Sandra Alexis Juutilainen

STRUCTURAL RACISM AND
INDIGENOUS HEALTH

A CRITICAL REFLECTION OF CANADA AND FINLAND
SANDRA ALEXIS JUUTILAINEN

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A critical reflection of Canada and Finland

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Abstract

The purpose of the study was to broaden understanding of structural racism by examining the relationships between Indigenous peoples and nation-states in the context of education and how this affects Indigenous lives. This thesis delves into understanding both the theoretical and methodological contributions that more critical analyses can have on: the role of de-colonial approaches to Indigenous health research methodologies so that the most urgent health inequities are addressed through more rigorous and Indigenous specific research processes; and to improve our understanding of the complex interactions that historical and contemporary legacies of residential schools and boarding schools have on the health and well-being of Indigenous populations in Canada and Finland.

The research design was a qualitative multiple case study informed by a public health critical race praxis. The study was completed in two phases; consisting of a literature study using content analysis of Indigenous research ethics protocols and policies, in Canada and the Nordic countries; and, three case studies developed from open ended questions from structured interview research comparing discriminatory experiences and its impact on self-perceived health with participants from Six Nations of the Grand River, Canada (n = 25) and the Sámi in Inari, Finland (n = 20); and their family members. The case studies were analyzed using both Western and Indigenous methodologies.

Results of Phase one shows how Indigenous resistance to colonial structures within academia in Canada and Finland has resulted in dialogical processes to create an ethical space for working between the differing worldviews of academia and Indigenous communities with the aim to produce ethically valid knowledge. Phase two results shows that regardless of contextual differences of the experiences in Canada and Finland, the main parallel outcomes are similar, i.e. the teachings of shame received in these educational environments. This produces both vulnerabilities and resiliencies and the negative effects of shame require an ongoing healing journey for both individuals and their families and communities at large.

Conclusion: For a more in depth understanding of structural racism and its influence on Indigenous health, investigations require methodological choices by both Western and Indigenous methodologies.

Keywords: boarding schools, health inequity, Indigenous peoples, Indigenous research ethics, structural racism
Tiivistelmä

Tutkimuksen päämääränä on tuottaa tietoa rakenteellisesta syrjinnästä. Tämä tapahtuu tutkimalla alkuperäiskansojen ja kansallissuhteiden välisiä suhteita koulujärjestelmissä sekä sitä, miten rakenteellinen syrjintä vaikuttaa alkuperäiskansojen jäsenten elämään. Tutkimuksen kriittinen analyysi tuottaa dekoloniaalisia lähestymistapoja terveystutkimuksen menetelmiin, jolloin tärkeimmät terveyserot paljastuvat alkuperäiskansalähtöisten tutkimusprosessien kautta. Tutkimus pykii lisäämään ymmärrystä siitä, millaisia väliaikaisia sekä nykypäivään asti ulottuvia vaikutuksia sisäoppilaitoksilla ja kouluasuntoloihella on ollut Kanadan ja Suomen alkuperäiskansojen jäsenten terveyteen ja hyvinvointiin.


Asiasanat: alkuperäiskanska, asuntola, rakenteellinen syrjintä, sisäoppilaitos, terveyserot, tutkimusmenetelmä
‘It’s education that got us into this mess, and it’s going to be education that gets us out’ Senator Murray Sinclair (former Canadian Chair Truth and Reconciliation Commission)
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20.4.2017 Sandra Alexis Juutilainen
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<th>Description</th>
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<tbody>
<tr>
<td>AFN</td>
<td>Assembly of First Nations</td>
</tr>
<tr>
<td>DIAND</td>
<td>Department of Indian Affairs and Northern Development</td>
</tr>
<tr>
<td>FPTACPH</td>
<td>Federal Provincial Territorial Advisory Committee on Population Health</td>
</tr>
<tr>
<td>G20</td>
<td>Group of 20 (Argentina, Australia, Brazil, Canada, China, France, Germany, India, Indonesia, Italy, Japan, México, Russia, Saudi Arabia, South Africa, Korea, Turkey, the United Kingdom, United States and European Union)</td>
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<tr>
<td>IRS</td>
<td>Indian Residential School</td>
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<tr>
<td>IRSSA</td>
<td>Indian Residential School Settlement Agreement</td>
</tr>
<tr>
<td>MIRR</td>
<td>Ministry of Indigenous Relations and Reconciliation</td>
</tr>
<tr>
<td>OCAP</td>
<td>Ownership, Control Access, Possession – principles of OCAP is self-determination applied to research</td>
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<tr>
<td>OHC</td>
<td>Our Health Counts: Urban Aboriginal Database Research Project</td>
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<td>RCAP</td>
<td>Royal Commission on Aboriginal Peoples</td>
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<tr>
<td>SAMINOR</td>
<td>A population based study of health and living conditions in areas with both Sami and Norwegian inhabitants in Norway</td>
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<td>TRC</td>
<td>Truth and Reconciliation Commission</td>
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<td>WHO</td>
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List of original publications

This thesis is based on the following publications, which are referred throughout the text by their Roman numerals:


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1 Introduction

Public health has broadened its scope to evaluate how people experience diseases and how economic, social and environmental factors influence health (Baum 1995). Modern public health is characterized by the use of different scientific perspectives and of different methodologies (Dahlgren, Emmelin & Winkvist 2007). Bhopal (2007:307) predicted: ‘in the future, historians and health scholars and researchers will subject our work (as epidemiologists) to scrutiny’. If the underlying purpose of epidemiology is one of understanding causal relationships and testing theories, then it cannot do without the insights that qualitative thinking provides (Williams & Elliot 2010). Additionally, the way in which researchers acquire knowledge in Indigenous communities may be as critical for the elimination of health disparities as the actual knowledge that is gained about a particular health problem (Cochran et al. 2008). Taking all of these factors into consideration, there have been great efforts to measure the social determinants of health and a newly emerging discourse on the determinants of Indigenous health, which aims to widen the lens for a more holistic understanding of the health inequity of Indigenous peoples in Canada. Further investigations of health (in)equity among Indigenous populations requires new work from critical approaches to expand our understanding of how discrimination/structural racism/colonialism between nation-states and Indigenous peoples affects health and well-being.

Entanglements of colonialism, structural racism and discrimination.

Racism and colonization are intertwined (Reading 2013) and have a cumulative negative effect on the health of Indigenous peoples in Canada. The two discriminatory processes of domination have often been melded together, making colonialism racism and vice versa, and should thus be understood as connected global systems that secure white dominance through time, property and notions of self (Byrd 2011 XXIII). Both in Canada and internationally, colonization has been recognized as having an entrenched negative impact on the health of Indigenous peoples (Cunningham 2009, Mowbray 2007, Young 2014).

Critical race theory is a useful tool for understanding relationships and power structures between dominant cultural groups/majority populations and Indigenous peoples. Graham et al. (2011) describe dominant cultural orientation discrimination within a tenet of critical race theory as discrimination that occurs in institutions (the focus of this study is on discrimination in education environments: residential
school, boarding school, academia) which often function on sets of values, principles, and foundations that are not culturally diverse or representative, irrespective of their racial make-up. Dominant cultural mores are frequently presented as universal and objective, and used to characterize those of differing cultural orientation as either not qualified for admission into or not suitable to succeed in institutions (p. 86). Historically, colonialism has manifested in many different ways in many different communities, and at its core, it emerges as a set of relationships in which one social group continually and habitually profits by exploiting the living environments, bodies, social organization and spiritualities of another group. Colonialism is distinct from occasional exploitation or profiteering, as it is marked by generations of subjugation to the extent that the profiting social group begins to build all social structures and institutions around themselves to support the belief in their superiority (Duarte & Belarde-Lewis 2015).

Kuokkanen (2007) asserts that discrimination cannot be defined solely in racism terms. She further elaborates, ‘When we focus on racism, we end up ignoring both colonial history and contemporary colonial, capitalist, and patriarchal relations that extend beyond racism and racial discrimination (p. 63).’ For the purpose of this study, structural racism is defined as the macro-level systems, social forces, institutions, ideologies, and processes that interact with one another to generate and reinforce inequities among racial and ethnic groups (Gee & Ford 2011, Puuronen 2011). I align with the thinking of Frolich, Ross and Richmond (2006) who emphasize the interactions of colonialism, structural racism and discrimination – act as determinants of inequity - and how they often do not act in isolation, but rather, interact (p. 139).

Why critical approach?

Public health is defined as the practice and science of protecting and improving the health of communities (Delgado & Stefanic 2001). A praxis or practical application of theory, for undertaking an examination of structural racism, is found within a public health critical race praxis (PHCR). PHCR tailors critical race theory (CRT) to the field of public health, thus facilitating the use of CRT for health equity research (Ford & Aihirhenbuwa 2010a p. 1390). This type of praxis is useful for understanding how racialization influences health inequity, in addition to its potential to influence the production of knowledge (Ford & Aihirhenbuwa 2010a p. 1397). PHCR is grounded in critical race theory, but applied to public health research. Using CRT’s tools for conducting research and practice within
community based research are intended to expose contemporary racial phenomena by expanding the vocabulary for discussing racial phenomena and its effects, and to explicitly incorporate the knowledge of racial and ethnic minority communities regarding marginality (Ford & Airhihenbuwa 2010b). According to Mieli (2012):

No one understands local issues better than the people who live them every day. When decisions are made at a great distance, they lose the immediacy and common sense bred from local experience. The only way to combat inequality and build a healthier society is through the meaningful participation of those most affected in the political process (p. 106–107). In regards to Indigenous health and wellbeing, it is imperative that solutions to the most pervasive issues of inequity come from the communities themselves. At its core, a critical race praxis for public health focuses on an iterative methodology for helping investigators remain attentive to equality while carrying out research, scholarship and practice. It also urges scholars to transform the hierarchies they identify through research (Ford & Airhihenbuwa 2010a, Graham et al. 2011). The usefulness of this type of praxis was attractive to me as an Indigenous investigator, whereby my own Haudenosaunee worldviews on equity are considered important starting points, and how this would allow me to remain attentive to equity based on Haudenosaunee concepts. Indigenous research must be approached from Indigenous perspectives which are critical by nature as they challenge exploitative and oppressive relationships; and at the same time have the relational aspect at the forefront of giving something back, in a tangible way, to the community involved in the research project (Corntassel & Gaudry 2014). Beliefs around health and well-being, from an Indigenous perspective, embody more than the medical-model: ‘absence of disease’, definitions of health. Indigenous peoples' concept of health and survival is both a collective and an individual inter-generational continuum encompassing a wholistic perspective incorporating four distinct shared dimensions of life. These dimensions are the spiritual, the intellectual/mental, physical, and emotional. Linking these four fundamental dimensions, health and survival manifests itself on multiple levels where the past, present, and future co-exist simultaneously (WHO 1999).

The purpose of this project is twofold: to examine structural racism embedded in policies and practices within education and the effects on Indigenous lives. The reproduction of racial phenomena in contemporary societies is articulated in the frame of structural racism, not by reference to a long distant past, but in relationship to its contemporary structure (Bonilla-Silva 1997). It is important to study discrimination and its effect on Indigenous health as an example of structural racism specifically within an educational context, due to the overtly or covertly
racially motivated policy it has had and the far reaching effects on all Indigenous population groups and members that continues to subsequent generations. More understanding is needed of the phenomena from different perspectives. For this project, two different countries and their education institutions at two different points in time are reviewed:

1. Within academia in regards to academic research processes, specifically, Indigenous research ethics in Canada and the Nordic countries with a focus on Finland are discussed as resistance to contemporary colonial practices within the academy.

2. Indigenous experiences within residential school in Canada and boarding school in Finland.
2 Background

2.1 Residential school, boarding school, truth and reconciliation

The Indian residential school system was not unique to Canada. Governments and missionary agencies in many countries around the world established boarding schools as part of the colonial process (Smith 2009). Parallel to the assimilation experiences of Indigenous children worldwide, boarding schools were created throughout the Nordic countries to shape the Sámi to adapt to Finnish, Swedish and Norwegian ways of knowing and being (Lehtola 2012, Axelsson & Sköld 2006, Minde 2005). In this background chapter, the education policies and practices of Indian Residential Schools in Canada and boarding schools in Finland are introduced, in addition to Canada’s Truth and Reconciliation Commission (TRC) and the dialogue of reconciliation in the Nordic countries. Canada’s TRC defines reconciliation as establishing and maintaining a mutually respectful relationship between Aboriginal and non-Aboriginal peoples in Canada. For that to happen, there has to be awareness of the past, acknowledgement of the harm that has been inflicted, atonement for the causes, and action to change behaviour. We are not there yet (TRC 2015 Vol 6 p. 3). As such, scrutiny of reconciliation processes and practices requires a critical lens.

2.1.1 Residential school in Canada

Despite the promise of the early treaties established between Indigenous peoples and early settlers to Canada, including the Two Row Wampum (see chapter 5.1.2), which entails respectful Nation to Nation relationships, Indigenous people became the target of colonial policies designed to exploit, assimilate and eradicate them. Based on racism, violence and deceit, these policies were devastatingly effective (Ontario MIRR 2016). The Canadian residential school experience is part of the history of imperialism of the past 500 years. In particular, it is part of the history of settler colonialism and that history is not over (TRC 2015 p. 23). Colonialism and racism dominated and drove systematic attempts to wipe out Indigenous languages, culture and tradition and has been articulated as cultural genocide (Ontario MIRR 2016, TRC 2015). In essence, Indigenous peoples were the first group to be racialized in Canada via the colonial Canadian government policy of Indian Residential schools with its mandate ‘to Kill the Indian in the Child’ (Canon &
Sunseri 2011). For more than 100 years, Indigenous children in Canada were forced to attend government-funded, church-run residential schools. One goal of the schools was to assimilate Indigenous people by weakening cultural and familial ties. Residential schools robbed Indigenous children of their identity and culture (see: TRC 2015). Those who attended were educated from the perspective of colonial settlers who denounced Indigenous language, culture and tradition. The lived experiences of many children were harsh, with thousands of children suffering from mental, physical and sexual abuse at the hands of those charged with their care (Ontario MIRR 2016, TRC 2012, 2015, 2016). The research of the TRC has identified 3200 deaths on the Truth and Reconciliation Commission’s Register of Confirmed Deaths of Named Residential School Students and the Register of Confirmed Deaths of Unnamed Residential School Students (TRC 2015 Vol 4). An inquiry into those deaths was never completed by the Canadian government and many questions remain unanswered about how the children died and where the gravesites are located. The legacy of the schools continues to the present day. It is reflected in the significant educational, economic, and health disparities between Aboriginal people and other Canadians — disparities that condemn many Aboriginal people to shorter, poorer and more troubled lives (TRC 2015 Vol 4 p. 3). Additionally, Ian Mosby’s (2013) research ‘Administering Colonial: Nutrition research and human biomedical experimentation in Aboriginal communities and residential schools, 1942–1952’, shows how bureaucrats, scientists, and a whole range of experts exploited their ‘discovery’ of malnutrition in Aboriginal communities and residential schools to further their own professional or political interests rather than to address the root causes of these problems, or for that matter, the Canadian government’s involvement in them (p. 171). The last residential school in Canada closed its doors in 1996. After over 100 years of cultural genocide embedded in education policy, an Indigenous led national level research project produced a report: The 1996 Royal Commission on Aboriginal Peoples (RCAP) recognized the future must include a place for those affected by the Residential Schools System, so as to enable them to stand with dignity, to remember, to voice their sorrow and anger and to be listened to with respect (RCAP 1996). Following the RCAP report, Gathering Strength, Canada’s Aboriginal Action Plan was unveiled. This included a Statement of Reconciliation acknowledging the Government of Canada’s role in the development and administration of Indian residential schools (DIAND 1997). In 2001, the federal Office of Indian Residential Schools Resolution Canada was created to manage and resolve the large number of abuse claims filed by former students against the federal government. In 2004, an
Assembly of First Nations Report on Canada’s Dispute Resolution Plan to Compensate for Abuses in Indian Residential Schools led to discussions for developing a holistic, fair and lasting resolution of the legacy of Indian Residential Schools. This led to the announcement of the Indian Residential School Settlement Agreement (IRSSA) in 2006. This was an agreement between the government of Canada and approximately 86,000 Aboriginal people removed from their families as children and placed in the Canadian Indian residential school system during the 20th century (AFN 2004). The IRSSA recognized the damage inflicted by the residential schools and established a $2 billion compensation package for the victims. The agreement was the largest class action settlement in Canadian history (AFN 2004). Additional supports were provided by First Nations and Inuit Health Branch, Health Canada to ensure cultural supports within the community and mental health counselling was available for those going through the Independent Assessment Process (Health Canada 2015). The IRSSA, mandated the Truth and Reconciliation Commission of Canada (TRC) to: Identify sources and create a complete historical record as possible of the Indian Residential Schools (IRS) system and legacy. The record shall be preserved and made accessible to the public for future study; and to, Produce and submit to the Parties of the Agreement a report including recommendations to the Government of Canada concerning the IRS system and experience including: the history, purpose, operation and supervision of the IRS, system, the neglect and consequences of IRS (including systemic harms, intergenerational consequences and the impact on human dignity) and the ongoing legacy of the residential schools (TRC 2015 Vol 4 p. 4). On June 11, 2008, the Prime Minister, on behalf of the Government of Canada, issued an apology in the House of Commons to former students, their families and communities (See appendix A). The apology is considered by many as a step towards reconciliation. However, there are also critiques of this action, since our then Prime Minister, Stephen Harper, proudly announced that Canada has no history of colonialism in a G20 meeting in 2009, one year after the apology (Shrubb 2010).

