



2022 DIABETES ACTION CANADA ANNUAL WORKSHOP

Summary Report

[Abstract](#)

***Diabetes Action Canada conducted an in-person Workshop on October 27th, 2022 – October 28th, 2022.
The theme for the event was “Building Strategic Relationships for Impact”***

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Diabetes Action Canada 2022 In-Person Workshop Report

Theme: *Building strategic relationships for impact*

Preamble

For the first time in three and a half years, members of Diabetes Action Canada (DAC) from across the country attended an in-person Workshop on October 27th and 28th, 2022. This important meeting was necessary not only to assemble our research teams for the first time in-person since the start of the pandemic, but also reignite enthusiasm in the Network to plan the important work ahead. In total we have 78 Participant at our event, including 26 Patient Partners (20 in-person; 6 online) 25 Investigators and principal knowledge users, 3 trainees and 16 guests, including Amy Lang, Executive Director, Patient-Oriented Research and Jennifer Campbell, Manager, Strategy for Patient-Oriented Research at CIHR.

Since establishing the Network in 2016, DAC has made significant impact in patient-oriented research (POR) focused on achieving improved health care experiences for those living with diabetes. Over these last 6 years, DAC has engaged more than 97 Patient Partners from different age, sex, gender, demographic, socioeconomic and ethnic backgrounds, representing the diverse population of those living with diabetes from across Canada. Contributing their experiential knowledge, our Patient Partners have engaged in co-designing 86 projects with our 113 investigators in our first funding term. Each project focuses on achieving the key components of the Quintuple Aims which include: improved patient experience, population health outcomes, health provider experience, health system cost, with focus on the health of the most vulnerable based on Equity, Diversity and Inclusion (EDI) principles. We have also established important digital health assets including our [National Diabetes Repository](#) of primary care electronic medical record data and the [Connect1d Canada](#) platform.

In April 2022, CIHR approved continued funding for DAC from 2022 to 2026. This new funding was designed to shift the Network from building our POR Programs to scaling and spreading our successful research outcomes. These activities are supported now by senior management expertise in three overarching Trans-sectoral Themes: Patient Engagement through an EDI Lens, Knowledge Mobilization-Implementation Science (KM-IS) and Evaluation; and, Digital Health Solutions for Learning Health Systems. These themes are designed to collaboratively support and guide our 7 POR Programs to scale and spread equitable models of health and social care services that will enable positive change in the way those living with diabetes experience the health system. As a Network, it is our ability to draw on the expertise and methodologies of our academic experts in these themes to assist POR Programs that will achieve impact in the Quintuple Aims. This renewed approach, referred to as DAC2.0, remains centered on Patient Partnership in the co-design and implementation of all our activities.

To kick off the Workshop, we focussed our activities on this fundamental strength with opportunities for our Patient Partners to set priorities and provide strategic advice to our research teams. A concurrent meeting was also held with our colleagues from myROaD - Maximize your Research on Obesity and Diabetes, a CIHR-funded health research training platform that will optimize the prevention, treatment and lived experiences for those affected by obesity, diabetes and cardiometabolic complications through advances arising from large interdisciplinary research teams. At the end of the first day the participants from the two meetings joined to attend a panel discussion focussed on patient engagement through an EDI lens that outlined the successes, challenges, impact and evaluation of this important work. On the second day, Workshop activities focussed on fundamentals in communication, knowledge mobilization, implementation science and evaluation activities to build capacity amongst our research teams and Patient Partners, a major focus of DAC2.0. The feedback we received from our Workshop was very positive with comments expressing the importance of in-person meeting for building relationships among our diverse membership of Patient Partners, Policy Decision-Makers, CIHR leaders, investigators and knowledge users from many disciplines.

Workshop Rationale and Planning

Since our last Workshop in 2019, Diabetes Action Canada has changed significantly to support the shift of our research activities towards a knowledge mobilization and implementation science framework. Since our last in-person event, Diabetes Action Canada underwent an external review in 2019 and completed its strategic plan for 2021-26, both activities highlighting the importance of Patient Partnership in research to better respond to the needs of those living with diabetes and achieve system change. Building relationships is key to effective patient engagement, and the importance of meeting face-to-face to learn from each other and establish collaborations was a major focus of this event.

The 2022 in-person Workshop was designed to launch DAC2.0 and set the stage for the important work ahead. This included the inaugural meeting of the DAC2.0 Steering Council with its new Chair, Dr. Cindy Bell. To help plan for this Workshop we struck a Planning Committee composed of both research and Patient Partner leads within our Network. The Planning Committee recommended that our plenary sessions focus on the new direction for DAC 2.0 and build capacity in knowledge mobilization, implementation science and evaluation. DAC leadership also worked extensively with the leads of each of its 3 Trans-sectoral Themes and 7 POR Programs, to learn how each program would benefit from in-person patient engagement in their programs and projects. The resulting agenda for the event included research team meetings, plenary sessions and the opportunity for some of our POR Programs to hold breakout sessions with Workshop participants. Feedback collected from the Workshop, indicated the latter activity as the most popular among participants, providing a valuable opportunity for input on ongoing projects and strategic directions necessary to achieve outcomes with impact.

The Workshop proceedings were conducted in English and the written materials as well as slides presented were provided in both French and English.

