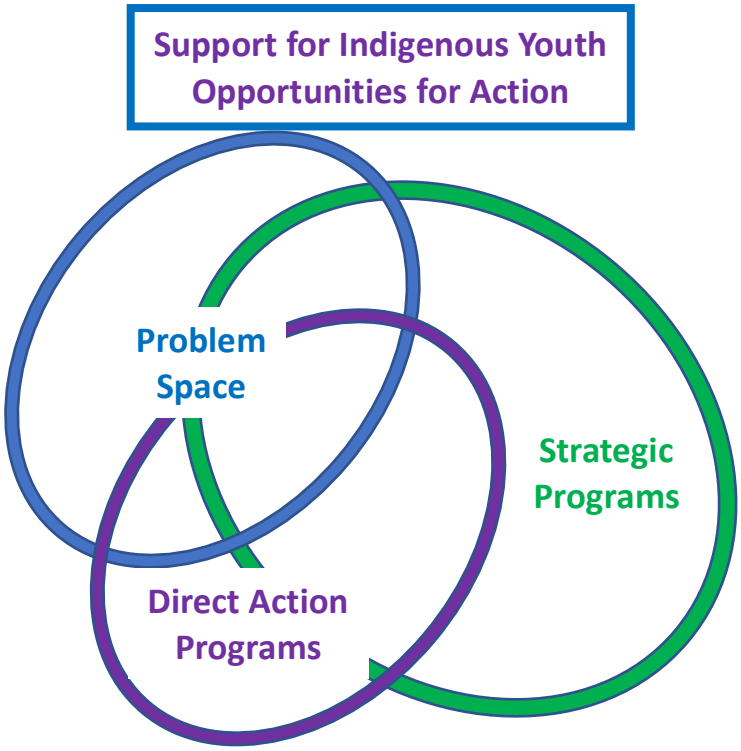
Executive Summary

Youth-onset Diabetes
in
Indigenous Peoples: Canada and Australia

Sir Frederick Banting Legacy Foundation (SFBLF)
Diabetes Issues Report #2020-08-31-SI
bantinglegacy.ca/Indigenous-youth



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.

Executive Summary - Contents

NOTE: The full report [62 pages] can be found at bantinglegacy.ca/indigenous-youth/ and includes the following Key Findings - Detail plus the list of 59 References

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 Research & Outcomes

Research Focus

This Report is a product of the SFBLF Summer Intern Research program. [bantinglegacy.ca/research]

It 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.

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.

SFBLF Diabetes Management and Education Centre (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.

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 here as Appendix F.]

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

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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 60 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

