Invited review

Call to action: A new path for improving diabetes care for Indigenous peoples, a global review

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ABSTRACT

Diabetes has reached epidemic proportions in Indigenous populations around the globe, and there is an urgent need to improve the health and health equity of Indigenous peoples with diabetes through timely and appropriate diabetes prevention and management strategies. This review describes the evolution of the diabetes epidemic in Indigenous populations and associated risk factors, highlighting gestational diabetes and intergenerational risk, lifestyle risk factors and social determinants as having particular importance and impact on Indigenous peoples. This review further describes the impact of chronic disease and diabetes on Indigenous peoples and communities, specifically diabetes-related comorbidities and complications. This review provides continued evidence that dramatic changes are necessary to reduce diabetes-related inequities in Indigenous populations, with a call to action to support programmatic primary healthcare transformation capable of empowering Indigenous peoples and communities and improving chronic disease prevention and management. Promising strategies for transforming health services and care for Indigenous peoples include quality improvement initiatives, facilitating diabetes and chronic disease registry and surveillance systems to identify care gaps, and prioritizing evaluation to build the evidence-base necessary to guide future health policy and planning locally and on a global scale.

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Contents

1. Introduction ................................................................................ 121
   1.1. Background ......................................................................... 121
   1.2. Purpose of this review ......................................................... 121
2. Review article search strategy and selection criteria .......................... 121

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1. Introduction

1.1. Background

There are more than 370 million Indigenous peoples (5% of the global population) occupying more than 90 countries worldwide. Indigenous peoples represent the largest minority group [1–3] with diverse histories, languages, cultures, religions and traditions [4]. While the 2007 United Nations Declaration on the Rights of Indigenous Peoples [5] affirms all Indigenous peoples the right to health and social services, Indigenous peoples “remain on the margins of society...and are generally in worse health than the rest of the population” [6]. Transnational efforts, alongside national and local agendas to prioritize Indigenous health, have failed to stem the tide of systemic health inequalities across the globe.

Over the past few decades, international awareness has been raised on the debilitating health and socio-economic and political challenges and inequalities faced by Indigenous peoples [5,7], with particular emphasis on diabetes and other non-communicable diseases. Recent projections estimate 415 million adults aged 20–79 have diabetes worldwide, including 193 million undiagnosed individuals (global diabetes prevalence rate of 8.8%), with trends reaching a staggering 642 million (10.4% diabetes prevalence rate) by 2040 [4,8]. This rise in diabetes prevalence has been noted in every country across the globe, representing a quadrupling of adults with diabetes worldwide [9]. Trends vary across region and income group (higher prevalence rates noted in lower middle income countries) [4,8,9]; however consistently reported in the literature is the disproportionate burden diabetes is placing on Indigenous peoples, with estimates having reached epidemic levels [4]. On a global scale, over 50% of Indigenous adults (>35 years of age) have type 2 diabetes mellitus (T2DM) [10].

1.2. Purpose of this review

The purpose of this article is to review the current literature on Indigenous peoples and T2DM and describe the evolution of the disease in Indigenous populations, describe the key risk factors and impact of diabetes and chronic disease on Indigenous peoples, and conclude with a call to action for programmatic primary healthcare transformation with strategies to improve chronic disease management and diabetes health and health equity for Indigenous peoples. This review provides a global overview of the key issues impacting T2DM in Indigenous populations, with specific strategies to improve diabetes care focused predominantly on Canada; however similar to the notions of King, Smith and Gracey [11], many principles important for improving T2DM in Indigenous peoples across the globe are similar when local factors are fully contextualized.

2. Review article search strategy and selection criteria

Given the scope of this review article, we have presented only those publications that provide a snapshot of the key issues facing Indigenous peoples both locally in Canada and on a global scale.