Diabetes Action Canada Annual Workshop 2022 - Planning Committee

Member	Program
Delgado, Pascual	Patient Engagement
Chambers, Tracey	Aging, Community and Population Health
Beleno, Ron	Aging, Community and Population Health
Boutin, Denis	Patient Engagement
Bowen, Jim	Knowledge Mobilization, Implementation Science and Evaluation
Di Giandomenico, Anna	Patient Engagement
Larrain Herrera, Carlos	DAC Admin
Gaudreau, André	Patient Engagement
Kastner, Monika	Knowledge Mobilization, Implementation Science and Evaluation
Maloney, Maryann	Patient Engagement
Mytkolli, Linxi	DAC Admin/Patient Engagement
Nagel, Hana	Patient Engagement
Lamb, Krista	DAC Admin/Communications
Lim, Mildred	DAC Admin
McGavock, Jon	Indigenous Peoples' Health
McQuire, Tracy	DAC Admin
Murray, Michelle	DAC Admin/Training and Mentoring
Nepinak, Barb	Indigenous Peoples' Health
Pow, Conrad	DAC Admin/Digital Health
Ramdass, Seeta	Patient Engagement
Tchernof, André	Training and Mentoring
Whiteside, Catharine	DAC Admin
Witteaman, Holly	Patient Engagement

The Workshop Proceedings and Outcomes – Day #1

On October 27th the DAC2.0 Workshop began with a meeting of the Collective Patient Circle. This was the first meeting of the Circle since the Network secured continued funding and the agenda focused on renewed goals and objectives for the Circle in DAC2.0. The meeting started with a description of the new structure for DAC2.0 and how the Collective Patient Circle fits into the governance of the Network. The group discussed representativeness within the Circle and how to better represent the Francophone and Immigrant Circle in the structure. Throughout the Workshop we heard feedback that the Francophone and Immigrant Circle will need a separate meeting to plan its goals and objectives and whether they should once again split into separate Circles as was the original structure when DAC was established in 2016. A detailed report or meeting outcomes was delivered as part of the Day 2 Program for the Workshop and outlined later in this report.

Concurrent with the Collective Patient Circle Meeting our Mental Health and Diabetes Research Program assembled in-person. This program was established in response to our 2022-26 strategic plan and has only met virtually. Shortly after DAC2.0 received continued funding from CIHR, this group received funding for its inaugural project in T1D and mental health through JDRF and Brain Canada. This team took the opportunity to meet for the first time in person to discuss their ongoing project as well as plan for the upcoming grant competitions.

Diabetes Action Canada 2.0 – Dr. Gary Lewis and Tracy McQuire

Following these important meetings and after a Networking lunch, the DAC Workshop officially launched with Dr. Gary Lewis, Co-Scientific Lead, and Tracy McQuire, Executive Director, discussing the transition from DAC1.0 to DAC2.0 and what is new for the Network in this next phase. Today, DAC2.0 has 217 members, 97 of whom are Patient Partners. In our first funding term we leveraged \$69,271,339 in additional funding, published 180 peer-reviewed and 272 plain language publications, granted 29 trainee and early career investigator awards, and delivered 30 research training workshops with 515 participants. In DAC2.0, our Network continues to focus on working with those living with or affected by diabetes to prevent the complications of diabetes, with a major focus on the most vulnerable in our society. DAC2.0 has a **mission** to co-design, implement and evaluate scalable, equitable models of health and social care services for all persons with type 1 (T1D) and type 2 (T2D) diabetes and a **vision** that all persons with T1D and T2D in Canada experience optimal health and wellness. The renewed structure of the Network has three Trans-sectoral Themes: Patient Engagement through and EDI Lens, Knowledge Mobilization – Implementation Science (KM-IS) and Evaluation, and Digital Health Solutions for Learning Health Systems. It has 7 POR Programs: Diabetic Retinopathy Screening; Indigenous Peoples' Health; Diabetic Foot Care and Prevention of Amputations, Mental Health and Diabetes; Innovations in T1D; Training and Mentoring; and, Older Adults with Diabetes. These Trans-sectoral Themes are supported by backbone management within

DAC2.0 to facilitate these important pillars or work in each of the 7POR Program. Each theme and program is led by co-scientific leads who are experts in their field.

As we launch DAC2.0 there are important changes that have already been implemented. The website (www.diabetesaction.ca) has been completely redesigned and launched shortly before the Workshop. Three new staff have been recruited to the Network: Carlos Larrain Herrera (Administrative Assistant), Linxi Mytkolli (Lead, Patient Engagement, KM-IS and Evaluation), and Julie Makarski (Research Manager, KM-IS). The existing staff have new roles: Tracy McQuire (Executive Director), Catharine Whiteside (Director, Strategic Partnerships), Conrad Pow (Lead, Digital Health), Krista Lamb (Lead, Communications), Michelle Murray (Lead, Training and Mentoring) and Mildred Lim (Business Manager). We closed this overview with a warm welcome to our new Steering Council Chair, Dr. Cindy Bell. Dr. Bell is an accomplished scientist and the parent of two daughters with T1D. She has been an advocate and ally for the diabetes community for more than thirty years and DAC2.0 is thrilled she has accepted the role.

