



Patient Partners as Agents of Change

The Diabetes Action Canada (DAC) 2024 Workshop
May 30th and 31st



Diabetes Action Canada

Preventing complications. Transforming lives.

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“This was a conference like no other. It was unique in several different ways. For starters no one had any identifying credentials on their name tags so the conversation flowed naturally without any intimidation of titles.” - Ryan Hooey

INTRODUCTION AND OVERVIEW

Introduction

The Diabetes Action Canada (DAC) 2024 Workshop, held on May 30th and 31st at the Chelsea Hotel in downtown Toronto, marked our most successful event to date. This gathering brought together researchers, healthcare professionals, Patient Partners, trainees, and collaborators in patient-oriented diabetes research under the theme “Patient Partners as Agents of Change.”

Top 5 Takeaways from the DAC Workshop Report

- 1 PATIENT-CENTERED CO-DESIGN:** The workshop was meticulously co-designed with Patient Partners, ensuring their voices and experiences were integral to every aspect of event planning and execution. This collaborative approach highlighted the importance of reciprocal knowledge sharing and the impactful role of Patient Partners in diabetes research and care.
 - 2 INNOVATIVE KNOWLEDGE MOBILIZATION:** The workshop showcased creative methods for closing the knowledge gap, including the use of art and film to convey complex health experiences and research outcomes. These innovative approaches not only facilitated deeper understanding but also engaged a broader audience in meaningful ways.
 - 3 FOCUS ON INDIGENOUS HEALTH:** Dedicated sessions and pre-event activities emphasized advancing anti-racism in healthcare and integrating Indigenous knowledge and practices. These efforts highlighted the systemic barriers Indigenous Peoples face and provided actionable strategies for fostering culturally appropriate care and improving health outcomes.
 - 4 ADVANCEMENTS IN DIGITAL HEALTH:** Interactive sessions explored opportunities for leveraging primary care data, applying artificial intelligence, and addressing socioeconomic disparities. The feedback and suggestions gathered will guide the development of digital health solutions that support both patients and healthcare providers, promoting integrated and proactive diabetes care.
 - 5 RECOGNITION AND NETWORKING:** The workshop included significant networking opportunities, such as the Speed Networking session, which facilitated connections across different roles and expertise levels. Awards recognizing outstanding contributions to patient-oriented research underscored the collaborative spirit and inclusivity of the DAC network, celebrating both new and established members.
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The DAC Team: (L to R) Mildred Lim, Julie Makarski, Gary Lewis, Tracy McQuire, Linxi Mytkolli, Krista Lamb, Carlos Larrain Herrera, Catharine Whiteside, Conrad Pow

Generating the Idea

In 2020, DAC conducted a strategic planning exercise and co-designed a five-year plan with Patient Partners. A key theme that emerged was the need for more meaningful engagement with Patient Partners, providing them with active roles in developing research and communicating outcomes.

In 2022, DAC received continued funding from CIHR as a SPOR Knowledge Mobilization and Implementation Science Network. The funding application focused on the role of Patient Partners in our research activities, with the primary guiding principle being to engage Patient Partners as Agents of Change.

Later in 2022, DAC held its first in-person meeting since the COVID-19 pandemic to launch the second funding term for the Network. During this meeting, we gathered feedback and ideas from participants for themes for our next in-person workshop, held on May 30th-31st, 2024.

“ Being at the DAC workshop as someone with lived experience provided me with a sense of hope that so many other community members researchers and healthcare providers are working towards the common goal of improving the lives of all people with diabetes. ” - Natalie Mangialardi

The following learning objectives emerged from this consultation:

- 1** Understanding the Role of Patient Partners in Knowledge Mobilization in Research
- 2** Appreciating the Role of Patient Partners as Change Agents
- 3** Exploring Successful Case Studies of Patient Partner Involvement
- 4** Identifying Challenges and Opportunities in Patient Engagement
- 5** Developing Strategies for Sustainable Patient-Healthcare Partnerships
- 6** Identifying Roles for Industry in Patient-Oriented Research

These learning objectives were refined by the DAC Steering Council (composed of 50% Patient Partners), the DAC Patient-Oriented Research Committee, and Patient Partner Circles. The overarching theme, “Patient Partners as Agents of Change,” was chosen to unify these objectives. All workshop activities were designed to address at least one of these objectives.



Attendee Overview

One of the standout features of the DAC Workshop was the remarkable diversity and breadth of organizational representation. This year, we were proud to host attendees from a wide range of institutions from across Canada, reflecting the collaborative and inclusive nature of our work. The presence of these organizations underscores how DAC serves as a bridge between researchers, Patient Partners, academic institutions, community organizations, and other stakeholders within the diabetes ecosystem. This diverse participation not only enhances the depth and breadth of discussions but also ensures that our collective efforts are grounded in varied perspectives and expertise.

Organizations Represented:

Healthcare and Research Institutions:

- Alliance for Healthier Communities
- Centre for Addiction and Mental Health
- East Wellington Family Health Team
- North York General Hospital
- Odense University Hospital
- Sunnybrook Research Institute
- The Ottawa Hospital
- Trillium Health Partners
- University Health Network
- Women's College Hospital

Indigenous-led Organizations:

- Indigenous Diabetes Health Circle (IDHC)
- Mississaugas of the Credit First Nation
- National Indigenous Diabetes Association (NIDA)

Academic Institutions:

- McMaster University
- University of Toronto
- Université Laval
- University of Alberta
- University of Calgary
- University of Manitoba
- University of Saskatchewan
- University of Southern Denmark
- Université de Montréal
- Université du Québec à Trois-Rivières

Community and Advocacy Organizations:

- Diabetes Canada
- National Indigenous Diabetes Association
- JDRF Canada (Breakthrough T1D)
- Obesity Canada

Collaborative Networks:

- Novo Nordisk Network for Healthy Populations, University of Toronto
- THETA Collaborative

Other Public and Private Organizations:

- First Nations Health and Social Secretariat of Manitoba
- Prince Edward Island Department of Health and Wellness
- Pluto Pictures
- Past President, Genome Canada
- Institute for Health System Transformation & Sustainability

Patient Partners and Trainees:

Numerous Patient Partners and trainees from various institutions, including McMaster University, University of Alberta, Université Laval, University of Ottawa Heart Institute, and more, contributing their invaluable lived and loved experiences to enrich our discussions and outcomes. Patient Partners brought over 850 years of wisdom to the workshop, embodying the extensive experience and knowledge within our network.

