UNDERSTANDING INDIGENOUS DATA GOVERNANCE WHEN COLLABORATING WITH POST-SECONDARY INSTITUTIONS

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UNDERSTANDING INDIGENOUS DATA GOVERNANCE WHEN COLLABORATING WITH POST-SECONDARY INSTITUTIONS

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DEDICATION

To all the *Siksikaitsitapiiks*, and Indigenous students, who are walking on their own educational path, to those who are working hard to achieve Indigenous Data Governance within academia, and those working hard to achieve Indigenous Data Sovereignty within our communities, this thesis is dedicated to you. This is a small piece of a data sovereignty puzzle, and I hope each of you find pieces on your journey that will contribute to the “data sovereignty revolution, in Indian country”.

ABSTRACT

Background: The Blood Tribe Department of Health (BTDH), with support from the Blood Tribe's Chief and Council, are moving toward self-determination by establishing a collaborative partnership with a local post-secondary institution to create sustainable models of governance. This thesis is a small but essential piece of the work being conducted to determine best practices for developing data collection tools to assess and evaluate the community needs of Kainai Nation while understanding the resources needed for BTDH to enact the Ownership, Control, Access, and Possession (OCAP) Principles of data storage and management.

Objective: This scoping review aimed to explore and describe what exists in the current literature on Indigenous Data Governance principles, and how the information is understood and utilized in collaborative health research initiatives. A goal and purpose for this review are to explore and understand the role that Indigenous populations or communities assume in collaborative research with academics and scholars.

Methodology: The search was conducted using nine databases from inception until May 2024. Two reviewers independently screened for inclusion and exclusion using the Arksey & O'Malley (2005) scoping review framework. The principal investigator conducted the final review for full-text articles, based on content and findings, with additional criteria added.

Results: Fifteen reports were included. Our included reports consisted of qualitative research (n=7), mixed methods approach (n=6), and quantitative studies (n=2). Findings are presented within a framework that discusses IDG in six areas: 1) study characteristics and demographics; 2) study objectives, designs and theoretical frameworks; 3) Indigenous data governance: an overview of community engagement; 4) ethical practices in research and data governance; 5) enacting community collaboration to guide and support Indigenous data governance; 6) limitations.

Conclusion: Themes identified related to Indigenous Data Governance (IDG), as well as challenges and barriers to implementing IDG in collaborative health research projects that are situated within universities. A collaborative approach involving stakeholders, culturally competent training and capacity building are approaches to move forward, but the establishment of Indigenous-led research institutes, a source of stable funding, and further collaborative research opportunities focusing on building and supporting IDG through building nation-specific data ecosystems are needed.

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To my colleagues, mentors, and friends in the Faculty of Health Sciences and across campus, thank you for your guidance and mentorship throughout my undergrad and graduate journey. To those who recognized my research potential, thank you for supporting me in learning and realizing my potential through research, projects, and employment opportunities. My experiences were invaluable and provided numerous avenues for grow and skill enhancement, while allowing me to center my epistemological frameworks within the research process. I appreciate having a safe space to grow intellectually and professionally.

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LIST OF ABBREVIATIONS

BTDH – Blood Tribe Department of Health

CARE – Collective benefit, Authority for control, Responsibility and Ethics

CBPR – Community-Based Participatory Research

FNIGC – First Nations Indigenous Governance Centre

IDG – Indigenous Data Governance

IDS – Indigenous Data Sovereignty

MOU - Memorandum of Understanding

OCAP – Ownership, Control, Access, and Possession

PAR – Participatory Action Research

REB – Research Ethics Board

UNDRIP – United Nations Declaration on the Rights of Indigenous Peoples

LIST OF KEY TERMS

Aiskinakii: to doctor

Ao’tisstapitayo’p: we have come to understand

Apaitsitapi: White Weasel People

Blackfoot Confederacy: term to include Siksika, Kainai, Piikani, and Amskapi Piikani.

Kaaashinnooniksi: grandparents

Kakyosin: coming to know

Kitaikihpowa: “What are you doing? (plural- asking a group of people)

Niitaikihpowa: What am I doing?

Niitsitapi: Real People

Ninnapiim: My husband

Siksikaistitapi: Blackfoot speaking people

Siksikaistitapiiks: All Blackfoot speaking people

Siksikaistitapiiaaki: Blackfoot speaking woman

Sokkinaapi: doctor, to bring back health, make well

Sokkinakia’pi: an all-encompassing term that includes everything that has do with health

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CHAPTER 1: INTRODUCTION

1.0 Background

The Blood Tribe Department of Health (BTDH), with support from the Blood Tribe's Chief and Council, are moving toward self-determination by establishing a collaborative partnership with a local post-secondary institution to create sustainable models of governance. This thesis is a small but essential piece of the work being conducted to determine best practices for developing data collection tools to assess and evaluate the community needs of Kainai Nation while understanding the resources needed for BTDH to enact the Ownership, Control, Access, and Possession (OCAP) Principles of data storage and management (Information Governance Centre, 2014). It is important for the reader to understand that a memorandum of understanding (MOU) has been signed between the University of Lethbridge and the Blood Tribe Department of Health to honour the health-related Calls to Action of the Truth and Reconciliation Commission, partnering to expand health services capacity and delivery to meet the needs of the population. This partnership includes supporting the Blood Tribe in prioritizing Blackfoot Ways of Knowing regarding health and healing and significantly expanding their capacity to support access to high-quality healthcare and services. The University of Lethbridge and the Blood Tribe Department of Health envision the partnership as a journey of co-creation characterized by shared values of humility, respect, honesty, kindness, collaboration, and strength.

1.1 Locating the Researcher

Indigenous scholars worldwide have emphasized the importance of situating oneself in relation to the research when employing a decolonial methodology in qualitative research (Kovach, 2009; Restoule et al., 2018; Smith, 2012; Wilson, 2008).

This process is necessary not only for building alliances but also for following protocol when engaging in knowledge transfers within Indigenous tribes or communities. It is important to "revisit the sense of belonging to a People and a History… to unsettle the Western colonial framework" (Gaudet, 2019, p. 51). This is a common practice when knowledge is transferred within my people. It is important to understand the origins of knowledge to comprehend its relationship to the individual.

This next section explores my relationship with *Siksikaistitapi* knowledge systems. It will illustrate my relationship with not only the knowledge but also the kinship alliances that have transferred that knowledge to me through oral transmission. It is written from a personal perspective, as the relationship one has with Indigenous knowledge is derived from personal kinship alliances, individuals who currently carry this knowledge. To begin this process, I position myself as an *Apaitsitapi* (White Weasel) woman whose matrilineal relations reside within the *Spikskoittapiiksi*, the Tall People Clan, within the Kainai Nation of the Blackfoot Confederacy, whose educational background is that of Public Health and Aboriginal Health. I received my undergraduate degree in Health Sciences from the University of Lethbridge.

Wilson (2008) defines *epistemology* as "the study of the nature of thinking or knowing that involves the theory of how we have come to have knowledge or how we know something" (p. 33). The forefront of epistemology questions the source(s) of the knowledge and the reliability of those sources, while the core of epistemology questions how one knows that the knowledge is real. This is why it is important for me to explain my lineage and acknowledge those who helped shape my identity throughout my childhood, as well as situate myself in relation to my research. *Siksikaitsitapi* knowledge is transferred through our *Kaaashinnooniksi,* our language, the land and all that dwells below and on its surface, our ceremonies, our stories, and the roles and responsibilities that we assume as we navigate through life's journey (Bastien, 2004). It is also crucial for me to explain the lineage from which I descend, as Blackfoot ways of knowing and knowledge are relational and dependent on the relationships that an individual experiences throughout their life course, from childhood to adulthood. Knowledge is often passed down to the next generation from grandparents through oral transmission (Bastien, 2004). Traditionally, this knowledge is passed down through the roles and responsibilities of our *Kaaahsinnooniksi* (grandparents) within my community, and it is dependent on the process of *kakyosin* (coming to know), which is based on the interrelationships of these natural alliances (Bastien, 2004). These ways of knowing will be employed as I engage with the literature and disseminate the knowledge shared through the data collection process, ultimately leading to the development of an Indigenous research paradigm grounded in *Apaitsitapi* (White Weasel) ways of knowing and understanding.

My name is *Tsikakiiakii,* which roughly translates to Clean Woman. In the Blackfoot language, some words are limited to the interpretation of the language in which they are derived. Blackfoot words are limited and lose meaning when translated into English because they are often place-based, time-oriented, and person-specific. The word *Tsikakiiakii* is one of those words, translated to have a generic meaning due to the limited English vocabulary available. Other translations have been shared with me over the years, including "to clean or remove the imbalance," "to bring balance or make whole," and "to remove all that is negative."

I am the eldest of eight children. I am the granddaughter of *Aasainio'tokaani* (Crying Head) and *Mesaminnastsiaki* (Long time treaty woman), *Na'pisstsaakii* (Cloth

Woman) and *Isstssiimi* (Rough Hair), *Natohkyiaakii* (Holy Bear Woman), *Tsiinakoan* (Gros Ventre) and Lucy Crying Head, *Ainnoota* (John Bare Shin Bone Sr.) and *Immi'tsimaaki (*Annie Bare Shin Bone). Most of whom I can only assume shared so much love with their children and grandchildren despite surviving colonization and residential school, especially *Natohkyiaakii,* who was a survivor of the Baker Massacre (Big Head, 2009) because their children, grandchildren, and great-grandchildren have showered me with love, respect and guidance throughout my childhood, teen years, and continue to do so now that I am an adult. I was raised by my grandparents, parents, and numerous kinship alliances, collectively, within the traditional Blackfoot territory on the Blood Reserve. I had many homes, which were dependent on the seasons.

During my earlier childhood years, I lived with my parents, Don and Yvonne Shouting and grandparents, Mr. and Mrs. Joe Shouting. I also spent a lot of time with my other grandparents, *Sipissioko'si* (Wallace Mountain Horse) and *Aakaikotaakimaaki* (Eileen Heavy Runner), *Siima'* (Duncan Bottle), *Akaiskiini* (Josephine Soop), all of whom were very active in ensuring our knowledge systems and teachings were instilled within their stories that they shared. Our creation stories are the basis for all that we know when we are children. They teach us to think critically and always be mindful of our presence ensuring that we are respectful towards our kin, our ways of being and understanding, the natural world in which we reside, and all that we come into contact with. My memories of my grandparents are loving and filled with laughter, where I was as intrigued by them as they were by me. I was a curious child who loved to ask questions, and my grandfather Wallace knew how to ease my curiosity through storytelling. Each one had their own unique way of sharing their knowledge with me. My grandmother, *Aokaikotakimaaki* (Eileen Mountain Horse), did this through quillwork, *Siima* (Duncan Bottle) through sharing stories of his travels and showering me with love, and my grandmother Josephine Soop would wait for me to get off the bus after school, often with snacks, and I would tell her and my uncle Everett Soop about my day. He would teach me how to draw while sharing stories with me. This is where I learned about practicing reciprocity, which I will explain later, and how knowledge is shared among members. I inherited my curiosity from my grandmother, Minnie (Mrs. Joe Shouting), who would encourage me to ask questions and seek out answers in a respectful way. She also taught me how to find humour in all that life has to offer. Lessons about humbleness and respect for all things and beings came from the discussions I had with my grandfather *Maistakatsi* (Peter Big Head). He would sit with me outside the store, on the sidewalk, and tell me stories about anything and everything. Once, we talked about how ants are precious to the earth and how important it is to remember that we are all equal in this world, no matter how small.

I experienced significant loss at an early age as my great-grandparents began making their journey to the sand hills. The sandhills are a sacred place where our spirits connect with our ancestors. During this time, my parents relocated our family to the city, creating a disconnect from everything I knew as a child. When I reached my early teen years, I moved back to the reservation with my grandmother *Sisinaakii* (Cecilia Gros Ventre Boy). She was my best friend and walked beside me until I had my first child, *Kitoh'kito'pi*. She taught me land-based teachings, including harvesting traditional plants used for medicine and ceremonies. She explained how these teachings are connected to place and time, emphasizing the importance of enacting our Blackfoot values on a daily basis, especially our interactions with the world around us. She also reminded me that I needed to learn how to live in two worlds, which is why I spent so much time with my great-grandparents from birth until they made the journey home to the sand hills. I wish I could tell you stories about all my grandparents and how their teachings have shaped who I am today, yet I feel like this could be a book in its own right. It is important to share a bit about who I am and the lineage I descend from, as *Siksikaistitapi* knowledge is relational and dependent on our alliances with our kin and the natural world (Bastien, 2004), which are established well before we are born into this world. It is our responsibility to nurture these relationships throughout our lifecycle. These alliances are the foundation of our existence and are essential for the renewal and alignment of coming to know who we are as *Niitsitapi.* This process includes seeking out this information from *Kaaahsinnooniksi,* our grandparents, and reaffirming this knowledge within our own kinship alliances. We call this process *Ao'tisstapitayo'p,* meaning "we have come to understand" (Bastien, 2004).

During my second year of university, I was hired as a research assistant by a professor in the Faculty of Health Sciences, as a research assistant, to conduct data collection and cleaning. This is when I realized I was very interested in research, and in particular, I was curious about how colonization has impacted my community. My grandmother, *Naapiakii* (Carolla Calf Robe), was also the Elder-in-Residence on campus. She helped me understand how I can exist within academia as an *Apaitsitapiakii* and engage in research practices while adhering to the ethical standards upheld by our own community and its members. Through our conversations, as well as numerous discussions with my relatives, I have figured out how to approach and conduct research in a way that aligns with my own paradigms, which are heavily reliant on my kinship alliances and the knowledge that was transferred through these alliances.

My ways of knowing have evolved through my lived experiences of engaging with the world around me and everything that exists within my realm. I was raised within the Blackfoot Confederacy in southern Alberta and northern Montana by my parents, grandparents, Elders, and community, collectively. This process involved being nomadic throughout my childhood to ensure I experienced land-based teachings and ceremonies tied to specific places, space, the cosmos, and times of the year. Through this journey, I have received knowledge that is reliant on my kinship alliances, which were at risk of disruption during the knowledge transmission phase due to colonial policies and practices such as the residential school systems. Some knowledge received was fragmented and incomplete, requiring me to do additional work to restore these knowledge gaps. It is important to acknowledge that this is my worldview and that it is unique to my personal lived experiences and my interpretation of knowledge gifted to me through my kinship alliances and relationships. While there may be similarities among individuals within my community, I do not speak for anyone else or the collective, and how they interpret my knowledge is reliant on their own relational experiences. It is also important to note that any Blackfoot knowledge shared in this thesis belongs to the Blackfoot Confederacy as a whole, as it originates from our collective knowledge systems.

My kinship alliances, lived experiences, and educational journey have weaved together to shape my reality and influence the work that I do. This thesis is part of that journey and an obligation I have to fulfill a vow I have made to my community. The knowledge shared in this thesis will contribute to the broader *Sokkinakia'pi* Collaborative Project between the Blood Tribe Department of Health (Kainai Nation) and the University of Lethbridge. *Sokkinakia'pi* translates to an "all-encompassing term that includes everything to do with health," with the prefix *Sokkinaapi* translating to "doctor, bring back health, make well," and the suffix *aiskinaki* means "to doctor."

1.2 Research Practices: Understanding Indigenous Health Outcomes

A legacy of harmful and culturally violent approaches to health research is woven into the shared history and experience of Indigenous populations and communities across Canada. Historically, colonial research has left Indigenous people feeling exploited. Continuing research practices with Indigenous peoples often positions them as underdeveloped and ignorant (Morton Ninomiya & Pollock, 2017; Smith, 2012), implying they have yet to reach their full potential. There have been multiple occurrences of Indigenous populations being used as test subjects for research advancements, notably in the nutrition experiments (Mosby, 2013) and the Qu'Appelle vaccine trials (Lux, 1998). Besides being subjected to unethical research, Indigenous nations and communities in Canada are frequently excluded from participating in large-scale surveys and studies. This exclusion has led to the Indigenous health information challenges due to the limited involvement of Indigenous leadership in governance and health data management (Smylie & Firestone, 2015). Canada has assumed a paternalistic role in managing Indigenous health data. The mishandling of Indigenous health information stems from colonial constructs used to establish and maintain a deficit discourse related to the lived experiences of Indigenous populations and communities, creating narratives of disempowerment, dependency, and deficiency. This has led to the framing of social issues as the "Indigenous problem," removing the historical context of how health disparities have come to exist within the population (Hyett et al., 2018).

Health information about Indigenous populations is often "produced and perpetuated by non-Indigenous people for non-Indigenous health policymakers," who then create policies to deliver health to First Nations communities in Canada (Walter, Kukutai, et al., 2021, p. 83). This methods produces stereotypical and damaging depictions, resulting in inequities for First Nations populations (The First Nations Indigenous Governance Centre, 2019).

Health research is an essential step in reducing health disparities within any population (Smith et al., 2015), but it has been common practice for researchers to conduct research with Indigenous populations and end their involvement when the study is completed without making any changes to benefit the overall health and well-being of Indigenous communities or individuals involved in the research (Campbell, 2014; Flicker et al., 2015; Smith, 2012). This results in the continued distrust that Indigenous populations project towards outside researchers who are entering their communities (Campbell, 2014; Flicker et al., 2015; Smith, 2012). Indigenous scholars and communities have expressed how Euro-Canadian approaches to health and health research often reinforce the hierarchies of Eurocentric ideologies by "othering" Indigenous knowledge and belief systems (Chilisa, 2012; Smith, 2012). There have also been occurrences where Indigenous health data have been used to pathologize Indigenous people, leading to increased stigmatization (Walter et al., 2025) and dehumanization. Canada is renowned for excellent health data governance practices; however, the quality of data for Indigenous populations is often compromised by misclassification errors and non-response bias that contribute to greater health inequities reflected in determinants of health, health status, and access to health care services between Indigenous populations and their non-Indigenous counterparts (Smylie & Firestone, 2015).

The *Constitution Act of 1867* and the *Canada Health Act of 1984* established that health care is a provincial responsibility in Canada. Meanwhile, the *Indian Health Policy of 1979* and the *Indian Act of 1985* declare that healthcare services for First Nations people fall under a Federal jurisdiction (as cited in Walter & Suina, 2019). This creates legislative confusion and removes accountability for services delivered to the population within healthcare organizations. Richmond and Cook (2016) explain that although the Government of Canada reports progress in closing the health and social gap for First Nations communities, health disparities persist with little acknowledgement of First Nations worldviews and self-determined collective approaches to governance. Canada's health information system uses multiple platforms to monitor incidence rates and factors related to both acute and chronic diseases at the population level, including government databases, health system information databases, registration systems, and population-based tracking systems (Smylie & Firestone, 2015) to facilitate population-based health interventions through provincial healthcare systems across Canada. However, Canadian population-based data do not accurately reflect Indigenous populations living in Canada, who account for only 5% of the total Canadian population (Canada, 2022).

Indigenous scholars have identified that health-related data on Indigenous populations is often incomplete, inaccurate, or misleading, resulting in an over-representation of poor health outcomes and lower life expectancy. This is a breach of treaty rights (Jamieson et al., 2021), and has motivated Indigenous groups worldwide to identify avenues to achieve data sovereignty through the development of data governance principles and practices (Cormack et al., 2019; Gupta et al., 2023; Rainie et al., 2017; The First Nations Indigenous Governance Centre, 2019; Toki, 2019). In doing so, First Nation communities can collaborate with healthcare providers and policymakers to identify potential obstacles to collecting accurate data, particularly regarding Indigenous identifiers, which will support the creation of nation-specific interventions and health promotion programs. This process involves working with local Indigenous organizations to ensure that identifiers correctly reflect the established definitions of Indigenous identity and nation membership.

1.2.1 Data Availability

Data governance is a framework defined as the management and stewardship of data, including consent, data collection, analysis, knowledge translation, and compliance with data disclosure and sharing (Abraham et al., 2019). Indigenous populations recognize the importance of data to support Indigenous rights to self-determination, and limited or missing data creates barriers to identifying Indigenous priorities and well-being (Cormack et al., 2019). Data has the ability to save lives, inform policymakers, and guide the development of interventions designed to eliminate poor health outcomes while improving access to healthcare services. The Social Determinants of Health (Raphael, 2020) framework was developed by analyzing larger datasets collected to understand how social and economic factors predict the health status of individuals and populations. The landscape of health data continues to evolve, relying on access to diverse datasets provided by health institutions, registries, and services. The level of access, who has access, and the amount of information shared vary depending on the circumstances and the reasons for requesting access, placing health data on a continuum of access (Irura, 2019).

The responsibility for Indigenous data in Canada is shared among the Federal Government, provinces and territories, and healthcare service providers. However, national agreements with First Nations communities in Canada regarding data governance do not exist (Walker et al., 2017). Understanding how provincial and territorial administrations handle vital registrations and health services is critical for comprehending jurisdictional differences across the country and how access to government-funded services is managed (Smylie & Firestone, 2015). Indigenous stakeholders have articulated the importance of participating in the governance and management of unique nation-specific data, including knowledge and information systems, alongside population-specific datasets (as cited in Smylie & Firestone, 2015, p. 71). This research aims to identify the necessary and ideal components to develop a framework that utilizes health data as a tool for Indigenous communities to pursue self-determination and enhance well-being by restructuring data governance and management systems to incorporate data-driven decision-making in healthcare services (Pinto & Smylie, 2013; Smylie et al., 2012). This framework will be presented within the Sokkinakia'pi Collaborative Project, which is beyond the scope of this thesis.

Indigenous Data Sovereignty (IDS) is defined as the right of Indigenous or First Nations people to own, manage, control, access, and serve as stewards of data that is derived from their communities. This data pertains to their populations, land within their traditional territories, knowledge systems, and cultural practices (Rainie et al., 2019; Snipp, 2016; Taylor et al., 2016; Walter & Suina, 2019). To achieve IDS, First Nations communities must establish proper mechanisms and legal frameworks to derive mutual benefit from data use (Rainie et al., 2019). This process requires active engagement from First Nations communities in the "decision-making process across data-ecosystems from data conception to control of access to and usage of data" (Walter & Suina, 2019, p. 237). Doing so will create space where First Nations communities can:

- implement data governance (Hall et al., 2015; Snipp, 2016; Taylor et al., 2016; Walter & Suina, 2019) through the establishment of data governance frameworks (Severinsen et al., 2021),
- define data ownership and access rights (Campbell, 2014; Schnarch, 2004),
- implement data management practices (Browne et al., 2016),
- build data capacity and literacy through training and workshops (Fournie et al., 2023; Hayward et al., 2021; Schnarch, 2004),
- practice data transparency and accountability within the community (Pinto et al., 2023), and establish nation-specific ethical data principles (Tuck &

McKenzie, 2015; Wright et al., 2016),
- establish data-sharing agreements with external partners to form collaborative partnerships, leveraging digital tools and platforms for data governance and ensuring intergenerational knowledge transfer through documented data governance practices and policies.

Unfortunately, Indigenous leadership often manages tribal government systems with limited resources, resulting in underfunded organizational services at the population level and restricting their ability to assert data sovereignty due to the costly process involved in transforming data into meaningful information (Quinless, 2022; Snipp, 2016; Walter & Suina, 2019). Snipp (2016) explains how privacy laws differ from country to country, meaning Indigenous data sovereignty (IDS) “may be legal to achieve in one country but illegal in another” (p. 39), which compromises First Nations’ capacity to achieve data sovereignty based on how information can flow across geographical boundaries, as differing policies and laws exist.

Research Question

Using a scoping review methodology, the following question for this research is addressed: How can academic institutions appropriately engage with and support Indigenous data governance and data sovereignty when conducting collaborative health research with First Nations Communities?

1.3 Purpose Statement and Research Objective

1.3.1 Purpose Statement

This thesis will examine the current landscape of Indigenous data sovereignty and governance principles. It aims to understand how these principles can guide the development of a First Nations health data governance framework and recommendations for creating Indigenous data sovereignty policies and collaborative agreements, including documenting processes related to advancing Kainai Nation's data rights, sovereignty, and governance. A scoping review of international peer-reviewed IDS literature will be conducted to explore how the identified methods to support IDS principles may be used to develop nation-specific principles for creating data collection tools, data sharing agreements, and collaborative agreements between institutions and First Nation communities. This may serve as a means to establish self-determination in understanding health needs and improving existing services and health plans.

1.4 Research Significance

This research contributes to the field of health research and Indigenous governance and self-determination by emphasizing the importance of nation-specific knowledge systems within the wider discussion surrounding IDS. The presented scoping review supports the development of a data-sharing agreement and data management protocols that will benefit a First Nations community, Kainai Nation, that is currently collaborating with a post-secondary institution, the University of Lethbridge, and the researcher. The review offers a summary of effective practices being adopted worldwide by Indigenous peoples and guides the development of data collection and assessment tools that set the foundation for evidence-based practices in data collection and dissemination within a First Nations community. The aim is for these practices to eventually be incorporated as standardized data collection and assessment tool(s) to inform and guide the renewal of a health services plan for Kainai First Nation community to achieve health data governance and self-determination and establish data governance protocols within institutions and data sovereignty within the nation.

