DIABETES CANADA

SUSTAINING MOMENTUM TO IMPLEMENT THE DIABETES FRAMEWORK (SMIDF):

DIABETES RESEARCH WORKSHOP

JANUARY 2025

Summary

This grey paper provides key findings about the Sustaining Momentum to Implement the Diabetes Framework (SMIDF): Diabetes Research Workshop 2025.

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About Diabetes Canada

Diabetes Canada is a national health charity representing more than 4 million people in Canada diagnosed with Diabetes. Diabetes Canada leads the fight against diabetes by helping those affected by diabetes live healthy lives, preventing the onset and consequences of diabetes, and discovering a cure. It has a heritage of excellence and leadership, and its co-founder, Dr. Charles Best, along with Dr. Frederick Banting, is credited with the co-discovery of insulin. Diabetes Canada is supported in its efforts by a community-based network of volunteers, employees, health care professionals, researchers, and partners. By providing education and services, advocating on behalf of people living with diabetes, supporting research, and translating research into practical applications, Diabetes Canada is delivering on its mission. Diabetes Canada will continue to change the world for those affected by diabetes through healthier communities, exceptional care, and high-impact research.

For more information, please visit: www.diabetes.ca.

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We would like to thank all co-chairs, working group members/panelists, and attendees for their contributions to the Diabetes Research Workshop. The insightful discussions and inputs allowed for learning and knowledge sharing, enabling a deeper understanding of the current landscape of diabetes research along with next steps to ensure a cohesive research strategy that will support the implementation of the Framework for diabetes in Canada.

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Title: Sustaining Momentum to Implement the Diabetes Framework (SMIDF): Diabetes Research Workshop, January 2025

Project Overview: The Sustaining Momentum to Implement the Diabetes Framework (SMIDF) project, supported by the Public Health Agency of Canada (PHAC), is overseen by Diabetes Canada. Its goals include bringing together key stakeholders to learn about and use the Framework guidelines, help identify and share diabetes best practices, support the dissemination of findings across governments and beyond. It strongly promotes the foundation for collaboration across sectors to reduce the impact of diabetes.

This project began in 2023, and the result of this 3-year project will be a highlight of successful diabetes programs/interventions/projects and the dissemination of findings for adoption and scaling to identify and share best practices for addressing diabetes, including the identification of barriers in health equity-deserving communities.

Diabetes Research Workshop: Diabetes Canada, the Canadian Institutes of Health Research Institute of Nutrition, Metabolism and Diabetes (CIHR INMD), and Diabetes Action Canada (DAC) (CIHR Strategy for Patient-Oriented Research Network for Diabetes and Its Related Complications) collaborated to convene a one-day Workshop. The Workshop gathering included researchers and bureaucrats from across Canada who engage with the four CIHR research pillars. It was designed to bring together various research branches and knowledge users to collectively reflect and advise on research pathways and future directions, while addressing the Framework themes recognizing the complexities of all forms of diabetes across the lifespan and intersectionality with other chronic diseases and social determinants of health. Focus on health equity gaps for people at highest risk was prioritized. Early on, it was learned that the Framework was less well-known within many research circles, and this initial meeting was an important learning and sharing platform.

Location and Date: Peter Gilgan Centre for Research and Learning in Toronto, ON, on January 30, 2025, from 9:00 am to 4:00 pm EST.

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1.0 Executive Summary

Sustaining Momentum to Implement the Diabetes Framework, supported by PHAC, brought together research-focused stakeholders to identify opportunities and to promote collaboration towards the Framework for Diabetes in Canada. Research is one of six components of the Framework, intended to reflect the importance of research as a priority to improve diabetes health outcomes. Simultaneously, research is the mechanism that will drive forward progress in the other five Framework components. Therefore, it was advantageous to undertake a research-focused workshop to bring together diabetes research stakeholders from across Canada to focus on how to promote improved collaboration across all types of research. They identified opportunities that if addressed will meaningfully accelerate prevention, treatment and support for persons living with or at risk of developing diabetes. Targeted commitment to these research priorities identified together with the research community will improve health outcomes and quality of life for people living with diabetes and its complications.

The overarching recommendation is that interventions focused on the intersection of diabetes, social determinants of health, and obesity, cardiometabolic, and other chronic diseases have the highest return on investment and are recommended as research priorities. To maximize impact within this intersection, the following research priorities emerged:

1. Collaboration
    a. Establish a pan-Canadian diabetes research network connecting hubs of excellence to increase collaboration and build research capacity
    b. Support cross-disciplinary and intersectoral research to address upstream social, economic and environmental risk factors for diabetes and its consequences

2. Social determinants of health
    a. Adapt surveillance systems to better capture structurally under-served and highest risk communities
    b. Develop diabetes-focused pan-Canadian research biobanks and repositories that link de-identified health and social information to enable research spanning biologic and molecular mechanisms through to social and environmental factors to capture diabetes risk index
    c. Prioritize health and social services and interventions that better support persons with diabetes at highest risk for complications

3. Health services
    a. Integrate health services research into comprehensive diabetes clinical registries to support better clinical care, monitoring and population-based research enabled by data
    b. Support policy research into diabetes prevention, access to treatments including medications and devices to capture how policy and access changes influence health outcomes

c. Establish and implement community- and patient-oriented research to evaluate emerging models of primary and community-based care that can better reach underserved communities

The workshop discussions highlighted that there is opportunity to learn from other health systems in the different provincial health systems, enabling policy and health services research to identify successful interventions that decrease diabetes complications and cost to the healthcare system. Following the guidance of the Framework, prioritizing collaboration will enable stakeholders to develop and mobilize diabetes interventions and improve access to diabetes-related resources and healthcare.

The report herein captures the key takeaways of the one-day workshop and outlines specific research recommendations to inform improved access to diabetes-related resources and healthcare, ensuring all persons with or at risk of developing diabetes in Canada receive the prevention, treatment, and support they need. This will enable success of the Framework in improving health outcomes and a better quality of life for those affected by diabetes across Canada.

2.0 Goals of the Diabetes Research Workshop

At the Workshop, the participants were asked to address the following (pre-circulated) questions:

1. Based on the Diabetes Framework research component, what are the current gaps in research across the four pillars that must be filled to address improving diabetes prevention and care in Canada, aligned with the specific stated Diabetes Framework research opportunities?
2. Considering the current diabetes research in Canada, in the next 5 years what are the most effective ways forward for implementing the research and building capacity necessary to address these gaps?
3. How can leaders in diabetes research best leverage existing and new resources for current and future researchers to advance this implementation?

3.0 Diabetes Framework Overview

The Government of Canada introduced the Framework for Diabetes in Canada on October 5, 2022, after 10 years of consultation and review. The Framework was designed to establish a cohesive policy direction that aligns stakeholders from multiple sectors toward shared goals in diabetes prevention and management. By providing a common policy foundation, the Framework aims to bring together diverse stakeholders—including government, healthcare providers, non-profit organizations, and private sector partners—to collaboratively address the growing impact of diabetes in Canada. It prioritizes identifying existing gaps in diabetes management approaches, minimizing duplication of efforts, and creating mechanisms to monitor and report on progress. These efforts will enable stakeholders to work together more effectively and make informed decisions that can be adapted over time.

The Framework's scope emphasizes the need for coordinated, complementary actions that support a comprehensive approach to diabetes prevention and treatment. It lays the groundwork for meaningful, multi-sectoral collaboration, which is essential to tackle the widespread health and social effects of diabetes. Ultimately, the Framework's intended outcome is to improve access to diabetes-related resources and healthcare, ensuring Canadians receive the prevention, treatment, and support they need. By achieving this, the Framework seeks to foster improved health outcomes and a better quality of life for those affected by diabetes across Canada.

The Framework is comprised of six interdependent and interconnected components that represent the range of areas where opportunities to advance efforts on diabetes could be beneficial. The principles and the components (below) form a dynamic environment within which to create change in Canada.

Summary of the Framework[1]

STAKEHOLDER ENGAGEMENT SUMMARY

The Public Health Agency of Canada, with the Morris J. Wosk Centre for Dialogue based at Simon Fraser University, undertook a virtual engagement process to help identify gaps and priorities for advancing efforts on diabetes in Canada, and inform the development of the Framework.

