

Diabetes Action Canada

Preventing complications.
Transforming lives.



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Canadians with Diabetes

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Director's Report

As Diabetes Action Canada 2.0 is launched, we are pleased to look back at the successes of the previous year and the overall impact of our SPOR Network to date. These accomplishments have paved the way for an exciting 2022/23.

Our research teams and Patient Partners had their work published in peer-reviewed journals, we received funding to continue our training and mentoring programming, and our National Diabetes Repository supported multiple research studies to improve outcomes for people living with diabetes.

In addition, we are proud of the multiple podcasts, webinars and other outreach materials our teams produced to help better inform our community about topics of importance to them.

In 2021/22, we supported a novel project that engaged pancreatic islet scientists with Patient Partners. The subsequent publication was an example of how researchers working in basic science fields can engage meaningfully with persons who have lived experience of diabetes to create valuable, peer-reviewed research projects. We endeavour to encourage and facilitate more of these types of collaborations.

Our Network also worked closely with Diabetes Canada and JDRF Canada, along with many other stakeholder organizations on a National Framework for Diabetes, ensuring the voice of our members was represented in discussions and planning. With this new Framework recently launched by the Federal Government, we will continue to advise and contribute to its implementation within the provinces and territories.

We are so proud of all our Network members for their accomplishments in the past year and thrilled to continue bringing important advances in diabetes management and care to all Canadians who need them.



Tracy McQuire
Executive Director



Gary Lewis
Co-Scientific Lead



André Carpentier
Co-Scientific Lead

Tracy McQuire

Gary Lewis

André Carpentier

Diabetes Action Canada at a Glance in 2021/22

97 Patient Partners from across Canada



120

Investigators from across Canada



27 plain-language publications

19 peer-reviewed publications



18 conference or symposia presentations

Diabetes Action Canada 2.0 Launches!

Diabetes Action Canada's next phase is launching, with exciting new programs and plans that will take the learnings from the last six years and begin the process of implementing them to improve health outcomes.

This second stage is made possible thanks to a new round of funding from the Canadian Institutes for Health Research (CIHR) and matching funds from our partner organizations across the country. This continued support for Strategy for Patient-Oriented Research (SPOR) Networks like ours will allow us to continue to connect patients with lived experience with researchers, health professionals and health system decision-makers across Canada.

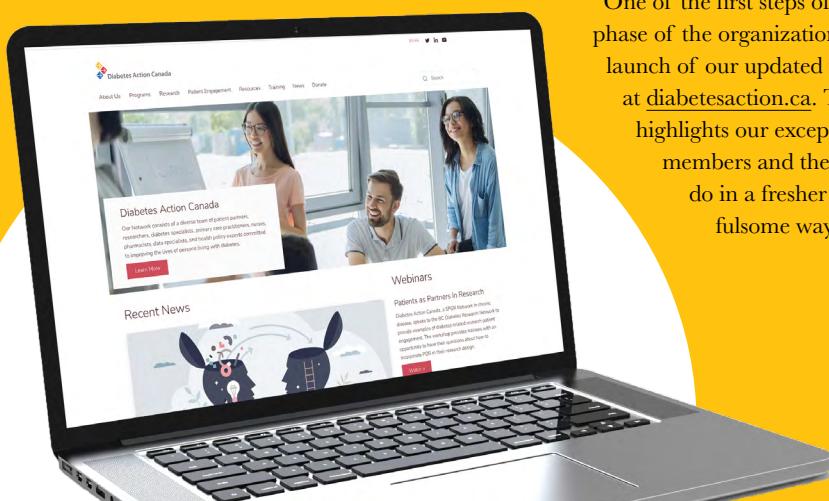
"Diabetes Action Canada 2.0 is an important next step for our organization," says Executive Director, Tracy McQuire. "This funding will allow us to scale the findings we've made and work with our partners to create sustainable, long-term programs."

In phase one, Diabetes Action Canada laid the groundwork for success. Projects funded and supported by the Network helped improve access to screening for diabetic eye disease and foot ulcers. These initiatives have the potential to reduce the complications of diabetes, including vision loss and amputation. The organization also developed the National Diabetes Repository, which provides researchers with access to health care data that can be mined for critical information about the needs of Canadians living with diabetes and ways to improve access and care. Other programs focused on increasing support for older adults with diabetes and reducing diabetes risk for Indigenous populations.

Phase two of Diabetes Action Canada's strategic plan has an emphasis on knowledge translation and mobilization, as well as digital and data-driven solutions, community and population-based surveillance, mental health support and increased access to health care services for those from marginalized groups. In addition, Diabetes Action Canada will focus more resources on support for policy change, including work already underway to develop a National Diabetes Strategy for Canada.

