

DIABETES

# Diabetes Action Canada

**SUMMARY REPORT 2017-18**

JULY 2018





## OUR GOALS

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

Prevent lower limb amputations through a chiropody-led community based intervention to treat and prevent diabetic foot ulcers

Prevent blindness through a comprehensive retinal tele-ophthalmology retinal screening programs and artificial in in each province

Connect persons living with type-1 diabetes (T1D) with clinical research opportunities through an opt-in T1D Registry



## Diabetes Action Canada

Preventing complications.  
Transforming lives.

Revolutionise how we use health data to better through the National Diabetes Repository to understand those living with diabetes and enable self-management

Translate knowledge from research outcome to healthcare and policy practice

Prevent diabetes and its complications among Indigenous youth through the Indigenous Youth Mentorship Program (IYMP) - a multi-generational mentoring and resilience-focused empowerment program

Integrate Sex and Gender to understand how men and women differ in their experience with health, access to health care and responses to therapies



Promote independent and improved quality of life for older adults with diabetes and multiple chronic conditions

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

Evaluate our impact as a research network to measure our ability to make meaningful contributions to improve the experience of those living with diabetes

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# Opening remarks

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Diabetes Action Canada is emerging as a catalyst research consortium focused on scaling-up effective healthcare solutions that directly improve outcomes for people living with diabetes. We are addressing the most important challenges articulated by individuals with experiential knowledge of the key barriers to prevention and treatment of complications associated with both Type 1 and 2 diabetes. Our Mission is to develop patient- and research-informed innovations in equitable healthcare delivery designed to prevent diabetes and its related complications and to achieve the Quadruple Aim goals (improve: patient experience; population outcomes; health professional experience; health system cost). We strategically partner with patients, charitable organizations, private industry, government and policy makers to achieve our Mission.

After two years in operation, Diabetes Action Canada is already seeing meaningful contributions to preventing diabetes and its related complications. Over the last year, we have launched a new organizational structure for our research activities that replaced the term *Goal Groups* with either *Goal-Directed Programs* or *Enabling Programs*. Specific **Research Goal-Directed Programs** (expanded upon and explained in easy to understand language and greater detail below) are those that directly address 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 vital support and services to the Research Goal-Directed Programs to accomplish their research objectives in a truly patient-oriented research fashion. These include: Patient Engagement; Training and Mentoring; Knowledge Translation; and, Sex and Gender.

In 2017-18, Diabetes Action Canada expanded its research portfolio to include two new Goal-Directed Programs. These programs were launched based on feedback from our Patient Partners about their most feared challenges and complications in managing diabetes. First, Diabetes Action Canada introduced a new collaboration with the McMaster University School of Nursing Aging, Community and Health Research Unit (ACHRU) co-led by Drs. Maureen Markle-Reid, Jenny Ploeg and Ruta Valaitis to launch a new Research Goal-Directed Program – **Aging, Community and Population Health**. The goal of this Program is to work together with older adults with multiple chronic conditions and their family caregivers to promote self-management and improved outcomes. Recently, this group secured new funding to scale-up their previously successful research through the **CIHR Operating Grant: SPOR Primary Integrative and Health Care Innovation Network Programmatic Grants** with Diabetes Action Canada as a funding partner.

Second, Diabetes Action Canada has engaged the vascular surgery and chiropody teams at St. Michael's Hospital (Toronto) to form a new Research Goal-Directed Program – **Foot Care to Prevent Amputations**. This team has recently developed a pilot end-to-end healthcare delivery path at St. Michael's Hospital that tracks patients with diabetic foot ulcers that require intensive treatment from admission to hospital, to rehabilitation – a previously fragmented process. Recently, this team was successful in securing funding for their chiropody-led program to reduce amputations in patients with diabetes and chronic renal failure from the CHIR Operating Grant competition for SPOR Innovative Clinical Trials with Diabetes Action Canada as a funding partner. We see great potential to make meaningful change in diabetic foot care. We are establishing collaboration with the Indigenous Diabetes Health Circle (IDHC), a healthcare team that has established a community-based foot care program to prevent amputations in Indigenous and underserved areas in Ontario, to assist in evaluating its effectiveness.

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As part of a SPOR Network, each research Program endeavors to learn from the patient experience and engages patients in developing and studying customized solutions for the delivery of timely and effective care related to diabetes and its complications. Each Program manages projects across the country to directly address the concerns articulated by individuals living with diabetes. In addition, Diabetes Action Canada has a mandate to improve access to healthcare solutions and reduce the inequities in healthcare delivery among vulnerable and underserved areas, including our Indigenous Communities. Therefore, a majority of our projects focus on scaling up programs that are innovative in their approach increasing access to diabetes care for these high needs groups. We evaluate the effectiveness of these programs and use that information to introduce improvements, enhance impact and reduce costs.

In the following report, you will learn about the important work that Diabetes Action Canada has accomplished and the projects we will continue to develop as we plan for the remainder of our funding term. This report is the truncated version of the full annual report that was submitted to CIHR in June 2018 and is meant to highlight our outcomes to date.



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](#)



Jean-Pierre Després, CQ, PhD, FAHA, FIAS  
Professor, Department of Kinesiology, Faculty of Medicine,  
Université Laval  
Director of Research in Cardiology, Québec Heart and Lung  
Institute Research Centre  
Director of Science and Innovation, Alliance santé Québec  
Co-lead of a Strategy for Patient-Oriented Research (SPOR)  
Network - [Diabetes Action Canada](#)



Catharine Whiteside, CM, MD, PhD, FRCPS(C), FCAHS  
Executive Director, Diabetes Action Canada - CIHR SPOR  
Network Emerita Professor and Former Dean of Medicine  
University of Toronto

# Patient engagement is the heart of what we do

Patient engagement and patient-oriented research go hand in hand. At Diabetes Action Canada, we believe that partnering with the people whose lives are touched by diabetes is critical to achieving our goals of finding real solutions to improve the lives of people and families who are living with this condition. Our Patient Engagement and Knowledge Translation Program co-leads Drs. Joyce Dogba, France Legaré (all from the University of Laval) published a recent paper in *Health Expectations* detailing the process of determining the topics most important to people living with or caring for someone living with diabetes. The findings of this paper have led to the organizational structure of our research Network and continue to inform our community of investigators and stakeholders.

Diabetes Action Canada strives to include a wide range of people living with diabetes (young and old, those with both Type 1 Diabetes [T1D] and Type 2 Diabetes [T2D], men

and women) from diverse ethnicities and backgrounds as Patient Partners at all levels of our network. There is a growing understanding that some populations, such as Indigenous Peoples, new immigrants and seniors are not as often involved in research. To this end, we are working continuously to ensure that people involved as Patient Partners in Diabetes Action Canada are reflective of all Canadians whose lives are touched by diabetes.

Within Diabetes Action Canada, the Patient Engagement Program has established three Patient Circles: the Collective Patient Circle (16 Patient Partners); the Francophone Patient Circle (10 Patient Partners, to be renamed the Francophone and Immigrant Patient Circle); and, the Indigenous Patients Advisory Circle (10 Patient Partners). Each Patient Circle includes a variety of persons living with diabetes from across Canada with a shared mission to foster patient-oriented research relevant to diabetes and to contribute to better

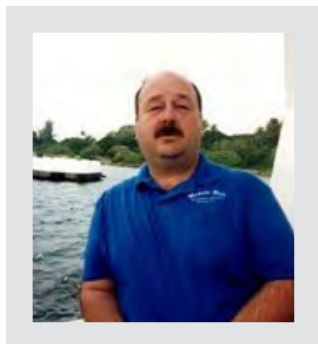


Diabetes Action Canada Patient Partners at the 2018 Annual Workshop. *Row one, from L to R:* Denis April, André Gaudreau, Patrice Bleau, Jaime Borja, Nadia Tabiou, Sasha Delorme, Serena Hickes, Richard Piché, Afifa BenGuiza. *Row two:* Virtue Bajurny, Debbie Sissmore, Shayla Hele, Alex M. McComber, Barb Nepinak, Clarence Nepinak, Kate Farnsworth, Holly Witteman, Elaine Brière. *Row three:* Ross Gray, Malcolm Sissmore, Jill Wright, David Wright, Danielle Bérubé.