As part of this review, the search strategy and selection criteria included: “Indigenous” or “Aboriginal”, and “diabetes” or “type 2 diabetes mellitus”, linked with “pediatric”, “children”, “pregnancy”, “gestational diabetes”, “mortality”, “complications”, “cardiovascular disease”, “hypertension”, “lower limb amputation”, “retinopathy”, “neuropathy”, “nephropathy”, “risk factors” and “social determinants of health”. Additional search terms were: “Maoris”, “American Indian”, “Alaskan Native”, “First Nations”, “Inuit”, and “Métis”. This review focused on original publications and reviews from PubMed over the past decade (preceding March 2016); however historically significant literature published prior to this time frame have been included to document epidemiological trends of type 2 diabetes in Indigenous populations since the mid-1950s. Publication titles and abstracts were screened to determine relevance and impact to this review. Where needed, grey literature was examined for key insight, including the United Nations, International Diabetes Federation and World Health Organization.

2.1. Terminology

Although the term diabetes will be used throughout this manuscript, the focus of this review article will be type 2 dia-
betes mellitus (T2DM) as the most prevalent form of diabetes and its overwhelming prevalence in Indigenous populations [4,10,22–26]. In countries where Indigenous populations have maintained traditional lifestyle patterns, relatively low prevalence rates are noted, such as the Organ Asli of Malaysia [27] and Chilean Aymara and Mapuche (1% and 4% global age-adjusted prevalence rate respectively, compared to the countrywide estimate of 10.4%) [28]. However, Indigenous populations living in contexts that have been significantly shaped by colonialism and global forces of economic and social change have seen rapid increases in T2DM prevalence rates, including the North American Sioux, New Zealand Maori, and Greenland Inuit [4,10,22,23,29,30]. Indigenous populations of the Pacific islands have the highest rates of diabetes prevalence in the world, with some regions of Australia (Aboriginal and Torres Strait Islanders), presenting rates as high as 26–30%, six-times higher than the general population [31]. In the United States, diabetes disproportionately affects American Indians and Alaskan Natives, with diagnosed diabetes rates more than twice as high as rates for non-Hispanic Caucasians [32]. A recent trend analysis of diabetes prevalence among Alaskan Natives highlighted an age-adjusted prevalence increase from 17.3 in 1985 to 47.6/1000 in 2006 [33], while Pima Indians showed an incidence rate of 23.5 cases per 1000 person-years in 2003 (compared to a US national estimated incidence of 8 cases per 1000 person-years in 2008). In Canada prior to the 1950s, T2DM was of little consequence in Indigenous populations; however the 1980s and 1990s saw a rapid increase in prevalence in regions where continuous surveillance was conducted. In the Sioux Lookout Zone (northern Ontario), prevalence increased 45% from 1983–1994, while Saskatchewan noted prevalence rates doubling during the period from 1980 to 1990. More recently, Indigenous peoples in Canada have T2DM rates 3–5 times higher than the general population, with diabetes noted as one of the fastest growing diseases among Indigenous populations [34–41].

3. Describing the evolution of the diabetes epidemic in Indigenous populations

3.1. Epidemiology of diabetes in Indigenous communities

Following World War II, social and political changes in countries such as Canada and the United States laid the foundations upon which the transition from infectious diseases (for example, tuberculosis, smallpox and influenza) to chronic diseases (such as diabetes) took place as the dominant expressions of poor health in Indigenous communities [18,19]. During the course of this transition, in 1965, the National Institute of Health and the Indian Health Services collaborated on seminal diabetes research with the Pima Indian community in Arizona, USA. Over the 10-year period between 1967 and 1977, diabetes prevalence rates increased 42%, and by the start of the 1980s, approximately 50% of Pima Indians (aged 35+) had diabetes (primarily T2DM). To date, the Pima Indian tribe in Arizona has one of the highest rates of diabetes in the world, with approximately 50% of adults aged 30–64 diagnosed with T2DM [10,20,21]. This foundational research put diabetes on the map as a significant and growing concern, and over the past four decades the story of the growing diabetes epidemic in Indigenous populations has continued unabated in Canada and around the globe. Within this general trend, published epidemiological literature has shown considerable variation across Indigenous populations.
diabetes mellitus (GDM) has a diabetogenic impact on women and is considered a key predictor and contributor to the epidemic of T2DM in Indigenous populations around the globe [4,34,46–56]. Chamberlain et al.’s systematic review [52] reported GDM prevalence rates for Australian Indigenous females ranging from 1.33% to 18.51%, while prevalence rates of GDM in Canada’s First Nations population reported 3 times higher than the non-First Nations population [47,51]. GDM screening is important for capturing accurate prevalence rates, and limited/inconsistent screening practices and inconsistent study designs help to explain the varying rates of GDM noted in the literature [57–59]. In Cape York, Australia, a three-fold increase in GDM was observed over a two year period with the introduction of universal screening [58].

