



Diabetes Action Canada

Preventing complications. Transforming lives.

Summary Report 2018 – 2019



**Engaging persons
with diabetes**

Preventing lower
limb amputations

Preventing
blindness

**Revolutionizing how
we use health data**

Preventing diabetes in
Indigenous youth

Building capacity
in patient-
oriented research

**Connecting with
those living with T1D**

Promoting independence in older
Canadians with diabetes

Integrating sex and gender
into diabetes research

**Translating
knowledge into
practice**

Evaluating our
impact

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Introductory Letter

Diabetes Action Canada has passed the half way mark of our funding cycle. In 2018-19 we recognized the importance of demonstrating the impact of our activities to fulfill our mission of improving the health and wellness of persons living with diabetes. This year we launched a new Research Program in Health Technology Assessment and Network Analytics led by experts skilled in critical evaluation. Specifically, experts constituting this program will assist us in analyzing the value created by the evolution of our SPOR Network and its contribution providing diabetes health care solutions addressing the most urgent challenges articulated by our Patient Partners. The complete analysis will be available in the Fall of 2019 and will set in motion ongoing prospective evaluation that will inform the strategic directions of the next phase of Diabetes Action Canada.

AS A REMINDER OF OUR ORGANIZATIONAL STRUCTURE, DIABETES ACTION CANADA is composed of six Research Goal-Directed Programs and five Enabling Programs. Our Research Goal-Directed Programs directly address the most challenging diabetes complications, with particular focus on vulnerable populations. These include: Diabetic Retinopathy Screening; Indigenous Peoples Health; Innovations in Type-1 Diabetes; Digital Health for Diabetes Research and Care; Foot Care to Prevent Amputations; and, Aging, Community and Population Health.

Enabling Programs provide collaborative support and services to the Research Goal-Directed Programs to assist in the design and implementation of patient-oriented research. These include: Patient Engagement; Training and Mentoring; Knowledge Translation; Health Technology Assessment; and, Sex and Gender.

In this annual report, we highlight each research program and the outcomes that specifically focus on improving patient experiences for those living with diabetes in Canada. As we examine the impact achieved by

Diabetes Action Canada, we appreciate more and more the transformative role our Patient Partners play in co-designing the research projects. Patient Engagement has been a learning process for all members of our Network. Patient Partner narratives are extremely effective in providing context to the daily struggles of living with diabetes, patient experiences in health care and the challenges encountered in self-management. In this annual report we also describe the outcomes of our Annual Workshop that took place in Toronto, May 31st – June 1st, 2019. This year we invited our Patient Partners to share their stories to enable improved communication between those who live with diabetes and those who investigate and treat persons living with diabetes. By becoming better listeners, we have evolved our research network activities to more effectively address the challenges and gaps in care faced by Canadians living with diabetes, particularly vulnerable populations. We continue to level the playing field by eliminating the traditional power imbalance between health professionals and those living with diabetes, creating a respectful and highly effective partnership that is already yielding very effective results.



We hope you enjoy learning about the important achievements and the impact that Diabetes Action Canada has achieved to date. We also invite you to visit our new interactive Diabetes Action Canada website at diabetesaction.ca to learn more about our members and their contributions. Your ongoing support and commitment to our Network has been instrumental in achieving our patient-oriented research goals and we thank you.

Gary F. Lewis, MD, FRCPC

Professor, Department of Medicine and Department of Physiology, University of Toronto

Director, Banting and Best Diabetes Centre, University of Toronto

Sun Life Financial Chair in Diabetes

Drucker Family Chair in Diabetes Research

Co-lead of a Strategy for Patient-Oriented Research (SPOR) Network - Diabetes Action Canada

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Executive Director, Diabetes Action Canada - CIHR SPOR Network

Emerita Professor and Former Dean of Medicine
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Executive Summary

DIABETES ACTION CANADA IS A NATIONAL RESEARCH CONSORTIUM supported by the Canadian Institutes for Health Research Strategy for Patient-Oriented Research Program and both public and private sector sponsors. We are a catalytic organization of over 100 scientists, knowledge users, health professionals working with over 75 Patient Partners (persons living with diabetes) who co-design, implement and evaluate scalable health care and system solutions for the prevention of diabetes complications. We focus on bringing patients, their caregivers and researchers together to identify the health concerns of those living with diabetes and to co-create research projects that address these concerns. We partner and collaborate with university research teams across Canada, non-profit organizations, and provincial governments to plan, execute and evaluate these research projects so that we can improve patient outcomes and experiences. We focus on addressing the urgent health care needs of the most vulnerable populations with the highest rates of diabetes complications including seniors, new immigrants, Indigenous Peoples and those living in lower socioeconomic environments. We pay special attention to sex and gender inequities and discrimination and include a sex and gender lens in the design and execution of all of our projects.

Diabetes Action Canada is engaged in a variety of innovative activities to improve the patient experience and health of persons living with diabetes in Canada

Engagement with our Patient Partners is the cornerstone of our activities and we continually learn from their experiential knowledge to create research questions that generate outcomes that address their needs in the Canadian health system. Therefore, our research projects focus on designing, implementing and evaluating community-based programs to prevent diabetes complications. Applying health technology and data-informed solutions to address gaps in our health system is a major priority. Our goals include the following:

Engage persons living with diabetes to integrate the patient perspective into every step of the research process including the co-design of research questions, defining research objectives, collecting data and evaluating results;

Revolutionize how we use health data by developing technology and data-informed solutions for the improved treatment and prevention of diabetes complications. As a first step, we have launched Canada's first National Diabetes Repository in Canada with health information of over 110,000 persons with diabetes from the electronic medical records of primary care practices in five provinces;

Connect persons living with type-1 diabetes (T1D) with clinical research opportunities through a web-based and mobile app patient engagement and communication platform co-designed by those living with T1D;

Prevent diabetes and its complications among Indigenous youth by continuing to ripple out the successful Indigenous Youth Mentorship Program (IYMP) proven to improve resilience in Indigenous Youth, promoting wellness and reducing risk of developing diabetes. This program is now expanding into 30 sites across Indigenous communities in multiple provinces;

Promote independent and improved quality of life for older adults with diabetes and multi- morbidity through a community-engagement treatment program that improves self-management, reduces depression and necessity for acute care. The Steering Committee for this project is composed of provincial Health Ministry policy decision-makers who advise on future adoption of this model of care through improved practice and policy;

Prevent blindness by developing a national retinal tele-ophthalmology retinal screening program proven to be cost effective and accessible to vulnerable populations. To facilitate this program implementation, automated diagnostics of retinal images based on a new, comprehensive artificial intelligence-based process in collaboration with the Montreal Institute for Learning Algorithms is underway;

Prevent lower limb amputations by implementing a chiropody-led community-based intervention in collaboration with primary care to treat and prevent diabetic foot ulcers;

Translate knowledge from research outcomes to healthcare and policy practice by developing evidence-based practical tools for improving health professions workflow and shared decision-making with persons living with diabetes;

Build capacity in patient-oriented research by supporting the next generation of researchers to learn from the patient experience;

Integrate Sex and Gender to understand how male, female and non-binary individuals differ in their experience in diabetes self-management, accessing health care and responding to therapies;

Evaluate our impact as a research network by measuring our ability to make meaningful contributions to the Quadruple Aim of improving patient experience, population health, experience of health professionals and reducing cost to the health care system.

