Fighting Diabetes and Preserving a Legacy



The SFBLF Diabetes Management and Education Centre (DMEC) is located in Alliston, Ontario, Canada at the Banting Homestead Heritage Park, birthplace of Sir Frederick Banting, co-discoverer of insulin and Canada's first Nobel Laureate.

> P.O. Box 137, Alliston, Ontario, Canada, L9R 1T9 www.bantinglegacy.ca info@bantinglegacy.ca

> > Charitable Reg. No. 80740 6145 RR0001

This project was made possible through financial support by Merck Canada Inc.

The funders had no role in determining the focus or scope of the study, the preparation, review, or approval of the content or any decision regarding dissemination of the report.

Contents

Introduction	PAGE
SFBLF Mission	4
SFBLF Research Focus & Outcomes	5
Acknowledgements	6
Motivation, Goals & Scope	7
Key Findings - Summary	
Problem Summary	9
Findings Summary	
A. Gaps in capability and knowledge	10
B. Unique factors increase the challenge	13
C. The critical but difficult role of education	15
D. Need for a comprehensive team approach	16
Outcomes from imposed context factors [Figure 1.4]	16
Summary Demographics - Canada & Australia [Table CFS 1]	17
Examples of Indigenous Support Organizations [Table 4.1]	17
Opportunities for Action	
Create a national strategic context for youth-onset diabetes	
Assessment of current status	18
What is missing?	19
How these actions could help	19
Set and enable key priorities	
Priorities for immediate action	20
Enlist the help of the school system	21
Emulate successful approaches	23
SFBLF free tools and resources	24

Key Findings - Detail	PAGE
1.0 Understanding Youth-onset Diabetes	26
1.1 Relative Severity of Youth-onset Diabetes1.2 Diabetes Risk Factors1.3 Additional Risk Factors for Indigenous Youth1.4 Outcomes and Impact	
2.0 Prevalence and the Surveillance Gap	33
2.1 Diabetes Prevalence in Indigenous Youth2.2 Considering the Surveillance Gap2.3 Surveillance Capability - Overview - Canada and Australia2.4 What Data Elements are Required?2.5 Surveillance is Difficult	20
3.0 Indigenous Demographics	39
 3.1 Population of Indigenous Peoples - Canada and Australia 3.2 Youthful and Increasingly 'Urbanized' 3.3 Geographic Distribution 3.4 Languages 3.5 Schools and Indigenous Youth 	
4.0 Indigenous Diabetes Support Programs	44
4.1 Indigenous-specific Support Organizations4.2 National and Regional Initiatives4.3 Diabetes at School	
References	53
Appendices	
A.1 Diabetes Basics	57
A.2 Courteach list A.3 Count the Children	58 59

SFBLF Mission

SFBLF Mission and Programs

Fight Diabetes and Preserve a Legacy.

SFBLF Diabetes Programs are focused on youth and young adults and the enablers and resource allocation decision-makers who support them.

Reducing the risks of youth-onset Type 2 diabetes and diabetes-related complications in Type 1 and Type 2 diabetes; helping to mitigate the in-school challenges faced by youth with diabetes; and their often daunting 'transition' from paediatric to adult healthcare are key priorities.

Programs are delivered via classroom activities and events at the historic birthplace of Sir Frederick Banting; and online through e-Learning, tutorials and risk assessment tools.

SFBLF

- * A registered Canadian charitable organization federally incorporated as an NFP.
- * An all-volunteer Board supported by a Program Director, Advisory Board, Diabetes Outreach team, collaborative partners nationally and internationally, other volunteers and donors.
- * SFBLF has raised and invested over \$3 million CAD to rescue, restore and enhance the historic buildings and site infrastructure at the BHHP, create informative exhibits and educational programs in support of our Mission. The result is a unique Canadian venue for the enjoyment of our communities, all Canadians and visitors worldwide.

SFBLF Diabetes Management and Education Centre (DMEC)

- * The SFBLF DMEC is located in Alliston, Ontario, Canada at the 107-acre Banting Homestead Heritage Park (BHHP), birthplace of Sir Frederick Banting, co-discoverer of insulin and Canada's first Nobel Laureate.
- * Since opening the venue to the public in mid-2014, over 12,500 visitors have participated from 10 provinces/territories, 27 US states and over 36 countries.
- * As at end of 2019, total Program Participation Hours exceed 40,000



SFBLF Research & Outcomes

Research Focus

This Report is a product of the 2019 Summer Intern Research program undertaken through May to end of August; augmented subsequently in 2020 with research by SFBLF Board members, input and critique from collaborative partners in Canada, Australia and the USA.

This is the seventh research initiative by SFBLF since mid-2014 to help in the fight against diabetes with a focus on youth in response to challenges arising from the:

- * need to resolve the relative absence of surveillance data for diabetes in youth;
- * increasing appearance of mental illness comorbidities with diabetes in youth;
- * need for increased awareness and early intervention to reduce risk and help prevent or delay youth-onset Type 2 diabetes and complications for both Type 1 and Type 2;
- * need for broader implementation of in-school support systems for students with diabetes;
- * need for improved transition processes to ensure continuity of care for youth with diabetes.

Included in our annual issues reports are selected comparisons with Australia, USA and UK where applicable and available.

2017 - Youth Living with Diabetes and Comorbidities, Available Surveillance Data

- A Status Assessment bantinglegacy.ca/count-the-children

2018 - In-school Support for Youth Living with Diabetes bantinglegacy.ca/in-school-support 2020 - Youth-onset Diabetes in Indigenous Peoples: Canada & Australia

bantinglegacy.ca/indigenous-youth

Research Outcomes

Insights gained from results of the Intern Research Program are shared widely and have led to development of new SFBLF programs, online assessment tools, e-Learning courses and short tutorials and where practical, advocacy initiatives directed at others with greater resources and broader expertise.

The 3 'issues' reports produced (2017, 2018, 2020) have been published on the SFBLF web site and circulated widely around the world. Resulting online tools, eLearning courses and tutorials (2016 to the present) are available also on our web site. Lessons learned have been incorporated into our ongoing School Tours and Group Tours diabetes education programs and shared at our Annual Transition Symposium for HCPs (now in its 9th year).

Courses

* Mental Health & Diabetes in Youth eLearning bantinglegacy.ca/e-learning

* Understanding Diabetes eLearning bantinglegacy.ca/understanding-diabetes

Tools

* Type 2 Diabetes Risk Self-Assessment for Youth (8-18) bantinglegacy.ca/diabetes-risk

* Diabetes and Food Security bantinglegacy.ca/diabetes-and-food

Resources

* Peer support networks for T1 & T2 Youth bantinglegacy.ca/peer-support-networks

* Software APPS for Self-management bantinglegacy.ca/sm-apps

Recognition

* National Recognition Award for Canadian Schools (with an in-school support program) bantinglegacy.ca/national-recognition-program

www.bantinglegacy.ca

info@bantinglegacy.ca

Acknowledgements

The Board of Directors of the Sir Frederick Banting Legacy Foundation (SFBLF) gratefully acknowledge the contributors listed below.

Project Team

SFBLF Board:

- * Elisa Venier, MD, Family Physician, SFBLF Director: Project Lead & Intern Mentor
- * David Sadleir, PhD., PEng., SFBLF President: Research & Report Synthesis **Research Interns:**
 - * Katherine Morelli B.A., (2020) Mathematics, Minor Biology, McGill University
 - * Michael Venier, BSc. Hon., (2019), Physics, McGill University
 - * Hazen Enman, B.A. Hon., (year 2) English & Modern Languages, Oxford University

Reviewers

- * Amy Hess-Fischl, MS, RDN, CDE, Teen Program, Kovler Diabetes Centre, University of Chicago, USA
- * Karolyn Hardy-Brown, MD, Paediatrician, SFBLF Director
- * Melinda Hazlett, MD, Paediatrician, SFBLF Director
- * Trevor Hunt, MD, Paediatrician, SFBLF Director

Outreach Contacts

Explorations for this report included direct outreach in both Canada and Australia to:

- * Government agencies with a specific mandate to provide support to Indigenous Peoples.
- * Indigenous leadership; individuals and key organizations
- * University departments with an Indigenous-specific focus
- * Research networks with an Indigenous focus, direct or indirect
- * Researchers, analysts and selected authors of key papers

The contact list is included in this report as Appendix A.2

Not all responded but we wish to thank all those who helped assemble key data and offered critique and advice.

This project was made possible through financial support by Merck Canada Inc.

The funders had no role in determining the focus or scope of the study, the preparation, review, or approval of the content or any decision regarding dissemination of the report.

Motivation, Goals and Scope

Motivation

To realize our Mission, SFBLF requires knowledge about youth-onset diabetes including "What is?" and the nature and scale of associated trends and context. One cannot manage or support effectively what cannot be measured.

Goals of this Report

Shine a brighter light on the unique circumstances of youth-onset diabetes for Indigenous Peoples by:

- * describing the current situation, with quantification where available;
- * identifying needs and opportunities for supporting action by others who have greater capacity and expertise;
- * identifying new content to support SFBLF program delivery;
- * identifying new opportunities for development of support tools for Indigenous T1 and T2 youth;
- * promoting action that will help improve the quality of life for Indigenous youth and their families; specifically, for Canada and Australia.

Scope and Approach

```
Indigenous Canada = First Nations, Métis and Inuit
Indigenous Australia = Aboriginal and Torres Strait
Islanders
Age ranges unless otherwise stated:
* Child = 5 - 11
* Adolescent = 12 - 19
* 'Youth' = children & adolescents 5 -19
```

The search (May 2019 - July 2020) included review of published reports, research papers and outreach to government departments (at the national, provincial, state, territory level) with responsibilities for serving Indigenous communities; university departments with a related interest; organizations with a specific relationship to Indigenous communities; and organizations with a national diabetes-advocacy mandate; professional medical organizations and children's hospitals.

Aspects of this Report draw on earlier SFBLF 'issues' Reports; specifically:

- * Youth Living with Diabetes and Comorbidities Available Surveillance Data, [including global perspectives and comparisons with Canada, Australia, United Kingdom and United States], (2017-09-01) bantinglegacy.ca/count-the-children
- * *In-School Support for Students Living with Diabetes* [including comparisons with Canada, Australia, United Kingdom and United States], (2018-09-17) bantinglegacy.ca/in-school-support.

Draft segments of this Report were shared with colleagues in Canada, Australia and the United States for review and critique.

Selection of content included in the Report is the sole responsibility of SFBLF.

Highlighted References

There are hundreds of relevant papers and reports; many now somewhat dated (circa 2005 - 2015).

Of the 50 plus papers reviewed, the following contemporary publications are representative, especially helpful and together cite a valuable list of dozens of relevant references:

Canada

- > Leung, Lawrence, *Diabetes mellitus and the Aboriginal diabetic initiative in Canada: An update review*, J Family Med Prim Care 2016 Apr-Jun; 5(2): 259-265
- > Institute of Health Economics. Diabetes care and management in Indigenous populations in Canada: Summary report of a pan-Canadian policy roundtable. Edmonton (AB): Institute of Health Economics; 2018.
- > First Nations Information Governance Centre, National Report of the First Nations Regional Health Survey Phase 3: Volume One, (Ottawa: 2018). Revised edition, July 2018.
- > Halseth, Regine, The Prevalence of Type 2 Diabetes Among First Nations and Considerations for Prevention, Feb 2019, National Collaborating Centre for Aboriginal Health, Prince George, BC.

Australia

- > Australasian Paediatric Endocrine Group guidelines: Screening, assessment and management of type 2 diabetes mellitus in children and adolescents, MJA 213 (10), 6 July, 2020
- > Titmuss, A., Maple-Brown, L., et al, *Emerging diabetes and metabolic conditions among Aboriginal and Torres Strait Islander young people*, MJA 210 (3), Feb 18, 2019
- > Australian Government. Australian National Diabetes Strategy 2016-2020.
- > Lee, A. S., S. Colagiuri, and J.R. Flack, Successful implementation of diabetes audits in Australia: the Australian National Diabetes Information Audit and Benchmarking (ANDIAB) initiative. Diabetic Medicine, 2018. 35(7): p. 929-936.
- > Type 2 diabetes in Australia's children and young people: a working paper. Diabetes Series no. 21. Cat. no. CVD 64. AIHW, Canberra, 2014 [Not recent but in the context of the search for improved surveillance, this paper is an exemplar.]

Common

- King, Malcolm, Alexandra Smith and Michael Gracey Indigenous health part 2: the underlying causes of the health gap, , Lancet 2009; 374: 76 85
 An in-depth description of the underlying causes of health disparities between Indigenous and non-Indigenous people. This paper is comprehensive and contains both a Canadian and Australian perspective with an extensive analysis of the impact of colonialism. The topics covered include Indigenous notions of health and identity; mental health and addictions; urbanization and environmental stresses; whole health and healing; and reconciliation.
- > Maple-Brown, L. J. and Denella Hampton, Indigenous cultures in countries with similar colonisation histories share the challenge of intergenerational diabetes, Comment, The Lancet, Vol 8, May 2020

Key Findings - Summary

[The focus of this report is on Indigenous Youth but many of the findings included are equally applicable to all youth]

Problem Summary

For all youth

- * Youth-onset diabetes is rising globally; relatively more so for Type 2 than Type 1.
- * Despite strong supporting evidence from many countries, the result cannot be quantified. A few countries do have well-established national processes for tracking the increasing prevalence of youth-onset diabetes.
- * The global rise in youth-onset Type 2 is a relatively 'new' phenomenon with the result that there are gaps and imbalances in knowledge across the full spectrum of research, surveillance, prevention, diagnosis and treatment as compared to youth-onset Type 1.
- * Youth-onset Type 2:
 - > is initially invisible and progressive; cell damage can be in progress at time of diagnosis
 - > is potentially more severe than youth-onset T1 and more severe than adult-onset T2
 - > is occurring at ever-younger ages.
 - > can be accompanied by comorbidities such as obesity, hypertension and mental disorders; bi-directional causal relationships can exist between/among these conditions
 - > increasingly is proving unresponsive to diet, exercise and oral medication and may also require insulin.
- * School age youth with diabetes may spend as much as 40 hours per week in school and in transit to school. They need special accommodations to help manage their diabetes, be safe at school and enjoy a full learning experience.
- * Managing diabetes requires constant vigilance, day-in and day-out. Ensuring continuity of care for any chronic disease is a major challenge in most countries. If comorbid conditions exist, the challenge is greater, usually requiring a multi-disciplined team; not an easy requirement for rural and remote communities. Youth with diabetes and their families need early help to prepare for transition to adult healthcare.

Additional factors affecting indigenous youth

- * Historic colonialism, geographic remoteness and a broader view of 'health and wellness' have combined to:
 - > increase diabetes risk
 - > produce much higher diabetes prevalence 3 to 7 times or higher
 - > add complexity for healthcare delivery
- * Age of onset for Type 2 is even younger in indigenous youth than for non-indigenous
- * The growing youth cohort means increasing numbers 'at risk' for Type 2 diabetes
- * The negative impact of youth-onset diabetes is much greater, both in scale and intensity, for indigenous youth compared to non-indigenous.

Understanding the needs of, and providing support for, Indigenous youth are multi-faceted, daunting and continuing challenges



A. Gaps in Capability and Knowledge

1.0 Positive support exists across a wide spectrum

Youth-onset diabetes is a complex subject in any context. Indigenous Peoples face additional unique challenges that increase their relative risk for diabetes and intensity of diabetes impact.

