A Scoping Review: Comparing Federal Health Policy and the Associated Impacts on Access to Care in First Nations and American Indians/Alaska Natives

Communities.

by

Denise Webb

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### **Abstract**

Canada and the United States each have a federal responsibility to deliver health services in First Nations (FNs) and American Indian/Alaska Natives (AIANs) communities. Yet, inequitable access to healthcare continues to disproportionately impact both communities. Little research has compared federal health policies between the two countries to see how they may help to explain the current state of healthcare access. This study aims to fill this gap. To do so, I completed a scoping review and three validation interviews with Indigenous health policy experts. The findings suggest that Canada exercises a greater use of informative policy instruments, compared to regulatory instruments in the United States. Policies in the two countries were frequently described as impacting similar dimensions of access. This study offers perspective on key policies involved in healthcare access, the contextual differences between the two countries Indigenous health policy making practices, and may inform future policy analysis.

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# Definition of Terms

Table 1. Definition of Terms

Access (to	Ability to/or opportunity to make use of needed health care services,
care)	considering aspects of social (cultural appropriateness, free from racism and
	discrimination) and physical accessibility (timely care, close in proximity)
	(Davy et al. 2016)
American	American Indian Alaska Natives (AIANs) peoples living in the United States
Indians/Alaska	from one of the 573 federally-recognized tribes (Indian Health Service, n.d.)
Natives	
(AIANs)	
First Nations	First Nations (FNs) peoples living in Canada on-reserve (in community),
(FNs)	regardless of Indian status
Indigenous	In the context of this study, Indigenous refers to First Nations and American
	Indian/Alaska Natives peoples collectively
Policy	"A set of interrelated decisions taken by a political actor or group of actors
	concerning the selection of goals and the means of achieving them within a
	specified situation where these decisions should, in principle, be within the
	power of these actors to achieve" (Jenkins, 1978, p. 15). May take the form
	of legislation, regulation, organizational, financing or other government
	actions
Policy Actors	Federal decision makers, including government organizations and agencies
Self-	In the context of this study, self-determination in healthcare refers to the
Determination	ability to participate in decision-making practices and possess control and an
in healthcare	active role regarding individual and/or community healthcare, health service
	planning, and/or delivery (Reading & Wien, 2009)

## Chapter 1. Introduction

Canada and the United States have a legislated federal responsibility to fund and deliver health services to First Nations (FNs) and American Indian/Alaska Natives (AIANs) communities, <sup>1,2</sup> based on treaty and trust agreements such as the 1867 British North America Act (Mashford-Pringle, 2011) and the 1787 Constitution of the United States (Indian Health Service, n.d.). Despite this obligation, inequitable access to healthcare services continues to disproportionally impact both FNs and AIANs communities in the two countries (Kramer & Weller, 1988; Ramraj et al. 2016; Government of Canada, 2016a; Indian Health Service, 2019). There is considerable evidence documenting access barriers, such as remote geographic locations (Lavoie et al. 2015), racism in healthcare systems (Ramraj et al. 2016), culturally inappropriate and unsafe care (NCCIH, 2019), and chronically under-funded federal health services (Warne & Frizzell, 2014).

Kramer and Weller, (1988, p. 1) compared health disparities between FNs and AIANs, stating "surprisingly no detailed comparative study has been undertaken of the health and health care delivery systems of Native peoples in Canada and the United States", despite the physical proximity and high number of Indigenous peoples in both countries. Kramer and Weller (1988) focused on health disparities, with little consideration for policy impacts. Similarly, Mashford-Pringle (2011) compared federal health policies shaping Indigenous healthcare delivery systems in Canada and the United States, although this work did not focus on the impacts on access to care. There has been limited research that compares federal health policies between the two countries to see how they may provide some insight into the current state of healthcare access. Through a scoping review, the purpose of this study is to fill this gap by documenting and comparing federal health policies in terms of policy levers, content and language, and their associated impacts on access to healthcare. This study addresses the following research questions:

- 1. What is known about federal-level health policy and the associated impacts on access to primary healthcare services for FNs and AIANs communities in Canada and the United States?
- 2. What are the similarities and differences between the two countries?

<sup>&</sup>lt;sup>1</sup> "FNs" and "AIANs" acronyms will be used for the duration of the thesis

<sup>&</sup>lt;sup>2</sup> The Canadian federal government is also responsible for the delivery of health services for Inuit peoples. However, this population is out of scope for the current study.

## Chapter 2. Situating Myself in the Research

Patnaik (2013) describes situating oneself in research as a way to improve the transparency of the research process and to help the readers clearly understand the perspectives that guided the methods and led to the conclusions. It also presents an opportunity for me to become self-aware of my positionality and acknowledge how it has come to shape and influence my research process (Patnaik, 2013). To that end, before I share my research journey, I wish to situate and properly introduce myself to the readers.

I approach this research as a non-Indigenous person, with Irish and Scottish settler ancestry from rural areas of Cape Breton and Cumberland County, Nova Scotia. I have the privileges of a white, middleclass woman, and grew up in an urban center outside Halifax. My lived experiences in this environment have come to shape my ways of knowing, and undoubtedly adjust the lens on how I perceive the world around me.

As a non-Indigenous researcher, my interest in Indigenous health stems from my lived experiences during my undergraduate degree at St Francis Xavier University. Here I played, worked, and volunteered with neighbouring Indigenous communities, learning new ways of knowing and beginning to challenge my narrow lens of seeing the world. In these roles I began my journey as an ally. Through relationships I acquired a deep passion to continue learning and working in the field of Indigenous health, specifically in tackling issues of health inequities. These experiences have led me to this master's research.

In reflecting and looking back at my research process, it has been a delicate practice of understanding, but not knowing. I have gained extensive knowledge through reading and listening, however, despite my best intentions my positionality holds me back from truly knowing. As I learn the policy impacts on access to care in First Nations and American Indian/Alaska Natives communities, I do not have the experience nor the perceptions to fully conceptualize the meaning behind the literature I am reading and words I am hearing. Thus, with this awareness I have approached the research process and discoveries with an open mind and heart, constantly challenging my interpretations and asking questions.

The research methods, analysis, and conclusions are a result of this process – continuously learning and challenging assumptions. Although painted with my biases and settler positionality, this research stems from a fruitful journey and brings significant contributions to the field of

Indigenous health. It is intended to ignite a learning process for all readers also interested and eager to understand.

## Chapter 3. Background

This chapter describes how the research topic was selected and defined, reviews the healthcare delivery structures in FNs and AIANs communities, and summarizes what is currently known about barriers to equitable access to care.

## 3.1 Selecting the Research Topic

This research study builds on previous work completed by Dr. Angela Mashford-Pringle, and my personal interest in policy research and access to care in Indigenous communities. Mashford-Pringle studied federal health policies in Canada and the United States (2011) as well as practices of self-determination in healthcare, in Northern Ontario FNs communities (2013). This prior research shed light on how Canada and the United States differ in their policy and decision-making practices concerning Indigenous health; as well as how federal policies play a significant role in healthcare delivery in Indigenous communities. Her research also prompted an important question: what can be learned by comparing two countries that differ in their political and healthcare systems, and use of legislation, but face similar challenges with regard to inequitable access to care in both FNs and AIANs communities? I chose to focus on comparing health policies in the two countries to explore this question further.

With this study I set out to build upon previous work and to gather all that is known about federal Indigenous health policies and their associated impacts on access to care. This study marks the beginning of an ambitious quest, as I begin to identify all federal policies that impact access to healthcare, expand the Indigenous health policy research field, and inform future policy.

## 3.2 Narrowing the Research Focus

Canada and the United States make use of federal health structures to fund and deliver care in FNs and AIANs communities. This study focuses only on federal-level structures exclusive of provincial, territorial, and state policies and governments, so as to maintain a discussion specific

to FNs and AIANs peoples and narrow the research focus. If this study were to include provincial, territorial and state policies, it would then require widening the scope to include discussions on Medicare in Canada, and Medicaid in the United States (both described below). These health coverage programs have been widely studied and are not designed specifically for FNs nor AIANs populations; and therefore, I do not focus on them in this study.

Moreover, healthcare structures and organizations in Canada arising from tripartite selfgovernment agreements between federal, provincial or territorial, and Indigenous governments were not included due to their deeply fragmented and complex nature (NCCIH, 2011a). Selfgovernment agreements resemble modern treaties, signed in areas where historic treaties were not negotiated (NCCIH, 2011a). They allow for Indigenous communities to assume greater control in the planning and delivery of health and social services and policy, compared to those without an agreement. For example, the James Bay and Northern Quebec Agreement has led to the development of healthcare structures managed and administered by James Bay Cree and Nunavik Inuit. This particular arrangement is unique to Canada, as the health facilities are linked to the Quebec provincial healthcare system and co-funded by federal and provincial governments (NCCIH, 2011a). Furthermore, the First Nations Health Authority (FNHA) was established in 2013 through tripartite agreements between FNs in British Columbia (BC), the province of BC and the federal government. The FNHA is a province-wide health governance structure operated by FNs peoples, independent of federal provision with regards to health services (FHNA, n.d.). There are many other agreements within Indigenous communities across Canada, each unique in their administrative and funding arrangements (NCCIH, 2011a).

Similar Indigenous-led health systems exist in the United States, such as the Southcentral Foundation in Matanuska-Susitna Borough, Alaska (Southcentral Foundation, n.d.), and various tribally-ran health facilities and hospitals within Navajo Nation (IHS, n.d.c). Both structures are owned and operated by AIANs communities, however the Southcentral Foundation was established through the Cook Inlet Region Inc. non-profit agency, and tribally-ran hospitals and facilities are tangible outcomes of federal policies.

As each self-government agreement in Canada and independent health structure in the United States are unique to their province, territory or state, and Indigenous community, their comparability within and across countries is limited. Therefore, I focus solely on federal-level health policies impacting access to care for FNs/AIANs populations in the two countries.

## 3.3 Healthcare Delivery in FNs and AIANs Communities

The Government of Canada First Nations Inuit Health Branch (FNIHB) funds and delivers a range of primary and community-based care for acute and chronic conditions for "Indian status" FNs peoples living in community and below the 60<sup>th</sup> parallel (Government of Canada, 2008; Indigenous and Northern Affairs Canada, 2020). There are 634 FNs communities (FNs reserves) eligible for services (AFN, n.d.). "Indian status" FNs peoples must be registered with the federal government under the Indian Act (Government of Canada, 2020).<sup>3</sup>

FNIHB healthcare is delivered on-reserves by registered nurses with extended scopes of practice. For more specialized services, patients are referred to provincially/territorially funded hospitals off-reserve and in urban centres (Government of Canada, 2008). Under the Health Transfer Policy, which is discussed in further detail later, FNs communities may assume some level of control and autonomy over the planning and delivery of federally funded healthcare.

Each Canadian province and territory administer their own health system for its residents. Collectively these health systems are referred to as Medicare; these are universal tax-financed health coverage systems available to all provincial/territorial residents. FNs peoples are covered by their province's/territory's Medicare program; however, Medicare-funded services are not available on FNs reserves (Martin et al. 2018; Lavoie, 2018). In addition to Medicare, all registered FNs peoples (regardless of place of residence) are enrolled in the Non-Insured Health Benefits Program (NIHB), a supplemental insurance program covering services not offered by provincial/territorial Medicare plans (Government of Canada, 2016).

In the United States, the Indian Health Service (IHS) under the Department of Health and Human Services, is the primary healthcare service provider in tribal communities.<sup>4</sup> The IHS is federally funded and available to all AIANs peoples who are a member of, and living in, one of the 573 federally-recognized tribes (Indian Health Service, n.d.). Although intended to provide supplemental health insurance, the IHS provides healthcare to the majority of AIANs peoples (Cunningham, 1996). Medicaid, a federal and state-funded coverage program, is also available and may finance care provided at IHS facilities. As I will discuss later, AIANs tribal communities may assume control over their healthcare planning and delivery, either alongside or independent of the

<sup>&</sup>lt;sup>3</sup> The term "Indian" is used to reflect the terminology of the 1876 Indian Act

<sup>&</sup>lt;sup>4</sup> The terms "tribal" and "tribe(s)" are used to reflect the language of the Indian Health Service and other policies

IHS, under the 1975 Indian Self-Determination and Education Assistance Act (Willging et al. 2018; Warne & Frizzell, 2014; Indian Health Service, n.d.b.; Bylander, 2017). The IHS Purchased/Referred Care (PRC) program may fund patient's travel expenses and direct costs to seek essential care not available in community (Indian Health Service, n.d.a.; Wong et al. 2006; Center on Budget and Policy Priorities, 2017).

The federal responsibility to fund and deliver care for FNs and AIANs peoples stem from treaty, trust, and legislative agreements. The British North America Act (BNA) in Canada declares FNs peoples as wards of the state and FNs healthcare as under federal jurisdiction. In the United States, Article 1, Section 8 of the 1787 Constitution of the United States defines the federal obligation to provide health services to AIANs (Indian Health Service, n.d.). As a result, AIANs peoples are the only population within the United States to be entitled to federally-funded healthcare (Warne, 2007). Organized healthcare for both FNs and AIANs was developed in response to disease outbreaks stemming from colonizers intruding Indigenous land (Mashford-Pringle, 2011). Earlier versions of the FNIHB and IHS were then established in the early 1900s in efforts to keep settlers healthy and contain the spread of disease. Mashford-Pringle (2011) provides a detailed history of federal policies shaping FNs and AIANs healthcare in Canada and the United States.

## 3.4 Barriers to Accessing Care

Extensive research suggests several barriers impacting access to care in FNs and AIANs communities. Figure 1 lists these barriers and highlights the common issues across the two countries. In Canada, issues in resource availability and a lack of trained healthcare professionals in FNs communities are commonly cited barriers to care (FNIGC, 2018). While a similar issue exists in the United States, it is characterized by a lack of AIANs trained healthcare professionals which results from historical discriminatory health and education policies as well as an underfunding of health education programs (Warne, 2007). A lack of AIANs healthcare professionals has also led to inadequate access to culturally appropriate care (Warne, 2007), another common issue shared between the two countries.



Figure 1. Summary of Barriers to Accessing Healthcare in FNs and AIANs Communities

Culturally appropriate care, often described as traditional healing practices and medicines integrated into healthcare programming, is inadequate in both FNs and AIANs communities (Horrill et al. 2019; Noe et al. 2014). Both the FNIHB and IHS fail to allocate sufficient funding in support of cultural integration into their provided services (Smith & Lavoie, 2008; Noe et al. 2014). Moreover, FNs communities in Canada often face challenges in receiving traditional medicine due to a lack of knowledge on where one may access it (FNIGC, 2018). However, despite such challenges, there are opportunities to receive culturally appropriate care but these are outside of federally-funded organizations. Indigenous-led and administered health organizations such as Anishnawbe Health Toronto (Anishnawbe Health Toronto, n.d.) and Aboriginal Health Access Centres across Ontario (Alliance for Healthier Communities, n.d.) provide health programming specific to the cultural needs of their serviced communities on and off-reserves.

Figure 1 also points to jurisdictional disputes as a barrier to accessing health services common to the two countries. In Canada there is a lack of clear definition of federal and provincial/territorial responsibilities to finance and deliver health services to FNs peoples (Lavoie, 2018; Lavoie, 2013). When travelling to receive care unavailable in community, loose policy guidelines regarding the financing of care in settings off-reserve contribute to bureaucratic debates between federal and provincial/territorial governments causing delayed care (Lavoie, 2013). In the United States, there are similar disputes about whether Medicaid or the IHS is responsible for financing care at IHS facilities and/or tribally-ran hospitals (Wong et al. 2006; Schneider, 2005).