Breakout Sessions

Following this overview, four of our research programs facilitated strategy sessions to gather feedback from attendees on current and future research projects. Below are brief descriptions used to help guide participants towards their desired discussion outcomes:

1. Co-designing national program for general population T1D screening – Drs. Bruce Perkins, Peter Senior

Approximately 300,000 Canadians live with T1D and the incidence of T1D in children in Canada is among the highest in the world. Screening the general population for T1D does not occur, with previous research focused only on screening family members. Unfortunately, over 90% of those diagnosed with T1D do not have any family history, leaving family-based screening unable to identify the majority at risk. CIHR and JDRF have launched a funding opportunity to create a T1D Screening Research Consortium to develop a single nationally coordinated research group to explore how to implement a general population T1D screening program in Canada. Other countries have had success in this area and this Consortium is tasked with developing a plan that builds on experiences from other countries, but adapts to the Canadian population and the health care system.

This outcomes of this session were intended to guide the DAC Innovations in T1D Research team on their next steps.

2. Impact of COVID on equity and access to digital diabetes care – Dr. Joe Cafazzo

The COVID pandemic put immense pressure on the Canadian health system to pivot from in-person visits to delivering digital remote care. This not only minimized contact and potential virus transmission, it provided an accessible option to maintain care in the midst of a global health crisis. Digital health care was a welcome change for many, with health care provider visits possible with minimum interruption to daily life, including reduced travel burden. Now,

digital health remains a preferable option for many with physicians (and their patients) slow to return to in-person visits.

This session sought to better understand the Patient Partner perspective of digital health care for their diabetes visits. Questions centered on how digital health has impacted their care – for better or worse, how to improve digital health delivery in vulnerable populations that have limited access to technology, and how to ensure that digital health care can be optimized for diabetes care.

3. Foot care and access to care pathways – Dr. Sonia Meerai

Diabetic foot ulcers (DFU) are a common complication for persons with diabetes and can affect people in multiple ways. DFUs are often painful, odorous and can leak through dressings, all of which limit people from getting out and about as they would like to. Finding and treating DFU early can prevent ulcers from progressing and reduce the risk of losing limbs in severe cases. On top of the physical issues, DFU management is a preventable, high cost to our health care system. So much so that the Ontario government has identified DFU and limb preservation as priorities for improvement. Over the past few years, a number of clinics in Ontario have developed care pathways to guide staff on the best way to care for DFUs. We are now conducting a study to understand what is working and what we can do better. We are especially interested in hearing about how the pathways are working for patients and what outcomes matter most in the pathway.

This session was conducted in collaboration with the Conference Board of Canada to advise on developing a DFU care pathway to ensure that individuals experiencing these ulcers, or at risk of developing these ulcers, do not get left behind in our current health care system. Questions focused on learning about the Patient Partner perspectives on previous experiences with diabetic foot ulcer monitoring, management and treatment in the health care system.

4. Diabetic Retinopathy Screening and access to care pathways – Dr. Aleksandra Stanimirovic

Diabetic Retinopathy (DR) is a serious sight-threatening complication of diabetes that is preventable. In Canada, DR accounts for 80% of blindness in persons with diabetes and is the leading cause of blindness in working-age individuals. Early detection through regular diabetic retinal screening (DRS) is an effective method of avoiding vision loss by enabling earlier intervention and timely treatment. It is recommended that all people with diabetes receive regular DRS, either annually or bi-annually. Current DRS practice in Canada falls remarkably short of recommended rates, resulting in preventable vision loss. This public health issue requires a systematic way of consistently identifying all those that have not had DRS with clinical practice guideline-recommended frequency.

The team has received funding to demonstrate how existing provincial-level administrative data (data from family physicians) can be used to help manage DRS in the population by notifying people when they should be screened to avoid DRS. The team will also be working with a variety of primary health care providers (i.e., family physicians, nurses, pharmacists, optometrists, and personal support workers) to reach younger adults living with T1D, Indigenous peoples, recent immigrants, and residents of inner cities and remote areas, who have lower screening rates. This research forum sought to learn about Patient Partner perspectives on current diabetes retinopathy screening, the use of provincial data to remind individuals of their screening, how information on screening is currently obtained, and guidance about how we can continue to research this issue.

Once these strategy sessions concluded all participants, including those attending the concurrent myROaD event, assembled for the plenary session.

Plenary Session: Patient Partnership with DAC – Successes, Lessons Learned and Future Directions

Moderated by Seeta Ramdass

Speakers: Monika Kastner, Rebecca Ganann, Linxi Mytkolli and Valeria Rac

In our first funding term, DAC established a robust Patient Partnership program and learned a great deal in the process. This panel was designed to not only to highlight the successes gained by the Network, but also speak to what we learned along the way. The outcome of this session was to provide our researcher and Patient Partner teams actionable steps to continually improve the integration of Patient Partners in the research process. There were four speakers in the panel and below is a summary of each of the presentations:

Speaker #1 Monika Kastner: Optimizing the Integration of DAC Patient Partners in Research

DAC is currently supporting a qualitative study to understand *how best to empower and integrate* Patient Partners as *valuable* members of DAC 2.0 research teams. Thirteen focus groups (9 English language and 4 French language) with 35 Patient Partners (46% living with T2D and 37% living with T1D) were conducted. The outcomes of this study will enhance DAC2.0 research to be more responsive to the needs of those living with diabetes, improved outcomes and quality of health care. Preliminary results have led to the following recommendation for more integrated Patient Partnership:

1. What Patient Partners need

- Having clear, understandable information to optimize their contributions
- Feeling prepared and empowered to share their experiences
- Feeling respected

