FROM COMPLIANCE TO CONNECTION: HOW PRIMARY CARE PROVIDERS CAN SUPPORT DIABETES CARE IN A GOOD WAY

by

Amy Rose Palumbo

B.A., Mount Allison University, 1999 B.N., University of Calgary, 2005

CAPSTONE SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING-FAMILY NURSE PRACTITIONER

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

July 2025

© Amy Palumbo, 2025

ABSTRACT

This integrative review, "From Compliance to Connection: How Primary Care Providers Can Support Diabetes Care in a Good Way," explores how primary care providers (PCPs) can more effectively support diabetes self-management among Indigenous adults in Canada. Type 2 Diabetes Mellitus (T2DM) disproportionately affects Indigenous communities, a disparity rooted in colonialism, intergenerational trauma, and systemic inequities. Historically, Western medicine has pathologized Indigenous bodies and dismissed Indigenous knowledge, reinforcing narratives of "non-compliance" and undermining trust in care relationships. Using an integrative literature review methodology, 11 studies were identified through CINAHL, Google Scholar, and hand searching. These were appraised using the Critical Appraisal Skills Programme (CASP) and an adapted Aboriginal and Torres Strait Islander Quality Appraisal Tool. Findings were analyzed through a culturally grounded qualitative synthesis. The review revealed that diabetes is often experienced not only as a physiological condition, but also as a relational and psychological disruption. Barriers to effective management included biomedical dominance, lack of cultural safety, ineffective diabetes education, and the framing of resistance as non-compliance. However, promising practices emerged: the integration of traditional medicine, use of culturally resonant strategies like peer support and talking circles, and the alignment of biomedical concepts with Indigenous worldviews. This review urges PCPs to move from authority-driven models toward relational, culturally-grounded care. It concludes with implications for practice, education, and research, centring Indigenous-led approaches in all aspects of diabetes care.

TABLE OF CONTENTS

Abstract	1
List of Tables	V
Glossary	V
Acknowledgement	vi
Chapter 1: Introduction	1
Chapter 2: Background	2
The Burden of Diabetes: Indigenous Populations Role of Primary Care Providers in Diabetes Language Matters Research with Indigenous Peoples. What is Needed	6 6 7
Chapter 3: Methods	10
Problem Identification Literature Search Search Strategies Data Evaluation Data Analysis	12 13 14
Chapter 4: Findings	17
Study Methodologies	24 28
Chapter 5: Discussion	36
Implications for Practice: Addressing Colonial Legacies in Indigenous Diabetes Care Implications for Education	44
Chapter 6: Conclusion	54
References	57
Appendix 1: Database Search Strategy	68
Appendix 2: Prisma Flow Diagram	69

70

Appendix 3: Summary of Data	a Extraction
-----------------------------	--------------

Appendix 4: Comparison of OCAP® and TCPS 2 Chapter 9 and CBPR Frameworks for Ethical Research with Indigenous Peoples 81

List of Tables

Table 1: Methodologies of Selected Studies	17
Table 2: Sample Size in Each Study	18
Table 3: Ages of Participants in Each Study	19
Table 4: Diabetes Profile of Participants in Each Study	21
Table 5: Demographic Profiles of Selected Studies	. 22

Glossary

Anti-racism: is the practice of actively identifying, challenging, preventing, eliminating and changing the values, structures, policies, programs, practices and behaviours that perpetuate racism. It is more than just being "not racist" but involves taking action to create conditions of greater inclusion, equality and justice (Turpel-Lafond, 2020, p. 8).

Colonialism: occurs when groups of people come to a place or country, steal the land and resources from Indigenous peoples, and develop a set of laws and public processes that are designed to violate the human rights of the Indigenous peoples, violently suppress their governance, legal, social, and cultural structures, and force them to conform with the colonial state" (Turpel-Lafond, p. 2020)

Cultural Humility: a process of self-reflection to understand personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a life-long learner when it comes to understanding another's experience (First Nations Health Authority, 2021, p. 5)

Cultural Safety: Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care (First Nations Health Authority, 2021, p. 5)

Racism: is the belief that a group of people are inferior based on the colour of their skin or due to the inferiority of their culture or spirituality. It leads to discriminatory behaviours and policies that oppress, ignore or treat racialized groups as "less than" non-racialized groups (Turpel-Lafond et al., 2020, p. 8).

Systemic racism: is enacted through routine and societal systems, structures, and institutions such as requirements, policies, legislation, and practices that perpetuate and maintain avoidable and unfair inequalities across racial groups including the use of profiling and stereotyping (Turpel-Lafond, 2020, p. 8).

Acknowledgement

I would like to express my deep gratitude to my supervisor, Dr. Catharine Schiller, whose kindness, accommodation, encouragement, and thoughtful feedback guided this capstone and helped carry me through self-doubt to completion.

I extend heartfelt thanks to the Indigenous Peoples whose knowledge, experiences, and resistance informed this work. Although this project did not involve direct community collaboration, I am indebted to the authors, Elders, storytellers, and community members whose insights shaped this review. They have informed how I will carry forward with humility and a commitment to ongoing learning as a family nurse practitioner.

To my partner, Sheldon; my parents, Ed and Rosalind; my parents' partners and dear family, Lorna and Bruce; my parents-in-law, Melanie and Brian; my sister-in-law, Rachelle; and my beautiful children, Emilio and Rosa—thank you for your endless patience, space, emotional encouragement, practical support, and intellectual companionship throughout this journey. To my friends, especially Zamantha, thank you for your encouragement and steady presence, which made this possible.

Finally, I respectfully acknowledge that this capstone was written and researched on the unceded, ancestral territories of the Ligwiłdaxw people—the We Wai Kai, We Wai Kum, and Kwiakah First Nations—as well as the ʔayʔajuθəm-speaking peoples of the Homalco, Klahoose, and K'ómoks First Nations. I recognize that I study, live, work, and play on these lands as an uninvited guest.

Chapter 1: Introduction

From the onset of colonization, Western medicine played a central role in pathologizing Indigenous bodies, serving as a tool of control and assimilation. Medical authority was used to justify intrusive involvement in the lives and health of Indigenous peoples, grounded in racialized assumptions of white superiority and a baseless fear of "interracial contagion" (Reading, 2018, p. 8). In this way, medicine became an instrument of colonization, reinforcing systems of oppression under the facade of caring for those who were being colonized (Reading, 2018). The experiences of many Indigenous peoples with diabetes have been shaped deeply by this history. Diabetes is experienced within a different context for Indigenous populations, which has implications not only for biological health, but also for mental health, cultural wellness, political power and access, community sovereignty, and the health of Indigenous lands and traditions (Dutton, 2018, p. 8).

This integrative review seeks to center the lived experiences and voices of Indigenous peoples with diabetes, offering a narrative that illuminates how primary care providers can more effectively support self-management within this population. Acknowledging the profound historical and intergenerational impacts of colonization, it is essential to recognize how these forces continue to shape the psychological burden of a diabetes diagnosis among Indigenous peoples, compounded by ongoing experiences of stigma, culturally incongruent care, and the marginalization of traditional healing practices—practices that must be respectfully centred to support holistic and effective diabetes care.

Chapter 2: Background

The Burden of Diabetes: Indigenous Populations

This chapter provides an overview of type 2 diabetes mellitus (T2DM) and its significance among Indigenous populations in Canada. It begins by outlining the pathophysiological mechanisms, symptoms, and complications of T2DM. The chapter then highlights the disproportionate prevalence of T2DM among Indigenous peoples and examines how colonial systems have shaped these health disparities. It describes the concept of diabetes self-management (DSM) and critiques how mainstream approaches often overlook Indigenous knowledge and lived experience. Finally, it identifies the critical role of primary care providers (PCPs) in addressing these gaps and sets the stage for exploring culturally appropriate, community-informed models of care that support Indigenous health and self-determination.

Type II Diabetes

Type 2 diabetes mellitus (T2DM) is a chronic metabolic disorder characterized by disruptions in glucose homeostasis, primarily due to impaired insulin secretion by pancreatic beta cells, increased hepatic glucose production, and decreased insulin sensitivity in peripheral tissues (Galicia-Garcia et al., 2020). These mechanisms lead to elevated circulating blood glucose levels, often developing gradually and without noticeable symptoms, which is why T2DM is commonly referred to as a "silent" disease (Wood, 2021).

Many individuals who develop T2DM also have metabolic syndrome—a cluster of interconnected risk factors that include central obesity, insulin resistance, hyperglycemia, hypertension, elevated triglycerides, low HDL cholesterol, and a chronic pro-inflammatory state (Wood, 2021). Lifestyle factors such as physical inactivity, poor diet, and excess body weight significantly contribute to the development of T2DM, and these factors are now being observed

in younger populations. Once considered a condition primarily affecting older adults, T2DM is increasingly being diagnosed in children and adolescents, making it a concern across the lifespan (Wood, 2021).

Early symptoms, when present, may include fatigue, frequent urination, excessive thirst, blurred vision, and slow-healing wounds. Over time, persistent hyperglycemia can lead to both microvascular and macrovascular complications, including damage to the eyes (retinopathy), kidneys (nephropathy), peripheral nerves (neuropathy), and major blood vessels, increasing the risk of heart attack and stroke (Wood, 2021). Importantly, the progression from prediabetes to T2DM can often be halted or reversed through lifestyle modifications such as healthy eating, regular physical activity, and weight loss. However, without intervention, T2DM can result in serious and irreversible outcomes, including blindness, kidney failure, and cardiovascular disease (Wood, 2021).

Diabetes Epidemic

Prior to the 1950s, T2DM was virtually non-existent in Indigenous populations in Canada; in the last several decades, it has reached epidemic proportions with rates 3 to 5 times that of the general population (Public Health Agency of Canada [PHAC], 2018; Sinclaire et al., 2023). In the 25-year period from 1980-2005, rates increased by 10.8% in First Nations women and 4.2% in First Nations men (Halseth, 2018). According to the Pan-Canadian Health Inequalities Data Tool, age-standardized rates of diabetes are now 17.2% for individuals living on reserve compared to 12.7% for First Nations living off reserve, 9.9% among Métis, and 4.7% among Inuit peoples, compared to 5% in the non-Indigenous population (PHAC, Pan-Canadian Public Health Network & Statistics Canada, 2024). Prevalence is increasing with onset at a younger age, continued higher rates amongst women, poorer disease management and worse

outcomes (Sinclaire et al., 2023). This disproportionate burden results from colonial processes and structures that have dramatically altered the socioeconomic, political and cultural systems of First Nations peoples (Halseth, 2019) that had previously combined to prevent T2DM from being present in that population. While it is recognized that an approach grounded in reciprocal relationships with healthcare providers that embraces diversity, tailors care to each individual's unique needs, addresses the social determinants of health, and honours a patient's own priorities is required for meaningful change for Indigenous patients (Diabetes Canada, 2025d), rates of diabetes have continued to rise.

Diabetes Self-Management

Diabetes self-management (DSM) refers to the ongoing process by which individuals with the disease take responsibility for managing their condition. It involves making daily decisions and taking action to maintain healthy blood sugar levels, prevent complications, and improve overall well-being. Effective self-management can reduce the risk of serious complications, such as heart disease, kidney damage, nerve damage, and vision problems (American Diabetes Association [ADA], 2024; Centers for Disease Control and Prevention [CDC], 2023; National Institute of Diabetes and Digestive and Kidney Diseases, 2023; World Health Organization [WHO], 2021). Key aspects of the DSM process include healthy eating, physical activity, blood glucose monitoring, adherence to medications, healthy and effective problem-solving, reducing lifestyle and modifiable risk factors, and implementing healthy coping mechanisms (Diabetes Canada, 2025b). A prerequisite for DSM is Diabetes Self-Management Education (SME), a collaborative process between patients and healthcare providers that arm individuals with the knowledge and skills to inform decisions and increase their capacity and confidence to apply these skills in daily life situations (Diabetes Canada, 2025c).

Biomedical Gaps in Indigenous Diabetes Care

The effectiveness of DSM is measured by a blood test called the Hemoglobin A1C (HgA1c), or glycated hemoglobin, which reflects an individual's level of blood glucose control over the prior 3-month period, expressed as a percentage (Eyth & Nalk, 2023). HgA1C is the gold standard for assessing diabetes control within the Western model of healthcare, and if the target level is not achieved, providers report frustration with the individual patient and place responsibility on that person. Almost inevitably, a narrative of non-compliance will ensue (Sinclaire, 2023). Most studies that address DSM for Indigenous populations do so from the perspective of physicians, and those studies place their emphasis on *patient factors* from a deficit perspective (Crowshoe et al., 2018). Rather than acknowledge the context for diabetes in Indigenous populations, and the impact that this context may have on DSM, emphasis is placed on the deficits of *individuals*, *bodies*, and *behaviours*.

There exists a long-standing body of Indigenous knowledge and community-driven approaches to SME that are deeply effective and culturally resonant. These include land-based healing, traditional food systems, intergenerational knowledge transmission, language revitalization, and ceremony—all of which contribute to holistic wellness and self-determination in health. Unfortunately, these Indigenous-led solutions have been rendered invisible or delegitimized within mainstream biomedical discourse, which continues to prioritize individual behaviour change and glucose metrics over relational and cultural approaches to health (Greenwood et al., 2015; Hart, 2010; Smylie, 2014). This epistemic suppression reflects broader colonial dynamics in health systems, where Western knowledge is privileged and Indigenous knowledge systems are systematically marginalized (Reading, 2018; Smylie, 2009). Recognizing and amplifying Indigenous approaches is essential, not only for improving diabetes outcomes but

also for restoring autonomy, dignity, and cultural continuity among Indigenous patients and communities.

Role of Primary Care Providers in Diabetes

Primary care providers (PCP), such as nurse practitioners and physicians, provide *primary care*. Through the provision of longitudinal, comprehensive, coordinated and personcentred care, the primary care model aims to optimize population health and minimize health disparities across communities (WHO, 2025). PCPs treat diseases and disorders by prescribing medication, ordering diagnostic tests, managing results, and consulting or referring to other health professionals when needed (British Columbia College of Nurses and Midwives [BCCNM], 2025). In the context of T2DM, PCPs are likely to be the first and most frequent point of contact for patients, providing continuity of care with a comprehensive overview of health issues and social supports (Diabetes Canada, 2025a; Kushner et al., 2022).

Language Matters

This paper will use several terms interchangeably to describe First Peoples who are geographically located in what is colonially known as Canada. "Indigenous" is a collective designation to describe First Peoples in Canada, specifically First Nations (both status and non-status), Inuit, and Métis Peoples (Dutton, 2018; Kesler, 2020). While it is often considered a preferred term due to its association with Indigenous rights movements, and its use in agreements such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the term "Indigenous" still defines groups primarily in relation to their colonizer and is not a word that has been derived from Indigenous language or practice (Kesler, 2020). In recent times, "Indigenous" has been used by the Canadian government to denote the "Ministry of Indigenous Affairs" as well as by the province of British Columbia to name the "Declaration on

the Rights of Indigenous Peoples Act" (Kesler, 2020; Queen's University, 2025). "Aboriginal" is a word used to describe the same broad grouping of peoples in the Canadian context and became part of the legal lexicon in the Constitution Act of 1982 to replace the word "Indian." The term "Aboriginal" is less preferred by some due to its association with Canadian government policy, yet it remains largely acceptable when used within a Canadian context.

Historically, the language used to describe Indigenous Peoples by institutions and in public discourse has caused harm, failing to acknowledge how Indigenous communities identify themselves, perpetuating colonial dominance and failing to assume a reconciliatory stance.