- 1.1 Fortunately, there are dozens, if not hundreds, of organizations with a specific or indirect focus on supporting Indigenous Peoples. These range from national, provincial, state and territorial governments through Indigenous-specific and more general diabetes advocacy groups as well as many Indigenous community led initiatives.
- 1.2 There are many university research networks and departments that have an Indigenousspecific mandate or include an Indigenous focus in aspects of their research and teaching.
- 1.3 Hundreds of healthcare facilities and 1000s of healthcare professionals are directly involved in providing healthcare services to Indigenous Peoples.

Table 4.1 provides a sample list of support organizations in both countries. Explorations for this report included outreach to several of these organizations.

September 2020 Youth-onset Diabetes in Indigenous Peoples - Canada & Australia

2.0 Absence of youth-onset diabetes surveillance = a global knowledge gap

Despite this very broadly-based, large scale commitment, major knowledge gaps remain with respect to quantifying the incidence and prevalence of Indigenous youth-onset diabetes in particular, and for all youth in general.

Youth-onset diabetes surveillance is a major capability gap leading to a major knowledge gap in the majority of countries. Canada and Australia are no exceptions.

- 2.1 Both countries have demonstrated capability to undertake effective, continuing national surveillance relative to youth. What is 'missing' is the apparent priority and 'will' to bring that capability to bear consistently on each of diabetes, diabetes-related complications, overweight/obesity and mental illness as well as the emerging comorbidities especially, diabetes, obesity and mental illness in youth.
- 2.2 Theoretically, given the often-required initial hospitalization of a youth with Type 1, more data should be readily available. If such data are available, they are not being shared widely.
- 2.3 Surveillance for Type 2 diabetes is much more difficult. The condition can go undiagnosed for years and may be confused with other conditions initially.
- 2.4 Neither country has cohesive, complete, national surveillance data sets (prevalence or incidence) for youth age 19 and under (including Indigenous) for any of the following cases:
 - a. Diabetes by type, gender, age stratification and ethnicity
 - b. Overweight and obesity by gender, age stratification and ethnicity
 - c. Mental illness by type (or at least 'group'), gender, age stratification and ethnicity
- 2.5 Age of onset, a critical variable, is often overlooked or at least not reported.
- 2.6 Mass screening for youth-onset Type 2 diabetes is considered impractical and too costly. If weighed against the already large and growing economic burden of diabetes, the costbenefit relationship might be compelling; more so if reduced quality of life and longevity are considered. In Canada, Australia and some other countries, Guidelines exist that emphasize the need for regular diabetes screening of 'high risk' cohorts including Indigenous youth.

The extent to which these Guidelines are being followed for youth is unreported.

	Statis	First Nations		
	Canadian Community Health Survey (CCHS) StatCan	Canadian Health Measures Survey (CHMS) StatCan	Aboriginal Peoples Survey (APS) Statcan	First Nations Regional Health Survey (RHS) FNIGC
Children/Youth Content	12 years of age and older	3 - 79 years of age	15 years and older	* 11 and under * 12 - 17 * 18 and older
FN - On Reserve	omitted	omitted	omitted	included
FN - Off Reserve	included	included	included	included
Metis	not identified	not identified	included	omitted
Inuit	not identified	not identified	included	omitted
Frequency	annual	2 year cycles; diabetes incl in all cycles	every 5 years	evolving in Phases since 1997; Phase 3 reported in 2018

Table 2.2: Illustrating National Surveillance Gaps and Inconsistencies - Canada

SFBLF

3.0 Data, essential for rational healthcare resource allocation, are incomplete, inconsistent or non-existent

Canada has approximately 440,000 school age (5 - 19) Indigenous youth; Australia 230,000. How many of these youth are living with diabetes? No one knows the answer.

One cannot manage effectively what cannot be measured.

There is solid evidence that higher incidence and higher prevalence of diabetes prevail among Indigenous populations. For adults, that means at least 4 to 7 times greater prevalence than for non-indigenous; evidence suggests this can be much higher in some cases.

The extent to which the same imbalance applies to Indigenous youth remains unknown although there are studies involving selected groups that clearly indicate a similar imbalance.

Unfortunately, the surveillance data problem is further amplified by the relative absence of other data elements essential to effective prevention, detection and treatment of youth-onset diabetes.

- 3.1 There are many sources for relevant qualitative information but also with 'gaps'.
- 3.2 Quantitative data, other than demographics available via the national census, are difficult to find; ranging from poor to non-existent. Census data are not sufficiently dis-aggregated.
- 3.3 In Canada, there is better information available for First Nations than for Métis and Inuit Groups. In all cases, however, data pertaining to youth are at best, mixed, incomplete and inconsistent.
- 3.4 In Australia, the quality and completeness of available data also have gaps but are similar for both Aboriginal and Torres Strait Islander groups and in general, more data are available about youth than is the case in Canada.

Questions we tried to answer about Indigenous Youth

As the Table summarizes, this exploration faces significant gaps in available information.

Table 3.1: (Questions and	Available	Information -	Youth-onset	diabetes
--------------	----------------------	-----------	----------------------	--------------------	----------

Main Topic and Questions	Available	Information
	Canada	Australia
Demographics		
1. Demographic profile for indigenous youth and young adults by Group?	very	good
2. Breakdown within Group by age, gender, location	g	ood
3. Related growth trends?	f	air
Diabetes Surveillance		
1. Prevalence of youth-onset diabetes among Indigenous Peoples by Group and what are the trends?	poor to none	partial via NDSS
2. Breakdown of youth-onset diabetes data by Indigenous Group, age, gender and diabetes type?	none	
3. Factors unique to Indigenous Peoples that affect diabetes prevalence?	very good	
4. Existing diabetes surveillance systems with a specific or at least an inclusive Indigenous component?	good info mixed da	on systems; ata content

Schools	
1. School-age Indigenous children/youth attending provincial, state, territorial or exclusively Indigenous schools?	incomplete, inconsistent
2. Of those schools, how many have in-school support processes for students living with diabetes?	unknown
3. Of those in-school support processes, how many include specific accommodation for Indigenous health and wellness expectations?	
Healthcare Delivery	
1. Identify Impediments to effective and sustained delivery of health care support for Indigenous youth?	
2. Identify Socio-cultural factors that influence effective health care	good
delivery for Indigenous youth?	
3. Identify National, provincial, state or territorial initiatives to improve	
delivery of health care support for Indigenous Peoples?	

B. Unique Factors Increase the Challenges

4.0 Three added unique factors affect diabetes prevalence in Indigenous Peoples

As with other populations, diabetes prevalence is determined by a combination of modifiable and unmodifiable risk factors. Three unique factors combine to increase diabetes risk for Indigenous youth. These factors amplify the risks inherent in the nature of youth-onset diabetes.

Degrees of 'modification' are possible in the long term but pragmatically, these factors add complexity and cost, impede progress, increase relative disadvantages and generally, make it more difficult to improve on 'modifiable' factors such as community economics and social supports. Figure 4.0 near the end of the Summary compares risk factors and outcomes.

4.1 Colonialism

The single most dominant and lingering reality affecting the prevalence of diabetes among Indigenous populations in both Canada and Australia. It has perpetrated relative economic, social and cultural poverty; and with intergenerational impact.

4.2 Geographic remoteness

An inherent historical reality for some but currently, being adjusted by increasing urbanization. In some cases, geographic remoteness can be an advantage in terms of nurturing a healthy lifestyle but can remain a barrier for healthcare delivery.

4.3 Broader perception of 'health and wellness'

For Indigenous Peoples, the concept of health and wellness incorporates physical, emotional and mental wellbeing along with a spiritual connection to land and food. This holistic balance is essential to support a healthy person and this concept of balance also extends beyond the individual to incorporate aspects of a healthy community. This reality requires a much broader approach to healthcare delivery in support of indigenous people.

5.0 In-school support systems for Indigenous students require additional considerations

All students living with either Type 1 or Type 2 diabetes require support to be safe at school and to enjoy a full learning experience. There are additional considerations for supporting Indigenous students arising from factors such as their perceptions of 'health and wellness'.

- 5.1 The demographics for Indigenous students participating in provincial/state/territorial or exclusively Indigenous schools in both countries are difficult to find.
- 5.2 As a result of the youth-onset diabetes surveillance gap, little is known about the number of Indigenous students living with diabetes.
- 5.3 While programs exist in both countries to encourage, if not mandate, in-school support systems for students with diabetes, specifics regarding the degree of implementation remain elusive. That, in turn, means little is known about the extent to which such support systems also include recognition of the unique expectations and needs of Indigenous students.
- 5.4 School systems remain an 'under-utilized' potential source of data to help close the surveillance gap.

6.0 Healthcare delivery for Indigenous youth also faces unique challenges

In the last decade or two, both countries have launched major initiatives to improve the delivery of healthcare to their Indigenous peoples and continue to do so.

- 6.1 The scope and continuity of such programs, however, are highly variable.
- 6.2 Indigenous healthcare delivery is too often based on traditional clinical models and fails to incorporate Indigenous expectations and needs regarding different perceptions of health and wellness and community engagement.
- 6.3 The unique context for many Indigenous communities means that modifiable factors such as food security, economic capacity and diabetes education must be addressed 'first', or at least in parallel, for effective healthcare delivery.
- 6.4 Geographic remoteness can contribute to delays in response and difficulties in maintaining caregiver continuity and hence, impede timely and sustained healthcare delivery.
- 6.5 The 'urbanization' of Indigenous peoples has been in progress for decades in both countries due to multiple factors including demographic growth, mobility and changing patterns of self-reported identity.
- 6.6 The number of Indigenous people living in a metro area of 30,000 or more in Canada grew by almost 59% (2010-2016) and now over 52% live in such areas. The comparable number for Australia is 30%.
- 6.7 Urbanization means different, but not necessarily 'better', outcomes for Indigenous peoples. In urban locations, Indigenous Peoples still can be disadvantaged and often face discrimination.
- 6.8 It also means added pressures on urban healthcare delivery resources in terms of numbers, types and education required to be effective.
- 6.9 Both countries have made dramatic efforts to mitigate the historical impact of 'colonialism' and those efforts continue across a very wide spectrum. All of these initiatives have an indirect but very positive effect in improving overall Indigenous health and wellness.

7.0 The increasing 'youthfulness' of the Indigenous demographic means more and 'smarter' investment in direct and indirect healthcare support is required

In both countries, Indigenous populations are collectively younger and growing faster than nonindigenous (2010-2016).

- 7.1 In Canada, Indigenous groups represent 4.9% of the total population but their youth under age 25 represent 7.9% of the total population under age 25. In Australia, the comparable numbers are 3.3% and 6.7%
- 7.2 For Indigenous youth age 19 and under in both countries, the gender ratio is approximately 49% female: 51% male. Diabetes impact and patterns are different by gender.
- 7.3 This growing youth cohort means ever-increasing numbers 'at risk' for Type 2 diabetes.
- 7.4 A growing school age population means the need for more investment in schools and may be a precursor of a growing young adult population relatively unable to find employment.
- 7.5 In-school support systems for Indigenous students with diabetes not only require additional accommodations for the students but also additional education for teachers and staff.

C. The Critical but Difficult Role of Education

8.0 Providing education for diabetes prevention and self-management is essential

Education is required at several stages in the diabetes support process; e.g., helping families and youth to understand the nature of diabetes and what they can do to reduce their risks.

- 8.1 Encouraging schools to help with and reinforce general diabetes awareness can be very effective but is yet another demand on already stretched teaching resources.
- 8.2 A diagnosis of diabetes of either type can be a shock for the individual and the family. Learning what needs to be done to adjust family menus and related shopping lists takes some time. Access to, and affordability of, healthy foods may raise new stresses. Learning how to 'count carbs' can be a challenge especially, for younger patients. Reluctance to discuss 'food security' issues can result in unexpected outcomes for the treatment regimen.
- 8.3 For insulin-dependent cases, learning how to administer insulin can be daunting; all the more so for younger patients.
- 8.4 Emerging technology such as continuous glucose monitors and insulin pumps can make a major positive difference in the self-management process, but they are expensive, require frequent calibration and are not applicable to all. New software applications, accessible online, add help. None should be used without advice from qualified healthcare providers (HCPs). That, in turn, increases the knowledge requirement for HCPs and can make the self-management learning curve steeper.
- 8.5 Language 'barriers' and cultural expectations create additional demands for educational content and the manner in which it is delivered.
- 8.6 Universities, colleges, diabetes research organizations, professional healthcare provider organizations and diabetes advocacy groups must consider strengthening the Indigenous youth focus in their educational curriculum.

D. Need for a Comprehensive 'Team' Approach

9.0 Greater collaboration is required - Communication is a 'two-way street'

The negative and long-lasting impacts of diabetes in Indigenous youth need to be minimized. A broadly-based, coordinated, collaborative approach is the only hope of achieving that goal.

The scale and scope of required plans and actions for prevention, diagnosis and treatment means:

- 9.1 Programs cannot be developed nor actions implemented by the healthcare sector alone. Governments at all levels, the education sector, employers and Indigenous leadership (individuals and communities) need to participate pro-actively.
- 9.2 Healthcare educators, clinicians and researchers must continue to collaborate and share knowledge persistently to help establish priorities and find solutions.
- 9.3 Direct and culturally appropriate engagement with Indigenous communities is essential. All involved need to be part of the team.

	Impo			
Health/Wellness Factor	Historic Colonialism	Remote	Nature of Diabetes	Outcome
Cultural * Language * Land * Spirituality	impeded	can be positive		Cultural Poverty * loss of language * disconnections from land and spirituality
Economic * Income * Employment * Education * Food * Housing	impeded	disadvantage		Economic Poverty * low income * unemployment * lack of education * food insecurity * poor living conditions
Social * Supports * Identity	impeded	disadvantage		Social Poverty * stereotyping * racism * stigmatization
			- P	
Modifiable Risk * Lifestyle * Diet	impeded	disadvantage	more difficult to modify factors	Higher Incidence & Prevalence
Unmodifiable Risk * Age * Gender * Family History	intergenerational impact		earlier onset	Higher Incidence & Prevalence
	Combine to add complexity, impediments and cost for Indigenous * Healthcare Access, Delivery and Research * Diabetes self-management * In-school support * Surveillance * Medical education and training			

Figure 4.0 Outcomes from imposed context factors affecting Indigenous health

	Canada	Australia
Groups		
Indigenous Groups	* First Nations * Métis * Inuit Each of these 5 groups has the languages, cultural tradit A small % in both countries self-id	* Aboriginal * Torres Strait Islanders ir own distinct identity, history, tions and spiritual beliefs. lentify as being in more than group.
Demographic	s [2016 Census]	
Total Population	 Total Indigenous: 1,683,785 4.9% of the 35.1 million Canadians 7.9% of the population under age 25 	 Total Indigenous: 798,400 3.3% of the 24.5 million Australians 6.7% of the population under age 25
Age 19 and under	 * 715,100 under age 25 * 593,725 age 19 and under * approx 49% female; 51% male * 448,090 'School Age' (5-19) * 15,500 schools 	 479,040 under age 25 age 19 and under - n/a approx 49% female; 51% male 230,677 'School Age' (5-19) 9,503 schools
Location	First Nations * >50% in the west (BC, AB, SK, MN) * 24.2% in Ontario <u>Métis</u> * 80.3% in Ontario and western provinces <u>Inuit</u> * 75% live in Inuit Nunangat; across the northernmost border of Canada	Aboriginal * 63% live in NSW and Queensland * 24% in W. Aus and N. Terr. <u>Torres Strait Islanders (TSI)</u> * > 50% in Queensland * 24% in NSW (18%) and Vic (6%)
Growth Trends	 Indigenous groups are the youngest population in Canada with 44% less than age 25 	 Indigenous groups are the youngest population in Australia with nearly 60% less than age 25

Table CFS 1: Comparative <u>Demographics</u>.-- Summary

Table 4.1: Examples of Indigenous Support Organizations

Canada	Australia
Government	
 Indigenous Services Canada (ISC) Crown-Indigenous Relations and Northern Affairs Canada (CIRNAC) 	* National Indigenous Australians Agency (NIAA)
 Health Canada Statistics Canada 	 * Australian Institute of Health & Welfare (AIHW) * Australian Bureau of Statistics (ABS)
National, Provincial, Territorial Indigenous G	roups
 First Nations Information Governance Centre (FNIGC) Inuit Tapiriit Kanatami Métis National Council (MNC) National Collaborative Centre for Indigenous Health (NCCIH) Indigenous Diabetes Health Circle Union of Nova Scotia Indians 	 National Congress of Australia's First Peoples Australian Institute of Family Studies South Australia Aboriginal Health Partnership
Diabetes Advocacy Groups - with Indigenous-	specific or included focus
* National Indigenous Diabetes Association (NIDA)	 Australian Diabetes Educators Association (ADEA)
* Diabetes Canada * JDRF	 Australasian Paediatric Endocrine Group Diabetes Australia JDRF
Universities & Research Networks with an Ind	ligenous component
 Diabetes Action Canada Centre for Indigenous Peoples' Nutrition and Environment, McGill University Institute of Health Economics 	 Australian Indigenous <u>HealthInfoNet</u> [healthinfonet@ecu.edu.au] Baker Heart and Diabetes Institute Royal Darwin Hospital & Menzies Research Centre

Opportunities for Action



This Report illustrates the daunting complexity associated with Youth-onset diabetes in general and for Indigenous Youth in particular.

