

Diabetes Strategies in Canada and Abroad

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About DIABETES ACTION CANADA

Diabetes Action Canada is a Strategic Patient-Oriented Research (SPOR) Network in Diabetes and Its Related Complications launched in 2016. Our ***Mission is to develop patient- and research-informed innovations in equitable health systems and policy designed to prevent diabetes and its related complications and to achieve improved patient experience, population outcomes, health professional experience and health system cost.***

Supported by a 5 year peer-reviewed grant from the Canadian Institutes for Health Research matched by public and private sponsors, Diabetes Action Canada works with 80 Patient Partners from across Canada and 91 Researchers in 7 provinces. Our programs include specific research and capacity-building strategies co-designed with our Patient Partners to address the most urgent health challenges faced by Canadians living with diabetes. These include:

- Prevention of blindness through community-based screening for diabetic eye disease;
- Prevention of lower limb amputations through improved primary care screening for and early interventions of foot ulcers caused by the vascular and nerve disease related to diabetes;
- Prevention of diabetes in Indigenous youth through mentorship programs promoting self-esteem, healthy lifestyle and resilience;
- Improved self-management and independent living through customized care and community-engagement of seniors living with diabetes and other chronic conditions;
- Improved self-management, including glucose control, with technology-assistance; and,
- Establishing Canada's first diabetes national data repository of persons living with diabetes using digital technology to track how new models of community-based screening and treatment can prevent diabetes complications.

Our activities also include health system research into the spreading and scaling up of effective approaches that improve patient access to care for the prevention of diabetes complications. We share our evidence with health decision-makers in provincial Health Ministries and local health authorities, to promote health policy change and sustainable healthcare solutions for persons living with diabetes. We are training and mentoring a new generation of patient-oriented researchers in the field of diabetes and its related complications through a rigorous education program in which Patient Partners help to design and teach our trainees as well as their supervisors.

Diabetes Action Canada is poised to provide patient- and evidence-informed guidance and solutions for a National Diabetes Strategy.

SUMMARY and RECOMMENDATIONS

We present research findings and selected national and international evidence pertinent to the development and implementation of diabetes strategies to reduce the current and future burden of disease. Diabetes affects over 3 million Canadians with direct health care costs of over \$3 billion per year (1). Type 1 Diabetes is an autoimmune disease affecting youth and is not preventable, currently (2). It requires life-long self-management with daily glucose monitoring and insulin injection using technology-assisted devices not uniformly supported by the provinces. Type 2 Diabetes affects 90% of persons with diabetes, and has the highest prevalence among socio-economically challenged, new immigrants, Indigenous Peoples, and the elderly. Diabetes is the leading cause of: blindness in working age Canadians (3); kidney failure leading to end-stage organ failure and dialysis (4); and, lower limb amputation (5). Persons with diabetes in low income brackets without drug insurance must choose between food, rent and medications necessary for prevention of complications (6). Indigenous Peoples are at 3 to 5 times higher risk of developing diabetes compared to non-Indigenous Canadians with the highest rates of complications (7). Canada lacks standardization of screening for diabetes and its complications and early intervention across all provinces and territories, in part, due to lack of health data and outcomes monitoring. Those countries, e.g., Sweden, with established diabetes registries and regularly monitor health system performance at regional and population levels, have improved quality outcomes at reduced cost (8).

We recommend that the federal government establish a National Diabetes Strategy to improve health outcomes for persons and populations living with or at risk of developing diabetes. The most urgent attention on reducing complications related to diabetes is emphasized in the following specific recommendations.