"For the Diabetes Action Canada research community and in particular our Patient Partners, making sure the organization's work moves beyond the lab is a critical step to improving the lives of people living with diabetes," says Dr. Gary Lewis, Co-Scientific Lead for Diabetes Action Canada. "We look forward to working with all of our Network members to bring real and actionable change to those in our diabetes community."

One of the first steps of our new phase of the organization is the launch of our updated website at diabetesaction.ca. The site highlights our exceptional members and the work they do in a fresher and more fulsome way!



Welcome Dr. Cindy Bell

We are thrilled to welcome Dr. Cindy Bell as the new Chair of our Steering Committee. Dr. Bell is an accomplished scientist and the parent of two daughters with type 1 diabetes. She has been an advocate and ally for the diabetes community for more than thirty years.

Dr. Bell was the Canadian lead on the establishment of the first Medical Research Council of Canada - JDRF partnership in the mid-1990s. This partnership funded two cycles of projects in Canada, including work on the Edmonton Protocol. In addition, she and her husband have organized multiple golf tournaments in partnership with JDRF to raise research funds.

As a scientist, Dr. Bell also brings a research lens to her role with Diabetes Action Canada. She retired from her role as Executive Vice President, Corporate Development with Genome Canada in 2021, after more than twenty years in leadership roles with the organization. There, she was responsible for providing policy and strategic advice on scientific and other aspects of Genome Canada's programs, including overseeing and managing the peer review process used to establish research programs.

MAJOR publications

In 2021-22, Diabetes Action Canada researchers published multiple peer-reviewed papers based on their work with the Network, many with Patient Partners as co-authors. This work highlights the value of having those with lived experience as a meaningful member of research teams.

There were two key publications identifying the barriers and enablers to diabetic retinopathy screening in Canada for new immigrants and women of low socioeconomic status. These publications have led to follow-up studies including one identifying gaps in patient access to diabetic retinopathy screening, and a successful CIHR Project Grant to develop culturally competent tele-retinal programs that will support newcomers to obtain the screening they need to prevent vision loss.

As part of our Indigenous People's Health Program, a study was done on the barriers and enablers to providing care to Indigenous people living with diabetes. This provided concrete recommendations about improving diabetes care in a culturally respectful way. In addition, the anti-racism training program for healthcare providers, developed by Dr. Barry Lavallee, is currently being piloted in Manitoba.

Exciting new Diabetes Action Canada-supported research from the Drs. Bruce Perkins and Ahmad Haidar labs was published in *Nature Medicine*. This project looks at how combination medical therapy could have the potential to improve blood glucose control and the performance of an artificial pancreas. The paper, “Empagliflozin add-on therapy to closed-loop insulin delivery in type 1 diabetes: a 2 × 2 factorial randomized crossover trial” can be accessed on the *Nature Medicine* Website.

Other exciting publications!

Our Aging, Community and Population Health team published their paper: *Engagement of older adults with multimorbidity as patient research partners: Lessons from a patient-oriented research program*. In the *Journal of Multimorbidity and Comorbidity*.

The research paper shares the five challenges the team, led by Dr. Maureen Markle-Reid, learned from working with older adult partners throughout the research process. These were:

- actively finding patient partners who reflect the diversity of older adults with multimorbidity;
- developing strong working relationships with patient partners;
- providing education and support for both patient partners and researchers;
- using flexible approaches for engaging patients, and;
- securing adequate resources to enable meaningful engagement.

In January, Dr. Charles de Mestral and his team have a new paper in the JAMA Network Open journal. The paper, *A Population-Based Analysis of Diabetes-Related Care Measures, Foot Complications, and Amputation During the COVID-19 Pandemic in Ontario, Canada*, looks at the care of 1.4 million Ontarians living with diabetes during the pandemic versus before. The team aimed to clarify the impact of the pandemic on rates of diabetic foot ulceration and amputation, as well as diabetes care measures that influence amputation risk. Using data for the whole province of Ontario, available from ICES, De Mestral's team found that the outcomes were not as negative as data from other countries had suggested.

In February, BMJ Open Ophthalmology published a paper by Diabetes Action Canada researchers: *Diagnostic accuracy of teleretinal screening for detection of diabetic retinopathy and age-related macular degeneration: a systematic review and meta-analysis*. The paper, which looks at the diagnostic accuracy of teleretinal screening for the detection of diabetic retinopathy and age-related macular degeneration (two of the most common retinal diseases seen in most North American clinical practice), was part of a research project led by Dr. Tina Felfeli.