The Report also illustrates that despite this complexity, hundreds of worthy projects, studies and programs have been undertaken, completed, remain in progress or are planned. The positive outcomes from all that effort are very substantial. The 'collective capability' is formidable.

Yet, after several decades of progress, the 'Problem space' as summarized remains.

Encouraging 'more of the same' is part of the necessary actions. But, serious problems require serious and sustained overall leadership to resolve.

If one had unlimited funds and the requisite people resources:

- > Where would one 'start' in a quest to remove the shortfalls reflected in that 'problem space'?
- > Are there key impediments that, if removed, would facilitate 'better' and 'faster' effectiveness and increase positive health impact for all involved?

To be sure, more investment and a lot of it is required. Funding alone, however, will not achieve the required outcomes. Hundreds of millions have been spent in both Canada and Australia; continue to be spent; and funding commitments for some programs are being increased frequently.



- > help to optimize the impact of the 'collective capability'.
- > achieve an improved 'balance' between the focus on adults and the focus on youth
- > achieve much needed 'balance' in the respective emphasis on Type 1 and Type 2
- 2. Continue both strategic and tactical level actions in parallel and with improved coordination.

'Strategic guidance' needs to be provided from at least a national perspective to help focus all the tactical level initiatives that could emerge otherwise as independent and miss key needs

- 3. A 'national clearinghouse' could:
 - > assemble, analyze and categorize key results and make those available to all 'solution seekers' as well as the general public
 - > encourage emulation of successful approaches

If everyone who is trying to help has to 'start from scratch', as was essentially the case with the explorations necessary to assemble this Report, neither efficiency nor effectiveness will be served.

Such a clearinghouse would not need to be a major 'new' organization. Several existing organizations are very capable of performing such a task given a specific mandate.

If Canada and Australia were to collaborate in creating and sustaining such a clearinghouse, the mutual benefits to each could be substantial and have broad international impact.

- 4. Conceptual reference model could help:
 - > all involved to assess their initiative(s) in terms of relevance to existing knowledge gaps

- > to improve coordination and collaboration.
- > to summarize, track and report collective progress

'Bottom up' initiatives will continue with or without a more focused consideration of the context and how to 'fit each piece' into the unfinished and ill-defined jigsaw puzzle.

- 5. 'Funding programs' that use such a reference model could/should:
 - > inject a thoughtful 'steering effect' but with due care to avoid stifling creativity; especially, in the basic research milieu.
 - > include explicit encouragement to emulate proven, successful programs and approaches.
- 6. A propensity to seek pragmatic, evolutionary approaches will:
 - > reduce the time and cost to achieve early insights
 - > help to avoid disappointment and failure that often arise as a result of being overly ambitious.
- 7. Standards for many aspects would:
 - > facilitate more effective integration and comparison of results.
 - > reduce design and analytical complexity

For example, agreeing a set of base case data elements to be included in any surveillance study would help to avoid outcomes that thwart opportunities for comparative analyses; as would a common core set of required 'metrics' to be tracked in measuring progress of strategic programs

Note: Short-term consideration

Shifts in relative roles of government departments with responsibilities for programs and actions affecting Indigenous Peoples are in progress in both countries. It is essential to ensure clarity for all involved and to maintain continuity during the transition processes.

Improvement opportunities abound. It is helpful to consider these in four broad categories.

Create a national strategic context for youth-onset diabetes

Canada introduced a 5-year national diabetes strategy in 1999 that included the 'Aboriginal Diabetes Initiative'. The latter was expanded to a 3-phase program ending in 2015. The recent 'Diabetes 360' proposal from Diabetes Canada (2018) provides a framework for a national strategy and also includes specific consideration of Indigenous peoples. Diabetes Canada have asked the federal government for \$30 million to enable the program. [58]

Australia has a national diabetes strategy (2016-20) supported by implementation guidelines and a long list of tracking metrics. Among the goals is one directed specifically at Indigenous peoples. [38]

Both countries have initiated major, national 'Reconciliation' actions to mitigate the devasting impact of colonialism on their Indigenous peoples. All of these 'Reconciliation' actions have the potential, directly or indirectly, to improve the 'health and well-being' of Indigenous populations. [9] [10]

What is 'missing' in all of these undertakings is a matter of emphasis. A more specific, balanced, nationally coordinated approach is required with an immediate focus on the urgent need to confront the youth-onset Type 2 diabetes threat in general and for Indigenous and other high risk cohorts in particular.

Set and enable key priorities

Priorities for Immediate Action

- 1. Continue and strengthen aggressive national prevention programs.
- 2. Solve the youth-onset Type 2 diabetes surveillance problem. Virtually every published study focused on youth-onset diabetes identifies this need yet the current actions, including audits and benchmarking, reflect a dominant focus on adults in most countries.
- 3. Close the information gaps that surround the fundamental surveillance problem; e.g., progress of training for, and implementation status of, in-school support processes; the demographics for students living with diabetes at Board if not school level; tracking and reporting of the extent to which national guidelines for youth-onset diabetes screening are actually being followed.
- 4. A systematic, objective, national review of existing information systems and capability to identify opportunities for early incremental improvement vs building new systems.
- 5. An assessment of the potential for more affordable, or even 'free', access to technology devices and software applications that support the diabetes self-management process.
- 6. A systematic review of language translation needs required to broaden easy access to educational resources for both prevention programs and self-management support.

Enlist the help of the school system

Number of students at risk?

- * Canada had 4.9 million students enrolled in 15,500 elementary and secondary schools at the end of 2018.
- * At the end of 2019, Australia had 3.9 million students enrolled in 9,503 elementary and secondary schools.

Speculating on how many of these students are at risk of developing Type 2 diabetes would not be a productive exercise. Recognizing, however, that all of them, including their families, would benefit from being aware of the risks for Type 2 diabetes and what actions they can take to reduce their risk is a worthy objective.

A 'real life' example

Over 4,000 students, grades 4 to 12, have participated in the SFBLF School Tours program, usually in classes ranging from 25 to 40 students plus 1 or 2 teachers and occasionally volunteer parents. At the outset of every tour, students are asked to raise hands in response to two questions:

"Do you have diabetes?"

"Do you have family members living with diabetes?"

Responses to the first question usually result in zero to 3 or 4 hands being raised.

Responses to the second question, without exception, range from a low of 25% to a high of 85% SFBLF © 2020 21

If those youth are referencing parents and/or siblings, they are all at greater risk of Type 2.

Opportunities for action:

Schools could help with three related actions:

1. Raise awareness and help with prevention

- * Hold an annual school-wide Diabetes Awareness Day
- * Encourage all students to learn more about diabetes including discussion with families
- * Emphasize importance of healthy diet, daily exercise, and an appropriate body weight
- * Encourage students to take the SFBLF online Type 2 Diabetes Risk Self-Assessment Quiz

2. Implement an in-school support process for students with diabetes

The following practices were developed, and are in routine use, by an elementary school in Winnipeg, Manitoba, Canada. This school was the first winner of a 'gold' level award from the SFBLF National Recognition Program for Schools.

Focus the training challenge

General diabetes training for teachers and support staff is demanding and requires persistence.

- 1. Optimize the impact by creating a small Diabetes Response Team (DRT) for each student living with diabetes (or designated groups if numbers dictate).
- 2. Include trained student peers on the DRT.
- 3. Have a DRT member present to provide support for field trips and sporting events.

Lead by example

4. Encourage teachers who are living with diabetes to 'demonstrate' their blood sugar tests in front of students and thereby help to raise awareness and reduce 'stigma' and increase comfort levels for students with diabetes.

Enlist peers and reduce 'sugar low' impact risk

5. Provide a two-sided, "brightly coloured, laminated card" to all students living with diabetes to be handed to a classmate who will seek immediate help for a 'sugar low' as instructed on the card. Engaging peers helps to reduce peer bullying.



3. Contribute to collective knowledge of youth-onset diabetes prevalence

Count first; extrapolate later': a first step to obtain early and improved insights regarding the youth-onset diabetes surveillance challenge.

School systems hold the potential to make a significant contribution to narrowing the surveillance data gap for youth-onset diabetes and to do so relatively quickly and at modest cost.

Need for a pragmatic approach

The much larger problem of assembling a comprehensive National Diabetes Registry needs to be solved in both countries, BUT the urgent imperative is to focus first on our youth.

Since youth-onset Type 1 cases usually require a paediatric intervention at the outset, hospitals should have the details regarding youth-onset Type 1. Likewise, Paediatric Diabetes Education Centres (PDECs) should have reasonably complete data for Type 1 patients. If they have the data, no evidence could be found that it is being shared routinely with the public.

Every student living with a chronic disease, including diabetes, is expected to register, or at least identify, that condition with the school system. The expanding implementation of essential processes for in-school support of students with diabetes adds further incentive to collect these data. Some school boards require such data be reported centrally.

Sharing the diabetes data while preserving anonymity for specific students would quantify the current status and provide a basis for routine updating. That outcome is within practical reach if the school systems have the will to help. This is not a scientific nor complete solution obviously, but would provide significant progress relative to our current state of knowledge.

It is just a 'count' but sustaining the process on an annual basis would also provide new insight regarding 'trends'.

Such a process also would serve to increase awareness of the youth-onset diabetes threat.

A question of ethics?

As observed elsewhere in this report, surveillance data are valuable only if used to identify the need for prompt interventions, educate and inform rational resource allocation decisions to improve health outcomes.

In the context of the school system, how can one contribute to these goals while maintaining essential student privacy?

The process requires students remain anonymous in terms of public data reporting. Yet, if as a result of collecting such data, a student is identified as at risk of diabetes, one would like to take action to help.

A practical answer lies in design of a process that leaves students anonymous to the external system but easily identified, if necessary, within an individual school.

Appendix 3. of this Report describes the detailed process and data collection tools to achieve the above outcome.

SFBLF designed such a process in 2015 and have been looking ever since for even one school to implement the process and set an example for others.

Emulate successful approaches

1. Engage peers for prevention

Many programs that exist to engage youth in activities that promote healthy lifestyles are not suited to the unique needs and traditions of Indigenous Peoples. This is what inspired the development of the *Indigenous Youth Mentorship Program* (IYMP).

The IYMP approach to wellness was co-developed with Indigenous youth and leaders in Winnipeg and northern Manitoba along with researchers and community members, led by Dr. Jon McGavock from the University of Manitoba and Diabetes Action Canada.

Guided by an Indigenous medicine wheel concept and delivered by Indigenous adolescents for Indigenous children in their communities, the IYMP builds on the strengths of its participants and helps to create healthy inclusive communities. Plans are in place to expand the program to 13 communities across 5 provinces.

In 2016, the IYMP was emulated within 2 communities by Prof. Kate Storey of the School of Public Health, University of Alberta. The program is currently being expanded to 4 additional communities in Alberta.

2. Ensure the appropriate outreach for research

The Canadian and Australian collaborative initiatives, DREAM and DIABETES Across the LIFECOURSE, described in Section 4.2 reflect successful collaborative partnerships with Indigenous communities.

3. Expand Indigenous educational opportunities for medical learners, faculty and staff

In response to the Truth and Reconciliation Commission of Canada's Calls to Action, the Faculty of Medicine at the University of Toronto have expanded support for Indigenous members of their community; introduced a holistic and humanistic approach where Indigenous history, values and knowledge are respected and valued; and established an Elder-in-Residence role to support learners across U of T Medicine. [59]

4. Continue and strengthen international sharing of knowledge for prevention of youth-onset diabetes in Indigenous communities

In 2006, a joint International Diabetes Federation/ADA Symposium held as part of the 66th Scientific Sessions of the American Diabetes Association (ADA) addressed the issue of diabetes in indigenous populations, focusing on 3 high-risk groups from different regions of the world: Indigenous Canadians, Native Americans, and the people of the Torres Straight Islands. This Symposium considered several related perspectives: the rising tide of obesity; diabetes complications; clinical management; and primary prevention.

Among the conclusions of that Symposium were:

- * In light of the very high prevalence rates of obesity and type 2 DM in indigenous communities, more broadly focused, community-based primary prevention strategies are preferred.
- * These approaches are also more consistent with the holistic worldview of indigenous populations

In reviewing several excellent examples of prevention programs, the Symposium also noted that:

- * A common theme in all of these programs is a community-wide focus, with activities in local schools, including in most cases the development of school curricula, as well as other interventions in the community, such as radio/TV programming, grocery store interventions (shelf labeling, tours, and demonstrations), and partnerships and networking with existing community agencies
- * A key element in all of these programs is the use of a participatory research approach, in which responsibility, control, and decision making are shared by both the community and the researchers.

A published report of this Symposium ended with the following observation:

Recent examples of community-based primary prevention approaches and strategies to improve clinical management of diabetic patients are promising, although there is an urgent need for wider dissemination and institutionalization of these programs.

Opportunities for action?

The closing statement from the above Symposium is an example of dozens of such evidence-based needs addressing prevention, detection, surveillance and treatment that have been identified repeatedly in many published papers. The unanswered question is,

Who is responsible and accountable for ensuring that the required actions occur?

SFBLF free tools and resources

The following provide support for youth, families and their healthcare providers. All can be accessed for free on the SFBLF web site. All are optimized for access from mobile devices.

Prevention

* *Understanding Diabetes* eLearning course bantinglegacy.ca/understanding-diabetes The purpose of this self-paced course is to raise awareness about, and understanding of, diabetes and related risks, to foster prevention and to help youth living with diabetes to anticipate and prepare for the transition from paediatric to adult health care.

It consists of 3 short, narrated, graphics-supported Modules that together explain diabetes, the risks it presents for the collective well-being of the family; practical preventative steps that can be taken to reduce Type 2 risks; risk of complications in either Type 1 or Type 2; and how to prepare for a successful transition from the paediatric to adult healthcare system.