This scoping review contributes to a larger conversation on Indigenous governance, by exploring how one nation can achieve data sovereignty by establishing data governance principles and practices in their advocacy for health resources within their nation. This framework articulated through his scoping review process will offer guidance and support to other First Nation Communities in Canada to assert self-determination and health governance independently. The research associated with this review will also assist external parties, including non-Indigenous organizations, funders, policymakers, government partners, and academic institutions in creating culturally informed policies that promote data sovereignty and governance principles. This will enhance collaborative research efforts with First Nation communities.

CHAPTER 2: GENERAL SCOPE OF THE LITERATURE

2.0 Data Governance

Data, in its simplest form, consists of a set of characters that has no meaning unless used to make interpret an outcome or situation (Brous et al., 2016). For this chapter, data is defined as "information that includes facts and numbers used to analyze something or make decisions (Oxford, n.d.). In the 1980s and the early 1990s, data was viewed as a by-product of delivering services and the application that processed it, rendering it invaluable (Al-Ruithe et al., 2019). A shift occurred when decisions and processes became dependent on the results of data, creating a need to control and manage the volume of datasets within repositories (Begg & Caira, 2012). How data is handled, the purpose of collecting and analyzing it, how it is stored, and how it is used depend on the organization it is within.

Data management is often confused with data governance, leading to misunderstandings. Data management is defined as the "development, execution, and supervision of plans, policies, programs and practices that control, protect, deliver, and enhance the value of the data and assets" (as cited in Al-Ruithe et al., 2019, p. 841). In simpler terms, it describes how data is defined, stored, structured, and transferred, with data management being influenced by data governance (Alhassan et al., 2016). Data governance takes place when designated individuals make decisions to ensure effective management and use of resources (Alhassan et al., 2016). It is understood as the "authority, control, and shared decision-making over the management of the data assets," resulting in "high-level planning and control over data management" (as cited in Al-Ruithe et al., 2019, p. 941). Since there is no single definition of data governance, Abraham et al. (2019) analyzed various definitions of "data governance" and developed the following working definition:

> “Data governance specifies a cross-sectional framework for managing data as a strategic enterprise asset. In doing so, data governance specifies decision rights and accountabilities for an organization’s decision-making about its data. Furthermore, data governance formalizes data policies, standards, and procedures and monitors compliance” (p. 426).

Data governance frameworks are structured systems that include policies, procedures, and standards guiding the rules, protocols, processes, and regulations for data management within an organization or institution (Brous et al., 2016). Implementing data governance provides boundaries for data managers to oversee data and information assets appropriately when operating within a data governance framework. According to Abraham et al. (2019), a conceptual framework for data governance covers six dimensions:

1. Governance mechanisms represent the core and encompass structural, procedural, and relational mechanisms.
2. Organizational scope determines the organizational expansiveness of data governance and corresponds to the unit of analysis.
3. The data scope pertains to data assets that the organization governs.
4. The domain scope covers data decision domains to which governance mechanisms are applied, comprising of data quality, data security, data architecture, data lifecycle, meta data and data storage and infrastructure.
5. Antecedents cover the contingency factors which impact the adoption and implementation of data governance. This includes internal and external antecedents.
6. Consequences containing the effects of data governance, distinguishing between performance effects and risk management (p. 426-427).

The concept of data as an asset was introduced in 1994 when the Hawley Committee noted that recorded and collected data have value or potential value (as cited in Alhassan et al., 2016, p. 65). When population-based datasets are examined, the information can help society optimize systems, services, and policies, making it a tangible asset (Alhassan et al., 2016; Griffiths et al., 2021). Data can guide and transform how society prioritizes and sets strategic goals in community planning (The First Nations Indigenous Governance Centre, 2019), indicating that it can "influence both operation and strategic decisions" (Alhassan et al., 2016, p. 64). This has resulted in the "development of large databases by government ministries, departments, and agencies" (Irura, 2019, p. 165) to collect national statistics and allocate resources to combat health issues within provincial healthcare systems.

2.1 Health Data

Health data are managed by multiple sectors, resulting in a variety of data governance strategies and management policies due to the diverse range of stakeholders and data access options available. Data stored within private and government organizations create a dichotomous relationship between sectors interested in health data and the systems they are part of (Irura, 2019). Data stored in these systems are classified as electronic health records (EHR), including "neighbourhood- and community-level data such as economic and ethnic composition" (Alberti, 2014, p. 2). In Canada, critical health assessment involves monitoring information such as "population-level tracking of incidence and risk factors related to acute and chronic diseases," which has led to a reputation for state-of-the-art "socio-economic and health statistical methods" (Smylie & Firestone, 2015, p. 68). At the national level, organizations and initiatives support the coordination and standardization of provincial and territorial data sources, contributing to a pan-Canadian health care system and datasets (Smylie & Firestone, 2015; Spence, 2016). This results in a biased sample of non-aggregated data on Indigenous populations due to the limited percentage of Indigenous-specific statistics in the larger dataset (Firestone et al., 2014). These data sources require individual-level identifiers, which are used to secure funding for delivering population-level health care services and accessing government-funded health services.

2.2 Indigenous Data

For over a century, discussions about Indigenous data and information have taken place across various Indigenous and non-Indigenous levels of government, institutions, and communities (Griffiths et al., 2021; Hayward et al., 2021; Mahuika, 2019; Smith & Mitchell, 2020; Smith, 2012). Indigenous data is a broad term that refers to information and knowledge about individuals, groups, organizations, ways of knowing, and knowledge systems that include relational experiences with language, land, culture, and natural resources (Snipp, 2016; Taylor et al., 2016; Walter & Suina, 2019), which are collected, analyzed and disseminated (Pinto et al., 2023). Canada has been officially collecting data about Indigenous people since the end of the Seven Years' War in 1763. The physical remnants of these collection periods can be seen in museum collections housed across Europe and Canada. As colonization tactics advanced, information gathered about First Nations populations became valuable for creating policies aimed at furthering assimilation and control, while creating dependency on colonial systems. Health research in Canada has become reliant on Indigenous data as a means to establish its presence within the country, perpetuating long-standing marginalization and oppressive practices directed toward Indigenous peoples (Schultz et al., 2021).

Health data related to Indigenous populations has been collected and misused, creating a legacy of invisibility while continuing to collect population-level data from Indigenous communities (Griffiths et al., 2021). This highlights how health information systems lack relevant, consistent, and inclusive identity markers for Indigenous peoples in their centralized population data sets (Rowe, Carroll, et al., 2021; Sharma et al., 2024).

Researchers have noted how these approaches continue to create barriers for Indigenous leadership and participation in the governance and management of Indigenous health data (Kolahdooz et al., 2015; Lloyd-Johnsen et al., 2023; Smylie & Firestone, 2015). The exclusion of Indigenous partnerships in research processes continues to pose challenges for Indigenous communities when attempting to incorporate population-level data to inform their own healthcare services and health data management (Browne et al., 2016; Hayward et al., 2021; Smylie & Firestone, 2015). The absence of nation- or population-specific data sets has prompted Indigenous leaders to actively develop mechanisms aimed at rebuilding self-determining Indigenous relationships and approaches to community wellbeing (Rainie et al., 2017; Walter, Kukutai, et al., 2021).

2.3 Indigenous Experiences with Colonial Data Management Systems

Indigenous people living in the British Commonwealth settler states such as Canada, Australia and New Zealand continue to experience health disparities and inequities despite the advances made in healthcare delivery and practices (Firestone et al., 2014; Fournie et al., 2023). Academic research consistently highlights the health and socioeconomic gaps between Indigenous and non-Indigenous populations using a range of health indicators that reveal poor health outcomes for Indigenous groups, including shorter life expectancy, infant mortality and maternal mortality, low and high birth weights, child malnutrition, obesity in children and adults, educational attainment, and economic status (King et al., 2009; Markwick et al., 2014; Reading et al., 2013; Reading & Wien, 2009; Wilson & Cardwell, 2012). Additionally, Indigenous populations report mental health illnesses at disproportionately high rates (Kirmayer et al., 2000; Lee et al., 2022; Markwick et al., 2014; Rotenberg et al., 2016), higher prevalence of diabetes (Firestone et al., 2014; Fournie et al., 2023), cases of Missing and Murdered Indigenous

Women (Ancil, 2018; Lucchesi, 2019; National Inquiry into et al., 2019; Walsh, 2017), increased numbers of children in care (Blackstock et al., 2020; Kidd et al., 2019; Nicolai & Saus, 2013), homelessness (Anderson & Collins, 2014; Pijl & Belanger, 2020), and greater vulnerability to illicit substance dependency (Currie et al., 2015; Firestone et al., 2015; Marshall, 2015). Indigenous populations experience higher rates of mortality and morbidity compared to the general population (Adelson, 2005; Currie et al., 2015; Flicker et al., 2015; Reading & Wien, 2009; Smith, 2012), resulting in greater exposure to research being conducted to capture their experiences (Campbell, 2014; Flicker et al., 2015).

Research being conducted is producing an overwhelming amount of evidence resulting in an abundance of information and data about Indigenous populations. Although these approaches are productive in generating data relevant to health research, they are ineffective in constructing a narrative from the Indigenous perspective. This is partly due to the systemic misunderstanding and devaluation of Indigenous knowledge systems endemic to Euro-Canadian knowledge systems, the epistemic violence inflicted on those involved in research, and the ongoing Eurocentric dominance that continues to overshadow Indigenous knowledge and value systems (Restoule et al., 2018; Smith, 2012). This means Indigenous communities "must rely on outsiders, with the resources, to obtain and interpret this information… compromising the control over data" (Snipp, 2016, p. 40). Often, these data and information are subjected to further colonial classification and categorization of Indigenous populations (Gray et al., 2024).

Indigenous populations and academic researchers recommend that governments develop health policy responses informed by and evaluated with higher quality Indigenous data (Taylor et al., 2016). While high-quality Indigenous data is needed, there must be a clear, mutually agreed-upon process for how these data are collected and used in research, as well as who is collecting and engaging with the data. This would reduce the risks associated with potential conflicts between academic researchers and the aspirations of First Nations populations and their leaders. Federal and provincial statistical systems often fail to recognize the human rights and worldviews of Indigenous people, how data is generated and controlled, leading to biased results that reflect a primarily Euro-Canadian understanding of health (Firestone et al., 2014). Data that is generated within Canada is subjected to "protected data", producing a controlled gatekeeping of who can access the datasets (Rainie et al., 2019), which violates the Ownership, Control, Access, and Possession (OCAP) Principles established by the Information Governance Centre (2014). Indigenous data collected and analyzed by Euro-Canadian researchers are particularly vulnerable to exploitation, misrepresentation, and misuse, suggesting Indigenous people are often the producers of their inequitable outcomes (Campbell, 2014; Hyett et al., 2018; Pinto et al., 2023; Walter & Suina, 2019). This act has prompted academics and Indigenous leaders to mobilize and establish practices that protect against the misuse of data collected on Indigenous populations, moving toward data sovereignty (Rainie et al., 2019; The Maori Data Sovereignty Network, 2024; Thurber et al., 2021).

2.4 Data Sovereignty

Data sovereignty can be understood as the need to ensure information is managed according to the laws, practices, and customs (Snipp, 2016) of a First Nations population located within their territory. The *UN Declaration on the Rights of Indigenous Peoples* (UNDRIP) developed a set of Indigenous Peoples' Rights resulting in the creation of 46 articles, with Article 18 stating "Indigenous people have the right to participate in the decision-making in matters which would affect their rights in accordance with their own procedures" (Rainie et al., 2019). Additionally, Indigenous groups from Canada, New Zealand, and Australia have mobilized to inform IDS principles or recommendations being developed. Two landmark workshops were held in Australia, while OCAP principles of ownership, control, access, and possession were established in Canada (Information Governance Centre, 2014). New Zealand's Aotearoa-Te Mana Rāranga principles include Whanaungatanga and Whakapapa (relationality), Rangatiratanga (self-determination), Kotahitanga (collective vision), Manaakitanga (basic rights), and Kaitiakitanga (stewardship and sustainability of culture), with Australia's Maiam nayri Wngara (MnW) principles emerging from mapping the processes of Canada, New Zealand, and Australia's principles with the United Nations Declaration on the Rights of Indigenous Peoples (The Maori Data Sovereignty Network, 2024). These principles affirm Indigenous people's right to control their own data ecosystems, access their data in various formats, gather and analyze data, and define the relevance of data to meet their needs, enabling them to become self-determining and sustainable while remaining accountable to their collective interest.

2.5 IDG and Blackfoot Ways of Knowing

While Indigenous data governance principles such as the OCAP principles (Information Governance Centre, 2014) or the Collective benefit, Authority for control, Responsibility and Ethics (CARE) principles (Gupta et al., 2023) offer essential foundations for enacting Indigenous data sovereignty, their application must be grounded in the philosophical and cultural contexts of the nation in which they are used. Smith (2012) and Walter et al. (2025) argue that Indigenous data governance is most meaningful when it emerges from within Indigenous worldviews rather than being externally imposed, or adapted from Eurocentric governance models. In the Kainai context, Blackfoot ways of knowing and being provide essential guidance for implementing these frameworks in ways that reflect community values, spiritual responsibilities, and relational accountability (Bastien, 2004). Blackfoot epistemology is relational and cyclical, highlighting the interconnectedness within the community and framing knowledge as a living process embedded in relationships rather than a separable resource (Little Bear, 2012).

Siksikaistitapiiks lived practices and experiences of relationality, reciprocity, respect, and responsibility shape their approach in creating, sharing, and storing information (Little Bear & Heavy Head, 2004). In data governance, this means data should not be treated or managed as disconnected objects, but must remain connected to the people, lands, and contexts from which they originate. For example, decisions about data access and use should be made through collective consultation with Elders and community leaders who have the authority to interpret the cultural and ethical implications of the data. Reciprocity also requires that data collection and analysis provide tangible benefits to the community, such as improved health services, knowledge revitalization, and reaffirming cultural continuity. Respect and responsibility may also involve following ceremonial or protocol-based procedures before sharing the data externally, reflecting the spiritual aspect of stewardship in Blackfoot thought.

Implementing these principles within a data governance framework for Kainai could involve structures and processes that reflect Blackfoot governance systems, such as advisory councils that include youth, community members, Elders, and data stewardship models that value oral traditions and storytelling as legitimate data forms requiring culturally specific protection. Integrating Blackfoot ways of knowing and being into data governance can shift data management from a technical process to an ethical and relational practice, ensuring that the governance of health and other community data supports both community well-being and the integrity of their knowledge systems.

In summary, framing data governance through Blackfoot ways of knowing and being ensures that managing, using, and protecting data align ethically and culturally with Kainai worldviews. This approach emphasizes the importance of critically examining how Indigenous data governance and sovereignty are represented and implemented in health research within academic institutions. To address this, Chapter 3 outlines the methodological approach of this study, which uses the Arksey and O'Malley (2005) scoping review framework to systematically explore and analyze the existing literature. This framework offers a structured method for examining how Indigenous data governance principles are articulated, enacted, understood, and evaluated within health research settings. Additionally, the researcher will incorporate Indigenous relationality as a methodological approach to ensure the review process aligns with the relational, respect, and reciprocal values that underpin Blackfoot ways of knowledge creation and governance.

CHAPTER 3: SCOPING REVIEW

This chapter outlines the rationale for choosing a scoping review as a method for answering the stated research questions and describes the Arksey and O'Malley (2005) scoping review framework. The upcoming sections outline the study's purpose, aims, and six stages of the framework. Although the engagement, or consultation, stage is considered optional within the framework, it remains a key part of the overall project goals beyond this review.

3.0 Study Purpose and Aims

The purpose of this scoping review was to examine the existing evidence on Indigenous data governance models used in health research and to understand how these models support Indigenous populations in achieving data sovereignty to improve their health status and outcomes through health data governance. The objectives of this research were to identify:

1. Published articles and grey literature on Indigenous data governance principles and their impact on health research practices, and to identify the extent, range, and scope of evidence.
2. The connections made within the evidence gathered regarding the impact of IDG and how IDS is being used to determine how Indigenous health departments are addressing the socioeconomic barriers to accessing health services from an Indigenous lens.
3. Gaps in knowledge and research on this topic include incorporating an Indigenous lens at the individual, community, and global levels.

The findings will contribute to an understanding of Indigenous data governance (IDG) and the health of Indigenous people. Gaps and opportunities in the existing evidence are identified to guide future research, policy development, and capacity-building efforts aimed at strengthening Indigenous self-determination in health research. This research contributes to the global body of knowledge on implementing IDG and IDS to promote health equity. It aims to understand how Indigenous communities and populations manage and access Indigenous health data that has been operationalized within health research studies. The growing interest in data governance practices is expanding to encompass place-based Indigenous knowledge systems, which hold the potential to increase support for Indigenous people worldwide as Indigenous and non-Indigenous scholars collaborate to improve Indigenous health outcomes.

3.1 Rationale to Support Utilizing a Scoping Review

Scoping reviews emerged in the early 2000s and were officially recognized in 2005 as a methodological framework designed to synthesize evidence and map the existing literature within the chosen area of research (Peters et al., 2015). Scoping reviews have evolved to become a standalone tool used to determine the scope of a body of literature, offering a broad overview of key concepts and understanding the primary sources and types of evidence available on a specific topic (Arksey & O'Malley, 2005; Munn et al., 2018; Peters et al., 2015). This approach has enabled scholars to explore emerging research topics and contribute new insights to existing knowledge frameworks. Scoping reviews have proven to be useful when a research area has not been thoroughly reviewed (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2020). While the definition of scoping reviews has not been refined to a single, concise definition, there is a general agreement that they fill a void where other types of reviews have limitations (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2015). The structured and rigorous process involved in conducting a scoping review has established the methodology as a valid approach to understanding a body of literature in situations where systematic reviews are limited in guiding research objectives (Munn et al., 2018; Peters et al., 2015). Guided by a broadly formulated research question, this type of review is directed by the development of inclusion and exclusion criteria, which then shape the subsequent research methods. Broad questions are used to explore and develop more specific inquiries within the emerging research areas.

Arksey and O'Malley (2005) have developed a framework that incorporates a level of rigour comparable to other primary research processes (Levac et al., 2010; Munn et al., 2018; Peters et al., 2015; Peters et al., 2020). The rise of scoping reviews continues to produce publications that align methodological approaches with systematic review methodologies (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2015). Landa et al. (2011) and Armstrong et al. (2011) approaches to scoping reviews have all demonstrated rigour, transparency, and reproducibility, which are evident in the research protocols of the scoping review process, while acknowledging the differences that make the framework unique. The Arksey and O'Malley (2005) approach examines a broad spectrum of literature, allowing flexibility for an iterative process as the researcher becomes familiar with the evidence. This creates space to redefine the search terms and methods as the assessment of available information progresses.

The primary outcome of the scoping review is to map the evidence available and discovered throughout the search process. Arksey and O'Malley (2005) present four common stages to conducting a scoping review and require the following:

1) examine the extent, range, and nature of the research area.
2) determine the value of completing a subsequent systematic review.
3) summarize and disseminate research findings; and
4) identify gaps in the existing evidence

This study was conducted to investigate the scope, breadth, and characteristics of the scoping review, pinpoint gaps in the literature, and underscore potential avenues for further research in Indigenous data governance within institutional research.

3.2 Scoping Review Framework

The Arksey and O'Malley (2005) framework comprises five steps with an optional sixth step, with each step being discussed in detail following this section:

1) Identify the research questions and the starting point of the study to be guided by the subsequent search strategy
2) Identify the relevant studies, which involves the development of a comprehensive search strategy to ensure accurate and complete results
3) Selection of the studies, according to the predeveloped inclusion and exclusion criteria being revised throughout the review
4) Charting the data, including charting and sorting key material from the results into themes and trends
5) Collating, summarizing, and reporting the results, which includes presenting the results in a visual or narrative manner and
6) Consulting with relevant stakeholders.

The sixth step was applied to the overall study within which this review is situated (see Table 3.1). However, the researcher engaged in a reflexive process with the project Elders and the Sokkinakia'pi Collaborative Project Steering Committee throughout the review rather than only at the end of the review. Approval from the Research Ethics Board was not required for this study as the information analyzed is publicly accessible.

Table 3.1:
Arksey and O'Malley (2005) *Scoping Review Framework*

Arksey and O'Malley Stages	**Actions Included in Each Stage**
1. Identifying the research questions	Starting point of study that guides the search strategy
2. Identifying relevant studies	Developing a comprehensive search strategy to ensure accurate and complete results
3. Selection process	Developing a predefined inclusion and exclusion criteria that was continually revised
4. Charting the data	Charting and sorting key material from the results into themes and trends

Arksey and O'Malley Stages	Actions Included in Each Stage
5. Collating, summarizing, and reporting	Presenting the results as a visual or narrative
6. Consultation	Consulting with stakeholders at a later date

3.3 Methodological Approach

3.3.1 Stage One: Identifying the Research Question

Stage one of the Arksey and O'Malley (2005) framework is to identify the research question. To ensure transparency, rigour, and consistency, a predetermined search protocol was developed. This scoping review was conducted to answer the following research question: How can academic institutions engage with and support Indigenous data governance and data sovereignty when conducting collaborative health research with First Nation Communities? The phrasing of the research question and methodological terminology was deliberately designed to be comprehensive in order to encompass all aspects of IDG within the literature, considering the extensive range of descriptors used to refer to research involving Indigenous populations, communities, or individuals.

3.3.2 Stage Two: Search Strategy

Step two of the framework outlined by Arksey and O'Malley (2005) states that the scoping review needs to "be as comprehensive as possible in identifying the primary studies, published and unpublished, and reviews suitable for answering the research questions" (p. 23). To achieve the goal of identifying relevant and appropriate publications, the following steps were conducted when retrieving evidence from the pool of sources: meeting with a librarian, searching relevant electronic databases, including grey and open-source literature, and reviewing reference lists of relevant articles.

Meeting with the University of Lethbridge Health Sciences Librarian helped me to refine and expand keywords, concepts, and definitions to identify any limitations in searching the databases for relevant literature. Additionally, based on the research questions, the librarian helped determine appropriate databases and online journals related to the search area. A committee member with experience and expertise in scoping review methodology was consulted throughout the process of selecting search terms to ensure completeness and accuracy, resulting in a comprehensive search strategy. The iterative process involved a series of meetings conducted over the course of the study. The databases selected for the search were chosen in consultation with a librarian at the University of Lethbridge with demonstrated relevance to the broader topic area. A publication timeframe was applied according to the inclusion criteria to narrow the range of years searched for relevant studies, to streamline data collection and analysis. This also impacts the search terms, as Indigenous terms used to describe Indigenous people have changed across decades, and it is important to note that the terms used for this review will vary when compared to older reviews.

The search was limited to countries with Indigenous populations and similar themes and challenges related to colonization by the English and the power imbalances that emerge from the establishment and continuation of Eurocentric policies. This resulted in Australia, New Zealand, Canada, and the United States of America being selected as sample countries. The shared historical and contemporary experiences within sample groups influence how these groups have chosen to work together to achieve Indigenous governance, sovereignty, self-determination, and active reconciliation through collaborative processes (Rainie et al., 2019).

The search results included peer-reviewed articles, grey literature and open-source materials available in Australia, New Zealand, Canada, and the United States authored by Indigenous and non-Indigenous scholars and organizations. Grey literature is defined as any study that has not been published in a book or journal, which can include government or organizational documents such as reports, theses, dissertations, conference proceedings, and project reports (Hartling et al., 2017, p. 2). The search was limited to literature published between 2013 and May 2024. Although this timeframe may restrict sources that articulate concepts, frameworks, definitions, and theories rooted in academia and research, setting a publication window allowed us to synthesize, code, and analyze the available information in a timely manner.

3.3.2.1 Search Terms

Search terms were derived from the research question and expanded through searches of two databases. An initial search identified several papers, which were analyzed for common keywords, definitions, analogies, and index terms relevant to synonyms useful in the original search (Armstrong et al., 2011; Landa et al., 2011). These additional search terms were added to a master list that informed the final search strategy and were repeated used until saturation was reached (Landa et al., 2011). This process resulted in a comprehensive list of search terms (Appendix A). The search terms were applied to databases at the recommendation of the librarian, who highlighted systems that were likely to produce appropriate results related to research *with* Indigenous peoples. The search was conducted, resulting in a list of reliable databases to guide future research efforts.

3.3.2.2 Databases.

To ensure the search was comprehensive, the following databases were searched for relevant peer-reviewed articles: Academic Search Complete, Bibliography of Indigenous Peoples in North America, CINAHL Plus with Full Text, eBook Collection (EBSCOhost), Global Health, Health Source: Nursing/Academic Edition, Humanities International Complete, International Political Science Abstracts, SociINDEX with Full Text, and Alt HealthWatch. It was advised to expand to broaden the database search to gather all potential literature.