At DAC, we recognize and honour that people hold diverse and intersecting identities. This means that many of our network members might be “twofer” or “threefer”: people who hold two or more overlapping diabetes identities. They might live with diabetes, work in the diabetes field, and study it in their academic pursuits. This rich tapestry of experiences and perspectives is what makes our community so vibrant and effective in driving change.

This extensive representation highlights DAC's role in fostering interdisciplinary collaboration and knowledge sharing across the diabetes community. It is through these diverse contributions that we can continue to drive forward innovative research, effective knowledge mobilization, and impactful patient-centered care.

“ I left the conference feeling confident and ready to tackle more work with amazing people. I felt valued and safe and it’s important for me to be in those kinds of environments. Thank you for all the hard work you put into this year’s meeting. A+++!!! ” - **Sasha Delorme**

PATIENT PARTNERSHIP

Approach to Patient Partnership

The approach to Patient Partnership in research has evolved since DAC started in 2016. We lead the way through innovative programs and best practices to engage with Patient Partners, creating spaces and processes that allow for reciprocal knowledge sharing between the research community and the diabetes community.

Research is a two-way learning process between researchers and Patient Partners. Together, we apply our shared knowledge and ensure the community benefits from the outcomes. Our Patient Engagement Lead, Linxi Mytkolli, played a pivotal role in co-designing the workshop with Patient Partners, ensuring that their voices were integral to every stage of planning and execution.

Workshop Planning Committee

This year, we adopted a new approach to planning by forming a Workshop Planning Committee composed of Patient Partners

and staff who met monthly. We gathered feedback from our researcher members through monthly Patient-Oriented Research (POR) Program meetings to understand the needs of all participants. Our Executive Director, Tracy McQuire, and Business Officer, Mildred Lim, led the Workshop Planning Committee, orchestrating the strategic planning and coordination. Their dedication and attention to detail ensured the workshop ran smoothly, providing an enriching experience for all attendees.



Patient Partner David Wells



Patient Partners who attended the DAC 2024 Workshop.

By categorizing participants during the planning process, we created safe spaces for our sub-committees to be creative in designing the program. From developing engaging session topics to coordinating logistics and ensuring a seamless participant experience, the contributions of the Workshop Planning Committee and the POR Program Committee were invaluable in shaping the workshop's success.

Co-Planning with Patient Partners

The co-planning process with Patient Partners was a cornerstone of our approach. Patient Partners were involved in every step, from brainstorming session topics to selecting speakers and finalizing the agenda. The Workshop Planning Committee co-created a "Things to Know" document that clearly defined and communicated covered expenses, honoraria and cost limitations to Patient Partners and Trainees. Each presenter was invited to meet with the Workshop Planning Committee to review their presentation plan, ensuring the content was appropriate and included aspects of Patient Partnership. This collaborative effort resulted in a well-rounded agenda that resonated with all attendees and highlighted the importance of lived experience in diabetes research and care.

Before the workshop, we sent out all agenda information in advance to frontload the information for accessibility. We offered two daily check-ins for Patient Partners—one during breakfast and one at the end of each day. This was a time for them to connect with each other, ask questions, or share real-time feedback in case anything was wrong or needed attention. Additionally, we hosted a social dinner the night before the workshop exclusively for Patient Partners, providing a more intimate opportunity to connect and build relationships. At that dinner, and throughout the workshop, we had more than 850 years of lived and loved expertise brought by the Patient Partners!

Each night, including the night before the workshop, we also sent reminder emails of the check-ins the following day, and quick recaps of changes or pertinent information and agenda highlights.

All Patient Partners were given the food menus in advance of the workshop to facilitate their calculations for planning medications and movement according to how they each best managed their diabetes. The menus were also co-designed with Patient Partners, incorporating their desire for lots of vegetables, protein, and carb-free options, but also including carbs for those who wanted the autonomy and choice. They even chose to have donuts for dessert at one of the meals, a very welcomed choice,

emphasizing that all people with diabetes should have such options. Patient Partners who take insulin highlighted the importance of meal start times and punctuality because they time their insulin doses before a meal according to the agenda. Punctuality in the schedule was strictly respected as a very intentional response to the needs of Patient Partners.

These supports were co-designed WITH Patient Partners. They told us they wanted more opportunities to build connections and relationships with each other, hence the dinner. They also expressed not wanting their roles identified on their name tags to minimize hierarchical assumptions, so we did not include any roles on anyone's name tags—only first and last names.

Patient Partners wanted to co-present, so they were co-designers in our calls for abstracts and were supported to self-submit abstracts. We worked with all researchers to ensure they had Patient Partners as co-presenters.

To best prepare our presenters, we compiled a facilitator training with the best practices we use in Patient Partner sessions, including language tips, facilitation tips, check-in strategies, communication strategies, and different inclusion strategies Patient Partners have repeatedly told us enable their full participation. We invited all facilitators to a training in advance of the workshop, and sent out the slides as a resource for them afterwards.

Patient Partners wanted to know which presentations had lived experience in the presentation team, so we added a symbol to each agenda item that had a Patient Partner, indicating that someone with lived experience was presenting in that session. We also highlighted specific Patient Partner presentations in the nightly recap and highlight emails to facilitate their support for each other when another Patient Partner was presenting.

Research to Action Fellowship

At the workshop, we introduced a new DAC initiative called the 'Research to Action Fellowship'. This program aims to enable Patient Partners to transform research outcomes into practical real-world applications, leading the transformation of theoretical research frameworks into practical, actionable outcomes.

This six-month paid fellowship will culminate in a dedicated session at the Diabetes Canada Professional Conference in November 2024. It fosters collaboration between Patient Partners and healthcare decision makers. Fellows will participate in capacity-building workshops, receive monthly mentoring sessions, and collaborate with partner organizations to ensure research outcomes are quickly communicated through newly-acquired knowledge mobilization techniques within diabetes communities. The entire program is undergoing evaluation and has received Research Ethics Board (REB) approval for publication.