2. What researchers can do

- Provide adequate and relevant information to patient partners (team, project)

- Clearly communicate expectations
 - Be sensitive to Patient Partner needs
 - Show greater flexibility for participation
 - To not underestimate the roles that can broaden Patient Partner contributions
- 3. What DAC can do**
- Prepare Patient Partners and investigators for meaningful contributions to research
 - Provide access to appropriate resources, support and training

Actionable steps for DAC include the following:

- 1. Co-create an optimized tool that can be applied by DAC 2.0 researchers:**
 - *Patient Empowerment and intEgration In Research (PEER)* tool
- 2. Promote the use of the PEER tool by DAC 2.0 researchers**
 - Develop a PEER tool implementation guide
 - Provide training in how to use the PEER tool
- 3. Evaluate the use of PEER in DAC 2.0 research projects**

Speaker #2 Rebecca Ganann: Engaging with Impact: Aging, Community and Health Research Unit – Community Partnerships Program (ACHRU-CPP) for Diabetes Self-Management for Older Adults – Canada

The ACHRU-CPP strives to promote optimal aging at home for older adults living with diabetes and multiple co-morbidities. The entire program is co-designed with older adults, caregivers and providers, including education materials, program design and implementation. As the program seeks to scale, a reflective look on the lessons learned have yielded the following recommendations:

1. Advancing equity, diversity, and inclusion in research and patient partnership requires intentional actions
2. Creating planned, deliberate, authentic spaces for Patient Partner input
3. Mobilizing and centering Patient Partner voices to enhance real-world impacts – start to end

Actionable steps for DAC2.0 include the following:

- 1) Patient Partner experiences can drive urgency and inform innovations**
 - Voices matter, voices can strengthen potential for reach and impact
- 2) Inclusive design of engagement plan**
 - Engaging patients as equal partners in transdisciplinary research teams
 - Inform implementation and impact evaluation
- 3) Co-create care delivery models that integrate health and social care to support tailored, person-centred care for diverse older adults with diabetes**

Speaker #3 Linxi Mytkolli: Diverse Patient Partners: The past, present, and future of intersectionality at DAC

In the first iteration of DAC, our EDI strategy was implemented by two programs – Patient Engagement and Sex and Gender. Through our Sex and Gender team, led by Drs. Paula Rochon and Robin Mason, we learned about sex and gender based analysis plus (SGBA+) which is the process of integrating sex, gender and other demographic factors – such as race and disability – throughout the research process, from conceptualizing (e.g., research question development) through to completion (e.g., knowledge translation). To build capacity in this area the Women’s College Research Institute developed [The Health Researcher’s Toolkit: Why Sex & Gender Matter](#) consisting of a series of eLearning modules, many of which were co-designed with Patient Partners.

Our Patient Engagement team took great care to ensure inclusiveness of our Patient Partners including intentional recruitment of individuals living with different types of diabetes (including equal representation of persons living with T1D and T2D), from a spectrum of age, race, and socioeconomic backgrounds. The team took care to recruit those living in rural and urban communities, those who have not completed post-secondary education, English and French speakers, and new immigrants whose first language is neither.

In DAC2.0, the learnings from these two programs are harmonized in our key theme - Patient Engagement through an EDI Lens led by Drs. Joyce Dogba and Holly Witteman. The following are some recommendations to expand this theme to ensure broader representation of those living with diabetes:

- 1. Better representation of Patient Partners**
 - Increasing representation of diverse people living with diabetes via facilitated discussions with Patient Partners, researchers, and community partners on how to make the process safe and accessible
 - Areas of opportunity: age, ethnicity, geography, race, education
- 2. Analyzing data with an intersectional lens**
 - Leveraging data that is often already collected (such as age) in an intersectional analysis (disaggregation and discussion on sex and gender impacts on results)
- 3. Creating a shared understanding among researchers**
 - Engaging researchers to define a shared understanding of what intersectionality looks like in this work and how to uphold these values when working with Patient Partners
 - Working with Patient Partners to define concretely how this looks in practice
- 4. Diversifying communication and outreach methods**
 - Sometimes “who are we missing” is really “how are we missing them”
 - Ensuring that we work to promote already existing resources through channels outside of traditional academic and health system communications

- Leveraging online and in-person pre-existing communities to share information

Actionable steps for DAC2.0 include the following:

- 1. Facilitated sessions with circles and Patient Partners to understand our current representation and identify populations for recruitment**
- 2. Leveraging pre-existing patient-led resources to build training for researchers**
- 3. Creating relationships with community groups, online support groups, and other service providers**
- 4. Working with community and Patient Partners to better share and communicate opportunities**

Speaker # 4 Valeria Rac: Evaluating Patient Partnership and EDI

Evaluating the successes of our Network was instrumental in guiding our Network activities and positioning DAC favorably for securing continued funding from CIHR. In DAC 1.0 we conducted two network evaluations (one in year 3 and another in year 6) assess network's connectivity (membership and structure), health (resources, infrastructure and advantages of collaboration) and results (progress and impact). From these we learned a great deal on how network members were connected (especially patient partners), what was important to our Network members and how to better focus our activities towards outcomes that will demonstrate value. Patient Engagement was an area of keen interest with improvement evident in our implementation from our first to second evaluation. From these evaluations two papers have been published to date— one detailing the [social network analysis](#) and another detailing [the Network evaluation methods](#). A final paper describing the outcomes of the Network evaluation is in preparation.