3.3.2.3 Inclusion Criteria

The search was limited by the publication dates: January 1, 2013, to April 1, 2024. The following key terms were used (indigenous or native or aboriginal or indians or first nations) AND (data or statistics or database or open data or big data) AND (governance or self-governance) OR (sovereignty or self-determination) OR (OCAP Principles) OR ("ownership, control, access, and possession"). The following geographic subject headings were included: New Zealand, Canada, United States, and Australia. Source types included academic journals, books, and grey literature.

In alignment with the scoping review methodology, the search was expanded to identify additional grey literature by manually searching for primary reports, guidelines, and reference publications that were not included in the initial database search results. Additional references were incorporated into the scoping review, many of which were guidelines and reports from organizations that focus on building capacity within the stated topic. The scope allowed for robust data collection to address the research questions. The literature review focused on exploring how Indigenous communities or organizations define Indigenous sovereignty, Indigenous data governance and related principles or practices. This strategy led to identifying additional further resources within the generated search results, references, or bibliographies to explore the topic further. This proved helpful in the search as the databases needed to expand their reach due to the colonial stratification of Indigenous knowledge when presented within Eurocentric coding and classification systems.

3.3.3 Stage Three: Study Selection

Step three of the Arksey and O'Malley (2005) framework involves conducting the selection process using the predefined inclusion and exclusion criteria, which were continually revised. The focus of the study selection was on locating published and unpublished academic articles, which could have any type of study design, including quantitative, qualitative, or mixed methods. E-books were included because of the nature of the topic and the open-access mode of knowledge translation that Indigenous academics are implementing to disseminate information to broader Indigenous populations around the world. Physical books were excluded from the search strategy due to feasibility issues regarding their accessibility and to prevent any potential delays in the larger study. This exclusion aligns with Arksey and O'Malley (2005) in their discussion of the practicality of the search strategy considering project size and the number of team members available.

The initial pool of results includes a total of 6, 032 (Appendix B). The literature search identified potential relevant citations with two reviewers manually reading each title, which were then imported into EndNote. EndNote is a reference management software where duplicates are removed and then manually double-checked. The research team conducted the manual removal. Two reviewers conducted the selection process based on the inclusion and exclusion criteria. One of the reviewers was Melissa Shouting, the co-lead for the larger project, and the other was a university undergraduate student employed within health sciences who has experience as a research assistant in multiple faculties. To ensure rigour and transparency, both the researcher and reviewer engaged in the categorization of data into themes and trends. This approach was chosen due to the time-sensitive nature of the larger collaborative health project.

Full-text articles of potentially relevant citations were reviewed using a data characterization and utility form that included key characteristics to verify article relevance, data utility, and extract main features (Appendix C). These characteristics included the objective, methodology used, aims, country of study, publication year, journal and database, data analysis, key findings, authors' conclusions, principles or practices indicated, data governance definition, data sovereignty definition, and use of theoretical frameworks.

3.3.3.1 First Review: Inclusion Criteria

The inclusion criteria created for the first level of study selection was driven by the research question topics, specifically Indigenous data governance, sovereignty, and self-determination. The Joanna Briggs Institute (2015) states that the inclusion criteria should be based on three themes: a) participant description, b) concept or the phenomena of interest, and c) context. Together they are referred to as PCC. The inclusion criteria used in the first level of selection were the country of publication, date of publication (2013-2024), and the used of both of the following concepts in the title or the abstract of the publication: Indigenous data governance, and health research. Synonyms for these concepts were chosen in consultation with the librarian to ensure a robust search strategy for location and inclusion of studies.

At this stage, the reviewer looked for the presence of key words in the title or the abstract. The use of key words as inclusion criteria were designed to be broad to provide a sense of what publications linked the two concepts. The country of publication had initially been broad to include any country within the search. However, after the sample search it was determined that the databased in question did not have reliable and efficient means of filtering the search by geographical location due to differing concepts of "Indigenous" unrelated to Indigenous populations that were colonized under European expansion. This resulted in excluding any publications outside of the USA, Canada, New Zealand and Australia. The results were also filtered to include English only content.

3.3.3.1 First Review: Study Selection

In the first review, we applied a phased process to evaluate the initial pool of articles to ensuring that the selected studies were relevant to the research question and met the inclusion criteria. Articles were initially excluded due to duplication within the search results. This exclusion was conducted using the search tools feature within the electronic database, as well as in the reference management program EndNote ™. To ensure thoroughness and accuracy, the researcher also manually reviewed all results to check for remaining duplicates. A total of 27 duplicates were identified and excluded manually. The inclusion criteria were then applied to the title and abstract of each publication. Any title or abstract that did not meet the inclusion criteria was removed from further review and consideration. If the article could not be excluded based solely on the title or abstract, the full text was examined for relevance to the research questions and inclusion criteria.

A second search was conducted using Google Scholar and Google Search to identify additional peer-reviewed sources and grey literature. This method allowed for a comprehensive review of relevant sources that were missed in the initial search, which included checking the reference lists to identify more sources. The search concluded once saturations was reached, and no new articles appeared. During the secondary search, several authors and scholars were referenced or quoted in the articles from the initial search (n=6). This prompted an in-depth exploration of those authors and their studies and research, uncovering additional Indigenous and non-Indigenous authors. However, upon further examination it was clear that the authors work was theory based and not research based.

3.3.3.2 Second Review

The remaining articles were then reviewed a second time by applying a second level of inclusion to the title and the abstract. This set of inclusion criteria focused on data governance as a framework in the study and Indigenous people as active participants rather than just "Indigenous" mentioned throughout the first criteria. At this stage, additional exclusion criteria were introduced to eliminate studies that were program evaluations, articles that were intervention-based, agricultural studies, and population surveillance. It is recommended that during this second review the independent reviewer considers all articles to ensure rigour, consistency, and agreement (Levac et al., 2010). 163 records were considered at this point based on the search criteria. After removing duplicates, 120 records remained (Appendix C). A screening process involving title and abstract review was conducted according to the inclusion and exclusion criteria; 46 records remained for analysis. A full-text review was completed if there were discrepancies between the title and abstract; for example, if the title did not include keywords but the abstract included key phrases or vice versa.

It is common and encouraged that part of the scoping review process involves gaining a comprehensive understanding of how concepts are depicted within the evidence. This knowledge informs decisions regarding the inclusion or exclusion criteria for the subsequent stage. At the end of the second review, it was determined that data governance and data sovereignty are understood differently within health promotion and interventions applied to populations through health research. Approaches that identified data governance as a mode of communication were excluded because they were applied as interventions to address data management requests from Indigenous communities. Articles that speculated on the potential use of ownership, control, access, or possession of data were not considered frameworks and were excluded (see Appendix D). However, those focusing on the Indigenous population's self-determination in data governance as a framework were included, ensuring that the results reflect absence of Indigenous data governance, its impacts, and the barriers to implementing such frameworks within population settings.

3.3.3.3 Final Review

For the final review of the full-text articles based on content and findings within the scoping review process, an additional criterion was included. One of the research aims of this review was to understand how to incorporate an evidence-based method when developing collaborative partnerships. The researcher aimed to explore how the role of Indigenous populations or communities, along with data governance and sovereignty principles and frameworks would contribute to the development of policies that support Indigenous communities in achieving data governance and sovereignty in health research. At this stage, it was noted which governing principles and practices were present in each article. The remaining 15 articles demonstrated some level of data governance principles.

The resulting articles were then mapped, summarized, and analyzed for themes and trends (Appendix E). During the final review, the grey literature results were incorporated with all the other citations and subsequently excluded through the inclusion/exclusion review process. It is important to note that the final number of articles provided in Appendix E does not represent the total number of articles analyzed.

3.3.4 Charting the Data

Each of the final articles selected was summarized in a table (Appendix E) designed to guide data extraction. The goal of this step was to identify and map out the factors needing extraction from each article to help answer the research question (Abraham et al., 2019; Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2020). We then extracted relevant data and entered it into the Excel sheet to chart it (Appendix C). This process aimed to understand how the theories and models of IDG and IDS are incorporated or understood within the research (Levac et al., 2010). The charting process proved helpful in becoming familiar with the data through summarizing, synthesizing, and organizing the literature. Arksey and O'Malley (2005) describe a descriptive-analytical method that involves summarizing process information using a theory or model in a meaningful way (p. 26). The categories within the charts included: title and abstract, year of publication, country of study, study completion date, study objective or aim, methodology, measures, data analysis, key findings, and conclusions by author. This approach provided an overview of the trends in the literature and provided a gap analysis for future research. The sources of the literature and their geographical connections highlighted the differences in the thematic organization of data depending on the population, enabling further comparisons of the studies.

Additionally, an analysis was conducted to evaluate the methods for implementing data governance principles, defining Indigenous data governance, proposing policies for data governance and data sharing agreements, integrating place-based knowledge systems into governance policies and practices, developing strategies for sustainable collaborative partnerships to promote Indigenous data governance, and the applying theoretical frameworks.

3.3.5 Summarizing the Data

The final step required of the Arksey and O'Malley (2005) scoping review framework is to collate and summarize the results for presentation and discussion. The presentation of the results provided a map of extracted data that aligns with the review objectives (Peters et al., 2020). The data was initially organized by main conceptual categories, such as study characteristics, use or impacts of IDG and IDS on Indigenous health research, other key findings, and research gaps. This synthesis and analysis used a dual approach, combining both Eurocentric methods, weaved with *Siksikaitsitapi* methodologies. This process enabled the inclusion of Blackfoot data governance approaches in both reporting the results and, most importantly, in the discussion section.

Due to the project's timeline, the data collection and analysis took place concurrently. This helped with the writing process. The goal was to perform a thematic analysis to effectively synthesize the key characteristics of IDS principles and practices in order to implement IDG. Although Eurocentric methods may be used to gather the data, an Indigenous data governance perspective will guide the analysis. The researcher made a deliberate effort to strengthen and centre Indigenous knowledge throughout this process. The data highlighted the importance of understanding how Indigenous language systems, place-based knowledge, kinship alliances, and cultural practices and objects influence the development of Indigenous data sovereignty principles specific to each nation that they are being developed for. An overview of each theme will be discussed further in the next chapter. The results will serve as the building blocks for establishing an IDG framework with IDS principles grounded in a *Siksikaistitapi* paradigm. As an Indigenous researcher with ethical obligations to my nation and a health researcher committed to ethical practices within an academic setting, it is my duty to set boundaries on how the data is collected and analyzed to maintain its integrity within the field. This highlights the researcher's responsibility to minimize risks to participants and prevent data from being compromised.

3.4 Ethical Considerations

Transparency and reproducibility were essential considerations in conducting this scoping review (Arksey & O'Malley, 2005; Peters et al., 2020). To ensure transparency, documentation was meticulous throughout the search and review process. An annotated bibliography was used to understand how the literature aligns with the researchers' scholarship. This process allowed the researcher to document removal and inclusion of articles, along with the rationale. The researcher assessed all decisions regarding whether to include or exclude an article from the final review. As outlined by Arksey and O'Malley (2005) inclusion and exclusion criteria, along with search terms, were established before the search and later adjusted during the review. To maintain rigour throughout the iterative process, decisions about inclusion and exclusion criteria were catalogued. The researcher reviewed all forms, questions, criteria and conducted an independent double-check of abstracts and final articles.

While scoping reviews provide an overview of the breadth of evidence available on a topic, they do not consider the depth or quality of that evidence (Arksey & O'Malley, 2005; Armstrong et al., 2011; Peters et al., 2015). Some authors have argued that scoping reviews should incorporate a quality assessment process; however, they contend that this decision should depend on the available resources and the specific objectives of the scoping review itself. From an Indigenous perspective, while Arksey and O'Malley (2005) encourage an iterative approach to scoping reviews, their framework does accommodate an approach that would prioritize Indigenous voices to circle back in at any point. The volume of data produced in a scoping review can be substantial, making it difficult to find a balance between offering a comprehensive overview of all types of evidence discovered and delivering detailed data and assessments for a smaller selection of studies (Arksey & O'Malley, 2005). Scoping studies do not provide a comprehensive assessment of the quality of findings; instead, they generate a narrative summary of all available data (Arksey & O'Malley, 2005; Peters et al., 2015). This approach ensures that all data included in this review and does not limit the final number of articles, unlike a systematic review. Finally, to maintain the study's feasibility and meet realistic timelines, the publication timeframe must be limited.

CHAPTER: 4 RESULTS

The findings of the review are organized and presented within this chapter as the following sections: 1) study characteristics and demographics; 2) study objectives, designs and theoretical frameworks; 3) Indigenous data governance: an overview of community engagement 4) ethical practices in research and data governance 5) enacting community collaboration to guide and support Indigenous data governance 6) limitations. A total of fifteen articles were considered for analysis upon the final review to further understand the level of data governance principles and practices present.

4.1 Study Characteristics and Demographics

4.1.1 Study Characteristics

The discussion surrounding Indigenous data governance (IDG) has continued to evolve within the body of evidence, with the number of studies increasing over the last decade, resulting in a consistent distribution of publications in recent years. The evolution of research studies between 2009 and 2024 indicates that this topic of inquiry is emerging. The highest percentage of published studies occurred in 2022, accounting for 26.7% (n=4). Figure 4.1 illustrates the frequency of increased studies by year of publication.

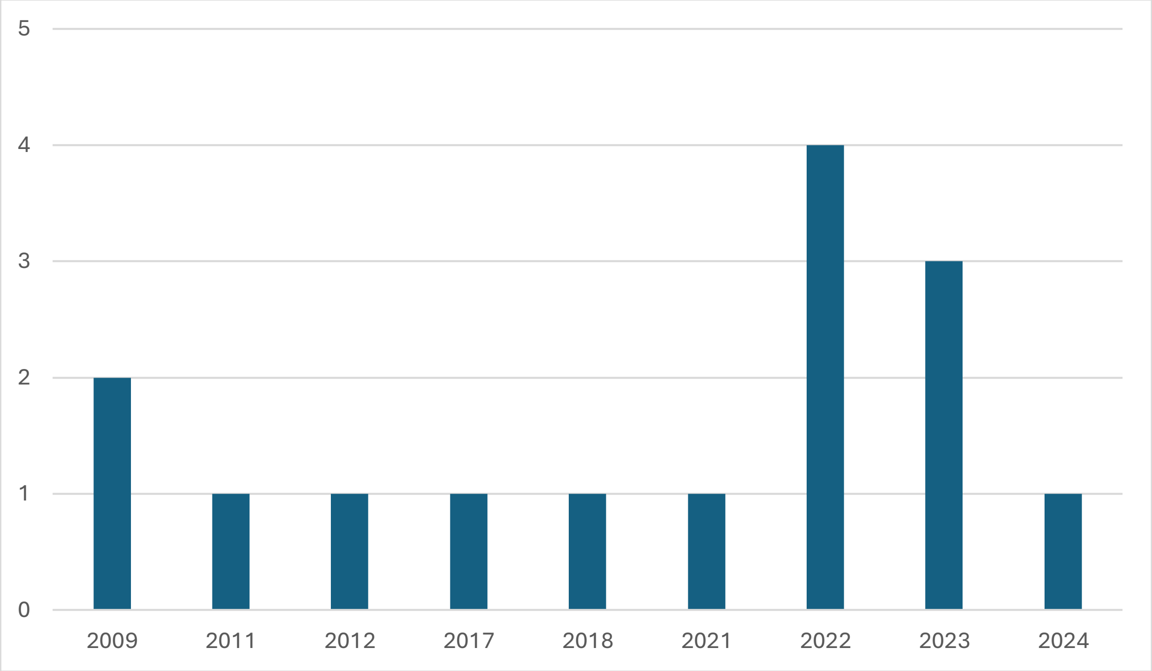

Figure 4.1 Frequency of Included Studies by Year of Publication

The geographic range of the included evidence spanned four countries; however, 73.3% (n=11) of the described research was conducted in Canada. One study was conducted in New Zealand, another in Australia, and a third was conducted in the United States of America.

The fifteen studies were published in nine journals. Two studies were published in the *International Journal of Indigenous Policy*, two studies were published in the *Canadian Journal of Public Health,* and two additional studies were featured in *PLoS One.* The remaining thirteen articles were found in nine different multidisciplinary journals, including *BMC Medical Research Methodology*, *Social Science*, *Medicine, BMJ Open*, *Australian Aboriginal Studies, BMC Pregnancy & Childbirth*, *Health & Human Rights: An International Journal*, *BMC Health Services Research*, *Journal of Agromedicine*, and *The International Journal of Indigenous Health.* This distribution confirms that the topic of Indigenous data governance in health research is significant across multiple disciplines, contexts, and populations.

4.1.2 Study Demographics

Descriptive studies are often characterized by their focus on providing detailed descriptions of a population, situation, or phenomenon as it naturally exists, attempting to examine cause-and-effect relationships (Aggarwal & Ranganathan, 2019). 53.3% of the articles (n=8) reported on some or all of the descriptive study characteristics (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thurber et al., 2021). Four of the studies reported the number of participants ranging from 8 to 3,597 (Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). One article included thirteen Indigenous communities representing a variety of healthcare providers, including psychotherapists, traditional healers, and social workers (Vukic et al., 2009). Only a few studies included all genders (n=4; 26.6%) (Boffa et al., 2011; Nickel et al., 2024; Reeves et al., 2023; Thurber et al., 2021), while one study focused solely on women (Haora et al., 2023). One study focused solely on youth (Thorburn et al., 2023). The following articles included participants from one or more Indigenous backgrounds (Boffa et al., 2011; Flicker & Worthington, 2012; Love et al., 2022; Minore et al., 2009; Nickel et al., 2022; Thorburn et al., 2023), with five being First Nations individuals living in Canada (n=5; 33.3%) (Bhawra et al., 2022; Maar et al., 2022; Nickel et al., 2024; Tompkins et al., 2018; Vukic et al., 2009), followed by Aboriginal Australians (n=2; 13.3%) (Haora et al., 2023; Thurber et al., 2021), and one each from Māori (n=1; 6.7%) (Reeves et al., 2023), and American Indian (n=1; 6.7%) regions (Rainie et al., 2017). The age of the participants was frequently reported; however, age groupings were inconsistent. Some articles reported the mean age of participants, while others provided a range of categories. It is challenging to compare the categories due to their variance. Appendix F summarizes the characteristics of the studies included in this review.

Income was less likely to be collected, and the categories were again inconsistent; this limited the researcher's ability to compare the data. Also, variation in currency across countries limited its usability for comparison at both the provincial and global levels. Thurber et al. (2021) compared education and employment, with the categories being consolidated into three sections, with an additional section to highlight the missing information. The categories were reductionist, including no school or primary school, Year 10, Year 12 and beyond. Employment was mentioned only in a general statement regarding the population living in Canada, in comparison to the non-Indigenous population. Bhawra et al. (2022) positioned Indigenous peoples in Canada as experiencing a disproportionate number of health, economic, and social inequalities compared to non-Indigenous Canadians, including elevated unemployment and poverty rates.

Information on urban and rural living was discussed inconsistently in the studies. Four studies (n=4; 26.7%) were conducted in rural settings (Boffa et al., 2011; Love et al., 2022; Maar et al., 2022; Vukic et al., 2009); two studies (n=2; 13.3%) was conducted in an urban setting (Haora et al., 2023; Nickel et al., 2022), with six studies (n=6; 40%) reporting a population from both an urban and rural setting (Bhawra et al., 2022; Minore et al., 2009; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018), while three studies (n=3; 20%) did not disclose this information (Flicker & Worthington, 2012; Reeves et al., 2023; Thorburn et al., 2023). Overall, gathering and comparing demographics is challenging due to inconsistent reporting of these characteristics and dependent on how researchers or communities define them.

4.2 Studies Objectives, Research Designs, and Theoretical Frameworks

This section outlines the objectives, designs, and frameworks that were developed and analyzed based on the fifteen final articles included in this study.

4.2.1 Study Objectives

The objectives that guided the fifteen studies were predominantly descriptive and exploratory, utilizing keywords such as "explore," "understand," "address," "analyze," "investigate," "assess," "evaluate," and "inform." The aims of the studies differed, with an intention of contributing to the field of data sovereignty or governance. The following aims were identified for the fifteen articles:

- Identify gaps, barriers, and successes associated with mental health services in Indigenous communities (Vukic et al., 2009),
- Understand the health needs of an Indigenous community (Bhawra et al., 2022),
- Explore an Indigenous community perspective on data-sharing (Reeves et al., 2023),
- Understand the determinants of TB transmission (Boffa et al., 2011),
- Understand the socioeconomic characteristics of drug use (Nickel et al., 2022),
- Examine the development of a culture-based intervention to treat addiction (Maar et al., 2022),
- Investigate and analyze the impact of the COVID-19 pandemic among First Nations communities (Nickel et al., 2024),
- Examine the data challenges faced by Indigenous communities (Rainie et al., 2017),
- Examine the determinants and effects of violence in communities (Thurber et al., 2021),
- Explore the feasibility of establishing Indigenous birthing centers in the community (Haora et al., 2023),
- Establish equitable partnerships with Indigenous communities in health research (Love et al., 2022),
- Explore innovative strategies to enhance diabetes care for Indigenous peoples (Tompkins et al., 2018),
- Assess the capacity to document Aboriginal peoples' health and service utilization in various Canadian communities (Minore et al., 2009),
- Investigate the perspectives of research ethics board members on reviewing and conducting research with Indigenous populations (Flicker & Worthington, 2012),

- Understand how Indigenous young people define and practice self-determination in wellness (Thorburn et al., 2023).

4.2.2 Research Designs

Fewer than half of the studies, 46.7% (n=7), employed a qualitative research method. A mixed-methods approach was used in 40% (n=6) of the studies, while a quantitative approach was applied in the remaining 13.3% (n=2) of the studies. The research varied in size, scope, methods, and target populations. This variability in the evidence reflects the diverse backgrounds and settings in which the advancement of Indigenous data governance and Indigenous data sovereignty has been examined. Figure 4.2 provides a summary of the research designs utilized.

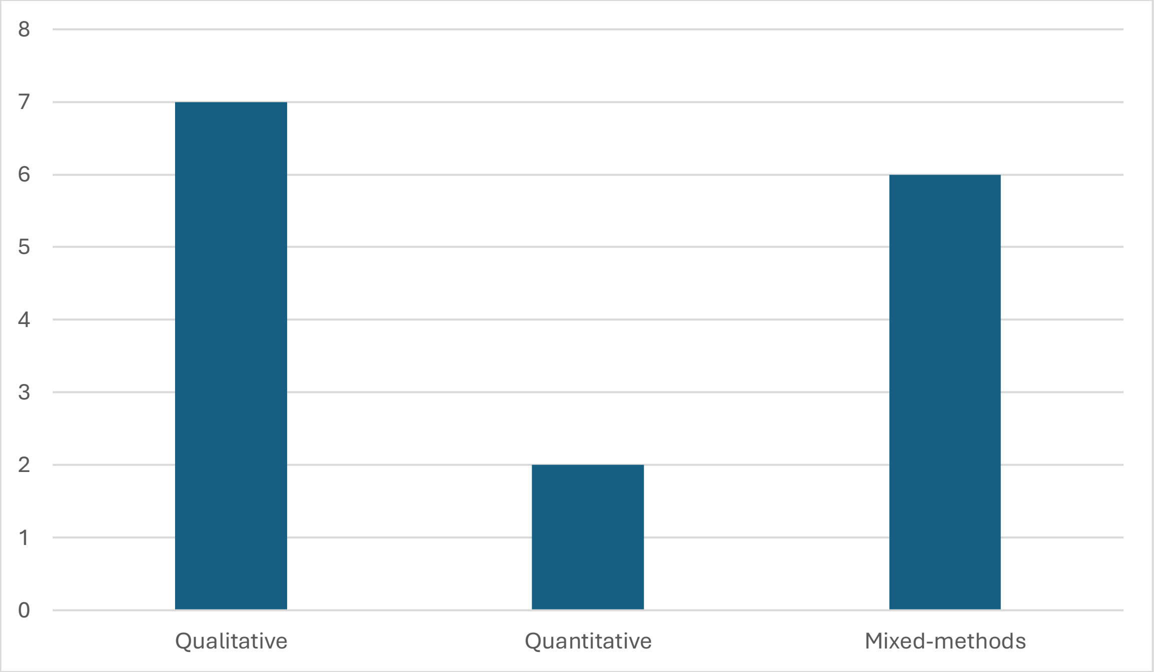

Figure 4.2 Summary of Research Designs of Included Studies

4.2.3 Research Designs

Over half of the studies, 60% (n=9), did not state or use a theoretical framework to guide the research or analysis (Flicker & Worthington, 2012; Love et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Six articles employed various theoretical frameworks, with four different authors utilizing a similar grounded theory that incorporates or centres on Indigenous knowledge (Bhawra et al., 2022; Boffa et al., 2011; Maar et al., 2022; Thorburn et al., 2023). One article employed a Constructivist Grounded Theory (Reeves et al., 2023), Realist Theory (Haora et al., 2023), and a theoretical framework addressing disparities in Canada (as cited in Haora et al., 2023).