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quality research on diabetes and its related complications. Patient Circles meet throughout the year to discuss projects and lend their expertise to researchers and administrators, as people who know what it is like to live with diabetes. Additionally, Patient Partners have the opportunity to become research team members. By sharing their lived experiences with the condition, they help ensure the science, publications, new projects and communication of our research findings are more relevant and more accessible to persons living with diabetes. In total, Diabetes Action Canada currently has 80 Patient Partners enrolled and participating at one level or another. Of these, 25 are currently actively collaborating on research projects.

## Meet some of our patient partners



### **HOWARD ENGLISH, WINNIPEG, MB**

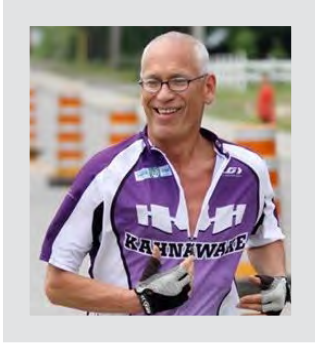
Howard is a Patient Partner co-facilitator for the Training and Mentoring Program. Howard is retired from the Canadian Military from Winnipeg who has lived with T2D since 2008. He had pre-diabetes for 15 years prior to that. He is a Patient Partner of the Collective Patient Circle. Since retiring, he has been involved in supporting diabetes care and research, including as a subject in two drug research projects, a Board Member of the Youville Clinic Centre of Diabetic Excellence in Manitoba, and a member of one of six Local Health Involvement Groups under the auspices of the Winnipeg Regional Health Authority. He took part in the Foundational

Training Seminar in Ottawa for Patient-Oriented Research volunteers and is enthusiastically providing input for improved care for Canadians living with diabetes.



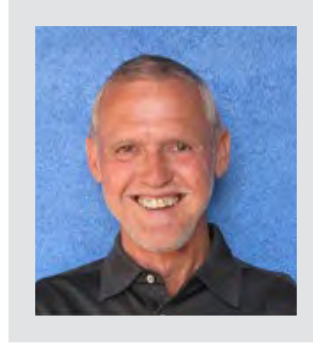
### **ANDRÉ GAUDREAU, SHERBROOKE, QC**

André is a Patient Partner co-facilitator for the Training and Mentoring Program. André is a writer, speaker and active advocate living with T2D in Sherbrooke, QC. He is an accomplished author, with his second book written and published in collaboration with people living with diabetes in France and Belgium. He established a website in order to inform people living with diabetes about research and to support those newly diagnosed in learning about lifestyles and diabetes management. He is actively involved in a variety of patient participation and diabetes research projects, such as: Liaison Officer for the board of French language SRAP (SPOR) patients, patient partner for the Centre for Diabetes, Obesity and Cardiovascular Complications of the Centre hospitalier universitaire de Sherbrooke, patient-partner of Réseau -1 Québec, patient partner for ComPaRe research in France on diabetes, and life coach with the Kidney League in France for people who are on dialysis. André wishes to use his experience to help guide researchers in understanding the realities of living with diabetes every day. He also hopes to contribute to improving quality of life for all people living with the diabetes.



**ALEX MCCOMBER, KAHNAWAKE, QC**

Alex is the Patient Partner co-lead for the Indigenous Peoples Health Program. Alex is a member of the Kanien'kehá:ka community of Kahnawake, in Quebec near Montreal. He has extensive experience working with the Kahnawake School Diabetes Prevention Project as a Diabetes Prevention Intervention Facilitator, Training Coordinator and Executive Director. He is the recipient of an Honorary Degree of Doctor of Science from Queen's University recognizing his exemplary work with a number of national diabetes organizations, including Health Canada's Aboriginal Diabetes Initiative. He strives to integrate the traditional knowledge of the Rotinonsonni (The People of the Longhouse) into his daily life and share traditional teachings through community support mechanisms. Alex holds close ties to Indigenous communities and believes strongly that health promotion, community mobilization and personal empowerment for healthy lifestyles are the key to healing multi-generational trauma.

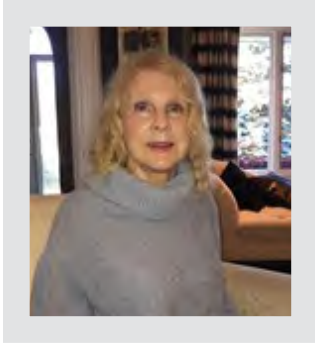


**DOUG MUMFORD, TORONTO, ON**

Doug is the Patient Partner co-lead for the Digital Health to Improve Diabetes Care Program. Doug has lived with T1D since 1968. Initially with only urine testing and animal-derived insulins, management was difficult to achieve and Doug is very grateful to be alive and healthy 49 years later! In 2009, he volunteered in a clinical trial to determine whether a Sensor-Augmented Insulin Pump could enable patients to lower their A1C. As a measurement and control engineer, he saw this as a tool finally capable of controlling blood glucose levels. His A1C level reduced notably during the trial and as a result has continued to use this technology to improve his blood glucose control.

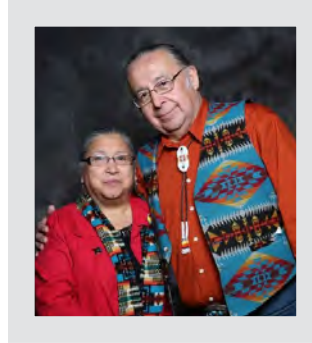
Hoping to help others living with diabetes, Doug has been an active volunteer over the years. He helped co-develop a Diabetes Patient Portal website, which will soon go live, and contributed to developing software to illustrate how insulin pump complex boluses actually affect blood glucose over their duration. Doug became involved in the SPOR initiative, joining the Collective Patient Circle. In addition, he has joined the Diabetes Action Canada health informatics project where he serves on the Technical Committee collaborating both as a patient and informatics expert.





**DEBBIE SISSMORE, PETERBOROUGH, ON**

Debbie is the Patient Partner co-lead for the Diabetic Retinopathy Screening Program and serves on the Diabetes Action Canada Steering Council. She has been living with T1D for 50 years. Due to diabetic retinopathy, she completely lost her eyesight 24 years ago. In 2003, she was part of a Clinical Islet Cell Transplant Trial (aka: Edmonton Protocol) and was fortunate to receive two islet cell transplants, which she is certain saved her life from diabetes complications. Research has played a major role in her health and well-being. Throughout the years she has had many opportunities to speak to community groups on behalf of Diabetes Canada and the Juvenile Diabetes Research Foundation (JDFR) about how research has had such a positive effect on the lives of so many.



**BARBARA AND CLARENCE NEPINAK, WINNIPEG, MB**

Barbara and Clarence Nepinak are members of the Indigenous Peoples Patient Circle. Barbara, a member of Pine Creek First Nation, is a mother and grandmother now retired after 35 years of federal public service. Barbara is active in the urban and surrounding areas, serving on Advisory Councils and Boards as an Elder and Cultural Advisor. Presently, she serves on the Special Indigenous Advisory Council to the Canadian Human Rights Museum. Clarence, a member of Pine Creek First Nation, is retired from the provincial/federal service of 27 years and continues to serve on national and local Boards and committees. Clarence is also a member of the Special Indigenous Advisory council for the Human Rights Museum, the St. James Historical Museum and Healthy Aboriginal Network in Vancouver.