Unclear guidelines often result in the IHS providing primary funds despite Medicaid's larger budget (Wong et al. 2006). As a result, these additional costs reduce the IHS budget which would otherwise cover the uninsured and/or medical travel expenses (Wong et al. 2006; Warne & Frizzell, 2014).

Lastly, Figure 1 highlights community control as another barrier persistent in FNs and AIANs communities. In Canada community control is often characterized as exercising selfdetermination and decision-making activities for and by FNs communities, while in most cases, still maintaining partnerships with the federal government (Dwyer, 2013; Kelly, 2011). Policies and programs have been introduced to promote self-determination in healthcare, however, these programs have been heavily criticized for their limited funding and resources (Lavoie et al. 2010a; Lavoie et al. 2007; Smith & Lavoie, 2008). In the United States, community control is often described as AIANs exercising self-government activities, and assuming full control over policy and decision-making practices, independent of federal political influence (Bylander, 2017; Henley, 2016). The Indian Self-Determination Education Assistance Act (ISDEAA) supports this process. Although, this policy in practice has also been contested due to failure of the federal government to deliver on its promises to support self-government activities with adequate financial means. To this end, tribal communities such as Navajo Nation have challenged the United States Senate to formulate its own political governing body, resembling power equivalent to an American state (Henley, 2016). Additionally, tribal communities have advocated for self-government power, to assume the role of the Senate in setting IHS financing priorities and practices. Such efforts have yet to succeed (Chino & DeBruyn, 2006; Center on Budget and Policy Priorities, 2017).

Each of the above issues impact the health and wellness of FNs and AIANs peoples living in community and require upstream approaches to work towards sustainable improvement. As described by The National Collaborating Centre for Determinants of Health (2014), national policy actions are examples of upstream approaches to public health challenges. While there have been many studies describing barriers to accessing care, this study sets out to identify the federal policies contributing to these barriers to inform policy analysis and actions; thus, its significance is paramount. With these goals in mind, the following chapters describe the research process.

## Chapter 4. Theoretical Frameworks

This study employed two frameworks to summarize and map out available literature on topics of Indigenous health policy and access to care. This chapter describes each framework.

### 4.1 Policy Framework

I used the Bemelmans-Videc et al. (1998) policy framework to categorize and describe Indigenous health policies identified in the review. Bemelmans-Videc et al. (1998) describe policy instruments as a "set of techniques by which governmental authorities wield their power in attempting to ensure support and effect or prevent social change" (p. 21). In using this definition, this study adopted Bemelmans-Videc et al. (1998) "threefold typology of public policy instruments" (p. 30), categorizing policies according to three broad categories: regulations (sticks), economic means (carrots) and information (sermons).

Sticks are often defined as laws, bans, rules or directives instituted by government bodies in order to enforce or restrict public behaviours or activities (Bemelmans-Videc et al. 1998). Carrots use economic measures such as taxes, grants or financial incentives, to promote or hinder activities, leaving it up to public discretion on whether individuals choose to participate. Sermons attempt to influence the public through the transfer of knowledge, and communication of reasoned argument and persuasion. Unlike sticks and carrots, sermons do not use enforcement nor tangible measures to influence public activities, rather, use communication campaigns and the value of education (Bemelmans-Videc et al. 1998).

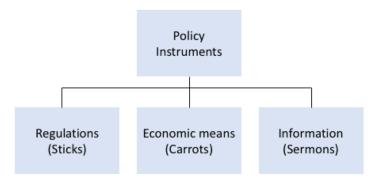


Figure 2. Policy Instruments Framework, adapted from Bemelmans-Videc et al. (1998).

## 4.2 Accessibility Framework

I used the Levesque et al. (2013) accessibility framework, adapted and altered by Davy et al. (2016) for this study. I chose this framework as it characterizes and accommodates for multiple forms of access, providing a comprehensive definition of access to care. In addition, it was the only framework that I was able to identify which included perspectives of Indigenous communities from both Canada and the United States.

Davy et al.'s (2016) scoping review sought to identify barriers to healthcare access among Indigenous populations in Australia, New Zealand, South America, Papua New Guinea, Canada and the United States. Researchers documented barriers to primary healthcare services, using Levesque et al.'s (2013) accessibility framework, although they found the framework to be limiting based on the perspectives they were collecting. For example, using the Levesque et al. (2013) accessibility framework, barriers to access would be categorized based on approachability, acceptability, availability, affordability and appropriateness. These broad categorizes then lead to more mutually exclusive explanations and barriers to accessing care. Davy et al. (2016) found that barriers were often interrelated and touched on more than one specific category. As well, the researchers argued that appropriateness and acceptability closely resembled each other, and it was more useful to adapt the appropriateness category to solely focus on the patient's ability to engage with health services by means of community education and health literacy. In response to this challenge, Davy et al. (2016) adapted the accessibility framework to take a more holistic approach which would account for barriers that are interconnected and created the "ability to engage" category.

For Davy et al. (2016) ability to engage refers to "how well the individual is able to engage with the care that is offered" (p. 2), without explicit mention of self-determination in healthcare. Self-determination as a substantial determinant of health identified by the National Collaborating Centre for Indigenous Health (Reading & Wien, 2009) in Canada and the National Indian Health Board (Shelton et al. 1998) in the United States. Thus, for this study, the ability to engage category will be expanded to clearly include one's ability to exercise self-determination. Each dimension of access is described below:<sup>5</sup>

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<sup>&</sup>lt;sup>5</sup> For an illustration of the Accessibility Framework, please refer to Davy, C., Harfield, S., McArthur, A., Munn, Z., & Brown, A. (2016). Access to primary health care services for Indigenous peoples: A framework synthesis. *International Journal for Equity in Health, 15*(1), 163-175, (removed for copyright purposes).

- **Approachability** is the ability to engage with health services by means of health literacy and community education, and to recognize the need for care and whether the healthcare service is known to exist
- Acceptability is the ability to seek culturally safe and professional care
- Availability is the ability to receive timely care without barriers pertaining to geographic location
- **Affordability** is the ability to pay for health services
- **Ability to engage** is the ability to exercise self-determination in healthcare i.e., to make decisions regarding an individual and/or community's healthcare and/or play an active role in health service planning and delivery

## Chapter 5. Design and Methods

This chapter describes the research methods and design for this study. I conducted a scoping review, drawing on guidelines developed by Arksey and O'Malley (2005) and the PRISMA extension for scoping reviews (Tricco et al. 2018). Subsequent sections describe the following steps in the research process: justification for a scoping review, the research questions, the search strategy and data collection, the inclusion and exclusion criteria, the charting and collating procedures, how I reported the results, and the validation interviews.

## 5.1 Justification for Scoping Review

The purpose of conducting a scoping review aligned perfectly with the objectives of this study. Scoping reviews serve a variety of purposes, as they may be used to map out key concepts surrounding a research area that has yet to be explored, identify gaps in the research, or may expand and clarify broad concepts to inform fields of practice (Peters et al. 2017; Arksey & O'Malley, 2005). As there is little research on Indigenous health policies a scoping review is the best approach to identify and map out federal Indigenous health policies, identify gaps in the literature, and expand and clarify the associated impacts on access to care. Peters et al. (2017) explain that scoping reviews may also be used to construct a "policy map". In this case, a "policy map" refers to the similarities and differences between policies in Canada and the United States and the policy instruments used.

A scoping review allows for a thorough and rigorous approach in a short period of time (Arksey & O'Malley, 2005). Its methods are transparent, limiting researcher bias, and it may also include a wide variety of academic and grey literature sources, minimizing publication bias (Thomas & Higgins, 2019). The structure of scoping reviews, however, does not require the assessment of the quality of evidence, nor evaluation of study outcomes (Arksey & O'Malley, 2005), and will therefore not take place in this study.

#### 5.2 Research Questions

Tricco et al. (2018) explain that the research question and objectives are typically finalized and tested by developing a scoping review protocol prior to beginning the study. This study did not develop a protocol, rather, multiple meetings were held between myself and the thesis committee, to explore and finalize the research questions. This research study sought to answer: What is known about federal-level health policy and the associated impacts on access to primary healthcare services for FNs and AIANs communities in Canada and the United States? And, what are the similarities and differences between the two countries?

The questions were constructed around the PICO framework (Thomas & Higgins, 2019), meaning, emphasis on the Population i.e., FNs in Canada and AIANs in the United States, Intervention i.e., federal-level health policy, Comparison i.e., Canada and the United States jurisdictions, and Outcome i.e., access to care.

## 5.3 Search Strategy and Data Collection

The search strategy used a three-step process described in the Joanna Briggs Institute, Manual for Evidence Synthesis, and its chapter on scoping reviews (Peters et al. 2017). First, searches for grey and academic literature written in English took place on appropriate data bases, by the advice of experienced librarians and the thesis committee. This step included PAIS Index, Sociological Abstracts (SA), Scopus, and Native Health Database (NHD).

A few citations from each database were pulled for examples and shared with the thesis committee to decide on relevance of the sources, which helped to adjust and finalize the search terms and strategy. All databases were then included in the study, except for Scopus. After attempts to narrow the search, Scopus yielded 3319 sources, compared to an average of 333 from PAIS

Index, SA, and NHD. Thus, an inclusion of Scopus was beyond the scope and capacity for this study and likely gathered noise. In terms of grey literature, additional databases were then included based upon the advice of both the thesis committee and experienced librarians, specifically Google Scholar, Government of Canada Publications, Indian Affairs, Indian Health Service, iPortal, National Collaborating Centre for Determinants of Health, National Collaborating Centre for Indigenous Health and the National Indian Health Board.

The second step included taking note of the text words, abstract key words and index terms used to describe relevant studies in order to formulate and confirm search terms for the review (Peters et al. 2017). As with the previous step a librarian consultation was included. Appendix A outlines the final search strategy including key words.

The third and final step involved checking the reference lists of relevant studies, to seek out additional literature and search terms associated with the topic (Peters et al. 2017). No additional studies were added through this step, as all spotted sources were found to be included in the search databases.

Once the search strategy, databases, and search terms were finalized, I ran searches from the databases beginning on January 27<sup>th</sup>, 2020. Grey literature searches were conducted by inserting key words/search terms in the "search" tab on the following websites: iPortal, Government of Canada Publications, NCCIH, NCCDH, NCCHPP, National Indian Health Board, US Department of Interior Indian Affairs, Indian Health Service, Indigenous Services Canada, and the FNIHB. Appendix B provides a complete list of key words and search terms for grey literature searches. Between January 27<sup>th</sup> – February 11<sup>th</sup>, 2020, I independently screened a few studies from the databases, and shared citations with the thesis committee providing examples of included, excluded and "maybe" sources. After gaining further familiarization with the literature I stopped running searches. This process helped to develop and finalize the inclusion and exclusion criteria for the study, in leu of pilot testing with the committee.

#### 5.4 Inclusion and Exclusion Criteria

The research question and PICO framework informed the inclusion criteria (Thomas & Higgins, 2019). Sources were included if: the discussion focused on First Nations (FNs) living in Canada on-reserve, and/or American Indian/Alaska Natives (AIANs) living in the United States in tribal

communities (*population*); federal-level health policies were the primary focus throughout the article (*intervention*); and access to primary healthcare services was evaluated, discussed and/or mentioned (*outcome*). Sources were excluded if: population of focus was not FNs/AIANs; the focus was on provincial/territorial and/or state policies and/or off-reserve Indigenous populations; and there was no focus on policies (e.g. the studies focused on measuring or discussing barriers and/or enablers to accessing health services without a policy discussion). Appendix C outlines the full inclusion/exclusion criteria guidelines.

Provincial and state policies were excluded so as to maintain the focus of the study on federal policies and narrow the scope (refer to Chapter 3). Thus, sources focused on Indigenous populations off-reserve were excluded, as associated policies would then operate on a provincial/territorial level. Identifying policies is one of the research objectives, therefore sources without a policy discussion were excluded from the study. Time restrictions were not considered for this study, to avoid the risk of missing key information as evidence of Indigenous health policies and treaties predates colonialization. All sources were confined to the English language, based on my personal language restrictions.

Once the inclusion criteria were finalized, I began title and abstract screening in late February 2020 with a 2<sup>nd</sup> reviewer (MSc student in Health Policy) to limit selection bias (Thomas & Higgins, 2019). Throughout this title and abstract screening process, and into full-text screening, I shared examples of sources with the thesis committee, to ensure I was on the right path and when necessary, to help solve disagreements between myself and 2<sup>nd</sup> reviewer.

## 5.5 Charting and Collating Results

The sources were charted and collated based on the primary focus of the review – how federal health policies impact access to care based on the five dimensions of access and by means of policy instrument. The following information was charted from the sources into an excel spreadsheet: author(s), year of study, title of source, location, population, article key words (if applicable), type of study (grey, academic journal article, policy document, thesis, etc.), database(s), a condensed summary, policy/policies mentioned, the categorization of policy instrument, the categorization of impact(s) on access, and "other" factors impacting access. Appendix D provides a summarized

form with key charted information from collected sources. The categorization process for policy instruments, impacts on access and "other factors" is described below.

### 5.5.1 Charting Policy Instruments

I independently categorized the policies according to their use of regulatory, economic, or informative policy instruments, following the definitions provided by Bemelmans-Videc et al. (1998). I highlighted and isolated information pertaining to how the policies were described in the literature. For the regulatory instrument, policies were described as using strict rules or strict guidelines for implementation. For example, the Indian Health Care Improvement Act in the United States and the Indian Act in Canada, are pieces of legislation that have strict rules and guidelines. Economic policies used financial dis/incentives to influence public behaviours, instigate change or maintain the status quo. Examples include the Health Transfer Policy in Canada and the Affordable Care Act in the United States. The HTP is optional for FNs to assume administrative roles from federal organizations, using funding and other resource incentives. The ACA allows individual states the option to expand Medicaid eligibility criteria, with special considerations to improve health coverage for AIANs in their state. The federal government uses financial incentives, offering to cover 100% of Medicaid-covered services delivered at IHS facilities. Lastly, informative policies employ information or education to reach policy goals, without any rules, legislated guidelines or financial dis/incentives. An example is the Truth and Reconciliation Commission of Canada. This policy is endorsed by the federal government and holds information and recommendations on how to improve the health and wellbeing of FNs peoples. It is not however, legislated nor paired with any financial incentives.

### 5.5.2 Charting Impacts on Access

This charting process was informed by the accessibility framework described above (Davy et al. 2016). For each collected source, I assigned the policies to one or more dimension of access, based on evaluations and/or discussions of the policies. Policy impacts on access may be positive (i.e., improving access to care) or negative (i.e., hindering access), however, it was not possible to chart their actual positive or negative impact due to a limited number of evidence-based evaluations

found for each policy. Thus, I coded each policy as impacting one or more of the following five dimensions of access, grouping together any described positive or negative impacts:

- 1. Approachability, if the policy impacts an individual's (or community's) ability to interact with health services, that is, recognizing they need care, and being aware of whether the health service exists in their community. Examples include the Aboriginal Diabetes Initiative in Canada and Cervical Cancer Mortality Prevention Act in the United States, as both set out to enhance community-based educational initiatives and screening procedures for their respective interventions to increase awareness of available services.
- 2. **Acceptability,** if the policy impacts the ability to seek culturally and socially appropriate, safe, respectful, and professional care responsive to individual and/or community-based needs. Policies such as Traditional Healer Services Travel Policy in Canada and the Indian Health Care Improvement Act in the United States support the development and funding of health services that are specific to community-based needs, including culturally-safe care. Thus, I charted these as impacting the acceptability of health services.
- 3. **Availability,** if the policy impacts the physical accessibility of health services, by means of geographic location and ability to receive care in a timely manner. The Medical Transportation Policy in Canada and the Purchased/Referred Care Program (formerly known as the Contract Health Services Program) in the United States are clear examples, as both establish a program to provide federal funding for individuals to receive timely access to care outside FNs and AIANs communities.
- 4. **Affordability,** if the policy impacts one's ability to pay for health services. An example is the ACA, improving the affordability of purchasing private health insurance for AIANs.
- 5. **Ability to engage,** if the policy impacts one's ability to exercise self-determination in healthcare. The Indian Self-Determination Education Assistance Act is one example, allocating funding and resources for communities to administer and plan their health programming.