Seven of the fifteen articles, all authored by different individuals, employed a framework that emphasized self-determination and empowerment through data governance or data sovereignty. Five studies utilized Community-Based Participatory Action Research models (Bhawra et al., 2022; Haora et al., 2023; Maar et al., 2022; Thurber et al., 2021). Haora et al. (2023) defined their Participatory Action Research (PAR) model as “a transformative advocacy lens which drives a social justice agenda” (p. 5), a process that engages partners to create locally led, co-created approaches for identifying and analyzing issues, and planning solutions that incorporate an Indigenous worldview. Bhawra et al. (2022)described Community-Based Participatory Research (CBPR) as a method that requires community engagement, creating space to amplify citizens’ voices and ensure representation in the decision-making process, which leads to sustainable solutions. Maar et al. (2022) also adopted CBPR, referring to it as a methodology that invites citizens of a First Nations community to collaborate as partners with an academic team (p. 5). Vukic et al. (2009) state that “community-based participatory research was the approach" for their study. However, they did not explain the processes used to classify it as CBPR. These methods were depicted as a means to build and strengthen relationships between researchers and Indigenous communities, with a focus on addressing the needs of the Indigenous population (Maar et al., 2022; Vukic et al., 2009). The researchers can develop the study in alignment with the Indigenous community's "cultural framework, expectations, and vision to support continuous and meaningful engagement throughout the project" (as cited in Bhawra et al., 2022, p. 2). The theory of CBPR recognizes that knowledge is a fundamental element in supporting Indigenous communities in regaining sovereignty over all aspects of their health outcomes (Rainie et al., 2017). This theory utilizes a multidimensional approach to knowledge, aiding Indigenous researchers and communities in their understanding of data management, data governance, and data sovereignty. CBPR guides researchers as they engage with data, empowering communities to identify their own research priorities (Bhawra et al., 2022).

4.3 Indigenous Data Governance in Study Design, Outcome, and Measures Used

Articles that underwent detailed extraction were reviewed for content discussing the use of Indigenous data governance approaches within the study design and methods for conducting research *with* Indigenous populations or communities. Indigenous data governance was described at both the individual and community levels. This included the importance of valuing traditions and knowledge sharing to support Indigenous communities and populations in their pursuit of self-governance and self-determination.

All studies considered some form of Indigenous data governance or data sovereignty in their design; 73.3% (n=11) of these studies identified strategies or frameworks employed to support Indigenous self-determination in their design and potential outcomes (Table 4.1). Self-determination is a central concept in Indigenous governance, where autonomy and the right to make decisions are regarded as essential for determining the use of data and information. The decision-making process included discussions regarding:

- Indigenous leadership (Flicker & Worthington, 2012),
- inter-tribal (Bhawra et al., 2022),
- cross-community (Bhawra et al., 2022; Maar et al., 2022) and
- decision-making mechanisms, such as advisory and steering committees (Bhawra et al., 2022; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021).

Three of the articles presented Indigenous data sovereignty as a primary outcome of the study (Love et al., 2022; Maar et al., 2022; Rainie et al., 2017). This conclusion was reached by identifying synonyms in the search term strategy that were perceived to encapsulate the concept of IDG.

Table 4.1
Methodologies or Frameworks to Support Indigenous Self-Determination

Strategies or frameworks mentioned to support Indigenous self-determination	- Self-determination through community inclusion (Rainie et al., 2017; Thorburn et al., 2023) - Community based participation (Maar et al., 2022) - Indigenous Rights Framework (Rainie et al., 2017) - Ownership, Control, Access, and Possession (Love et al., 2022; Minore et al., 2009; Nickel et al., 2024) - Participatory action research (PAR) (Bhawra et al., 2022; Haora et al., 2023; Tompkins et al., 2018) - Indigenous data sovereignty (Boffa et al., 2011; Nickel et al., 2024; Reeves et al., 2023) - Collective Benefit, Authority to Control, Responsibility, and Ethics (CARE) Principles for Indigenous Data Governance (Maar et al., 2022; Reeves et al., 2023) - Community-based action research (CBAR)(Thurber et al., 2021).

4.4 Indigenous Data Governance: An Overview of Community Involvement

In the included studies, the concept of Indigenous data governance was used inconsistently alongside terms such as Indigenous self-determination, Indigenous sovereignty, strengths-based approach, Māori governance, participatory action research, and Indigenous-led initiatives. More than one-third (n=13) of the studies referenced "Indigenous-led" in their definition of the concept of interest, particularly when discussing methods or approaches to community engagement with Indigenous peoples (see Table 4.3). Researchers described building relationships with the target population or Indigenous community by utilizing various approaches in each case. Some research was based on existing relationships with communities or longstanding partnerships (Bhawra et al., 2022; Reeves et al., 2023; Tompkins et al., 2018), some were developed over several years (Boffa et al., 2011; Haora et al., 2023), and others were newly established through facilitated community visits to engage with the community or population (Bhawra et al., 2022; Love et al., 2022; Nickel et al., 2022; Rainie et al., 2017; Thorburn et al., 2023; Vukic et al., 2009). Some articles did not explain how and when relationships were established between the research team and the Indigenous population or community (Flicker & Worthington, 2012; Maar et al., 2022; Nickel et al., 2024). One study focused on Aboriginal peoples, with the majority of the research team comprising Aboriginal and Torres Strait Islander peoples who implemented a Torres Strait Islander governance structure (Thurber et al., 2021, p. 6). Nickel et al. (2024) describe the process of building relationships through a decolonizing approach, which "included active involvement of First Nations researchers in the project as co-investigators and decision-makers, from the proposal stage to analysis and dissemination" as a method for fostering relationships (p. 5). Meanwhile, Thurber et al. (2021) outlined the process of building relationships with Indigenous communities through several key approaches. These include community self-nomination for study participation, community advisory groups, enhancing community research capacity, and service mapping to ensure meaningful community involvement in generating relevant and actionable results.

4.4.1 Facilitating Community Engaged Research

Indigenous or community advisory committees, groups, or councils often provide guidance and input throughout the research process to ensure that it benefits the community and meets their needs and interests (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Maar et al., 2022; Rainie et al., 2017; Thorburn et al., 2023; Thurber et al., 2021). Others have noted being influenced by priorities identified by the community(Haora et al., 2023; Love et al., 2022; Tompkins et al., 2018). Two studies indicated that they were led by the community (Rainie et al., 2017; Thurber et al., 2021); however, one study highlighted that community members were acknowledged as co-decision makers (Bhawra et al., 2022), and another study described community members as equal partners throughout the entire project (Boffa et al., 2011; Nickel et al., 2024). One study mentioned that co-decision makers, co-principal investigators, and co-investigators align with the principles of participatory research (Love et al., 2022). Several articles highlighted the application of the Ownership, Control, Access, and Possession (OCAP) principles in conducting ethical research *with* Indigenous health research communities (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Love et al., 2022; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Tompkins et al., 2018; Vukic et al., 2009). Table 4.2 lists excerpts from the literature highlighting the participation of Indigenous communities or populations in the development of the research design alongside the research team.

Table 4.2
Community Involvement

Excerpts from the literature illustrating the involvement of Indigenous communities or populations in developing the research design.	This project is governed by a Citizen Scientist Advisory Council which included researchers, Knowledge Keepers, and youth from Îie-à-la-Crosse (Bhawra et al., 2022).
	Aboriginal faculty and staff were involved in the DTT project from its inception, as well as other Aboriginal experts such as Elders, indigenous healers and health care providers… (Boffa et al., 2011)
	While BOOSt is a collaboration between First Nations and non-First Nations partner organizations, our approach privileges First nations knowledges, research methodologies, and ways of knowing, being and doing… (Haora et al., 2023)
	By doing so, a legal precedent was established by the team in which Indigenous partners were made equal participants in the full scope of the research project and co-authors on relevant outputs (Love et al., 2022)
	This project partners with Indigenous community co-investigators who work together to develop interventions to close the gap…(Hutchins et al., 2023)
	Community leadership collaborated on setting the research objectives, and a community advisory committee (CAC) with representation from community members and organization guide all aspects of the research process and ensures that the work meets the needs of the community (Maar et al., 2022)
	The design and interpretation of these distinctions-based analyses will be guided by Indigenous co-investigators on the team and will inform health and social planning and policy priorities for the respective Nations (Nickel et al., 2022)

	Our decolonizing approach also included active involvement of First Nations researchers in the project as co-investigators and decision-makers, from the proposal stage to analysis and dissemination (Nickel et al., 2024)
	Both tribes agreed to participate in the research and became partners in the entire process from conception to publication(Rainie et al., 2017).
	The research team consists of a diverse group of Indigenous and non-Indigenous researchers (Thorburn et al., 2023)
	In addition to the self-nomination process, local community groups played a substantive role in study development and implementation (Thurber et al., 2021)
	The CPS was developed through a collaborative partnership between FORGE AHEAD Indigenous community representatives, Western University research team members, and the First Nations and Inuit Health Branch (FNIHB) of Health Canada (Tompkins et al., 2018)
	Indigenous health directors collaborated with the university researchers on decisions about the research question, interview guide, design, data collection, write-up and dissemination (Vukic et al., 2009)

4.5 Indigenous Data Governance: An Overview of Community Engagement

Ten (66.7%) studies indicated the use of Indigenous guiding principles to inform their research (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thorburn et al., 2023; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). In Canada, several studies have recognized the significance of OCAP in their research processes (Boffa et al., 2011; Love et al., 2022; Minore et al., 2009; Vukic et al., 2009) and data governance principles (Haora et al., 2023) concerning Indigenous health research (Nickel et al., 2024). These principles guided the project to ensure that the governance of Indigenous data was respected (Haora et al., 2023; Vukic et al., 2009). One study reported that it received approval from the First Nations Health and Social Secretariat of Manitoba's Health Information Research Governance Committee and the Manitoba Métis Federation (Nickel et al., 2022). Community engagement varied across studies. Among those who reported collaborating with communities in the research design, they did so to ensure that project goals aligned with the interests of their community partners or to enhance the study's credibility and cultural relevance (Bhawra et al., 2022; Haora et al., 2023; Love et al., 2022). A few studies reported the use of Indigenous methodologies described as "two-eyed seeing approaches" (Bhawra et al., 2022), "mino-bimaadiziwin" (Maar et al., 2022), and a community-engaged process (Rainie et al., 2017).

In 53.3% (n=8) of the studies, Indigenous communities participated in designing the data collection process and advising on how the data should be collected (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Love et al., 2022; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Vukic et al., 2009). Two studies indicated that the involved communities owned and managed the data (Rainie et al., 2017; Tompkins et al., 2018). However, a few studies have noted community engagement during data collection, suggesting that the engaged community co-manages (Boffa et al., 2011; Haora et al., 2023) or co-owns these data (Bhawra et al., 2022; Love et al., 2022).

Four of the studies reported involving communities in data analysis by seeking feedback and input on the final results (Reeves et al., 2023; Thorburn et al., 2023; Thurber et al., 2021), which often ensures the accuracy and reliability of the findings (Nickel et al., 2022). However, a few studies did not report collaborating with communities to analyze the data (Flicker & Worthington, 2012; Maar et al., 2022; Minore et al., 2009). 53.3% of the studies (n=8) identified working with the community to provide recommendations based on the research (Bhawra et al., 2022; Boffa et al., 2011; Love et al., 2022; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Haora et al. (2023) eluded that the dissemination activities would occur in consultation and collaboration with their community partners.

Beyond sharing their findings during the analysis phase, five studies reported engaging in dissemination activities by collaborating *with* the community (Love et al., 2022; Rainie et al., 2017; Thorburn et al., 2023; Thurber et al., 2021; Tompkins et al., 2018). For instance, Tompkins et al. (2018) regionally tailored community reports to ensure the results were meaningful to the communities and accurately reflected the data. However, details were not provided. Another study organized a knowledge-sharing event with targeted community stakeholders, which involved facilitated discussions to interpret findings, reflect on feedback, and incorporate expertise from the group (Nickel et al., 2022, pp. 7–8).(Nickel et al., 2022, pp. 7–8). One article mentioned that progress reports were circulated to steering committees for feedback and to provide guidance to ensure the findings were shared in a culturally appropriate manner (Haora et al., 2023). Two studies (13.3%) reported using a unilateral approach to disseminate the knowledge generated from the research, indicating that the results were shared directly from the researchers *to* the community (Boffa et al., 2011; Vukic et al., 2009). Furthermore, 40% of the articles (n=6) did not provide details on how the knowledge would be shared with communities (Bhawra et al., 2022; Flicker & Worthington, 2012; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2024; Reeves et al., 2023).

Table 4.3 illustrates excerpts from the methods discussed in the reviewed articles, highlighting how the researchers understood and integrated Indigenous guiding principles when engaging in research *with* Indigenous communities.

Table 4.3
Indigenous Guiding Principles

Excerpts from the literature illustrating the incorporating Indigenous guiding principles into the research process	the application of a Two-Eyed Seeing lens enables us to leverage strengths of both Indigenous and Western Ways of Knowing to help focus on key priorities and develop solutions (Bhawra et al., 2022)
	The methodology aligned itself with the recently published Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People and the established principles of Ownership, Control, Access, and Possession (OCAP) (Boffa et al., 2011)
	BOOSt is a collaboration between First Nations and non-First Nations partner organisations, our approach privileges First Nations knowledges, research methodologies and ways of knowing, being and doing (Haora et al., 2023)
	This approach adheres to Indigenous data sovereignty principles and OCAP principles, and has been adopted at the direction of our First Nations research partners (Nickel et al., 2024)
	An interdisciplinary team informed the creation of survey questions that wove together cultural and local knowledge with Western epistemologies (Rainie et al., 2017)
	A kaupapa Māori methodology would be a useful way to extend the findings presented here by conducting a study specific to the perspectives of Māori participants in lifecourse research that is led by Māori, with Māori, and for Māori (Reeves et al., 2023)
	Another method called community-based participatory action research involves Indigenous communities in every step of the research process (Thorburn et al., 2023)
	The study design was informed by Aboriginal and Torres Strait Islander stakeholders and ethical principles (Thurber et al., 2021)

	The goal was to ensure culturally appropriate and feasible approaches that considered the characteristics and contexts of each region promoted participation through the support of local trusted signatories (Tompkins et al., 2018)
	Community-based participatory research, which is consistent with Ownership, Control, Access and Possession principles of research with Aboriginal communities, was employed for this work (Vukic et al., 2009)

4.5.1 Capacity Building and Empowerment

66.7% of the articles (n=10) did not mention the involvement of community-based research assistants to support the data collection process (Bhawra et al., 2022; Flicker & Worthington, 2012; Haora et al., 2023; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Reeves et al., 2023; Thorburn et al., 2023; Tompkins et al., 2018; Vukic et al., 2009). However, one study provided recommendations that highlighted the need for capacity-building and training initiatives to support community organizations and their members (Love et al., 2022). A few studies used the term ‘empower’ to describe methods aimed at fostering self-determination within the community by incorporating their knowledge and perspectives into the research process (Bhawra et al., 2022; Boffa et al., 2011). Several articles discuss aspects of capacity development aimed at enhancing self-determination; however, they do not explicitly state that they have offered opportunities to build capacity within the community (Maar et al., 2022; Minore et al., 2009; Nickel et al., 2024). One article mentioned training in data collection, analysis and presentation while ensuring they understood the importance of data and how it would be used (Rainie et al., 2017). Thurber et al. (2021) explained how a training manual was developed for ‘face-to-face’ training with community members to support capacity-building within the community (pp. 7-8).

Articles were also examined to understand the directional approach to capacity building within the studies. Some were unidirectional, as researchers included Indigenous populations to strengthen their understanding of the target population and cultural protocols (Flicker & Worthington, 2012; Nickel et al., 2024; Vukic et al., 2009), while others reported a unilateral approach to capacity building, where the research team offered learning opportunities from the researchers to the community (Maar et al., 2022; Minore et al., 2009; Nickel et al., 2022; Tompkins et al., 2018), rather than acknowledging that Indigenous communities can also provide capacity-building opportunities for the research team. Six articles suggested a bi-directional approach to capacity building, emphasizing that the research team participated in learning opportunities from the community to the researcher and from the researcher to the community (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Love et al., 2022; Rainie et al., 2017; Thurber et al., 2021).

Table 4.4 lists excerpts from the literature outlining strategies for building capacity and promoting empowerment within a nation, community, or population during the research process.

Table 4.4
Capacity Building and Empowerment

Excerpts from the literature illustrating the capacity building and empowerment	The empowerment approach involved community members represented through the Citizen Scientist Advisory Council engaging in co-production of the evaluation design and implementation by establishing key objectives for the evaluation, informing evaluation questions, building relevant and culturally responsive indicators, developing focus group guides, leading recruitment and data collection, and interpreting results (Bhawra et al., 2022)

	PNCs functioned as more than just advisory groups; members were involved in developing and clarifying research questions, creating interview tools, informing methods by which to develop Aboriginal capacity, interpreting findings, and participating in dissemination (Boffa et al., 2011)
	The PAR design applies a transformative/advocacy lens which drives a social justice agenda (i.e. equity in health access, autonomy, improved outcomes and experiences for First Nations families) (Haora et al., 2023)
	All members of the Pathways research team required training and education on Indigenous data sovereignty (Love et al., 2022)
	Aspects of the relationship include investing in capacity development, increasing community data capabilities, and embedding data within Indigenous languages and cultures (Maar et al., 2022)
	… there was clear agreement: Aboriginal stakeholders must be fully engaged throughout the process (Minore et al., 2009)
	To ensure that our study proposal aligns with the First Nations principles of ownership, control, access and possession and the Métis principles of ownership, control, access and stewardship (Nickel et al., 2022)
	Our decolonizing approach also included active involvement of First Nations researchers in the project as co-investigators and decision-makers, from the proposal stage to analysis and dissemination (Nickel et al., 2024)
	The department gathered citizen input through focus groups and planning sessions, and held community meetings to educate citizens and descendants on data terminology, to explain how Ysleta del Sur's data differs from and expands on other available data, and to share how Ysleta del Sur's government uses the data to make decisions (Rainie et al., 2017)

	all aspects of the research, including the analysis in the study presented here were approved by an institutional research ethics board and an Indigenous research advisory group (Thorburn et al., 2023)
	each participating community identified one individual as a local coordinator to drive the research process at the community level and to serve as the main point of contact for the study team (Thurber et al., 2021)
	Results were shared with participating communities and regional/federal partners through tailored reports (Tompkins et al., 2018)
	Community-based participatory research was the approach for this qualitative descriptive study aimed at increasing understanding of the gaps, barriers and successes/solutions in mental health services in Mi'kmaq communities (Vukic et al., 2009)

4.5.2 Culturally Informed Approaches: How Research is Conducted and Why?

Articles reviewed included recommendations for *how* research should be done with Indigenous communities. A prevailing sentiment in the literature was the necessity for the research to be participatory and to engage meaningfully with community members throughout the research process (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2022; Thorburn et al., 2023; Tompkins et al., 2018). The importance of the participatory nature and decision-making power of the community, alongside meaningful engagement, was emphasized as essential for supporting the self-determination of Indigenous peoples (Love et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thorburn et al., 2023).

Multiple studies have described the importance of communities having ownership over the research data, the knowledge that informs it, and its outputs (Bhawra et al., 2022; Boffa et al., 2011; Love et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). One study emphasized the importance of incorporating Indigenous data sovereignty principles, indicating that Indigenous data is subject to Indigenous governance and creating space for Indigenous methodologies to guide the research (Reeves et al., 2023).

Table 4.5 lists excerpts from the literature discussing approaches to ensure that research methods or designs are culturally informed by consulting with the Indigenous community or population.

Table 4.5
Culturally Informed Approaches

Excerpts from the literature illustrating the culturally informed approaches in research	the knowledge of historical issues, challenges, and success stories in the community is considered Indigenous Knowledge for this needs assessment, and more importantly, this Indigenous Knowledge informed the focus areas and next steps for this project (Bhawra et al., 2022)
	Aboriginal experts such as Elders, indigenous healers and healthcare providers, who made up committees which are described in detail herein (Boffa et al., 2011)
	Researchers will use ‘yarning’, a culturally appropriate conversation that is relaxed, flexible and includes developing relationships with participants prior to and during the story-telling (Haora et al., 2023)
	However, to facilitate sustainable, culturally safe, community-designed Indigenous practice models, the legitimacy of Indigenous knowledge and science alongside Western approaches to recovery needs to be acknowledged (Maar et al., 2022)
	Our goal in engaging public rightsholders, service providers and knowledge users in the research is to ensure that their first-hand knowledge and perspectives are represented in the work (Nickel et al., 2022)

	Our decolonizing approach also included active involvement of First Nations researchers in the project as co-investigators and decision-makers, from the proposal stage to analysis and dissemination (Nickel et al., 2024)
	Our goal in engaging public rightsholders, service providers and knowledge users in the research is to ensure that their first-hand knowledge and perspectives are represented in the work (Nickel et al., 2022)
	Our decolonizing approach also included active involvement of First Nations researchers in the project as co-investigators and decision-makers, from the proposal stage to analysis and dissemination (Nickel et al., 2024)
	An interdisciplinary team informed the creation of survey questions that wove together cultural and local knowledge with Western epistemologies (Rainie et al., 2017)
	This research was funded by the Social Sciences and Humanities Research Council through the Canada Research Chairs program, and all aspects of the research, including the analysis in the study presented here were approved by an institutional research ethics board and an Indigenous research advisory group (Thorburn et al., 2023)
	The study design was informed by Aboriginal and Torres Strait Islander stakeholders and ethical principles (Thurber et al., 2021)
	The goal was to ensure culturally appropriate and feasible approaches that considered the characteristics and contexts of each region, and promoted participation through the support of local trusted signatories (Tompkins et al., 2018, p. 3).
	Community-based participatory research, which is consistent with Ownership, Control, Access and Possession principles of research with Aboriginal communities, was employed for this work (Vukic et al., 2009)

4.5.3 Data Collection Tools: Nation-Specific or Culturally Relevant

Data collection refers to identifying relevant existing data and generating new data. Articles that underwent detailed extraction were reviewed for their content on the types of data collected and to investigate whether the data management and collection tools described in the articles were developed and implemented in partnership with, and tailored to, the specific needs, culture, and priorities of the nation, community, or group.

Regarding data collection, some studies reported involving Indigenous communities or partners in designing the data collection process and advising on how data should be collected (Bhawra et al., 2022; Love et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). This included, for example, how communities determined whether to conduct individual interviews (Thurber et al., 2021) and ensured that the methods were culturally appropriate(Bhawra et al., 2022; Love et al., 2022; Rainie et al., 2017). In other instances, communities reviewed data collection tools to confirm that the survey questions were suitable, coherent, and relevant to their needs (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Love et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). In many of the studies, community members also participated in recruiting participants and gathering field data by distributing surveys, leading focus groups, and supporting various data collection methods (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021). Community members primarily collected data alongside academic researchers; however, in one study, community-led data collection was conducted independently (Love et al., 2022). Three studies did not disclose information on the data collection tools or discussions with their community partners (Flicker & Worthington, 2012; Reeves et al., 2023; Thorburn et al., 2023). Forty percent (n=6) of the studies did not explicitly mention engaging with the community to develop or tailor existing data collection tools to the specific needs of the Indigenous community, population, or organization (Flicker & Worthington, 2012; Minore et al., 2009; Nickel et al., 2022; Reeves et al., 2023; Thorburn et al., 2023; Vukic et al., 2009).

Table 4.6 lists excerpts from the literature outlining how researchers integrated Indigenous or nation-specific data collection tools to accurately represent the nation, community, or population with which they collaborated.