* Type 2 Diabetes Risk Self-Assessment for Youth (8 - 18) bantinglegacy.ca/survey This tool is neither diagnostic nor predictive; just a fun, easy way to provide youth with awareness and encourage further screening if their 'score' indicates such would be prudent.

* Infographics and Action

bantinglegacy.ca/prevention-campaign

The SFBLF Diabetes Awareness and Prevention Campaign includes suggested actions for families, schools and teachers, employers, municipalities, healthcare providers and pharmacies.

September 2020 Youth-onset Diabetes in Indigenous Peoples - Canada & Australia

Included are 8 Infographics that can be downloaded and printed; 3 of which are specifically designed for use by schools to raise awareness of what it means to live with diabetes as well as to minimize peer bullying.

Self-management support

* Food and You

bantinglegacy.ca/diabetes-and-food-survey

SFBLF

The purpose of this tool is to encourage youth to dialogue with their caregiver about food security worries. The questionnaire can be completed online and the result downloaded to share with a caregiver or be emailed prior to a clinic appointment. It can be completed on a mobile device while waiting for an appointment.

* Software application support

bantinglegacy.ca/youth-diabetes/sm-apps

Organized, reviewed list of free software applications for IOS and Android devices to help with the diabetes self-management task.

Helping to bridge the HCP communication gap

* Mental Health & Diabetes in Youth eLearning bantinglegacy.ca/e-learning

The purpose of this self-paced course is to enhance understanding of respective challenges facing healthcare providers who support youth living with diabetes and those who support youth living with mental health challenges; nurture cross discipline communication; and provide planning and implementation frameworks, references and resource material.

The course is narrated, illustrated and includes 5 Modules. Estimated time for successful completion is 5 - 10 hours including study of additional resources provided. This course has been accredited by the Australian Diabetes Educators Association (ADEA). Completion of the course including a submission of the Overall Course Quiz with a result of 75% or better will result in a formal Certificate of Completion.

Key Findings - Detail

1.0 Understanding Youth-onset Diabetes

1.1 Relative Severity of youth-onset diabetes

Type 1 is an auto-immune disease in which the body's defence system attacks the cells that produce insulin. Type 1 can affect people at any age but usually develops in children and young adults.

Type 1 cannot be prevented and there is no cure. People with Type 1 need multiple, daily injections of insulin to control their blood glucose levels.

Type 2 is characterized by insulin resistance where the body does not fully respond to insulin and blood glucose levels keep rising, thus releasing more insulin. In some cases, this can 'exhaust' the pancreas. Historically, Type 2 occurred in older adults but is now occurring with increasing frequency in children, adolescents and young adults.

It is estimated that 70% (or higher) of Type 2 cases could be prevented by healthy diet, increased physical activity and maintaining a healthy body weight. That same regimen is the basic treatment for managing Type 2 but in many cases, oral medication is needed also to control blood glucose levels.

There is early evidence that some Type 2 cases may be 'reversible'.

"Type 2 diabetes in childhood has the potential to become a global public health issue leading to serious health outcomes. More information is needed urgently" IDF World Diabetes Atlas, 8th edition, Nov 2017 (p 60) [1]

- * Type 2 is initially 'invisible' but progressive and can go undiagnosed for years. It is estimated that 40% (or higher) of people living with Type 2 are not aware they have the disease [2]
- * Type 2 in youth can be more severe than Type 2 in adults and in cases, than Type 1 in youth, since at diagnosis, diabetes-related complications may be in progress. [3] [4]
- * Control of blood glucose levels in Type 2 adolescents deteriorates faster than in adults due to greater insulin resistance and beta-cell dysfunction. [4]
- * "Complication rates occur earlier and are higher, with increased mortality rates, in paediatric Type 2 diabetes compared with Type 1." [4]
- * Some youth with Type 2 are not responsive to diet, exercise and oral medication and soon also require insulin. Early anecdotal evidence suggests this might be as high as 50% of the cases.

Gestational diabetes (GDM) is a type of diabetes that consists of high blood glucose during pregnancy and is associated with complications to both mother and child. GDM usually disappears after pregnancy but women affected and their children are at increased risk of developing type 2 diabetes later in life.

"The disproportionately high prevalence of hyperglycaemia in Indigenous versus non-Indigenous pregnant women worldwide is contributing to an escalating epidemic of intergenerational type 2 diabetes in this population." [5]

1.2 Diabetes Risk factors

Diabetes researchers and medical professionals consider diabetes risk factors to fall in two main groupings, modifiable (things you can take steps to avoid) and non-modifiable.

	Modifiable Risks	Non-modifiable Risks
Туре 1	* None known	* Family history * Age
Туре 2	* Inactive life style * Overweight/obesity	* Ethnicity* History of gestational
Gestational	 * Unhealthy diet * High blood pressure * Cholesterol levels * Smoking * Prediabetes 	diabetes * Unexplained stillbirths

Table 1.2 Diabetes Risks

Understanding the diabetes risk factors is important for the design and implementation of prevention and treatment programs as well as for personal guidance regarding risk reduction.

Diabetes comorbidities and complications

There are bi-directional relationships between mental health and diabetes in youth; likewise, for obesity/over-weight and diabetes in youth. Such comorbidities increase the risk of developing diabetes-related complications and amplify the challenges for diagnosis, treatment, and continuity of care. [6]

Obesity is a major risk factor for youth-onset Type 2 diabetes and is also linked to higher rates of gestational diabetes. Diabetes can cause anxiety and stress which, in turn, can affect motivation and lifestyle and lead to poor diet and inactivity and hence, potential weight gain. One condition can 'mask' the other and lead to mis-diagnosis or even 'missed' diagnosis at the outset.

Some medication used to treat mental illness can trigger rapid weight gain and again, set the stage for higher risk of youth-onset Type 2. [6]

In general, diabetes, if not managed well, can lead to diabetes-related complications such as retinopathy, cardiovascular and kidney disease and in some cases, eventually lower limb amputation.

1.3 Additional risk factors affecting Indigenous Youth-onset Diabetes

All of the above apply to Indigenous Youth along with several additional factors.



Indigenous communities face several unique realities arising from the historical impact of colonialism. For many communities, practical impediments for healthy living and effective delivery of healthcare are also imposed by geographic 'remoteness'.

Cultural beliefs and experiences determine a wider interpretation of 'health and wellness' which in turn, influences expectations for, and approaches to, treatment. In-school support for Indigenous students living with diabetes also needs to respect and support these differences.

Indigenous groups are the fastest growing segment of both the Canadian and Australian population. In general, Indigenous populations are 'younger' than non-Indigenous groups in both countries. [see Section 3.0 for demographic details]

Colonialism

- * It is widely agreed that the most 'powerful', negative factor affecting Indigenous youth-onset diabetes prevalence is the lingering legacy of colonialism; including intergenerational impact.
- * Historic colonialism processes in both Canada and Australia have resulted in,

"... loss of traditional lifestyles and spirituality, displacement, marginalized land bases, sociocultural disruption, assimilation, systemic disadvantage, socio-economic marginalization, loss of control over one's lifeway, loss of overall community wellness, power imbalances, stress, racism, discrimination, and intergenerational trauma" [7]

- * Forced enrolment in residential schools, with children being separated from their families, is but one example of the devastating historical actions that perpetrated such outcomes; and with a lasting intergenerational impact.
- * Much has been done to correct this tragedy in both countries. Actions spearheaded by the Truth and Reconciliation Commission (2008 - 2015) in Canada and Reconciliation Australia [1991 - 2017] included public apologies from Federal and Provincial governments and are continuing across a very wide front. [9] [53]
- * CBC News have created a website "Beyond 94" specifically to tracjk and report the status of Canadian government actions taken in response to the 94 'calls for action' tabled by the Truth and Reconciliation Commission [53]

The National Centre for Truth and Reconciliation (NCRT) at the University of Manitoba, is the permanent home for all Canadian statements, documents, and other materials gathered by the Truth and Reconciliation Commission and now continuing by the NCRT [10]

Geographic Isolation

- * Geographic remoteness is an inherent historical reality for some but currently, is being adjusted by increasing urbanization in both Canada and Australia. [11] [12]
- * Approximately 48% of Canada's Aboriginal population live in rural and remote locations with low population density, lack of transportation infrastructure, and for some, the ability to speak only indigenous languages. [13]. In Australia, 70% of Indigenous people live in a rural or remote area of less than 30,000 people. [11] [12]
- * Geographic remoteness can be positive in terms of nurturing a traditional lifestyle.

For example, the majority of Inuit Peoples live in remote communities spread across the northernmost edge of Canada. That continues to provide them with opportunity to sustain aspects of traditional 'hunter-gatherer' lifestyle with the associated benefits of healthier food and physical activity. However, their natural environment is facing the negative impact of climate change on top of the impact of motorized transport. [11]

- * The lifestyle benefits of remoteness are offset by the disadvantages of difficult and delayed access to essential modern-day healthcare support [13] [14]
 - > absence of year-round road access requiring air transport for non-resident healthcare providers
 - > health centres, not hospitals, often staffed by nurses with access to physicians available only for short durations when a physician flies in
 - > access to specialized care and continuity of care a challenge or impossibility
 - > retention of healthcare personnel can be difficult
- * While the realities facing indigenous Peoples who live in urban areas (versus rural or remote far northern communities) are obviously 'different', they are not necessarily 'better'. In all cases, Indigenous Peoples can be disadvantaged and in urban locations, often face discrimination.

Environment, Economics, and Lifestyle

- * These factors are closely interconnected.
- * Irrespective of location, the influences of modern day society have caused Indigenous Peoples to experience dramatic and detrimental changes in diet and physical activities; both being key determinants for increased risk of Type 2 diabetes and for earlier appearance of diabetes-related complications in either diabetes type.
- * Depending on location, access to healthy foods, especially, fresh fruits and vegetables, may be very infrequent or even if easily accessible, just too costly. Increased reliance on processed food, which also may be of low quality, in turn, can lead to obesity with resulting increased risk of Type 2 diabetes.
- * Food insecurity is a widespread reality. A 2010 survey study found that about 70% of Inuit preschoolers in Nunavut were living in households with food insecurity. [15]

Education

- * Preventing diabetes requires an understanding of the risk factors and what practical actions need to be taken.
- * Living with diabetes is not easy and the 'first step' of learning the essential survival skill to self-manage the disease can be daunting. That can be even more so for a young person.

- * Knowing what and how to assemble a 'healthy diet' is essential knowledge for both prevention and on-going condition management.
- * Language barriers can increase the challenge for educators as can the relative absence of 'leave behind' reference material available in relevant languages.

Economic Poverty

- * This relates to income, unemployment, lack of education, food insecurity and poor living conditions.
- * A shocking 25% of Canadian Indigenous peoples (First Nations, Métis and Inuit) are living in poverty and 40% of Canada's Indigenous children live in poverty. [16] 19.3% of Aboriginal Australians live in poverty compared to 12.4% for other Australians [54]
- * Poverty has been associated with an increased risk of chronic disease, injury, poor infant development, a range of mental health issues (stress, anxiety, depression, and lack of self-esteem), and premature death. The burden of poverty falls most heavily on certain groups (women, children, ethnic and minority groups, and the disabled) and geographic regions. [17]
- * Low levels of income and education, and homelessness in urban Indigenous populations are major barriers to receiving healthcare. [13] Low income levels lead to challenges paying for prescriptions or non-insured healthcare, while low levels of education can lead to a lack of health literacy causing potential delays in the early diagnosis and treatment of many conditions like Type 2 diabetes. Homelessness can lead to mental illness and substance abuse problems.

Social Poverty

- * This relates to cultural identity and isolation, lack of social support and racism leading to negative stereotyping and stigmatization
- * Indigenous people frequently find themselves socially disadvantaged in ways that can negatively impact healthy lifestyles. Relationships between resource limitations, socioeconomic status, and the social environment directly impact diabetes prevalence through material deprivation.
- * Indirect factors such as stress, depression, anxiety and loss of control, further undermine health outcomes. This requires health-care providers to recognize such disadvantage as a normalized state for many Indigenous peoples; thereby, limiting choices, increasing levels of stress, and diminishing capacity for self-care and lifestyle change. Attention to limited resources among families is key to recognizing the contexts in which self-care occurs. Limited budgets for food and financial sharing result in the diversion of resources, making family an important source of support as well as a key stressor. [18]
- * The lack of social supports within indigenous communities along with stigmatization can negatively impact indigenous youth perceptions of self. Social poverty leads to the propagation of negative lifestyle behaviours such as smoking, substance and alcohol misuse, physical inactivity and unhealthy eating habits and subsequent obesity. This serves to deepen negative self evaluations and leads to a higher incidence of mental health issues (depression, anxiety, PTSD) and substance abuse issues.

All of these impact on the individual's self-determination and ability to achieve a healthy lifestyle and hence, increase diabetes risk.

Cultural Poverty

- * This relates to the loss of language and connection to the land, environmental deprivation, and spiritual, emotional and mental disconnection.
- * Worldwide, many Indigenous people have adverse health outcomes, especially related to lifestyle diseases, which can be traced back to the devastating effects of colonialism and resulting cultural poverty. [19]

1.4 Outcomes and Impact

Factors such as those cited above, combined with a growing and younger indigenous demographic create a very serious problem for both Canada and Australia.

For Indigenous Peoples, the concept of health and wellness incorporates physical, emotional and mental wellbeing along with a spiritual connection to land and food. This holistic balance is essential to support a healthy person and this concept of balance also extends beyond the individual to incorporate aspects of a healthy community. This reality requires a much broader approach to healthcare delivery in support of indigenous people. [7]

- * These factors have
 - > exacerbated and perpetuated negative perceptions of health care that are often not aligned with indigenous cultural beliefs. These negative perceptions of healthcare are subsequently handed down to youth and future indigenous generations.
 - > added complexity, impediments and cost for Indigenous healthcare access, delivery and related research.
 - > made diabetes self-management and culturally appropriate in-school support for Indigenous students living with diabetes more difficult.
 - > made the already challenging goal of achieving effective youth-onset diabetes surveillance more difficult.
 - > added new dimensions and requirements for related education and training of medical professionals.
- * Long-term consequences of the evolving Type 2 diabetes epidemic include
 - > reduced longevity and quality of life for youth with diabetes;
 - > increased cost and resource burden for families, healthcare systems, medical education curricula, school systems, employers, and countries.
 - > an increase in the future burden of disease.; e.g., increased rates of hospitalization and the need for dialysis arising from diabetes comorbidities and complications in youth [20]
- * It is estimated that the annual cost of diabetes to the Canadian economy is now just under \$30 Billion. [21]
- * In Australia, the total economic cost of diabetes has been estimated at \$14 billion, including direct health care costs and indirect costs such as reduced productivity, absence from work, early retirement and premature death. [22]

Figure 1.4 Outcomes from imposed context factors affecting Indigenous health

	Imposed Context Influence			
Health/Wellness Factor	Historic Colonialism	Remote Location	Nature of Diabetes	Outcome
Cultural * Language * Land * Spirituality	impeded	can be positive		Cultural Poverty * loss of language * disconnections from land and spirituality
Economic * Income * Employment * Education * Food * Housing	impeded	disadvantage		Economic Poverty * low income * unemployment * lack of education * food insecurity * poor living conditions
Social * Supports * Identity	impeded	disadvantage		Social Poverty * stereotyping * racism * stigmatization
Modifiable Risk * Lifestyle * Diet	impeded	disadvantage	more difficult to modify factors	Higher Incidence & Prevalence
Unmedifichle Diele				
* Age * Gender * Family History	intergenerational impact		earlier onset	Higher Incidence & Prevalence
	Comb impedimen * Healthcare * Diabetes se * In-school su * Surveillanc * Medical edu	ine to add comple nts and cost for In Access, Delivery a lf-management upport e ucation and trainin	exity, adigenous and Research g	

2.0 Prevalence and the Surveillance Gap

Absence of youth-onset diabetes surveillance data = a worldwide knowledge gap

One cannot manage effectively what cannot be measured.