Diabetes Action Canada researchers Drs. Alanna Weisman, Gillian Booth and Bruce Perkins, working with medical student Cimon Song, used our National Diabetes Repository to study the differences in terms of coverage for diabetes technologies, like insulin pumps and continuous glucose monitors, it is important to know if access and uptake are related. Their paper, *Impact of government-funded insulin pump programs on insulin pump use in Canada: a cross-sectional study using the National Diabetes Repository*, was published in *BMJ Open Diabetes Res Care*.

Islet Biologists Work with Patient Partners on New Research

While the involvement of people living with diabetes has become a critical and effective part of the research process in recent years, it is still not the norm in basic or fundamental research. This is the sort of lab-based research that looks at the physiological aspects of diabetes, such as cells and genes. For many researchers in this area, it was unclear how lived experience could play a part in their process.

This is starting to change, and a recent publication led by Dr. Rob Screamton at Sunnybrook Research Institute is showcasing the important role of those with lived experience in basic science projects.

The idea for this project was conceived at the Canadian Islet Research and Training Network Islet Biology course at the University of Toronto in the summer of 2021. It was spearheaded by students, who developed a review of the islet and diabetes research done during the pandemic. What made this process unique was how the research team consulted Diabetes Action Canada Patient Partners to learn from their perspectives about islet research and how they understood progress in the field.

In addition, the team wrote the entire review in both an academic version and one that used lay terms and was easy to understand by those in the public.

“There were several real positives associated with partnering with people living with diabetes on this islet biology literature review,” says Screamton.

“How to incorporate patient perspectives into bedside research that involves patients directly, in tangible ways, is relatively straightforward, but how to engage patients in fundamental research has so far lacked a roadmap. In this project, we were able to inform patients about current research and gain their perspectives on what was most meaningful to them. A strong message we heard was that the use of stem cells as a potential therapy was met with trepidation.”

Screamton and all of the team members were impressed with the level of interest and valuable insights that participants brought to the table. He felt it was a good opportunity to showcase ways in which these types of collaborations can be valuable to basic science. “This project, starting with a review of the current literature, has opened up many new and exciting partnership opportunities between researchers and Patient Partners, to allow for the translation of knowledge and for underlining the critical importance of fundamental research to finding new therapies and cures,” he says.

“One idea that emerged was that perhaps all scientific publications, in addition to a scientific summary and even graphical abstracts, both current standards, should also have a lay summary. Written by the scientific authors in partnership with people affected by the disease in question, this would help communicate not only the exciting research results but also its significance and potential importance to people affected by the disease. The thirst for knowledge is not just in the researcher population – it’s in the populations of people living with or affected by disease as well.”

The paper is open access and available now [on the website of the Canadian Journal of Diabetes](#).



Funding Success

In 2021/22 Diabetes Action Canada received funding support or funded projects in collaboration with multiple partners. This type of cooperation ensures that effective projects continue to move forward to better support the diabetes community.

Funding Highlights:

As we move into phase two of Diabetes Action Canada, the Network has a clear goal of translating the research and learnings from our first phase into understandable and implementable deliverables that aim to better support those living with diabetes in Canada. To further this, we are pleased to announce funding support from Diabetes Canada for our *Mobilizing Knowledge and Implementing Equitable and Cost-Effective Health and Social Care Services for Persons Living with Diabetes in Canada* project.

Our Digital Health Solutions for Learning Health Systems program received a Data Champions Pilot Project Grant from the Digital Research Alliance of Canada. This grant will support the ongoing work of our team as it looks at ways to use health data to improve outcomes for people living with diabetes.

Diabetes Action Canada member Dr. Bruce Perkins and his collaborators were awarded a Diabetes Canada End Diabetes: 100 Award. Their project, which will incorporate Patient Partners at all levels, looks at ways to reduce and prevent diabetic ketoacidosis (DKA) in type 1 diabetes. The research team will work to identify factors that may increase the risk of DKA, define ways that people with diabetes can mitigate DKA and then create an educational tool to help increase awareness around factors that can reduce risk. The team will then test the tool to ensure it is effective and helpful. Diabetes Action Patient Partner, Doug Mumford, will be a co-lead on the project.

On the pages that follow, we highlight other exciting new funding and how it will support Diabetes Action Canada priority areas, including the complications of diabetes, training and mentoring the next generation and mental health.



New Funding Highlights the Importance of Patient-Oriented Research

In late November, the Canadian Institutes for Health Research (CIHR) announced new funding for its Team Grant: Diabetes Mechanisms and Translational Solutions as part of the organization's 100 Years of Insulin program. Alongside CIHR co-funders Diabetes Canada, JDRF Canada and Kidney Foundation of Canada, exciting new research programs were announced. Among them, were several with a clear focus on patient-oriented research and where the teams worked with Diabetes Action Canada Patient Partners on their grant applications.

