



2018 DIABETES ACTION CANADA ANNUAL WORKSHOP

Summary Report

Abstract

Diabetes Action Canada conducted its Annual Workshop on May 4th – May 5th, 2018. The theme for the event was “Enabling Effective care Paths for People Living with Diabetes”

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2018 ANNUAL DIABETES ACTION CANADA WORKSHOP REPORT

THEME:

“ENABLING EFFECTIVE CARE PATHS FOR PEOPLE LIVING WITH DIABETES”

Workshop Preparation

The theme of the 2018 Annual Workshop was to address the following question. ***Based on progress to date, will the projects underway either in planning or implementation stages provide the evidence for design and scale up of care paths for prevention of diabetes and its related complications?*** The Diabetes Action Canada Program Leads, including Patient Partners, prepared for discussion with all the participants at the Workshop in breakout sessions leading to advice about their project deliverables and potential impact. The Workshop was conducted in English and in French with simultaneous translation (with headsets) in both languages. The majority of the visual presentations and written materials (agendas, facilitation notes) were provided in both English and French.

The leadership of Diabetes Action Canada extends our sincere thanks to the Workshop Planning Committee members (Table 1) and our staff (Tracy McQuire, Mildred Lim and Jessica Antwi) for their hard work and commitment to ensuring the success of the Workshop.

Table 1: List of the 2018 Diabetes Action Canada Workshop Planning Committee

Name	Role
Bajurny, Virtue	Patient Partner
Borja, Jaime	Patient Partner
Drescher, Olivia	Project Coordinator, Patient Engagement
Drummond, Neil	Co-investigator
Freitas, Adriana	Project Coordinator, Knowledge Translation
Gaudreau, André	Patient Partner
Gray, Ross	Patient Partner
Légaré, France	Co-Lead, Knowledge Translation
Lim, Mildred	Business Officer
Maman, Joyce Dogba	Co-Lead, Patient Engagement
McComber, Alex M.	Co-Lead, Indigenous Peoples Health
McGavock, Jonathan	Co-Lead, Indigenous Peoples Health
McQuire, Tracy	Manager, Research Operations
Mumford, Doug	Patient Partner
Murray, Michelle	Project Coordinator, Training and Mentoring
Nepinak, Barb	Patient Partner

Name	Role
Nepinak, Clarence	Patient Partner
Robertson, Tsoieon Kary	Administrative Assistant, Indigenous Peoples Health
Sadi, Pusha	Project Coordinator, Indigenous Peoples Health
Sissmore, Debbie	Patient Partner
Sutakovic, Olivera	Project Coordinator, Diabetic Retinopathy Screening
Whiteside, Catharine	Executive Director
Witteman, Holly	Co-Lead, Patient Engagement, Patient Partner
Zettl, Mary	Project Coordinator, Patient Engagement

Workshop Outcomes

Diabetes Action Canada - Overview – Dr. Gary Lewis, Co-Scientific Lead and Nominated Principal Investigator

Dr. Gary Lewis presented an overview of the current and anticipated future Programs of Diabetes Action Canada. The purpose was to provide a brief update to all the participants on the many activities managed by our SPOR Network. He emphasized the importance of the engagement of our Patient Partners in the co-design and implementation of all of these projects and activities.

The Diabetes Action Canada Programs are now organized into two main categories:

Specific Goal-Directed Programs

- Retinopathy Screening – to prevent blindness
- Indigenous Peoples Health – to address the diabetes epidemic among Canada’s Indigenous Peoples
- Aging, Community and Population Health Research – to support elderly people who have diabetes and a number of other associated illnesses
- Digital Health Solutions to improve Diabetes Research and Care
- Innovations in Type 1 Diabetes
- Foot Care to Prevent Diabetes-related Amputations

Enabling Programs that support the above Goal-Directed Programs

- Patient Engagement – to advise and inform the research of our Network
- Knowledge Translation – to move new knowledge gained from research into practice
- Training and Mentoring – to build the new generation of diabetes researchers as well as the members of our Diabetes Action Canada network team
- Sex and Gender – to integrate equality into diabetes research and care

Each Goal-Directed Program engages in research-related activities. The Enabling Programs provide guidance and support for all of the specific Goal-Directed Program Groups. Two new specific Research Goal-Directed Programs were added over the past year to address urgent needs for improving outcomes for all persons with diabetes. The first, **Aging, Community and Population Health Research**, aims to improve health outcomes for seniors with diabetes who live with multiple chronic conditions. The second, **Foot Care to Prevent Amputation**, aims to prevent the risk of developing foot ulcers leading to amputations. It is anticipated that over the next year considerable progress will be made in all Programs. For further details of the presentation please see (<https://diabetesaction.ca/diabetes-action-canada-annual-workshop-2018/>).

