Diabetes care and management in Indigenous populations in Canada

Summary report of a pan-Canadian policy roundtable

November 1, 2017

IHE INSTITUTE OF HEALTH ECONOMICS
ALBERTA CANADA

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The roundtable was supported by an unrestricted grant from Boehringer Ingelheim Canada.

The views expressed herein do not necessarily represent the official policy of Boehringer Ingelheim Canada.

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Declared Competing Interest of Authors

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Executive Summary

Introduction

The Institute of Health Economics (IHE), in partnership with Boehringer Ingelheim Canada, hosted a pan-Canadian policy roundtable on diabetes care and management in Indigenous populations in Canada on November 1, 2017 in Edmonton Alberta. The roundtable focused on type 2 diabetes (herein referred to as *diabetes*). This report summarizes the proceedings from this event, and presents key themes, lessons learned, recommendations, and next steps arising from the discussion between roundtable participants.

The roundtable focused on best practices to effectively engage Indigenous communities and populations in diabetes prevention, care, and management, and aimed to:

- discuss and share learnings and promising practices from successful community-led diabetes programs, highlighting approaches to effectively engage communities to co-develop prevention and treatment programs that meet community needs; and
- articulate lessons arising from informed discussion to support the development of policy and strategy at provincial and federal levels that, over the longer term, supports systemic change and effective community engagement for developing diabetes and other chronic disease preventions programs.

Key Themes and Lessons Learned

Throughout the discussion we identified four key themes, as outlined and discussed below:

- Historical influences and past experiences
- Community leadership and ownership
    - Working with and supporting communities
    - Patient and provider education
    - Collaboration and holistic care
    - Program population coverage
- Jurisdiction and governance
    - Capacity and sustainability
- Health data and community knowledge
    - Evaluation

While we have presented each theme individually, we recognize and acknowledge that they are not independent. Instead, they are highly interrelated and connected, and it is important that these interdependencies are acknowledged to inform policy and program development, and support improvements in diabetes care for Indigenous peoples.

Historical Influences and Past Experiences

In Indigenous populations, diabetes is inextricably linked to historical and ongoing cultural, social, political, and economic factors and processes including poverty, food insecurity, intergenerational trauma, mental health, and racism, among many others. These factors are both core contributors to the development of risk factors and onset of diabetes, as well as key components driving differences in treatment outcomes, complication rates, and mortality. In addition, these factors can make efforts to treat diabetes difficult, and, in many cases, it is not possible to begin effective treatment until other factors such as food security, education, running water, housing, safety, and mental health are addressed.

Community Leadership and Ownership

A common theme across the best practice presentations and in discussion was that care programming is enhanced and more effective when it is community-initiated and community-led. Community leadership creates an environment that facilitates ownership and responsibility of care programming, which can increase enthusiasm and participation, supports ongoing sustainability, and positions communities as leaders and partners in the development and implementation of care, which, altogether, supports improved individual and community health and well-being. In addition, community leadership can ensure that community needs are heard, and that programming is delivered in a way that respects and upholds local culture, traditions, beliefs, and values.

Working with and supporting communities

Recognizing the need for and benefits of community leadership, it is important that government policy, researchers, and care providers support these processes and understand and accept their role as partners supporting community objectives. As a foundational pillar, these partnerships need to be built on authentic relationships and principles of trust, respect, honesty, and reciprocity to be effective. Accordingly, developing these relationships and partnerships takes time, commitment, and investment, but are key to developing and implementing effective community programs. Likewise, developing effective, individual, therapeutic relationships relies on these same foundational principles such that community members are respected partners in their care, and so that care responds to patients' needs and what is important to them.

Patient and provider education

Patient knowledge is an important component of diabetes care and a key prerequisite to effective self-management, and can serve to empower and motivate patients. However, in many communities, patients have insufficient knowledge of their disease, treatment, and how to effectively manage their diabetes. Healthcare providers may also benefit from education in order to learn approaches to more effectively deliver diabetes education to patients and to facilitate knowledge transfer, as well as to learn approaches to motivate people to make healthy changes in their lives.

Collaboration and holistic care

For Indigenous peoples, the concept of health is defined holistically and much more broadly than just disease and treatment. Health incorporates physical, emotional, mental, and spiritual elements of life, and balance between these elements is essential to support a strong and healthy person. Therefore, programming should address the holistic well-being of patients and not just diabetes-related treatment. This work relies on communication, collaboration, and coordination between healthcare providers as well as other community services to deliver care that meets a range of diverse patient needs.

Program population coverage

All programs highlighted in the best practice presentations provided care and prevention programming to all age groups. This broad focus supports the development of healthy eating and living habits, and disease prevention, treatment, and management across age groups, and produces interesting opportunities for shared learning by creating bridges to connect with select patient groups that are otherwise absent from care and prevention programming.

Jurisdiction and Governance

The mix of federal, provincial, and community responsibility for the delivery of health services in many Indigenous communities creates ambiguity and unclear accountabilities and responsibilities between partners for the delivery of health services. In addition, this complicated separation of responsibility for health services creates bureaucratic hurdles that can impede access to timely care for many Indigenous people.

Capacity and sustainability

Building community capacity was identified as a key element of developing successful and sustained diabetes programming. In addition, building community capacity and training local community members may also mitigate the impact of high healthcare provider turnover, which was identified as an issue by representatives from communities across Canada. Limited funding was also noted as a challenge to program sustainability, and highlighted the need for increased end-of-grant planning, changes in health funding mechanisms, and increased investment in community health providers. Acknowledging the benefits of investment in building community capacity, there is also a need to address challenges to community healthcare provider capacity. In many communities, healthcare providers do not have the resources or capacity for new patients, and simultaneously lack resources and capacity for program improvements that would support the delivery of more proactive diabetes care to patients.

Health Data and Community Knowledge

Information systems and patient registries are the foundation for screening programs and are essential supports for proactive care. Information systems for diabetes care require substantial infrastructure, and should be implemented through work with communities to ensure that issues of trust, privacy, data access and control are addressed, and that systems are adaptable and responsive to community needs.

Evaluation

How care is evaluated can have a major impact on the findings, which, in turn, have implications on program policy and resource allocation. Too often, non-Indigenous methods that emphasize clinical outcomes are used to evaluate Indigenous programming. These methods often fail to acknowledge differences in Indigenous and non-Indigenous knowledge paradigms, and do not adequately capture Indigenous conceptualizations of health, especially the social, emotional, spiritual, and mental dimensions of health and well-being.

Conclusions

> "How do we, with your help and others, reconcile our health status? Well, I think for starters…you ask yourself, what do I do I do differently this time?...Otherwise, we're going to be here 50 years from now and you're going to be 50 years older and we're still going to be falling behind and not getting on top of this epidemic, this pandemic that's happened. We can't afford not to begin to move forward."
>
> *- Roundtable participant*

An overarching theme from the roundtable was *approaching care and Indigenous health differently*, to include Indigenous culture(s), values, worldviews, and traditions as core and foundational pillars in the development, implementation, and evaluation of healthcare programming. Communities require the opportunity to express their needs and to develop programming that specifically meets those needs in appropriate and acceptable ways. Accordingly, changes in our approaches to care are required, from the intervention- and symptom-centred medical approaches of Western medicine, to more proactive and holistic approaches based on Indigenous conceptualizations of health. Other areas where new approaches could be beneficial and improve patient care are enhanced patient and provider education, and scalable approaches to increase community care capacity.

Diabetes is an important area for urgent and focused attention given the impact on Indigenous populations and the strong link between diabetes and other disease conditions. For Indigenous patients in particular, there is a need to consciously create circumstances where they know that someone cares about them. The preconditions of "feeling loved" and "being heard" were emphasized in deliberations at the roundtable and spoke to sustained and authentic relationship building that empowers patients, gives hope, and creates a sense of value and dignity. Even without further investment, there are ways to improve the health and well-being of Indigenous people by:

> "learning to see people differently, and embracing one another with care, compassion, respect, and understanding to improve the quality of their lives, create social justice, equality, good health, and security, and inspire hope in others" (roundtable participant).

Limitations

It is important to consider the contextual factors when reviewing this document and its recommendations. As a summary report, it reflects the themes and discussion expressed by delegates, which is a function of their backgrounds, opinions, viewpoints, and experiences. As such, this report may offer an incomplete overview of important issues, considerations, and concepts regarding diabetes care and management in Indigenous peoples in Canada. Moreover, it is important to acknowledge that the best practices highlighted here are only examples of initiatives that have been implemented through significant engagement with communities to improve diabetes prevention, care, and management for Indigenous peoples.

Recommendations

These recommendations are based on the major themes discussed throughout the roundtable. The recommendations have been divided into two groups: *foundational* recommendations address necessary components that form the basis of relationships with Indigenous people and communities, and *applied* recommendations reference some actionable areas that could be immediately impactful. Of note, these recommendations align with recommendations for health system transformation outlined in the First Nations Health Transformation Agenda, as well as other past recommendations and recent lessons and opportunities for innovation in primary care to improve the health and well-being of Indigenous populations.

Foundational recommendations

1. **Formal mechanisms for Indigenous perspectives in program planning**. Indigenous health programming and policy should: be developed in collaboration with Indigenous leadership and community voices; include Indigenous worldviews and conceptualizations of health and well-being; and be tailored to the unique needs, culture, and values of each community. This should be accommodated explicitly and formally in the program development process and in outputs such as guidance and approaches to evaluation.
2. **Formal articulation of principles for interaction**. Work with Indigenous communities and clinical relationships with Indigenous patients should be predicated on authentic relationships and principles of trust, respect, honesty, and reciprocity. Principles for interaction should be explicitly articulated with some identified action items for regular evaluation of whether this has occurred.