PART 1

32 key informant interviews with **50 individuals**

PART 2

Two dialogues in two languages with **89 participants**

PART 3

884 respondents and **2,000 comments** on online survey

PURPOSE

- Provide a common policy direction for multi-sectoral stakeholders
- Identify gaps in current approaches, avoid duplication of effort, and provide an opportunity to monitor and report on progress

SCOPE

- Lay the foundation for collaborative and complementary action to be taken by all sectors to reduce the impact of diabetes in Canada

DESIRED OUTCOME

- Improve access to diabetes prevention and treatment to ensure better health outcomes for Canadians

CROSS CUTTING PRINCIPLES

- Addressing health equity
- Applying a person-centred approach
- Differentiating between types of diabetes
- Supporting innovation
- Promoting leadership, collaboration, and information exchange

FRAMEWORK COMPONENTS

- Prevention
- Management, treatment and care
- Research
- Surveillance and data collection
- Learning and knowledge sharing
- Access to diabetes devices, medicines and financial supports

Indigenous Engagement and a National Diabetes Framework

With respect to reconciliation and in recognition of Indigenous autonomy, self-determination, and sovereignty, the Public Health Agency of Canada has provided independent funding to the National Indigenous Diabetes Association (NIDA). NIDA is engaging with various Indigenous peoples, nations and organizations across Canada to develop an Indigenous Diabetes Framework. Through supporting open dialogue, NIDA sits on the Diabetes Canada SMIDF's Pan-Canadian Action for Diabetes advisory committee to promote mutual knowledge exchange and collaboration. Therefore, this Diabetes Research Workshop did not include research gaps and recommendations to address the unique and specific challenges for improving Indigenous Peoples health related to diabetes and its complications. For more information about NIDA, please visit their website (nada.ca).

Diabetes Research in Canada – Global Impact

Insulin, discovered in Canada in 1921 and made free to the world, is the first of many great Canadian diabetes research stories. Since that time, the return on investment in fundamental and pragmatic research in Canada has been enormously valuable to Canadians. From insulin to incretins like Ozempic/semaglutide, to cell therapies like the Edmonton Protocol and stem cells, to identification of immune cells that cause diabetes, to current clinical trials with novel therapies for both type 1 diabetes (T1D) and type 2 diabetes (T2D), Canadian research is recognized as world leading. Recent work has identified the reason for the increased diabetes risk in Indigenous populations, which is pointing to new ways of treating diabetes in at-risk populations.

Canadian researchers are poised to address all the themes outlined in the Framework that include; prevention, management (treatment and care), surveillance and data collection, learning and knowledge sharing, and access to diabetes devices, medicines and financial supports. Our Diabetes Research Workshop report provides strategic guidance for research that will support successful implementation of the Framework.

4.0 Workshop Background

"Diabetes" – is a chronic disease that occurs when the pancreas does not produce enough insulin and/or when the body cannot effectively use the insulin it produces. Approximately, 1 in 10 persons in Canada (and 1 in 4 over the age of 65 years) have a known diagnosis of diabetes (~ 4 million people). In addition, 14% of the population have diagnosed or undiagnosed diabetes and this number is estimated to rise to 18% in the next 10 years.[2]

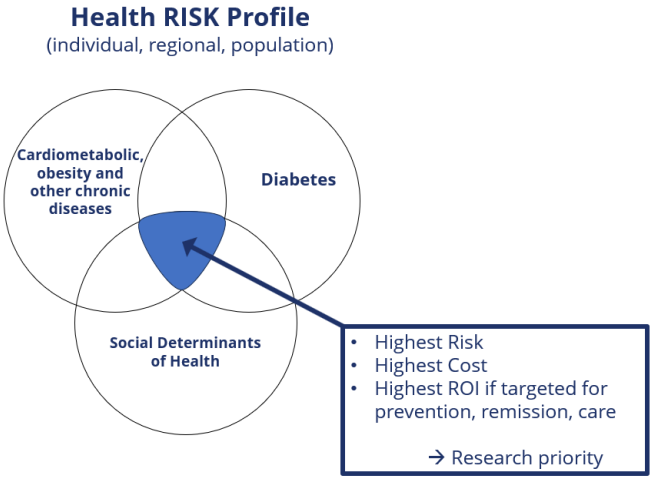
Diabetes constitutes one of the highest independent risk factors for most chronic conditions: cardiovascular disease; heart failure; stroke; most cancers (except prostate); kidney failure; vision loss; dementia; mental illness; and cirrhosis. T1D is an auto-immune condition that can begin at any age and is related to genetic and environmental factors and requires insulin for life. Historically, T2D has affected adults but is increasingly diagnosed in youth and young adults with prevalence

increasing in all age groups (now 27% of persons over 65 years in Canada). T2D management requires health behaviour modifications and/or medications. T2D and gestational diabetes are more prevalent in those persons who are structurally underserved including recent immigrant, east Asian, south Asian, Black, Indigenous and rural populations. Interprovincial barriers to health care also delay or prevent access to the right diabetes care and prevention at the right time for persons with diabetes who must relocate across the country.

Currently, diabetes is estimated to cost the Canadian healthcare system ~$18 billion annually (Diabetes Canada). "Early detection and optimal management are crucial to prevent the complications of all forms of diabetes including heart disease, ketoacidosis, foot ulcers, kidney and eye disease, and nerve damage." Public Health Agency of Canada Snapshot of Diabetes in Canada 2023.

To understand and address the underlying, heterogeneous and complex mechanisms of all forms of diabetes, collaboration among basic scientists, clinical trialists, health services and population health experts is required to create the precision medicine solutions for cost-effective prevention and treatment. Incorporation of community- and patient-partnered research models to align fundamental and pragmatic research priorities with real-world challenges faced by people living with diabetes has proven most effective. Successful translation of evidence from all pillars of research (biomedical, clinical, health services, and social, cultural, environmental and population health) into the most up-to-date, cost-effective, data-informed and technology-assisted treatments necessitates engagement of health service leaders, policy-makers and both public and private sector partnership and investment.

To guide recommendations for implementing the Framework research theme, Diabetes Canada, the CIHR Institute of Nutrition, Metabolism and Diabetes, and Diabetes Action Canada (CIHR Strategy for Patient-Oriented Research Network for Diabetes and Its Related Complications) collaborated to convene a one-day Workshop. PHAC funded the Diabetes Canada Sustaining Momentum for Implementing the Diabetes Framework project team who guided and supported this event. The Workshop gathering included researchers and others from across Canada who engage with the four CIHR research pillars. It was designed to advise about future research directions and learn about research pathways that are working, while addressing the Framework themes recognizing the complexities of all forms of diabetes across the lifespan and intersectionality with other chronic diseases and social determinants of health. Focus on health equity gaps for people at highest risk was prioritized.



See **APPENDIX** for details about the Workshop preparation and process.

The following report describes the Workshop goals and outcomes identifying the current research gaps and how to address them at the person, regional and population level. The report includes recommendations to help guide the strategic implementation of diabetes research among the current research centres, institutes and programs across Canada to fulfill the goals of the Framework.

5.0 Current Research Gaps and Recommendations by Framework Component

This section is organized across select Framework components, then subdivided further into person, region, and population levels with research approaches for each. It highlights consideration for next steps in research engagement based on the Workshop discussion.

PREVENTION and MANAGEMENT (Treatment and Care)

Person level

Diabetes is a heterogeneous condition. T1D is an autoimmune disease. T2D is a complex group of disorders characterized by hyperglycemia, with at least 4 types of underlying causes. Gestational diabetes occurs during pregnancy and can herald the future onset of T2D. All persons with hyperglycemia are at risk for diabetes complications, that vary based on underlying predisposition. Therefore, every person with diabetes and its complications has a unique set of risk factors based on biologic (genomic, proteomic, metabolic) and external (social, environmental) influences. The complexity of this risk is increasingly understood through combined efforts across Canada among our research centres with diabetes research expertise.

Gaps

- Current Diabetes Canada Clinical Practice Guidelines and precision medicine have low uptake with person-centered prevention, treatment and care across the Provinces and Territories.
- Lack of personalized approach to diagnosis, prevention and treatment through timely management requires an improved method of identifying risk of diabetes and its complications.
- Knowledge about the relationship between the immune system and pancreatic beta cell dysfunction in both T1D and T2D requires targeted biomedical research.
    - Identifying the precise triggers of the autoimmune attack on pancreatic beta-cells in T1D, why they don't regenerate in T1D and T2D.
- More research is needed on stem cell-derived beta cells, immune tolerance strategies and beta cell replication/growth restrictions.
- The relationship between environmental pollutants, processed foods, viruses, gut microbiome and insulin resistance, beta-cell function and inflammation needs clarification.
- A major gap exists in understanding the genetic and metabolic differences among persons that influence responsiveness to diabetes drugs.
    - We need to understand why some people develop severe complications (e.g., kidney failure, blindness, nerve and cardiovascular disease) while others do not.