Engage Persons Living with Diabetes

PATIENT ENGAGEMENT IS INTEGRAL TO ALL DIABETES ACTION CANADA ACTIVITIES AND THE CORNERSTONE OF OUR SUCCESS. We are continually impressed with their transformative influence on our research activities as they become deeply involved. We have seen project design completely change based on Patient Partner feedback to yield truly meaningful outputs and outcomes for the diabetes community. For example, our Innovations in Type-1 Diabetes (T1D) Research Program (featured below) changed their entire approach to building a T1D Patient Engagement Platform. This project, originally envisioned as a simple registry was transformed by input from Patient Partners eager for a Canadian-specific platform for those living with T1D to have their voices heard, their stories told, and their patient-reported data used to facilitate scientific advances that meet their health needs. This example was a great reminder that Patient Partner narratives are extremely effective in providing context to the daily struggles of living with diabetes, patient experiences in health care and the challenges encountered in managing the disease. After three years of funding, Diabetes Action

Canada is operating with 75 Patient Partners working as expert consultants and research team members across a wide spectrum of activities and governance levels. We have Patient Partners living with type-1, type-2 diabetes, or other types of diabetes spanning age 18 – 65+, living in either urban or rural areas, and representing different ethnicities, levels of education and professional backgrounds, minorities, vulnerable or underrepresented groups including new immigrants to Canada. Our Patient Engagement Program, led by Drs. Holly Witteman and Joyce Dogba (Université Laval), has established three Patient Circles: the Collective Patient Circle (16 Patient Partners), The Francophone and Immigrant Circle (10 Patient Partners) and the Indigenous Advisory Patient Circle (10 Patient Partners). These circles are safe environments for Patient Partners to share their experiences and consult on research projects. In addition, Patient Partners are involved directly in research activities. Patient Partners consult on research projects ad hoc, vote as members on all our governance committees, and each Research Program in Diabetes Action Canada has appointed a Patient Partner co-Lead.

What do our Patient Partners say?



“It’s easy for health care providers to recommend eating perfectly balanced meals three times a day and getting eight hours of sleep to have perfect blood sugars and therefore reduce the risk of complications, but to live like that is just not realistic, at least not for me...”

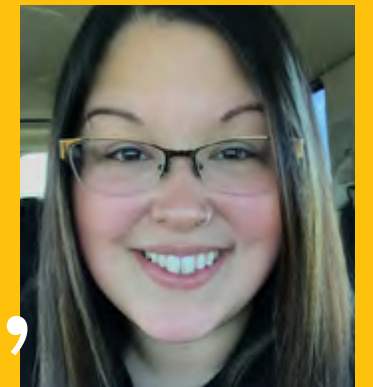
I want to have the chance to shape the research that is currently being done and have it be relevant and realistic to the struggles I face every day, and being a patient partner has given me that opportunity. ”

– Devin

“People assume that needles are the worst part of type 1 diabetes, but it’s actually the easiest part of it. We have to count every carbohydrate that goes into the body, which requires a different amount of insulin at every meal, and these ratios change without notice, so we must always be cautious and monitor his sugars after the needles...”

Diabetes Action Canada has allowed me to speak up for not only our own family but for families in my community that don’t have the chance. I was shy and didn’t think that our struggle was worth mentioning because I didn’t know people who truly understood or had the means to make a difference ”

– Sasha



“ [Patient-Oriented Research training] shows that sometimes it can be difficult to work in a team and that everyone is equal to the project: the experts are experts and the patient partners are also experts in their diseases and that together they can succeed in realizing big projects. ”

– André

Our publication based on a national survey of persons living with diabetes (*Diabetes-related complications: Which research topics matter to diverse patients and caregivers?*), used to establish the research priorities for our research Network, is among the most downloaded for the journal *Health Expectation*

Revolutionize How we Use Health Data

National Diabetes Repository

This novel, secure analytics platform designed and implemented by Dr. Michelle Greiver (University of Toronto) and colleagues now contains information from over 110,000 individuals with diabetes in Alberta, Manitoba, Ontario, Newfoundland and Quebec, and the same number of age-matched, non-diabetic controls. The National Diabetes Repository was created through collaboration with the Canadian Primary Care Sentinel Surveillance Network, using de-identified and encrypted primary care electronic medical records (EMRs) data that can be accessed by approved Diabetes Action Canada investigators for population-based and observational studies. The repository can also accept patient reported outcomes and experience measures directly from patients via the EMRs. Data from provincial administrative data sources can be linked, which will provide social determinants of health and outcomes data. To facilitate this, data sharing agreements are anticipated with the provincial organization members of the SPOR National Data Platform research program Privacy and data security are our highest priority.

In the Spring of 2019, Diabetes Action Canada launched its inaugural internal grant competition to explore the utility and value of using the National Diabetes Repository. The competition was a great success and three submissions were awarded \$15,000 each to support the projects. Proposals were reviewed by our Research Governing Committee and Scientific Advisory Committee and evaluated based on the following criteria: 1) the significance and alignment with our Network priorities; 2) questions that are in the best interest of patients; 3) innovative use of data/techniques; and, 4) team-based research. These awardees will use the data in our repository to investigate trends in adopting insulin pump therapies, mental health and health equity in vulnerable populations, and the feasibility of using machine learning to predict complications associated with type-2 diabetes.