Applied recommendations

1. **Active recruitment and development of workforce from community**. Community members should be trained as diabetes educators and care support workers to increase community care capacity, diabetes knowledge, and public health awareness, and to support culturally appropriate care and long-term program sustainability. For example, training traditional healers as diabetes educators and care workers supports the integration of traditional healing and Western medicine and increases access to culturally appropriate health services and treatment, which, in turn, can increase compliance with treatment and produce improved outcomes.
2. **Sustained engagement and mechanisms to support the sharing and development of best practices and tools for evaluation**. Program evaluation should be rooted in Indigenous conceptualizations of health and well-being and include views of health and aspects of well-being that are important to community members. This may include a variety of community-based, participatory methodologies. A repository of best practices, checklists, and tools should be created and made widely accessible to communities, researchers, and policymakers to support appropriate evaluation of Indigenous health programming. Moreover, there is a need for sustained prioritization in this area to encourage ongoing research to develop community-centred methodologies, and to create opportunities for pan-Canadian knowledge exchange and sharing of best practices.
3. **Reduce barriers to a comprehensive range of diagnostic and treatment modalities**. Diabetes care in many Indigenous communities is reactive and lacks essential technological infrastructure to support proactive care, including prevention, early detection, and ongoing monitoring and treatment. A full complement of available diagnostic tools and treatments for diabetes care should be available for providers in addressing diabetes in Indigenous populations without significant restrictions or barriers.
4. **Integrated population health surveillance**. Diabetes surveillance systems tailored to community needs that are adaptable, scalable, and integrated with patient electronic medical records (EMRs) and other reporting systems are required. These are important components of

proactive diabetes care, treatment, and management, and widespread adoption of these information systems and registries should be encouraged and supported in communities across Canada. Health data collection should conform with OCAP® (Ownership, Control, Access, Possession) principles.

Next Steps

Following the roundtable, there has been significant interest in ongoing activities that build on the relationships and partnerships developed during the roundtable to support policy development, knowledge translation and application, and pilot projects related to diabetes care in Indigenous populations. These activities will be co-developed with a range of communities, community leaders, and academic and clinical experts, and implemented throughout 2018 and into 2019 to drive meaningful policy change and support the health and well-being of Indigenous peoples in Canada.

Of note, revised clinical care guidelines for diabetes care in Indigenous peoples will be released in Spring 2018, and it is expected there will be opportunities to support uptake and translation into practice in combination with other recommendations made in this report.

Abbreviations

All abbreviations that have been used in this report are listed here unless the abbreviation is well known, has been used only once, or has been used only in tables or appendices, in which case the abbreviation is defined in the figure legend or in the notes at the end of the table.

EMR	electronic medical record
KSDPP	Kahnawake Schools Diabetes Prevention Project
OCAP®	Ownership, Control, Access, Possession
RADAR	Reorganizing the Approach to Diabetes through the Application of Registries

Glossary

The glossary terms listed below were obtained and adapted from the following sources:

- National Aboriginal Health Organization Terminology Guidelines, *International Journal of Indigenous Health* (*journals.uvic.ca/journalinfo/ijih/IJIHDefiningIndigenousPeoplesWithinCanada.pdf*)
- Diabetes Canada (*www.diabetes.ca/diabetes-and-you/complications*)
- British Columbia Ministry of Health (*www.primaryhealthcarebc.ca/resource_eccm.html*)
- *Indigenous Law Journal* (*hdl.handle.net/1807/17129*)

Aboriginal Peoples – A collective name for all of the original peoples of Canada and their descendants. Section 35 of the *Constitution Act of 1982* specifies that the Aboriginal Peoples in Canada consist of three groups – Indian (First Nations), Inuit, and Métis. It should not be used to describe only one or two of the groups.

Diabetes – A chronic, often debilitating and sometimes fatal disease, in which the body either cannot produce insulin or cannot properly use the insulin it produces. Insulin is a hormone that controls the amount of glucose (sugar) in the blood. Diabetes leads to high blood sugar levels, which can damage organs, blood vessels and nerves. The body needs insulin to use sugar as an energy source. *Note*: throughout this report we examine the impacts of type 2 diabetes (see below), and use *diabetes* to refer to type 2 diabetes.

Ethical space – Formed when two societies, with disparate worldviews, are poised to engage each other. It is the thought about diverse societies and the space in between them that contributes to the development of a framework for dialogue between human communities. The ethical space of engagement proposes a framework as a way of examining the diversity and positioning of Indigenous peoples and Western society in the pursuit of a relevant discussion on Indigenous legal issues and particularly to the fragile intersection of Indigenous law and Canadian legal systems.

Expanded Chronic Care Model – Identifies essential elements in a system that strives for enhanced chronic care management including: the community, the health system, self-management support, delivery system design, decision support, and clinical information systems. The model is based on the Chronic Care Model, and can be employed to achieve better health outcomes, resulting in healthier patients, more satisfied providers, and more cost-effective expenditure of healthcare resources.

First Nations – Many people prefer to be called *First Nations* or *First Nations People* instead of *Indians*. The term should not be used as a synonym for *Aboriginal Peoples* because it does not include Inuit or Métis. As the term generally applies to both Status and Non-Status Indians, writers should take care in using this term.

Indigenous – Means “native to the area.” In this sense, Aboriginal Peoples are indeed indigenous to North America. Its meaning is similar to *Aboriginal Peoples*, *Native Peoples*, or *First Peoples*.

Inuit – A circumpolar people, inhabiting regions in Russia, Alaska, Canada, and Greenland, united by a common culture and language. There are approximately 55,000 Inuit living in Canada. Inuit live primarily in the Northwest Territories, Nunavut, and northern parts of Quebec and coastal Labrador. The *Indian Act* does not cover Inuit. However, in 1939, the Supreme Court of Canada interpreted the federal government's power to make laws affecting "Indians, and Lands reserved for the Indians" as extending to Inuit.

Métis – Today, the term is used broadly to describe people with mixed First Nations and European ancestry who identify themselves as Métis. Note that Métis organizations in Canada have differing criteria about who qualifies as a Métis person.

Type 2 diabetes – Occurs when the body cannot properly use the insulin that is released (called *insulin insensitivity*) or does not make enough insulin. As a result, sugar builds up in the blood instead of being used as energy. About 90% of people with diabetes have type 2 diabetes. Type 2 diabetes more often develops in adults, but children can be affected.

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1. Introduction

1.1. Roundtable Overview

The Institute of Health Economics (IHE), in partnership with Boehringer Ingelheim Canada, hosted a pan-Canadian policy roundtable on diabetes care and management in Indigenous populations in Canada on November 1, 2017 in Edmonton Alberta. The roundtable focused on type 2 diabetes (herein referred to as *diabetes*). This report summarizes the proceedings from this event, and presents key themes, lessons learned, recommendations, and next steps arising from the discussion between roundtable participants. A background report reviewing the health and economic impact of diabetes in Indigenous populations in Canada was prepared for the event. The background report as well as the presentation recordings and presentation slides can be found at: *www.ihe.ca/research-programs/knowledge-transfer-dissemination/roundtables/dcmipc/dcmipc-about*.

1.2. Roundtable Objectives

The program and focus of the roundtable was developed through significant collaboration with an advisory committee, which consisted of Indigenous community members, researchers, and healthcare providers with extensive experience in diabetes care and management and Indigenous health. The roundtable focused on best practices to effectively engage Indigenous communities and populations in diabetes prevention, care, and management, and aimed to:

- discuss and share learnings and promising practices from successful community-led diabetes programs, highlighting approaches to effectively engage communities to co-develop prevention and treatment programs that meet community needs; and
- articulate lessons arising from informed discussion to support the development of policy and strategy at provincial and federal levels that, over the longer term, supports systemic change and effective community engagement for developing diabetes and other chronic disease preventions programs.

A copy of the program can be found in Appendix A.

In all, 49 delegates attended the roundtable, representing 34 unique organizations and communities from the Yukon, British Columbia, Alberta, Manitoba, Ontario, and Quebec, as well as several national/federal organizations. The delegates represented a range of backgrounds, including community members, clinicians (registered nurses, nurse practitioners, physicians), program managers and directors, Elders, and professors/researchers. See Appendix B for a list of the roundtable advisory committee members, as well as the participant affiliations.

Following presentations of examples of best practices from British Columbia, Alberta, and Quebec, delegates engaged in a discussion centred on the following three questions:

- What are key barriers/challenges that limit the success of diabetes treatment and management programs across the country?
- Are there common approaches/characteristics of successful programs that can be applied across Canada?
- Are there key lessons that might inform pan-Canadian strategies or priorities for more targeted policy dialogues or research?

2. Summary of Roundtable Presentations

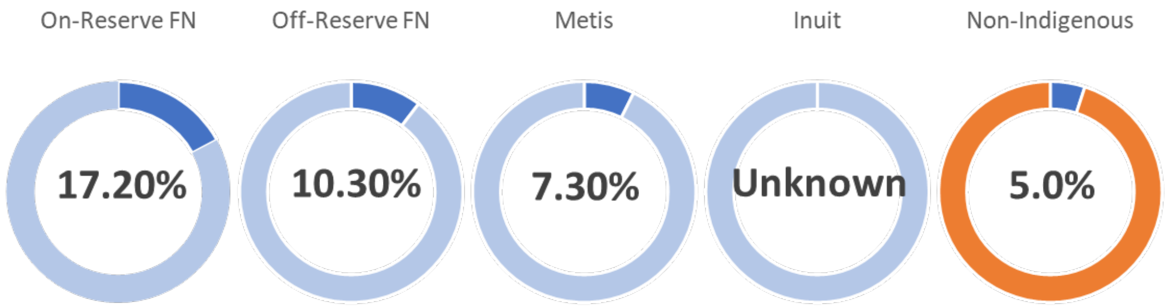
2.1. Context Setting

2.1.1. The Health and Economic Impact of Type 2 Diabetes in Indigenous Populations in Canada

John Sproule, Senior Policy Director, Institute of Health Economics[1]

Diabetes now affects a significant proportion of First Nations, Métis, and Inuit, and has risen to epidemic proportions in many communities (see Figure 1).[2] Indigenous peoples with diabetes also experience higher rates of complications, hospitalization, and mortality in comparison to non-Indigenous populations, which has been attributed, in part, to breakdowns in care pathways. As a result, care is often reactive and episodic[3] and is associated with high rates of emergency interventions and hospitalization, which are key drivers of excess healthcare costs for Indigenous patients with diabetes.[4]

FIGURE 1: National age-adjusted prevalence of diabetes by population



Adapted from: Pelletier et al. (2012)
FN: First Nations

Diabetes is a growing concern for many Canadians, but it has had an especially pronounced impact on Indigenous populations over the last 70 years.[5] The rapid emergence of diabetes is a complex issue that is fuelled and heavily influenced by a mix of socioeconomic deficits, complicated by historical and ongoing cultural, social, political, and economic factors and processes that perpetuate social and health inequalities for Indigenous peoples.[6] For many patients, geographic isolation, physician shortages, high rates of healthcare worker turnover, and limited access to necessary

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[1] This roundtable presentation was supplemented by the background report prepared for the roundtable, and therefore the content of this section of the summary report previously appeared in Institute of Health Economics (2017).