2.1.2 Boarding school in Finland

The Sámi are an Indigenous people residing in the Arctic area of Sápmi, which spans across the circumpolar area of four countries: Norway, Sweden, Finland and Kola Peninsula of Russia. With a total population of approximately 60,000–110,000 divided across the four countries (Axelsson 2011, Solbakk 2006). However, it is estimated that the numbers are larger than this due to the fact that within the
Nordic countries ethnicity is not registered and therefore exact numbers are not available. The number of Sámi living in Finland is approximately 10 000 (www.samediggi.fi 2014). In Finland and Sweden, a Sámi is defined as a person of Sámi origin who feels oneself to be Sámi and who either has Sámi as their first language or at least one parent or grandparent who had Sámi as their first language or whose parent or grandparent was/is enrolled in the electoral rolls of the Sámi Parliament. In Norway, ancestry, can be as far back as great grandparent. In Russia a Sámi is defined by self-ascription. The connectedness to Sámi ancestry, relationship to Sámi language and via language to Sámi culture and a feeling of being Sámi are important (Lehtola 2004).

Similar to research findings from the First Nations Regional Longitudinal Health Survey in Canada (See: RHS 2002/2003), research about perceived discrimination among the Sámi in Norway shows how loss of language, ethnic identity or confusion about the ethnic identity (being between two worlds) is a consequence of the colonial history and may have associations with health outcomes (Bals, Turi, Skre & Kvernmo 2010). Furthermore, the SAMINOR study, a quantitative, population-based study of health and living conditions in areas with mixed Sámi, Kven and Norwegian population, found ethnic discrimination to be an important variable related to health inequalities as measured by poor self-reported health (Hansen, Melhus & Lund 2010). In Sweden, a report on Sámi instances of discrimination cited the importance of relating individual and structural discrimination to each other, as well as to history and the distribution of power in society (Pikkarianen & Brodin 2008).

The term ‘colonization’ is frequently contested to describe the Finnish-state – Sámi relationship (see: Nyyssönen 2013, Lehtola 2015), even after Rasmus’ (2008) publication of research on Sámi boarding school experiences and after the bishop of Oulu diocese made a public apology for the misconduct towards the Sámi (Lehtola 2015 p.22). Some Finnish historians argue colonialism has no place in the discourse of Sámi history (see: Vahtola 1991, Lähteenmäki 2000, Enbuske 2008). In the Nordic context, Finland did not have a formal assimilation policy targeted at the Sámi. However, from the 19th century until World War II and into the 1960s, the Finnish government systematically repressed Sámi language and culture while engaging in the process of nation building (Nyyssönen 2007, Lehtola 2015). Nyyssönen (2009) and Lehtola (2015) articulate colonialism in a Nordic context and describe how Finns identify the Finnish policy as not being strict or intolerant as in Norway and Sweden. Nyyssönen (2009) further elaborates, ‘this does not, however, justify hasty conclusions that the Sámi were not subjugated or
discriminated against in Finland. Instead, it is appropriate to delve deeper into the nature of the relationship between the Sámi and Finns (p. 268).

While instances of colonization among Indigenous peoples worldwide have varying contexts, the commonality of being subjected to ideologies of inferiority when compared to the majority population have similar negative outcomes (Kuokkanen 2003). Furthermore, within the dialogue of Sámi experiences in Finnish boarding schools, the outcomes are comparable to other countries worldwide who had deliberate colonial policies of forced assimilation in place (Smith 2009, Kuokkanen 2003). According to Lehtola (2015), while the starting points have contextual and major differences, the structures of colonial performing and subjugations seem to be quite similar everywhere (p. 26).

In 1947, the new Public Education Act in Finland, made it compulsory for everyone to attend school. In connection with this, boarding schools were built for those children, both Finnish and Sámi, living in remote, rural communities (Lassila 2005, Rasmus 2008). Even though the boarding schools were attended by both Finnish and Sámi children, the education environment had a strong history of assimilation, and the Sámi school culture is colored with colonization (Rahko-Ravantti 2016). Boarding school demanded Finnish ways of being, forcing Sámi children to become “proper” Finnish citizens through a variety of practices, including: complying with a strict daily time schedule in an institutionalized setting, and adopting Finnish language, food, symbols, and clothing. Those who did not conform to the new identity were punished (Aikio-Launiemi 1995, Magga 1997, Rasmus 2008, Valle 1998, Valkonen 1998, Lehtola 2012). This resulted in a loss of cultural symbols and a fractured identity or feeling of being ‘between’ two worlds, not able to fully integrate into Sámi society or that of the dominant society (Aikio-Launieimi 1995, Magga 1997, Valle 1998, Valkonen 1998, Kuokkonen 2003, Lehtola 1994 p. 217–223, Rasmus 2008).

Similar to the situation in Canada, there have been apologies made throughout the Nordic countries to the Sámi. Lehtola (2015 p. 22–23) has described these reconciliatory activities which have taken place. The first apology to the Sámi in the Nordic countries was presented by King Harald V of Norway at the opening of the Norwegian Sámi Parliament in 1997. According to him, the Norwegian state was founded on the territory of two peoples – Sámi and Norwegians – and because the history of the Sámi was closely intertwined with Norwegian history, he deplored the unfairness of the Norwegianization policy (see: Om samepolitikken 2000:11). In 1998, Sweden’s minister of agriculture apologized for the injustices against the Sámi on behalf of the State. The Norwegian State presented its national apology in
2004, when it published an account of the effects of the Norwegianization policy on the Sámi (see Minde 2005). A State apology has not occurred in Finland. After the Swedish apology, in 1998, Finnish Minister of Justice, Jussi Järvenpää, stated: ‘There are currently no issues that would require an apology’. This is comparable to when Canada’s then prime minister Stephen Harper stated that Canada has ‘no history of colonialism’ to the world stage in a 2009 G20 meeting. The impact of apologies on reconciliation remains uncertain. Much depends on whether the apology boosts further reconciliation efforts or becomes only a means to placate Indigenous discontent (Tager 2014).
3 Review of literature

3.1 Decolonizing the academy: Critiques of academic knowledge production

Decolonization within the academy can be defined as the critical exploration of the foundations and approaches of research in order to find out how or if it can be said to have a distinct colonial bias (Olsen 2016). In the case of research in Indigenous communities, its colonial legacies and the role of research in the colonization of Indigenous communities and territories is unfortunately not a thing of the past, but an unending phenomena that continues in the present (Lawrence & Raitio 2016, Tuhiwai Smith 1999, Denzin, Lincoln & Smith 2008, Snarch 2004, Stordahl et al. 2015). Maori scholar Linda Tuhiwai Smith in her seminal work ‘Decolonizing Methodologies’, affirms that from ‘the vantage point of the colonized, which she chooses to privilege, the term ‘research’ is inextricably linked to European imperialism and colonialism (1999, 2010). The legacy of the colonial relationships between the academy and Indigenous communities has continued to manifest itself in multiple ways and is apparent in the process of how knowledge is currently produced. Sami scholar Rauna Kuokkanen has discussed this issue at length in her book, ‘Reshaping the University’, wherein she challenges the academy ‘to examine its practices and discourses of exclusion and foreclosure, its narrow intellectual foundations, and its hierarchical, hegemonic structures of knowledge’ (2007 p. 139). Many Indigenous scholars cite the paradox between unbalanced power relationships (between researchers and Indigenous people); and the production of knowledge that has resulted in errors in the realities of the lived experiences of Indigenous peoples (Brant-Castellano 2004, Keskitalo 1976, Kuokkanen 2006, Kovach 2009, Lehtola 2004, Snarch 2004). Corntassel and Gaudy (2014) have discussed colonialism within research as an extractive process. They further iterate ‘It becomes clear how researchers benefit from the project – publications, funding, tenure, respect as a knowledgeable person – while the community’s gains remain elusive’ (p. 170). They further emphasize how research is produced for a settler audience and not for Indigenous peoples themselves or to further Indigenous nationhood, and argue that academic research within an extractive process model is not only irrelevant, but unethical (Corntassel & Gaudy 2014).

Scholars have pointed out that the way researchers acquire knowledge in Indigenous communities may be as critical for eliminating health disparities as the
actual knowledge that is gained about a particular health problem (Cochran et al. 2008, Maar et al. 2011). An example of decolonizing research in practice was studied by Cargo et al. (2008) regarding the perceived influence of multiple community (Indigenous) and academic stakeholders involved in the Kahnawake Schools Diabetes Prevention Project (KSDPP). Their findings indicate strong community leadership aligns KSDPP as a model of community-directed research and suggests equitable participation by both Indigenous and academic stakeholders. As such, this model goes over and above a participatory action research which aims to ensure communities’ involvement. For the KSDPP, Indigenous community partners are perceived as exerting greater influence than academic partners in decision making.

3.2 Working in the space between cultural and academic ethical worldviews

The complexity of ethics when working in a space between cultural and academic ethical principles takes redefining and rethinking of research relationships and requires an ongoing return to the range of ethical principles within each environment (Edwards et al. 2008, Bull 2010, Vogel 2015). Indigenous worldviews are relational in nature (Hart 2010, Wilson 2008, Kovach 2008). Hart (2010) describes this relationality as a sense of spirit, communitism and respectful individualism. Communitism is the sense of community tied together by familial relations and the families’ commitment to it. The term was created to combine the meaning of community and activism. Respectful individualism entails a way of being whereby individuals enjoy great freedom in self-expression because it is recognized by the society that individuals take into consideration and act on the needs of the community as opposed to acting on self-interest alone (p. 3). Indigenous epistemologies and worldviews provide the lens for imagining the ethical space between Indigenous community and academic community.

A key aspect of Indigenous research involves ethical considerations of both the individual and community level consent. Dickert and Sugarman (2005) define community consent as a process that may occur after community consultation and does not preclude the need for individual consent. Rather, the community decides whether to permit investigators to solicit participation from community members. For community consent to be valid, there must be a legitimate political system in place, with representatives properly empowered to make such decisions on behalf...
of the community. In many aboriginal communities, such legitimate systems exist (p. 1124).

International recognition of Indigenous peoples’ rights was a supportive action to move the development of Indigenous ethical guidelines forward. For example, UNESCO’s ‘Universal Declaration on Bioethics and Human Rights’ (2005) gave specific attention to interests of Indigenous peoples in research affecting them and the role of communities in providing consent for such activities. The United Nations Declaration on the Rights of Indigenous Peoples gave further specificity to the right of Indigenous peoples to self-determination and their collective right to exercise control over expressions of their cultural heritage and intellectual property (United Nations 2007).

The main tenets of the framework for developing ethical guidelines and policy for Indigenous research worldwide are directly linked to self-determination. For example in a Maori context, the ethical guidelines framework has layers based on progressive expectations of ethical behavior, recognizing a minimum standard, and a best practice approach to research with Maori as it relates to the type of research being conducted. The praxis provides a space for cross-cutting concepts that relate to (Hudson et al. 2016):

a) Principles of the Treaty of Waitangi (Partnership, Participation, Protection)
b) Actions implied by the Treaty of Waitangi (Rights, Roles and Responsibilities)
c) Risk, benefits and outcomes of research
d) Maori values of whakapono (faith), tumanako (aspirations), aroha (awareness) (p. 164)

In the Canadian context, principles of ownership, control, access, and possession, (OCAP), is self-determination applied to research. It is a political response to persistent colonial approaches to research and information management (see Snarch 2004). The principles of OCAP have guided researchers working with First Nations, Inuit and Metis communities and have informed the development of national level ethics policy in Canada (CIHR 2007). The principles are described as follows:

Ownership: refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care-
taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.

**Control:** The aspirations and rights of First Nations People to maintain and regain control of all aspects of their lives and institutions extends to research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project, from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks and data management.

**Access:** First Nations Peoples must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized formal protocols.

**Possession:** While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

Discussions about Sámi research ethics across Sápmi have been taking place with new pathways being made towards their realization. At the Nordic level, there is indication of the three Sámi Parliaments coming together on this issue. The Social and Health Committee of the Finnish Sámi Parliament stated on September 11, 2014, the importance of ethical questions being clarified and asked their administration to be in dialogue with the Norwegian Sámi Parliament on this issue. In the same year, the executive board of the Swedish Sámi parliament noted at their meeting on December 9, 2014, the lack of Sámi competence in ethical review boards and decided to proceed with the issue (Stordahl et al. 2015). The mechanisms by which the three Sámi parliaments will work together to forge ahead with Sámi research ethics is evolving. At the same time, seminars and conferences across the Nordic nations are engaging in a dialogue of emic and etic approaches to Sámi research. The two concepts describe the distinction between studying behaviour from within a given cultural system (emic) and studying behaviour from the outside of a cultural system (etic) (Olsen 2016).
According to Gaski (2013), Sámi research in the Nordic region can draw much inspiration from both New Zealand and North America, in terms of having the boldness and strength of will to trust in our own knowledge and experience regarding the thematics, development and conduct of research projects (p. 118). He further asserts a pan-Sámi perspective in the sense of respecting common foundational values and traditions in the north, south, west and east. These values and traditions have been transmitted to succeeding generations through Sámi language, stories, through child rearing, proverbs, yoiks (songs) and attitudes (Gaski 2013). The Sámi language itself is the most important tradition bearer ‘as a reservoir of knowledge from which to draw (p. 115). While the values and traditions are evident in Sámi literature and art, they are absent in scholarly practice (Gaski 2013). Gaski compares the North American context to the Nordic context by maintaining that within the Nordic countries there hasn’t been an active campaign to Indigenize the academy. Gaski further articulates the situation as being more concerned about getting Sámi perspectives into research and not a question of taking Sámi epistemology as the point of departure, or theorizing from Sámi knowledge traditions. His analysis of the Nordic context is informed by the fact that the Sámi are using their own language in scholarly contexts, doing research, disseminating results and discussing research politics in Sámi, Norwegian and English simultaneously, but he also remarks how the Sámi are ‘heading back to the international arena at full speed’ (2013 p. 120).

In Norway, the Norwegian National Research Council and two research ethical committees have been in active negotiations for Sámi research ethics at the request of the Sámi parliament in Norway. However, these negotiations are only applicable to a limited range of research programs. More specific action has been taken via traditional (ecological) knowledge, the collection and coding of Sámi cultural values, philosophies and worldviews which shape the epistemological basis of Sámi knowledge (See: Porsanger & Guttorm 2011, Markkula & Helander-Renvall 2014). However, there is a need to broaden the concepts to fit other fields and further develop the inherent ethical praxis and knowledge that has already been generated in Sámi academic institutions (Stordahl et al. 2015). This endeavor

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1 In 1997, the Sámi Parliament in Norway reached a unanimous decision that ethical guidelines for Sámi research had to be created. However, this is not a current reality. See Stordahl et al. 2015 ‘Ethical guidelines for Sámi research: the issue that disappeared from the Norwegian Sámi Parliament’s agenda?’ for a detailed account of the two national parallel processes in Norway (research ethics and political) that have occurred since the 1997 decision.
would have the capacity to inform the core ethical principles of guidelines for Sámi research in Norway.

Regarding the situation in Sweden, Drugge (2016) completed a study of how scholars in Sweden within the field of Sámi research, relate to research ethics when planning for new research projects related to the Sámi. She found that various ethical guidelines for research are often referred to, but that a common view on what guidelines to use is lacking. Furthermore, in lieu of Sámi specific guidelines, scholars are likely to grab indiscriminately for the nearest ethical guidance available, leading to substantial differences in individual researcher’s strategies (Drugge 2016). Tunón, Kvarnström & Lerner (2016) completed a study analyses of core ethical principles in 13 codes and guidelines developed by International political contexts, Indigenous peoples and groups, and academic associations and institutions. From the 18 core principles found through their study, they determined six principles were similar throughout all the guidelines. The principles included: respect, recognition of rights, responsibility as a scholar, mindfulness, participation and mutual benefits (p. 68). The authors make it clear that awareness in Sweden of relevant guidelines applicable to Sámi research is low among researchers, in ethical committees of universities as well as in local communities. Therefore, the task of developing ethical guidelines for Sámi research can help rectify the situation. However, they caution guidelines that are developed as administrative items to tick off versus the building of good working relationships between the research team and local community, which should be the overarching endeavor of research with Sámi communities (Tunón, Kvarnström & Lerner 2016).

Rauna Kuokkanen, a north Sámi scholar has written extensively on the need for the academy to be more accepting of Indigenous episteme. She defines episteme as a fairly broad and flexible concept that covers aspects of epistemology, philosophy, cosmology, ontology and religion as well as various practices stemming from these, without being limited by them (2007 p. 56). In her book ‘Reshaping the University’, she argues that to discuss indigenous episteme is not to say that all indigenous worldviews are the same or that they can be generalized into a single taxonomy, or even that we can define an indigenous episteme, once and for all (Kuokkanen 2007). She later published Boaris dego eana (Old as the Earth) a book about Indigenous methodology and philosophy, and about the knowledge that is ‘our own inheritance, written in North Sámi language (Kuokkanen 2009).

From the body of research completed to date on the topic of ethical guidelines for Sámi research, it is noted that despite a lack of guidelines, other international
standards are used. However, it has been emphasized a one size fits all approach is not adequate and how Sámi research is in need of their own guidelines that include Sámi episteme. Furthermore, episteme in and of itself is not static, but dynamic and changing over time and subject to influences from other episteme (Kuokkanen 2007). For ethical guideline development, the implication is the necessity for the creation of living documents which are subject to ongoing updates over time. There are researchers (Sámi and non-Sámi) in the Nordic countries who have highlighted the power inequities within research practice and process and the importance of, and challenges that come with utilizing collaborative methods in their research with Sámi communities in the absence of Sámi defined guidelines for working with communities in a culturally appropriate and safe manner (Drugge 2016, Lőf & Stinnerbom 2016, Lawrence & Raitio 2016).