Table 4.6
Developing IDG Data Collection Tools and Approaches

Excerpts from the literature illustrating the development of IDG policies	In particular, when partnering with Indigenous communities, a Two-Eyed Seeing approach can provide valuable perspective to combine the strengths of Indigenous and Western Knowledges, including culturally relevant methods, technologies, and tools(Bhawra et al., 2022).
	PNCs functioned as more than just advisory groups; members were involved in developing and clarifying research questions, creating interview tools, informing methods by which to develop Aboriginal capacity, interpreting findings, and participating in dissemination(Boffa et al., 2011).
	The questionnaires were originally derived from those used in IBUS (Haora et al., 2023)
	The authors outline implications of a set of principles that Canada's First Nations have adopted, commonly referred to as OCAP (Ownership, Control, Access, and Possession), on the collection, storage, use, and interpretation of health data (Minore et al., 2009)

	The design and interpretation of these distinctions-based analyses will be guided by Indigenous co-investigators on the team and will inform health and social planning and policy priorities for the respective Nations (Nickel et al., 2022)
	The Voices project used expertise in demography and survey methodology from Colorado State University to create a reliable and valid survey and data collection process (Rainie et al., 2017)
	The development, modification and implementation of the interview schedule and survey instruments were led by Aboriginal and Torres Strait Islander people (Thurber et al., 2021)
	Six First Nations communities involved in development of FORGE AHEAD were asked to pilot the survey in August 2013 to ensure clarity, comprehensiveness, relevance of the questions, language and terminology, length of the survey, and ease of completing the survey (Tompkins et al., 2018)

4.6 Ethical Practices in Research and Data Governance

Articles that underwent detailed extraction were reviewed for their content on how ethics approval was approached and obtained. They were also assessed to determine how researchers engaged with the Indigenous community or population in securing ethical approval for Indigenous health research. All articles (n=15) referenced received ethics approval from university-level research ethics boards (REBs), outlining the ethical review as described in the policies, procedures, and practices commonly assessed in health research. This highlights that institutional ethical review of research involving Indigenous data primarily operates within a Eurocentric research framework. Four articles discussed Indigenous ethical administration (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Haora et al., 2023).

One article reported recommendations for engaging in ethical research with Indigenous communities, highlighting the need for revisions at the level of research ethics boards (REBs) (Flicker & Worthington, 2012). The following articles detail the importance of positioning councils and establishing advisory boards as a means to support and validate the ethical review of the proposed study (Bhawra et al., 2022; Boffa et al., 2011; Maar et al., 2022; Nickel et al., 2022; Rainie et al., 2017; Thorburn et al., 2023; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Creating such committees or councils allows Indigenous communities or populations to guide and fulfill their own aspirations in the research design. However, there is limited information on how to operationalize the underlying policies and processes.

4.6.1 Governance at the Indigenous Community-Level

An important part of this work involved reviewing the articles for content related to Indigenous Data Governance (IDG), particularly how it was approached and received. Articles described the effects of historical policies and the disparities in power dynamics existing between Indigenous peoples and governments, as well as between researchers or academic institutions and Indigenous communities. This includes a history of exploitation in research, which has resulted in mistrust among Indigenous peoples towards health research and data management and its uses (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Haora et al., 2023; Love et al., 2022; Maar et al., 2022; Nickel et al., 2022; Rainie et al., 2017). Further examination revealed an unequal distribution of power continued to exist in these studies between Indigenous communities and researchers, highlighting the need for governance processes in data use that acknowledge and respect Indigenous values and knowledge systems. Only four studies discussed or addressed whether Indigenous communities or populations own and control these data that pertains to them (Bhawra et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018).

Table 4.7 lists excerpts from the literature that describe Indigenous communities or populations owning and controlling the data that pertains to them.

Table 4.7
Data Control and Ownership

Excerpts from the literature illustrating the Indigenous communities' control or manage data that pertains to them	Data Availability Statement: Data are co-owned by the community and all data requests should be approved by the Citizen Scientist Advisory Council and the University of Regina Research Office(Bhawra et al., 2022).
	At both tribes, community engagement was an integral part of reclaiming Indigenous nation control over data (Rainie et al., 2017)
	To maximize the benefit that can come from the study, anonymized data will be available to communities, academics, services and government agencies for approved research purposes under Indigenous data governance arrangements (Thurber et al., 2021)
	community level data belonging to the respective community with full access to their data (individual community results were not shared with other communities, agencies, etc.) (Tompkins et al., 2018)

4.6.2 Indigenous Organization Collaboration and Affiliation

This research also assessed the 15 articles to understand the inclusion of Indigenous organizations in author affiliations. The presence of Indigenous organizations was evident in 33.3% (n=5) studies where one or more co-authors were affiliated with Indigenous health, research, or community organizations. These co-authors participated in the design, development, data collection, and analysis of the research study (Haora et al., 2023; Love et al., 2022; Rainie et al., 2017; Reeves et al., 2023; Thurber et al., 2021).

Thurber et al. (2021) listed the co-authors, identifying them as members of their respective Indigenous communities (p. 3). Table 4.8 lists excerpts from the literature describing how researchers collaborated with or included Indigenous organizations or populations as equal partners.

Table 4.8
Community Affiliations

Excerpts from the literature illustrating the Indigenous organization and affiliation	In the urban North Brisbane site, the BOOSt partners are the Institute for Urban Indigenous Health (IUIH), the Moreton Aboriginal and Torres Strait Islander Community Health Service (MATSICHS), and My Midwives (a private midwifery organisation) (Haora et al., 2023)
	the team in which Indigenous partners were made equal participants in the full scope of the research project and co-authors on relevant outputs (Love et al., 2022)
	Both tribes agreed to participate in the research and became partners in the entire process from conception to publication (Rainie et al., 2017)
	In the present study, the first author led the analyses with input from the principal investigator of this specific project (the second author) as well as the interviewer (the last author) and the three other authors (who are Māori researchers) (Reeves et al., 2023)

4.6.3 Approaches to Consent

Articles that underwent detailed extraction were reviewed for content on how researchers approached ‘consent’ when engaging in research with Indigenous populations or communities. The majority of these studies did not describe how consent was approached. Of the 15 studies included in this study, 53.3% (n=8) obtained consent from individual participants (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Two studies employed a waiver of consent to access participants' health data (Haora et al., 2023; Nickel et al., 2022). Another approach to consent was to obtain permission from community leaders or community organizations involved in the research (Boffa et al., 2011; Maar et al., 2022; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Table 4.9 lists excerpts from the literature illustrating how researchers obtained consent from the population.

Table 4.9
Receiving Consent

Excerpts from the literature illustrating the consent: Individual and community consent	Written consent was obtained from all focus group participants and verbal consent was obtained from all key informants participating in interviews (Bhawra et al., 2022)
	… it is now considered best practice to seek community as well as individual consent to participate when conducting research with Aboriginal participants, but respecting individual rights is still important to those who participate (Boffa et al., 2011)
	For participants recruited to complete questionnaires, consent will be acquired for the use of routinely collected electronic health records data, and for merging of records with participants' survey data(Haora et al., 2023).
	For routinely collected data, we have a waiver of consent approved for all cohorts of women. This covers both clinical and costing outcome measures (Haora et al., 2023)
	Participation was voluntary, and at the start of each activity, we explained the purpose of our research and received consent from participants (Maar et al., 2022)
	The Laurentian University Research Ethics Board and the Manitoulin Anishinaabek Research Review Committee granted ethics approval for this research project, and the Wiikwemkoong Chief and Council provided approval through a Band Council Resolution (Maar et al., 2022)

	The Manitoba Government's Health Information Privacy Committee (HIPC No. 2019/2020- 32 and No. 2020/2021- 43) reviewed the proposal and waived the requirement for individual informed consent on the basis that the study uses de- identified administrative data, none of the participants were directly involved in the study and there was low risk of any individual being personally identified (Nickel et al., 2022)
	Both tribes agreed to participate in the research and became partners in the entire process from conception to publication (Rainie et al., 2017)
	In 2012 and 2013, the project conducted face-to-face surveys with 819 families living in 547 structures; 150 respondents consented to voice recording of their interviews (Rainie et al., 2017)
	Written voluntary informed consent was obtained from participants… Participants aged 16 or 17 years required additional written consent from a parent or carer… the study team sought nominations from communities to participate, rather than adopting the traditional approach of 6 recruiting specific communities.(Thurber et al., 2021)..
	The survey asked communities to complete the official community name, community address and population sizes, with instructions for one survey per community to be completed by the person most familiar with how healthcare was organized and operates (for example, Health Director, Nurse-in-charge or Band Council leader)… Participation in the CPS was voluntary and completion of the survey indicated consent… (Hackett et al., 2016)
	The study was approved by ethics review boards at Dalhousie University and the Mi'kmaq Ethics Watch. Approval was also obtained from the 13 chiefs … One researcher (AV) obtained informed consent and conducted the interviews (Vukic et al., 2009)

4.7 Enacting Community Collaboration to Guide and Support IDG

Another aspect of this work was to identify how researchers described various measures taken to ensure their research was conducted with the involvement and approval of communities as a means to guide and support Indigenous data governance and data sovereignty in health research. Several aspects of data management were assessed, including data management principles, data sharing, community access to secondary data, and data storage and management.

4.7.1 Data Management Principle

Articles that underwent detailed extraction were reviewed for content describing how Indigenous organizations, experts, or populations developed data management protocols. The majority of these studies did not provide details regarding these protocols (Boffa et al., 2011; Flicker & Worthington, 2012; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2024; Reeves et al., 2023; Thorburn et al., 2023; Vukic et al., 2009). Of the 15 studies that included this information, seven reported engaging in discussions about data management with their community partners or stakeholders (Bhawra et al., 2022; Haora et al., 2023; Love et al., 2022; Nickel et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). Table 4.10 lists excerpts from the literature discussing the application of data management principles in their study.

Table 4.10
Developing IDG Policies

Excerpts from the literature illustrating the data management discussions	Discussions with I ˆle-à-la-Crosse about data sovereignty centered around citizen ownership of data, community access, and ensuring data privacy and security (Bhawra et al., 2022)

	A data management plan will standardize and guide the management of data throughout the study (Haora et al., 2023)
	This draft addressed roles, responsibilities, and data-sharing protocols (Love et al., 2022)
	Voices also generated interest in tribal regulation and governance of research and data and in research as an activity by and for Cheyenne River people. The tribe has a Tribal Research Review Board ordinance in the approval process, and Voices staff members have begun conversations with leadership and departments about improving data stewardship and management (Rainie et al., 2017)
	To maximize the benefit that can come from the study, anonymised data will be available to communities, academics, services and government agencies for approved research purposes under Indigenous data governance arrangements (Thurber et al., 2021)

4.7.2 Data Storage and Access

It was also important to identify, within the reviewed articles, how data was stored and how access was managed. The majority of these studies (n=7; 46.7%) did not provide details regarding data storage and access (Boffa et al., 2011; Flicker & Worthington, 2012; Minore et al., 2009; Nickel et al., 2022; Reeves et al., 2023; Thorburn et al., 2023; Vukic et al., 2009). Of the 15 studies that included this information, five (33.3%) studies detailed how access to data is determined and how data is stored (Haora et al., 2023; Love et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). Table 4.12 lists excerpts from the literature detailing how data access was managed and stored.

Table 4.12
Data Storage and Access

Excerpts from the literature illustrating the storage and access	All data were aggregated, anonymized, and securely stored in a cloud server (Bhawra et al., 2022)
	A data management plan will standardise and guide the management of data throughout the study and all datasets will be stored in a secure institutional Microsoft® SharePoint storage folder, with restricted access (Haora et al., 2023)
	An adapted framework with key elements of the agreements was established with each community research partner and included the following: a definition of the parties; establishment of each party's authority to share and receive the data; provisions regulating the use and restrictions of data disclosure; security and privacy requirements; policies and procedures and oversight committee; a determination of whether data are project or program specific; provisions for the publication of results; and provisions on how a party can terminate the agreement and how data will be destroyed or archived (Love et al., 2022)
	Research studies using First Nations data require ethics approval from the Health Information Research Governance Committee at the First Nations Health and Social Secretariat of Manitoba and we comply with their policies for data access, linkage and sharing (Nickel et al., 2024)
	The tribal enrollment office serves as the main data storage facility for all data at Ysleta del Sur… Tribal Ventures stores the Voices data for future analysis and use (Rainie et al., 2017)
	If the community partner organizations cannot meet requirements for secure storage of unit-record data, aggregated data will be provided in the form of frequency tables, with categories aggregated to ensure no small cells (<5) are presented (Thurber et al., 2021)

	only authorized team members had access to the survey data for research purposes, community receipt of individual data and a regional/national summary, and possession of the data remaining with each community and the FORGE AHEAD research team (data stored in a password-protected database and locked filing cabinet) (Tompkins et al., 2018)

4.8 Limitations

This review has several limitations. It includes only publications in English, which may result in underrepresentation from countries that publish in languages other than English. This limits the variety of the publications and our ability to adequately assess the quality of the articles. Therefore, we categorized the publication types to inform readers about the review process and understand how the themes and discussion points have emerged.

One limitation in this emerging research field is the lack of published articles on developing rigorous and accessible Indigenous governance within health research. Few articles discussed governance development, and many provided limited details on research processes. However, it is possible that researchers omitted details about their level of community engagement. Restrictive journal requirements may have reduced their ability to include the methodology or compelled them to focus on reporting the results of their studies. We also found that Indigenous governance systems have been developed as part of existing frameworks, primarily outside academic publications focused on Indigenous health research. Furthermore, we examined only articles published from 2013 to April 2024, which may have led to the omission of earlier discussions on this topic, The author recognizes that these discussions have occurred since the late 1990s and early 2000s. It is imperative to acknowledge that the intent of this review was to assess whether and how each study reported IDG within this body of literature, rather than to evaluate whether a study was participatory in nature. This is an important discussion that highlights the need for editorial decisions made by journals regarding whether Indigenous engagement should be a required reporting standard when publishing research *with* Indigenous communities or populations.

Another limitation of this scoping review is that although two reviewers independently screened articles for inclusion and exclusion criteria to enhance rigour and reduce selection bias, the subsequent in-depth analysis and data charting were conducted by a single reviewer. This may introduce potential bias and limit the reliability of data interpretation from a health research perspective.

Another significant limitation to acknowledge is that Eurocentric literature reviews often fail to effectively capture Indigenous knowledge systems. Eurocentric methods of analyzing literature are viewed as paradoxical spaces that can be contradictory and ambivalent when evaluating Indigenous frameworks embedded within Eurocentric research designs. I recognize that, in some ways, I am critiquing the Eurocentric scientific approaches we are assuming. Nevertheless, this review provides a snapshot of a broad body of work as a means to identify areas for further inquiry and enhancement.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

5.0 Introduction

This chapter discusses the findings of this scoping review from the perspective of a *Siksikaistitapiiaaki* through an Indigenous governance lens. In doing so, this chapter is grounded in Indigenous self-determination, which seeks to promote data sovereignty and relational accountability in health research *with* Indigenous communities or populations. Additionally, it aims to expand on the themes introduced in the previous chapter and examine how Indigenous data governance (IDG) is understood, the level of community engagement, and the ethical considerations for decolonial health research practices when working *with* Indigenous populations and communities. This chapter also examines the strengths and gaps in current research practices. It offers direction for the future of IDG by supporting Indigenous-led health data research in collaboration with academic institutions. It provides an opportunity to reflect on how the included studies support the research objectives and address the guiding research question: "*How can academic institutions appropriately engage with and support Indigenous data governance and sovereignty when conducting collaborative health research with First Nations communities?*"

A *Siksikaistitapi* relational review process is used throughout this discussion chapter, requiring the researcher to be accountable to all their relations and to consider potential research implications that could have negative impacts on the community and its members (Smith, 2012; Wilson, 2008). This enables a decolonial method of dissemination to occur, moving away from a Eurocentric approach that presents each theme in separate sections, isolating the findings. Instead, it moves through the themes in a circular motion, recognizing the work that has been done, while acknowledging that there is progress to be made in achieving data governance. This chapter discusses the results of the scoping review while acknowledging the constant flux and motion of the literature and knowledge learned, demonstrating an interconnectedness where overlaps are dominant rather than peripheral. This will enable the reader to understand and visualize the connections, overlaps, and tensions that arise in health research while positioning the research to recognize the community, context, and experiences of Indigenous people.

5.1 Study Characteristics, Designs, and Theoretical Frameworks

This section explores how IDG or IDS is described within the study characteristics, designs, and theoretical frameworks. The study's characteristics, design, and theoretical frameworks describe the overall qualities of the research, including its reliability, objectivity, and validity. This is achieved by stating the purpose, sharing the methodology, study design, and data collection and analysis methods. The following section explores these areas in order to understand how researchers from the scoping review considered IDG principles when determining their research approaches.

5.1.1 Study Characteristics

The conversation about Indigenous data governance in academic settings continues to evolve, reflecting the changing role of research *with* Indigenous populations, particularly as Indigenous-led interventions emerge *in collaboration* with post-secondary institutions. When reviewing the literature, it was apparent that this topic has intrigued researchers from multiple disciplines such as health and human rights, Indigenous health, public health, and the social sciences. The discussion surrounding IDG has continued to evolve, with 2022 producing the highest number (n=4) of publications. While published studies had an international scope, 73.3% (n=11) occurred in Canada (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Love et al., 2022; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Thorburn et al., 2023; Tompkins et al., 2018; Vukic et al., 2009).

While the distribution of the identified publications reflects Canada's growing interest in IDG, Indigenous perspectives from the U.S., New Zealand, and Australia appear to be largely absent from the discussion. Furthermore, the concentration of studies in Canada suggests that advocacy and funding are closely aligned with Indigenous governance principles, such as OCAP ® (Information Governance Centre, 2014) and the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) (*Research, 2007*)*. However, further analysis revealed that the researchers' philosophical background may influence how one understands Indigenous governance principles, creating a limitation in supporting Indigenous communities in advancing towards data governance and sovereignty.

5.1.2 Research Designs

Most of the studies were conducted with exploratory objectives, employing terminology such as "understand," "explore," "analyze," or "inform." This language is common in qualitative and community-centred research; however, its alignment with Indigenous governance depends on the individuals *who* formulate the research questions and the degree to which these questions reflect the priorities of the Indigenous communities. Most studies employed qualitative and mixed methods designs, which offer a promising perspective from a governance standpoint. These methodologies can enhance relationality, context specificity, and dialogue (Botha, 2011; Chilisa & Tsheko, 2014).

Research *with* Indigenous populations or communities requires evidence that highlights how the framework's processes align with its theoretical principles of the framework and are effectively operationalized to benefit the community and their stakeholders. In doing so, it demonstrates that researchers have adhered to both the cultural and ethical protocols of the Indigenous community, respecting Indigenous rights and ensuring that the processes actively work to rectify past harms and colonial practices, while supporting reconciliation and recognizing the need for Indigenous data sovereignty for First Nations communities (Smith, 2012; Walter, Kukutai, et al., 2021; Walter & Suina, 2019).

5.1.2.1 Study Demographics

The review covers a wide range of demographic data reporting on Indigenous populations, such as Indigenous status (Bhawra et al., 2022; Boffa et al., 2011; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thurber et al., 2021), age (Boffa et al., 2011; Nickel et al., 2024; Thurber et al., 2021), gender (Boffa et al., 2011; Nickel et al., 2022; Nickel et al., 2024; Reeves et al., 2023; Thurber et al., 2021), income (Nickel et al., 2024; Thurber et al., 2021), education (Reeves et al., 2023; Thurber et al., 2021), geographical location (Flicker & Worthington, 2012), employment (Rainie et al., 2017; Thurber et al., 2021) and whether they have dependents (Reeves et al., 2023).

Only 53.3% (n=8) of the articles (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thurber et al., 2021) reported on some or all of the descriptive study characteristics, revealing a gap in the health literature. Focusing on Indigenous outcomes with limited demographic data diminishes the community's experiences and complex intersectional realities (Smith-Morris et al., 2022). Where public health metrics are used to promote healing for broader Canadian populations, they have been used to incorporate and subjugate Indigenous bodies by producing deficit-based research practices (Smith-Morris et al., 2022; Walter & Suina, 2019). The categorization or omission of essential demographic data, such as place of residence, presents a methodological flaw in understanding the ongoing challenges faced by Indigenous communities in Canada. IDG frameworks aim to address this flaw by involving Indigenous communities to provide data oversight and participation throughout *all* stages of the research process (Kukutai, 2025; Kukutai & Taylor, 2016; Walter et al., 2025).

Furthermore, the use of inconsistent demographic categories creates a data gap that prevents Indigenous communities from utilizing the information for local governance and policy development, while also diminishing the uniqueness and diversity that exists across Indigenous populations in Canada (Quinless, 2022; Walter, 2013). During this scoping review it was evident that pan-Indigenous methods of data collection have become normal practices within health research, characterizing First Nations, Métis, and Inuit experiences, realities and histories as being synonymous (Meng et al., 2025; Smylie & Firestone, 2015; The First Nations Indigenous Governance Centre, 2019). It is important to provide clarification as to whether the chosen categories were simply a descriptive statistic meant to characterize the sample or if they were consistently reflected in the study's overall implications.

Historically, Indigenous populations have been excluded from research across levels of government (Smylie & Firestone, 2015). Governments decided what type of data was collected, how it was collected, how it was reported, how it was utilized and who it would benefit. Often, data were used to frame Indigenous realities as deficits, creating harmful narratives about Indigenous populations without historical context. This reflects an approach that removes transparency and accountability to Indigenous communities while simultaneously creating barriers to informed decision-making processes that affirm Indigenous data governance and sovereignty within the research (Rainie et al., 2017; Rowe et al., 2022; Walter, Kukutai, et al., 2021). Comprehensive population demographics are essential for reducing false positives within populations and for accurately representing a population sample (Jones et al., 2021). Smylie and Firestone (2015) affirm that the social structuring of data governance and management must shift from systems that reinforce social exclusion to systems in which First Nations populations are fully and centrally involved in data decision-making. Smylie and Firestone (2015)affirm that the social structuring of data governance and management must shift from systems that reinforce social exclusion to systems in which First Nations populations are fully and centrally involved in data decision-making.

Working *with* Indigenous populations to standardize groupings for research is essential for creating generalizable comparisons and facilitating data sharing for Indigenous communities in future research endeavours. Indigenous nations and communities experience unique health outcomes due to their geographical location and access to resources, requiring a nation-based approach to data collection and analysis. Community leaders and health experts can and should assess institutional data management policies to ensure they align with IDG principles and practices (Browne et al., 2016; Mashford-Pringle & Webb, 2023). It is important to disaggregate the data examining the Indigenous status of individuals; however, it is also important to aggregate the data when analyzing the social determinants of health to gain a clear understanding of the population’s health outcomes.

Ultimately, Indigenous data governance spans a broad range of disciplines and sectors. The range of publication distributions and sources referenced in this review varied from Public Health to Agromedicine. This variation displays the diversity and breadth of this topic in the literature. Transdisciplinary methods provide opportunities to ground and centre frameworks within the realities of the Indigenous community, designed to encompass all facets of Indigenous experiences and their knowledge systems. Publishing across various fields should not undermine the distinctiveness of Indigenous governance; instead, it should reinforce Indigenous-led approaches and frameworks as fundamental, rather than supplementary, components of rigorous research design and reporting in all disciplines (Loewen & Kinshuk, 2012; Ryder et al., 2020; Walter & Suina, 2019).

5.1.3 Theoretical Frameworks

Nine studies (60%) studies within this review did not state a theoretical framework (Flicker & Worthington, 2012; Love et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009), which, from a governance perspective, represents a missed opportunity to collaborate and ground the research in Indigenous knowledge systems. Theoretical frameworks provide the reader with the necessary information to understand why the researcher is using the chosen methods to explore the research or test the theory (Sinclair, 2007). Frameworks "describe the concepts and relationships in a given phenomenon" so that the researcher can explore these data collected without distorting it (Garvey & Jones, 2021). Theoretical frameworks are chosen based on their appropriateness and connect the research to existing knowledge. Omitting the framework information creates a gap in understanding why and how the researcher is engaging with the phenomenon of interest. When conducting research *with* Indigenous populations or communities, it is also important to clearly articulate the relationships that exist between the researcher and the community. Providing the theoretical information ensures that there is a level of accountability for the methods being used, while also positioning the reader to understand the researcher's intentions and engagement processes.

Of the studies that did not identify a theoretical framework, five (33.3%) mentioned grounded theory and Indigenous knowledge systems (Nickel et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009) were cited alongside CBPR (Nickel et al., 2024) and theories of self-determination (Haora et al., 2023). This highlights a systemic issue where Indigenous methodologies or knowledge systems are often mentioned, but also dismissed within health research (Kolahdooz et al., 2015; Lavallee & Poole, 2010; Mitchell, 2019).

If certain theoretical frameworks are to be used to conduct research *with* Indigenous people, they must extend beyond academic concepts; they must serve as tools to guide how knowledge is created or validated. If a study states that the frameworks are utilized to advance self-determination, that study must provide details on how such frameworks make space for Indigenous epistemologies, cosmologies, and legal systems to influence their research. To effectively advance IDG within health research, collaborative research initiatives *with* Indigenous populations must begin with a strong theoretical foundation. This approach signals a shift in perspective from viewing Indigenous data or communities as subjects for study to one that prioritizes Indigenous self-determination, relational responsibility, and data sovereignty, as illustrated by works such as Meng et al. (2025),Rainie et al. (2019); Walter and Suina (2019).