Youth-onset diabetes surveillance is a major capability gap leading to a major knowledge gap in the majority of countries. Canada and Australia are no exceptions.

Unfortunately, the surveillance data problem is further amplified by the relative absence of other data elements essential to effective prevention, detection and treatment of youth-onset diabetes in Indigenous populations

Hence, as for all youth, the prevalence of diabetes in Indigenous youth is unknown.

This section of the report characterizes youth-onset diabetes prevalence for indigenous youth using selected examples and summarizes the relative surveillance capability for Canada and Australia.

2.1 Diabetes Prevalence in Indigenous Youth

Canada has approximately 440,000 school age (5 - 19) Indigenous youth; Australia 230,000. [11] [12] How many of these youth are living with diabetes? No one knows the answer.

While there is a decided absence of national surveillance data to quantify diabetes prevalence for Indigenous youth, there is considerable knowledge available to describe the situation for Indigenous adults.

There is wide agreement and solid evidence that higher incidence and higher prevalence of diabetes prevail among Indigenous populations. For adults, that means at least 4 to 7 times greater prevalence than for non-indigenous; evidence suggests this can be much higher in some cases.

The extent to which the same imbalance applies to Indigenous youth remains unknown although there are studies involving selected groups that clearly indicate a similar imbalance.

Absent general quantification, selected examples that illustrate scale and direction of Indigenous youth-onset diabetes are provided.

There are many commonalities that apply to both Canada and Australia.

Diabetes landscape - Indigenous Canada

"Indigenous peoples in Canada, in particular First Nations, bear a disproportionate burden of diabetes due to the complex interaction of multiple determinants of health, many of which are rooted in colonial processes and structures that have altered socio-economic, political and cultural systems." [7]

- * Since the early 1940s, diabetes has become the most significant noncommunicable disease among Indigenous Peoples. [23]
- * The overall crude prevalence for diabetes ranges from 2.7% to 19%; which is 3 5 times higher than for non-Indigenous cohorts. [23]
- * First Nations have a much higher prevalence (15.3%) than the Métis (5.8%) and Inuit (4.3%).
 [24]

- * Significant prevalence differences can exist also within a Group by geographic region. For example, age-adjusted First Nations On-Reserve (17.2%) and Off-Reserve (10.3%) [25]
- * In Northern Quebec, the age-adjusted prevalence in 2009 approached an alarming 29%, [26]
- * By region, the First Nations in the James Bay Cree region have the highest prevalence of diabetes, followed by Northern Alberta and British Columbia. [26]
- * The incidence of diabetes in Aboriginal youth < 20 years of age in Alberta was an increasing trend from 1997 to 2005. [55]
- * Indigenous Peoples tend to develop diabetes at a younger age and have increased rates of complications, hospitalization, and mortality in comparison to the non-Indigenous population in Canada. [25] cites several original source papers with time frames ranging from 2005 to 2014]

The alarming rise of diabetes among Indigenous Peoples in Canada has been attributed to many interacting factors. Some of these also create impediments to delivery of essential healthcare services including prevention efforts

Diabetes landscape - Indigenous Australia

"Young Indigenous Australians experience a much greater risk than their non-Indigenous counterparts .. Indigenous Australians aged 10-39 had [T2] incidence rates (2006-11) that were 4 times those of non-Indigenous Australians ..." [27]

- * Estimates of the prevalence of diabetes in specific Aboriginal and Torres Strait Islander communities are highly variable—some as low as 4%, others as high as 33% [28]
- * Western Australia data indicate a 20-fold difference of Type 2 diabetes in Indigenous youth aged 16 years or less compared with non-Indigenous youth [29]
- * 2007 New South Wales study suggested that type 2 diabetes was 6.1 times as common among Indigenous young people aged 0–19 years than among non-Indigenous young people [30]
- * Northern Territory study reported that Indigenous youth represented 88% of youth type 2 diabetes diagnoses. [31]

2.2 Considering the Surveillance Gap

At the end of the day, surveillance data for youth are valuable only if used inform rational resource allocation decisions to improve health outcomes; to educate; and ultimately, to identify and implement effective action that increases awareness, reduces risk, nurtures prevention, improves the quality, delivery and continuity of healthcare, including access to such services and in the process, contributes to sustained and enhanced quality of life and well-being.

The usefulness of diabetes surveillance data that exist is diminished by the absence, and/or inconsistent inclusion, of variables such as geography, age ranges, gender, diabetes type, groups involved and time frames. Repetition of essential studies in order to obtain trends is minimal.

This is largely the same reality in both Canada and Australia. Australia has one national system that while voluntary, is slowly closing the knowledge gap (NDSS).

Canada has among the largest number of health surveillance systems with a youth component but remains unable to provide a comprehensive, national, systematic, sustained picture of youthonset diabetes, even in aggregate. [6] [7]

There are some Canadian exceptions at the Provincial and regional level. For example, Nova Scotia have an evolving data base that contains statistics for youth-onset diabetes. The Paediatric

Diabetes Network in Ontario has reasonably complete data for youth-onset Type 1 diabetes. Generally, such data are not published or shared widely. The Ontario Diabetes Database (ODD) includes only those 20 years of age or older and does not distinguish between diabetes type. [32]

Most studies that exist are based on an adult cohort. Extrapolating such results to youth is unlikely to be appropriate.

	Statis	First Nations		
	Canadian Community Health Survey (CCHS) StatCan	Canadian Health Measures Survey (CHMS) StatCan	Aboriginal Peoples Survey (APS) Statcan	First Nations Regional Health Survey (RHS) FNIGC
Children/Youth Content	12 years of age and older	3 - 79 years of age	15 years and older	* 11 and under * 12 - 17 * 18 and older
FN - On Reserve	omitted	omitted	omitted	included
FN - Off Reserve	included	included	included	included
Metis	not identified	not identified	included	omitted
Inuit	not identified	not identified	included	omitted
Frequency	annual	2 year cycles; diabetes incl in all cycles	every 5 years	evolving in Phases since 1997; Phase 3 reported in 2018

Table 2	2.2:	Illustrating	National	Surveillance	Gaps and	Inconsistencies	- (Canada	1
		musuating	1 autonai	Survemance	Uaps and	Inconsistencies	-	Janaua	e

Notes re Data Availability and Quality:

- 1. The age of available data and the lack of consistent cohort focus combine to result in reported data that appear, on occasion, to be contradictory.
- 2. Several helpful papers are now quite dated and have long been 'archived' with the result that original online reference links are not correct.

2.3 Surveillance Capability - Comparative Overview - Canada and Australia

- * National processes exist but are widely variable in approach, content and frequency across diseases.
- * Significant differences in criteria used to collect data make it difficult to compare relationships, e.g. diabetes, obesity, mental health which are often comorbid.
- * Inconsistent use of age ranges and exclusion of gender distinctions within and across disease surveillance studies diminish the utility of the data.
- * Generally, what data do exist are not made widely available to the general public.

Factor	Canada	Australia
Surveillance Org	ganizations	
National with General health focus	 PHAC - Public Health Agency of Canada StatCan - Statistics Canada CIHI - Canadian Institute for Health Information 	 AIHW - Australian Institute of Health and Welfare ABS - Australian Bureau of Statistics NHS – National Health Service
National with Diabetes focus Indigenous- specific	 4. DC - Diabetes Canada 5. National Collaborating Centre for Indigenous Health 6. First Nations Information Governance Centre 	 4. NDSS - National Diabetes Services Scheme (operated by DA) 5. DA - Diabetes Australia 6. ANDA - Australian National Diabetes Audit [Adults only] 7. Australian Bureau of Statistics (NATSISS) 8. AIHW - Australian Institute of Health & Welfare (AATSIHS)
Other organiz	zations with a surveillance activity exist at th	e Provincial, State and Territorial levels
Surveillance Sys	tems	
Relating to youth at least in part	 Canadian Chronic Disease Surveillance System (CCDSS) Canadian Paediatric Surveillance Program (CPSP) Canadian Community Health Survey Canadian Health Measures Survey Survey on Living with Chronic Disease in Canada - diabetes component 	 National Diabetes Services Scheme (NDSS) National Health Survey (NHS) National Survey of Mental Health and Wellbeing (NSMHWB) National Survey of Children's Health
Indigenous- specific	 6. Aboriginal Peoples Survey 7. First Nations Regional Health Survey 8. First Nations Regional Early Childhood, Education and Employment Survey (FNREEES) 	 5. National Aboriginal and Torres Strait Islander Social Survey (NATSISS) 6. Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS)

Table 2.3: Surveillance Organizations, Systems and Capability - Examples

2.4 What data elements are required to close the youth 'surveillance gap'?

Condition Data	Demogra	phic data
* Diabetes Type	* Age	* School and Board
* Age at diagnosis	* Gender	* Grade
* Medication(s)	* Indigenous Group	* Town/City
* Insulin Type(s)	* Other ethnicity	* Province

Table 2.4: Surveillance Data Needs

Diabetes researchers would seek several other data elements; e.g., screening history, comorbidities, A1c, blood pressure and BMI history, insulin delivery and self-management support devices used.

What matters first, given the current state of knowledge, is to assemble the basic elements as quickly as possible to create early insight regarding the 'scale' of the problem with a determined focus on youth. More data elements can be added with a pragmatic, on-going process.

What also matters is to ensure the basic data collection process includes continuous updating so reliable trends can be identified and assessed.

Many attempts to create national, comprehensive data bases for diabetes surveillance have 'failed' as a result of an approach that is initially 'too ambitious' with attempts to include 'all data' elements that might be useful in one research context or another.

This results in 'paralysis by analysis', unduly extended development time and ever-escalating project cost. More pragmatic, evolutionary approaches are needed.

The Opportunities for Action section of this report suggests one such approach.

SFBLF believes, "**Count first; extrapolate later**" is a valuable, pragmatic strategy that could lead to much earlier and more affordable insights regarding youth-onset diabetes prevalence.

2.5 Surveillance is difficult

In fairness to all, it must be acknowledged that surveillance is not easy. Many factors can contribute to making the task of surveillance very difficult indeed.

General considerations such as existing systemic shortfalls and cost, combined with study design and disease-specific characteristics, can present challenges.

Poor design of supporting data collection and data base frameworks can impede or limit the subsequent analyses opportunities including the ability to make meaningful comparisons with other studies.

Coding schemes used in administrative medical records and data bases often 'combine' disease types;

e.g., 'diabetes' used for both Type 1 and Type 2.

'Code structures' for identifying data elements in an electronic data base are a very prosaic, somewhat boring, technical consideration and as a result, often ill-considered by designers. Examples abound of the resulting failures to be able to compare studies even within the same organization; never mind, with studies from other organizations.

Figure 2.5: Nature of the Surveillance Challenge



3.0 Indigenous Demographics

Australia

Two groups of Indigenous peoples: Aboriginal and Torres Strait Islanders.

Each with unique histories, languages,

cultural practices and spiritual beliefs.

3.1 Population of Indigenous Peoples - Canada [11] and Australia [12]

Canada

Three groups of Indigenous peoples: First Nations, Métis and Inuit. Each with unique histories, languages, cultural practices and spiritual beliefs.

First Nati Metis Inuit	ons	2016 censu [with s	s for each country some updates]	Т	Aboriginal orres Strait Islanders
35.1 milli	ion	Total Coun	try Population	24	.5 million
1.7 millio	on	Total Indiger	nous Population	0.	8 million
4.9%		% of Coun	try Population		3.3%
44,000)	# with	multiple ID		26,800
44%		% age	under 25		60%
* First Nations	977,230	58.4%	* Aboriginal	739,288	92.6%
* Métis	587,545	35.0%	* Torres Strait	32,345	4.0%
* Inuit	65,025	3.9%	* Multi ID	26,767	3.4%
* Multi ID	21,310	1.3%			
* Other	22,670	1.4%			

Sub Groupings - Canada [33]

Status

Some Indigenous Peoples are 'registered' with the Federal Government; meaning they are entitled to a specified list of benefits. All 3 Main Groups have members with 'registered' status; First Nations being the majority.

NOTE: an Indian Reserve is a tract of land set aside under the Indian Act and treaty agreements for the exclusive use of an Indian band. Band members possess the right to live on reserve lands. Band administrative and political structures are frequently located there.

On or Off Reserve

The **reserve** system relates to First Nations bands and **people**, referred to in a legal context as **Indians**. Métis and Inuit **people** normally do not **live on reserves**, though many **live** in **communities** that are governed by land claims or self-government agreements



3.2 Youthful and Increasingly 'Urbanized'

In both countries, Indigenous populations are collectively:

- * younger than non-indigenous
- * growing faster than non-indigenous (2010-2016)
- * increasingly living in urban as opposed to 'remote' locations
- * but also, are 'aging' with the number of Indigenous aged 65 or over expected to double by 2036. Currently, however, the number of Indigenous 14 years of age and under overwhelms the proportion age 65 and older by factors ranging from 3- to 6-fold depending on group.

In Canada, Indigenous groups represent 4.9% of the total population but their youth under age 25 represent 7.9% of the total population under age 25.

In Australia, the comparable numbers are 3.3% and 6.7%

The growth rates differ for each group and by province, state or territory. There are marked geographic differences within a group; for example, Inuit outside of their ancestral territory of Nunangat, grew by 62% vs 20% within Nunangat.

The number of Indigenous people living in a metro area of 30,000 or more in Canada grew by almost 59% (2010-2016) and now over 52% live in such areas. The comparable number for Australia is 30%.

The urban Indigenous population is the fastest-growing population segment in Canada.

The 'urbanization' of Indigenous peoples has been in progress for decades in both countries. That change is due to multiple factors including demographic growth, mobility and changing patterns of self-reported identity.



Figure 3.2 Canada - Australia Indigenous youth ratios compared

3.3 Geographic Distribution

Where do Indigenous Canadians live?

The Indigenous population is spread across Canada but with markedly different geographic distribution for each Group.

* First Nations

- over half live in the western provinces (BC, AB, MN, SK)
- almost one-quarter (24.2%) live in Ontario
- 44.2% of those with registered or treaty Indian status lived on reserve in 2016

* Métis

- 80.3% live in Ontario and the western provinces
- In 2016, for the first time, Ontario had the largest Métis population
- nearly two-thirds of Métis live in a metropolitan area

* Inuit

- almost three-quarters live in Inuit Nunangat
- outside of Inuit Nunangat, the highest proportion live in the Atlantic Provinces, primarily, Newfoundland and Labrador (23.5%)
- outside of Inuit Nunagat, 56% live in a metropolitan area of at least 30,000 people; largest urban Inuit populations being in Ottawa-Gatineau, Edmonton and Montreal

Note: The term, 'Inuit Nunangat', refers to the area of Canada stretching from the westernmost Arctic to the eastern shores of Newfoundland and Labrador. It refers not only to the land, but also to the surrounding water and ice, which Inuit consider to be integral to their culture and way of life.



https://www150.statcan.gc.ca/n1/pub/89-634-x/2008004/figure/6500054-eng.htm

SFBLF

Where do Indigenous Australians live?