3.3 Indigenous health in Canada and Finland

Hunt (2015) specifies health, from an Indigenous perspective, as often communal rather than individual. She further asserts that Indigenous peoples have complex socio-cultural and spiritual relationships with lands and ecosystems; thus destruction of, or isolation from, land have a significant factor on health. Stories and experiences from Indigenous perspectives can give us insight into how knowledge and worldviews interrelate, and can open up new perspectives and raise consciousness (Balto & Østmo 2012). Indigenous perspectives are central to a better understanding of the relationship between colonialism and health inequity.

Canada’s history of colonialism and paternalistic wardship resulted in the creation of the reserve system; whereby First Nations experienced forced removal and relocation to new and unfamiliar lands; the forced removal of children from their homes to attend residential schools; inadequate services to those living on reserves; racist attitudes towards First Nations peoples. These historical experiences combined and the continued lack of acknowledgment of their combined effects of painful relations with Canada contribute to the health disparities currently experienced by First Nations people (Adelson 2005). Life expectancy and the burden of disease for Aboriginal Canadians differ from that of other Canadians. From the data that are available, we know the following:

- In 2017 the life expectancy for the total Canadian population is projected to be 79 years for men and 83 years for women. Among the Aboriginal population, the Inuit have the lowest projected life expectancy in 2017, of 64 years for men.
and 73 years for women. The Métis and First Nations populations have similar life expectancies, at 73–74 years for men and 78–80 years for women. Life expectancy projections show an average increase of one to two years from the life expectancy that was recorded for the Aboriginal population in 2001. (StatsCan 2017)

- 44.1% of First Nations adults reported their health as thriving (e.g., “excellent” or “very good”) compared to 60% of the general Canadian population. (FNIGC 2012)
- Diabetes rates are 3–5 times higher in First Nations than in the general Canadian population, a situation compounded by barriers to care for Indigenous Peoples. (CDA 2017)
- A higher proportion of First Nations adults with at least one chronic health condition (compared to those First Nations adults without a chronic health condition):
  - were overweight (79.2% vs. 67.5%),
  - were rarely physically active (50.3% vs. 39.7%),
  - reported moderate or high depression (34.4% vs. 20.8%),
  - reported suicidal thoughts (24.3% vs. 17.7%),
  - reported suicide attempts (14.9% vs. 9.5%),
  - reported use of opioids (5.0% vs. 3.6%) and sedatives/sleeping pills (6.3% vs. 3.7%) without a prescription.

Mental health issues are closely related to issues of identity (King, Smith & Gracey 2009). Thus, the variation in the rates of suicide and other indices of distress in First Nations communities suggest the importance of considering how different individuals, families, communities and nations have responded to the continuing stresses of colonization (King, Smith & Gracey 2009). At the time of the 2008/2010 First Nations Regional Health Survey, among those who reported attending residential school, 13.7% said it had a positive impact on their health and well-being and one-third (32.8%) said the experience had no impact. Over half 53.4% said the experience had a negative impact (FNIGC 2012). This is similar to findings of the Our Health Counts Urban Aboriginal Health survey findings: 6% of participants were students at residential schools and 40% had a family member who were at residential schools. Of those respondents, 65% felt personal negative impact to their health and well-being and 34% felt negatively impacted as a family member (Smylie et al. 2011). Specific circumstances and process of colonization
differ widely internationally. Yet most Indigenous people share the common experience of having their traditional ways of life disrupted, as well as experiencing socio-economic and political marginalization and racial prejudice (Hunt 2015).

In Finland, the Sámi population residing in several municipalities in Lapland (Enontekliö, Inari, Utsjoki and the northern part of Sodankylä) live totally integrated with the majority Finnish population. The Sámi are not separately distinguished by their social security number or by any other means. In terms of health care access, every Finnish resident has the right to health services regardless of ability to pay or place of residence. However, due to the demographic difference among municipalities, especially in northern Finland, there is a variation in the health service needs (Lammintakanen & Kinnunen 2012). Today equality is not realized where services available in Sámi language are concerned (Pohjola 2016). Heikkilä (2016) found in a pilot study conducted in the Sámi homeland area, that the Sámi are clearly dissatisfied with both access to and quality of welfare services. When compared with the satisfaction rates found in similar surveys of the majority Finnish population, the Sámi are notably less satisfied (p. 657).

A limited number of studies have been completed in the area of Sámi health in Finland. Results published by Soininen & Pukkala (2008) and Soininen (2015) of a cohort study of 2091 Sámi and 4161 non-Sami people found that the health and mortality statistics of Sámi in Finland include:

- The total mortality rate does not differ from that of the general population, but there are big differences in the details of mortality patterns (i.e. Cancer mortality is lower, especially among Sámi men, and accidents and suicides are more common among Sámi when compared to non-Sámi).
- The mortality from accidents and violence was high.
- The mortality from breast cancer among Sámi women was low.
- Mortality from suicides among Sámi men was 70 % more common than in the general population.
- High rates of substance abuse, suicides and other mental health concerns.

According to Young et al. (2015), unlike other health indicators, where disparities between Sami and non-Sami are very small or non-existent, there is an excess of suicide among Sami, as much as 2.5 times higher for Sámi men than among Finnish men during the period 1997–2005. However, for the same time period there is no

\[\text{welfare services defined for the study described as: overarching concept that refers to public services such as social and health services, education, legal aid, employment, social security as well as services needed in everyday life, examples being banking, the post and grocery shops.}\]
excess risk of suicide for Sámi women. Stoor et al. (2015) explored cultural meanings of suicide among Sámi in Sweden and found suicide to be understood as an act that takes place and makes sense to others when a Sami no longer has the power to maintain a Sami identity, resulting in being disconnected from the Sami world and placed in an existential void where suicide is a solution. Suicide prevention and mental wellness have been identified as an important public health issue for all Sami within the Nordic countries (Redvers et al. 2015, Stoor et al. 2015, Young et al. 2015). Further dialogue on what constitutes adequate or useful evidence in suicide intervention, within the context of small northern communities, and within Indigenous worldviews and understandings, should also be made visible in research (Redvers et al. 2015). The Sámi in Finland are working hard to reverse the effects of colonization process, but there is still much progress to be made; especially since the effects of years of cultural repression still exist (Lehtola 2012).

### 3.4 Widening the lens to better understand health inequity

Previously, Young et al. (2008), had indicated that discrimination and being disrespected as indigenous groups could possibly be causally related to different health problems (i.e. high suicide rates, alcohol abuse and poorer reporting of health status) in many circumpolar communities. Despite the large number of studies investigating the association between discrimination and health, a great number of questions remain unanswered (Pascoe & Smart 2009). Health equity describes inequalities in health that are deemed to be unfair or stemming from some form of injustice. Because identifying health inequities involves normative judgment, science alone cannot determine which inequalities are also inequitable nor what proportion of an observed inequality is unjust or unfair (Kawachi, Subramanian & Almeida-Filho 2012). Other research suggests that the present day social forces driving racial inequalities in health are conceptualized as being the result of historical legacies of social oppression, with racism as the link between race and health. Recent studies have documented that individuals who report experiencing racism have greater rates of illnesses (Chae et al. 2011, Williams & Mohammad 2009). While this type of research is important to give a greater understanding of root causes of health inequities, it still places the experiences of racism at the individual level (Williams & Mohammed 2009, Paradies & Cunningham 2012, Gee & Ford 2011). Gee and Ford (2011) suggest that studies of disparities should more seriously consider the multiple dimensions of racism as fundamental causes of health disparities, particularly structural racism. By investigating forms of
structural racism from an Indigenous perspective we can build on the discourse about oppression and its link to the present health inequalities experienced by Indigenous peoples worldwide. Structural racism is defined as the macro-level systems, social forces, institutions, ideologies, and processes that interact with one another to generate and reinforce inequities among racial and ethnic groups (Gee & Ford 2011, Geronimus & Thompson 2004, Jones 2000, Powell 2008). Boarding schools and residential schools are prime examples of structural racism as Indigenous culture, language and identity are deemed at a value of ‘less than’ by the majority society. Because structural racism is embedded in societal level institutions, policies, and practices, it influences health through multiple pathways (Viruell-Fuentes et al. 2012). Students were taught that in order to be ‘successful’ one had to adapt the values and language of the dominant society, thereby creating inequality with respect to culture and identity. Canadian research empirically explores the role of Canada’s residential school system on attendees (Elias et al. 2012, Bombay et al. 2011) and the impact of stressors on second generation residential school survivors (Bombay et al. 2011). Bombay et al. (2011) discuss limitations of their study on impacts on second generation residential school survivors as it is a quantitative and correlational analysis, and stated that it lacks the richness that might be obtained from a combined quantitative/qualitative approach.

Williams (1997) created a framework for the study of the role of race in health, placing racism as a basic cause (or root cause) of health status. When reflecting on this earlier work and the ongoing research about Indigenous health, we know: plenty of research in the past has been produced about the surface causes of health inequality, and more recently research has been produced in Canada and Finland on the social causes (see FPTAC 1999, Mikkonen & Rapheal 2010, Marmot 2011, Mikkonen 2012, Palosuo & Sihto 2016). However, to truly understand Indigenous health inequity, a consideration of culture, biology and geographic origins, racism, economic structures and political and legal structures are necessary. These basic causes described by Williams (1997) and others are all of the circumstances that impact Indigenous lives. A common history of colonialism and resulting economic, social and cultural marginalization has had profound health impacts on Indigenous peoples not only in Canada, but also around the world (Gracey & King 2009, King, Smith & Gracey 2009). Colonization has been defined as a determinant of Aboriginal health (Moffit 2004, Baskin 2007) and aboriginal status as a social determinant of health (Mikkonen & Rapheal 2010). However, the literature on health inequalities have struggled to move beyond a social factors approach that
mimics epidemiology and brackets out any broader reflection on either social structures or the meanings that people give to situations of inequality they experience (Williams & Elliot 2010). Currently, racism is not one of the determinants of health in the Public Health Agency of Canada’s framework (Health Canada 2014) even though racism is a form of social exclusion and it impacts socio-economic status, which is considered to be a structural determinant of health according the World Health Organization (WHO 2007). In the Canadian context, Loppie-Reading and Wein (2009) have stated how colonial systems with a consequential hierarchical distribution of resources, power, and freedom of control have created social stratification along ethnic lines and influences Aboriginal health. Health disparities for Aboriginal people in Canada have manifested from a long history of oppression, systemic racism and discrimination (Warry 1998). Frolich, Ross and Richmond (2006) further assert that the resultant health disparities are inextricably linked in unequal access to resources such as education, training and employment, social and health care facilities and limited access to, and, control over lands and resources (p. 136). Gee and Ford, (2011) have suggested the importance of studying structural racism and its link to health inequity. Since structural mechanisms do not require the actions or intent of individuals (Bonilla-Silva 1997), they are constantly reconstructing the conditions necessary to ensure their persistence (Link & Phelan 1995). Even if interpersonal discrimination was completely eliminated, racial inequities would likely remain unchanged due to the persistence of structural racism (Gee & Ford 2011). According to deLeeuw, Linsday and Greenwood (2015), colonialism has yet to be fully and consistently accounted for as a significant determinant of Indigenous health (p xi). Furthermore, when colonialism is mentioned, it is usually situated as a historical event rather than an ongoing process that continues to impact negatively on Indigenous health outcomes (Axelsson, Kukutai & Kippen 2016). Therefore, investigations that explore the interconnections of discrimination, structural racism and colonialism, in the past and present, are necessary for a more robust understanding of health inequity of Indigenous peoples.

deLeeuw, Linsday and Greenwood (2015), profess the social determinants of health dialogue provide some important insights. Within their book ‘Determinants of Indigenous Health: beyond the social’, their introductory reflection retells how within the social domain, colonialism has not yet fully and consistently been accounted for as a significant determinant of health. Indigenous peoples globally experience the greatest health disparities and they identify colonialism as perhaps the most important determinant of (ill) health (see: Loppie-Reading & Wien 2009,
Richmond & Ross 2009, Bourassa, McKay-McNabb & Hampton 2004, de Leeuw, Greenwood & Cameron 2010). Secondly, much of the literature and research about social determinants of Indigenous peoples’ health remains a subsection of more broad discussions of social determinants of health. New research has provided a comparative analysis of more than 20 countries covering a diverse set of socio-economic characteristics, political arrangements and colonial histories. The analyses clearly show that inequities persist, with generally poorer social and health outcomes for Indigenous peoples relative to mainstream populations (see Anderson et al. 2016). However, the situation in Norway, Sweden and Finland have produced a paradox in relation to the health status of the Sámi as the Sámi experience similar and sometimes better health than mainstream populations in the Nordic countries (Soininen 2015, Hansen 2015). Paradis (2016) is perplexed by this and goes on to say ‘assuming such equality is real (rather than say, due to difficulties in enumerating this population), we can ask if such health equity constitutes a ‘failure’ of colonization to maintain the subjugation of the indigene or success in assimilating them to the health ‘norm’. Does such equity represent empowerment for the Sámi or has it come at the cost of ‘lost’ culture, control or power? Answers to such questions depend on how we understand the nature of Indigenous disadvantage’ (p. 90–91).
4 Aims of the study

The purpose of this study was to broaden understanding of structural racism by examining the relationships between Indigenous peoples and nation-states in the context of education and how this affects Indigenous lives. Structural racism is viewed through an expanded approach to include its interconnections with colonialism, and discrimination. This study explored structural racism in various educational contexts: the academia; and Residential schools in Canada and Boarding schools in Finland. The multiple case study analysis was completed in two phases. The first phase draws on a comparative literature study of Indigenous research ethics protocols and policies, in Canada and the Nordic countries. The second phase builds on data collected during the Master’s research project (see questionnaires in English and Finnish, appendix B), which investigated the impact of discriminatory practices in education and health on Indigenous peoples in Canada and Finland (see Juutilainen 2011). The three case studies developed for this project more closely examined the experiences of structural level racism within education and its influence on Indigenous health. The data was collected during structured interview research conducted in a First Nations community in Canada (Six Nations of the Grand River) and a Sámi community in Finland (Inari municipality) with members who had attended a residential school or boarding school or had a family member attend.

Over-arching research question: How can multiple case study analysis of Indigenous groups from two different countries and contextual experiences within the education system broaden our understanding of the phenomena of structural racism? The specific aims of each phase were:

Phase one

To review the dialogue and process for the development and implementation of Indigenous research ethics protocols and policies (or lack thereof) in Canada and Finland; and, their potential for de-colonizing the academy.

a) Indigenous critiques of colonial style research practices began around the same time in Canada and within the Nordic countries. Why are there guidelines and policies for research with First Nations, Métis and Inuit peoples of Canada but not for Sámi research in the Nordic countries? (I)

b) How do Indigenous research ethics create an ethical space between academic researchers and Indigenous communities? (I)
c) What are the elements of the Canadian process that are supportive for developing guidelines and policies for Sámi research in the Nordic countries? (I)

Phase two:

To investigate the lived experiences of attending or having a family member attend a residential school/boarding school.

a) What are the parallel lived experiences of First Nations who attended residential school in Canada and Sámi who attended Boarding schools in Finland? (II)

b) How is past, present with respect to the relationship between the effects of the lived experiences of residential school/boarding school and health and wellbeing, at the individual and intergenerational level? (II, III, IV)
5 Methodology

5.1 Research design and Methods

5.1.1 Multi-case study research design and critical approach

The original publications presented in this study were based on case study research design. In this thesis a multi-case study approach was applied. It is a particular effort to examine phenomena having a number of cases, parts or members (Stake 2006). The distinctive need for case study research arises out of the desire to understand complex social phenomena (Yin 2014 p. 4). According to Yin (2014), using a variety of data at various time frames allows for different viewpoints of realities, categorized in multiple ways (p. 188). Herein, data from two different countries, Canada and Finland, at various time frames within educational contexts are examined to capture the different dimensions of the phenomenon structural racism. Sequential timing was not used in the development of the qualitative case studies, ie Phase one did not inform the development of the subsequent case studies of phase two due to the differing contexts within the education system. Phase one of the study, was a literature study (Original publication I) using content analysis, from the perspective of Indigenous resistance, of the dialogical processes in both Canada and the Nordic countries for the development of Indigenous research ethics protocols and policies. Phase two: the empirical research (Original publications II, III & IV) are case studies that were developed from data that was collected in Canada and Finland during master's research project on experiences of discrimination and its impact on self-perceived health (see Juutilainen 2011). The purpose of developing the three case studies was to undertake a deeper analysis of the theme of structural racism that arose from the Master's data, with the aim of gaining a broader understanding of structural racism in the context of two different countries, within different education contexts, at two different points in time. The first case study (Original publication II) of phase two was developed for further understanding of contextual differences between the two countries and their education systems, assimilation policies and practices and their mutual outcomes on Indigenous lives. Data from Canada and Finland was triangulated to examine Indigenous experiences within residential school and boarding school. Paper III was developed to explore the intergenerational impacts of Indian residential school, only the data from the female responses from Canada were used. This case study
examined the ways is which ‘past is present’ with regards to resilience by prefacing the Haudenosaunee concept of mothers of the nation to examine the resilient experiences of Haudenosaunee women who had a family member attend Indian residential school. Paper IV was developed from the data collected in Finland regarding Sámi experiences in Finnish boarding school. A new, feminist, materialist post-human lens is utilized to examine vulnerabilities that resulted from attending a Finnish boarding school. This lens is a new and novel theoretical and empirical analysis providing a deeper analysis of ‘past is present’ within a Sámi women’s discriminatory experiences in Finnish boarding school. The purpose of using the different paradigms was not to mix paradigms but to widen the lens of the phenomena at two different points in time, in two different countries; and, to demonstrate in different ways how past is present within these experiences.