Conscientious language use by institutions and within public discourse is of critical importance to acknowledge the traditional and preferred names for specific groups and to cease the insinuation that Indigenous Peoples "belong" to Canada. For example, referring to "Canada's Aboriginals" as a noun implies that they belong to Canada, whereas referencing Aboriginal Peoples of Canada as an adjective, while still overly general, is more appropriate. Authors referenced in this integrative review used a spectrum of terms: "Aboriginal," "First Nations," and "Indigenous," according to the context of their study and the time in which their research was conducted. It is important to acknowledge the variation in culture, language, and experience, and to use the names that communities, regions and groups have chosen for themselves.

Research with Indigenous Peoples

Research involving Indigenous peoples has a fraught history, characterized by unethical, exploitative practices that treated Indigenous individuals as subjects rather than human beings. Notably, atrocities such as nutritional experimentation on children who resided in residential schools exemplify how research was used to advance colonial agendas without consideration of the harms being caused (Hayward et al., 2021; Reading, 2018). Indigenous communities have

criticized research for continuing to ignore community needs, reinforcing power imbalances, privileging academic advancement over community benefit, and promoting stigma while disregarding Indigenous ways of knowing and being (Hayward et al., 2021). Continuation of these research practices that are rooted in systemic racism reinforce the marginalization and invalidation of Indigenous voices, thereby upholding Western biomedical paradigms for diabetes care that sustain colonial structures and ongoing harm (Sinclaire et al., 2023). Although Indigenous peoples have consistently asserted their perspectives, their voices have often been excluded when shaping research agendas and informing diabetes service delivery (Sinclaire et al., 2023). In response, ethical frameworks have been developed to promote research that is culturally appropriate, beneficial, and grounded in principles of self-determination. However, the consistent implementation of these standards remains uneven and continues to evolve.

What is Needed

Western medicine is a bystander to the epidemic of T2DM in Indigenous populations, who have been left to navigate complex, multilayered health and social service systems that perpetuate a harmful colonial legacy. International, national, and provincial legislation, along with reports and health authority agreements, have acknowledged the lack of agency as a significant barrier to Indigenous well-being. Indigenous voices remain misrepresented and underrepresented within the prevailing narrative of diabetes care. To effectively address this issue, a new narrative must be developed—one that is informed by the lived experiences and perspectives of Indigenous patients themselves.

Such an approach is essential for identifying the specific barriers within the current healthcare framework and developing more culturally responsive solutions. We must expand and transform our understanding of T2DM within a specific cultural context, seek alternative

explanations within that context, and value those stories that reveal a more favourable construction of Aboriginal healing needs and identities to put forward a more balanced understanding of the Aboriginal experience of living with T2DM (Barton, 2008, p. 34-35). PCPs are integral to the comprehensive management of T2DM, being involved in diagnosis, treatment, monitoring for complications, and the provision of continuous, longitudinal care. As pivotal stakeholders in the healthcare system, PCPs have a responsibility to transition from passive oversight to active leadership in addressing the growing burden of T2DM in Indigenous populations. Their engagement is essential to driving meaningful, system-wide change.

This integrative review will discuss the diabetes epidemic and examine how current approaches to primary care must evolve to address this issue effectively, with a focus on delivering care in culturally appropriate and responsive ways.

Chapter 3: Methods

According to Torracco (2016), an integrative literature review is a methodological approach designed to generate novel insights and theoretical contributions in relation to a specific topic. This form of review systematically evaluates, critiques, and synthesizes representative literature in a cohesive manner, enabling the development of new conceptual frameworks and perspectives. It is particularly suited to areas that have not undergone a recent, comprehensive synthesis or are situated within emerging fields where existing literature may be fragmented, contradictory, or misaligned. By addressing such gaps and inconsistencies, integrative literature reviews offer a depth of critical appraisal that contributes to the advancement of knowledge and fosters a deeper understanding of complex or evolving subject areas (Torraco, 2016).

The approaches outlined by both Torraco (2016), and Whittemore and Knafl (2005), were foundational to the development and execution of this capstone. This integrative review was designed to critically examine, evaluate, and synthesize empirical and theoretical literature regarding the ways that PCPs can positively impact DSM for adult patients who are Indigenous. Given that this topic intersects with diverse domains—including chronic disease management in primary care, Indigenous health, relational care, and cultural safety—it was evident from the outset that the existing literature was likely to be fragmented, variably conceptualized, and lacking a cohesive synthesis through which to address these elements. Stages 1 through 4 are addressed below as part of this chapter. Stage 5, data analysis, focuses on interpretation of findings, a discussion of those findings, and recommendations for practice, research, and education; Stage 5 will be covered in subsequent chapters.

Problem Identification

This integrative review was guided by the research question: "How can PCPs positively impact adult patients who have Type 2 Diabetes Mellitus and who are Indigenous?" This question was developed using the PIO (Population, Intervention, Outcome) framework, which ensured clarity and alignment with the purpose of the review (Melnyk & Fineout-Overholt, 2023).

The population (P) of interest was adult patients who are Indigenous (First Nations, Inuit, and Métis peoples) and living with T2DM. This population was selected in recognition of the disproportionate burden of diabetes among Indigenous Peoples and the need to centre their unique cultural, historical, and social experiences within healthcare research.

The intervention (I) focused on the role of PCPs and the specific ways in which their actions, attitudes, and relational approaches influence patient experiences (Melnyk & Fineout-Overholt, 2023).

The outcome (O) was the impact of PCP approaches on T2DM, which could include engagement with care, patient empowerment, and trust in the healthcare system. These outcomes were understood in a broad, culturally-informed sense that included relational- and community-based understandings of health and healing that transcended Western biomedical concepts of health.

By applying the PIO framework, this review systematically investigated the intersection of provider behaviour and patient outcomes within a culturally-specific context, ensuring a focused and meaningful synthesis of the literature.

Literature Search

A comprehensive and systematic literature search was conducted for this integrative review using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database and Google Scholar. CINAHL is a comprehensive academic database for literature related to medicine, nursing and allied health disciplines for peer-reviewed evidence-based topics in medicine, practice articles, nursing and related allied health disciplines (University of Northern British Columbia [UNBC], n.d). It was selected as the most appropriate database to identify literature that addresses the intersecting biopsychosocial dimensions relevant to this specific research question, areas often underrepresented in more biomedically-oriented databases. Google Scholar is a search engine that was included in the literature search strategy due to its broad, multidisciplinary scope and ability to capture diverse forms of scholarship, including grey literature, policy documents, theses, and reports (UNBC, n.d.). This is particularly important when exploring complex, socially embedded health issues, such as Indigenous experiences with diabetes, where critical perspectives, community-based research, and culturally-grounded knowledge may be underrepresented. While these database searches were central to systematic literature retrieval, hand searching was also employed to ensure the comprehensive identification of relevant literature. This process included reviewing reference lists of key articles, searching grey literature sources, and scanning Indigenous organizational reports that may not have been indexed in research databases. This approach aligned with recommendations for integrative reviews that seek to include diverse sources of knowledge (Toronto & Remington, 2020; Whittemore & Knafl, 2005).

Search Strategies

Initial search terms were grouped by key concepts: diabetes (e.g., "Diabetes Mellitus, Type 2," "Diabetic Patients"), Indigenous populations (e.g., "Aboriginal Canadians," "Indigenous Peoples," "Native American People"), health care quality and accessibility (e.g., "Healthcare Disparities," "Quality of Health Care"), self-management (e.g., "Self-Care," "Blood Glucose Self-Monitoring"), and primary care providers (e.g., "Nurse Practitioners," "Family Physicians"). To conduct this literature search, subject headings and keywords that corresponded to the key concepts of the research question were combined in CINAHL using the Boolean operators "AND" and "OR". For a full list of the search terms and combinations that were used in this integrative review, see Appendix 1.

Google Scholar was used to search for additional literature, including grey literature and resources that were not indexed in the CINAHL database. A simplified search string ("type 2 diabetes AND self-management AND Indigenous patients") was used for this Google Scholar search, yielding ten additional articles that had not been previously captured. The hand searching process described process yielded two additional articles.

Inclusion criteria for the integrative review were the following: (a) empirical or relevant grey literature; (b) focused on Indigenous adult patients (> 18 years) with T2DM as the population of interest; (c) related to a DSM intervention; (d) published in English; and (e) described patient experiences with PCPs and Western medicine. Exclusion criteria were: (a) a different population of focus than Indigenous adults with T2DM (e.g. non-Indigenous children); (b) a study population located outside of Canada; (b) non-T2DM specific; (c) did not capture the lived experience of participants; and (d) publication before 1999 (Toronto & Remington, 2020).

Articles needed to be published in the English language due to limitations in translation and interpretation resources, and English is the language spoken by the author of this integrative review. The required date range (i.e. after 1999) was chosen to balance the inclusion of relevant literature with the need to reflect more recent ethical standards and research methodologies. While the initial search strategy had been designed to include articles that focused on Indigenous populations both inside and outside Canada, a sufficient number of articles within the Canadian context were retrieved, thus enabling a focus on the cultural, historical, and health system within a single country. The experiences and perspectives of Indigenous peoples in Canada have been shaped by a distinct history, specific healthcare policies, and unique sociopolitical conditions that differ from those present in other countries. A focus on Canada-based literature only allows for a more specific understanding of the barriers, facilitators, and culturally specific factors that influence diabetes care and self-management among Indigenous populations in Canada.

Following the application of the inclusion and exclusion criteria, a total of 61 studies were imported into Covidence for screening (Covidence, n.d.).

After the removal of five duplicate records, the abstracts of the remaining 56 articles were reviewed by the author for relevance to the research question. Based on this screening, 37 articles were excluded. Of the 19 full-text articles assessed for eligibility, eight were excluded as they did not meet the inclusion criteria. A total of 11 articles have been included in the final integrative review (see Appendix 2 for the PRISMA diagram).

Data Evaluation

All of the studies included in this integrative review employed a qualitative methodology, with one study (LaVallée & Howard, 2011) incorporating a mixed methods design. To critically appraise the methodological and cultural rigour of the 11 included studies, two complementary

tools were used and applied to each study: the Critical Appraisal Skills Programme (CASP, 2024) tool for qualitative research and the Aboriginal and Torres Strait Islander Quality Appraisal Tool (Harfield et al., 2018). The CASP tool provided a structured, rigorous, well-established framework for assessing the methodological quality of qualitative studies, focusing on elements such as research design, data collection, ethical considerations, and the coherence of findings. This tool ensured that each study included in this integrative review met foundational standards of credibility, relevance, and transparency in qualitative inquiry (CASP, 2024). It was selected for its ability to support a more nuanced and in-depth evaluation of methodological quality in qualitative research (CASP, 2024).

The Aboriginal and Torres Strait Islander Quality Appraisal Tool (ATSI QAT) was adapted for use in evaluating research involving First Nations, Inuit, and Métis peoples in Canada. While originally developed for the Australian context, the tool's emphasis on Indigenous governance, cultural protocols, relational accountability, and community benefit makes it highly relevant for assessing the ethical and cultural dimensions often overlooked in conventional appraisal frameworks (Harfield et al., 2020). This 14-item tool foregrounds Indigenous ways of knowing and being, evaluating whether a particular study has been guided by Indigenous priorities, has used appropriate cultural protocols, and has meaningfully engaged the Indigenous community represented in the research study throughout the research process (Harfield et al., 2020). Used together, these two tools enabled a robust and culturally respectful appraisal of the literature by ensuring that both scientific and community-based ethical standards were being considered.

In the case of the mixed methods study by LaVallée and Howard (2011), while quantitative elements were included, the study was fundamentally qualitative. The use of

quantitative data was limited in scope and not intended to meet standards of quantitative rigour.

Therefore, a mixed methods analysis was not appropriate.

Data Analysis

Given the focus of this integrative review on the ways that PCPs could positively impact the DSM experiences of Indigenous patients, a qualitative synthesis approach was employed to analyze and interpret data across 10 diverse qualitative studies and one mixed methods study that was primarily qualitative in design and intent. The aim was to identify recurring patterns, themes, and conceptual insights related to diabetes care contexts. Following the principles of integrative review methodology outlined by Whittemore and Knafl (2005), data from the included studies were extracted, organized, and coded. Key findings related to the research question were highlighted. Given the focus on Indigenous populations, particular attention was paid to the cultural context of each study, and data were analyzed with an awareness of historical, social, and political contexts. The final themes reflect recurring concepts and ideas across studies (see Appendix 3).

Chapter 4: Findings

The following is a synthesis of findings drawn from the literature to answer the question, "How can PCPs positively impact adult patients who have Type 2 Diabetes Mellitus and who are Indigenous?" Study Methodologies

Each of the 11 studies in this literature review employed a range of qualitative methodologies to explore the lived experiences of Indigenous adults in Canada with T2DM.

While one study employed a mixed methods approach, combining qualitative and quantitative methodologies, its approach was fundamentally qualitative (LaVallée & Howard, 2011).

Collectively, these studies emphasize the value of context, agency, storytelling and lived experience in generating meaningful insights for the construction of a new narrative regarding diabetes self-management for Indigenous communities (Table 1).

Table 1Methodologies of Studies Included in Integrative Review

Study	Туре	
Barton et al. (2005)	Narrative inquiry	
Barton (2008)	Narrative inquiry	
Bruyère and Garro (2000)	Narrative inquiry	
Dutton (2018)	Community-based participatory research	
Gregory et al.(1999)	Naturalistic inquiry	
Hernandez et al. (1999)	Grounded theory	
Johnson et al. (2022)	Responsive interviewing	
Kulhawy and Wibe (2018)	Qualitative descriptive analysis	
LaVallée and Howard (2011)	Mixed methods	

Pilon et al. (2	019)
-----------------	------

Grounded theory

Sherifali et al. (2012)

Qualitative descriptive analysis

Across the studies, sample sizes ranged from 4 (Barton, 2008) to 138 participants (LaVallée & Howard, 2011), with most studies including a majority of women. Table 2 provides details of the demographic breakdown in each study. Female participants outnumbered males in nearly all studies (Barton et al., 2005; Barton, 2008; Bruyère & Garro, 2000; Dutton, 2018; Hernandez et al., 1999; Kulhawy-Wibe et al., 2018; LaVallée & Howard, 2011; Pilon et al., 2019; Sherifali et al., 2012), and one study included participants who identified as Two-Spirit (LaVallée & Howard, 2011).

Table 2
Sample Size in Each Study

Study	Number of Participants	Gender
Barton et al. (2005)	N = 8	w = 5, m = 3
Barton (2008)	N = 4	w = 3, m = 1
Bruyère and Garro (2000)	N = 22	w = 12, m = 10
Dutton (2018)	N = 10	w = 7, m = 10
Gregory et al. (1999)	N = 20	w = 12, m = 8
Hernandez et al. (1999)	N = 10	w = 6, m = 4
Johnson et al. (2022)	N = 10	w = 4, m = 6
Kulhawy-Wibe et al. (2018)	N = 5	derived from larger study $n = 78$, $w = 61.5\%$ of larger study participants, $m = 38.5\%$
LaVallée and Howard (2011)	N = 138	w = 106, m = 30, 2S = 2

Pilon et al. (2019)	N=22	w = 13, m = 9
Sherifali et al. (2012)	N = 24*	w= 85.5%, m= 14.5%
Total	N = 273	

Note. N=total sample size, w= female participants, m= male participants, 2S= 2 spirit participants, *=average number of sharing circle participants per session (4 sessions total)

Participants across the studies ranged in age from 18 to 83 years, with most falling within their 30s and 70s. One study focused specifically on Elders (Barton, 2008), although the authors did not define a specific age range associated with that honourary title. Some studies reported an age range (Gregory et al., 1999; Hernandez et al., 1999; Johnson et al., 2022) while others reported only a mean age (Kulhawy-Wibe et al., 2018), and one study did not provide age data at all (Barton et al., 2005). Notably, LaVallée and Howard (2011) included a large and diverse sample of participants aged 18 to 79, with nearly half under 45, thereby offering insight across multiple life stages.