Diabetes Action Canada, in collaboration with the Fields Institute Centre for Quantitative Analysis and Modelling (Fields-CQAM), and the Vector Institute for Artificial Intelligence held a two-day data workshop on June 17th and 18th, 2019. Trainees and established researchers

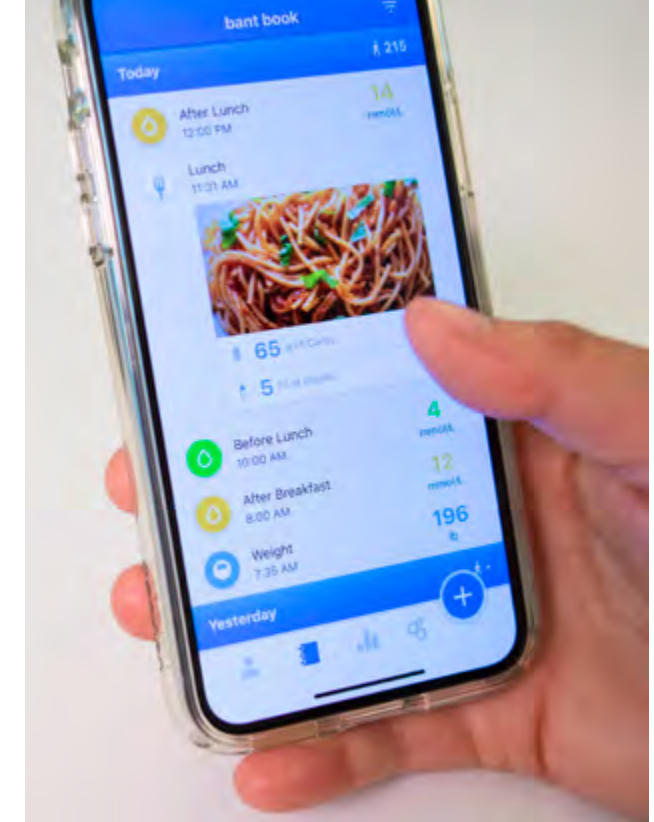
applied advanced analytics to the de-identified dataset within our National Diabetes Repository. The exercise provided much needed insights into the feasibility of using advanced mathematic modelling and artificial intelligence learning models on Canadian EMR data in a secure high-performance computing environment. Using two testing environments, the results of this workshop showed that our data can be used for: 1) machine learning to predict patient responses to the SGLT2 inhibitor class of diabetes therapies with high accuracy based on their health records; and, 2) artificial intelligence to identify the characteristics of sub-group patients, including their medication history, that are associated with different HbA1c trajectories. Taken together, we were able to demonstrate that artificial intelligence and advanced analytics could be applied to our dataset to provide useful information for both patients and physicians in selecting treatment options to manage their condition.

Want to learn more about our Research Governing Committee? We recently published a paper on this novel patient-oriented governance framework and guiding principles in *British Medical Journal Open*, entitled "*Participatory governance over research in an academic research network: the case of Diabetes Action Canada*". [Link to this article here](#)

bant Mobile Application

The transformative potential of timely access to personal health data is recognized by Canadian policy and decision-makers, but Provinces are at varying stages of enabling patients access to their data. Diabetes Action Canada investigators, Drs. Joe Cafazzo and Shivani Goyal, in partnership with the Centre for Global eHealth Innovation at University Health Network, recognize this issue and are using a mobile application *bant* to find solutions. *bant* (named after Sir Frederick Banting, co-discoverer of insulin) originally designed to assist glucose monitoring in children with type-1 diabetes, has now evolved into a powerful tool to assist self-management of any individuals with type-1 or type-2 diabetes.

Diabetes Action Canada is now taking *bant* to the next level, collaborating on:

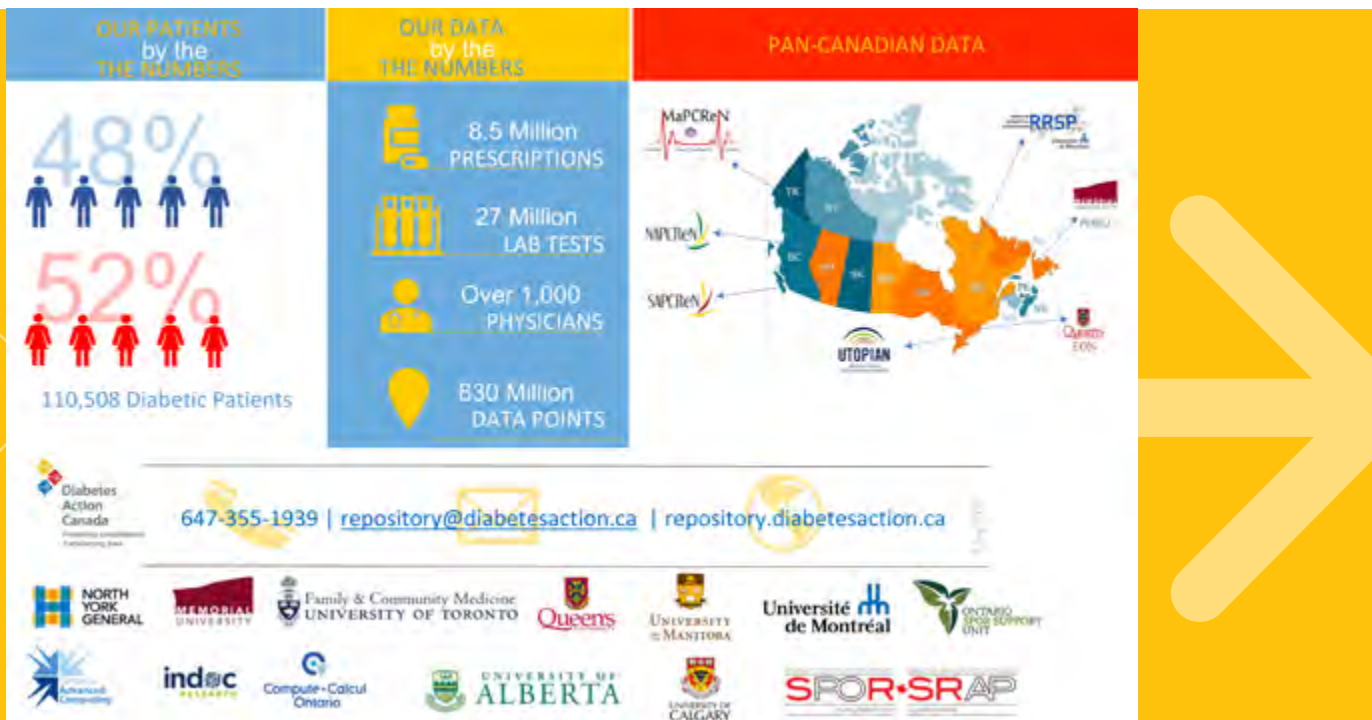


'bant book' driving improved self-management of diabetes

- Building and deploying the patient engagement platform that increases access to cutting edge type-1 diabetes research across the country. This platform is being designed in collaboration with the Innovations in Type-1 Diabetes Program, is a simple, easy to use format for both researchers and individuals living with type-1 diabetes, with the ultimate goal of accelerating type-1 diabetes research across Canada; and,
- In collaboration with TELUS Health, *bant* has now completed its proof-of-concept integration with the MyAlberta Personal Health Record (PHR) to demonstrate the feasibility of patient access to personal diabetes health information. Currently, the business model for deploying apps through the PHR in Alberta is being developed, with the goal of wide scale implementation of *bant*.

Additionally, tools are being incorporated into *bant* to improve researcher's ability to collect self-management data, and to explore secure and convenient channels for individuals to communicate with their care providers at critical moments.

All of these projects are focused on improving access to diabetes care, connecting care providers with actionable data, and fueling diabetes research.