There is an important intergenerational dimension to the impact of GDM in Indigenous populations, which leads to poor outcomes for both the mother and offspring during pregnancy, at birth, and over the life course [60]. Maternal glycaemia during pregnancy was associated with increased birth weight and risk of diabetes in Pima Indian offspring (United States), even when mothers were normal glucose tolerant during pregnancy [61]. Other health implications for the mother include risk of caesarean section [62] and preeclampsia, while risks for the offspring include an increased risk of preterm delivery [51], jaundice [51], shoulder dystocia [51], congenital abnormalities [63], macrosomia [51,62], neonatal hypoglycaemia [51,64], and more recently an increased risk of cardiovascular disease [65]. Furthermore, recent literature by Oster and Toth highlighted the overall age-adjusted prevalence of antepartum and intrapartum stillbirth was significantly higher (p < 0.001) in First Nations pregnancies than in non-First Nations pregnancies in Alberta Canada [66], highlighting the increased perinatal mortality that has been noted elsewhere around the globe [64].

Risk factors for GDM include: older maternal age ≥ 35 years, increased weight ≥ 91 kg, previous stillbirth, caesarean section, birthing of an infant large for gestational age (LGA), proteinuria, and early pregnancy BMI ≥ 25 kg/m². [29,48,50–52,58,67]. First Nation ethnicity is an independent predictor for GDM [48]. As noted by Saad, Wilson and Donovan [59], research has not sufficiently evaluated the role of socioeconomic status, a key risk factor for obesity and GDM among Indigenous women [59,68–71], and future research should further investigate this critical relationship. Of specific concern noted in the literature is the increased risk of developing T2DM after GDM for both mother [4,34,52,72–75] and child [76,77]. High rates of progression from GDM to T2DM have been reported amongst Indigenous women worldwide, with 30–70% of Indigenous women in Canada [78], New Zealand [73], and the United States [79,80] reporting this progression within four years postpartum. Indigenous women in Australia had a greater than fourfold risk of developing T2DM within 8 years of GDM, compared with non-Indigenous women (hazard ratio 2.55, 95%CI 2.63–7.88, p < 0.0001) [75]. Furthermore, a key emerging trend in the literature is the evolving growth of T2DM as the fastest growing pediatric chronic disease worldwide [81]. A disease limited to adults prior to 1985, this progression was first noted in children in the Pima Indians in the USA (6/1000 children) [82] and Canadian Oji-Cree First Nations (0.5/1000) [83] in the 1980s. Interactions between the pre-natal and post-natal environment and genetics, including in utero exposure, infant nutrition, early life events, rising childhood obesity rates, and a reduction in physical activity, appear to be contributing to these increasing rates of T2DM in Indigenous children, placing particular attention on poverty, food insecurity and the devastating impact of colonialism on families and communities (a topic that will be discussed in greater detail in Section 3.2.3) [77,81,84,85].

Risk factors for progression from GDM to T2DM include: GDM prior to 17 weeks gestation, multiparity, pre-pregnancy obesity, family history of diabetes, history of GDM in previous pregnancies, and limited or partial breastfeeding at hospital discharge [48,50,52,68,75].

Pregnancy is considered an optimal time to identify women at greatest risk for developing GDM and T2DM, and subsequent offspring through intergenerational risk [58]. This ‘window of opportunity’ offers care providers a strategic time to introduce strategies for long term risk reduction for mother and offspring [86]; however systematic care gaps with limited and late screening practices were consistently found in the literature [57–59,87]. This highlights the urgent need for screening in early pregnancy, with improved awareness of pre-existing diabetes and effective interventions needed to decrease the risk to mother and offspring [29,48,52,67]. As noted by Chamberlain et al. [86], the benefit of improved screening during pregnancy would be outweighed if effective prevention, treatment and postpartum care was not provided, and low rates of postpartum glucose screening have been documented in Australia [67,87] and Canada [51]. Thus, it is important to ensure effective longitudinal care patterns are established to reduce the long-term complications of GDM in Indigenous women and children over the life course.