A National Diabetes Strategy must:

1. Establish diabetic population-wide, community-based, cost effective and timely screening programs for diabetic eye disease and early intervention to prevent vision loss;
2. Support the implementation of evidence-based standardized care paths and support for screening and early intervention for diabetic foot ulcers to prevent amputations;
3. Implement early screening for kidney disease and the support necessary for treatment of risk factors to prevent progression to kidney failure;
4. Recognize those Canadians at highest risk for diabetes and its complications and, with the Provinces and Territories, establish health promotion and disease prevention systems that provide effective clinical tools for health professionals and patients, and population-based solutions;
5. Implement, in partnership among the federal, provincial and territorial governments, effective strategies in response to the “*calls to action*” of the Truth and Reconciliation Commission to address the specific health needs of all Indigenous communities including First Nations, Métis and Inuit Peoples, related to the prevention of diabetes and its complications;
6. Recognize the importance for support of technology-assisted self-management of Type 1 diabetes that requires life-long strict glucose monitoring and insulin treatment to prevent complications; and,
7. Include standardized data-driven community-based performance management of diabetes and its related complications to track patient outcomes to enable continual quality improvement based on evidence.

EVIDENCE-INFORMED SUPPORT FOR DIABETES STRATEGIES IN CANADA

Published data from the Canadian Chronic Disease Surveillance System show that diabetes prevalence doubled between 2000 and 2010 from 1.2 to 2.4 million (9). However, estimates did not include undiagnosed diabetes. The Public Health Agency of Canada reported that this prevalence was likely underestimated by 30% as a result of undiagnosed diabetes. According to the Canadian Diabetes Cost Model commissioned by Diabetes Canada, the prevalence of diabetes in 2015 was 3.34 million and projected to rise to 4.77 million by 2025(1). In 2015, the financial burden of diabetes for our publicly funded healthcare system was estimated at \$3 billion in direct costs (\$1.8 billion in drug costs, \$717 million in physician visits). By 2025, the direct costs are estimated to increase by 41% (1). The prevalence of Type 2 Diabetes among First Nations People is consistently reported as 3 to 5 times higher than the general Canadian population (7). For persons diagnosed with diabetes, regular screening for complications and for assessment of glycemic control is essential for evidence-based diabetes management. The Canadian Community Health Survey data from 2014 indicate that in the past 12 months, 83% of persons with diabetes received at least one glycemic control blood test (A1C); 74% received a urine test for kidney disease; 66% received a dilated eye exam, and 51% received examination for high risk diabetic foot (10). Large variations exist among provinces for the number of persons with diabetes who receive these four essential screening tests with the lowest rates in Manitoba, Newfoundland and Labrador, New Brunswick and Quebec (11).

The following summarizes the most urgent challenges raised by the Patient Partners of Diabetes Action Canada who live with diabetes. The results of a patient survey conducted by our Patient Engagement Research Group prior to launching **Diabetes Action Canada**, inform these priorities (12). This survey identified views of the general population in Canada. Our subsequent engagement with Indigenous Peoples has informed us directly about their specific needs.

1. Diabetes – Leading Cause of Blindness in Working-Age Canadians

Diabetic eye disease involves changes to the blood vessel in the eyes that can progress to blindness. Progressive eye disease often goes unnoticed until vision is lost; therefore, persons with diabetes should have regular, comprehensive, dilated eye examinations. Effective therapies provided by specialist physicians are available that prevent vision loss. The screening and necessary physicians' services are fully covered by public health insurance. The key problem is that standardized ocular screening programs for persons living with diabetes are not available. In Ontario, a study from the Institute for Clinical and Evaluative Sciences reported that over 400,000 persons living with diabetes have not received a dilated eye exam in the last 2 years (13). A recent study conducted by Diabetes Action Canada Investigators demonstrated that instituting community-based eye screening in collaboration with the Ontario Telemedicine Network, identified 9% of previously unscreened persons with sight-threatening, treatable disease. A recent report from the UK demonstrated that when screening was offered to all persons living with diabetes in a geographic region, vision loss due to diabetes was reduced by 50% over an 8 year period and no longer the leading cause of blindness in the working-age population (14).

In collaboration with communities in urban and rural settings, including Indigenous communities, **Diabetes Action Canada** is designing and testing screening approaches that reach out to those persons who require screening for diabetic eye disease. These telemedicine methods are cost-effective and can be scaled up to serve regional and provincial/territorial populations.

Recommendation 1

A national diabetes strategy must establish diabetic population-wide, community-based, cost effective and timely screening programs for diabetic eye disease and early intervention to prevent vision loss.