Research Approach Recommendations

- Establish a national diabetes research network connecting hubs of excellence to coordinate collaborative discovery efforts, build research capacity and a pan-Canadian training pipeline.
    - This could expand access to genomic, proteomic, and metabolomic platforms for researchers to investigate disease mechanisms that will inform a personalized medicine approach to diabetes and its complications prevention and management.
- Develop diabetes-focused research to integrate biobanks and patient-derived cell repositories linked to de-identified health and social information across Canada. This will enable nationally-relevant research on the intersection between genetic, metabolic, social and environmental factors that contribute to diabetes risk, management response, and health outcomes in Canada. Collaboration with other networks, e.g., CLSA, CanPath, would create economies and an integrated health approach.
- Identify the underlying molecular connections between obesity, inflammation and insulin resistance that predispose to T2D and gestational diabetes to develop reliable imaging or biomarkers for predicting early beta-cell dysfunction, especially in high-risk individuals.
- Guided by current evidence, design research to create a "risk index" that reflects the heterogeneity of diabetes risk and complications based on biologic and external factors. In addition to a risk index for developing diabetes, a risk of complications index would inform treatment plans for persons living with diabetes.
- Develop research that will improve knowledge about individualized drug responses related to the genetic and metabolic heterogeneity among persons with diabetes.
- Implement and evaluate the use of the "risk index" to guide shared decision-making between the person and their health care provider(s) for evidence-based, customized treatment plans and evaluate the health outcomes.
- Research to design, implement and evaluate structured diabetes prevention programs.

Regional level

Best practices across the globe (e.g., Sweden, Scotland, Hong Kong) have identified the importance of regional clinical diabetes registries to provide benchmarking data to improve health outcomes. These regional clinical registries contain individual identifiable data (not merely anonymized data) of all persons with diabetes. Test results and data notifications are provided to both the person with diabetes and their primary and/or specialist health care providers. Access to this information facilitates communication between patients, their health care providers, and other providers leading to more timely and efficient high-quality care. These data repositories allow for providers to recognize the incidence and prevalence of different types of diabetes in their communities and can impact screening programming and timely education outreach. This approach supports person-centered individualized care plans including treatment – surveillance and outcome review (benchmarking). This alleviates the administrative burden on the patient and health care provider to track the complexity of diabetes clinical-guideline management for diabetes and facilitates necessary and timely surveillance and intervention.

Population level

Canada's unique challenges include large recent immigrant populations in urban environments, and geographically isolated rural and Indigenous communities where diabetes and its complications are more prevalent.

Gaps

- Standardized, clinical guideline-directed health services for persons with diabetes are not supported uniformly within or among our provinces/territories compared to countries outside of Canada (i.e. Sweden, Scotland, Hong Kong) which have identified the importance of regional clinical diabetes registries to provide benchmarking data to improve health outcomes.

Research Approach Recommendations

- In Canada, clinical registries for T1D are emerging led by the CAPACITY (improving pediatric diabetes clinical care), BETTER (education for all persons with T1D in Canada) and CanScreen T1D (preventing/delaying pediatric T1D in collaboration with the Ontario BORN registry) research teams. Building on the evidence arising from these projects will inform the value of clinical registries for health care providers and policy decision makers.
- Establish health services research into designing and implementing diabetes clinical registries focused on supporting: 1) better clinical care (access to identifiable data by the circle of care and patients); 2) health service monitoring and quality improvement (access to anonymized and, in special cases identifiable, data by administrators and prescribed entities); and 3) population-based research.
- Develop health services research to co-design cost-effective integrated care models with primary care physicians, non-physician providers and structurally underserved community patient partners where diabetes is considered a "best use case" for risk identification of chronic conditions to guide region-specific interventions.

Gaps

- Canada has failed to establish population-wide prevention and quality care for persons at risk of developing or living with diabetes based on rising prevalence of this condition particularly among structurally underserved communities.

Research Approach Recommendations

- Cross-disciplinary and intersectoral collaboration and research is necessary to address the upstream social, economic and environmental conditions that impact structurally underserved populations.
- A knowledge mobilization approach relevant for all chronic disease prevention and management could be guided by focusing on diabetes as a marker of health inequality. Pragmatic research must address the needs and barriers to diabetes health promotion through collaboration, coordination and working directly with patients, care givers, community groups, health care providers and policymakers.
- Iterative evaluation of population-based interventions to determine the most cost-effective solutions would lead to sustainable investments by both public and private sectors to improve diabetes health quality outcomes.

SURVEILLANCE AND DATA COLLECTION

Accurate and timely diagnosis and treatment of diabetes requires laboratory testing of blood glucose, hemoglobin A1c levels and, in the case of T1D, more specific disease markers. Prevention of diabetes complications necessitates clinical guideline-directed monitoring of kidney, nerve, eye, cardiovascular, liver, and cognitive function as well as mental health. Importantly, social determinants of health must also be considered for person-centered treatment planning and follow-up. Access to the right information at the right time is essential for any person with diabetes and their health care providers. This includes timely laboratory and other diagnostic data, coupled with the intersecting social, geographic and cultural determinants of health information that must inform appropriate prevention and treatment plans.

The following summarizes many of the current health information gaps related to diabetes surveillance and data collection and the multi-disciplinary research approaches recommended to address these gaps.

Person level

In Canada, 80% of persons with diabetes receive health care predominantly in primary- and community-based settings.[3] Generally, persons under the age of 18 with T1D or rare forms of diabetes are cared for in pediatric settings and beyond 18 years in the adult healthcare system. The health information about persons with diabetes resides within the medical record system of their primary care and/or specialist care provider who also serve as gatekeepers to testing and referrals for diagnosis, surveillance and monitoring. Data sharing with patients and their circle of care is emerging as electronic medical record (EMR) systems become more interoperable. In settings where persons are rostered within a health care team practice, usually their health information resides in comprehensive, analytic EMR data system that acts as clinical registry; timely surveillance of diagnostic testing can be achieved through alerts to both patients and their health care providers.

Gaps

- Most of our overburdened primary- and community-care providers in Canada have not established advanced data-enabled systems because of cost and the time it takes to manage this type of data-informed surveillance and intervention.
- Consideration of social determinants of health as part of shared decision-making for treatment plans are often lacking.
    - Therefore, lack of a standardized, data-informed approach to identify those persons with prediabetes or diabetes at highest risk of poor health outcomes is a major gap.

Research Approach Recommendations

- Implementation science research could be used to design, implement and evaluate improved models of primary and specialist point of care that incorporate data-informed surveillance and clinical guideline-based treatment.
- Iterative evaluation and cost-effectiveness analysis of how to capture, access and incorporate individual patient data, including patient-reported experience and outcomes and social determinants of health into personalized prevention and treatment, would identify the feasibility of instituting these improved practice models. A systematic approach that is co-designed with patients and providers on which data should be collected, how to collect it, and a robust data governance strategy is required.
- Evaluation of the efficacy of new AI-based tools connected to EMRs and real time data integration at point of diabetes care is already underway in a few primary and hospital-based care sites across Canada. The next step is understanding how to spread and scale these new tools for improving diabetes prevention and management through knowledge mobilization research.[4,5]

Regional level

The standardization of timely data collection necessary for real time surveillance of persons with diabetes to optimize prevention and care by region (provinces/territories) or sub-regions (urban, rural) has never been achieved in Canada. Therefore, understanding how to implement this standardization, customized to the needs of each region, requires a coordinated and collaborative effort among researchers in primary care and diabetes (specialist) care, health data experts, health information policy-makers, and regional patient- and community partners.