The SUGARNSALT Team Grant looks at "Sodium glucose co-transport-2 inhibition diabetes and kidney function loss in type 1 diabetes". The team is being led by Dr. David Cherney from UHN Research and includes co-investigators Dr. Bruce Perkins, Dr. David Campbell and Dr. Anita Layton – all of whom are Diabetes Action Canada researchers.

"Patient partners have been involved from the beginning to include trial components that are relevant to their experiences," explains Cherney.

"We have included components of the trial that are meaningful to them, including measures of kidney function, and also included an entire aim related to patient preferences and reported outcomes. We will also be meeting on a regular basis to make sure our methods and approaches remain patient focused."

Led by Dr. Patrick MacDonald from the Alberta Diabetes Institute, a second funded project looks at "A deep phenotyping network for understanding human islet variation in health and diabetes". For their application, the team brought together members of the Diabetes Action Canada Collective Patient Circle to ensure the work met the needs of those living with diabetes.

"We appreciate this funding from CIHR, INMD and JDRF, and the support we received from Diabetes Action Canada and their Collective Patient Circle for input and guidance as we developed this program," says MacDonald. "Our project seeks to build a cellular and molecular atlas describing pancreatic islets in both health and disease, with a goal of making this resource available to answer many questions from the broader scientific and health communities. Interaction with Diabetes Action Canada, and engagement through a patient focus group, taught us much about the kinds of questions and the sources of data that are important and also about how we can better integrate patient feedback with our program going forward. We will continue to develop these important interactions to help bridge gaps between cellular work on islets and the needs of the community."

Having received ongoing support from Diabetes Action Canada, to develop a data-informed diabetic retinopathy screening approach in Ontario led by Drs. Valeria Rac and Michael Brent from UHN Research, Dr. Rac received a team grant for the project "Preventing vision loss from diabetic retinopathy: Guiding primary care diabetic retinopathy screening in Canada through the use of provincial healthcare administrative data", launched in BC, AB, NL and ON."

The only team to have a Patient Partner listed as a Principal Investigator, the group has benefitted greatly from the inclusion of Debbie Sissmore, who lives with vision loss due to diabetic retinopathy, and her husband, Malcolm. During the application process, this team learned from focus groups of Patient Partners, facilitated by Diabetes Action Canada, about the need for a more systemic approach to the prevention of diabetic retinopathy.

"Our Team Grant application had a very holistic approach to engaging Patient Partners," says Dr. Valeria Rac. "The insights gained from Debbie and Malcolm Sissmore and our focus group fully guided our application. In line with the Diabetes Action

Canada approach, we wanted to make sure that patients' perspectives and needs were at the forefront, and we will continue to do that throughout our diabetic retinopathy screening project."

"We must find a better way to be able to move quickly and not wait on bureaucracy while there are eyes out there than are going blind and that can be prevented if retinopathy is detected early enough for treatment," say the Sissmore's who are committed to working to improve outcomes for those at risk of developing diabetic retinopathy.

Led by Dr. Bruce Verchere at the University of British Columbia, the fourth funded team is looking at "Immunometabolism in diabetes: harnessing metabolic crosstalk between islets and immune cells for therapy". They drew on the input from the Collective Patient Circle, and Diabetes Action Canada facilitated focus groups as they designed their application, and found the experience extremely valuable.

"One hundred years since the discovery of insulin by Canadian researchers, there is no cure. And just what is a 'cure'? In a patient engagement session in partnership with Diabetes Action Canada, our team learned from T1D patients and caregivers what a cure meant to them," says Verchere. "For most, they wanted to be free of the constant disease burden; one patient described, 'to live a life that looks like anyone without diabetes; no devices, no insulin, no complications, no anxiety. Our team learned the urgency to move research forward and the importance of communication findings to all.'

Diabetes Action Canada is thrilled to see patient-oriented research at the core of so many of these funded projects and looks forward to working with each team as they move forward to ensure the needs of those living with diabetes are front and centre.

Diabetes Action Canada Training and Mentoring Program key partner in National Training Platform

On March 31st, the Government of Canada announced new funding to support training and development programs in the health care space. Diabetes Action Canada is pleased that our new Training and Mentoring program co-lead Dr. André Tchernof at the Université Laval, received one of these awards, entitled *Maximize your Research on Obesity and Diabetes (myRoAD): Canada-wide training and mentoring platform from molecules to communities*.

The project, which aims to support early-career investigators in the diabetes, obesity and cardiometabolic space, will help ensure training excellence for those who are planning a career in this area.

“It’s great timing,” says Tchernof, who collaborated with health care programs across the country to develop the plan for this platform. “When we met with all the investigators at centers across Canada, we were really impressed by the enthusiasm of all the teams.”