3.2.2. Lifestyle risk factors
A significant focus in the literature are the lifestyle risk factors for diabetes, such as smoking, obesity, physical inactivity, and unhealthy eating habits characterized by non-traditional Indigenous diets high in sugar, fats and processed foods [43]. Indigenous people in Canada have among the highest smoking rates in the world [88], and a recent national study assessing diabetes clinical care among 19 First Nations communities in Canada found that almost 40% of participants were active smokers (compared to 12% in the general population with T2DM) [89], and documented BMI ≥ 40.0 kg/m² in 19.7% of participants. Obesity rates are rising across the globe in all populations, progressively impacting younger generations. Specifically, Indigenous children in Canada are presenting with significantly higher obesity rates compared to non-Indigenous children. Obese children are more likely to become obese adults [90–92], and the Heart and Stroke Foundation in Canada has declared a “full-blown cardiovascular crisis” due to rising obesity rates for Indigenous peoples in Canada [93] and the long-term health risks associated with T2DM.

3.2.3. Social determinants of Indigenous health
Social determinants of health are inextricably linked to the health inequalities of Indigenous peoples in Canada [94] and around the globe, including a particularly powerful relation-
ship between social determinants of health and T2DM [11,17,95]. Social determinants are increasingly being included in the conversation and context of diabetes that can facilitate or constrain diabetes-related vulnerabilities, capacities, behaviors and management [94]. Reading and Wein (2009) [94] highlight social determinants at proximal (e.g. health behaviours, physical and social environment), intermediate (e.g. community infrastructure, resources, systems and capacities) and distal level (e.g. historic, political, social and economic contexts) that shape health outcomes and thus health inequities for groups within a society. Contextualizing diabetes within the influence of social determinants of health provides an understanding of both the health issues that contribute to diabetes and progression to diabetes-related complications, but also the direct impact diabetes in turn has on exacerbating subsequent social determinants of health. One cannot address rising obesity rates and related progression of T2DM without addressing the underlying social determinants of poverty and food insecurity intricately linked to illness and disability. Arising from the conversation of social determinants of health in the literature is the devastating impact of colonization on Indigenous peoples worldwide. Recently, the World Health Organization recognized colonization as the most significant social determinant of health affecting Indigenous peoples at the distal level, because the concept powerfully elucidates many of the current barriers, practices, and effects of the intermediate and proximal determinants [17,96]. Racism and colonization are intricately connected, as Cunningham (2009) states: “Racism not only justified historic colonization but compounds its contemporary effects” [10,17]. The cross-generational impact of colonization and racism have inextricably formed foundational roles in the emergence of T2DM in the latter half of the 20th century, with the introduction of government policies that countered Indigenous values, cultures and lifestyle. This forced acculturation has led to vast inequities and disparities in Indigenous peoples’ health, including economic poverty (income, unemployment, lack of education, food insecurity, poor living conditions), social poverty (cultural identity and isolation, lack of social support and racism leading to negative stereotyping and stigmatization), and cultural poverty (loss of language and connection to the land, environmental deprivation, and spiritual, emotional and mental disconnection) [11,17,42,97-100]. Indeed, it is critical for health behaviors to be understood within the broader social, cultural, economic and historical determinants and their colonial contexts to provide a more accurate understanding of systemically produced health inequities [12]. Colonial contexts around the world have led to historic-political and psycho-social factors that have severely undermined Indigenous identity, knowledge, values, culture and spiritual practices. Despite the centrality of the social determinants of health to diabetes and chronic diseases in Indigenous peoples, we need more research to understand and explain the complexity of how various social determinants shape healthcare, health behaviors, and health outcomes [94], including an emphasis on how this can impact policy, programming and healthcare practice to foster health equity for Indigenous peoples.