5.1.2 Race consciousness: researchers’ position in two countries

Research begins with philosophical assumptions and investigators’ worldviews, paradigms, or sets of beliefs that inform the way studies are carried out. Interpretive and theoretical frameworks further shape investigations. These three elements: assumptions, worldviews, and frameworks frequently overlap and support each other (Graham et al. 2011). According to Giacomini (2010) theory matters not only for justifying and shaping research methodologies, but also for creating meaning and implications from research findings. The overall project draws on a public health critical race (PHCR) praxis, grounded in critical race theory, utilizing a methodology that is framed by race consciousness in society and one’s personal life, and, encompasses four key focuses: contemporary patterns of racial relations; knowledge production; conceptualization and measurement; and, action (Ford & Airhihenbuwa 2010a). According to Ford and Airhihenbuwa (2010a), understanding the causes of racial health inequities requires a solid understanding of the salience of racialization in society and in one’s personal life. Therefore, race consciousness frames the whole research process (p. 1392). Since this research project involved two countries, I have had to situate myself within the work and reflect on my own race consciousness while working in both Canada and Finland. During presentations about my research project in Finland, I often begin by locating myself within my research project and my motivations for working with Indigenous communities. Part of this introduction to audiences is a brief discussion about my identity as a Haudenosaunee woman who is also of Finnish-Canadian heritage, and
how my own identity has brought me to specific places: in my previous work with First Nations communities in Canada; and, for graduate studies in Finland. After one such presentation, a Finnish researcher welcomed me to Finland and said ‘In Canada, you are a minority but here in Finland you are part of the majority’. She meant well in her greeting. I’ve been warmly welcomed to Finland and I appreciate the immediate inclusion to Finland, the land of my ancestors. However, upon later reflection of her greeting, it made me think of how Indigenous peoples are often categorized: as minorities. Yet, Indigenous peoples are not minorities. They are original peoples of settled lands and it is the relationships between settlers and original peoples that have been historically fraught with inequity. This inequity finds its way into contemporary relationships. Her statement also made me think about how I would go about my research practices in Finland. Working for a decade in First Nations communities in Canada I was well aware of First Nations communities distrust of outside researchers. At the same time, it wasn’t my goal to be an Indigenous scholar who proclaims only emic approaches are suitable for Indigenous research. There are both Indigenous and non-Indigenous scholars who take serious consideration of colonialism as a starting point of any academic endeavour. However, one of my key assumptions is my responsibility to Indigenous communities (in my home country and abroad). I abide by the principles of OCAP (see chapter 3.2) which ensures reciprocal, respectful research relations that extend beyond individual ethics and encompass the community collective with the main aim of ensuring the production of knowledge is meaningful to the community being studied. For this study the philosophical worldview I draw upon, as a Haudenosaunee scholar, is the Two Row Wampum, a Haudenosaunee philosophical principle of equity based on the original treaty between the Haudenosaunee and Dutch settlers. It is the basis for subsequent treaties made with the British, French and America.
The Two Row is best understood as a Haudenosaunee term embodying the ongoing negotiation of their relationship to European colonizers and their descendants. The underlying concept of Kaswetha emphasizes the distinct identity of the two peoples and a mutual engagement to coexist in peace, friendship and respect without interference in the affairs of the other (Parmenter 2013). The Two Row Belt, as it is commonly known, depicts the kaswenthha relationship in visual form via a long beaded belt of white wampum with two parallel lines of purple wampum along its length. The lines symbolize a separate-but-equal relationship between two entities based on mutual benefit and mutual respect for each party’s inherent freedom of movement. Neither side may attempt to “steer” the vessel of the other as it travels along its own, self-determined path (Parmenter 2013). Longboat (2010) poignantly describes the vessels travelling down the river of life, metaphorically, as the big ships represent the structures of a colonizing society with the captain at the helm organizing large groups of people in a hierarchical fashion of which his crew might be loyal or prone to mutiny in contrast to the Aboriginal canoe, which is maneuvered by the cooperative efforts of its occupants. ‘How each culture addresses its educational prerogatives is a reflection of how they have designed their boats’ (emphasis added, p. 227).

A component of my ongoing efforts to decolonize my own thinking was to participate in the Two Row Wampum Renewal Campaign. The Two Row was renewed by a symbolic enactment along the Hudson River in 2013, the 400 year anniversary of the Two Row Treaty. I participated in the historic event as a paddler.

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1 Haudenosaunee symbols, available at: http://wampumchronicles.com/tworowwampumbelt.html

2 See Appendix C.
with my cousin, Ellie Joseph (Six Nations of the Grand River), along with Indigenous and non-Indigenous paddlers. We travelled down the Hudson River together the distance from Albany, New York to New York, New York pausing to take in educational events along the shores of the Hudson River. It was at this epic enactment where I gained knowledge from Indigenous peoples’, who have inspired me to think in new ways while remembering our past. In particular, from the opening address for the Two Row Wampum Renewal Campaign in Troy, New York, 2013, Haudenosaunee historian Rick Hill, stated:

‘I have met a lot of smart people along my journey. Native people who still carry the knowledge about our ancestral past and oral history. They not only taught me facts that took place but instilled in me a sense of thinking what does it mean. Each generation has to think about what does life mean, what does spirit mean, what do our treaties mean? While there is no one definitive answer, every generation has to think about that’.

Rick’s words resonated with my own experience within academia and how I approach research with Indigenous communities. In thinking about what our treaties mean, I have had to rethink how colonialism, structural racism and discrimination are entangled and how this has impacted Indigenous individuals (including myself!), communities and Nations, specifically its impact to relationships: be it relationship with self, own communities, Nation and with other Nations.

5.1.3 Research site selection and data collection tool

The research site selection was completed during the Master’s research project ‘Less than’: Two Indigenous communities’ experiences of discrimination and its impact on self-perceived health - A comparative study of Sámi in Finland and Six Nations of the Grand River. I originally chose these communities based on my supervisors’ long-standing relationships with the Sámi community in Finland; and my previous working relationships with Six Nations of the Grand River, Canada. Since I was located in Finland for the duration of the Master’s and PhD project with only one or two trips back to Canada per year, time to build initial research relationships with the community were minimal. Therefore, I chose Six Nations, where I had already established working relations with the Director of Health and the community from my previous work there as a Registered Dietitian. Factors for the situation to work with a Sámi community were multifaceted since I arrived in
Finland not having any contacts in the Sámi community and did not speak the local language. Therefore, I relied on my supervisors’ contacts and their established working relationships with the Sami community of Inari municipality in Finland. Members of the research team were able to facilitate introductions to networks at SamiSoster, a NGO in Finland dedicated to uphold and promote the Sami people’s position and rights as indigenous people within social and health services and in other questions concerning welfare, both nationally and internationally. This project would not have been possible without well-established working relationships with both Inari municipality and Six Nations of the Grand River for assistance with advice on the relevance of questions asked in the survey questionnaire and to facilitation of participant recruitment. Permission to collect the data for the Master’s project and its subsequent use for the case studies developed for this research project was granted from the University of Oulu and the Six Nations Ethics Committee. The data collection tool (see appendix B) was adapted from subsections for the ‘Our Health Counts Adult Survey’. Permission for use of subsections of the ‘Our Health Counts Adult Survey’ for this study was granted by the Governing Council Committee of the ‘Our Health Counts’ research project, an urban Aboriginal research project developed using a community participatory action research designed to identify health indicators relevant to Ontario’s Urban Aboriginal Population in Canada. For the data collection in Finland, the research team decided to translate the survey to Finnish since it would be a language accessible to all participants in Inari. The original survey contained 73 closed and open ended questions that solicited responses about socio-economic status, experiences of discrimination while accessing health services, individual level discrimination and racism and residential school and boarding school experiences. For the Masters research 29 of the 73 questions were analyzed. This study further analyzed 17 of the questions under the Section: Impacts of Colonization, subsection A: Residential School/Boarding School and B. Discrimination. The three case studies developed for Phase two of this study, using responses to the closed and open ended questions and spontaneous narrative data generated during the interviews were used as follows: Paper II: Section 3: Impacts of Colonization, subsection A. Residential School: questions 14 through 20, and subsection B. Discrimination: question 29, the data that had been translated to English from the Finland data collection and the date collected in Canada was used in this case study. Paper III was developed from Section 3: Impacts of colonization, questions 18 through 20, and question 29 using only the female responses from Canada Paper IV was developed from Section 3: Impacts of Colonization questions
13 through 29, using both the text which was transcribed to English from Finland data, in addition to the original Finnish data of the selected transcript of one Sámi woman for the analysis. (see Appendix B and C for questions in English and Finnish). More details are provided about the analysis of each case study in section 5.1.5

5.1.4 Research participants

Six Nations of the Grand River, Canada

Data (n = 25 interviews) was collected between January 4–15, 2011. Purposive sampling method used: snowball sampling to recruit participants who had attended an Indian residential school or had a family member attend. The ratio of female to male participants was 60 %:40 %. Participants self-identified as: Mohawk (60 %); Onondaga (4 %); Cayuga (32 %) and Tuscarora (4 %). The majority of the participants had a family member attend Indian residential school (n = 23); and attended an Indian residual school (n = 2). Age range of participants: 18–39 years (24 %), 40–59 years (60 %), 60–79 years (16 %). Recruitment of participants was facilitated with the assistance of staff at the Gane Yohs Community Health Centre, and through advertising across list-serve network at Six Nations. Since the interview covered topics that were sensitive in nature, local mental health contacts were provided at the end of the interview. Interviews were audio recorded with permission of the participant, and later transcribed for analysis.

Inari Municipality, Finland

Data (n = 20 interviews) was collected at two different time periods in Inari: April and June 2011. Purposive sampling method used: snowball sampling to recruit participants who had attended at Finnish boarding school or had a family member attend. The ratio of female to male participants was 60 %:40 %. Participants self-identified as: North Sámi (65 %), Skolt Sámi (20 %), and Inari Sámi (15 %). Most of the participants had attended a boarding school (n = 16) and also had a family member attend (n = 18). Age range of participants: 18–39 years (25 %), 40–59 years (35 %), and 60–79 years (40 %). Participants were recruited by the Planner at the Sámi Parliament and a Public Health Nurse from Ivalo. Informed consent was provided by all participants. Consent forms and the questionnaire were translated
to Finnish at the University of Oulu and also reviewed by the Planner at the Sámi Parliament for clarity of content in the Finnish language. Due to the sensitive nature of the research topic and to build rapport between myself and the research participants, it was important that I was introduced by local people who are visible in the Sámi community. Additionally, I sat in on all the Finnish interviews with the translators. Some of the questions required further clarification, which I then was able to provide to the translators. Three translators worked on collecting data: Anne Miesperä, master’s student, University of Oulu (17 interviews); Dr. Lydia Heikkilä, Planner, Sámi Parliament (one interview); Tarja Artijeff, RN (two interviews. All interviews were audio recorded with permission. Due to the sensitive nature of the interviews, participants were provided with local mental health providers after the interviews took place. Data was later transcribed in Finnish by Anne Miesperä, and translated from Finnish to English by Matti Luonua.

5.1.5 Materials and methods for case study (I–IV)

Phase one of the study was a literature study using content analysis of the dialogical processes for developing guidelines and policies for Indigenous research ethics in Canada and the Nordic countries with a focus on Finland. The intent of the literature study was to gain further insight into the ability of ethical guidelines and policies for decolonizing research processes. Materials for the literature study came from a variety of sources: National policy in Canada updated in 2014: Tri Council Policy Statement: ethical conduct for research involving humans, Chapter 9 Research Involving the First Nations, Inuit and Métis peoples of Canada; various Indigenous community guidelines and protocols developed across Canada; discussion papers on Indigenous research ethics from Canada and the Nordic countries; and, seminar proceedings in Canada and the Nordic countries. A close reading of all the materials was completed though a critical lens to examine the complex and unequal power relations between academic researchers and Indigenous communities, and the colonial practices within academic research processes. For the literature study, a qualitative content analysis method was used (Krippendorff 2004, Holsti 1969). It is a method for interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns. The major research question and related data analysis were informed by prior research and publications on the topic (Potter & Levine-Donnerstein 1999). The aim was to create a comprehensive, condensed depiction of the examined phenomenon, articulating the results to the wider contextual understanding and previous research.
results (Tuomi & Sarajärvi 2002). Critically examining the dialogical process for policy development of Indigenous research ethics in Canada and comparing the similar processes in the Nordic countries provides context and increased understanding of the processes and their current outcomes while at the same time, taking a closer examination of Canada’s policies and its capability for building authentic research relationships and the importance of ensuring the policy is a living document, subject to updates. The paper examines the similar pathways of Indigenous self-determination whereby Indigenous peoples have discussed, organized, developed and implemented ethical protocols to ensure research is conducted in a respectful manner and is of direct benefit to their communities (Paper I).

Phase two of the study was an investigation of colonial education policies and practices within residential school in Canada and boarding school in Finland, and how it impacted those who attended or the intergenerational impacts to those who had a family member attend. Three case studies were developed using the closed and open-ended questions from structured interview data that was originally collected for studying the effects of discrimination on the self-perceived health of Indigenous people in Canada and Finland (see original survey questions Appendix B & C). Although the research tool was a structured interview survey with both closed and open ended questions, additional narrative data was produced from the spontaneous dialogue that occurred when answering the closed ended questions. The main goal of the case studies was to look more closely at the narrative data of the lived experiences within residential school and boarding school. For this study the open ended questions and the spontaneous narrative data collected during interviews when respondents answered the closed ended questions about residential school in Canada and boarding school in Finland, individual experiences of discrimination and the impact of colonization on health, both individually and intergenerational experiences and Indigenous identity were used. A close reading of all the narrative responses pertinent to the development of the three case studies was completed and produced 75 pages of material. When reading the data attention is focused on: who is telling? where is this happening? when did it happen? what is happening? and why? (Dey 1993). To support the aim of becoming immersed in the data, the narrative material is read through several times (Burnard 1991, Polit & Beck 2004). Different approaches were taken for the development of the three case studies in order to broaden the understanding of manifestations of structural racism in two different contexts. Additionally, the use of multiple approaches demonstrate in different ways how past is present within these experiences.
The first case study developed (Paper II) arose out of the major themes from the original data set in regards to the impact of colonization on Indigenous health, specifically experiences within residential school in Canada and boarding school in Finland. The intention was to build on the theme that emerged from the Master’s research to produce a deeper analysis of racism at the structural level (e.g. education policies and practices) by examining the open ended responses about residential school and boarding school experiences. Paper II further analyzed Section 3: Impacts of Colonization, subsection A. Residential School: questions 14 through 20, and subsection B. Discrimination: question 29 (All responses from Canada and the Finland) Narrative data was not only contributed in the open ended questions about residential school/boarding school experiences, and discrimination, but also arose while answering specific closed ended questions (see questions: appendix B & C). The questions solicited responses about first-hand and intergenerational experiences of racially motivated oppression and discrimination experienced within the confines of residential and boarding schools. For paper II, the data from the two cases, Canada and Finland, were triangulated to gain an enlarged scope of the related phenomena of structural racism, internationally, and to investigate key differences in experiences between the two countries due to contextual differences in the education policies of Canada and Finland. As a limitation of this paper, a deeper understanding of Sámi epistemology would have been required to fully explain the differences in experiences. While the co-authors of the paper had years of working experience in working with the Sámi community, the need to have a Sámi co-author and reviewers was identified. Therefore, for this particular case study, the prevalent parallel experiences are highlighted. This contributes to an understanding of the parallel lived experiences within residential school and boarding school and how past is present within the intergenerational experiences. Involving community was an important component to taking a decolonized approach to research processes. As such, a co-author from Six Nations participated in analysis of the Canadian data and writing of the paper, in addition to the two supervisors from the research team in Finland. A close reading of all the data was completed by the lead author, the health director from Six Nations and the two members of the research team. The narrative data produced 75 pages of narrative material. Collaboratively, the authors of Paper II decided on the emergent themes (Individual and Intergenerational impacts to health and wellbeing, fracturing of Indigenous identity, coping with negative self-worth and resilience). For this thesis, further analysis highlights the parallel experiences of shame and its effect(s) on Indigenous health and wellbeing.
Case study III was developed based on the majority of participant narratives from Six Nations of the Grand River were intergenerational experiences in residential school, i.e., a member of their family had attended Indian residential school. Additionally, from my own understanding of what I hear from communities in Canada and read in the literature, there is a necessity to capture resiliencies in Indigenous research (Kershaw & Harkey 2011, Stout & Peters 2011, Kirmayer et al. 2011). Upon reflection of my own Haudenosaunee identity, I chose to preface a Haudenosaunee concept which embodies resilience of Haudenosaunee women. Paper III investigates the intergenerational experiences of 13 Haudenosaunee women who had a member of their family attend an Indian residential school. The data was chosen to further understand how past is present in relation to resilient experiences of those who had been impacted at the intergenerational level by Indian residential school. While other research on intergenerational experience of Indian residential school focuses on vulnerabilities, I prefaces resilience, specifically the resilience that is found within examples of how the Haudenosaunee women embody the concept of mothers of the nation. For the analysis of case study III, Haudenosaunee women as mothers of the nation defined by Sunseri (2011) conveys ‘mothering’ within a Haudenosaunee perspective is a concept that does not necessarily have the same meaning as it does in other cultural contexts. Although one understanding of mothering is related to the literal meaning of biological reproduction, mothering also encompasses other roles, such as caring for all the children of one’s clan, caring for the earth, and sharing responsibilities for the well-being of the community. Hence, because of the broad and exclusionary meaning of the term ‘mothering’, women who did not biologically produce children are still regarded and treated as ‘mothers of the nation’ (p. 72). Data used to develop this case study included two closed ended questions about having a family member attend a residential school. Its impact to the women’s health and wellbeing were examined in addition to the spontaneous narrative material these questions evoked along with open ended questions for further elaborations of the women’s thoughts on intergenerational experiences of residential school. The responses to these questions produced 39 pages of narrative data, which was analyzed through a critical Indigenous lens which posits Haudenosaunee women as mothers of the nation. This approach was taken using a Haudenosaunee concept of care-giving to further understand the resilience of the women who have had traumatic experiences as a result of having a family member attend an Indian residential school.