Table 3

Ages of Participants in Each Study

Study	Age Range of Participants	
Barton et al. (2005)	Unspecified	
Barton (2008)	Elders (age range unspecified)	
Bruyère and Garro (2000)	25 - 73 years old	
Dutton (2018)	40 - 79 years old Not stated = 2 40 - 49: $n=150 - 59$: $n=370 - 79$: $n=4$	
Gregory et al. (1999)	28 - 68 years old	

Hernandez et al. (1999)	32 - 75 years old
Johnson et al. (2022)	35 - 70 years old
Kulhawy-Wibe et al. (2018)	Mean age = 56.1 (age range unspecified)
LaVallée and Howard (2011)	18 - 79 years old 18 - 29: $n=10$ 30 - 39: $n=18$ 40 - 49: $n=35$ 50 - 59: $n=36$ 60 - 69: $n=28$ 70 - 79: $n=9$
Pilon et al. (2019)	45 - 78 years old Mean = 61 years old
Sherifali et al. (2012)	34 - 83 years old

Note. Age classes are provided as presented by the authors.

All 11 studies included in this integrative review explicitly involved participants diagnosed with T2DM. One study (Johnson et al., 2022) indicated the inclusion of individuals with T2DM in the article title but then provided no further details about time since diagnosis or the treatment regimen used. Another study (Sherifali et al., 2012) included both individuals living with T2DM and those living with, or caring for, someone with the condition. LaVallée and Howard (2011) included a mixed sample of participants with T2DM, prediabetes, gestational diabetes, and Type 1 diabetes. Reported time elapsed since participant diagnosis of T2DM varied significantly, ranging from less than one year to over 32 years.

Treatment regimen details were inconsistently reported. In 8 of the 11 studies, the type of diabetes treatment being used by each participant was not specified (Barton et al., 2005; Barton, 2008; Bruyère & Garro, 2000; Dutton, 2018; Johnson et al., 2022; Kulhawy-Wibe et al., 2018; LaVallée & Howard, 2011; Pilon et al., 2019). Two studies described a range of treatment approaches being utilized by participants, including diet modification, oral medications, insulin

therapy, and lifestyle management (Hernandez et al., 1999; Sherifali et al., 2012). One study noted that its participants were receiving treatment for T2DM but did not specify the type (Gregory et al., 1999).

 Table 4

 Diabetes Profile of Participants in Selected Studies

Study	Diabetes Type	Time Since Diagnosis	Additional Criteria
Barton et al. (2005)	T2DM	5 to 20 years prior	
Barton (2008)	T2DM	Unspecified	
Bruyère and Garro (2000)	T2DM	Unspecified	
Dutton (2018)	T2DM	1 to 20 years prior	
Gregory et al. (1999)	T2DM	<1 to 32 years prior <i>Mean 10.4 years</i>	Receiving Treatment (not specified)
Hernandez et al. (1999)	T2DM	2 to 32 years prior	Receiving Treatment Diet; $n = 1$ Oral; $n = 4$ Insulin; $n = 5$
Johnson et al. (2022)	T2DM	Unspecified	Insulin; n = 3
Kulhawy and Wibe (2018)	T2DM	Unspecified <i>Mean 12 years</i>	
LaVallée and Howard (2011)	T2DM Pre-diabetes Gestational diabetes T1DM	<5 to 20+ years prior <5 years = 49% 6-10 years = 25% 11-19 years = 12% 20+ years = 14%	
Pilon et al. (2019)	T2DM	5 to 30 years prior Mean 17.4 years	
Sherifali et al. (2012)	T2DM	Unspecified	Receiving Treatment (not specified) Lifestyle, Oral and Injection

The studies included participants from several Indigenous communities across Canada. The following Indigenous communities were represented within this integrative review: First Nations (Barton et al., 2005; Barton, 2008; Bruyère & Garro, 2000; Hernandez et al., 1999; Johnson et al., 2022; Kulhawy-Wibe et al., 2018; Pilon et al., 2019; Sherifali et al., 2012), Métis (Dutton, 2018; LaVallée & Howard, 2011), and individuals with multiple Indigenous identities (Dutton, 2018; Gregory et al., 1999; LaVallée & Howard, 2011). Participants resided in various regions across Canada, including British Columbia (Barton et al., 2005; Barton, 2008), Manitoba (Bruyère & Garro, 2000; Gregory et al., 1999), Ontario (Hernandez et al., 1999; Johnson et al., 2022; Pilon et al., 2019; Sherifali et al., 2012), Alberta (Kulhawy-Wibe et al., 2018), and the Northwest Territories (Dutton, 2018). Some studies focused on specific First Nations, such as the Nuxalk (Barton et al., 2005; Barton, 2008), Opaskwayak Cree (Bruyère & Garro, 2000), Siksika (Kulhawy-Wibe et al., 2018), and Dene (Dutton, 2018), while others involved urban Indigenous populations or multiple communities. Participants included Elders, traditional medicine practitioners, and healthcare administrators, reflecting a wide range of roles and cultural perspectives within their communities.

Table 5

Demographic Profiles of Selected Studies

Study	Demographics	Geography
Barton et al. (2005)	Nuxalk Nation = 8	Bella Coola, BC
Barton (2008)	Nuxalk Nation = 4	Bella Coola, BC
Bruyère and Garro (2000)	Opaskwayak Cree Nation = 22	The Pas, MB
Dutton (2018)	Dene Métis = 7 Dene = 1 Cree = 2	Fort Smith, NWT

Gregory et al. (1999)	Urban Aboriginal = 20 Primarily Cree	Winnipeg, MB
Hernandez et al. (1999)	First Nation Community = 10 (details not provided)	Southwestern ON
Johnson et al. (2022)	First Nations = 10 (details not provided) Involved in traditional medicine = 3 Elders = 5 Healthcare administrators = 2	Sioux Lookout, ON
Kulhawy-Wibe et al. (2018)	Siksika Nation = 5	95 km East of Calgary, AB
LaVallée and Howard (2011)	First Nations = 127 Métis = 9 Multiple Indigenous identities = 2	Toronto, ON
Pilon et al. (2019)	7 First Nations communities = 22 (details not provided)	Northern ON
Sherifali et al. (2012)	First Nations community members (details not provided) Living with T2DM = 19 Caregiver of someone with T2DM = 5 Columbia, MB = Manitoba, NWT = Not	Hamilton, ON

Note. AB = Alberta, BC = British Columbia, MB = Manitoba, NWT = Northwest Territories, ON = Ontario.

This integrative review found that diabetes is experienced not only as a physiological illness but also as a profound psychological and relational disruption, shaped by intergenerational trauma, colonial histories, and ongoing systemic inequities. Central to these findings are themes of fatalism, denial, and a sense of inevitability. Yet, within this landscape of fear and resignation, many participants also described a movement toward self-determination, resilience, and cultural reclamation. The studies illuminate how challenges such as paternalism in healthcare, ineffective communication, and knowledge gaps intersect with opportunities for culturally-grounded diabetes care, which includes the integration of traditional ways of knowing and being, and peer support. These findings frame diabetes not only as a medical condition but as

a reflection of broader social, historical, and spiritual realities that must be addressed through both clinical and cultural approaches.

Diabetes: Psychological Impact

Fatalism

Several studies documented that participants perceived their development of T2DM as an inevitable result of being Indigenous; authors referred to this belief system as 'fatalistic' because these participants viewed important parts of their life journey as being out of their control (Bruyère & Garro, 2000; Dutton, 2018; Gregory et al., 1999; Kulhawy-Wibe at al., 2018; Johnson et al., 2022; Pilon et al., 2019). However, other studies in this integrative review revealed that some participants held a more nuanced understanding of the trajectory of this illness. While some individuals first expressed a sense of inevitability about their diagnosis, they later came to understand diabetes as a condition shaped more by their own personal choices and behaviours (Barton et al., 2005; Dutton, 2018; Johnson et al., 2022; LaVallée & Howard, 2011; Pilon et al., 2019). This latter perspective highlighted a distinct shift over time from fatalism to self-determination.

Inevitability. A recurring theme across multiple studies was the perception of T2DM as an inevitable, uncontrollable, and ultimately fatal condition. Gregory et al. (1999) found that all participants had close family members affected by diabetes and had witnessed its devastating effects, reinforcing a belief that the illness was beyond the control of both individuals and healthcare providers. This belief fostered an even more pervasive sense of fatalism and fear. Similarly, Johnson et al. (2022) reported that participants not only expected to develop diabetes but also anticipated that they would experience severe complications, such as amputations, as part of their disease trajectory.

Among Nehinawin Cree participants, Bruyère and Garro (2000) observed a striking linguistic distinction that underscored this sense of helplessness. Instead of using *ponipimatsiw* ("he quits living"), which implies agency and intent, participants used *nipw* ("he dies"), a term typically reserved for animals. This shift in language reflects a broader cultural narrative that positions diabetes as something outside of human control. Kulhawy-Wibe et al. (2018) further described the emotional toll of this perception, with several participants describing diabetes as a "death sentence." Such fatalistic beliefs were accompanied by distress, denial, and withdrawal from care, complicating efforts to engage patients in self-management. Similarly, both Dutton (2018) and Pilon et al. (2019) found that a sense of inevitability was a persistent undercurrent throughout their interviews. Many participants viewed diabetes as genetically determined and unavoidable—an outcome they had long anticipated. These findings reveal that for many individuals who are Indigenous, diabetes is experienced not simply as a chronic illness but as a looming and inescapable threat.

Self-Determination. Barton et al. (2005) documented, that prior to participating in the study, one participant had experienced a shift in their understanding of T2DM—from viewing the illness as an inevitable fate to recognizing the role of personal agency in its management. This shift had been catalyzed by a peer living with diabetes who had encouraged the participant to take responsibility for their health by adhering to medication and monitoring dietary choices. As a result, the individual had relinquished their "sick person" identity and embraced a more proactive and empowered approach to living with the disease. Dutton (2018) also challenged the notion of fatalism and passive surrender to diabetes and emphasized that while the participants experienced distress, they did not passively surrender to their diagnosis and were able to adapt and embrace self-management in their own unique ways. A participant in LaVallée and

Howard's (2011) study described T2DM as a teaching tool rather than a death sentence and explained that diseases such as diabetes represented human beings out of balance with creation. Where previously, Elders would have made sure that everyone ate and that food distribution was balanced in accordance with the calendar of nature, this flow has been lost; however, all of the knowledge needed to take care of diabetes was still there for Indigenous peoples to use.

Participants in Pilon et al.'s (2019) study challenged the notion that diabetes was the result of fate, instead linking it to the disruption of traditional diet and lifestyle that had occurred with colonization. While it was recognized that there was no returning to the way things were, this was not viewed as a reason to accept the consequences of a poor diet and unhealthy lifestyle. One participant remarked, "So to me it's the way you live, just because your parents have diabetes doesn't mean you have to have diabetes...it's the way we live, I would say, it's up to you to prevent it" (Pilon et al., 2019, p. 261). A participant in Johnson et al.'s (2022) study expressed that Anishinaabe¹ people were being guided by the negative and destructive things they had been told, including that they had no control over diabetes. This was a sentiment that deeply influenced their approach to the disease yet what they needed to understand, based on the teachings of the ancestors, was a "sense of control and belief in oneself" (p.55)

Denial

Denial was identified as a significant barrier to diabetes self-management for participants. It was also cited as a limiting factor in study recruitment.

Part of the Process. Denial was a common coping response in the aftermath of a diabetes diagnosis. Dutton (2018), Hernandez et al. (1999) and Sherifali et al. (2012) found denial to be

¹ Also spelled *Anishnaabe*, *Anishinaabeg*, and *Anishnawbe*, depending on regional and community preference. Multiple spellings are used in this capstone to honour the diversity of languages, dialects, and identities within Anishinaabe nations.

part of the process of coming to terms with diabetes. Participants in Hernandez et al.'s (1999) study described denial as pushing the diagnosis out of their mind, avoiding taking medications and the daily responsibility of diabetes until they reached a turning point and recognized that diabetes was something they could no longer ignore (Hernandez et al., 1999). According to one participant in Sherifali et al.'s (2012) study, denial, accompanied by anger, depression and fear, was an initial barrier to reaching out for emotional support and assistance; however, in the words of a second participant, once you became able to move through denial, you were "halfway there" in terms of effective diabetes self-management (Sherifali et al., 2012, p. 179). Similarly, a participant in Dutton's (2018) study described their journey with diabetes as moving through denial to acceptance and effective diabetes self-management (p. 74).

Effect on Study Recruitment. Dutton (2018) and LaVallée and Howard (2011) reported denial of a diabetes diagnosis to be a factor that impeded the recruitment of participants into their respective studies. Due to high rates of denial, depression, and distress associated with diabetes diagnosis in Indigenous communities, the University of Toronto Health Sciences Research Ethics Board (REB) recommended limiting the recruitment of participants for Dutton's (2018) study to *voluntary only*. Non-voluntary recruitment, which would have involved approaching participants about their diabetes when they were not in a state of acceptance, was seen as compounding a participant's distress about their diagnosis. As a result, recruitment for that study occurred exclusively through participants reaching out to the researcher themselves and requesting to participate. While the author agreed with the decision ethically, it led to a smaller-than-ideal sample size. LaVallée and Howard (2011) found that 34.2% of participants (n = 138) in their study were categorized as being in denial, or having been in denial in the past, about having

diabetes. However, the authors also noted that, while this number was significant, the actual rates of denial were likely underrepresented.

Challenges to Primary Care Diabetes Management

Paternalism in Healthcare

Paternalism is present when those in a position of authority restrict the freedom and rights of those who are subordinate to them (Oxford English Dictionary, n.d.). Several studies reported paternalism as a barrier to feeling safe in the healthcare system, and likened PCPs to authority figures encountered in residential schools. Other studies emphasized PCP ignorance about power dynamics and the impact they had on caring for Indigenous patients.

Power Imbalance

According to several authors, PCPs embodied an approach to diabetes care that was reminiscent of authority figures in residential schools (Dutton, 2018; Pilon et al., 2019), characterized by control and unilateral decision-making (Barton, 2008). Participants felt judged and perceived as dirty and non-compliant by their provider and feared what would happen if they did not do what they were told (Dutton, 2018). One storyteller described being berated for bringing up the use of traditional medicines for diabetes and was told "take this and that's it" in reference to Western medicine, and "if you mix anything with it, that's your problem and not mine" (Pilon et al., 2019, p. 262). Another participant in the same study described that diabetes care options were either very limited or had been imposed upon them, while traditional medicines were forbidden.

Participants in Gregory et al.'s (1999) study described both distressing and positive interactions with healthcare providers. The negative experiences included being berated and threatened that death would occur if the rules of diabetes care were not followed. Positive

experiences consisted of being offered advice and information with permission to accept or reject it.

Lack of Contextual Understanding

A lack of awareness and appreciation among healthcare providers of power imbalances in the provider/patient relationship created a significant barrier to effective diabetes care for Indigenous patients (Dutton, 2018; Johnson et al., 2022; Kulhawy-Wibe et al., 2018). In addition to this disconnect, Indigenous patients felt that their lived experiences, particularly the lasting trauma of residential schools, were misunderstood or dismissed by those providing care (Pilon et al., 2019). Together, these dynamics contributed to a broader sense of mistrust and disconnection regarding clinical encounters.

Biomedical Diabetes Paradigm

According to participants in 5 of the 11 studies, PCPs viewed diabetes as being in individual bodies, as an exclusively physiologic phenomenon, with focus placed on blood glucose levels, medications monitoring, diet, and weight loss, whereas participants viewed diabetes through the lens of collective experience and historical processes (Barton, 2008; Dutton, 2018; Pilon et al., 2019; Bruyère & Garro, 2000). LaVallée and Howard (2011) found that 42.3% of participants completely or very much agreed that PCPs were too concerned with statistics and prescribing medications.