4. Describing the impact of diabetes on the health of Indigenous peoples: diabetes-related comorbidity and complications

Rising diabetes prevalence rates have inevitably led to increased diabetes-related comorbidities and micro- and macro-vascular complications for Indigenous peoples worldwide [101], with recent trends noting the higher risk Indigenous minorities have for developing complications at a younger age [102]. Diabetes complications include cardiovascular disease, hypertension, lower limb amputation, retinopathy, neuropathy and nephropathy. Rates of cardiovascular disease in the general population with diabetes appear to be decreasing in Canada [103] and the United States [104]; however findings from the Strong Heart Study in the United States found increasing incidence of cardiovascular disease among American Indians with T2DM, with rates twice as high as the general population [105]. Similar trends have been found in Canada’s Métis [106] and First Nations populations [89,107,108]. First Nations people with T2DM have mortality rates estimated at 19.5 per 100,000 (versus 13.3 per 100,000 in the general population) [34,89,109,110], and diabetes-related complication rates 2-5 times higher [34,89,108]. A recent national study assessing the T2DM burden and clinical care gaps among 19 First Nations communities in Canada found that 13.3% had coronary artery disease, over 10% were diagnosed with neuropathy and retinopathy, and over 50% of the study participants had chronic kidney disease [89,111]. Diabetic nephropathy is the leading cause of end-stage renal disease (ESRD) in adults accounting for approximately 50% of cases worldwide [112]. Indigenous peoples are at a much higher risk of developing ESRD compared to non-Indigenous peoples, including New Zealand Maori [113], Pima Indians in the United States [114] and First Nations people in Canada [108,111]. High prevalence of chronic kidney disease among First Nations people with diabetes was related to modifiable and treatable risk factors, with earlier age of diabetes diagnosis and longer duration of diabetes leading to higher rates of ESRD [111]. Similar to Naqshbandi and colleagues’ (2008) comprehensive global review of complications in Indigenous peoples [101], reporting of nephrology complications was extensive both in Canada and globally, with limited research focused on other complications such as neuropathy and retinopathy in Indigenous populations. One exception was a review noting a decline in diabetic retinopathy in the United States; however this trend was not mirrored throughout the globe and retinopathy in various ethnic groups across the world documented higher prevalence rates in people of Indigenous tribal descent [115,116].

Emergent trends in the pediatric literature paint an alarming picture of micro- and macro-vascular complications associated with early onset diabetes. In a national prospective surveillance study in Canadian children less than 18 years of age with T2DM (2010 and 2012), First Nations heritage and exposure to maternal diabetes during pregnancy was associated with persistent albuminuria in the first year after diagnosis [117]. A population-based longitudinal study in Manitoba demonstrated renal and neurologic complications within 5 years of diagnosis, and major complications (dialy-
The cost of T2DM is reaching unprecedented levels in Canada and serves as the primary point of contact for the foundation of any high-performing healthcare delivery system. The importance of systematic and validated diabetes registry and surveillance data to determine diabetes prevalence rates, associated complications and morbidity/mortality rates. Developing registry and surveillance systems for Indigenous people and communities, with limited or absent literature on other diabetes-related complications available to inform this review. More comprehensive T2DM complication research is needed to inform practice and policy for optimal prevention and management of diabetes, and ensuring current standards of care for Indigenous peoples are met to delay the onset of diabetes and reduce long-term complications. This will require focused and strategic initiatives proven to improve diabetes and chronic disease care and management in Indigenous populations, and we propose a call to action for programmatic primary healthcare transformation as an avenue to bridge the pervasive and debilitating inequities in Indigenous health.