#### 5.5.3 Charting "Other" Factors

When applicable, I charted key points from the sources which provided further explanations on how and why the policies impact access to care. I charted these insights as "other" factors. This process facilitated an inductive approach to identify themes that capture additional policy impacts, that would otherwise go unmentioned due to the narrow lens of the policy framework. Additional impacts were related to the policy described by the source, as well as the dimensions of access employed by this study. For example, funding structures were often cited as additional factors impacting access, by studies examining the Health Transfer Policy, Purchased and Referred Care Program, Medical Transportation Policy, among others.

### 5.6 Reporting Results

After categorization, the policies were consolidated into a single list, ordered by date, and colour coded according to the type of policy instrument. This list is located in Appendix E. The impacts of each policy on access were then summarized and consolidated, and added into Appendix E. The dimension of access was assigned to the policy if the description in the literature met the above categorization criteria one or more times. I then tallied up the total number of impacts on each dimension, stemming from each policy instrument, to summarize the relationship between policy instruments and impacts on access. This is presented in Table 4 in the results. I then analyzed the "other" factors using an inductive thematic analysis to identify emergent themes. This was completed by highlighting topics that were mentioned by multiple sources. Four themes emerged and are discussed in the results section. Each emergent theme is documented and colour-coded in Appendix D.

#### 5.7 Validation Interviews

Arksey and O'Malley (2005) recommend incorporating validation interviews into scoping reviews to strengthen the findings of the study and identify insights beyond what is available in the literature. I conducted three interviews to gain new perspectives and to validate my interpretation of the findings from leading policy experts and academics in the field of Indigenous health. They also served as an opportunity to identify any literature that was missed by the search. Questions were based on both the deductive and inductive findings, exploring the experts' perspectives on the results according to their work, research, and lived experiences. Appendix F provides an outline of the prompting questions. I applied for ethics approval from the University of Toronto, however,

the university's Research Ethics Board indicated this study was exempt as the interviews would not be recorded, were for validation purposes and not for primary data collection.

Interviewees were selected based on frequency of their publications included in the review, as well as advice from the thesis committee. The three experts included: Dr. Josee Lavoie, University of Manitoba; Dr. Donald Warne, University of North Dakota; and Dr. Gregory Marchildon, University of Toronto. Dr. Lavoie specializes in Indigenous health policy in Canada; Dr. Warne specializes in AIANs health policy in the United States; and Dr. Marchildon specializes in comparative health policy. The information gained through the interviews is integrated into the results and discussion sections.

## Chapter 6. Results

The findings are discussed in this chapter, including the search results; descriptive characteristics of the sources included; an overview of the charted and isolated variables; and inductive findings informed by emergent themes.

#### 6.1 Search Results

Electronic searches conducted between January 27<sup>th</sup> to February 11<sup>th</sup>, 2020, yielded 1604 sources, including an additional 15 articles by the advice of the thesis committee. 359 duplicates were removed. After screening 1260 titles and abstracts with a second reviewer, 234 were included for full-text screening; and 179 sources were excluded due to the following reasons: 74 sources did not focus on federal-level health policies; 53 did not have a discussion on impacts on access to care; 16 did not mention nor focus on FNs and/or AIANs populations; 10 were opinion-based or from news articles; 8 were focused on access to services outside primary care; and 5 were inaccessible. Another 13 sources were excluded for "other" reasons, including: discussions on the criminal justice system; focused on forced sterilization; user guides for health personnel; summary articles on sources included in the review; and outdated programs and/or policy reforms that did not reach implementation. As a result, 55 sources met the inclusion criteria. After the screening process an addition two sources were added by the advice of the expert interviewees, thus 57 sources were included in this study. Appendix G includes the flow chart describing this review process.

## 6.2 Types of Sources and Databases

This section describes the sources, by type of source (Table 2) and by database (Table 3). As shown in Table 2, there were more sources from Canada (n=31) than the United States (n=26). As shown in Table 3, the Government of Canada Publications database yielded the majority of grey literature sources for Canada, offering a wealth of information on policies, initiatives and programs, funded and delivered by the federal government. The Native Health Database and PAIS covered the United States federal policies and programs, in the form of grey and academic literature.

Table 2. Types of Sources Included

Type of Source	Canada	<b>United States</b>	Total
Grey Literature	12	11	23
(Policy/Institutional Documents)			
Journal Articles	18	12	30
Thesis	1	1	2
Book Chapter(s)	1	2	3
Total	32	26	58*

<sup>\*</sup>one journal article counted twice, comparison of Canada and the United States

Many sources were identified in more than one database; thus Tables 2 and 3 report those identified after the removal of duplicates. Few articles from Indian Health Service and the National Indian Health Board were collected from their institutional websites, although, their citations were found in the Native Health Database and PAIS Index.

Table 3. Number of Included Sources from Databases

Database	Canada	<b>United States</b>	Total
Government of Canada Publications	11	0	11
Native Health Database	0	9	9
PAIS Index	2	7	9
Sociological Abstracts	6	1	7
iPortal	6	1	7

Google Scholar	3	3	6
Indian Health Service	0	2	2
National Indian Health Board	0	1	1
Other Source – Recommended by Thesis	3	2	5
Committee, Validation Interviews			
Total	31	26	57

Sources from Canada consist of institutional documents from Health Canada and the First Nations Inuit Health Branch, outlining policy initiatives and programs funded by the federal government. Journal articles provided mainly policy evaluations, most often the Health Transfer Policy (HTP) and Indian Act (Lavoie et al. 2007; Government of Canada, 1994; Health Canada, 2006; Lavoie et al. 2010; Lavoie & Forget, 2008). The Indian Health Policy was the only policy to be retrieved in its original form.

Sources from the United States consist of institutional documents from arms-length agencies and AIANs advocacy groups, such as the United States Government Accountability Office, the Indian Health Service, and the National Indian Health Board. Grey literature and journal articles captured policy evaluations, mainly of the Indian Self-Determination Education Assistance Act (ISDEAA), Affordable Care Act (ACA), and the Indian Health Care Improvement Act (King 2012; 2013; U.S. Commission on Civil Rights, 2004; Shelton et al. 1998). Only one journal article offered a comparison of federal health policies shaping Indigenous healthcare in Canada and the United States (Mashford-Pringle, 2011).

#### 6.3 Isolated and Charted Variables

Appendix D provides a summarized list of the included sources and their charted variables. From the 57 sources included, 30 federal Indigenous health policies were identified in Canada, and 23 in the United States, with dates ranging from the 1763 Royal Proclamation, to the 2011 Budget Control Act in the United States and 2015 Truth and Reconciliation Commission in Canada. Tables 10 and 11 in Appendix H list all the policies along with their dates and explanations.

Of the 30 health policies identified in Canada, the Health Transfer Policy (n=13)<sup>6</sup> and Indian Act (n=5) were most often discussed, as all other policies were mentioned less than or equal to four times. Of the 23 policies identified in the United States, the Affordable Care Act (n=12), Indian Self-Determination Education Assistance Act (n=7), Indian Health Care Improvement Act (n=5), and Purchased and Referred Care Program (n=4) were the most commonly cited policies. All other policies were mentioned less than or equal to three times.

#### 6.3.1 Policy and Accessibility Frameworks

Figure 3 summarizes the categorization of policies, according to their use of regulation, economic means, and informative policy instruments. The findings suggest that Canada employs relatively equal use of each instrument, whereas in the United States, policies are more often legislated and there is less use of economic instruments than in Canada. Informative policy instruments are also more frequently used in Canada (n=11 policies) compared to the United States (n=2).

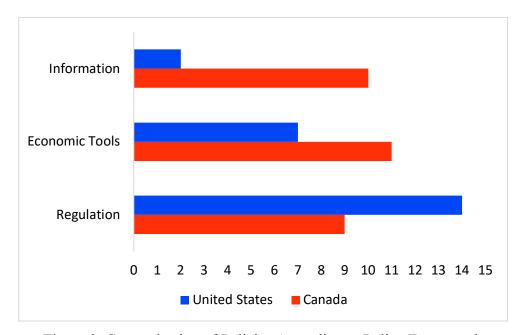


Figure 3. Categorization of Policies According to Policy Framework

<sup>&</sup>lt;sup>6</sup> "N" referring to the number of times each policy was identified in the literature

Table 4 summarizes the relationship between policies and their instruments, and associated impacts on access according to the five dimensions of the accessibility framework. Tables 8 and 9 in Appendix E showcase the complete analysis, indicating how each policy was categorized according to policy instrument and impacts on access. Subsequent sections provide a narrative of examples to further explain associations between the two variables.

Table 4. Policy instruments and Associated Impacts on Access

Regulation	Approachability	Acceptability	Availability	Affordability	Ability to Engage
Canada					
United States					
<b>Economic Tools</b>	Economic Tools				
Canada					
United States					
Information					
Canada					
United States					
LEGEND: n = number of associated impacts, charted from the literature					
Canada:	0	5	10		
United States:	0	7	14		

**LEGEND:** n = number of associated impacts, charted from the literature

Regulation and Acceptability, Availability, and Ability to Engage

The analysis above demonstrates that in both Canada and the United States regulatory policies are most often associated with the availability (n=7 in Canada; n=13 in the United States), acceptability (n=5; n=5), and ability to engage (n=3; n=6) dimensions. Examples include the Indian Act and British North America Act (BNA) in Canada (Brooks et al. 2013; Kelly, 2011; Lavoie, 2003; 2013; Mashford-Pringle, 2011), and Civilization Act (Mashford-Pringle, 2011) and Snyder Act in the United States (Thierry et al. 2009; Frias, 2003), and the Royal Proclamation (Mashford-Pringle, 2011).

As discussed earlier, the BNA in Canada establishes Indians<sup>7</sup> as under federal jurisdiction, holding the federal government legally responsible for providing services to FNs peoples in community (*availability*) (Kelly, 2011). The Indian Act established the reserve system and strict

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<sup>&</sup>lt;sup>7</sup> Terminology used to reflect legislative language of the BNA and Indian Act

criteria to become a "status Indian", a prerequisite to receive federal healthcare (Kelly, 2011). The Indian Act also triggered a series of strict policies prohibiting traditional cultural practices and medicines in healthcare, thereby impacting the *acceptability* of care available to FNs peoples (Brooks et al. 2013).

In the United States, the 1819 Civilization Act initiated delivery of minimal health services to AIANs tribal communities, allocating health-related funds, however, for the purpose of protecting white settlement populations (Mashford-Pringle, 2011) (*availability*). The 1924 Snyder Act later established formal funding arrangements to ensure healthcare *availability* for AIANs peoples. The Act also characterized the types of services to be made available, focusing on community-based needs (*acceptability*) (Thierry et al. 2009).

Prior to formal establishment of Canada and the United States, the Royal Proclamation was an agreement between Indigenous peoples and British rule in European settlements (now North America), ensuring the sovereignty of Indigenous peoples (Mashford-Pringle, 2011). For the time being Indigenous peoples had greater control over their land, and autonomy over health practices (*ability to engage*).

#### Economic Means and Acceptability, Availability, and Ability to Engage

Table 4 illustrates that in both countries' economic tools and incentives most often impact the acceptability (n=7 in Canada; n=5 in the United States), availability (n=8; n=7) and ability to engage (n=4; n=5) dimensions of access. Examples consist of the Health Transition Fund (Health Canada, 2002; 2001; Lavoie, 2018), Aboriginal Diabetes Initiative (Brooks et al. 2013) and First Nations Inuit Home and Community Care Program (FNIHCCP) (Health Canada, 2015; Lavoie et al. 2011) in Canada, and the Prevention and Public Health Fund (Warne & Delrow, 2017) and Special Diabetes Program for Indians in the United States (National Indian Health Board, 2017).

Between 1997 and 2001, the Health Transition Fund supported the development of pilot projects in many FNs communities across Canada (Health Canada, 2002). Communities had the option to participate in programming designed to fund and support health initiatives in areas of home care, integrated service delivery, pharmaceuticals, and primary healthcare (*availability*) (Health Canada, 2002). Pilot projects were shown to improve access to culturally appropriate and community-specific care (*acceptability*) and enhance the skills and capacity of community members and healthcare professionals involved in service delivery (*ability to engage*). In some

cases, community education and health awareness had also improved (*approachability*) (Health Canada, 2001). The pilot projects later informed contemporary community-based programming such as the Aboriginal Diabetes Initiative and the FNIHCCP, both of which remain active today and contribute similar positive-based outcomes (Brooks et al. 2013; Health Canada, 2015).

The Prevention and Public Health Fund in the United States was established through the 2010 Affordable Care Act. With this program, tribal communities may apply for federal funding to design and develop public health and preventative programming for their communities (*ability to engage, availability*), often specific to their health and cultural needs (*acceptability*) (National Indian Health Board, 2017). Some programs include tobacco prevention, child immunizations and infectious disease prevention (NIHB, 2017; Warne & Delrow, 2017). Similarly, the Special Diabetes Program for Indians is available for tribal communities to provide culturally appropriate diabetes care (*acceptability, availability*) (NIHB, 2017).

## Information Tools and Acceptability, Availability, and Ability to Engage

Table 4 demonstrates that informative policy instruments in both Canada and the United States impact the acceptability (n=4 in Canada; n=1 in the United States), availability (n=3; n=1), and ability to engage (n=9; n=1) dimensions of access. In all areas of access, heavier impacts exist in Canada compared to the United States, due to its greater use in informative instruments. Examples include the White Paper, Red Paper, and Indian Health Policy in Canada (Kelly, 2011; Mashford-Pringle, 2011; Crombie, 1979; Lavoie, 2013), the Concept Paper in the United States (Gurr, 2013), and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (Kelly, 2011; U.S. Department of the Interior, 2011) in both countries.

The 1969 White Paper and 1970 Red Paper mark official correspondence between the Canadian federal government and the National Indian Brotherhood (now Assembly of First Nations). The White Paper was commissioned by the federal government to consult with FNs partners and develop recommendations to improve Indigenous health and healthcare access across the country. Upon completion, the White Paper was exclusive of the collected FNs perspectives and rather, recommended to remove Indian status, abolishing the reserve system and Indian status rights, including the right to federal health services (*availability*) (Kelly, 2011; Mashford-Pringle, 2011). The National Indian Brotherhood responded with the Red Paper, emphasizing the "federal responsibility for health care to Indians and the desire to strengthen community control of health

programs" (Kelly, 2011, p. 2) (*availability, ability to engage*). In response, Canada released the 1979 Indian Health Policy, intended to establish a new relationship between the federal government and Indigenous peoples (Mashford-Pringle, 2011). The policy recognized and acknowledged the importance of culture and traditions in Indigenous health systems, as well as the integral role of community participation in healthcare delivery (*acceptability, ability to engage*) (Crombie, 1979; Mashford-Pringle, 2011). The Indian Health Policy remained an informative tool without a plan for implementation (Lavoie, 2013).

