teachings in *IQ* is that we should not treat children like eggs or like rocks; rather, we should treat them like able humans so that they may become able humans. We all have a responsibility to do this. “I want people to understand that when a person behaves like an egg or if they have become hardened like a rock, they are very dangerous people to society, compared to the people who have become able human beings” (Akittiq & Akpaliapik Karetak, 2017, p. 144).

**Personal Reflection:** There have been times in my life where I have been the rock, or the egg, and it is through the spiritual work that I have done that I can now integrate those multiple parts of me to be both strong and sensitive, simultaneously. Over time, I continue to learn how to operate as the ethical space, so the paradoxes and curiosities are simply fuel for further examination and action, not a deterrent or detractor from the work that I’m here to do.

*Where I’m From*

From ethical theory to the way we actually act not a question of fact but a matter of fact. To look back from humble beginnings to nine round innings A nomadic life not tamed by the skyscrapers that tower over the city My own standing committee on how to do me. From simplicity to complexity and to weave them together A proud carrier of my eagle feather (Excerpt, Digital Story, November 2017)

**Ethics Theory and REBs: Where Hearts and Minds Collide**

The key is that researchers and REB members become able humans and that REBs (and funders and universities and hospitals and all the other players in the
research big leagues) become able institutions. These are not two separate acts that occur independently from each other; they are necessarily interconnected. Gwen articulated some of the same concerns I have as I observe ethics review becoming further professionalized, further privatized, and further standardized. This can compromise the diversity of thought, integrity, and wisdom of an REB, and there is a trend of REB members being appointed instead of nominated; it is counter-intuitive (and arguably counter-ethical) to be appointed as an ethics reviewer; how can we expect unable humans to embody able practise?

I think that the [Western] model is counter-intuitive to the actual philosophy of being ethical. You don't assign someone the responsibility of ensuring everyone's behaving ethically. You have to have that innately in you to be passionate about ensuring everyone's behaving ethically. And so, people should self-identify that that's their interest and that's their passion and that's their love. And that's their motivation for being there. Their motivation isn't because it's part of their job description or because their supervisor told them to be there. You have to be there because you love it. And you care about it. And you care about others in the community. When it comes to an REB, it's humanistic and so we just ask other human beings to come forward and share their knowledge and experience, regardless of who they work for or whether they even work at all. It really comes back down to the core principles, the core values and our responsibility to care for other human beings around us. (Gwen Healey)

Many participant contributors talked about how important the composition of the REB is and how people in leadership roles at their institutions are instrumental and influential in the operation of research practices within their institutions. Johanne reminds us to approach the work with love and Riley reiterated the necessity of administrative leadership support in universities to promote and practice ethical research/review with Indigenous Peoples.

It's feeling the energy of the transaction in the research ethics board meetings so that when I'm delivering, maybe a tough message about something that the other members of my research ethics board don't know and maybe should know, that they can see through my energy that I'm delivering it with love for
my community and love for them and not in a way where I'm reprimanding them, like “you did this wrong!” I think it's really easy when you correct somebody for them to become offended and then to put up a wall and stop that future learning and the only way to break through that learning is to have people genuinely get to know each other. (Johanne McCarthy)

Our administration is like “anything is possible”. (Riley Kucheran)

There is an important distinction to be made between authenticity and acknowledgement. As mentioned previously, there are some Indigenous scholars who are being vocal about the rhetoric of reconciliation. Like Riley, I know that the change can only begin to occur when academic institutions move their words into actions. It is not enough to merely pay lip-service to the important notions of Indigenous inclusion in academia; the actions must follow.

This section has briefly described some of the theoretical considerations regarding research ethics which provides a solid foundation to lead into Section II: Applying Ethics. The notions of ethics described in this current section are pertinent and essential to understanding the application of ethics in the policies in Canada. Specifically, I will discuss the development and evolution of the Tri-Council Policy Statement and some of the common responses and reactions to it from those associated with Research Ethics Boards.
Section II: Applying Ethics

The research regulatory system in Canada is “guided by procedural norms rather than adhering to any particular principle-based ethics code” (Gontcharov, 2016, p.15). It has been set up as rules-based rather than principles-based which presents a number of operational and bureaucratic challenges. With the abundance of haphazardly applied ethics theory in research ethics policy (in particular, during the ethics creep and the moral panic) researchers and REBs are left to reconcile the divergence between ethics in the books and ethics in the field that results from a bureaucratic practice of prospective research ethics review.

In this section, I highlight the challenges-in-practice that arise from the current regulatory system by discussing some of the key confusions, contentions, and considerations that are prevalent in research/review with Indigenous Peoples. This discussion is not meant to be exhaustive. Rather, I am drawing attention to the most commonly discussed issues as brought forward from participant contributors, my observations, and the literature. Igor (Gontcharov, 2016) raises some of the important general issues for all non-biomedical research:

Among the challenges, captured in the rich phenomenology corresponding the expansion, which is itself described in politically-laden terms of “ethics creep”, “ethical imperialism”, and “methodological colonialism”, are the tensions and gaps corresponding the standardization and unification in approaches to research governance in various disciplines, and emerging between various policy actors and institutions, such as academic associations and existing mechanisms of peer-review. (p. 4)
There have been substantial additions within the existing mechanisms in the past couple of decades with the rise and fall of the National Council on the Ethics of Human Research (NCEHR); the growth of the Canadian Bioethics Society (CBS); the advancement of the Canadian Association of Research Ethics Boards (CAREB); the gatherings of the Canadian Association of Research Administrators (CARA); and Orion Human Research Accreditation (launched in the spring/summer 2018 while this dissertation was underway). Though it is important to note these key players in research governance in Canada, it is not the focus of this study to discuss them in detail; the focus is about how REBs do/not apply the TCPS 2 Chapter 9: in research/review with Indigenous Peoples. Danielle describes the evolution she has seen in her work in research ethics since Chapter 9 was added to the TCPS.

Before TCPS2, it was a consideration that Indigenous research needs to be given special attention, but it really wasn't until TCPS2 that specifically shined the spotlight and said, "Okay everybody, wake up. You have to know this, and you have to apply it." It's a step in the right direction and every single university REB in Atlantic Canada for sure is aware and is honestly doing their best to make it work and to adhere to the TCPS2 and make sense of it in a way that does not put additional burdens on Indigenous communities because you're asking them to be involved in research. There's good work going on, good change, but it just takes a long time. (Danielle Connell)

**TCPS Chapter 9: A Creation Story**

I provided some contextual information in Chapter 4 about the evolution of research ethics policy in Canada and now that we are talking about the TCPS Chapter 9 specifically, it is time to introduce Susan Zimmerman. She is the Executive Director of the Secretariat on Responsible Conduct of Research and has been in that role since 2007. Susan described in more detail the evolution of the TCPS, specifically as it pertains to Chapter 9 (Appendix I: Summary of Chapter 9 Articles).
[Considerations for research with Indigenous Peoples] was Section 6 of the 1998 version and it stated there, right at the beginning, that during the drafting of the policy suggestions were made to create a section dealing with research involving Aboriginal peoples. But the feeling was at that time was that there had not been sufficient consultation done with Aboriginal peoples to include something that was going to be policy for a government agency. So, what they settled on at that time was a set of guidance, which was described as a starting point for discussions about what an appropriate policy would be. So that was in 1998.

Then when I arrived in 2007, the various aspects of that 1998 document were under consideration for review and a decision was made that rather than revising bits and pieces of the TCPS, we should actually take a step back and the look at the document as a whole and rethink it rather than just tweaking it here and there. Many subcommittees had been looking at specific issues and I wanted to pull them all together into a reconsidered, a revised version. And as you can see from comparing the 1998 version to what was eventually the 2010 second edition, we made wholesale changes to the structure, to the underlying principles and of course had a full-fledged robust chapter on research involving First Nations, Inuit, and Métis Peoples. That Chapter 9 specifically grew out of more robust consultations with two groups that informed the thinking of the Secretariat and the Panel on Research Ethics and those were a consortium, and these predated my arrival. There was a consortium of national Aboriginal organizations that included the Assembly of First Nations, the Inuit Tapiriit Kanatami, the Métis National Council, the Native Women's Association of Canada, and the Congress of Aboriginal Peoples. And all of those groups sent representatives to the consortium, so they were there in their official capacity to talk about how - first of all to provide input and also to provide feedback the drafts that were being considered for official commentary or feedback from those organizations.

In addition to that, we had established what was called the Technical Advisory Committee on Aboriginal Research. And that was a committee composed of researchers with experience and expertise in research involving Indigenous peoples and there were both Indigenous and non-Indigenous members and I think we included their names in the TCPS2 and we acknowledged them along with all other experts we had consulted. So, we had those two groups providing us with input and guidance. And then there were, for the entire TCPS2, there were two rounds of public consultations, both on paper, so we distributed the draft electronically, and face-to-face so that we did go across the country and talk with specific groups. And we did do outreach specifically to Aboriginal communities and researchers to get direct feedback from them.
I think the important thing to emphasize in the evolution of what is now Chapter 9 was that there was a very considered and deliberate intention by the Panel on Research Ethics and the Secretariat to have a chapter that was integrated into TCPS2 but that was specific to research involving Indigenous peoples. We do believe it's the first time globally that an ethics document integrated this kind of guidance into a general ethics statement, so not having it off into a special set of guidance. And we felt that was very important because it emphasized the fact that good research practice includes good research practice when you’re conducting research with and about Indigenous people. (Susan Zimmerman)

The intention behind Chapter 9 was to shift the way that researchers and REBs (should) conduct their research/reviews; it seems it is working, slowly, as Danielle noted at the start of this section, and navigating governance is where challenges often lie as Chris more fully explains:

[Chapter 9] shifts things by requiring, or encouraging if not requiring, engagement with the community. It should shift some of the decision-making ability into the hands of Indigenous people and the hands of Indigenous governance structures. What it doesn't do is give us a lot of ideas about how to do that in the midst of some of the complications that arise. It doesn't talk about -- what is often the reality where we have communities divided and there's different governance structures and it's a complex and often contested landscape. (Chris Turner)

Many REB members noted the usefulness of Chapter 9, especially the importance of policies that encourage/require researchers to engage with communities they want to work with/around/on to ethically conduct research with Indigenous Peoples. However, even with a general appreciation and acceptance of the policy in principle, several complications have arisen from its inclusion in practice:

I'm very fond of Chapter 9, I think it's a nice piece of work, and I think it's missing a few things. Unfortunately, I think there are times when it may be interpreted a little too strictly and people may make assumptions and say, "Well, you can't speak to anybody who belongs to that First Nation, however defined, unless you've got the consent of the band". That's a real over simplification and that's a dogmatic interpretation of the TCPS. I think the TCPS leaves us enough room to be thoughtful about whose consent is required when and the danger I
think is that people interpret it very strictly and that ends up being a real barrier to research. (Chris Turner)

Researchers and REB members made lots of excuses and skirted lots of responsibilities before 2010 when there was no chapter on the ethics of research with Indigenous Peoples in the TCPS, and some still try to plead ignorance or confusion when called on their (unethical) practise. For Indigenous researchers and REB members in particular, this is frustrating:

If it's mystifying at all to anybody it's because they haven't read Chapter 9. They haven't read the CIHR [Guidelines] or they haven't gone beyond their own narrow areas of research interests. (Raven Sinclair)

I echo Raven’s observation and was relieved to hear Suzy talk about the practice at Université du Québec en Abitibi-Témiscamingue (UQAT), where it has become standard operating practice for (most) students and researchers to engage meaningfully with Chapter 9 and with the Indigenous people and communities they are researching in:

It became a reflex for students and professors now. They can't pass over Chapter 9 anymore, and they know that. They are dealing with it. Maybe they are not happy about that, I don't know. But when they're coming to me for discussions to see if they should go ahead with a project or so on. They're all ready now. They've read Chapter 9. They want to see how to apply it and which way, but at least it became a reflex to work with it, which I'm happy for. (Suzy Basile)

Even if we do not know all the intricacies of research/review with Indigenous Peoples, there are ways that we can meaningfully and helpfully contribute in our roles on institutional REBs. Brenda talked about the importance of working in relationship with new REB members to share teaching and learning about the complexities and considerations in research/review with Indigenous Peoples:

I sit down with every new member of the REB and we go through Indigenous research. I say, "Make sure you understand Chapter 9. Make sure you read the tutorial” and I explain our process. Regardless of if we think it's in our mind, a perfect application, at best we will only give conditional until it goes through
the appropriate community REB. And explain why sometimes, the community members we're explaining a little bit more. But we're looking at information on the relationship that they have, how information is going to be shared, very specific on data ownership to make sure that, that something is addressed in the application on who owns the data. How they may be looking at individual participants, but you have to look at the effect on community relationship. The whole point of confidentiality and the anonymity, wherever appropriate. (Brenda Gagne)

**Applying TCPS Chapter 9 in Other Jurisdictions**

One of the most frequently asked questions that I receive at my presentations, training, and workshops is about the application of Chapter 9 in other jurisdictions (i.e. in non-Indigenous communities). It is important to remember the constitutionally unique position that First Nations, Inuit, and Métis Peoples have in Canada and the fiduciary responsibilities and treaties that exist with the Crown; however, the community-based approaches favored in Chapter 9 and the articulation of the necessity of engagement, can be applied in *any* project, in *any* community:

When the TCPS was developed, I think a lot of people saw the way that people work with First Nations as something of a model that people were trying to use to develop protocols to deal with other kinds of identifiable communities. (William McKellin)

It is not only Indigenous research(ers) that prefer a relational and community-driven approach. Chapter 9 can help researchers in the social sciences and humanities articulate the ethical dimensions and considerations in their study within the regulatory framework of the TCPS without compromising their responsibilities to their community partners. Susan Zimmerman talked about the current revisions to TCPS2 and while there is no substantial change to Chapter 9, there has been an additional of guidance on using Chapter 9 for other community-based research:

There is a change in the [newest revision of TCPS to be released in Spring 2019]. It's not a substantive change to Chapter 9, but it's an integration of policy advice
or interpretation advice we've been giving all along, which is when Chapter 9 came out, people said, "Wow this is really interesting stuff that I could use. I don't necessarily do research involving Aboriginal people, but I do research with other types of communities, and the stuff on community engagement and that kind of guidance I find useful. Can I use Chapter 9 as guidance?" And we've said all along, "Look if it helps you do work with specific communities, by all means." We've now included wording to that effect explicitly in the TCPS. So, it's not a change to Chapter 9 per se, but it's a kind of broader application of Chapter 9 that speaks to the fact that people find this guidance useful because what's unique about it is the guidance on research involving communities. Although of course there are aspects of Chapter 9 that are unique to Indigenous peoples in Canada because of the historical and constitutional status of Indigenous peoples and their specific history. (Susan Zimmerman)

**Pragmatic Mistaken for Uncritical**

During my comprehensive exam defences (December 15, 2017), one of my committee members observed that I was surprisingly uncritical of the *TCPS* and asked if I had a critique to share. (Of course I do!) The *TCPS* is not prescriptive (though I have observed some REBs treating it as though it were); but it is guidance. It is not procedural; but it shows a process. It is not the law; but it is policy. Yet, when/where there is no ethics police force, seemingly little or no consequences to action, and no real enforcement, how do we use (and recreate) *TCPS* into a tool that does what it is intended to do?

The idea behind Chapter 9 was definitely to approach this type of research out of a spirit of respect and acknowledgement of the importance of respecting community codes, that lovely idea of ethical space that was acknowledged in the preamble. (Susan Zimmerman)

Honestly, I am not sure I am capable, even with all of the other innovators on #TeamJulie who have joined me in this journey, to talk about dismantling the entire research establishment and the State of Canada that my current critique of *TCPS2* would require. As is evidenced throughout this dissertation, I am not focussed on deficits, I
know there are abundant logistical and operational challenges that plague the entire research regulatory system at academic institutions and the REB is just one cog in that wheel.

**Personal Reflection:** Chapter 9 is not perfect. It might not even be excellent. But it’s pretty good. And it gives researchers a tool in their pocket. Better than life before Chapter 9 – during both my undergraduate and Master’s research, I had no policy to back me up other than what I knew was happening at CIHR before the *Guidelines* were released. And then the UPEI REB asked me to join. What?! AND, they were humble, knowing that they didn’t know best when it came to Indigenous research ethics. It was refreshing to be welcomed to talk with them about my work and have them listen intently as I described the points of contention between Indigenous ethics and the REB structure. I got to see inside the black box before my perception of it was tainted; I also saw people could be eager to understand what I wanted to share with them. So, it is not my intention to deconstruct the *TCPS* or to assert its necessary demise; rather, I am attempting to demystify the REB black box, necessarily examining the perspectives and practises related to Chapter 9, so that the emergence of ethical excellence can occur. I am joining the other Indigenous scholars globally in the movement to decolonize research/review with Indigenous Peoples.

The rigid structure of institutions, REBs, and research funding mechanisms inherently contradict what is needed for ethical research with Indigenous Peoples because these systems are built on, and maintained by, colonial culture and influences,
and lack integration of Indigenous epistemologies and sciences. Mohawk scholar, Marlene Brant-Castellano (2004) reminds us that Indigenous Peoples “have always conducted research within their communities to update and adapt knowledge” (p. 106). This conflicts with Western, biomedical perspectives which shape research projects and REBs (Beauchamp and Childress, 1994), disallowing space for methods and approaches that do not align with the Western paradigm.

Cree scholar Kelley Bird-Naytwohow and his colleagues (2017) clearly articulate that “the histories of Canadian colonization and the resultant health inequities signals crucial need for targeted research to reveal the characteristics, conditions, and contexts of resilience and wellness among contemporary Indigenous [Peoples and communities]” (p. 3). The only way that we can ensure a decolonizing approach is when Indigenous Peoples are research leaders.

Some participant contributors also shared reflective commentaries on the limitations of Chapter 9, like Karen and Johanne from Mohawk College who did a joint interview – a relational researcher’s dream come true as it allowed me to experience their relationship in action. During our conversation, they shared so much that their stories alone could fill an entire dissertation (and such is the power of a collaborative interview). Among many observations, Johanne described a key consideration that is missing from Chapter 9 and articulates the gap between Indigenous and Western ways of understanding ethical research as a critical piece that needs to be integrated.

What Chapter 9 misses and what even our question misses is that engaging the community and including the community looks very different depending on the community. There's a continuum of protocols that every community has, and you need to understand more of the process of how to engage the community.

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75 Linda Tuhiwai Smith (1999) provides an excellent commentary on colonization and imperialism that any researcher working with Indigenous Peoples should refer to in order to gain understanding of necessary context.
instead of “what protocol do I use?”. I think in Western institutions, we look for the one right answer instead of the right process of how do I figure out the answer that's right for this community? It's a relationship. The idea would come, but still were missing that with the applications that we're seeing. It's like they have the question that maybe might not be fulfilling a purpose for the Indigenous community and with our historical context of being over-researched and experiencing that helicopter-type research when they come in and they get the information and they mine it and they take it away and it benefits the community not at all, I think that that's kind of what's missing from Chapter 9 and from the perspective of the research ethics is that that type of, that locus of control is no longer ethical, and it's nowhere in this document, right? And understanding that the control has to be returned to the community and the power and the data has to return to the community. Rather than us being subjects of study we have to be partners. (Johanne McCarthy)

While I share in many of the sentiments that Johanne shared, I was also heartened to hear Susan Zimmerman talk about the spirit and intention of Chapter 9 and that it is purposefully un-prescriptive to allow for community autonomy in research.

The important thing about Chapter 9 is that it sets a framework for respectful conversation between researchers and communities. And that's why I believe that it's important for the TCPS to be as un-prescriptive as possible in how that conversation goes forward but leave it to communities to set the tone and the terms on which they wish to engage with researchers. The innovation of Chapter 9 was to emphasize engagement and partnerships and to take time to establish those relationships. That was a key message of Chapter 9. And the idea that engagement is going to look different and be at different levels of intensity if you like depending on the situation. So that leaves a lot of responsibility and a lot of autonomy to researchers and those they're engaging with and to communities to set up the right relationship. And that's what people are struggling with, but I think that's a really good and appropriate struggle. And I think more direction from Ottawa or from the [Tri] agencies is probably not really the right way to go. (Susan Zimmerman)

Though there will unlikely ever be a time when consensus is reached about the relevance and usefulness of the TCPS, it was clear in this study that there is information in the policy that is helpful to researchers and REBs. There will always be room for improvement and areas that can be further developed. This is actually the purpose of the
policy: to be a living document that shifts and evolves as does the research landscape in Canada. I was inspired by those participating in this study who found ways to make Chapter 9 work for them and for the Indigenous communities they serve.

**Finding a Way Through Relationship and Process: Manifesting the Ethical Space**

One way for researchers to take action is to purposefully and respectfully take direction from Indigenous Peoples and their teachings. Brant-Castellano (2004) tells us that “traditional teachings are conveyed through examples, through stories and songs, in ceremonies and, most importantly, through engagement with the natural world which is governed by the laws of life just as humans are” (p. 100). While the goal for many Indigenous communities is to have a fully formed, autonomous research office where research projects are always initiated by the community, some communities recognize that they are not yet in a position to do so. No matter what stage of community research governance exists, it is incumbent on researchers to seek the appropriate community governance structures to obtain community consent – even when there is no clear or obvious structure in place – and it is the responsibility of the REB to ensure that they do (Flicker et al., 2007). In the meantime, until projects are generated and administered locally, researchers who initiate projects must take the lead from Indigenous partners and follow the guidance from them.

Researchers have a responsibility to enter into agreements of mutually beneficial outcomes. REBs have a responsibility to verify that the type of “community-driven, capacity-building, empowering research that Indigenous communities, Indigenous scholars, and non-Indigenous scholars are demanding become the norm and we want the REB process to enable that kind of…methodology such an approach often entails, not
disable them” (Steinberg & Castelden, 2015, p. 4). Negotiating the ethical space demands that researchers, REBs, and Indigenous Peoples collaborate to find solutions in addressing the policy-to-practice gap that currently exists by constantly and continuously navigating the ethics of engagement.

Mythical Mutterings: ‘It's too hard to do Indigenous research’

Personal Reflection: Sometimes I hear the whispers (or sometimes it is shameless and belligerent and loud) of non-Indigenous researchers and students as they carry on and on about how hard Indigenous Peoples and community are making research, how cumbersome it is, how time-consuming, how laborious. All I hear them say in these moments is: ‘it is too hard for me to be ethical’ and/or ‘I’m not skilled enough at my craft to do what they are asking’ and/or ‘I don’t know what I’m talking about, how do they expect me to explain it?’. I have never heard a researcher talk about collecting data before they get their institutional REB approval, yet I hear people talk about (some even have the audacity to ask me how to) collecting data while the community review is underway, and the research not yet approved. I call people on it. I remember the day I said to one person: ‘Would you do those focus groups at that time in that community if you were still waiting to hear back on your REB submission?’ which was of course met with a firm, ‘No!’ This person was displeased when I further responded and explained that ethical research/review means that people stop asking me why they can’t just do what they want and why they have to wait for the community to participate/consent/have a say.
There is a prevalent commentary in the literature and from my experience of hearing others, that the ethics review structures for research with Indigenous Peoples inhibits researchers from doing their research. These were not the common narratives in this study. However, one participant, Dr. Anonymous, articulated those common concerns that I hear at universities from researchers and students.

The way it works is if you're doing a study, even if you’re just doing focus groups and even if it seems to be a fairly innocuous study, if it's with Indigenous populations, it's high risk therefore you have to go through the ethics board. If you're doing it anywhere in an Aboriginal population, you have to go through our ethics board and their ethics board. It's causing a huge delay in your research. So, you might have a delay with us as the first step of course, because it's a high-risk population, so you've had to go to full board with us, you've had to wait for us to satisfy our request and usually they're significant, because everybody’s very, very touchy on high risk populations. But as soon as you start trying to be more sensitive, you're putting yourself in this Catch-22 where you're stuck in an ethics rotation for ever and ever. Then you get that approval and you have to go to the Aboriginal ethics board and wait for their feedback, so like this could take six months to a year just to get ethics approval. So, it's really slowing down and discouraging people from doing research. It's like, "Oh, my god. We don't want to do anything where we'd have to go through this process." (Dr. Anonymous)

It is still common discourse from researchers that “everything is too hard in Indigenous research” and “it is just not worth it” so some people will not entertain the idea of engagement long enough to even know if they want to be involved in the field of study or not:

I think that some people will just intentionally avoid anything having to do with Indigenous people because it's ‘too hard’. “You never get through the REB”. “You'll never get through the REB”. “They'll never let it through”. Which I think is unfortunate, because it’s a myth. It just means that people have to be a little more attuned to communities -- a lot more in some cases. (Chris Turner)
The myths – assumptions and misconceptions – that the REB will disallow ethical practice is pervasive. So many researchers buy into the myth and it is evidenced in their practice.

It is a deterrent to people doing research because people do avoid doing research knowing that they have to jump through all of these hoops with all of these different ethics boards. (Dr. Anonymous)

I have heard these kinds of comments for nearly 15 years. Though Dr. Anonymous was adamant that these processes are a deterrent and a hoop for researchers to jump through, Brenda articulated that it is about ensuring ethical research, not creating more hoops to jump through.

We're looking at participants and how they're protected. How they're impacted. How their community is impacted. It's not that we're making a hoop for them to jump through, and it's not that we're trying to stifle their research, but these are the requirements. (Brenda Gagne)

Like Brenda, Susan reiterated the intention of encouraging ethical research with Indigenous Peoples has not been met with resistance from those who have been doing research this way already.

Of the things I'm struck by and I think still holds true is that when we started out with this and we got a lot of pushback on Chapter 9 that it was going to put a chill on research involving Aboriginal peoples because we were making it ‘too complicated and too burdensome’. That tended not to come from people who were actually doing this kind of work already, who told us, "You know, this is just good practise. This is what we do without having been told to do it. I would never be able to go back into this community if I hadn't built this relationship. And if I did it poorly, I could destroy that relationship and I wouldn't be welcome here again." So that's the kind of thing that encourages me that we were on the right track with Chapter 9, that we weren't imposing onerous and useless burdens on researchers but that we were actually, kind of, explicitly articulating good practice and good guidance. (Susan Zimmerman)

Indigenous communities, especially those with research protocols and processes, contend that they are not there to discourage and deter all research, they are there to
encourage and attract *ethical* research. That means taking the time necessary to build relationships through engagement with communities, which often does not align with institutional deadlines. And truly thinking through the research in collaboration versus determining how to get permission to implement a pre-determined agenda. We are *all* responsible to take the time to build and maintain relationships, including Indigenous researchers, too.

**Etuaptmumk in Action: We Must Work Together for Resolutions**

It is not just settler researchers who are experiencing growing pains related to the policy and practice of research with Indigenous Peoples. As more and more Indigenous Peoples are making our way into higher level academic positions, we face our own set of challenges with research/review. It is hard for Indigenous academics too, just in different ways. Sometimes it is about balancing ethical viewpoints and acting from a sacred place, a spiritual place, of reconciling conflicting ethical protocols. In the past this meant omitting aspects of culturally and spiritually grounded protocol from paper processes as Raven explains:

One of the early problematic pieces was that the ethics boards would require us to submit a proposal *prior* to contact with the participant. But Indigenous protocol requires us to build relationships before we even consider a research proposal. So direct contravention of each other. As a doctoral student, I did a little study because I was encountering these sorts of issues and I wanted to find out how had [Indigenous] scholars dealt with these conflicts. And a person said to me “we just didn't tell them, because we couldn't. If we wanted our projects to go through, if we wanted to do our thesis, our dissertations, we couldn't tell them that we had spent three years preparing and that I got my topic, my subject from a dream”. (Raven Sinclair)

There were some early criticisms of the regulatory system that was demanding that researchers partner with communities, but communities did not always have the research
infrastructure in place to support the demand from researchers (this is still sometimes the case). As described in earlier chapters, many First Nations, Inuit, and Métis communities have developed research protocols and processes; however, not all communities have this, so the tension remains that sometimes researchers over-burden communities who are under-resourced to address the researcher needs/wants.