The vast majority of Australian Indigenous people live on the mainland and of those, the majority live in Queensland and New South Wales.

Of the 32,345 Torres Strait Islanders, 86% live on the mainland with only 4,400 on the Islands and they represent approx. 98% of the Island population.

Note: Torres Strait Islands lie off the north east coast of Australia and are part of Queensland. There are 133 islands of which 38 are inhabited.

State/Territory	Aboriginal	Torres Strait
Queensland	620/	> 50%
New South Wales	03%	24%
Western Australia	2.40/	
Northern Territories	2470	
Victoria	120/	6%
S. Australia, Tasmania, ACT	1370	
Torres Strait Islands		14%

 Table 3.3: Location of Australian Indigenous People

3.4 Languages

What languages are spoken by Indigenous Canadians?

The languages of Indigenous peoples in Canada are grouped in 12 families reflecting more than 70 distinct languages of which more than 30 are spoken by at least 500 people.

In 2016, almost 261,000 Indigenous people could speak an Indigenous language. In general, the number who could speak an Indigenous language was higher than the number with an Indigenous mother tongue. This suggests that people are learning an Indigenous language as a second language.

What languages are spoken by Indigenous Australians?

At the time of European settlement in Australia (circa 1788), more than 250 Indigenous Australian languages including 800 dialectal varieties, were spoken. Today, only 13 traditional languages are still acquired by Indigenous children. Approximately another 100 are spoken to various degrees by older generations and many of those languages are at risk.

The numbers who speak the 13 traditional languages are very small. For the 6 languages with the largest number of speakers, the numbers range from 4,264 speakers for Djambarrpuyngu to 1,702 speakers of Kunwinjku.

Over 13,000 people reported [12] they speak a 'new' Indigenous language developed since 1788 from contact between English speakers and Indigenous language speakers; for example, Kriol (Katherine region and across the Kimberley), Yumpla Tok (Torres Strait and Cape York) and Aboriginal English.

3.5 Schools and Indigenous Students

The demographics for Indigenous students participating in provincial/state/territorial or exclusively Indigenous schools in both countries are difficult to find and compare.

In Canada, there are 437,435 Indigenous youth age 5 to 19. representing 7.4% of the total 5.9 million Canadians age 5 to 19. [excluding 10.7 k 'multi ID/other'].

SFBLF

In Australia, there are 230,677 Indigenous youth age 5 to 19 representing 5.2% of the total 4.5 million Australians age 5 to 19.

Group	5 - 9	10 - 14	15 - 19	Total	%
Canada					
First Nations	101,105	92,280	88,100	281,485	64.3
Métis	44,580	43,990	47,180	135,750	31.0
Inuit	7,595	6,525	6,080	20,200	4.6
Total	153,280	142,795	141,360	437,435	
%	35.0	32.6	32.3		
Australia					
[breakout n/a)					
Aboriginal					
Torres Strait					
Total				230,677	

 Table 3.5: School Age Indigenous Youth [excluding Multi ID/Other]

Number of elementary and secondary schools (2019):

Canada = 15,500; Australia = 9,503

Indigenous Canada [34]

- * The federal government shares responsibility with First Nations for the provision of education to children ordinarily resident on reserve and attending provincial, federal, or band-operated schools.
- * In 2006-07, Indian and Northern Affairs Canada supported the education of 120,000 First Nations K–12 students living on reserves across Canada. Band-operated schools located on reserves educate approximately 60 per cent of the students living on reserves, while 40 per cent go off reserve to schools under provincial authority, usually for secondary school.
- * First Nations children living off reserve are educated in the public elementary and secondary schools in their cities, towns, and communities, with the provinces and territories providing the majority of educational services for Indigenous students.

Indigenous Australia [35]

- * The majority of Aboriginal and Torres Strait Islander students were enrolled in government schools (83.7%)
- * The Northern Territory had the highest proportion of Aboriginal and Torres Strait Islander students at 39.1%
- * The remaining states and territories recorded enrolments, ranging from 1.7% in Victoria to 9.2% in Tasmania

SFBLF

4.0 Indigenous Diabetes Support Programs

4.1 Indigenous-specific Support Organizations

There are dozens, if not hundreds, of organizations with a specific or indirect focus on supporting Indigenous Peoples. These range from national, provincial, state and territorial governments through Indigenous-specific advocacy groups and more general diabetes advocacy such as Diabetes Canada and Diabetes Australia.

In addition, there are countless university research networks and departments that have an Indigenous-specific mandate or that include an Indigenous focus in their research and teaching.

Hundreds of organizations and 1000s of healthcare professionals are directly involved in providing healthcare services to Indigenous Peoples.

Many support programs are the result of independent initiatives by Indigenous communities or collaborations with others. They are highly effective due to inclusion of cultural and spiritual dimensions and respect for the different meaning of 'health and wellness'.

Explorations for this paper included outreach to many of the organizations listed below.

Canada Australia Government * Indigenous Services Canada (ISC) * National Indigenous Australians Agency * Crown-Indigenous Relations and Northern (NIAA) Affairs Canada (CIRNAC) * Australian Institute of Health & Welfare * Health Canada * Statistics Canada (AIHW) * Australian Bureau of Statistics (ABS) National, Provincial, Territorial Indigenous Groups * First Nations Information Governance Centre * National Congress of Australia's First Peoples * Australian Institute of Family Studies (FNIGC) * Inuit Tapiriit Kanatami * South Australia Aboriginal Health Partnership * Métis National Council (MNC) * National Collaborative Centre for Indigenous Health (NCCIH) * Indigenous Diabetes Health Circle * Union of Nova Scotia Indians Diabetes Advocacy Groups - with Indigenous-specific or included focus * National Indigenous Diabetes Association * Australian Diabetes Educators Association (NIDA) (ADEA) * Diabetes Canada * Australasian Paediatric Endocrine Group * JDRF * Diabetes Australia * JDRF

Table 4.1: Examples of Indigenous Support Organizations

Universities & Research Networks with an Ind	igenous component
 * Diabetes Action Canada * Centre for Indigenous Peoples' Nutrition and Environment, McGill University * Institute of Health Economics 	 * Australian Indigenous HealthInfoNet [healthinfonet@ecu.edu.au] * Baker Heart and Diabetes Institute * Royal Darwin Hospital & Menzies Research Centre

4.2 National and Regional Initiatives

In addition to the myriad research studies in support of Indigenous health in general and diabetes in particular, there have been major national and regional initiatives by governments and others to understand and improve the health and well-being of Indigenous Peoples both in Canada and Australia. Some are on-going and many have evolved over time to reflect the changing context.

Many of these programs are a sub-set of programs for the general population which span a very wide spectrum: major prevention and research programs; on-going support programs such as for 'diabetes in schools'; provision of diabetes monitoring devices such as Continuous Glucose Monitors; delivery support such as insulin pumps, lancets, test strips and insulin; establishment of medical 'guidelines' and related benchmarking processes. Not all of theses program have universal accessibility or applicability; for example, there may be age-range limitations.

Table 4.2 Examples of Government and other National Initiatives

	Canada	Australia
Federa	l Government	
	* Canadian Diabetes Strategy (CDS) 1999	* Australian National Diabetes Strategy 2016 - 20
	* Aboriginal Diabetes Initiative (ADI) 1999 - 2015 [part of CDS]	* Diabetes in Australia: focus on the future 2017
	- three 5-year phases 1999; 2005; 2010 \$C523 million	* Australian National Diabetes Information Audit and
		Benchmarking (ANDIAB) Initiative
Nation	al Organizations	
	* Diabetes at School (CPS/CPEG)	* Diabetes Australia guidelines
	* Diabetes Canada (DC) guidelines	* Diabetes in Schools

Canadian Diabetes Strategy (CDS) and the Aboriginal Diabetes Initiative (ADI)

The Aboriginal Diabetes Initiative (ADI) was one of the four key components of the Canadian Diabetes Strategy (CDS) launched in 1999, as a 5-year program with C\$115 million of funding. The three other components were: Prevention and Promotion of Diabetes, National Diabetes Surveillance System and National Coordination [36]

* Aboriginal Diabetes Initiative (ADI) 1999 - 2015 \$C523 million

ADI Phase 1 (1999-2004) C\$58 million with initial objectives mirroring that of CDS.

September 2020 Youth-onset Diabetes in Indigenous Peoples - Canada & Australia

SFBLF

ADI Phase 2 (2005-2010) C\$190 million for another 5 years to reinforce on-going activities and to expand four other key areas of services; disease prevention and health promotion; diabetes screening and treatment; workforce training and capacity building; research and disease surveillance.

ADI Phase 3 (2010-2015) C\$275 million for another 5 years with a focus on: extending prevention initiatives to children, youth, parents, and families; preventing pregestational and gestational diabetes; enhancing food security and improving access to more nutritious traditional food; reinforcing practice guidelines and disease management for health-care providers. [37]

Indigenous Children in foster care - Canada

On June 21, 2019, the Government of Canada enacted new legislation, The Act respecting First Nations, Inuit and Metis children, youth and families, "to reduce the number of Indigenous children and youth in care and improve child and family services". [56]



www.sac-isc.gc.ca/eng/1541187352297/1541187392851

This Act, co-developed with Indigenous, provincial and territorial partners, came into force on January 1, 2020. The Act:

- * affirms the rights of First Nations, Inuit and Métis peoples to exercise jurisdiction over child and family services
- * establishes national principles such as the best interests of the child, cultural continuity and substantive equality
- * contributes to the implementation of the United Nations Declaration on the Rights of Indigenous Peoples
- * provides an opportunity for Indigenous peoples to choose their own solutions for their children and families

Australia - National Diabetes Programs

In 2015, the Australian Department of Health tabled the *Australian National Diabetes Strategy* 2016 - 2020. This high-level strategy prioritized Australia's response to diabetes, and the complications and comorbidities of diabetes and described ways to help reduce the negative

effects of diabetes. Prescribed action included a review of current diabetes services and care; all with the aims of:

- * maximizing the use of existing, limited healthcare resources
- * better coordination of healthcare resources across all levels of government
- * focusing resources where they are needed most

The strategy did not replace or override any existing processes already in use by the Australian healthcare system.

The strategy included 7 goals including Goal 5: reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples. [38]

Diabetes in Australia: focus on the future is an implementation plan for the 'Strategy' intended to operationalize each of the Strategy's goals (AHMAC 2017). 55 indicators were identified for on-going measurement and benchmarking. [39]

Australian National Diabetes Information Audit and Benchmarking Initiative (ANDIAB) continues but has so far, been implemented only for adults. [40]

Canada and Australia – Working together - Regional Initiatives [57]

The following two initiatives were developed in partnership with Indigenous peoples and communities.

"In 2010, an Indigenous stakeholder advisory group was formed to work in partnership with the Diabetes Research Envisioned and Accomplished in Manitoba (DREAM) research group in Canada. The goal was to bring together western medical knowledge and the knowledge of Indigenous scholars (elders, caregivers, and individuals with lived experience) to elevate prevention and care efforts of Indigenous youth who have or at risk of having type 2 diabetes. Indigenous and non-Indigenous researchers, community members, and stakeholders meet quarterly to share ideas, successes, and struggles. This partnership has been instrumental in prioritizing patient and community-reported outcomes, building components of community-based interventions, and engaging Indigenous trainees in science and clinical research."

"The DIABETES across the LIFECOURSE: Northern Australia Partnership commenced in the Northern Territory, Australia in 2011. This partnership of researchers, policy makers, and health service providers aims to improve systems of care and health outcomes for people with type 2 diabetes in remote northern Australia. In 2017, an Indigenous Reference Group was established in response to an identified need by key partners for Indigenous leadership and guidance. This group advises investigators to ensure that research is conducted in culturally appropriate ways."

4.3 Support for Diabetes at School [41]

Why are support processes necessary?

- * Students living with diabetes carry an additional developmental burden. They face many day-to-day challenges to effectively self-manage their condition. Whether living with Type 1 or Type 2 diabetes, students at school, and while in transit to school, need varying levels of support in order to be safe and to have a positive and full experience.
- * Implementation of a diabetes support program in a school helps to raise general awareness of the risks for youth-onset Type 2 diabetes and provides a unique opportunity to contribute to the pressing need for effective prevention of youth-onset Type 2 diabetes in the general student population.
- * Self-managing diabetes is a 24/7 requirement, is not an easy task and lapses can lead to medical emergencies. The diabetes 'condition' is not a consistent, stable process.

"The biggest struggle I had to face was the misunderstanding from teachers and classmates. I do not like to draw attention to myself. The only problem is, when you're having a low in the middle of a lesson, it is hard to not become the centre of attention when you must check your blood sugar and eat some snacks. I would sometimes become a distraction which would upset teachers and led to a lot of questions being asked of me such as, "ewww why won't your finger stop bleeding?" and, "I hate blood can't you go to the washroom and do that?" which made me beyond uncomfortable".

- T1 diagnosed at age 13

Attention to diet, physical activity, frequent blood glucose monitoring and the administration of insulin or oral medication is essential. Students living with diabetes need help to achieve and sustain their disease self-management skills, including support 'accommodations' while in school.

- * In-school support requires a standard framework for guidance but the actual accommodations must be individualized to reflect the disease condition and the developmental stage of the student. An Individual Care Plan (ICP) is required.
- * Most existing policies or guidelines reflect a dominant focus on Type 1. Given increasing youth-onset Type 2, it is essential to include guidance regarding support for Type 2.
- * Students living with diabetes are subject to humiliation, increased anxiety and stress all of which can negatively impact the stability of their blood glucose levels, increase their risk of medical emergencies and dilute their motivation to learn.
- * Parents and families of youth with diabetes face disruption to work schedules absent a support program; sometimes requiring parents to resign from jobs or re-locate to be nearer their student's school in case of emergency
- * Providing in-school support for Indigenous students with diabetes has additional requirements such as consideration of, and respect for, their expectations rooted in their history, culture and a different definition of 'health and wellness'.

What is the current status of in-school support processes?

Knowledge vs Action

- * Basic knowledge about the required processes, facilities and capabilities for effective, daily support of youth living with diabetes in school is well established
- * Professional medical organizations and diabetes-specific advocacy groups, including 'concerned parents', and health care experts in major teaching hospitals have taken various initiatives to advance awareness of the need and offer guidance.
- * Recommended 'best practice' guidelines have been published by professional medical organizations and disease-specific advocacy groups such as the International Diabetes Federation and national diabetes organizations in Canada, Australia and several other countries. [41]
- * 'Templates' for Individual Care Plans and Consent Letters and other documentation tools exist.
- * Instructional materials to support the training required for school personnel, parents and affected students exist in many forms including multi-media presentations, videos and posters as do recommended curricula.

- * These reference aids may not be available in all of the languages required or with consideration of cultural expectations required for effective support of all communities and constituents.
- * A very important aspect of support is to ensure that processes exist to facilitate the movement of students with diabetes between school levels and within a level. Ensuring continuity of care and protecting students from being 'lost in transition' are critical requirements.
- * The creation of standard policies or guidelines and implementation of required programs are lagging behind due to combinations of several factors:
 - > systemic complexity arising in large part from the 'de-centralized' governance responsibility for 'education' in both countries
 - > belief that a standard policy is inappropriate and needs are better met by 'local' decision-makers
 - > belief that existing processes within the healthcare system are sufficient to meet the required support needs
 - > limited resources to achieve the required education for teachers and staff
 - > probable unwillingness to act; usually citing 'higher priorities' as the reason

Progress in Canada and Australia

- * Both Canada and Australia have programs to encourage, if not mandate, in-school support systems for students with diabetes, but specifics regarding the degree of implementation remain elusive.
- * As a result of the youth-onset diabetes surveillance gap, little is known about the number of Indigenous students living with diabetes.
- * The extent to which in-school support systems also include recognition of the unique expectations and needs of Indigenous students is unknown.