[2] Pelletier et al. (2012).

[3] Eurich et al. (2017).

[4] Jacobs et al. (2000); Pohar and Johnson (2007); Simpson et al. (2003).

[5] Pelletier et al. (2012).

[6] King et al. (2009); Iwasaki et al. (2004); Jacklin et al. (2017); Green et al. (2003); Rock (2003).

supplies due to complex government funding impedes access to timely care.[7] Furthermore, these issues may exacerbate other Indigenous-specific determinants of health (see Table 1) and perpetuate ongoing negative experiences with care that is perceived as inferior and not aligned with cultural beliefs.[8] Altogether, these factors may lead to avoidance of healthcare providers, increased mistrust of physicians, and resistance to other service providers, which may limit the effectiveness of many health interventions and programs.[9]

TABLE 1: Determinants of health in Indigenous populations

Conventional DoH	Indigenous DoH	Other DoH with Indigenous-specific impact
Income Social status Poverty Education Employment Social supports Genetics	Colonization Connectivity to land Self-determination Historical trauma	Globalization Racism Gender Worldview

Adapted from: King and McGavock (2017); King et al. (2009); Jacklin et al. (2017)

DoH: determinants of health

2.1.2. The First Nations Health Transformation Agenda

Addie Pryce, Director of Health, Assembly of First Nations

The Health Transformation Agenda contains 85 recommendations for federal, provincial, and territorial governments as a means to support First Nations health transformation and improvement.[10] The agenda is built on three main pillars:

1. **Relationships**: Federal, provincial, and territorial governments hold a responsibility for advancing First Nations health and supporting self-determination for health services delivery, in accordance with Treaty and international rights and in keeping with commitments towards reconciliation. Relationships between First Nations and federal, provincial, and territorial governments are essential to First Nations health transformation and need to be built on the principles of reciprocal accountability, respect, openness, and transparency.
2. **Meaningful and sustainable investment**: Improving First Nations health is an investment that will be associated with a significant and meaningful return across all sectors (e.g., health, social services, and justice). First Nations governance and leadership is required to identify priority areas for investment, and allows for shared decision-making between partners, which ensures reciprocal accountability in program development, delivery, and health outcomes. Health transformation must be based on a holistic understanding of health and wellness, and

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[7] Jacklin et al. (2017).

[8] Jacklin et al. (2017).

[9] Jacklin et al. (2017).

[10] Assembly of First Nations (2017).

founded on principles of cultural identity and language. Some potential areas of shared interest may include clarifying jurisdictional ambiguity, cultural humility and safety in health services delivery, establishing networks of patient navigators, and support for traditional healing, among many others.

3. **First Nations capacity**: With limited resources, there is a need for meaningful investments in capacity-building in communities and a recognition that skills and community knowledge extend beyond the confines of university degrees and other credentials. Community members can and should be trained as caregivers and care support, and should have the opportunity to provide input into the development of programs and the community health transformation agenda.

Federal, provincial, and territorial governments have committed to work with First Nations, Inuit, and Métis to improve access to health services, to improve the health outcomes of Indigenous peoples, and to discuss progress. However, in the era of reconciliation, federal, provincial, and territorial governments must respect the rights of First Nations to self-determination, including the right and responsibility to determine, establish, and administer their own health and wellness programming.

2.1.3. Keynote Address

Chief Dr. Robert Joseph, Chief, Gwawaenuk First Nation, Ambassador, Reconciliation Canada

The discourse between Indigenous and non-Indigenous peoples is not always on the same level, and our collective experiences and relationships are impacted by the legacy of residential schools and colonialism. However, there is a need to discuss these issues and our history, to stimulate progress and improve health, social, and economic conditions for Indigenous peoples.

There is a direct correlation between Indigenous and Canadian history, federal, provincial, and territorial policy, and current health and social conditions for Indigenous peoples. These conditions have been driven by a deep layer of racism and discriminatory policy in our country for over 150 years, where the central goal was to eliminate Aboriginal peoples as distinct, legal, social, cultural, religious, and racial entities, allowing the government to divest its legal and financial obligations to Indigenous peoples. As mentioned by the Truth and Reconciliation Commission, lands were seized, movement was restricted, languages were banned, spiritual leaders were persecuted, spiritual practice was forbidden, and families were torn apart to destroy the social and political institutions of Indigenous peoples, and to disrupt and prevent the transmission of cultural values and identity from one generation to the next. Indeed, the very establishment of residential schools can best be described as cultural genocide that has had, and continues to have, a resounding impact across generations of Indigenous people.

These policies and ongoing discrimination and racism have resulted in major gaps in the health and well-being of Indigenous people in comparison to other Canadians. Today, Canada ranks 5th on the United Nation's Human Development Index.; however, if judged solely on the economic and social well-being of Indigenous people, Canada would rank 48th. Indigenous people account for 4% of the total population but nearly 25% of the incarcerated population. They are more than twice as likely to live in poverty, are nearly twice as likely to have diabetes, are six times more likely to suffer alcohol-related deaths, more than three times more likely to suffer drug-induced deaths, and, tragically, have suicide rates that are nearly twice as high as in the overall Canadian population. In addition, life expectancy is three to six years shorter. These statistics are both tragic and eye-opening, and demonstrate a staggering gap between the health and well-being of Indigenous people and other Canadians.

> "…it's very difficult for the diabetics in our communities to embrace the medicine that you bring when so many of us live with hopelessness, despair, and marginalization."

To address these gaps, we must embrace reconciliation as a core value, learn from the past, and develop relationships to work together to focus and align our work, to plan together, to hold each other up, and to support each other to respond in the right ways. We must engage in discussion that transforms our understanding of each other, to see each other differently and to recognize our common humanity. And, we need to have a deeper appreciation of our shared history so that we can truly and deeply apply ourselves to improving the health status of Indigenous people in this country.

To start, this involves addressing several Calls to Action, including government recognition that the current state of Aboriginal health is a direct result of past policies (Call to Action #18).

Truth and Reconciliation Commission of Canada: Calls to Action (Health #18-24)

18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

20. In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.

21. We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.

22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

23. We call upon all levels of government to:

- **ii.** Increase the number of Aboriginal professionals working in the health-care field.
- **ii.** Ensure the retention of Aboriginal health-care providers in Aboriginal communities.
- **iii.** Provide cultural competency training for all health-care professionals.

24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the *United Nations Declaration on the Rights of Indigenous Peoples*, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.

Source: Truth and Reconciliation Commission of Canada (2015).

It also involves and requires new approaches, new perspectives, and new relationships. Despite the power of Western medicine to treat and heal disease, there are limitations. There are underlying conditions and social issues that influence the acceptability, appropriateness, and overall effectiveness of medical treatment, and approaches that solely rely on Western medicine have had only a modest impact on Indigenous health. And so, we must approach Indigenous health issues differently.

These approaches require increased emphasis on cultural safety, investment in and a focus on relationships, and recognition and incorporation of traditional culture, values, and healing methods in patient care.

Culturally safe care requires healthcare providers to examine their attitudes and perspectives about the people they serve, who, like everybody else, want a sense of dignity and to be respected and be seen. When this happens, patients will respond in new ways to treatment requirements, and will be empowered to maintain and manage their health. Further, this type of care will support the development of strong, authentic relationships between providers and patients, which is paramount to shift the dynamic of success now. These relationships, when built on respect and honour, increase trust and understanding, and empower patients to be involved in their health care, to own and be accountable for their health condition, and to take care of themselves in ways that they can. Relationships are the cornerstone to inclusivity, are essential to support systems, and are conducive to the development of best practices, supporting innovation, out-of-the-box thinking, and patient empowerment.

New approaches to care also involves a holistic approach to diabetes care in communities, and the incorporation of other, non-medical forms of support as well as traditional culture, values, and healing methods in patient care. It involves a number of different care providers and community services integrated together to achieve better outcomes for patients, and involves the input and incorporation of Indigenous ways, including greater recognition, respect for, and inclusion of traditional ways of knowing, healing, and living.

There are many ways that Aboriginal people see the world. Their world views are rooted in the sanctity of creation and connectedness to the environment, to the world around us, to animals, to the birds, and to the fish in the seas. Through their eyes, we are all one. If we believe that and begin to exercise respect for this notion, then Indigenous people are going to be healthier, more empowered, more connected, and more inspired. It will overcome the impact of residential schools and reignite the notion of humanity, self-respect, and value in Indigenous people.

We are in a new era when it comes to Aboriginal health. We are recognizing the impacts of colonialism and our shared history, and are searching for new ways to move forward together to make a difference. In this journey together, relationships are important, empowerment is important, trust is important, integration of services is important, inclusivity is important, and strong networks, strong families, and strong community support are important and instrumental to improve the health and well-being of Indigenous people. These things do not cost money, but serve to elevate the spirit of patients and communities and demonstrate that they are valued, and that they belong and are connected to all of us. Through these connections we can begin to understand each other, and begin to find the benefits of being human and acknowledging each other, and of being compassionate, caring, and loving towards one another.