The history of people initially having difficulty working with First Nations communities, simply because the First Nations communities didn't have the infrastructure. I think that's been largely resolved now by the communities. (William McKellin)

William is right in that there have been substantial advancements made in this area, and we still have a long way to go. Mi’kmaq scholar, Carla Moore and her colleagues identify that, despite the vast policies and guidance on research ethics for health research with Indigenous Peoples, “understanding between communities and campuses and within and across campus jurisdictions, are necessary to better understand the nuances of ethical Indigenous research and the disconnects between policy(ies) and practise(s)” (Moore et al., 2017, p. 13).

The utilitarian judgements made by settler REB members for or on behalf of Indigenous Peoples and communities, without their engagement and consent, serves to further amplify unethical research practises and an unbalanced power dynamic.

But again, it's just words on paper, right? And they can talk about honoring Indigenous cultural protocols, but what comes up in my mind when I talk about what protocols are is very different than what comes up in an uninitiated, non-Indigenous researcher's mind. They're probably thinking beads and trinkets. And I'm thinking about certain ceremonial protocols that have years of teaching behind them, and a certain way of understanding the world that may link to a lot of different Indigenous ethics. (Raven Sinclair)

Both Indigenous and non-Indigenous researchers and REB members are grappling with the complexities of research governance of Indigenous research and it is
imperative that we all work together to understand the best ways to work through these intricacies in a way that does not supersede community autonomy and self-determination. We must work together to find solutions to common problems and continue in our efforts to do differently in research/review with Indigenous Peoples.

**Researchers have a role to play**

Despite valiant attempts and good intentions from REB members themselves, a culture of skirting ethics has emerged. There are many scenarios where researchers give themselves an exemption (without any communication with the REB or the community) from the processes and protocols that Indigenous communities have in place to exercise their self-governance of research in their territory:

It's the work that historians, archaeologists, and even journalists are doing without any consent or any partnerships with the communities, even if they work with archives or with artifacts from many Indigenous groups. They don't need to do any kind of [ethical review] -- or ask for any kind of permissions. I think they do, but officially they don't *have to* do it. It's also the same with the researchers of natural sciences. If they do some collecting samples of whatever kind of bug on traditional lands, to them they don't have any kind of permissions to ask because they don't deal with humans. That's what they think. But from the Indigenous point of view, as soon as you do a research with or on the traditional land -- it's the same as if you were dealing with the people themselves. It's all seen as a whole. This should be the next challenge that we may face. I know some historians and archaeologists that are very open-minded about it. And they will be the first ones who will take this kind of approach if they have to. But for others, don't even talk about it. They don't feel obligated, or they don't see why they should ask any permission to any kind of human being because they work on archives or artifacts. (Suzy Basile)

Despite the growing stack of ethics policies (or perhaps because of them), researchers find ways to skirt the ethics process/procedure/responsibility. For those operating with a consequentialist framework, they are doing nothing wrong. You see,
there are no ethics police – there is no mechanism to ensure the policy is enforced. No one is issuing tickets for offenses and collecting cash for missteps. I observe some people operating within a deontological framework (i.e. they believe they have a duty to do the action), and there are a lot more people who are consequentialists (those people who act according to what the consequence of their action will be. [i.e. I will do what is right for fear of what will happen if I do wrong]). There are still unresolved issues, we are left to find ways to operate outside that structure.

Gwen talked about how they have worked in Nunavut to enhance the ethical conduct of research in the communities by taking it into their own hands, to become their own ethics police, so to speak:

Perhaps universities would laugh at us, but anyway, we're going to do it our way. Everybody's coming together from the perspective that we're acting on the values of our communities while also balancing the requirements of the TCPS2. They become ambassadors, going to other communities and talking or teaching or sharing about ethics or, you know, I mean it can go anywhere, right? Beyond just project review when you come together in a values-based way. That's one of the founding values of our center is that we conduct ourselves ethically with goodness and kindness in a heart-centered way that emulates the values of our community. So, all of our research projects have to be cognizant of that. We only go where we're invited and where people have approached us we used a more community-centric study design. (Gwen Healey)

Everyone has a responsibility to ensure ethical research/review with Indigenous Peoples and it is unhelpful to place blame on one person or the other, asserting their malicious intent. I do not think that many researchers and REB members are malicious; I think people are uninformed or uninitiated, but not malicious. We need to be open-minded and kind in our learning as we are all mis-stepping and over-stepping in lots of ways as we navigate the complex landscape of research/review with Indigenous Peoples.
Looking Inside the Black Box

I enjoyed the fun and messy job of inviting REB members, chairs, and administrators to be a community of participant contributors in my research. The REB is a dynamic and idiosyncratic community, and a community under substantial influences from their respective institutions and the individuals that comprise them. In performing the REB dance, researchers and REB members themselves can get caught up in and focus more on their performance of ethics, and less in their practice of ethics. It is a fallacy to assume that REB members themselves are free from these tensions.

As the practice of research ethics review becomes more about relationships between researchers and REBs, it is important to demystify the black box of the REB for the relationship to flourish. This means practicing in the open, transparently, ‘in public’ as Socrates intended, for what is ethics without the citizenry? A key challenge that emerged since REBs have adopted online systems is that they have put all their forms and documents behind a closed door. In many cases, a user login from the institution is required to access the online systems:

A lot of universities now you can't even see what their application says, because either they've gone with the programs where it's submitted electronically and so you can't see what questions that you're asking, or all of their tools and their templates are hidden on the intranet and you can't access unless you're a member. I've got tons of stuff on the intranet, but what's on the intranet is also on the internet, because I'm all about transparency. So, if a participant in any study that's coming out of our university wants to know what's on the application, they can see it. (Brenda Gagne)

Personal Reflection: The black box that is the REB is on a black table, under a black sheet, behind a black curtain, and all contained by a black fence. Now, not only can we not see the internal operations and mechanisms in motion, we cannot even see the parts that comprise it. The move to electronic formats and
digital submissions means that people who do not have a login ID from that institution cannot even see the forms (now what’s a #dorklete to do if I can’t just randomly read REB protocol questions on a Saturday afternoon?)

The reductionist nature that REBs and researchers employ in an effort to “comply with the TCPS” means that we are in a time when “the protocol is truer and more real that the research itself” (Gontcharov, 2016, p. 89). I do not hear students and researchers say that their primary mission is to protect participants or to build relationships with participants or to engage meaningfully with participants – I hear people talking about *compliance to a policy* rather than their *responsibility to the people*. We have to be able humans, working together and listening to each other, to address common issues that alleviate the sickness that is pervasive in systems (i.e. their colonial structure and stature) to create able institutions.

**Responsible and Responsive REBs**

In the experiences and articulations that I have heard and observed in the past dozen years, REB members and administrators themselves are thinking and talking about themselves. They are often reflexive in their practise, attempting to be able humans within unable institutions as they navigate and negotiate a dynamic and evolving regulatory and governance landscape.

My board is fabulous. They want to do their very best by the participants. And we understand that Indigenous communities and culture had requirements that we don't always encounter in other community-based research or participatory-action research. And those types of research are difficult to navigate as an ethics board, under simple circumstances. And then you throw into the mix is that we have to be very cognizant of cultural requirements and protection of participants and their stories and their songs. (Brenda Gagne)
Personal Reflection: As a young student, sitting on the REB brought up a new tension for me: what I was experiencing as a REB member did not align with the perceptions and perspectives of my peers and professors. The people on the REB weren’t monsters. Not a single one of them had a dragon’s head or vampire teeth. Where did all the myths come from and what can we do to help demystify them?

Despite REBs self-identifying as open in their practice, the fear of the REB is ever-present. Again, this is not my experience since I have found that many REBs are comprised of #dorkletes like me who are happy to discuss and debate the ethical dimensions of a project. Yet, REB fear is pervasive.

Fear shouldn't be part of it. We're happy to help out in that way as much as we can. We don't want to be a barrier to the research either. We're just there to try and help people along with it there. "If you want me to pre-review your application, just send it to me, and I'll sit down with you." Especially the students, but anybody, and I have chats with faculty as well as students and go through their applications and say, "No, no, no. Don't do it this way. You need to do it this way. And make sure that you include this. Or don't say this. You need to do it this way instead." And the vast majority are like, "Wow, this is great. This really helps." And it does, because the review comments are substantially fewer and it goes through a lot faster for them. So, they can make the first round of changes much more quickly just on their own time before they actually submit, so it helps all around I think. But we are trying, much harder that way in terms of being particularly careful about being approachable and helpful. (Joy Knight)

Igor talked a lot about the distinction between appearing ethical and being ethical: “from a procedural standpoint of research ethics boards, appearing ethical is more important than being ethical, since prospective review can only deal with appearances” (Gontcharov, 2016, p.103). I cannot count the number of times that I have
overheard researchers say, “I am just writing it that way because that’s what the REB wants to hear”, or “how do I say this in a way that the REB will approve?” It is because of such pervasive commentary that I am not sure we should (or even could) abolish the prospective research review approach. This is why my dissertation is not about a removal, it is about a revolution.

‘It's not about the forms’.

Research is relational; ethics is relational. How much might things change if others can see inside the black box? What if everyone viewed ethics the way that I did? What if more people joined the #dorksports and realized ethics is about what you do not about the forms you fill out? What would it look like if more undergraduate students had the opportunity that I had to see inside the black box so that I could make my own opinion about what happened in there? What would happen if we started talking to each other? Trusting each other? What if we all just focused on ourselves and becoming able humans/institutions? William described the importance of relationship and reiterated that research ethics is not actually about the forms, which is often how students and researchers view it:

It is about relationships and I think that needs to be highlighted, to get people to pay attention. It's not about forms. So, if people see the application as the beginning of the relationship, that's going to give them the feeling that the application is a hindrance. Whereas if they begin the relationship beforehand, then the application is just the culmination of the relationship. (William McKellin)

‘No, for now’ not ‘no, forever’.

While the mythical monster may mutter that REBs are ‘out to get’ or ‘slow down’ or ‘shut down’ researchers, this perception has not been validated in practice
from the observations of the participant contributors in this study and myself. It may be a ‘no, for now’, but it is not a ‘no, forever’; it is a process, a discussion, not a test. REBs are generally not in the business of stopping research or inhibiting researchers yet it has become dominant discourse which substantially impacts the relationship between researchers and REBs. Chris, William, and Brenda all relayed a similar message regarding this common discourse:

We don't say no, we say no for now, you know, “we need more info” or “can you please change this”. There's a lot of myth out there about REBs and about the process. (Chris Turner)

We have very few projects that ever get denied of any sort. We spend a lot of time trying to make sure that research can take place ethically, rather than seeing our job simply as being gatekeepers and expecting people to figure out how to get through the gate…. I think people are afraid if they say that they've been talking to [the community] then they'll be told that they shouldn't be doing that. When in fact they'd be encouraged to do that. Part of it is I think people feel that if they don't get approved on the first go, they're being seen as unethical. (William McKellin)

Most REBs are flexible and we will do whatever we have to do to make it work. Our job isn't to decline research, it's to ensure it's in keeping with the TCPS. (Brenda Gagne)

It is about researchers articulating a meaningful understanding of how they will implement their research and acknowledging and planning to navigate worst case scenarios. It is not about preparing a “perfect research plan” document where nothing will ever go ethically wrong; it is about identifying where the ethical tensions are, naming them, and mitigating them in a specific, tailored way appropriate for the community and participants. Sometimes this means acknowledging that some tensions may be unresolvable, and a position will have to be taken from a particular standpoint and it be left to the REB to approve or not, and/or changing the research design in such a
way as to alleviate the tension. REBs should support researchers in “getting there” while maintaining the integrity of the research.

**A Radical Shift: Beyond the Settler-Imposed Vulnerability Complex**

While it is important for researchers and REBs to address how they operate according to preferred practices, we also need to move away from the language of ‘high risk’ population and ‘vulnerable’ population. As Johanne so eloquently described, vulnerability is something that happens *in relationship*:

> It's not okay to call me vulnerable anymore, that's not a healing relationship. You can't call me vulnerable unless you're willing to look at your role in my vulnerability, because vulnerability comes in a relationship. And somebody's who's supporting that vulnerability instead of supporting your growth and your resilience. And so that's changed the vulnerable people to resilient people. (Johanne McCarthy)

This can be a tricky place for settler researchers and REB members who are well-intentioned, attempting to “protect” Indigenous Peoples. Several of the participant contributors spoke to how important it was to move past the old narratives and dominant (oppressive) commentaries.

**Personal Reflection:** As much as I appreciate settler researchers who work in relationship, am hopeful in the contributions they make (for example, see Kathy Snow’s excellent paper 76 *What does being a settler ally in research mean? Graduate students experience learning from and working within Indigenous research paradigms*, 2018) and am grateful for them sharing the heavy lifting, I am also done with the other types of settler researchers. The ones who do not see us as human, the ones who see us as innately vulnerable and needing their

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help/advice/protection. In my experience of listening to people articulate their motivations, I’m not sure how many of them have actually listened to themselves. In their efforts to ‘protect’ Indigenous Peoples in research, well-intentioned researchers and REB members can lose sight of what Indigenous Peoples need protection from: settler research(ers). This colonial mindset only further perpetuates the problems and closes off the opportunities to meaningfully collaborate to build partnerships.

Johanne and Karen talked this through in their shared interview and how they are doing it. Johanne talked about the impressions and imprints that these stereotypes and biases have on her as an Indigenous person sitting on an REB and Karen talks about courage that non-Indigenous REB members need to do differently. I know that the preceding conversation from Karen and Johanne is still not the norm and is not the perspective that many researchers and REB members come with in their practise; however, this radical shi(f)t is required:

And we have to have the courage, for many reasons, to say “we're just not going to approve this”, or “this can't happen”. (Karen Henderson)

It is hard to say whether or not the dominant perspective of Indigenous Peoples being inherently vulnerable has lessened in the past several years (i.e. Indigenous Peoples are not more vulnerable, the life contexts and social circumstances create risk). I still hear the remnants of this racist and colonial bias, so I think we still have a long way to go; however, there are some people (like the participant contributors who joined in this study) who are thinking differently about notions of vulnerability and are infusing their practice with the new learning that comes from thinking differently.

We've gotten away from associating Indigenous people or labelling Indigenous people as vulnerable and opened up this space that characterizes persons or
groups in vulnerable circumstances. I think that's a really good step in the right direction because it allows us the intellectual space to think about a community being in a vulnerable situation or position because of the historical context, because of institutional racism and systemic racism and all the other things that are at play, but gets us away, I hope, from a paternalistic kind of approach. (Chris Turner)

Chris articulates the importance of this shift as integral and I agree that it needs to happen before people or institutions can attempt to do differently. We cannot do differently so long as we have the impression that Indigenous Peoples are inherently vulnerable. It was refreshing to talk to people like Danielle who shared her insight on how her thinking about vulnerability changed over time:

I have evolved, happily evolved my way of thinking about vulnerable populations -- that these communities and these groups of people do not wish to be referred to as vulnerable populations. The things we are doing to them is what makes them vulnerable and to be conscious of when we're reviewing an ethics application not just are the methods sound and the data being treated properly, but what are you asking this community to do? How much time are you asking them to commit? And where are you asking them to travel, what are you asking them to do that's out of their normal daily routine? Are you imposing yourself upon this community and asking them to put in tens to hundreds of hours of volunteer time so that you can write a paper? (Danielle Connell)

There's always a risk and the reflex of the REBs that are there to ensure protection of participants, but at the same time, acknowledge the fact that these are people that have wills and intelligence, so that reflex has to be checked sometimes. That's where a really good Chair comes in, because that kind of reflex of, "Oh, we have to protect these people." it's something that sometimes has a tendency to not take over, but it's like an instinct, you want to protect. And you have to realize that these people have agency and they have intelligence and they have, regardless of the type research, we have to give them credit for what they're -- they can say no, so the role of the REB is really to make sure that they're informed of everything, but to give them a choice. (Catherine Paquet)

REB members are tasked with balancing individual and collective interests, assessing risks and harms, and knowing the level and extent to which they are there to protect. Research ethics codes have been developed to protect participants in research,
but it is not the role of REBs to assert unnecessary and unlawful power over Indigenous Peoples, deciding for them what is best for them. The protection that Indigenous Peoples and Nations often need in research is from the institutionalization of research and researchers’ dominance over Indigenous ways of conducting research.

We are All Learners: The Magic Happens Outside Our Comfort Zone

Even though a lot of participant contributors specifically used students as the example in describing some of the challenges of a rookie researcher in Indigenous research, understanding these dynamics is essential for anyone new to a community, regardless of their position and stage in their career, and for those who have long journeyed in the realms of what it is to know. We are all learners. I am including some of the commentaries here so that we can all come back to basics, to refresh ourselves on the key components of what it looks like to do differently in research/review with Indigenous Peoples. Chris described some of the key complexities the REB faces when reviewing protocols where the researchers has not engaged with the community.

It's challenging because sometimes we review projects from master’s students who are enthusiastic and excited and they want to do something and they have good intentions, but they also have very little grounding and very little understanding of what they're proposing and really they cook up this project, which really aligns with what they want to do, it aligns with their program of study and fits with what their supervisor understands.

They come to us, and they haven't even visited the community yet. And the supervisor never visited the community either so that's a real problem for us is there's no community engagement of any kind let alone the kind of deep community engagement and co-design of research that is preferable, if not required. And that's one of the things that we grapple with here as the REB grapples with is that, if by requiring Master’s students for example to engage with communities in a deep way, we preclude that research from being done. That's an opportunity to figure out how we can support those students to do that work and the REB can only do so much, it's really kind of a matter of saying to
faculty, saying, "You know, if you want to put your graduate students to work on this stuff, you really need to help them with those relationships."

And so preferably it's the faculty themselves who want to do this kind of work or supervise this kind of work already have a relationship with those communities that's long standing and has had many conversations about what the community needs and wants in terms of research and so has an idea of how to match community needs with research resources. And maybe then there's more of an opportunity to put graduate students to work.

It's frustrating for an REB to come back on a graduate student that what they've proposed, while meaningful, it is just not doable because they first have to do three months or however long it takes community engagement and to ask those fundamental questions about is this research really in the best interest of the community? Is it designed in a way that will actually benefit the community? Are the research products actually going to be of some use to the community? Are you going to just do this thesis and then disappear? Or, what is your plan for reciprocity? How are you going to make that happen?

A lot of graduate students just go, "Whoa, I'm going to do something else. This is, you know, so and so REB and blah, blah, blah." You know what they say about us, right? “You know, they stopped me from doing this research”.

The approach that we take is we really -- we try to educate and encourage. We don't flat out say, "No, you can't do this." What we say is "You know, we like this, we think it's really promising, we want you to go engage with the community and see if they think it's really promising too and get back to us with what you've done or what you're proposing to do and then we'll work together to try and make this a community-engaged project." At which point, I think we lose a bunch of people. (Chris Turner)

The learning that happens at the REB is important in the regulatory system and there needs to be adequate expertise to review the research that is proposed. Researchers and REB members themselves often identify under-resourcing as a major challenge. They say that adequate expertise from a variety of backgrounds is not always evidenced by the composition of the REB. Riley shares his passion for interdisciplinarity and argues its essential role in research/review with Indigenous Peoples
It boils down to interdisciplinarity. Imagine that we have history person, a science person, and an on-the-ground person who are all looking at urban issues. But they're in three different areas of the university. When it's a question, "What are better cities?" and that research question actually involves a whole different view across the university. What if we had a bank of questions regarding [university/community] specific Indigenous issues that all of our researchers could take on. What are our questions that researchers should be tackling that are informed by communities themselves. It's completely flipping who is determining what research is being done. (Riley Kucheran)

Even though some researchers imagine REBs as monsters to be slayed or deceived, the REB members I spoke with seem harmless, open to dialogue, and supportive of research (though I am keenly aware of some of the challenges with REBs as well). They are also as frustrated as the rest of us with the systems and they know that they do not know what the best approach is all the time; they too are looking for guidance from communities, and it can only come to them through the written researchers’ protocols. This leaves REBs powerless to determine the authenticity/sincerity/commitment of the engagement.

Every researcher, regardless of discipline, has a responsibility to engage with and get permission from Indigenous peoples/communities. I am horrified (and not surprised) to hear of the many stories of researchers ‘shopping for ethics approval’ (e.g. a recent example in Newfoundland and Labrador where a biotech company publicly discussed their experience with the NL Health Research Ethics Authority77 – Big Money Research is shopping for ethical approval and talking about the economic benefits of their agenda not being acknowledged – and without answering the questions about economic benefit for whom?. Participant contributors in #TheJuliestPhD shared some of the tough stuff and told stories of difficult scenarios and how they worked/are working

in their practise, what they have learned along the way, and what their visions are for how we can do better.

I know some researchers will go to another board, like in another university who don't have the Indigenous glasses let's say, or some other board who will make sure that it passes. And I saw it in the past. They will take one of their partners, one of their research partners and go to another board to get the research certification. But then it's to the community, to put their foot on the floor. And say, "No." "No means no." Many Indigenous communities are kind of mad about these ones who are passing under the line of ethics guidelines. (Suzy Basile)

**Personal Reflection:** I would love it if all humans inherently took on the responsibilities of our spiritual mandates, but I know that is not currently what is happening. If ‘everyone is responsible’ then no one is. On this subject – ethical research/review with Indigenous Peoples – we no longer need to convince people.
Section III: Practicing Ethics

The final section of this chapter was difficult to write because it is all circular – there is no beginning and there is no end – and my best attempts to write those circles into lines left me lost somewhere in a maze of tetrahedrons. This section highlights five specific thematic and (relative) chronological elements necessary in research with Indigenous Peoples and discusses some of the practical implications of these components for researchers and institutional REBs in the governance of research involving Indigenous Peoples. First, I discuss ethics-led research, noting the importance of ethics permeating all stages of research (i.e. ethics before methods). Then, I discuss decolonizing approaches to research through the ethics of engagement, where I discuss intentions, idiosyncrasies, and Indigenization. This is followed by the breakdown of the paradigm of individual consent in research by discussing two related components: Indigenous governance and control and collective consciousness and consent. Finally, the section ends by reiterating that research is relational, giving examples of Etuaptmumk that can be practised by researchers and REBs.

Participant contributors reiterated the common challenges that REBs face that align with what Nicholls et al. (2015) noted from their scoping review:

[M]embership; time; cost; variation; satisfaction; policy adherence; working hours; outcome; training; knowledge; structures and procedures; number of protocols; committee/board member views; researcher views; participant views; committee/board decision making; post approval monitoring; number of committee/boards in the region; and views of healthcare professionals. (p. 8)
Some of the additional key challenges that participant contributors talked about in this study were: privacy, conflicts of interest, jurisdiction, inadequate funding, defining community, and liability versus ethics. One way to begin to resolve these challenges is to focus on research ethics before or with the research design process.

To address the power imbalances and historical experiences of Indigenous communities, while also honouring their resilience and expertise in their lived experience, a common mitigation strategy that researchers use is to employ community-based or participatory approaches. However, “the cursory adoption of participatory methodologies is not necessarily viewed as sufficient for fulfilling the requirements of respectful research partnerships with Aboriginal Communities” (Brown, 2005, p. 84). Researchers must go further than this and support the community processes to identify the appropriate approach rather than assuming, overlaying, or imposing a personal theoretical or methodological position (Fouché et al., 2017):

There has to be improved education on Indigenous research methodology and context, our history and our relationship that we’ve had with research. People don’t understand why we say no, and they position us as non-collaborative and non-helpful. And I think it's because there's no education in the mainstream about the context of your relationship with institutions and researchers and how much harm has been done and how much harm we’re healing from as communities as Indigenous communities. (Johanne McCarthy)

Simultaneously, there is a critical need to ensure that Indigenous epistemologies are included throughout the research process (Wilson, 2008). This means research in Indigenous communities is to be driven by their agenda and governed by their laws. Likewise, research methods should reflect, or at least not contradict, Indigenous ways of collecting, storing, analyzing, interpreting, and reporting on data (Bull, 2010; 2016). As Raven mentioned, it is a journey to learn the processes and there are a lot of resources
out there to help novice researchers and REB members learn more and practice better (I have included some from my research in Appendix E).

It's a process and not a brief process. You can't watch a few YouTube videos and understand Indigenous worldview, although it would help. There are a few good ones out there like Leroy Little Bear. (Raven Sinclair)

There is no prescription for how these beginning points of research may look but as Amanda describes, it is all about the relationships that researchers have with communities:

That strong partnerships and working with the content area group, you know even the best scientifically designed research studies won't help you get the perfect answer. You really need to work with whoever it is that the research is about. And then that's where sort of the fun stuff happens. And you think you're going to do one thing and then you end up doing curriculum. But I think just that ongoing back and forth with the community partners is what really makes the research most important and most relevant. (Amanda Sheppard)

Raven went on to describe in detail what a relationship means and what kinds of questions we need to ask ourselves in our research endeavors.

The relationship piece, Indigenous people are no longer there to be the passive willing subjects of whatever it is you desire to do as a researcher, so you have to develop that relationship and that's the piece I think is probably the biggest barrier. You have to develop the intellectual understanding and then you've got to do the work. Then you've got to go out there and meet people. You know, in every community, in every sort of urban community there's non-Indigenous people who are part of all the Indigenous activities and it doesn't take long to become accepted, but you have to be a decent person, right? And participate and be willing and they've established those relationships and in time we forget they're not Indigenous. It's like oh yeah, I forgot that. If you don't have Indigenous people in your life, Indigenous friends and colleagues, if you've never been into an Indigenous person's house, don't do Indigenous research. And from my perspective too, if someone doesn't sort of meet those basic criteria, of, you know, having Indigenous friends and maybe even extended family and relationships with community -- people in community. Then I would question their motivation for wanting to do Indigenous research.

78 Leroy Little Bear: Indigenous Knowledge and Western Science
Because to me, that's a very sort of privileged Euro-centric perspective, that I can do this just because I want to and just because I think I can, and I should be able to. Well, no. It doesn't work that way. (Raven Sinclair)

The awareness is increasing on the part of the REB and as Brenda explained, the REB has a role to play in ensuring relational research is occurring with Indigenous Peoples:

In some aspects the pre-education of researchers, of what they need to do with communities -- I mean I had someone come in that wanted to do research and it's like, "Well, who do you know in the community?" And "What's your relationship?" And it's like, "Oh, I don't have any. I'm just going to show up." And it's like, "M-hm, yeah, that's not going to work." (Brenda Gagne)

There is an abundance of guidance and resources on the ethics of research with Indigenous Peoples that REBs and researchers have a responsibility to engage with in their efforts to conduct ethical research/review with Indigenous Peoples. Appendix E provides some of the key resources and readings that researchers and REBs may find helpful in their educational endeavors.