Our Data at a Glance

Connect persons living with type-1 diabetes (T1D) with clinical research opportunities

THE INNOVATIONS IN TYPE-1 DIABETES RESEARCH (IT1D) PROGRAM HAS EVOLVED considerably since it was conceptualized in the original SPOR grant. Initially envisioned as a Clinical Trial Research Program, under the leadership Dr. Bruce Perkins (University of Toronto), Dr. Peter Senior (University of Alberta) and Kate Farnsworth (Patient Partner), the iT1D Program has expanded its research agenda to investigate novel digitally assisted methods to connect and engage the T1D Community in clinical research. Patient engagement has had significant positive influence on how the iT1D group achieves its renewed vision and has transformed its approach to plan research questions and design.

Building a Type-1 Diabetes Digital Engagement Network

Our Patient Partners, who live with T1D, have made it very clear that they feel disconnected from current clinical trials, researchers and research outcomes. In parallel, researchers struggle to connect with this diverse and geographically dispersed populations. This disconnect is an impediment

to recruitment to clinical trials and research, thereby hindering scientific advances that could greatly inform treatment pathways and improve health outcomes. To bridge this gap, the iT1D Program is currently developing a Canadian specific T1D digital patient engagement network (with proof of concept in Ontario). Using this digital platform, those living with T1D can enroll online using a very short questionnaire to determine their demographic, location and research interests as well as provide consent to be contacted for clinical research opportunities. Once enrolled, those living with T1D can explore clinical research opportunities and provide their opinion to help set targeted research priorities that address their specific needs. Conversely, researchers are able to directly engage the T1D Community in clinical research opportunities and in deciding research questions for patient-oriented research projects. Taken together, the T1D digital network will provide an opportunity that currently does not exist in Canada, to learn from patient experience and build shared understanding of life with T1D.



Diabetes Action Canada and T1D Think Tank Network Insight Session participants.

iT1D Patient Engagement and Collaborative Insight Session with the T1D Think Tank Network

Our Patient Partners who live with T1D were instrumental in shaping the direction of the Digital T1D Patient Engagement Platform. During the process of planning the T1D patient engagement network it became clear that for our research program to achieve success a stronger connection with people living with T1D must be established. With this in mind, it seemed a natural fit to collaborate with the Type-1 Diabetes Think Tank Network (T1DTTN) to learn from patient narratives and understand their experience in healthcare and quality of life. On November 30th, 2018 Diabetes Action Canada and the T1DTTN came together to hold its first collaborative activity called an Insight Session. This event was a full-day workshop that brought researchers, health care professionals (HCPs), people living with T1D and other stakeholders together to learn new skills in communication, share experiences and discuss research conceptually and projects in progress. The event started with story-telling by persons living with T1D that provided a framework for communication that was used throughout the event to share personal and research experiences, build trust and create mutual understanding. Participants in the session were invited to share their stories in small and large groups throughout the event.

Researchers presented their research projects - both funded and proposed - using the story-telling framework, and gathered feedback from the group digitally (using live polling) and verbally. The T1D patient engagement digital network was introduced to the audience by Dr. Shivani Goyal (Diabetes Acton Canada co-investigator) and a draft prototype was demonstrated on mobile phones. Each activity was followed by a larger group reflection and sharing, that guided a more fulsome discussion with ideas and feedback building on individual comments. Both positive and critical feedback was received and it was very clear to researchers that the T1D community must be heard when planning research and they must feel empowered by their participation in research. Overall, the participants enjoyed the opportunity for open and honest communication between people living with T1D and researchers. Participants were inspired by the personal stories and found them an effective reminder about the difficulties faced by those people living with T1D. A graphic summary (previous page) was prepared throughout the day to capture the key points and discussion and a summary video is currently in production and expected to be completed in the near future.

[A full report on the event is available on our website here](#)



Graphic summary of T1D Think Tank and Diabetes Action Canada Collaborative Insight Session

Prevent Diabetes and its Complications Among Indigenous Youth



Participants of the inaugural Wabishki Bizhiko Skaanj (wah-bish-kih biish-ih-goo skaa-nch) learning pathway in Winnipeg

OUR INDIGENOUS PEOPLES HEALTH PROGRAM AND INDIGENOUS PATIENT CIRCLE HAVE BEEN VERY ACTIVE in 2019, working with other Diabetes Action Canada teams to establish research priorities in Indigenous health and diabetes. In 2018-19, the Indigenous Patient Circle conducted a series of gatherings to discuss the important challenges among their communities and how we, as research teams, can best engage in meaningful diabetes complications prevention research with Indigenous Patient Partners in a culturally appropriate and respectful manner.

The Indigenous Youth Mentorship Program (IYMP), under the leadership of Dr. Jon McGavock (University of Manitoba) and Dr. Alex McComber (McGill University), has obtained a new 5-year grant from the CIHR Indigenous Pathways Implementation program to ripple out its highly successful IYMP across Canada into a total of 30 sites. IYMP is a peer-led afterschool healthy living program delivered by Indigenous high school mentors for their younger elementary-aged peers to promote wellness, reduce susceptibility to type 2 diabetes that is grounded in an Indigenous model of resilience. This program includes after-school physical activities, healthy snacks, games, education, and leadership activities customized to each community to reflect local cultural values.

In April, the Indigenous Patient Circle in collaboration with the Can-SOLVE Chronic Kidney Disease (CKD) SPOR Network hosted the inaugural Wabishki Bizhiko Skaanj (wah-bish-kih biish-ih-goo skaa-nch) learning pathway in Winnipeg Manitoba, entitled, *“Starting the journey towards culturally safe patient-oriented research with Indigenous communities”*. This learning pathway aims to enhance researchers’ and patient partners’ knowledge and awareness of histories of Indigenous peoples in Canada and the impact of colonization and racial biases on Indigenous health. It introduces culturally safe patient-oriented research practices with Indigenous communities as partners and helps to foster a climate where the unique history of Indigenous Peoples is recognized and respected to conduct research in an equitable and safe way. This process also involves developing an ongoing personal practice of critical self-reflection with a focus on one’s own power and privilege, especially as these relate to Indigenous people.

The Indigenous Patient Circle has held a series of gatherings to articulate their mission and set research priorities for Diabetes Action Canada research activities involving Indigenous Peoples. Our Indigenous Patient Circle has defined their mission as: *“Indigenous partners empowering wholistic approaches to wellness”* and have identified the research priorities for our Network to further address the most important diabetes-related health challenges for Indigenous Peoples in Canada. These include: diabetes education within the communities and schools, rippling out of the Wabishki Bizhiko Skaanj, building and nurturing partnerships with Indigenous health organizations, and communicating the successes of IYMP.