Report from Patient Partners

The three Patient Partner Circles were invited to provide an overview of their engagement with Diabetes Action Canada including their goals and activities. The following summarizes their presentation and discussion.

Collective Patient Circle

The report from the Collective Patient Circle was presented by Sasha Delorme and Howard English. They opened by reminding the Workshop participants that their Circle includes members from the two other advisory Circles (the Francophone and Immigrant Patient Circle and the Indigenous Patient Circle described in greater detail below). The collective expertise of all the members informs our Network at multiples levels.

The Mission of the Patient Circles is to build capacity and momentum in patient-oriented research by regularly assembling Patient Partners to accomplish the following:

- Give feedback on Network research;
- Discuss areas and priorities for future research;
- Bring patient perspectives to researchers in their design and preparation of grant applications;
- Build connections between Patient Partners, Network researchers and health care professionals; and,
- Spread knowledge of Network activities (in and outside of the Networks).

The Collective Circle is composed of individuals with Type 1, Type 2 or other types of diabetes, pre-diabetes and caregivers ranging in age from 20 to 73 years from five provinces (BC, SK, MB, ON, QC). Over the past year, they have held seven meetings with shared responsibility of chairing these meetings and the implementation of effective, respectful and professional communication. Five members liaise with the other two Patient Circles. An additional 15 Patient Partners have been recruited to Diabetes Action Canada through member of the Collective Circle over the past year. An important activity for this Circle has been the provision

of feedback to Diabetes Canada on the dissemination and implementation strategy for their 2018 Clinical Practice Guidelines.

The Collective Patient Circle members have been very active in providing feedback to researchers on their SPOR grant applications and project content. Five researchers shared full grant proposals and one-page summaries with the Collective Patient Circle and the members provided oral and written feedback during a Circle meeting or through email. Many of the members are directly involved in co-design of research projects including the integration project with the Sex and Gender Program and the environmental scan project with the Knowledge Translation Program. Most of the members are engaged in the 'Patient as Teachers' research project with the Patient Engagement Program. A number of members are actively engaged as co-Leads in the Goal-directed programs or on key oversight Committees including the Diabetes Action Canada Steering Council and Repository Research Governing Committee.

Eleven members of the Collective Circle have completed the Network's Patient-Oriented Research training program and found the modules to be informative. It was appreciated that the same training is also offered to patients, practitioners, caregivers and researchers.

Here are some quotes about how the Collective Circle Patient Partners experience their engagement with Diabetes Action Canada:

"It is rewarding to have a voice and influence research that is being done in and for our community."

"We understand just how relevant and important our knowledge and experiences are to our community and research being conducted for it."

"Diabetes Action Canada has allowed us to create meaningful relationships with many individuals."

"We have learned a lot about current research and how our community can and should be involved in this research to create relevant and useful data".

"...added to my life a sense of belonging and that my voice is being heard.has made a huge impact in my life"

Francophone and Immigrant Patient Circle

This report was presented in French by Nadia Tabiou, Patrice Bleau and Jaime Borja. Their opening statement referred to the overall Mission of the Patient Circles (above) and that the collective Patient Partner expertise from this Circle informs the Network at multiples levels:

- Comment and bring feedback on francophone research projects;
- Bring together diverse points of view from rich cultural backgrounds; and,
- Support the development of research projects in French

Currently, this Patient Circle has 13 members (7 women, 6 men) ranging in age from 38 to 82 years. It is composed of individuals from six different countries (Canada [Quebec], Brazil, Chile,