2. Diabetes – Leading Cause of Lower Limb Amputation in Canadians

One of the greatest fears of persons with diabetes is lower limb amputation. Untreated diabetic foot ulcers are the major cause of amputation and premature death due to infection. Foot ulcers are a result of loss of sensation due to diabetic nerve damage and vascular disease affecting the lower limbs. Strong evidence shows that by identifying those individuals at high risk of developing foot ulcers and providing a path of specialized care along with self-management, infection and lower limb amputation can be prevented (15). In Canada, the incidence of lower limb amputations in the diabetic population has risen over the last 2 decades. In Ontario, every four hours a person with diabetes undergoes some form of lower limb amputation related to foot ulcer disease. In 2015, of the \$1.5 billion direct cost of diabetes care in Ontario, diabetic foot ulcers cost \$320-400 million (physician visits, hospital stays, long-term care, home care) and \$35-60 million in indirect costs (lost productivity and premature death) (16).

Among the most effective treatments for ulcers and their prevention are off-loading devices that remove pressure from the feet and promote healing. But, this uninsured cost is often prohibitive for the most vulnerable patients. In 2017, the Ontario government announced funding for off-loading devices, the first province or territory to provide this necessary treatment (17). However, individuals at high risk also require treatment by chiropodists or podiatrists and this care is not covered by public health insurance.

In Alberta, the Diabetes, Nutrition and Obesity Strategic Clinical Network (SCN) recognized that 85% of amputations related to diabetic foot ulcers could be prevented. The SCN has instituted a province-wide diabetes foot care clinical pathway that assists healthcare providers to identify foot problems, facilitate early intervention and support patients in receiving appropriate care from the right provider, at the right time (18) Once patients at high risk for diabetic foot ulcers are identified, they are referred to one of four high risk foot teams across the province for specialist care. Further, the SCN has published a comprehensive set of diabetic foot care clinical pathway tools and resources for both patients and providers to guide improved self-care management and foot screening by primary care (19).

The evidence is abundant that diabetic foot ulcers can be prevented with improved self-management, appropriate screening by primary care teams, early referral to specialized foot care teams and treatment with off-loading devices (15). Provincial and territorial funding for this comprehensive clinical care pathway is necessary. **Diabetes Action Canada** has launched a multi-disciplinary research team that is designing and evaluating chiropody-led interventions for the early treatment and continual follow up of individuals at high risk for foot ulcers. Working with primary care, Indigenous communities, local and provincial health authorities, scalable solutions must be forthcoming and spread across the entire diabetes population as soon as possible.

Recommendation 2

A national diabetes strategy must support the implementation of evidence-based standardized care paths and support for screening and early intervention for diabetic foot ulcers to prevent amputations.

3. Diabetes – Leading Cause of Kidney Failure in Canadians

Diabetes is the most common cause of kidney disease in Canada, affecting up to 50% of persons with diabetes in their lifetime (20). Kidney failure is a devastating condition that reduces both length and quality of life (21). High glucose, high blood pressure and vascular disease associated with diabetes all cause kidney damage. All of these risk factors can be reduced by good glucose and blood pressure control and with medications that are specifically designed to reduce progression of diabetic kidney disease (22). The earlier kidney disease related to diabetes is detected and risk factors treated the

more likely progression to advanced kidney disease and need for dialysis or transplant will be avoided. Blood and urine testing for kidney disease should be performed annually. All individuals with chronic kidney disease should be considered at high risk for cardiovascular events such as heart attacks and strokes and should be treated to reduce these risks (23). Comprehensive population screening for early signs of diabetic kidney disease must be instituted across the provinces and territories to curb the increasing number of individuals with diabetes progressing to kidney failure.

Diabetes Action Canada is collaborating with the SPOR Network in Chronic Kidney Disease (CanSOLVE CKD) on provincial strategies to establish community-based screening and early treatment for diabetic kidney disease and related risk factors.

Recommendation 3

A national diabetes strategy must implement early screening for kidney disease and the support necessary for treatment of risk factors to prevent progression to kidney failure.