Furthermore, the 2009 Concept Paper in the United States was developed in partnership between the National Indian Health Board and Senate Committee on Indian Affairs to inform tribal health policy and healthcare reform. It recommended to improve local access to health services and expand treatment and program options, to better align with community-based needs (*availability, acceptability*) (Gurr, 2013). As a result, the policy paper went on to inform the reauthorization of the Indian Health Care Improvement Act in 2010.

In 2007 Canada and the United States federal governments signed the UNDRIP. This informative policy was signed to direct future Indigenous policy development and to guide relations between governments and Indigenous peoples (Kelly, 2011; U.S. Department of the Interior, 2011). With regard to health, Article 23 affirms:

Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions (United Nations, 2007, p. 18).

Canada and United States federal governments are thus accountable to the UNDRIP directives, especially those impacting one's *ability to engage* with health services.

In summary, acceptability, availability, and ability to engage are the most common dimensions of access impacted by federal health policies with minimal impacts on the approachability and affordability of health services. The latter will be discussed in detail in the proceeding chapter.

Moreover, policies in Canada do not have an associated impact on all five dimensions of access. In the United States one policy, the Affordable Care Act, meets this description, as it is described as: improving Medicaid informative tools to be culturally and language appropriate (*approachability*); expanding health coverage options to select services specific to individual needs (*acceptability*); reinstating the federal obligation to deliver quality health services in tribal communities (*availability*); improving the affordability of health coverage (*affordability*); and providing further funding and grant opportunities for tribal communities to continue to exercise self-determination in their health practices and delivery (*ability to engage*) (Ingram et al. 2012).

#### 6.3.2 Inductive Findings

This section describes thematic findings based on the emergent patterns identified in the literature. Four themes were identified: first, the differences in policy language and how the two countries address their **federal responsibly**; second, the impacts on access stemming from **healthcare funding** models; third, a **lack of care coordination** resulting from ambiguities in policies; and fourth, the contrast in **federal approaches to FNs and AIANs self-determination** in healthcare. With regard to the fourth theme, although the impacts on self-determination in healthcare have been previously discussed, the following section provides further explanation on how and why the policies impact self-determination. Appendix D lists how often each theme was discussed and from which sources.

#### Policy Language and Federal Trust Responsibility

As part of their policy analysis, Thierry et al. (2009), Warne and Frizzell (2014), Lavoie (2003; 2018), and Brooks et al. (2013) all look into the language of federal Indigenous health policies, identifying further implications on Indigenous health rooted in the content and terminology of the policies. Much of the literature employed similar methods, shedding light on how Canada and the United States differ in their policy "language" (Warne & Frizzell, 2014, p. 263; Thierry et al. 2009, p. 1543). Of interest to this study, the difference in policy language reflects differing approaches that Canada and the United States have taken to acknowledge their federal trust responsibility to deliver health services in FNs and AIANs communities.

In Canada, treaty and legislative agreements such as the Medicine Chest Clause and BNA hold the federal government accountable to fund and deliver health services in FNs communities (Young, 1984; Jacklin, 2008). The Indian Act holds the Governor in Council accountable to make regulations "to provide medical treatment and health services for Indians" (R.S.C., 1985, c. I-5). However, in subsequent policies the federal government continues to assert itself as delivering health services on "humanitarian grounds" (Lavoie, 2003) out of goodwill, as opposed to legal responsibility. In a report to the Auditor General of Canada on healthcare access in remote FNs communities, the federal government exclaims that FNs individuals "rely on the federal government's support to access health services within their communities" without mention of a legal responsibility to deliver such services (Government of Canada, 2015, p. 2).

This lack of acknowledgement of a legal responsibility stimulates a domino effect curtailing equitable access to acceptable and available healthcare services (Lavoie, 2003). As healthcare in Canada is primarily under provincial jurisdiction, in the absence of explicit federal obligations, there is ambiguity in jurisdictional responsibility to fund and deliver care in FNs communities (Lavoie, 2018; 2013). In addition, there is a disconnect between federal and provincial policies, creating gaps in community-based delivery of essential services. Federal programs may be administered in community, however, contain components that are contradictory to provincial regulations. This has resulted in further health inequities and restrains on access to care (J. Lavoie, personal communication, Sept 16, 2020).

Lavoie (2018) suggests the development of a national policy framework as one approach to address this issue. Within this proposed policy would be a clear description of federal obligations to deliver health services and principles for programs to follow, using the Canada Health Act as a template as it provides clear directions for mainstream Canadian healthcare. A mechanism would then be developed to fill in gaps between the national policy and provincial regulations, to ensure all health services are effectively and appropriately delivered in FNs communities without legal interruption (J. Lavoie, personal communication, Sept 16, 2020). A national policy framework would thus entrench federal obligations in policy, keep the federal government accountable, prevent offloading responsibilities to the provinces and instill a mechanism to connect provincial and federal policies, and protect FNs legal right to healthcare (J. Lavoie, personal communication, Sept 16, 2020).

In comparison, the policy language in the United States overtly acknowledges the federal trust responsibility to deliver healthcare to AIANs tribal nations, thereby largely avoiding such disconnects between federal and state policies. The IHCIA explicitly states "Federal health services to maintain and improve the health of the Indians are consonant with and required by the Federal Government's historical and unique legal relationship with, and resulting responsibility to, the American Indian people" (25 U.S.C. § 1601). By reinforcing transparent federal accountability, the United States has avoided the jurisdictional issues with regard to the delivery of care that are prevalent in Canada. Services are delivered in community, without legal interruption, however, pending available funds. Acceptability and availability issues persist as a result of an unwillingness to adequately follow through with federal responsibilities (U.S. Commission on Civil Rights, 2004; Warne & Frizzell, 2014). As described below, this reluctance to follow through has translated into severe under-resourcing and underfunding of the IHS (D. Warne, personal communication, August 27, 2020).

### Funding Issues

The literature points to health service funding models in both Canada and the United States as further complications impacting access to care for FNs and AIANs peoples. Examples include funding models within the operational policies of the FNIHB and IHS, as well as the funding arrangements described in the IHCIA, Transfer Act, Annual Appropriations Bills and the Congressional Budget Act in the United States.

Both the FNIHB and IHS allocate little funding into public health education, thereby impairing the approachability of health services in community (Orians et al. 2004; Warne et al. 2012; Lavoie et al. 2007). Moreover, to fund the Health Transfer Policy and the Purchased and Referred Care Program, both the FNIHB and IHS allocate funding based on historical expenditures, regardless of inaccurate or out-of-date data, population growth, nor changing community needs (King, 2012; Lavoie et al. 2007; Gregory et al. 1992). Specific to the HTP, funds are not reflective of the level of responsibility transferred to the community to effectively deliver health services as predetermined in the transfer agreement (Lavoie et al. 2007; Jacklin, 2008).

Furthermore, the IHCIA ensures annual appropriations from Congress to expand the variety of health services delivered to tribal communities as well as allocate funding in support of the IHS (Ross et al. 2016). Two challenges come with this arrangement. First, the Transfer Act

deems all AIANs health-related activities to be a matter of public health service (Warne & Frizzell, 2014), causing congressional appropriations to vary and to compete with other public health programming needs (Frias, 2003). Second, the 1974 Congressional Budget Act states that all appropriations from Congress in support of the IHS are subject to discretionary funding, as opposed to mandatory (Westmoreland & Watson, 2006; Provan & Carson, 2000; Frais 2003).

Westmoreland and Watson (2006) explain that this discretionary designation poses barriers to receiving equitable funding, as allocations vary on an annual basis, require community-led advocacy, and run the experienced risk of yearly reductions in appropriations. As a result, available services in community are depleted. Funding is not adjusted according to inflation, community-based needs nor changing demands of healthcare such as technology advances or new medications (Westmoreland & Watson, 2006). As a potential solution, both Frias (2003) and Westmoreland and Watson (2006) propose changing the IHS to an entitlement program, to receive mandatory funding, similar to that of Medicaid and Medicare. This solution runs the risk of changing IHS service eligibility criteria, currently established by tribal communities. Once an entitlement program, developing eligibility criteria falls under congressional authority, which may lead to new requirements in efforts to reduce spending, thus creating gaps in eligibility (D. Warne, personal communication, August 27, 2020).

### Lack of Care Coordination

Thirteen sources described a lack of care coordination in both FNs and AIANs communities, often referring to ambiguities and gaps in policies. In Canada, the Medicine Chest Clause sparks this pattern in history, failing to specify what constitutes the "medicine chest" and the specific services the federal government is obliged to deliver in FNs communities (Young, 1984). The Medicine Chest Clause has received political attention, undergoing provincial supreme court challenges and interpretations. However, the Canadian federal government has yet to take a concrete position detailing the practical meaning of the Clause with regard to health service delivery and availability (NCCIH, 2011a).

Similarly, the 1979 Indian Health Policy set out to improve FNs healthcare access, and opportunities to exercise community control (Crombie, 1979). Yet, the policy did not provide a sufficient explanation on how its goals would be achieved (Lavoie, 2013; Kelly, 2011). Canada's fragmented healthcare system is an additional contributor to the ambiguous nature of receiving

health services in FNs communities (G. Marchildon, Personal Communication, Sept 20, 2020). Canada employs a two-layered universal health coverage system, also known as Medicare, providing hospital and physician services to all constituents, funded by a tax-financed system. The care of FNs peoples was largely unaddressed with the introduction of the Canada Health Act and Medicare, rendering the financing and coverage of FNs peoples ambiguous and left to interpretation (Kelly, 2011; Lavoie, 2018). The experience of Jordan River Anderson is one such example. While waiting to receive community care, Jordan Anderson died in hospital as provincial and federal governments disputed over the financing responsibilities of his care (Lavoie 2018; Walker et al. 2018).

FNs peoples are covered by Medicare however, as it is provincially governed its services do not extend onto FNs reserves. If a necessary service is not available in their community FNs peoples must travel off-reserve by means of the Medical Transportation Policy; which in of itself is ambiguous (Lavoie et al. 2015). Eligibility criteria to seek care under the policy is consistently changing and largely dependent on the discretion of federal bureaucrats (Lavoie et al. 2015). As numerous policies and health programs seek to co-exist, a mechanism is required to fill in the jurisdictional gaps and improve the coordination of care (Lavoie, 2013; 2018).

In the United States, a lack of care coordination exists with the implementation of the Affordable Care Act (ACA) (Artiga et al. 2013; Frerichs et al. 2019). The adoption of the ACA is at the discretion of the state, meaning, its associated Medicaid expanded eligibility criteria and special provisions for AIANs peoples to purchase private health coverage is dependent on the state's decision to employ the policy. Medicaid expansion under state discretion has created inequalities within tribal communities, as many tribes expand across state lines. This issue is of particular concern for tribes in the midwestern regions of the United States, as very few states have adopted the ACA (Frerichs et al. 2019). As a result, unequal impacts on the availability and affordability of health services exists within and across tribal communities (Artiga et al. 2013; Frerichs et al. 2019).

### Federal Approaches to Self-Determination in Healthcare

Literature suggests that regardless of the policy instrument, policies focused on supporting or incentivizing self-determination keep the federal government in control over the human and financial resources necessary to exercise self-determination in healthcare (Government of Canada,

1994; Health Canada, 2008; 2006; Jacklin, 2008; Warne & Frizzell, 2014). Examples of these policies include the Health Transfer Policy (HTP), Health Integration Initiative, Inherent Right to Self-Government Policy, Non-Insured Health Benefits Program, Indian Self-Determination Education Assistance Act (ISDEAA), and Indian Health Care Improvement Act. The following discussion will focus on the HTP and ISDEAA.

The HTP and the ISDEAA are programs designed for communities to assume some level of control over health services and to tailor programs according to community-based needs and culturally appropriate practices (Smith & Lavoie, 2008; Warne, 2011; Shelton et al. 1998). In Canada, eligible communities may enrol with the HTP and assume control, however program funding remains based on historical expenditures, failing to adjust to changing community demographics (Lavoie et al. 2007; Smith & Lavoie, 2008). As the population grows and residents are living longer, with increasingly complex and financially-demanding chronic disease, communities receive inadequate funding to deliver appropriate services (Smith & Lavoie, 2008). Moreover, the HTP and its related health programming are designed and developed without FNs consultation, nor input on necessary services. Meaning, FNs communities may gain community control over health services that are designed by federal bureaucrats, which may or may not pertain to their needs, or fall within their cultural practices or preferences. Similar arguments pertain to the Non-Insured Health Benefits Program. FNs peoples are encouraged to enroll and take control of managing their own healthcare, however, are faced with heavy federal control, and minimally structured administrative processes to facilitate clear transfers of essential resources to receive care (G. Marchildon, personal communication, Sept 23, 2020).

In the United States, a specific provision has helped the ISDEAA to overcome this obstacle. Under title 5 of the ISDEAA, tribal communities may opt into a funding agreement known as the "638 compact". The "638 compact" instills allocations of a total budget amount to tribal communicates, allowing flexibility in the planning of health programs and resource allocation to better design and deliver services specific to community-based needs (Warne & Frizzell, 2014). Tribal communities thus independently assume full control over health service planning, delivery, and funding, with little intrusion from the federal government (D. Warne, personal communication, August 27, 2020). In comparison, the HTP in Canada is not protected by legislation, nor does it guarantee a specific level of funding or high degree of flexibility. Rather, and the greatest level of transfer allows communities to administer health programs specific to

their priorities, so long as programs align with a pre-established 3-5-year plan and mandatory services are provided (immunization, communicable disease control, environmental health) (Lavoie et al. 2010). Mental health services and traditional healing practices are not funded by the HTP, regardless of need expressed by communities (Smith & Lavoie, 2008). Although the HTP and ISDEAA share numerous similarities in their opportunities and objectives, distinct differences may translate into a policy lessons between jurisdictions.

# Chapter 7. Discussion

This chapter delves deeper into the findings, suggesting conclusions, highlighting the significance, and putting the results in the context of contemporary politics of today's society. The study's gaps, strengths and limitations, and suggestions for future research will follow this discussion.

### 7.1 Approaches to Indigenous Health Policy

Based on the findings federal policies in Canada and the United States shared similar impacts on access, however, differ in policy instruments. This section explores these findings in depth, providing potential explanations.

### 7.1.1 Similar Impacts on Access

Impacts of policies on access to care may reflect differing perspectives at the policy table and priority areas at the time of decision making. For example, delivering health services that are culturally appropriate, community-based, and offer the opportunity for community control, are consistent policy objectives across both countries, suggesting acceptability, availability, and ability to engage to be policy priorities. Minimal impacts on approachability and affordability may reflect a gap in prioritizing these areas of access.

### **Approachability**

FNIHB and IHS operating and funding policies in Canada and the United States produce limited opportunities for community engagement (Lavoie et al. 2016; Warne et al. 2012). The Health

Transition Fund and Aboriginal Diabetes Initiative were the only programs identified in Canada to receive federal funding in support of community outreach and educational programming (Health Canada, 2001; Brooks et al. 2013). Moreover, both FNIHB and IHS fail to recognize cancer screening and community-based education as within the scope of federally-funded health services (Lavoie et al. 2016; Warne et al. 2012). The Cervical Cancer Mortality Prevention Act in the United States is designed to support community-based education, however it is mainly funded through the Centers for Disease Control and Prevention, not the IHS (Orians et al. 2004). Other related cancer screening programs operate under the IHS funding policies, producing minimal program impacts (Orians et al. 2004). This limited focus on approachability may also be alluded to severe under funding of public health programming within the IHS and across the United States (D. Warne, personal communication, Aug 27, 2020; Friedler, 2020).