The final case study was developed to further analyze the Sámi experience in Finnish boarding schools by drawing on new feminist materialist and posthuman
theories to explore discrimination. Paper IV enlisted a native Finnish speaking lead author who is also of Sámi heritage to conduct an in depth analysis of one Sámi woman’s articulations of experiences of discrimination in and beyond Finnish boarding school. It was important to have a native Finnish speaker re-read the Finnish transcripts and listen to the Finnish interview recordings. Prior to the selection of the one Sámi woman’s experiences, both the lead author, Tuija Huuki, and myself, re-read the English transcripts from all 20 participants from Inari municipality of the open ended responses to questions about: boarding school attendance, Sámi identity, and colonization and its impacts to Sámi health and wellbeing, which produced 27 pages of narrative data. The lead author also listened to the Finnish audio recording materials and read the Finnish transcripts. The data from one Sámi woman’s experiences was selected for her nuanced articulation, not only of her own experience, but of her observations of the wider Sámi community.

For the analysis of case study IV discrimination was defined as: force relations, emerging dynamically though assemblages of, for example, material, corporeal, historical, organic and affective elements. In keeping with a decolonial research process, we recognize how much past research about Sámi people has been conducted by outside researchers, and as such, we asked two Sámi scholars to review earlier drafts of the paper and they provided constructive remarks.

5.2 Ethical issues

In this study the principles of Indigenous research ethics (see OCAP, chapter 3.2) formed the overall guidance for the research practices at every stage of the research process. Requests for use of data originally collected at Six Nations of the Grand River for Papers II and III were submitted to the Six Nations Ethics Committee and granted approval for use in those papers and to be included in this doctoral thesis. This is a requirement for further use of data collected at Six Nations of the Grand River. Initial consent to collect data in their territory is not a permission to ‘collect data and later use for multiple publications’. Permission is required each time the data will be used in a different way. This is an example of Indigenous self-determination applied to research, whereby the community has a say in when and for what purpose the data may be used. Another aspect of community collaboration for Paper II included a co-author from Six Nations. The data from Finland was approved for use in the articles and thesis by the University of Oulu. The lead author of Paper IV is a native Finnish speaker who also has Sámi heritage, an earlier draft of Paper IV was reviewed by two Sámi scholars. For the data analysis of
papers II, III, IV, all identifying information of study participants was removed to protect anonymity. The final thesis will be made available to the ethics committee at Six Nations, and University of Oulu library. Presentations of final results will be made at an annual research event at Six Nations of the Grand River, and in Inari Municipality. The data set from Canada remains property of Six Nations and could be accessed through a proposal to the Six Nations ethics committee for future use. As an Indigenous researcher, I abide by the principles of OCAP even while abroad. However, local processes are key. The current process in Finland for ownership of data after the study is completed requires that the data collected in Inari municipality in Finland remains the property of the University of Oulu.
6 Results

6.1 Summary of the results

Health research conducted in Canada have brought to the fore an abundance of research which focuses on vulnerabilities or deficits of Indigenous peoples with little investigation into what makes people resilient while enduring traumatic life experiences. The situation in Finland differs in the sense that there is sparse data collected on the health and wellbeing of the Sámi that would be needed to inform policies and programs. As such, academic research conducted ‘on’ First Nations and Sámi has parallel, but at the same time, divergent meanings. Notably, Indigenous resistance to academic research in both countries have produced a parallel dialogue in regards to Indigenous research ethics that draws on both individual and collective resiliencies, which emphasizes a collective healing of the relationships between academia and Indigenous communities. The common thread throughout all of the case studies is the resistance to structural racism within education. It is this resistance that make a people resilient. The results of phase one of the study details how resistance within academia, led by Indigenous groups, produced the self-determined action in both Canada and Finland to move Indigenous specific research ethical guidelines and policy forward. While the process has resulted in a state level policy in Canada, Finland’s dialogue is moving forward, along with Norway and Sweden, for the development of Sámi research ethical guidelines in the Nordic countries. Indigenous specific guidelines were initially developed in Canada to promote health through research (CIHR 2007). Resistance is embedded in the guidelines. It is a self-determined response to the health situation of Indigenous peoples in Canada. Health through research can only be accomplished when Indigenous communities are active participants in research processes. As previously defined, health from Indigenous perspectives encompasses the realms of not only the physical, but includes the mental, emotional and spiritual. Indigenous ethical guidelines and policy serve to bridge differing worldviews and at the same time meet the needs that are most urgent in communities. Investigating structural racism via residential school and boarding school experiences within Phase two of the study, found a subsequent phenomenon of shame as a strong affect among the parallel lived experiences of attending residential school in Canada and boarding school in Finland. Additionally, this was transmitted to both attendees and to future generations. Shame as a strong affect
produces effects of resilience and vulnerabilities in Indigenous lives. Moreover, it is the resistance to the daily teaching of shame experienced in residential school and boarding school that provides a better understanding of what makes Indigenous people resilient. Another important finding was the notion of past is present and how it appears in both instances of vulnerability and resilience. The magnitude of vulnerability was found when using a new feminist materialist post human lens to better understand the synergy of forces in play during experiences in the account of one Sámi woman’s discriminatory experiences in Finnish boarding school. Resilience explored via the Haudenosaunee concept of ‘mothers of the nation’ show how Haudenosaunee women who experienced the intergenerational effects of Indian residential school are maintaining their role as mothers of the nation in the wake of Indian residential school legacies. This concept encompasses both individual and collective resiliencies.

6.2 Resistance, Self-Determination and Knowledge Production

Resistance of Indigenous peoples in connection to academic research and knowledge production comes in the form of their self-determined action of moving Indigenous research ethics protocols and policy forward. According to Smith (2010) and many other scholars who take the vantage point of colonized people, the term research is inextricably linked to European imperialism and colonialism, as research has been part of colonization, carrying stereotypes of primitivism and using the knowledge, ideas (and I would add lands) of Indigenous peoples as resources. Resistance to this brand of research is best described as a resilience. Resilience moves the project of decolonizing the academy forward as it privileges the right of a people to construct knowledge in accordance with their own self-determined definitions of what is real and valuable. This topic has been on the agendas of Indigenous scholars, politicians and activists in Canada and the Nordic countries since the early 1970s. While the outcomes are different in each country, situating self-determination as the starting point of Indigenous research ethics aims to build an equitable relationship between Indigenous peoples and academic researchers (Paper I). The quest for developing and implementing Indigenous specific ethical guidelines, protocols and policy is connected with the evolving role of research in Indigenous communities in regards to: how knowledge is produced; Indigenous epistemologies; power; decision making; and, self-government. Research is now being conducted for and by Indigenous people, with increasing numbers of Indigenous scholars, using new approaches and methodologies with a
community, participatory-action based focus. When viewed in this way, research has the potential to reawaken Indigenous communities and rebuild and repair damaged relationships between academic researchers and Indigenous communities (Paper I).

6.3 Creating an ethical space through dialogical processes

The central role of ethical guidelines and policy for Indigenous research aims to bridge conceptual worldviews. Indigenous research ethics allow an ethical space between academia’s ‘publish or perish’ paradigm and the Indigenous paradigm of ‘partner or perish’. It is in this space where authentic relationships are built (Paper I). Building authentic relationships increases the capacity to produce ethically valid knowledge. Authentic processes in research are ones that enable researchers to understand the cultures and values of the peoples they study, and enable the people studied to participate actively in the process. This co-learning process is important because it enables the researchers to produce valid knowledge that will be useful to the peoples studied (Bull 2010), similar to the Maori mantra ‘nothing about us, without us’. This process certainly takes more time and can be a source of tension for academics as they strive for their own survival within the ‘publish or perish’ culture of the academy.

Creating an ethical space for Indigenous research via guidelines and policy writing in Canada took form through an interactive approach containing country-wide, multilevel sub-processes which were brought together through collaborative efforts. The dialogical processes included a wide scope of interaction in the process to ensure a greater representation of community needs. The process began in the area of health research, with the aim to promote health through research while at the same time being inclusive of Aboriginal values and traditions. The development of the CIHR guidelines and chapter 9 of the TCPS2 are the result of extensive consultations at the community, regional and national level. As guidelines and policy have been evolving in Canada over a number of years, a key premise is meaningful engagement with community as integral to any research project with Aboriginal peoples.

An Indigenous epistemological starting point for doing research in a good way implies an ethical way of relationship building, and, using methods and methodologies from Indigenous perspectives (Paper I). While this is new to the academy, more space is emerging to accommodate Indigenous episteme into research projects. A cautionary note comes along with guidelines and policy that
they don’t merely function as another administrative task but serve to build relationships with the community and academic researchers as a key component. As such, researchers are required to have a thorough understanding of historical and contemporary colonial relationships specific to the communities they are working with and Indigenous self-determination. Nation-wide policy and guidelines serve as a minimum standard. However, specific community protocols must be additionally known and followed (Paper I).

The situation in the Nordic countries is more complex, despite the dialogical processes occurring to move Sámi research ethics forward in Norway, Sweden and Finland. The most telling feature that restricts the movement toward de-colonial research processes via Indigenous research ethics is directly related to how the nation-states recognize their role in the colonization of Indigenous people (Paper I). In Norway, there have been certain steps taken by the government since the 1980s to relinquish the former assimilation policy, accompanied with a dialogue on the right of the Sámi to their own history (Paper I). However, in Finland and Sweden, these same efforts by their national governments are lagging behind the developments in Norway. Finland did not have a pronounced assimilation policy during times of nation building. However, the Sámi language and cultural ways of being were systematically repressed during this time period. Regardless of a pronounced assimilation policy or nation building practices, the outcomes of these colonial processes were relatively similar as experiences in the everyday lives of the Sámi across the Nordic countries (Paper I). Recognizing the colonial burden is the starting point to developing the concerted efforts to overcome it, and Norway, Sweden and Finland are at different phases in this effort. This makes the coordination of Sámi research ethics at the Nordic level a more complex task (Paper I). The contextual challenges are amplified when attempting to coordinate a variety of actors across the territory of Sápmi with four nation-states: Norway, Sweden, Finland and Russia. As such, negotiations are needed with four national research councils, research ethical regimes, numerous Sámi and non-Sámi research institutes and four Sámi self-government institutions -- all framed within different minority policies, colonial histories, divergent decolonization processes, and resources and capacities provided by the national authorities for Sámi research. Taking all of these factors into consideration provides more insight as to why the development of Nordic level Sámi research ethics continues to be a challenging endeavor (Paper I).

A comparative approach between Canada and the Nordic countries is a helpful undertaking to reflect on the best practices of the dialogical processes for
Indigenous research ethical guidelines and policies that would be valid for moving the project forward in the Nordic countries. However, this is not a one-size fits all approach, nor should it be. It requires a dialogue about what is most appropriate for the Sámi community within an inclusive, consultative process. Paper I, details the best practices from the Canadian context for building authentic research relationships with Indigenous peoples via research protocols, guidelines and policies that could be applicable for advancing the developments in the Nordic context for Sámi research including:

1. If Indigenous research guideline and policies are to serve as tools of decolonizing the academy, then they must include Indigenous epistemological starting points. Therefore, Sámi ethical guidelines would include their own epistemological starting points, along with continued discussion about authentic research relationships and definitions of Sámi community.

2. Build on existing knowledge generated by Sámi scholars, communities, NGOs in regards to traditional (ecological) knowledge, the collection and coding of Sámi cultural values, philosophies and worldviews, which constitute the epistemological basis of Sámi knowledge (Porsanger & Guttorm 2011, Markkula & Helander-Renvall 2014). There is a need to extend this work to other fields and to make visible the inherent ethical praxis and knowledge that has been developed in Sámi academic institutions.

3. Start the process within a specific area, for example, health research with Indigenous communities, then later converge with others into shared principles.

4. Practical research projects as an avenue to include Indigenous guidelines. In Canada, a First Nations and Inuit designed and managed research project (RHS) produced comprehensive ethical guidelines that would guide the longitudinal study. Correspondingly in Finland, negotiations between the National Institute of Health and Welfare (THL) and Sámi actors are discussing a Sámi Regional Health Survey to be initiated in the future. This would be an ideal research project to include Sámi research guidelines.

5. Once guidelines are developed: Funding Agencies are an important actor for the implementation guidelines. In Canada, the Agencies (CIHR, NSERC; SSHRC) require adherence to the TCPS2 Policy Chapter 9: Research involving First Nations, Métis and Inuit peoples of Canada, for funding of research projects which are working with Indigenous communities. In similar fashion, once Sámi guidelines are developed, all national level funding bodies in the Nordic countries: Forskningsrådet in Norway, Vetenskapsrådet in Sweden and
the Academy of Finland could adopt a research funding regulation and practice. Research plans should be required to detail how they will adhere to the Sámi guidelines within their project through all phases -- from development of research plans to dissemination of results.

6. When the TCPS2 policy was under development, it was widely distributed for comment from Aboriginal NGOs, and communities. This is an important step to ensure the guidelines undergo an inclusive review process. Currently within the Nordic dialogue, the community level involvement has been absent. Therefore, it is an important step to ensure the inclusion of the Sámi community when developing guidelines.

7. Some Indigenous communities in Canada have their own ethical guidelines in addition to the TCPS2 policy. Community level protocols always take precedence, in addition to National guidelines and policy, once developed. This could also be useful in the Nordic countries if there are community specific protocols.

8. Alike the Institute of Aboriginal Peoples Health in Canada, it would be an important step for Finland to establish a Sámi Health Research Institute, similar to the existing Sámi Health Research Centre in Norway. These research institutes are valuable arenas for the implementation of Sámi research guidelines and for Sami research that reflects Sami epistemologies and research methods and serves to answer the most relevant issues to the Sámi community.

9. Similar to the process for policy development in Canada, Sámi ethical guidelines, once developed, have the potential to initiate Sámi research policy making in Finland--by reflecting the Pan-Sámi interest, but at the national research policy level.

Ethical guidelines and policy for Indigenous research are a minimum standard to provide guidance to researchers when they are working with Indigenous communities. The guidelines and policies are not created as an administrative ‘to do’ list. When embedded in Indigenous epistemologies, ethical guidelines and policies serve to build authentic relationships between academic researchers and Indigenous communities, produce ethically valid knowledge and repair damaged relationships from previous colonial research – damage which still lingers in the collective memory of Indigenous peoples.
6.4 Lived experiences of Shame – individual and intergenerational impact

Although First Nations and Sámi were subject to different education policies and practices, both endured learning in an institutionalized environment which ingrained into their young minds that their Indigenous culture, identity and language are at a value of ‘less than’ as compared to the majority population. This overt example of racism at the structural level resulted in a subsequent phenomenon of experiencing shame as a strong affect. Probyn (2010) describes shame within affect theory, as a strong affect, which has the ability to get into our bodies, altering our understanding of ourselves and our relation to the past (p. 86). Similar experiences received in residential school and boarding school had a much broader reach, as detailed in results of Papers II, III and IV, whereby shame altered understandings of self and relationship to the past, and also within families, communities, nations and with non-Indigenous neighbours. This far reaching impact was discussed within the context of how Indigenous communities are intertwined, and as a result, the abuses learned in residential and boarding school made their way back to the community. There was a strong emphasis on how the punishment received for speaking their Indigenous language brought shame to attendees of residential school and boarding school (Paper II). Narrative responses of attendees iterated how they were degraded in the schools, by being treated as though they were dirty or rotten, or experiencing name calling and labelled ‘dirty’ and ‘rotten’. This affected self-esteem by engraining feelings of shame into their mind, body and spirit. In the context of Canada, name calling took a different form and students were assigned a number and not ever called upon by their own name. This Othering, all in the name of nation building, for both Canada and Finland was planted into the minds of children as young as 6 years old. This was the absolute worst possible start any child could have on their life path. Furthermore, this shame had staying power and was transmitted to subsequent generations.

During the interviews with Haudenosaunee participants, those who had a parent attend residential school reflected on how shame was transmitted intergenerationally. Home life was described as ‘chaotic’ when various life experiences reinforced the notion to be ashamed of Indigenous identity. Conflicting notions of identity and belonging were described by a participant:

‘Once my parents ended up taking me out of the schools here (on reserve) because they didn’t want me to learn all the traditional teachings and sent me
an hour away to go to another school. It was just chaotic. So I really did grow up feeling that to be native was to be very, it was a less-than, an embarrassing, and inferior culture’ (Haudenosaunee respondent, Paper II).

The firsthand experiences in residential school and boarding school was a pathway to becoming - a different person, no longer fitting in the community - not a kid anymore. The burden of shame of not speaking Indigenous language or knowing Haudenosaunee ceremonies combined with the feeling of not being the same person after attending residential school carried a heavy weight that no school aged child should have to endure. A participant summed up the experience as:

‘If I have to take a view, I was never the same person afterwards: emotionally, mentally. There was something different about me after that. I didn’t feel like the same kid. I wasn’t a kid’ (Haudenosaunee respondent, Paper II).

Additionally, Sámi respondents spoke of the shame they felt when losing the language of the traditional livelihoods, and going back to their communities and not knowing their rightful place as a Sámi. (Paper IV). One of the Sámi participants describes the local knowledge lost upon returning to the community after attending boarding school:

‘They laughed when I couldn’t do, as with much skill what everyone else did. I didn’t know all the handicraft what everyone else did. I didn’t know everyone’s ear markings - I couldn’t catch a reindeer with a lasso - these kinds of things that were everyday life’ (Sámi respondent, paper IV).

This type of discrimination received from one’s own community members was further examined using new feminist materialist and posthuman thinking, on how Sámi to Sámi discrimination operates and why it exists. It was found to be a practice that was not a conscious intent to be deliberately mean to someone from your own community, but can be seen as an unconscious affective practice (Walkerdine 2010 p. 112), manifesting as ways for coping with struggles to keep their communities alive in the face of the multiple changes caused by cultural assimilation (Paper IV).