5. Call to action: strategies to improve chronic disease management and diabetes care in Indigenous populations

5.1. Existing strategies to improve chronic disease management and diabetes care

The cost of T2DM is reaching unprecedented levels in Canada [12,120] and globally [4], and strategies must include a focus on primary prevention of T2DM, reduction of risk factors and optimal management of the disease to reduce diabetes-related complications and mortality. These strategies must be contextualized within primary healthcare, as it forms the foundation of any high-performing healthcare delivery system [121,122] and serves as the primary point of contact for patients with chronic disease and diabetes [123]. Strengthening primary healthcare is crucial to reducing health inequities of Indigenous peoples with diabetes, and programmatic health-system interventions are necessary to reduce the burden of T2DM on Indigenous populations. Around the globe, various strategies and initiatives have been implemented to improve chronic disease management and diabetes care and outcomes for Indigenous peoples. These initiatives range in size and scope, from community-level health promotion and prevention initiatives to national diabetes registry and surveillance systems. A systematic review of primary healthcare initiatives in Indigenous adult populations in Australia, Canada, New Zealand and the United States, provided limited evidence on system or service level attributes that improved Indigenous T2DM health outcomes (A1c, diabetes-related hospitalizations and other primary care health endpoints) [124]. Of the 13 studies published between 2001 to present that met inclusion criteria (interventions designed to change/improve health system, clinical system or service level), 10 were multi-faced interventions, and 6 reported lowered A1c or reduced DM-related hospitalizations or amputations. The review highlighted the general reliance on intermediate health outcomes and observational studies, and stressed the need for careful and rigorous research design to provide an evidence-base to inform primary healthcare policy and practice decisions [124]. This call for a robust evidence base to inform practice and policy is further exemplified in the review of intervention research in Indigenous populations in Australia, Canada, New Zealand and the United States, suggesting that high-quality interventions proven to prevent or treat T2DM and gestational diabetes among Indigenous populations is lacking [125].

Another review of the literature noted the lack of high-quality surveillance data in the general population [8] and for Indigenous peoples to identify care gaps, highlighting the importance of systematic and validated diabetes registry and surveillance data to determine diabetes prevalence rates, associated complications and morbidity/mortality rates. Developing registry and surveillance systems for Indigenous people and communities, along with processes and supports for effective implementation and sustainability, would help fill the information system gaps that are necessary to inform best practice and health policy [126]. These types of systems have been shown to improve quality of care for people with diabetes [41,127], and to our knowledge, only Australia [128], the United States [129] and Canada have established national surveillance systems for Indigenous people. Canada’s national surveillance system is populated with administrative data procured from a collaborative network of provincial and territorial systems [130], thus lacking in individual level clinical data. A national pilot web-based surveillance system with clinical indicators has been trialed in Canada [131] with established regional surveillance systems for the James Bay Cree in Quebec Canada [132]; however a national surveillance program with patient level clinical data in Canada is lacking and should be prioritized.

It is important to note that strategies to improve chronic disease management and diabetes care in Indigenous communities must take the healthcare funding and delivery of health services into consideration to contextualize these strategies within the larger political infrastructure and funding constraints applicable in each region. For example, in Canada, federal government funding by the First Nations and Inuit Health Branch (FNHIH) is provided for public health and prevention services to registered First Nations living on-reserve and Inuit residing in traditional communities [133]. Similarly, the Aboriginal Diabetes Initiative supports First Nations and Inuit residing in traditional communities and...
provides health promotion and diabetes prevention activities and services [134]. Physician and hospital care are provided by provincial and territorial governments [135]. The organization of healthcare in Canada has led to numerous barriers to high quality diabetes care for Indigenous Canadians, including fragmented and inaccessible healthcare (depending on geography, degree of community isolation, and registered Aboriginal status) leading to limited or non-existent primary and preventative health care, poor coordination between provincially funded hospitals/specialty care and federal nursing care, high healthcare staff turnover, and limited or non-existent surveillance [97] [17]. In some areas of Canada, lack of physician or hospital support within 100 km of the community [136] has led to significantly higher admissions to hospital for ambulatory care sensitive conditions [11,137,138], with primary healthcare dominated by acute and episodic care management [89,139,140] provided by nurses and other non-physician health professionals. This has led to higher per capita healthcare costs for Indigenous peoples in Canada, with 40–60% greater utilization of physicians, hospitals and dialysis noted in Saskatchewan [141].