Non-Compliance

A recurring theme across the reviewed literature was the mischaracterization of Indigenous peoples as "non-compliant" within the context of diabetes care (Dutton, 2018; Gregory et al., 1999; Kulhawy-Wibe et al., 2018; Pilon et al., 2019). Participants described that this label was often applied when they did not adhere to prescribed regimens—such as

medication use, dietary restrictions, or weight loss—yet these instances of non-adherence occurred within coercive and prescriptive clinical encounters that left little room for dialogue or shared decision-making (Dutton, 2018; Pilon et al., 2019. The label of non-compliance was experienced not simply as a clinical judgment but as a continuation of colonial stereotypes rooted in the residential school era—stereotypes that painted Indigenous peoples as disobedient, dirty, or uneducated (Dutton, 2018). This stigmatizing perception discouraged many from seeking help or engaging in self-management practices, as it reinforced feelings of shame, powerlessness, and marginalization within the healthcare system (Kulhawy-Wibe et al., 2018).

Diabetes Education Delivery

Several authors found that the delivery of diabetes education by PCPs was either ineffective or non-existent, and many participants reported that their need for information to empower themselves to manage their own illness remained unmet. Others reported that when diabetes education was high quality, it helped them move from a place of ignorance and fear to feeling empowered to manage their diabetes.

In four of the 11 studies, ineffective communication emerged as a central barrier to diabetes education for Indigenous patients. Barton et al. (2005) and Gregory et al. (1999) both reported that participants experienced healthcare encounters as rushed, with limited explanation and little time for teaching and learning, which created barriers to learning about and understanding diabetes. One participant reported that healthcare providers often did not take the time to explain medical information thoroughly and this participant felt they were being perceived as unwilling to listen (Gregory et al., 1999). Hernandez et al. (1999) and Dutton (2018) noted persistent confusion and misunderstandings amongst participants despite repeated interactions with their provider.

In contrast, when providers took the time to explain the condition and treatment options in detail (Dutton, 2018), participants reported feeling less stress, reduced anxiety, and improved capacity for self-management. One participant valued the approach of their provider, where they felt able to maintain transparency about any skepticism and a decision to refuse pharmaceutical treatments, yet still access provider support (Dutton, 2018).

Knowledge gaps

Knowledge gaps about the cause of diabetes, the disease process itself, and how to manage it were widespread amongst study participants. Gregory et al. (1999) found that 11 of their 20 study participants could not explain the cause of diabetes and 14 of their 20 study participants were unable to explain what diabetes was. Hernandez et al. (1999) and Barton et al. (2005) found a lack of knowledge and tentativeness of understanding; individuals were unable to correlate symptoms of feeling unwell, a lack of energy, and poor eyesight to long-term diabetes complications such as heart and kidney damage (Barton et al., 2005). One participant in the Hernandez et al. (1999) study had been on insulin for 6 years yet monitored their blood sugars and took insulin in a way that was incongruent with effective and safe diabetes management.

Participants in Dutton's (2018) study described how, without the health literacy to understand diabetes, individuals fell through the cracks. One participant reported that several close friends who admitted not understanding their illness, and who simply took whatever pills the PCP prescribed, had died because they did not know how to navigate the healthcare system or ask for things that they needed. Kulhawy-Wibe et al. (2018) described diabetes knowledge gaps as a major source of stress for individuals. While there was a desire to do something, participants were paralyzed by not knowing what to do and not feeling empowered to act (Kulhawy-Wibe et al., 2018).

Facilitators to Diabetes Self-Management

Traditional Healing Practices

Traditional medicines and knowledge played a significant role in healing and care of diabetes for Indigenous peoples and was viewed as a vital component that should have been integrated into their treatment, providing cultural relevance, holistic support, empowerment and a way to address the historical and social context influencing health (Johnson et al., 2022; LaVallée & Howard, 2011; Pilon et al., 2019; Sherifali et al., 2012). Traditional healing practices to address diabetes included traditional foods and medicinal plants (Barton et al., 2005; Bruyère & Garro, 2000; Dutton, 2018; LaVallée & Howard, 2011), and ceremonial practices such as healing circles, smudging, and sweat lodges, all used to feel calmer and manage diabetes (Barton et al., 2005; Johnson et al., 2022; LaVallée & Howard, 2011). Elders were sought to provide healing, understanding, and advice about living with diabetes (Gregory et al., 1999; Johnson et al., 2022). Healing practices encompassed a wide array of beliefs, ceremonies, and relational systems rooted in worldviews where wellness arises from balance—physical, emotional, spiritual, and communal. Johnson et al. (2022) highlighted the importance of the ceremonies that were described by Anishinaabe participants in Sioux Lookout, Ontario, such as smudging and sweat lodges, which are guided by spiritual protocols and involve sacred medicines like sage and sweetgrass. These practices serve to symbolically and spiritually cleanse negative energies and restore kindness and relational harmony, reinforcing motivation for self-care and holistic wellbeing.

Traditional medicines, referred to as *ininiwimuskiki* in the Nehinawin Cree language, are vital expressions of Indigenous healing knowledge. Bruyère and Garro (2000) explained that, for many Indigenous people, healing is considered to be inseparable from spirituality and the

sacredness of all life. Diabetes, in this context, is not merely a physiological condition but a disruption in spiritual and communal balance, requiring responses that are holistic, culturally grounded, and spiritually engaged. Cultural activities such as berry picking and fishing are also recognized as meaningful components of wellness. Barton et al. (2005) and Barton (2008a) describe how these land-based practices are used to facilitate physical activity but also to strengthen cultural identity and self-determination.

There were significant challenges associated with using traditional medicine due to knowledge being lost (Bruyère & Garro, 2000), lack of access to those medicines, particularly in urban settings (Gregory et al., 1999; LaVallée & Howard, 2011), lack of experience in seeking help from traditional healers or Elders for diabetes (LaVallée & Howard, 2011), and Western institutions undermining traditional medicines and sacred knowledge of Indigenous peoples (Johnson et al, 2022).

Integrate Culture with Biomedicine

Several authors found that when biomedical concepts could align with existing cultural frameworks, diabetes self-management was successful and led to wellness amongst study participants. Through the analysis of study data translated from Nehinawin (Cree language), Bruyère and Garro (2000) gained a nuanced understanding of the ways in which Western biomedical knowledge of T2DM could be integrated into existing cultural frameworks and patterns of Nehinaw thought. For example, the biomedical understanding that exercise helps to metabolize sugar so that it does not become "stuck" somewhere in the body and cause damage is congruent with the Nehinaw framework that "ancestors worked hard," giving it relevance. Incorporating traditional foods and boiling them rather than frying was strongly accepted, as this was what the ancestors did.

Barton et al. (2005) found that outdoor activities such as fishing or berry picking for exercise led to significant amounts of weight loss for patients. While Barton (2008a) found that participants viewed medical care as the most appropriate treatment for diabetes, they also used traditional medicinal, spiritual, and ceremonial purification practices. While aches, pains, fatigue and feeling unwell were treated with Western medicines, they were also treated with traditional medicine in the form of traditional foods, spiritual and ceremonial practices, and healing circles. Combining these modalities led to finding harmony between being diabetic, being Aboriginal, and being well.

Peer Support

Engaging with other individuals living with diabetes through healing or sharing circles was consistently identified as a meaningful and supportive practice. Six of the 11 studies emphasized that talking circles function as culturally resonant spaces that promote diabetes management by facilitating health education, emotional connection, lifestyle change, and community engagement (Barton et al., 2005; Gregory et al., 1999; Harnandez et al., 1999; Johnson et al., 2022; LaVallée & Howard, 2011; Sherifali et al., 2012). Johnson et al. (2022) highlighted that receiving diabetes support within a culturally safe environment helped participants restore their sense of balance and control, reconnect with ancestral understandings of health, and foster kindness and positive energy. Similarly, LaVallée and Howard (2011) reported that 75% of study participants found sharing circles to be "completely" or "very much" helpful. These gatherings combined ceremony and cultural teachings with diabetes education, which many described as transformative. Participants reported feelings of empowerment, hope, and support, along with a reduction in fear and frustration, and gained practical strategies for self-management.

Barton et al. (2005) found that healing circles provided a space where individuals could seek the wisdom and experience of others living with diabetes. In Sherifali et al.'s (2012) study, a participant who attended four culturally grounded sharing circles featuring smudging, prayer, traditional teachings, and social connection reflected that such gatherings were not only supportive but could serve as a foundation for community-based health initiatives involving healthy eating and physical activity. Likewise, participants in Gregory et al.'s (1999) study valued learning from other Indigenous people managing diabetes, while Hernandez et al. (1999) noted that peer learning and role modelling reflected a traditional First Nations approach to knowledge sharing and community care.

Chapter 5: Discussion

The studies included in this integrative review focused on three main themes: the psychological impact of diabetes, challenges of primary care diabetes management, and facilitators to diabetes self-management. This chapter will discuss the significance of the findings in the context of primary care provision and discuss ways to include them in practice, education, research, and policy.

Implications for Practice: Addressing Colonial Legacies in Indigenous Diabetes Care

While colonization is often viewed as a historical event, PCPs must recognize that its structures and impacts remain deeply embedded in today's healthcare system. These ongoing colonial influences continue to shape the experiences of Indigenous peoples, including their access to and engagement with diabetes care. By acknowledging both the historical and present-day effects of colonization, PCPs can better understand the systemic barriers Indigenous patients face. This awareness can guide providers to use their sphere of influence to support more effective diabetes self-management. By using a more nuanced approach to understanding patient history, a commitment to relational practice, and shifting perspective to reimagine what meaningful diabetes care can look like, PCPs can collaborate with Indigenous patients to co-create pathways to wellness, ones that promote health rather than manage decline.

Recognizing the Enduring Impact of History

Recognizing the enduring impact of colonization is essential to understanding current challenges in diabetes care for Indigenous patients. Findings revealed that many PCPs lacked awareness of how profoundly colonial histories continue to shape Indigenous experiences of health care (Johnson et al., 202). This lack of historical consciousness often manifested in clinical interactions that unknowingly reproduced colonial dynamics. Providers frequently

adopted prescriptive and authoritative communication styles, presenting diabetes management as a rigid set of rules rather than a collaborative process. Medication regimens were imposed with minimal explanation, and expectations were enforced with implicit or explicit threats, leaving patients feeling silenced, disrespected, and powerless (Barton, 2008; Dutton, 2018; Gregory et al., 1999; Pilon et al., 2019). These encounters contributed to a deep sense of mistrust and emotional withdrawal.

Even when providers acted with good intentions, the lingering legacy of colonialism created barriers to open dialogue and trust. Many Indigenous patients bring to each clinical encounter an acute awareness of the historical power imbalances between themselves and representatives of Western institutions, including health care professionals. These power differentials, rooted in histories of cultural suppression, forced assimilation, and systemic exclusion, continue to shape perceptions of safety and engagement in care (Crowshoe et al., 2019). Without a deliberate effort to acknowledge and address these dynamics, therapeutic relationships remain compromised, hindering effective, long-term diabetes management.

Towle et al. (2006) emphasize the importance of expanding the concept of "patient history" beyond biomedical metrics. In the context of diabetes, this means a departure from exclusive focus on measures such as HgA1c levels and medication adherence. Recognizing patients' personal histories within the broader context of collective historical trauma offers a more holistic understanding of their diabetes health behaviours. Though rarely discussed openly in clinical spaces, these historical experiences continue to inform how Indigenous patients interpret provider behaviour and engage with medical advice (Kirmayer et al., 2003).

Building relational trust requires moving beyond disease-focused frameworks for diabetes and instead viewing the patient as a whole person. This involves understanding patients'

stories not only in the context of illness but within the continuity of their lived and inherited experiences (Crowshoe et al., 2019). When providers make the effort to listen deeply and engage authentically, patients are more likely to feel seen, respected, and supported (Towle et al., 2006). In turn, this relational approach can begin to counteract the effects of historical trauma, creating space for healing, empowerment, and meaningful collaboration in diabetes care (Crowshoe et al., 2019; Towle et al., 2006). Exploring patients' perspectives on previous adverse experiences and centring their priorities within the plan of diabetes care fosters an effective health care relationship where a space to discuss issues such as denial and fear can exist.

Relationship as Medicine

Several studies have shown that relational approaches grounded in humility, empathy, and respect can rebuild trust and foster meaningful engagement in diabetes care. When PCPs took a genuine interest in their patients' lives and approached with humility rather than a prescriptive or top-down approach, relationships became therapeutic (Jacklin et al., 2017). One participant, for example, felt honoured when a provider admitted their limited understanding of diabetes and asked to be taught (Jacklin et al., 2017). Relational gestures—such as calling patients at home or involving family members in diabetes care planning—were also seen as culturally resonant expressions of empathy. These practices were closely linked to increased patient trust and improved perceptions of the healthcare system (Jacklin et al., 2017). Taking less professional distance and objectivity to share aspects about oneself to enact a more reciprocal relationship with patients (Crowshoe et al., 2019). Relationships develop over long periods of time and add depth to the PCP-patient interaction (Gibson et al., 2015). By understanding the PCP-patient relationship as a form of medicine, as described by Walker and Behn-Smith (2020), healthcare encounters can shift from being transactional to more meaningful and healing. This

relationality is not a soft add-on to biomedical care—it is the foundation upon which sustainable diabetes self-management is built. It is an approach to care that may be particularly valuable in addressing the psychological impacts of diabetes, especially among populations affected by systemic and historical trauma.

Diabetes Education

Rushed clinical encounters that allowed no time for patients to ask questions or absorb information from their PCPs were identified as a significant barrier to effective diabetes education (Barton et al., 2005; Gregory et al., 1999). This lack of time and engagement contributed to ongoing confusion and psychological distress, as patients remained uncertain about the etiology of diabetes and the strategies required for its effective management (Dutton, 2018; Hernandez et al., 1999; Kulhawy-Wibe et al., 2018). Towle et al. (2006) emphasize that time is an essential enabler of trust. Without adequate time, appointments feel rushed or transactional, leaving Indigenous patients to feel dismissed or unseen, reinforcing feelings of marginalization. Approaching diabetes education at a slower pace, in a more relational way, creates space for patients to process information, integrate it into their lived experience, and ask questions to confirm their understanding (Crowshoe et al., 2018b; Gibson et al., 2015). In the context of diabetes education, devoting time to patient relationships, rather than focusing exclusively on biometric targets, is recommended by the Diabetes Canada Clinical Practice Guidelines Expert Committee. The committee asserts that poor success in diabetes selfmanagement reflects health service limitations, where care is approached in a way that is socially and culturally irrelevant to the context of Indigenous peoples (Crowshoe et al., 2018b).

Non-Compliance: Indigenous Resistance in Diabetes Care

The findings from the selected studies challenge the dominant narrative of noncompliance as a patient deficit and instead call for a re-evaluation of how historical trauma
shapes health behaviours. Behaviours often labelled as non-compliance, such as missed
appointments or selective engagement, can be viewed as feedback, highlighting how the system
itself continues to fall short in providing culturally responsive, equitable care. These findings
underscore the enduring influence of colonial remnants in diabetes care and their profound
implications for clinical practice. The persistent framing of Indigenous patients as non-compliant
reflects a colonial logic that reduces complex health behaviours to individual failure,
disregarding the structural and historical forces that shape them (Crowshoe et al., 2018; Dutton,
2018). Rather than interpreting non-adherence as a lack of responsibility or motivation, it should
be understood as a protective or necessary response to a healthcare system that continues to
marginalize Indigenous voices and exclude Indigenous knowledge systems.