Problem Summary

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

Problem Summary

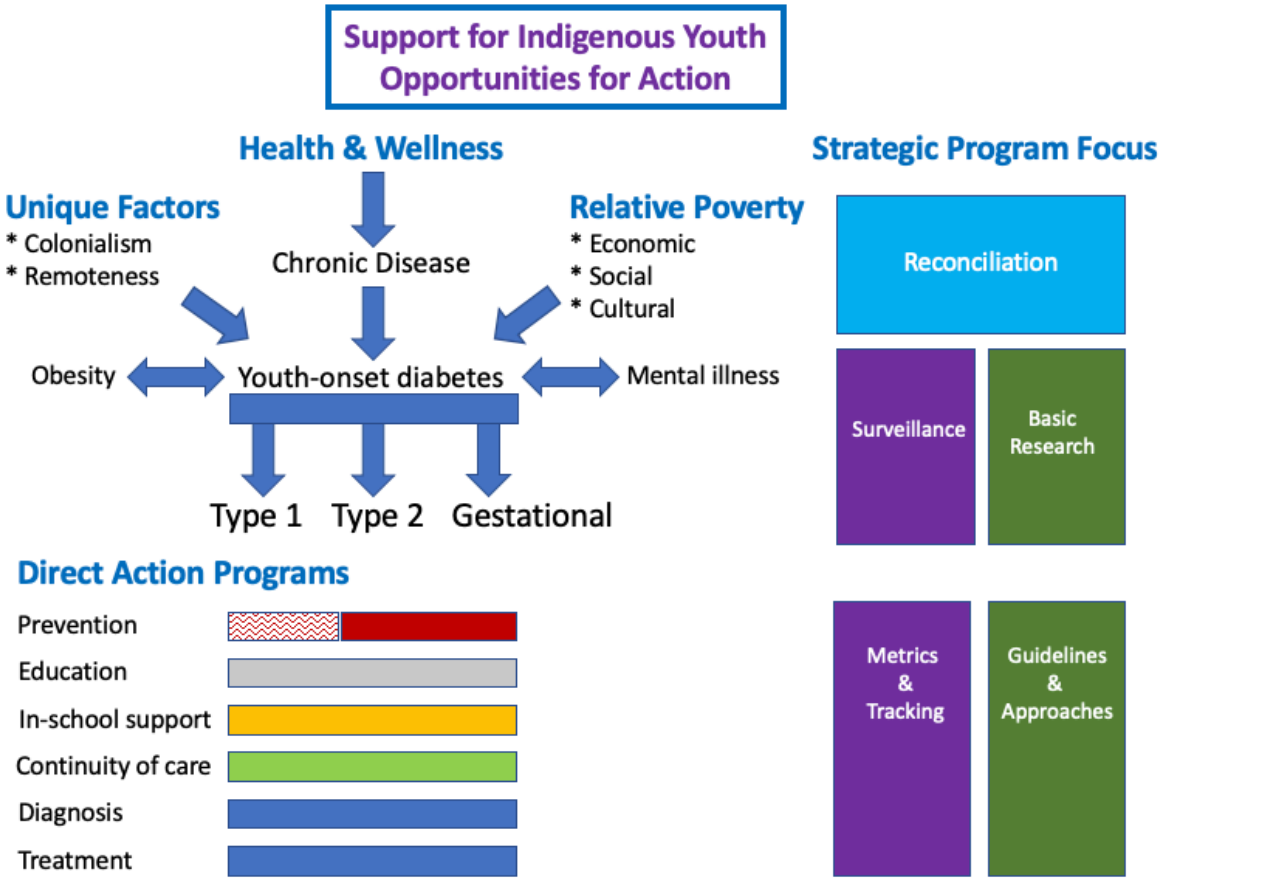
For all youth

* 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



Key Findings - Summary

The full Report illustrates the daunting complexity associated with Youth-onset diabetes in general and for Indigenous Youth in particular. [bantinglegacy.ca/Indigenous-youth]

The Report also illustrates that despite this complexity, in both Canada and Australia, 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' as summarized above 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.

Positive support exists across a wide spectrum but despite that, major gaps remain.
[App. E. includes a sample list of support organizations in both countries]

A. There are Gaps in Capability and Knowledge

1.0 Absence of youth-onset diabetes surveillance = a global knowledge gap
[App. D. includes a Canadian example and list of involved organizations in both countries]

2.0 Data, essential for rational healthcare resource allocation, are incomplete, inconsistent or non-existent.
[App. E. includes an assessment of relative data availability in both countries]

B. Unique Factors Increase the Challenges

3.0 Three added unique factors affect diabetes prevalence in Indigenous Peoples:
* Colonialism * Geographic remoteness * Broader perception of 'health and wellness'
[App. F. provides a summary chart illustrating the combined risk impact]

4.0 In-school support systems for Indigenous students require additional considerations arising from perceptions of 'health and wellness'.

5.0 Healthcare delivery for Indigenous youth also faces unique challenges arising from 'remoteness', urbanization and the need to address key modifiable risk factors in parallel.

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

C. Education is Critical but Difficult

7.0 Providing education for diabetes prevention and self-management is essential but language barriers and cultural expectations increase the delivery challenge.

D. A Comprehensive 'Team' Approach is Essential

8.0 Greater collaboration is required. Communication is a 'two-way street'.
Required 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.

What is missing?

In summary, SFBLF believe the answer to that question includes:

1. A set of national priorities focused exclusively on the youth-onset Type 2 diabetes threat in general and for Indigenous youth and other high risk cohorts in particular;
2. A need to continue strategic and tactical level actions in parallel and with improved coordination;
3. A 'national clearinghouse' to assemble, analyze, categorize and report key results;
4. A conceptual reference model of the problem/opportunity space;
5. Funding programs that use such a reference model to inject a thoughtful 'steering effect'; but without limiting creativity especially, in basic research;
6. A propensity to seek pragmatic, evolutionary approaches;
7. Standards for many aspects in the solution space to facilitate comparative analyses.

Opportunities for Action

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.

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.

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.

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 diabetes prevention programs with increased emphasis on youth.
2. Solve the youth-onset Type 2 diabetes surveillance problem. Virtually every published study with a focus 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 surveillance information systems and capability in order 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%

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

An elementary school in Winnipeg, Manitoba, Canada was the first winner of a 'gold' level award from the SFBLF National Recognition Program for Schools. This pragmatic, cost-effective approach focuses the training challenge by using Diabetes Response Teams that include peers; leadership by example through teachers with diabetes demonstrating their blood glucose tests in front of students; and a very clever 'sugar low' alert card provided to all students with diabetes. The details are included here as Appendix B.

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

'Count first; extrapolate later': a first step to obtain early and improved insights as part of meeting 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 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?

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, or diabetes-related complications, 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 C.. describes a 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. The Indigenous Youth Mentorship Programs (IYMP) at the University of Manitoba and at the University of Alberta reflect what is needed to make a difference for Indigenous youth.

2. Ensure the appropriate outreach for research involving Indigenous Youth

The Canadian and Australian collaborative initiatives, DREAM and DIABETES Across the LIFECOURSE, [details in the full Report] 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.

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.

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?

App. A. 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.

  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
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.

App. B. 'Gold Level' approach to in-school support

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.