Canadian status

- * In November 2017, the Canadian Paediatric Society (CPS) and the Canadian Paediatric Endocrine Group (CPEG) published a report summarizing existing in-school support policies and processes for each Province and Territory in Canada [42]. The report included a quality 'grade' assessment largely based on whether or not a formal 'policy' existed.
- * As of September 2018, based on research conducted by SFBLF and that engaged with all 13 provinces/territories at Cabinet level, 1 province and 2 territories had neither a 'policy' nor a 'guideline'; 6 provinces had a formal, mandated policy; 3 provinces and 1 territory had guidelines. In a few cases, the policy (Ontario) or guideline (Manitoba) encompasses other 'prevalent medical conditions'.
- * As part of that research, SFBLF contacted the 5 Provinces that had a policy at the start of 2018 and requested data on the number of boards/authorities and schools that had acted on the policy. No responding Province or Territory provided the number of boards or authorities who have acted on available policy or guidelines and none identified how many schools had a support program in place. One acknowledged they did not have that data despite their very long-standing policy.
- * Two provinces specifically stated they would not introduce a policy because they felt they had achieved such an effective integration at the operational level with their healthcare system that such was not necessary. In both cases, the ensuing results tend to substantiate their position.

- * One of the key points revealed in the SFBLF 2018 research project is that existence of a policy or guideline does not guarantee action at the school level. On the other hand, absence of a policy or guideline does not mean lack of action.
- * Some school boards have proceeded on their own to develop the required policies. Complete data on the numbers who have done so are not available. However, the Diabetes Advocacy initiative [43]assembled a significant set of links to many school board 'policy' documents that are either diabetes-specific or related thereto.
- * The Diabetes at School website operated by CPS and CPEG is a resource for schools, parents and caregivers designed to help school-aged children with Type 1 diabetes [44]

The status of support program implementation progress as of mid-2020 remains unknown. Unfortunately, whatever may be the case, progress in Canada has been halted by the onset of the COVID-19 pandemic.

Australian status

- * The *Diabetes in Schools Report 2017* called for a nationally consistent approach to diabetes support in schools: "Under the Federal Government's Education and Care Services National Law and supporting Regulations, all services providing or intending to provide education and care must have a diabetes policy".
 - > Some states and territories had a specific policy regarding aspects of diabetes support in schools, some did not. Some states and territories mandated the need for schools to have individual diabetes management plans in place for children and young people with diabetes, some did not.
 - > In some states and territories, individual health professionals and local diabetes organizations have attempted to address diabetes training needed for teachers and schools, but this was variable and not supported with sufficient funding. There was also variability across and within the public, private and religious school sectors." [45]
 - > This document also included a very specific list of Recommendations directed at state departments of education and schools for Policies and Planning, Training Support, Access to Diabetes Training, Reducing Stigma and Discrimination. [45]
- * The Diabetes Australia 'School' web page includes:
 - > a link to the Diabetes in School 2017 Report cited above as well as information for teachers, a statement on 'Duty of Care', links to individual state and territory diabetes offices as sources for information about support strategies.
 - > Mastering Diabetes is a new NDSS resource to help families, teachers and paediatric endocrinology teams. It has been designed to help teachers and families support children with type 1 diabetes at school and preschool, helping children to learn, grow and have fun. It is available as a PDF or an eBook.
 - > A summary list (with links) of resources created by Queensland, Victoria and New South Wales is included as is a link to a dedicated website developed by NDSS for 16-25 year olds living with diabetes. A telephone Helpline for all is operated by NDSS. [46a]
- * On September 4, 2018, the Minister for Health, Australia announced funding of \$6 million over two years to develop a "nationally consistent training program for teachers and school staff including the safe administration of insulin, hypoglycemia management and "normalizing" diabetes in schools so the students are not stigmatized." [46b]

- * On November 14, 2019, (World Diabetes Day], Diabetes Australia CEO, Professor Greg Johnson announced that DA would:
 - > begin contacting all parents and families of the 11,000 Australian children with Type 1 diabetes to urge them to register their interest in a new Diabetes in Schools program set to commence in early 2020. [47]
 - > This new program, funded by the Australian Government through the National Diabetes Services Scheme, will provide an integrated package of information, training and support for parents and families, schools and staff, and health professionals to better support students with type 1 diabetes.

The status of implementation progress as of mid-2020 is unreported. Unfortunately, whatever may be the case, progress in Australia has been definitely impacted by the onset of the COVID-19 pandemic. However, the relatively rapid response by Australia to contain the COVID-19 virus has led to 'earlier' opening of some schools and may in turn hasten the implementation of the new Diabetes in Schools program.

Diabetes Australia have a 'chalkboard' website specifically to help parents of youth with diabetes to understand the evolving considerations arising from COVID-19. [48]

4.4 Peer Support Networks are Needed

Why are peer networks helpful for youth with diabetes?

- * Youth living with diabetes, like all young folk, want to be happy, have a sense of self-worth, a feeling of accomplishment and enjoy life. They have an added wish and that is to learn to thrive, not just survive, in the face of their condition.
- * Youth living with diabetes face additional challenges in life including from time-to-time, a sense of isolation, maybe even 'shame' and on occasion, a feeling of being overwhelmed by the day-to-day demands of self-managing their condition. In school, they may be confronted with peer bullying and general humiliation arising from actions required to maintain essential self-management protocols.
- * Individuals who do not understand diabetes can easily, without meaning to, cause those living with diabetes to feel isolated and humiliated.
- * Support from family, friends, healthcare providers and teachers is essential but sometimes the well-intended 'oversight' can be wearisome. The amount of information provided by healthcare providers in relatively brief sessions can be somewhat 'defeating'. The associated questions regarding adherence to essential protocols can be discouraging; perhaps leading to incomplete and inaccurate responses.
- * An opportunity for young folk to just 'step aside' from their normal routine and have a chance to informally and candidly share their experiences and feelings with peers who are also living with diabetes can make a positive difference in outlook, help to 'keep things in perspective', reduce the sense of isolation and contribute to an improved quality of life.
- * A very important consideration for the effectiveness and safety of such networks is that there be an experienced mentor providing a degree of 'oversight; for example, a trusted adult and/or easy access to a healthcare team.

September 2020 Youth-onset Diabetes in Indigenous Peoples - Canada & Australia SFBLF

* Many examples of peer networks exist but networks specifically in support of Indigenous youth living with diabetes could not be found for Canada or Australia. It is highly likely, however, that many such networks exist with varying focus at the university and college level.

Peer networks for youth-onset diabetes prevention

Collaborating with the school system

Many programs that exist to engage youth in activities that promote healthy lifestyles are not suited to the unique needs and traditions of Indigenous Peoples. This is what inspired the development of the *Indigenous Youth Mentorship Program* (IYMP).

The IYMP approach to wellness was co-developed with Indigenous youth and leaders in Winnipeg and northern Manitoba along with researchers and community members, led by Dr. Jon McGavock from the University of Manitoba and Diabetes Action Canada. [49]

Guided by an Indigenous medicine wheel concept and delivered by Indigenous adolescents for Indigenous children in their communities, the IYMP builds on the strengths of its participants and helps to create healthy inclusive communities. Plans are in place to expand the program to 13 communities across 5 provinces.

In 2016, the IYMP was emulated within 2 communities by Prof. Kate Storey of the School of Public Health, University of Alberta. The program is currently being expanded to 4 additional communities in Alberta [50]

More evidence needed?

A 2018 paper assessed 20 examples of "Indigenous Youth Peer-Led Health Promotion.."; 9 Australian, 4 Canadian and 7 US. The report concluded that, "*Currently, there is limited high quality evidence for the effectiveness of peer-led health interventions with Indigenous young people, and the literature is dominated by Australian-based sexual health interventions. More systematic research investigating the effectiveness of peer-led in[ter]ventions is required, specifically with Indigenous populations. To improve health outcomes for Indigenous youth, greater knowledge of the mechanisms and context under which peer-delivered health promotion is effective in comparison to other methods of health promotion is needed." [51]*

Despite this somewhat discouraging conclusion, more efforts could and should be made at the 'community' level to establish Indigenous Youth peer network support.

2021 is the 100th Anniversary of the discovery of insulin at the University of Toronto, Canada. Insulin has saved the lives of hundreds of millions and continues to do so.

Celebrate Banting Day/World Diabetes Day November 14

References

- [1] World Diabetes Atlas, 8th Edition, IDF, November 2017 https://www.idf.org/elibrary/epidemiology-research/diabetes-atlas
- [2] World Diabetes Atlas, 9th Edition, IDF, November 2019 https://www.diabetesatlas.org/en/
- [3] Long-Term Complications and Mortality in Young-Onset Diabetes, Constantino. M.I. et al, Diabetes Care 2013 Dec 36(12) 3863-3869, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3836093/, retrieved August 24, 2017
- [4] Peria, Curran et al, *Screening, assessment and management of type 2 diabetes mellitus in children and adolescents:* Australasian Paediatric Endocrine Group guidelines, MJA 213 (1); 6 July 2020; https://onlinelibrary.wiley.com/doi/full/10.5694/mja2.50666
- [5] Maple-Brown, L., Denella Hampton, *Indigenous cultures in countries with similar colonisation histories share the challenge of intergenerational diabetes*, The Lancet, Vol 8, May 2020; https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(20)30072-3/fulltext
- [6] Persaud, S; Sadleir, D; Venier E. *Youth Living with Diabetes and Comorbidities Available Surveillance Data A Status Assessment*, SFBLF Sept 2017, Clinical Innovation Support Paper #2017-09-01-SI, www.bantinglegacy.ca/count-the-children
- [7] Halseth, Regine, Feb 2019, *The Prevalence of Type 2 Diabetes Among First Nations and Considerations for Prevention*, National Collaborating Centre for Aboriginal Health. https://www.nccih.ca/34/Publication.nccih?type=1; retrieved JN 12, 2020
- [8] First Nations Information Governance Centre, *National Report of the First Nations Regional Health Survey Phase 3: Volume One*, (Ottawa: 2018). 200 pages. Published in March 2018. https://fnigc.ca/first-nations-regional-health-survey.html; retrieved Jan 12/20
- [9] Reconciliation Australia, *The State of Reconciliation in Australia [Summary]*; ISBN 978-0-9945103-2-7, https://www.reconciliation.org.au/wp-content/uploads/2017/11/State-of-Reconciliation-Report_SUMMARY.pdf; accessed Aug 6, 2020
- [10] National Truth and Reconciliation Centre, University of Manitoba, Winnipeg Canada http://nctr.ca/about.php
- [11] Statistics Canada (StatCan) 2016 Census for Canada, https://www12.statcan.gc.ca/censusrecensement/2016/dp-pd/index-eng.cfm
- [12] Australian Bureau of Statistics, 2016 Census for Australia, https://www.abs.gov.au/websitedbs/censushome.nsf/home/2016
- [13] National Collaborating Centre for Aboriginal Health, Access to Health Services as a Determinant of First Nations, Inuit and Métis Health, 2011 https://www.nccahccnsa.ca/docs/fact%20sheets/social%20determinates/Access%20to%20Health%20Services_Eng %202010.pdf, access check Sept 7 2020
- [14] Karly B. Smith,¹ John S. Humphreys ¹ and Murray G. A. Wilson² Addressing the health disadvantage of rural populations: How does epidemiological evidence inform rural health policies and research? Aust. J. Rural Health (2008) 16, 56-66 https://doi.org/10.1111/j.1440-1584.2008.00953.x access check Sept 7 2020
- [15] Egeland, Grace, Pacey, A et al, Food insecurity among Inuit preschoolers: Nunavut Inuit Child Health Survey, 2007–2008, CMAJ 2010 Feb 23; 182(3): 243-248 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2826465/ access check Sept 7 2020

- [16] www.povertyinstitute.ca/poverty-canada access check Sept 7 2020
- [17] Poverty as a social determinant of First Nations, Inuit, and Métis Health 2009-10, nccah-ccnsa.ca/docs/fact%20sheets/social%20determinates/NCCAH_fs_poverty_EN.pdf
- [18] Diabetes Canada Clinical Practice Guidelines Expert Committee. Diabetes Canada 2018 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. Can J Diabetes. 2018;42(Suppl 1):S1-S325. http://guidelines.diabetes.ca/cpg/chapter38
- [19] Malcolm King, Alexandra Smith and Michael Gracey Indigenous health part 2: the underlying causes of the health gap, Lancet 2009; 374: 76 85, https://www.researchgate.net/publication/26647622_Indigenous_Health_Part_2_The_Underlying_Causes_of_the_Health_Gap, retrieved Mar 10, 2020
- [20] Titmuss, A., Maple-Brown, L., et al, *Emerging diabetes and metabolic conditions among Aboriginal and Torres Strait Islander young people*, MJA 210 (3), Feb 18, 2019 https://www.mja.com.au/journal/2019/210/3/emerging-diabetes-and-metabolic-conditions-among-aboriginal-and-torres-strait, access check Sept 7 2020
- [21] Diabetes Canada Press Release Feb 12/19: https://www.diabetes.ca/media-room/pressreleases/new-data-shows-diabetes-rates-and-economic-burden-on-families-continue-to-rise-inontario--] access check Sept 7 2020
- [22] Sainsbury, E., Yumeng Shi, et al, Burden of Diabetes, Prelim Report, July 2018 https://sydney.edu.au/content/dam/corporate/documents/faculty-of-medicine-andhealth/research/centres-institutes-groups/burden-of-diabetes-its-time-for-more-action-report.pdf access check Sept 7 2020
- [23] Leung, Lawrence, Diabetes mellitus and the Aboriginal diabetic initiative in Canada: An update review, J Family Med Prim Care 2016 Apr-Jun; 5(2): 259-265 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5084544/, retrieved Jan 8/20
- [24] *Canada 2011: Diabetes in Canada: Facts and Figures from a Public Health Perspective* https://www.canada.ca/en/public-health/services/chronic-diseases/reportspublications/diabetes/diabetes-canada-facts-figures-a-public-health-perspective.html
- [25] Institute of Health Economics, *Diabetes care and management in Indigenous populations in Canada A pan-Canadian policy roundtable*, November 1, 2017, Alberta, Canada https://www.ihe.ca/advanced-search/diabetes-care-and-management-in-indigenous-populations-in-canada-summary-report-of-a-pan-canadian-policy-roundtable
- [26] Kuzmina E L, Dannebaum D, et *al Cree Diabetes Information System (CDIS): 2009 Annual Update,* https://www.creehealth.org/sites/default/files/2009%20CDIS%20report.pdf
- [27] AIHW 2014 Type 2 diabetes in Australia's children and young people: a working paper. Diabetes Series no. 21. Cat. no. CVD 64. Canberra https://www.aihw.gov.au/getmedia/bc5d50e5-8ca0-474d-be77f96234d9a532/15203.pdf.aspx?inline=true access check Sept 7 2020
- [28] Burrow, S., & Ride, K. (2016). Review of diabetes among Aboriginal and Torres Strait Islander people. https://ro.ecu.edu.au/ecuworkspost2013/2226, access check Sept 7 2020
- [29] Haynes A, Kalic R, Cooper M, et al. Increasing incidence of type 2 diabetes in Indigenous and non-Indigenous children in Western Australia, 1990-2012. Med J Aust 2016; 204: 303. https://www.mja.com.au/journal/2016/204/8/increasing-incidence-type-2-diabetes-indigenousand-non-indigenous-children access check Sept 7 2020