Clinicians are called to develop critical consciousness—a process of sustained self-reflection that involves recognizing how personal biases, institutional norms, and the legacy of colonialism may influence interactions with patients (Kumagai & Lypson, 2009). This requires shifting the clinical gaze away from reductive notions of "non-compliance" and toward an understanding of how structural factors such as racism, poverty, intergenerational trauma, and the ongoing impacts of colonial control inform health behaviours and access to care. By acknowledging and addressing these broader determinants, providers can work to redistribute power within the clinical relationship, which in turn fosters a culturally safe, relational approach to diabetes management. This shift not only enhances trust and engagement but is essential to advancing equity in diabetes care. Providers must frame diabetes care as a space for

empowerment rather than compliance. Such actions are essential to challenging the colonial narratives that render diabetes as inevitable and Indigenous patients as passive recipients of care (Crowshoe et al., 2018; Jacklin et al., 2017).

Integrating Traditional Medicine

Findings from the reviewed studies underscore the importance of integrating Indigenous cultural frameworks with biomedical approaches as key facilitators of effective diabetes selfmanagement (Barton et al., 2005; Barton, 2008; Bruyère & Garro, 2000; Dutton, 2018; Gregory et al., 1999; Hernandez et al., 1999; Johnson et al., 2022; LaVallée & Howard, 2011; Pilon et al., 2019; Sherifali et al., 2012). A notable example of such integration is the Aboriginal Diabetes Wellness Program (ADWP), which has been operated by the Capital Health Regional Authority in Edmonton, Alberta, since 1995 (Toth et al., 2005). The program was established through collaborative partnerships involving Indigenous communities, governmental bodies, academic researchers, and local healthcare providers, with guidance from Indigenous Elders. The ADWP combines conventional biomedical care with traditional Indigenous healing practices, guided by principles of cultural respect and inclusion. Its design reflects a deliberate effort to contextualize biomedical information within culturally relevant frameworks, thereby enhancing accessibility, engagement, and effectiveness for Indigenous participants. For instance, nutrition and lifestyle counselling are adapted to include traditional foods such as wild game, Bannock, roots, and berries, alongside culturally meaningful activities like hunting and dancing. Additionally, the program is tailored to address the unique social and geographic contexts of Indigenous peoples living in both rural and urban settings, acknowledging and responding to the diverse realities that shape their health experience (Toth et al., 2005).

The integration of Indigenous knowledge systems with biomedical models in diabetes care, such as ADWP, has important implications for clinical practice. Clinicians should prioritize collaborative partnerships with Indigenous communities in program development and service delivery, ensuring that interventions are co-designed and locally relevant. Incorporating Indigenous ways of knowing into clinical encounters not only improves health outcomes but also supports broader efforts toward reconciliation and the decolonization of health care systems.

Talking Circles

In the reviewed studies, connecting with other individuals living with diabetes was identified as a helpful strategy (Barton et al., 2005; Gregory et al., 1999; Harnandez et al., 1999; Johnson et al., 2022; LaVallée & Howard, 2011; Sherifali et al., 2012). Talking circles represent a culturally grounded and effective approach to diabetes management among Indigenous patients. They have been found to be an effective platform for knowledge sharing, emotional support, and community-driven lifestyle change, while also fostering trust and connection. Integrating talking circles into diabetes care may enhance patient engagement and contribute to improved health outcomes.

In studies conducted by Struthers et al. (2003) and Toth et al. (2005) talking circles were found to be an effective form of support, providing a culturally safe and effective approach to diabetes care for Indigenous communities through sharing knowledge and experiences by participants, providing a space for emotional support, and serving as a catalyst for participants to make meaningful lifestyle changes, and community empowerment (Struthers et al., 2003; Toth et al., 2005). Talking circles were found to provide a culturally grounded space where individuals receive clear, relevant, and up-to-date information about type 2 diabetes, often filling a gap left by previous encounters with health services (Struthers et al., 2003). Through storytelling and

peer dialogue, participants could build their understanding of diabetes prevention, management, and the physical impacts of the disease in ways that are both accessible and meaningful (Struthers et al., 2003; Toth et al., 2005).

Beyond knowledge transmission, talking circles function as a source of emotional and psychological support (Struthers et al., 2003; Toth et al., 2005). They offer a safe environment for participants to express grief, fear, anger, and shame related to their diagnosis, emotions that are often silenced in clinical settings. This open sharing fosters a sense of trust, belonging, and mutual support, contributing to participants' emotional well-being and a sense of not being alone in their experiences (Struthers et al., 2003; Toth et al., 2005).

Importantly, talking circles have been shown to catalyze meaningful lifestyle changes. Participants report improvements in self-management behaviours, such as incorporating traditional and healthier foods, increasing physical activity, and becoming more conscious of nutrition and stress management. Some have reported weight loss, improved blood sugar control, and enhanced overall well-being because of what they learned and experienced in the circles (Struthers et al., 2003; Toth et al., 2005). These outcomes demonstrate the potential of talking circles to support diabetes self-management in culturally relevant ways.

Furthermore, the collective nature of talking circles promotes community empowerment by facilitating shared understanding, collaborative problem-solving, and culturally aligned decision-making. Rooted in traditional Indigenous knowledge systems, the circles support a holistic view of health that integrates the physical, emotional, spiritual, and social dimensions of wellness (Struthers et al., 2003; Toth et al., 2005). They may also incorporate traditional healing practices, such as prayer or consultation with Elders and medicine people, thereby restoring balance and cultural continuity in care (Struthers et al., 2003; Toth et al., 2005).

Talking circles represent a powerful and practical strategy to support Indigenous patients who are living with diabetes. They illustrate how an Indigenous led, culturally based strategy for diabetes self-management can improve individual diabetes outcomes at the individual and community levels. They represent a way to give agency to Indigenous-led healing modalities... decolonizing approach to diabetes self-management and are a paradigm for change that PCPs should be aware of. Primary care providers can support diabetes self-management for patients who are Indigenous by expanding their understanding to recognize that Indigenous-led approaches as effective and meaningful. Referring patients to talking circles for diabetes self-management or supporting the concept in collaboration with Indigenous communities with culture and providing a needed antidote to colonization trauma-informed care, and reconciliation. As such, they represent a powerful, practical strategy for supporting Indigenous patients living with or at risk of diabetes.

Implications for Education

Experiential Learning

Towle et al. (2006) found that experiential learning, such as listening directly to patients' lived experiences, needs to be taught as a core skill in the context of biomedical education. This type of learning helps future PCPs build trust and improve communication with Indigenous patients, especially when care is shaped by the impacts of historical trauma like residential schools. The authors emphasized that increasing lectures on colonial history alone is not enough; instead, teaching relational, experience-based approaches is essential for providing culturally safe care, particularly in managing chronic conditions like diabetes (Towle et al., 2006).

Educational outcomes related to diabetes management for future PCPs must be oriented to valuing outcomes in diabetes care that extend beyond biometric indicators such as blood

glucose levels or HgA1c. Relational outcomes—such as trust, connection, and mutual understanding—are critical, particularly when working with Indigenous patients, for whom historical and cultural contexts deeply influence engagement with care. The Southcentral Foundation's (SCF) Nuka System of Care offers a transformative model of chronic disease management in which relationship is regarded as the primary outcome of care (Southcentral Foundation [SCF], n.d.). In this model, patients are referred to as "customer-owners," underscoring shared responsibility, mutual respect, and self-determination. Unlike conventional models that emphasize measurable clinical targets, the Nuka model deliberately de-centers biometric outcomes in favour of building and sustaining relationships as the foundation for long-term health and healing in diabetes care (Gottlieb et al., 2008).

This model has important implications for how PCPs are trained with respect to providing diabetes care. Over 90% of SCF customer-owners reported that having a strong relationship with their provider improves their health, and those with stronger provider relationships experience better outcomes. SCF has surpassed the 90th percentile in Healthcare Effectiveness Data and Information Set (HEDIS) measures for diabetes care, including annual testing and HgA1c control as well as decreased emergency department use and increased satisfaction with care (Gottlieb et al., 2008; SCF, n.d.). These findings emphasize the need to reframe education for PCPs to centre on relational competence as an essential component of effective healthcare delivery.

Traditional Medicine and Decolonizing Diabetes in Primary Care

In the educational milieu, PCPs must be taught to value and honour traditional medicines, as a gesture of reconnection to traditional ways. Learning about Indigenous traditional medicines and healing practices can help future PCPs understand their value and legitimacy as complete

systems of care, and use their knowledge to be a force of re-connection to culture (Corntassel, 2012) rather than continue to approach diabetes care in a colonial way. By valuing and integrating traditional knowledge in their approach, PCPs can offer a more relevant, meaningful and effective approach to diabetes care (Obomsawin, 2007). Teaching future PCPs about traditional medicines is therefore not optional or ancillary—it is a matter of ethical practice, reconciliation, and health equity. It fosters a decolonizing approach that moves beyond the dominance of Western biomedical frameworks and supports Indigenous self-determination in health care.

Additionally, this learning ensures that clinical practice aligns with broader ethical obligations of the healthcare system. Beyond individual clinical interactions, education for PCPs must prepare them to uphold commitments made in the Truth and Reconciliation Commission's (TRC, 2015) Calls to Action, particularly Call to Action #22, which urges all those who work in healthcare to recognize the value of Indigenous healing practices and use them in treatment when requested by Indigenous patients.

Implications for Research

Considerations for Ethical and Culturally Appropriate Research with Indigenous Peoples

The included studies reflect a broad range of ethical and culturally appropriate fulfillment of research standards with Indigenous Peoples. In the Canadian context, frameworks such as the Ownership, Control, Access, and Possession (OCAP®) principles and Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2) are foundational (First Nations Information Governance Centre [FNIGC], 2025; Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], and Social Sciences and Humanities Research Council of Canada [SSHRC], 2018).

These guidelines recognize and respond to the historical and ongoing harms caused by exploitative and extractive research practices. They each provide a distinct yet complementary framework that emphasizes respect for Indigenous governance, community engagement, and the recognition of Indigenous knowledge systems. Complementing these frameworks, Community-Based Participatory Research (CBPR) has emerged as a valuable methodological approach that aligns closely with them. CBPR promotes collaboration, shared decision-making, and mutual benefit by involving communities as active partners in all stages of the research process (Castleden et al., 2012; Jagosh et al., 2012). Together, these frameworks and approaches contribute to ethical research practices that are grounded in relational accountability, cultural safety, and Indigenous self-determination (see Appendix 3).

OCAP®

The OCAP® principles constitute a community-driven framework and standard developed by the FNIGC to establish a First Nations-led standard for ethical research (FNIGC, 2025). Specifically designed for First Nations communities, organizations, and researchers, OCAP® represents the ideal benchmark for research that respects Indigenous data sovereignty and self-determination (FNIGC, 2025; Konczi & Bill, 2024; LaVallée & Howard, 2011). Although rooted in a First Nations context, the framework is increasingly recognized as relevant and applicable to research involving Inuit, Métis, and other Indigenous Peoples across Canada (Schnarch, 2004; Wright et al., 2023).

OCAP® addresses the long-standing power imbalances in research, in which Indigenous Peoples are often over-researched, misrepresented, and subjected to harmful or culturally inappropriate methodologies. In many cases, sensitive research data was released without consent, leading to further stigma and mistrust (Dutton, 2018). The OCAP® principles respond

to this legacy by affirming that Indigenous communities own the data collected from them and hold proprietary rights over how it is used and stored (Konczi & Bill, 2024; LaVallée & Howard, 2011). Communities have the right to control all aspects of the research process, from determining the purpose and design of studies to selecting researchers and governing data collection, analysis, and dissemination (FNIGC, 2025; Konczi & Bill, 2024; LaVallée & Howard, 2011). OCAP® ensures that communities have access to data and findings in ways that are meaningful and accessible, while the principle of possession emphasizes that data should be physically housed within the community or an Indigenous organization of their choosing (FNIGC, 2025; Konczi & Bill, 2024). In the context of diabetes self-management research, applying OCAP® offers a pathway to restore trust, center Indigenous leadership, and ensure that research is conducted in respectful, reciprocal, and culturally-grounded ways.

Highest Ethical and Culturally Appropriate Standards

Two studies included in this review (Dutton, 2018; LaVallée & Howard, 2011) describe explicit adherence to OCAP® guidelines. Dutton (2018) reports that the study's design, methodology, and researcher conduct were guided by OCAP® principles, with a consistent emphasis on community control and respect for local autonomy throughout the research process. The study was proposed to the leadership of three local Indigenous governments in Fort Smith, Northwest Territories – two First Nations and one Métis Council – who approved to proceed without objections in keeping with establishing some degree of community control. The research agreement with study participants clearly outlined limitations on data control, noting that once stories were shared, they became part of the public domain and could not be withdrawn, even if the participant later chose to leave the study. Anonymized stories were to be retained in the community for up to seven years to support future community-led research, after which they

would be destroyed. The study did not provide specific information about long-term community ownership or data governance.

LaVallée and Howard (2011) demonstrated strong adherence to OCAP® principles by centring Anishnawbe Health Toronto (AHT) as the lead authority in the research process. AHT exercised full ownership and control over the project, including researcher selection, administration, and oversight of how data were used and shared. A formal agreement was created to recognize AHT as the sole owner of the data and grant them final review and approval of project documents. Access and possession were also upheld through active community involvement in data interpretation and dissemination, with findings shared directly with participants, the Governing Circle, and key community members, ensuring transparency, accountability, and cultural relevance throughout the research (Dutton, 2018).

The absence of these principles in much of the literature underscores ongoing issues of data extraction and limited Indigenous oversight in diabetes-related research. This gap highlights the need for future scholarship to uphold Indigenous data sovereignty and prioritize community-led methodologies that are grounded in respect, accountability, and relational ethics (FNIGC, 2020).

Tri-Council Policy Statement

Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2) provides specific guidance for conducting research involving First Nations, Inuit, and Métis peoples in Canada. It emphasizes the importance of community engagement, respect for Indigenous governance, and the inclusion of Indigenous perspectives throughout the research process. Furthermore, it highlights the ethical imperative of mutual respect, culturally relevant practices, and the recognition of Indigenous knowledge systems. Researchers are urged

to ensure that their work benefits the community, supports capacity building, and respects Indigenous rights to data ownership and control – all principles that are aligned with OCAP®. Rather than approaching Indigenous peoples as subjects of research, TCPS 2 advocates for partnership-based methodologies that reflect Indigenous self-determination and uphold ethical integrity (CIHR, NSERC, & SSHRC, 2022).

Three studies included in this review demonstrated strong adherence to the relevant principles of TCPS 2 (Dutton, 2018; LaVallée & Howard, 2011; Pilon et al., 2019). Dutton (2018) outlines explicitly how the research protocol for that study was approved by the University of Toronto Health Sciences REB and that a research license had been obtained from the Northwest Territories government. She extensively discussed her positionality as a non-Indigenous researcher and described how she maintained transparency and reflexivity while working with an Indigenous community, addressing power imbalances, and engaging consistently with community advisors.

Member Checks

Member checks, also referred to as participant or respondent validation, are a critical component of qualitative research, used to enhance the credibility and trustworthiness of findings. This process involves returning preliminary interpretations, themes, or results to participants, allowing them to confirm, clarify, or challenge how their experiences and perspectives have been represented (Lockwood et al., 2015). By inviting participants to reflect on the accuracy of data interpretation, member checks not only strengthen methodological rigour but also promote relational accountability in the research process.

This practice is especially important in research involving Indigenous communities, where ethical imperatives extend beyond standard academic protocols to include principles of

reciprocity, respect, and shared authority. Omitting member checks risks replicating colonial power structures, in which researchers retain exclusive control over the narrative and analysis, denying participants agency and voice in shaping how their knowledge is represented and interpreted. Such hierarchical dynamics are inconsistent with ethical standards for conducting research in Indigenous contexts and undermine efforts to support self-determination and relational accountability in knowledge production.