Cohen et al. (2025) state that "CBPR frameworks are collaborative approaches to research that value multiple types of expertise and build equitable partnerships between academic researchers and members of the population(s) being studied" (p. 558). CBPR is a preferred approach when non-Indigenous researchers are conducting research with Indigenous communities. “Community-based” research alludes to the “strong community connections” when research is situated within a community or centered around an issue that is important to the community (Israel et al., 1998).

CBPR is usually deployed to engage challenges and tensions associated with power imbalances when conducting collaborative research with “marginalized” populations (Postma, 2008). While theoretical frameworks are established theories within research and guide the study, the absence of frameworks when citing Indigenous knowledge suggests that the researcher did not examine their own approaches to address power imbalances within the theory of Eurocentric research approaches.

CBPR frameworks are considered equitable when applied to Indigenous-led research, illustrating models of balanced power sharing within collaborative research approaches. However, the process of classifying the methods as CBPR was often not provided within the reviewed literature. Deploying culturally aligned research methods and frameworks must be grounded in meaningful relationships and respect for the community. Relationality is key when presenting research findings to the broader research community, as it reinforces the use of epistemological frameworks alongside community-centred frameworks used to conduct research with Indigenous communities, while establishing such theories to guide the research and validating them in the process. This is important because other researchers can utilize the study design, with the same community, to determine its validity, repeatability, and generalizability, leading to the establishment of nation-specific frameworks of inquiry.

5.2 IDG in Study Design, Outcomes, and Measures; Whose Standards

This section explores how IDG or IDS was described as being embedded or included within the research designs, intended outcomes, and measures employed. Research designs are determined by the research questions and refer to the overall strategy used to examine the phenomenon (Creswell & Poth, 2018). Desired study outcomes and aims guide the research, so clearly defining how these align with IDG or IDS will ensure effective methods are used and prevent potential biases from entering the research design. IDG and IDS require nation-specific data measures and metrics to ensure the research design aligns with the principles of data governance. This following section explores these areas to determine the extent of alignment with IDG principles within institutional research initiatives.

5.2.1 Governance as Embedded Design, Not Just an Afterthought

All fifteen studies (100%) within our review mentioned IDG or Indigenous Data Sovereignty (IDS) in their design, with eleven studies (73.3%) outlining strategies that support Indigenous self-determination (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Love et al., 2022; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2024; Rainie et al., 2017; Reeves et al., 2023; Thorburn et al., 2023; Tompkins et al., 2018). A common feature across the reviewed studies was the variation in how IDG was implemented, with terms such as 'data sovereignty,' community-led, Indigenous-led, and 'participatory research' used to describe their research approaches and methods.

Only three studies (20%) (Love, 2004; Maar et al., 2022; Rainie et al., 2017) considered Indigenous data sovereignty as a key outcome, indicating that although the principles of data governance are widely recognized as important, they are referenced more than they are effectively implemented. Achieving IDG requires a systemic shift that balances power dynamics beyond understanding a single determinant of a phenomenon; it requires a holistic approach that considers the broader social determinants of health contributing to the outcome.

Multiple studies (n=5; 33.3%) describe the application of including Indigenous leadership in decision-making when outlining the research process (Bhawra et al., 2022; Flicker & Worthington, 2012; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021). Four studies (26.7%) described the use of IDG mechanisms, such as advisory and steering committees (Bhawra et al., 2022; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021), to ensure the research followed the principles of IDG frameworks. IDG frameworks require Indigenous communities to have authority and agency at all stages of the research process, where participation extends beyond roles such as liaisons or advisors and includes acting as co-creators, co-researchers, and decision-makers.

The crux of IDG is to support the advancement of Indigenous self-determination. This requires researchers to position Indigenous leaders and communities as decision-makers through autonomous strategies, determining how the research will benefit the community rather than the other way around. These frameworks are indispensable, as they facilitate collective decision-making and reflect Indigenous values related to relational accountability and community consensus. However, research that fails to clearly describe Indigenous engagement throughout the study, even if limited to consulting roles, may perpetuate Eurocentric hierarchies in knowledge production (Campbell, 2014; Information Governance Centre, 2014). Indigenous communities, scholars, and researchers value and support knowledge sharing combined with the development of legal frameworks and data systems to support IDG. This requires repositioning authority within the community to decide how data is collected, interpreted, and used to protect and develop their resources and infrastructures (Rainie et al., 2019; Taylor et al., 2016; Walker et al., 2017; Walter, Kukutai, et al., 2021).

5.2.2 Self-Determination as an Outcome, Moving Beyond Passive Inclusion

Three studies (20%) identified Indigenous data sovereignty as a key outcome (Love et al., 2022; Maar et al., 2022; Rainie et al., 2017), demonstrating a transformative shift in research. This corresponds with a fundamental principle of Indigenous governance, where data are recognized as both political and relational, as well as Indigenous data must serve the priorities of the nation from which it originates (Walter, Kukutai, et al., 2021). Indigenous communities are recognizing the need to leverage Indigenous health data to advocate for Indigenous self-governance and data sovereignty within Canada's health systems, which requires advocating at provincial and federal levels.

Participatory research frameworks (Thorburn et al., 2023), community data ownership (Boffa et al., 2011), and culturally grounded methodologies (Bhawra et al., 2022; Maar et al., 2022) were described as opportunities for Indigenous communities to lead and develop social and human capacity to advance IDG. When researchers cite Indigenous-led approaches as a means to self-determination it is important to clarify the processes of how Indigenous voices and recommendations were being prioritized, particularly when the research is presented as being conducted *by* and *for* Indigenous peoples. Institutional policies and academic journals policies must change to require that this invaluable information is shared beyond the research team with the broader research community, thereby establishing standards for those engaging in collaborative research with Indigenous communities.

The frameworks discussed within this review have the ability to function as IDG mechanisms for supporting self-determination beyond health systems; however, the language of "inclusion" that is often used implicitly implies Indigenous peoples do not own or control the data. Rather it is suggested that the inclusion of Indigenous voices and perspectives is within the research team's control. Although the OCAP© principles state that Indigenous communities have ownership, control, access, and possession of data before, during, and after the research process (as cited in Minore et al., 2009; Nickel et al., 2024), it was unclear whether the communities owned or controlled the data in most cases. The process of enacting the principles was not described in these published studies, so it is also unclear how the research team and the institution supported the Indigenous group in practicing data governance within the project.

5.2.3 Metrics and Measures: Whose Standards Count?

The measures and health indicators used to assess health outcomes are principal elements within an IDG framework. The indicators and measurements used to generate health data about Indigenous people in Canada are not standardized and have been critiqued by Indigenous and non-Indigenous scholars for removing the histories and experiences of Indigenous nations (Hayward et al., 2021; Smylie & Allan, 2018). This contributes to an evidence gap that may perpetuate health disparities, which are often viewed through a deficit-based lens, that pathologizes the Indigenous community and ignores the underlying root causes of health inequities (Hayward et al., 2021).

Established and emerging Indigenous scholars are reclaiming the right to explore our diverse realities through research practices and initiatives that aim to benefit our communities on our terms and generate an understanding within our unique ways of being and knowing as Indigenous peoples. When reviewing the literature, four studies

(20%) stood out by articulating their approaches in a way that ensured the measures and metrics reflected the knowledge and realities of the Indigenous population or community through meaningful engagement.

- One Indigenous community developed, modified, and utilized all survey instruments (Thurber et al., 2021);
- while another study involved their advisory group to create the interview tools (Boffa et al., 2011);
- and lastly two studies used both Indigenous and Western Knowledges to develop culturally relevant tools (Bhawra et al., 2022; Rainie et al., 2017).

Applying these frameworks facilitates a shift from deficit-based indicators to strength-based, community-driven measures which aim to support self-determination for Indigenous communities. IDG frameworks have the potential to improve health tracking by ensuring community involvement in governance of information management and evaluation processes (Hayward et al., 2021; Rainie et al., 2017). IDG principles allow the researcher(s) and community to determine the appropriate measures and metrics for studying health inequities and identifying health interventions that may reduce these inequities within the community while also acknowledging the unique social determinants that impact health for all Indigenous populations living in Canada.

Data collection methodologies have historically depended on Eurocentric paradigms that are fundamentally rooted in systems of classification and representation. These paradigms categorize data through binary oppositions, dualisms, and hierarchical structures (Quinless, 2022; Smith, 2012). Such classification systems have been employed to evaluate Indigenous peoples' humanness and their level of civilization (Lavallée et al., 2014), consequently dehumanizing Indigenous populations and marginalizing their knowledge systems in the process (Smith, 2012). It is essential for

Indigenous communities to redefine the parameters and metrics used in the assessing health outcomes, ensuring they align with the community's priorities.

5.3 Defining Indigenous Data Governance

5.3.1 Characteristics of Indigenous data governance

This section assesses how IDG was defined and discussed within the scoping review studies. Data governance, as determined directly or indirectly by all studies, falls into three categories: community-led priorities, engaging with participatory structures, and capacity building and accountability.

5.3.1.1 Community-led- Priorities

Ten studies (66.7%) indicated that the research was community-driven, emerging from needs or gaps identified by the community (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Love et al., 2022; Maar et al., 2022; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Vukic et al., 2009), which is an essential characteristic of governance-oriented research. However, it was discovered that four of the ten studies (26.7%) assessed community needs without providing the details surrounding how these needs were identified, articulated or how they were confirmed (Flicker & Worthington, 2012; Minore et al., 2009; Nickel et al., 2022; Reeves et al., 2023). IDG frameworks require collaboration between communities and their research partners to develop collaborative mechanisms that uphold data sovereignty, extending beyond the ownership and control of the data. When IDG frameworks are properly applied, researchers can address power imbalances, enabling Indigenous communities to set their research objectives and priorities.

5.3.1.2 Engaging Participatory Structures

Most studies (n=13; 86.7%) used terms such as “Indigenous-led” or viewed participatory processes mainly as a means to demonstrate evidence of ‘governance-level’ engagement (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Hutchins et al., 2023; Love et al., 2022; Maar et al., 2022; Nickel et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thorburn et al., 2023; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). In this context, governance means that communities are not just involved to provide feedback; instead, they take on leadership roles, provide direction, and share ownership of the research process. A good example includes Indigenous advisory councils or engaging in roles such as co-investigators (Bhawra et al., 2022; Rainie et al., 2017; Thurber et al., 2021), where decision-making authority is given to the community. These examples demonstrate alignment with Indigenous governance principles by stressing community control, accountability, and authority throughout the entire research lifecycle process.

Four studies (26.7%) missed an opportunity to include community participation details in their methods section (Hutchins et al., 2023; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Providing details on community involvement ensures transparency and builds relational trust. The principles of IDG are reflected in the manner of community engagement reported. Participatory rhetoric alone is not enough; it is essential to articulate how communities participate in decision-making throughout the research process. Providing evidence supporting how the research design was chosen based on the needs of the community is crucial to advancing Indigenous-led governance structures within health research.

5.3.1.3 Capacity Building and Accountability

Two studies focused on community capacity building and community empowerment (Rainie et al., 2017; Thurber et al., 2021). Community capacity building is essential for governance structures to reflect tribal cultural values and priorities, while equipping communities with the skills, resources, and knowledge necessary to develop effective research capacity within their communities (Smith, 2016). Transformational change requires researchers to avoid using unidirectional or one-sided methods in capacity building, such as providing training to communities without reciprocal learning from the community. Such unilateral approaches perpetuate colonial patterns by reinforcing Eurocentric methodologies and mindset of the superiority.

Although empowerment leading to self-determination was discussed in several studies, only two studies provided evidence regarding how such empowerment is operationalized beyond rhetoric (Bhawra et al., 2022; Boffa et al., 2011). The term was used to describe methods aimed at fostering capacity-building development to further support Indigenous data governance and sovereignty. This enables communities to conduct research, manage data, and effectively advocate for their needs, ultimately shaping policies and programs that align with their values as a community and are informed by their knowledge systems (Taylor et al., 2016).

5.4 Community Engagement through an IDG Lens

This category highlights how community engagement is a key component of Indigenous data governance, serving both as a methodological approach and as a guiding principle for ethical research. Indigenous populations describe community engagement as a *relational*, *reciprocal*, and *responsibility-based* approach rooted in the rights of Indigenous nations to oversee research within their communities. Contrarily, it is seen as a transactional process within traditional research practices (Kukutai & Taylor, 2016). The reviewed studies exhibit varying degrees of alignment with their conceptual frameworks as discussed in the following sections.

5.4.1 Depth and Timing of Engagement: Early and Ongoing Involvement

Indigenous governance frameworks emphasize the significance of initiating and maintaining engagement from the onset of research through to its dissemination and the mobilization of knowledge. Three studies described researchers building relationships with the target population or Indigenous community (Bhawra et al., 2022; Reeves et al., 2023; Tompkins et al., 2018), while others described long-term relationships (Boffa et al., 2011; Haora et al., 2023). However, most described newly established engagement approaches (Bhawra et al., 2022; Love et al., 2022; Nickel et al., 2022; Rainie et al., 2017; Thorburn et al., 2023; Vukic et al., 2009) or did not provide information on how relationships were created with the communities (Flicker & Worthington, 2012; Maar et al., 2022; Nickel et al., 2024).

Engaging ethically and meaningfully with First Nations, Métis, and Inuit communities within Canada ensures that such communities have decision-making authority over their data, reducing data misuse and promoting transparency in how data is handled (Andersen et al., 2025; Walter, 2013). The principles of IDG require data governance to be facilitated by the community, requiring long-term commitment and ongoing engagement with research bodies and universities (Walter & Carroll, 2021; Walter, Russo Carroll, et al., 2021). This approach creates space for research participants and community members to participate in confirming the results of the data collection, making sure they are properly interpreted and reflect the realities of the community (Walter et al., 2025). The ongoing involvement of community experts and members in the research process through Indigenous-led engagement processes ensures that the data collected is relevant, useful (Gabel, 2025), and applicable to enhancing or advancing community priorities, thus supporting IDG.

5.4.2 Distinctions-Based Approach to Community Engagement

Three studies (20%) employed community-based methods, including yarning (Haora et al., 2023), a "two-eyed seeing" approach (Bhawra et al., 2022), and mino-bimaadiziwin (Maar et al., 2022) to leverage strengths and develop solutions collaboratively with community stakeholders. These methods provide guidance for decision-making, ensuring alignment with community protocols, values, and relational benefits. (Mashford-Pringle & Webb, 2023) define "distinctions-based" as recognizing the unique histories, cultures, and worldview of First Nations, Métis, and Inuit groups instead of examining then as homogenous group (p.76). Effective community engagement under IDG frameworks must prioritize a community-centred, distinctions-based approach, acknowledging the unique histories, experiences, and worldviews of First Nations, Métis, and Inuit communities rather than treating them as a single homogenous group (Mashford-Pringle & Webb, 2023).

When culturally specific engagement strategies are absent or inadequately described, there exists a risk of defaulting to the generic, Eurocentric models of engagement that fail to honour the diversity and sovereignty of Indigenous nations. IDG is not monolithic; therefore, research must reflect the distinct knowledge systems, protocols, and legal orders of each nation with which it engages. Using a nation-focused approach enables the community to customize policies, programs, and legislation to meet their specific needs and priorities, respecting their identities and circumstances (Hayward et al., 2021; Mashford-Pringle & Webb, 2023; Rainie et al., 2017). Incorporating IDG frameworks within health research will provide health care systems with information that will support the provision of culturally-safe healthcare while tackling systemic issues like racial biases and discrimination (as cited in Mashford-Pringle & Webb, 2023).

IDG principles and frameworks must be grounded in the community's nation-specific epistemologies, rather than combining multiple Indigenous epistemological frameworks, which is considered methodological pluralism. Methodological pluralism occurs when researchers employ various research frameworks or approaches to explore a topic, aiming for a more comprehensive or detailed understanding of a phenomenon (Anderson & Sharrock, 1986; Hancock et al., 2018). This approach, although helpful in research methods, can impose external knowledge when studying Indigenous data sets and further marginalize Indigenous populations.

5.5 Ethical Standards: A Clash of Two Worlds

This section explores how IDG or IDS understood in relation to "ethics" or ethical standards from an Indigenous worldview. Ethics, when described from a Eurocentric lens, is often described from the individuals' point of view with the intention of minimizing harm to the participant during data extraction. However, Indigenous ethical responsibility is often described as holistic and relational and recognizing the traditional beliefs and ceremonial practices of the Indigenous group, which is a clear departure from the Eurocentric viewpoint.

5.5.1 Ethics Beyond Institutional Approval

All the studies reviewed received approval from an institutional Research Ethics Board (REB). Four studies (26.7%) approached Indigenous communities to secure approval to conduct research *with* the community (Bhawra et al., 2022; Boffa et al., 2011; Flicker & Worthington, 2012; Haora et al., 2023). Two studies (13.3%) received approval from tribal leadership, such as Chief and Council (Maar et al., 2022; Vukic et al., 2009) and a third study received approval from Indigenous-led ethics committee (Nickel et al., 2022), thereby recognizing that IDG frameworks require ethics approval beyond institutional research ethics boards. These approaches to community-based ethics approval illustrate that the researchers' process was guided *by* Indigenous communities rather than merely seeking consent from Euro-Canadian institutions alone. Furthermore, it can also help ensure that Indigenous communities retain control over the research process, including the management and interpretation of data, to prioritize their objectives and outcomes.

Indigenous Advisory Boards are essential when researchers and scholars are conducting research *with* Indigenous communities. This analysis identified a gap associated with the limited availability of information on policies and processes for establishing advisory boards. This is concerning, but understandable, due to the uniqueness of each Indigenous First Nation and community situated within Canada. Universities have resources that are incomparable to Indigenous nations and communities, and university resources are usually linked to "public funding", requiring them to focus on delivering measurable research performances (Smith, 2012). However, this also means that universities potentially have the resources to financially compensate members of the advisory boards while measuring the outputs and impacts to demonstrate the value of the investments in terms of research and economic returns to society. Many Indigenous communities and early-career Indigenous researchers lack the financial resources to implement advisory boards when conducting research *with* their own communities. To overcome this obstacle and align institutional research with IDG principles, Indigenous-led research institutes should be established within universities, with faculty-specific advisory boards or steering committees composed of subject-matter experts from both the Indigenous nation and the university.

5.5.2 Indigenous Organizations and Authorship

Five studies (33.3%) included Indigenous co-authors who were affiliated with Indigenous health, research, or community organizations, therefore serving as a key contributor to IDG practices of ownership (Haora et al., 2023; Love et al., 2022; Reeves et al., 2023; Thurber et al., 2021). Ensuring that Indigenous scholars and community members hold authorship roles guarantees that the research is understood, applied, and shared through a distinctions-based Indigenous perspective, which contributes to community ownership of their knowledge systems.

When Indigenous scholars, researchers, or community members take on roles such as co-authors, principal or co-investigators, or data stewards, it demonstrates the research team's commitment to respecting ethical principles, including shared authority and relational accountability (Rainie et al., 2017). This demonstrates that the researchers recognize the community's intellectual property and their active participation in the research process (Kukutai & Taylor, 2016; Walter et al., 2025). Co-authorship amplifies Indigenous voices, perspectives, and governance by embedding Indigenous discourse into academic data systems and data structures (Gabel, 2025; Rowe, Bull, et al., 2021). Additionally, when community members have access to published findings concerning their community, they gain the opportunities to develop research skills, statistical literacy, and expertise, thereby promoting long-term benefits for their data infrastructure (Yap & Yu, 2016). While university libraries have access to databases through subscription plans that can be expensive. Indigenous communities do not always have access to such databases, which is why Indigenous researchers and scholars are opting for open-access resources (Andersen et al., 2025; Rainie et al., 2019).

In the context of public health, evidence-based strategies require systematic planning to alleviate poor health outcomes and advocate for policy changes. Policy changes are driven by evidence-based approaches to research when presented to Euro-Canadian governing bodies. The use of best evidence in the decision-making process requires a complex cycle of observation, theory, and experiential approaches to understanding health protection, disease prevention, health maintenance, and health promotion (Gillam et al., 2012). Demonstrating an evidence-based approach requires research findings to be published within academic institutions to validate the research process and the recommendations produced. Establishing Indigenous-led research institutes in partnership with tribal colleges and entities would support data-driven, evidence-based research publications providing Indigenous nations and communities with the resources needed to advocate for sufficient support to enhance economic and social outcomes.

5.5.3 Collective and Community Consent

Eight studies (53.3%) within the current study provided details about obtaining individual consent (Bhawra et al., 2022; Boffa et al., 2011; Haora et al., 2023; Maar et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Although Indigenous leaders and subject-matter experts have stressed the importance of consent, the use of individual consent waivers, especially for administrative data, raises significant governance concerns regarding the retention of Indigenous identifiers outside of IDG infrastructure.

Another concern is that consent waivers, if not presented in a culturally safe manner, can damage the trust between Indigenous communities and external entities and may increase the risk of data misuse (Rodriguez-Lonebear, 2016). In the absence of community involvement in these decisions, even the employment of de-identified data may sustain colonial research practices. The process of de-identifying strips the data of its cultural, social, and historical context, which may result in the misinterpretation or misappropriation of data and may inadvertently reinforce the stereotypes or deficit narratives (Walter, 2016).

Five studies described obtaining consent through community leaders or community organizations (Boffa et al., 2011; Maar et al., 2022; Thurber et al., 2021; Tompkins et al., 2018; Vukic et al., 2009). Ethical research *with* Indigenous communities requires recognition, respect, and upholding Indigenous governance systems. IDG frameworks affirm Indigenous peoples' right to protect their social, cultural, and spiritual well-being, ensuring that the research conducted in their communities supports the development of their data infrastructure and resources (Gabel, 2025; Kukutai, 2025). When ethics are understood from an Indigenous governance perspective, they extend beyond the scope of university-based research ethics boards. This includes respecting Indigenous laws, maintaining relational accountability, and safeguarding the rights of Indigenous peoples to protect, govern, and benefit from their knowledge and data. In doing so, the researchers can gain insight into community-specific cultural protocols, traditions, and governance structures, thereby supporting effective risk management and minimizing harms to all stakeholders involved in the research project (First Nations Information Governance, 2016).

5.6 Enacting Community Collaboration to Support Indigenous Governance

Indigenous populations often articulate holistic conceptualization of health that values and integrates the physical, spiritual, mental, and emotional aspects of a person in a way that "privileges interconnectedness, collaboration, reciprocity, spirituality, and humility" (Flicker et al., 2015). This interconnectedness encompasses the existing kinship alliances, community, and all that connects the individual in their daily life (Smith, 2012; Wilson, 2008). An Indigenous approach to health also involves maintaining a state of health and well-being across all aspects of the person, which are constantly interconnected. Achieving this state requires access to all necessary elements, including the practice of traditional beliefs and ceremonies, to sustain and restore balance among all areas of health (Little Bear, 2012). If health outcomes are reliant on the interconnectedness within the community, then engagement between researchers and the community must also adopt a holistic approach. The next section explores how researchers engage with Indigenous communities throughout the research process.

5.6.1 Data Collection Tools: Culturally Relevant or Nation-Specific

Data collection tools can decontextualize health issues if they reduce, remove, or fail to capture data associated with protective factors while examining a population. Eurocentric data collection instruments often overlook community strengths when focusing on health deficits that exist within Indigenous populations (Hyett et al., 2018). When reviewing the included studies, there was little discussion about the cultural sensitivity of the data collection instruments, which is a significant omission that deviates from IDG principles.

Indigenous data governance requires collaboration between communities and their research partners to develop mechanisms that uphold data sovereignty and extend beyond the ownership and control of these data. Eurocentric data collection tools may overlook Indigenous communities' unique political, social, and cultural contexts, disregarding Indigenous knowledge systems (Paine, 2020). IDG frameworks prioritize Indigenous languages, cultural values and practices, and knowledge systems to support the development of data collection tools that reflect Indigenous realities (Rainie et al., 2019; Walter & Carroll, 2021). When Indigenous communities design their own data collection instruments, it also fosters both technical and human resource capacity within Indigenous communities, while preventing biases, deficit framing, and colonial perspectives that are often generated by Eurocentric-based data collection tools (Hayward et al., 2021). Developing data collection tools and instruments that recognize Indigenous social experiences allows the community and collaborative partners to respond to community needs by developing transformative health interventions with the aim of improving social equity for the community (Castellano, 2004; Hyett et al., 2018; Rainie et al., 2019; Walter, Kukutai, et al., 2021).

5.6.2 Indigenous Data Management

Data management is a general term for how one organizes, structures, stores, and cares for the information being collected. Seven studies (67.7%) mentioned data management in collaboration with their community partners or stakeholders (Bhawra et al., 2022; Haora et al., 2023; Love et al., 2022; Nickel et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). IDG principles emphasize the importance of developing data management plans that reflect Indigenous laws, values, and priorities regarding the storage, protection, access, and destruction of data.