At the workshop, we introduced the first cohort for the Fellowship – all with a mix of lived and loved experience in type 1 and type 2 diabetes.



Al Martin (DAC Fellow 2024) and Ian Patton (Obesity Canada)

“The biggest takeaway for me was that sharing our lived experience can make a real difference and that DAC creates a safe space where our needs are heard and respected.” - Kitty Shephard

The Fellows include:

- 1 SENAYA KARUNARATHNE** with a background in science communication, focuses on improving diabetes outcomes in the South Asian community.
- 2 RYAN HOOEY** a seasoned advocate living with diabetes for over 30 years, concentrates on enhancing technology access for Indigenous communities.
- 3 AL MARTIN** combines personal diabetes experiences with a strong advocacy for patient-centered healthcare.
- 4 CINDY LUFULUABO** pursuing a Master's in Public Health, is committed to developing culturally relevant health programs.
- 5 MATT LARSEN** a graduate student focusing on diabetes and homelessness, aims to improve knowledge mobilization.
- 6 JEREMY STORRING** an active community advocate, leverages his experience to advance diabetes care and policy.
- 7 NATALIE MANGIALARDI** with a background in community health education, focuses on mental health.
- 8 ROSAN WESLEY** an Indigenous Cree counselor, brings personal insights into diabetes care within her



DAC Research to Action Fellows: From L to R: Senaya Karunaratne, Matt Larsen, Cindy Lufuluabo, Ryan Hooey, Rosan Wesley, Natalie Mangialardi, Al Martin, Jeremy Storrington

Catalyst for Change Award

During the workshop, we introduced the inaugural Catalyst for Change Award in response to calls from the DAC Patient Partner community. This award was co-designed with input and direction from Patient Partners over the span of a year. We began by scoping existing patient partner awards globally to understand their key features. An overview of these features was presented to the Patient Partner circles to support the design of the award.

The entire process, from the name of the award to the nomination process, prize and evaluation criteria, was co-designed to ensure transparency and manage expectations. Nominations and self-nominations were open to all DAC network members, including Patient Partners, researchers, clinicians, and collaborators. This award recognizes the profound impact these individuals have made in furthering DAC's mission through their involvement in research advisory committees and advocacy efforts. More details about the award can be found here: [The Catalyst for Change Award – Diabetes Action Canada](#).

Each awardee participated in a panel discussion during which they shared their experiences, insights, and the impact of their work that led to their recognition.



DAC Catalyst for Change Awardees: (From L to R) Ryan Hooey, Kate Farnsworth, Linxi Mytkolli (DAC Lead for Patient Engagement), Matt Larsen

The adjudication committee selected the following three awardees for this inaugural award:

1 KATE FARNSWORTH: Kate is a prominent advocate in the type 1 diabetes (T1D) community, known for her leadership in the DIY #WeAreNotWaiting movement. She has empowered patients and caregivers to develop and share innovative diabetes management tools, including a Do It Yourself (DIY) closed-loop system, often called an “artificial pancreas,” which automates blood sugar regulation. Kate has been involved in DAC’s Innovations in T1D Program since its inception and serves on the DAC Steering Council.

2 RYAN HOOEY: Ryan is the Patient Partner lead for the DAC Diabetic Retinopathy Screening Program and advocate for better diabetes devices for those who have lost their sight due to diabetic retinopathy. Diagnosed with type 1 diabetes at seven, he lost his vision to diabetic retinopathy at 26. Ryan is actively engaged in the diabetes community, holds a leadership role at the Canadian National Institute for the Blind (CNIB), and collaborates closely with Diabetes Canada on advocacy initiatives.

3 MATT LARSEN: Matthew is a master’s student at the University of Calgary, specializing in Community Health Sciences. His research focuses on the experiences of individuals with homelessness and diabetes, particularly examining coping strategies and resilience. He started with DAC as a Patient Partner in 2018 when he was living with diabetes and experiencing homelessness. In his role at DAC, he has contributed to many research projects and is a member of both the DAC Equity, Diversity, and Inclusion Committee as well as the Collective Patient Circle.



The Inaugural Joint Circles Meeting

At DAC, we have three patient circles: the Collective, Indigenous, and Francophone circles. They meet separately but share information with each other through overlapping members. However, they have expressed the desire for more opportunities to work together and collaboratively contribute to DAC processes and decision-making.

To support this request, we brought the three circles together for a joint meeting at the

workshop. All of the circle chairs and over 80% of the Circle members were in attendance. At the meeting, Dr. Monika Kastner and Julie Makarski presented the preliminary results from their evaluation of patient engagement practices throughout the DAC network. This was followed by a brainstorm on how to implement the findings. Feedback from this meeting will inform the circles' priorities and activities for the upcoming year.

“I was humbled by the number of people who have dedicated their time to helping us and the chance to share my stories.” - Al Martin



Patient Partner André Gaudreau

Recognition of Contributions

To recognize the contributions of the Workshop Planning Committee and others involved in the event several small but meaningful gestures were made. The Workshop Planning Committee members were acknowledged by name at the beginning of the agenda. They were also recognized during the introduction of the event to the larger group.

All members of the Workshop Planning Committee, speakers, and Steering Council members received handwritten thank-you cards from DAC leadership, along with small art prints purchased from Indigenous artist and Patient Partner Michael Alexander. All participants at the workshop were gifted small DAC pins. Patient Partners who attended the event also received art prints from Michael Alexander.

It was incredibly important to recognize the emotional and physical toll that attending these events can have on Patient Partners. These small tokens were well received, as we aim to create inviting and safe spaces for everyone to learn from each other.

At the event, we also recognized two of the foundational members of our network. A video tribute was played at the beginning of the workshop to honor Clarence Nepinak, who passed away in November 2022, shortly after our last DAC Workshop. And André Gaudreau was acknowledged for his contributions to the Training and Mentoring Program development and his ongoing work with the National Health Research Training Platform, MyRoad. Follow-up news stories about these remarkable individuals were featured on our website.