Gaps
• Lack of harmonized clinical data to benchmark outcomes between provinces/programs to evaluate how the different provincial policies and regional health care resources impact broader population health outcomes.
Research Approach Recommendations
• Research focused on how to effectively establish regional clinical registries, where persons diagnosed with diabetes agree to share their data within the circle of care, and their care providers are supported by experts in diabetes data management. The goal would be to bridge the current surveillance and data collection gap; regional clinical registries would give patients access to their own data to improve self-management. A value proposition to patients and healthcare providers will ensure broad representation and reduce volunteer bias in the registry. • Leveraging the current investment in research teams that have established diabetes clinical and education registries (e.g., CAPACITY, BETTER) to enable research focused on how to mobilize evidence into improved, sustainable practice supported by regional health care policy and appropriate funding. • Development, implementation and testing of tools that integrate clinical practice guidelines into electronic medical records to increase care delivery aligned with best available evidence. These tools provide healthcare providers with reminders, benchmarks, and data collection prompts. For example, Practice360 launched in Newfoundland and Labrador in 2019.[6]

Population level

The federal government has invested in collecting standardized, retrospective population data that is useful for evaluating national and provincial health outcomes, e.g., by CIHI, PHAC, StatsCan. Similarly, the provinces have invested in collecting administrative data that is evaluated retrospectively for health quality outcomes, e.g., ICES, BC Population Health Network. Some of these population data systems have generated important databases that have been used by researchers to identify major gaps in diabetes surveillance and management. However, population data systems introduce concern because lab data (specifically, type of diabetes diagnosis) is often missing, whereas treatment choice and personal level data is not included administrative databases. Further, these insights have not (in general) been applied to influence service design and delivery or to address inequities. For instance, diabetic retinopathy screening in Ontario is as low as 40% in the most structurally underserved populations of new immigrants and Indigenous communities.[7] The prevalence of lower limb amputations in the Ontario diabetes population has increased over the last decade, while the heart attack and stroke rates have decreased.[8] This is in contrast to countries that have developed population screening and early intervention to reduce the incidence of these complications. Timely access to provincial administrative data could be used for data-informed improvements to clinical care if the challenge of missing data is addressed and data are made available in a timely manner to health care providers. However, this approach is hampered by current privacy constraints and lack of support through public health legislation.

Gaps

- Some of these population data systems have generated important databases that have been used by researchers to identify major gaps in diabetes surveillance and management. However, these insights have not (in general) been applied to influence service design and delivery or to address inequities
- Provincial administrative data has missing data and is not collected in a timely process to be useful for real time clinical care. Improvement in data collection is hampered by current privacy constraints and lack of support through public health legislation.

Research Approach Recommendations

- By accessing high-quality comprehensive data on all persons with diabetes who enter the health care system, population health research could evaluate the current barriers and facilitators to improving health outcomes, particularly for the structurally underserved.
- Researchers from multiple disciplines could collaborate on evaluating how better data that link more detailed and comprehensive health information to social and environmental data could inform the intersectional impact of the upstream social, environmental, and structural factors that affect populations at high risk for diabetes and its complications. This evidence would guide interventions to tackle these factors systematically with knowledge mobilization and implementation science strategies.
- To address the current actual and perceived health data privacy constraints related to enabling access to data for improved diabetes prevention and management, innovative solutions for data governance and accountability must be sought in collaboration with experts in law, ethics, health services and population health.

LEARNING AND KNOWLEDGE SHARING

Accessible, accurate, current, timely, culturally appropriate and reliable messaging on diabetes within the general population and local communities, through healthcare professionals and digital platforms are unavailable in many regions across Canada. Understanding and improving the effectiveness of these communications for diabetes prevention and management to reduce the risk of complications particularly in structurally underserved communities, are not well understood.

Generally, diabetes has been folded into chronic disease management within individual practices and by regional health organizations. Although the goal is to achieve better integrated care, the specific responsibility for diabetes prevention and management may be perceived as someone else's problem diminishing the need for personalized diabetes risk assessment. Moreover, young people with diabetes are first managed within the pediatric clinical setting; however, after the age of 18, when they may be most mobile related to education and employment opportunities, they must transition to adult care, often in a new regional location. Since health data are not always shared between healthcare centres or readily shared between provinces in Canada, mobile young adults with any type of diabetes often fall through these health service gaps and fail to obtain the care they need at a time of vulnerability.

Person level

For children with T1D, the onus is on their caregivers to provide care and education. As teens they graduate towards self-care which is not an easy task. Self-management of diabetes relies on:

1. understanding the complexities of developmental stage and factors influencing behaviour
2. biologic risk factors, (e.g., hypertension)
3. economic and social supports, (e.g., affordable medications, food security)
4. need for timely diagnostic surveillance to prevent end organ complications
5. adequate capacity to handle these complex cognitive, emotional and psychosocial tasks.

Gaps
• Those persons with the highest risk index for poor health outcomes related to diabetes, also have the most onerous task, and least capability in achieving successful self-management. One-time-only diabetes education programs and reliance on busy primary or specialist care practices are insufficient to cope with these challenges. At worst, many people do not have access to primary care, which is amplified in structurally underserved communities.
Research Approach Recommendations
• To address the complexity of improving self-management for persons with diabetes at high risk for poor health outcomes, research experts in integrated care with patient- and community- partners could co-design, implement and evaluate new supportive care models including customized coaching, navigation, peer support. (note – this concept is not new and has been established for other chronic conditions such as cancer, congestive heart failure and chronic pulmonary disease). There is good evidence for effectiveness of team-based, integrated care models on improving diabetes outcomes and quality of care.[9] • Research to assess the effectiveness and sustainability of web-based diabetes-related decision-making tools (increasingly AI-assisted) for supporting improved self-management is underway already in Canada. The next research question is how to customize these tools to better serve persons living with diabetes to ensure acceptability, accuracy, reliability and accountability. • Research into understanding how structurally underserved (e.g., Black, new immigrant, Indigenous) and high risk (e.g., south and east Asian) communities can better support persons with diabetes in their midst and how these measures could be spread and scaled (e.g., programs offered by Access Alliance in Toronto, Indigenous Diabetes Health Circle in Ontario) is essential.

Regional level

Most regions in Canada have invested in diabetes education programs within clinical care settings, many customized to serve their local communities. Generally, persons are referred to these programs when first diagnosed with diabetes, with longitudinal care continued by their health care providers. In some settings that have sufficient funding and capacity, full integration of the diabetes nurse educator, nutritionist, pharmacist, social worker is available to the primary or specialist care practitioner such that the patient is followed at variable intervals. Successful self-management of diabetes for many requires timely access to experts.

When provided with specialized regional care programs, e.g., cancer surveillance and treatment, primary care physicians readily accept this expert support. In countries that provide this type of diabetes regional support, the diabetes complication rates fall dramatically, e.g., Denmark, Sweden, UK, Hong Kong.[10] Effective interventions do not need to be expensive or require highly trained staff. For instance, Indigenous community health workers have reduced lower limb amputation rates of persons with diabetes in Ontario.

Gaps

- Best-practice settings are not currently available in most communities, leaving persons with diabetes, particularly the structurally underserved, without the support they need within their region.
- The majority of persons with diabetes in Canada are cared for by solo primary care or specialist physicians who cannot provide the ongoing integrated, personalized care necessary to optimize diabetes prevention and management.

Research Approach Recommendations

- Apply health technology/resource assessment (HTA) research of the current investments in regional diabetes education programs and how they could evolve into standardized integrated care services could address how to implement effective diabetes prevention and management for improved health quality outcomes. Emphasis could be placed on identifying and proactively engaging those persons at highest risk for complications within the structurally underserved communities in each region.
- This HTA would analyze the potential, and ultimately actual, return on investment from both economic and societal value related to improved diabetes health outcomes of these standardized integrated diabetes care services. It would also need to evaluate expanding scope and role of healthcare providers (e.g., nurses, dietitians, and pharmacists) to facilitate more timely and efficient diabetes care and reduce the burden on primary care physicians.
- Use of AI-based risk prediction tools for risk of diabetes and risk of complications to inform health resources allocation and population planning to better match demand with supply.[11]

Population level

The diagnosis of diabetes, similar to mental health disorders, carries stigma worsened in the context of social injustice and racism. Education of health professionals and the general public about the underlying causes of all forms of diabetes would be of benefit in reducing this burden suffered by persons with diabetes. In 2024, Diabetes Canada in its "Change the Conversation" initiative unveiled the first-of-its-kind national survey on how widespread stigma, judgement and discrimination is experienced by those who live with diabetes and the impact of those social experiences on their quality of life.

Gaps

- Nearly 86% of persons living with T1D and nearly 69% of those living with T2D experience shame and blame for having diabetes. This survey also reported that 40% of persons with T1D, and 56% of persons with T2D never or rarely ask for support to manage their diabetes when they need it.[12]
- Stigma leads to worse health outcomes as it interferes with people with diabetes seeking medical care. Dr. Michael Vallis, expert advisor for this report, entitled *Social Experiences of Living with Diabetes in Canada*, states the following. *"People who live with diabetes deserve more understanding and empathy in all the places they find themselves – their workplace, schools, among friends and family, and even in healthcare settings"*.