The use of member checking and collaborative validation techniques varies across the included studies. This has important implications for the credibility and cultural appropriateness of the research. Several authors actively engaged in member checking or similar methods to validate their findings and ensure the alignment of their results with community perspectives. Dutton (2018) engaged community advisors in group analysis sessions, where transcripts were shared and discussed to refine themes and insights. This process allowed participants to guide the analysis and apply theoretical concepts to the lived experiences of the community. Similarly, Hernandez et al. (1999) conducted focus groups with study participants to verify findings and ensure that the grounded theory met criteria for fit, work, and relevance. They also presented a verbal report of the findings to the Band Council, ensuring further community validation. Johnson et al. (2022) used member checking of written interview summaries to confirm the reliability of their research. Additionally, Anishinaabe elders and traditional healers were deeply involved in the study, providing explicit permission for publication, approving the final draft, and participating in the authorship process. This collaborative approach ensured that the research maintained cultural accuracy and relevance. Lavallée and Howard (2011) similarly adopted a collaborative approach by interpreting results with a diverse group of stakeholders, including research participants and community leaders. They shared cluster maps and findings with these

groups for feedback, ensuring that the research process and outcomes were grounded in community knowledge. Sherifali et al. (2012) formalized their member checking process by presenting key findings to participants of the sharing circles, who were given the opportunity to confirm the data's accuracy and offer additional insights. This promoted data credibility and helped ensure that the participants' voices were reflected in the findings.

However, some studies did not mention or use member checking explicitly, raising concerns about the depth of participant involvement in the analytical process. For instance, Barton (2005) and Barton (2008) did not refer to member checking, even though the latter emphasized a narrative inquiry approach involving "co-participation and co-construction" of stories. Similarly, Bruyère and Garro (2000) conducted interviews in the Cree language but did not specify the use of member checks for data validation. Kulhawy-Wibe et al. (2018) used inductive thematic analysis but did not mention member checking or participant validation. Pilon et al. (2019) explicitly stated that participants did not engage in the analytical process, though the researchers planned to return to the community later for input on the findings.

Lastly, Gregory et al. (1999) justify the omission of member checks through an explicit description of how data collection was carried out by a research assistant who was diabetic, identified as "Aboriginal," and worked in healthcare. The authors justify this choice by positioning the research assistant's diagnosis, identity and background as qualifications that replace the need for member checking. The research assistant was viewed as a representative of all "Aboriginals", which creates a dichotomy between the white authors and the "Aboriginal" community.

These differences in methodology underscore the importance of explicitly involving participants in the research process, especially in qualitative studies with Indigenous

communities. Member checking serves as a critical tool for enhancing the trustworthiness of research and ensuring that findings reflect the perspectives and experiences of those being studied. Assessing the presence or absence of this process offers insight into the methodological and ethical integrity of the research in the context of research with Indigenous people and diabetes self-management.

Chapter 6: Conclusion

This integrative review has critically examined the complex landscape of T2DM amongst Indigenous populations in Canada. It centres the understanding that the disproportionate burden of T2DM is not merely a biological phenomenon but a deeply entrenched legacy of colonial processes and structures that have systematically pathologized Indigenous peoples and marginalized their sophisticated and deeply integrated knowledge systems. The prevailing Western biomedical paradigm, with its focus on biometric outcomes and individual focus on "non-compliance," has proven ineffective and often harmful, failing to address the interconnected historical, social, and spiritual facets of Indigenous health experiences.

The findings revealed that, for many individuals who are Indigenous, a T2DM diagnosis is experienced as a profound psychological and relational disruption, deeply shaped by intergenerational trauma and ongoing systemic inequities that frequently manifest as a sense of fatalism and denial. Within primary care, challenges such as paternalistic approaches, a lack of contextual understanding of Indigenous lived experiences, and the mischaracterization of "noncompliance" continue to perpetuate colonial dynamics, hindering effective diabetes management and fostering mistrust.

Importantly, this integrative review illuminates powerful facilitators for healing and effective diabetes self-management that emerge from Indigenous ways of knowing and being. The integration of a diversity of traditional healing practices, including traditional foods, medicinal plants, and ceremonial practices like smudging and sweat lodges, was consistently identified as vital for holistic well-being and culturally relevant care. Furthermore, peer support, particularly through talking circles, emerged as a profoundly effective and culturally resonant

strategy for health education, emotional connection, and community-driven lifestyle change, fostering trust and a sense of collective empowerment.

The implications of this review are far-reaching across practice, education, and research. For practice, PCPs are called to move beyond passive oversight to active leadership in decolonizing diabetes care. This requires a fundamental shift from an authoritarian, compliance-based approach to one grounded in building relational trust, humility, and empathy. PCPs must recognize and address the enduring legacies of colonialism, understand "non-compliance" as a potential form of Indigenous resistance or a reflection of systemic failings, and proactively support the integration of traditional Indigenous medicines and community-led modalities like talking circles into care plans.

For education, it is imperative to train future PCPs in experiential learning and relational competence, valuing outcomes that extend beyond mere biometric indicators to encompass trust, connection, and mutual understanding. Educational curricula must instill a deep respect for and understanding of traditional Indigenous medicines, aligning with the TRC's (2015) Calls to Action, specifically Call to Action #22, which advocates for recognizing and using Indigenous healing practices.

For research, strict adherence to Indigenous data sovereignty principles is non-negotiable. Frameworks such as OCAP® and Chapter 9 of the TCPS 2 are foundational for ensuring research is culturally appropriate, beneficial, and genuinely community-led (FNIGC, 2025; TRC, 2015). This commitment is essential to counter the historical harms of extractive research and to foster respectful, reciprocal, and ethically sound knowledge production that truly serves Indigenous communities.

In conclusion, transforming diabetes care for Indigenous peoples requires a profound paradigm shift from an individualistic, compliance-driven model to a holistic, relational, and culturally grounded approach. By embracing Indigenous ways of knowing and being, fostering genuine partnerships, and actively working to dismantle colonial structures within healthcare, PCPs can move from merely managing a disease to supporting the revitalization of Indigenous health and well-being in a good way. This journey is not just about clinical outcomes; it is about reconciliation, reclaiming agency, and fostering a future in which Indigenous peoples can thrive in health and spirit.

References

- Allan, B., & Smylie, J. (2015). First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Wellesley Institute.

 https://www.wellesleyinstitute.com/publications/first-peoples-second-class-treatment/
- American Diabetes Association. (2024). Standards of medical care in diabetes—2024. *Diabetes Care*, 47(Suppl. 1), S1–S112. https://doi.org/10.2337/dc24-S001
- Browne, A. J., Varcoe, C., Lavoie, J., Smye, V., Wong, S. T., Krause, M., Tu, D., Godwin, O., Khan, K., & Fridkin, A. (2016). Enhancing health care equity with Indigenous populations: Evidence-based strategies from an ethnographic study. *BMC Health Services Research*, 16(1), Article 544. https://doi.org/10.1186/s12913-016-1707-9
- Barton, S. S., Anderson, N., & Thommasen, H. V. (2005). The diabetes experiences of Aboriginal people living in a rural Canadian community. *Australian Journal of Rural Health*, 13(4), 242–246. https://doi.org/10.1111/j.1440-1584.2005.00709.x
- Barton, S. S. (2008a). Using narrative inquiry to elicit diabetes self-care experience in an Aboriginal population in Canada. *Canadian Journal of Nursing Research*, 40(3), 16-36. https://cjnr.archive.mcgill.ca/article/view/2136
- Barton, S. S. (2008b). Discovering the literature on Aboriginal diabetes in Canada: A focus on holistic methodologies. *Canadian Journal of Nursing Research*, 40(4), 26-54. https://cjnr.archive.mcgill.ca/article/view/2152
- Bruyère, J., & Garro, L. C. (2000). "He travels in the body": Nehinaw (Cree) understandings of diabetes. *The Canadian Nurse*, 96(6), 25-28.

 https://www.proquest.com/docview/232048769?fromopenview=true&pq-
 origsite=gscholar&sourcetype=Scholarly%20Journals

- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2022). *Tri-Council policy statement: Ethical conduct for research involving humans. Chapter 9:**Research involving the First Nations, Inuit and Métis peoples of Canada.

 https://ethics.gc.ca/eng/tcps2-eptc2 2022 chapter9-chapitre9.html
- Castleden, H., Morgan, V. S., & Lamb, C. (2012). "I spent the first year drinking tea": Exploring Canadian university researchers' perspectives on community-based participatory research involving Indigenous peoples. *The Canadian Geographer*, *56*(2), 160–179.

 https://doi.org/10.1111/j.1541-0064.2012.00432.x
- Centers for Disease Control and Prevention. (2023). National diabetes education program:

 Diabetes management. U.S. Department of Health and Human Services.

 https://www.cdc.gov/diabetes/managing/index.html
- Covidence systematic review software. (n.d.). *Veritas Health Innovation*. https://www.covidence.org
- Critical Appraisal Skills Programme. (2024). CASP checklist for qualitative research [online].

 Retrieved March 25, 2025, from https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.pdf
- Crowshoe, L., Henderson, R. I., Green, M. E., Jacklin, K. M., Walker, L. M., & Calam, B. (2018a). Exploring Canadian physicians' experiences with type 2 diabetes care for adult Indigenous patients. *Canadian Journal of Diabetes*, 42(3), 281–288. https://doi.org/10.1016/j.jcjd.2017.06.012

- Crowshoe, L., Dannenbaum, D., Green, M., Henderson, R., Naqshbandi Hayward, M., & Toth, E. (2018b). Type 2 diabetes and Indigenous peoples. *Canadian Journal of Diabetes*, 42(Suppl. 1), S296–S306. https://doi.org/10.1016/j.jcjd.2017.10.022
- Crowshoe, L. L., Henderson, R., Jacklin, K., Calam, B., Walker, L., & Green, M. E. (2019).

 Educating for Equity Care Framework: Addressing social barriers of Indigenous patients with type 2 diabetes. *Canadian Family Physician*, 65(1), 25-33.

 https://www.cfp.ca/content/cfp/65/1/25.full.pdf
- Diabetes Canada. (2025a). Diabetes Canada clinical practice guidelines. Chapter 6:

 Organization of diabetes care. Diabetes Canada [website]. Retrieved March 8, 2025,
 from https://guidelines.diabetes.ca/cpg
- Diabetes Canada. (2025b). *About diabetes: Management and self-care*. Diabetes Canada [website]. Retrieved May 8, 2025, from https://www.diabetes.ca/about-diabetes/management-and-self-care
- Diabetes Canada. (2025c). Diabetes Canada clinical practice guidelines. Chapter 6: Self-management education and support. Diabetes Canada [website]. Retrieved March 23, 2025, from https://www.diabetes.ca/health-care-providers/clinical-practice-guidelines/chapter-7#panel-tab FullText
- Dutton, J. (2018). Lessons from stories of diabetes self-management: Enunciating culture in health decision-making in the third space (Publication No. 10937052) [Doctoral dissertation, University of Toronto]. ProQuest Dissertations and Theses Global.

 https://www.proquest.com/openview/c58c88cc60af36e9af54b9dffeb5527a/1?pq-origsite=gscholar&cbl=18750&diss=y

- Eyth, E., & Naik, R. (2025). Hemoglobin A1c. In *StatPearls*. Stat Pearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK549816/
- First Nations Health Authority, First Nations Health Council, & First Nations Health Director's Association. (2021, April 22). *Anti-racism, cultural safety & humility framework*. First Nations Health Authority [website]. https://www.fnha.ca/Documents/FNHA-FNHC-FNHDA-Anti-Racism-Cultural-Safety-and-Humility-Framework.pdf
- First Nations Information Governance Centre. (2020). *The OCAP® principles*. https://fnigc.ca/ocap-training/
- First Nations Information Governance Centre. (2025). *The First Nations principles of* OCAP®. https://fnigc.ca/ocap-training/
- Flick, U. (2018). Strategies for managing diversity in qualitative research. In *Strategies for managing diversity in qualitative research* (2nd ed., pp. 79-94). SAGE Publications Ltd. https://doi.org/10.4135/9781529716641
- Galicia-Garcia, U., Benito-Vicente, A., Jebari, S., Larrea-Sebal, A., Siddiqi, H., Uribe, K. B., Ostolaza, H., & Martín, C. (2020). Pathophysiology of type 2 diabetes mellitus.
 International Journal of Molecular Sciences, 21(17), Article 6275.
 https://doi.org/10.3390/ijms21176275
- Gibson, O., Lisy, K., Davy, C., Aromataris, E., Kite, E., Lockwood, C., Riitano, D., & Brown, A. (2015). Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: A systematic review. *Implementation Science*, 10(1), Article 71. https://doi.org/10.1186/s13012-015-0261-x

- Gottlieb, K., Sylvester, I., & Eby, D. (2008). Transforming your practice: What matters most.

 Family Practice Management, 15(1), 32–38.

 https://www.aafp.org/pubs/fpm/issues/2008/0100/p32.html
- Gregory, D., Whalley, W., Olson, J., Bain, M. G., Harper, G., Roberts, L., & Russell, C. (1999).

 Exploring the experience of type 2 diabetes in urban Aboriginal people. *Canadian Journal of Nursing Research*, 31(1), 101-115.

 https://cjnr.archive.mcgill.ca/article/view/1512
- Halseth, R. (2019). The prevalence of type 2 diabetes among First Nations and considerations for prevention. National Collaborating Centre for Aboriginal Health.

 https://www.nccih.ca/docs/health/RPT-Diabetes-First-Nations-Halseth-EN.pdf
- Harfield, S., Pearson, O., Morey, K., Kite, E., Glover, K., Canuto, K., Streak Gomersall, J.,
 Carter, D., Davy, C., Aromataris, E., & Braunack-Mayer, A. (2018). *The Aboriginal and Torres Strait Islander Quality Appraisal Tool: Companion document*. South Australian Health and Medical Research Institute.
 https://sahmri.blob.core.windows.net/communications/Aboriginal-and-Torres-Strait-Islander-Quality-Appraisal-Tool-Companion-Document-1.pdf
- Harfield, S., Pearson, O., Morey, K., Kite, E., Canuto, K., Glover, K., Arya, D., Davy, C.,
 Aarsman, S. L., Braunack-Mayer, A., & Brown, A. (2020). Assessing the quality of
 health research from an Indigenous perspective: The Aboriginal and Torres Strait
 Islander Quality Appraisal Tool. *BMC Medical Research Methodology*, 20(1), Article 79.
 https://doi.org/10.1186/s12874-020-00959-3
- Hayward, A., Sjoblom, E., Sinclair, S., & Cidro, J. (2021). A new era of Indigenous research:

 Community-based Indigenous research ethics protocols in Canada. *Journal of Empirical*

- Research on Human Research Ethics, 16(4), 403-417. https://doi.org/10.1177/15562646211023705
- Hernandez, C. A., Antone, I., & Cornelius, I. (1999). A grounded theory study of the experience of type 2 diabetes mellitus in First Nations adults in Canada. *Journal of Transcultural Nursing*, 10(3), 220–228. https://doi.org/10.1177/104365969901000313
- Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., Sirett, E., Wong, G., Cargo, M., Herbert, C. P., Seifer, S. D., Green, L. W. & Greenhalgh, T. (2012).
 Uncovering the benefits of participatory research: Implications of a realist review for health research and practice. *The Milbank Quarterly*, 90(2), 311–346.
 https://doi.org/10.1111/j.1468-0009.2012.00665.x
- Johnson, R., Fiddler, T., Pirozek, J., Gordon, J., Sodhi, S., Poirier, J., Kattini, R., & Kelly, L. (2022). Traditional medicine and type 2 diabetes in First Nations patients. *Canadian Journal of Diabetes*, 46(1), 53–59. https://doi.org/10.1016/j.jcjd.2021.05.007
- Kesler, L. (2020, February 10). Aboriginal identity and terminology. *First Nations and Indigenous Studies Program, University of British Columbia* [website]. Retrieved January 11, 2025, from https://indigenousfoundations.arts.ubc.ca/aboriginal_identity_terminology/
- Kirmayer, L., Simpson, C., & Cargo, M. (2003). Healing traditions: Culture, community and mental health promotion with Canadian Aboriginal peoples. *Australasian Psychiatry*, *11* (Suppl. 1), S15–S23. https://doi.org/10.1046/j.1038-5282.2003.02010.x
- Konczi, A. E., & Bill, L. (2024). Advancing First Nations principles of OCAP®. In G. Garvey (Ed.), *Indigenous and tribal peoples and cancer* (pp. 37-39). Springer.