As we start to plan for our third Network evaluation, actionable steps informed by the lessons learned in the first two evaluations are as follows:

- 1. A greater integration of Patient Partners through leadership/co-leadership roles – hired as part of the research teams**
- 2. Evaluate EDI in the third cycle of Network Evaluation - look at the network itself (e.g., structure, leadership positions), and the studies supported by DAC (e.g., study participants)**
- 3. Refinement of Network Evaluation questionnaires to include broader activities for Patient Partner engagement and EDI**

After each speaker presented, the floor opened up for lively discussion. Comments related to best practice in patient engagement, Patient Partner initiated research and how we apply and discuss EDI were raised. The role of Patient Partners and best practice in engaging and acknowledging these individuals was discussed. Ensuring that processes for appropriately acknowledging authorship and contributions of Patient Partners are not prohibitive is essential

for DAC to communicate to funding agencies and academic journals. Patient Partners should not be expected to go through the same onerous process to be named as co-applicants on grants, but should have a streamlined process that is more community-centred. Patient Partner initiated projects are emerging within the Network, but connecting researchers to these projects continues to be a challenge and that we strive to improve in DAC2.0. A potential opportunity is a Patient Partnership special issue in the Canadian Journal of Diabetes and an interesting opportunity for communicating advances in Patient Partnership and for educating groups that historically recognize only researchers as contributors to research. The question of increasing the number of our Patient Partners was raised. The logistics of expanding our reach is important, including assurance that relationships are preserved with our current community of Patient Partners. Finally and very importantly, the language we use when discussing our equity-denied groups is very important and should be carefully considered and authentic with reference to the population being described.

Following this panel, members of the DAC2.0 Steering Council assembled for their inaugural meeting and other Workshop participant gathered for photos, networking and reception.

The Workshop Proceedings and Outcomes – Day #2

On October 28th, we had an opportunity to convene as one group and update our colleagues on the proceedings the day before. We also heard from Dr. Amy Lang, Executive Director for the POR program at CIHR, and held two workshops focused on building capacity in knowledge mobilization and implementation science. Below is a high-level summary of each session.

myROaD, a Canada-wide health research training and mentoring platform from molecules to communities – Dr. André Tchernof

The myROaD Program had an opportunity to meet on October 27th to discuss planning for this newly funded National Health Research Training Platform funded by CIHR. The vision for myROaD is ***to help trainees and early career investigators develop into competent, interdisciplinary team members who can collectively address the complexity of obesity, diabetes and cardiometabolic diseases.*** Key partners in this platform include Diabetes Action Canada, Obesity Canada, Diabetes Research Envisioned and Accomplished in Manitoba (DREAM), Cardiometabolic Health, Diabetes and Obesity Research (CMDO) Network, Canadian Islet Research and Training Network (CIRTN), and IMPART – Inflammation and Metabolism, Physical Ability and Research Translation Virtual Network. myROaD will include two core structures; a core training program and core mentorship program. The governance structure is established and almost all committees, each of which includes both Trainees and Patient Partners, are operational.

The purpose of meeting in-person at the Workshop was to assemble the team for optimal planning and to integrate Patient Partnership through the proposed structure for myROaD. Key outcomes Key outcomes included:

- Patient Partnership with the platform, including understanding what opportunities exist to integrate Patient Partner perspectives and to meaningfully create a patient-driven platform
- Establish relationships and collaborations with our Patient Partners and platform committee members.
- Brainstorm how to incorporate and operationalize Patient and Community Partner perspective into the platform activities (analysis of the information is ongoing).
- Identify elements that will favor the success of the platform as well as the barriers that may impede its success (analysis of these elements is ongoing).
- Identify the next steps, including the facilitators and barriers in achieving immediate tasks to plan and build the platform (analysis of these elements is ongoing).

Analysis of the feedback collected is ongoing and a more detailed report on the myROaD specific activities will be created separately.

Future Directions for Patient-Oriented Research in Canada – Dr. Amy Lang

The Canadian Institutes for Health Research (CIHR) has made a significant investment in POR to achieve greater impact on treatments, services, experiences, quality and affordability of health care. This investment was part of the Strategy for Patient-Oriented Research (SPOR) Program that was established 10 years ago and includes: SPOR SUPPORT Units (SSU) in every province and territory, seven Networks – including Diabetes Action Canada (as one of the five Chronic Disease Networks), three SPOR Facilitating Networks, and innovative clinical trials. The SPOR Program was recently evaluated and positive impacts showed that Canada is aligned with international trends in patient-oriented research, activities are addressing key health concerns and stakeholder engagement is leading a culture change in research.

CIHR released the [2021-2031 Strategic Plan](#): A Vision for a Healthier Future and has realigned POR (Including the SPOR Program) into the Learning Health Systems Portfolio. This positions POR and the work of the SPOR programs as foundational to respond to each of the priorities outlined in the plan. Challenges remain in embedding EDI across the research ecosystem, and requires help from the SPOR Programs to develop this expertise and evaluate progress in this important area. As many of the SPOR Programs are entering into their second phase an opportunity exists to collaborate and develop best practices in patient partnership, capacity building and performance measurement to expand and integrate patient-oriented research across all pillars of health research.