Clarence and Barb are Advisory Council members at the University of Brandon, Arts & Cultural Industries and Research in Developmental Origins of Chronic Diseases in Children Network (DEVOTION) at the University of Manitoba. Clarence has developed a Historical Oral History Walking Tour in Winnipeg that takes place on selected dates in July and is sponsored by the Forks Renewal Corporation. Clarence will receive the Keeping the Fires Burning award through Ka Ni Kanichuik this summer (2018) in recognition of his contributions of Wisdom and Knowledge.

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## **Our Patient Partners in action as Scientific Ambassadors at the Diabetes Canada professional conference**

In early November 2017, nearly 2,000 people assembled at the Shaw Conference Centre in Edmonton, Alberta for the Diabetes Canada professional conference. For the first time ever, among these people were four patient partners representing Diabetes Action Canada as Scientific Ambassadors: Serena Hickes, Gloria Lourido, André Gaudreau and Howard English. Of the more than 40 sessions that took place at this conference, our Scientific Ambassadors attended 22 presentations, collectively. We asked our Scientific Ambassadors to share their experiences participating in these presentations and their overall impressions from the event. A detailed report was created by our Patient Engagement Goal Group and is available on our website in both French and English. Some highlighted quotes from of Scientific Ambassadors:

“At the beginning, I thought that as a patient, I had nothing to do in a scientific conference, but after my participation, I realized that we have a role to play in this type of conference.”

– Gloria Lourido,  
Scientific Ambassador

“The presenters were very well qualified, entertaining and the topics that I attended, although interesting and informative were more for the professional attendees. I felt I did gain a great amount of patient-related information.”

– Howard English,  
Scientific Ambassador

## **Our Indigenous Peoples Patient Circle co-develops a respectful engagement approach to patient-oriented research**

In collaboration with Can-SOLVE CKD (SPOR Chronic Disease Network in Chronic Kidney Disease) and their Indigenous Patient Engagement and Research Council, our Indigenous Peoples Patient Circle members are creating a new training platform to enable respectful partnerships with Indigenous People in Research. This learning pathway, named **Wabishki Bizhiko Skaanj** (wah-bish-kih biish-ih-goo skaa-nch) aims to enhance the Indigenous perspective and support partnerships that consider existing racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health and culturally safe health research practices. This learning pathway will ultimately change the way that researchers approach and engage members of the Indigenous Community and it is expected to be adopted by Canadian Institutes of Health Research (CIHR) to augment the existing Patient Engagement curriculum.

# Diabetes Action Canada using health data to transform diabetes management



## National Diabetes Repository for secondary use of data

By 2020, over three million Canadians (~10 per cent of the population) will have diabetes, with vulnerable populations, including Indigenous Peoples and new immigrants, more likely to be affected. Those living with diabetes have an increased risk for heart disease, stroke, kidney failure, nerve disease, blindness, mental illness, and decreased life expectancy – all conditions that not only affect those who have the condition, but the loved ones who care for them. Earlier diagnosis and effective interventions to prevent diabetes complications are needed, as is improved access to chronic disease self-management support systems and medical care. These improvement strategies must be achieved in large part through digital health solutions that improve access to patient data by clinicians, patients and researchers.

Diabetes Action Canada is enabling a digital health solution, with the recent successful launch of a proof-of-concept Diabetes Repository led by Dr. Michelle Greiver (University of Toronto). This National Diabetes Repository contains de-identified primary care electronic medical record (EMR)

data of patients with diabetes. With application of privacy and security compliant methods, these data reside in a data safe haven and can be safely linked with other relevant data (retinopathy screening reports, and clinical trial information) for analytics. Diabetes Action Canada investigators are now able to access this repository data for their patient-oriented observational or population-based studies. Through partnerships with the Canadian Primary Care Sentinel Surveillance Network (CPSSCN), Southern Alberta Primary Care Research Network (SAPCRen), Northern Alberta Primary Care Research Network (NAPCRen), Réseau de recherche en soins primaires de l'Université de Montréal (RRSPUM), and University of Toronto Practice-Based Research Network (UTOPIAN) this diabetes repository currently has data from Ontario, Quebec and Alberta representing over 50,000 patients with diabetes. Plans are currently underway to expand this dataset to include primary care patient data from other provinces and territories.

To ensure the use of this data aligns with the vision and mission of Diabetes Action Canada and that research studies have received appropriate ethics review, a volunteer Research Governing Committee was established. Half of

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the members of the committee are persons living with diabetes and the other half of primary care physicians and researchers, an unprecedented composition, truly reflecting patient engagement. On January 20th, 2018, the Research Governing Committee assembled for the first time to participate in a training workshop to learn about the specific goals of the proof-of-concept Diabetes Repository, the role of the Research Governing Committee members and how it all ties together. Since then, this Committee has met bi-monthly and approved two data usage requests with more to come. This governance model will ensure that the Diabetes Repository data will be used for studies that fulfill our mission of developing patient- and research-informed innovations in healthcare delivery designed to prevent diabetes complications.

The proof-of-concept Diabetes Repository was a key component of our original SPOR grant proposal as it brings Canada closer to linking digital health systems and patient health data to ensure accurate surveillance of diabetes-related risk factors. The work from this repository will also inform our expanded digital health strategy, which will include a pan-Canadian T1D precise registry. This registry has the initial primary purpose to facilitate timely and effective recruitment of persons living with T1D for clinical trials. Our goal is to position the National Diabetes Repository as a tool for researchers to provide the evidence necessary for health system change to improve the outcomes of Canadians living with diabetes and its related complications.

## **Mobile application – *bant***

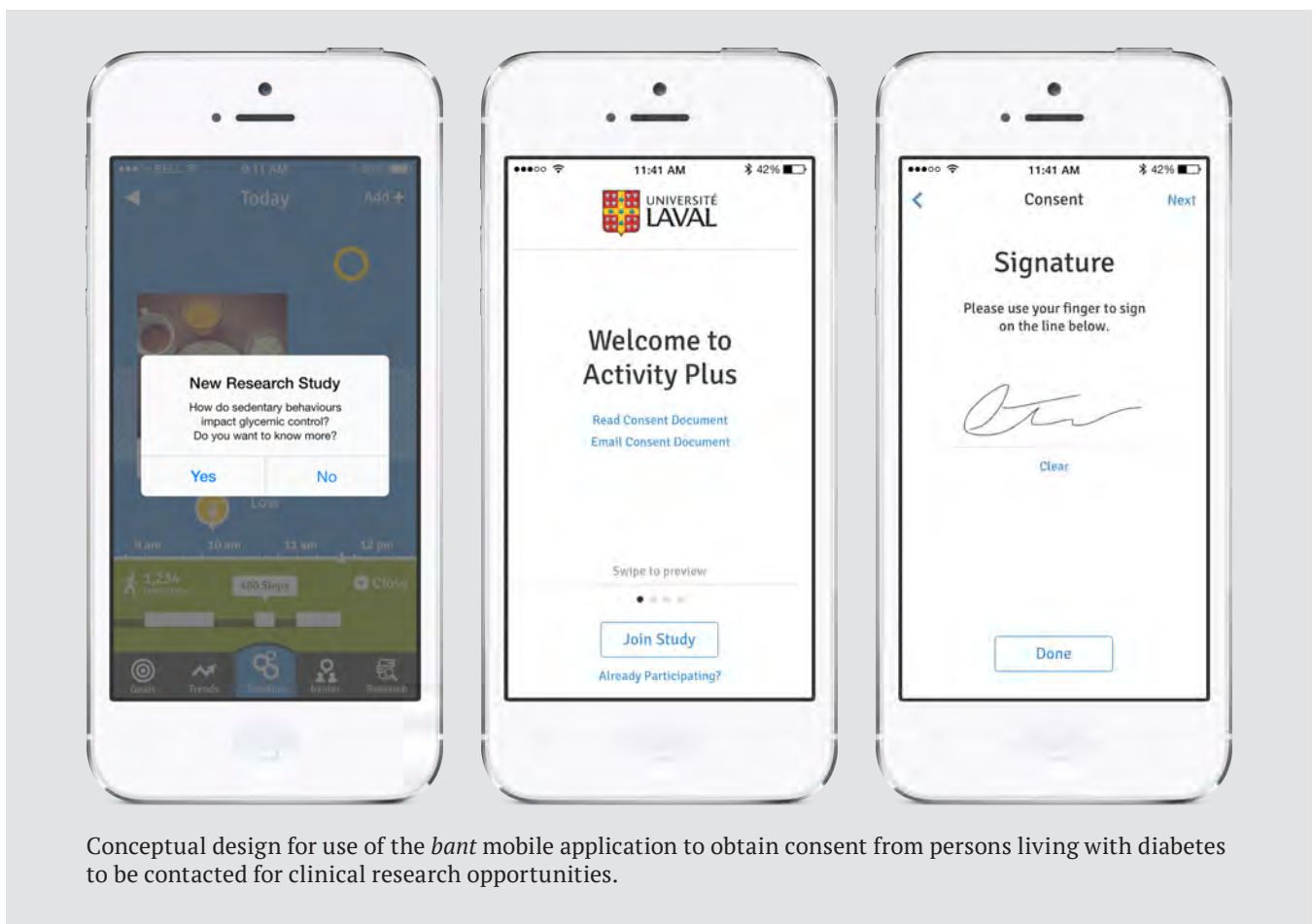
In a recent edition of *The Economist* (Feb. 3, 2018) entitled “DOCTOR YOU: How data will transform health care”, the authors discussed the transformative potential of timely access to personal health data enabling patients and their providers to implement care paths for improved outcomes. To date, many pieces of a digital health record system are in place, but patients are still unable to access their data and health professionals are unable to reach out proactively for preventative and follow-up care. Drs. Joe Cafazzo and Shivani Goyal (University Health Network and University of Toronto) are bridging this gap with innovations in digital communication.