**Engagement: Intentions, Idiosyncrasies, and Indigenization**

The literature has clearly demonstrated that a new environment for ethical research with Aboriginal communities is emerging – one in which respectful partnerships which meaningfully acknowledge and accommodate certain inalienable rights and responsibilities are fast becoming the norm. (Brown, 2005, p. 85)

In *Decolonizing Methodologies*, Māori scholar, Linda Tuhiwai Smith (1999) says, “the word itself, 'research', is probably one of the dirtiest words in the Indigenous world's vocabulary” (pg. 1) and due to a history of unequal power relations and ongoing colonial constructs and systems, Indigenous Peoples demand researchers locate
themselves within a decolonizing framework. An important aspect of decolonizing research is to support the exploration of research questions identified by and, where possible, through a process defined and led by Indigenous Peoples. There is a clear emphasis on the motivations of a research project and as Gwen says, it is the responsibility of the researcher to situate themselves and their research within the larger historical and contemporary context:

“Why are you here?” You can't be doing this because you need to push out more publications or you're going for tenure or whatever it is, you think it's fascinating that Inuit live differently than the life you know wherever you're from. Those are not good reasons to do research here and we need to clearly know your motivation. We need to clearly see the link between your study and what the outcomes are for our people, our community. You are operating within a historical context where anthropologists came here and pulled people's teeth out without ever explaining why. They just abused their power and authority in our community and now people are terrified of research in that one community for sure. [Researchers say] “well you just make it too hard to do research there”. Well, maybe this isn't the place for you. If you can't respect that then it's not the place for you. I don't think we're making it hard, I don't think we're making it difficult. I think we're forcing people to have to learn a new context. And if they're unwilling to do that, then I don't think that's on us. (Gwen Healey)

Ideally, Indigenous communities themselves are identifying research priorities and determining research questions. In cases where that is not happening, and a researcher has their own idea, the researcher is then responsible for engaging with the community at that very first stage to see whether or not the researcher’s brilliant idea is aligned with a community need/want. Like Riley says, this has to happen at the beginning and carry on throughout the duration of the study:

It needs to be at the ideation stage. You have an idea for a project, okay great. You need to figure out what the community thinks of that idea. And this is flipping up the whole system, is foregrounding community leads and communities determining the research agendas. It's not like shooting arrows in the dark. Like maybe the community will need this. It's like no. This
community has listed us their ten top priorities, their ten research questions that they need, that they could use assistance and like then we go out and find researchers to do those questions. (Riley Kucheran)

**Context Matters**

Without understanding the context they are working in, researchers may inadvertently cause harm in their study. Johanne reiterates this necessity and calls on REBs to ensure that Indigenous Peoples sit on the board and that innovative visual learning tools be created to assist researchers and REB members in their educational efforts.

So as part of an historical context, providing context for why we are doing this, an understanding of why we're doing this, not so much the history of this is everything that's gone wrong, but why it's important and why. I mean I guess to avoid re-traumatizing people, you need to know some of that, but also, my bottom line is really you need someone from the Indigenous community sitting on your board. Because I don't think -- I don't know if this can be written down. I think what we've talked about videos and more visual learning tools would be helpful. (Johanne McCarthy)

The argument is that colonial academic culture, which privileges the knowledge acquisition and production of non-Indigenous Peoples, results in research that is of an exotic (and essentializing and usually unusable) nature (Kovach, 2004). For example, research conducted in Indigenous communities often has little or no measured impact on health or social well-being, despite great claims made in funding applications regarding how positive and beneficial the research will be (Brant-Castellano, 2004). Several participant contributors emphasized the importance of reciprocity in research. Riley expressed his view by telling some of his learnings as an Indigenous researcher:

I think hammering down the reciprocity, and compensation is not reciprocity, but you need compensation. And the giving back; your research needs to directly affect or directly benefit the recipients. My example of working with this Indigenous business owner, like I just worked for her, I made sales for her,
I organized her back house, I tuned up her website. As an intern for this Indigenous fashion designer, that was a daily giving back in exchange for just observing, not taking up her time or her space. I got so much data, it's such good research, and it's just from helping her. Maybe ask her a few things, but it was really just observing. I was getting everything I could possibly dream of just from watching and helping her. So, destabilizing the idea of what it means to give back. And my relationship with that person is ongoing, and something I found very difficult for my master's research was having to stop the research, I was like “this research is never going to stop, Indigenous research is life”. (Riley Kucheran)

I agree with Riley’s articulation that Indigenous research is life and that there is no end point (another difficult reality for Western researchers to fully comprehend and enact when used to thinking in ‘one-off” studies):

Just because that study is done, their relationship should not be ending at that point. This is a life-long thing. (Brenda Gagne)

There are fundamental and foundational aspects of Western and Indigenous research that collide; Riley explained that a shift from epistemologically-centric understanding of research/review is required:

People are very epistemologically-centric and until they can really get it, that Indigenous epistemology and ways of understanding the world is fundamentally different, they're not going to understand that that's why research has to be fundamentally different and much more robust, and that's exacerbated by the fact that research history with Indigenous people's been pretty shitty. (Riley Kucheran)

**Templates and Tick-boxes**

While there is no template for what engagement looks like, one fundamental component includes shifting perspectives and moving away from colonial biases. Many REBs have come to rely on templates and checklists to get their work done in their attempts to “standardize” and “stream-line” complex, contextual processes. While there are some excellent examples of templates and checklists (Appendix H, for example),
these forms fail to assess contextually-relevant elements that are essential to Indigenous research ethics and tends to simplify and reduce Indigenous research ethics to a series of yes/no questions without requiring researchers to demonstrate that they have given any real thought to the actual ethical conduct of their study. Even the template lovers amongst us, like Brenda, recognizes that sometimes they just do not work.

I love templates and things that could be provided just as fill in the blanks, but this is not the type of research that a template is really helpful. And talking in general about community-based research, each community is different, each study is different. And, we have tried templates and it winds up not making any sense because they're not really applicable, but they're just trying to fill in the blanks and, get up and running. (Brenda Gagne)

The idea of ‘standardizing research ethics’ needs to be revisited and challenged. REBs need to take time to “reflect on and develop awareness of [personal] assumptions about Indigenous [Peoples and communities] they carry, as that vison shapes their reality and informs their engagement with [Indigenous Peoples and communities] in contrary ways” (Bird-Naytowhow et al., 2017, p. 7). While it can be helpful in their learning to review templates and checklists, they need to remember that the actual ethical conduct of research cannot be reduced to a checklist; where is the room for nuances and contexts and post-modern realities in a checklist? It is the responsibility of researchers (and REBs, as appropriate) to educate themselves about the communities and people they seek to engage in research, and to understand both the globally significant and locally relevant context in which they operate.

We're talking a fundamental shift in valuing knowledge, and that just goes way back to the devaluing of like ‘oh, they don't know anything, I'm going to go teach them these skills.’ And so how do you voice that? Like how to ask like a PI: “have your thought that you're like devaluing Indigenous knowledge systems because of your lived biases over your entire life?” That's shaking someone to the core, I'm saying “hey, you actually have some major biases and you're devaluing Indigenous knowledge”. (Riley Kucheran)
Though Riley and others expressed that it can be difficult to speak up in these cases and we all know it can be difficult to be on the receiving end of such commentary, we also agree that these uncomfortable conversations can be a catalyst for action.

‘There’s no one-size-fits-all’.

Kenna comprehensively described how they have applied TCPS Chapter 9 at the University of Victoria. This is not intended to come across as the best way or the only way, but it is a good starting point to grapple with the questions that researchers need to be asking themselves, and that REBs need to look for in their reviews:

[Our REB form] asks questions about where the research will take place and if it includes land that's under self-government by Indigenous people. It talks about what the criteria for participation is, and if it includes Indigenous participants, communities, or organizations. It asks about Indigenous artifacts, traditional knowledge, unique characteristics, whether Aboriginal identity or membership in the Aboriginal community will be used for the purposes of analysis and whether the research will refer to Aboriginal communities, people's language or culture. And if you answer yes to any of those questions, it asks you what kind of community engagement you have been involved in and to provide details about your community engagement and append any appendices you may have. If you say you don't have any community engagement, then it asks you to briefly describe why community engagement will not be sought and how you can conduct a study that respects Aboriginal communities and participants in the absence of community engagement.

This section of the application is very broad and encompassing. It's not meant to dictate what that community engagement looks like. We understand that different communities have lots of different ways of being engaged and even within communities we've seen research studies where certain members of the communities are supportive of the research and the other members of the community are not, and how the researcher navigates that is what we're looking for there.

And then also there's situations where researchers will not seek community engagement at this time. So, they may be doing a study on street-entrenched
youth and not expecting to focus on Indigenous street-entrenched youth. But then as their project develops, maybe they come to see that they have more street-entrenched youth so they want to have that as a focus, who are Indigenous peoples and then in that case they would be looking at involving the Native Friendship Centre or an Indigenous researcher on campus who would mentor them in their culturally-safe approach to those participants.

There's no one size fits all. What we're really looking for is that the researcher is explaining to us what is most appropriate for their participants in their context and why. All this stuff is very contextual. It depends on the nature of the study, so studies that will include Indigenous people or have a large number of Indigenous participants without having a focus on specifically looking at Indigenous participants. (Kenna Miskelly)

As Kenna describes, there are several ways in which Indigenous Peoples and communities may be involved in research so we, researchers and REBs, have to work in a dynamic, quick-and-nimble way that respects these contextual nuances.

**Mo’ money, mo’ problems.**

Given the increased attention to Indigenous health research in particular – and exponential increases in funding and other opportunities that go along with this increased attention – many researchers are quick to engage with ideas of research about Indigenous Peoples, but often fail to address their own personal and/or institutional biases (e.g., racism, colonial influence) that prevent them from engaging with people meaningfully. “Community engagement – if done uncritically and in the service of ethical guidelines rather than in service to ethical research – can itself cause harm” (Brunger & Wall, 2016, p. 1862). There is an increase in attention being paid to this issue and increasingly more researchers calling out this practise. The burden once again falls on Indigenous researchers, who, as Suzy describes, now have a harder time acquiring the funds meant to support Indigenous research.
With this new wave of specialists, we are facing the consequences of it, because now the challenges, the competitions, it's harder [for Indigenous researchers] to get the funding (Suzy Basile)

Suzy described a common challenge for Indigenous researchers who work ethically in relationship with communities. The systems and structures of the funding agencies in Canada are not set up to support Indigenous research meaningfully, but changes are underway. For example, the Canada Research Coordinating Committee\(^79\) (comprised of membership from the Tri-Agencies – CIHR, SSHRC, and NSERC) was established in 2017 and then in June 2018, they released a special call for proposals, Indigenous Research Capacity and Reconciliation: Connections Grants\(^80\). In September 2018, I worked with the Research and Education Office at NunatuKavut and collaborated with nearly a dozen institutional REBs in Atlantic Canada to propose a gathering to discuss ethical research/review with Indigenous Peoples. Funding was received and the \textit{Naalak Gathering: A Regional Dialogue on Indigenous Research Ethics} will take place in Happy Valley-Goose Bay in March 2019.

Research funding structures in Canada tend to focus on government and industry-led priorities, and protect institutional liability, but rarely promote locally relevant community research questions and interests (Moore, 2015). This disconnect and power imbalance between research mechanisms and communities under investigation underpins all non-Indigenous research governance structures, making it increasingly difficult for Indigenous Peoples to garner full control of the research agenda (Tobias et al., 2013), which is essential to negotiating collective consent. There is substantial burden put on communities in research from the “funding structure that asserts the

\(^{79}\) http://www.ic.gc.ca/eic/site/127.nsf/eng/home

necessity for community engagement but does not provide the resources and support necessary to do so” (Riddell et al., 2017, p. 3). These timelines and structures can cause a lot of difficulty for both researchers and REBs, as Brenda and Catherine explain:

Timelines are huge. If you have funded research, you have particular timelines that you have to follow, but community-based research is very fluid and doesn't always follow a timeline. So, it creates issues both for the community and for the researcher. The federal funding requirements and guidelines don't always sync well with what has to be done within the community and with the community. (Brenda Gagne)

It is sometimes difficult to meet the timelines that are set by granting agencies for example, because researchers have to build those relationships and maintain those relationships. And it also puts pressure on the REB. (Catherine Paquet)

Though the TCPS is not primarily concerned with funding, the country’s foremost granting agencies that comprise it – CIHR, SSHRC, NSERC – specifically align with the TCPS ethics framework and thus need to fund projects appropriately so they can be implemented ethically. Carla Moore and her colleagues elaborate on this critique by saying that “factoring time into developing respectful relationships is an important consideration for both funding agencies and academic institutions” (Moore et al., 2017, p. 11). While it will take some time for these national structures to change, we can all do our part to influence the shift. Also, as Amanda describes, the time constraints to do so not only or always occur on the community side:

If you read about Indigenous health research, there's always -- not always -- but sometimes you'll read about how research will take longer because you're working with community and they have their own time, other priorities and things may take longer and that type of thing. And I think because of the great relationships that we have, the holdups of our research projects are usually in-house. So, I think it's sometimes lazy just to say research will take longer if you're working with community because in our case, I don't think that that's fair. (Amanda Sheppard)
One of the ways that TCPS, funders, REBs, and others can address these issues is to be transparent about the complexities and to publish examples of real-life scenarios that have occurred, including the challenges, and importantly, how they were addressed. We need to stop being afraid to discuss our mistakes and missteps. We will only learn from them when we start to discuss them and to learn how to do differently next time:

We need a basic framework that says in these kinds of situations, this is how we handle it. On this real, specific community type of research, we have a set of principles, a framework that we stick to. On this higher-level stuff, we grapple with these questions about what is the appropriate level of engagement? Who are the appropriate governing structures to engage with? (Chris Turner)

As I have said previously, there is no prescription that will provide researchers and REBs with an exact formula for operating within Indigenous ethics of engagement. The onus is on the researcher to initiate the conversation by speaking to Indigenous community members who can ensure the correct governance bodies are aware of the project and that adequate engagement has occurred. Researchers need to take direction from Indigenous Peoples: the communities get to decide how, and to what extent, the engagement process will take place.

**Indigenous Governance and Control: Whose Research Agenda is it?**

Engagement is underway when researchers have partnered with Indigenous Peoples and can identify the necessary, locally-specific processes and protocols they must undertake with the community/leadership/spiritual people. Now they can, together, begin to determine and seek necessary approvals from the Indigenous governance structures impacted by the anticipated research (if they are not already part of the research).
REBs are built on policy and guidance with the fundamental principles of autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 1994) in relation to individual participants in research and TCPS2 core principles are respect for persons, concern for welfare, and justice (CIHR et al., 2014). While this orientation to the individual is a fundamental element of both health research ethics review and health research itself, this is not sufficient in Indigenous research/ethics/communities. The ethics of extraction is long embedded in Indigenous communities. Though as Inuit we are taught to never take from another without their explicit permission, this tends not to be common practice in research.

Researchers must have an orientation to—be in relationship with—the collective in order to meet the ethical imperative of community consent. Establishing community consent does not erode the necessity for individual consent; rather, it is an additional process that provides a layer of protection for communities, by communities (not unlike multiple institutions reviewing this study protocol even though it was already reviewed and approved by several others). This practice is essential because many (Indigenous) communities have their own experience of or have witnessed others being misrepresented and exploited in research (Brunger & Russell, 2015). Many participant contributors discussed the complexity of community consent and engagement, noting a few key issues that remain unresolved:

It's a daily challenge, trying to reconcile community or collective rights versus individual rights and a regional perspective versus a community perspective. And trying to make researchers understand that they're not just a researcher, they're also a participant. Trying to make them understand that this is learning for them as well. They're not necessarily the expert. And that's hard for some researchers to let go of, the thought that they're an expert in an area when in many cases, it's the community that's the expert. [The community] knows what's wrong; they know perhaps what needs to be done, or they know what's
working and why it's working. And for an outsider to come in and say that it has to be done differently, that's just not okay. (Brenda Gagne)

There are many complexities and considerations regarding the authority to determine research in Indigenous communities and is beyond the scope of this study to discuss in great detail and with specific nuance. Despite the complexities and uncertainties in all cases, there is general agreement that Indigenous Peoples and Nations themselves have the inherent right to decide and determine what and how research is conducted with their people and on their land.

**Pushback on protocol: The common struggles.**

None of the following issues are unique to Indigenous research since many of them are commonly experienced by researchers who operate outside dominate Western and biomedical models of research. When we attempt to conduct ethical research with communities within the constructs and confines of the bureaucratic research regulatory system, we will inevitably face challenges and find a way to overcome them:

Indigenous Peoples aren’t waiting for others to do it for them…[so] we developed this tool for researchers coming into Nunavut, which articulate ethics from a different point of view, ensuring that projects align with our values81. (Gwen Healey)

Many Indigenous communities are now cautious and are challenging the research community to be cognizant of research practises based on “exploitation, racism, ethnocentricity, and harmfulness” (Smith, 1999). Kaufert, Glass, Freeman, & LaBine (2004) point out that “[c]ommunities still have distinct legal and constitutional

81 Appendix H includes the Qaugiartiit Health Research Centre Reviewer Health Research Ethics Checklist
rights and thus, have political legitimacy to make decisions about issues, including health research projects, which directly affect the community” (p. 20). There has been an ongoing shift for Indigenous Peoples where we are no longer willing to allow research to happen that we have not been a part of developing or that we do not consent to happening in our territories:

We are not a subject of research anymore. And the communities or the institutions -- Indigenous communities or institutions -- needs to be a partner of the research and to do the research with and not on or above or whatever. I can still hear and see this attitude sometimes. That: I'm going to work on you; I'm going to help you; I will find the solutions for you guys. I'm like wow, maybe you should stop and check what already exists first and make sure that you build a research project with the people you're going to work with and not arriving with all your material ready and expect to do your interview before the end of the day. It doesn't work like that anymore. (Suzy Basile)

Researchers are ethically obligated to educate themselves on the protocols and practises of the people of the territories in which they work, and REBs are ethically responsible to ensure that Indigenous community governance structures are respected by requiring that researchers demonstrate the engagement process and documentation of community consent. The level and extent to which communities participate is decided by the community themselves. Researchers do not get to decide when adequate engagement has occurred and must take direction (i.e., not ‘suggestions’ or ‘recommendations’ – direction) from the Indigenous partners throughout the duration of a project with respect to all aspects of the research process. This might challenge some Western concepts of privacy and confidentiality:

I think those basics are missing and it's very clear when you're reading some studies that people are trying to make a comparison and fill the gaps. Though they may have good intentions they don’t know the first thing about Indigenous

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82 In this research study, participant contributors joined me in-relationship and we have been blurring the lines of western notions of confidentiality and privacy. Participant contributors agreed to be named (with the exception of Dr. Anonymous).
relationships. We need to find a way to change that. I don't think people can do research responsibly without having that background. (Johanne McCarthy)

Conflicts of interest.

Like ideas of privacy and confidentiality, Western notions of conflicts of interests are continually challenged in Indigenous research where relationships are integral and integrated, not extra or excluded. Describing our relationships and locating ourselves in the research is an attempt to ‘disclose’ those conflicts of interest. As William says, there is no requirement that no conflicts exist, just that we document potential conflicts, how we will manage them, and identify new ones when they arise:

Sometimes there are questions about whether there are conflicts of interest. If people are working in small communities, they may be getting a close relative signing off on the Memorandum of Agreement. Then people have to declare the conflict of interest and as long as it's declared and it's documented, that usually doesn't pose an insurmountable problem. (William McKellin)

Data issues.

Data itself can pose many challenges for researchers and REBs. There is still consideration confusion about data analysis/interpretation, management, ownership of data, and responsibilities to/for data. There is no shortage of descriptive research on Indigenous Peoples yet, still, so little is conducted that includes Indigenous epistemologies and methodologies. Leroy Little Bear, a member of the Kainai First Nation, describes what this looks like in practise: “[Researchers] have done a fairly decent job of describing the customs…but they have failed miserably in finding and interpreting the meaning behind [them]. The function of Aboriginal values and customs is to maintain the relationship[s] that holds creation together” (Little Bear, 2000, p. 81). Therefore, it is essential that Indigenous Peoples are involved throughout the entire
research process and that they provide their expert guidance on how to interpret findings within context. For me and most Indigenous researchers, this is a natural way to conduct research. However, it can cause discomfort for some of those researchers who are not accustomed to these collaborative models of research.

Well, all questions of validation of the results. Like, I know that some researchers are not comfortable doing it, because they think that it gives too much power to the council or to the respondent or the participant of the research to change or to modify the interpretations of the results. I'm not afraid of that. I tell them many times, and I did many sessions of validations of the results with many people, and it always was a plus more than a less. So, of course, it depends on what kind of issue you work with, but still I never face any resistance or any problem doing this kind of exercise. And the communities appreciate that. They say: “Finally we have a word to say. We can see in advance what will be written about us, and maybe explain or understand better the way that research is done and influence the result. Because who will live with the result after all the researchers are gone, going back home, back in town, or south or somewhere, but we have to stay with everything that is left behind”. (Suzy Basile)

An issue that's coming up is the whole data management plan thing and the requirement for sharing of data and we're at a bit of a crossroad there because I'm fully aware that there is some data from Indigenous communities that just should not be shared ever. Like if you're asking about their medicine, what they've used for centuries for their community, there's always that worry that that information will get out to pharmaceuticals and people wind up making a crap ton of money and nothing ever goes back to the community. Some of this is sacred knowledge that you can talk about in a round-about way, but not with specifics. (Brenda Gagne)

The respect and honouring of communities’ ownership of their data can create tensions when there is conflict in the analysis, interpretation, or dissemination of those data. In some cases, research results are never released, and this is its own difficulty for researchers to accept. That being said, if they are committed, if they have a relationship with the community, if they are creative and resourceful, they will find an alternate way that is supported by the community to talk about the research. When communities say “no”, and a researcher fights against this, it is evidence that the researcher has deep
reflection to do and conversations to have about other ways of working with the data.  

There is a global movement in Indigenous Data Sovereignty, with networks in New Zealand, Australia, and the United States (Kukutai & Taylor, 2016).

I have been reminding students and researchers for years that without Indigenous Peoples participating in their Indigenous-project, they would have no project. I am kind when I deliver this message and I am deliberate in my intentions: to help researchers understand the value of working in relationships with communities. In these partnerships, it is not only the Indigenous people who benefit; everyone does. Suzy backed me up and gave me hope:

Without Indigenous people, these researchers won't do research. They will probably do research on many other things or people -- but without us, they will not do what they do and sometimes they forget that fact. I still see some attitude, like we shouldn't say a word and let us be researched, which is to my point of view an old-fashioned idea. And more and more researchers are open to establish partnerships with Indigenous people even before thinking about a research project and will try to build it with instead of build on. But this is an ongoing process. (Suzy Basile)

While the progress that Suzy mentions is occurring, there still remains several points of contention for searchers, REBs, and communities. Perhaps one of the most complex and contentious issue regarding data is the sharing and access to data, specifically raw data. Suzy went on to describe this challenge:

The main problem would be about the sharing of raw data. And some communities would like to have all the material that is collected, even if it's not analyzed yet. And some or institutions or researchers don't want to give all their material like that -- the results of it, yes. This is one of the challenges let's say. But sometimes they come to an agreement together that they will involve the communities in the analysis of the data. They will find a way to share as much as possible. But it also depends -- that's what I say to some communities. Sometimes you collect really private data. Maybe it's better that it's not near the hand of anybody that's rubbing by the council or something. So, you need to think about that too. If you don't have any archive center or proper storage area,
you should be more worried about that than the researcher's closet in his office. The protocol that I know are following the principles and the values of the policies. Because most of the protocols I know are based on the OCAP [ownership, control, access, possession] principles. And the OCAP principles are in Chapter 9 now, saying that OCAP principles should be respected. So, we're all going in the same direction. Easy to say I know. So far, I don't see any big problem with that. (Suzy Basile)

**Ownership and jurisdiction.**

Traditionally, Inuit share everything. The modern-day notions of “ownership” and “jurisdiction” are foreign concepts and colonial constructs fraught with conceptual and technical discrepancies easily identified by Inuit philosophers. There are inherent tensions that we Indigenous Philosophers face when we operate within Western systems. What do you do with the property of data with the community that you work with? How can you share it and how could -- as an example, the life story could be published under the name of the person who gave you the interview and then you become the editor instead of the author? This is a way to give back the property of the content of the story to someone you have been interviewing. So, this kind of concrete example could be more tangible for new researchers. (Suzy Basile)

I think it needs to be really clear that whether you're a student or researcher or whoever you are, that content, those data, those stories, that all belongs to the individual or the community. And you have to work with them to interpret it and disseminate it. It never becomes [the researcher’s]. (Amanda Sheppard)

In some instances, community approval bodies and processes mirror institutional REBs in their composition and process (for example, see NunatuKavut Community Council, 2006); sometimes there are no specific research governance mechanisms in place, yet collective consent and approvals are still required (See: Brunger et al., 2014; Brunger et al., 2015; Fitzpatrick et al., 2016; Harding et al., 2012; Inuit Tapiriit Kanatami & Nunavut Research Institute, 2007); and sometimes alternative, locally relevant, processes may need to be undertaken at the community level (e.g., seeking a
Band Council Resolution in support of the research, or getting a research license from provincial or territorial body)\textsuperscript{83}:

Sometimes communities have very structured processes, and researchers, non-Indigenous researchers find those structured processes easier to follow and sometimes Indigenous communities don't have their structured processes and non-Indigenous researchers have to navigate relationship building and trust building, and this is not something that all of the researchers have the capacity to do. So, the research ethics board isn't the one that tells them that. We let the community guide them or not guide them as the community thinks is appropriate. (Kenna Miskelly)

The process is not always clear and straightforward so researchers and REBs have to do their homework (i.e., do some research) when it comes to knowing who to engage and where to get collective consent. If a study is done in partnership, these challenges are often easier to navigate. Sometimes, though, the complexity is heightened when the “community” in a study does not refer to a geographic community:

On Chapter 9, what we mainly hear when we go out is people having difficulties with the application, the taking the principles -- on which there seems to be general agreement -- and putting them into practise. So I think one of the things people find the most challenging is what is appropriate engagement with an Indigenous community, especially in the urban setting. So it's a little clearer where you have a geographically defined community, but as you know we define community in three separate ways of which a geographic community like a reserve is only one. So communities of interest and organizational communities are harder to nail down and harder to know with whom should you be engaging? What is appropriate engagement? And we appreciate that those are challenges. It's not clear to us whether a change to the wording of the TCPS is going to make that better or easier. That becomes more an issue of what are best practises? Or what are good practises for community engagement? So when we initially put out the 2010 version with Chapter 9 we tried to give examples of first of all, what is a geographic community? What is a community of interest? What is an organizational community so that people would see their communities reflected in that, and we also tried to give examples of the fact that there is a spectrum of community engagement. Depending on the focus of your research you might

\textsuperscript{83} This is not a comprehensive list of possibilities and researchers are required to consult jurisdictionally-specific guidance that applies in the territories they plan to conduct research.
need to engage absolutely fully and completely, the community is essentially a partner in your research, all the way down to this research touches only very tangentially on Indigenous peoples and how might the research process be sensitive to that, but that might be not like engaging an entire community, but simply being sensitive to the fact that some Indigenous individuals may be involved in this research and how can you be sensitive to that and ensure that that's reflected in say a consent form. (Susan Zimmerman)

Chris talked about some of the different ways that Indigenous Peoples and communities may be involved or implicated and how that may be defined in a research protocol:

It takes some investigation to figure out the ways that Indigenous people are involved, whether it is involving a particular community or communities or whether it maybe research that involves Indigenous people but not only Indigenous people and not particularly on an Indigenous related topic. So, the first step is really to tease apart how the project engages with Indigenous people, and whether there are risks to a particular community, however you want to define it - a community of practice, it could be a geographic community, it could be a number of geographic communities - and that really determines the approach we advocate. (Chris Turner)

A primary goal of researching with Indigenous Peoples is “to radically shift, if not invert, the balance of power between the academy and Indigenous research partners – and to meaningfully acknowledge Indigenous partners as nations, not stakeholder groups – with jurisdiction over research in their communities and on their traditional lands” (Stiegman & Castleden, 2015, p. 4). It is not enough to say the words: our actions must follow. And it takes time and effort to do so:

It’s beyond just the pen and paper, it's about the historical trauma and it's about protecting me as the one who's always -- in a sense it's like we've been abused, right? So, we've been abused and traumatized by research. And then me being the victim although I don't like calling myself the victim -- me being the victim is expected to teach my abuser how they're hurting me. (Johanne McCarthy)

There is no one way to understand and apply jurisdictional considerations in research/review with Indigenous Peoples and there remains some serious complexities
that need to be resolved (such as the role that collective research review bodies have to determine whether or not an individual community member can share a life story, for example). Though this research did not address or answer these complexities specifically, it was clear from participant contributors that there is a responsibility from the institutional REB to adhere to and promote the community appointed jurisdictional review bodies when available.