### **Affordability**

Only two policies in Canada, the Medical Transportation Policy, and the amendments to the Indian Act in Bill C-31 were associated with the affordability of health services, with impacts on an individual and community level. The Medical Transportation Policy impacts the individual, as the policy operates under a reimbursement system and patients must first pay out-of-pocket to receive financial support for health services outside of the community (Health Canada, 2010). As found by the First Nations Information Governance Centre (2018) *Regional Health Survey,* many First Nations peoples identified the unaffordable nature of transportation costs as a primary barrier to receiving essential care. Furthermore, Lavoie and Forget (2008) describe Bill C-31 and its restrictions on who may receive health services based on Indian status and past marital relationships. Prior to Bill C-31, FNs women lost their Indian status when married to a non-FNs partner. The Act corrected the discriminatory policy and many FNs women regained their status in 1985, however, children of these relationships were not supported by the changes. Such children are without Indian status and right to healthcare. As the FNIHB budget does not accommodate for the additional need, communities must provide the financial support to deliver care despite limited budgets; thereby cultivating affordability impacts on a community-level.

In the United States, five policies were associated with affordability (appendix E), and in comparison to Canada, these policies are designed to limit financial burdens for the individual and community. For example, the 2010 ACA expanded Medicaid eligibility criteria and includes

special considerations specific to AIANs peoples to purchase health insurance shaped around individual-based needs (Indian Health Service, 2017). Moreover, the ISDEAA provides multiple opportunities for communities to finance and fund health services, including the ability to generate third-party revenues, evidently expanding the basket of community-covered services (Warne, 2011).

In summary, the content of the policies demonstrate priority areas in availability, acceptability, and ability to engage, and an absence in approachability. Interestingly, policy impacts on affordability are minimal for both countries, however, differ in either improving affordability or posing financial risks to the individual or community. This contrast may suggest a difference in how the two countries prioritize the issue of affordability of health services in their decision-making practices.

### 7.1.2 Different Policy Instruments

The United States employs a greater use of legislation compared to Canada, however, the impacts on access remain the same, which begs the questions: *how* this is achieved and *why*. The following discussion will attempt to provide explanations.

The National Collaborating Centre for Indigenous Health (NCCIH, 2019) characterizes access to care in FNs communities as a social determinant of health, describing three pillars to equitable access – accessibility, availability, and acceptability. The definitions of each are slightly different from the accessibility framework employed by this study, as accessibility refers to physical access and local proximity of health services; availability touches on human resources and fully equipped health facilities to deliver care in community; and acceptability deals with culturally safe and professional care, free from racism and biases (NCCIH, 2019). To simplify instruments and impacts on access, the NCCIH definitions will be used. Table 5 illustrates how in each scenario the United States takes a legislative approach while Canada does not.

Table 5. Policy Instruments and the 3 Pillars to Equitable Access to Care

	Canada	United States	
Type of Access	Policy & Instrument	Policy & Instrument	
(according to			
NCCIH, 2019)			
Accessibility	First Nations and Inuit Home and	Affordable Care Act (2010)	
	Community Care Program (1999)	- Legislated	
	- Not Legislated		
Availability	Health Transfer Policy (1986)	Indian Self-Determination Education	
	- Not Legislated	Assistance Act (ISDEAA) (1975)	
		- Legislated	
Acceptability	Truth and Reconciliation	Indian Health Care Improvement Act	
	Commission of Canada (2015)	(IHCIA) (2010)	
	- Not Legislated	- Legislated	

#### *How is this achieved?*

In terms of accessibility, the FNIHCCP provides funding and training to deliver essential home-based services to eligible FNs peoples living in community, whereas the legislated Affordable Care Act under Section 4002 established the Prevention and Public Health Fund, designed to fund and deliver community-based services dependent on expressed needs (Warne et al. 2017). For availability, the Health Transfer Policy provides necessary financial and human resources to deliver a pre-determined basket of services at local federally-funded health offices, centres, or nursing stations (Lavoie et al. 2015). The ISDEAA follows a similar structure, however, its legislation protects funding of services and tribal autonomy over health planning.

Lastly, the Truth and Reconciliation Commission of Canada provides recommendations for policy-makers with explicit mention of the need for culturally appropriate care. Call to Action #23 recommends to "increase the number of Aboriginal professionals working in the health-care field; ensure the retention of Aboriginal health-care providers in Aboriginal communities"; provide cultural competency training for all healthcare professionals" (TRC, 2015, p. 3). In 2015, Prime Minister Justin Trudeau promised his government will "in partnership with Indigenous

communities, the provinces, territories, and other vital partners, fully implement the Calls to Action of the Truth and Reconciliation Commission" (Prime Minister of Canada, 2015). Meanwhile in the United States, Congress passed legislation (IHCIA) requiring all IHS staff to receive and complete culturally relevant training, especially within the scope of community-based mental health services (Heisler, 2011).

### Why?

An explanation on *why* there is a differing use of legislation in federal Indigenous health policy is twofold. After consultations with Indigenous health policy experts, the reasoning may come down to differences in political culture (G. Marchildon, personal communication, Sept 23, 2020) and national cultures of solidarity (J. Lavoie, personal communication, Sept 16, 2020). In terms of political culture, the United States presidential system results in greater legislation, based on its operations within House of Representatives and the Senate. Regardless of the policy issue or area, legislative decisions are negotiated between the Senate and House of Representatives at the federal level. This structure is replicated at the state level. All political actions move through this environment, favouring the adoption of clear and precise, rules and guidelines. Informative tools without legislation are less likely to be passed. Canada's parliamentary system differs. The decentralization of Canada's federation creates multiple levels of government, all playing a role in setting policy directions alongside the Cabinet. Moreover, legislation specifically in areas of health, are less likely to be passed at the federal level, as it must be transferrable and flexible to accommodate for multiple levels of government (federal, provincial, municipal). Thus, federal policies with loosely structured guidelines are more often the result in Canada.

An alternative explanation is the differing culture of solidarity. Canada tends to be more relational than the United States, as reflected in national values attached to Canada's universal health coverage system. Tuohy (2018) explains that Medicare is part of the "national identity" of Canada, reflecting a "sharing community" (p. 12). This sense of social solidarity is likely translated into policy-making practices in Canada, as policies are often the outcome of relationships and reaching mutual understandings and agreements (J. Lavoie, personal communication, Sept 16, 2020). The New Federal Government Indian Relationship, Indian Health Policy, Royal Commission of Aboriginal Peoples (RCAP) and the Truth and Reconciliation Commission are all precise examples, that have emerged from discussions and focusing on relationships. For example,

the RCAP commits the federal government to a new relationship, focusing on distinct priority areas to build on and improve Indigenous health status across the country (Kelly, 2011), however, it does not involve the passing of legislation. These documents pave the way for further policy and program development, ultimately bypassing a legislative process.

Moreover, this relational tone underpinning federal government actions in Canada is also likely contributing to the relationship between informative tools and associated impacts on the ability to engage dimension of access (refer back to Table 4). Many of the informative policies, released after 1970, encourage and enable opportunities to exercise self-determination in healthcare. Kelly (2011) describes these policies as "policies of recognition" (p.2) i.e., an era of supporting self-determination and Indigenous culture in healthcare services. This era comes after a series of federal policies rooted in cultural assimilation and discrimination against Indigenous peoples and cultures. The wave of specifically informative policies identified in this review (New Federal Government Indian Relationship, Indian Health Policy, Inherent Right to Self-Government Policy, RCAP) which seek to support self-determination are thus likely due to Canada's relational approach to building and restoring relationships with Indigenous peoples.

The United States takes a more litigative approach to Indigenous health policy making, which may also be explained using the health system as an example. The privatization of healthcare in the United States has lent itself to be a corporatist society and far from a "sharing community". Healthcare is thought to be an individual right, and policy decisions are made from the point of maximizing profits, as opposed to building relationships. Private healthcare systems demand strict rules and guidelines, deeming legislation an appropriate approach. Relationship-building with AIANs communities still holds some purpose in United States legislation, such as the 2010 Indian Health Care Improvement Act, which set out to strengthen communicative relationships between federal and tribal governments (Warne et al. 2017). However, relationship-building does not play a significant role as observed in Canada. Nonetheless, these observations help to explain the relatively high use of informative tools in Canada, compared to the United States.

### 7.2 "Invisible Policies"

"Invisible Policies" were also identified in Canada in this review. Lawford (2016) describes the Evacuation Policy as an "invisible policy", as it informs clinical practice for federally-funded

nurses working in FNs communities, although it has yet to be documented in any policy directives or legislative statutes. Rather, it is expressed through the FNIHB *Clinical Practice Guidelines for Nurses in Primary Care*, dealing with obstetrics and pregnancy in FNs communities (FNIHB, 2011). The "invisible" Evacuation Policy ensures that expecting FNs mothers living in their community travel to urban centres off-reserve to have a hospital delivery regardless of baby's condition (Lawford et al. 2018).

Jordan's Principle is another example of an invisible policy. It is also without documentation nor legislation, rather, it is a federal principle and "legal requirement resulting from the Orders of the Canadian Human Rights Tribunal" in which provincial and federal governments must abide (AFN, n.d.a). This lax approach has been contested, describing the principle as taking a loose and ambiguous structure, resulting in difficulties in regulating and monitoring its implementation in practice (Walker et al. 2018). Walker et al. (2018) explain that the lack of clarity embedded in Jordan's Principle creates a disconnect between federal and provincial governments, causing unequal access and implications for receiving timely care. As long as the principle remains "unwritten", it fails to keep the federal government accountable and contributes to further health inequities among FNs children and youth (Walker et al. 2018).

The policy framework employed by this study was able to capture the Evacuation Policy and Jordan's Principle, as both are strictly implemented into practice, falling into the regulation category. It is in their implementation processes where clear documentation may serve as a benefit to improve transparency and accountability of the federal government.

# 7.3 The Findings and Today's Political Context

Policy issues often gain traction as a result of a national crisis or disaster (Kingdon, 2011). The current impacts of the COVID-19 global pandemic are key examples, shedding light onto health and social issues across international borders. However, the pandemic has also highlighted cases of strength and resilience in Indigenous communities within Canada and the United States.

In Canada, FNs communities have come together to implement community-based public health protocols, successfully controlling the spread of infection, flattening the curve ahead of the rest of Canada (Banning, 2020). The community's response to the pandemic has thus demonstrated the positive outcomes of exercising self-determination. Protocols are specific to community needs

and include implementation of appropriate measures to protect vulnerable populations and keep Elders safe (Banning, 2020; Auger, 2020). For example, Haida Gwaii in British Columbia and Beausoleil FNs in Ontario have restricted non-essential travel into their communities by restricting access onto their islands to community members only (Slepian & Gall, 2020; Beausoleil First Nation, 2020) and closing their beaches and parks to the general public (Beausoleil First Nation, 2020).

Despite such strides, the pandemic has also brought to light historic issues of inadequate and over-crowded housing, contaminated water sources, and severely underfunded and underresourced health systems which are all community-based catalysts to the spread of infection (Johnson, 2020; Carling & Mankani, 2020). FNs leaders and academic allies have called on Canada's federal government to uphold its legal obligation and improve its support, by allocating the necessary resources for FNs communities to fully equip their health facilities and continue to implement strategies proven to keep their community safe and healthy from the virus (Johnson, 2020).

Meanwhile in the United States tribal communities have also come together to protect their community, implementing public health measures to control the spread (Friedler, 2020), however such efforts are met with political barriers. In Pine Ridge and Cheyenne River reservations, tribal communities set up COVID-19 checkpoints to facilitate contract tracing and control who may enter into the community, turning away those infected with the virus. In response, the Governor of South Dakota attempted to shut down the checkpoints, ultimately impeding on tribal sovereignty and violating their right to self-government (Friedler, 2020). Moreover, the Trump administration withheld COVID-19 relief funds and delayed appropriations for tribal communities (Davidson, 2020), and as a result, communities such as Navajo Nation were unable to develop public health strategies to control the virus, causing the highest infection rate in the country (Davidson, 2020; Doshi et al. 2020).

COVID-19 has also emphasized the inequities surrounding IHS basic health facility structure, and its severe underfunding. Warne (2020) explains "our ability to investigate outbreaks and conduct surveillance in a public health crisis is really diminished because of policy decisions from Congress, to never fully fund IHS" (Friedler, 2020). The need for culturally competent care is also brought to light, as public health strategies designed to combat the virus are developed from a western-dominated standpoint, absent of Indigenous worldviews. For example, setting

restrictions on tobacco use, largely neglecting its cultural significance in Indigenous ceremonies (Friedler, 2020).

The on-going outcomes of COVID-19 reflect the findings of this study. This public health crisis has provided clear and explicit examples of severe underfunding of health services, as well as barriers to exercising full self-determination, to accessing fully-equipped health services at the community level, and to culturally-appropriate care. As the public health issues of the pandemic continue to gain political attention, this study may serve as a resource for policy makers searching for policies to build from which are at the core of FNs and AIANs healthcare access. The significance of this study is especially important as policy windows begin to open in Canada and the United States.

In Canada, the political agenda momentarily switched focus to FNs health issues, as the federal government announced \$82.5 million in support of culturally appropriate mental health programming in FNs communities (Indigenous Services Canada, 2020). In the United States, health and social issues are the minds of constituents as the country heads into a federal election in November 2020. In terms of AIANs health issues, the Trump administration has yet to release any plans to improve the IHS system and funding. However, the leader of the opposing democratic party, Joe Biden, has explicitly stated his plan to support tribal sovereignty both through funding arrangements and policy strategies, planning to continue the legacy of the Obama administration (Biden-Harris, 2020). Thus, as policy issues are heightened, and changes on the horizon, the significance of this research is highly relevant in today's society.

## 7.4 Identified Gaps in the Literature

This scoping review identified three gaps within the literature, highlighting areas which may benefit from further research. First, only one study provided a comparison of Indigenous health policies in Canada and the United States (Mashford-Pringle, 2011), suggesting room for additional comparative policy analysis across the two countries. Second, the limited impacts of federal health policies on the approachability dimension of access may point to a gap in policies addressing public health outreach in primary care, especially in the context of Indigenous healthcare settings. Only two policies in both Canada and the United States impacted this area of access, raising the

question of whether and why health education and other public health measures have yet to receive significant attention by Indigenous health policy actors.

The final gap pertains to availability of policy documents in Canada. The original Health Transfer Policy, Evacuation Policy and Non-Insured Health Benefits Program are all unavailable to the public and thus were not identified by this scoping review. After ten years of the Health Transfer Policy, 41% of eligible communities enrolled in a transfer (Health Canada, 2005), however, their transfer agreements are not publicly available to review nor to learn from. In March 2018, 819,977 FNs peoples from across Canada were eligible for the Non-Insured Health Benefits Program (Government of Canada, 2020a), however researchers are unable to attain the original documents of both the Health Transfer Policy and the Non-Insured Health Benefits Program (G. Marchildon, Personal Communication, Sept 23, 2020). Moreover, all FNs mothers are subject to the Evacuation Policy, regardless of the condition of their pregnancy (Lawford, 2016). The lack of documentation of such impactful policies may reflect the limited level of transparency within the Canadian federal government. Transparency was not explored in this study; thus, further research is suggested to investigate this area and whether or not clear, accessible documentation plays a role in impacts on access.