“For myself what made this conference a particular success was the incorporation of research using art and creativity as a means of conveying qualitative data. The Reshape T1D Collection the film Low and the Home Sweet Home(less) photo exhibit were individually and collectively phenomenal.” - **Shayla Hele**

KNOWLEDGE MOBILIZATION

Creative Methods for Closing the Knowledge Gap

The workshop provided an opportunity to showcase the innovative approaches our research teams use in collaboration with Patient Partners to interpret and mobilize research outcomes. Research published in academic journals often takes years to be applied in real-world settings. By utilizing innovative knowledge mobilization techniques, research

can be more readily understood, applied, and adopted by the community, ensuring that outcomes reach those who need them most without delay. Our Knowledge Mobilization Manager, Julie Makarski, was instrumental in crafting and implementing the knowledge mobilization strategies that were central to the workshop.



Images from the “Home Sweet Homeless” - Photovoice Exhibit



Jamie Boisvenue introducing the Reshape T1D team

Key Sessions on Art and Film

Reshape T1D Project

Two sessions at the workshop explored creative methods for closing the knowledge gap: art and film. The Reshape T1D project, initially supported in DAC1.0, seeks to understand how individuals living with type 1 diabetes (T1D) interact with and experience the healthcare system. Led by Jamie Boisvenue (Researcher), the team interviewed individuals with T1D to understand their interactions with the health system and the gaps they encounter when seeking care. Findings showed a desire for safe and empathetic spaces to learn, share, and receive guidance in managing diabetes.

In addition to presenting interview data, the study explored artistic ways to reflect the emotional responses, frustrations, and burdens of participants. At the workshop, 11 pieces of art created by PhD candidate, artist, and Patient Partner Jasmine Maghera were displayed for attendees to reflect on their own experiences. An interactive breakout session led by



Images from the Reshape T1D Art Exhibit

Jamie Boisvenue, Kathleen Gibson (Patient Partner), Heather Hinz (Patient Partner), and Julie Makarski (DAC KT Professional), delved deeper into how individuals with T1D respond to this visual representation of T1D lived experiences and the effectiveness of using visual arts as a knowledge mobilization tool.

Screening of 'Low'

The workshop also featured a screening of the short narrative film 'Low,' which depicts the challenges faced by those living with diabetes and experiencing homelessness. The film is a powerful and realistic portrayal of the barriers encountered by individuals with diabetes in under-resourced emergency shelter environments. Accompanying the film was the "Home Sweet Homeless" Photovoice Exhibit. The story is informed by the research and lived experiences of the Calgary Diabetes Advocacy Committee (CDAC), a group that leads community-based research and advocacy projects to improve the experiences and outcomes of their peers.

Following the film, there was a panel discussion with the team, including David Campbell, Matt Larsen, and Calgarian filmmaker Scott Westby. 'Low' was the most mentioned part of the workshop, with many audience members deeply affected by its portrayal of the confusion between hypoglycemia symptoms and those of addiction or other distress. This film provided a compelling example of how research outcomes and strategies to improve health systems can be communicated and understood by those delivering care.

“ I signed up to participate in the T1D art exhibition breakout room since I love art and creative thinking. When I first saw the option to participate in something like this at an academic conference, I had to do a double take; I thought, 'How could art be applied to something like T1D?'. Little did I know, art provides an excellent outlet to understand and express the complexities of T1D. ” - **Senaya Karunarathne**

The Program

Great care was taken to create a balanced program that underscores the impact of DAC’s operational services on our research efforts. The program was meticulously co-designed with a variety of network members, including Patient Partners, trainees, researchers, operational staff, and clinician scientists. A highlight of the agenda was its variety of presenters, including trainees and Patient Partners. Notably, over 90% of the sessions featured someone presenting with lived or loved experience of diabetes. This was indicated on the agenda with a handshake symbol, signifying that the presentation was being done by or in partnership with someone with lived or loved experience of diabetes.



DAC Steering Council Co-Chair and Patient Partner
Seeta Ramdass

Communications and Promotion of the Workshop

Throughout the Workshop, we employed a diverse approach to our communications and social media strategy. Our Communications Lead, Krista Lamb, contributed content to our LinkedIn, Instagram, and X (formerly Twitter) accounts. We posted updates covering various topics, including the pre-Workshop event on Anti-Racism in Healthcare, keynote speakers, and announcements of our Catalyst for Change Award and Abstract Award winners.

Sample posts include:

Anti-racism training post:

X post
LinkedIn post

Day one post:

X post
LinkedIn post
Instagram post

Panel 1:

X post

Screening of ‘Low’:

X post

Catalyst for Change Winners:

X post
LinkedIn post

Abstract Award Winners:

X post
LinkedIn post
Instagram post

Team thanks:

Instagram post



These posts were shared in real-time during the event and later reposted as ICYMI (In Case You Missed It) updates afterward. As of now, X posts have garnered over 4,000 views, while our Instagram posts reached 180 accounts. On LinkedIn, these posts achieved more than a 50% engagement rate.

Additionally, Patient Partners played a significant role in enhancing our social media presence. Many shared updates on their platforms throughout the event and some were contracted to share their perspectives and insights about the workshop in other ways. Patient Partners also contributed by writing blog posts about the event, which were featured on our website. Each Patient Partner was compensated \$150 for writing the piece.

We also offered to tag participants on our social media accounts if they wanted the added visibility and platform for their work. Asking was an intentional decision, as some Patient Partners do not want to be “outed” for having diabetes, while others are looking for networking expansion and visibility.

Using our website and social media accounts as a platform for this work was a way to change what workshop evaluation looks like. While quantitative evaluation surveys are crucial, storytelling is also a valued and important method of evaluating and sharing our work.

Sample blog posts can be found here:
[DAC Blog Posts](#)

Translations

As a pan-Canadian Network, DAC is dedicated to creating safe and inclusive environments for all members, including those whose first language is French. To ensure DAC Francophone colleagues could fully participate in the DAC Workshop, we provided all materials in both French and English. The agenda was distributed in both languages beforehand and was accessible during the event through QR codes. All presentation materials were translated to ensure printed materials, including posters, slides, and handouts were available in both languages.

Read the agendas:

English: [DAC 2024 Detailed Agenda](#)

French: [DAC 2024 Detailed Agenda - FR](#)

This approach was especially beneficial for visually impaired participants who needed to upload materials to readers before the event. Additionally, one of the posters was provided in braille.