4. Type 2 Diabetes – More Commonly Affects the Most Vulnerable Canadians

There is robust evidence that Type 2 Diabetes can be delayed or even prevented through healthy behaviour interventions (increasing physical activity level and improving overall nutritional quality, losing high risk body fat), and drug treatment. An obesity epidemic, a marker of our unhealthy lifestyle, is currently paralleling and fueling the diabetes epidemic worldwide with over 60% of Canadian adults and close to one-third of children and adolescents having overweight or obesity (24). Drs. Paul Oh (25) and Jean-Pierre Després (26), investigators in **Diabetes Action Canada**, have demonstrated that interventions targeting lifestyle behaviours provided in rehabilitation programs and the work setting can have a positive impact on the health status of individuals with diabetes. It is urgent that the federal, provincial and territorial governments develop and evaluate clinical and population-based strategies to prevent and treat the rising rates of obesity, promote physical activity and reduce sedentary time.

Canada's diversity requires that health promotion, disease prevention and management strategies be culturally appropriate and tailored to specific populations. The most vulnerable for developing Type 2 Diabetes include those individuals over 40 years: with a parent or sibling with diabetes; who is a member of a genetically-predisposed high-risk group (Indigenous, Hispanic, South Asian, Asian or African descent); with a history of pre-diabetes; and/or a history of gestational diabetes (1, 27). The Public Health Agency of Canada has developed the Canadian Diabetes Risk Questionnaire to help Canadians find out their risk of developing Type 2 Diabetes or pre-diabetes (28).

A person's ability to adopt healthy behaviours is affected by many factors, including the social, environmental, cultural and economic conditions in which they live (the "determinants of health"). In the Canadian Community Health Survey, the prevalence of Type 2 Diabetes in the lowest income group was 4.14 times higher than in the highest income group (29). In the National Population Health Survey, the low income group was associated with a 77% higher risk of developing Type 2 Diabetes compared to the high income group (30). The determinants of health conditions contributing to this disparity include; income, education and literacy, employment and working conditions, availability of affordable healthy foods, environment and housing, social support and connectedness, and access to health care (31).

Diabetes Action Canada, in collaboration with the Aging Community and Health Research Unit at McMaster University (32) recognizes that seniors with diabetes are high users of the health system because of their many other chronic conditions. Most diabetes disease management programs and guidelines in Canada are entirely focused on diabetes only and do not address the challenges to patients and providers of managing related conditions. Our research focuses on how to scale up and

spread successful interventions focused on improved self-management through community-engagement services, nurse-led navigation and case management. The results will inform the development and dissemination of a new and innovative community-based model for diabetes care that can be adapted and implemented for older adults with diabetes across Canada.

A key determinant for improved diabetes outcomes for individuals at high risk of complications is the availability of drug insurance. Canada is the only country with a universal health care system that does not provide universal coverage for prescription drugs. Because pharmacological therapy is a critical component of chronic disease management, the inclusion of prescription drugs in a national pharmacare program is called “the unfinished business” of Medicare (33). One-third of working Canadians have no drug benefit insurance (34,35). For these individuals, taking medications, especially lifelong treatment of diabetes and preventions of its complications (blindness, lower limb amputations, kidney disease) is difficult because of high costs. Patients may reduce their adherence to medications, may delay renewing their prescriptions, or may forgo needed therapy entirely. Indeed, one quarter of Canadian households report cost-related non-adherence to prescription drugs (36).

Recommendation 4

A National Diabetes Strategy must recognize those Canadians at highest risk for diabetes and its complications and, with the Provinces and Territories, establish health promotion and disease prevention systems that provide effective clinical tools for health professionals and patients, and population-based solutions.

5. Diabetes – Three to Five Times Increased Risk for Indigenous Peoples

The high rates of diabetes in Indigenous Peoples coupled with the added challenge of barriers and access to care (7) they experience, make this one of the most urgent health challenges in Canada. Compared to non-Indigenous Canadians, our Indigenous Peoples develop diabetes at younger ages (37), Indigenous women experience higher rates of diabetes during pregnancy (38), and they develop complications including kidney disease and lower limb amputations more frequently (39).