Their mobile app, called *bant* (after Sir Frederick Banting), originally designed for assisting the glucose monitoring in children with T1D, has evolved into a powerful tool assisting the self-management of individuals with T1D and T2D. In partnership with eHealth Innovation at the University Health Network, *bant* is expanding beyond a self-management tool towards a portal for patient-driven diabetes self-care, where individuals can access their health information, securely communicate with their providers at critical moments, and easily engage in cutting-edge research initiatives across the country. To achieve the latter, our teams are working to develop an e-Consent platform and framework to enable patients to view relevant research studies, opt-in, consent, and control which data types are shared directly on their mobile device.

The *bant* mobile application will also engage researchers to remotely collect patient reported outcome measures (PROMS) and administer study questionnaires/surveys at the desired frequency, directly on the patient's mobile device (see figures below). This infrastructure will enable clinical researchers to more easily identify patients based on study criteria, present patients with targeted research opportunities and interventions, obtain consent and enrol patients into clinical trials directly through the system rather than traditional opportunistic recruitment methods, and

link patient reported outcomes and research data within the National Diabetes Repository.

Together, the National Diabetes Repository and the *bant* mobile application are necessary components of the Diabetes Action Canada digital health strategy and provide an unprecedented opportunity for managing diabetes and its related complications.



Conceptual design for use of the *bant* mobile application to obtain consent from persons living with diabetes to be contacted for clinical research opportunities.

# Building capacity for the next generation of Patient-Oriented Researchers

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Our Training and Mentoring and Knowledge Translation Enabling Research Programs have developed many unique and innovative programs to build capacity in Patient-Oriented Research. Here are a few examples:

- **Diabetes Action Canada/Diabetes Canada Joint post-doctoral fellowship award:** This competition occurs in conjunction with Diabetes Canada Annual Research Competitions and is advertised on both the Diabetes Canada and the Diabetes Action Canada websites. The incumbent of this award must demonstrate that their research aligns with the principles of patient-oriented research. This award is adjudicated by Diabetes Canada during their annual competition award process.
- **Patient-Oriented Research (POR) Early Career Investigator Mentorship Awards in Diabetes and its Complications:** This award promotes networking and optimal integration of early career investigators into Diabetes Action Canada and the Canadian diabetes research community. Up to two annual mentorship awards are awarded to early career investigators to work with an internal mentor and an external mentor. The internal mentor must be affiliated at the same research centre as the early career investigator. The external mentor is affiliated with a different research centre from that of the early career investigator. At least one mentor must be a regular member of Diabetes Action Canada.
- **Patient-Oriented Research (POR) Inter-centre Trainee Internship Awards in Diabetes and its Complications:** This award is to promote networking and optimal integration of trainees into Diabetes Action Canada and the Canadian diabetes research community. Up to two annual internships are awarded to trainees. Diabetes Action Canada invites researchers who are PI's or Co-I's of the Network to propose collaborative projects in the areas of diabetes and its complications and for which a trainee will complete his/her training in another laboratory (in another research centre). This project will involve a Diabetes Action Canada Network PI or Co-I with one or more collaborators of another Patient-Oriented Research centre.
- **Quebec Cardiometabolic Health, Diabetes and Obesity Research Network (CMDO) Winter Camp:** This four-day interactive workshop is open to PhD students, postdoctoral fellows, residents and research professionals from Diabetes Action Canada to participate in a Winter Patient-Oriented Research Training Camp (French program). This program offers internationally renowned speakers and participants discussing research in cardiometabolic health, diabetes, obesity, knowledge translation and patient-oriented research.
- **Patient-Oriented Research Training (French and English):** Diabetes Action Canada offers training in Patient-Oriented Research related to diabetes that is continually improved based on participant feedback. This training follows the Patient-Oriented Research curriculum as recommended by CIHR, augmented with interactive and team-building activities. This training is facilitated by both patients and co-investigators and the content includes strategies in patient engagement, team-building and understanding roles within Patient-Oriented Research as well as research design.

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- **Trainee Day:** This session, offered in tandem with the Patient-Oriented Research training and in collaboration with Diabetes Canada prior to the Diabetes Canada Professional Conference, focuses on the skills needed by postdoctoral fellows to transition to independent investigators. In particular, content includes an introduction to Sex and Gender considerations in the design and integration in research with human subjects, patient engagement, knowledge translation and dissemination and tactics for working as a network.
  - **Knowledge Translation (KT) Scholarship Program:** This program is for graduate students and postdoctoral fellows who are supervised by members of Diabetes Action Canada. This scholarship is in partnership with a pan-Canadian consortium of knowledge translation scholars, KT Canada. In 2017-18, two PhD students and two postdoctoral fellows supervised by members of our Network were awarded KT scholarships. Awardees are enrolled in KT Canada monthly meetings where they are having the opportunity to learn from and connect with prominent names in KT research. Also, they will participate in a formal KT research training at the KT Canada Summer Institute 2018, in Toronto.



# Respectful engagement of Indigenous People

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## **Rippling out the Aboriginal Youth Mentorship Program (AYMP) to the inner-city**

Not too long ago it was almost unheard of for a child to develop what has traditionally been an adult onset condition, that of T2D. Yet T2D is the fastest growing pediatric chronic condition, with Indigenous populations among the most affected. In Canada, nearly half of new cases of T2D reported in endocrinology clinics are among Aboriginal youths and this trend is expected to continue unless changes in lifestyles and environments are achieved. Indigenous and Aboriginal health strategies are a top priority of federal and provincial policy makers, as Canadian agencies seek to address concerns articulated in the *Truth and Reconciliation Commission of Canada: Calls to Action*.