- Kulhawy-Wibe, S., King-Shier, K. M., Barnabe, C., Manns, B. J., Hemmelgarn, B. R., & Campbell, D. J. T. (2018). Exploring structural barriers to diabetes self-management in Alberta First Nations communities. *Diabetology & Metabolic Syndrome*, 10, Article 87. https://doi.org/10.1186/s13098-018-0385-7
- Kumagai, A. K., & Lypson, M. L. (2009). Beyond cultural competence: Critical consciousness, social justice, and multicultural education. *Academic Medicine*, 84(6), 782–787. https://doi.org/10.1097/ACM.0b013e3181a42398
- Kushner, P. R., Cavender, M. A., & Mende, C. W. (2022, October 14). Role of primary care clinicians in the management of patients with type 2 diabetes and cardiorenal diseases. *Clinical Diabetes*, 40(4), 401–412. https://doi.org/10.2337/cd21-0119
- Lavallée, L. F., & Howard, H. A. (2011). *Urban Aboriginal Diabetes Research Project report*.

 Anishnawbe Health Toronto. https://iportal.usask.ca/record/35183
- Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal for Evidence Based Healthcare*, 13(3),179–187.

 https://journals.lww.com/ijebh/fulltext/2015/09000/qualitative_research_synthesis_methodological.10.aspx
- Melnyk, B. M., & Fineout-Overholt, E. (2023). Chapter 7: Critically appraising qualitative and mixed methods evidence for clinical decision making (5th ed., pp. 282-286). Wolters Kluwer.
- National Institute of Diabetes and Digestive and Kidney Diseases. (2023). *Diabetes education*.

 National Institutes of Health. https://www.niddk.nih.gov/health-
 information/diabetes/overview

- Obomsawin, R. (2007). Traditional medicine for Canada's first peoples. *National Aboriginal Health Organization*. Retrieved May 27, 2025, from https://lfs-indigenous.sites.olt.ubc.ca/files/2014/07/RayObomsawin.traditional.medicine-1.pdf
- Oxford University Press. (n.d.). *Paternalism*. In *Oxford English Dictionary*. Retrieved May 25, 2025, from https://www.oed.com
- Public Health Agency of Canada, the Pan-Canadian Public Health Network, Statistics Canada, & the Canadian Institute for Health Information. (2018). *Health inequalities in Canada: A national portrait* [electronic version]. Public Health Agency of Canada.

 https://www.canada.ca/en/public-health/services/publications/science-research-data/key-health-inequalities-canada-national-portrait-executive-summary.html
- Pilon, R. S., Benoit, M., Maar, M., Cote-Meek, S., Assinewe, F., & Daybutch, G. (2019).

 Decolonizing diabetes. *International Journal of Indigenous Health*, 14(2), 252–275.

 https://doi.org/10.32799/ijih.v14i2.32958
- Queen's University. (2025). *Indigenous terminology guide* [website]. Office of Indigenous

 Initiatives. Retrieved January 11, 2025, from https://www.queensu.ca/indigenous/ways-knowing/terminology-guide
- Reading, C. (2018). Structural determinants of Aboriginal Peoples' health. In M. Greenwood, S. de Leeuw, & N. M. Lindsay (Eds.), *Determinants of Indigenous Peoples' health in Canada: Beyond the social* (2nd ed., pp. 3–15). Canadian Scholars.
- Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *International Journal of Indigenous Health*, *1*(1), 80-95. https://jps.library.utoronto.ca/index.php/ijih/article/view/28934

- Sherifali, D., Shea, N., & Brooks, S. (2012). Exploring the experiences of urban First Nations

 People living with or caring for someone with type 2 diabetes. *Canadian Journal of Diabetes*, 36(4), 175–180. https://doi.org/10.1016/j.jcjd.2012.07.005
- Sinclaire, M., Lavallée, B., Cyr, M., & Schultz, A. (2023). Indigenous Peoples and type 2 diabetes: A discussion of colonial wounds and epistemic racism. *Canadian Journal of Diabetes*, 47(5), 451–454. https://doi.org/10.1016/j.jcjd.2023.01.008
- Smith, L. T. (2021). *Decolonizing methodologies: Research and Indigenous Peoples* (3rd ed.). Zed Books.
- Southcentral Foundation. (n.d.). Nuka system of care. https://scfnuka.com
- Stewart, M., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centred care on outcomes. *Journal of Family Practice*, 49(9), 796-804. https://www.mdedge.com/jfponline/article/60893/impact-patient-centred-care-outcomes.
- Stewart, M. A. (1995). Effective physician–patient communication and health outcomes: A review. *Canadian Medical Association Journal*, *152*(9), 1423-1433. https://pmc.ncbi.nlm.nih.gov/articles/PMC1337906/
- Struthers, R., Hodge, F. S., Geishirt-Cantrell, B., & De Cora, L. (2003). Participant experiences of talking circles on type 2 diabetes in two Northern Plains American Indian tribes.

 Qualitative Health Research, 13(8), 1094–1115.

 https://pmc.ncbi.nlm.nih.gov/articles/PMC3103143
- Torraco, R. J. (2016). Writing integrative literature reviews: Using the past and present to explore the future. *Human Resource Development Review*, *15*(4), 404-428. https://doi.org/10.1177/1534484316671606

- Toronto, C. E., & Remington, R. (2020). A step-by-step guide to conducting an integrative review. Springer Publishing Company. https://doi.org/10.1007/978-3-030-37504-1
- Towle, A., Godolphin, W., & Alexander, T. (2006). Doctor-patient communications in the Aboriginal community: Towards the development of educational programs. *Patient Education and Counseling*, 62(3), 340-346. https://doi.org/10.1016/j.pec.2006.06.006.
- Truth and Reconciliation Commission of Canada. (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. http://www.trc.ca
- Turpel-Lafond, M. E. (2020). *In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care*. British Columbia Ministry of Health.

 https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf.
- United Nations. (2007). *United Nations Declaration on the Rights of Indigenous Peoples*.

 https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html
- University of British Columbia. (n.d.). 'In Plain Sight' report: Systemic racism in BC healthcare.

 Faculty of Medicine: School of Population and Public Health. https://spph.ubc.ca/in-plain-sight/
- University of Northern British Columbia. (n.d.). *CINAHL (Cumulative Index to Nursing and Allied Health Literature)*. University of Northern British Columbia Geoffrey Weller R. Library. https://libguides.unbc.ca/az/databases?a=g

- Walker, L. M. & Behn-Smith, D. (2018). Medicine is relationship: Relationship is medicine. In
 M. Greenwood, S. de Leeuw, & N. M. Lindsay (Eds.), *Determinants of Indigenous*Peoples' health in Canada: Beyond the social (2nd ed., pp.320-331). Canadian Scholars.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x
- Wood, M. E. (2021). Diabetes mellitus. In T. M. Buttaro, P. Polgar-Bailey, J. Sandberg-Cook, & J. Trybulski. (Eds.), *Primary care interprofessional collaborative practice* (6th ed., pp. 1121-1142). Elsevier.
- World Health Organization. (2021). *Global report on diabetes*. World Health Organization. https://www.who.int/publications/i/item/9789240062680
- Wright, A. L., Butt, M. L., Miller, V., Jacobs, B., & Ferron, E. M. (2023). The use of graphic facilitation to support adherence to OCAP® principles in research with Indigenous communities. *International Journal of Qualitative Methods*, 22. https://journals.sagepub.com/doi/10.1177/16094069231190557

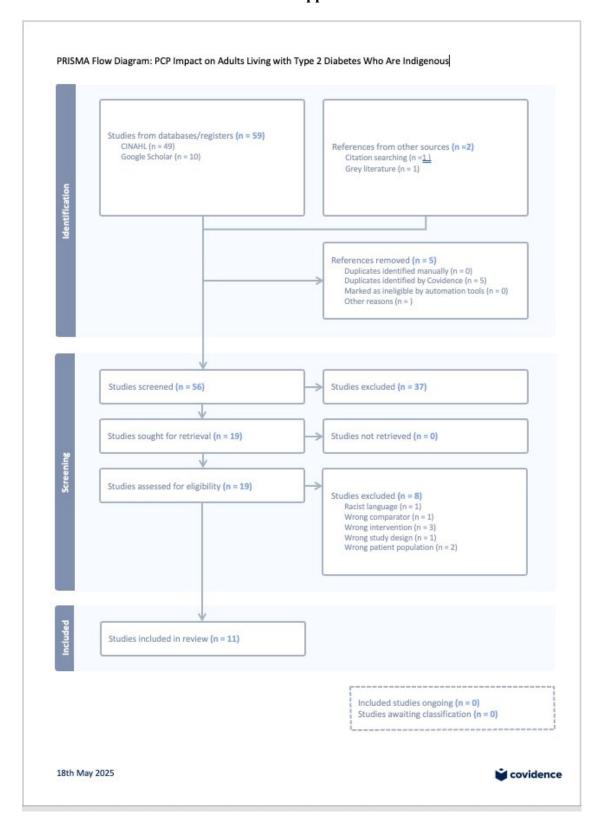
Appendix 1

Database Search Strategy

Search	Database	Search Terms	Results
S1	CINAHL	("Diabetes Mellitus, Type 2") OR ("Diabetic Patients") OR ("diabetes type 2 or diabetes mellitus type 2 or diabetes 2")	150,742
S2	CINAHL	("Aboriginal Canadians") OR ("Indigenous Peoples") OR ("First Nations of Australia") OR ("Alaska Natives") OR ("Aboriginal Australians") OR ("Indigenous Health") OR ("Indigenous Women") OR ("Apache (Native American People)") OR (MH "Medicine, Native American Traditional")	17,962
S3	CINAHL	(MH "Quality of Health Care") OR (MH "Healthcare Disparities") OR (MH "Health Services Accessibility") OR (MH "Primary Health Care")	271,025
S4	CINAHL	(MH "Self Care") OR (MH "Blood Glucose Self-Monitoring") OR (MH "Self Care Agency") OR (MH "Self Medication") OR (MH "Self Administration")	56,177
S5	CINAHL	(MH "Primary Care Nurse Practitioners") OR (MH "Physicians, Family") OR (MH "Family Nurse Practitioners") OR (MH "Nurse Practitioners") OR (MH "Adult Nurse Practitioners")	45,815
S6	CINAHL	S1 AND S2 AND S3	152
S7	CINAHL	S1 AND S2 AND S4	49
S 8	CINAHL	S2 AND S5	56
	Google Scholar	type 2 diabetes AND self-management AND Indigenous patients	10

Note: MH indicates a CINAHL Medical Subject Heading (controlled vocabulary).

Appendix 2



Appendix 3

Summary of Data Extraction

Article Reference

Barton, S. S., Anderson, N., & Thommasen, H. V. (2005). The diabetes experiences of Aboriginal people living in a rural Canadian community. *Australian Journal of Rural Health*, 13(4), 242–246. https://doi.org/10.1111/j.1440-1584.2005.00709.x

Purpose and Context

- -To better understand the challenges of living with T2DM for Nuxalk peoples in the remote community in Bella Coola, BC
- N=8 initially interviewed (women=5, men=3), 4 of the participants engaged in 6 follow-up conversational interviews (women, n=3, men, n=1)
- -diagnosed with diabetes in the last 5-20 years, open to talking about their 'diabetic life stories'
- -sampling= purposive, by invite from trusted members of the research team
- -informed consent obtained, anonymity preserved

Type of Study and Design

Descriptive qualitative design

Strength and Limitations

Strengths:

- -honours listening, learning and storytelling to generate an understanding for more culturally safe management of diabetes
- -portrays diverse responses elicited by participants and does not try to homogenize data for ease of reporting
- -consent and ethics approval obtained

Limitations:

-cultural background/positionality of researchers not described/influence of researchers on the research not explored

-methods unclear

Relevance to Research Question

Psychological Impact

Fatalism:

-shift from seeing diabetes as inevitable to recognizing personal agency

Challenges to Primary Care Diabetes Management

Diabetes education delivery:

- -communications with PCP hard to understand, encounters too rushed for teaching and learning
- -provider not doing enough to explain how diabetes medications worked
- -would like providers to relate in a more personal way

Knowledge gaps:

- -unable to correlate symptoms of feeling unwell with long-term complications such as heart and kidney damage
- -patients took their medications but did not understand how they worked

Facilitators to Diabetes Self-Management

Integrate culture with biomedicine:

-outdoor activities such as fishing and berry picking for exercise led to significant amounts of weight loss

Peer support:

-healing circles offered an environment where the support of others with diabetes could be sought for their wisdom

Barton, S. S. (2008). Using narrative inquiry to elicit diabetes self-care experience in Aboriginal population. *Canadian Journal of Nursing Research*, 40(3), 16–36. https://doi.org/10.1111/j.1440-1584.2005.00709.x

Purpose and Context

- -to examine the experience of Elders living with T2DM in a remote Nuxalk community in Bella Coola, BC
- -participants selected for ability to provide a rich life story and reveal meaning in their experience of diabetes, n= 4 (women, n=3; men, n=1)

Type of Study and Design

-Narrative inquiry based on hermeneutic phenomenology

Strengths and Limitations

Strengths:

- -analysis is deep, rich, evocative and complex, conveys concepts of Aboriginal epistemology, findings novel
- -duration of the study was long (3 years of active research, 2 years of research, reflection and writing) **Limitations:**
- -information about methods vague, no ethics approval
- -author/researcher does not describe the recruitment process or their relationship to the participants, influence of the researcher on the research and vice versa not described
- -themes not easily delineated, difficult to follow article

Relevance to Research Question

Facilitators to Diabetes Self-Management

Integrate culture with biomedicine:

- -participants viewed medical care as most appropriate for diabetes treatment but also used traditional medicine, ceremony and traditional practices
- -combining modalities led to finding harmony between being diabetic, being Aboriginal and being well

Bruyère, J., & Garro, L. C. (2000). "He travels in the body": Nehinaw (Cree) understandings of diabetes. *The Canadian Nurse*, 96(6), 25-28.

https://www.proquest.com/docview/232048769?fromopenview=true&pq-origsite=gscholar&sourcetype=Scholarly%20Journals.

Purpose and Context

Purpose:

-Listen to Nehinaw perspectives on T2DM and explore how First Nations people themselves understand T2DM, illuminate challenges in providing effective transcultural healthcare

Context:

- -Opaskwayak Cree Nation (OCN) near The Pas, Manitoba
- Nehinaw speakers with T2DM aged 25-73
- N=20+2 (women = 10+2, men = 10) (+2 = pre-test volunteers who were included because their answers did not differ from informants)

Type of Study and Design

- -Narrative inquiry
- -Structured qualitative interview conducted in Nehinawin (Cree language)

Strengths and Limitations

Strengths:

- -interview questions reviewed and revised by an Elder
- -interview conducted primarily in Nehinawawin (Cree language)-enriches understanding, provides nuanced perspective

Limitations:

- -few details about methods provided
- -interview questions not shared
- -no mention of ethics approval

Relevance to Research Question

Psychological Impact of Diabetes

Fatlism

Inevitability:

-death from diabetes in Nehinawin (Cree language) described in an unconventional way that implies lack of control

Facilitators to Diabetes Self-Management

Integrate culture with biomedicine:

-biomedical understanding that exercise helped metabolize sugar was congruent with Nehinaw framework that "ancestors worked hard" gave it relevance, boiling food rather than frying also accepted because that is what the ancestors did

Dutton, J. (2018). Lessons from stories of diabetes self-management: Enunciating culture in health decision-making in the third space. [Doctoral dissertation, University of Toronto]. ProQuest Dissertations and Theses Global.