Of particular interest in primary healthcare literature is the emerging role and potential of quality improvement (QI) initiatives for improving the health of patients with chronic diseases and T2DM. QI interventions have been used extensively over the past two decades within healthcare systems to improve primary healthcare and diabetes outcomes, with increased emphasis on the Chronic Care Model (CCM) [142,143] and the Expanded Chronic Care Model (ECCM) [144] as the most recognized approaches to optimize chronic disease and the primary healthcare system. These models outline how healthcare partners can collaborate to improve care by including patients, families, the community, the healthcare system [145] and determinants of health [144,146–148]. The quality of diabetes care and improvement in health outcomes following QI interventions for Indigenous peoples with diabetes have been documented in the literature in Australia and the United States. In Australia, the Audit and Best Practice for Chronic Disease program used continuous QI to demonstrate improvement in HbA1c testing from 41% to 72%, with an increase in the proportion of people at target HbA1c (<7.0%) (19–28%) [149]. The United States has seen improvements in patient health outcomes and a reduction in racial and ethnic disparities following QI initiatives [147,148], with improvements in blood glucose and lipid control following implementation of the Indian Health Services Diabetes Care and Outcomes Audit [150]. Provincial and federal governments in Canada have embraced the CCM/ECCM through reform strategies to transition towards a chronic disease management approach [151,152], and QI interventions guided by them have demonstrated improvement to T2DM outcomes [153–157]; however Indigenous peoples, for the most part, have been excluded in Canada from these opportunities [158,159].

Within this context of inequities and gaps in primary healthcare for Indigenous peoples in Canada, the 5-year (2013–2017) TransFORmation of IndiGenous Primary HealThcare Delivery (FORGE AHEAD) Research Program [160] was developed. As Canada’s first national QI research program in Indigenous communities, FORGE AHEAD has undertaken an innovative approach with First Nations communities to support the development and evaluation of healthcare models that support locally-driven strategies that seek to enhance chronic disease prevention and care across Canada. FORGE AHEAD is theoretically based [89,107,108,161,162] and grounded in over two decades of research in primary care, diabetes research with First Nations communities [39,89,163–165] and evaluation of primary care QI initiatives [154,155,166,167]. FORGE AHEAD uses participatory research principles and approaches to implement a program that seeks to provide knowledge translation and exchange to benefit community partners [168]. The program honours OCAP® principles described by the First Nations Information Governance Centre [169] through activities that build on Indigenous strengths to improve diabetes prevention and care [168,170–172]. Activities in FORGE AHEAD are developed with and for First Nations partner communities. Program activities include assessment of the current healthcare delivery, funding models and best practices used in First Nations communities in Canada [173], assessment of community and clinical readiness to address and adopt chronic disease care [174], and evaluation and cost analysis of community and clinic QI initiatives to improve chronic disease management (including a diabetes registry and web-based surveillance system [131]). FORGE AHEAD will culminate in the development of a scale-up toolkit for improved chronic disease management in Indigenous communities. The FORGE AHEAD activities seek to make improvements on many fronts, including information systems, healthcare delivery processes, models of healthcare delivery, access to patient resources and patient outcomes. A comprehensive process and outcomes evaluation approach is being applied to FORGE AHEAD to foster an evidence base to inform Indigenous primary healthcare practice and policy. In Canada, despite significant government investment to address the growing burden of diabetes over the past decade [43,175,176], no substantive evidence exists to determine whether investments have led to improvements in diabetes prevalence, complications, or associated costs [177,178]. The evaluation of FORGE AHEAD has been designed to addresses the lack of critical and comprehensive evaluations noted in the literature, with the goal of providing the evidence necessary to inform primary healthcare practice and policy [166,167].

While promising, the emerging QI literature does not yet fully understand if, how, in what ways, and in what contexts QI can work to improve Indigenous peoples’ chronic disease management and diabetes outcomes. Can QI lead to systemic improvements to process delivery measures and/or clinical outcomes across multiple settings? Can traditional QI methodology be easily transposed into Indigenous contexts, or will it need to be adapted to fit with Indigenous peoples’ realities and visions for their health care? In what ways will mainstream health institutions, organizations, researchers and providers need to support Indigenous and non-Indigenous communities, clinics, administrators and practitioners to successfully implement QI programs that improve health processes and outcomes for Indigenous peoples? What are the costs or resources necessary to successfully run QI programs in clinics or healthcare centers that service Indigenous peoples? These, amongst other questions, will be impor-
5.2. Call to action: programmatic health system transformation