Multi-jurisdictional quagmires.

Like many of the ethical challenges I discuss in this dissertation, multi-jurisdictional quagmires are not unique to Indigenous research, though it can certainly be amplified because of the historical and contemporary context and the complex governance structures within Indigenous nations and communities. Attempts to standardize and harmonize research ethics review in Canada has been fraught with institutional and jurisdictional complications, and there are no examples of national centralization for review, despite many efforts to create such a structure (see for example, Heath Canada, National Association of Friendship Centres, Inuit Tapiriit Kanatami).

Since ethics is context-specific, I am not surprised that previous attempts to centralize have not worked. There are, however, regional ethics harmonization initiatives that are underway (see for example, Newfoundland and Labrador Health Research Ethics Authority84). In British Columbia (BC) as Kenna from the University of Victoria succinctly describes, a key component of harmonization is the idea that ethics is

84 https://www.hrea.ca/
a conversation and there are ample opportunities for innovation and collaboration just around the corner when we start engaging in dialogue:

In B.C. now, we have what's called the “B.C. ethics harmonization initiative”. It’s an initiative to reduce duplication of research effort on the part of the researcher. So, researchers only need to apply to one research ethics board in B.C. in the major academic institutions and in the health authorities. So it's the five health authorities and the major academic UVic, SFU, UBC, UNBC and so [the researcher] submits one ethics application and all the research ethics boards review concurrently and the REB administrators facilitate the concurrent review of the research ethics application so it is still reviewed in each jurisdiction, like under the jurisdiction of that board but then everything goes back to the researcher as one and they respond as one and then they get their approvals to all the -- all the institutions that they require it from.

So we don't review everything, of course we only review stuff that involves UVic but that has really built up a lot of collegiality among the boards and a lot of support for facilitating, you know, we all know each other know, we talk to each other, we are very comfortable sharing information with each other. We still are under our own jurisdictions, so we don't do so much of -- the way you review on a research ethics board where you actually say what do you think about this, I don't know, what do you think about that?

We don't do so much of that, but in terms of who should -- the other part of this harmonized initiative is that one board becomes the board of record and that means they take the administrative - they're responsible for the administrative oversight and that board reviews this study first and they write up the provisos and they send the study and their provisos to all the other boards involved and those boards then review the study and decide if they have additional questions or concerns. And so that has been an interesting question about who should be board of record in terms of some of these studies and what makes sense for the study for the researchers. It's been good. It's been a really good learning opportunity for everybody, like I said everybody gets to know everybody and this is kind of how I know some of these details that I wouldn't have known before. (Kenna Miskelly)

Even without standardization or harmonization practices, researchers often express frustration with the lack of coordination and communication among REBs. In multi-jurisdictional studies (including this one), there can be as many REB processes as there
are study sites. Many participant contributors expressed concern with this current model and several mentioned actively addressing these concerns in their regions.

It's silly and that's what really kind of gets under my skin about the research ethics board. If somebody in the University of [X] or University of [Y] has gone through this process and approved it as ethically sound, that should require nothing more than a delegated review at best. And I mean that's what should be done across all academic institutions, because really this is not rocket science. Let's pick a form and figure it out. (Dr. Anonymous)

The *TCPS* talks about reciprocity agreements as a means to mitigate the challenges of multi-jurisdictional review but there does not seem to be a lot of reciprocal practice when it comes to the review and approval of research protocols. Dr. Anonymous went on to articulate her frustration with the current operation.

There's no agreement with any ethics board and it's almost like they try to out-ethics each other. And so, everybody's saying well, “How can we facilitate your ethics application?” Well, we can facilitate them by making everybody work together. Like everybody get along, right? And that's what it comes down to. Why can't you respect each other's work ethics and get along? And if University X says it's a good submission, believe them. And if University Y says it's a good submission, believe them. They're an ethics board. Take their word for it. (Dr. Anonymous)

Of course, Indigenous Peoples endure/d all kinds of terrible research practices because someone in power whether at the community or organizational levels just “took the REB’s word for it” being ethical. The whole reason this dissertation exists is to challenge the idea that any REB can speak for Indigenous Peoples in research decision making – how can REB members who have never visited a community review research or possibly know what will be potentially harmful to the community? While most participant contributors supported this viewpoint, the comments by Dr. Anonymous are an important reminder that different people are at different points on their journey rather than a reflection on REB frameworks, TCPS2, and Indigenous research ethics.

However, the current structure could stand to learn from the regional harmonization
processes (like BC) or the licensing processes (like NU) so that we collaborate on ethics governance and reduce the burdens on researchers while promoting local community jurisdiction of research, rather than compete to ‘out-ethics’ each other.

**Confusion in urban jurisdictions and complex Indigenous governance.**

“Community jurisdiction” in urban areas and in cases where one individual is a leader of multiple communities can complicate the consent process even further because there is not necessarily clear direction with respect to who should be approached for community consent. Chris discussed a pertinent example to illustrate this complexity and confusion:

It gets much more complex when you have multiple researchers from multiple institutions doing research on multiple communities and then it becomes more difficult to define community and because of that it becomes more difficult to engage with “A community” when it may be a far more ambiguous community. So, for example, if somebody's proposing to do research on dental hygiene in Indigenous communities with a fairly broad geographic scope -- so they're not talking with or engaging with specific geographic communities, but rather they're engaging with Indigenous people and it is a project that's not about dental hygiene for the whole citizenry, it is dental hygiene with Indigenous people. And so, it's a full-on Indigenous topic and full-on Chapter 9 applies but identifying a particular governance structure that can speak on behalf of or engage with the researchers on behalf of this “community” becomes very difficult. If they're a member an Indigenous health authority, that may be useful, there may be sort of the larger forms of Indigenous political agency, like tribal councils and treaty societies and these sort of more overarching -- in B.C. of course, we have at pan-provincial organizations, the Assembly of First Nations, the First Nations Summit, B.C. Union of Indian Chiefs, so it's tricky for the REB and for researchers to actually figure out what is the appropriate governance structure that they should be engaging with. (Chris Turner)

Though the example and context that Chris speaks about is from BC, these complexities are mirrored in all provincial and territorial regions of Canada. It can be helpful to think of it like this: The approach to community consent generally
recommended is similar to research being conducted in a school—researchers are required to get approval from the school board, Principal, teacher of class, parents of children participating, and finally the children themselves. As William stated:

We have to remember communities have their own politics. (William McKellin)

This general model can help but does not address the reality of political and jurisdictional conundrums that permeate Indigenous research.

Always a question of urban, like what do we do if the student or the researcher wants to do something with the Friendship Centre, which is around the corner. Do they need to go back to the communities? With them? Okay, but which communities? It's always these questions of depending who is going to work? Depending what -- who is going to be part of the research? And what -- is the Friendship Centre partner of the research on that? That could change a lot of things too. So it's always this kind of confusion between the urban and the community that could give the community consent. (Suzy Basile)

While relatively straightforward in some communities, like schools, this process does not always line-up with the complex realities of authority structures within Indigenous and otherwise defined communities (Mitchell, 2012). For example, the lines of accountability may not be obvious in some communities where there is no active Elders or politically appointed council:

So, the TCPS doesn't speak to that as far as I know, there's no discussion about how a researcher should navigate that. It does acknowledge that there are complex governance structures. (Chris Turner)

So there's a whole spectrum of how one engages, and I'm still not sure to what extent changing a policy document is going to help with that, but that's a large part of what we're hearing when we dig down about, "Oh, Chapter 9 is difficult." It's not so much the wording of the articles doesn't make sense, it's how do we actually do that in practise? And for that, I think the Secretariat and the Panel have a role to play in educational materials. We certainly have tried that with a webinar that's focused on Chapter 9 and a module of the course on research ethics, a stand-alone module of the course on research ethics that also tries to take you through Chapter 9. I suspect we need to do more perhaps education and
outreach on this, and we would be responsive to specific requests for changes. (Susan Zimmerman)

Alternatively, it may be that the “obvious” authorities to consent are precisely those who, because of their position of power, may curtail research that others in the community deem to be of benefit. For example, consider the scenario of a researcher examining Indigenous Chiefs’ perspectives on and treatment of women—community members may be eager to participate in such a study but how would “community consent” be obtained? It is unlikely that chiefs would agree to this given that they may be the “target” of the research.

It becomes tricky when we are on one hand trying to respect the autonomy of people to decide for themselves what is best for themselves and then on the other hand also recognizing the importance of the community and its governance structures. I think REBs need to be careful about is getting so locked into this idea that you must have band consent that it ends up precluding a bunch of really meaningful research that the citizenry may be very much in support of but the political elites may not be, because they perceive it as a risk. (Chris Turner)

There are many more questions than answers when it comes to the appropriate consent required in communities. There is no one way to do it and researchers are required to engage with community partners to understand and obtain the suitable consent. This is the epitome of grayness that ethics is all about.

**Collective Consciousness and Consent: On Whose Authority?**

Policy that directs researchers to negotiate collective consent requires that researchers and REBs explicitly attend to the politics of risk—the ways in which collective identity and research risks are co-constructed. The simplification of community negotiation by making it look like individual consent on a larger
scale is inappropriate and misleading to both communities and researchers.

(Brunger & Russell, 2015, p. 377)

Once researchers are engaged with communities and have identified the
Indigenous governance structures and processes to be undertaken, obtaining collective
consent is required. This is ongoing. Just as governance structures are widely varied, so
too, are the methods to obtain collective consent (See for example: Fitzpatrick, 2016;
Brunger et al., 2014; Sherman et al., 2012; Sylvestre et al., 2017; Tobias, J.K., 2015;
Bird-Naytowhow et al., 2017. The TCPS2 (CIHR et al., 2014) includes guidance for
researchers on what to do in research with Indigenous Peoples – engage with
communities; however, a clear discrepancy still exists in the application of this policy in
terms of how to do it.

It is not only in Indigenous research where notions of collective risks and
benefits in research are prevalent. The ethical dilemmas that present themselves when
balancing collective and individual interests in research is examined in genetics and
other fields where it is recognized that there may be negative implications from the
research. There is a general understanding that where an entire community may be
negatively implicated even if only few people from the community participate,
individual consent is necessary but not sufficient (Burgess & Brunger, 2000; Kaufert et
al., 2004; Weijer et al., 1999). “It is the group’s collective autonomy that is challenged if
researchers, with informed consent of only a few individuals in the group, can probe for
information about the whole group” (Greely, 1997, p. 1412). Brenda alludes to this gray
area that researchers and REBs find themselves in when attempting to balance
individual and collective interests and consent.
How do you reconcile all of this together and still try and do what's right? Sometimes it's like a mine field. We’re trying to make sure that what we do is right and that we're doing right by the communities. (Brenda Gagne)

Neither individual nor collective consent should be seen as a moment in time; rather, they are both ongoing processes of negotiation and asking the question, “is this ethical?”. Stiegman and Castleden (2015) succinctly summarize that the focus of the REB “should be on evaluating the strength of research-community partnerships and structures of mutual accountability that have been established, while acknowledging the jurisdiction of the nation in question and deferring to their authority” (p. 5). This is especially necessary in cases where Indigenous communities and nations have established their own REB (or equivalent)85.

Likewise, there is general agreement that health research can present genuine risks for socially identifiable populations and that individual informed consent is not sufficient for ethical research involving Indigenous peoples (Brunger & Weijer, 2007; Bull, 2016; Moore, 2015). By controlling their own research agenda, Indigenous Peoples are able to use their spiritual and philosophical foundations (i.e., ontologies and epistemologies) to guide the work as a way of mitigating challenges embedded within academic institutions.

It is important to note that controlling the research agenda does not mean that only Indigenous people can conduct research with Indigenous Peoples; non-Indigenous people can participate in relationship to/with communities. Communities who are actively engaged in research priority development will have a greater sense of involvement, ownership, and accomplishment, and are in an ideal position to recruit

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non-Indigenous researchers to work in relationship with them to address their self-determined priorities (Schnarch, 2004). This community-driven approach generally elicits practical outcomes which yield direct benefits to the community (Sinclair, 2003). This is not to say that only community-based research among Indigenous people is ethical or that all research must provide explicit benefit to the community.

Since the TCPS is not translated into practise, and individual researchers and REBs are left to interpret the application of the policy, there is uncertainty among both REB members and researchers about how to/what does it look like to actually engage communities to obtain free, prior, and informed collective consent (Stieglitz & Castleden, 2015). Joy acknowledges that the research landscape is changing and that more education is required:

People are well intentioned, but they're not aware of the steps that they need to go through. Things are changing, the research community is changing, the research landscape is changing, and it has changed dramatically for Indigenous persons, but not enough yet. The only way we can get it changed sufficiently or continue to change is to educate more people about how research should be done in concert with instead of on people. (Joy Knight)

The necessity of collective consent does not erode the requirement of individual consent and should not be seen as a way around the general ethics protocol for research involving humans. This is an ongoing dilemma for REBs, as Brenda describes:

But getting REBs to understand the impact of the research on the community, versus the individual, is still difficult, because we tend to think of participants as the person giving the interview or answering questions or questionnaire or providing a sample, but in fact it has a huge community impact. And trying to reconcile the participant not as one, but as we, is still difficult. (Brenda Gagne)

The collective consent process is compulsory in addition to the existing requirements for individual consent and can be described as a “careful negotiation of the
complexity of authority and representation” (Brunger & Russell, 2015, p. 377). Chris talked a bit about what it looks like to negotiate these complexities:

Here [in BC] it's often a Reserve community, so an Indian Act defined Reserve, so the REB would ask the researcher to come up with, if they haven't already, a community engagement plan and ultimately demonstrate to the REB that they have community support. That can look differently in different places in different types of projects. One of the challenging things is there are very complex governance structures in Indigenous communities, and so we are aware that simply asking a researcher to engage with the Chief and Council is not necessarily the whole story. Often there are other governance structures that may not be as visible to some. (Chris Turner)

Sometimes part of the community engagement process is to undergo formal review to obtain collective consent. People frequently ask me what it looks like at the community level with research protocols are reviewed. Gwen shared a bit about what it looks like for them at Qaujigiartiit Health Research in Nunavut:

People are often looking at it with an eye to common ethical concerns. Like how will this benefit the community? What are the risks of participating? Will this draw negative attention to the community in any way? Will anybody be harmed from participating? You know, those are a lot of questions people are asking. Why are you doing this? What's your motivation for being here and doing the study? (Gwen Healey)

**MOU, research agreement, data-sharing, and other names for relationship.**

Gwen describes the process for creating research agreements in Nunavut:

We do a separate research agreement. We have a template that we kind of hand out to the researchers. And we say this is our expectation, that we have to enter into a community research agreement and there’s multiple reasons why. So, there's turnover, there's multi-year projects, where you know, maybe we can all commit to something in a meeting on the phone, and then everybody forgets three years later what happened and nobody's got a copy of the minutes or has read them. And so, the research agreement really just clearly outlines why we all came together in this space to do this work and what everybody gets out of it and what our shared communication protocol is. It's a really simple template with, I think seven or eight line-items that have to be articulated or addressed in the
agreement. And then any kind of financial agreement is separate on top of that usually with a finance department, so, like a contract [office]. (Gwen Healey)

There are many ways that these agreements can take shape and Kenna explained a few key ones:

We see communities that do full MOUs, have complete, formalized, research ethics processes with forms, we've had communities ask researchers to provide power calculations in terms of whether they'll approve or not. Is this in this community’s best interest? We also see communities that do verbal consent. We see also as I said-- community-driven research, where the community has actually sought out the researcher or the partnership between the researcher and the UVic research, or the community and the UVic researcher we see research -- we see students we are Indigenous students from communities interviewing their own family about certain things and we've learned a lot. We've learned that it's really inappropriate to ask students if elders require approval from the community to participate in research because the elder has that knowledge and is self-informed about that. So, asking whether there should be a community consultation when an elder is going to be interviewed is inappropriate. So, we don't ask that any more. (Kenna Miskelly)

Researchers and REBs are finding their footing as they negotiate collective consent. Even the order of review (i.e. REB review then community review, or community review then REB review) can be complex and is different in different places. Brenda described what they do at Mount Saint Vincent University:

For the most part, we have our researchers go through our REB first. I know the norm is to go through the Mi'kmaw Ethics Watch first. We do it a little bit differently here. We go through the ethics application via the board and once it's in a shape where we're comfortable with it, we will then bestow a conditional clearance. That condition is based on clearance by the Mi'kmaw Ethics Watch or another Indigenous ethics group if it's not going through the Mi'kmaw Ethics Watch. They aren't able to start their research study until that is in place. And they do have to send a copy to us. So we have found that by doing only conditional clearance, that by the time that it goes to the Mi'kmaw Ethics Watch, it's actually in pretty good shape, they've not declined any of our applications by our researchers to date. (Brenda Gagne)
Relational ethics: Reflexivity and reciprocity.

Researchers need to adhere to Indigenous governance structures by obtaining free, prior, informed collective (and individual) consent, and actively work on the relationship, all while navigating their own positioning in the world, generally and in their research, specifically. Reciprocity is not a buzz word, it is an ethical imperative as Riley explains:

A lot of research just asks for a lot of people's time. It's like “I want to interview this service provider for two to three hours”. I always say “think about less time. Think about meeting on their time and not asking for an interview in the middle of the day or something like that”. Because people say “oh, in the spirit of reciprocity I'm offering a ten-dollar voucher”. That's not the spirit of reciprocity. I have to explain, and even I don't have the best words to articulate it. It's much deeper than that. (Riley Kucheran)

Research is relational: All my relations.

It was unanimous, and unprovoked, that there is no blanket approach to research/review with Indigenous Peoples. There is no one size fits all. There is no magic bullet, but there is power in relationship. Indigenous research is relational; and every relationship looks different:

You have to know what it takes to have a long-standing relationship and that really is the sort of thing that informs the kinds of things that you look for in an application. (William McKellin)

Researchers are required to build relationships on the foundation of respect, relevance, reciprocity, and responsibility (Kirkness & Barnhart, 1991) in an authentic way (Bull, 2010). After communities are engaged in the research process, Indigenous governance is adhered to, and collective consent is obtained, researchers are ethically obligated to continue working in relationship with Indigenous Peoples throughout the
duration of the project, including the development of manuscripts or other dissemination materials.

**Multiple Worldviews Collide: Etuaptmumk in Action**

When the community is engaged, Indigenous governance is adhered to, appropriate consents are confirmed, and active relationship-building with Indigenous Peoples is underway, it will be time to begin collaborative-thinking about the way the research will be conducted. There is general agreement that involvement of, and engagement with, Indigenous Peoples in research is necessary (as discussed repeatedly in this and earlier chapters), yet there still remains a need to acknowledge and address how knowledge itself is created, by whom, and for what purposes (Kovach, 2009; Tuhiwai Smith, 1999). Western science is largely interested in *what*, whereas Indigenous science is concerned, influenced, and shaped by *how* and *why* (Martin, 2012). “Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definition of what is real and what is valuable” (Brant-Castellano, 2004, p. 102). Research institutions have a responsibility to support and encourage this self-determination. As Brenda notes, it requires a commitment to ongoing education:

> We do it because it's right. I'm not being facetious here. I'm not an expert in Indigenous research, but since I've been in this job [nearly 15 years] I go to conferences, I go to workshops, I hear things, I read things and I'm fully aware that there's been some really cruddy research that has happened, that has had a detrimental impact on Indigenous communities and people. So, by asking these questions, coming up with these additional questions and things, it helps to mitigate those issues. (Brenda Gagne)
As I have mentioned earlier, it is about timing, not time. Most participant contributors reinforced this notion and noted that we need to cease the opportunities that are presenting themselves in this time and place:

There are number of things we can do and follow up on this discussion; We shouldn't let things die because there is momentum. (Geneviève Dubois-Flynn)

It is apparent that there are many unresolved tensions, many confusions, complexities, and conundrums. Researchers and REBs continue driving around the ethics rotary, holding their map (TCPS2 Chapter 9) in their hands, eyes peeled to see the signs to in the right direction. We have gotten so caught up in chasing something that we have lost sight of what ethics is all about.

I included a large portion of my findings/analysis/discussion in this chapter, because these common considerations were shared by the participant contributors and because I have been in and around these same conversations for more than 12 years (the whole time during my relationship with ethics in research). It made sense to present my longitudinal, autoethnographic analysis with the support of my participant contributors. We also began exploring other way of doing – we have to do differently. And that is the key messages of #TheJuliestPhD. In the next chapter we will look at practical ways to begin your journeys toward ethical research/review with Indigenous Peoples and get a glimpse of a possible Ethics Utopia.
CHAPTER 6: BECOMING ABLE HUMANS AND ABLE INSTITUTIONS

I have mostly told the story as we have wandered together through this narrative. I hope it has become clear to you that REBs are still grappling with how to approach review and approval for research with Indigenous Peoples, including how to apply TCPS2 Chapter 9 in practice. Given the fluid nature of research ethics, generally, and the dynamic and contextual protocols in Indigenous research ethics, specifically, I imagine we will always have learning to do. However, many advancements and several innovations are already in action. We can learn from what others are already doing. We can learn from listening, observing, and practicing. As the landscape for research with Indigenous Peoples shifts and evolves over time, so, too, ought our policies and practises of research ethics.

To meaningfully shift our practice, we must move beyond the cursory conversations of competencies and capacities to undertake the work (i.e. life journey) of becoming able humans and able institutions. To do this work requires only one competency: to be alive; and one capacity: to be open. Sometimes it conflicts and sometimes it is confusing. This is the journey. This chapter highlights the innovations, endorsements, wisdom, guidance, and visions of the participant contributors in this study. There is no ‘recommendations’ section in this dissertation, which is intentional. Yet, I suspect many people may find this paper in seeking an instruction manual on how to do ethical research/review with Indigenous Peoples. So, once again, and along with the other 17 participant contributors, I offer this chapter as guidance, much of which is not new but now more of us are saying it (closer to the tipping point?). This dissertation is me doing my part (using what I have learned, observed, and practised, sharing it,
integrating it, and acknowledging my limitations) to encourage the growth of able humans and able institutions.

One of the (many) great things about having conversations with Indigenous research ethics innovators and early adaptors is that everyone brings numerous ideas and visions about how we can all do differently to the dialogue. How we can do better. Participant contributors were rarely pointing fingers or placing blame because they recognize that there is a collective responsibility to do ethical research/review with Indigenous Peoples and that there are individual obligations we all must enact and respond to in our roles in the research structure and regulatory system. Co-conspiring with other systems-level thinkers, like I did in this research, meant the commentaries shared were very pragmatic and reflected a realistic approach to their suggestions and endorsements. We also had great conversations about what an ethics utopia might look like (more on that later in this chapter). Generally, the participant contributors and I agreed that education and training materials related to Chapter 9 (and all of the TCPS for that matter) needed to evolve (technologically and technically, and theoretically and empirically) to reflect the evolution in the complexities, considerations, and opportunities in research/review with Indigenous Peoples. For me, accomplishing this is about using what we already have and harnessing the energy of the works already underway.

It was repeatedly reinforced by those who joined me in this research that we have everything we need to create more robust and ethical review of research with Indigenous Peoples and on Indigenous lands. As you will recall from Chapter 4, I believe that everything that can be known is already known and that all we can do is find different ways to overlap those different things we know. It is not unlike music or
fashion or hairstyles. There really are a finite number of ‘original’ pieces; the rest, we create from overlapping those originals and this is especially true in research. This study is no exception. We need to find ways to mapiatilippà (put it on, so that it overlaps). If there are only two messages you, dear readers, take away from this dissertation I hope it is this: there are lots of ways you can practice your learning with respect to Indigenous research/review, and that there is always room for all of us to learn. It helps take the pressure off when we strive for excellence instead of perfection. As my friend, Jann, says ‘it’s a practise, not a perfect’.

I won't say they're solutions, they're [practices] sort of towards solutions in our quest to suck less. (Chris Turner)

Part I in this chapter discusses decolonization – of our minds and of the systems – and presents a collection of concepts and ways to practice piliriqatigiingniq (working collaboratively) that can support the journey of becoming able humans and able institutions. To be clear, these are not a set of instructions because there is no one way to resolve the many tensions, conflicts, and confusions that arise, there are only processes, practises, and possibilities. I offer this general guidance as a starting point, not a finish line. I directly address how I understand researchers, REBs (members, chairs, and administrators), funding agencies, and universities can #justsuckless implementing Chapter 9, and step into their responsibilities of ensuring (and encouraging) more rigorous and ethical research (with everyone, not just Indigenous Peoples). In Part II, I describe some innovations underway and offer pathways toward solutions to some of the complexities discussed in earlier chapters. Then, finally, in Part III I present #TheJuliestPhD ethics utopia – a vision for the future of an ethics Mawi’omi (gathering [place/space]).
Section I: Collective Responsibility to decolonize all the things

To “decolonize all the things” means attending to our individual and institutional biases. We must acknowledge colonial influences in our daily lives: in our educational systems – embedded deeply in our pedagogies; our institutional orientations; our communities; our families; and in ourselves. We must see ourselves as susceptible to the messages of dominant narratives that are disconnected from peoples and lands. We have to challenge the influence of these dominant narratives and how they frame our thinking. And because they are deeply embedded, to a point that we are not always even aware of their presence, it will take deliberate practice in our efforts to decolonize ourselves and our institutions.

Decolonize Your Mind: Becoming Able Humans

I start this chapter with my poetic voice. I tried a few different ways to address this topic in my scholarly voice, but it will take pages and many circles to cover the ground I need to here. For me, all of this – this whole dissertation – is about how we treat one another. In some ways this poem captures both my frustrations and my hopes. It is a piece called “Collective Responsibility” and I wrote it in October 2017 in response to the question “what does it mean to decolonize your mind?” This is a question I have been asked many times and have been reminded by Elders not to forget. It was timely to write this piece a few weeks after resuming my doctoral studies as I attempted to re-immerses myself in an academic world, attempting to do Indigenous research.
Collective Responsibility

To decolonize is to criticize
to open our eyes and to question why.
To question what we’re told as fact
To look back. To think critically about history
To question what we think we know
To investigate, not interrogate.
To understand, to stop possessing the land
Ask my views, not second-hand assumptions

It’s personal. It’s political
Because somehow we believe that we have to deceive
We consider media slants instead of personal stories
extracting people and resources from our territories
We forget to see the interconnectedness
Our selfishness, apprehensive because it’s effective
To stop making excuses
To end empty truces
To stop saying you’re sorry when your actions never change.
To feel the change
To see the change
To be the change.