2.2. Engaging Communities: Examples from across Canada

2.2.1. Diabetes and My Nation

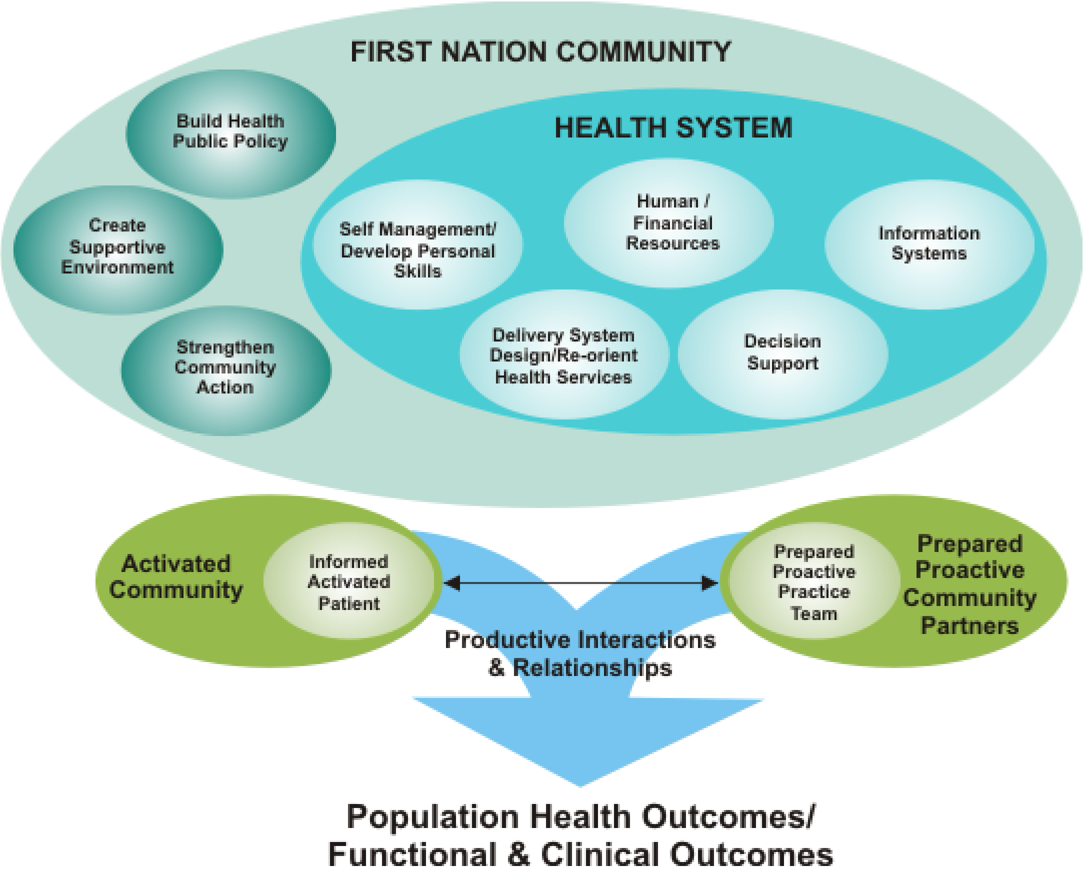
Hesham Nabih, President, HN Consultants Ltd.

Diabetes and My Nation is a community-based health management model that applies culturally appropriate and holistic methods to achieve evidence-based outcomes for the prevention and management of diabetes in First Nations communities. The program works with communities to support several aspects of diabetes care, including education and awareness, screening, treatment, self-management, and the adoption of healthy lifestyles.

A key prerequisite of Diabetes and My Nation is that First Nations choose to be a part of the program, and invite Diabetes and My Nation into their communities to support the development of programming that meets self-identified community needs. Diabetes and My Nation does not determine or instruct communities on initiatives and activities. Instead, program representatives share what needs to be done (an overall direction) and empower communities to identify their needs, and find their own ways to accomplish these goals, providing support throughout the development and implementation of community programs.

All programming is based on Indigenous conceptualizations of health and well-being, and incorporates the medicine wheel as the foundation of healing. Accordingly, care is holistic and addresses physical, mental, emotional, and spiritual aspects of health. Diabetes and My Nation utilizes aspects of the Expanded Chronic Care Model to support improvement in diabetes care and prevention by accounting for both community and health system characteristics (see Figure 2).

FIGURE 2: The Expanded Chronic Care Model



Source: Diabetes and My Nation (2018)

Key components of Diabetes and My Nation include the following:

- Building bridges and relationships with providers inside and outside of the community
- Building collaboration within communities
- Self-determination: provide support for community identified needs
- Community empowerment and ownership
- Community knowledge and awareness
- Community motivation to overcome diabetes and support, sustain, and enhance programming
- Collaboration with, and support for community champions (e.g., Firekeepers)
- Acknowledgement and awareness of the impact of residential schools, colonization, and ongoing systemic racism and social exclusion on the health and well-being of Indigenous peoples

Programming is available for adults (The Circle of Diabetes Self-Management), youth (Our Spirit Lives), and school-age children (Health Warriors). In addition, community gatherings are developed and hosted that serve both to connect community members to traditional ways of living and eating, and to create opportunities to educate community members and increase diabetes awareness and knowledge within communities. In many cases, each age-specific program serves to increase awareness throughout the community as a whole, providing opportunities for healthcare providers to form therapeutic relationships with community members, and to identify, screen, and support those who may have diabetes or who are at high risk for developing the disease.

For more information, please visit: *www.diabetesandmynation.com*.

2.2.2. Kahnawake Schools Diabetes Prevention Project

Amelia Tekwatoni McGregor, Elder and Community Advisory Board Member, Kahnawake Schools Diabetes Prevention Project

The Kahnawake Schools Diabetes Prevention Project (KSDPP) began in 1994 as a 3-year National Health and Development Research Program (NHDRP) research project, and is a partnership between the Mohawk community of Kahnawake, represented through a Community Advisory Board, and the Kahnawake Education Center, Kateri Memorial Hospital Centre, McGill University, Université de Montréal, and, more recently, Queens University. KSDPP was developed out of community concern for high rates of diabetes, coupled with perceived increases of obesity in children and, importantly, Mohawk traditions to care for and protect future generations.

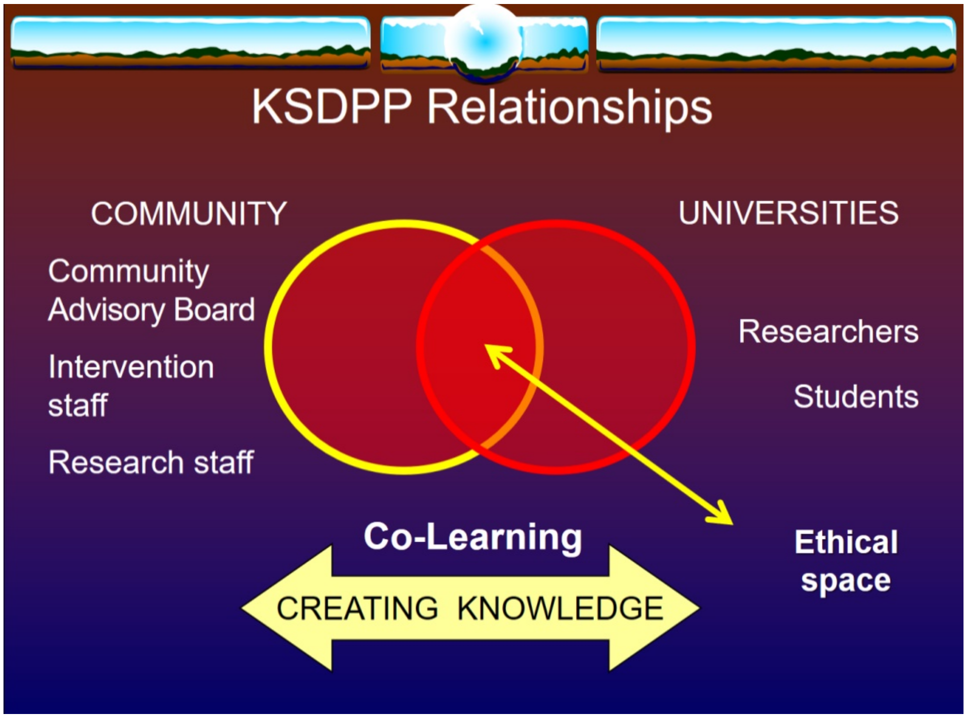
From the outset, the goal of KSDPP has been to prevent type 2 diabetes in future generations of Kahnawakero:non ("people of Kahnawake") through the promotion of healthy eating habits, daily physical activity, and a positive attitude. In 1995, Kahnawake developed a Community Vision, and also the KSDPP Code of Research Ethics (reviewed and revised 2005-2007).

The Community Vision states:

> "All Kahnawakero:non are in excellent health. Diabetes no longer exists. All the children and adults eat healthily at all meals and are physically active daily. The children are actively supported by their parents and family who provide nutritious foods obtainable from family gardens, local food distributors and the natural

> environment. The school program as well as local organizations maintain programs and policy that reflect and reinforce wellness activities. There are a variety of activities for all people offered at a wide range of recreational facilities in the community. All people accept the responsibility to co-operatively maintain a well community for the future Seven Generations."

The Code of Research Ethics was developed by community and academic partners with the community leaders "to establish a set of principles and procedures that will guide the partners to achieve the goals and objectives of the KSDPP."[11] Underlying the Code of Research Ethics are the principles of reciprocity and respect between all partners, creating a space for shared learning to occur.



KSDPP Relationships

COMMUNITY

Community Advisory Board

Intervention staff

Research staff

UNIVERSITIES

Researchers

Students

Co-Learning

CREATING KNOWLEDGE

Ethical space

The main governing body for KSDPP is the Community Advisory Board, which includes representatives from education, health, recreation, the Grand Council, social services, and economic development, as well as a spiritual adviser. The Community Advisory Board represents KSDPP as well as the community-at-large, participates in knowledge transfer, and are local ambassadors of wellness.

The Community Advisory Board is made up of volunteers and is responsible for ongoing sustainability, partnerships and research, program development and enhancement, and leadership. As such, these local champions are key to long-term changes that address obesity and diabetes in the community, and improving the health and well-being of community members.

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[11] Kahnawake Schools Diabetes Prevention Project (2007).