Dr. Lang closed her talk with a timeline of the SPOR Strategy to-date with an optimistic view of the future of SPOR and plans for a renewed strategy and governance for the future of POR.

DAC Value 101 – Krista Lamb

Diabetes Action Canada was named to reflect the power of ‘Action’ in catalyzing change within our health system to improve the health and wellness of those living with diabetes. Although DAC has written many academic and lay audience publications to articulate our value, members still struggle to confidently and succinctly describe the work of DAC. The purpose of this activity was to help our membership say more with less when communicating our stories and their impact.

Key messages are essential to communicating our value, but often we use too many words that effectively dilute the meaning of our statements. Krista discussed the importance of customizing key messages depending on the audience and considering what the listeners finds important. Telling stories that focus on the impact to those living with diabetes, rather than including academic and research jargon will capture more audiences. Explaining the need and how DAC plans to meet that need refocuses our messages toward action. Finally, using inclusive language matters in how we describe those living with diabetes and their condition.

Knowledge Mobilization, Implementation Science (KM-IS) and Evaluation Workshop – Dr. Monika Kastner, Julie Makarski

In DAC2.0, knowledge mobilization and implementation science is a key theme to ensure that the evidence generated by our world-leading researchers is implemented in the real world to improve both patient and practitioner experiences. KM-IS is an important bridge to move research results into practice and policy and, with a good plan, information can flow to those who can use it effectively in a fraction of time. DAC2.0 has three main goals in KM-IS to support our research teams in planning effective KM-IS plans for their current and emerging projects:

- 1) Increase knowledge and skills in KM-IS for DAC Investigators, patients and the community
- 2) Build KM-IS capacity (increase application and uptake of DAC1.0 projects and outputs)
- 3) Increase the DAC network’s KM-IS profile, visibility and accomplishments

To plan activities in KM-IS for DAC2.0, an introductory webinar led by Dr. Kastner [Knowledge Translation. What is it, why is it important and how do we achieve it?](#) followed by a KM-IS needs assessment survey in early 2022 was completed. The results showed that members of DAC (including Patient Partners, researchers, and staff) would like to see training in how to include Patient Partners in research, how to apply KM-IS frameworks, how to manage and track KM-IS, how to scale us and how to access experts in KM-IS. This Workshop was designed to respond to these needs and provide valuable tools to help our teams plan effective and active KM-IS plans. To start, the spectrum of activities in KM-IS were described, including:

- **Integrated KT:** Bringing together and collaborating with all knowledge users during every stage of the research.
- **Knowledge creation:** Combining research evidence on a particular topic, disease, intervention, program from research conducted across the globe (i.e. systematic review), and/or developing interventions, programs, tools, or any innovation using research results or outputs.
- **Dissemination:** Making knowledge users aware of the knowledge. Can be achieved passively (publications, presentations) or interactively (infographics, social media, website, tools, decision aids, plain language news, etc.).
- **Implementation:** More intensive and deliberate strategies to move effective research results into practice and policy (i.e., how to make it happen).
- **Sustainability:** When an intervention, program or practice become part of routine care.
- **Scalability:** Ability to expand the reach of effective interventions, programs, practices that have been implemented in one setting to other settings.
- **Evaluation:** Ensure that the intended impact is achieved, iterative improvement is possible and efforts are successful and worth investments.

The audience worked through two different research examples to plan for each of the activities described above in developing a comprehensive KM-IS plan – one biomedical research project examining SGLT2 inhibitors in closed-loop automated insulin delivery systems (recently published by Dr. Bruce Perkins) and another health service project evaluating the efficacy of the Aging, Community and Health Research Unit - Community Partnership Program and potential to scale. Each round table was to select one of the two case studies and discuss relevant KM-IS activities relevant to the case. The session concluded with a report back to the larger group on the collective responses from each table.

POR Program Strategy Session Report Backs

Co-designing national program for general population T1D screening – Drs. Bruce Perkins, Peter Senior

Initial concepts and research questions needed to launch a general population T1D screening were discussed. Patient Partners, researchers (including online participants), stakeholders from Diabetes Canada were consulted and the following feedback was collected:

- With the incident rate of T1D already being quite low, selecting an ideal sample size for this project that is feasible within the constraints of the call will be a challenge
- Potential harms in receiving information about likelihood of developing T1D need to be fully understood and addressed in this proposal. This includes impact on life insurance, overmedication, mental health supports
- Expanding a national T1D screening program to those misdiagnosed with T2D as adults, would help activate the correct care pathway.

- Establishing a care pathway for those who receive a genetic risk score indicative of developing T1D needs to be established. If novel treatments are part of this pathway, scope of practice must be considered as part of the care pathway.
- Mental health supports are a critical part of this proposal as the burden of knowing T1D is inevitable can put significant strain on an individual. Immediate access to culturally competent education, and community and peer supports will be an essential part of the project.

Impact of COVID on equity and access to digital diabetes care – Dr. Joe Cafazzo

During the pandemic, many individuals living with diabetes have grown accustomed to virtual health care visits to monitor their condition. As the health system rebounds from this sudden pivot to virtual care, many are left conflicted by the desire for convenience in virtual care with the value of in-person health visits. The strategy session sought to learn the benefits and challenges of virtual care, as experienced by those living with diabetes. Below is a summary of key themes that emerged from the discussions:

Positive themes:

- The convenience of not having to travel to an appointment, especially for those in remote areas, or wishing to include family members from remote areas in their visit, is a driver for many to use virtual care. This also translated to time savings, and financial savings from travel, parking and limited time away from work.
- More opportunities for asynchronous care were experienced, which made it easier when managing multiple appointments with care team members.