As with every Diabetes Action Canada project, Patient Partners will be involved at every step of the process. The Strategy for Patient-Oriented Research (SPOR) Support Units from Ontario, Quebec and

the Maritimes participated in the planning, as did multiple patient-focused organizations. Tchernof notes that because there is a SPOR Unit at the University of Laval, where his lab is, he expects they will be very involved with every aspect of the project as it moves forward.

The new platform, which will have an emphasis on equity, diversity and inclusion, will provide interdisciplinary training and mentorship that will help participants develop the skills they need to excel in the field. This will include things like science communication, knowledge mobilization and grant writing, as well as information specific to diabetes and obesity research.

Diabetes Action Canada has always advocated for the incorporating of sex and gender and Indigenous Ways of Knowing in research and is pleased to see this as a requirement of this grant. The program will also support training in unconscious bias, which is an essential skill for students and trainees.

“In a time when relying on scientific evidence has never been more important, our government recognizes the need to invest in the next generation of qualified health research talent. This new platform will help fill a gap in the career development opportunities available to trainees and early career researchers and will allow Canada to create the scientific knowledge we will need to build a more resilient future,” said The Honourable Jean-Yves Duclos, Minister of Health in the government’s announcement.

Read the CIHR announcement here!



New research project tests the use of technology to support those with diabetes distress

On March 3rd, Brain Canada and JDRF announced the winners of their Addressing Mental Health in Type 1 Diabetes Team Grants competition. Diabetes Action Canada was thrilled that one of our supported projects was selected.

Dr. Peter Selby from the Centre for Addiction and Mental Health (CAMH) will be the lead investigator looking into “Technology-enabled comprehensive care for young adults with type 1 diabetes (T1D) experiencing diabetes distress”. He is joined by co-investigators Drs. David Castle and Gillian Strudwick from CAMH and Dr. Diana Sherifali from McMaster University, who also co-lead the newly established Mental Health and Diabetes research program for DAC, as well as Dr. Bruce Perkins from the Leadership Sinai Centre for Diabetes and Dr. Peter Senior, Director of the Alberta Diabetes Institute, who lead the Innovations in T1D program. Five Diabetes Action Canada Patient Partners helped develop the grant application and they will be at the table throughout the planning for this research proposal.

This project looks specifically at co-developing effective supports to help people between 18 – 29 with T1D manage diabetes distress, a condition which affects more than 40% of those living with the condition. Diabetes distress is the emotional burdens and worries that accompanies the need to constantly self-manage diabetes.

“We have heard from people living with diabetes how important and how real diabetes distress is,” says Perkins. “This team is figuring out how to help people identify distress, and how to help deal with it using virtual care. We are confident that this could change the way the health care system actually helps real people with real issues in an efficient way.”

With an increasing number of people using technology to help them manage their diabetes, this project incorporates proven technologies like video chat and text messages to offer mental health support. The program being developed uses techniques from, *The Optimal Health Program*, which was designed to explore the origin of wellbeing within every person, and to support those who use it to promote

self-agency in the face of life’s challenges. With trained mental health and diabetes experts guiding the process, the hope is to safely reduce barriers to needed resources.

“To improve patient-centred approaches, we will be able to co-design and test technology to bridge the gaps in care delivery between the mental health system and diabetes care and empower people to manage their own mind-body wellbeing,” says Selby.

For the Patient Partners involved in the research planning phase, access to appropriate support systems and education about how to find these resources were key priorities. Currently, diabetes-focused mental health interventions are limited, especially outside major city centres. It is also difficult to find health care providers with experience diagnosing or treating diabetes distress. Technology may be able to help by leveraging the available resources and reducing barriers to access, but it can only help if it is designed with the unique needs of people living with diabetes at the forefront.

“I think everyone with T1D struggles at some point with diabetes distress and mental health, but rarely is this raised with health care providers,” says Senior. “It would be easy for researchers to propose a solution based on assumptions or their narrow perspective. However, unless we take the time to hear from people living with diabetes about how they experience the problem and have them direct the design of a solution, there is a huge risk that we will miss the mark.”

The research team also includes Diabetes Action Canada researcher Dr. Joe Cafazzo and the Connect1d Canada team. The project will begin the initial phase of the project this spring.





Supporting Indigenous Canadians with Diabetes

In 2021/22 Our Diabetes Action Canada Indigenous Peoples Health (IPC) Program was led by an Indigenous scholar (Dr. Alex McComber) and a settler scientist (Dr. Jon McGavock) with interests in preventing type 2 diabetes among Indigenous youth and enhancing patient engagement. The IPC guided our DAC 2.0 Indigenous People Health Research plan and have recently completed a planning session in Winnipeg to support the Network's programs in this community.