Daily experiences of having shame embedded into your being were the parallel realities of Indigenous children who attended residential school in Canada and boarding school in Finland. The education received within an institutionalized environment was a pathway to being forced to navigate the space of being between two worlds, that of the majority population and of their own communities, often not feeling like they fit totally into either place. It would be expected that
vulnerabilities would arise in the lives of those (and their families, communities and nation) who endured this damaging form of education. However, participant narratives further described how their deep-rooted shame led to life experiences that occurred within the realms of both vulnerabilities and resiliencies.

6.5 Effects of shame: vulnerabilities and resiliencies

The nation building processes in both Canada and Finland excluded Indigenous peoples, and pushed them to the margins of society. Whether it was via a pronounced policy which was mandated ‘to kill the Indian in the child’ or whether it was a practice within education institutions which allowed and encouraged the systematic repression of Sámi identity, language and culture are examples of how structural racism worked via policy and practices which produced both vulnerabilities and resiliencies for Indigenous peoples. While Canada’s policy violently announced and implemented its assimilation goals; Finland did not have a formal assimilation policy. However, its practices within boarding schools produced similar negative effects to Indigenous identity (Paper II). As introduced above, the strong affect, shame, specifically the shaming of Indigenous identity by the majority populations resulted in the negative effects of language and cultural losses, and the fracturing of Indigenous identity (Paper II, III, IV). The narratives by both individuals who attended residential school or boarding school and their families describe the vulnerability of the fracturing of Indigenous identity as feeling between two worlds and had a negative effect of (dis)connectedness with their own identity, their families, communities, and the majority society (Paper II, III, IV). The fracturing of Indigenous identity also has the ripple effect of fracturing Indigenous perspectives of health, or holistic definitions of health that include the physical, mental, emotional and spiritual realms. While conducting her masters research in Canada, one of the participants interviewed 68 community members about holistic viewpoints of health and she found that her interviewees were easily able to talk about health in the physical realm but found that discussing connections to spirit and emotions were absent in the interviews. This finding led to the conclusion that Indigenous peoples are still colonized in the present day (Paper III).

When coping with the trauma of receiving an education in a foreign language, in an institutionalized environment, participants discussed both their vulnerabilities and resiliencies (Paper II, III). Areas of vulnerability included internalizing the attacks to culture, language and identity which produced feelings of low self-worth. Coping with feelings of negative self-worth transformed into anger, stress,
depression and low self-esteem. Receiving an education in a foreign language was coupled with the exclusion of Indigenous education principles. Participants in Canada and Finland openly discussed the learning environment as comparable to a prison or institution. This created learning difficulties that followed attendees into adult life, which had negative impacts on their choice of jobs and income earning potential (Paper II). Some of the coping mechanisms included to deal with these traumatic experiences included: overeating ‘stuffing feelings’, inability to show emotions, using drugs and alcohol as forms of escape, workaholic tendencies, living ‘perfectly ordered’ lives or keeping a very sterile environment (Paper II, III). Vulnerabilities were also found within their relationships with the majority population. Some respondents noted they felt a need to overcompensate, or feeling that one had to prove to the majority society how ‘good’ they were to be accepted (Paper II). This was iterated by participants in Canada and Finland:

‘Even if you did have an education, you had to be ‘extra’ good. You had to be better than someone with the same education. You had to be a little bit better to get them to accept you’ (Haudenosaunee respondent Paper II)

and,

*Still just like when being Sámi you have to stay sharp to be as good as a Finn. Somehow this kind of defensive state and apologetic attitude, it’s probably because they always belittled, pushed down, and so that’s how I’ve had to struggle with myself* (Sámi respondent, Paper II)

Relationships with the majority population was not the only area that made participants vulnerable. It also occurred within their own communities. This was considered worse than an unequal relationship with the majority. Not being accepted by your own community caused distress for participants from Canada and Finland (Paper II). This was reiterated in the Sámi context, when respondents talked about Sámi language loss and lost skills in the traditional livelihoods, which made them feel as though they no longer were a part of the community or accepted by their own people, or felt they were not as ‘good’ a Sámi (Paper II, IV).

Vulnerabilities were discussed as something that is not static. Healing was seen as a dynamic process. Participants talked about the ongoing healing work that is required to overcome traumatic life experiences and how these experiences from the past can re-appear in the present (Paper II, III, IV). To further understand what makes people resilient in the face of adversity, equal attention was given to the narratives of the resiliencies of the populations--both individual resilience and
collective resilience. Resilience is described as acts of resistance to the strong affective charge of shame that resulted from attending residential and boarding schools. Individuals’ capacity for resilience was viewed as a source of power and was a key focus on the stories of resilience by both Haudenosaunee and Sámi respondents’ reflections of their ongoing healing journey.

‘As I was growing up, it was confusing. I had to do a lot of learning, teaching and healing so that I can function in a healthy way, so that I don’t continue doing those things that I was taught to do. And that is an ongoing process, there is always something that comes up. (Haudenosaunee participant Paper II)

and

‘More negative than positive, living in the boarding school has caused a lot of things that I’ve had to later sort of go through, caused traumas that I’ve had to work on later’ (Sámi participant Paper II)

Additionally, the work being done with the community to restore culture and languages was discussed as a collective resilience (Paper II). The work of Kershaw and Harkey (2011) about Aboriginal women as caregivers for Indigenous identity, inspired a closer look at the responses from Haudenosaunee women through the lens of the Haudenosaunee concept of mothers of the nation. From the narratives of Haudenosaunee women from Six Nations of the Grand River who had a member of their family attend an Indian residential school, resilience was a recurring theme, especially within the discussions around cultural and language renewal. Manifestations of resilience were talked about as a vital feature of a self-determined identity that retells the fact: ‘despite all the harms done to us….we are still here’. This is a key finding of how Haudenosaunee women continue their role in the present day as mothers of the nation in the wake of residential school legacies (Paper III).

The women in the study elaborated on their self-reflection as a multifaceted process. Their healing embodied historical knowledge of their community; and required empathy and an inner motivation to move forward; and the realization that healing is an ongoing process (Paper III). Generational healing was noted by women who had stopped the cycle of abuse within the parenting of their own children and who were now observing interactions between their children and grandparents (who attended residential school). They were helping grandparents to express emotions. Some of the women made career choices based on their own personal healing journey or were drawn to professions that have a wider impact to
health and well-being of the community (Paper III). The narratives revealed how solutions to vulnerabilities come from the community. Indigenous peoples know their communities best and described their belief in re-building Indigenous identity needs to start at birth, as reflected by a participant:

‘the line of work that I am in, I’m around babies…if we can change the way that our attitude is towards our people–it should begin right at birth’ (Haudenosaunee participant, paper III),

Indigenous language was at the core of re-building communities and Indigenous identities. However, there are challenges to overcome, such as lack of funding within the community to support language activities and proximity to the community to participate in language initiatives. Women who are raising their children using their language (Mohawk) and writing curriculum for language activities within the community, are champions of this issue. Language and cultural renewal was discussed as both an individual and community empowerment: a collective resilience. This is a key finding of how Haudenosaunee women continue their role in the present day as mothers of the nation in the wake of residential school legacies by ensuring both individual and collective resilience (Paper III).

There were parallel experiences of Haudenosaunee and Sámi in discussions about collective resilience. In light of more open discussions in Finland about boarding school attendance, the impacts to health and wellbeing was recognized. It was noted that future work needs to be done to support survivors of boarding schools in their healing process. This recognition and understanding of the need to have supports in place for former attendees of boarding school is described by a Sámi participant:

Now that we talk about the boarding school times and this when the children have been subjected to all kinds of actions there, and the church talks about apologizing, that people dare to think how bad the situation has been. There would be a lot to do- Actually there would be concrete things to do, need of support, chances to talk about things (Sámi participant Paper II)

To gain a better understanding of discrimination, case study IV aimed to shift attention away from the human actor to a wider field of power relations. Discrimination was defined as force relations, emerging dynamically through assemblages of, for example, material, corporeal, historical, organic, discursive and affective elements in and beyond Finnish boarding school.
Previous studies have examined name calling as one of the prevalent discursive means for controlling and violating the Sámi (Rasmus 2008, Puuronen 2011). Particularly, name calling has been examined as a form of ethnic controlling in regards to the majority population citizenship. Although words and phrases are important indicators in discriminatory practices, the discrimination experienced by the young Sámi in boarding schools is not only occurring within common speech (Paper IV) The product of the several human and non-human forces behind discriminatory experiences in Finnish boarding schools, as described in this vignette from Paper IV:

"If it was always when being there, you were dirty, you were like this, always the rotten. It was like this regular expression, a rotten Lappish [mätöläppalainen], it was always like rotten [mätö, mädän tynyt], it was a thing that has affected my self-esteem a terrible amount. It's in a way mentally affected, surely affects to this day and it affects a lot for sure... Especially mocking the clothes was one of these that they bullied and mocked, that I experienced as being really hard. And that I was always considered lower, a rotten Lapp that you were like a rotted person... I remember for my childhood how then I always used to decide that never, if I someday have children, they don't have to experience that ever nor that they have to be ashamed of their clothing. Because with us our mother sewed all the clothing, also the underwear that were mocked horribly. We bought this kind of flannel fabric. There just weren't any clothes to buy. (Aletta, Paper IV)

The expression of rotten [“mätö”], used in the parochial language of North-Finnish dialect of particular localities, carries a particular mixture of connotations of addled organic material, laziness and rural poverty. Here we can see how the rotten materiality as connected with clothes on the Sámi person’s “dirty” and lazy body intra-act with discourses of proper modern young Finnish citizenship. Non-normative, traditional Sámi citizenship is materialized here by the intra-actions of materiality (clothes), the discursive (the rotten as something repulsive and contaminating), the time (untreated material that in a matter of days or weeks results becoming poisonous and spoil), socio-economic status (poverty) and the space (rural north). The word "mätö" [rotten] carries a materiality itself as addledness, and the clothes are not simply representational here but material objects discursively made rotten by the Finns and thus contaminant, and symbolically connected to the body of the Sámi person living a poor life in the wilderness, which afford the discrimination greater affective and immediate force (Paper IV).
Through posthuman material-discursive the name calling comes to matter through a long history of material-discursive intra-actions of multiple dynamical forces. “Rotten Lapp” can be seen as a racialized assemblage entangled with space, time, class and matter through which an embodied addled, remote, poor, relic of the past – the Sámi abject – is formed. The argument is that the discrimination young Sámi people faced in boarding schools is not simply located in the past or in the human, nor is it to be located between the discourse (the Sámi as the Other) and the stigmatized subject (“rotten Lapp”). Rather than being a backdrop against how events occur, this excerpt shows how history is an inherent force of a normal young citizen. Entangled with the discourse, the name calling materializes through history (traditional life styles vs. modern) and organic and inorganic material objects which work together to produce of what has been called a “rotten Lapp” (Paper IV). This type of analysis brings to the fore powerful insights into the magnitude of these discriminatory experiences, not only situated in the past, but their ability to reappear in the present. Discrimination described here is not solely located within the individual subjects, but emerges in configurations of force relations as material-discursive flows of forces, that include entanglements of discourses, places, materialities and embodied practices, attacking a person’s identity, body, capabilities and desires to belong and be recognized as competent and legitimate members of communities (Paper IV).
7 Discussion

7.1 Reconciliation, recognition and de-colonial processes

Reconciliation takes form within Indigenous specific research ethics, which have been created to repair damaged relationships between academic researchers and Indigenous communities. Recognition through (critical) research is self-determination. The acts of self-determination in Indigenous communities in both Canada and Finland have produced an ongoing dialogue about the need for Indigenous perspectives within academic work. This does not mean throwing out all Western research methodologies, but to posit Indigenous epistemology as an equal research framework (see Smith and Simpson 2014). Within this framework is the main tenet of giving back to the community where the research has taken place (Wilson 2008, Kovach 2009, Kuokkanen 2007). The situation in Canada has produced various ethical guidelines for academic research and a national level policy. However, this is not the case in Finland for Sámi research. The aim of this study is not to merely compare the situations in each country, but to conduct a critical analysis of how the national level policy in Canada and guidelines operate in practice (see Stiegman & Castleden 2015). There is always a need for re-negotiating terms of policy. Therefore, the documents in Canada have been created as living documents to include necessary changes over time and to keep the dialogue between academic researcher and communities active.

In the Nordic countries, according to Ledman (2015), members of the majority society still have substantial homework to do in regards to identifying and embracing their own lack of knowledge, and in discovering how they are also part of and responsible for the reproduction of discriminatory and colonial structures within academia (p. 160). Indigenous knowledge opens up the door to producing ethically valid knowledge. Kristen Stoor articulates Sámi stories as knowledge: ‘The oral tradition originates from the perspective of the insider, and it provides a different view than that available to the outsider’. Stoor (2015) further elaborates how stories within the oral tradition are situated within the context of values, supporting the narrative situation, narrative environment and narrative function (p. 64). Knowledge about Indigenous peoples produced in this way provides robust insight while paying attention to ethical validity that situated knowledges engender. Furthermore, when taking into consideration the colonial situation in the Nordic countries: ‘when stronger forces came to our land and overpowered us and we had
to fight back with our words and wisdom, using nature as our friend. What we have is our songs and stories and as long as we have these we are still a nation. Our history is oral. Oral history is our life’ (Stoor 2015 p. 67–68).

In addition to producing ethically valid knowledge, Indigenous perspectives are greatly needed for efforts to find solutions to inequity. For example, the TRC calls to action are solutions from an Indigenous perspective on how to repair the vulnerabilities created by settler acts of cultural genocide. I view the truth and reconciliation recommendations, when fully implemented, as the self-determined effort of Indigenous people in Canada to create an ethical space, by repairing and restoring the damaged relationship, between Indigenous peoples of Canada and Canadians, back to good health. In Dr. Ryan Meili’s book ‘A Healthy Society,’ the author states how a focus on health can revive a Canadian democracy:

‘The answer to the problems faced by these (First Nations) communities is in the communities themselves, in their strengths, their traditions and their ideas and innovations. Taking this approach means going beyond narrow interpretations of the duty to consult to real partnerships. The only way to work toward a better future for Aboriginal people in Canada is to work alongside them (p. 108, 109).

However, despite Indigenous and allied efforts for reconciliation, true reconciliation lies within the actions of the settler state. As Simpson & Smith ascertains ‘because the settler state remains in full force, it has the ability to retract whatever limited forms of recognition it grants and never actually has to question itself or even consider its own history very deeply.’ (2014 p. 11). We see examples of this in the Canadian context when just one year after the national apology to residential school survivors, our then Prime Minister, Stephen Harper stated at a G20 summit that Canada has ‘no history of colonization’ (Shrubb 2010). And our current Prime Minister, Justin Trudeau, has promised to implement all the recommendations of the Truth and Reconciliation Commission, while to date less than half of the recommendations have been implemented. Justice Sinclair, former Truth and Reconciliation Commission Chair says the federal government’s actions don’t match promises and further notes ‘there hasn’t been a lot of progress on the federal end of things, for example, there is no covenant on reconciliation to identify principles for advancing reconciliation; there are few strategies for advancing the United Nations Declaration on the Rights of Indigenous Peoples, and, there is no national council for reconciliation that would monitor progress (Galloway 2017). The goal of investigating parallel experiences of the situation in Canada and
Finland is not to elaborate on how far ‘ahead’ Canada is on Indigenous issues. It has completed activities such as: the national apology to residential school survivors, and a Truth and Reconciliation commission which arose out of a large class action suit. However, I question the legitimacy of these initial powerful acts of recognition which can later be dishonoured. The national apology and the TRC are certainly examples of best practices (at the moment they are recognized by the government). Although, the true measure of these best practices is in how they are upheld via action. The dialogue in Finland on the necessity for an apology to boarding school survivors has been met with a response of ‘there is no need for an apology’ by national authorities. As such, the situation is currently an ‘inaction’ whereby the nation-state hold the power, and are able to ignore the human rights injustices experienced by the Sámi throughout history and in contemporary contexts. When we critically examine the nation-state/Indigenous relationship in both countries, they are in similar situations whereby it is the nation-state who commands the power to recognize, retract or remain inactive in regards to human rights and political injustice.

### 7.2 Social Determinants of Indigenous Health

Relationships between Aboriginal and non-Aboriginal Canadians have been fraught with inequity in a historical and contemporary context. As outlined in the RCAP 1996, there was an emphasis on creating a new relationship between Aboriginal and non-Aboriginal peoples in Canada, highlighting the importance of a better understanding of the past. Furthermore, if the relationship is to be transformed and move forward in a different direction, then the authority of Aboriginal peoples to chart their own futures within the Canadian federations must be recognized (RCAP 1996 Vol 3 Ch 1:7). The final report from the WHO commission for the Social Determinants of Health (CDSH 2008) concluded that poor Indigenous health results from the effects of a toxic combination of policies (p. 36). These policies, even if they vary across time and cultures, are one of the results of the ongoing process of colonialism (Axelsson 2015). However, the Indigenous peoples of the Nordic countries are in a more unique situation as compared to Indigenous peoples worldwide. Paradis (2016) has alluded to what he calls the ‘Nordic paradox’ by stating: ‘what do we make of the Nordic paradox where Indigenous peoples report similar health status as the majority population? Does this mean, as he asserts, that perhaps ‘colonization has brought Indigenous peoples in the Nordic countries to good health’? These are dangerous neo-colonial
assumptions. If the questions Paradis asks are to be further explored, then they must include Sámi perspectives from the Nordic countries. These questions cannot be fully answered using biomedical markers to health and wellbeing alone, they require an inclusion of the social determinants of Indigenous health, specifically interconnections of structural racism, colonialism and discrimination. Notably similar experiences of First Nations in Canada and Sámi in Finland occurred within the confines of residential school and boarding school which provided and environment that allowed conditions of colonialism, structural racism and discrimination to interconnect. This produced the strong effect of shame, which results in both vulnerabilities and resiliencies of the affected individuals and their families. These effects did not end with one generation and healing among the vulnerable and resilient is an ongoing journey. Furthermore, Justice Sinclair indicated in the TRC (2015) that the wounds inflicted from the Indian Residential Schools are not only specific to the Aboriginal population, but rather that the whole of the Canadian population has suffered as a result of the shameful Indian policy from which the Indian Residential schools were created. At the national level, Canada has suffered the tragic break down of relationships between Aboriginal and non-Aboriginal Canadians fuelled mainly by the persistence of racism and other forms of discrimination toward Aboriginal people (Richmond & Cook 2016). In the case of Finland, a discriminatory policy was not blatantly visible. However, it was embodied via similar discriminatory practices wherein Sámi children were subject to parallel experiences of those attending residential school in Canada.