# 7.5 Strengths and Limitations

This study had a number of strengths. The validation interviews served as a primary strength and "added value" to the study (Arksey & O'Malley, 2005). The additional perspectives stemming from Indigenous health policy experts brought forward new insights on the impacts on access from select policies, lending perspectives the literature was not able to capture. For instance, the validation interviews largely informed explanations on the differing use of policy instruments. The interviews uncovered new insights, suggesting the differences allude to political culture and national solidarity. The new insights then prompted further exploration into the legalisation practices in the two countries.

Furthermore, the validation interviews also provided additional resources to explore. These resources helped to inform and strengthen the findings, as well as provide additional background information relating to policy practices; health statistics; and advocacy groups for FNs and AIANs healthcare both in Canada and the United States.

However, there were also some limitations with this study. One limitation is that the research process was heavily influenced by my own perspectives, largely informed by my western and settler worldviews. I thus made a point to challenge my perspectives and methods throughout the research process, through consultations with my thesis committee and validation interviews with Indigenous researchers.

With regard to the scoping review protocol, data collection was restricted to collecting articles and sources written in English, due to my personal language constraints. Scoping reviews are not meant to be exhaustive, thus it is also possible that additional policies and relevant sources are not included in the study. Additionally, the credibility of scoping reviews is enhanced by the inclusion of a second reviewer at the charting and data analysis stage. This study included a second reviewer for screening, but not for charting and analysis, thus reducing somewhat the credibility of the findings. Though the validation interviews helped to overcome these two limitations.

Furthermore, I was unable to chart and summarize actual evidence-based positive and negative policy impacts on access to care, due to the limited number of policy evaluations found in the literature. Moreover, the accessibility framework included perspectives of Indigenous populations in Canada and the United States, however, it is not specific to FNs and AIANs values and worldviews. These two limitations thus present areas of research that would benefit from further exploration, as policy evaluations are recommended, as well as framework development more tailored to both FNs and AIANs perspectives.

Validation interviews helped to expand my understanding of the findings, however, the interview questions were based on my own interpretations, thereby setting a boundary to the scope of their response. The interviews were also limited in numbers, due to time constraints and practicalities of the COVID-19 pandemic and work-related disruptions.

#### 7.6 Future Directions

This research has set out to broadly inform future policy analysis, highlighting key policies to investigate and impacts on access to further understand. Additional questions have come forward, touching on areas of self-determination, political cultures, public health initiatives, and future provincial and state policy analysis. Based on the similar structures of the HTP and ISDEAA, future research is highly recommended to compare evaluations of these programs, both in terms

of the health outcomes and measures on the ability to exercise self-determination. Very few studies have evaluated the ISDEAA (D. Warne, personal communication, Aug 27, 2020) and based on its unique provisions to protect tribal sovereignty, it would be interesting to see if such regulations translate into better health outcomes, and whether there are policy lessons hidden within its language and structure that may help to inform the HTP.

The differing political cultures between Canada and United States sparks further questions on how negotiations play out, between Indigenous communities and federal governments. Future research is suggested that looks into the legal rights and capacities of FNs and tribal communities, to gain insight into whether the legal environment would impact the use of policy instruments in both countries. As this study did not evaluate the quality of evidence identified, it is unknown if the use of policy instruments from either country is preferred or detrimental to healthcare access. A greater exploration into the legal rights and political actions taken by FNs and AIANs communities, informed by a qualitative study, would help to fill this gap.

In reference to the ambiguities and gaps between federal and provincial health policies in Canada, future work is suggested to explore possible mechanisms to close the gaps and connect the two health systems. It is highly likely that such mechanisms were set in place during the COVID-19 pandemic, linking FNs communities with provincial and federal governments, in efforts to provide essential health services and resources without political disruptions and contain the spread of the virus (J. Lavoie, personal communication, Sept 16, 2020). A scoping review is strongly recommended, to gather future publications outlining such efforts and to learn from their experiences. This sort of study may help to establish mechanisms and improve coordination of care for FNs peoples dealing with jurisdictional disputes.

Finally, it is recommended to extend the scope of this study and to look into impacts stemming from provincial and state policies. Important policies such as tripartite self-government agreements in Canada, and state relationships with tribal nations, would help to inform a more holistic perspective on the impacts on access, and would further improve the opportunity for policy lessons.

# Chapter 8. Conclusion

This scoping review sought to answer the following research questions: What is known about federal-level health policy and the associated impacts on access to primary healthcare services for FNs and AIANs communities in Canada and the United States? And, what are the similarities and differences between the two countries? After exploring 57 sources and consulting with three Indigenous health policy experts, I am able to answer such questions.

Thirty federal Indigenous health policies in Canada and twenty-three in the United States were identified in the review, all linked to one or more dimensions of access. Interestingly, both countries shared similar associated policy impacts on the acceptability and availability of care, as well as the ability to engage with health services. Minimal impacts on the affordability and approachability dimensions were also shared between the two countries. In terms of answering the *how* health policies impact access, this research shed light onto the policy instruments involved in FNs and AIANs healthcare access. It uncovers impacts stemming from policy language and funding structures embedded in policy frameworks.

This research began with a phenomenon: two countries with differing political societies and healthcare systems, experiencing similar health inequities and inequitable access to care in Indigenous communities in which their federal governments are legally responsible to deliver health services. This study serves to provide a comprehensive overview and understanding of this *inequitable access to care*, by highlighting both the policies involved, and the common dimensions of access affected. It offers a view into the role policy instruments play in impacting access, as well as insight into how and why the Indigenous health policy environments differ between the two countries. Nevertheless, as policy actions lead to upstream approaches to public health challenges (NCCDH, 2014), this study is a starting point for policy analysis in a search for cross-jurisdictional lessons targeted towards improving access to care. Whether it is focusing on the acknowledgement of the federal trust responsibility, or the proceeding actions that follow, future research is highly recommended to take on this exploration, and to solve the complicated puzzle that is healthcare delivery in Indigenous communities in Canada and the United States.

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# **Appendices**

Appendix A. Search Strategy for Academic Databases

### PAIS Index, 365 results:

(same strategy for sociological abstracts, 450 results)

((ti("FNMI") OR ab("FNMI") OR mainsubject("FNMI")) OR (TI,AB("FNIM") OR mainsubject("FNIM")) OR (ti("AI/AN\*") OR ab("AI/AN\*") OR mainsubject("AI/AN\*")) OR (ti("native American") OR ab("native American") OR mainsubject("native American")) OR (ti("Indians of North America")) OR ab("Indians of North America")) OR mainsubject("Indians of North America")) OR (ti("native Canadian")) OR ab("native Canadian")) OR mainsubject("Indians of North America")) OR (ti("native Canadian")) OR ab("native Canadian")) OR mainsubject("native Canadian")) OR (subject("Native North Americans")) OR (TI,AB(("first nation")) OR "first national") OR "first nationals" OR "first nations" OR "first nationwide")) OR TI,AB(Indian\*) OR TI,AB(Aboriginal\*) OR TI,AB(Indigenous) OR TI,AB(("american indian")) OR "mainsubject". EXACT("Indian Reservations")) OR MAINSUBJECT. EXACT("Indian Reservations")) OR MAINSUBJECT. EXACT("American Indians")) OR (MAINSUBJECT. EXACT("North American Cultural Groups") OR MAINSUBJECT. EXACT("Indigenous Populations")))

### AND

(TI,AB(access NEAR/3 (healthcare OR "health care")) OR TI,AB(access NEAR/3 ("health services")) OR (MAINSUBJECT.EXACT("Health Care Utilization") OR MAINSUBJECT.EXACT("Health Care Services Policy") OR MAINSUBJECT.EXACT("Health Care Services") OR MAINSUBJECT.EXACT.EXPLODE("Primary Health Care")) OR MAINSUBJECT.EXACT("health Services") OR subject("Health services utilization") OR subject("Health care access") OR subject("Health care"))

**AND** 

((TI,AB("health polic\*") OR TI,AB(polic\*) OR TI,AB(legislation) OR TI,AB(law) OR TI,AB(laws) OR TI,AB(statute\*)) OR MAINSUBJECT.EXACT.EXPLODE("Legislation") OR MAINSUBJECT.EXACT("Health Policy"))

### Native Health Database, 193 results:

("FNMI" OR "FNIM" OR "AI/AN" OR "native American" OR "Indians of North America" OR "native Canadian" OR "Native North Americans" OR "first nations" OR "first national" OR "first nationalist" OR "first nationally" OR "first nationals" OR "first nations" OR "first nations" OR "first nationwide" OR "Indians" OR "Aboriginal" OR "Indigenous" OR "American Indians" OR "Alaska native" OR "Indian Reservations" OR "American Indian Reservations" OR "North American Cultural Groups" OR "Indigenous Populations")

AND

("health policy" OR "policy" OR "legislation" OR "law" OR "laws" OR "statute")

**AND** 

("access to healthcare" OR "access to health care" OR "healthcare access" OR "health care access" OR "access to health services" OR "health services access" OR "Health Care Utilization" OR "Health Care Services Policy" OR "health Care Services" OR "Primary Health Care" OR "health Services" OR "Health services utilization" OR "Health care access" OR "Health care")

## Appendix B. Key Words for Grey Literature Searches

### iPortal:

first nations AND access to care first nations AND health policy american indians AND access to care american indian AND health policy

#### **Government of Canada Publications:**

health policy and indigenous health policy and first nations health policy and aboriginal health policy and indian first nations and health policy and health services indigenous and health policy and health services aboriginal and health policy and health services indian and health policy and health services first nations and health policy and access to care indigenous and health policy and access to care aboriginal and health policy and access to care indian and health policy and access to care first nations and health policy and healthcare (and health care) access access to care and indigenous access to care and first nations access to care and indian access to care and aboriginal health care and indigenous health care and aboriginal health care and first nations health care and indian

### **NCCIH:**

access to care AND policy health care access health policy

#### NCCDH:

access to care AND policy health care access Indigenous or first nations or aboriginal health policy and indigenous health policy and first nations

#### NCCHPP:

first nations indigenous aboriginal

# National Indian Health Board, US Department of Interior Indian Affairs, Indian Health Services:

(American indians OR alaska natives) AND (access to care OR access to health services) AND (health policy OR legislation)

### **Indigenous Services Canada:**

(access to care OR access to health services) AND (health policy OR legislation) policy health care health care access healthcare

### **First Nations Inuit Health Branch:**

(access to care OR access to health services) AND (health policy OR legislation) policy health care health care access healthcare

# Appendix C. Inclusion and Exclusion Criteria

Table 6. Inclusion and Exclusion Criteria

Inclusion	Exclusion			
Population concept:	Population concept:			
- Focused on FNs and/or AIANs (NOT metis,	- Focused on alternative population group outside			
Inuit, non-FNs/non-AIANs)	Canada/United States with no discussion on			
- For Canada – Focused on FNs living on-	FNs/AIANs			
reserve/in community (not off-reserve)	- For Canada/FNs – Focused on off-reserve populations			
	- Focused on sub-populations e.g., populations with a			
	specific illness/specialized chronic disease. Ex: case			
	studies on HIV/AIDS programming			
Intervention concept:	Intervention concept:			
- Must be focused on FNs/AIANs-specific	- Policy only mentioned (ex: in implications) and is			
federal-level health	NOT the focus throughout the article			
policy/program/initiative	- Policy focus outside of primary healthcare sector e.g.,			
- Health policy focus throughout article	nutrition, gender, harm reduction, abortion, climate			
- May include 'unwritten policies' e.g.,	change and/or drug policies			
UNDRIP, Jordan's Principle, Evaluation	- Focused on the problem i.e., access to care without			
Policy – all policies, however, not officially	discussion on policy			
documented	- Programs/initiatives not relevant to accessing primary			
- May include <b>programs/initiatives</b> with	healthcare services			
clear objectives or expressed impacts on	- Outdated programs/initiatives with no relevance to			
access to healthcare services (common for	accessing healthcare services, were never enacted or			
Canada as there are fewer official policies)	only in planning/goal-setting stage			
- Outdated programs/initiatives with	- Policy discussions/recommendations that are more			
relevance to accessing healthcare services	general and non-specific to any established			
(refer to exclusion for examples when NOT	policy/program/initiative (keep for discussion, not for			
to include)	analysis)			

- Policy discussions/recommendations that				
are specific to an established				
policy/program/initiative				
Outcome concept:	Outcome concept:			
- Explicitly addresses access to primary	- Only focused on access to care (no policy focus – see			
health care services (preventative care,	above) ex: focus is on primary healthcare utilization			
health promotion, screening, pregnancy and	rates			
delivery, and/or chronic care management	- Focused on health disparities, solely barriers to care,			
initiatives that are community-based, etc.)	access to safe injection sites, budgetary concerns			
- Explicitly mentions barriers to accessing	- Outside primary healthcare services e.g., access to			
care (financial, cultural, physical, etc.)	specialist care, dental/vision care, mental health*			
- Discusses a policy/program/initiative with				
an objective/purpose that may be directly	*As of now, no Indigenous mental health policy exists in			
linked to accessing primary health care	Canada/United States, thus, only include if the article			
services	discusses a policy brief on the topic or, the impacts on			
	mental health from an alternative policy			
Location/Jurisdiction:	Location/Jurisdiction:			
- Canadian/American federal-level	- Jurisdiction outside Canada/US			
jurisdictions	- Focused on Canadian provincial policies/off-reserve			
- On-reserve in Canada	FNs communities			
	- Provincial/state policies			
Language:	Language:			
- Written in English	- Not written in English			
	Type of Document:			
	- Opinion-based, commentary, personal emails, etc. (use			
	for discussion, not analysis)			

# Appendix D. Charted Variables and Collected Sources

# LEGEND:

Key findings for thematic analysis:

Government Funding Lack of Care control over Selfissues Coordination Trust Responsibility

Determination

Table 7. Charted Variables and Collected Sources

	Author	Year	Title		Policy/Policies	Key findings for thematic	Evaluation or
				Population		analysis	Discussion?
1.	Artiga, S.,	2013	Health coverage and care		Affordable Care Act	Jurisdictional divide in policy	Discussion
	Arguello, R., &		for American Indians and			creates unequal/inequitable	
	Duckett, P.		Alaska Natives	AIANs		access to health services	
2.	Brooks, L.,	2013	Policy (mis)alignment:		Indian Act;	Policy language and intentions	Discussion
	Darroch, F., &		Addressing type 2 diabetes		Aboriginal Diabetes	has eroded cultural practices,	
	Giles, A.		in Aboriginal communities		Initiative;	impairing access to culturally	
			in Canada		Non-Insured Health	safe care, program	
					Benefits Program	development not addressing	
				FNs		root causes	
3.	Bylander, J.	2017	Propping up Indian health		Affordable Care Act	Using economic means to off-	Discussion
			care through Medicaid.			load federal responsibilities to	
						provide care for AIANs, poses	
						threats for AIANs health	
				AIANs		coverage	
4.	Frerichs, L.,	2019	Regional differences in		Affordable Care Act	Inequities in policy, policy	Evaluation
	Bell, R., Lich,		coverage among American			discoordination across regions	
	K., Reuland, D.,		Indians and Alaska			leads to inequities in insurance	
	& Warne, D.		Natives before and after			coverage	
			the ACA	AIANs			
5.	Frias, H.	2003	Should Indian health care		Annual Interior	Inequitable funding policies	Discussion
			be an entitlement.		Appropriation Bill	restricting self-determination	
				AIANs		and access to care	