Building on the principles of Wabishki Bizhiko Skaanj, we held a gathering April 2019 to explore opportunities for researchers to partner with Indigenous communities to prevent type 2 diabetes, and gather feedback to assist our Diabetic Retinopathy Screening Research program in identifying barriers to establishing tele-ophthalmology

care in their communities. This gathering was a great success with researchers understanding the importance of engaging Indigenous Patient Partners as equals and enabling their collaboration to proceed while respecting Indigenous tradition, using clear language and establishing clear objectives so that personal connections

are established. Our Diabetic Retinopathy Screening Program also gathered new insights into the challenges faced by Indigenous communities and how factors like geography, lack of continuity of care, and upfront travel costs are preventing those at risk from getting their eyes screened.

Promote Independent and Improved Quality of Life for Older Adults

AS THE POPULATION AGES, THE PREVALENCE OF TYPE-2 DIABETES AND MULTIPLE CHRONIC CONDITIONS WILL INCREASE. More than 40% of people with type-2 diabetes have three or more chronic health conditions associated with poorer self-management, reduced quality of life, premature mortality and increased unplanned use of health care services (e.g., hospital admissions). Recognizing the diverse and often complex needs of older adults, our Aging, Community and Population Health Program, led by Drs. Maureen Markel-Reid, Jenny Ploeg and Ruta Valaitis (McMaster University), was awarded a 4-year CIHR SPOR Primary Integrative and Health Care Innovation grant, co-funded by Diabetes Action Canada, to test a novel patient-centred intervention focused on improving diabetes management in older adults with multiple chronic conditions, and to support their family caregivers.

With a vision of working to promote optimal aging at home, this group has launched two important studies.

The first is a population-based analysis using the CIHR/Canadian Institute for Health Information (CIHI) Dynamic Cohort and ICES data with information on high users of the health care system in Alberta and Ontario, to identify the characteristics of older adults with diabetes and multi-morbidity who are high users of healthcare services. This information will be used to determine eligibility criteria for recruitment into their second study that will evaluate a self-management intervention co-created by patients, caregivers and community partners focused on improving diabetes management in older adults with

multiple chronic conditions. This community-engagement program, consisting of nurse-led care coordination, home visits and monthly community-based wellness sessions, jointly hosted by community partners, has the ultimate goal of promoting independence among older Canadians living with diabetes. Our Aging, Community and Population Health Program will collaborate with our Knowledge Translation Program to evaluate the factors necessary to customize and launch this program in three Provinces across Canada and attract attention of policy and decision-makers to influence primary care practice. The Steering Committee for this patient-oriented research includes Patient Partners and Policy Decision-Makers from Alberta, Ontario, Quebec and PEI.

We are also thrilled to announce that our Aging, Community and Population Health Program operating out of McMaster School of Nursing Aging, Community and Health Research Unit (ACHRU) along with the McMaster Institute for Research on Aging (MIRA) have formed the newest research centre in the Ontario SPOR SUPPORT Unit (OSSU). OSSU is a collaborative of 15 health research centres across the province that provides scientific knowledge and supports high quality patient-partnered research with the goal of improving health and the health system. The new Centre, called the MIRA | Collaborative for Health & Aging, has received \$300,000 from OSSU to establish its activities over the course of one year. Parminder Raina, Director of MIRA and Maureen Markel-Reid (co-Lead, Aging, Community and Population Health) and co-Director of ACHRU will co-lead the new OSSU centre.

Prevent Blindness in Canadians Living with Diabetes

THOSE LIVING WITH DIABETES HAVE AN ELEVATED RISK OF EYESIGHT DETERIORATION, which is the leading cause of blindness in adults under 60 years of age. Diabetic Retinopathy (DR) is one of the most feared complications of diabetes and accounts for 80% of diabetic-related blindness. Early detection of DR by regular screening effectively avoids vision loss from diabetes as individuals at risk can receive necessary treatments to prevent irreversible retina damage. Our Diabetic Retinopathy Screening Program, led by Dr. Michael Brent (University of Toronto) and Dr. David Maberley (University of British Columbia), has identified and recently published evidence showing that the large gaps in screening for diabetes-related eye disease amongst the most vulnerable diabetic populations, e.g., Indigenous Peoples, new immigrants, persons living in lower socioeconomic environments, can be addressed through cost-effective tele-ophthalmology screening programs. The key barriers to such programs are identifying those at risk for vision loss and ensuring timely intervention and follow up. In collaboration with Dr. Jeremy Grimshaw (University of Toronto), Canada Research Chair in Health Knowledge Transfer and Uptake, and primary care researchers, Drs. Noah Ivers (University of Toronto) and Joyce Dogba (Laval Université), a study is underway to identify the barriers and facilitators of retinopathy screening from the perspective of vulnerable persons living with diabetes. Preliminary data in this study reveal that language barriers, continuity of care, transportation to specialty clinic and misunderstanding of the screening process, are keeping individuals from screening for DR. Further to this study, in collaboration with the Institute for Health System Solutions and Virtual Care at Women's College Hospital, a study of the barriers to screening from the perspective of primary care practitioners is underway. The outcomes from these research projects will guide the launch of a comprehensive tele-ophthalmology screening trial in three large Community Health Centres in inner city Toronto. The goal is to evaluate a new population-based approach to identify unscreened individuals, invite them

for screening, and facilitate timely treatment and follow-up to prevent loss of vision. If successful, this data-informed population approach could be scaled and spread across Canada for DR screening as well as for screening other diabetes complications.

Telehealth retinal screening programs have the potential to scale up as part of a national population-based screening program. To accomplish this, diagnostic capacity constraints among Canadian ophthalmologists must be considered. Dr. Marie-Carole Boucher and her colleagues at the University of Montreal and Montreal Polytechnique are well underway to establish a curated, valid database of retina images from Canadians with diabetes and related eye complications that are analyzed by machine learning algorithms. The goal is to establish an artificial intelligence-based system to accurately diagnose not only diabetic retinopathy, but also other vision threatening conditions including age-related macular degeneration and glaucoma, to establish the capability for comprehensive eye disease screening using tele-ophthalmology. The intent is to improve access to high quality ophthalmological care by reducing image reading times and increasing clinician productivity.



Prevent Lower Limb Amputations

RECENTLY, DIABETES CANADA PUBLISHED SOME STAGGERING STATISTICS ON THE RATE OF AMPUTATION for those with diabetic foot ulcers, a major and feared complication of diabetes. Ontario reported one of the worst outcomes among the provinces in Canada, with an estimated lower-limb amputation rate of one every four hours. This past year, our Foot Care and Prevention of Amputations Research Program secured funding through the SPOR Innovative Clinical Trial Multi-Year Grant to take an alternate approach, using the expertise of chiropodists, to manage and prevent this devastating outcome for diabetic foot ulcers. Chiropodists are specialists in foot care and have a scope of practice that includes assessing, diagnosing and treating lower limb and foot disorders.