Research Approach Recommendations

- Health professions education and behaviour research is necessary to address the important challenge of diabetes stigma and distress. Why is it occurring and what can be done to change the attitudes of health professionals caring for persons with diabetes?
- Education and communications research should focus on understanding the barriers and facilitators to effectively educating teachers, employers and how to change public perceptions about the challenges persons with diabetes face.

ACCESS TO DIABETES DEVICES, MEDICINES AND FINANCIAL SUPPORTS

Many people in Canada struggle with accessing necessary treatments and supports due to various obstacles including language barriers, absence of culturally sensitive care, lack of financial coverage, varying quality of treatment, and discrimination from the healthcare system. Additional supports to alleviate barriers to care must be explored, and collaboration with industry encouraged to support innovation in accessible diabetes devices.

Person level

In 2023, Diabetes Canada published a report providing updated data on out-of-pocket costs for people living with diabetes in Canada. Out-of-pocket costs for persons living with T1D can be as high as $18,306 per year and for persons living with T2D can be as high as $10,014 per year in certain areas of Canada. Drug costs become "catastrophic" when they are more than 3% of a family's annual income. Over half of persons living with T1D either experience costs above 3% of their family income or, given other financial burdens and lack of resources, fail to adhere to the treatment recommended by their doctor. This is likely also the case for persons living with T2D and will inevitably lead to their poorer health outcomes.

As part of personalized diabetes care, the Framework identifies a gap in reducing cost to individuals with diabetes that could be bridged by:

- Prevention or remission of diabetes and its complications lessening the need for drugs and devices; and,
- Ensuring the least cost to patients for most effective drug and device prescriptions and timely access to eligible social service benefits to support treatment for persons unable to afford the cost.

Gaps

- Ability to identify those persons with diabetes who are at highest risk of poor health quality based on financial and social needs.
- Understanding how to more effectively support the financial burden of necessary health care, including self-management of persons at risk of developing or living with diabetes.

Research Approach Recommendations

- Research goals must focus on developing the most efficient and cost-effective diagnostic and therapeutic tools that are well-validated and result in robust targets for testing in clinical trials with an equity lens.
- Researchers could take advantage of new digital tools (e.g., AlphaFold, AI/ML) to accelerate discovery of new molecules for cost-effective diabetes and related drug development, customized for individual biological risk and personalized medicine targeting.
- Clinical trials could focus on eliminating diabetes as a risk factor by testing promising remission and prevention therapies based on validated risk scores including "omics" for prevention and remission.
- Health services research should focus on how to identify persons with diabetes at highest risk of non-compliance based on financial burden and to support their needs.

Regional level

Emphasis should be placed on understanding how improving support for the prevention and treatment needs of the highest risk, structurally underserved persons with diabetes could enable regional health system leaders and policy decision-makers to deploy their resources more strategically. Care should be taken to ensure that as well as access to the most appropriate drugs and devices, education, training and ongoing support will be required to realize their potential benefits.

Gaps

- Each provincial and territorial health authority regulates the financial support for diabetes drugs and devices. There exists a lack of information about the effectiveness of these programs and the return on investment that could be realized in health services if more up-front funding was offered for the right treatment at the right time.

Research Approach Recommendations

- Research that analyzes the effectiveness of current policy for support for diabetes prevention (including diagnostic surveillance) and treatment (drugs, devices, education, coaching, navigation) would define how changes in policy could improve health outcomes with economic and societal return on investment. Sufficient time horizons must be considered given the chronicity of diabetes and the development of long-term complications. Include benchmarking across provinces/territories to establish the impact of differential coverage across Canada.
- Using current provincial administrative sources linked to primary care and hospital data, population health and epidemiology researchers can track how regional changes in policy could have immediate, intermediate and long-term effects on improving health services utilization for diabetes prevention and care.

Population Level

In 2024, the Government of Canada introduced Bill C-64 - *An Act Respecting Pharmacare*, legislation that would create a framework to develop a national pharmacare plan. This plan would commit the government to provide coverage for diabetes medications, as well as a fund for devices. The government has published a draft formulary outlining the diabetes medications that would be covered that, unfortunately, are not aligned with the most current diabetes clinical practice guidelines, nor with the Non-Insured Health Benefits Plan.

Gaps

- After consultation with patients and stakeholders across the country, Diabetes Canada has produced a comparison document[13] that demonstrates that for many uninsured persons living with diabetes in Canada, most of the commonly prescribed medications will not be covered by the public plan. This will create a major gap for the un- and underinsured persons with diabetes.

Research Approach Recommendations

- While insulin pumps and continuous glucose monitors have improved diabetes management for those who have access to these devices, more research into refining the function and cost of these devices as well as access and prescribing bias would help support wider use for improving diabetes outcomes at a population level.
- The evidence necessary to modify the national pharmacare formulary to address the needs of the un- and underinsured persons with diabetes across Canada, must be forthcoming as quickly as possible through the research efforts of health services and policy experts.
- Health economic analysis and modeling of how investment by the federal and provincial governments in providing the most effective drugs and devices for diabetes among the most structurally underserved in the Canadian population would save the current costs related to diabetes complications including end-stage kidney failure (dialysis), blindness, lower limb amputations, heart failure and stroke.

6.0 Building Diabetes Research Strength in Canada

As outlined in the Framework and highlighted during the Workshop, participants emphasized how diabetes and related research could be enhanced through expanding collaboration, communication and capacity building for:

- improving quality health outcomes for persons with or at risk of developing diabetes; and,
- reducing the health services burden for management of diabetes and its complications.

Communication

Despite the increasing incidence and high prevalence of diabetes in Canada, with rising cost of treating its complications, effective communication about the need for action based on research-generated evidence is challenging. Many researchers may not have acquired knowledge mobilization skills in their training. Therefore, the CIHR INMD has adopted the knowledge mobilization tools and consultation service developed by Diabetes Action Canada.

Capacity Building

Building and sustaining diabetes research in Canada, requires ongoing training and mentoring of the next generation of investigators in all four CIHR Pillars. Building on strengths in human islet biology, the Canadian Islet Research and Training Network was established in 2020 to facilitate collaboration and training of pillar 1 researchers (www.islets.ca). Maximize your Research on Obesity and Diabetes (MyROAD) is a training and mentoring platform that supports trainees from all four CIHR Pillars (www.myroad.ca). The Canadian Diabetes Epidemiology Group is a nascent network of epidemiology and population health researchers. Each may provide insights to enhance success that may be replicated and/or integrated with a (much needed) clinical research network that may be addressed at least in part by Diabetes Clinical Trials Network (under the broader Accelerating Clinical Trials initiative).

Event Feedback

In alignment with the Framework guidelines, it is hoped that this is the first of many collaborative research meetings. As further outreach and engagement is needed across disciplines and pillar research with greater contributions from governments and decision makers to help promote research, focus research energies, and support dissemination beyond researchers.

7.0 Conclusion

The SMIDF Project is an instrumental initiative by Diabetes Canada and PHAC. The Research Workshop aimed to encourage further momentum in the diabetes research community and beyond. As the first ever research workshop of this project, it serves as a beacon for fostering outreach, collaboration, identifying barriers, and promoting a more equitable approach to diabetes care, thereby positively impacting public health outcomes across Canada.

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8.0 APPENDIX

8.1 Presentations by Working Group Pillar Leads

To frame the day's discussions, presenters shared insights on the key gaps within their respective pillar of research, as highlighted by CIHR (Figure 1). Their presentations provided valuable context and laid the foundation for the discussion sessions that followed.

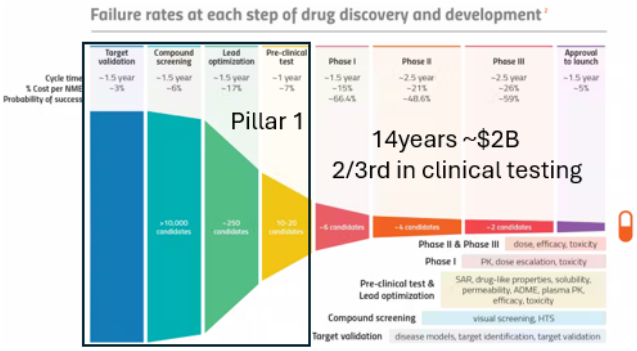
Figure 1. Summary of the pillars of research as highlighted by CIHR (https://www.cihr-irsc.gc.ca/e/53146.html)

8.2 Presentation Overview

8.2.1 Gregory Steinberg- Pillar 1; Biomedical Research

To advance equitable and scalable diabetes therapies in Canada, for pillar 1 we need to improve efficiencies related to target validation, preclinical testing, and the drug discovery process ensuring that only the most well-validated and robust therapeutic targets are moved forward into clinical development. Given the complexity and expense of proper target validation, multiple factors—such as diet, genetics, experimental conditions, and fasting durations—must be rigorously controlled.

