Canadian National Diabetes Framework - Focus and Priorities

A Paper to Further Inform the Evolution of a National Diabetes Framework

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Purpose of this Paper

Diabetes is a multi-faceted, very complex chronic condition. Shaping a National Diabetes Framework is also complex and challenging.

This Paper provides recommendations and suggestions for added context; and to help advance identification of priorities for Action; and for the content of a National Diabetes Framework to complement that mandated by Bill C-237.

In preparing this paper, SFBLF is motivated by our Mission and by having participated in all but the initial 'key informant interviews'. The Engagement Report from those 50 interviews notes:

"... The list of recommendations included in each section reflects a wide breadth of stakeholder input and does not necessarily reflect consensus opinion or order of priority."

Content

About SFBLF

Sir Frederick Banting Legacy Foundation (SFBLF) is a federal NFP (2005) and registered Canadian charitable organization (2006) located at the birthplace of Banting in Alliston, ON, Canada.

The Mission of SFBLF is diabetes prevention and support for diabetes self-management through education, advocacy and process innovation with an emphasis on youth.

SFBLF is governed by an all-volunteer Board supported by an Advisory Board and community, regional, national and international collaborative partners.

A. Essential Missing Elements Requiring Immediate Priority Action

Whatever may be the outcome and content of a National Diabetes Framework, there are several high priority requirements that need to be pursued at least in parallel, if not first.

One cannot make rational resource allocation decisions for, or manage effectively, what is not being measured. Hence:

1. Create and Sustain a National Diabetes Registry beginning with our Youth

a. Despite having among the largest number of health surveillance systems with a youth component, Canada remains unable to routinely track and provide annual, public reports on the prevalence and incidence of youth-onset diabetes and which include age, gender, ethnicity, type of diabetes, date of diagnosis and geographic location.

b. A comprehensive registry is ultimately required, and the action process should ensure a step-wise approach to achieving that outcome, but the most pressing need is to start by solving the youth-onset diabetes surveillance challenge.

2. Analyse and Report Current Diabetes Prevention and Treatment Delivery Capacity

a. What is the current state for access to diabetes education, diagnosis and treatment at least at the provincial and territorial level? What is the relative capacity available for remote, rural and urban locations?

b. How well aligned are the curricula of, and participation in, higher education programs that will ensure an adequate supply of highly trained professionals to provide diabetes care and research?

Despite knowledge gaps, there is no reason to delay practical action. Hence:

3. Increase the emphasis on and broaden Diabetes screening for youth; track and report results

a. It is acknowledged that universal screening for diabetes is likely unaffordable and also has some inherent risk, e.g., 'false positives' and missed or mis-diagnosis. Nonetheless, it is essential to ensure standard guidelines exist across Canada and that whatever screening is being done, be reported annually to the public.

b. In parallel, it is a safe and easy matter to provide readily accessible, on-line 'awareness' and self-assessment tools for youth in the spirit of the CanRisk tool but absent any attempt to be diagnostic or predictive. SFBLF, in collaboration with international medical colleagues, developed such a tool readily available on the SFBLF website, bantinglegacy.ca/survey/

4. Speed up the translation of Diabetes research results into practice

a. The Discovery of Insulin at the University of Toronto galvanized and motivated the Canadian medical research community and created a new context for those seeking, and wishing to support, more Canadian medical research successes. It took only months to expand and refine mass production of insulin and with continuing quality improvement and cost reduction.

b. Canada has a demonstrated leadership position in medical research across a very wide spectrum including diabetes. Unfortunately, the speed of response described above is rare in today's world. The peer-reviewed 'publish or perish' syndrome takes a long time and there are hundreds of reputable journals. Who has time to read it all? Consideration should be given to creating/appointing a group with the mandate to 'popularize' diabetes research results for those who could take practical action on the ground .. as well as for the general public .. and with a mandate to do so in a timely way. To the extent that researchers are 'talking to themselves and peers', Canada will take longer than necessary to act on valuable research outcomes.

B. Summary Mandate of Bill C-237

Bill C-237 – June 29, 2021
National Diabetes Framework

Designed to support improved access to diabetes prevention and treatment to ensure better health outcomes for Canadians.