6.	Gov of Canada,	1979	Indian Health Policy		Indian Health Policy	Addresses approaches to	Original Policy
	Health and					improve Indigenous health	Document
	Welfare Canada,					however without a clear plan,	
	National Indian					keeps up ambiguous theme of	
	Brotherhood			FNs		Canadian policies	
7.	Gov of Canada,	1986	An evaluation of the Adult		Adult Care Program	Unclear policy	Evaluation
	Indian and		Care Program and its			framework/structure linked to	
	Northern Affairs		component health and			unequal distribution/utilization	
	Canada		home support services for			of services, unmet needs and	
			elderly and disabled			inequitable access	
			Indians on Manitoba			_	
			Indian reserves	FNs			
8.	Gov of Canada,	2015	Access to health services		Medical	Insufficient	Evaluation
	Office of the		for remote First Nations		Transportation	documentation/coordination of	
	Auditor General		communities		Policy;	policies, services not allocated	
					Health Transfer	to meet community-needs	
				FNs	Policy		
9.	Gov of Canada,	1994	Health services		Health Transfer	Self-determination limited due	Evaluation
	Privy Council		development in an		Policy	to federal fiscal control	
	Office, Royal		Aboriginal community: the				
	Commission on		case of Peguis First Nation				
	Aboriginal		/ by Benita Cohen.				
	Peoples			FNs			
10.	Health Canada	2001	Final report, Health		Health Transition	Project which engaged	Evaluation
			Transition Fund Project		Fund	community improved access to	
			NA1012: Diabetes			care specific to community	
			Community/Home			needs	
			Support Services for First				
			Nations and Inuit.	FNs			
11.	Health Canada	2008	Health Integration		Health Integration	Improved access, however,	Evaluation
			Initiative (HII): First		Initiative	only with select communities	
			Nations and Inuit Health			and with fiscal limitations	
			Branch, evaluation report.	FNs			

12.	Health Canada,	2006	The evaluation of the First		Health Transfer	Self-determination hindered by	Evaluation
12.	Departmental Departmental	2000	Nations and Inuit Health		Policy	government control over	Z varaation
	Audit and		Transfer Policy: final		Toney	necessary resources	
	Evaluation		report.			necessary resources	
	Committee		Teport.	FNs			
13.	Health Canada,	2015	First Nations and Inuit	1110	First Nations and	FNIHB explicitly neglecting	Discussion
10.	First Nations	2013	Home and Community		Inuit Home and	federal obligation to deliver	Discussion
	and Inuit Health		Care (FNIHCC): 10-year		Community Care	health services, first time	
	Branch		plan (2013-2023).		Program	culturally appropriate care	
	Branch		piun (2013-2023).		Trogram	emphasized in FNIHB	
				FNs		programming	
14.	Health Canada,	2017	Jordan's Principle and	1110	Jordan's Principle	Policy to address jurisdictional	Discussion
1	First Nations	2017	Canada's approach to		vorawii s i iiii eipie	confusion over the provision of	2 15 4 615 51 511
	and Inuit Health		support its			health services. Ambiguous	
	Branch		implementation.			policy to address concerns of	
				FNs		ambiguous responsibilities	
15.	Health Canada,	2010	Medical transportation		Medical	Policy recognizes importance	Original Policy
	First Nations		policy framework: Non-		Transportation	of culturally appropriate care,	Document
	and Inuit Health		Insured Health Benefits		Policy;	however, with limitations and	
	Branch		(NIHB) Program		Traditional Healer	maintained government	
					Services Travel	control, limiting full self-	
				FNs	Policy	determination	
16.	Health Canada,	2005	Ten Years of Health		Health Transfer	Self-determination mandates,	Evaluation
	First Nations		Transfer First Nation and		Policy;	however, not regulated and still	
	and Inuit Health		Inuit Control		Inherent Right to	up to discretion of community	
	Branch				Self-Government	and limited by federal controls	
				FNs	Policy		
17.	Health Canada,	2002	Aboriginal Health.		Health Transition	Informative tool to highlight	Evaluation
	Health Policy				Fund	access issues without any	
	and					regulated policy framework to	
	Communication					implement sustainable	
	s Branch			FNs		solutions	

18.	Heisler, E.	2011	The Indian Health Care Improvement Act reauthorization and extension as enacted by the ACA: Detailed summary and timeline	AIANs	Affordable Care Act	Detailed background info on ACA implications on AIANs healthcare	Discussion
19.	Gregory, D., Russell, C., Hurd, J., Tyance, J., & Sloan, J.	1992	Canada's Indian health transfer policy: The Gull Bay Band experience	FNs	Health Transfer Policy	Self-determination in health care, community-specific needs	Discussion
20.	Gurr, B.	2013	The Ruling Relations of Reproductive Healthcare for Native American Women	AIANs	1836 US and Ottawa/Ojibwe Treaty; Concept Paper; Indian Health Care Improvement Act 1976; ISDEAA	US follows similar pattern of assimilation then self-determination. AI policy language notes trust responsibility, however, congressional actions point otherwise (contradictory)	Thesis Dissertation
21.	Indian Health Service	n.d.	Chapter 3 - Purchased/Referred Care	AIANs	Purchased/Referred Care	Travel policy limited in its funding for health services, only select services/circumstances	Original Policy Document
22.	Indian Health Service	2017	Health Reform for American Indians and Alaska Natives	AIANs	Health Care Improvement Act; Affordable Care Act	Financial coverage, community needs	Discussion
23.	Ingram, C., McMahon, S., Guerra, V., & Weiss, A.	2012	Implications of Health Reform for American Indian and Alaska Native Populations	AIANs	Affordable Care Act	ACA impacts all forms of access, up to the States to effectively implement	Discussion
24.	Jacklin, K.	2008	Strength in adversity: Community health and healing in Wikwemikong	FNs	Health Transfer Policy	Policy language not reflective of outcomes. HTP actually limits SD and decision-making	Thesis Dissertation

						power in FNs health care and health policy	
25.	Kelly, M.	2011	Toward a New Era of Policy: Health Care Service Delivery to First Nations	FNs	Treaty 6, Medicine Chest Clause; British North American Act; Indian Act; White Paper; Red Paper; Indian Health Policy; Canada Health Act; Health Transfer Policy; Royal Commission on Aboriginal Peoples; UN Declaration on the Rights of Indigenous Peoples	Access impacted by political ideology, national mood, all regulations lead to jurisdiction confusion/ambiguities	Discussion
26.	King, K.	2012	Indian Health Service: Action Needed to Ensure Equitable Allocation of Resources for the Contract Health Service Program	AIANs	Contract Health Services Program (PRC)	Policy language in ISDEAA and IHCIA & funding formulas causing inequitable to care	Evaluation
27.	King, K.	2013	Indian Health Service: Most American Indians and Alaska Natives Potentially Eligible for Expanded Health Coverage, but Action Needed to Increase Enrollment	AIANs	Affordable Care Act	Access to care at the discretion of states and government control over information dissemination	Evaluation

28.	Lavoie, J.	2018	Medicare and the care of		Canada Health Act;	highlights issue of	Discussion
40.	Lavoic, J.	2010	First Nations, Metis and		Canadian	jurisdictional confusion	Discussion
			Inuit		Constitution 1982;	3	
			muit		,	impeding on equitable access to care and where it exists in	
					Jordan's Principle;	various written and unwritten	
					Royal Commission		
					on Aboriginal	policies. When it is addressed	
					Peoples;	also depends on political	
					Kelowna Accord;	landscape and ideology	
					Community Health		
					Representatives;		
					Health Transition		
					Fund;		
					Truth and		
					Reconciliation		
					Commission of		
				FNs	Canada		
29.	Lavoie, J.	2013	Policy silences: why		British North	Jurisdictional confusion,	
			Canada needs a National		American Act;	ambiguities in policy	
			First Nations, Inuit and		Indian Act;		
			Métis health policy		Canada Health Act;		
					Indian Health		
					Policy;		
					Health Transfer		
				FNs	Policy		
<b>30.</b>	Lavoie, J.	2003	The value and challenges		Indian Act;	Policy language creates	Discussion
			of separate services: First		Health Transfer	limitations in accessing health	
			Nation in Canada		Policy;	services, due to jurisdictional	
					Treaty 6, Medicine	gaps, limited resources and	
					Chest Clause;	failure of federal government	
					British North	to acknowledge its obligation	
					American Act;	to FNs peoples	
				FNs	Canada Health Act		

31.	Lavoie, J., &	2011	Legislating identity: The		Bill C-31, Indian Act	Funding & inequality issues	Discussion
	Forget, E.	2011	legacy of the Indian Act in		amendments	and the second seconds	2150000001
	8,		eroding access to care	FNs			
32.	Lavoie, J., &	2008	The cost of doing nothing:		British North	Discriminatory and ambiguous	Evaluation
	Forget, E.		Implications for the		America Act;	policy language leads to	
	8,		Manitoba health care		Indian Act, Bill C-31	inequities in accessing care	
			system	FNs		1 1	
33.	Lavoie, J.,	2011	Is it worthwhile to invest		FNIHCCP	National trend towards home	Evaluation
	Forget, E., Dahl,		in home care?			care, community-based needs,	
	M., Martens, P.,					improved efficiency/access	
	& O'Neil, J.			FNs		, , , , , , , , , , , , , , , , , , ,	
34.	Lavoie, J.,	2007	Why equity in financing		Health Transfer	Policy builds community	Evaluation
	Forget, E., &		First Nations on-reserve		Policy	compacity, however, set back	
	O'Neil, J.		health services matters:			by inequitable funding	
	,		Findings from the 2005			formulas	
			nationals evaluation of the				
			Health Transfer Policy	FNs			
35.	Lavoie, J.,	2010	Have investments in on-		Health Transfer	Local access to care and	Evaluation
	Forget, E.,		reserve health services and		Policy	control (self-determination) on	
	Prakash, T.,		initiatives promoting		-	health outcomes	
	Dahl, M.,		community control				
	Martens, P., &		improved First Nations'				
	O'Neil, J.		health in Manitoba?	FNs			
36.	Lavoie, J.,	2015	Negotiating barriers,		Medical	Ambiguities in policies	Discussion
	Kaufert, J.,		navigating the maze: First		Transportation	restricting equal access to care,	
	Browne, A.,		Nation peoples' experience		Policy	gaps in policies	
	Mah, S., et al.		of medical relocation	FNs			
37.	Lavoie, J.,	2016	Managing Matajoosh:		Medical	FNIHB not meeting	Discussion
	Kaufert, J.,		determinants of first		Transportation	community-needs, funding	
	Browne, A., &		Nations' cancer care		Policy	issues	
	O'Neil, J.		decisions	FNs			

38.	Lawford, K., &	2012	An Analysis of the		Evacuation Policy	Policy language impairs self-	Discussion
	Giles, A.		Evacuation Policy for			determination and fuels	
			Pregnant First Nations			cultural assimilation	
	2.5.14. =	10=0	Women in Canada	FNs	~		
39.	Mail, P.	1978	Hippocrates Was a		Community Health	CHRs similar to Canada's,	Discussion
			Medicine Man: The Health		Medic Training	builds community compacity	
			Care of Native Americans		Program (CHRs)	and removes cultural barriers	
			in the Twentieth Century	FNs			
40.	Mashford-	2011	How did we get from		Royal Proclamation;	Patterns of assimilation	Discussion
	Pringle, A.		there? American Indians		Civilization Act;	policies similar in Canada and	
			and Aboriginal peoples of		Indian Removal Act;	US, have shaped healthcare	
			Canada health policy		Indian Citizenship	access today	
					Act;		
					Indian		
					Reorganization Act;		
					House Concurrent		
					Resolution 108;		
					Transfer Act;		
					British North		
					America Act;		
					Medicine Chest		
					Clause (Treaty 6);		
					Indian Act;		
					Hawthorne Report;		
					White Paper;		
					Red Paper;		
					New Federal		
					Government Indian		
					Relationship;		
					Indian Health		
					Policy;		
				FNs &	Health Transfer		
				AIANs	Policy		

41.	National Indian Health Board	2017	Tribal nations health briefing: 2017 presidential transition	AIANs	Indian Health Care Improvement Act; Affordable Care Act; Budget Control Act; Special Diabetes Program for Indians; Prevention and Public Health Fund	Trust responsibility upheld under IHCIA, impacts on access imbedded in funding models	Discussion
42.	Nixon, R.	1970	Proposed recommendations relating to the American Indiansmessage from the President	AIANs	House Concurrent Resolution 108 (Termination Policy)	Unwritten policy underpinning AIANs policies in mid-20th century US, lead to termination of AIANs rights and tribal sovereignty	Discussion
43.	U.S. Commission on Civil Rights, Office of the General Counsel	2004	Broken promises: evaluating the Native American health care system. Draft report for the Commissioners' Review	AIANs	Indian Health Care Improvement Act	Background info on proposed legislative changes reflective of community needs in healthcare	Evaluation
44.	Orians, CE., Erb, J., Kenyon, KL., Lantz, PM., Leibow, EB., Joe, JB., & Burhansstipanov , L.	2004	Public education strategies for delivering breast and cervical cancer screening in American Indian and Alaska Native populations.	AIANs	Cervical Cancer Mortality Prevention Act of 1990 (1994 amendments)	Increased tribal control related to improved access, a lot on approachability	Discussion
45.	Provan, KG., & Carson, LM.	2000	Behavioral health funding for Native Americans in Arizona: policy implications for states and tribes.	AIANs	Indian Self Determination Education Assistance Act; Indian Reorganization Act	Funding models impairing equitable access to care	Discussion

46.	Ross, R., Garfield, L., Brown, D., & Raghavan, R.	2016	The Affordable Care Act and Implications for Health Care Services for American Indian and Alaska Native Individuals	AIANs	Affordable Care Act; Indian Health Care Improvement Act; Indian Self Determination Education Assistance Act	Direct impacts of ACA and IHCIA on health care access	Discussion
47.	Shelton, BL., Dixon, M., Roubideaux, Y., Mather, D., & Smith-Mala, C.	1998	Tribal perspectives on Indian self-determination and self-governance in health care management. Executive summary.	AIANs	Indian Self Determination Education Assistance Act	Self-determination in healthcare, policy language towards tribal sovereignty	Evaluation
48.	Skinner, D.	2015	The Politics of Native American Health Care and the Affordable Care Act.	AIANs	Affordable Care Act	Trust responsibility neglected, impairing self-determination in healthcare	Discussion
49.	Smith, R., & Lavoie, J.	2008	First Nations Health Networks: A Collaborative System Approach to Health Transfer	FNs	Health Transfer Policy; First Nations Health Networks	Community capacity building, funding issues, community-based needs	Discussion
50.	Thierry, J., Brenneman, G., Rhoades, E., & Chilton, L.	2009	History, law, and policy as a foundation for health care delivery for American Indian and Alaska Native children	AIANs	Snyder Act; Transfer Act; House Concurrent Resolution 108 (Termination Policy); ISDEAA; IHCIA 1976	Government offloading responsibilities despite acknowledging trust obligation	Discussion
51.	Walker, J., Harris, S., Thomas, J., Phillips, M.M., & Stones, A.	2018	A national legacy framework for comprehensive and sustainable access to mental health services for Indigenous children and	FNs	Jordan's Principle	Ambiguities in policies and discoordination creating unequal access	Discussion

			youth: Mental health in Canada				
52.	Warne, D.	2011	Policy Issues in American Indian Health Governance	AIANs	Indian Self Determination Education Assistance Act	Progress towards self- determination achieved through regulatory measures in policy	Discussion
53.	Warne, D., Delrow, D., Angus- Hornbuckle, C., & Shelton, B.	2017	Impact of ACA repeal on American Indians and Alaska Natives.	AIANs	Affordable Care Act; Indian Health Care Improvement Act 2010	ACA and its implications on the IHCIA impact all dimensions of access, huge threat if repealed	Discussion
54.	Warne, D., & Frizzell, LB.	2014	American Indian Health Policy: Historical Trends and Contemporary Issues	AIANs	US Treaties; Snyder Act; Transfer Act; Indian Health Care Improvement Act; Indian Self Determination Education Assistance Act; Affordable Care Act; Contract Health Services Program (PRC)	Policy language supports self-determination but does not allocate adequate resources to do so	Discussion
55.	Warne, D., Kaur, J., & Perdue, D.	2012	American Indian/Alaska Native Cancer Policy: Systemic Approaches to Reducing Cancer Disparities	AIANs	Contract Health Services Program (PRC)	Review Lavoie et al (2016) for similar discussion on FNs cancer care policies	Discussion
56.	Westmoreland, TM., & Watson, KR.	2006	Redeeming hollow promises: the case for mandatory spending on health care for American	AIANs	Congressional Budget Act 1974	Funding models for IHS impairing equitable access to care	Discussion