Dr. McComber, a member of the Kanien'kehá:ka (Mohawk), Bear Clan, coordinated the activities of the Indigenous Patient Circle (IPC). He helped develop research priorities within the program through several face-to-face meetings with the IPC, and regularly reported to our Network governance, to both inform and to seek advice about collaboration with the other Research Program Leads. Dr. McComber is also PI of the Network Environment for Indigenous Health Research team grant housed within Kahnawake and McGill University and he is now co-leading the Indigenous Program of the Quebec SPOR Support Unit.

The IPC will be led by Tamara Beardy in 2022/23, as Dr. McComber shifts his focus to this new role. We thank him for his incredible commitment to our organization and supporting our IPC for so many years.

Dr Barry Lavallee (Métis/Saulteaux, Bear/Makwa clan) and Lorraine MacLeod co-lead the development and evaluation of cultural safety training for primary care providers working with Indigenous people living with diabetes. This work is housed within an Indigenous organization, the First Nations Health and Social Secretariat located in Winnipeg. Their entire research team is Indigenous and provides lectures and direction to our Network on anti-racism within clinical care and research activities.

Dr. Malcolm King (Mississaugas of the Credit First Nations) chaired our Steering Council, and Roslynn Baird (Cayuga), Director of the Indigenous Diabetes Health Circle, was a Steering Council member.

Members (Elders and Patient partners) of the IPC continue to provide guidance, recommendations and identify priority areas for the Indigenous Peoples Health Program.

Our Indigenous Patient Circle (IPC) consists of twelve persons with representatives from Anishinaabe, Haudenosaunee / Kanien'kehá:ka, Néhiyawéwin, Innu, Inuit, Coast Salish and Oji-Cree nations, Indigenous scientists, health care providers and Indigenous community-based organizations that provide diabetes care and education services.

Among these members are four persons identified as Elders and Knowledge Keepers within their communities. The two Elders

on the IPC include Barbara and Clarence Nepinak (Treaty 1 Territory, Anishinaabe, Bear Clan) and Robert Fenton (Anishinaabe, Thunder Bay area) provided guidance to Dr. McComber and the IPC. The IPC identified research priorities and provided guidance and consultation for several DAC-funded projects as well as the Network application for DAC 2.0. The IPC was involved in co-designing our annual Learning Pathway gatherings for Patient Partners, trainees and DAC researchers.

Our Indigenous Youth Mentorship Program (IYMP) was co-developed with Indigenous youth and community Elders from across Canada. This team is funded by a CIHR Pathways to Equity Component 3 team grant. Youth and Elders sit on the IYMP national advisory circle as community members in Winnipeg and northern Manitoba, providing guidance and leadership for decision-making on the team. Each site's community team within IYMP is led by a young adult health leader and community champion, who work and are members of the Indigenous community.

An Elders and youth national advisory circle guide IYMP operations, revised and approved team

[Read our message to Alex here!](#)

Health Data-Informed Solutions for Better Diabetes Care and Complications Prevention

The people with diabetes who are most at risk for poor health outcomes, often have inadequate access to health care when they need it most. While the reasons for this are complex, the ability to provide the right care at the right time relies on health and social service professionals working together to promote screening for diabetes complications. This requires access to relevant health information to identify and access those at risk.

To address patient-oriented research questions that matter most to those living with diabetes and serve as a resource for the analytics required for evidence-based care, Diabetes Action Canada created a unique digital health asset: the National Diabetes Repository.

In collaboration with the Canadian Primary Care Sentinel Surveillance Network and Patient Partners, we created a unique repository of primary care electronic medical record (EMR) data from 149,961 persons with diabetes (48% women, 52% men) and the same number of age-matched non-diabetic controls from across five provinces. The Repository contains over 1.5 billion data points including medications, lab results and risk measurements such as blood pressure. It has been used by our investigators to develop algorithms to differentiate persons with Type 1 and Type 2 diabetes and can be linked to provincial health data to track hospitalizations, surgeries, and screening for diabetes complications.

The Repository has already been used in 11 different projects that involve a broad scope of analytics including machine learning and artificial intelligence. Another novel feature is the Research Governance Committee composed of 50% Patient Partners who oversee the utilization of this database to ensure that every project will be relevant to the health needs of people living with diabetes.

In 2019, Dr. Holly Witteman, co-lead for Patient Partner Engagement, and Dana Greenberg, Patient Partner and Co-Principal Investigator, received a CIHR Catalyst Grant to “Answer questions that matter to people living with diabetes using the Canadian National Diabetes Repository”. Our Patient Partners are now directly querying the data as citizen scientists, demonstrating the value of this asset.