Many programs exist to engage youths in activities that promote healthy lifestyles, however not all are suited to the unique needs and traditions of Indigenous Peoples. This is what inspired the development of the Aboriginal Youth Mentorship Program (AYMP). This resilience-based approach to wellness was co-developed with Indigenous youth and leaders in Winnipeg and northern Manitoba along with a group of researchers and community members, currently under the direction of Dr. Jon McGavock from the University of Manitoba.

Delivered by Indigenous adolescents for Indigenous children in their communities, the AYMP builds on the strengths of its participants and helps to create healthy inclusive communities. It is guided by an Indigenous medicine wheel concept of health called the Circle of Courage from Lakota scholar Dr. Martin Brokenleg and consists of four elements: belonging, independence, mastery and generosity.

The program includes after-school peer-led physical activities, healthy snacks, games, and education and leadership activities for elementary school-aged students. Each community has the opportunity to tailor components of the program to meet its own unique needs, teachings and cultural values.

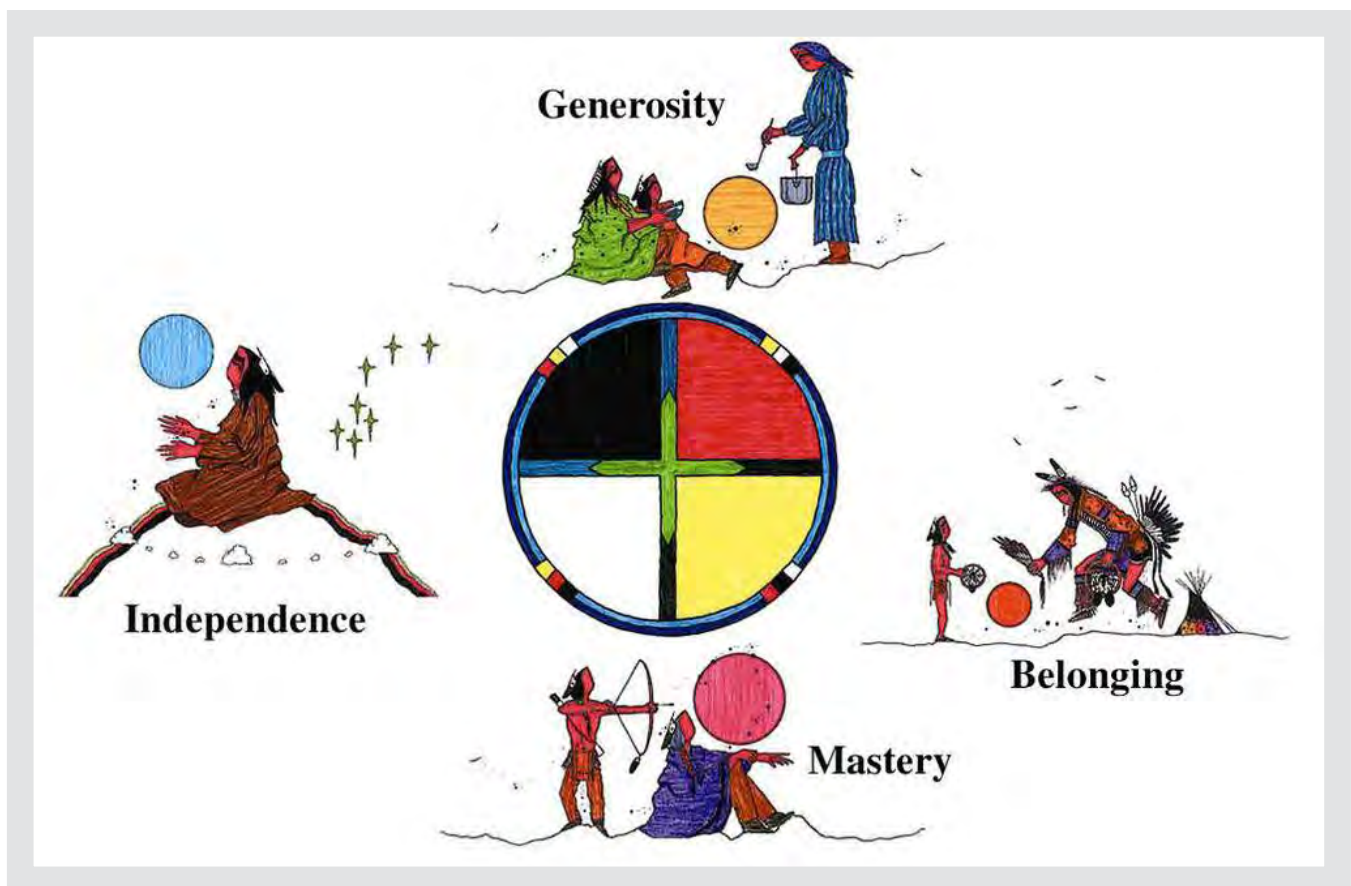
The AYMP is currently offered in 12 Indigenous communities across Canada. Initial results have shown that children and youths that participated in the program experience increased self-esteem, reduced weight gain and healthier dietary choices, compared to those not in the program. Initial evaluation of the program indicated up to a 12 per cent reduction in the incidence of T2D. Given this success, it is the mission of both Diabetes Action Canada and AYMP to ripple out this program more broadly in Indigenous and First Nations communities.

With the help of philanthropic donors, Diabetes Canada and Manulife Financial, we are one-step closer to accomplishing this goal. With the funding received by these partners (\$200,000) we have opened another AYMP site at the First Nations School in Toronto – the first inner-city urban site. Once the effectiveness of this program is evaluated we plan to open additional sites in Northern Ontario in 2018-19. As we plan for the future of AYMP we must consider the challenge of oversight and capacity, as this program is led by part-time youth leaders and volunteers. To sustain this program, the mentorship opportunities and experience of empowerment must continue and resources must be planned accordingly to deliver this program in a manner that encourages continued involvement of its participants and evaluation of outcomes.



Prevention of diabetes and its complications in Indigenous populations is a serious health concern and top priority for our governments and healthcare systems. The unique AYMP relationship-based mentorship approach that encourages culturally sensitive healthy living among children and youth to prevent T2D has meaningful impact related to the Quadruple Aim indicators and addresses a top priority to promote Indigenous health in Canada.

Diabetes Action Canada will continue to work with partners to ripple out this successful program to ensure the Indigenous and Aboriginal Youths are exposed to opportunities to establish healthy lifestyles that will prevent diabetes.



Indigenous medicine wheel concept of health called the Circle of Courage. This model of positive youth development was first described in the book *Reclaiming Youth at Risk*, co-authored by Larry Brendtro, Martin Brokenleg, and Steve Van Bockern. The model integrates Native American philosophies of child-rearing, the heritage of early pioneers in education and youth work, and contemporary resilience research. The Circle of Courage is based in four universal growth needs of all children: belonging, mastery, independence, and generosity.