			Indians and Alaska Natives				
57.	Young, KT.	1984	Indian Health Services in Canada: A Sociohistorical Perspective	FNs	Medicine Chest Clause	Policy language rooted in cultural assimilation, ambiguities in policies create inequitable access to care	Discussion

Appendix E. Policy Instruments & Impacts on Access

Table 8. Canada - Policy Instruments & Impacts on Access

Ability to Engage **Affordability** Availability Approachability Acceptability **Dimensions of Access** 1876 1876 1961 1969 1970 1970 1976 1979 1982 1982 1984 1985 1986 1986 1995 1996 1997 1999 1999 2003 2005 2005 2005 2007 2010 2015 37% 2011 30% 33% Date nherent Right to Self-Government Policy **Traditional Healer Services Travel Policy** New Federal Gov't Indian Relationship **Fruth and Reconciliation Commission** Community Health Representatives Treaty 6, Medicine Chest Clause First Nations Health Networks Medical Transportation Policy Aboriginal Diabetes Initiative Health Integration Initiative Canadian Constitution 1982 British North America Act Health Transition Fund Health Transfer Policy Royal Proclamation Indian Health Policy Bill C-31, Indian Act Adult Care Program Hawthorne Report Canada Health Act lordan's Principle **Evacuation Policy** Kelowna Accord **UNDRIP** Canada **Economic Tools** White Paper Information Regulation Indian Act **Red Paper** Canada RCAP

\*date unknown

Table 9. United States - Policy Instruments & Impacts on

United States		Dimensions of Access	cess			
	Date	Approachability	Acceptability	Availability	Affordability	Ability to Engage
Royal Proclamation	1763					>
Civilization Act	1819			>		
Indian Removal Act	1830			>		
U.S. and Ottawa/Ojibwe Treaty	1836			>		
Indian Citizenship Act	1924			>		
Snyder Act	1924		>	>		
Indian Reorganization Act	1934					>
House Concurrent Resolution 108	1953			>		>
Transfer Act	1954			>		>
Community Health Medic Training Program (CHRs)	1970		>	>		>
Congressional Budget Act	1974		>	>		
ISDEAA	1975		>	>	>	>
Indian Health Care Improvement Act	1976		>	>		>
Purchased/Referred Care Program	1991			>		
Cervical Cancer Mortality Prevention Act	1994	>	>	>		>
Special Diabetes Program for Indians	1997		>	>		
UNDRIP US	2007					>
Concept Paper	2008		>	>		
Reauthorization of IHCIA	2010		>	>	>	>
Affordable Care Act	2010	>	>	>	>	>
Prevention and Public Health Fund	2010			>		>
Budget Control Act	2011			>		
Annual Interior Appropriations Bills*	n.d.		>	>	>	
Regulation	61%					
Economic Tools	30%					
Information	%6					

\*no date (n.d.) because annual occurrence

## Appendix F. Validation Interview Prompting Questions

- 1. How do the findings from the search resonate with you, based on your knowledge and experience with First Nations or American Indian/Alaska Natives health policy?
  - a. Are there any key policies missing from the review that you would suggest including in the study?
- 2. How do the preliminary findings of the review align with your work or research experience in relation to Indigenous health?
- 3. What other sources should be considered in this comparison of health policy impacting access to care for Indigenous peoples between Canada and the United States?
- 4. Is there anything else you would like to me know that will help to inform the study?

## Appendix G. PRISMA Flow Chart, Review Process

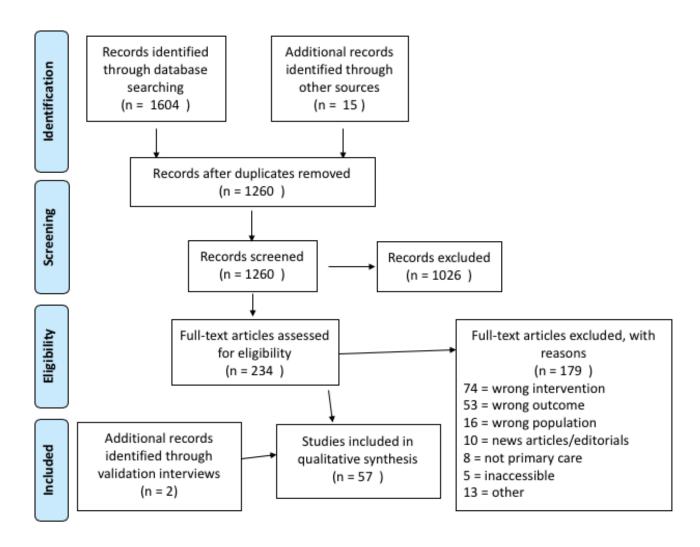


Figure 4. Review Process (PRISMA Flow Chart)

## Appendix H. Full Policy List with Details

Table 10. Indigenous Health Policies in Canada

Canada	
Policies	Date
Royal Proclamation	1763
• Guidelines for European settlement of Indigenous territories in what is now	
North America. States all land considered Indigenous land until ceded by	
treaty. Forbids settlers from claiming land from the Indigenous occupants,	
unless it has been first bought by the Crown and then sold to the settlers	
British North America Act	1867
<ul> <li>Creation of Canadian Constitution, all matters of Indigenous peoples</li> </ul>	
deemed responsibility of the federal government	
Treaty 6, Medicine Chest Clause	1876
<ul> <li>Only historic numbered treaty to exchange of land for health services</li> </ul>	
between Indigenous peoples and colonial settlers. Specified federal	
obligations to signatory FNs peoples with regards to healthcare	
Indian Act	1876
• Federal policy in attempt to cultural assimilate FNs peoples into western,	
settler cultural. Sparked series of discriminatory policies and bans against	
Indigenous culture	
Hawthorne Report	1961
Commissioned by P.E. Trudeau Liberal government. Sought to describe	
health disparities of FNs peoples. Recommended to assimilate Indigenous	
peoples in western culture and to leave reserve lands	
White Paper	1969
Official recommendation by P.E. Trudeau Liberal government to abolish	
the Indian Act, along with treaty, land and Indian status rights	
Red Paper	1970

Response to White Paper by Indian Brotherhood (now Assembly of FNs),     emphasizing Indian statuses/rights and disagreement with the White Paper	
emphasizing Indian statuses/rights and disagreement with the White Paper	
recommendations	
Community Health Representatives	1970
Federally-funded program to train community members living on-reserve	
on how to assist in delivering health services alongside registered nurses	
New Federal Gov't Indian Relationship	1976
Federal government's commitment to reframe from attempts of cultural	
assimilation of Indigenous peoples. States its commitment to recognize	
Indigenous culture as distinct from western colonial culture	
Indian Health Policy	1979
Developed by Conservative government, in attempt to rebuild Indigenous-	
federal government relationships and strengthen community control and the	
Indigenous healthcare system	
Canadian Constitution 1982	1982
Formally entrenched Indigenous and treaty rights in the Canadian	
Constitution, including right to healthcare	
Adult Care Program	1982
Federally-funded program to deliver community-based, culturally	
appropriate services	
Canada Health Act	1984
Creation of Canadian Medicare program. FNs people living on-reserve still	
under responsibility of federal government	
Bill C-31, Indian Act	1985
Amendment to 1876 Indian Act, granted FNs women their Indian status	
and Indigenous rights, who previously lost their status due to marriage with	
a non-FNs partner	
First Nations Health Networks	1986
Combined FNs communities with transfer agreements through the Health	

Health Transfer Policy	1986
Federally-funded program, provides opportunity for FNs communities to	
assume administrative and planning control over health services	
Inherent Right to Self-Government Policy	1995
Federal government recognition of Indigenous people's inherent right to	
self-government, introduced improved ways for FNs to engage in	
healthcare services	
Royal Commission on Aboriginal Peoples	1996
• Investigated relationship between federal government and Indigenous	
peoples in Canada, provides many policy recommendations to improve	
Indigenous health in areas of social, education and health services	
Health Transition Fund	1997
• "\$150 million fund which from 1997-2001 supported 140 projects across	
Canada to test and evaluate innovative ways to deliver health care services"	
(Health Canada, 2007)	
Aboriginal Diabetes Initiative	1999
Federally-funded program dedicated towards funding diabetes services and	
education for FNs communities, attempt to reduce rates of diabetes	
First Nations and Inuit Home and Community Care Program	1999
Federally-funded program to deliver home and community care that is	
culturally appropriate for FNs and Inuit peoples. Attempt to improve	
primary care health services	
Health Integration Initiative	2003
Active from 2003-2006, funded pilot projects across Canada which aimed	
to improve the integration of federal health services into	
provincial/territorial health system. Attempt to improve coordination of	
FNs healthcare services	
Kelowna Accord	2005

<ul> <li>Policy recommendations in areas of social services, education and health,</li> </ul>	
as result of consultations between the federal government and direct	
communication with Indigenous communities	
Medical Transportation Policy	2005
Federally-funded service to transport FNs peoples to receive essential care	
not available within their community	
Traditional Healer Services Travel Policy	2005
Federally-funded service to transport FNs peoples to receive culturally-	
appropriate and traditional care not available within their community,	
however, within their region	
Jordan's Principle	2007
Child-first principle. Federal principle ensuring all FNs children receive	
equitable care within a time frame that is needs-based	
United Nations Declaration on the Rights of Indigenous Peoples – Canada	2010
<ul> <li>Federal agreement to recognize, promote and protect the rights of</li> </ul>	
Indigenous peoples in all its actions	
Evacuation Policy	2011
Regulates First Nations mothers mandatory travel to urban centres, off-	
reserve, for hospital delivery. Nurses under their care are required to	
"arrange for transfer to hospital for delivery at 36-38 weeks' gestational	
age" regardless of the mother's or baby's conditions (FNIHB, 2011, p. 6)	
Truth and Reconciliation Commission of Canada	2015
Component of the Indian Residential Schools Settlement Agreement with	
the Canadian federal government. Includes the 94 Calls to Action – policy	
recommendations to begin the process of reconciliation.	
Non-Insured Health Benefits	?
• Federally-funded health insurance program for FNs and Inuit peoples,	Date
regardless of place of residence. Insures services outside of those covered	unknown
under Medicare and provincial plans i.e., vision, dental, select prescriptions	

Table 11. Indigenous Health Policies in the United States

United States	
Policies	Date
Royal Proclamation	1763
Guidelines for European settlement of Indigenous territories in what is now	
North America. States all land considered Indigenous land until ceded by	
treaty. Forbids settlers from claiming land from the Indigenous occupants,	
unless it has been first bought by the Crown and then sold to the settlers	
Civilization Act	1819
• Federal commitment to provide essential health services to AIANs peoples,	
to avoid risk of spreading disease. As well, federal government	
implemented school system in efforts to assimilate AIANs peoples into	
western, colonial culture	
Indian Removal Act	1830
Forced relocation of AIANs tribes by federal government in attempt to	
buy/sell tribal land in the southern United States	
U.S. and Ottawa/Ojibwe Treaty	1836
• First treaty to exchange Indian land for health services provided by the	
federal government	
Snyder Act	1921
• first legislative authority for Congress to appropriate funds specifically for	
Indian healthcare	
Indian Citizenship Act	1924
Forced all AIANs to become American citizens and to abide by colonial	
laws and regulations	
Indian Reorganization Act	1934
Federal attempt to decrease federal control and improve AIANs self-	
government capacities. Restored tribal governance by implementing in	
tribal councils	
House Concurrent Resolution 108 (Termination Policy)	1953

• Beginning of series of termination policies into the 1970s. Objective to	
remove AIANs from their land, abolishing treaty rights	
Transfer Act	1954
Transfer Indian health services to be a matter of public health services	
Community Health Medic Training Program (CHRs)	1970
<ul> <li>Federally-funded program to employ and train AIANs community</li> </ul>	
members to work alongside healthcare professionals in their community to	
aid in delivering health services	
Congressional Budget Act	1974
Deems Indian Health Service funding a discretionary program	
Indian Self-Determination Education Assistance Act	1975
Federally-funded program for tribal communities to assume healthcare	
service planning and delivery roles from (contracting) or alongside	
(compacting) the Indian Health Service	
Indian Health Care Improvement Act	1976
Authorized annual appropriations from congress in support of the Indian	
Health Service (IHS) and AIANs healthcare, as well as other implications	
including Medicaid and Medicare reimbursement for care delivered at IHS	
and tribal health facilities	
Cervical Cancer Mortality Prevention Act	1994
Federally-funded program in support of cancer education, screening and	
procedures for AIANs peoples, attempt to reduce cancer prevalence	
Purchased/Referred Care Program	1991
Federally-funded service to transport AIANs peoples to receive essential	
care not available within their community	
Special Diabetes Program for Indians	1997
Federally-funded program in support of diabetes education, screening and	
procedures for AIANs peoples, including culturally appropriate services.	
Attempt to reduce diabetes prevalence	
United Nations Declaration on the Rights of Indigenous Peoples – United States	2007

<ul> <li>Federal agreement to recognize, promote and protect the rights of</li> </ul>	
Indigenous peoples in all its actions	
Concept Paper	2008
Drafted and issued by National Indian Health Board with recommendations	
to the Indian Health Care Improvement Act and for AIANs healthcare	
reform	
Indian Health Care Improvement Act (reauthorized)	2010
• Permanent reauthorization of the Act, meaning permanent authorizations to	
receive annual congressional appropriations in support of IHS. Also	
included provisions to IHS funded services, in order to expand and include	
additional essential services e.g., mental health	
Affordable Care Act	2010
• Expanded Medicaid eligibility criteria for AIANs peoples, as well as other	
additional coverage option benefits	
Prevention and Public Health Fund	2010
Under the Affordable Care Act, tribal communities can apply for funding	
grants designed to support public health programming such as infectious	
disease and tobacco programs and other community-based services	
Budget Control Act	2011
Controls when federal spending exceeds funding cap at end of a fascial year. All	
federally-funded programs, including the IHS receive cuts and budget restrictions	
Annual Interior Appropriations Bills	Annual
In reference to annual Congressional appropriations to fund the IHS	occurrence