While all presenters delivered their talks in English, we arranged for simultaneous French translation so the Francophone participants could fully engage in the sessions. Audience questions were accepted in both French and English, and most of our moderators were bilingual to facilitate seamless communication.



“ We were also treated to hear the stories of several Indigenous people who came to share and teach us about living with diabetes in communities that have been forgotten by many of us. ” - Al Martin

INDIGENOUS PEOPLE’S HEALTH

Pre-event and Main Workshop Activities

Pre-event: “Cultivating Equity: Advancing Anti-Racism in Healthcare”

The workshop began with a pre-event designed by the DAC Indigenous Patient Circle: “Cultivating Equity: Advancing Anti-Racism in Healthcare.” This day-long session, attended by trainees, Patient Partners and staff, featured a diverse program incorporating traditional Indigenous knowledge and practices with presentations addressing unconscious bias, racism in healthcare, and the Truth and Reconciliation Commission’s Calls to Action.

Councillor Leslie Maracle, who oversees the Nation Wellbeing and Wellness portfolio for the Mississaugas of the Credit First Nation, opened the event by sharing her experiences as a frontline worker in the community.

Invited guests included members of the First Nations Health and Social Secretariat of Manitoba (FNHSSM), as well as Dr. Barry Lavallee, a Métis and Anishinaabe physician and advocate for culturally appropriate healthcare. Dr. Lavallee delivered a powerful message emphasizing the deep connection of Indigenous Peoples to the land and the ongoing harm caused by systemic racism and colonial structures that continue to affect Indigenous communities today.

Breakout sessions and role-playing exercises highlighted the uncomfortable truths of misconceptions, stereotyping, and racist behaviors in healthcare settings. One session,



Cultivating Equality: Advancing Anti-Racism in Health Care session attendees



Elder Barb Nepinak

led by Cheryle Dreaver, Carla Cochrane, and Mike Alexander, revealed the disappointing and harmful experiences many Indigenous Peoples face when accessing care, and the extra efforts required to combat unconscious bias and racism in their healthcare interactions.

The event concluded with a sharing circle where participants discussed the impact the day had on all attendees personally and professionally. This session effectively spotlighted the systemic barriers that persist despite the Truth and Reconciliation Commission's Calls to Action, and how research can better integrate Indigenous knowledge and practices.

The evaluation from this workshop was very positive, and the session is ready to be scaled to larger audiences.

Main Workshop Session: “Disrupting First Nations-specific Racism”

The discussion on anti-racism in healthcare continued into the main workshop activities. Cheryle Dreaver and Carla Cochrane from FNHSSM presented a plenary session titled “Disrupting First Nations-specific Racism: Moving Beyond Cultural Sensitivity Training; Exploring Power and Privilege; Connection to Health and Diabetes.” This interactive session examined the inherent power and privilege held by some and not others and how these dynamics are interpreted in healthcare

interactions. The session also explored the relationship between power, privilege, and social determinants of health, and how this intersectionality influences diabetes prevention and management. It concluded with calls for participants to identify their own unconscious biases, interrupt racist behaviors, and empathize with those who have less privilege and power. Information about a 10-week anti-racism training developed by FNHSSM in partnership with DAC was circulated at the event.



Guest Speakers Cheryle Dreaver and Carla Cochrane from the First Nations Health and Social Secretariat of Manitoba (FNHSSM)



Members of the Indigenous Peoples Circle (IPC): (L to R) Elder Barb Nepinak, Emily McIvor, Sasha Delorme, Tamara Beardy, Melissa Handerson, Michael Alexander

Key Outcomes and Future Initiatives

Insights Gained from the Sessions

The sessions on anti-racism in healthcare provided valuable insights into the systemic barriers that Indigenous Peoples still face within the healthcare system, despite the Truth and Reconciliation Commission's Calls to Action. Participants reflected on their personal and professional experiences, discussing how they could integrate these learnings into their practice and advocacy work. The importance of integrating Indigenous knowledge and practices into research and healthcare was emphasized, as well as the need for ongoing education and training to address unconscious bias and systemic racism. Research involving Indigenous Peoples should prioritize Indigenous-led partnerships, with appropriate funding to ensure their full participation. Projects requesting Indigenous Peoples engagement must address the needs identified by Indigenous communities, rather than added as an afterthought.

Plans for Future Activities and Initiatives

The Indigenous Patient Circle also updated participants on their achievements in DAC2.0 through a panel discussion on Day 2 of the event. Through storytelling and video clips, they shared their experiences, challenges, and triumphs in navigating the complexities of a diabetes diagnosis and advocating for Indigenous health and wellness. They discussed their plans for the remaining funding term, including expanding membership, setting guidelines for effective engagement with Indigenous partners, and scaling the anti-racism workshop.

Moving forward, DAC aims to continue supporting and expanding the anti-racism training program, increase collaboration with Indigenous partners, and ensure that research and healthcare initiatives are culturally relevant and responsive to the needs of Indigenous communities. The positive feedback from the pre-event and main workshop sessions has provided a strong foundation for these future initiatives.

“The DAC workshop showed me that in order to have the courage to share what really matters to us we just need a safe space that facilitates open-hearted listening and the trust that our stories will not only be honored but understood.” - **Matt Larsen**

DIGITAL HEALTH

Digital Health Breakout Session

Summary of Discussions and Findings

Our Digital Health team is evolving to meet new challenges in primary care research, data access, and the privacy considerations essential for data collection and use. To support these efforts, they held an interactive breakout session with Patient Partners, healthcare providers, trainees, policymakers, and technology experts to explore opportunities for leveraging primary care data. The session focused on applying artificial intelligence, addressing socioeconomic disparities to provide equitable care, and establishing pathways for comprehensive management.

The two-hour session yielded several valuable insights and discussions that highlighted the need for collaboration between healthcare groups, emphasizing the importance of co-designing tools with both patients and healthcare providers. Particular emphasis was placed on ensuring primary care physician buy-in and process adoption without hindering their work. Discussions underscored the necessity of building on existing work to create a cohesive healthcare ecosystem.