# Diabetic retinopathy screening: addressing the most common cause of blindness

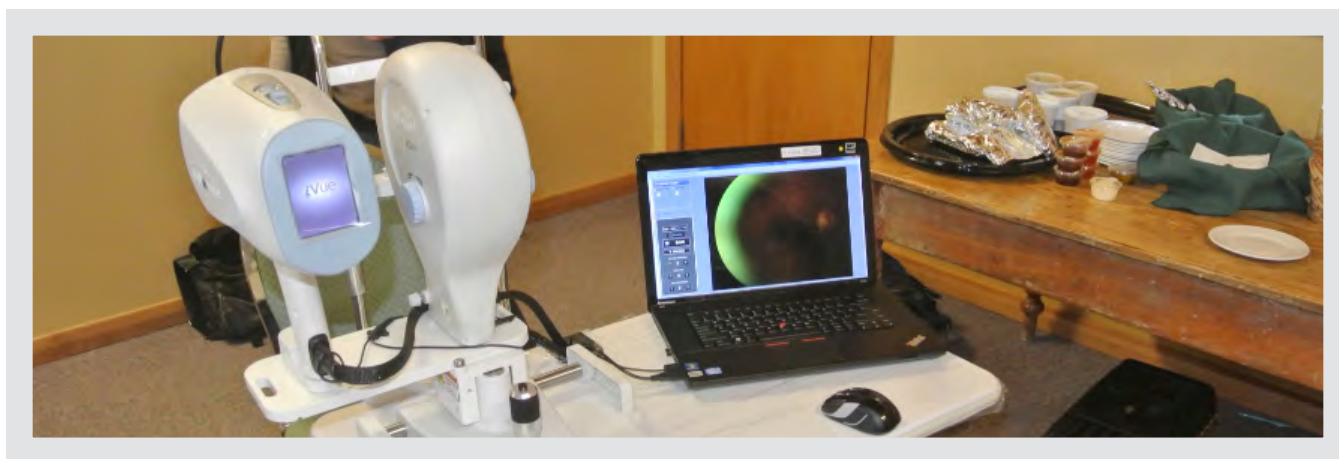
Diabetic retinopathy remains the most common cause of blindness in working age Canadians. The Diabetic Retinopathy Screening group is implementing and evaluating a best practices approach for screening of this disease and early intervention to prevent blindness with high potential to scale-up across provinces.

In partnership with the Ontario Telemedicine Network (OTN), Diabetes Action Canada is working with each Local Health Integration Networks (LHINs) to develop a customized and sustainable program that can integrate into existing regional chronic disease management programs through Community Health Centres (CHC), Family Health Teams, Diabetes Education Programs and other services.

Dr. Michael Brent (University Health Network and University of Toronto), the national co-lead for our Diabetic Retinopathy Screening Goal Group, has developed a screening program with expert technologists at OTN to establish screening in inner city and remote communities with high prevalence of diabetes. The program has been deemed a priority project across all Ontario LHIN's and provides an excellent example of increasing accessibility for equity of care and scale-up potential for this program in other provinces and Territories.

In British Columbia, our Retinopathy Screening Goal-Directed Program, co-lead Dr. David Maberley (University of British Columbia), is establishing pragmatic evaluation of two new screening sites, one in the remote Bella Bella Heiltsuk First Nation community and one in east side downtown Vancouver. These will be highly valuable sites for modeling effective community-based diabetic retinopathy screening and the role of Diabetes Action Canada is to evaluate outcomes related to blindness prevention and cost saving for the healthcare system.

Diabetes Action Canada and OTN are also exploring collaborations with the Canadian National Institute for the Blind (CNIB) Mobile Eye Care van. This van serves over 30 communities in Northern Ontario and provides diagnostic and intervention services in eye care, as well as education to local health professionals. By collaborating with CNIB, Diabetes Action Canada has an opportunity to advance Indigenous community-based diabetic eye services in remote and under-represented areas.



Imaging equipment used of tele-ophthalmology diabetic retinopathy screening. Image captured by Dr. Michael Brent on site of a remote screening location.



## **Expanding diabetic retinopathy screening in Canada using artificial intelligence: a new collaboration supported by Diabetes Action Canada, the University of Montreal and the Montreal Polytechnique**

Diabetic retinopathy (DR) is a complication of diabetes that accounts for 80 per cent of diabetic-related blindness. Early detection of DR by regular screening effectively avoids vision loss from diabetes as necessary treatments prevent irreversible retina damage.

Diabetes Action Canada recognizes retinopathy screening as a top priority. This prevention measure is shared amongst provincially funded telehealth and health authorities that are establishing screening programs to reach under-served and vulnerable populations. Telehealth retinal screening programs have the potential to scale-up as part of a broader population-based screening program. To accomplish this, diagnostic capacity constraints among Canadian ophthalmologists must be considered. To address this, Diabetes Action Canada is now collaborating with a group of investigators at the University of Montreal, Department of Ophthalmology and the Montreal Polytechnique, who collaborate with the Montreal Institute for Learning

Algorithms (MILA). MILA is a federation of University of Montreal researchers focused on machine learning and artificial intelligence-based analytics.

With funding from Diabetes Action Canada and the University of Montreal, these investigators are now developing algorithms using advanced technology to read retinal fundus photo images and optical coherence tomography (OCT) images for diagnosis of diabetic retinopathy and other eye disease. The fundamental goal is to improve access to high quality ophthalmological care by reducing image reading times and increasing clinician productivity.

Together, Diabetes Action Canada and University of Montreal are interested in investigating the role of artificial intelligence in retinal image analytics and its potential for application in clinical contexts in Canada and beyond. Following algorithm development and validation, this group envisions creating a national consortium that could leverage advanced technology to deliver high-value retinal and OCT image analysis across Canada.

This research collaboration was recently featured in an article in *Le Journal de Quebec*, found [here](#).

# Diabetes Action Canada supports innovative clinical research to improve treatment of T1D

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The Innovations in Type-1 Diabetes (iT1D) Goal-Directed Program is currently conducting six clinical trials with a team of 13 principal investigators and co-investigators from three provinces – Ontario, Quebec and Manitoba – investigating innovative therapies to treat and improve the lives of those living with T1D. The Program co-leads are Dr. Bruce Perkins (University of Toronto) and Dr. Peter Senior (University of Alberta). These studies include patient-oriented research studies evaluating new therapies in diabetic neuropathy, artificial pancreas, adjunct drugs and immunotherapies. This year, the iT1D Research Program was able to participate in a first of its kind CIHR SPOR Innovative Clinical Trial (iCT) multi-year operating grant competition, with funding matched by the JDRF. This competition not only focused on designing innovative clinical trials to reduce the burden of continual self-management of persons with T1D, but also had a large emphasis on patient engagement in designing these trials with outcomes that will be accessible, manageable and directly applicable to their direct health concerns. Of the eight applications that went forward in this competition, three were funded to a maximum of \$3,000,000 over four years. Diabetes Action Canada co-investigators Dr. Gillian Booth and Dr. Remi Rhabasa-Lhoret were among the awardees, as well as Dr. Farid Mahmud from the Can-SOLVE CKD SPOR Network. Below is a brief description of each study.

## **EVALUATING INNOVATIVE HEALTH CARE SOLUTIONS TO IMPROVE OUTCOMES FOR PERSONS WITH TYPE 1 DIABETES USING A NOVEL ELECTRONIC DATA REPOSITORY**

Dr. Booth and her team propose a clinical trial testing a novel electronic delivery of health care and related support services to people living with T1D in addition to usual care including frequent, brief virtual visits with their diabetes care team to share and discuss blood glucose patterns, diabetes self-management, coping strategies, personalized goals and action plans. This intervention will also have structured online educational courses, tools and supports. These virtual

visits will use video conferencing technology that can be securely accessed free of charge from any personal device (PC, tablet, smart phone).

## **BEHAVIORS, THERAPIES, TECHNOLOGIES AND HYPOGLYCEMIC RISK IN TYPE 1 DIABETES: THE BETTER STUDY**

Dr. Rhabasa-Lhoret and his team will examine better strategies to reduce episodes of hypoglycemia. This includes an online educational strategy to help patients wearing medical devices to monitor blood glucose levels in real time to optimize functionality of these devices. This study has also developed a peer-to-peer discussion forum to offer social support and personal strategies to reducing hypoglycemia.

## **ADOLESCENT TYPE 1 DIABETES TREATMENT WITH EMPAGLIFOZIN FOR HYPERGLYCEMIA & HYPERFILTRATION TRIAL, “ATTEMPT” TRIAL**

Dr. Mahmud and his team are examining the effects of a group of medications, called sodium glucose co-transporter two inhibitors (SGLT2i) in teens with T1D. These medications have previous evidence of success in adults with T2D to improve diabetes control and prevent long-term kidney and heart issues due to high blood glucose levels.