The second major theme discussed addresses drug discovery and optimization, particularly how compound screening and lead optimization are evolving with AI and machine learning. Traditional drug screening required billion-dollar libraries with millions of compounds, making entry into this space highly restricted to a few large pharmaceutical companies. However, AlphaFold and AI-driven modeling are democratizing the process, though expertise and computational resources are still necessary.



The goal of achieving more equitable therapies for diabetes prevention, treatment and remission starts in pillar 1 by ensuring:

✓ Only most well-validated and robust targets are advanced to clinical development

✓ Targets being developed are scalable (small molecules>peptides>siRNAs>cell therapies)

Target Validation and Pre-Clinical Testing

- Like all things...the devil is in the details....and target validation is complex and expensive to do properly.
  - Diets, sex, genetics, source of animals, temperature, #mice per cage, fasting durations, time of experiment.....there is a lot to control for!!!
  - ✓ **National Pre-clinical Diabetes Core**
  - All variables are controlled, difficult techniques established (e.g. hyper-insulinemic clamps) with consistent reporting (e.g. EE) with the aim of promoting reproducibility and translation.

Compound Screening and Lead Optimization

- Traditional drug screening relied on Billion $ libraries consisting of 100K-1M cpds that were screened using equally expensive assays→ limiting barriers of entry.
- AlphaFold and AI/ML have democratized process but still need expertise and computing power.
- ✓ **National Diabetes Virtual Screening Core**
- Generate hits that can be commercially synthesized and tested in PI lab in screening assays. Top hit synthesized and provided to Preclinical Diabetes Core. IP is retained by PI and institution for partnering (e.g. licensing/newco) getting across valley of death

8.2.2 Hertzel Gerstein- Pillar 2; Clinical Research

Achieving optimal diabetes care and diabetes-related health outcomes requires the creation of a national diabetes platform to virtually integrate new and existing registries of people with, or at risk for diabetes. Such a platform should contain care-relevant data, drugs and links to facilitate prospective follow up through administrative databases. It would greatly facilitate the ability of Canadian researchers and policy makers to estimate the burden of diabetes; and identify effective and ineffective therapies for diabetes prevention, remission, and prevention/delay of its serious health consequences. It would require a concerted attempt to remove interprovincial barriers and may also require enabling legislation. Such a platform could easily grow with the addition of new health related data from hospital electronic health records, private practices, drug stores and other parts of the Canadian health system. Emerging hospital initiatives such as those at Hamilton Health Sciences (in which all registered patients are now informed that their medical information may be reviewed to determine their eligibility for approved research and whether they will be asked to consent) will continue to drive the utility of such a platform.

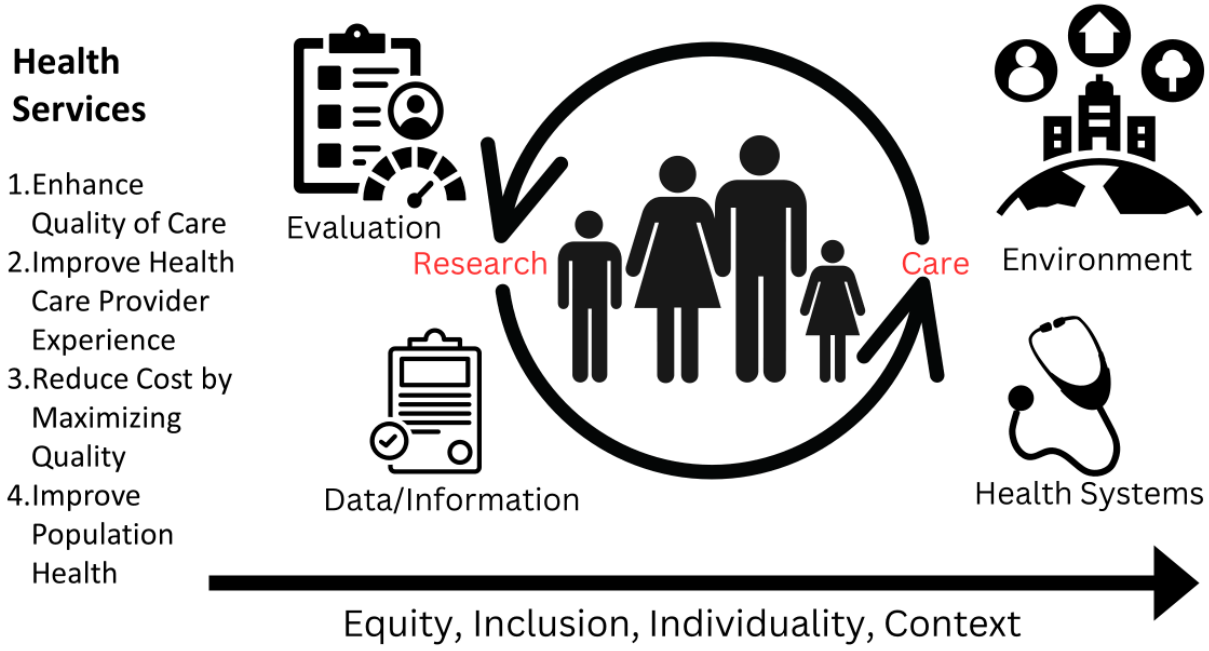
We recognize and highlight in the "breakout session 3" section of the Appendix of this report examples of quality Canadian diabetes registers and EMR systems that exist, however their independence and fragmentation is a limit on a national scale.

8.2.3 Brandy Wicklow- Pillar 3; Health Systems and Services Research

The introduction to research gaps in pillar 3 presented specific areas of data collection, harmonization, national representation/inclusion and contextualization as fundamental concepts to inform optimization of health services and systems.

With a patient, family, and community centered approach, research must be inclusive, intentionally examining the impacts of systems and services in different communities, cultures and social constructs. Research must be equitable in its ability to reach and represent all impacted populations and amplify the voices of peoples in Canada who are underrepresented.

Research in health systems and services needs to evaluate the status quo and new innovations and interventions to identify the policy impacts of interventions including the economic short- and long-term impacts.



8.2.4 Lorraine Lipscombe- Pillar 4; Social, Cultural, Environmental, and Population Health Research

Pillar 4 research addresses upstream 'social, cultural, environmental, and economic factors that impact the health of a population'. While downstream research to help people with diabetes have better outcomes is very important, this needs to be coupled with changes in social and living conditions that make healthy choices achievable. As the epidemiologist Michael Marmot stated, "What good does it do to treat people and then send them back to the conditions that made them sick?"

Furthermore, as inequities in diabetes risk and burden are rooted in upstream structural and social determinants of health, a population-based, cross-disciplinary, multi-sectoral approach is essential to reduce these inequities and promote sustainable health improvements.

Suggestions on how to advance diabetes research under each pillar are summarized below:

Pillar 1

- Propose the establishment of a **National Pre-Clinical Diabetes Core** aimed to standardize and optimize preclinical testing by maintaining controlled variables, establishing difficult experimental techniques, and ensuring reproducibility of findings
- The establishment of a **National Diabetes Virtual Screening Core** would enable researchers to identify and synthesize high-potential drug candidates, which can then be tested in preclinical models in the **National Pre-Clinical Diabetes Core**.
    - This framework ensures that intellectual property (IP) remains with the principal investigators and institutions, allowing for licensing opportunities and bridging the critical gap between early-stage discoveries and commercial development.