Negative themes:

- Technology access and literacy was a barrier and often phone calls were more convenient.
- Opportunities for organic discussion with practitioners that led to increased understanding of experiences were reduced, leading to less spontaneity to react to the needs in the moment.
- Cost savings was experienced by those who were already outfitted with technology, costs were incurred by those who had limited access and support for devices and internet.
- Private virtual clinics emerged filling the access gap, but created poor continuity of care and exacerbated equity issues.
- The pandemic revealed the digital limitations of our health care system, with many systems not interoperable and data not easily assessable to care teams.

Future vision:

- Hybrid models need to be developed to ensure that interactions with the health system are appropriate, convenient and address issues experienced by those living with diabetes. Billing codes need to reflect this hybrid model so that individuals are not inconvenienced due to outdated policies.

- Government policy to reflect access to technology and connectivity as a basic human right
- Government intervention of private sector offering for-profit health care is needed to ensure equitable care.

Foot care and access to care pathways – Dr. Sonia Meerai

The team reflected on diabetes care holistically including impacts on mind, body and spirit, with a later focus on foot care. Screening for diabetic foot ulcers is not part of typical practice in our healthcare system and is often overlooked by practitioners. Those seeking care must do so at an additional cost, since foot screening does not have a distinct fee code and is billed under a primary care visit in Canada. This makes it harder for at-risk individuals to obtain foot care, until the threat of amputation becomes apparent. This session was the first of a series of Patient Partner engagement activities to understand individual experiences with diabetic foot ulcer monitoring, management and treatments. The following is a summary of key points of discussion:

- Health information gathering by physicians is quite complex with foot care often landing in free text fields that are not used in data analytics. This could lead to missed opportunities in foot screening
- Foot care screening goes beyond the surface and must consider an individual's family history, sociocultural context and history – including the impacts of colonization, to understand risk for developing diabetic foot ulcers.
- A systematic approach to foot care is needed, especially in communities with limited access to health care services, and increased socioeconomic risk factors to developing foot ulcers.
- The roles of primary care physicians and caregivers in foot screening was discussed as well as opportunities for holistic diabetes care to ensure systematic complications screening, prevention and management.

Diabetic Retinopathy Screening and access to care pathways – Dr. Aleksandra Stanimirovic

Diabetic retinopathy continues to be the leading cause of blindness in working-age Canadians. This vision loss is often preventable with early detection and treatment. This strategy session sought to understand the barriers for those living with diabetes to getting diabetic retinopathy screening and how our teams can facilitate screening as they plan for implementation of their recently funded Insulin 100 Team Grant. The following feedback was collected:

- Many people living with diabetes are unaware of the risks of diabetic retinopathy, treatment option and how lack of treatment could result in rapid irreversible vision loss. More education on diabetic retinopathy screening, in simple terms, translated in multiple languages to respond to community needs, will help with accessing this information. Also, social media strategies can assist in educating youth and young adults, who are often caregivers in their family.

- Access to care can be problematic, especially opportunities for screening can only occur during the traditional workday. Flexible opportunities to get screened will help with those who are unable to interrupt their work day.
- Decentralized diabetes care, requiring multiple care specialist's appointments at different times can add to burnout and reluctance to screen for one more thing. Finding a care team that suits an individual can be a challenge and those who do not have a relationship or trust with their physicians, dieticians, nurse, etc. may be reluctant to reach out.
- Stigma and attitude that complications associate with diabetes are the result of poor management from the individual, can lead to reluctance of individuals with engage with the health system
- Primary care physicians may not know about the screening for complications, or may neglect to mention it during routine appointments. Chart alerts have proven to be unsuccessful since the data collection of screening is not systematic and relies too heavily on organizational management of individual practitioners. Diabetes educators may be a better steward to monitoring for this type of screening
- Providing creative approaches to diabetic retinopathy screening (i.e., portable handheld cameras enabled with artificial intelligence) delivered by trained community workers will help with increase rates among those in community and/or at-risk settings
- Government support for screening programs with systematic monitoring for diabetes complications screening would make great impact on screening rates and preventing life altering complications.

Patient Circle Report Backs

Collective Patient Circle

The Collective Patient Circle met in-person for the first time in over three years. This was a great opportunity to reconnect and to revisit work from DAC1.0 that is continuing into DAC2.0. Dana Greenberg presented some of the high level outcomes from this meeting to inform our work ahead. These included:

1. A keen interest in mental health and learning how the Circle can be more involved in projects in this area was expressed. Members of the Circle want not only to be updated on project progress in this space, but want to see it grow.
2. The Circle would like more researchers to come to the meetings, present their work, and learn about opportunities to expand Patient Partnership and Knowledge Mobilization.
3. Communications with the Circle needs to be improved, with opportunity for asynchronous access to information. Emails can get lost or get disorganized. Having a centralized location for information would be extremely helpful in preparing for meetings, revisiting documents, learning of Patient Partner opportunities within the Network.