Kanien’kehá:ka Decision Making

2. People Across the Fire

(Consensus through discussion)

Researchers

1. Well keepers

(Global input develops agenda)

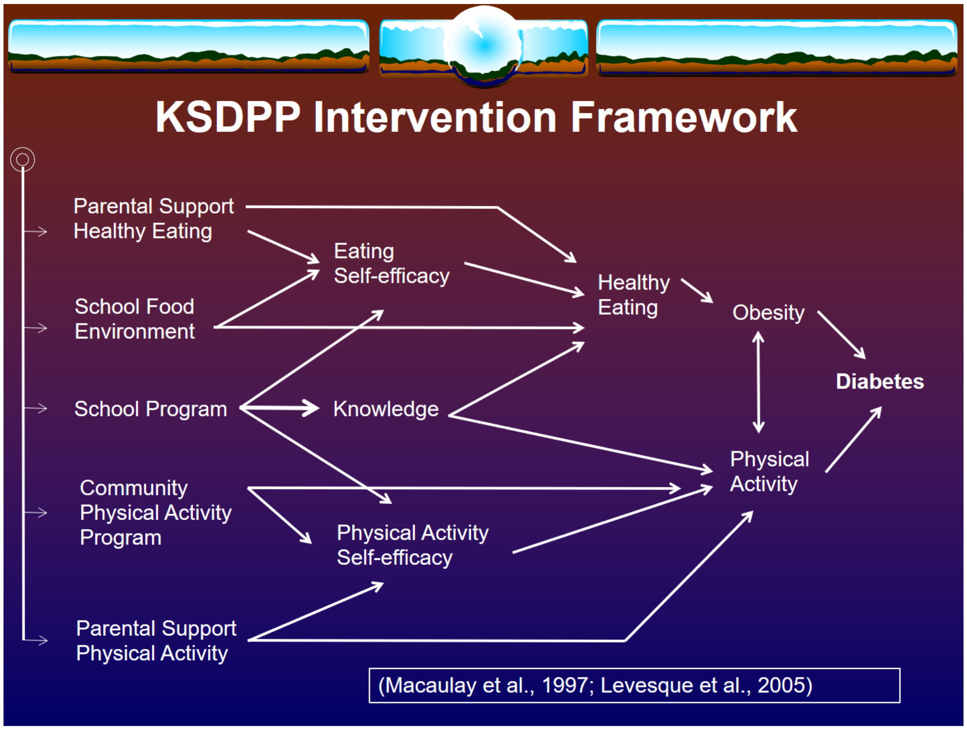
Staff

3. Fire Keepers

(Confirm the decision of the two sides)

Community Advisory Board

Broadly, KSDPP focuses on promoting healthy physical activity and eating habits through community- and school-based interventions. The framework involves interventions that are targeted both at youth as well as parents and the general community, providing healthy eating and physical activity support for parents and children, as well as supporting policy that limits unhealthy food selections in schools to promote the intake of healthy food choices.



KSDPP Intervention Framework

Parental Support Healthy Eating

School Food Environment

School Program

Community Physical Activity Program

Parental Support Physical Activity

Eating Self-efficacy

Knowledge

Physical Activity Self-efficacy

Healthy Eating

Obesity

Physical Activity

Diabetes

(Macaulay et al., 1997; Levesque et al., 2005)

For more information, please visit: *www.ksdpp.org/*.

2.2.3. Reorganizing the Approach to Diabetes through the Application of Registries (RADAR)

Dr. Dean Eurich, Professor, School of Public Health, University of Alberta
Kari Meneen, Team Lead, RADAR, Diabetes Care Coordinator, Okaki Health Intelligence Inc.

Work with First Nations needs to be completed with a commitment to authentic relationships that are based on trust, respect, and honesty, and that listen to and address community identified needs. This work must also acknowledge and respect the diverse culture and languages within each community, as well as the inherent rights of First Nations, such as treaty rights, and what these rights mean to each community. The development of authentic relationships, listening to communities, and trust, respect, and honesty are necessary prerequisites to effective community engagement, which, in turn, prioritizes community leadership, builds community engagement, and supports the delivery of health and social services that meet community needs.

How to Engage the FN Communities

- Has to be a partnership….
  - Commitment to authentic engagement
    - Stop talking and listen….
  - Shared respect, **trust**, accountablilty, and commitment to a **long-term relationship**
    - *“Researchers come in and do their ‘thing’ and leave and we are no better off than when they came in”*
  - Acknowledgement of the inherent rights of the FN
    - Once you take the time to understand things, it can make supporting care much easier
- **Goals**
  - Commitment to address the **priorities and needs of the FN communities**…outcomes have to be of **value to the FN communities…**

In many First Nations communities, diabetes care is reactive and relies on patients to present to a healthcare provider. However, patients frequently delay or avoid medical care and treatment due to previous, negative experiences with the health system and care providers, and only present to care when they experience severe symptoms resulting from chronic hyperglycemia. In addition, community healthcare providers are also operating at maximum capacity, and are unable to develop additional programming or take on more patients due to resource limitations. Together, these processes, as well as geographic dispersion, create barriers to timely care for many First Nations people, and minimize opportunities for disease prevention, treatment, and support for ongoing management.

Alternatively, proactive diabetes care can support significant improvements in the health and well-being of patients. One important aspect of proactive care involves actively screening and engaging with high-risk individuals, and routinely monitoring their health over time.

Information systems are the foundation for screening programs and are essential supports for proactive care. RADAR uses an electronic medical record (EMR) program with back-end analytic capabilities (connected to other software, i.e., Health Canada, Netcare) to identify, and track diabetes and at-risk patients to support their care and disease management. RADAR also capitalizes on a range of opportunities to connect with patients and high-risk individuals, such as when they present to health centres with non-diabetes related issues, influenza vaccine clinics, and social gatherings.

Diabetes Canada's clinical practice guidelines stress that information systems are a key part of tracking diabetes in communities. In addition, the guidelines emphasize the importance of "The 5 Rs" (Recognize, Register, Resource, Relay, Recall) for effective diabetes care which are incorporated in RADAR.

The 5 Rs for care for patients with diabetes

- **Recognize**: Identify diabetes risk factors in community members and screen appropriately for diabetes.
- **Register**: Enter individuals into an easily accessible information system to track patients with diabetes and risk factors.
- **Resource**: Human resources and a range of interdisciplinary care personnel (i.e., physicians, diabetes nurse educator, pharmacist, dietitian, other specialists) are needed to support patient self-management, and to operate effective screening and care programs. In many First Nations communities, community care providers are already working at full capacity and more resources are needed to develop and implement screening programs and to care for new patients.
- **Relay**: Information sharing between the patient and care providers within, and outside of communities to support coordinated care and timely management.
- **Recall**: Recall systems support ongoing care, timely review of risk factors, and the proactive management of complications and risk factors for complications, to help patients reach health targets over time.

Adapted from: Diabetes Canada (2018)

Information systems for diabetes care require substantial infrastructure and can be difficult to implement in First Nations communities due to issues of trust, privacy, data access, and control. Often, these challenges stem from previous negative experiences with researchers and the health and education systems. However, authentic relationships built on respect and reciprocity, and support for community-led initiatives, can help to bridge these gaps.

RADAR is built on a two-component system. The first is a technological component that integrates an electronic patient registry with an EMR system that includes back-end population analytics capabilities and compatibility with other information systems to support seamless information sharing with other care providers (inside and outside of the community). The population analytics capability of the patient registry system is connected to the EMR, and allows communities to quickly identify patients within their populations with substantial risk factors for diabetes so that these individuals can receive appropriate clinical care to reduce their risk for diabetes, and to screen and monitor for disease progress in an appropriate manner.

The EMR program has been built specifically for use in First Nations communities, with built-in features that supports Health Canada reporting, and plans to incorporate features that directly interact with Netcare (the provincial EMR system) to automatically pull information and update clinical records within the EMR. The EMR tracks medications, laboratory reports, tasks, targets, and completed assessments, and includes a diabetes care module that tracks and supports patient care and assessment specific to diabetes. In addition, communities have significant input on the EMR system, and, every three to four months, the build team implements changes recommended by frontline workers and care staff.

The second component of RADAR is the use of centralized care coordinators that support patient care and management. The care coordinators address capacity issues and support adherence to guideline recommended care in First Nations communities through a sustainable, economical, and scalable model. Working electronically, care coordinators can support diabetes care in multiple communities from one centralized location. They are able to work with care providers through remote case conferences, and otherwise support the proactive delivery of guideline-recommended care by ensuring clinical records are continuously updated; identifying patients who require follow-up or are due for care or assessment; and enter tasks, outcomes, and clinical reminders into the system.

A formal evaluation of RADAR will be completed in 2021. However, initial anecdotal evaluation has found that, at a minimum, the RADAR program has improved communication and information sharing within and outside of communities, and has supported improvement in access to multidisciplinary care for patients.

For more information, please visit: *http://www.okaki.com/whatwedo.html#rad*.

3. Summary of Roundtable Discussion

3.1. Overview

Following the best practice presentations, Dr. Keith Dawson moderated a discussion between roundtable participants. The following three questions were formulated to stimulate participant reflection and guide discussion; however, the conversation was not limited to these questions.

- What are key barriers/challenges that limit the success of diabetes treatment and management programs across the country?
- Are there common approaches/characteristics of successful programs that can be applied across Canada?
- Are there key lessons that might inform pan-Canadian strategies or priorities for more targeted policy dialogues or research?

3.2. Key Themes and Lessons Learned

Throughout the discussion we identified four key themes, as outlined and discussed below:

- Historical influences and past experiences
- Community leadership and ownership
    - Working with and supporting communities
    - Patient and provider education
    - Collaboration and holistic care
    - Program population coverage
- Jurisdiction and governance
    - Capacity and sustainability
- Health data and community knowledge
    - Evaluation

While we have presented each theme individually, we recognize and acknowledge that the issues are not independent. Instead, they are highly interrelated and connected, and it is important that these interdependencies are acknowledged to inform policy and program development, and support improvements in diabetes care for Indigenous peoples.

3.2.1. Historical Influences and Past Experiences

> "The target organ is really the brain, it's really about loss of hope. What's the storyboard of Indigenous healing? How does diabetes turn into recovery and how do we reclaim well-being? And what is the trajectory of getting better and wellness rather than the trajectory of illness?"
>
> *- Roundtable participant*

In Indigenous populations, diabetes is inextricably linked to historical and ongoing cultural, social, political, and economic factors and processes including poverty, food insecurity, intergenerational trauma, mental health, and racism, among many others. These factors are both core contributors to the development of risk factors and onset of diabetes, as well as key components driving differences in treatment outcomes, complication rates, and mortality.

> "I think multi-generational trauma exacerbated by poverty is driving diabetes, and diabetes is really just a symptom of the multi-generational trauma and poverty that has been experienced in so many communities. So, it's been 25, 30 years of work, and to be honest, very little has been accomplished in that period of time because we haven't addressed the underlying causes of causes."
>
> *- Roundtable participant*

In addition, these factors can make efforts to treat diabetes difficult, and, in many cases, it is not possible to begin effective treatment until other factors such as food security, education, running water, housing, safety, and mental health are addressed.