Just as the discovery of insulin transformed the lives of those with diabetes, the application of digital health, including the use of information technology/electronic communication tools and services to facilitate wellness, is ready to become the ‘insulin’ of the 21st century, and Canada is poised to lead the world in this field exactly 100 years after that momentous discovery.

Partnerships and Public Policy Highlights

In June 2021 the Private Member's Bill C-237: An Act to establish a national framework for diabetes, passed unanimously in Parliament. Subsequently, Health Canada charged the Public Health Agency of Canada (PHAC) to provide recommendations on the steps necessary to establish this framework, and report in June 2022.

Dr. Catharine Whiteside, DAC Director of Strategic Partnerships, serves on the PHAC External Advisory Committee that assisted in preparing this report along with representatives from Diabetes Canada, JDRF, Diabète Québec and other key stakeholders from the provinces and territories.

Our Network is working with Diabetes Canada and JDRF to ensure that the Patient Partner perspective is considered and integrated into this planning. DAC 2.0 aims to contribute to digital solutions and knowledge mobilization strategies as core elements of the National Diabetes Framework.



Dr. Catharine Whiteside



Dr. Joyce Dogba

Equity Diversity and Inclusion

and their caregivers at the start of research project planning to understand how to articulate the most meaningful questions and relevant potential outcomes. We ensure strong representation from people with different types of diabetes (including equal representation from the T1D and T2D communities), a spectrum of age, rural and urban communities, English and French speakers and new immigrants whose first language is neither, and those who have not completed post-secondary education.

Our researchers will engage with Patient Partners at the individual and community levels to co-design equitable, scalable and effective care pathways for improving health and wellness. Our EDI Champions, Drs. Joyce Dogba and Holly Witteman, in collaboration with Dr. Robin Mason from the Women's Xchange at Women's College Hospital, will ensure sex and gender based

analysis (SGBA+) is incorporated into all projects to highlight potential differences among people with diverse identity characteristics.

At Diabetes Action Canada we recognize how identity characteristics such as race, age, geographic location, newcomer status, Indigenous identity and a variety of social determinants of health can interact with sex and gender to compound inequities. We require all members of our Network to be trained in these areas to access our support and participate as members in our research community.

Diabetes Action Canada is committed to applying equity, diversity and inclusion (EDI) principles to the composition of the governing bodies, membership on research teams, inclusion of Patient Partners, and the engagement and recruitment of research participants. Our Network is committed to inclusion with strong representation of women and visible minorities on our applicant team, Steering Council and amongst our Patient Partners.

We recognize the critical importance of engaging persons from diverse communities

Resources

Listen to our podcast!

When Patient Partners are involved in research, extraordinary things can be achieved. Actions on Diabetes shares the stories of Diabetes Action Canada researchers and Patient Partners as they work together to transform the lives of all Canadians with diabetes. [Seasons 1 and 2 are available now on our website, Spotify, Apple Podcasts and all the major podcast providers.](#)



Do's & Don'ts:

Guidelines for Researchers, Patient Partners and anyone new joining Diabetes Action Canada!
By Dana Greenberg, David Wells, Sasha Delorme and Virtash Bajwa

1 Treat patient partners as equals.
✓ **Patient partners are experts in their own right.**
✓ **DO** Accept that patient partners' lived experience will provide valuable insight that a researcher/medical professional may not have.

2 Patient partners do not want to be included in a tokenistic manner - they want to be a true part of the project.
✓ **DO** Involve patient partners to engage in all aspects of the project, make sure to do so for their input. Ensure that every patient partner feels that everyone has an opportunity to speak.
✗ **DON'T** invite patient partners onto the project because you "have" to and then ignore the potential for their valuable contributions.

3 Clearly set out expectations from the beginning of the project, so that expectations are managed for both patient partners and researchers.
✓ **DO** Ensure that the researcher makes a welcome call to each patient partner to explain the project and increase confidence and understanding.

4 Involve patient partners from the beginning of the project.
✗ **DON'T** invite patient partners into projects when most decisions have already been made.
✓ **DO** involve patient partners right from the beginning to help shape the research objectives.

5 Don't waste the patient partners' time.
✗ **DON'T** get patient partners to review information or provide feedback if it's not going to be considered and used in the project.

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Resources for working with Patient Partners

6 Carefully consider the number of patient partners you want to involve in the project.
✓ **DO** Involve at least two patient partners in every project. Too few can feel intimidating and too many can be overwhelming. If there is a need to have many patient partners involved, consider organizing them into smaller groups.

7 Keep communication open and ongoing throughout the entire project.
✓ **DO** Keep patient partners informed of each step of the project including end results
Example:
• Invite patient partners to meetings, even if they are administrative, but allow the patient partner the ability to opt out if they are not integral to the meeting being too update them on what is happening.
• Do ask patient partners if they want to be included in publications as co-authors.