To stop persecuting others and to free our own damn selves
The mask I live in that you put on my face
Displaced from my own space.
Now I stand where you demand 'no Muslim ban on stolen land'.
The stolen land you took from me?
Why is it that you can’t see?
I don’t need no degree and it’s not hyperbole that colonization is killing me
The amputation of your reputation
the devastation of our segregation
the regulation of my emancipation.
We always have a choice to make after that first (mis)take
for your own sake and my heartbreak
the outbreak of the never-ending mistake.
Colonization is not just those dudes who came here in boats
the lethal dose when our kids lose hope

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86 A spoken-word version of this piece can be found at:
https://www.youtube.com/watch?v=mnbyWZFL6OE
It’s in all of us. Pervasive. Invasive.
Your story is persuasive but not grounded in fact or reality
Staggeringly, unacceptable, unescapable.
It’s your mascot, your afterthought
an apology described only in epidemiology
the anthology of failing ecology.

You want to reconcile, meanwhile, you don’t want the truth
Your affinity for bigotry
The acceptability of insensitivity
My replaceability. Your susceptibility
Our collective responsibility
The epitome of delinquency.
A dependency explicitly and deliberately to drive us apart

My reflexivity. Your belligerency
My agility. Your epiphany
The resiliency of reciprocity
the simplicity of authenticity
In this collectivity, we are effectively broken.

Indigenization’s in your imagination
The conceptualization of departmentalization
A confirmation in legislation of transformation through quantification.
The manifestation of discrimination
The decolonization of a malformation.

To decolonize your mind is to shift perspective
to alter our collective consciousness.
Authenticity is the variety of humanity.
To love and to be loved. To give and to share
Our burden to bear for what's got us here
The electric chair of social welfare
The transferability of vulnerability
The sustainability of compatibility.
You and me.
Our collective responsibility.

(October 2017)
I am leaving some work for you, the reader, to engage with the messages in this poem and to find ways to apply its principles in your practice. Participant contributors talked at length about their own personal learning journeys. It all starts with the understanding that it is not your research (you share it with the people who allow you to do research with them) and Indigenous Peoples are not defined by you or your research agenda:

We need to know about language and about self-determining identity. Our identity has been in a large part been given to us by, or enforced upon us, not even given to us - not nicely, but given to us by mainstream society, so what I would call myself is not [ab]original and so constantly having to say I'm “not not-original”. I am the original person of this continent and so constantly having language about things like “people are our Indigenous students”. No, there's no ownership, you don't own me. (Johanne McCarthy)

Learn the history of the lands where you live/grew up/study/work, maybe even how to introduce yourself in a local Indigenous language. There is a critical need for researchers to do their homework, and that can often mean going beyond the walls of the university, meeting with people in their communities (urban, rural, remote, reserve) and to learn about locally contextual information (and this should be part of any rigorous research). Kenna reiterated the importance of, for example, learning the local greeting and to learn about the histories on/of the lands where we do our research and where we were raised/live as part of developing an understanding of local dynamics:

Learn the greeting, know the greeting. Learn about where you're from, what were the residential schools in your neighborhood, what were the Indigenous hospitals there? (Kenna Miskelly)

**Personal Reflection:** If you have not done this work and you are proposing research with an Indigenous community, can you honestly propose ethical research? We need to be critical of ourselves and our motivations. Grant application timelines, REB submission deadlines, and funding limitations are not
acceptable excuses for neglecting to learn about the place(s) where you intend to
do research. We must be willing to take a hard look at the excuses we often give
for ‘skipping’, ‘skirting’, or ‘scuffing’ the process of truly engaging with and
learning about a community before we attempt to ‘help’ them.

Check out some existing opportunities to (digitally and/or IRL) learn about
Indigenous cultures and world views and seek out others in-person. There is a
substantial increase in the number of mainstream programing available as a starting
point on the self-education path, such as CBC’s Unreserved, a weekly radio show, and
8th Fire, a 4-part series. Reporter Connie Walker is also one of many Indigenous
people producing podcast series and social media content to draw attention to shared
history and the links to contemporary Indigenous realities and identities. Karen (who
identifies as non-Indigenous) explains how programs like these can lead to deeply
meaningful personal reflections if you actually listen to, watch through, and engage with
the subject matter. She sees these opportunities for reflexive practice to be invited to
engage with a human experience and imagine standing in someone else’s moccasins – as
helpful in her learning.

I listen to CBC radio and they've had special segments where I've heard more
of the history about the children being taken away and I remember sitting in my
car and it's just one of those moments where it catches you at the right time
where it hits you and I’m crying in my car and I’m going, "Oh, my God, I get
it." That's horrendous, and not just hearing it as story or words but putting
yourself in the situation. (Karen Henderson)

Privilege Ethics and Adapt Methods

Usually researchers determine the methods and approach they want to use and
then attempt to overlay an ethical framework. Depending on the discipline, ethical
tensions are responded to in different ways, and as evidenced in this paper, often in
ways that privilege methods over ethics. There is a call for research to be done differently (hence, the methods need to shift to respond to the ethical needs, not the other way around). This is a critical shift in thinking that is essential to decolonize our minds. It does not come naturally because it requires unlearning before relearning.

Becoming an able human is a life-long commitment; not a weekend course or an online module you can do at your leisure. There is no certificate of completion. Sometimes it can be difficult and often it can be uncomfortable. And it is always an opportunity to do differently. For me, my journey of becoming an able human is guided by and grounded in *Inuit Qaujimajatuqangit* (IQ). I offer the principles of IQ again to remind you of how I practice it, not as a means to convince or convert you to my way of thinking, but to open your mind to the possibilities of what becoming an able human might look like for you, within your belief system and traditions. I wish everyone to become able humans within their own contexts, for when we are all able, we will have all done our part to influence our contexts in this time and place.

- Inuuqatigiitsiarniq (respecting others, relationships and caring for people);
- Tunnganarniq (fostering good spirit by being open, welcoming and inclusive);
- Pijitsirniq (serving and providing for family or community, or both);
- Aajiiqatigiinniq (decision making through discussion and consensus);
- Pilimmaksarniq or Pijariuqsarniq (skill development through practice, effort, action);
- Piliriqatigiinniq or Ikajuqtigiinniq (working together for a common cause);
- Qanuqtuurniq (being innovative and resourceful); and
- Avatittinnik Kamatsiarniq (respect and care for the land, animals and environment).

My efforts to decolonize my mind includes daily routines, including being confronted with trip-ups as I find myself intertwined in colonial structures and assumptions, feeding stereotypes or challenging beliefs, and sometimes not even
recognizing my own colonial-based biases. Even though I am aware of dominant colonial narratives, it does not make me immune to their influences. I deliberately set a daily intention to practice and embody IQ, to learn from my mistakes and missteps, and to continue on my personal quest to #justsuckless in all my work.

**Decolonize Research Ethics: Becoming Able Institutions**

Throughout historical and contemporary acts of colonization, “science was used to support an ideological and racist justification for subjecting Indigenous cultures and ways of knowing…The racism inherent in this evolutionary paradigm contributed to the genocidal policy toward Aboriginal peoples in the Americas” (Kovach, 2009, p. 77). As mentioned, the very foundation of Indigenous sciences is multi-faceted, interconnected, and often incongruent with Western biomedical research paradigms. “[R]esearch is not an innocent or distant academic exercise but an activity that has something at stake and that occurs in a set of political and social conditions” (Smith, 1999, p. 5). So, when I talk about decolonization in research, I mean the “decolonization back to the immediate relational, and spiritual underpinnings of Indigenous thought” (Sium & Ritskes, 2013, p. II). Rigney (2001) calls this Indigenist research, that is, a response to colonial impositions in research to decolonize based on three foundational and inter-connected principles: political integrity, resistance, and privileging Indigenous voices. For Indigenous people, the self is in society as opposed to Western ideas of the self and society. We cannot arbitrarily or artificially differentiate between the two; we are both. Thus, our practice must include simultaneously decolonizing ourselves and society.
Unnamed Found Poem
You ain’t woke
You’re sleep walkin’, Talkin’ reconciliation
As if some indication of restoring relations
You’re hoarding resources
Nightmares in broad daylight. My fight. My light
ReconciliACTION
Just a fraction of what you can do
To #justsuckless. To do your best
Do something in your becoming
an able human
(March 2018)

It is about using what we already have and drawing on work already done.

Ideally, Indigenous people *always* identify the research priorities and the research questions. Though some may see this as an implausible aspiration, it does not seem so difficult to me. As Chris and others mentioned in our conversations, we could start to address this immediately by creating repositories of researchers’ knowledge and expertise along with communities’ research questions and priorities. There would be substantial value in this being a national database, but the legwork could be done regionally to share the workload and to ensure regionally specific and accurate information is collected and maintained. This will take a commitment from academic institutions and Indigenous communities to communicate with each other consistently and collaboratively with no one side being more obligated to communicate to the other. Institutions can take the lead in initiating the relationship and correct any past indiscretions as required to move forward. Communities cannot be expected to “forgive and forget” because institutions are “suddenly” interested in doing more meaningful research and want communities to communicate with them. It is about mutual respect and honouring the knowledges communities hold in a good way. It is also about being
willing to undertake what is necessary to make the relationship “right” where difficulties still remain unresolved, unreconciled.

**It is about practicing reciprocity, both giving and receiving.** Acknowledging all of the contributions, amount of work, and who is (or is not) getting compensated for what they do is an essential piece of shifting how research is conducted. Indigenous communities and organizations experience research fatigue when many requests come in a brief period of time. Understanding this dynamic is essential to building fair and equitable research relationships. Communities who do not respond in a “timely manner” cannot be viewed as disinterested or difficult when there are multiple and complex needs of the people doing the work of responding to while researchers push words around on paper about the issue being responded to. True allies in the work understand that communities will reflect and comment on research ideas, proposals, and protocols when they are able to (and are more likely to do so when the research seems relevant and helpful to what they are already responding to). This is reciprocity – the idea that communities will benefit from the research they invest time and energy in, and that the outputs/impacts will provide guidance and direction beyond ‘needing more research’.

**It is about meaningful pedagogical shifts at the institutional level.**

Pedagogy shifts will prepare new researchers with the capacities to undertake research with Indigenous communities with confidence. Academic programs need to adjust and adapt expectations (and instill these in the students they raise up) in way that reflects the flexibility that is required to do ethical research in some community contexts. This means shifting the idea that the research (program) timeline is more important than the
qualities of the research being undertaken. Ideally this is accomplished in a way that encourages students to take up the challenge of being so thoughtful in their research approach and relationship building that they slay their ethics “monsters” with protocols approved in the first review and are excited about the fairness of their process (just like #TheJuiliestPhD). It also means institutions need to create space for students and researchers to take up the ethical practises and processes that will facilitate efficient and ethical research review. This may require examining tuition structures and other administrative elements that, currently, can be financially punitive to people who choose to be part of Indigenous research. Two-year graduate programs and three-year operating grant funding envelopes can make for uncomfortable tensions (and create circumstances where people opt out of Indigenous research all together and where Indigenous students and researchers face difficulty in finding their place within the system).

**It is about ethics being a conversation.** If there was one message that participant contributors (all 18, including me) had to share, it is that *ethics is a conversation.*

And one conversation can change your entire trajectory. (Riley Kucheran)

Institutions are obligated to have internal conversations across disciplinary and departmental boundaries and it is my hope that my research may also influence a movement for external/public conversations about research ethics. Ethics are, by definition, a public debate and the black-box REB model does not reflect this meaning. As Riley so succinctly states, conversations between REBs and researchers can change research for the better. It is not more difficult to do trustworthy and ethical research, it just requires people to know what they are taking about, which is the premise of
scholarly work; that is, by virtue of “getting a PhD”, my social capital will go up and what I say will allegedly be valued more, perhaps even considered ‘expertise’. Therefore, we are obligated, as researchers and REBs, to know what we are talking about in a way that we identify and can describe how we will mitigate worst case scenarios rather than prepare an ethics protocol that appears as though there are no ethical issues or tensions (which is highly unlikely given how value-laden all research is, even the research that is argued to be ‘objective’ is value-laden because a human designed it). It is also our responsibility to know when we do not know and to then defer to those who do hold the knowledge.

It is about acknowledging all cultures involved, including institutional ones. An integral component in becoming able humans and able institutions is to recognize, acknowledge, and accept the institutional cultures that we co-create as humans working and interacting as a campus community. One way to address this cultural reality is to create REB and researcher learning opportunities. It is not surprising that ‘time constraints’ are often cited as the reason that REBs do not engage more fully with education and training on how to ethically review and approve protocols for research with Indigenous Peoples. Some participant contributors talked about ways in which they are using the limited time they have to help advance their practice. For example, the University of Victoria REB is committed to setting aside part of their regularly scheduled board meeting to engage in further learning about topics that are relevant to and identified by the REB members themselves:

Our board meeting is an hour and a half, and we have about half an hour where we will review a study and then we have about half an hour of somebody coming in and giving a talk to the board. We do a survey with them every two years and the board members at that point identify the areas that they would like us to
bring speakers in about and research involving Indigenous communities and Indigenous researchers working in their own communities are always topics that the board asks for. (Kenna Miskelly)

This is an example of an iterative REB practice where they are checking in with themselves and self-identifying areas where they need development proactively rather than waiting for issues to arise with all of the media fallout and other consequences of reactivity. To take it to a new level, students and other faculty might be invited to join the last 30 minutes of the meeting, too, as a means of demystifying REB thinking and processes.

**It is about demystifying the black box.** Not only does this approach that Kenna mentioned provide education and training to REB members, a side effect of this approach is how it also helps foster a relationship between REB members and researchers. These kinds of actions are steps toward demystifying the black box of the REB and build transparency between REBs, campus communities, and the public (who the research is supposed to serve in most cases). Joy reiterated the importance of the REB conversations in their ongoing learning at the University of Prince Edward Island:

> The continuity for us comes through discussions at the end of each of our meetings in terms of what's been challenging for you? What did you enjoy about the last batch of reviews? Or what did you find challenging? So those discussion points they helped to keep everything up-to-date in many ways. And we're constantly encouraging people to branch out and to look at new things, to review in new areas that they may not be knowledgeable about. (Joy Knight)

I know for some people their modus operandi is just a paycheck. But it's a lot more than a paycheck to most of us. There are a lot of like-minded people and you just need to get them into your network, have conversations, keep your connections with them fresh. And don't be afraid to ask, "Hey, can I come to your campus and visit for a couple of hours? I just want to hang out and watch -- can I observe your REB and how it works." So, if you know of another really functional research ethics board who really has their shit together, ask to
sit in and observe and watch it in action. That's my best advice. (Danielle Connell)

While some researchers and REBs can be quick to dismiss their responsibilities or to place blame or obligation on others, the participant contributors in this study recognize that we all have a role to play:

I think it's the institutions’ responsibility to come up with the money. And it is the [Secretariat on Responsible Conduct of Research]'s responsibility to create more training resources for administrators and reviewers. So, CAREB is on the hook, the [SRCR] is on the hook, and the institution is. If this is going to work, it's got to be -- everybody's got to be on the same page. And everything's got to commit to more than just, "Well, we're going to try harder." (Danielle Connell)

It is about our individual roles within a collective responsibility. We can collectively #justsuckless if we commit to doing our part as individuals within Canada’s research ethics policy infrastructure. Joy reiterated Danielle’s position and further explains how no one person or place is responsible to ensure the full implementation of TCPS2 and Chapter 9; everyone is responsible; we are all responsible.

The [SCRC] should be responsible for, at least partially, for helping out. They are our guiding body. Perhaps CAREB could do something as well. In terms of providing some guidance and learning materials. And I would share them. I would keep them for educating, I could educate the campus as well, which could only help everybody. Everybody moving along on the ladder. (Joy Knight)

Within the collective responsibilities we are all bound to through TCPS and for ethical research/review for Indigenous Peoples, there are some specific calls from participant contributors for different players in the ethics regulatory system. And there are lots of ways for all of the players within the research system do practice this.

It is about guidance for Chapter 9 revisions. As we heard previously, REBs look to the TCPS for guidance and insight on the ethical dimensions of research with
humans. Since Chapter 9 was a focal point of the discussions with participant contributors, this section discussed some specific innovations and suggestions for the SRCR in the evolution of Chapter 9 because leading and finalizing any revision is in their mandate/scope of responsibility within Canadian research ethics regulation. Brenda also encouraged the SRCR (and REBs and researchers) to position the TCPS as a policy that includes flexibility in adaptation according to context to encourage/ensure research excellence.

The TCPS is what it is, right? I mean it's our guideline, and I tell our own researchers, “we consider that the floor, aim for the ceiling”. These are our minimum guidelines. Let's be better. And it's not that we're trying to be more restrictive or more policy laden, it's let's just try and make sure that every study that leaves our hands is the best that it can be. (Brenda Gagne)

One of the key improvements that was suggested for Chapter 9 is that it includes more concrete examples for interpretations of its Articles and provide scenario examples of how to integrate OCAP® and other Indigenous-based ethics review processes.

The next step would be to go further with the OCAP principles, because it's nice to read about it. This is another big question I get sometimes, “Yes, I would like to respect these principles, but I don't know how to start, or where to start. Can you help us?” (Suzy Basile)

Examples in the TCPS would be extremely helpful. Real-life examples and better descriptions of how to apply certain procedures, certain policies. (Brenda Gagne)

Indigenous research ethics landscapes continued to shift, adapt, and change after Chapter 9 came out in 2010, and there are calls for revisions to reflect how governance for/of research with Indigenous Peoples evolved in the past eight years, and continues evolving. Perhaps it’s the idea that the TCPS2, while legislated as policy, is also a “living document” that is growing a culture of practice. Acknowledging limitations of Chapter 9 and how to work in these contexts may also be helpful. As Karen and Johanne
explain, REBs can work within a context of changing landscapes when there is a deeper understanding of Chapter 9 and the insights and contradictions contained within it:

KAREN: We should do a video explaining Chapter 9 and why is it important and then on what's not in Chapter 9, which I don't know if you can teach people that. It's the stuff we've learned over the last four years that you don't even know you're looking for until you start talking about it.

JOHANNE: I make everybody else read Chapter 9 too. And when it comes to terminology, you know the terminology section needs to be updated. We're beyond that now and we're in a more respectful place and that needs to be captured in these documents.

For the most part, participant contributors thought that Chapter 9 gave them a framework or set of guiding principles to assist them in their efforts in reviewing research with Indigenous Peoples. At the very least, no one sensed that it was an impediment to research or that it was a barrier for researchers or REBs (though Indigenous communities who initiate and run their own research may have a differing view, as well, researchers with commentaries like Dr. Anonymous shared with me appear to struggle). Interestingly, many of the criticisms, concerns, and contentions about Chapter 9 come from the practise, not the policy. TCPS (generally speaking) is written in a way that allows room for interpretation and application as appropriate to specific research contexts:

There are certain key points of Chapter 9 that we refer to quite often. One is that the REB is not trying to overstep. Sometimes there's misunderstanding when you send a notice out and you ask questions. Things may appear as directive and we definitely don't want to be overstepping or directing points of view that the community has themselves or should be making. (Kenna Miskelly)

**It is about guidance for researchers.** Some REBs are evolving and adapting and finding new ways to approach building a relationship with researchers (it is all
After Amanda shared her detailed account of the processes work at Cancer Care Ontario, I asked if she could tell me what that first interaction would look like when a new researcher approached CCO to do research in First Nations, Inuit, and/or Métis communities. There are some institutionally-specific points that she mentioned but the general message she provides is a useful starting point for researchers and REB members who are just beginning their work with respect to learning about and building an understanding the ethical nuances of doing ethical research with Indigenous Peoples:

I'd ask you to introduce yourself and present the research questions and justification for the research questions. And then it would depend what the research question was. If it was to do a province-wide research project, we would probably take it to [our provincial committee] meeting, because those folks around the table combined can better represent the provincial perspective. We would take it to them and make sure that it's a topic that's of relevance and importance. And then figure out the best way to move with that work. If it were to be accepted and it was deemed a priority around the table, then we would have the researcher take an in-house training in OCAP that we've created and fill out some forms to show that the work they're going to do is going to be with members of our team. And we will act as sort of the middle man to our community partners. If the research question was something really specific like doing a survey about cancer screening with youth at one particular high school, we would connect directly with the group that our Partnership Liaison Officers deem is most appropriate and ask them is this is worthwhile. So sometimes a research question wouldn't necessarily be brought to the whole table, if it's something really specific like that, but I guess the point I'm trying to make is it's always vetted by the most appropriate First Nation, Inuit, or Métis partner to move to the next step. (Amanda Sheppard)

**It is about guidance for Research Ethics Boards (REBs).** Not surprisingly, participant contributors had a lot to say about the policies and practise of REBs and gave suggestions on what REBs can do differently. These are suggestions of actions and innovations that are already underway at some institutions in Canada and participant contributors wanted to share what they already do so that other REBs can find the
options that resonate with them and are relevant to their locally-specific context (Part II in this chapter provides more detail on innovations in action).

**It is about Indigenous inclusion and integration.** The most common requirement that people mentioned was to have at least one designated seat on institutional REBs that allows for the participation of Indigenous people. Though many participant contributors acknowledged that non-Indigenous people may have some relevant knowledge and experience, it is necessary for at least one seat to be filled by an Indigenous person. As Karen mentioned, there has to be someone on the board who comes with the living experience of being Indigenous – with all the complexities and epistemological collisions that come with those realities. Johanne also reiterated that as much as it is excellent progress to have Indigenous people sitting on REBs, there is a need to have more than one person. There is substantial burden put on Indigenous Peoples sitting on these kinds of committees (as is true of academic culture more broadly – the one Indigenous faculty member assigned to be the Indigenous voice for all things, whether or not the thing is even remotely in their subject or content expertise or interest, or whether they are from the local territories where most of the research is being conducted):

JOHANNE: They have to mandate that they always that had an Indigenous person on a research ethics board. For not just Indigenous projects, but for every project so that it strengthens the relationship of trust that we can start to restore that trust and really pay attention to the emotion and the history and the impact that the research has had on Indigenous populations. Even more than one, like two or three, so that there is a system of support. I feel relatively supported because I'm surrounded by many Indigenous academic family members and I have a great research ethics board that is open and loving and welcoming and nurturing. And I don't think that online is the way
to go when you're talking about ethics or anything that can impact human beings.

KAREN: Rather than having an ad hoc person who you just call in when someone ticks the Indigenous box. [TCPS] says each REB should have a member with knowledge of Indigenous ethics or Aboriginal ethics but it's more than that. It needs to be someone from an Indigenous community with the history and background and the emotions that go with it.

It is about sharing space and building relationships within the REB. Johanne and Karen talked about the importance of face-to-face interactions for the REB as there is great learning opportunities that present themselves when we share space and energies together. They echoed the importance of sharing time together and getting to know each other, beyond the scope of research protocol review:

JOHANNE: We talk a lot about the importance of us being face to face. And feeling the energy of the transaction in the research ethics board meetings so that when I'm delivering, maybe a tough message about something that the other members of my research ethics board don't know and maybe should know, that they can see through my energy that I'm delivering it with love for my community and love for them and not in a way where I'm reprimanding them, like you did this wrong, right? Because I think it's really easy when you correct somebody for them to become offended and then to put up a wall and stop that future learning and the only way to break through that learning is to have people genuinely get to know each other on a personal level and to see each other's energy. So, I don't stop if I see somebody's upset, I keep going until they understand my point of view.

KAREN: Just as importantly, we need to see Johanne getting upset. And we see the hurt and the anger and all the emotions that come with it. That is a really strong learning tool. You can't beat that because you feel that, and you don't forget it and even if your wall does go up at the time, the next day is hits you and the learning sinks in and you go, “okay, I get it and you know better next time”.
Gwen adds to this call for building understanding among REBs, researchers, and communities. She notes there is an obligation for communities to explain how they want things to be done/change, as well as to be open and invite the ethics conversations as part of sharing space and relationship and building understanding. It is about humanity, after all, and our relationships to one another:

If we want things to change, we have to explain to people how we do things. If they don't understand, we have to explain it. And, you know, it's part of how we welcome people to our communities it's part of how we share space we see others, how we continue our relational practices how we maintain our connections and it's all based on knowledge-sharing and skill development and skill-acquisition. We have to carry that forward as well in our work, where people who are less knowledgeable need to be made more knowledgeable and we have to tell them, “no, you’re not doing it right”. This is a better way. (Gwen Healey)

One way that communities can invite ethics conversations into their lands is to reach out to academic institutions in the region and inform them that the community has an ethics review process and/or what the protocol is to conduct research in your territory:

I keep coming back to education and I think it needs to be in person. We need to get people in a room together and just extend that fig leaf and say, "We need your help. We need you to tell us what we need to know." (Danielle Connell)

**It is about revising policies to reflect promising practices.** Regarding REB policy changes, participant contributors primarily mentioned two things. First, as previously discussed, to have a designated seat for an Indigenous person. This needs to be written in the Policy, not just introduced in an ad hoc way since there can be substantial practice change when there is person-change within an REB. The second policy change is to require documentation of community engagement and/or approval prior to granting institutional REB approval. It would be helpful for both of these to be
standard operating procedures (SOP) within institutional REBs so that the research governance leadership can be held at the community level:

Number one would be do everything you can to attend CAREB [Canadian Association of Research Ethics Boards] national every year. Obviously doing the core tutorial, you have to do it, whether it's mandatory or not. You have to read Chapter 9 from start to finish and then find someone who is an expert and ask questions. Don't wait for the problem to present itself before you figure out what article 2 really means. Figure it out now. Tap into your network of colleagues whether it's in research administration or research ethics or within your academic networks, CAREB obviously is an excellent conduit for this, but you've got to build your network of people you can call. You've got to put your name out there, you've got to put your face out there, make cold calls, ask for e-introductions to people, find out who's who and find out who out of those people are good mentors and who don't mind you calling them and saying, "Oh, I don't know what to do with this thing." And unfortunately, it takes mistakes to learn what not to do. I've learned more from screw ups than I have from training at CAREB. Come to CAREB. Tell your horror stories, and we'll all go, "Oh, God, us too." (Danielle Connell)

One thing that we [CAREB-ACCER Board] discussed is that as CAREB moves around the country it's a good opportunity to have points of view from different communities at the national annual conference. (Catherine Paquet)

**It is about working together to lighten the load.** Though limited time and resources are often cited as inhibiting progress, several participant contributors talked about our collective responsibility to just do it, regardless of whether or not there are resources in place to support it:

If we're going to be involved in this topic then it's our collective responsibility to just do it. Whether there are financial resources available or not. That is just part of our value system to be doing it. The only way for it to be sustainable is for us to remember, that this is just our responsibility, that we just have to do it if we went to see it done better, then it will take all of us, and the more of us who are involved the less work it will be. (Gwen Healey)

More hands make light of the work. If more people came together to create ideas and tips and processes, actual examples - the good, the bad, and the ugly. (Brenda Gagne)
It can seem overwhelming and daunting for researchers and REBs who are new to research/review with Indigenous Peoples – there are a lot of policies, documents, and guidance and it can be difficult to discern what is locally and contextually relevant.