> "You can't eat fish if you don't have fish. I don't know who said that but I thought 'that's so clever' because, as a healthcare provider, you can talk about diabetes, you can be the expert on diabetes and simplify it to plain language…but if that person doesn't know how to fish, or that person has a child who has a drug addiction, or if that person has all these other issues, it doesn't matter how beautiful your charts are…you can't help that person address that issue. And as a diabetes educator, when I had people in my office telling me that they had all these other mental health issues I was at a loss…So, if we're not equipped either as an individual or as a community to address all of these other issues, yes, working with the person one on one, bringing it down to their level of literacy and understanding is very, very, very important, but it's only a part of it because the bigger picture is the environment in which they're living in."
>
> *- Roundtable participant*

3.2.2. Community Leadership and Ownership

A common theme across the best practice presentations and in discussion was that care programming is enhanced and more effective when it is community-initiated and community-led. In Kahnawake, the diabetes program was borne out of community recognition that obesity and diabetes rates were increasing, as well as Mohawk traditions to care for and protect future generations. Similarly, Diabetes and My Nation works with communities that request their programming and support and invite them into their communities.

Community leadership creates an environment that facilitates community ownership and responsibility of care programming, which can increase enthusiasm and participation, supports ongoing sustainability, and positions communities as leaders and partners in the development and implementation of care, which, altogether, supports improved individual and community health and well-being.

In addition, community leadership can ensure that community needs are heard, and that programming is delivered in a way that respects and upholds local culture, traditions, beliefs, and values.

Working with and supporting communities

Recognizing the need for and benefits of community leadership, it is important that government policy, researchers, and care providers support these processes and understand and accept their role as partners supporting community objectives. As a foundational pillar, these partnerships need to be built on authentic relationships and principles of trust, respect, honesty, and reciprocity to be effective. Accordingly, developing these relationships and partnerships takes time, commitment, and investment, but are key to developing and implementing effective community programs.

Likewise, developing effective, individual, therapeutic relationships relies on these same foundational principles such that community members are respected partners in their care, so that care responds to patients' needs and what is important to them. Notably, these same principles are essential to delivering culturally safe care, and are also basic elements of relational care, which is rooted in the values and teachings of Inuit, Métis, and First Nations cultures, and has been a successful approach to care for Indigenous patients.[12]

Care providers from outside of the community must also acknowledge and respect the inherent rights of Indigenous communities, such as treaty rights, and what these rights mean to each community, as well as the diversity between Indigenous groups and communities.

Other aspects of community leadership and working with communities, including patient and provider education, collaboration and holistic care, and universal program population coverage are discussed in more detail below.

Patient and provider education

Patient knowledge is an important component of diabetes care and a key prerequisite to effective self-management, and can serve to empower and motivate patients. However, in many communities, patients have insufficient knowledge of their disease, treatment, and how to effectively manage their diabetes. The presence of these knowledge gaps suggests a need for increased patient education, which could benefit from increased educational opportunities including more programming as well as the adoption of alternative educational tools such as electronic education and self-management tools. In addition, healthcare providers may also benefit from educational opportunities in order to learn approaches to more effectively deliver diabetes education to patients and to facilitate

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[12] Canadian Aboriginal Aids Network (2008).

knowledge transfer, as well as to learn how to more effectively motivate people to make healthy changes in their lives. Another option, given concerns of community health worker capacity, is to train community members as diabetes educators to deliver programming and support patient education.

> "There's lots of people who can be diabetes educators including family members, community members, and individuals…[it's about] communities taking on roles that don't necessarily require professional qualifications to deliver it."
>
> *- Roundtable participant*

Notably, diverse approaches to increase diabetes knowledge have been utilized across the country. In particular, one program mentioned, Moms in Motion, used a combination of community educator training, educational toolkits for patients, group educational sessions, social engagements, and social media to engage and educate community members and (gestational) diabetes patients.[13]

Collaboration and holistic care

> "Diabetes is a healing problem, not just a medical problem."
>
> *- Roundtable participant*

For Indigenous peoples, the concept of health is defined holistically and much more broadly than just disease and treatment. Health incorporates physical, emotional, mental, and spiritual elements of life, and balance between these elements is essential to support a strong and healthy person. Therefore, programming should address the holistic well-being of patients and not just diabetes-related treatment. This work relies on communication, collaboration, and coordination between healthcare providers as well as other community services to deliver care that meets a diverse range of patient needs.

Program population coverage

All programs highlighted in the best practice presentations provided care and prevention programming to all age groups. This broad focus supports the development of healthy eating and living habits, and disease prevention, treatment, and management across age groups, and produces interesting opportunities for shared learning by creating bridges to connect with select patient groups that are otherwise absent from care and prevention programming. For instance, the adult male population is often difficult to reach; to overcome this difficulty and engage with this demographic, Diabetes and My Nation uses community events that teach traditional practices in order to create opportunities for diabetes education and awareness. In addition, shared learning occurs when children and youth share their knowledge gained through school programs with their parents and other members of their families and extended families.

3.2.3. Jurisdiction and Governance

The mix of federal, provincial, and community responsibility for the delivery of health services in many Indigenous communities creates ambiguity and unclear accountabilities and responsibilities

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[13] See: *momsinmotion.ca/* and *www.canadianjournalofdiabetes.com/article/S1499-2671(17)30472-0/pdf*.

between partners for the delivery of health services. In addition, this complicated separation of responsibility for health services creates bureaucratic hurdles that can impede access to timely care for many Indigenous people.

Challenges in managing diabetes and complications can also be linked to jurisdictional variation in public and private insurance coverage for medications and supplies for those managing their diabetes.[14] This also extends to differences in formularies dependent on the provider and jurisdiction, resulting in disparate and inequitable access to supports based on where patients live.[15]

Capacity and sustainability

Building community capacity was identified as a key element of building successful and sustained programming. In the best practice presentations, "Firekeepers" or community champions, volunteers, and community-trained educators and care providers were key to the ongoing success of diabetes programs, acting as champions and as ongoing links of community knowledge. In addition, building community capacity and training local community members may also mitigate the impact of high healthcare provider turnover, which was identified as an issue by representatives from communities all across Canada. Other programs, such as RADAR, were built on care models that provide community knowledge, care, and program continuity throughout community care staff turnover by using centralized care coordinators.

Limited funding was also noted as a challenge to program sustainability, and highlighted the need for increased end-of-grant planning and increased investment in community capacity.

Acknowledging the benefits of investment in building community capacity, there is also a need to address challenges to community healthcare provider capacity. In many communities, healthcare providers do not have the resources or capacity for new patients, and simultaneously lack resources and capacity to spend time on program improvement to deliver proactive care. These care providers take on multiple roles in communities and are overworked and under-resourced, which may lead to burnout and, consequently, high provider turnover.

3.2.4. Health Data and Community Knowledge

Information systems and patient registries are the foundation for screening programs and are essential supports for proactive care. These systems require substantial infrastructure, and should be implemented through work with communities to ensure that issues of trust, privacy, data access and control are addressed, and that systems are adaptable and responsive to community needs. Authentic relationships built on respect and reciprocity, and support for community-led initiatives can help to bridge these gaps.

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[14] Institute of Health Economics (2017).

[15] Canadian Diabetes Association and Diabetes Québec (2011).

Evaluation

> "The word 'value' is in evaluation, and I've been thinking about whose values count, and what this means when we are working in a pluralistic health system where we are giving equal weight to these two systems. And then, there's the problem of rigor and evidence…and I say, we have to weigh these things equally. We have to come up with Indigenous evaluation methods that are designed with the participation of communities that are used by communities so they can assess the value of their own programs to them."
>
> *- Roundtable participant*

> "One of the problems is that the measure of quality for diabetes care in Western medicine is an improvement in health, and they mean *physical* health, and not *mental* health."
>
> *- Roundtable participant*

Program evaluation is an important aspect of healthcare improvement, and can be used to support process improvement and the effective allocation of resources. However, how care is evaluated can have a major impact on the findings, which, in turn, have implications on program policy and resource allocation. Too often, non-Indigenous methods that emphasize clinical outcomes are used to evaluate Indigenous programming. These methods often fail to acknowledge differences in Indigenous and non-Indigenous knowledge paradigms, and do not adequately capture Indigenous conceptualizations of health, especially the social, emotional, spiritual, and mental dimensions of health and well-being.

4. Conclusions

> "How do we, with your help and others, reconcile our health status? Well, I think for starters…you ask yourself, what do I do I do differently this time?...Otherwise, we're going to be here 50 years from now and you're going to be 50 years older and we're still going to be falling behind and not getting on top of this epidemic, this pandemic that's happened. We can't afford not to begin to move forward."
>
> *- Roundtable participant*

An overarching theme from the roundtable was *approaching care and Indigenous health differently*, to include Indigenous people, communities, culture, values, worldviews, and traditions as core and foundational pillars in the development, implementation, and evaluation of healthcare programming. Embracing this approach invokes a spirit of reconciliation, and requires a willingness to see each other in different ways, and to begin to understand each other and invest in relationships built on respect, reciprocity, compassion, trust, dignity, and understanding as core principles. These relationships serve to empower patients, communities, and populations, and are a key to any improvement in Indigenous health.

Overall, these changes in our approach to Indigenous health give communities the opportunity to express their needs, and to develop programming that specifically meets their needs in appropriate and acceptable ways. Accordingly, changes in our approaches to care are required, from the intervention- and symptom-centred medical approaches of Western medicine, to more proactive and holistic approaches based on Indigenous conceptualizations of health. A holistic approach to care requires integration, alignment, and communication between a mix of community services, and medical, non-medical, and lay care providers, which not only serves to support the delivery of culturally appropriate care, but is also instrumental to overcome social, economic, and sometimes geographic and financial barriers that otherwise impede access to health and social services and contribute to poor health outcomes for many Indigenous peoples.

Other areas where new approaches could be beneficial and improve patient care are enhanced patient and provider education, and scalable approaches to increase community care capacity.