Required Content

* What is diabetes and prediabetes

* Diabetes prevention and treatment
  - > HCP and related professionals training, education
  - > Clinical practice guidelines
  - > Improve data collection
  - > Promote related research
  - > Promote related information and knowledge sharing
  - > Consider existing frameworks, strategies and best practices
  - > Consider health inequalities

* Ensure the disability tax credit helps as many persons with diabetes as possible

C. Translating Bill C-237 into action

The Bill establishes a required focus on Diabetes prevention and treatment with an equally clear objective of achieving "better health outcomes for Canadians"; and requires consideration of the topics as shown above.

What is required to turn that mandate into practical and effective action?

The Bill provides some starting guidance, specifically [excerpt];

* *The Minister of Health must consult ".. with the representatives of the provincial governments responsible for health, Indigenous groups and with other relevant stakeholders*
* *Within one year after the day on which this Act comes into force, the Minister of Health must prepare a report setting out the national framework for diabetes and cause the report to be tabled before each House of Parliament on any of the first 15 days on which that House is sitting after the report is completed.*
* *Within five years after the day on which the [initial] report ... is tabled in Parliament, the Minister of Health must prepare a report on the effectiveness of the national framework for diabetes and on the current state of diabetes prevention and treatment .. "*

Achieving this mandate requires an equally clear understanding of the CONTEXT in which the quest must be pursued. There are realities, some 'specifically Canadian' and some related to the nature of diabetes itself, that combine to make this task especially challenging. Four key examples are included in the following Table 1.

Table 1: Context realities affecting the development and implementation of a Canadian National Diabetes Framework

Two are 'condition-specific' and affect the planning and analyses for development of a Framework:
1. Knowledge and data gaps regarding the prevalence, incidence and location of diabetes in Canada by affected cohort; associated trends; and the capacity available to deliver healthcare in support of diabetes.
2. Differences in the 'types' of diabetes which dictate differences in needs for prevention, diagnosis, treatment, clinical practice guidelines and essential standards; all requiring age- and culturally-appropriate responses.
Two are imposed by the Canadian reality and affect the implementation of resulting actions:
3. Jurisdictional differences in healthcare delivery responsibility.
4. Canada's geography and population demographics including impact of remote locations.

D. Shaping a National Diabetes Framework (NDF) Document

An NDF document should serve as a guiding reference for all Canadians and facilitate coordinated and consistent action by those with the knowledge, expertise and resources to do so.

The utility and impact of the Framework document would be enhanced by organizing the content to be informative, compelling and to stand as an exemplar for other nations.

The Framework document should include the mandated content, supported by other perspectives:

INTRODUCTION	* Understanding Diabetes Risk and What can be Prevented * Existing Canadian Diabetes Context * Impact of COVID on Prevention, Treatment and Delivery of Diabetes Healthcare * Complexity and the Need for Multi-Level Collaboration
STRATEGIC FRAMEWORK	* Vision Statement * Guiding Principles * Target Audiences to be Helped and Protected * Goals and Related Action Priorities
IMPLEMENTATION	* Measurement Plan including Reporting to the Canadian People * Implementation Development Process and Timeline

In the spirit of considering "existing frameworks, strategies and best practices", cited in Bill C-237, SFBLF recommends that PHAC review the following documents:

1. *Australian National Diabetes Strategy 2021-2030,* Australian Government, Department of Health, November 2021, https://www.health.gov.au/resources/publications/australian-national-diabetes-strategy-2021-2030
2. *National Paediatric Diabetes Audit [UK]*, RCPCH, https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-paediatric-diabetes-audit
3. *Rural Diabetes Coalition and Diabetes Prevention Opportunity Points*, SFBLF 2021, https://www.bantinglegacy.ca/prevention/ and bantinglegacy.ca/prevention/action/

E. Consultation Process to Date

Background

The Government of Canada enacted Bill C-237 - An Act to Establish a National Diabetes Framework, which received Royal Assent on June 29, 2021.

The Public Health Agency of Canada (PHAC) subsequently initiated a series of public engagements to support Bill C-237, coordinated by the SFU Morris J. Wosk Centre for Dialogue. Specifically:

* February - March 2022 - 50 'key informant interviews' resulting in publication of the National Diabetes Framework - Stakeholder Engagement Report

* April 7 and 12, 2022 - two virtual dialogue sessions [one English; one French] to provide opportunity for a wider group of stakeholders to discuss and share views within a context shaped by the 'Themes' and 'System-Wide Challenges' identified in the Stakeholder Engagement Report but with degrees of adjustment in packaging and emphasis. A report summarizing resulting revisions or adjustments is yet to be published.