Though there is no blanket approach and it is always advisable to seek guidance from the communities and people with whom we seek to work with in research, there are some innovations in action that we can learn from in our efforts to become able humans and able institutions. The following section describes a few of them and provides links to additional resources.
Section II: Innovations in Action

There are many examples across Canada of how REBs and researchers are already doing differently in their application of Indigenous research ethics. In this section, I highlight a few specific examples shared with me (there are many more examples to be found coast-to-coast-to coast in Canada and I encourage you to find the ones near you). These rich descriptions serve to inspire action and demonstrate that there is flexibility and space within the policy to do differently:

The TCPS very much talks about the importance of respecting community codes and we definitely tried to design Chapter 9 in some cases deliberately non-prescriptively, so not saying ‘thou shalt do this or that in all cases’, because we wanted TCPS to be able to fit in and mesh with Indigenous generated codes. (Susan Zimmerman)

This section chronicles some of the existing innovations and forward thinking of participant contributors that I think can be helpful in our quests to do ethical research/review with Indigenous Peoples (Appendix E includes other key resources and guidance suggested by participant contributors and that I have found during my study).

REB Directory(ies): We Need to Know the Players

Everyone in this study discussed the integral role that relationship plays in ensuring ethical research/review with Indigenous Peoples; yet, a common challenge across regions was a lack of clarity of who else was participating on REBs as well as a lack of understanding of who else in the region (beyond the institution housing the REB) ought to be involved in the research review and approval process. As discussed in earlier chapters, there is still significant confusions about who, what, when, and where to obtain collective consent in research. One way to start to address this is to build directories of REBs and other affiliated research review committees. This will not solve everything,
but it is a great starting point. Two of the participant contributors (Joy and Danielle) are collaborating to develop a regional directory of REBs in Atlantic Canada. The goal is to have a ‘living website’ that provides information on all of the research review bodies in the region:

As part of the directory, each of the REBs has a section under the directory, under their name that says ‘purview’, so each of these First Nations review committees can write, "Any researcher who is looking to recruit from population X needs to talk to us." So, if we could have instructions from each of these groups about what we need to do and who we need to send them to. That would be -- that's a big thing and that would have to come from the bands or from the advisory committees themselves. (Danielle Connell)

**Long-term Commitments Work: “It needs to be a marriage not a one-night-stand”**

When I worked on a research project in 2009, a participant talked at great length about how researchers could do better in their efforts to conduct community-based research. Succinctly he said, ‘it needs to be a marriage, not a one-night stand’. All these years later, I still use this quote because it so pointedly describes what is required – a commitment. There are many examples throughout this dissertation that demonstrate the possibilities that open up when we invest in relationship (and even more out there for you to find on your own learning journey). The following commentary from Amanda at Cancer Care Ontario (CCO) touches on so many of the key components of building relationships, prioritizing relationships, and investing in relationships. And these relationships are happening between many different players:

Cancer Care Ontario is a provincial organization that delivers cancer services in the province. It's also mandated to deliver some of the treatments, supply staff, and do research. In the last few years it's been quite successful doing what it's mandated to do, and under the CCO umbrella is also the Ontario Renal Network. Cancer Care Ontario is one of several of these bodies across the country. Among those cancer care agencies across the country, CCO is the only one to have this dedicated Aboriginal Cancer Control Unit. The reason that the unit was formed
was based on some surveillance data which described cancer incidents and mortality among First Nations people in Ontario.

If people don't know about us and don't know to contact us, we have sort of a block in place. If the person has not contacted us at all, but they're proposing to do anything related to First Nations, Inuit, Métis, or if they say Aboriginal or Indigenous or any terminology like that it would be flagged in-house, and they would be directed to us. It would never be approved without us knowing about it.

The first years were spent building partnerships with partners, Indigenous partners, and that sort of hard work in the beginning has been really rewarding because trust was established, reporting mechanisms were established, you know there's two way -- there's very clear paths of communication in both directions. So, I would recommend starting with partnerships.

We at the Aboriginal Cancer Control Unit sort of said in our heads all the time is like, "How is this going to benefit communities?" Because it's really easy to just go on a tangent when something's of interest to you, but what we really need to be -- what we're focusing on is what will benefit communities. And I think that helps shape the day, the project, the results. (Amanda Sheppard)

Cancer Care Ontario has a reputation for building meaningful relationships with First Nations, Inuit, and Métis because, as Amanda described, they always consider the benefits (and risks) to community in any of their undertakings.

**Ongoing Training and Mentorship: We Need to Build Supportive Practices**

Education and training is crucial for anyone working in research/review with Indigenous Peoples. Like Riley, I see so many researchers get to the REB review stage of their work without ever having conversed with community, let alone receive their consent or permission to do the researchers’ proposed study. Riley described some of his experiences as an REB member that led him to initiate REB office hours specifically for researchers and students who are proposing to conduct research with Indigenous Peoples. Since ethics is a conversation and Indigenous research is relational, I was
excited to see this initiative at Ryerson University and hope that other academic institutions will follow suit to build such mentorship opportunities:

I was seeing Indigenous proposals that had already done so much work. And they're not stopping -- and it's not the REB's place to stop research, like, very clearly the first meeting I went to: ‘We're not in the business of stopping proposals, we're in the business of putting proposals through and making sure that they do the least harm.” It's like, okay, [but]… I think we do have the authority to stop proposals, like technically, if it's very problematic. But no -- it's like, it's about just, it going through. So, it's like okay well what if we're catching these problematic proposals, or problematic research projects at the beginning. And so, I was like let's do office hours, because there's already office hours. I'll sit in some of the office hours and be like an Indigenous person to do that, try to mitigate things long before they're even writing up their grant proposals. (Riley Kucheran)

So, we must use our iliqquisiq (our patterns of behavior and being) and silatuniq (our abilities to think and behave wisely) in research/review with Indigenous Peoples. To ommak (come alive) we must naalak (list/pay attention) in our efforts to become able humans and able institutions. This approach encourages the co-creation of relevant and useful collaborative research products. We can learn from the innovations in this section, as well as from the visions in the final section of this chapter – #TheJuliestPhD Ethics Utopia.
Section III: #TheJuliestPhD Research Ethics Utopia: The Gathering Place

I have spent a lot of time thinking about what a research ethics utopia might look like. Then, after having conversations with participant contributors, it became clear that many of us have shared visions. Together we are re-imagining what research/review with Indigenous Peoples could be if we did not get held up/back by the current regulatory system. Together we are visioning ‘what else’ in order to do differently. I wrote and re-wrote this section in many ways trying to accommodate an academic voice. I struggled to find the right words to express my vision, yet no version seemed to capture the essence of my message. So, I end this chapter in the way that it started, using my poetic voice.

My utopia exists outside of the current regulatory model; it imagines what can be rather than what it is. There are no artificial boundaries or borders in the utopia; interdisciplinary research is standard operating practise. This section is about visioning. It is the conscientious planning I introduced at the beginning of this story. The planning that my ancestors did to ensure my survival in the face of every effort to eradicate me. I should not exist; I should not know my ancestors. We were never supposed to be here having to have these conversations together. There is no ‘grand colonial plan’ to get us out of this because we were never supposed to realize all the ways we are hurting one another without knowing one another. It is about what is possible if we imagine and dare to #justsuckless. My visions are not bound by space and time, nor by policy or process. This section is not about the context of the 2019 research regulatory system in Canada; it is about a future context that is possible when we ‘do the thing [we] think [we] cannot do’.
An Ethics Mawi’omi

It’s about presence,
the gifts we all bring
Where relationships are greater than everything
It’s gratitude.
The interlude
Where our spirits are fed through our gifts that led
Curiosity for all to see
Artificial versus authentic
Beyond superficial. Beneficial
Telling and retelling, Narrative coherence
Non-interference
Not keeping up appearances

Sage burning, returning to nature
To creator. Tables turning
There’s debates and dialogues cuz ethics ain’t a monologue
Collaboration and coordination; Ethics is a conversation
We let go of ‘expert’ and ‘ego’
Learn to grow from things you don’t know

At the gathering place we are all a book
A living library, necessary to mobilize
We realize we are full of the heart berry
Literary. It is contemporary and it is traditional
Not conditional. Not conventional
Revolutionary. Aspirational
Harmony. To sympathise not stigmatize
We do not compartmentalize in the gathering place
A safe space to be uncomfortable
To radically shift what it is to be vulnerable

The ethics playground, the merry-go-round
Writing circles into lines.
The breakdown of egocentricity
When we find common ground in authenticity, the humanity.
The take down of toxicity.
Dynamic electricity comes around, It’s profound, the simplicity.

Building on the wisdom, regardless of the system
Optimism where cynicism lived in a gathering place
Where we embrace each other’s diversities
A user interface not based at universities  

It’s abstract and actual.  
It’s virtual and physical. Flexible hours, operational  
Open minded, never closes  
No paper application; it moves beyond consultation  
A demonstration of innovation. Actionable. Nothing is unpassable  

The audacity of the biomedical monopoly  
We don’t need your interventions to synthesize and analyze  
To pathologize behind your disguise  
I draw attention to the tensions  
We need you to recognize, to be comprehensive,  
for to you to pay attention to the dimensions  
To ask questions, to learn lessons  
Cultures collide, and most people hide  
But I’m (almost) Dr. Brightside  
If you’re mystified, open your eyes  
Understand the land on which you occupy  
Thinking it doesn’t apply while the rest question why  
Finding a way to write to right  
from the wrongs that we’ve felt all along.  

Limitless if not for the limits we put on ourselves  
Placed on shelves, feeling overwhelmed until we’re compelled.  
We will never find the answers in the mind that creates the problem  
It’s humankind. A state of mind  
Where possibilities blossom  
To solve them we look deeper to spirit, to heart center  
The epicentre of unconditional love  
It’s all relational. It’s what we’re made of.  
Intergenerational. A journey of self for everyone  
All becoming able humans  

We must reveal it to heal it  
Indigenous science is transformative  
You must believe it so you can see it.  
Nature’s gift, demonstrating the teachings we seek  
To hold on to the lessons we keep. To critique coercion.  
In the revised version there’s only choice.  
From assimilation to affirmation
Thought creates reality, defying gravity.
The biology of belief. The psychology of relief
It’s the fresh air of the salt water
The coming together that makes us stronger
We stop fearing the REB monster

To live by a compass and not by a clock
Not a roadblock, no combination lock
It’s not about Columbus, it’s about what you do to us. Injustice.
Not measuring toughness, fighting for justice
The mental blocks of the after shocks
Not bound by the current system; only by the people within them.

There’s less paper and more prayer. We are all aware
The square peg in a round hole.
Beyond quality control to that which makes us whole.
Dialogue as Erminic and Socratic
Nothing is dogmatic; Inclusion is automatic
We address systematic barriers.
Become able humans and able institutions
A redistribution of the supposed ‘solutions’
Resolutions and revolutions worth pursuing

It starts with humility. Our agility and flexibility
A responsibility to ethics, not liability

Science and spirit are not separate
Consent. Respect. Our responsibilities we live it.
There is no president in the gathering place
We all know our role in the space
Our collective responsibilities to be the best that we can be
Colonization unstructured in the ethics rapture

There are no space takers, only space makers
It doesn’t matter if you’re Dr. Fancy-pants
or you had to make your pants.
It is foundationally and fundamentally the way you interact with me.
From the moral panic toward a moral practise
Active and organic,
dynamic and idiosyncratic.
I close my eyes, so I may see
the possibility of an ethics Mawi’omi.
CHAPTER SEVEN: MATUMANI (NOW, HERE IN THIS PLACE, AT THIS
TIME IN THE STORY)

I struggled with what to call this last chapter because ‘conclusion’ did not fit. This is not the end of this research. It is not the end of this conversation. It is not the end of anything (other than me finally being able to tell my family I am no longer a student!). For me, and for the practice of research/review for research with Indigenous Peoples, this is simply a place and time in the story. There are many emerging and unfolding stories and this dissertation is in no way meant to be a final destination or a completion of my understanding on these subjects.

This is just the beginning. “In the context of narrative inquiry, the production of research texts follows the art of engagement in a storied research relationship that is never final, and could always be otherwise” (Caine, Estefan, and Clandinin, 2013, p. 582). Making the decision to stop (for now) was difficult; though it was made easier by the enthusiasm that participant contributors brought to the study (most of whom are now part of the family so further collaborations are inevitable). They have shown a commitment to and responsibility toward ethical research/review with Indigenous Peoples. I had to remind myself of my research questions and intentions to make this decision to “stop for now”.

Research Questions and Intentions

This dissertation reflects the stories of REB members, chairs, research administrators, policy makers, and myself, as they relate to the ethics review and approval for research with Indigenous Peoples. To recap, the question(s) that guided this research were:
What are the perspectives and practises of people connected to REBs (including me) regarding the review and approval of protocols for research with Indigenous Peoples?

- How are REBs implementing Chapter 9 of the TCPS 2?;
- What is the current landscape of research/review with Indigenous Peoples?;
- How do REBs currently approach protocols involving Indigenous Peoples?;
- How do the policies and the practices mis/align?;
- What are the possibilities and opportunities for advancement the future?; and
- What REB innovations of review with Indigenous Peoples currently exist?

How does someone navigate being “Indigenous in the academy”?

- What is it like to be an Indigenous ethicist within an academic setting?
- How can Indigenous philosophies and epistemologies be intertwined in academic performance?

The intentions behind this research are to:

- Ground my research spiritually, through ceremony and engaging with Inuit Qaujimajatuqangit (IQ Principles) throughout my PhD research journey;
- Systematically and comprehensively examine, synthesize, and analyze literatures to depict the complexities in governance of Indigenous research;
- Interview those associated with REBs to collect case stories about research/review with Indigenous Peoples;
- Co-create a model of guiding questions and considerations for researchers and REBs to inform evaluating ethics protocols’ alignment with TCPS2: Chapter 9; and
- Create an autoethnographic digital story about my relationship to research ethics.

When I realized that I had addressed these questions and intentions, I knew it was time for me to let go of any the “extra” ideas I have/had during my PhD and to end here, at this place, in this time in the story. Of the intentions above, the one that is less “complete” is number four: Co-create a model of guiding questions and considerations
for researchers and REBs to inform evaluating ethics protocols’ alignment with TCPS2:

Chapter 9. There are so many samples, templates, and resources that participant contributors gave (Appendix E) that it seemed redundant to create another model for the sake of checking of this box. Instead, I commit to continuing my efforts to compile information as it becomes available on this topic from the innovators and earlier adaptors that have joined me/will continue to join in becoming able humans and able institutions.

**Opening Minds and Shifting Paradigms**

We collectively find ourselves oscillating in this place between multiple worlds where epistemologies, ontologies, and methodologies sometimes overlap/conflict; where local priorities reflect/reject research agendas or priority funding announcements; where Indigenous knowledges are becoming visible/invisible within academic health research; where complex governance structures are challenged/influenced by globally significant and locally specific events; where health disparities persist, in spite of/ despite (misplaced) efforts to address them; where collective consent is prescribed the same process as individual consent; and where communities, researchers, and REBs are left unsure how to proceed responsibly against a complex historical and ongoing backdrop of colonialism and inequality. Gwen describes how we can shift our language and perspective to encourage ethical research/review:

I guess just recognizing how important it is to instead of trying to make ourselves fit into some model for what an REB should look like that, we really want it to be based in that idea of like first principles or first philosophy of why it's important to be ethical and to be kind and good to each other. Not just like, "I've got to go through ethics review." You know, just how people talk about it in general and researchers are disrespectful and that's because I think that the processes have become so burdensome and bureaucratic. And so instead, look at our privilege to even be able to do this work. Like that's what we say at
[Qaujigiartiit Health Research] Centre all the time. It's a privilege to be able to do what we do. We're just so lucky. We get to talk to people, and we work with our Elders, and we do so many things that hopefully will contribute positively to our communities. (Gwen Healey)

*Aulajik (Remember from Past Experience)*

Let us learn from the collective wisdom, the tensions, and the misunderstandings, the slip-ups and melt-downs, the opportunities and the possibilities as we continue our journey to becoming able humans and able institutions. Though it will challenge you – emotionally, spiritually, intellectually – I know you can do it. I know it because like my mother always says, “you will because you can”.

Researchers are ethically obligated to educate themselves on protocols and practises of the people of the territories in which they work, and REBs are ethically responsible to ensure that Indigenous governance structures are respected by researchers by requiring that researchers demonstrate their engagement process and community consent in their ethics protocols. Both are equally responsible to ensure that the research conducted (after the REB approves the plan) is ethical. Now is where the rubber hits the road and is often where paper-driven approaches (to what should be a discussion) begin to fail the ultimate purpose of the process, which is the protection of research participants throughout and after the research:

It would be good to have something that's more interactive, less reading and more listening. It's good practice for them when they get into the community, learning to listen. That's a problem that researchers have. Despite every good intention, sometimes researchers think that they know everything, and that it has to be a particular way. And working with not only Indigenous communities, but any community, that's not the way it is. You have to listen in order to be heard and it's -- for some researchers it's new for them. They have good intentions, they've got a good research project, but they're not always well versed in what they need to do and there's a limit as to what an REB can do. (Brenda Gagne)
REBs themselves need to be more actively engaged in education and training to enhance their capacity to review research with Indigenous Peoples. For REB members to know how to evaluate the degree to which engagement has/needs to take place, they need to increase their knowledge of and relationship to First Nations, Inuit, and Métis Peoples and communities. There are many ways training and education materials can be produced and used. Given the specific audience of researchers and REBs, participant contributors suggested a few ways that we can attempt to approach future collaborations in education and outreach. I was reminded of the teaching in *IQ* that experiential learning is a major component to becoming an able human.

Like most new REB members, Joy remembers when she first started and how difficult it was to be in an unfamiliar environment with little guidance on the locally-specific context as it relates to the governance of research, specifically with Indigenous Peoples. Training in general can be improved for REBs and there are specific ways that participant contributors suggested improvement regarding research/review with Indigenous Peoples:

I knew nothing starting out, so I wish somebody had sat down and walked me through exactly what I needed to know. It would have been very helpful to have had somebody sit down with me for a couple of weeks or a month even and say, "Okay. Here's the reading that you should do. Here's how it goes. Here's a list of contact people that you can call on if you get stuck. Here's your contacts over at the [Indigenous Government] or [Indigenous Agency] and why don't you call them up and have coffee with them and get to meet them and we can all sort of sit down have a chat with them and have a meet and greet sort of thing." That would have been ever so helpful. (Joy Knight)

Currently, most REB members receive little to no training aside from the TCPS CORE Tutorial (which is currently undergoing a revision to reflect the changes to the updated *TCPS* that is slated to be released later this year). I have heard the call loud and clear from participant contributors that more interactive and accessible education and
training materials are needed for researchers and REBs in their quest to learn more about ethical research/review with Indigenous Peoples. I will actively continue my work with REBs, researchers, and policy makers, doing my part to positively impact the theory, application, and practice of ethics.

Though there are a multitude of possible challenges and potential solutions that are context-specific, there are some general ethical issues that researchers and REBs have encountered, confronted, and resolved through a memorandum of understanding or research agreement of some sort. We can all learn from the work of others and open our minds to new conversations about how we work ethically in research.

REBs have a responsibility to verify that the type of “community-driven, capacity-building, empowering research that Indigenous communities, Indigenous scholars, and non-Indigenous scholars are demanding become the norm and we want the REB process to enable that kind of…methodology…, not disable them” (Steinberg & Castelden, 2015, p. 4). Negotiating the ethical space demands that researchers, REBs, and Indigenous Peoples collaborate to find solutions in addressing the policy-to-practice gap that exists by constantly and continuously navigating the ethics of engagement. However, asserting and assessing levels of community/Indigenous engagement through paper-driven REB processes continues to fail researchers and communities, and may be failing REBs too as they navigate matters of institutional liability alongside research trustworthiness and ethics. The level and extent to which communities participate is decided by the community themselves. Researchers do not get to decide when adequate engagement is achieved and must take direction from the Indigenous partners throughout the duration of a project.

It's a lifetime of coming to know what ethical research is. (Riley Kucheran)
Atautsikut (All Together)

My research questions (and answers and experiences) are fascinating to so many people (from my transcriptionist to my hair stylist), not because of the topic of research regulatory systems or research ethics policies (believe me, that typically makes peoples’ eyes glaze over), it is because what I am really asking about is research relationships. It is about how we interact with the people and worlds around us. It is about how we shape (and are shaped by) these relationships. We cannot possibly know our impact but we need to remember that everything we do has the potential for influence, whether intentionally or not. We influence each other. Our thoughts influence our actions. Our actions influence our relationships. It is all a circle. Part of the beauty is that we do not know who is watching. Who is listening. Who is paying attention. We have an opportunity all day every day to do differently. As Caine, Estefan, and Clandinin (2013) maintain:

This conceptualization of self in the midst of lives and relationships necessitates a shift in attention from methodological considerations about prescribing how to construct research correctly, to sensitivity to the conditions around which we become with each other. (p. 580)

Where I’m From

From contemplating a moral imperative
To engaging with my own narrative
From second guesses to life's lessons
The integration of me and life to illustrate the complexity
it’s not perplex to me for me to be
The social justice freedom fighter
not just for me but for anyone who needs me to be
I use the voice that's been given to me
To challenge the dominate view contributing to the danger of a single story
(Excerpt, November 2017)
The intricate weaving of humankind and human relationships is not meant to be
disentangled, it is meant to be embraced, explored, examined, and lived. We can learn
from the intricacies of the interconnectedness, rather than attempt to ignore it or unravel
it with futility. It is here in this place, in this time in the story that we can begin to
understand the ethical space. Gontcharov (2016) explains that “[t]he questions of ethics
are the questions of governance and self-governance, which transcend disciplinary and
jurisdictional borders” (pg. 44). In my study, these lines are less obvious. I guess that is
part of the point. Ethics is not something that exists outside of ourselves. It is within us
and throughout us. I am this duality.
Epilogue

My current (novice) understanding of IQ supported this entire dissertation. I have found myself consciously and unconsciously becoming a more able human throughout this study which demonstrates for me the inherently interwoven nature of me and my research. It also means that this has been a far more emotional endeavor than I expected. I have learned a lot – about myself, about the systems, about the ways innovators and early adaptors are doing differently.

The process and product of this PhD has given me invaluable insight, not just into the governance of research with Indigenous Peoples, but into myself. If ethics is about what is right and what is wrong, we all need to do the work of examining ourselves. I was in my early 20s the first time I actually heard these words when someone said them, “the only way to change the world is to change yourself”. Of course, I thought I knew what that meant but it took many more years before I really understood that. And what a wonderful thing to realize that the only person we can change (ourselves) is the only person that needs to change for the world to change.

During the early stages of PhD 2.0, I had lots of dreams of the fancy things I would do as the products of #TheJuliestPhD. It was creative and thought-provoking and thought-challenging. Then I realized that my dreams of what I wanted to do and that which was required of me to be done were two very different things. So, I made a compromise with myself – I have still given myself creative license to push academic boundaries a little bit with the integration and inclusion of a digital story and multiple voices in the format by which this dissertation is transmitted. It allowed me to be creative enough while demonstrating my ability to perform the antics of academia (as the wise fox reminded me when I first started to collect data for this research). I know
that there are lots of interesting and exciting projects that will spin off from this dissertation research and some of my Knowledge Translation and Exchange strategies will benefit from my earlier creative ideas.

Until then, naalak (to listen and pay close attention). I hope you have found a piece of guidance you feel you can pick up and move forward with in this dissertation. For those of you with little or no knowledge in this area, I encourage you to go back to the people I have referenced in this work. I encourage you to sit with your discomfort as you learn more about the historical and contemporary context of research/review with Indigenous Peoples. I encourage you to ask questions. Reach out. Find other people in your institution who are learning alongside you. Visit an Indigenous urban, rural, remote or reserve community. I encourage you to seek out people who are further along in their learning on this subject and build relationships with them. I encourage you to find others who are not as far along as you are and support them in their learning. You will not only learn more of the technical pieces, you will be enacting a central tenant: building relationships. Remember in Chapter 4 when I introduced the IQ principles and talked about the inherent integration of experiential learning for Inuit? Here is an opportunity to try that on for real. Your story is just beginning and as Sarris (1997) says:

[S]tories are inner things: you’re interacting with a living story. The way western [people are] taught to read is to find meaning, the symbols. Instead I say no, a story is not something you figure out the meaning of but something you carry with you the rest of your life to talk back and forth with. (p. 229)

Nakummek – Thank you – Merci
References


Simon, G. (2012). Relational Ethnography: Writing and Reading in Research Relationships [44 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 14*(1), Art. 4,


Appendix A: Narration for Digital Story: Where I’m from

I’m from crashing waves and wood smoke burning
From cold winter days and life-long learning
I’m from mustard pickles and bottled beets
From trapping and fishing and hunting for meat
From country roads to city streets
I’m from ‘everything happens for a reason’ and ‘you will because you can’
I’m from a dipper, not a saucepan
I’m from administering junk mail and playing school
Imagination my most prized tool
I’m from trying it first and pioneering
From helping others and volunteering
I’m from power in numbers and strength of community
From no immunity to discontinuity
From every opportunity to search for unity
My vision is in my dreams for that which is unseen
I’m from unnamed dirt roads to the 401
Why am I the one? Leaving the midnight sun
Doing what I can with that which is undone.
From everyone in my business to anonymity
The proximity of creativity
From strong Bull women, from generation to generation
From the formation of my own creation
I’m from confrontation and contemplation
A demonstration of determination
I’m from the fluctuation of incarnation
From not knowing one day to the next to doing my best
From the normalization of aggravation
From the visualization of beautification
From a conversation to convocation
I’m from concrete jungles and hugging trees
I’m from snow banks taller than me and a cool summer’s breeze
I’m from ‘throw salt over your shoulder’
and ‘if you’ve got nothing nice to say, don’t say anything at all’
From a free-for-all to protocol

I’m from bungalows and ocean views
From piercings and tattoos
I’m from being judged by them and not by me

87 The full digital story can be viewed online: https://www.youtube.com/watch?v=BXbVq5v6UaA
From humility and agility
From susceptibility to possibility
I’m from pedagogies and philosophies
From paradoxes and curiosities
I’m an interdiscipliarian. A contractarian and a humanitarian
I’m from consent and confidentiality
From thinking about it critically
From the practicality of morality
I’m from conflicts of interest, I know that I’m different
I’m from justice and autonomy
Mutual exclusivity is not for me, It’s all a false dichotomy
It’s the space between when we feed the machine
The *ethical space* that we find in that place
My identity not bound artificially
To be free is authenticity
From poverty to prosperity, I’m from the gifts that were put in me

I’m from basic literacy to decolonizing the academy
From ‘the road less travelled’ to a life unraveled
To demystify and exemplify
From getting lost at a marginal cost
To finding myself, the myth dispelled
From captivity to freedom
From the Grand Canyon to the Coliseum
My sensitivity is my reflexivity
No room for negativity or inactivity
The inspection of introspection
I’m from Vienna sausages to ‘that’s just the way it is’
From standing still to flying the world
I’m from the ancient land, my netherworld
With northern lights trapped in the rock
This is not what I planned, I didn’t understand
Labradorite in my line of sight
I’m my own prototype
From writer’s block to the path that I walk
I cannot lose but I can choose
I’m from ‘an eye for an eye makes the whole world blind’
Leave no one behind
The forget-me-not from the one you forgot

I’m from the land and the sea
The animosity of atrocities
From a preoccupation of being mismatched, the outcast
From the devastation of domination
From the aftermath of backlash
To fighting back.
I’m from traditions and technologies
Blank stares and apologies
My existence is resistance
I tried to keep my distance but my persistence is optimistic
The probability of my success
Statistically significant
the predicament not definitive
My willingness is no coincidence, it’s serendipitous
The impetus from my imagination, the acceleration of exploration
It was in the instant that I went against it
'You're still here' echoes in my mind
As my heart breaks for those who are gone
I'm here for them. For you. For me.
My resiliency runs deep in my veins
I will not take in vein that I remain not to refrain but to retrain

I'm from Tom Petty and Kenny Rogers
From ‘we get what we give’ and we share what we’ve got
I went in head first, for better or worst
We are who are
Distance from afar
Objects in the rear-view mirror appear closer than they are
Force fed a single story
Pain and poverty in all its glory
Though a chapter, it's not the book
I found my hook from the way you look when I speak my truths
I'm from the aurora borealis
I’m from chaos and balance
I’m from the mountains and the land
To understand a dreamland where the ocean meets the sand
I personify darkness to light
stars in the night
I know I'm alright and I'm not afraid to fight
The power of my ancestors in me
Power and love in equal proportion, Life's distortions

I'm from the vision of my grandmothers
And the prayers of her ancestors
Her independence weaved into my existence
I'm from 'practice makes perfect' and the Doppler effect to learn to connect
From over protection to misdirection
From retrospection to resurrection
The opportunistic infection at the intersections of natural selection
I'm from ethics review and collaboration
A fascination with innovation
From punctuation to publication
From suffocation to restoration
From policy to practice
The global atlas
I'm provocative
A paradox
Pandora's box
From the equinox, who we are is in the stars
I'm from ideologies and institutions
From apologies to resolutions
From 'whatever doesn't kill you makes you stronger' and 'laughter makes you live longer'
It makes me a fighter and the load feels lighter
It’s my grit
That bit that you can’t describe
a heartbeat deep inside
The window seat in the flight of life

Compassion through interaction.
Satisfaction with my own expansion
Extraction, just a fraction of my own distraction
It’s relational not sensational.
I take personal responsibility.
It’s my own self-advocacy
I have the right to be myself, to love myself. To honor me.
It’s all about hope, a slippery slope to learn to cope.
My resiliency, my legacy.
Reclaiming my identity

Tokenism. Animism. The instinctual bit you bury inside
You make it hide in this game of seek. What's this you speak?
The serenity of my identity is not up for debate.
My name’s sake. You activate this welfare state while I accommodate a heart full of hate.
From epistemological collisions To making tough decisions
From being scared to tears to facing fears
From holding on to letting go
From questioning why to starting to know
A discursive analysis of society's paralysis
What's here for us? Where do we go?
This much I know, We let go of ego and follow our heart
That's the only start
Instead of criticize, I realize my own potential and that's essential

The danger of a single story
That I could've become. Destined to become
Started to become
When that narrative overpowered
No happy hour, Spirit devoured
But I’ve overcome with no rule of thumb from the beat of the drum
From statistical analysis to individual variance
From philosophical debate to examining my own self
From skirting sickness to weaving wellness and asking for help
From imaginary friends to a visionary end
From 'just do your best' and 'forget all the rest'
From ethical theory to the way we actually act
not a question of fact but a matter of fact.