Diabetes is an important area for urgent and focused attention given the impact on Indigenous populations and the strong link between diabetes and other disease conditions. As we enter this new era, there are many initiatives underway that have been built on a spirit of reconciliation, and have embraced respect, reciprocity, understanding, as core principles. These initiatives consciously create circumstances where patients know that someone cares about them. The preconditions of "feeling loved" and "being heard" were emphasized in deliberations at the roundtable and spoke to sustained and authentic relationship building. Even without further financial investment, there are ways to improve the health and well-being of Indigenous people by:

> "learning to see people differently, and embracing one another with care, compassion, respect, and understanding to improve the quality of their lives, create social justice, equality, good health, and security, and instill hope in others" (roundtable participant).

4.1. Strengths and Limitations

Importantly, this report reflects the themes and discussion expressed by delegates throughout the roundtable, which was a half-day event. Subsequently, it may offer an incomplete overview of important issues, considerations, and concepts regarding diabetes care and management in Indigenous peoples in Canada, and may only represent the thoughts, viewpoints, and experiences of the organizations and individuals in attendance. Further, many initiatives across Canada have worked with communities to create substantive improvements in diabetes care for Indigenous peoples, and those presented here are only a few examples that were identified and able to attend the roundtable.

Despite these limitations, the roundtable was attended by a diverse group of individuals and organizations, representing a range of backgrounds, professions, communities, provinces, territories, and national agencies with varying roles in Indigenous health and diabetes care, management, and treatment. The diversity of our delegates and strong representation of community voices to share local experiences, knowledge, and needs was a key to the success of the event and a strength for this report.

Altogether, these details are important contextual factors that impact our findings and recommendations, which should be considered in association with other recent reports and recommendations.

4.2. Recommendations

These recommendations are based on the major themes discussed throughout the roundtable. The recommendations have been divided into two groups: *foundational* recommendations address necessary components that form the basis of relationships with Indigenous people and communities, and *applied* recommendations reference some actionable areas that could be immediately impactful.

Of note, these recommendations align with recommendations for health system transformation outlined in the First Nations Health Transformation Agenda,[16] as well as other past recommendations[17] and recent lessons and opportunities for innovation in primary care to improve the health and well-being of Indigenous populations.[18]

Foundational recommendations

1. **Formal mechanisms for Indigenous perspectives in program planning**. Indigenous health programming and policy should: be developed in collaboration with Indigenous leadership and community voices; include Indigenous worldviews and conceptualizations of health and well-being; and be tailored to the unique needs, culture, and values of each community. This should be accommodated explicitly and formally in the program development process and in outputs such as guidance and approaches to evaluation.
2. **Formal articulation of principles for interaction**. Work with Indigenous communities and clinical relationships with Indigenous patients should be predicated on authentic relationships and principles of trust, respect, honesty, and reciprocity. Principles for interaction should be explicitly articulated with some identified action items for regular evaluation of whether this has occurred.

Applied recommendations

1. **Active recruitment and development of workforce from community**. Community members should be trained as diabetes educators and diabetes care support workers to increase community care capacity, diabetes knowledge, and public health awareness, and to support culturally appropriate care and long-term program sustainability. For example, training traditional healers as diabetes educators and care workers supports the integration of traditional healing and Western medicine and increases access to culturally appropriate health services and treatment, which, in turn, can increase compliance with treatment and produce improved outcomes.
2. **Sustained engagement and mechanisms to support the sharing and development of best practices and tools for evaluation**. Program evaluation should be rooted in Indigenous conceptualizations of health and well-being and include views of health and aspects of well-being that are important to community members. This may include a variety of community-based, participatory methodologies. A repository of best practices, checklists, and tools should be created and made widely accessible to communities, researchers, and policymakers to support appropriate evaluation of Indigenous health programming. Moreover, there is a need for sustained prioritization in this area to encourage ongoing research to develop community-centred methodologies, and to create opportunities for pan-Canadian knowledge exchange and sharing of best practices.
3. **Reduce barriers to a comprehensive range of diagnostic and treatment modalities**. Diabetes care in many Indigenous communities is reactive and lacks essential technological

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[16] Assembly of First Nations (2017).

[17] Harris et al. (2013); Office of the Auditor General of Canada (2013).

[18] Henderson et al. (2017).

infrastructure to support proactive care, including prevention, early detection, and ongoing monitoring and treatment. A full complement of available diagnostic tools and treatments for diabetes care should be available for providers in addressing diabetes in Indigenous populations without significant restrictions or barriers.

4. **Integrated population health surveillance**. Diabetes surveillance systems tailored to community needs that are adaptable, scalable, and integrated with patient EMRs and other reporting systems are required. These are important components of proactive diabetes care, treatment, and management, and widespread adoption of these information systems and registries should be encouraged and supported in communities across Canada. Health data collection should address community concerns of trust, privacy, data access, and control, and conform with OCAP® (Ownership, Control, Access, Possession) principles.[19]

4.3. Next Steps

Following the roundtable, there has been significant interest in ongoing activities that build on the relationships and partnerships developed during the roundtable to support policy development, knowledge translation and application, and pilot projects related to diabetes care in Indigenous populations. These activities will be co-developed with a range of communities, community leaders, and academic and clinical experts, and implemented throughout 2018 and into 2019 to drive meaningful policy change and support the health and well-being of Indigenous peoples in Canada.

Of note, revised clinical care guidelines for diabetes care in Indigenous peoples will be released in Spring 2018, and it is expected there will be opportunities to support uptake and translation into practice in combination with other recommendations made in this report.

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[19] First Nations Information Governance Centre (2018).

Appendix A: Roundtable Program

Diabetes Care and Management in Indigenous Populations in Canada: *A Pan-Canadian Roundtable*

INSTITUTE OF HEALTH ECONOMICS
ALBERTA CANADA

DATE: 1ST NOVEMBER 2017

TIME: 12:00PM – 6:00PM

LOCATION: WESTIN EDMONTON HOTEL, DEVONIAN ROOM
10135 100 ST NW, EDMONTON, AB

PROGRAM

12:00 – 12:45	Lunch
12:45 – 1:00	Welcome and Blessing • Elder Marvin Littlechild, Treaty No. 6
1:00 – 1:50	Context Setting: • Overview of Roundtable background report: The economic impact of Type 2 Diabetes in Indigenous populations in Canada. John Sproule Senior Policy Director, Institute of Health Economics • The First Nations Health Transformation Agenda Addie Pryce Director of Health, Assembly of First Nations • Keynote Address Chief Dr. Robert Joseph O.B.C. Chief, Gwawaenuk First Nation; Ambassador, Reconciliation Canada
1:50 – 3:05	Engaging Communities: Key Learnings and approaches to engage community leadership, ownership, and address local needs. Examples from across Canada: • Diabetes and My Nation Hesham Nabih President, HN Consultants Ltd. • Kahnawake Schools Diabetes Prevention Project Amelia Tekwatonti McGregor Elder and Community Advisory Board Member, Kahnawake Schools Diabetes Prevention Project

	• Reorganizing the Approach to Diabetes through the Application of Registries (RADAR) Dr. Dean Eurich Professor, School of Public Health, University of Alberta Kari Meneen Team Lead, RADAR; Diabetes Care Coordinator, OKAKI Health Intelligence Inc.
3:05 – 3:25	Break
3:25 – 4:45	Panel reflection and group discussion: *Based on the presentations and your own experiences:* • What are key barriers/challenges that limit the success of diabetes treatment and management programs across the country? • Are there common approaches/characteristics of successful programs that can be applied across Canada? • Are there key lessons that might inform Pan-Canadian strategies or priorities for more targeted policy dialogues or research? Panelists: 1. Dr. Jon McGavock Associate Professor, Faculty of Health Sciences, University of Manitoba; Research Scientist, Children's Hospital Research Institute of Manitoba 2. Lerinda Wright Registered Nurse (RN), Seabird Island Band Mobile Diabetes Team Moderator: • Dr. Keith Dawson Professor of Medicine, University of British Columbia; Endocrinologist, Vancouver General Hospital Group Discussion
4:45 – 5:00	Wrap-up: Key themes and messages • John Sproule, Institute of Health Economics • Mehmood Alibhai, Boehringer Ingelheim
5:00 – 6:00	Reception

The event is supported through an unrestricted grant from Boehringer Ingelheim Incorporated.

SPEAKERS AND PANEL MEMBERS

Overview Presentation and Opening Remarks

John Sproule

Senior Policy Director, Institute of Health Economics (IHE)

John Sproule has been the IHE's Senior Policy Director since 2007. During his time at IHE John has been seconded to work for the Alberta government in both the Ministers Office for 2012-13 and the Deputy Ministers Office in 2015/16. He has also worked part time while at IHE for Alberta Innovates Health Solutions in support of provincial health innovation strategies. Prior to joining the IHE he served as Vice-President of Strategic Planning and Community Engagement at Vancouver Coastal Health Authority. From 1998 to 2005 he worked with Merck Frosst Canada Ltd in health and industry policy planning (including secondment to Merck Sharpe & Dohme Australia). Before that John worked with the Alberta government as Director of the Office of the Deputy Minister of Health, working with the Ministry from 1987 to 1998 and managing significant policy and legislative changes in the Alberta health system. He has served on many federal/provincial committees in health and as a Board member with a number of health policy academic associations including Canadian Health Economics Research Association, Canadian Association for Population Therapeutics, Canadian Association for Health Services and Policy Research, Health Technology Assessment International (host agency rep) and served as the Chair of the Pacific Northwest Economic Regional Health Care Working Group. John has a Master of Public Management from the University of Alberta.

First Nations Health Transformation Agenda

Addie Pryce

Director of Health, Assembly of First Nations

Addie joined the Assembly of First Nations (AFN) as the Director of Health in June 2017. Addie has worked exclusively in First Nations programming throughout her career at the community level, and with regional and national organizations. Over the last four years, Addie worked with the First Nations Information Governance Centre (FNIGC). Her work with FNIGC was preceded by a 32-year career with the Federal Government, including in various capacities with FNIHB. Addie is from the Nisga’a Nation of Gingolx, located on the north coast of BC.

Keynote Speaker

Chief Dr. Robert Joseph O.B.C.