- [30] Craig ME, Femia G, Broyda V, et al. Type 2 diabetes in Indigenous and non-Indigenous children and adolescents in New South Wales. Med J Aust 2007; 186(10): 497–499. https://www.mja.com.au/journal/2007/186/10/type-2-diabetes-indigenous-and-non-indigenouschildren-and-adolescents-new access check Sept 7 2020
- [31] Stone M, Baker A, Maple-Brown L. Diabetes in young people in the Top End of the Northern Territory. J Paed Child Health 2013; 49: 976–979 https://pubmed.ncbi.nlm.nih.gov/23735047/ access check Sept 7 2020
- [32] Green ME, Jones CR, Walker JD, Shah BR, Jacklin K, Slater M, Frymire E, eds. *First Nations and Diabetes in Ontario*. Toronto, ON: ICES; 2019. https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/First-Nations-and-Diabetes-in-Ontario, retrieved Jan 27/20 access check Sept 7 2020
- [33] Indigenous Peoples and Communities (Sub-Groupings) Canada, CIRNAC, https://www.rcaanccirnac.gc.ca/eng/1100100013785/1529102490303 retrieved Jan 25/20
- [34] Council of Ministers of Education, https://www.cmec.ca/299/Education-in-Canada-An-Overview/index.html access check Sept 7 2020
- [35] Australian Bureau of Statistics update, 4221.0 Schools, Australia, 2019 https://www.abs.gov.au/ausstats/abs@.nsf/mf/4221.0 access check Sept 7 2020
- [36] Stewart P. Building a National Diabetes Strategy: A Strategic Framework. Canada: Ministry of Health of Canada; 2005. Available from: http://www.publications.gc.ca/collections/ collection_2008/phac-aspc/HP5-5-2-2005E.pdf. [Last assessed on 2016 Jun 30]. This paper is no longer available online - see [23]
- [37] Health Canada. Aboriginal Diabetes Initiatives Program Framework; 2010-2015. Available from: http://www.hc-sc.gc.ca/fniah-spnia/pubs/diseases-maladies/_ diabetes/2010-2015-frame-cadre/index-eng.php. [Last accessed on 2014 Jan 03] This paper is no longer available online.
- [38] Australian Government, Department of Health, *Australian National Diabetes Strategy 2016-2020*. https://www.health.gov.au/resources/publications/australian-national-diabetes-strategy-2016-2020 access check Sept 7 2020
- [39] Australian Government, AIHW, *Diabetes Indicators for the Australian National Diabetes Strategy 2016-20* [updated Oct 10, 2018] https://www.aihw.gov.au/reports/diabetes/diabetesindicators-strategy-2016-2020/contents/summary access check Sept 7 2020
- [40] Lee, A.S., S. Colagiuri, and J.R. Flack, Successful implementation of diabetes audits in Australia: the Australian National Diabetes Information Audit and Benchmarking (ANDIAB) initiative. Diabetic Medicine, 2018. 35(7): p. 929-936 https://onlinelibrary.wiley.com/doi/full/10.1111/dme.13635 access check Sept 7 2020
- [41] Lawrence, S.E., Cummings, E.A., et al, *Managing type 1 diabetes in school: Recommendations for policy and practice*, Position Statement, Paediatr Child Health 2015;20(1):35-39 https://www.cps.ca/en/documents/position/type-1-diabetes-in-school
- [42] *Are We Doing Enough?*, November 2016 {p. 25], CPS, Prov/Terr policy status and rating https://www.cps.ca/uploads/advocacy/SR16_ENG.pdf access check Sept 7 2020
- [43] Diabetes Advocacy [operated by a Mother of a youth living with Type 1 diabetes] https://www.diabetesadvocacy.com access check Sept 7 2020
- [44] Diabetes at School, CPS, CPEG, www.diabetesatschool.ca access check Sept 7 2020

- [45] Diabetes Australia, Diabetes in Schools January 2017 https://static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/7dc95662-684e-4f31-8a4ee579d20f58e4.pdf p 2.and 3, retrieved, Aug 8/18, access check Sept 7 2020
- [46a] Diabetes Australia Schools https://www.diabetesaustralia.com.au/school
- [46b] Schools across Australia to get help to support children with type 1diabetes [Sept 4 2018], https://www.diabetesaustralia.com.au/news/15540?type=articles, accessed Sept 17, 2018
- [47] as1diabetes, Diabetes NSW & ACT, https://as1diabetes.com.au/news/new-national-diabetesin-schools-program-to-start-in-2020/ access check Sept 7 2020
- [48] NDSS, Diabetes in Schools, *COVID-19 Chalkboard* https://www.diabetesinschools.com.au/covid-19-chalkboard/ access check Sept 7 2020
- [49] Indigenous Youth Mentorship Program, University of Manitoba, http://www.jonmcgavock.com/aymp_access check Sept 7 2020
- [50] Indigenous Youth Mentorship Program, University of Alberta, https://www.ualberta.ca/publichealth/news/2019/september/mentorship-program-supports-indigenous-youth.html access check Sept 7 2020
- [51] Vujcich, D. et al, Indigenous Youth Peer-Led Health Promotion in Canada, New Zealand, Australia, and the United States: A Systematic Review of the Approaches, Study Designs, and Effectiveness Front. Public Health, 13 February 2018
 https://www.frontiersin.org/articles/10.3389/fpubh.2018.00031/full access check Sept 7 2020
- [52] Sadleir, D., Elisa Venier, et al, *In-school Support for Students Living with Diabetes*. SFBLF Diabetes Issues Report #2018-09-17-SI bantinglegacy.ca/in-school-support
- [53] CBC News, *Beyond 94*, [website to monitor progress of the 94 calls to action issued by the Truth and Reconciliation Commission], https://newsinteractives.cbc.ca/longform-single/beyond-94?&cta=1 access check Sept 7 2020
- [54] The Poverty Report 2014, Australian Council of Social Service https://www.acoss.org.au
- [55] Oster, R. T. et al, Recent epidemiologic trends of diabetes mellitus among status Aboriginal adults, CMAJ 2011 Sept 6; 183(12), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3168663/ access check Sept 7 2020
- [56] Indigenous Services Canada, Statement by Minister Marc Miller, Jan 1/20 https://www.canada.ca/en/indigenous-services-canada/news/2019/12/statement-by-the-ministerof-indigenous-services-on-the-coming-into-force-of-an-act-respecting-first-nations-inuit-andmetis-children-youth-and-fam.html
- [57] Maple-Brown, Louise J., Sian Graham, Jackie McKee, Brandy Wicklow, Walking the path together: incorporating Indigenous knowledge in diabetes research, Lancet Diabetes Endocrinology, 2020 Jul;8(7):559-560 https://www.thelancet.com/journals/landia/article/PIIS2213-8587(20)30188-1/fulltext
- [58] Diabetes Canada, *Diabetes 360: A Framework for a Diabetes Strategy for Canada*, July 2018, https://www.diabetes.ca/DiabetesCanadaWebsite/media/Advocacy-and-Policy/Diabetes-360-Recommendations.pdf
- [59] Faculty of Medicine, University of Toronto, Strategic Plan 2018-23; 2020 Updates, Indigenous Medical Education. https://medicine.utoronto.ca/asp

Appendices

Appendix A.1: Diabetes Basics

- * **Diabetes** is a chronic disease that occurs when the pancreas is no longer able to make insulin or when the body cannot make good use of the insulin it produces.
- * **Insulin** is a hormone, made by the pancreas, that acts like a key to let glucose from the food we eat pass from the blood stream into the cells in the body to produce energy. All carbohydrate foods are broken down into glucose in the blood. Insulin helps glucose get into the cells.

There are several types of diabetes. The most common forms are Type 1, Type 2 and Gestational. Globally, Type 2 represents approximately 90% of all cases.

* **Type 1** is an auto-immune disease in which the body's defence system attacks the cells that produce insulin. Type 1 can affect people at any age but usually develops in children and young adults.

Type 1 cannot be prevented and there is no cure. People with Type 1 need multiple, daily injections of insulin to control their blood glucose levels.

* **Type 2** is characterized by insulin resistance where the body does not fully respond to insulin and blood glucose levels keep rising, thus releasing more insulin. In some cases, this can 'exhaust' the pancreas. Historically, Type 2 occurred in older adults but is now occurring with increasing frequency in children, adolescents and young adults.

It is estimated that 70% (or higher) of Type 2 cases could be prevented by healthy diet, increased physical activity and maintaining a healthy body weight. That same regimen is the basic treatment for managing Type 2 but in many cases, oral medication is needed and increasingly, insulin also may be required to control blood glucose levels.

There is early evidence that some Type 2 cases may be 'reversible'.

- * **Gestational diabetes (GDM)** is a type of diabetes that consists of high blood glucose during pregnancy and is associated with complications to both mother and child. GDM usually disappears after pregnancy but women affected and their children are at increased risk of developing type 2 diabetes later in life.
- * Diabetes-related complications People with diabetes have an increased risk of developing a number of serious health problems. Consistently high blood glucose levels can lead to serious diseases affecting the heart and blood vessels, eyes, kidneys, nerves and teeth. In addition, people with diabetes also have a higher risk of developing infections. In almost all high-income countries, diabetes is a leading cause of cardiovascular disease, blindness, kidney failure, and lower limb amputation.

Maintaining blood glucose levels, blood pressure, and cholesterol at or close to normal can help delay or prevent diabetes complications. Therefore, people with diabetes need regular monitoring.

It is estimated that 65% of diabetes-related complications in both Type 1 and Type 2 can be prevented or at least delayed with sustained, effective diabetes management protocols.

[Above summarized from the International Diabetes Federation https://www.idf.org/aboutdiabetes/what-is-diabetes.html]

Appendix A.2: Outreach List

[April 2019 - June 2020]

Canada

Government

Office of the Prime Minister Indigenous Services Canada Public Health Agency Canada

Indigenous Organizations

First Nations Information Governance Centre Indigenous Works Inuit Tapiriit Kanatami Métis Nation National Collaborative Centre for Indigenous Health National Indigenous Diabetes Association Union of Nova Scotia Indians

Universities/Colleges/Research Networks

Canadian Paediatric Society	
Diabetes Action Canada	
Institute of Health Economics	
McGill University	Centre for Indigenous Peoples
Ryerson University	School of Nutrition
University of Alberta	School of Public Health
University of Guelph-Humber	Kinesiology Department
University of Manitoba	Indigenous Health Liaison Library
University of Manitoba	Rady Faculty of Health Sciences
University of Toronto,	Department of Nutritional Sciences

Australia

Government

Australian Institute of Health and Welfare (AIHW)

Indigenous Support Organizations

Australian Diabetes Educators Association, Canberra (ADEA) Diabetes Australia National Indigenous Australians Agency (NIAA)

Research Networks

Baker Heart & Diabetes Institute, Melbourne Royal Darwin Hospital & Menzies Research Centre

SFBLF

Appendix A.3: COUNT THE CHILDREN

Project Objectives



- 1. The primary objectives of this project are:
 - a. "Count the number of students in the elementary and secondary school system living with either Type 1 or Type 2 diabetes".
 - b. Conduct that count in a manner which protects student privacy and that facilitates annual repetition in order to gain insight regarding relevant trends.
- 2. There are 2 secondary objectives:
 - a. Promote diabetes prevention by raising awareness and understanding of diabetes.
 - b. Create further incentive for schools to implement an in-school support process for students with diabetes.

Why is this project important?

- * Youth-onset diabetes is growing worldwide; more so for Type 2 than Type 1.
- * Despite a very broadly-based, large scale commitment, major knowledge gaps remain with respect to quantifying the incidence and prevalence of youth-onset diabetes. No one knows how many children/youth are living with diabetes but all agree the numbers are escalating.
- * A few countries do have a process for tracking the prevalence of youth-onset diabetes. Most do not; including Canada and Australia for example.
- * Such 'surveillance data are valuable only if used to identify the need for prompt interventions; educate; and inform rational resource allocation decisions to improve health outcomes. One cannot manage effectively what cannot be measured.
- * The much larger problem of assembling a comprehensive National Diabetes Registry needs to be solved, BUT the urgent imperative is to focus first on our youth.
- * Type 1 diabetes cannot be prevented. 70% of Type 2 cases can be prevented or at least delayed by a healthy diet, regular exercise, maintaining appropriate body weight and not smoking. 60% (or higher) of diabetes-related complications in both Type 1 and Type 2 cases also can be prevented or delayed with a similar regimen supported by regular screening.
- * School systems hold the potential to make a significant contribution to narrowing the surveillance data gap for youth-onset diabetes and to do so relatively quickly and at modest cost.
- * Sharing the diabetes data while preserving anonymity for specific students would quantify the current status and provide a basis for routine updating. That outcome is within practical reach if the school systems have the will to help.
- * This is not a scientific nor complete solution obviously, but would provide significant progress relative to our current state of knowledge.
- * It is just a 'count' but sustaining the process on an annual basis would also provide new insight regarding 'trends'.
- * Such a process also would serve to increase awareness of the youth-onset diabetes threat.

- a. Appoint a staff member as the Project Contact person for the study team.
- b. Compile an integrated list of all students living with diabetes (Type 1 or Type 2) by grade
- c. Assign a unique ID number to each student
 - [the resulting Table is to be held securely by the school for cross-reference purposes should follow up be required in the interests of the student's health and well-being]
- d. Advise all involved parents/guardians of the study and obtain parental permission letters where necessary.
- e. Inform all involved students that:
 - > their data will be used in a study to improve collective knowledge of youth-onset diabetes.
 - > their privacy will be protected and no external investigator will be aware of individual student names

[If the school already has a registration process for students with diabetes and/or if the school requires an annual Individual Care Plan to be filed with the school, those documents may provide some of the data being sought.]

- f. Transfer data from the registration document or the Individual Care Plan for each student to the anonymous Diabetes Surveillance Data Collection Sheet and have each student complete any missing data. [sample Data Collection Sheet attached]
- g. Mail the completed data sheets with the covering Transmittal Form to the external study coordinator.

Study Protocol

- * No data will be shared between or among participating Boards or any third party without prior written agreement from involved Boards
- * No member of the Study team will approach, interview or seek identification of any student.

Documents List

- 1. School identification sheet
- 2. CONFIDENTIAL Cross-reference table
- 4. Transmittal Form

- 3. CONFIDENTIAL Data Collection Sheet
- 5. Parental permissions letter (use if required)

Supporting Opportunities for Action

2. Raise awareness and help with prevention

- * Hold an annual school-wide Diabetes Awareness Day
- * Encourage all students to learn more about diabetes including discussion with families
- * Emphasize importance of healthy diet, daily exercise, and an appropriate body weight
- * Encourage students to take the SFBLF online Type 2 Diabetes Risk Self-Assessment Quiz

3. Implement an in-school support process for students with diabetes

* Ensure the process includes consideration of students with either T1 or T2 diabetes and culturally appropriate approaches for support of Indigenous youth.

SFBLF

September 2020 I outil onset Diabetes in Inalgenous I copies Canada a Musei ana

SFBLF

FREDERICK &

CONFIDENTIAL DATA SHEET FOR STUDENTS WITH DIABETES



SFBLF © 2020