To look back
From humble beginnings
To nine round innings
A nomadic life not tamed by the skyscrapers that tower over the city
My own standing committee on how to do me
From simplicity to complexity and to weave them together
A proud carrier of my eagle feather

From the inaugural student member on the REB
To dipping my toes in the Baltic Sea
From shy and timid to challenging my limits
To testing my strength and doing it anyway
Healing is just beginning from the pain deep inside.
The trauma runs through my blood
But there's a flood of resiliency that carries me through the animosity and uncertainty.
From my ancestors who prayed
That one day
I'd be here
With who I am and what they knew
To try anew a different way
The road less travelled
And here I stand
on the blessed land that takes my hand
To be true to myself and do the right thing
To examine my life and the adventures it brings
The consequences of putting up fences
Leaves people defenseless
To hoard what we find and to push people out

From contemplating a moral imperative
To engaging with my own narrative
From second guesses to life's lessons
The integration of me and life to illustrate the complexity
it’s not perplex to me for me to be
The social justice freedom fighter
not just for me but for anyone who needs me to be
I use the voice that's been given to me
To challenge the dominate view contributing to the danger of a single story
Exploratory
To find the power of love
Instead of the love of power
It’s my superpower to be empowered
To learn to let go. To absolve.
To dissolve the single story
To evolve in all my glory
The theory and practice of social change
To rearrange the action of exchange
From the first to graduate high school to breaking the cycle
From moving away yet not leaving it behind to finding mine
From 'you can do it if you put your mind to it'
and to do it you just have to go through it
Empathy, breathlessly, conscious
To walk a mile. To think a while
I shoot for the moon but sometimes I’m too busy gazing at stars from afar
My strength through resiliency from the communities that entrust in me
The legacy I want to see that came before me
My ancestors were investors in me. My identity
So much to question and so much to learn
The fire inside burns, with no limitation
My foundation is All My Relations
Appendix B: REB Reviews and Approvals

Ms Julie Bull
Interdisciplinary Graduate Studies
Dear Ms Bull,

As Chair of the Research Ethics Board at the University of New Brunswick (Fredericton), I have reviewed your revised application (Research is relational and reflexive: Peoples, policies and priorities at play in ethically approving health research with indigenous peoples -- REB #2018-017) for its compliance with Tri-Council Policy (TCPS) and with UNB Policy (UPRIH). On the basis of the review, I am pleased to inform you that, in my opinion, your project now appears to be in compliance with TCP and UPRIH. Accordingly, please consider this letter to represent official notification of REB approval of your project for a period of three years from the date of this notification.

Please note that, in the future, if you find that you must make any changes to your protocol, those changes must be considered and approved by the REB before they are implemented. Please submit the REB Case Modification Request form, available online through the Research Ethics page of the Office of the VP (Research).

Annual Reports for this project are due on the 15th of January each year, provided that this date is at least six months after the date of project approval. Final reports are due 90 days after project completion. Both of these reports can be found on our website at http://www.unb.ca/research/ors/forms/index.php#ethics.

Best wishes for the successful completion of your research project.

Although your application was processed via Expedited/Delegated Review, for your information we are providing a list of current Research Ethics Board members.

Sincerely,

R. Steven Turner, Chair
Research Ethics Board
To: Julie Bull
Re: REB 2018-138: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play
in Ethically Approving Health Research with Indigenous Peoples
Date: April 20, 2018

Dear Julie Bull,

The review of your protocol REB File REB 2018-138 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2018-138) on future correspondence.

Congratulations and best of luck in conducting your research.

[Signature]

Dr. Patrizia Albanese, PhD
Chair, Ryerson University Research Ethics Board
2018
Northwest Territories Scientific Research Licence

Issued by: Aurora Research Institute – Aurora College
Inuvik, Northwest Territories

Issued to: Ms. Julie R Bull
University of New Brunswick
607-95 High Park Avenue
Toronto, ON
M6P 2R8 Canada
Phone: (416) 700-9952
Fax: (416) 593-4694
Email: juliebull@gmail.com

Affiliation: University of New Brunswick

Funding:

Team Members:

Title: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Objectives: To talk to research ethics board members, chairs, and other research administrators about the review and approval of research involving Indigenous peoples.

Dates of data collection: September 7, 2018 to December 31, 2018

Location: Fort Smith

Licence No. 16402 expires on December 31, 2018
Issued in the Town of Inuvik on September 07, 2018

* original signed *

Pippa Seccombe-Hett
Vice President, Research
Aurora Research Institute
Minimal Risk Approval – External Approval - Delegated

Study Title: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Approval Date: 2018 March 23                  Expiry Date: 2019 March 23
Principal Investigator: Julie Ball              Institution: University of New Brunswick

Document(s) Approved in this Letter:
- SFU ORE External Application, received 2018 March 23
- Dissertation Proposal, dated 2018 January 7
- University of New Brunswick REB Approval Letter, dated 2018 February 13
- University of New Brunswick REB Application
- Interview Guiding Questions
- Participant Recruitment Invitation Script
- Recruitment Poster
- Consent Script for Interview
- Participant Contributor Consent Page

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human participants.

The approval for this Study expires on the Expiry Date. An annual renewal form must be completed every year prior to the Expiry Date. Failure to submit an annual renewal form will lead to your study being suspended and potentially terminated. The Board reviews and may amend decisions or subsequent amendments made independently by the authorized delegated reviewer at its regular monthly meeting.

This letter is your official ethics approval documentation for this project. Please keep this document for reference purposes.

This study has been approved by an authorized delegated reviewer.
RE: REB # 2018-06
Title: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples
PIs: Ms. Julie Bull, UNB
Dr. Mary McKenna (Supervisor)

Dear Ms. Bull,

Thank you for your recent application for ethics approval. The REB conducted a review of your submission for compliance with the Tri-Council Policy Statement, Ethical Conduct for Research Involving Humans (2014) (hereinafter “TCPS2”) and the St. Thomas University Research Ethics Board Senate document. The Board is pleased to grant approval for the above named research for a period of one year.

Please note the following regarding all research that has been granted ethical approval by the REB:

1. If there are any substantial changes to the research plan or research protocol the Chair of the REB must be promptly notified (see Article 6.16, TCPS2). This includes the reporting of unanticipated issues (Article 6.15, TCPS2) or requests for amendment.
2. If the project continues after one year, please file an Annual Renewal form with the REB to renew your ethical approval.
3. When the project has been completed please notify the Chair of the REB by completing the Final Report form.

(These and other resources are available on the St. Thomas University REB website.)

Your REB certificate number should also appear on all public documents associated with this research as well as any documents shared with potential and active participants. These documents should also contain the contact information for the REB Chair (rebechair@stu.ca), should your participants have any questions or concerns about their involvement in the study or their rights as participants.

Should there be any further ways the REB can assist your research, please don’t hesitate to follow up. I can best be reached via email (rebechair@stu.ca) as can Danielle Connell, the REB Coordinator, at: reb@stu.ca (or phone: 452-0647).

Best wishes for a successful research process!

Sincerely,

Karla O’Regan, PhD
Research Ethics Board, Chair

cc: Dr. Mary McKenna (Supervisor)
Office of Research Services
Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Julie Bull

DEPARTMENT
Graduate Studies
University of New Brunswick

REB#
2018-077

SUPERVISOR: Dr. Mary McKenna

TITLE: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

APPROVED ON: April 20, 2018
RENEWAL DATE: April 20, 2019

APPROVAL OF:
University of New Brunswick Application for Review of Research Involving Humans, Invitation to Take Part in Research, Consent Script, Recruitment Flyer, Participant Contributor Consent Page

Full Board Meeting ☐ Delegated Review ☒

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html.

Raven Sinclair, BA, CISW, BJSW, MSW, PhD
REB Chair

Please send all correspondence to:
Research Office
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4893
research.ethics@uregina.ca
To: Julie Bull
   University of New Brunswick

Protocol Number: REB Ref # 6007577

Title: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Date Approved: March 14 2018
End Date: March 13 2019

This research proposal has been reviewed and approved by the UPEI Research Ethics Board. Please be advised that the Research Ethics Board currently operates according to the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans (2014) and applicable laws and regulations.

It is your responsibility to ensure that the Ethics Renewal form is forwarded to Research Services prior to the renewal date. The information provided in this form must be current to the time of submission and submitted to Research Services not less than 30 days prior to the anniversary of your approval date. The Ethics Renewal form can be downloaded from the Research Services website (http://www.upei.ca/research/forms).

Any proposed changes to the study must also be submitted on the same form to the UPEI Research Ethics Board for approval.

The Research Ethics Board advises that IF YOU DO NOT return the completed Ethics Renewal form prior to the date of renewal:
- Your ethics approval will lapse
- You will be required to stop research activity immediately
- You will not be permitted to restart the study until you reapply for and receive approval to undertake the study again.

Lapse in ethics approval may result in interruption or termination of funding.

Notwithstanding the approval of the REB, the primary responsibility for the ethical conduct of the investigation remains with you.

Sincerely,

Lyndsay E. Moffatt, Ph.D.
Chair, UPEI Research Ethics Board
April 20, 2018

Dear Julie Bull,

RE: Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

PI: Julie Bull

The UVic Research Ethics Board Vice-Chair, Dr. Chris Lalonde, has looked at the University of New Brunswick’s Research Ethics Board documentation and certification. We have no questions about the study or concerns about inviting UVic REB personnel to participate.

As stated earlier in the information for external researchers we sent you, we will not issue you a UVic ethics certificate and it is up to the UVic REB personnel to decide whether they wish to join the study.

If ethical concerns arise from the participants, please direct them to the University of New Brunswick’s Research Ethics Board.

Kindly retain this email for your records.

All the best with your research.

Sincerely,

Kenna
Appendix C: Interview Guide

1. Understanding the Institution and System
   - How are protocols involving Indigenous Peoples reviewed at your institution?
   - What is the composition of the REB and process of review?
   - Is there current training for REB members on research with Indigenous Peoples?
   - Are there Indigenous Peoples sitting on your REB? If no, is there ad hoc expertise if no members? How are they chosen and trained?
   - Do you get an opportunity to discuss chapter 9 with other REBs? What are the issues and topics that arise?

2. Considerations and Challenges
   - What challenges arise in reviewing research with Indigenous Peoples?
   - What challenges, obstacles do you face in applying chapter 9?
   - How are they address these challenges? How are these challenges informed (or not) by TCPS 2 Chapter 9?
   - If there are discrepancies between REBs and communities, how are they handled?
   - Are there any other challenges you can think of?

3. Successes and Opportunities
   - Are there aspects or examples of things that are successful?
   - What do you know now that you wish you knew when you started reviewing health research with Indigenous Peoples?
   - Do you have research agreements or data sharing agreements in your REB?
   - What has been helpful to increase your knowledge?
   - What has been the best advice you’ve been given about reviewing health research with Indigenous Peoples?
   - What would you tell new REB?

4. Visions for the future
   - Do you know how others are doing it?
   - What do REBs need from communities? From their institutions?
   - Have you seen any change in practice since TCPS2 in 2010?
   - How can chapter 9 be improved to meet your needs?
   - Are there things you’ve seen other REBs do that are working?
   - Do you have any advice for REB members joining a board for the first time regarding health research with Indigenous Peoples?
   - Are there other things your REB needs that we haven’t already talked about?
   - Are there documents/resources developed to help REB members apply Ch. 9?
   - Do you have any additional resources you’d like to share?
Appendix D: Participant Invitation

Faculty of Graduate Studies
University of New Brunswick
Invitation to Take Part in Research

Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Hello. I’m Julie Bull and I am collecting stories about the facilitators and barriers to applying the *Tri-Council Policy Statement Chapter 9: Research involving First Nations, Inuit, and Métis*. I’m interested in any stories or artifacts (such as videos, literature, photos, art) you have on the topic that you are willing to share. The goal is to produce accessible materials that will be useful for REB members and research administrators in reviewing and approving research with Indigenous Peoples. This study is being conducted to fulfill partial requirements of Doctor of Philosophy in Interdisciplinary Studies in the Faculty of Graduate Studies at the University of New Brunswick (UNB). I’m conducting this research under the supervision of Dr. Mary McKenna at UNB.

**Why have I been invited to participate?** You have been invited to participate in this study because of your role in research ethics review for health research with Indigenous Peoples. Your experiences and expertise as a REB member, chair, or research administrator can contribute to the conversation about how to apply TCPS Chapter 9.

**How can I contribute?** There are a variety of ways you can participate in this study. You can participate in an interview with me that will be done face to face if you live in the Greater Toronto Area or by GoTo Meeting if you live elsewhere in Canada; you can contribute your own digital story or collaborate in a collective story with other participants; or you can send me artifacts (resources, literature, videos, photos, art that are publicly available and not bound by any privacy or confidentiality clause) that depict your understanding of the governance of health research with Indigenous Peoples.

**Are there any possible benefits from participation in this study?** It is not known whether this study will benefit you directly. However, you may find it rewarding to talk about your experiences with research ethics review for health research with Indigenous Peoples and contribute to the dialogue on this work. It is unlikely that there will be direct benefits to you personally, however, by better understanding what REBs need to apply TCPS Chapter 9, REB members and research administrators may contribute to your work.

**Are there any possible risks from participation in this study?** This research does not involve more than minimal risk. However, there is always a possibility that during

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88 If your institution would like me to undergo REB review at your institution prior to your participation, please let me know and I will complete the necessary documentation required.
the interview you may choose to talk about disturbing experiences with unethical research/review. Your participation in the research project will pose no intentional harm to you and is entirely voluntary. You may stop your participation in the research project at any time, without penalty or prejudice. There will be no questions asked that will violate conditions of confidentiality pertaining to your service on a Research Ethics Board; this study seeks to understand your experiences with applying TCPS Chapter 9, not any specific research/er information from your institution.

**What if I change my mind during or after the study?** You are free to withdraw at any time and can do so without providing an explanation. If you choose to withdraw from this study, I will ask your permission to retain any data that has been collected so far. You are free to decline this request. Data that have already been processed will not be able to be withdrawn (i.e. once the digital product has been completed).

**What will happen to the information when this study is over?** The data from this study that is kept will not bear participants’ names or be identifiable after the completion of the project, unless you’ve agreed to have your name used in the project. Raw data will be destroyed when analysis is complete.

**How will the results of the study be published?** The primary publication product for this study will be the compilation of contributions in an open access digital source (i.e. e-book, YouTube video, or another online digital tool). The results of this study will also be published in conventional academic ways such as journal articles and conference presentations.

**What if I have questions about this study?** If you have any questions about taking part in this study, you can meet with the researcher or supervisor of the study:

- **Ms. Julie Bull:** phone: 416-700-9952; email: Julie.Bull@unb.ca
- **Dr. Mary McKenna:** phone: 506-451-6872; email: Mary.Mckenna@unb.ca

You can also talk to someone who is not involved with the study at all but can advise you on your rights as a participant in a research study and is the person for you to contact if you have any concerns about the ethical conduct of this project. This person is the Chair of the UNB Research Ethics Board:

- **Dr. Steven Turner:** phone: 506-453-5189; email: turner@unb.ca

This project has been approved by the Research Ethics Board of the University of New Brunswick and is on file as #2018-017

This project has also been reviewed and approved by the Research Ethics Board at Ryerson University and is on file as #2018-138

This project has also been reviewed and approved by the Research Ethics Board at the University of Regina and is on file as #2018-077

For more information or to contribute to this study contact Julie Bull at Julie.Bull@UNB.ca
Appendix E: Additional Resources and Reading

The following list is not exhaustive but it is a good starting point for people who would like additional information. In the electronic version, you can simply click the title and it will take you directly to the website. For those reading the print version, you will need to do a little more work and copy/paste the titles to find the correct webpage.

NunatuKavut Research Advisory Committee

Nunatsivut Government Research Ethics Committee

Mi’kmaq Ethics Watch

Native Council of Prince Edward Island Research Advisory Committee

Mi’kmaq Confederacy of Prince Edward Island Research Ethics

Six Nations Council Research Ethics Committee Protocol

Guidelines for Ethical Aboriginal Research

CIHR Guidelines for Health Research involving Aboriginal People

Tri Council Policy Statement Chapter 9 CORE Module

Ethics in Indigenous Research Workshop York University 2018

Institute for Clinical Evaluative Sciences Indigenous Portfolio

First Nations Information Governance Centre OCAP® Principles

Carleton University Institute on the Ethics of Research with Indigenous Peoples Resource List

National Aboriginal Health Organization Principles for Métis Research

Data sovereignty

Indigenous Data Sovereignty: Toward and Agenda

Data sovereignty New Zealand

Data sovereignty Australia

Data sovereignty United States
Protocols, Standards, and Guidelines for Working with Indigenous Peoples

Canada


Assembly of First Nations. Ethics in First Nations Research.


Best Practises Tools for OCAP Compliant Research (First Nations Information Governance Centre (FNIGC)


Canadian Institutes for Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People.

Tri-Council Policy Statement (TCPS 2) Webinar – Chapter 9: Research Involving First Nations, Inuit and Métis Peoples of Canada

Collaborative Research: an “indigenous lens” perspective. Canadian Coalition for Global Health Research.

Conduct of Traditional Knowledge Research: Wildlife Management Advisory Council North Slope.


Femmes Autochtones du Quebec Inc. Quebec Native Women (FAQNW) (2012) Guidelines for Research with Aboriginal Women

First Nations Environmental Health Innovation Network. Research Ethics Protocols and Guidelines

First Nations Regional Longitudinal Health Survey: Code of Research Ethics

Guidelines for Ethical Research in Manitoba First Nations 2014 Principles, practices, and templates

Guidelines for Ethical Aboriginal Research. Aboriginal Health Research Review Committee in collaboration with Manitoulin First Nations leadership and community agencies


Kahnawake Schools Diabetes Prevention Project (Ethics).

Negotiating Research Relationships with Inuit Communities (Tapiriit Kanatami and the Nunavut Research Institute).

OCAP Principles on First Nations Ownership, Control, Access and Possession

Protocols & Principles for Conducting Research in an Indigenous Context (University of Victoria).


Royal Commission on Aboriginal Peoples Data for Seven Generations An Information Legacy of the Royal Commission on Aboriginal Peoples


Six Nations Ethics Policy Conducting Research at Six Nations

Honouring the Truth, Reconciling for the Future, Summary of the TRC Report

International

African Studies Association Ethical Conduct Guidelines


Aboriginal Health Council of SA Aboriginal Researcher Registry

Australian Institute of Aboriginal and Torres Strait Islander Studies.

Ethical Guidelines for Research Involving Aboriginal and Torres Strait Islander Peoples.

Guidelines for Ethical Research in Australian Indigenous Studies (Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).


Katoa Ltd: Research Ethics

Māori Research Ethics: An Overview

Maori Research Ethics: Rangahau Te Ara Tika - Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members

National Indigenous Research and Knowledges Network

Researching in Indigenous Contexts: Some Ethical Implications & Responsibilities for Researchers

SAMHRI - Wardliparingga Aboriginal Research Unit

The Lowitja Institute - Australia's National Institute for Aboriginal and Torres Strait Health Research

Reflections on Ethic for Ethnically Non-Indigenous Researchers

Collecting Traditional Knowledge, Using it and Handling the Materials.

Developing a Community-Based Research Orientation: Resources for Investigators Desiring to Work with American Indian & Alaska Native Communities.  
http://genetics.ncai.org/tips-for-researchers.cfm

http://www.indigenousgeography.net/ethics.shtm


Research Centres and Organizations (working on Indigenous Research)

Canadian Polar Commission

Association of Canadian Universities for Northern Studies

Arctic Research Consortium for the United States

Aurora Research Institute

Centre of Indigenous Culture, Research, Language and Education (CIRCLE)

International Arctic Social Science Association ArcticNet

Nain Research Centre

Nunavut Research Institute

Nunavik Research Centre

Yukon Research Centre
Multimedia

Aboriginal Health Ethics and Research

Anti-Aboriginal Racism in Canada: A Social Determinant of Health

Cultural Protocols When Researching with Australian Aboriginal Communities

Native Peoples and Genetic Research

Reconciling Ethical Research with Métis, Inuit, and First Nations People.

Research Involving First Nations, Inuit and Métis Peoples of Canada.

Social Media Research and Indigenous Communities.

Stronger Ethics, Stronger Research: Tribal Governance as a Key Community Health Speaker

Yarning about Indigenous Ethics


Julie Bull youtube channel: https://www.youtube.com/channel/UCCwjgrhZE3pdEx7A_HFwCFQ?view_as=subscriber

Al Jezeera

Other action-oriented websites

Indigenous Research Centre Institute, Carleton University.

Indigenous Research and Ethics, University of Calgary.

York University Ethics in Indigenous Research Workshop 2018
Appendix F: Participant Contributor Consent Form

Faculty of Graduate Studies University of New Brunswick
Consent to Take Part in Research

Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Researcher: Ms. Julie Bull, PhD Candidate

You have been invited to take part in a research study. It is up to you to decide whether or not you participate. Before you decide, I will tell you more about the study and you will have an opportunity to ask any questions you may have.

Hello. I’m Julie Bull and I am collecting stories about the facilitators and barriers to applying the *Tri-Council Policy Statement Chapter 9: Research involving First Nations, Inuit, and Métis*. I’m interested in any stories or artifacts (such as videos, literature, photos, art) you have on the topic that you are willing to share with me. I’m conducting this research under the supervision of Dr. Mary McKenna at the University of New Brunswick. This study is being conducted to fulfill partial requirements of a Doctor of Philosophy in Interdisciplinary Studies (IDST PhD) in the Faculty of Graduate Studies at the University of New Brunswick.

**Description of the study process:** I’m inviting you to do a one-on-one interview that will take about one hour, depending on how much you have to say. You will be interviewed about your involvement in, and ideas about, research ethics review for health research with Indigenous Peoples, specifically regarding the implementation of *TCPs* Chapter 9. The interview will take place at a time and place convenient to you if you live in the Greater Toronto Area and it will be audio recorded. If you live in other parts of Canada, interviews will be conducted virtually using GoTo meeting. The interview will be recorded and then transcribed to text. You will not be required to participate in anything after the interview but if you choose to, you will have the opportunity to read through the text of your interview after transcription is complete. You are invited to be involved throughout the analysis of the project at your discretion. Your level of participation is your choice and we can discuss that as we go. You are also invited to share a digital story or artifacts (such as literature, videos, art, photos that are publicly available and not bound by any privacy or confidentiality clause) that depict your understanding of research ethics review for health research with Indigenous Peoples.

**Are there any benefits to participating?** It is not known whether this study will benefit you directly. However, you may find it rewarding to talk about your experiences with research ethics review for health research with Indigenous Peoples and contribute to the dialogue on this work. It is unlikely that there will be direct benefits to you.
personally, however, by better understanding what REBs need to apply TCPS Chapter 9, REB members and research administrators may contribute to your work.

**Are there any risks to participating?** This research does not involve more than minimal risk. However, there is always a possibility that during the interview you may choose to talk about disturbing experiences with unethical research/review. If you become upset during the interview, we can take a break, or turn off the recorder while you talk it through or stop the interview altogether and schedule a different time. Your participation in the research project will pose no intentional harm to you and is entirely voluntary. You may stop your participation in the research project at any time, without penalty or prejudice. If, after completion of the interview, you decide that you would like to withdraw your participation, you may do so up until the time the data has been de-identified and combined with the other data collected (if you choose to be anonymous) or at which point the final product of this research is complete (if you choose to be named or have your voice/video/picture included). There will be no questions asked that will violate conditions of confidentiality pertaining to your service on a Research Ethics Board; this study seeks to understand your experiences with applying TCPS Chapter 9, not any specific research/er information from your institution.

**Confidentiality:** Data will be kept confidential. Your name will not be on the typed transcript of the interview (unless you choose to be named as such). The transcript will be reviewed by the researcher to make sure there is no information that may accidentally identify you if you do not want to be identified (e.g., your position or institutional affiliations). As well, you will be sent a copy of the transcript and you will have the opportunity to review it and have information removed if you feel it might accidentally reveal your identity if you choose. This step is optional. You are under no obligation to participate beyond the interview if you choose not to. The digital recording of your responses will be destroyed after data analysis is complete and only de-identified text transcripts will be kept unless you choose to have your recorded voice used in the final product of the study.