Across the globe diabetes in Indigenous Peoples is linked to a common thread of colonization that is recognized by the World Health Organization as the most important determinant affecting their health (40). We must understand that the impacts of colonization have undermined Indigenous cultures and values leading to intergenerational effects on mental health, loss of self esteem, family relationships and Indigenous ways of knowing and connecting to the land (41,42). To redress the legacy of residential schools and related colonial policies in Canada, in 2015 the Truth and Reconciliation Commission made 94 calls to action including for the domain of health (43). The “*calls to action*” number 18 calls the “*federal, provincial, territorial and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the healthcare rights of Aboriginal people as identified in international law, constitutional law and under the Treaties*” (43).

The recently published Diabetes Canada Guidelines emphasize the urgent need to implement screening and prevention strategies in collaboration with Indigenous community leaders, Indigenous peoples with diabetes, health-care professionals and funding agencies to promote environmental changes and prevent the risk of diabetes in all Indigenous populations. These Guidelines set out an “Education for Equity” framework for addressing the social barriers and facilitating improved diabetes outcomes using a cultural approach. This framework is embedded within a set of principles that recognize: colonization as the predominant cause of health inequities for Indigenous Peoples; health care equity as the provision of appropriate resources according to need; and, empowerment focused on building capacity within Indigenous communities to address the social determinants of diabetes and its related complications (44).

Diabetes Action Canada is supporting the rippling out and evaluation of a very successful Aboriginal Youth Mentorship Program (AYMP). This is a 90 minute once per week after-school, peer led, health promotion program based on multi-age mentoring of children aged 10 years by grades 7 through grade 12 students to reduce risk factors for Type 2 Diabetes. The program was developed and delivered in partnership with the community and University of Manitoba at the request of the regional health authority with collaboration between study investigators and stakeholders in Garden Hill (Kistiganwacheeng) First Nation Manitoba following the principles of participatory action research and the Canadian Institutes of Health Research. The curriculum was co-developed by teachers and Aboriginal youth in Winnipeg. AYMP was designed to improve holistic health in youth by providing programmatic components that are targeted at a child's social health, physical health, mental health and spiritual health. All aspects of Indigenous culture are integrated into this program. This initiative was carried out successfully in Garden Hill, an isolated First Nation reserve community in northern Manitoba, where the incidence of Type 2 Diabetes among youth is exceptionally high. The skills of youth mentors were expanded to enhance their ability to provide instruction and support to younger children. Significant enhanced self esteem and decreases in the risk factors associated with diabetes were noted. Authors stated that the risk of metabolic syndrome was reduced by 12% among participants. This is a significant research project that has successfully, for the first time, achieved a positive impact on the risk of Type 2 Diabetes among very high risk First Nations children (45). The curriculum is an excellent resource to guide future work in this area and is now rippled out to 13 sites, the most recent in the First Nations School in inner city Toronto.

Recommendation 5

National, provincial and territorial governments must implement effective strategies in response to "calls to action" of the Truth and Reconciliation Commission to address the specific health needs of all Indigenous Communities including First Nations, Métis and Inuit Peoples, related to the prevention of diabetes and its complications.

6. Type 1 Diabetes – Requires Life-Long Self-Management and Continual Screening and Early Treatment for Complications

The cause of Type 1 Diabetes that affects children and youth is very different from Type 2 Diabetes and is not associated with obesity, inactivity or ethnic predisposition. Type 1 Diabetes requires daily glucose monitoring and insulin injections, a 24/7 life-long job. The complications arising from high glucose levels are all the same as those affecting individuals with Type 2 Diabetes with the necessity for screening for eye disease, kidney disease, foot ulcers and all cardiovascular risk factors. Achieving near normal blood glucose targets is not easy, but is the most important factor in preventing diabetes complications. Significant technological advances including real time continuous glucose monitoring and smart insulin pumps herald a new era of improved glucose control for individuals living with Type 1 Diabetes. The funding for these important devices is not readily available in every province and represents another example of lack of a standardized approach to support for Canadians living with diabetes. Specialized, multi-disciplinary centres are required to implement standardized, quality care.