4. The Patient Engagement Standing Committee of the Steering Council has yet to be formed and the Circle discussed whether this was necessary. The Circle agreed that this smaller Committee would be beneficial in amplifying the work that would be discussed at the larger Circle level.
5. The need for ground rules for both Patient Partners and researchers when engaging in activities was also raised. Building on the important work of the Do's and Don'ts these ground rules would help set expectations for both parties so that share understanding of roles within the research process and what is feasible in the proposed research project is achieved.
6. Understanding the gaps in our current Patient Partner Circles and who is missing, why they are missing, and what can we do to change that is important. We recognize the importance of representation at the circle, and look forward to the future conversations as part of consultation plan to inform the EDI strategy.

Indigenous Patient Circle

The Indigenous Patient Circle had the opportunity to meet in Winnipeg, Manitoba in late September to discuss their future vision for DAC2.0. Jon McGavock presented virtually, starting with a reflection on how the Circle started, the PATH exercise that was conducted in Kahnawake, Quebec when the Network was first established, and where they wish to go for DAC2.0. Jon detailed two main streams of the work:

1. Creating and disseminating the knowledge translation tools about the lived experiences of adolescents living with T2D; and,
2. Adapting an anti-racism training program developed by the First Nations Health and Social Secretariat of Manitoba (FNHSSM) and Dr. Barry Lavallee to include trainees and researchers, particularly within pediatric clinical and research settings.

DAC2.0 is currently recruiting two positions to support this important work – an Indigenous Peoples' Health Coordinator, and an Administrative and Communications Assistant. A report on this in-person meeting is still pending and will be distributed broadly to the Network once received.

The Workshop concluding with final remarks from our co-Scientific Lead Dr. André Carpentier. The energy from assembling in-person for the first time post pandemic was felt by all and enthusiasm for the work ahead was shared among all Workshop participants.

Special Acknowledgements

In closing, we would like to thank all our speakers and facilitators who contributed to this fantastic event. In particular, our Patient Partners, Seeta Ramdass who moderated the panel on Patient Partnership and Dana Greenberg who presented the Collective Patient Circle update. Our strategy session facilitators, Bruce Perkins, Peter Senior, Joseph Cafazzo, Madison Taylor,

Sonia Meerai, and Aleksandra Stanimirovic, were exceptional at leading these sessions and demonstrating the DAC approach to patient engagement. To, Krista Lamb and Monika Kastner, we thank-you for leading interesting and relevant workshops for the work ahead for our Network and to Monika Kastner, Valeria Rac, Rebecca Ganann, and Linxi Mytkolli we appreciate your time presenting a thought provoking panel which lead to exciting discussion. Thank-you to Jon McGavock from tuning in from afar to present and a very special thank-you to our guests from CIHR, Amy Lang and Jennifer Campbell for their presentation, participation and encouragement on the future of POR in CIHR.

This Workshop would not be possible without the hard work of the DAC admin team and I want to thank Carlos Larrain Herrera, Conrad Pow, Michelle Murray, Linxi Mytkolli and Krista Lamb for all their help in making this event a success. Finally, this Workshop would not be possible without the hard work of Mildred Lim who worked tirelessly with the venue and our members to make sure everything ran smoothly. We have an exceptional team and we are lucky.

Appendix 1: Summary of Participant Evaluation

Diabetes Action Canada Workshop 2022 October 27th and 28th, 2022

Participant Category:

Patient Representative	12
Steering Council / Standing Committee	1
Principal / Co-Investigator of DAC	4
Other	8

Please indicate the extent to which you agree or disagree with the following statements:

	Strongly Agree	A
The duration of the Workshop was just right.	13	1
The Workshop addressed the theme “Telling our Stories about Patient-Oriented Research Outcomes and Challenges to Envision the Future”	15	1
The Breakout Sessions were helpful.	11	1
There was opportunity for me to express my views and/or have my questions addressed.	12	1
On the whole, the presentations and discussion items were informative.	12	1

Which segment of the Workshop did you like most?

The following are paraphrased from the evaluation form and consultations among DAC Staff and Patient Partners. In summary the participants enjoyed the Patient Engagement Panel, the breakout sessions, and opportunities to Network.

- In-person event was great for reconnecting with colleagues and Patient Partners
- The panel on Patient Partnership and EDI
- The session run by Krista on key messages for the Network
- Focus groups were very engaging and the report-backs were helpful for those who wished to participate in more than one session

- Logistics, including the maintaining the schedule went well.
- Patient Partnership in planning the Workshop.
- The CIHR Leads for Patient Oriented Research attended and were fully engaged in Workshop activities.

Which segment of the Workshop did you like least?

The following are paraphrased from the evaluation form and consultations among DAC Staff and Patient Partners. In summary, the participants did not like having too many concurrent events and wanted more time to Network.

- Concurrent meetings with DAC and myROaD made it hard to network
- French translations were rushed and needed further edits to capture the nuances.
- More Patient Partner engagement opportunities to learn about priorities and opportunities to guide research projects
- More lay summaries for complex research processes and projects
- More opportunities for Patient Partners to present
- More opportunities to Network (i.e. Poster Presentations and/or unstructured time)
- The photographer in a more central location

What would you like to see added or removed from future Workshops?

In summary, the participants would like more opportunity to participant in small group discussions/breakout sessions, and an opportunity for the Patient Partners to have a plenary session. More time to Network was a common theme. In sum the comments were very positive with thanks to DAC for bringing everyone together.

Any other comment or feedback