Pillar 2

- The creation of a national diabetes platform to facilitate the ability of Pillar 2 researchers to close several research gaps. These include:
    - Creation and validation of an easily measured and acceptable index of optimal person-based care.
    - Testing a variety of different care policies for their ability to achieve optimal care.
    - Identifying the benefits and risks of screening for undiagnosed diabetes, prediabetes and stage 2 diabetes.
    - Testing different personal interventions for remitting type 1 and type 2 diabetes in affected individuals.
    - Test different societal, policy or other interventions for preventing type 2 diabetes in communities.
    - Developing and validating "omics" scores for diabetes remission, prevention and long-term consequences using clinical data and emerging biobanks
    - Create a national biobank to facilitate "omics" research and identification of therapeutics targets

Pillar 3

- Data needs to be fulsome including multiple sources (clinical, PROM/PREM, community-based), be interoperable, and organized in a way that is useful, useable and informs new research questions, benchmarks current clinical services, and informs improvements in health care for all forms of diabetes
- Data needs to cross provincial and health authority boundaries and recognize the heterogeneity within each diabetes type
- Data should be available for advocacy efforts and implementation of innovations should be done with evaluation metrics built in
- Improving nationally representative healthcare data sources, data, and research informed healthcare delivery will require partnerships between clinicians, health system players, intersectoral partners (education, built environment, employment, housing), community organizations, industry
- Translational approaches are needed to bring best practice evidence from bench to bedside to family, community, province and nation.

Pillar 4

- As per the Framework, we need more cross-disciplinary, intersectoral collaboration
    - Research teams across a wide range of disciplines, in addition to decision makers, governments, and advocacy groups are needed, to learn from each other, integrate diverse perspectives that spark innovative solutions, and to understand the best strategies for deployment
- Need to engage and empower marginalized communities in research (as per Framework)
    - Necessary to identify unmet needs, empower advocacy for change, and co-design locally driven, inclusive and responsive solutions that are feasible and sustainable
- Harness data and digital technology to support 'precision prevention' strategies at a population and policy level
    - Population-based data research can estimate burden and distribution of risk; support resource planning and system-level decision-making; simulate intervention or policy scenarios to estimate potential benefits; and allow for natural experiments to demonstrate impact

8.3 Breakout Discussions

A series of breakout discussions were organized to assess the current state of diabetes research, with the goal of identifying existing gaps, challenges and opportunities for further advancement in the field. For the first breakout sessions, attendees were grouped according to the four pillars. This allowed for in-depth discussion and encouraging collaboration within their areas of expertise. The second and third breakout discussions involved mixed groups from different pillars, to encourage diverse perspectives and foster interdisciplinary collaboration. Below is a summary of the key insights shared during these sessions.

Breakout session #1

Question: What are the current gaps in research across the four pillars that must be filled to address improving diabetes prevention and care in Canada, aligned with the specific stated Diabetes Framework opportunities?	
Pillar 1	**Pillar 2**
Communication • Defining diabetes and its relationship with chronic metabolic conditions • Lots of misunderstanding surrounding diabetes • How to support the importance of diabetes research, both across pillars and chronic conditions • More attention to how diabetes can prevent many other chronic conditions and broaden the impact and how to capture it Collaboration /integration • How to encourage cross pillar and cross chronic condition interventions –consider more diverse research • Current emphasis on how to move pillar 1 research to pillar 2, also need to focus on how to design pillar 1 research questions from pillars 2-4 • Need to increase literacy of non-pillar 1 researchers regarding pillar 1 research • Encourage discussion by collaborating with non-scientists (i.e. policy makers, government etc.) Translation • Lack of connection to industry in Canada • How we use resources in terms of centralized resources, tools, and processes- but using the most translatable models i.e. thermoregulation, thinking about potential therapeutics across Social Determinants of Health (SDoH)	Individualization and personalization • How we can personalize treatment Comparative effectiveness studies • What works best for groups of people Greater focus around delay and prevention of all diabetes types Data • Need to collect from clinical studies or people on treatments to inform further research and care The need to normalize research • Encourage greater participation in research by communicating its value and benefits Defining diabetes • Creating a classification of diabetes that is therapeutically relevant classification vs biological relevant classification

Question: What are the current gaps in research across the four pillars that must be filled to address improving diabetes prevention and care in Canada, aligned with the specific stated Diabetes Framework opportunities?	
Pillar 3	**Pillar 4**

Need data from all sources (clinical, PROM/ PREM, community-based), that is representative, complete and interoperable and is organized in a way that is useful and useable
• Need data that informs research questions and helps define the problem and answer research questions and crosses provincial and health authority boundaries
• Data-informed approaches to care
Need research that describes the policy impact of interventions
• Cost-savings, cost-effectiveness
• Need research to understand policy impact among different populations, cost savings and return on investments among specific populations/communities, i.e., people without insurance, in Indigenous communities – hard to find health economists – important with respect to equity
Research that embeds developmental evaluation
• Ensure intervention adoption and equity is optimized
Implementation science/ research questions where data can be used to motivate action at the point of care and in community. I.e., translational research
• This will require partnership between clinicians, health system players, intersectoral partners (education, built environment, employment, housing), community organizations, and industry.
	Data
	• Data is more than a snapshot of an individual's current health—it reveals patterns, predicts outcomes, and informs both upstream prevention and downstream care
	Inclusive Research Participation
	• Diabetes research must prioritize the voices of those most affected, including individuals who lack access to primary care or public health coverage (e.g., no OHIP)
	• Rather than focusing solely on demographic identities, research should center lived experiences to ensure findings are relevant and actionable for those facing the greatest barriers.
	Multisectoral Collaboration & Accessible Knowledge Sharing
	• Effective diabetes research requires collaboration across sectors—including healthcare, community organizations, policymakers, and researchers—to drive meaningful change
	• Research outcomes should be communicated in clear, accessible formats to engage not only those directly impacted by diabetes but also allied health professionals and decision-makers who can implement findings into practice
	  • This takes advocacy, communication, public relations, advertising, and those impacted speaking more
	Equity
	• Equity work is currently siloed and hard to radiate through community care
	• Poorer outcomes in rural areas compared to urban centres
	  • Evaluate opportunities for remote visits, incentives for primary care and EMRs.

Figure 2. Top research gaps as identified by each pillar from break out session 1

Breakout session #2

Based on the gaps highlighted in the first breakout session, the top 3 discussed by the pillar groups were used to initiate the 2nd breakout session, as seen in figure 2. Elements of the Appreciative Inquiry Approach were used to guide discussions. Attendees were divided into four mixed pillar groups to address the following questions:

- **Define**: What is the current state of your chosen gap/goal in Canada?
- **Discover**: What initiatives, policies, programs, and/or interventions are you aware of that currently support your chosen gap/goal?
- **Dream**: What should your chosen gap/goal look like in the next 5 years in Canada? Consider key outcomes.
- **Design**: What policies, initiatives, programs and/or interventions are needed to create that vision?
- **Deliver**: How can we deliver on this vision? Consider: Who will or needs to champion this work? What conversations need to be had? What groups need to form, or be further supported? What organizations/departments need to collaborate?

The two topics repeatedly discussed were data and collaboration (also key Framework themes). Below is a table summarizing those shares.

Topic	Collaboration	Data
Define	• Currently minimal engagement across research pillars, sectors, and disciplines	• Data sharing is a barrier • Need better data – gender, ethnicity, EDI • Data is necessary and foundational for all pillars but not sufficient • Lifespan is not accounted for, what do we need to know at each stage of lifespan is something that needs to be considered, agreed upon and collected
Discover	• Canadian Islet Research and Training Network is a network of biomedical research groups studying pancreatic islet cells with a major focus on training and mentoring. Although focused on biomedical research they provide opportunities for trainees to engage with patient partners and introduce cross-pillar collaboration as a powerful approach for multidisciplinary research and team grants	• CAPACITY is a national pediatric diabetes registry project • Institute for Clinical Evaluative Sciences (ICES) • BORN in pediatric diabetes

Dream	• Engaging allied health as a bottom-up/ medium-up approach as opposed to top-down approach	• Platform to standardize data collection – e.g., in pillar 1 omics data
		• Getting policymakers on board to remove barriers, similar to what was done with cancer care, to improve care and save money
		• Consider minimal data set, that can be flexible and adaptive, iterative
		• Try to coalesce around the ultimate goals and use of data so it meets everyone's needs e.g., some groups developing communities of practices so data can be used for audit and feedback
		• Focus on quality not just quantity
		  • Should be going for comprehensive data not exhaustively complete
		  • Comprehensive includes patient reported outcomes, staff experience, community perspectives, SDoH
		• Can we position diabetes as the next cancer
		  • That level of urgency
		  • Learning from cancer that there isn't the same level of stigma