Three studies (20%) provided information about the development of data management plans with Indigenous communities (Haora et al., 2023; Love et al., 2022;

Rainie et al., 2017). These examples illustrate a gradual shift towards self-governing data systems, where Indigenous nations are not only guiding research but also maintaining custodianship over the outputs. Indigenous communities require the implementation of collaborative data management protocols as they establish governance frameworks that define how data are collected, stored, accessed, and utilized (Walter et al., 2025).

Universities and REBs require researchers to disclose this information when applying for ethical approval. However, it is rarely disclosed or shared with the collaborating community. Therefore, collaboration between communities and their research partners is essential for developing IDG mechanisms such as policies, protocols, and agreements that reflect Indigenous community values, needs, and priorities (Gabel, 2025). This also involves supporting capacity building within the community in areas such as resource management, technical health expertise, educational opportunities and workforce development to manage data effectively, all while working towards the community's self-determined goals (Smith, 2016; Walter et al., 2025). Globally, Indigenous scholars, researchers, and allies are recognizing this need and are driving systemic change through the development of community data systems, such as community censuses, registries, and databases, to maintain control and ensure data accuracy and relevance (Walter, Russo Carroll, et al., 2021).

5.6.2.1 Indigenous Ownership and Data Control

The most significant aspect within an IDG framework is *who owns and controls the data*. Four studies indicated that Indigenous communities would hold ownership and stewardship over the data collected and are the decision-makers of how the data will be used to serve their community's needs (Bhawra et al., 2022; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). However, eleven studies (73.3%) did not specify the entities responsible for controlling or possessing the data after it was collected (Boffa et al., 2011; Flicker & Worthington, 2012; Haora et al., 2023; Love et al., 2022; Maar et al., 2022; Minore et al., 2009; Nickel et al., 2022; Nickel et al., 2024; Reeves et al., 2023; Thorburn et al., 2023; Vukic et al., 2009). There was a clear lack of identifying and acknowledging Indigenous ownership and control in these assessed studies, highlighting potential issues with data extraction and dispossession that violate IDG principles, and risk further harm for the communities involved.

IDG principles affirm the rights of Indigenous peoples to oversee the collection and use of data concerning their communities, territories, populations, and resources with the aim of having full ownership over the data (Taylor et al., 2016). When Indigenous communities gain authority and ownership over their data, they disrupt the cycle of historical data extraction and exploitation, supporting self-determination and nation-building (Gabel, 2025). However, this requires shifting power dynamics by enabling Indigenous peoples to reclaim authority over their data systems (Walter et al., 2025) within universities (Marley, 2021). Such a shift would provide Indigenous communities with the resources to build their own data infrastructure, which in turn would empower community health leaders to make informed decisions for the future (Kukutai & Taylor, 2016). Most importantly, data sovereignty allows Indigenous communities to hold external entities accountable for actions and decisions that impact them (Gabel, 2025; Quinless, 2022; Walter et al., 2025; Walter, Kukutai, et al., 2021).

5.6.3 Community Access and Control Over Secondary Data

A core principle of Indigenous data governance is that data collected *about* communities should remain accessible *to* and under the *control of* Indigenous peoples. Three studies (20%) discussed access to primary or secondary data and data repatriation processes, outlining how communities have access to data based on their own priorities (Love et al., 2022; Rainie et al., 2017; Thurber et al., 2021). This signifies a shift from seeing research as a community-focused method to a means of Indigenous self-determination and data sovereignty.

Five (33.3%) studies provided information on data return or secondary access (Love et al., 2022; Nickel et al., 2024; Rainie et al., 2017; Thurber et al., 2021; Tompkins et al., 2018). Indigenous communities face significant data gaps, particularly in research that reflects their cultural, social, and economic realities (Walter, 2025). It is crucial for scholars and the universities they work within to promote data transparency and facilitate access to secondary data for Indigenous communities to use over time (Walter et al., 2025). Secondary data possesses the potential to mitigate data deficiencies by providing information that may not be obtainable through their own data collection efforts. Secondary data is information that has been collected by other individuals or organizations for a purpose other than its current use. It is typically readily available through reports, dashboards, or open-access datasets. Such data can be used to identify health trends with the potential to support health promotion initiatives aimed at improving community well-being (Walter et al., 2025). Additionally, secondary data is a resource communities can use to advocate for services and resources when negotiating with government bodies, health organizations, and stakeholders (Snipp, 2016).

5.6.4 Storage, Access, and Security

Data storage and access are often viewed as logistical issues in academic research; however, from an Indigenous governance perspective, these elements hold importance in IDG frameworks. Indigenous communities have consistently questioned data access, its storage locations, and the methods of safeguarding, as these mechanisms are closely tied to trust, sovereignty, and authority. Two studies (13.3%) provided information on data access and data within community-based research infrastructures (Rainie et al., 2017; Tompkins et al., 2018). These practices reflect meaningful collaboration and show the necessary operational planning required to support Indigenous entities' self-governance.

Most of the studies (n=7; 46.7%) did not provide details about the mechanisms of access management or whether data agreements had been established in collaboration with Indigenous governance bodies (Boffa et al., 2011; Flicker & Worthington, 2012; Minore et al., 2009; Nickel et al., 2022; Reeves et al., 2023; Thorburn et al., 2023; Vukic et al., 2009). Institutional policies and research bodies can unintentionally restrict community access to Indigenous data stored within the institution (Andersen, 2025). If this happens, Indigenous communities lose control over their data access and usage because of institutional policies, practices, and legal frameworks (Tsosie, 2021; Walter & Carroll, 2021). Research bodies may mishandle sensitive information by neglecting cultural protocols, commodifying Indigenous data, or using the information in ways that conflict with the community's priorities, thereby perpetuating colonial and systemic forms of violence(Rodriguez-Lonebear, 2016).

5.7 Reflexive Process

Reflexivity is the process of examining one's biases, values, and experiences that they bring to the study (Creswell & Poth, 2018). It requires a critical approach, addressing the why and how of research. Indigenous scholars such as Margaret Kovach (2009) and ShawnWilson (2008), encourage researchers to move away from Eurocentric research paradigms and to center Indigenous knowledges and systems. The following section builds on the theoretical works of Blackfoot scholars *Iikaiskiniwa* (Low Horn) Leroy Little Bear (2012), *Sikapinaki* (Blackeyes Woman)- Betty Bastien (2004), Māori scholar Linda Tuhiwai Smith (2012), Opaskwayak Cree scholar Shawn Wilson (2008), and Plains Cree/Salteaux scholar Margaret Kovach (2009) and many other Indigenous scholars who have contributed to the emergence of Indigenous approaches to research in academic institutions. The citations used for the above section are formatted to reflect the kinship alliances that exist between the researcher and the scholars and will be the only section formatted in this manner. Indigenous scholars, theorists, and academic allies have advocated for and been integral in creating safe spaces for novice Indigenous scholars to understand how they can exist as *Nitsitapi* (Real People) within academic institutions worldwide. The emergence and inauguration of Indigenous researchers have established a space in academia where those traditionally researched can now become researchers themselves (Held, 2019; Restoule et al., 2018; Smith, 2012), fostering innovative approaches that capture the true essence of Indigenous peoples' unique experiences. The creation of this space has encouraged emerging Indigenous scholars to openly discuss integrating Indigenous knowledge systems into their own approaches to academic work and research (Held, 2019; Restoule et al., 2018), leading to the emergence of Indigenous theoretical and methodological frameworks that aim to reduce health inequities among other advances through co-creation and knowledge sharing. Such approaches are creating learning environments within academic institutions where Indigenous scholars can share their worldview with non-Indigenous scholars, while pursuing research *within* their own communities. However, this has also led to the commodification of Indigenous knowledge in various ways, often benefitting those of Euro-Canadian or settler descent who continue to incorporate Eurocentric frameworks with fragmented pieces of Indigenous beliefs and knowledge systems (Little Bear, 2012). This pattern was evident in the studies examined, where *consultation with* Indigenous communities was often limited to the design process and data collection phase. IDG principles emphasize ongoing engagement and involvement from inception to dissemination. Indigenous scholars can adopt these principles and practices to reformulate existing methods, presenting community-centred paradigms that may help address disparities and inequities faced by Indigenous communities worldwide

The term *Kitaikihpowa* means "What are you doing?" (plural- asking a group of people) in the Blackfoot language. It is a term used by the *Siksikaitsitapi (Blackfoot people)* to engage with their own research within their own lives. The continuation of Eurocentric approaches to health research within or among Indigenous populations has led me to ask numerous times, *niitaikihpowa?* What am I doing… and why are we doing it this way? This has become a fundamental question I ask before I engage in any research journey, join a research team, and most importantly, before I engage in any kind of data collection.

Indigenous populations experience high rates of mortality and morbidity compared to the rest of the population (Adelson, 2005; Currie et al., 2015; Flicker et al., 2015; Reading & Wien, 2009; Smith, 2012), resulting in increased exposure to research aimed at capturing their experiences (Campbell, 2014; Flicker et al., 2015). While these approaches can generate valuable health data, they are ineffective in building narratives from an Indigenous perspective. This is partly due to systemic misunderstandings and the devaluation of Indigenous knowledge systems endemic to Euro-Canadian frameworks, the epistemic violence inflicted on Indigenous participants, and the ongoing dominance of Eurocentric perspectives over Indigenous knowledge and value systems (Restoule et al., 2018; Smith, 2012). Engaging in a reflexive process requires examining every aspect of how one understands and interacts with the knowledge they have gained and are contributing to. This process involves including research team members and Elders in thorough discussions to explore how the knowledge interacts with our traditional knowledge systems and how I can position the knowledge and skills that are being learned to benefit the collective, rather than just the individual.

This required me to engage in a reflective process with the Elders, Indigenous members of the Sokkinakia'pi Collaborative Committee, and the research team. This process actively practices IDG by checking in with advisory members and steering committee members, privileging Indigenous leadership roles, tribal decision-making authority, and Blackfoot knowledge systems (Smith, 2016; Walter et al., 2025) to guide my own research process. IDG principles are designed to help Indigenous communities define data sovereignty in relation to their own knowledge systems and structures. We discussed how the term *sovereignty* is regarded as sacred, encompassing our relationships with the natural world, mutual relations among community members, and the preservation of knowledge and language systems that originate from the land, both now and into the future. I realized that data governance is multifaceted and requires the researcher to actively support community capacity-building opportunities through knowledge sharing. I was prompted by the Elders to seize opportunities to share the information I was learning with my peers, community members, and Elders within my community. This was done through informal opportunities such as community engagement discussions to unpack what was learned and clarify my thought processes while examining how our community collectively understands the information. This approach empowered the community with knowledge to better understand our rights and to explore what IDG and IDS mean to them, while ensuring both individual and collective accountability within the community.

It was during these discussions that I realized although Indigenous communities possess systems that uphold sovereignty, there are systems in place designed to limit the discussion of sovereignty extending beyond colonial borders: borders that were imposed on us through colonial assimilation practices, policies, and legislation. However, as Indigenous people, we must have a collective right to determine how the governance of our data extends beyond reserve systems and situate it within our traditional territories. If data encompasses language and land, then our IDG principles and practices should also incorporate land-based governance practices and policies. This requires Indigenous scholars and communities to establish relationships with academic institutions, research methodologies, and their knowledge frameworks, as well as participate in Indigenous-led research initiatives that integrate their unique perspectives to inform decision-making. Indigenous scholars are therefore expected to employ their own tribal procedures that can preserve original contexts and relationships and apply Indigenous interpretations to these data to prevent data misappropriation.

Another point that emerged during discussions with the project Elders was that universities possess resources unmatched by Indigenous nations and communities. These resources are often produced from "public funding" research sectors, which causes leading institutions to concentrate on achieving measurable research outcomes (Smith, 2012). What we refer to as "public funding" is not always publicly and broadly available; research funding streams have limitations regarding who can apply for and hold the funds, and often tribal colleges located on a reserve do not meet the criteria for applications.

Although funding opportunities have increased for Indigenous communities to conduct community-based research outside academic institutions, the concept "community-based" can also serve as a barrier to achieving IDG. When Indigenous communities apply for community-based research projects, they are often awarded funding dollars through provincial or federal government funding streams. These funding awards often require generalized reporting in the form of project reports or agency reporting forms. This results in publications in the form of grey literature rather than evidence-based reporting through academic publication processes which is often dependent on the publication goals of the academic researchers. One approach to achieve IDG within our communities would be to establish research institutes within Euro-Canadian institutions in partnership with tribal governing systems and colleges.

This thesis employed an Indigenous methodology to explore how Indigenous data governance can be fostered within a post-secondary institution during health research *in collaboration with* a First Nations community. Establishing this space to incorporating Indigenous protocols and customs into the analysis of relevant articles enhances the understanding of practical approaches to Indigenous data governance. It is important to recognize that true data sovereignty cannot be fully achieved within post-secondary institutions; instead, these institutions must work towards the highest possible form of Indigenous governance: a governance approach that is Indigenous-designed, Indigenous-led, and grounded in Indigenous worldviews. Such an approach would ensure that effective mechanisms are established, enabling Indigenous peoples to make informed decisions regarding Indigenous data, thereby promoting accountability and transparency. The insights gathered from this scoping review will inform the research framework, discussions, and recommendations for the Sokkinakia'pi Collaborative Project, aiming to implement best practices in supporting Kainai data governance within the institution to advance data sovereignty within the community.

5.8 Future Implications for IDG for Kainai Nation

IDG is a concept that is emerging throughout many post-secondary institutions across Canada. A primary aim of IDG is to provide Indigenous communities with the resources and tools necessary to build their capacity, enabling them to achieve self-determination in various aspects of their lives and community outcomes. Post-secondary institutions can support this advancement by establishing partnerships with the community and its leadership. Applying IDG principles in practice can prove challenging, as the primary concept requires Indigenous involvement from inception. This creates an ethical dilemma when determining when and how to begin this process. Resources such as funding, time, capacity and training are required to orient both institutional members and community members to the responsibilities of upholding IDG (Jennings et al., 2025).

It is imperative for academic institutions to conduct an internal review to determine the feasibility of supporting Indigenous communities to achieve IDG within the institution. This includes cultural training for all staff and researchers to address knowledge gaps such as understanding the concepts of sovereignty, self-determination, and the impact of colonization on the community, including their health outcomes in relation to their unique social determinants of health. Meanwhile, those in leadership positions who aim to lead the IDG movement within the institution should engage in an iterative process to determine how the community wants to begin the relationship to support IDG in universities and IDS in communities through policy development. This process includes ongoing internal learning and assessment practices as well as potentially adjusting as the project unfolds and evolves to ensure the institution is continuing to meet the needs of the community.

Both the institution and the community should collaboratively determine research protocols and data management protocols specific to the community's governance structure. Future steps will need to consider and develop engagement strategies that support equitable practices in alignment with Kainai methodologies and traditional knowledge protocols. The establishment of a Kainai Research Institute will support the community in defining IDG while creating space to conserve and reclaim Indigenous knowledge systems within the institution. It is important to develop community-centred governance policies and principles *with* the community. Through acknowledging this, I am unable to provide recommendations beyond this to advance IDG without community consultation.

5.9 Conclusion

This study investigated the concept of IDG and its comprehensions, operationalization, and implementation within health research and academic settings when engaging with Indigenous populations or communities. The scoping review framework by Arksey and O'Malley (2005) was used to understand the extent of existing evidence and the relationship within the role of IDG frameworks, which are used to create culturally grounded and self-determined health research practices that effectively identify the needs and priorities of Indigenous communities. Following a rigorous process, an initial search yielded 6,032 citations. Of these, 139 studies were assessed for eligibility, and fifteen met the inclusion criteria. Data were extracted and analyzed using various methods and tools, and discussed in Chapters Three, Four, and Five. This ensured the review process embodied relational accountability, respected Indigenous knowledge systems, and aligned with community priorities during the dissemination.

It is clear from the review that scholars and researchers recognize the value of Indigenous data in supporting Indigenous self-determination and reducing health disparities. However, the analysis also revealed knowledge or conceptual gaps in how health researchers perceive IDG within universities. IDG frameworks aim to balance decision-making processes, enabling Indigenous peoples to define data collection methods, establish data control mechanisms, and collectively benefit from their tribal data and information systems (Haines et al., 2018; Smith, 2016). This requires a nation-specific approach that provides accurate representation and reflection in the data through nation-led interpretations in collaboration with nation leaders and health experts (Carroll et al., 2022; Smith, 2012). This can be achieved by developing nation-specific data collection tools, in collaboration with community health experts, to reflect the realities and experiences of the community. This approach would ensure that the research team has access to knowledge about the ethical data protocols established by the community, which should be a primary goal for any research project conducted within a First Nations community.

This review contributes to the global knowledge of IDG, and its conceptualized within the evidence, and how collaborative partnerships between universities and Indigenous nations and communities can further support the advancement of IDG. The range of approaches used to support IDG are vast and requires policies and principles to be co-developed by the nation within whose traditional territory the university is located. These findings and the discussion provide a foundation for designing research approaches that support collaborative health research initiatives, ultimately promoting Indigenous self-determination.

These frameworks present foundational methods, principles, and practices that enable communities to monitor health research, ensuring it remains accountable to Indigenous communities and led by Indigenous peoples. The literature emphasized IDG frameworks and principles as a continuum of practices and relationships rooted in community protocols, priorities, and social determinants of health. This review will contribute to the IDG discussion by summarizing the frameworks used and how researchers understood and integrated IDG principles into research methods, data sharing agreements, and research policies. It also highlights the gaps and stresses the importance of Indigenous-led governance structures in health research, as well as the need for long-term, community-driven assessments of how data governance impacts health equity. The findings are applicable across various disciplines, contexts, and sectors. They highlight that effective IDG requires multi-level partnerships, continuous resources, and meaningful engagement from the initial stages of research to dissemination and data management, including data transfer and repatriation. Policy, research, and practice should focus on establishing clear, place-based or nation-based definitions of IDG that are co-developed with local Indigenous communities.

Additionally, it is important to align research ethics policies with Indigenous governance principles to enhance the capacity of both Indigenous and non-Indigenous researchers to effectively apply governance frameworks. Opportunities exist to improve collaboration between Indigenous communities, their leadership, health systems, research bodies and their institutions, and governments in promoting Indigenous health objectives and priorities while safeguarding data sovereignty. The lessons learned from this review will provide recommendations to further advance IDG for Kainai leadership and its tribal entities, with support and in collaboration with partnering institutions and the research body, extending beyond the scope of the thesis journey.

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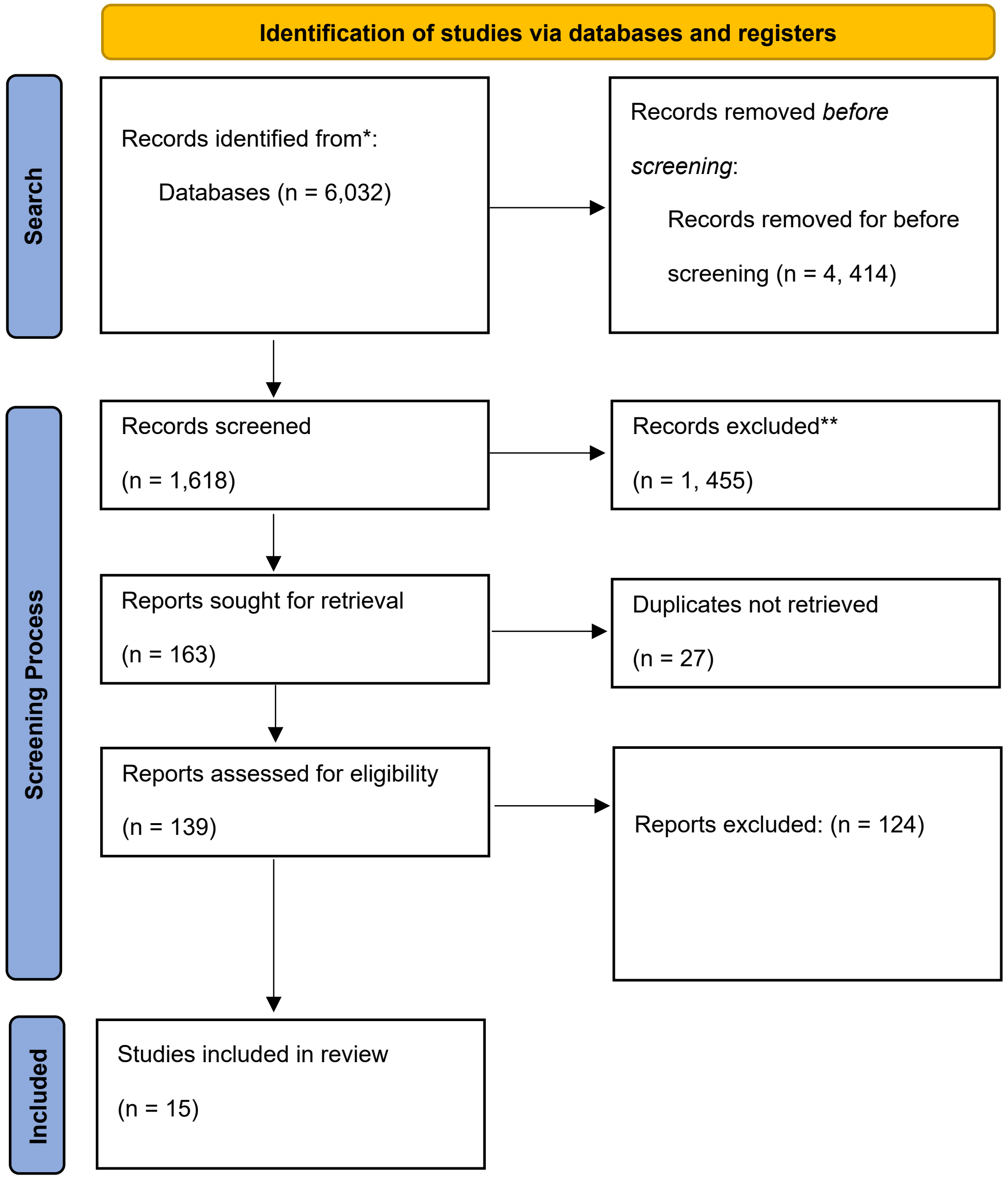
Appendix A
Search Strategy and Terms

Indigenous Search Terms	Data Search Terms	Governance Search Terms
* searched with OR	AND * searched with OR	AND * searched with OR
Indigenous	data	governance
native	database	sovereignty
aboriginal	big data	OCAP
Indian*	open data	ownership
first nations		control
		access
		possession
		principles

Fig A-1 *Search Strategy and Terms*

Appendix B
Flow Diagram for Screening Process



Appendix C
Template for Data Extraction

Reviewer:
Date:
APA Citation:

Data to be extracted	Notes
Title and Abstract	
Year of Publication	
Country of Study	
Time of study completion	
Study Objective and Aims	
Methodology	
Study Type	
Key Findings	
Data Analysis	
Authors Conclusions	
Implications for Policy	
Implications for Practice	
How is data defined in the study?	
How is data governance defined in the study?	
How is Indigenous data defined in the study?	
Other relevant details of IDG	
Study Objective and Aims	
How is sovereignty defined in the study?	
How is data sovereignty defined in the study?	
How is Indigenous data sovereignty defined in the study?	
Other relevant details of IDS	
Was Indigenous data governance a factor in the design of the study?	
How was Indigenous data governance stated or used?	
Theories and models of Indigenous data governance or Indigenous data sovereignty incorporated or understood in the research?	
How are collaborative partnerships defined and implemented within the study?	