* April 28 - May 9, 2022 - an online 'Survey' providing an opportunity to identify, on a '5 point scale', the importance of suggested 'Priorities for Action' and to add written comment for each; and to answer via written input, a question relating to each of the 'System-Wide Challenges'; both segments being also largely, but not exclusively, based on the Engagement Report.

  The analysis of results from this Survey also remain to be published but the accumulation of results, evident throughout the Survey and summarized at the end, identify the vast majority of responses, to all but a very few questions, was 'very important' or 'extremely important'; hence, further complicating the challenge of identifying priorities and an Action sequence.

None of the above explorations addressed the unique needs of Indigenous peoples in relation to diabetes as a more extensive and longer-term Indigenous-led engagement is being planned to recognize the principles of reconciliation and the right to self-determination. [PHAC]

Perspectives on the Questions and Responses

The questions posed and the nature of the consultations to date reflect an integration of at least three perspectives:

* Acquisition of opinions to support creating a ‘framework’
* Identification of 'access and support' needs for education, technology and family/patient financial support.
* Identification of required research and related approaches

Many of the questions posed seemed to be seeking information about, "How to get there from here?" but absent any identification of what is 'here' (current context and capability) and what is 'there' (a description of the desired end state).

The vast majority of responses, to all but a very few questions, was 'very important' or 'extremely important'; hence, further complicating the challenge of identifying priorities and an Action sequence.

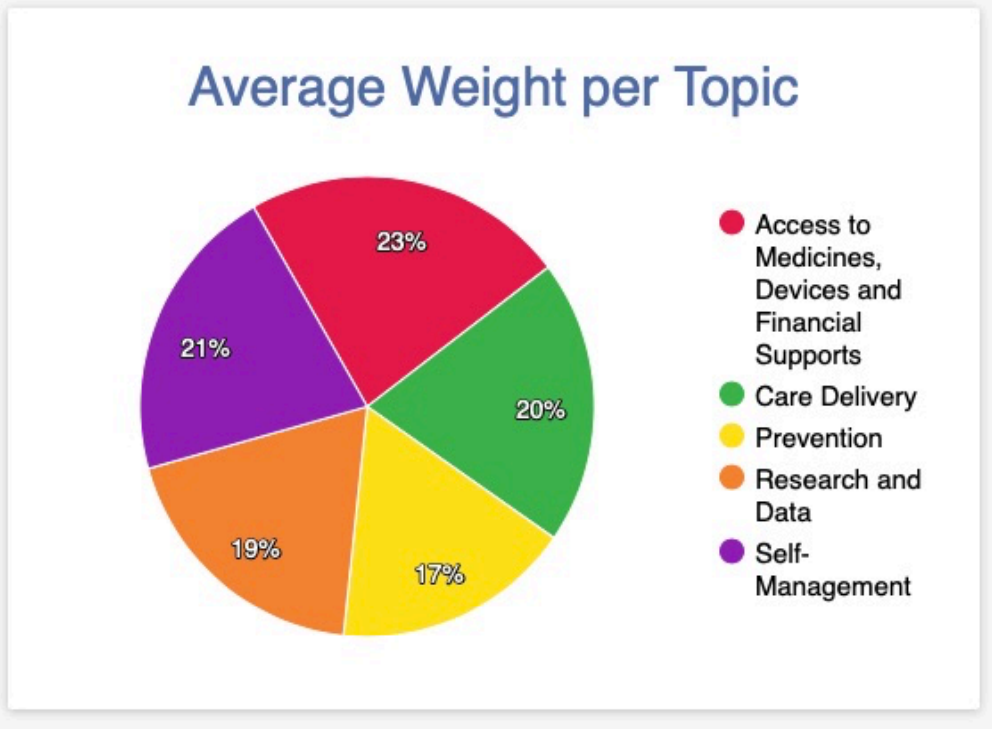
The 'generality' of many questions asked, made it difficult to provide useful responses, e.g.,

> **How can we build capacity throughout the systems that support people living with diabetes? What do we need to do more of? What needs to change?**

The question assumes the responder is well informed of current status. Even so, it is unanswerable short of writing a book. Capacity for what? What types of systems? What kinds of "people living with diabetes"? First, it would be essential to know what is the current 'capacity' by type of system; and by specific cohort of "people living with diabetes”.

The 'steering effect' of the framework [see App 3] in which the questions were presented, the absence of any supporting context information, the generality and complexity of some questions, the disparate knowledge base of the responders, the unbalanced degree of participation from many perspectives including geographic and demographic, and the absence of focus on key topics, such as surveillance and support for youth, significantly increase the risk of drawing unsupported conclusions.