The intervention of chiropodists, when engaged at the right time, has proven to reduce the instances of lower limb amputations related to diabetic foot ulcers.

In the proposed multi-centre study (Ontario, Manitoba and Alberta), Drs. Subodh Verma and Mohammed Al-Omran (University of Toronto) and their team propose a chiropody-led approach that will focus on early treatment of foot ulcers and prevention of relapse for persons with diabetes on dialysis. Individuals with diabetes and kidney failure are among the most vulnerable to developing foot ulcers. This study will measure the impact of this strategy on the quality of life of those affected, the rate of lower-limb amputation and related hospitalization, and hospital readmission. This study, if successful, has the potential to demonstrate a cost effective and patient-oriented treatment plan that will improve how diabetic foot ulcers are managed in in the Canadian health system.

Our Foot Care team has also completed the first Canadian comparative study investigating the economic burden associated with diabetic foot ulcers. Their analysis indicated that diabetic foot ulcers leading to prolonged



hospitalization, and often resulting in amputation, are more costly than any other chronic condition including heart failure and chronic obstructive lung disease. These findings demonstrate the urgency for improving early detection and intervention to prevent diabetic foot ulcers within primary care and community-based practices. In response to this economic analysis, the team has recently developed a pilot end-to-end health care delivery path at St. Michael's Hospital in Toronto that tracks patients with diabetic foot ulcers that require intensive treatment from hospital admission, to rehabilitation - a previously fragmented process. This process is a chiropody-led approach that includes assessments from entry into the emergency room to rehabilitation with appropriate triage from internal medicine, infectious disease, vascular and plastic surgery. The intension of this pathway is to provide continuity of comprehensive care for individuals with diabetic foot ulcers following standardized treatment plans promoting limb preservation.

Translating Knowledge into Practice

THE KNOWLEDGE TRANSLATION (KT) ENABLING RESEARCH PROGRAM, under the co-leadership of Drs. France Légaré and Sophie Desroches (Université Laval) has established an integrated program with Diabetes Action Canada to facilitate the transfer of knowledge into healthcare practices. The goal of this program is to build capacity in patient-oriented KT in diabetes and its related complications and to develop and foster strategic partnerships with health organizations and policy decision-makers to effectively disseminate the evidence generated by Diabetes Action Canada.

Our KT team plays a catalytic role within Diabetes Action Canada assisting our researchers in evaluating the potential for scale-up of their successful evidence-based products. Dr. Légaré and her team, also assist in establishing meaningful partnerships to translate knowledge into practice. Here are examples of our KT research program in action.

- Our Aging, Community and Population Health Research Program consulted this group to scale their successful program of implementing home care with the elderly living with diabetes. This Research Program went on to secure funding from CIHR to implement the envisioned scale-up of this important program in Ontario, Quebec and PEI.
- Our Digital Health to Improve Diabetes Care Program has worked with our KT team to enable Quebec-based primary care data into the Canadian Primary Care Sentinel Surveillance Network, thereby populating our National Diabetes Repository.
- Our Diabetic Retinopathy Goal-Directed Program has collaborated with our KT program and the Ottawa Health Research Institute to identify and understand the barriers to retinopathy screening experienced by ethno-cultural minorities who have high risk of diabetic retinopathy in Ontario and Quebec. These patient perspectives will inform the design of a fit-for-purpose intervention that will reduce these barriers in our health care system.



Diabetes Action Canada staff present at the International Shared Decision Making Conference at Université Laval

Our KT Research Program has established a robust academic program that has produced many interesting resources to enable knowledge translation in diabetes. For instance, Dr. Desroches is working collaboratively with our Patient Partners to conduct an environmental scan of the KT initiatives and tools for health care practitioners and patients to enable prevention of diabetes complications that are available across Canada. The goal is to create an easily accessible 'KT toolkit'.

Our KT Research team is also collaborating on analyzing the impact of networking (internal and external) within Diabetes Action Canada. This project is under the co-leadership of Dr. Mathieu Ouimet (Université Laval) and Dr. Valeria Rac (University of Toronto) and will provide tangible evidence of the success of Diabetes Action Canada as a national SPOR Network and its impact on the health challenges identified by persons living with diabetes and its related complications.

Dr. France Légaré co-chaired the organizational committee for the 10th International Shared Decision Making Conference held at Université Laval in Quebec City, Canada from July 7-9 2019. This conference was a certified **Patients Included** event, demonstrating to their commitment to include the experiences and insight of patients as the experts in their own health conditions

Integrate Awareness of Sex and Gender into Diabetes Research

MEN, WOMEN AND NON-BINARY INDIVIDUALS EXPERIENCE HEALTH AND HEALTH CONDITIONS LIKE DIABETES DIFFERENTLY. Sex, the biological attributes of males and females, and gender, the socially constructed aspects of being a man or being a woman are particularly important to consider while studying barriers and access to care, and novel treatments or models of care delivery. Considering sex and gender in research and clinical care means more robust study findings and ultimately better health outcomes. Because of this, applying the sex and gender lens to research is becoming a requirement of research funding calls and award applications.

Our Sex and Gender Enabling Program, supported by the Women's Xchange at Women's College Hospital in Toronto and under the leadership of Drs. Paula Rochon and Robin Mason (University of Toronto), is bringing a sex and gender lens to all our research activities, ensuring that Diabetes Action Canada researchers recognize the important differences among diverse patient populations. Through their Sex and Gender Support Services, the team provides support on elevating the extent to which sex and gender are considered in project proposals, potentially increasing project funding success. Diabetes Action Canada has already seen the positive effects of incorporating sex and gender into its research involving human subjects. In this reporting period, the team reviewed 13 patient-oriented research proposals.



Currently the Sex and Gender team is monitoring the effectiveness of their collaboration with our research and training programs over the course of the first five years of our Network by analyzing both quantitative and qualitative outcomes. They are also developing checklists and other tools to support Network investigators through the implementation and dissemination phases of their studies.

To further assist our research investigators, the Sex and Gender team worked with our Patient Partners and other stakeholders to develop a series of online educational modules about integrating sex and gender into research, titled, **The Health Researcher's Toolkit: Why Sex & Gender Matter**. These modules are available for researchers, Patient Partners and Health Care Practitioners to learn how to effectively integrate a sex and gender lens into various study designs. The Sex and Gender program also developed a set of **metrics** in 2017 that help investigators assess how sex and gender have been taken into consideration at every stage of a particular research study. This tool is now used widely by CIHR, provincial Ministries of Health and other SPOR funded entities. Sex and gender are now integral to our research with outcomes expected to increase the knowledge of how diabetes and its related complications are experienced by women, men, girls, boys and non-binary individuals. Knowing this will inform how treatments are planned, how pharmaceutical and devices are prescribed, how complications can be prevented, and how we can better understand self-management behaviours.