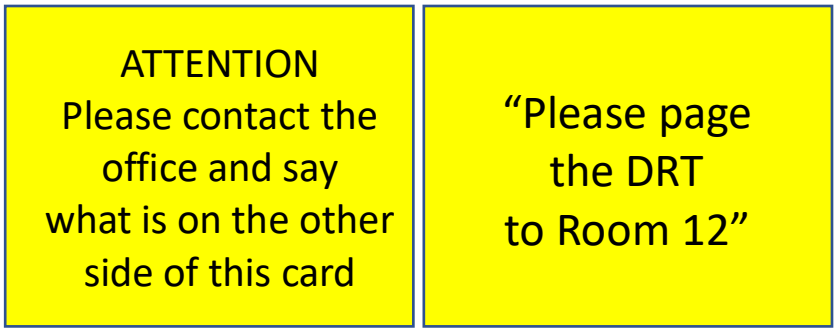
1. Optimize the impact by creating a small Diabetes Response Team (DRT) for each student living with diabetes (or designated groups if numbers dictate).
2. Include trained student peers on the DRT.
3. Have a DRT member present to provide support for field trips and sporting events.

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.



App. C. How schools can help with surveillance

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.

Count the Children – Process Overview

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
3. CONFIDENTIAL Data Collection Sheet
4. Transmittal Form
5. Parental permissions letter (use if required)

CONFIDENTIAL DATA SHEET
FOR STUDENTS WITH DIABETES

This section for school staff use only

Date yyyy/mm/dd Individual ID No.

Ethnicity of the student

Following sections to be completed by all students with diabetes

Grade Date of Birth [yyyy/mm/dd] Female Male

Your diabetes diagnosis:

Date of diagnosis [yyyy/mm/dd] Try to identify year if you are unsure of details

Type 1 Type 2 Medication Induced Other

If you use insulin: What kind of insulin do you take?

I take my insulin using:	Syringes	Pens	Pump

If no pump, how often do you inject your insulin most days? 1 or 2 3 or 4 more than 4

I use a Continuous Glucose Monitor (CGM) YES NO

If you do not use a CGM, how often do you check your blood glucose in school including extra-curricular activities? 2 or 3 4 or 5 more than 5

If you do not use insulin: What medications do you use to help manage your diabetes ?

Please tell us something about yourself [optional]

Do you eat breakfast every day? YES NO

Do you smoke? YES NO

Do you feel well physically and mentally most days? YES NO

Have you experienced any complications related to diabetes? YES NO

How often do you exercise per week?

How often do you see your healthcare professional per year?

Do you have an individual care plan on file with your school? YES NO

Thank you very much for your help

App. D. Surveillance Perspectives

Table 2.2: Illustrating National Surveillance Gaps and Inconsistencies - Canada

	Statistics Canada Systems			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 2.3: Surveillance Organizations, Systems and Capability - Examples

Factor	Canada	Australia
Surveillance Organizations		
National with General health focus	1. PHAC - Public Health Agency of Canada 2. StatCan - Statistics Canada 3. CIHI - Canadian Institute for Health Information	1. AIHW - Australian Institute of Health and Welfare 2. ABS - Australian Bureau of Statistics 3. NHS – National Health Service
National with Diabetes focus	4. DC - Diabetes Canada	4. NDSS - National Diabetes Services Scheme (operated by DA)
Indigenous-specific	5. National Collaborating Centre for Indigenous Health 6. First Nations Information Governance Centre	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 organizations with a surveillance activity exist at the Provincial, State and Territorial levels		
Surveillance Systems		
Relating to youth at least in part	1. Canadian Chronic Disease Surveillance System 2. Canadian Paediatric Surveillance Program 3. Canadian Community Health Survey 4. Canadian Health Measures Survey 5. Survey on Living with Chronic Disease in Canada - diabetes component	1. National Diabetes Services Scheme (NDSS) 2. National Health Survey (NHS) 3. National Survey of Mental Health and Wellbeing (NSMHWB) 4. 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	5. National Aboriginal and Torres Strait Islander Social Survey (NATSISS) 6. Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS)

App. E. Comparative Data Tables

Table CFS 1: Comparative Demographics - Summary

	Canada	Australia
Groups		
Indigenous Groups	* First Nations * Métis * Inuit	* Aboriginal * Torres Strait Islanders
	Each of these 5 groups has their own distinct identity, history, languages, cultural traditions and spiritual beliefs. A small % in both countries self-identify as being in more than group.	
Demographics [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 Métis * 80.3% in Ontario and western provinces Inuit * 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. Torres Strait Islanders (TSI) * > 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 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 Groups	
* 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 Indigenous 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

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 (Province/State/Territory, urban/rural, on- and off- reserve?	good	
3. Related growth trends?	fair	
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 on systems; mixed data 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. To what extent are national guidelines for youth-onset diabetes screening actually being followed?	unknown	
2. Identify Impediments to effective and sustained delivery of health care support for Indigenous youth?	good	
3. Identify Socio-cultural factors that influence effective health care delivery for Indigenous youth?		
4. Identify National, provincial, state or territorial initiatives to improve delivery of health care support for Indigenous Peoples?		

App. F. Combined Risk Impact for Indigenous Peoples

Figure 4.0 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**
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			

App. G. 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