The 'results' provided at the end of the online Survey included the following chart. What does it mean in terms of establishing the Framework? Is 'Prevention' to be treated as the lowest priority?



F. Divide and Conquer

The scale and complexity of this quest impose significant time and resource demands to achieve the outcomes mandated by Bill C-237.

It is essential to consider approaches that would lead to early results while in parallel, creating an effective strategic framework.

By far, the dominant number of responders to the Survey self-identified as 'living with diabetes' or 'caring for a person living with diabetes'.

Not surprisingly, therefore, an overall impression arising from the many 'comments' added in the Survey responses, is a very strong emphasis on, ”please help me now”. A strategic framework is not required to move confidently on some of those needs.

For example, begin seeking adjustments to the Tax Act and an attempt to achieve greater uniformity of such supports across the provinces and territories. Those actions would go a long way to satisfying many of the ‘commenters’ [beyond finding a cure for T1 which was the other dominant view shared].

G. Attachments

1. Nature of Youth-Onset Diabetes
2. NDF Stakeholder Engagement Report Process - Excerpt
3. Comparison of Topics & Themes created by/presented to Stakeholders

Appendix 1: Nature of Youth-onset Diabetes - 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 35 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.

Appendix 2:
NDF Stakeholder Engagement Report Process - Excerpt

Dr. Diane Finegood and Dr. Lee Johnston (SFU Morris J. Wosk Centre for Dialogue) conducted 32 interviews that included 50 individuals. While key informants were selected to represent a broad range of sectors, we acknowledge that this representation is incomplete. Phase 2 of the dialogue process will extend the breadth of PHAC's consultation to include a wider array of voices.

The key informants interviewed represent a wide range of expertise related to diabetes, including:

- Persons living with type 1 or type 2 diabetes
- Specialists in areas such as endocrinology, nephrology, food and nutrition science, epidemiology, and pediatrics
- Representatives from non-profit organizations dedicated to supporting people living with diabetes (types 1 and 2) and obesity
- Clinician scientists and researchers with experience working in participatory, community-based settings
- Individuals and organizations working to promote healthy living, dietary change, physical activity and heart health
- Experts in health innovation and data collection/management for health improvement
- Representatives of foundations that support work to address diabetes and related conditions
- Private sector representatives with knowledge of diabetes drugs and technologies
- Researchers and clinicians with strong ties to marginalized and high-risk communities

It should be noted that while issues relevant to Canada's Indigenous populations did surface during these interviews, formal consultations led by Indigenous organizations is being done in a different stream of work.

The interview contents were coded and then organized into key areas of focus relevant to diabetes. The following section presents summaries of the data as well as specific recommendations to address issues that emerged in each area.

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Appendix 3:
Comparison of Topics and Themes created by/presented to Stakeholders

Stakeholder Engagement Rpt Feb - March, 2022	Virtual Consultations Apr 7 & 12, 2022	Online Survey Apr 28 - May 9, 2022
System-wide Themes * Equity * Centering people with diabetes * the post-COVID context **Issues and Opportunities** * Prevention * Health care - Health System - Delivery of care - Patient Support - Screening - Obesity * Access to drugs, devices and financial supports * Data * Research and innovation * Indigenous peoples and diabetes	**Session #1** **System-wide challenges** * Themes 1. Inequities 2. Stigma 3. TxD 4. Collaboration 5. Capacity **Session #2** **Priorities for Action** 1. Prevention 2. Care Delivery 3. Self-management 4. Research and data 5. Access to medications, devices, financial supports	**Priorities for Action** * Prevention * Care Delivery * Self-Management * Research and Data * Access to medications, devices, financial supports **System-wide challenges** 1. Inequities 2. Stigma 3. TxD 4. Collaboration 5. Capacity
Participants: * 50 * No demographics reported but see App 2	**Participants:** * Estimated just over 100 * No demographics reported	**Participants:** * Responses to questions ranged from approx 240 to 600 * Some demographics, e.g., - 173 Ontario; 102 BC; 94 Alta; 44 Man; 29 SK, 26 PQ; 20 NS; 17 NB; 16 NFLD/Lab; f5 PEI; 4 Yuk; 1 Nun; 0 NWT - 76% of responders identified as female - 235 'living with diabetes'; 178 'caring for a person with diabetes'; 80 advocates; 73 CDEs; 54 Researchers; 15 Endos; 6 PCPs; 120 other categ