Topic	Collaboration	Data

Design	• Incentivize industry to participate more actively in training the next generation and participating in the research industry in Canada
	• Effective community- and patient partner- engagement and knowledge mobilization must be core elements of all research programs
		• Registry (like ICES) – can be used to ask and answer research questions
		  • Allowing data to be used to impact care, i.e., contact individuals to impact their care e.g., retinopathy – only one example in Canada, for cancer, to get people to go for screening which is legislated
		• Link social insurance numbers to comprehensive health data
		• Centre policy in social determinants of health
		• Research registries vs. clinical registries, strong desire to move towards data that conform care directly to individuals
		• Data linkage: lots of data, more powerful if we can link it
		• Use data for specific questions: Who is experiencing vision loss? Where do they live? How do we reach them? Is there variability in care?
		  • This may inform decision making/policy
		• Establish a policy of "comply or get out"
		  • Empower people and suggest that there is a risk if they don't participate
		  • i.e. COVID-19 data sharing was done poorly- the value proposition is if you do a better job at data sharing there would have been a better COVID-19 response

Deliver	• Collaborating with medical boards and associations
	  • Identify the areas where you can get some traction
	  • Introduce concepts during medical school or PhD training
	• Network among current diabetes research centres of excellence, to leverage and share investment could better utilize our limited resources in Canada compared to the capacity in the USA, UK, and other countries (e.g., Denmark) with high investments in diabetes
		• Bring together various groups that have an interest and have started registries
		• Bring community representatives, especially from underserved areas, people with lived experience (diabetes and prediabetes), allied health professionals, NGOs, funder, researchers across pillars, policy makers

During the group share backs and discussions, the following points were discussed:

1. Language: Suggesting diabetes to be linked with the term “health issue” instead of disease, led to a discussion. A participant emphasized that doctors treat disease, not broad health issues, highlighting the importance of precise language and word choice when addressing complex topics like diabetes. There was a suggestion to consider reframing the definition of diabetes between preclinical and clinical or to include “cardiometabolic disease”, which could be relevant to pillar 1 researchers. This approach would open opportunities for collaboration across fields such as neuroscience, immunology, etc.
2. Beyond diabetes: Benefit of having other networks, competencies, and skills outside of diabetes collaborate with diabetes research i.e. if your area of focus is mental health and have the necessary skills and knowledge translation, greater links with the diabetes community could mutually improve experiences for those living with diabetes.
3. Entering the research field can be very competitive. It was discussed that creating tax incentives for companies (currently unknown in Canada) to invest in research can encourage Canadian innovation
4. Data pathways: Data sharing is complicated when receiving ethics approval. Ethics boards are often administratively heavy and can be a barrier to sharing data. A major part of the knowledge mobilization strategy is showcasing and communicating to the public how their data is being used and why.
5. Diabetes and knowledge mobilization: Collaborative, evidence-based strategy for engaging the public, with consideration of Canada’s various community’s as well as age demographics, and how people consume information. As highlighted in the Framework and in this workshop, collaboration and communication are a priority across sectors, people with lived experience, governments, researchers, and HCPs to reach the various people in Canada with clear messaging. Engaging health service leaders and policy-makers through effective communication and relationship building strategies with the diabetes research community is essential for implementing the Framework for Diabetes in Canada.

Breakout session #3

After the first and second breakout sessions, this 3rd breakout session occurred organically with attendees being facilitated by Dr. Rosenblum and Ms. Cehovin. Attendees were asked to provide examples of how researchers, governments, and communities are engaging with the previously identified gaps.

Question: What programs, infrastructures, pilots, initiatives, etc. are dealing with one or more of the gaps?		
CAPACITY: "The CAPACITY registry aims to address Canada's need for: • data reflecting everyday characteristics and lived experience of young people with diabetes, along with long-term health outcomes; • increased understanding about regional differences in diabetes care and how care might be improved; and • practical ways to use this data to improve care for kids, with the values of equity, diversity and inclusion informing each step."[14]	Alberta's Tomorrow Project (ATP): "ATP's mission is to investigate why some people develop cancer and chronic diseases like heart disease and diabetes, while others do not. The answers to be discovered over the next several decades will not only help shape how cancer and other illnesses are detected, diagnosed, and treated – but most importantly, how they can be prevented in the first place."[15]	Diabetes Research Connect: "Diabetes Research Connect (DRC) is a cutting-edge collaboration between Diabetes Action Canada (DAC) and the Canadian Primary Care Sentinel Surveillance Network (CPCSSN). By aggregating data from CPCSSN, Diabetes Research Connect provides a holistic view of diabetes trends and outcomes across the country. This integrated platform enables researchers to analyze a wealth of information, from patient demographics to treatment efficacy, helping to identify patterns and develop targeted interventions for better diabetes management."[16]
BETTER: "is a Canadian research initiative led by researchers, individuals living with type 1 diabetes (including LADA) or having a child living with it, healthcare professionals, and policymakers."[17]	ACT CANADA CONSORTIUM: "ACT (Accelerating Clinical Trials) Canada was established to facilitate, optimize, and accelerate the conduct, implementation, and result translation from high-quality, high-impact randomized controlled trials to improve health in Canada and around the world."[18]	Connect1d: "is a patient-driven digital platform that allows those with type 1 diabetes (T1D) to easily learn about advances in innovative care, while contributing to Canadian research in the areas that matter most to them. Connect1d Canada also allows researchers to easily engage people living with T1D of diverse backgrounds from across Canada, enabling rapid recruitment into research studies."[19]
BORN registry: "The BORN registry provides a system to collect and store information and share insights about children and youth living with diabetes in Ontario who receive care from a Paediatric Diabetes Education Program. Healthcare providers will use the information in the BORN Registry to track children's health, improve care, and identify patterns to make diabetes management better for everyone."[20]	MyRoad: "The MyRoad Core Training and Mentoring Program will help train the next generation of scientists to mobilize new and emerging evidence into practice and policy."[21]	Novo Nordisk Network for Healthy Populations: "The mission of the NHP is to reduce inequities in risk and burden of diabetes and related cardiometabolic conditions across the lifespan, through better care, lower risk factors and healthier living environments in Peel Region and beyond."[22]
Other programs mentioned: Non-diabetes related: Cystic Fibrosis Canada International: Joint Asia Diabetes Evaluation (JADE)		

8.4 Recommendations

In addition to the granular suggestions outlined in the "design" and "delivery" sections of the second breakout session, the following overview between the Framework research component and recommendations is provided. These are expanded upon in greater depth and highlight alignment with the Framework for Diabetes in Canada research opportunities, to support both strategy and actionable steps.

Framework Opportunities	Recommendation
Enhance investments for innovative diabetes research for all types of diabetes in Canada to support strong investigator-initiated and strategic research.	Leverage investment in existing diabetes research centres across Canada by creating incentives to improve collaborative networking among establish hubs of diabetes research excellence. The purpose is to enhance and accelerate the depth and breadth of investigation by attracting and strengthening collaboration with existing pan-Canadian networks (e.g., Stem Cell Network, Diabetes Action Canada) to drive innovation for prevention and management of diabetes.
Enhance research with innovation and health equity considerations by targeting intervention research on the social determinants of health that are root causes of inequities.	Prioritize research that develops, implements and evaluates data-informed and technology-enabled solutions that are feasible, efficient, and cost-effective for improving evidence-based diabetes quality care and complications prevention in community- and primary-care settings with an equity lens, e.g., develop Canadian-led open-access databases that aggregate multi-omics for diabetes research.
Build stronger connections between researchers, practitioners, industry, policy-makers and people with lived experience to establish research priorities on diabetes to pool resources, drive innovation, and achieve common goals to advance diabetes research.	Establish research to analyze the effectiveness of current policy for support for diabetes prevention (including diagnostic surveillance) and treatment (drugs, devices, education, coaching, navigation) and to define how changes in policy could improve health outcomes with economic and societal return on investment.
Enhance investments for innovative diabetes research for all types of diabetes in Canada to support strong investigator-initiated and strategic research.	Create private sector (biotech)-partnered team/translational incentives to increase collaborations among universities, research institutes and biotech startups to attract pharma/business to Canada. This will facilitate the translation of fundamental discoveries into real-world applications and generate made-in-Canada diabetes prevention and treatment solutions.
Build stronger connections between researchers, practitioners, industry, policy-makers and people with lived experience to establish research priorities on diabetes to pool resources, drive innovation, and achieve common goals to advance diabetes research.	Support training and mentoring programs that retain top talent focused on diabetes innovation and healthcare and provides skill development in engaging a broad range of stakeholders (including people with diabetes and policy-makers) to guide future multi-disciplinary, cross-pillar collaborative research.

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