Appendix D
Template for Potential Use of Framework

Reviewer:
Date:
APA Citation:

Data to be extracted	Notes
Title and Abstract	
Year of Publication	
Country of Study	
Time of study completion	
Authors indicated use of the following:	
OCAP	
Ownership	
Control	
Access	
Custodianship	
Authors Conclusions	
Accountable to Indigenous People	
Amplifying Indigenous voices	
Relevant and Reciprocal	
Sustainability	
Self-Determination	
Data Governance	
In-practice (community)	

Appendix E
Final List of Reviewed Articles

Source	Objectives, Research or Questions	Methodology	Theoretical Framework	Study Design	Analysis	Results	- IDG Principals or Practices
Bhawra, J., Buchan, M. C., Green, B., Skinner, K., & Katapally, T. R. (2022). A guiding framework for needs assessment evaluations to embed digital platforms in partnership with Indigenous communities. PloS One, 17(12), e0279282. https://doi.org/10.1371/journal.pone.0279282	This paper aims to provide researchers and evaluators with a framework (step-by-step guide) to conduct needs assessments for digital platforms in collaboration with Indigenous communities.	The methodology used in the study involved a community-based participatory research approach with key steps including framework development, community engagement with the Northern Village of ˆIle-à-la-Crosse, Saskatchewan, Canada.	The authors developed a novel needs assessment framework using a Two-Eyed Seeing approach, combining Indigenous and Western Knowledge. This framework was designed to guide needs assessments for digital platforms in collaboration with Indigenous communities, emphasizing the importance of incorporating Indigenous perspectives, cultural frameworks, and community engagement throughout the study.	community-based participatory research (CBPR)	All documents identified through the environmental scan were reviewed for key themes. A list of existing school and community programs was compiled and organized by theme (i.e., education-focused, nutrition-focused, health-focused, etc.). Follow-up conversations with key informants verified the continued planning and provision of these programs. Following the 6-step method by Braun and Clarke (2006), a thematic analysis was conducted to systematically identify key topic areas and patterns across discussions [53]. A shortlist of themes was created for the key informant interviews and focus groups, respectively. A manual open coding process was conducted by two reviewers who reached consensus on the final coding manual and themes. Separate analyses were conducted for key	Through discussions with the community, four priorities were identified: (1) the Coronavirus pandemic, (2) climate change impacts on the environment, (3) mental health and wellbeing, and (4) food security and sovereignty. Given the timing of the needs assessment, the community identified the Coronavirus pandemic as a key priority requiring digital initiatives.	- First Nations OCAP Principles emphasizing Ownership, Control, Access, and Possession of data by Indigenous communities. - Two-Eyed Seeing Approach integrating Indigenous Knowledge and Western Ways of Knowing. - Meaningful Control and Ownership of Data by Indigenous communities. - Data Sovereignty and Social Justice for marginalized communities. - Community Engagement and Self-Determination in data governance. - Community-Based Needs Assessments Framework for understanding community priorities. - Guiding Framework for Community-Based

					informant interviews and focus group discussions; however, findings were synthesized to identify key themes and sub-themes in key priorities for the community, community supports and barriers, as well as digital connectivity and infrastructure needs.		Needs Assessments to Embed Digital Platforms for ethical data use. These theories and models aim to empower Indigenous communities, uphold their rights in data management, and promote self-determination in decision-making processes.
Boffa, J., King, M., McMullin, K., & Long, R. (2011). A process for the inclusion of aboriginal people in health research: Lessons from the determinants of TB transmission project. Social Science & Medicine (1982), 72(5), 733-738. https://doi.org/10.1016/j.socscimed.2010.10.033	The study objectives and aims are to investigate the determinants of TB transmission among the Canadian-born population, both Aboriginal and non-Aboriginal, in the prairie provinces of Canada by Exploring socio-cultural, biomedical, environmental, and historical factors influencing TB transmission within the study population.	The methodology used a collaborative approach to health research involving Aboriginal peoples. Key components of the methodology involved alignment with the CIHR Guidelines for Health Research Involving Aboriginal People and the principles of Ownership, Control, Access, and Possession (OCAP).	The authors did not explicitly state in the document whether a theoretical framework was used to develop or guide the study.	Mixed-methods study	The document does not explicitly provide detailed data analysis results or statistical finding	The study highlights high TB rates among Canadian-born and Aboriginal groups, with challenges in community engagement, ethical issues, political influences, methodological hurdles, and disparities on the prairies. It mentions successful partnerships with Aboriginal communities, cross-provincial collaboration, and insights into TB transmission among tribal and urban populations.	- Ownership, Control, Access, and Possession (OCAP) model - Principles from First Nations-driven policy documents - Community-based and participatory action research processes - Aboriginal forms of conflict resolution and integration - Cultural sensitivity training for non-Aboriginal study coordinators - Inclusion of Aboriginal health

							researchers and experts - Respect for Indigenous Knowledge Systems - Community Consent - Ethical Principles in Research Relationships - Cultural Sensitivity in Data Collection.
Flicker, S., & Worthington, C. A. (2012). Public health research involving aboriginal peoples: Research ethics board stakeholders' reflections on ethics principles and research processes. Canadian Journal of Public Health, 103(1), 19-22. https://doi.org/10.1007/BF03404063	The objective of this study was to explore REB stakeholder perspectives on the principles and practices of reviewing and conducting public health research with Aboriginal populations.	This analysis emerged from a larger study examining barriers to effective ethics review for community-based research (CBR). Twenty-four semi-structured qualitative interviews were conducted with REB staff, chairs, members (academic, community and student), and ethics policy key informants with knowledge of the ethics review process, including four Aboriginal participants. Interviews were professionally	The authors did not explicitly state in the document whether a theoretical framework was used to develop or guide the study.	Qualitative Study	Interviews were professionally transcribed verbatim and imported into NVivo 8 qualitative data management software.15 A key theme that resulted from the initial coding framework (including 16 major codes and 128 subcodes) was research ethics processes in research involving Aboriginal communities.16-18 The co-authors undertook a more extensive thematic analysis of the node on ethics and Aboriginal research, as well as a node/subnodes on innovative practices, which contained examples of research ethics practices with Aboriginal communities. The first	Three dominant themes emerged: 1) the importance of understanding Aboriginal research as a distinct form of research; 2) the unique nature and complexity of negotiating community consent; and 3) the importance of trust and relationship-building.	- OCAP Principles (Ownership, Control, Access, Possession) developed by the National Aboriginal Health Organization (NAHO) as key Indigenous data governance principles. - Community-based participatory research

		transcribed verbatim and thematically analyzed using NVivo 8 qualitative data management software.			author did the initial analysis; the second author provided colleague review; and consensus on the core themes was reached through discussion.		
Haora, P., Roe, Y., Hickey, S., Gao, Y., Nelson, C., Allen, J., Briggs, M., Worner, F., Kruske, S., Watego, K., Maidment, S., Hartz, D., Sherwood, J., Barclay, L., Tracy, S., Tracy, M., Wilkes, L., West, R., Grant, N., & Kildea, S. (2023). Developing and evaluating birthing on country services for first nations Australians: The building on our strengths (BOOSt) prospective mixed methods birth cohort study protocol. BMC Pregnancy and Childbirth, 23(1), 77-77. https://doi.org/10.1186/s12884-022-05277-8	The study aims to determine the feasibility, acceptability, safety, effectiveness, and cost-effectiveness of establishing Birthing on Country services, including birth centers, in urban and rural settings. .	The methodology used in the study involves using a comprehensive and multidimensional research endeavor that encompasses various methodologies and approaches, including cohort study design, participatory action research (PAR) approach, prospective birth cohort design, non-randomized interventional trial approach, mixed-methods approach, and principles of Indigenous research methodologies. It involves developing, implementing, and evaluating new Birthing on Country services with a focus on First Nations communities and their ways of knowing.	The authors utilized theoretical frameworks such as the RISE Framework, Indigenous Data Sovereignty principles, Community-Based Participatory Research (CBPR), Participatory Action Research (PAR), and Realist approaches to guide the study. These frameworks emphasized the importance of incorporating Indigenous perspectives, community engagement, and Indigenous data sovereignty throughout the research process	Mixed-methods Study The study design also involved a participatory action research approach, privileging First Nations knowledges, research methodologies, and ways of knowing, with a focus on social justice and equity in health access	The data analysis for the study involves a comprehensive approach that integrates quantitative and qualitative methods to evaluate the effectiveness, feasibility, cultural safety, and cost-effectiveness of the Birthing on Country services. It includes: Statistical analysis of clinical outcomes and survey data; Thematic analysis of qualitative data from interviews and focus groups; Cost-effectiveness analysis; Cultural safety assessment; Analysis of social and emotional well-being outcomes; Comparative analysis between different cohorts and service models; Mixed-methods integration to provide a holistic understanding of the outcomes.	•First Nations mothers are 3-5 times more likely to experience maternal mortality, and babies are 2-3 times more likely to be born preterm, low birth weight, or not survive their first year. •The Birthing in Our Community (BiOC) service, established in an urban setting, reported significant benefits including a 37% reduction in preterm births and improved outcomes for mothers and babies. •First Nations birth centers are highlighted as crucial for providing culturally and clinically safe care, with evidence showing they provide safe perinatal care for low-risk women.	- Community-Based Participatory Research (CBPR) - Participatory Action Research (PAR) - Cultural Safety - First Nations Governance - Community Engagement - First Nations Governance Indicators - RISE Framework - Yarning Methodology - First Principles - IBUS (Indigenous Birthing in an Urban Setting) model.

Love, R. P., Hardy, B., Beffernan, C., Heyd, A., Cardinal-Grant, M., Sparling, L., Healy, B., Smylie, J., & Long, R. (2022). Developing data governance agreements with Indigenous communities in Canada: Toward equitable tuberculosis programming, research, and reconciliation. *Health and Human Rights, 24*(1), 21-34.	The study objectives and aims include advancing public health goals by establishing equitable and beneficial research and health programming relationships with Indigenous peoples in Canada. Promoting Indigenous data sovereignty and self-determination to support Indigenous-led strategic planning and decision-making in public health research and programming.	The methodology involved a qualitative approach to developing and implementing Data Governance Agreements (DGAs) with select First Nations and Métis partnering communities in Canada in the context of tuberculosis prevention and care.	The study used a theoretical framework, based on the concept of ethical space as described by Willie Ermine	Qualitative Study	The document does not provide detailed information on the specific methods used to analyze the collected data. However, it does describe the process of repatriating tuberculosis (TB) surveillance data to the communities and supporting them in interpreting and contextualizing the data.	The document does not provide specific results from the data collection itself.	- Indigenous Data Sovereignty, including the OCAP® principles. - Ethical Space of Engagement. - Two-Eyed Seeing. - Community-Based Participatory Research (CBPR). - Decolonizing Methodologies. - Genomic Justice. - UNDRIP (United Nations Declaration on the Rights of Indigenous Peoples). - TRC (Truth and Reconciliation Commission of Canada) recommendations.
Maar, M., Ominika, T., & Manitowabi, D. (2022). Community-led recovery from the opioid crisis through culturally-based programs and community-based data governance. *International Indigenous Policy Journal, 13*(2), 1-28.	The study aimed to explore the development of a cultural-based Opioid Agonist Therapy (OAT) clinic within a First Nations community in Canada.	Methodology follows a community-based participatory approach that invites citizens of Wiikwemkoong2 Unceded Territory to collaborate as partners with the academic team	The study employed a theoretical framework rooted in Indigenous knowledge and the concept of mino-bimaadiziwin, which describes holistic health and well-being from an Anishinaabe perspective.	Qualitative Study	The researchers performed a thematic analysis of interview transcripts using NVivo 12 qualitative research software. All authors reviewed each theme individually, and consensus was reached through discussion. The analysis aimed to understand the	The study found that the Naandwe Miikan clinic in Wiikwemkoong Unceded Territory effectively combines culturally safe, community-based approaches with Opioid Agonist Therapy (OAT) to tackle the serious	- First Nations Information Governance Centre's OCAP (Ownership, Control, Access, and Possession) principles - The CARE (Collective Benefit, Authority

https://doi.org/10.18584/iipj.2022.13.2.13792					development of the OAT clinic, the community's needs, and the integration of Indigenous knowledge and culture into recovery.	social impacts of the opioid crisis. However, challenges included limited access to health data and funding models that support culturally-based services. The COVID-19 pandemic also interrupted access to harm reduction services and Indigenous healing practices.	to Control, Responsibility, and Ethics) principles for Indigenous data governance.
Minore, B., Katt, M., & Hill, M. E. (2009). Planning without facts: Ontario's aboriginal health information challenge. *Journal of Agromedicine, 14*(2), 90-96. https://doi.org/10.1080/10599240902739802	The study aimed to address Ontario's absence of a comprehensive Aboriginal health information system by examining data collection systems in other Canadian jurisdictions and determining the requirements for Ontario to establish a system that tracks the health status and service use of First Nations, Métis, and Inuit populations.	The researchers described the methodology used included two main approaches. A comprehensive literature review and in-depth interviews. Data was analyzed using inductive procedures, focusing on recurring concepts and their relationships. The researchers followed a framework categorizing factors into coverage and quality, jurisdiction and utility, governance and relevance, and infrastructure and capacity.	No, the researchers did not explicitly describe the use of a theoretical framework in the document	Qualitative Study	The researchers used an inductive analysis approach to examine the data. This involved narrowing down the information by focusing on recurring concepts and their relationships. The data were independently coded by the researchers, then compared and validated through consensus. This method helped them identify key themes and patterns in the data	Differences in data collection systems, gaps in information, and challenges in identifying Aboriginal populations affect Aboriginal peoples' use of health care services. They also discussed operational and conceptual challenges related to health information systems, including issues of data quality, jurisdictional collaboration, and the application of OCAP principles.	- The study cited the OCAP principles (Ownership, Control, Access, and Possession) as core practices for Indigenous data governance.

Nickel, N. C., Enns, J. E., Freier, A., McCulloch, S. C., Chartier, M., Casidsid, H. J. M., Balogun, O. D., Mulhall, D., Dragan, R., Sarkar, J., Bolton, J., Konrad, G., Phillips-Beck, W., Sanguins, J., Shimmin, C., McDonald, N., Mignone, J., Hinds, A., Nickel, N. C., . . . Jones, J. (2022). Characterising methamphetamine use to inform health and social policies in Manitoba, Canada: A protocol for a retrospective cohort study using linked administrative data. *BMJ Open, 12*(10), e062127-e062127. https://doi.org/10.1136/bmjopen-2022-062127	The research objectives were to describe the socioeconomic characteristics of individuals with a history of methamphetamine use; evaluate health services in use and pharmaceutical interventions in Winnipeg; and conduct knowledge transfer and exchange to inform health policy.	The researchers conducted a retrospective cohort study utilizing linked, deidentified administrative data from the Manitoba Population Research Data Repository to investigate methamphetamine-related health system contacts in Winnipeg from 2013-2021. They analyzed sociodemographic characteristics, health service utilization, and the efficacy of interventions while engaging a multidisciplinary Evidence-to-Action group to direct knowledge dissemination and inform health policy development.	They referenced Pal's research on policy analysis and activation, emphasizing a multidisciplinary and iterative method for addressing complex problems. This framework was used to shape the Evidence-to-Action (E2A) group and encourage a more inclusive, comprehensive approach to policy creation regarding methamphetamine use in Manitoba.	Retrospective cohort Study	The study used several analytical methods including generalized linear mixed models, time-trajectory analysis, and interrupted time series analysis.	The results were not shared.	- First Nations Principles of Ownership, Control, Access, and Possession. - Metis Principles of Ownership, Control, Access, and Stewardship (OCAS). - Approvals from Indigenous organizations - Indigenous co-investigators.
Nickel, N. C., Phillips-Beck, W., Enns, J. E., Ekuma, O., Taylor, C., Fileatreault, S., Eze, N., Star, L., Lavoie, J., Katz, A., Brownell, M., Mahar, A., Urquia, M., Chateau, D., Lix, L., Chartier, M., Brownell, E., Tso Deh, M., Durksen, A., & Romanescu, R. (2024).	The aim of the study was to examine whether prioritizing First Nations for COVID-19 vaccination was associated with faster vaccine uptake among Fist Nations compared to all other Manitobans.	The researchers conducted a retrospective cohort study utilizing linked administrative data from Manitoba's healthcare system, comparing First Nations to All Other Manitobans (AOM	They adopted a nation-based approach to decolonize COVID-19 research.	Retrospective cohort study	Statistical analyses employed negative binomial models for rates and RMST for vaccination timing, with adjustments made for covariates.	The study revealed that Manitoba First Nations had higher COVID-19 testing and infection rates than All Other Manitobans (AOM), with testing 2- 3 times and infections up to 4 times higher. Prioritization led to faster vaccine uptake,	- First Nations principles of OCAP - Nations-Based Framework - Collaborative approaches - Decolonize approaches

COVID-19 diagnostic testing and vaccinations among first nations in manitoba: A nations-based retrospective cohort study using linked administrative data, 2020-2021. *PLoS Medicine, 21*(2), e1004348-e1004348. https://doi.org/10.1371/journal.pmed.1004348						with First Nations getting their first and second doses about 15 and 13 days earlier.	
Rainie, S. C., Schultz, J. L., Briggs, E., Riggs, P., & Palmanteer-Holder, N. L. (2017). Data as a strategic resource: Self-determination, governance, and the data challenge for Indigenous nations in the United States. *International Indigenous Policy Journal. 8* (2) https://doi.org/10.18584/iipj.2017.8.2.1	The aim of the research was to examine how Indigenous nations in the United States can address critical issues related to inconsistent, irrelevant, and poor-quality data by asserting tribal data sovereignty and governance.	The methodology included a review of the literature, case studies, interviews, and community engagement.	The research employed a theoretical framework centered on Indigenous data sovereignty and data governance. This framework is grounded on the inherent rights of Indigenous nations to oversee the collection, ownership, and utilization of data concerning their peoples, territories, and resources.	Qualitative study design with case studies	The study examined how the tribes addressed critical data issues, such as inconsistency, irrelevance, mistrust, and external control, and how their initiatives promoted self-determination and governance.	The findings demonstrated that community-led, nation-focused data initiatives can deliver previously inaccessible information, improve data quality and relevance, and support tribal self-determination and governance. Both tribes effectively regained control of their data, using it strategically to shape policies, allocate resources, and advocate for their communities.	- Community engagement, - Tribal research review boards - Culturally-informed methodologies to build trust and protect tribal data.
Reeves, J., Treharne, G. J., Ratima, M., Theodore, R., Edwards, W., & Poulton, R. (2023). A	The aim of the study objectives were to explore perspectives on data-sharing of participants in the	The study used a constructivist grounded theory approach to explore participants'	The study used a constructivist grounded theoretical framework.	The study design was a qualitative research study using a	The analysis followed a constructivist grounded theory methodology with three levels of coding; open coding;	The findings were organized in three factors: cohort considerations supersede individual	- Māori Data sovereignty - Cultural sensitivity

one-size-fits-all approach to data-sharing will not suffice in life course research: A grounded theory study of data-sharing from the perspective of participants in a 50-year-old life course study about health and development. *BMC Medical Research Methodology, 23*(1), 118-118. https://doi.org/10.1186/s12874-023-01940-6	Dunedin Study as a lifecourse study.	perspectives on data-sharing. This methodology included semi-structured interviews with members of the Dunedin Multidisciplinary Health and Development Study.		constructivist grounded theory approach.	selective coding; and advanced coding using inductive processes and abductive processes until data saturation occurred.	agreement; community-based researchers; participant approved data governance. They recommended tailored, transparent, and informed consent processes for data-sharing in lifecourse.	- Local governance - Alignment with Māori values - Data management and oversight - Collective benefit
Thorburn, R., Ansloos, J., McCormick, S., & Zantingh, D. (2023). Role of Self-Determination in Health and Wellness: A qualitative study with Indigenous youth health leaders across Canada. *International Journal of Indigenous Health*, *18*(2). https://doi.org/10.32799/ijih.v18i2.39519	Research Question: How are Indigenous youth leaders describing and enacting self-determination in their work with Indigenous youth health?	It employed qualitative research methods, specifically semi-structured interviews with 15 Indigenous youth leaders aged 18–35 from across Canada. These interviews were conducted via video between November 2019 and May 2020.	The study does not name a specific theoretical framework but broadly refers to Indigenous self-determination theory as the guiding framework	Qualitative study design with thematic analysis	The researchers used Braun & Clarke's reflexive thematic analysis, which includes six stages: familiarization, generation, searching, reviewing, defining, and producing themes. NVivo software was employed for coding the data. The research team also conducted member checking, where participants reviewed the analysis to confirm their statements were interpreted accurately.	The study identified three major themes that describe how Indigenous youth leaders enact self-determination in relation to health and wellness: self-determination through traditional healing and embracing cultural wellness practices, sharing lived experiences and meeting people where they are, and community inclusion and intuitive practice.	- Indigenous research advisory group - Member checking
Tompkins, J. W., Mequanint, S., Barre, D. E., Fournie, M., Green, M. E., Hanley, A. J., Hayward, M. N., Zwarenstein, M., Harris, S. B., FORGE	The objective of the study was to develop and implement the Community Profile Survey (CPS) as part of the FORGE AHEAD research	A Community Profile Survey (CPS) was developed with input from Indigenous representatives and	The FORGE AHEAD research program utilizes quality improvement theory, tools, and processes. However, it	Cross-sectional Survey.	The study used descriptive analysis to summarise the data collected from the Community Profile Survey (CPS). Community-specific	The survey received responses from 84 out of 440 First Nations communities, 83% of the communities had health centers, but only 4% had	- First Nations Principles of Ownership, Control, Access, and Possession.

AHEAD Program Team, & On behalf of the FORGE AHEAD Program Team. (2018). National survey of Indigenous primary healthcare capacity and delivery models in Canada: The TransFORmation of Indigenous PrimAry HEAlthcare delivery (FORGE AHEAD) community profile survey. *BMC Health Services Research, 18*(1), 828-828. https://doi.org/10.1186/s12913-018-3578-8	program to create a comprehensive, community-based, national-level repository of information on healthcare delivery, funding models, infrastructure, and diabetes-specific programs in Indigenous communities across Canada.	Health Canada. It was piloted in six communities to ensure clarity and relevance. The survey was sent to 440 First Nations communities across Canada by email, fax, or mail. Communities could complete it online or on paper.	does not specify a framework.		reports were distributed, and aggregate-level reports were shared with regional and federal partners.	hospitals. 40% of the communities had diabetes registries, but only 21% tracked cases with surveillance systems. Many had diabetes care programs, though services like dialysis and lab tests required travel. Challenges included limited specialists, long travel distances, and low survey participation, emphasizing the need for improved access, funding, and diabetes care programs.	- Community input on survey content. - Restricting access to survey data to authorized team members for research purposes. - Providing communities with their data while sharing only aggregate-level data with regional and federal partners.
Thurber, K., Colonna, E., Wells, S., Salmon, M., Calabria, B., Olsen, A., Guthrie, J., Brinckley, M., Cohen, R., Priest, N., Banks, E., Gray, M., & Lovett, R. (2021). Data for action: The family and community safety for aboriginal and Torres Strait Islander peoples (FaCtS) study. *Australian Aboriginal Studies (Canberra, A.C.T. : 1983), 2021*(1), 3-21.	The FaCtS Study aimed to improve understanding of family, community safety, and violence in Aboriginal and Torres Strait Islander communities.	A community-based action research framework led by Aboriginal and Torres Strait Islander peoples.	The study employed a community-based action research framework as its theoretical foundation.	Mixed-methods study	The analysis methods were not disclosed; however, triangulation of data from multiple sources and approaches allowed for a more comprehensive understanding of family and community safety in these areas.	The FaCtS Study revealed diverse violence experiences in Aboriginal and Torres Strait Islander communities, alongside shared challenges needing tailored responses. While family violence services existed, barriers like limited hours and transport affected access. Community insights highlighted impacts, resilience, and solutions, emphasizing hope and strength. The study offered the first large-scale data on service needs, guiding community action,	- Study advisory group - Community advisory group - Study executive group - Community-based action research framework - Community self-nomination approach - Capacity building - Community feedback

						policy, and service improvements. Community-specific reports provided detailed findings to help improve safety	
Vukic, A., Rudderham, S., & Misener, R. M. (2009). A community partnership to explore mental health services in First Nations communities in nova scotia. *Canadian Journal of Public Health, 100*(6), 432-435. https://doi.org/10.1007/BF03404339	The research objective was to identify the gaps, barriers, and successes or solutions related to mental health services in Mi'kmaq communities in Nova Scotia	The study employed community-based participatory research (CBPR) as its methodology.	A theoretical framework was not mentioned.	Qualitative descriptive study	The study employed a thematic content analysis approach. The analysis used constant comparative methods, comparing interviews to identify patterns. NUDIST software helped organize data. This strategy led to triangulation and auditing of the research process through field notes. Data were categorized into barriers, successes, and solutions.	The studies identified barriers and successes in delivering effective mental health services, emphasizing the need for culturally appropriate, community-based, and sustainable mental health programs in Mi'kmaq communities.	- The study cited the OCAP principles (Ownership, Control, Access, and Possession) as core practices for Indigenous data governance

Appendix F
Study Characteristics

Characteristics	Number of Studies	
	n	%
Published Year		
2009-2010	2	13.3
2011-2012	2	13.3
2013-2014	0	0
2015-2016	0	0
2017-2018	2	13.3
2019-2020	0	0
2020-2021	1	6.7
2022-2023	7	46.7
2024	1	6.7
Country		
Canada	10	66.7
Australia	3	20
New Zealand	1	6.7
United States of America	1	6.7
Indigenous Groups		
Aboriginal Australian	2	13.3
American Indian	1	6.7
First Nations living in Canada	7	46.7
Māori	1	6.7
Unspecified	3	20
FNMI combined	1	6.7
Gender		
Male	0	
Female	1	6.7
Unspecified	9	60
All genders	5	33.3
Outcome Measured		
Health Care Utilization	4	26.7
Maternal Health	1	6.7
Public Health and Prevention	1	6.7
Infectious Diseases	1	6.7
Other health outcomes	2	13.3
Community engagement	1	6.7
Community well-being	1	6.7
Health Care Data	4	26.7
Region Study		
Rural	3	20
Urban	1	6.7
Both	4	26.7
Not Described	7	46.7