Digital Health Lead, Alex Singer

Future Strategies

Proposed Strategies for Improving Digital Health and Integrated Care Models

Building on the valuable recommendations from the meeting and feedback from the breakout session, our Digital Health team will work closely with partner organizations to develop a renewed strategy focused on optimizing existing resources. This strategy will prioritize the following areas:

- 1 OPTIMIZING DATA ACCESSIBILITY FOR RESEARCH:**
Ensure that the work produced by DAC improves primary care research, making data more accessible for patient-oriented research.
- 2 ENHANCING INTEGRATED CARE MODELS:**
Continue to promote integrated care models that reduce the burden on primary care practitioners and improve patient outcomes by streamlining processes and incorporating preventive care strategies.
- 3 ENSURING EQUITABLE ACCESS TO CARE:**
Develop strategies to address socio-economic disparities in healthcare access, ensuring that digital health solutions are inclusive and serve marginalized populations effectively.
- 4 FOSTERING COLLABORATION WITH HEALTHCARE PROVIDERS:**
Engage with primary care physicians and other healthcare providers to ensure their buy-in and support for new digital health initiatives, ensuring these tools are adopted without disrupting their workflow.

By focusing on these strategies, the DAC Digital Health team aims to create a more cohesive and effective healthcare ecosystem that supports both patients and healthcare providers in the management of diabetes and other chronic conditions.



“It was exciting to have the opportunity to share insights on the impact of patient engagement in research and have the chance to connect with diverse participants with different life experiences and connections to diabetes.” - **Kitty Shephard**

RESEARCH AND NETWORKING

Research Presentations and Posters

Overview of Research Projects

Diabetes Action Canada’s systematic service approach enhances research design, aiming for better project outcomes. At the workshop, we showcased various research projects that applied principles of Patient Partnership and Knowledge Mobilization, with a focus on Equity, Diversity, and Inclusion (EDI). To plan the program, we issued a call to all DAC members to submit research fitting the workshop theme “Patient Partners as Agents for Change.” The call and application details can be found here: [DAC 2024 Call for Abstracts](#).

We offered three methods for presenting research: Three-minute oral presentations as part of a panel, printed poster presentations, and creative works. Applicants selected their preferred presentation method during the application stage. We received 24 abstracts through our online application system: 11 from

researchers, 4 from Patient Partners, and 9 from trainees. Thirteen applicants requested poster presentations, one requested creative works, and the remaining 10 were adjudicated by the Workshop Planning Committee for selection as an oral presentation. Presentations not selected for oral presentation were offered a Poster Presentation, and all applicants accepted.

The assessment criteria, shared during the application process, focused on the role of Patient Partners in planning, co-designing, implementing, and mobilizing research plans. We encouraged submissions of ongoing research to provide an opportunity for workshop participants to learn, collaborate, and enhance knowledge mobilization efforts. Abstracts were accepted in both English and French; however, all researchers chose to present in English.



Highlights of Oral Presentations and Poster Sessions

The agenda for the Workshop, including the detailed program and abstracts, can be found here: [DAC 2024 Workshop Agenda](#). Below is an overview of the research presented:

Research 3-minute Oral Presentations:

PANEL 1: “Equity and Inclusion in Diabetes Research: Overcoming Barriers and Enhancing Engagement” (May 30th, 2024)

Moderator: Seeta Ramdass, Patient Partner Vice Chair of our Steering Council

Presentations:

- Equitable Uptake and Appropriate Use of Technologies for Adults with Type 1 Diabetes (EQUAT1D): Presenter: Joyeuse Senga
- Adopting a Social Justice and Equity Lens to Co-design a Community-Based Diabetes Screening Intervention in Peel Region: Presenter: Ghazal Fazli
- Indigenous Diabetes Wellness: Co-development of an Indigenous Peer Support Program: Presenter: Sara Scott
- We Can Persist - Exploring the Experience of Shame and Methods of Developing Resilience Amongst People with Lived Experience of Homelessness and Diabetes: Presenter: Matt Larsen

PANEL 2: “Sharing Successful Research Projects Incorporating Patient Partnership: Highlighting Measurable Outcomes and Lessons Learned” (May 31st, 2024)

Moderator: Cindy Bell, Chair of our Steering Council

Presentations:

- Helping Women with Diabetes Quit Smoking: A Gender-informed Approach to Brain Health: Presenter: Osnat Melamed
- The Changing Landscape of Access to Tele Retinal Screening in Toronto Community Health Centres (CHCs) in Urban Settings Among Those Who Self-Identify as Women of Lower Socio-Economic Status (SES): Presenter: Aleksandra Stanimirovic
- From Bench to Community: Innovative Partnerships to Enhance Conversations on Research Breakthroughs in Diabetes: Presenter: Cassandra Locatelli
- Barriers and Enablers to Diabetic Ketoacidosis (DKA) Prevention in Adults with Type 1 Diabetes (T1D): An Implementation Science Study: Presenter: Wajeeha Cheema

Research Posters:

Fifteen posters were showcased, each with a large-print English version and a smaller-print French version for reference. DAC staff translated all English posters into French, ensuring maximum engagement for Francophone members. During the workshop, we held two poster sessions that included poster viewing and timed presentations. These sessions provided participants the opportunity to learn from the presenters, fostering important conversations about ongoing research and advancing the collective understanding of diabetes-related patient-oriented research.

Creative Works:

The ReShape T1D Study Art Exhibit: Eleven pieces of art, created by researcher, artist, and Patient Partner Jasmine Maghera were presented. These visually and emotionally represented the experiences of individuals with type 1 diabetes, reflecting their personal journeys, challenges, and interactions with the healthcare system. Participants were encouraged to interact with the art during throughout the event, sharing their reflections through a survey accessible by QR codes.

“Home Sweet Homeless” - Photovoice Exhibit: Led by researcher David Campbell, this exhibit used photography to highlight the experiences of individuals with diabetes who have experienced homelessness. The photographs, accompanied by written narratives from the participants, challenge stereotypes and encourage viewers to consider the complex realities of diabetes and homelessness.

Outcomes from our Breakout Sessions

Before the workshop, all participants chose one of five interactive breakout sessions. These two-hour sessions were held on Day 1, and the outcomes were shared on Day 2 during a panel discussion. Each session was led by a research team aiming to actively engage with Patient Partners to gain insights on how to implement their research more effectively, identify areas for improvement, and enhance their Patient Partnership activities..