A call to action is necessary to transform primary healthcare to facilitate the timely prevention and optimal management of diabetes to reduce the growing and debilitating burden of diabetes on Indigenous peoples and communities. A programmatic health system lens must be applied based on evidence-based practices and strategies, and these strategies must be flexible to contextualize Indigenous communities’ local traditions, knowledge, history, language, culture and concepts of health and wellness. Aligning with the Truth and Reconciliation Commission of Canada, a wide range of improvements are needed in health systems and health services to improve outcomes for Indigenous peoples with T2DM. Improvements should include the development of health administrators and practitioners that have the interest and capacity to work effectively alongside Indigenous health leadership, quality health training and education that enables practitioners to provide safe and effective care, and effective and efficient delivery of care that combats Indigenous stereotypes at the level of patient interactions. Supports are also necessary to develop the capacity of Indigenous communities, such as the need for Indigenous peoples to play a central leadership role in their peoples’ health, supports to expand the base of Indigenous practitioners, professionals and administrators, and opportunities and support for the development of diabetes-related infrastructure and resources [11,97,179]. Primary healthcare transformation and successful primary healthcare delivery remains one crucial site in a robust and multi-dimensional approach to Indigenous health equity. Collaboration with community leaders, healthcare professionals and funding agencies to support primary healthcare reform and community-driven diabetes prevention and management initiatives must be prioritized to foster community capacity and improve diabetes care in Indigenous communities for optimal long-term benefit [11,97,179,180].

The social, economic, and political context in which healthcare has been understudied must become a key consideration in efforts to transform and improve primary healthcare for Indigenous peoples [179]. One cannot tackle the epidemic of diabetes without mediating the social issues that contribute to the disease and create barriers to its management. This review recommends an approach to T2DM prevention and management that fosters an understanding of how health-related structures and behaviors interact to produce inequitable diabetes-related experiences and outcomes for Indigenous peoples. Research has demonstrated the need to address intergenerational psychosocial factors to reduce the burden of T2DM in Indigenous peoples across the life span [81], and the urgent need to empower Indigenous peoples with knowledge of T2DM risk factors and associated complications. Indigenous programs and research must incorporate traditional concepts of health and healing, self-governance, and capacity building with communities that focus on the promotion of autonomy and self-determination, and target the detrimental colonial influences and racism for success in any new innovation moving forward [11,179,181]. This call for primary healthcare transformation aligns with the Truth and Reconciliation calls to action by highlighting the importance of registry and surveillance systems to identify care gaps, and prioritizing evaluation of initiatives to build the evidence-base necessary to inform future best practice and policy [179]. This call to action is necessary to transition from the historically piece-meal and limited Indigenous health research funding (less than 1% of funding through the Canadian Institutes of Health Research is dedicated to Aboriginal health projects) [182], to adopt a programmatic lens capable of transforming primary healthcare and empowering Indigenous peoples and communities [183]. The FORGE AHEAD research program is a notable example of a national research collaborative adopting a programmatic lens, focused on Indigenous community empowerment and creation of community partnerships. FORGE AHEAD highlights the overarching programmatic lens necessary to build capacity at the local community level, yet designed to scale up as a national population health intervention to improve the health of Indigenous peoples with T2DM and chronic disease.

6. Summary

The purpose of this global review article was to describe the evolution of the diabetes epidemic in Indigenous populations and to understand the risk factors and impact of diabetes and chronic disease on Indigenous peoples. This review provides continued evidence that dramatic changes are necessary to reduce diabetes-related inequities in Indigenous populations, with a call to action to support programmatic primary healthcare transformation capable of empowering Indigenous peoples and communities and improving chronic disease prevention and management. Promising strategies for transforming health services and care for Indigenous peoples include quality improvement programs, facilitating diabetes and chronic disease registry and surveillance systems to identify care gaps, and prioritizing evaluation of initiatives to build the evidence-base necessary to guide future health policy and planning locally and on a global scale.

Conflict of interest

None.

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REFERENCES


Earle L. Understanding Chronic Diseases and the Role of Traditional Approaches in Aboriginal Communities. Prince George, British Columbia, Canada: National Collaborating Centre for Aboriginal Health; 2011.