Are sex and gender considerations universally applied in diabetes research? No! Learn more in this recent publication by our Sex and Gender team titled, **"Measuring the data gap: inclusion of sex and gender reporting in diabetes research"** in the journal *Research Integrity and Peer Review*

Build research expertise in patient-oriented research in Diabetes

SINCE 2017, OUR TRAINING AND MENTORING PROGRAM LED BY DRS. ANDRÉ CARPENTIER AND MATHIEU BÉLANGER (Université de Sherbrooke) has developed and implemented a curriculum in patient-oriented research that continues to be iteratively improved based on participant and Patient Partner feedback. Valuable collaborations have been established from the outset with the Cardio-Metabolic Health Diabetes and Obesity Network in Quebec and Diabetes Canada.

The training workshops held by Diabetes Action Canada have attracted graduate students, postdoctoral fellows and researchers from across Canada and is the only SPOR Training program provided in both French and English. All of our training workshops are co-facilitated by Patient Partners and offered across the country to optimize participation of our geographically dispersed membership. The Training and Mentoring Program was also involved in the Indigenous Peoples Health Learning Pathways training program, Wabishki Bizhiko Skaanj that was co-developed with the Indigenous Peoples Engagement and Research Council of Can-SOLVE CKD conducted in April 2019 in Winnipeg. This pathway aims to enhance researcher's knowledge and awareness of racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health and wellness and culturally safe health research practices.

To build capacity for our next generation of patient-oriented researchers in diabetes, we also offer two novel fellowship opportunities in addition to our regular postdoctoral fellowship program. First, our Internship Awards provide trainees the opportunity to propose projects in patient-oriented research in diabetes, in collaboration with Diabetes Action Canada investigators at different institutions. Second, our Mentorship Awards support early career investigators engaged in patient-oriented diabetes research within the first 5 years of their university faculty appointment. This Mentorship Award requires participation of a local faculty mentor from the same university as the early career investigator and a faculty mentor from another university. In 2018-19 three awards for each of these competitions were granted.

The overall Training and Mentoring Program is now under formal review and analysis by Dr. Monika Kastner (University of Toronto), an expert in Knowledge Translation and Implementation, who will provide a publishable report on the impact of Diabetes Action Canada's training and mentoring program. Diabetes Action Canada is urging every co-investigator in our Network to complete a training workshop to better understand the critical value of Patient Engagement in the design and implementation of patient-oriented research.

Evaluate our Impact as a Research Network

AS DIABETES ACTION CANADA PASSES THE MID-POINT OF ITS 5 YEARS OF CIHR AND SPONSORSHIP FUNDING, we are launching a comprehensive evaluation of the impact of our research activities and effectiveness of our Network led by Dr. Valeria Rac at the Toronto Health Economic and Technology Assessment (THETA) Collaborative at the University Health Network.

We already report annually on our research activities using traditional research metrics, such as publications,

grants funding, national and international presentations. However, for the purposes of this evaluation, we are interested in analyzing our performance and understanding the interactions and strengths of our entire Network, the effectiveness of our patient engagement strategies and the outcomes and impacts of our research programs – both on their own and as part of our Network. At the conclusion of this evaluation, we will have some early evidence about the value of our Networks and

its ability to translate our innovative diagnostic and therapeutic approaches to point of care. We will also identify key success factors - including the role of patient engagement - to improve health outcomes and enhance patients' health care experience through integration of evidence into the health care system and clinical practice.

Diabetes Action Canada will also institute measures for continuous improvement to enable the leadership and investigators to enhance their efforts for meaningful impact in real time. We anticipate a full report to be completed by the by the end of 2019.

Diabetes Action Canada Assembles for its Annual Workshop to Tell Our Stories about Patient-Oriented Research as We Envision the Future

ON MAY 31ST- JUNE 1ST, 2019, MEMBERS OF DIABETES ACTION CANADA PARTICIPATED IN OUR FOURTH ANNUAL WORKSHOP. After three full years in operation, we highlighted our many accomplishments – presented by Patient Partners, Investigators, Trainees, Clinicians and Collaborators. Stories were presented about our journey and the impact our Patient Partners have made on planning and implementing meaningful research.

Prior to the Workshop, we held a one-day Patient-Oriented Research (POR) Training session co-facilitated by our Patient Partners Howard English and André Gaudreau. Among the attendees were Dr. Jean-Pierre Després, the co-Scientific Lead for the Network, Dr. Holly Witteman and Dr. Peter Senior, Diabetes Action Canada Steering Council members. POR Training is a requirement for all members of Diabetes Action Canada and a fun and interesting opportunity to develop a safe environment for diverse stakeholders to share their perspectives and to contribute to research in a meaningful way. This training has been adapted from the CIHR curriculum on Patient-Oriented Research to include many hands-on and interactive activities that illustrate patient-oriented research concepts, promote the sharing of personal perspectives on research and the building of trusting relationships.

On May 31st our Workshop began with a welcome by our Steering Council Chair, Dr. Malcolm King and opening ceremony by Spiritual Elders Barb and Clarence Nepinak.

The theme of this year's Workshop was *"Telling Our Stories about Patient-Oriented Research Outcomes and Challenges to Envision the Future"* and we kicked off our activities by hearing stories from our Patient Partners who described their experiences living with diabetes and working with Diabetes Action Canada. We then held a series of rapid-fire oral poster presentations to highlight tangible research outcomes within our network. To finish the morning we had a plenary session discussing *"Advocating for change in the health system by connecting with decision-makers"* a goal that emerged during our 2018 Annual Workshop. Thank-you to our presenters, Maureen Markle-Reid, Mathieu Ouimet, Joe Cafazzo, Valeria Rac and our respondent Diane Finegood.



Diabetes Action Canada's Executive Director, Dr. Catharine Whiteside at the 2019 Annual Workshop



Diabetes Action Canada Patient Partners at the 2019 Annual Workshop

In the afternoon, we were pleased to invite Dr. Holly Witteman, Diabetes Action Canada Co-Lead for our Patient Engagement Research Program, Steering Council Member and person living with type-1 diabetes to give an interactive keynote on *Power Dynamic and Health Research, Care and Policy*. Holly invited Patient Partners Sasha Delorme and Alex McComber and Investigators, Jon McGavock and Peter Senior to discuss their experiences about understanding their power within the healthcare system, or lack thereof, in situations where they were either at an advantage or disadvantage. This led to interesting discussions as we learned how these power struggles occur, are recognized and eventually overcome.

Following the keynote, four of our research programs facilitated breakout sessions to gather feedback from attendees on research planned and underway. These sessions were excellent opportunities to learn from a diverse group of stakeholders. Among those who participated were CIHR Director, Dr. Norm Rosenblum, and Associate Director, Dr. Mary-Jo Makarchuk, of the Institute of Nutrition, Metabolism and Diabetes, and Project Lead, SPOR Major Initiatives, Tia Moffat. Later that evening Tia Moffat and SPOR Executive Director David Clements joined our Steering Council meetings where we had an opportunity to discuss the next phase of the SPOR program and the necessity of renewal.