 $\underline{https://www.proquest.com/openview/c58c88cc60af36e9af54b9dffeb5527a/1?pq-origsite=gscholar\&cbl=18750\&diss=y}$

Purpose and Context

-Increase understanding of the factors that influence the diabetes self-management behaviours of Indigenous peoples

Context:

-Fort Smith, Northwest Territories, population 2500, predominantly Dene-Métis, self-identified as Indigenous, living with T2DM, over 18 years old -n=10

Type of Study and Design

-Community Based Participatory Research (CBPR)

Strengths and Limitations

Strengths:

-study design, methods and researcher conduct followed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Research Involving the First Nations, Inuit and Métis Peoples of Canada (2014) and the OCAP guidelines

-in-depth critical analysis

Limitations:

-sample size smaller than intended

Relevance to Research Ouestion:

Psychological Impact of Diabetes

Fatalism

Self-determination:

-author refutes notion of universal resignation to diabetes for Indigenous peoples based on literature review (p. 22)

-participant learned to adjust their own insulin "because the doctors don't know what's going on"

Denial

Part of the process:

-coming to terms with diabetes required moving through denial to acceptance and effective diabetes self-management

Effect on study recruitment:

-approaching individuals with diabetes about recruitment into study was seen as a potential cause of distress if person was in 'denial' therefore deemed unethical by research ethics board

Challenges to Primary Care Diabetes Management

Paternalism in healthcare

Power imbalance:

-approach resembled authority figures from residential school, judged as dirty and non-compliant, feared not doing what they were told

-participant correlated how people are treated and how likely they are to seek care

Diabetes education delivery:

-quality diabetes education helped to move out of fear and worry into empowerment and action with self-mangement

Knowledge Gaps:

-without health literacy to understand one's own health you fall through the cracks

Gregory, D., Whalley, W., Olson, J., Bain, M. G., Harper, G., Roberts, L., & Russell, C. (1999). Exploring the experience of type 2 diabetes in urban Aboriginal people. *Canadian Journal of Nursing Research*, 31(1), 101-115. https://cjnr.archive.mcgill.ca/article/view/1512

Purpose and Context

- To determine the general experience of Aboriginal people living with T2DM in the urban setting of Winnipeg, Manitoba
- Urban dwelling Aboriginal people, status and non-status (Indian, Métis, Inuit)
- -recruited from urban diabetes resource clinics
- -N = 20 (women = 12, men = 8)

Type of Study and Design

- -naturalistic
- -person-centred face to face interviews

Strengths and Limitations

Strengths:

- -aims to understand the experience of people with lived experience
- -elaborate detail and justification

Limitations:

- -omit member checks
- -outdated language, i.e. refers to research assistant as "an aboriginal," tokenistic
- -limited details about about sampling method

Relevance to Research Question

Diabetes: Psychological Impact

Fatalism

Inevitability:

-20/20 participants had immediate family members living with diabetes, felt nothing could be done to stop them from getting it

Challenges to Primary Care Diabetes Management (Paternalism- Power imbalance):

- -distressing encounters with providers, participants berated and threatened to death if rules of diabetes not followed
- -berated by care providers for not following rules related to diabetes, scared by doctor who threatened death if rules not followed

Diabetes education delivery

- -doctor visits rushed, no time for teaching and learning, mostly for looking at blood sugars and assessing medications
- -doctors don't take the time to explain, popular perception that providers don't want to listen

Knowledge gaps:

-11/20 participants could not explain the cause of diabetes, 14/20 unable to explain what caused it

Facilitators to Diabetes Self-Management

Peer support:

-learning from other Aboriginal people with diabetes as welcome strategy

Hernandez, C. A., Antone, I., & Cornelius, I. (1999). A grounded theory study of the experience of type 2 diabetes mellitus in First Nations adults in Canada. *Journal of Transcultural Nursing*, 10(3), 220–228. https://doi.org/10.1177/104365969901000313

Purpose and Context

- -investigate the experience of having T2DM for First Nations adults
- -large First Nations community in Southwestern Ontario
- N=10 (males = 6, females =4)

Type of Study and Design

- -grounded theory, open-ended interview questions
- -emergent fit mode employed: used when there is already a theory that can be extended and refined during the research process

Strengths and Limitations

Strengths:

- -data ownership shared with community
- -research methodology congruent with research question
- -results shared verbally with Band Council
- -high level of transparency about research design, methods, and interview questions

Limitations:

- -study designed to provide 'cultural context' yet impact of colonization not even mentioned
- -ideas about First Nations culture not derived from study participants
- -First Nations culture understood through tropes derived from non-Indigenous sources (i.e. gerontology textbook)
- -model used was designed for 'Whites with Type I diabetes'

Relevance to Research Question

Psychological Impact of Diabetes

Denial

Part of the process:

-being in denial about having diabetes led to not taking medications regularly, normalizing and minimizing diabetes until recognition diabetes no longer something that can be ignored

Challenges to Primary Care Management of Diabetes

Knowledge gaps:

-took medications incorrectly and in a way that could be unsafe

Johnson, R., Fiddler, T., Pirozek, J., Gordon, J., Sodhi, S., Poirier, J., Kattini, R., & Kelly, L. (2022). Traditional medicine and type 2 diabetes in First Nations patients. *Canadian Journal of Diabetes*, 46(1), 53–59. https://doi.org/10.1016/j.jcjd.2021.05.007

Purpose and Context

-'re-tell' participants' stories and explore the role of traditional medicine in diabetes treatment -Sioux Lookout, Northern Ontario, N = 10 (men = 6, women = 4)

Type of Study and Design

- responsive interviewing (Rubin & Rubin) where study participants are 'conversational partners' who have an active role in determining the shape of the discussion through storytelling -oral tradition and personal experience of participants valued

Strengths and Limitations

Strengths:

- -harmonized, integrated understanding of the participants viewpoints
- -culturally sensitive orientation throughout

Limitations:

- -authors do not declare their own cultural backgrounds
- -authors do not assess their impact on the research and vice versa

Relevance to Research Ouestion

Diabetes: Psychological Impact (Fatalism-Inevitability):

-expectation of poor outcomes, always wondering who the next amputee in the family would be Challenges to Primary Care Management of Diabetes (Paternalism in healthcare-Lack of contextual understanding):

-providers being unaware of power imbalance a barrier to care for Indigenous patients, led to disconnection and mistrust

Facilitators to Diabetes Self-Management

Peer support:

-sharing circles a way to receive support in a culturally safe manner and a chance to return to thinking about health as the ancestors did

Kulhawy-Wibe, S., King-Shier, K. M., Barnabe, C., Manns, B. J., Hemmelgarn, B. R., & Campbell, D. J. T. (2018). Exploring structural barriers to diabetes self-management in Alberta First Nations communities. *Diabetology & Metabolic Syndrome*, 10(1), Article 87. https://doi.org/10.1186/s13098-018-0385-7

Purpose and Context

- -highlight the structural barriers to effective diabetes self-management described by study participants.
- -FN peoples with T2DM living in FN communities adjacent to a major city in Alberta, n= 5 (subset from a larger study with 34 participants)

Type of Study and Design

- -qualitative descriptive analysis
- -follows phenomenological principles
- -sub cohort of patients from FN communities with T2DM from a larger qualitative study
- -purposive sampling via signage in physicians' offices, pharmacies, clinical databases and a FN kidney disease prevention clinic

Strengths and Limitations

Strengths:

-barriers elucidated

Limitations:

- -sample size small even for qualitative research
- -sample not fully saturated and derivative

Relevance to Research Question

Psychological Impacts of Diabetes (Fatalism- Inevitability):

-perception that diabetes was a death sentence

Challenges to Primary Care Management of Diabetes (Knowledge gaps):

- not understanding diabetes was a major source of stress, desire to do something but paralyzed by not knowing what to do and not feeling empowered to act

Lavallée, L. F., & Howard, H. A. (2011). *Urban Aboriginal Diabetes Research Project report*. Anishnawbe Health Toronto. Toronto, ON. https://iportal.usask.ca/record/35183

Purpose and Context

- -to gather information regarding Aboriginal cultural perspectives about diabetes and barriers to diabetes management.
- -to identify challenges that Aboriginal people living with diabetes in the Greater Toronto Area experience.
- -to uncover misconceptions and cultural nuances to identify barriers and interventions that will enable positive health outcomes in Aboriginal people with diabetes.
- -N = 138
- -adults18-79 years old, male, female or two-spirit who were diagnosed with T2DM, pre-diabetes, gestational diabetes or TIDM and identified as First Nations, Inuit or Métis

Type of Study and Design

- -Governing Council selected to advise on and oversee the project
- -concept mapping (using Concept Systems software)-provides both qualitative and quantitative data -sharing circles
- -questionnaire
- -Anishnaabe Symbol-Based Reflection (ASBR, n=14)
- -photovoice: participants given cameras to act as recorders and portray various topics related to diabetes (n=9)

Strengths and Limitations

Strengths:

- -multiple forms of assessment used so that triangulation possible
- -voices of Aboriginal people living with diabetes at the centre
- -authors provide elaborate detail about how they adhere to the Tri Council Policy Statement Guidelines 2 (TCPS2) chapter 9 articles 9.19
- -OCAP adhered to- Anishnawbe Health Toronto is the sole and rightful owner of the data and controls how the findings will be shared
- -the results interpreted collaboratively by the research team, a group of research participants, members of the project's Governing Circle, the Anishnawbe Health Diabetes Education Team, healers and staff physician
- -researchers' reflections published with the study results

Limitations:

- -unable to obtain a random sample
- -Inuit, Métis, two-spirit and men under-represented

Relevance to the Research Ouestion

Psychological Impact of Diabetes (Denial- Effect on study recruitment):

-denial reported in 34.2% of study participants actual rates likely underrepresented due to recruitment methods

Facilitators to Diabetes Self-Management

- -support and companionship of sharing circles were 'completely' or 'very much' helpful for 75% of participants
- -cultural teachings can help us live well and manage our diabetes (like medicine wheel: spiritual, emotional, physical and mental) 63.5% very much completely, 85.5% somewhat to completely

Pilon, R. S., Benoit, M., Maar, M., Cote-Meek, S., Assinewe, F., & Daybutch, G. (2019). Decolonizing diabetes. *International Journal of Indigenous Health*, *14*(2), 252–275. https://doi.org/10.32799/ijih.v14i2.32958.

Purpose and Context

- -to explore the impact of colonization on the lived experience and perceptions about developing T2DM for Indigenous Peoples living in the North
- -7 First Nations communities in Northern Ontario
- -Indigenous adults living with T2DM, N = 22

Type of Study and Design

- -qualitative
- -constructivist grounded theory guided by a decolonizing approach
- -used elements of Community Based Participatory Action Research approach

Strengths and Limitations

Strengths:

- -community consultation and approval obtained to conduct the study
- -centres participant lived experience using in-depth interviews
- -collaborates with communities to share the position of power and take a decolonizing approach
- -quotes used to illustrate themes

Limitations:

- -authors declare importance of researcher positionality in Indigenous research yet do not describe theirs to readers
- -authors acknowledge importance of addressing preconceived ideas, notions, experiences and theories and that it is important to reflect on these throughout research process yet do not show evidence of doing this
- -no member checking described

Relevance to Research Question

Challenges to Primary Care Diabetes Management (Paternalism- Power imbalance):

-providers reminiscent of authority figures in residential school, participants berated bringing up traditional medicines

Lack of contextual understanding

-trauma of residential school misunderstood or dismissed by providers leading to distrust, disconnection from providers in clinical encounters

Facilitators to Diabetes Self-Management

Counter misperceptions:

-diabetes not caused by fate

Sherifali, D., Shea, N., & Brooks, S. (2012). Exploring the experiences of urban First Nations People living with or caring for someone with type 2 diabetes. *Canadian Journal of Diabetes*, *36*(4), 175–180. https://doi.org/10.1016/j.jcjd.2012.07.005

Purpose and Context

- -Understand the lived experience of First Nations people living with (79.2%) or caring for (20.8%) someone with T2DM in an urban setting
- -Aboriginal Health Centre, Hamilton, Ontario
- -self-identify as Aboriginal and 18 years of age or older, diagnosed with T2DM or caregiver for someone with diabetes
- -willing to commit to attending 4 sharing circles (focus groups)
- -N = 24

Type of Study and Design

Qualitative descriptive design

Strengths and Limitations

Strengths:

- -qualitative descriptive approach best method to answer the research question
- -research method enabled interweaving a culturally sensitive approach and include a First Nations Elder and Healer to elucidate findings
- -data analysed concurrently and triangulated by 3 researchers and member checked with 9 sharing circle members to ensure accuracy of findings

Limitations:

-findings may be unique to this study as participants access same services – not generalizable -participants recruited at a social event- those unable to attend for reasons such as illness, lack of transportation or finances not included

Relevance to Research Ouestion

Psychological Impact of Diabetes (Denial- Part of the process):

-once you were through denial you were halfway there in terms of effective diabetes self-management **Barriers to Self-Management**

-need for ongoing education, support and timely advice about diet and benefits

Facilitators to Diabetes Self-Management

Peer support:

-sharing circles a way for diabetics to get together, eat healthy food, exercise together as a community -smudge, prayer, traditional teachings and social time valued at study sharing circle

Appendix 4

Comparison of OCAP® and TCPS 2 Chapter 9 and CBPR Frameworks for Ethical

Research with Indigenous Peoples

Feature	OCAP ®	TCPS 2 Chapter 9	CBPR
Full Name	Ownership, Control, Access, and Possession	Tri-Council Policy Statement 2: Chapter 9 – Research Involving the First Nations, Inuit and Métis Peoples of Canada	Community-Based Participatory Research
Developed by	First Nations Information Governance Centre (FNIGC)	Tri-Council Agencies (CIHR, NSERC, SSHRC)	Originated in public health and social sciences; no single governing body
Primary Audience	First Nations communities and those conducting research with them	Researchers in Canada conducting research involving Indigenous Peoples	Researchers and communities across diverse contexts, including but not limited to Indigenous settings
Focus	Data sovereignty and self-determination in research		Equal partnership between researchers and communities throughout the research process
Core Principles	First Nations have the right to own, control, access, and possess their data	Respect for Indigenous knowledge, community engagement, and self- determination; community and individual consent	Co-learning, mutual benefit, community empowerment, shared ownership of research
Scope	Primarily applies to First Nations data governance	Applies to all research involving First Nations, Inuit, and Métis in Canada	Can be applied in any research context with marginalized or underrepresented communities
Status	A set of community- defined standards	National policy guideline required for Tri-Council- funded research	A flexible, values-based approach rather than a formal policy
Consent Requirements	Community and individual consent, with emphasis on collective rights	Requires both individual and, where appropriate, community consent	Emphasizes collaborative decision-making, often includes community-level consent processes

Feature	OCAP ®	TCPS 2 Chapter 9	CBPR
Knowledge Sharing	Emphasizes community control over how findings are used or shared	Encourages inclusion of Indigenous perspectives in dissemination	Community partners co- own and help share research findings
Power Dynamics	Aims to rebalance power in research by centering Indigenous authority	Encourages addressing power imbalances through respectful engagement	Seeks to flatten hierarchies between researchers and communities through collaboration

Note. Abbreviations are as follows:

OCAP®: Ownership Control Access and Possession

TCPS 2: Tri Council Policy Statement: Ethical Conduct for Research Involving Humans, Chapter 9

CBPR: Community-Based Participatory Research.

Information adapted from Castleden et al., 2012; CIHR, NSERC, & SSHRC (2022); First Nations Information Governance Centre (2025) and Jagosh et al., 2012.