All of these studies were co-developed with patients and directly address the concerns articulated by those living with T1D. Diabetes Action Canada is thrilled to be collaborating with each of these investigators. As research synergies and new collaborations emerge, Diabetes Action Canada is designing a digital health platform to support these research studies. In particular, the Innovations in the T1D Goal-Directed Program will be forming a Steering Committee to establish a framework for planning and implementing a T1D Registry to assist in implementation of these clinical trials. The core purpose of the T1D Registry is to facilitate timely and effective recruitment of subjects to clinical trials, while enhancing communication with individuals living with T1D on current clinical trials and how to participate.

# Sex and gender improves the health and quality of clinical research

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Men and women differ in their experience of health, access to health care and response to therapies such as drug interventions. In addition, there is great diversity among the Canadian population that can affect interactions with our healthcare systems. These include, but are not limited to, education, socio-economic status, geographic location, ethnicity, etc. Understanding these differences, whether they be physiological, behavioural or circumstantial, can increase the relevance and adoption of research outcomes and result in better healthcare delivery models that will benefit Canadians living with diabetes.

The relevance of sex and gender is now a core element in all of our Diabetes Action Canada research activities. In our Network we have established a “sex and gender facilitator” model, whereby research programs designate one member of their group to be the point-person for regular communication with the Sex and Gender Program, co-led by Dr. Paula Rochon and Dr. Robin Mason (University of Toronto) at the Women’s Xchange (SPOR SUPPORT Unit). This group has also developed a novel tool entitled, *Essential Metrics for Assessing Sex & Gender Integration in Health Research Proposals Involving Human Participants*, that can assist researchers in assessing the role and relevance of sex and gender populations in their research studies. By understanding the roles of sex and gender in shaping health experiences, researchers can understand how different populations will be affected by their study outcomes.

The Sex and Gender Program within our network enhances the integration of sex and gender considerations throughout all research processes and products of Diabetes Action Canada and builds capacity of the Diabetes Action Canada research team members to integrate sex and gender in their research activities. To create a robust program in sex and gender, this team is working to establish an integrated program across all Diabetes Action Canada Research Programs to ensure consideration of equality, sex and gender in every study design. Already this group has reviewed and provided feedback on 11 new grant applications directly related to Diabetes Action Canada.

Ultimately, the approach of integrating sex and gender into our research activities will be evaluated and used to understand and measure the overall impact of our Network as applied to reducing inequality in health systems and population research.

# Knowledge Translation: moving research into practice

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The Knowledge Translation (KT) Goal-Directed Research Program, under the co-leadership of Drs. Sophie Desroches and France Légaré (University of Laval), has established an integrated program with Diabetes Action Canada to facilitate the application of research findings into healthcare practices. The goal is to facilitate the support for new models of care that will result in better outcomes and better experience for individuals living with diabetes at reduced cost.

To date, our KT team has assisted our researchers in evaluating the potential to scale-up their successful evidence-based products. Some examples of our KT research program in action are below:

1. Our newly formed Research Program in Aging, Community and Population Health Research has 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.
2. Our Digital Care team has worked with our KT team to enable Quebec-based primary care data from the Canadian Primary Care Sentinel Surveillance Network to populate our proof-of-concept National Diabetes Repository.
3. Our Diabetic Retinopathy Goal-Directed Program has used the expertise of our KT program to identify and understand barriers faced by ethno-cultural minorities with a high risk of diabetic retinopathy face in our health care system and enablers to overcome these barriers.

Our KT Research Program is also working collaboratively with our Patient Partners, to conduct an environmental scan of the KT tools available across Canada relevant to Diabetes Action Canada activities. The goal is to create a 'KT toolkit' of existing evidence-based approaches in diabetes care for dissemination to physicians and health care professionals to standardize improved care. This is being done in close collaboration with investigators who were engaged in the development of the 2018 Diabetes Canada Clinical Practice Guidelines and has the potential in informing the Diabetes Canada initiative for developing a National Diabetes Strategy. This team is also creating a research plan for analyzing the impact of networking (internal and external) within Diabetes Action Canada. This will provide tangible evidence of the impact of our research Network and how we have help to prevent diabetes complications.

# Diabetes Action Canada's annual workshop informs how to enable effective care paths

On May 3-5th, 2018, members of Diabetes Action Canada, including patients, partners, researchers, clinicians and staff assembled for an intensive planning-based workshop to ensure that our programs and research activities are truly addressing the needs of those living with diabetes.

On the first day of this event, a Patient-Oriented Research (POR) Training session was offered for our Patient Partners and Members. Among the attendees were Dr. Gary Lewis, the co-Scientific Lead for the Network; Dr. Jan Hux, President of Diabetes Canada; and Dr. Diane Finegood, Diabetes Action Canada Steering Council member. This POR Training Session was an opportunity to develop a common understanding of patient engagement in health research and how research teams can successfully engage diverse stakeholders. This training followed the curriculum content prepared by CIHR in Patient-Oriented Research focused on building capacity. The participants experienced many hands-on activities to illustrate patient-oriented research concepts, how to effectively share their research interests and build trusting relationships.

On May 4th, the workshop began with a welcome by our Steering Council Chair Dr. Malcolm King, and an opening ceremony was given by Spiritual Elder Mr. Garry Sault. The theme for this year's workshop was *"Enabling Effective Care Paths for People Living with Diabetes"*. Five of our Goal Group leads facilitated breakout sessions to discuss the potential impact of the projects underway and those in the planning stages.

With our research activities happening across the country, these breakout sessions brought Patient Partners, collaborators and sponsors together to interact and strategically plan for next steps in designing healthcare solutions that address the diverse needs of those living with diabetes.



Above: Dr. Jean-Pierre Després, Maureen O'Neil (keynote speaker), Dr. Catharine Whiteside and Dr. Gary Lewis. Below: Drs. Jenny Ploeg and Maureen Markle-Reid for the Aging, Community and Population Health Goal-Directed Program.



On May 5th, the Goal Group Leads, including Patient Partner Co-leads, reported on the outcomes of the breakout sessions. Important advice was received and will assist in directing the direction and aims of our Diabetes Action Canada activities.

We were pleased to welcome Maureen O’Neil, President of the Canadian Foundation of Healthcare Improvement (CFHI), who honoured us with a spectacular keynote address. Maureen opened with a description of how the CFHI developed a community-based INSPIRED Chronic Obstructive Pulmonary Disease (COPD) Collaborative. This program required patients, strategic partners and government agencies to successfully scale-up community-based care across Canada to meet the needs of those living with COPD. This was followed by an interactive session in which workshop participants posed questions to Maureen relevant to Diabetes Action Canada projects.

Provocative and informative discussion followed about the importance of understanding the needs of patients with chronic conditions to improve their self-management and optimize community-based resources. Strategic partnering and scaling up effective care paths were key points of interest.