Recommendation 6

A National Diabetes Strategy must recognize the importance for support of technology-assisted self-management of Type 1 diabetes that requires life-long strict glucose monitoring and insulin treatment to prevent complications.

7. Lack of Data-Driven Performance Management of the Health System to Improve Outcomes for Canadians Living with Diabetes and Its Related Outcomes.

Electronic Medical Records (EMR) and Administrative data (health and social) can provide information to improve the delivery of patient care and impact policies, system planning and evaluation. These data are a valuable resource that can be used to identify patterns and potential risk factors. Data combined with innovative technology allows novel treatment options: care can be personalized to patients ensuring they receive the care they need when they need it. The combination of *deep data* (EMR) and *broad data* (administrative) provides the potential to create predictive models to identify those with complex care needs – who are considered the most vulnerable in the community. These patients can be followed through the health care continuum – from a doctor’s office, to hospital, to out-patient, to rehab and then through community-based services. Diabetes and its related complications offer a “best-use case” for management of complex chronic disease by leveraging enhanced digital surveillance.

EXAMPLE - The National Swedish Diabetes Register (NSDR) tracks personal health information of the entire population of individuals in Sweden living with diabetes. The register can be accessed by both patients and health care providers; it supports disease monitoring and improved performance, follow-up on treatments and complications; and it supplies vital data and insights for research. Sweden ranks among the highest performing OECD countries for outcomes related to diabetes and its complications while spending less per capita than Canada on health care. Since introducing the NSDR, data collected from 1996 to 2014 have provided evidence of(8):

- Improvement in risk factor control;
- Much less variation in outcomes between units;
- Real-time statistics are publicly available;
- Focus on Patient Reported Outcome Measures; and
- Focus on early diagnosis.

Diabetes Action Canada has developed a National Diabetes Repository to help monitor and prevent complications arising from diabetes. Through enhanced informatics, this repository will apply privacy-aware methods to safely contain and link data (primary care EMR, retinopathy, patient reported experiences, and clinical trial data) and make it available to investigators for research purposes. The power of data can be used to transform the lives of those suffering from diabetes and its related complications. Our National Diabetes Repository is being established to provide evidence where information can be safely accessed to benefit patients and the public.

Provincial Administrative Datasets and Additional Data Elements

Agreements can be established to link provincially based data in the repository to provincial administrative datasets, such as Alberta Health Services and Ontario’s Institute for Clinical Evaluative Sciences. Linkage with administrative data will allow observational studies to include important outcomes available in those datasets (for example lower limb amputations, hospital admissions and emergency department visits). Other data elements will be added into the repository, including diabetic eye screening and clinical trial data. Providing both clinical and research trial data to the repository enables the generation of a personalized risk-benefit ratio for patients; data from trial patients that are similar to patients in the clinical cohort could be used to personalize the choice of medications and doses (46).

Recommendation 7

A National Diabetes Strategy must include standardized data-driven community-based performance management of diabetes and its related complications to track patient outcomes to enable continual quality improvement based on evidence.

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Biosketch of Dr. Catharine Whiteside CM MD PhD FRCP(C) CAHS

A University of Toronto graduate, Dr. Whiteside served as Dean of Medicine and Vice Provost Relations with Health Care Institutions at the University of Toronto from 2006 -14 and was recognized with WXN Canada's Most Powerful Women Top 100 Award in 2012.

Dr. Whiteside was awarded the 2007 Medal for Research Excellence from the Kidney Foundation of Canada and the Canadian Medical Association 2009 May Cohen Award for Women Mentors. In 2015 she was awarded an Honorary Fellowship in the College of Family Physicians of Canada and in 2016 received the OMA's Advocate for Students and Residents Award.

She currently serves as a Director on the Boards of Baycrest Health and The Scarborough and Rouge Hospital Foundation and is Chair of the Board of the Banting Research Foundation. In 2016, she was appointed as a Member of the Order of Canada. Dr. Whiteside now holds the position of Executive Director of *Diabetes Action Canada*, the SPOR Network in Diabetes and Related Complications.