You will be identified by a pseudonym in the final transcript, if you choose not to be identified by your name. Only Julie Bull and Dr. Mary McKenna will have access to the raw data resulting from this research. These data (transcripts) will be kept with the researcher (Julie Bull) at her home office in a locked filing cabinet until she has completed her Doctoral Dissertation (estimated 2019). At that point, all raw data will be destroyed.

**Voluntary participation:**
- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the interview for whatever reason, or up until approximately summer 2018 when data will be analyzed and compiled.
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop, I will ask you how you would like me to handle the data collected up to that point (returning it to you, destroying it, or using the data already collected).
- If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your level of participation is your decision.
Throughout the study, the researcher (Julie Bull) will:
- discuss the study with you and answer your questions
- keep confidential any information which could identify you personally, unless you prefer to be named in the study for your contributions
- be available during the study to address problems and answer questions

If you decide not to take part or choose to leave the study at any point, this will not affect your relationship with Julie Bull nor will it affect any future collaborations or relationships with the University of New Brunswick.

Questions: If you have any questions about taking part in this study, you can meet with the investigator or supervisors who are in charge of the study. These people are:

**Ms. Julie Bull**
phone: 416-700-9952
email: Julie.Bull@unb.ca

**Dr. Mary McKenna**
phone: 506-451-6872
email: Mary.Mckenna@unb.ca

You can also talk to someone who is not involved with the study at all but can advise you on your rights as a participant in a research study and is the person for you to contact if you have any concerns about the ethical conduct of this project. This person is the Chair of the UNB Research Ethics Board:

**Dr. Steven Turner**
phone: 506-453-5189
email: turner@unb.ca

This project has been reviewed and approved by the Research Ethics Board of the University of New Brunswick and is on file as #2018-017

This project has also been reviewed and approved by the Research Ethics Board at Ryerson University and is on file as #2018-138

This project has also been reviewed and approved by the Research Ethics Board at the University of Regina and is on file as #2018-077
Participant Contributor Consent Page

**Title:** Research is Relational and Reflexive: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Name of Participant: ________________ Date of Interview: __________________

Do you have any questions or would like any additional details at this point?
[document questions here (use reverse if more space required); answer queries from participant contributor]

[Read these aloud to participant contributor and check box according to their answers]

- You have read the consent
  - Yes { }     No { }
- You have had the opportunity to ask questions/to discuss this study
  - Yes { }     No { }
- You have received satisfactory answers to all of your questions
  - Yes { }     No { }
- You have received enough information about the study
  - Yes { }     No { }
- You understand that you are free to withdraw from the study
  - Yes { }     No { }
  - at any time
  - without having to give a reason
  - without affecting your future relationships with Julie or UNB
- You understand you may not benefit from participating in this study
  - Yes { }     No { }
- You agree to have the interview digitally recorded and transcribed
  - Yes { }     No { }
- You agree to have the interview conducted via GoTo meeting
  - Yes { }     No { }
- You agree to be named in the reporting of this study
  - Yes { }     No { }
- You prefer to remain anonymous in the reporting of this study
  - Yes { }     No { }
- You would like to review the transcript of your interview
  - Yes { }     No { }
- You agree to be contacted during analysis for follow up
  - Yes { }     No { }
- You agree to have your voice used in the digital component of study
  - Yes { }     No { }
- You agree to be listed as a participant contributor in the study
  - Yes { }     No { }
- You agree to take part in this study
  - Yes { }     No { }

**To be signed by the researcher:**
I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant contributor fully understands what is involved in being in the study, any potential risks and benefits of the study, and that they have freely chosen to participate.

_____________________________           __________________________
Signature of investigator                  Date
Appendix G: CAREB Posters
Appendix H: Protocol Example

QAUGIARTIT HEALTH RESEARCH CENTRE

Reviewer Health Research Ethics Checklist

The purpose of this checklist is to provide a guide for the reviewer as to the kinds of ethical issues you should think about when reviewing a proposal for health research in Nunavut.

Community Engagement:
- Has there been any consultation with the community before the submission of the proposal? If so, what kind and with whom?
- Are there community partners (individuals, organizations, advisory groups, etc.) involved in the project?
- Are community members involved in collecting information or guiding the project?
- How will community members be acknowledged for their contributions? Will it be in the form of publication credits, remuneration (payment), or some other way? Is this adequate/fair?

Community research agreement:
- Has a community research agreement been proposed to determine the responsibilities of community partners and researchers in the project? If so, who will represent the community to sign it?

Research Methods:
- Are research data management methods appropriate?
  - length of time
  - sensitive methodology
  - ensuring confidentiality
  - security and storage of files and data
  - data access issues once the study is complete

  Yes

Risks and Benefits:
- Are there risks associated with this project? If so, are they clear? Do they affect a person or the community (or both or neither)?
- Are there benefits associated with this project? If so, are they clear?

Advertisements and Recruitment:
- Are there advertisements to recruit participants or advertise the study? Are they appropriate?

Confidentiality:
- Are the confidentiality protections appropriate? For example, what steps have they taken to make sure confidentiality will be maintained, and given the small populations of northern communities, are they adequate for the North?
- How do they propose to handle negative or sensitive results? Is this adequate/fair for the community?

Participant Withdrawal:
- Are there appropriate mechanisms for participants to withdraw from the study?

Updated JAN 2014

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89 For more information and most updated checklist, visit
QAUGIARTIIT HEALTH RESEARCH CENTRE

Financial or Other Compensation:
- Is there compensation to participants?
- Is it appropriate to their time and effort?
- Is it coercive (does it influence them to participate when normally they wouldn’t)?
- Do they propose dollar amounts of compensation to participants? If so, is this acceptable?
- What is the funding source?
- Will the funding source want rights over data or publication?

Consent forms:
- Are they consistent with protocol?
- Is there a draft consent form submitted?
- Is the language (language and reading level) appropriate for participant population?
- Does it include a waiver of legal rights?
- Is the method of obtaining consent appropriate? Will it explained properly (i.e. by a person or through a video)?

Sharing Knowledge:
- Is there a clear explanation of how the research results will be shared with the community?
- Is it in a form that community members will understand?

Conflict of Interest:
- Are there any conflicts of interest (including with funders or with participants)?
- Have they been appropriately managed?

Scientific Review:
- Are the Hypothesis/research questions appropriate for the region?
- Are the recruitment/sampling strategies appropriate?
- Are the study numbers justified?
- Has there been a scientific review and/or ethical review by the proponent’s university, organization, or any other northern body?

Any other reviewer comments:

Date & signature of primary reviewer

Updated JAN 2014
Appendix I: TCPS Chapter 9 Summary of Articles

Requirement of Community Engagement in Aboriginal Research

**Article 9.1** Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community. The conditions under which engagement is required include, but are not limited to:

a. research conducted on First Nations, Inuit or Métis lands;
b. recruitment criteria that include Aboriginal identity as a factor for the entire study or for a subgroup in the study;
c. research that seeks input from participants regarding a community’s cultural heritage, artefacts, traditional knowledge or unique characteristics;
d. research in which Aboriginal identity or membership in an Aboriginal community is used as a variable for the purpose of analysis of the research data; and
e. interpretation of research results that will refer to Aboriginal communities, peoples, language, history or culture.

Nature and Extent of Community Engagement

**Article 9.2** The nature and extent of community engagement in a project shall be determined jointly by the researcher and the relevant community and shall be appropriate to community characteristics and the nature of the research.

Respect for First Nations, Inuit and Métis Governing Authorities

**Article 9.3** Where a proposed research project is to be conducted on lands under the jurisdiction of a First Nations, Inuit or Métis authority, researchers shall seek the engagement of formal leaders of the community, except as provided under Articles 9.5, 9.6 and 9.7.

Engagement with Organizations and Communities of Interest

**Article 9.4** For the purposes of community engagement and collaboration in research undertakings, researchers and REBs shall recognize Aboriginal organizations, including First Nations, Inuit and Métis representative bodies, and service organizations and communities of interest, as communities. They shall also recognize these groups through representation of their members on ethical review and oversight of projects, where appropriate.

Complex Authority Structures

**Article 9.5** Where alternatives to securing the agreement of formal leadership are proposed for research on First Nations, Inuit or Métis lands or in organizational communities, researchers should engage community processes and document
measures taken, to enable the REB to review the proposal with due consideration of complex community authority structures.

Recognizing Diverse Interests within Communities

**Article 9.6** In engaging territorial or organizational communities, researchers should ensure, to the extent possible, that they take into consideration the views of all relevant sectors – including individuals and subgroups who may not have a voice in the formal leadership. Groups or individuals whose circumstances make them vulnerable may need or desire special measures to ensure their safety in the context of a specific research project. Those who have been excluded from participation in the past may need special measures to ensure inclusion in research.

Critical Inquiry

**Article 9.7** Research involving Aboriginal peoples that critically examines the conduct of public institutions, First Nations, Inuit and Métis governments, institutions or organizations or persons exercising authority over First Nations, Inuit or Métis individuals may be conducted ethically, notwithstanding the usual requirement of engaging community leaders.

Respect for Community Customs and Codes of Practise

**Article 9.8** Researchers have an obligation to become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research. Inconsistencies between community custom and this Policy should be identified and addressed in advance of initiating the research, or as they arise.

Institutional Research Ethics Review Required

**Article 9.9** Research ethics review by community REBs or other responsible bodies at the research site will not be a substitute for research ethics review by institutional REBs, and will not exempt researchers affiliated with an institution from seeking REB approval at their institution, subject to Article 8.1. Prospective research and secondary use of data and human biological materials for research purposes is subject to research ethics review.

Requirement to Advise the REB on a Plan for Community Engagement

**Article 9.10** When proposing research expected to involve First Nations, Inuit or Métis participants, researchers shall advise their REB how they have engaged, or intend to engage, the relevant community. Alternatively, researchers may seek REB approval for an exception to the requirement for community engagement, on the basis of an acceptable rationale.
Research Agreements

Article 9.11 Where a community has formally engaged with a researcher or research team through a designated representative, the terms and undertakings of both the researcher and the community should be set out in a research agreement before participants are recruited.

Collaborative Research

Article 9.12 As part of the community engagement process, researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research, and the level of ongoing engagement desired by the community.

Mutual Benefits in Research

Article 9.13 Where the form of community engagement and the nature of the research make it possible, research should be relevant to community needs and priorities. The research should benefit the participating community (e.g., training, local hiring, recognition of contributors, return of results), as well as extend the boundaries of knowledge.

Strengthening Research Capacity

Article 9.14 Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.

Recognition of the Role of Elders and Other Knowledge Holders

Article 9.15 Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge. Community advice should also be sought to determine appropriate recognition for the unique advisory role fulfilled by these persons.

Privacy and Confidentiality

Article 9.16 Researchers and community partners shall address privacy and confidentiality for communities and individuals early on in the community engagement process. The extent to which limited or full disclosure of personal information related to the research is to be disclosed to community partners shall be addressed in research agreements where these exist. Researchers shall not disclose personal information to community partners without the participant’s consent, as set out in Article 3.2(i).
Interpretation and Dissemination of Research Results

**Article 9.17** Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report, and before finalizing all relevant publications resulting from the research.

Intellectual Property Related to Research

**Article 9.18** In collaborative research, intellectual property rights should be discussed by researchers, communities and institutions. The assignment of rights, or the grant of licences and interests in material that may flow from research, should be specified in a research agreement before the research is conducted.

Collection of Human Biological Materials Involving Aboriginal Peoples

**Article 9.19** As part of community engagement, researchers shall address and specify in the research agreement the rights and proprietary interests of individuals and communities, to the extent such exist, in human biological materials and associated data to be collected, stored and used in the course of the research.

Secondary Use of Information or Human Biological Materials Identifiable as Originating from Aboriginal Communities or Peoples

**Article 9.20** Secondary use of data and human biological material identifiable as originating from an Aboriginal community or peoples is subject to REB review. Researchers shall engage the community from which the data or human biological materials and associated identifiable information originate, prior to initiating secondary use where:

a. secondary use has not been addressed in a research agreement and has not been authorized by the participants in their original individual consent; or
b. there is no research agreement; and
c. the data are not publicly available or legally accessible.

**Article 9.21** Where research relies only on publicly available information, or on legally accessible information as defined in Article 2.2, community engagement is not required. Where the information can be identified as originating from a specific community or a segment of the community at large, seeking culturally informed advice may assist in identifying risks and benefits for the community.

**Article 9.22** REB review is required where the researcher seeks data linkage of two or more anonymous datasets or data associated with human biological materials and there is a reasonable prospect that this could generate information identifiable as originating from a specific Aboriginal community or a segment of the Aboriginal community at large.
Curriculum Vitae

JULIE R. BULL, PhD

Research Methods Specialist, Aboriginal Engagement and Outreach
Provincial Systems Support Program, Center for Addiction and Mental Health
Toronto, Ontario, Canada

EDUCATION

Interdisciplinary PhD 2009-2012; 2017-2019
University of New Brunswick
- Supervisors: Drs. Mary McKenna and Renee Linklater
- Area of Research: Indigenous Research Ethics
- Dissertation title: Research is Reflexive and Relational: Peoples, Policies, and Priorities at Play in Ethically Approving Health Research with Indigenous Peoples

Master of Applied Health Services Research 2006-2008
First class standing
University of Prince Edward Island
- Supervisors: Drs Fern Brunger and Malcolm Murray
- Area of Research: Aboriginal Research Ethics
- Thesis title: Defining our ‘Ethical Space’: Labrador Innu, Inuit, and Inuit-Métis Perspectives on the Governance of Health Research

Bachelor of Arts (honours) Psychology and Philosophy 2001-2006
First class standing
University of Prince Edward Island
- Area of Research: Aboriginal post-secondary education
- Supervisor: Dr. Colleen MacQuarrie
- Thesis title: Marching to the Beat of a Different Drum: Aboriginal Students Speak out about Challenges faced at University

PUBLICATIONS


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90 This CV is from February 2019. For updated version and more information, please visit www.juliebull.net
Indigenous research ethics: Claiming research sovereignty beyond deficit and the colonial legacy. L., George; Tauri, J. & Te Ata o Tu MacDonald, L. (eds).


RESEARCH GRANTS


HONOURS AND AWARDS

<table>
<thead>
<tr>
<th>Award</th>
<th>Year</th>
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<tbody>
<tr>
<td><strong>Doctoral Scholarship</strong></td>
<td>2018</td>
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<tr>
<td>Atlantic Indigenous Mentorship Program</td>
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<tr>
<td><strong>Alumni Travel Award ($500)</strong></td>
<td>2018</td>
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<tr>
<td>University of New Brunswick</td>
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<tr>
<td><strong>Graduate Studies Travel Award ($500)</strong></td>
<td>2018</td>
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<tr>
<td>University of New Brunswick</td>
<td></td>
</tr>
<tr>
<td><strong>Emerging Research Scholar Change Maker Award</strong></td>
<td>2018</td>
</tr>
<tr>
<td>Ontario Ministry of Education</td>
<td></td>
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<tr>
<td><strong>Labradorian of Distinction</strong></td>
<td>2017</td>
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<tr>
<td>Member of Parliament Yvonne Jones</td>
<td></td>
</tr>
<tr>
<td><strong>President’s Award for Excellence in Community Engagement</strong></td>
<td>2016</td>
</tr>
<tr>
<td>Memorial University of Newfoundland, Canada</td>
<td></td>
</tr>
<tr>
<td><strong>International Travel Award ($3500)</strong></td>
<td>2015</td>
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<tr>
<td>Hokkaido University, Japan</td>
<td></td>
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<tr>
<td><strong>International Polar Year Conference Travel Award ($2000)</strong></td>
<td>2012</td>
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<tr>
<td>International Arctic Science Committee and Government of Canada</td>
<td></td>
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<tr>
<td><strong>Vanier Graduate Scholarship ($150,000)</strong></td>
<td>2010</td>
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<tr>
<td>Canadian Institutes of Health Research</td>
<td></td>
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<tr>
<td><strong>Doctoral Fellowship ($20,000)</strong></td>
<td>2010</td>
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<tr>
<td>Dr. Paterson, Tier 1 Canada Research Chair</td>
<td></td>
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<tr>
<td><strong>Graduate Student Fellowship (Doctoral Award) ($19, 000)</strong></td>
<td>2010</td>
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<tr>
<td>Atlantic Aboriginal Health Research Program</td>
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<tr>
<td><strong>Student Travel Award (NAHO) ($2000)</strong></td>
<td>2009</td>
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<tr>
<td>CIHR Institute of Aboriginal People’s Health</td>
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<tr>
<td><strong>Jens Peder Hart Hansen Fellow Award ($500)</strong></td>
<td>2009</td>
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<tr>
<td>International Union for Circumpolar Health</td>
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<tr>
<td><strong>Travel Award (International Congress on Circumpolar Health) ($2000)</strong></td>
<td>2009</td>
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<tr>
<td>Health Canada</td>
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</table>
Student Travel Grant ($1500) 2009
Canadian Bioethics Society

CIHR Institute of Aboriginal Peoples’ Health Travel Award ($1500) 2009
CIHR Institute of Aboriginal Peoples’ Health

Graduate Student Fellowship (Doctoral Award) ($19,000) 2009
Atlantic Aboriginal Health Research Program

National Aboriginal Achievement Award Scholarship ($2500) 2008
National Aboriginal Achievement Foundation

Graduate Student Fellowship (Doctoral Award) ($19,000) 2008
Atlantic Aboriginal Health Research Program

National Aboriginal Achievement Award Bursary ($1000) 2008
National Aboriginal Achievement Foundation

Publication and cash award ($500) 2008
Aboriginal Healing Foundation: Reconciliation Project

J. Elmer Hynes Aboriginal Student Achievement Award ($1000) 2008
University of Prince Edward Island

Master’s Student Scholarship ($17,500) 2008
Atlantic Regional Training Centre

Graduate Student Fellowship (Master’s Award) ($17,000) 2008
Atlantic Aboriginal Health Research Program

Graduate Student Fellowship (Master’s Award) ($17,000) 2007
Atlantic Aboriginal Health Research Program

National Aboriginal Role Model Program Recipient 2007
National Aboriginal Health Organization (Health Canada)

Master’s Student Scholarship ($17,500) 2007
Atlantic Regional Training Centre

Scientific Director’s Award of Excellence 2007
CIHR – Institute of Aboriginal Peoples’ Health

Joint Indigenous Institute on the Social Determinants of Health 2007
Johns Hopkins University, Baltimore, Maryland (declined by recipient)

Master’s Student Scholarship ($17,500) 2006
Atlantic Regional Training Centre
Graduate Student Fellowship (Master’s Award) ($17,000) 2006
Atlantic Aboriginal Health Research Program

Undergraduate Student Internship Scholarships (x4) ($16,000) 2004-2006
Atlantic Aboriginal Health Research Program

INVITED/KEYNOTE PRESENTATIONS

2018


Holland Bloorview REB Retreat at Holland Bloorview Hospital, Toronto, ON, November 13, 2018.


2017


**2016**


**2015**


**2014**


2013


2012


2011


2010


34. Bull, J. R. (2010). Leading the Way: From Labrador to the Vanier. Keynote address presented at the University of Prince Edward Island Faculty of

2009


2008


2007


Invited Guest Lectures/Class Presentations


PEER REVIEWED PRESENTATIONS AT INTERNATIONAL MEETINGS

2018


2017


2016


2015


2012


2010


2009


PEER REVIEWED PRESENTATIONS AT NATIONAL MEETINGS

2018


2016


2014

2013


2012


2011


2010


2009


2008


2006


2005


REVIEWS

- International Journal of Circumpolar Health
- International Journal of Culture and Mental Health
- Canadian Journal of Public Health
- Critical Public Health
- Canadian Journal of Community Mental Health
- International Journal of Social Research Methodology

RELEVANT PROFESSIONAL EXPERIENCE

Research Ethics Policy Consultant 2018-present
NunatuKavut Community Council

Research Methods Specialist 2017-present
Centre for Addiction and Mental Health (CAMH), Toronto

Sessional Professor 2015-2017
Indigenous Studies Program, University of Toronto

Sessional Professor 2016-2017
Public Health and Social Policy, University of Victoria

Research Ethics Policy Consultant 2015-2016
Native Council of Prince Edward Island

Trainer/Facilitator 2015-2016
Canada School of Public Service, Toronto

Research Coordinator 2014-2015
Center for Research on Inner City Health, St. Michael’s Hospital
Executive Director 2015-2015
Toronto Aboriginal Support Services Council

Acting Executive Director 2014-2014
Toronto Aboriginal Support Services Council

Research & Policy Officer 2013-2014
Toronto Aboriginal Support Services Council

Qualitative Data Consultant 2009-2013
Labrador Metis Nation Community Health Needs Assessment

Research Assistant/Coordinator 2009-2011
Talking with their Feet (funded by CIHR)

Qualitative Research Consultant – Aboriginal content 2009
Atlantic Seniors Housing Research Alliance (funded by SSHRC)

Project Manager/Director 2008 - 2010
Aboriginal Education at UPEI (Funded by Health Canada)

Research Coordinator 2008
Pathways to Health for Mi’kmaq Families (Funded by Mi’kmaq Confederacy of PEI)

Research Assistant, University of New Brunswick 2007-2008
Supporting Mother-Infant Relationships Affected by Intimate Partner Violence (CIHR)

Research Assistant, Horizon’s Community Development Associates 2007-2008
An Environmental Scan for the Aboriginal Health Human Resources Initiative

UNIVERSITY COURSES TAUGHT

1. Inter-professional Practice (HLTH 404): School of Public Health and Social Policy, University of Victoria (2016)

2. Engaging in International and Global Health Development Work (INTS 461): School of Public Health and Social Policy, University of Victoria (2016)


PROFESSIONAL ACTIVITIES & AFFILIATIONS

- REB member, Centre for Addiction and Mental Health 2018-present
- Council Member, Association of Polar Early Career Scientists 2016-present
- Speaker, International Indigenous Speaker’s Bureau 2016-present
- Member, MDAO Research Advisory Committee 2014-present
- TCPS Ch. 9 Education Committee, Secretariat on Research Ethics 2011-present
- Mentor, Indigenous Women in Leadership, Coady International 2011-present
- Member, NunatuKavut Community Council Research Committee 2010-present
- Board of Director, One Laptop Per Child Canada 2016-2017
- Interim Chair, Native Council of PEI Research Committee 2015-2016
- Pan Northern Ethics Group, Arctic Health Research Network 2009-2012
- Ethics Working Group, Aboriginal Health Research Network 2009-2012
- Committee Member Diversity Week, UPEI 2010
- Chair, Cultural Connections Planning Committee, UPEI 2010
- Board of Director, Atlantic Aboriginal Health Research Program 2009-2012
- Invited Contributor, Ethics in Mental Health Programming 2009
- Student Member, Canadian Bioethics Society 2009-2012
- Member, Children’s Health and Applied Research Team, UPEI 2009-2011
- Student Member, Canadian Society of Circumpolar Health 2009-2013
- Committee Member International Development Week, UPEI 2009
- Chair, Cultural Connections Planning Committee, UPEI 2009
- Member, Research Ethics Board UPEI 2009-2011
- Member, Canadian Applied Health Services and Policy Research 2009-2010
- Board of Director, Atlantic Aboriginal Health Research Program 2008-2011
- Selection Committee 2008-2009 National Aboriginal Role Models 2008
- Health Advisory Committee, Congress of Aboriginal Peoples 2007-2012
- National Youth Council, Congress of Aboriginal Peoples 2007-2009
- Founder/President First Nations, Inuit, Metis Group, UPEI 2007-2008
- Inaugural Student member, Research Ethics Board, UPEI 2007-2008

CONFERENCE PLANNING


3. **APECS Goals of ICARP III – the future of Arctic research from the perspective of early career researchers** (2015). Funded by Association of Polar Early Career Scientists (APECS). Toyama, Japan

4. **Conducting Research with Urban Aboriginal People** (2014). Funded by the Toronto Aboriginal Support Services Council. Toronto, Canada


### CONFERENCE SESSION CONVENER


4. **Zaika, Y., Fugmann, G., Vlakhov, A., Bull, J.** (2016). *Gaining a better understanding and awareness of the Arctic through education and outreach*. Session convened at the University Arctic Congress, St. Petersburg State University, St. Petersburg, Russia, September 12-16.

### ADDITIONAL EDUCATION AND TRAINING

<table>
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<tr>
<th>Program</th>
<th>Year</th>
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<tr>
<td>Implementation Science</td>
<td>2017</td>
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<tr>
<td>Centre for Addiction and Mental Health</td>
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<tr>
<td><strong>Introduction to Drupal Training</strong></td>
<td>2009</td>
</tr>
<tr>
<td>University of Prince Edward Island, Charlottetown, PE</td>
<td></td>
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<tr>
<td><strong>Aboriginal Intervention Research Training</strong></td>
<td>2008</td>
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<tr>
<td>Atlantic Aboriginal Health Research Program, Halifax, NS</td>
<td></td>
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<tr>
<td><strong>Research Ethics Board 101, Social Sciences &amp; Humanities Training</strong></td>
<td>2008</td>
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<tr>
<td>National Council on Ethics in Human Research, Halifax, NS</td>
<td></td>
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</tbody>
</table>
Building Bridges and Gaining Strength: Health Advisory Workshop  
Congress of Aboriginal Peoples, Gatineau, QE  
2008

Project Management Workshop  
Atlantic Regional Training Centre Training, Halifax, NS  
2007

Safety Circles: Collaborative Planning Process for Women in Crisis  
Status of Women Canada, Charlottetown, PE  
2007

Standard First Aid and CPR  
Canadian Red Cross, Montague, PE  
2007

Program Evaluation Workshop  
Atlantic Regional Training Centre Training, Fredericton, NB  
2007

Introductory Tutorial for the Tri-Council Policy Statement:  
Ethical Conduct for Research Involving Humans (TCPS)  
2007

Human Services: Integrating Theory and Practise  
Psychology Department, University of Prince Edward Island  
2006

Weaving a Cultural Tapestry  
Charlottetown, PE  
2006

Canadian Institutes of Health Research Ethics workshop  
Atlantic Aboriginal Health Research Program, Moncton, NB  
2005

Arts 400: Leading an Arts Seminar  
University of Prince Edward Island  
2005

OTHER VOLUNTEER SERVICE

- NunatuKavut Research Advisory Committee  
  2010-present
- Idea City event volunteer  
  2013-2016
- Recovery Network Toronto event volunteer  
  2012-2016
- Mood Disorders Association of Ontario  
  2011-2016
- Volunteer Canadian Cancer Society Relay for Life  
  2010
- Volunteer Island Inferno V: Kickboxing championship  
  2010
- Tracadie Guide Leader Girl Guides of Canada  
  2007/08
- Volunteer: Institute of Public Administration of Canada (IPAC)  
  2006
- Volunteer East Coast Music Awards (ECMA)  
  2006
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<tr>
<td>- Rural Routes Podcast. September 22, 2017: <a href="https://soundcloud.com/ruralroutes/s2e2-indigenousandruralresearchethics">https://soundcloud.com/ruralroutes/s2e2-indigenousandruralresearchethics</a></td>
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<td>- Native Currents Podcast, July 10, 2016: <a href="https://soundcloud.com/native-currents/native-currents-episode-4">https://soundcloud.com/native-currents/native-currents-episode-4</a></td>
</tr>
<tr>
<td>- Youtube Channel: <a href="https://www.youtube.com/channel/UCCwjgrhZE3pdEx7A_HFwCFQ?view_as=subscriber">https://www.youtube.com/channel/UCCwjgrhZE3pdEx7A_HFwCFQ?view_as=subscriber</a></td>
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