Below are the takeaways from each of the five breakout sessions. Additional information on the respective sessions can be found in [Appendix 2](#) of the Workshop agenda.

1 Diabetes Distress: an experiential workshop on ideal collaborative care

Facilitators: [Peter Selby](#), [Carly Whitmore](#) and [Linxi Mytkolli](#)

Summary:

This workshop utilized story weaving (narrative and improvisation) to explore the experiences of patients, families, and providers navigating diabetes care. The focus was on relational-based care to reduce diabetes distress exacerbated by stigma and shame. Through discussions and an improvised activity involving a ball of yarn, participants shared perspectives, identified synergies, and discussed improvements in health and social care to support mental health for people with diabetes.

Outcomes:

- **Enhanced Understanding:** Participants gained insights into the experiences of all partners in diabetes care, fostering empathy and connection.
- **Identification of Synergies:** The activity highlighted points of commonality and connection among participants, enhancing collaborative efforts.
- **Strategic Planning:** The group collectively identified gaps in health and social care and strategized opportunities for further development to support mental health in diabetes care.
- **Emotional Reflection:** Participants experienced emotional release and reflection, symbolized by the untangling of the ball of yarn, leading to a lighter, more reflective state post-session.



2 Advancing Digital Health for Diabetes: Collaborative Planning and Strategy Workshop

Facilitators: [Alex Singer](#), [Kevin Samson](#) and [Conrad Pow](#)

See the above section on Digital Health for an overview of this session.

3 What are your thoughts about the use of Artificial Intelligence to help screen for complications of diabetes? Application of the Model for ASsessing the value of Artificial Intelligence (MAS-AI)

Facilitators: [Iben FASTERHOLDT](#), [Sonia Meerai](#), [Aleksandra Stanimirovic](#), [Valeria Rac](#), [Jim Bowen](#)

Summary:

Artificial Intelligence (AI) is increasingly being incorporated into healthcare, particularly in the development of medical devices designed to analyze diagnostic images. To address the implications of AI-supported technologies, Denmark has developed the Model of Assessment of Artificial Intelligence (MAS-AI). This model evaluates AI technologies across various domains including ethical, legal, safety, clinical, economic, organizational, and patient aspects. This session provided a concise overview of AI technology in healthcare and detailed the MAS-AI model, focusing on the domains it evaluates. The following outcomes reflect key considerations raised by Patient Partners regarding the use of AI in healthcare.

Outcomes:

- **Building Trust in AI:** Addressing the challenge of building trust in AI among individuals who already distrust conventional healthcare systems.
- **Educational Awareness:** Understanding the context in which AI is used in healthcare necessitates comprehensive education about when, how, and what role AI plays in an individual's healthcare journey.
- **Integrating Equity:** Equity should not only be a separate domain but also an integrated measure across all domains of the AI evaluation model to ensure that AI technologies benefit all segments of the population equally.
- **Accessibility and Cost:** It is crucial to consider how AI impacts populations that lack timely access to technologies due to cost barriers.



4 Optimizing the Integration and Engagement of DAC Patient Partners in Research: Phase 2 of the DAC Patient Partner in Research Study

Facilitators: [Monika Kastner](#) and [Isabella Herrington](#)

Summary:

An ongoing research project, led by Dr. Monika Kastner, began as part of DAC 1.0 and continues to study the needs of Patient Partners for meaningful engagement in research. Data has already been collected from Patient Partner consultations in both English and French, with additional input gathered during the Patient Partner Joint Circle meeting held the evening before the workshop.

To ensure a balanced perspective, it is crucial to include researchers' views on patient partner engagement. Therefore, this interactive session was conducted to gather feedback from DAC researchers, discuss the findings from consultations with DAC Patient Partners, and seek suggestions for developing a comprehensive engagement strategy.

Outcomes:

- **Customization:** Strategies in Patient Engagement should be relevant and tailored to specific research types.
- **Flexibility:** Engagement approaches should not be prescriptive; a flexible model considering all researcher and/or collaborator needs is essential.
- **Differentiate Roles:** Strategies should address the distinction between patient advocacy and patient partnership roles, understanding the type of contributions Patient Partners wish to make.
- **Techniques:** Mentorship among Patient Partners, trainees, and researchers can build relationships and empathy for effective engagement.
- **Inclusivity:** Strategies should be socio-culturally safe, trauma-informed, and considerate of diverse contributions and perspectives, avoiding reinforcement of power dynamics.

5 Mobilizing Knowledge for Clinical Quality Improvement in Type 1 Diabetes: The Reshape T1D Study Art Collection

Facilitators: [Jamie Boisvenue](#), [Jasmine Maghera](#), and [Kathleen Gibson](#)

Summary

The Reshape T1D Study, featured in both a plenary session and creative works display, is a qualitative research project led by patients and clinicians that examines the healthcare experiences of individuals with type 1 diabetes. The breakout session included a 20-minute presentation that outlined the study and showcased its art collection. Following this, participants had the opportunity to reflect individually and participate in group discussions focused on three specific pieces of artwork.

Outcomes:

- **Effective Engagement:** The session demonstrated the effectiveness of using art to engage diverse participants in meaningful dialogue about diabetes.
- **Intimate Interaction:** The large room allowed for private interaction with the artwork, fostering intimate and personal engagement despite the smaller group size.
- **Knowledge Translation:** The results suggest that art-based knowledge translation could be an effective strategy for incorporating insights into diabetes clinical practices and spreading awareness within diabetes communities.

Networking

Description of the Speed Networking Session

The facilitated Speed Networking session was created in response to requests for more opportunities to build connections across the network. Patient Partners and trainees expressed a preference for opportunities where power structures were diffused, so we intentionally designed this session to address those needs.

We asked a variety of members to be mentors for the Speed Networking, including Patient Partner leaders, executive directors, clinician scientists, program managers, and more. The mentors' roles were not identified on their name tags to ensure an equal playing field, and participants were invited to take a seat at a table without knowing the mentor's background. Structured rotations allowed participants to spend 10-15 minutes at each table, fostering an environment where both mentors and participants could learn from each other.