Chief, Gwawaenuk First Nation; Ambassador, Reconciliation Canada

Chief Dr. Robert Joseph, O.B.C. is a true peace-builder whose life and work are examples of his personal commitment. A Hereditary Chief of the Gwawaenuk First Nation, Chief Joseph has dedicated his life to bridging the differences brought about by intolerance, lack of understanding and racism at home and abroad. His insights into the destructive impacts these forces can have on peoples’ lives, families and cultures were shaped by his experience with the Canadian Indian Residential School system. As one of the last few speakers of the Kwakwaka’wakw language, Chief Joseph is an eloquent and inspiring Ceremonial House Speaker. He shares his knowledge and wisdom in the Big House and as a Language Speaker with the University of British Columbia, an internationally recognized art curator and as co-author of “Down from the Shimmering Sky: Masks of the Northwest Coast”.

In 2003, Chief Joseph received an Honorary Doctorate of Law Degree from the University of British Columbia for his distinguished achievements in serving BC and Canada. In 2012, he was presented The Diamond Jubilee Medal by the Right Honourable David Johnston, Governor General of Canada. In 2014, he received the Jack P. Blaney Award for Dialogue from Simon Fraser University and an Honorary Doctorate of Divinity from Vancouver School of Theology for his work in reconciliation and renewing relationships between Indigenous peoples and all Canadians. In 2015, Chief Joseph was presented a Deputy Ministers' Recognition Award for Collaboration and Partnerships and was appointed to the Order of British Columbia, the Province of British Columbia's highest honour. In 2016, Chief Joseph received the Wallenberg-Sugihara Civil Courage Award and the Indspire Lifetime Achievement Award. Chief Joseph is currently the Ambassador for Reconciliation Canada and a member of the National Assembly of First Nations Elders Council. He was formerly the Executive Director of the Indian Residential School Survivors Society and is an honourary witness to Canada's Truth and Reconciliation Commission (TRC). As Chairman of the Native American Leadership Alliance for Peace and Reconciliation and Ambassador for Peace and Reconciliation with the Interreligious and International Federation for World Peace (IFWP), Chief Joseph has sat with the leaders of South Africa, Israel, Japan, South Korea, Mongolia and Washington, DC to learn from and share his understanding of faith, hope, healing and reconciliation.

Presentations

Hesham Nabih
President, HN Consultants Ltd.
Hesham Nabih has 30 years of experience developing environmental and health management solutions for government agencies and major industries. Among his projects are Live Well with Diabetes, a web based diabetes education program, Virtual Diabetes Centre, and Diabetes and My Nation (a First Nation community based diabetes prevention and management program).

Amelia Tekwatonti McGregor
Elder and Community Advisory Board Member, Kahnawake Schools Diabetes Prevention Project
Amelia Tekwatonti McGregor is a Kanienkeha:ka woman who was born, raised and always lived in the community of Kahnawa:ke. She is from the Bear Clan Family. She sees herself as energetic, considers herself to have common sense as well as a strong sense of humour. She is an only child and so she decided at a very young age to have more than one child. She & her husband Joseph have been married for over fifty years and are working on the next fifty!! They are the proud parents of five daughters who gave them six granddaughters and four grandsons, one of which is a foster child who has just turned seven years old in January. Her mother was a woman who lived with diabetes, so the seeds of interest were planted to become involved in the Kahnawak:ke Schools Diabetes Prevention Project (KSDPP). She is a volunteer member of the project through the community advisory board (CAB) since 1994. She has served as the Chairperson of its Executive Committee since 2004. When her term ended, there was opportunity to become the Elder of that committee where she has remained up to the present. KSDPP has given her the opportunity to attend many workshops and conferences all over Canada as well as to Australia and New Zealand.

Dr. Dean Eurich
Professor, School of Public Health, University of Alberta
Dr. Eurich is a Professor in the School of Public Health, and the Program Director for the Clinical Epidemiology program at the University of Alberta. His other roles include: ACHORD Research Associate, Member of the Alberta Diabetes Institute Research & Trainee Steering Committee at the U of A, member of Diabetes Canada National Research Council, Chair for the New Investigator Awards Committee of Diabetes Canada, and is a Joint Lead, Career Development in Methods and Health Services

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Research for Alberta's Strategy for Patient Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) unit.

Dr. Eurich's research focuses largely in the areas of chronic disease, and health promotion and prevention activities. Within those core areas, his research targets diabetes, cardiovascular disease, cancer, and respiratory illness.

Kari Meneen

Team Lead, RADAR, Diabetes Care Coordinator, OKAKI Health Intelligence Inc.

Kari Meneen-Haggerty is a Registered Nurse and Certified Diabetes Educator with extensive experience working in First Nation Communities. Kari has worked in the communities as a Home Care Nurse, Retinal Photographer, Diabetes Educator and currently as a Care Coordinator for a Diabetes initiative called RADAR (Reorganizing the Approach to Diabetes through the Application of Registries).

Kari has been providing front line diabetes care and management to patients with diabetes for almost 8 years. In her current role she supports front line nurses and community health workers in improving the care and outcomes of patients with diabetes. She is passionate about improving access to diabetes care and the health outcomes of First Nations peoples and communities. Kari's skills include nursing education, nursing process and project management. She holds a degree a Bachelor of Arts in Applied Psychology from Concordia University College (2005), a Bachelor of Science in Nursing from University of Alberta (2010) and is currently completing a Master of Business Administration from Athabasca University.

Panel Presentations

Panelists

Dr. Jon McGavock

Associate Professor, Faculty of Health Sciences, University of Manitoba; Research Scientist, Children's Hospital Research Institute of Manitoba

Dr. McGavock is an associate professor in the Department of Paediatrics and Child Health within the Faculty of Health Sciences at the University of Manitoba. He is currently the co-leader of the DREAM Theme at the Children's Hospital Research Institute of Manitoba. Dr. McGavock held a CIHR New Investigator Salary Award from 2010-2014 and currently holds a CIHR Applied Health Chair in Obesity and Resilience in Indigenous Youth. His research program is focused on the prevention and management of type 2 diabetes in youth, with a particular focus on physical activity. His research program has three distinct pillars designed to span the spectrum of mechanistic human physiology studies to community-based participatory action research.

Dr. McGavock's formal training is in Kinesiology. He completed a Bachelor's Degree in Physical Education at the University of Manitoba (1997), a Masters Degree in Exercise Physiology at McGill University (1999) and a PhD in Exercise Science at the University of Alberta (2003). Following his doctoral degree he completed a CIHR-funded post-doctoral fellowship within the Albert-based STIHR training program TORCH (2003-2004) and a Heart and Stroke Foundation/CIHR Target Obesity Fellowship in Internal Medicine and Cardiovascular Exercise Physiology with Drs. Benjamin Levine and Ron Victor UT Southwestern Medical Centre (2004-2006).

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Lerinda Wright

Registered Nurse (RN), Seabird Island Band Mobile Diabetes Team

Lerinda Wright is a member of the Norway House Cree Nation in Manitoba. Lerinda has been working as a Registered Nurse for the past 28 years both in First Nations communities and Provincial Health Authorities. She recently joined the Seabird Island Mobile Diabetes Team in BC in 2015, and is one of four core team members that travel the southern parts of BC, covering 86 First Nations Bands. There are currently three mobile diabetes clinics serving BC First Nations: The Inter-Tribal Health Authority Tele-Ophthalmology Project (Vancouver Island, British Columbia), Carrier Sekani Family Services Mobile Diabetes Telemedicine Clinic (northern British Columbia), and Seabird Island Mobile Diabetes Telemedicine Clinic (southern mainland British Columbia). The latter two also provide point-of-care laboratory testing, physical assessments and data entry into the Virtual Diabetes Centre platform. With a mandate to see known diabetics on reserve, the team also is able to offer professional development for health care providers and screening opportunities at health fairs and communities events with Band members who are at high risk.

Moderator

Dr. Keith Dawson

Professor of Medicine, UBC; Endocrinologist, Vancouver General Hospital

Dr. Keith Dawson is an emeritus Professor of Medicine (Endocrinology) at the University of British Columbia and Vancouver General Hospital. A graduate of Princeton University (AB), Columbia University (MD) and McGill University (PhD), He was a member of the McGill Faculty of Medicine and since 1978 the University of British Columbia Faculty of Medicine, teaching and treating people with diabetes. He is author of some 50 research papers in the field.

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Appendix B: Roundtable Participants

TABLE B.1: Roundtable advisory committee members

Dr. Lindsay Crowshoe (University of Calgary)	Dr. Braden Manns (University of Calgary)
Dr. Keith Dawson (University of British Columbia)	Dr. Angela Mashford-Pringle (University of Toronto)
Dr. Dean Eurich (University of Alberta)	Ms. Lara McClelland (Alberta Health)
Chief Robert Joseph (Gwawaenuk First Nation)	Ms. Kari Meneen (Okaki Health Intelligence Inc.)
Dr. Malcolm King (Simon Fraser University)	Dr. Jeff Reading (Simon Fraser University)
Dr. Alex McComber (Kahnawake Schools Diabetes Prevention Project)	

TABLE B.2: Roundtable participant affiliations

Alberta Health	Health Canada First Nations and Inuit Health Branch
Alberta Health Services	Kahnawake Schools Diabetes Prevention Project
Alberta Innovates	Kee Tas Kee Now Tribal Council
Assembly of First Nations	National Aboriginal Diabetes Association
BC First Nations Health Authority	Okaki Health Intelligence Inc.
Canadian Association for Long Term Care	Ontario Long Term Care Association
Carrier Sekani Family Services	RADAR
Children's Hospital Research Institute of Manitoba	Seabird Island Mobile Diabetes Clinic
CIHR Institute of Aboriginal Peoples' Health	Simon Fraser University
Diabetes Action Canada	Southern Chiefs Organization
Diabetes and My Nation	Treaty No. Six
Diabetes Canada	Tribal Chiefs Centures Inc.
Diabetes Task Force Solutions	University of Alberta
Government of Alberta	University of British Columbia
Gwawaenuk First Nation	University of Calgary
Health & Social Services, Yukon Government	University of Manitoba
Health Canada	West Region Treaty 2 & 4 Health Services

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This report provides a summary of the proceedings from the IHE roundtable on diabetes care and management in Indigenous populations in Canada, held on November 1, 2017. The roundtable aimed to: discuss and share learnings and promising practices from successful community-led diabetes programs, highlighting approaches to effectively engage communities to co-develop prevention and treatment programs that meet community needs; and articulate lessons arising from informed discussion to support the development of policy and strategy at provincial and federal levels that, over the longer term, supports systemic change and effective community engagement for developing diabetes and other chronic disease preventions programs.

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