8 Refrain from using jargon and acronyms in communicating with patient partners.
✓ **DO** provide explanations and terms of reference to patient partners prior to meeting
Example:
• Explain what the discussion will be about.

9 Make space for patient partners to speak up.
✓ **DO** Allow patient partner to then feedback at the end of every topic, or point of discussion.
Example:
• At the end of the meeting, ask patient partners if they have any additional questions.
• Encourage patient partners to speak up at the end of the meeting to ask for feedback. This should happen throughout the meeting.

10 Materials and event spaces must be accessible.
✓ **DO** Have a conversation with patient partners to assess any accessibility issues and provide appropriate accommodations. This conversation should be incorporated into the welcome call.
Example:
• Provide written materials that follow the Diabetes Action Canada Accessibility Policy.
• For persons who are visually impaired, include text descriptions of graphics and tables, so that screen reading software can read the text.

www.diabetesaction.ca

For Patient Partners to work effectively as part of a research team, their participation must be valued and respected. To support researchers in understanding how to collaborate in the best way possible, Diabetes Action Canada's Patient Partners have created two resources. The first, Do's and Don'ts for Patient Engagement, helps research teams better incorporate people living with diabetes into research programs. The second gives those living with diabetes more information on how to participate in Diabetes Action Canada research programs. Visit our site now to read and download!

Watch a Webinar

Our webinars provide in-depth information on Diabetes Action Canada programs and projects. Visit our website to find the latest episodes on Knowledge Mobilization and so much more. Miss a live webinar? [You can watch many of them online now.](#)



Financials

2021-22 Donors of Cash & In-kind for DAC 1.0

Donor	Match Cash	Match In-Kind	Total Commitment
Alliance Santé Québec/ULAVAL	1,100,000	150,000	1,250,000.00
AstraZeneca	875,000	-	875,000.00
Bayer	1,000,000	-	1,000,000.00
Boehringer Ingelheim	34,800	-	34,800.00
Cardiovascular Health, Diabetes & Obesity Research (CMDO)	500,000	-	500,000.00
Centre de formation médicale du Nouveau-Brunswick (CFMNB)	275,000	-	275,000.00
Centre for Global e-Health Innovation	-	250,000	250,000.00
Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale (CIUSSS-CN)	-	127,801	127,801.00
Diabetes Canada	1,000,000	-	1,000,000.00
Diabetes Research Envisioned & Accomplished in Manitoba (DREAM)	-	2,450,000	2,450,000.00
Donald & Gretchen Ross	50,000	-	50,000.00
Ed and Fran Clark - Project OPEN	660,000	-	660,000.00
Ed and Fran Clark - Limb Preservation Project	250,000	-	250,000.00
Fighting Blindness Canada	282,000	-	282,000.00
Foundation Fighting Blindness	-	500,000	500,000.00
Heart & Stroke	272,568	-	272,568.00
Remi - Institut de Recherches Cliniques de Montréal	3,269,455	-	3,269,455.00
Janssen Inc. - Training & Mentoring Postdoc Fellowship	50,000	-	50,000.00
Juvenile Diabetes Research Foundation	717,500	-	717,500.00
Merck	1,286,376	-	1,286,375.71
Michael Smith Foundation for Health Research	100,000	-	100,000.00
New Brunswick Health Research Foundation (NBHRF)	375,000	500,000	875,000.00
North York General Hospital	-	144,878	144,878.00
Novartis	50,000	-	50,000.00
Research Manitoba	1,121,197	-	1,121,197.00
Seniors in the Community Diabetes Project (private donor)	29,800	-	29,800.00
St. Boniface Hospital	-	40,000	40,000.00
Sun Life Assurance Company of Canada	1,000,000	-	1,000,000.00
The Koschitzky Family (private donor)	250,000	-	250,000.00
University of Montreal	250,000	-	250,000.00
Université de Sherbrooke centre de recherche	700,000	-	700,000.00
University of Toronto - Department of Family and Community Medicine	-	411,044	411,044.00
University of Toronto - Department of Medicine	500,000	-	500,000.00
University of Toronto - Heart & Stroke/Richard Lewar Centre of Excellence in Cardiovascular Research (HSRLCE)	1,358,757	-	1,358,757.00
WinSanTor	183,097	100,000	283,096.72
Wolfond Chair in Digital Health	-	800,000	800,000.00
TOTAL	17,540,549	5,473,723	23,014,272.43

Acknowledgements

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 | The Wolfond Family

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Diabetes Action Canada

Preventing complications. Transforming lives.