This intentional design diffused power structures, encouraged knowledge sharing, and facilitated connections between individuals who might not have otherwise interacted. It allowed for the recognition that the value and wisdom an executive director brings is equally as valuable as that brought by a Patient Partner.

Held at the end of Day 1 before dinner, this session provided an injection of energy and enthusiasm, allowing participants to approach and learn from others without feeling intimidated. Feedback from workshop evaluations showed that this session was a favorite among participants, many of whom noted how it personally and professionally benefited them.



“I have been to at least five conferences and this one was by far my favorite. All the details really made it epic. The menu was sent via email with carb counts so people could give insulin knowing the amount no accolades on the name tags which made it easier to approach someone and ask how they're involved with DAC.” - **Sasha Delorme**

Abstract Awards

Details on Award Criteria and Winners

Abstracts presented as both oral and poster presentations were evaluated by Patient Partners to recognize outstanding contributions to diabetes patient-oriented research. Awards were based on several criteria, including the overall quality of the presentation, the degree of patient partnership integration—whether in theory or practice—and effectiveness in communicating through visuals, lay language, and creative means. These awards celebrate excellence in research, spotlighting presentations that demonstrate creativity, rigor, and potential for real-world application.

Of the three winners, two awards went to Patient Partner recipients and one award went to a project outlining an Indigenous Wellness Program co-designed with Indigenous Communities. All awardees were also new members of the DAC network, highlighting the inclusive and collaborative spirit of our community.

Award Categories and Winners:

- 1 Best Overall Oral Presentation: Wajeeha Cheema**, Patient Partner and volunteer with the Lunenfeld-Tanenbaum Research Institute and Leadership Sinai Centre for Diabetes, presented “Barriers and Enablers to Diabetic Ketoacidosis (DKA) Prevention in Adults with Type 1 Diabetes (T1D): An Implementation Science Study,” focusing on developing educational tools and infographics to promote behavioral changes and reduce DKA implications.
- 2 Best Overall Poster Presentation: Natalie Mangialardi and Kitty Shephard**, Patient Partners with DAC and members of the Patient Advisory Council, presented their poster titled “Beyond the Usual Participant Profile,” exploring a novel and comprehensive approach to engaging young adults aged 18-29 living with T1D.
- 3 Most Innovative Patient-Oriented Research: Sara Scott**, Registered Nurse and PhD Student under Dr. David Campbell, presented “Indigenous Diabetes Wellness: Co-development of an Indigenous Peer Support Program,” focusing on co-designing an Indigenous peer support protocol.



Abstract Award Winners: L to R: Wajeeha Cheema, Kitty Sheppard, Natalie Mangialardi, and Sara Scott

“ Using our website, as well as our social media accounts, as a platform to share our work is very important to us. It was also a way to change what workshop evaluation looks like. While we are used to having evaluations be quantitative, storytelling is a very valued and important method of evaluating and sharing back our work. ” - **Linxi Mytkolli**

EVALUATION

Participant Feedback

What Participants Liked Most About the Workshop

The evaluation for the workshop received a record number of responses, with 54 out of 110 participants completing the survey. Of those who completed the evaluation, 22 were Patient Partners, 12 were researchers, 4 were trainees, 2 were representatives from non-profit/charitable organizations, and 14 identified as ‘other.’

Participants appreciated the variety of sessions beyond traditional research presentations, such as networking exercises, art exhibits, and interactive activities. The opportunity to connect with diverse attendees, including Patient Partners, healthcare professionals, researchers, and individuals from various backgrounds, was particularly valued. Many

noted the unique chance to hear firsthand experiences from Patient Partners, which provided deep insights and shifted perspectives. The inclusive atmosphere, where titles were not used on name tags, fostered a sense of equality and openness.

Overall, attendees enjoyed the engaging mix of media, including movies, videos, and art, and praised the workshop’s organization, variety, and focus on patient engagement and interdisciplinary collaboration. The event was seen as a valuable, inspiring, and educational experience, with many expressing the desire for it to be hosted again on an even larger scale.



Suggestions for Improvements and Changes

Attendees provided several suggestions for improving future workshops:

Logistics: Better navigation instructions for the hotel and adjustments to the air conditioning settings were recommended.

Program Pacing: Participants suggested a slower pace for the program to allow more time for interaction and reflection.

Patient Partner Involvement: Many expressed a desire for more opportunities for Patient Partners to share their perspectives and connect with each other.

Trigger Warnings: The addition of trigger warnings for sensitive content was recommended.

Poster Sessions: Participants wanted more space around poster areas and more structured attention to poster presentations.

Networking and Breaks: There were suggestions for longer breaks, an easier method for networking, and extending the workshop to allow for relaxation and informal interactions.

Meals and Facilitation: Recommendations included providing plated meals and better support for session facilitators.

Representation: While there was recognition of the efforts to include Indigenous communities and Francophone Patient Partners, participants suggested that better representation could be achieved in future events.

Overall Impressions and Evaluation Results

The workshop received overwhelmingly positive feedback, with attendees expressing gratitude and appreciation for the well-organized and informative event. Participants felt seen, heard, and valued, highlighting the inclusive atmosphere and the opportunity to network with diverse individuals.

The event was praised for its impactful content, excellent organization, and the successful integration of Patient Partners into the discussions. Many attendees emphasized the importance of expanding such initiatives on a larger scale and expressed eagerness for future events. The dedication and teamwork of the DAC team, particularly Tracy McQuire and her team, were widely commended.

Overall, the sentiment from participants was one of satisfaction, inspiration, and anticipation for continued collaboration in diabetes research and advocacy.



DAC Team Members Tracy McQuire and Linxi Mytkolli

“This event really personified how collaboration and equity are at the core of their mission and I am so excited to see what the future brings.” - Kitty Shephard



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Contact Us

For more information, please contact:

Diabetes Action Canada

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

T: 416-340-4800 x2522

E: info@diabetesaction.ca

www.diabetesaction.ca

To support Diabetes Action Canada, please contact:

Shannon Carkner, CFRE
Campaign Director, Major Gifts UHN Foundation

T: 437-335-1156 **E:** shannon.carkner@uhn.ca

X @_DiabetesAction **in** diabetesactioncanada

Strategy for Patient-Oriented Research