7.3 Parallel experiences and mutual outcomes in Canada and Finland

When examining residential school and boarding school experiences, the main findings of this study, reflected the daily teaching of shame received in these education environments. Reports of: ‘you were dirty’, ‘you were rotten’, ‘when I was there everyone had a number’, ‘I grew up feeling less than’, ‘embarrassing, inferior culture’ were common. These lived experiences exemplify the non-human status Indigenous peoples were given during the time of residential school and boarding school in Canada and Finland. In present day public health discourse, there are a plethora of programs which emphasize childhood ‘best start’ programs based on love, care, proper nutrition, and connectedness. We know a healthy start in early life increases the chances of a healthy adult life. However, Indigenous children attending residential school in Canada and boarding school in Finland had
a regime of a ‘worst possible start’ education program which instilled a deep rooted shame of their Indigenous identity.

After this worst possible start, is it a surprise that individuals subject to teachings of shame would become vulnerable? Ahmed, Mohammed and Williams (2007) describe ways in which discrimination may adversely affect the health of individuals: by creating ethnic divisions in socioeconomic status; and, whereby members of ethnic minorities internalize the majority population’s discriminatory ideologies. Research about perceived discrimination among the Sámi in Norway shows how loss of language, ethnic identity or confusion about the ethnic identity (being between two worlds) is a consequence of the colonial history and may have associations with health outcomes (Bals, Turi, Skre & Kvernmo 2010). Furthermore, the SAMINOR study, a quantitative, population-based study of health and living conditions in areas with mixed Sámi, Kven and Norwegian population, found ethnic discrimination to be an important variable related to health inequalities as measured by poor self-reported health (Hansen, Melhus & Lund 2010). In Sweden, a report on Sámi instances of discrimination cited the importance of relating individual and structural discrimination to each other, as well as to history and the distribution of power in society (Pikkarianen & Brodin 2008).

The systematic repression of Sámi language and culture alienated Sámi people from their own cultural background which results in long-term detrimental health consequences (Hassler, Kvernmo & Kozlov 2008). Indigenous identity and communal belonging are important issues that affect the social, cultural, and physical health and well-being of individuals and communities (Palmater 2011). Furthermore, structural level racism maintains an exceptional amount of power through mechanisms that lead to the denial of human and political rights (Puuronen 2011). In essence, this makes Indigenous peoples invisible or subhuman and denies one of a self-determined identity. This kind of action at the state level then ripples out to the citizens of the nation.

Despite all this, we also know that resistance to racist ideologies produces a resilience among Indigenous groups. On Indspire’s Annual Aboriginal Achievement Award show (2016), Lifetime Achievement award recipient, Chief Robert Joseph (Gwawaenuk, First Nation, British Columbia, Canada), offered a telling definition of resilience. As a former attendee of an Indian residential school, he was taken from his family home at 6 years of age and lived in an Indian residential school until the age of 16. He stated ‘the secret of resilience is love: love for yourself, for your people and for humankind’. Arriving at this point in one’s healing journey is no small undertaking. In her research on the intergerational
impacts of residential school on mothering, Ing (2006), expressed that ‘coming to terms with one’s identity is a long process if denial was the norm. It affects individuals in different ways but it is still devastating until you can begin to replace the shame and guilt with facts’ (p. 122).

Stout and Peters (2011) research on the intergenerational effects of residential school on professional women exposes the myth that the effect of the residential school system begins and ends with the survivors. They further iterate ‘where this myth is found, it needs to be roundly refuted with the knowledge of those who continue to live the residential school legacy and embody the resiliency of multiple generations (p. 73). Resistance for Indigenous women is a multi-layered process. According to Makokis (2008), an Indigenous woman must first deal with the historical impacts that colonialism has imposed on her people/community, closely followed by sexism. Then she must deal with every other layer of oppression that a group of oppressed, colonized people endures. I would identify this as the starting point to understanding determinants of Indigenous health. In Canada, Indigenous women carry a disproportionate burden of ill-health and disease including higher rates of hypertension, heart disease, diabetes, gallbladder cancer, HIV/AIDS, substance abuse, mental illness and suicide (Paper III). Other research has discussed colonization and ongoing colonial practices as root causes of many Aboriginal women’s mental health issues (Allan & Smylie 2015, Bourassa et al. 2005, Cannon & Sunseri 2011, Dion-Stout et al. 2001, Yellow Horse Brave Heart 1999). However, First Nations women from within ‘at risk’ populations tend to be the focus of studies on intergenerational effects of residential school attendance. This overlooks the experiences of resilient women. (Paper III). Resilience from Indigenous perspectives has been examined by Kirmayer et al. (2011) and their research found diverse notions of resilience among Aboriginal peoples in Canada, which include: culturally distinctive concepts of the person that connect people to community and the environment; the importance of a collective history; the richness of Aboriginal languages and traditions, as well as, individual and collective agency and activism. Employing indigenous concepts of resilience, such as that of the Haudenosaunee mothers of the nation, allows for a broader understanding of what makes people who have experienced traumatic experiences, resilient. Without the knowledge of Indigenous concepts and worldviews, important information would not be captured.

Answering research questions about the Sámi experience within the Nordic countries, which boast more equitable societies, can benefit from new and novel analysis as found in case study IV, by utilizing new feminist materialist and
posthuman thinking to encompass all the forces that combine with colonialism and structural racism to give discriminatory events powerful affective charges. The findings of Paper IV shifts attention away from the individualized account to a wider field of power relations. This is a useful methodology for investigating how past is present, especially since national authorities in Finland do not consider to have played a role in harsh assimilation policies targeted at the Sámi, as compared to neighbouring Sweden or Norway.

7.4 Summary of strengths and limitations of the study

The study contributes to new knowledge about the timelines of the dialogue for developing Indigenous research ethics in the Nordic countries in Paper I. Additionally, in Finland the discourse on Sámi experiences within Finnish boarding schools are mentioned in a few academic theses and this study adds to the growing body of knowledge with the aim to make visible the need for acknowledging the past while at the same time moving forward towards reconciliation. The new feminist materialist and posthuman analysis in paper IV provides a new way to analyse data regarding the present day vulnerability created by discriminatory experiences within Finnish boarding schools. This is specifically important in the Nordic context. This type of analysis shows the depth of experiences of discrimination and all the force relations (including structural racism and colonialism) that impact Sámi lives. Also, having a native Finnish speaking co-author, as the lead author of paper IV, review the audio recordings and transcribed data that was collected in Finnish ensured a rich analysis and paid special attention to details that may have otherwise been ‘lost in translation’. It was also important to have Paper IV reviewed by two Sámi scholars. In both countries, good working relationships between members of the research group and the communities of Six Nations of the Grand River and Inari municipality ensured all aspects of the original data collection occurred in a timely manner. Having a co-author from Six Nations and with researchers who had long standing relationships with the community in Inari municipality was a strength for data analysis in Paper II. It was necessary to have the co-authors from Finland and their insights highlighted the need to have a deeper understanding of Sámi epistemology when looking at the data from Finland. Other limitations of the study included sample size, a language barrier in Finland and the data collection tool. The sample had more participants from Canada who had family members attend an Indian residential school. In Finland, most of the participants had first-hand experience in boarding school in addition to having
family members attend. The language barrier had several impacts, not just on the data collection or materials translation but also on the background research on Sámi issues. The working languages are North Sámi, Norwegian, Swedish and Finnish. Working with co-authors who are fluent in these languages was helpful to the research process. However, it is important to note that researchers who wish to work on Sámi issues need collaborators who are fluent in the languages of the technical reports and research papers, to be able to actively participate in Sámi conferences and dialogue (which are in Sámi language or one of the Nordic languages). It then becomes imperative for the researcher to be fluent in two or more of the languages. I did not have the language skills that would have allowed for more in-depth participation in dialogues and understanding gained from additional research materials.

7.5 Concluding remarks and implications for further research

In 2017, both Canada and Finland are celebrating milestone years in their history (150 years and 100 years, respectively). In the Canadian context, a celebrated musician, Gord Downie, has been an active ally for Indigenous issues, surrounding residential school and reconciliation. In light of his diagnosis of terminal brain cancer, at a final performance in Kingston, Ontario with his band the Tragically Hip, he stated ‘Canada should not be celebrating 150 years, but what we should be celebrating is the next 150 years ahead’. I agree and envision a Canada that can impact the annals of history when Indigenous peoples have their rightful place as co-creators of the country that has been built on their homelands. In tandem, it will also be interesting to watch the relationship between the Sámi and the Nordic nation-states as the issue of Sámi experiences within Finnish boarding schools will be further brought to the fore through the doctoral research of Sámi scholar, Minna Rasmus. Sámi political representatives continue to press for past injustices to be addressed and for recognition of an enduring colonial present (Drugge 2016). In neighbouring Sweden, the establishment of a truth and reconciliation commission has been proposed as one way forward, an issue originally raised by Sámi youth organization, Sáminuorra (Drugge 2016).

In June 2015, the TRC released its Executive Summary, which included 94 recommendations, or ‘Calls to Action,’ directed to governments, churches, organizations and all Canadians (see: TRC 2015). Important questions to ask in

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5 for more information see: https://www.downiewenjack.ca/
further studies include: How do we repair the vulnerabilities created by settler acts of cultural genocide? How can the Canadian experience of the process of reconciliation assist other nation states who are also recognizing through research the colonial impacts on health and well-being of Indigenous peoples? What are the steps needed to move beyond recognition, and apologies to action when the nation state itself struggles with the notion of colonization? Critical studies of parallel experiences of Indigenous peoples and their historical and contemporary relationships to nation-states are a pathway to further insight. The overall aim would not be mere comparison, especially when the respective situations have divergent contexts, but to build an account of parallel experiences and mutual challenges. Through this format, a critical examination of each country’s colonial processes and de-colonial movements may occur and best practices can be shared and re-designed, taking into consideration appropriate Indigenous epistemology.
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Appendices

Appendix A: Statement of Apology – to former students of Indian Residential Schools in Canada
Appendix B: English Interview Questions
Appendix C: Finnish Survey Questions
Appendix D: Truth and Reconciliation Calls to Action for Education
Appendix E: Two Row Wampum Renewal Campaign
Appendix A: Statement of Apology – to former students of Indian Residential Schools

The treatment of children in Indian Residential Schools is a sad chapter in our history. For more than a century, Indian Residential Schools separated over 150,000 Aboriginal children from their families and communities. In the 1870's, the federal government, partly in order to meet its obligation to educate Aboriginal children, began to play a role in the development and administration of these schools. Two primary objectives of the Residential Schools system were to remove and isolate children from the influence of their homes, families, traditions and cultures, and to assimilate them into the dominant culture. These objectives were based on the assumption Aboriginal cultures and spiritual beliefs were inferior and unequal. Indeed, some sought, as it was infamously said, "to kill the Indian in the child". Today, we recognize that this policy of assimilation was wrong, has caused great harm, and has no place in our country.

One hundred and thirty-two federally-supported schools were located in every province and territory, except Newfoundland, New Brunswick and Prince Edward Island. Most schools were operated as "joint ventures" with Anglican, Catholic, Presbyterian or United Churches. The Government of Canada built an educational system in which very young children were often forcibly removed from their homes, often taken far from their communities. Many were inadequately fed, clothed and housed. All were deprived of the care and nurturing of their parents, grandparents and communities. First Nations, Inuit and Métis languages and cultural practices were prohibited in these schools. Tragically, some of these children died while attending residential schools and others never returned home.

The government now recognizes that the consequences of the Indian Residential Schools policy were profoundly negative and that this policy has had a lasting and damaging impact on Aboriginal culture, heritage and language. While some former students have spoken positively about their experiences at residential schools, these stories are far overshadowed by tragic accounts of the emotional, physical and sexual abuse and neglect of helpless children, and their separation from powerless families and communities.

The legacy of Indian Residential Schools has contributed to social problems that continue to exist in many communities today. It has taken extraordinary courage for the thousands of survivors that have come forward to speak publicly about the abuse they suffered. It is a testament to their resilience as individuals and to the strength of their cultures. Regrettably, many former students are not with us
today and died never having received a full apology from the Government of Canada. The government recognizes that the absence of an apology has been an impediment to healing and reconciliation. Therefore, on behalf of the Government of Canada and all Canadians, I stand before you, in this Chamber so central to our life as a country, to apologize to Aboriginal peoples for Canada’s role in the Indian Residential Schools system. To the approximately 80,000 living former students, and all family members and communities, the Government of Canada now recognizes that it was wrong to forcibly remove children from their homes and we apologize for having done this. We now recognize that it was wrong to separate children from rich and vibrant cultures and traditions that it created a void in many lives and communities, and we apologize for having done this. We now recognize that, in separating children from their families, we undermined the ability of many to adequately parent their own children and sowed the seeds for generations to follow, and we apologize for having done this. We now recognize that, far too often, these institutions gave rise to abuse or neglect and were inadequately controlled, and we apologize for failing to protect you. Not only did you suffer these abuses as children, but as you became parents, you were powerless to protect your own children from suffering the same experience, and for this we are sorry. The burden of this experience has been on your shoulders for far too long. The burden is properly ours as a Government, and as a country. There is no place in Canada for the attitudes that inspired the Indian Residential Schools system to ever prevail again. You have been working on recovering from this experience for a long time and in a very real sense, we are now joining you on this journey. The Government of Canada sincerely apologizes and asks the forgiveness of the Aboriginal peoples of this country for failing them so profoundly.

In moving towards healing, reconciliation and resolution of the sad legacy of Indian Residential Schools, implementation of the Indian Residential Schools Settlement Agreement began on September 19, 2007. Years of work by survivors, communities, and Aboriginal organizations culminated in an agreement that gives us a new beginning and an opportunity to move forward together in partnership. A cornerstone of the Settlement Agreement is the Indian Residential Schools Truth and Reconciliation Commission. This Commission presents a unique opportunity to educate all Canadians on the Indian Residential Schools system. It will be a positive step in forging a new relationship between Aboriginal peoples and other Canadians, a relationship based on the knowledge of our shared history, a respect for each other and a desire to move forward together with a renewed understanding
that strong families, strong communities and vibrant cultures and traditions will contribute to a stronger Canada for all of us.

June 11, 2008
On behalf of the Government of Canada
The Right Honourable Stephen Harper,
Prime Minister of Canada
Appendix B: English Interview Questions

Title of Research Project:

"The legacy of colonization and its impact on Indigenous Health: a comparative case study of Sami in Finland and First Nations in Ontario, Canada."

Purpose of the Research

The purpose of the study is as follows:

1. To investigate the research question: What is the impact of colonization on the health of Indigenous people in Finland (Sámi) and Canada (First Nations).
2. To compare the impact of colonization on health experienced in these two populations.
3. Also to look at the impact of racism on health as Indigenous people access mainstream healthcare services.

Description of the Research

The study will explore the legacy of colonization and its impact on the health of Indigenous people; in particular, comparing two populations: the Sami in Finland and First Nations in Ontario, Canada. Availability of healthcare services for the Sámi and First Nations are typically mainstream health services, therefore another area to be explored within this study is the issue of racism experienced while accessing mainstream services and its subsequent impact on health. Both populations: the Sámi of Finland and First Nations in Canada have experienced the negative effects of colonization, while in different ways and to varying degrees, this study does not strive to compare the severity of colonization experienced between the two populations, but rather to provide a snapshot of its consequences on the health of Indigenous people in Finland and Canada. Data will be collected in two rural sites and will include age groups across the adult (over 18 years old) lifespan. Research sites included in this study are: Inari, Finland and Six Nations Indian Reserve, Canada.

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6 This was the working title of the study at the time of data collection.
Section 1: A. Sociodemographics

1. What is your gender?
   Male
   Female

2. In what year were you born?

3. How do you self-identify?
   Are you First Nations?
   Yes
   No (end interview)

   a) What is your reserve or band affiliation?

   b) What is your Nation?

4. What language do you speak most often at home?
   (please specify)

B: Housing and mobility

5. Where do you live now? (please specify)
   On-reserve
   Off-reserve

6. During your childhood years, where did you live? (please specify)
   On-reserve
   Off-reserve
7. When thinking about your living experiences. Do you think they have had an impact on your health?
   YES
   NO
   Don’t know
   No response

8. If answered yes to question 7, please explain why?

Section 2: Health Care Services

9. Have you ever been treated unfairly (e.g. treated differently, kept waiting) by a health professional (doctor, nurse, dentist, etc) because you are First Nations?
   Yes
   No (skip to question 12)
   Don’t know (skip to question 12)
   No response (skip to question 12)

10. How long ago did this happen?
    Within the past 12 months
    Longer than a year ago
    Don’t know
    No response

11. Has this stopped or delayed you from returning to a health service?
    YES
    NO
    Don’t know
    No response
12. Do you have any additional thoughts/comments about the health care services you have accessed in the present or past?