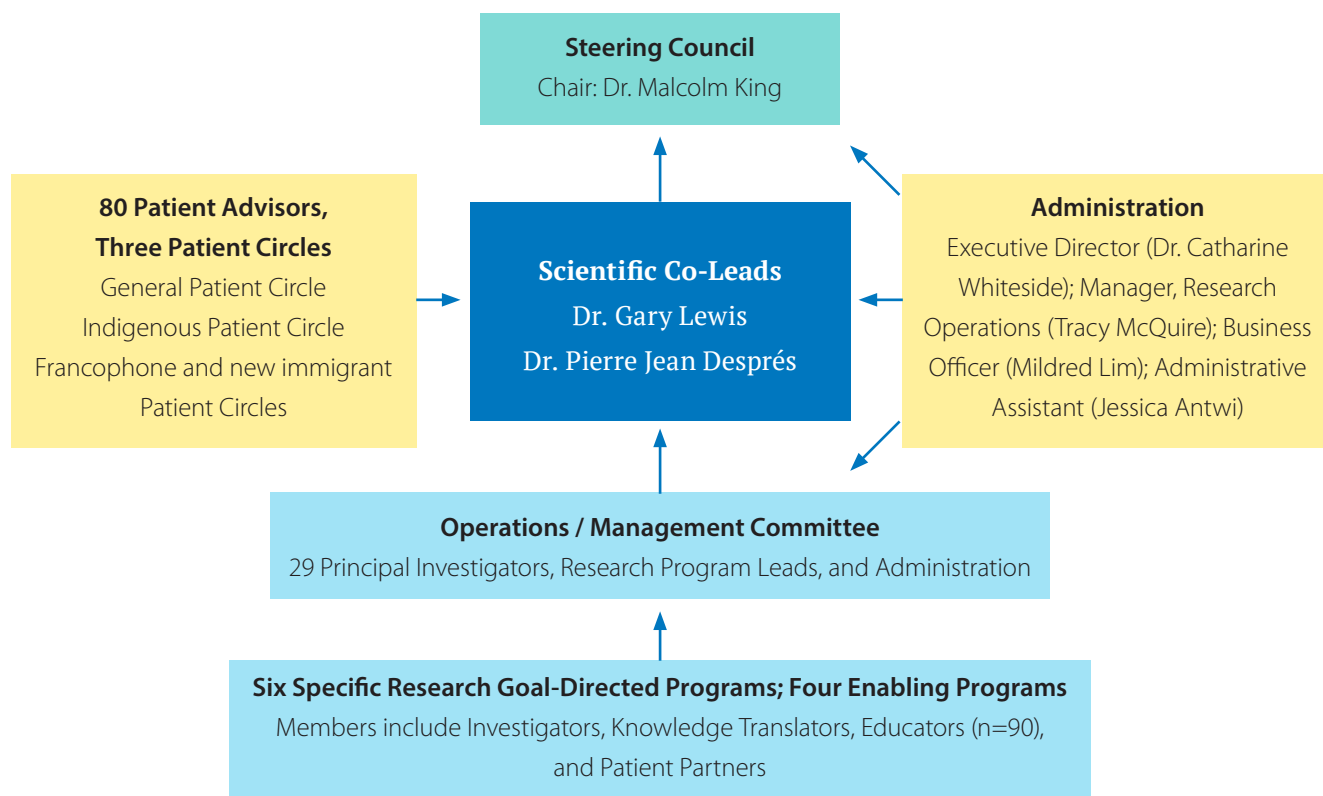
A detailed report from our Annual Workshop will be available by the end of June 2018 and published on our website. We have also scheduled next year’s Annual Workshop from May 31-June 1st, 2019, so mark your calendars!



Diabetes Action Canada Project Coordinator team. Pictured front left to back right: Pusha Sadi, Tracy McQuire, Conrad Pow, Mary Zettl, Olivera Sutakovic, Michelle Murray, Adriana Freitas, Helena Medeiros, Jessica Antwi and Mildred Lim.



# Governance



Diabetes Action Canada has instituted a robust governance structure that guides all of our research activities and management, summarized above. The **Steering Council** is the highest level of governance, comprised of patient partners, healthcare providers, strategic partners and Network researchers. It ensures all Network activities align with our Mission. Our Steering Council meets quarterly and makes final decisions on Network membership, Research Program proposals and business plans. 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 to scale successful research projects, and spending and funding commitments 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.

All of the Research Program Leads and Principal Investigators form our **Operations and Management Committee**. 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, 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.

# List of funding partners

## Sponsors of match cash and in-kind for 2017-18\*

SPONSOR	MATCH CASH	MATCH IN-KIND
Alliance sante Quebec	\$220,000	<b>\$30,000</b>
AstraZeneca	\$150,000	
Bayer	\$200,000	
Caprion Proteome	Withdrawn	<b>\$80,391</b>
Cardiometabolic Health, Diabetes and Obesity Research Network (CMDO)	\$100,000	
Centre de formation medicale Nouveau-Brunswick (CFMNB)	\$55,000	
Centres de recherche – Univesité de Sherbrooke	\$200,000	
Centre for Global e-Health		<b>\$50,000</b>
CIUSSS-CN		<b>\$24,876</b>
The Koschitzky Family (iT1D)	\$50,000	
Diabetes Canada	\$200,000	
Children's Hospital Research Institute of Manitoba (DREAM)		<b>\$445,149</b>

\* Listed here is the one-year sponsorship detail of our five-year program. List continues on the next page.

### Sponsors of match cash and in-kind for 2017-18, cont'd

SPONSOR	MATCH CASH	MATCH IN-KIND
Foundation for Fighting Blindness		<b>\$95,000</b>
Heart and Stroke Foundation	\$91,356	
H&S/Richard Lewar Centre of Excellence in Cardiovascular Research	\$250,000	
Inst de Recherches Cliniques de Montreal	\$1,429,304	
Juvenile Diabetes Research Foundation (JDRF)	\$240,000	
Merck	\$200,000	
Michael Smith Foundation for Health Research	Withheld	
New Brunswick Health Research Foundation (NBHRF)	\$75,000	<b>\$100,000</b>
North York General Hospital		<b>\$28,541</b>
Research Manitoba	\$318,066	
Sun Life	\$200,000	
University of Toronto – Department of Family & Community Medicine		<b>\$95,924</b>
University of Toronto – Department of Medicine	\$100,000	
Wolfond Chair in Digital Health		<b>\$100,000</b>
TOTAL:	<b>\$4,018,726</b>	<b>\$1,049,881</b>

# Funding disbursements

## Breakdown of funding disbursements and allocation in 2017-18

INSTITUTION	DISBURSEMENT OF CIHR FUNDS IN 2017-18	MATCH FUNDS (RESTRICTED & UNRESTRICTED)	IN-KIND
Laval University	\$532,860	\$321,220	\$54,876
University Health Network	\$973,882	\$932,218	\$245,000
University of British Columbia	\$133,750	-	-
University of Manitoba	\$235,566	\$235,566	\$445,149
University of Sherbrooke	\$213,144	\$370,000	\$180,391
University of Toronto	\$459,561	\$416,935	\$124,465
Women's College Hospital	\$48,150	\$26,850	-
First Nations Health & Social Secretariat of Manitoba	-	\$230,000	-
Institute de Recherches Cliniques de Montreal	-	\$1,429,304	-
TOTAL:	\$2,596,913	\$3,962,093	\$1,049,881

## Breakdown of funding disbursements and allocation in 2017-18

GOAL GROUP	2017 -18 ADJUSTED PLANNED	2017-18 ACTUAL	2017-18 VARIANCE
Knowledge Translation and Patient Engagement	\$1,464,841	\$1,408,145	\$56,696
Training and Mentoring	\$374,118	\$189,351	\$184,767
Digital Health for Diabetes Research and Care	\$1,786,042	\$1,624,805	\$161,237
Diabetic Retinopathy	\$622,435	\$424,422	\$198,013
Innovations in Type 1 Diabetes	\$450,588	\$464,117	-\$13,529
Indigenous Peoples Health	\$161,900	\$170,006	-\$8,106
Sex and Gender	\$75,000	\$32,083	\$42,917
Governance and Administration	\$661,210	\$683,616	-\$22,406
TOTAL:	\$5,596,134	\$4,996,545	\$599,589

# Contact us

For more information, please contact:

## **Diabetes Action Canada**

Toronto General Hospital  
200 Elizabeth Street  
Eaton Building, Room 12E242  
Toronto, Ontario M5G 2C4 Canada

T: 416-340-4800 x2522

E: [info@diabetesaction.ca](mailto:info@diabetesaction.ca)

[www.diabetesaction.ca](http://www.diabetesaction.ca)

Twitter: [@\\_DiabetesAction](https://twitter.com/_DiabetesAction)

LinkedIn: [diabetesactioncanada](https://www.linkedin.com/company/diabetesactioncanada)