June 1st, followed much of the format of the previous day with the day kicked off by Patient Partner stories and rapid-fire oral poster presentations. Our second plenary session focused on *“Access to Effective Care Paths and Overcoming Barriers”*, another topic emerging from our 2018 Workshop, and featured talks from Dr. Maman Joyce Dogba, Ann-Marie McLaren, Dr. Michelle Griever, Dr. John McGavock and Dr. Paula Rochon. Collectively, we learned about some of the important initiatives that are underway focused on improving health care experiences and the impact of Diabetes Action Canada as a backbone organization in facilitating this research. A detailed report from our Annual Workshop is available on our [website](#).

A special thank-you to Patient Partners Sasha Delorme, André Gaudreau, Dana Greenberg, Marley Greenberg, Kate Farnsworth, Conrad Pow, Shayla Hele, Pina Barbieri, Devin Cleary Gooden and Debbie Nuna for sharing their stories with us. It was a moving reminder about our mission of improving health outcomes for persons living with diabetes.

Diabetes Action Canada Governance

DIABETES ACTION CANADA GOVERNANCE STRUCTURE CONTINUES TO FUNCTION AT A HIGH LEVEL WITH EXTERNAL EXPERTS, including Patient Partners, health professionals, researchers, government (health) bureaucrats, and private sectors volunteers advising our research activities and management. The 2018-19 governance structure is summarized in Figure 1.

The Steering Council is the highest level of governance and ensures all Network activities align with our mission and vision. Our Steering Council meets quarterly and makes final decisions on Network membership, Research Program proposals, new research activities and business plans. It was at the advise of our Steering Council that Diabetes Action Canada launched its comprehensive evaluation and return on investment analysis to demonstrate the impact of our research network.

Members of the Steering Council, along with other relevant experts, serve on Standing Committees that include: 1) Strategic Partnerships and Innovation (includes major sponsor representatives); 2) Governance and Nomination; and, 3) Finance and Audit. These standing committees are in place to ensure our Network governance is operating effectively, the right stakeholders

are engaged at the right time, and fund disbursements and expenditures are on target. A Steering Council Executive, comprised of Steering Council Chair, Standing Committee Chairs, Co-Scientific Leads, and Administrative Leads, sets the agenda and reviews all the materials for the Steering Council meetings.

Our Operations and Management Committee is comprised of our Research Program Leads and Principal Investigators. This committee meets monthly by teleconference chaired by Dr. Gary Lewis, Co-Scientific Lead for Diabetes Action Canada. This Committee advises the Steering Committee about strategic directions for research, knowledge translation and training and mentoring activities based on patient feedback, research outcomes and strategic partnerships. This Committee enables communication, relationship building, collaboration, and synergy among our key research KT and education leaders. Every Program is expected to have a Project Coordinator to facilitate research activities. The Project Coordinators Committee meet monthly, chaired by the Manager of Research Operations, to discuss Network and Program operations and to identify opportunities for collaboration.



Figure 1: 2018-19 Diabetes Action Canada governance structure

Sponsors of Match Cash & In-Kind for 2018-19

SPONSOR	MATCH CASH	MATCH IN-KIND	MATCH CASH (Total Commitment)
Alliance sante Quebec	\$220,000	\$30,000	\$1,100,000
AstraZeneca	\$150,000		\$750,000
Bayer Canada	\$200,000		\$1,000,000
Boehringer Ingelheim	\$34,800		\$34,800
Cardiometabolic Health, Diabetes and Obesity Research Network (CMDO)	\$100,000		\$500,000
Centre de formation medicale Nouveau-Brunswick (CFMNB)	\$55,000		\$275,000
Centre for Global eHealth Innovation		\$50,000	
Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale (CIUSSS-CN)		\$25,498	
Centres de recherche – Université de Sherbrooke	\$140,000		\$700,000
Diabetes Canada	\$200,000		\$1,000,000
Diabetes Research Envisioned & Accomplished in Manitoba (DREAM)		\$490,000	
Donald & Gretchen Ross (private donor)	\$50,000		\$50,000
Foundation for Fighting Blindness		\$100,000	
Heart and Stroke Foundation	\$92,356		\$272,568
Institut de Recherches Cliniques de Montreal	\$1,398,035		\$3,269,455
Juvenile Diabetes Research Foundation (JDRF)	\$0		\$717,500
Merck	\$200,000		\$1,286,376
Michael Smith Foundation for Health Research	\$0		\$100,000
New Brunswick Health Research Foundation (NBHRF)	\$75,000	\$100,000	\$375,000
North York General Hospital		\$28,969	
Novartis Pharmaceuticals Canada	\$50,000		\$50,000
Research Manitoba	\$178,355		\$1,121,197
Sun Life Assurance Company of Canada	\$200,000		\$1,000,000
The Koschitzky Family (private donor)	\$50,000		\$250,000
University of Montreal	\$100,000		\$200,000
University of Toronto – Department of Family & Community Medicine		\$92,443	
University of Toronto – Department of Medicine	\$100,000		\$500,000
University of Toronto - Heart & Stroke/Richard Lewar Centre of Excellence in Cardiovascular Research	\$250,000		\$1,358,757
WinSanTor	\$0		\$259,935
Wolfond Chair in Digital Health		\$200,000	
TOTAL	\$3,843,546	\$1,116,910	\$16,170,588

Breakdown of Funding Disbursements and Allocation in 2018-19

INSTITUTION	CIHR FUNDS	MATCH FUNDS (Restricted & Unrestricted)	IN-KIND
First Nations Health & Social Secretariat of Manitoba		345,000	
Institute de Recherches Cliniques de Montreal		1,398,035	
Laurentian University		16,500	
McMaster University		196,563	
Ottawa Hospital Research Institute	85,543		
St. Michael's Hospital		20,000	
University Health Network	1,044,671	725,689	350,000
Université Laval	470,610	324,020	55,498
University of Manitoba	120,855	155,655	490,000
University of Montreal	100,000	100,000	
University of Sherbrooke	188,244	370,000	100,000
University of Toronto	562,821	409,955	121,412
Women's College Hospital	42,525	32,475	-
TOTAL	2,615,269	4,093,892	1,116,910



Diabetes Action Canada at a Glance



Diabetes Action Canada gratefully acknowledges the following contributors. Your support and partnership has allowed us to bring together researchers, healthcare providers and patients from across the country with the goal of transforming health outcomes for people with diabetes.

Project and Institutional Partners



Patient Representative Strategic Partners



Foundational Partners



Philanthropic Donors

Donald and Gretchen Ross
The Koschitzky Family
Wolfond Chair in Digital Health

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Diabetes Action Canada

Preventing complications. Transforming lives.