Section 3: Impacts of colonization

The following section may have questions that may cause mild distress. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at any time.

A. Residential School

13. Were you ever a student at a federal residential school, or federal industrial school? (federal industrial schools were schools for young men that mostly operated in the prairie provinces and the United States)
   - Yes
   - No (skip to question 18)
   - Don’t know (skip to question 18)
   - No response (skip to question 18)

14. At what age did you go there?

15. How many years were you there?

16. Out of all the years you attended residential school, how many times did you get to go home?
17. Do you believe that your overall health and well-being has been affected by your attendance at residential school?
   - Yes, negatively impacted
   - Yes, positively impacted
   - No impact
   - Don’t know
   - No response

18. Were any of the following members of your family ever a student at a federal residential school or federal industrial school? Select all that apply.
   - Your grandmothers
   - Your grandfathers
   - Your mother
   - Your father
   - Your current spouse or partner
   - Your brothers or sisters
   - Your aunts or uncles
   - Your cousins
   - Other relatives
   - No (Skip to next section)
   - No response (skip to next section)

19. Do you believe that your overall health and well-being has been affected by a member of your family attending residential school?
   - Yes, negatively impacted
   - Yes, positively impacted
   - No impact
   - Don’t know
   - No response

20. Do you have any additional thoughts/comments about the issues we have discussed so far?
B. Discrimination

21. Have you ever been treated unfairly because you are First Nations?
   - Yes
   - No (skip to question 24)
   - No impact
   - Don’t know
   - No response

22. How long ago was your last experience with this type of unfair treatment?
   - Within the past 12 months
   - Longer than a year ago
   - Don’t know
   - No response

23. Has that experience negatively affected your self-esteem?
   - No effect
   - Little effect
   - Some effect
   - Strong effect
   - Very strong effect
   - Don’t know
   - No response

24. Do you believe that your overall health and well-being have been affected by racism?
   - Yes
   - No (skip to question 6)
   - Don’t know
   - No response

25. If Yes, how? Can you share an example with me?

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26. Do you have any others thoughts/comments on the issue of discrimination?

27. Have you ever felt the need to identify yourself with the majority culture and deny your First Nations status?
   Yes
   No

28. If answered Yes, what did you change in your life?

29. Any final comments or is there anything else you would like to add about the impact of colonization on the health of Indigenous people?

Thank you for your time to answer these interview questions. Your input is valuable and will help to document the impact of colonization on the health of First Nations. We discussed some sensitive topics today. If this has caused you any distress at all and you would like to talk to someone further about this, I have a list of services that are available in your area.

Provided List of Services
   Yes
   No

Provided $25 gift card (for participation)
   Yes
   No

Date: ____________________________

Signature of Participant: ____________________________

Name of Participant: ____________________________
Appendix C: Finnish Survey Questions

Tutkimuksen tausta

Tutkimuksen nimi

“Terveydenhuollossa ja asuntolaelämässä koetun syrjinnän vaikutukset alkuperäiskansojen terveyteen: yhtäläisyydet ja erot Inarin kunnassa asuvien saamelaisten ja Grand River, Six Nations -kansojen välillä”

Tutkimuksen tarkoitus

1. Tutkia terveydenhuollon ja asuntolaelämän syrjivien käytäntöjen vaikutusta itse koettuun terveyteen kahdessa alkuperäiskansayhteisössä.
2. Tutkia rasismin vaikutusta itse koettuun terveyteen kahdessa alkuperäiskansayhteisössä.
3. Verrata Inarissa asuvien saamelaisten (Suomi) ja Grand River Six Nations – kansojen (Kanada) kokemusten yhtäläisyyksiä ja eroavaisuuksia.

Tutkimuksen kuvaus:

Tutkimuksen hyödyt ja käyttötarkoitukset


Osa 1: A. Taustatiedot

1. Sukupuolesi?
   Mies
   Nainen

2. Minä vuonna olet syntynyt?

3. Kansalaisuus?
   (Lisäkysymys tarvittaessa: Oletko saamelainen?)
   Kyllä
   En ole (haastattelu loppuu tähän)

4. Mikä on äidinkielesi
   Suomi
   Inarin saame
   Pohjoissaame
   Kolttasaame
B: Asuminen ja liikkuminen

5. Missä asut nyt? (paikkakunta, kylä tms.)
   _____________________________ (ole hyvä ja tarkenna)

6. Missä asuit lapsena?
   _____________________________ (ole hyvä ja tarkenna)

7. Kun ajattelet asumisolosuhteitasi, esimerkiksi paikkakuntaa, kylää, sijaintia tai asumistyyppiä, onko sillä/niillä mielestäsi ollut jotain vaikutusta terveyteesi? (täsmennä onko kyseessä lapsuuskoti, nykyinen asuinpaikkasi vai mikä?)
   Kyllä
   Ei
   En osaa sanoa/En tiedä
   Ei vastausta

8. Jos vastasit kyllä kysymykseen 6, selitä tarkemmin millä tavoin?
   _____________________________

Osa 2: Terveydenhuoltopalveluiden tarjonta

Seuraavan osion kysymykset käsittelevät terveyspalveluiden tarjontaa ja pääsyä niihin. Sinun ei tarvitse vastata mihinkään sellaiseen kysymykseen, mihin et halua vastata, ja voit pitää tauon milloin tahansa koet niin tarvitsevasti.
9. Ovatko terveysalan ammattilaiset (lääkäri, sairaanhoitaja, hammaslääkäri jne) koskaan kohdelleet sinua huonosti? Koetko, että sinua on esim. kohdeltu eri tavoin, annettu odottaa tms. sen vuoksi, että olet saamelainen?
   - Kyllä
   - Ei (siirry kysymykseen 12)
   - En osaa sanoa (siirry kysymykseen 12)
   - Ei vastausta (siirry kysymykseen 12)

10. Milloin tämä tapahtui?
    - Viimeisen 12 kuukauden aikana
    - Kauemmin kuin vuosi sitten: Kuinka monta vuotta sitten?
    - En osaa sanoa
    - Ei vastausta

11. Onko tämä tapahtuma/kokemus vaikuttanut tai lopettanut terveyspalveluiden käyttösi?
    - Kyllä
    - Ei
    - En osaa sanoa
    - Ei vastausta

12. Onko sinulla jotain lisättävää, ajatuksia tai kommentteja terveydenhuoltopalveluista, joita olet saanut nykyään tai nuoruudessasi?

Osa 3: Yhteiskunnallisten syrjintä- ja sulauttamiskäytäntöjen seuraukset

Seuraavassa osassa on ehkä joitain kysymyksiä, jotka voivat herättää epämukavia tuntemuksia tai muistoja. Muistathan, ettei sinun tarvitse vastata sellaisiin kysymyksiin, joihin et halua vastata, ja voit pitää tauon aina halutessasi.
C. Asuntolakokemuksen

13. Olitko koskaan oppilaana suomalaisessa kansa- tai peruskoulussa, jossa oli
asuntola tai joudutko asumaan koulukenäynnin vuoksi alivuokralaisena tai
muussa perhemajoitusessa?
   Kyllä (missä?)
   En (siirry kysymykseen 18)
   En osaa sanoa/en tiedä (siirry kysymykseen 18)
   Ei vastausta (siirry kysymykseen 18)

14. Minkä ikäisenä menit sinne?

15. Kuinka monta vuotta olit siellä?

16. Kuinka usein pääsit käymään kotona?

17. Koetko, että asuntola-ajalla tai muilla kouluajan majoitusjärjestelyillä on
ollut vaikutusta yleiseen terveyteesi ja hyvinvointiisi?
   Kyllä, negatiivinen vaikutus (voitko kertoa miten?)
   Kyllä, positiivinen vaikutus (voitko kertoa miten?)
   Ei vaikutusta
   En osaa sanoa
   Ei vaikutusta
18. Kävikö joku perheenjäsenistäsi koulua, jossa joutui asumaan asuntolassa, alivuokralaisena, perhemoitoksessa tms.? Valitse seuraavista:

- Isoäitisi (molemmat)
- Isoisäsi (molemmat)
- Äitiisi
- Isäsi
- Puolisosi tai kumppanisi
- Veljesi tai sisaresi
- Tätisi, enosi tai setäsi
- Serkkusi
- Muut sukulaiset
- Ei kukaan (siirry seuraavaan osaan)
- Ei vastausta (siirry seuraavaan osaan)

19. Onko perheenjäsenesi asuntolassa tms. edellä mainitussa majoitoksessa oloajalla ollut mielestäsi vaikutusta sinun yleiseen terveydentilaan ja hyvinvointiin?

- Kyllä, negatiivinen vaikutus (voitko kertoa miten?)
- Kyllä, positiivinen vaikutus (voitko kertoa miten?)
- Ei vaikutusta
- En osaa sanoa
- Ei vastausta

20. Onko sinulla jotain lisättävää, ajatuksia tai kommentteja tästä keskustelemastamme asiasta?
D. Syrjintä

21. Oletko koskaan kokenut tulleesi epäoikeudenmukaisesti kohdelluksi sen vuoksi, että olet saamelainen?
   
   Kyllä
   Ei (siirry kysymykseen 25)
   Ei vaikutusta
   En osaa sanoa
   Ei vastausta

22. Kuinka kauan aikaa on viimeksi kokemastasi epäoikeudenmukaisesta kohtelusta?
   
   Tapahtui viimeisen 12 kuukauden aikana
   Kauemmin kuin vuosi sitten
   En osaa sanoa
   Ei vastausta

23. Onko tällä ollut vaikutusta itseluottamukseesi?
   
   Ei vaikutusta
   Hieman vaikuttanut
   Jonkin verran vaikuttanut
   Voimakkaasti
   Erittäin voimakkaasti
   En osaa sanoa
   Ei vastausta

24. Koetko, että rasismi tai syrjintä ovat vaikuttaneet yleiseen terveyteesi ja hyvinvointiisi?
   
   Kyllä
   Ei (siirry kysymykseen 26)
   En osaa sanoa
   Ei vastausta

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25. Voitko kertoa esimerkin?

26. Onko sinulla lisättävää, ajatuksia tai kommentteja liittyen syrjintään ja rasismiin?

Osa 4. Elintavat ja terveyskäyttäytyminen

27. Oletko koskaan kokenut tarvetta identifioitua suomalaiseen enemmistöön ja kieltää olevasi saamelainen?
   
   Kyllä
   
   Ei
   
   En osaa sanoa
   
   Ei vastausta

28. Oletko joutunut elämäsi aikana muuttamaan käyttäytymistäsi tai luopumaan jostakin asiasta voidaksesi tai jouduttuasi samaistumaan suomalaisyhteiskuntaan? Mistä?

29. Onko sinulla vielä jotain loppukomenttia tai jotain muuta mitä haluaisit lisätä kolonisaation tai syrjinnän vaikutuksesta alkuperäiskansojen terveyteen?

Kiitoksia ajastasi ja vastauskistasi. Vastauksesi on arvokas, ja se auttaa osaltaan selvittämään syrjinnän ja sulauttamiskäytäntöjen vaikutuksia saamelaisten terveyteen sekä parantamaan tilannetta terveyspalveluissta ja koululaitoksessa. Olemme keskustelleet ehkä joistakin sinulle herkistä asioista. Jos se on aiheuttanut sinulle epämiellyttävää tunnetta, ja haluaisit puhua jonkun kanssa asiasta, minulla on lista tällä alueella olevista henkilöistä ja palveluista, joihin sinun on mahdollisista ottaa yhteyttä.

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Tarjottu lista palveluista

Kyllä
Ei

Päiväys: 

Haastateltavan allekirjoitus:

Haastateltavan nimi:

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Appendix D: Truth and Reconciliation Calls to Action for Education

Of the 94 Calls to Action, # 62–65 outline in detail steps in regards to: Education for Reconciliation

62. We call upon the federal, provincial, and territorial governments, in consultation and collaboration with Survivors, Aboriginal peoples and educators to:
   
i. Make age-appropriate curriculum on residential schools, Treaties and Aboriginal peoples’ historical and contemporary contributions to Canada a mandatory education requirement for Kindergarten to Grade Twelve students.
   
ii. Provide the necessary funding to post-secondary institutions to education teachers on how to integrate Indigenous knowledge and teaching methods into classrooms.
   
iii. Provide the necessary funding to Aboriginal schools to utilize Indigenous knowledge and teaching methods in the classroom.
   
iv. Establish senior-level positions in government at the assistant deputy minister level or higher dedicated to Aboriginal content in Education.

63. We call upon the council of ministers of Education, Canada to maintain and annual commitment to Aboriginal education issues, including:
   
i. developing and implementing Kindergarten to Grade Twelve curriculum and learning resources on Aboriginal peoples in Canadian history, and the history and legacy of residential schools.
   
ii. sharing information and best practices on teaching curriculum related to residential schools and Aboriginal history.
   
iii. building student capacity for intercultural understanding, empathy, and mutual respect.
   
iv. identifying teacher-training needs relating to the above.

64. We call upon all levels of government that provide public funds to denominational schools to provide and education on comparative religious studies, which must include a segment on Aboriginal spiritual beliefs and practices developed in collaboration with Aboriginal elders.

65. We call upon the federal government, thought the Social Sciences and Humanities Research Council, and in collaboration with Aboriginal peoples, post-secondary institutions and educators, and the National Centre for Truth
and Reconciliation and its partner institutions, to establish a national research program with multi-year funding to advance understanding of reconciliation.
Appendix E: Two Row Wampum Renewal Campaign

We will travel down the River of Life together...

On July 20, paddlers from the Oneida Nation, other Haudenosaunee (Iroquois), and indigenous nations will be joined by non-native allies near Albany, NY. Over 200 people each day will paddle side-by-side down the Mohawk River to honor and share the agreements contained in the 400-year-old Two Row Wampum treaty.

This message of peace, friendship, respect for sovereignty, and respect for the laws of nature is reinforced by the message of the Okaota Unity Riders from Manitoba, Canada, as well as the Peace Walk organizes in the South. The riders will be rowing and walking side by side in parallel with the paddlers.

Honoring the Treaties, Respecting the Laws of Nature, Peace, Friendship Forever

...as long as the grass grows, as long as the rivers run downhill, and as long as the sun rises in the east and sets in the west.

This treaty is still in effect.

Summer 2013

THE UNITY RIDE

www.honorthenetworow.org

@HonorTheTwoRow

NYC Two Row Wampum Renewal Campaign

Honor Nation Treaties to Protect the Earth

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We the People, in the spirit of Truth, Condolence and Healing join with each other in the Two Row Wampum Renewal Campaign to “polish the silver covenant chain” that ties together the Native Peoples and Nations of Turtle Island (North America) with the people of the United States and Canada in a bond of peace, friendship and environmental responsibility that we intend to honor forever more. We call upon all local, state and federal legislators, executives and judges to honor the spirit and letter of treaties made with Native Nations and peoples. We personally and individually promise that we will:

1. Learn about and honor treaties made between Native Nations and European Representatives, commitments inherited later by the United States and Canada that secure for Native and First Nations the right to self-determination and sovereignty to determine their political status and freely choose and pursue their own way of life and; that all problems between our peoples will be resolved by diplomatic means between equals;

2. Correct the one-sided history that inaccurately emphasizes “discovery” and “development” of North America by Europeans while ignoring many thousands of years of accomplishment in governance, agriculture, and arts in the daily life and practices of Native and First Nations peoples;

3. Support full acknowledgement and just amends for deliberate policies to remove Native and First Nations peoples from their lands, destroy the base of their livelihoods, suppress their nations and their governments, undermine and disrespect their cultures, brutalize their children and poison their lands;

4. Work toward fair, just and respectful resolution of outstanding Native and First Nations land disputes which includes the restoration and clean-up of all environmentally damaged lands and waters;

5. Call on the United States and Canada to fully implement the United Nations Declaration on the Rights of Indigenous Peoples;

6. Personally care for and respect the natural world on which we all depend and resist energy policies and practices, including hydro-fracking, that intensify the looming climate and environmental crises and instead fight for renewable and alternative energy and economic policies that put the well-being of all people and our ecosystems ahead of the accumulation of wealth for the wealthy.

Honoring Two Row

Since the beginning of the relations between our peoples, the Two Row Wampum Treaty has been the alternative to removal, assimilation, patronizing relations and the policies of attempted genocide. We hereby promise to renew the Two Row, to polish the silver chain of friendship between our peoples beginning today and for many generations to come.
Original publications.


Original publications are not included in the electronic version of the dissertation.
1396. Määttä, Juhani (2016) The heritability and morphology of lumbar Modic changes and their association with pain

1397. Koskela, Marjo (2016) Wound healing and skin in severe sepsis

1398. Lahinen, Taija (2016) Radio speech communication and workload in military aviation: a human factors perspective


1400. Podlipská, Jana (2016) Non-invasive semi-quantitative and quantitative ultrasound imaging for diagnostics of knee osteoarthritis

1401. Akural, Ibrahim Ethem (2016) Pain management options after tonsillectomy and third molar extraction

1402. Hyninnen, Nina (2016) Ikääntyviä muistisaarataroja kirurgisella vuodeosastolla

1403. Siponen, Maria (2017) Oral lichen planus – etiopathogenesis and management


1405. Lepojarvi, Sannamari (2017) Normal variation of the tibiotalar joint in dynamic computed tomography


1408. Wang, Qin (2017) Epidemiological applications of quantitative serum NMR metabolomics: causal inference from observational studies


1410. Försti, Anna-Kaisa (2017) Incidence, mortality, comorbidities, and treatment of bullous pemphigoid in Finland

1411. Aarnivala, Henri (2017) Deformational plagiocephaly: prevalence, quantification and prevention of acquired cranial asymmetry in infants

1412. Tauriainen, Tuomas (2017) Complications associated with preoperative anemia, perioperative bleeding and blood transfusions after isolated coronary artery bypass grafting

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