Cuba, Togo, Tunisia). In July 2017, the Immigrant Patient Circle and Francophone Patient Circle decided to merge and subsequently three meetings with the amalgamated group have been held. This Circle has contributed to implementing Patient partnerships with Université Laval's integrated Health Network. It has contributed to the review of a SPOR research grant application (in French) submitted by Dr. André Carpentier. Members of the Circle have now engaged in the co-design of three new SPOR research projects that are focused on challenges faced by ethno-cultural minorities. In addition, three members provide a bilingual liaison with the Collective Patient Circle. Patrice Bleau has been recruited to serve on the Diabetes Action Canada Repository Research Governing Committee. Two members were Scientific Ambassadors at the Diabetes Canada Professional conference in Edmonton in 2017. Patient Partner engagement and expertise is being provided to both the Knowledge Translation and Retinopathy Screening Programs. Eight members have completed the Network's Patient-Oriented Research Training sessions.

Overall, the members of this Patient Circle are satisfied with their participation in Network activities. In particular, they confirm that the Network is successfully promoting and building awareness of the Patient-Oriented Research approach within its activities. They are recommending that a dozen new Patient Partners be recruited for Diabetes Action Canada and that more involvement in Network activity be organized, e.g., collaboration with the Training and Mentoring Program where Patient Partners co-facilitate the training sessions. The Circle articulated the ongoing challenge that the majority of research is conducted in English.

A recommendation of the Workshop members was that more new immigrant Patient Partners be recruited from across Canada, not just from Quebec.

Indigenous Patient Circle

This report was presented by Alex M. McComber. The Indigenous Patient Circle provides a platform to voice the unique issues and perspectives of Indigenous Peoples and their health. Composed of 11 Indigenous representatives from across Canada, these Patient Partners are affected by Type 1 and 2 Diabetes as patients and caregivers. They influence the work of researchers by taking part in strategic goal planning and orientation of the Network. The Indigenous Partner organizations include: San'Yas Indigenous Cultural Safety Training; First Nation Health and Social Secretariat of Manitoba; National Aboriginal Diabetes Association; Indigenous Diabetes Health Circle; Chiefs of Ontario; and, Kahnawake Schools Diabetes Prevention Project. SPOR Partner organizations with whom our Indigenous Patient Partners and researchers collaborate include: Can-SOLVE- CKD (Kidney); Centre for HealthCare Innovation (MB Support Unit); Manitoba Centre for Health Policy; Ontario SPOR SUPPORT Unit; and, Quebec SPOR SUPPORT Unit.

Since the inception of the Indigenous Patient Circle, its members have engaged in the following activities. In May 2016, Patient Partners were invited to the first annual meeting of Diabetes Action Canada and their participation had important impact on the subsequent planning and direction of the SPOR Network. In September 2016, members of the Indigenous Patient Circle

met in Thunder Bay and Diabetes Action Canada researchers and staff participated in the National Aboriginal Diabetes Association annual meeting. In November 2016, a PATH Exercise was conducted with the Patient Circle in Kanhawake, QC, assisted by an expert facilitator and attended by Gary Lewis, Diabetes Action Canada's Co-Scientific Lead. The Indigenous Patient Partners are now actively engaged in the prospective planning with the Indigenous Peoples Health Program for the ripple-out of successful projects including the Aboriginal Youth Mentorship Program and new projects.

In May 2017, the Diabetes Action Canada Annual Workshop focused on the health challenges of Indigenous Peoples living with diabetes with most of the Indigenous Patient Circle members contributing to the learning of the participants by sharing their lived experience and knowledge. In conjunction with this meeting, the members of the Indigenous Patient Circle visited Anishnawbe Health in Toronto to establish a new relationship with this inner city urban Indigenous Community Health Centre. In September 2017, the Indigenous Patient Circle met in Niagara Falls and attended the Indigenous Diabetes Health Circle conference. In October 2017, the Patient Partners of Diabetes Action Canada and Can-SOLVE-CKD met in Vancouver to engage in Patient-Oriented Research training development. In November 2017, Diabetes Action Canada hosted an Indigenous Health Symposium at the Diabetes Canada annual conference in Edmonton with major emphasis on the needs of Indigenous Peoples living with diabetes.

In March 2018, Patient Partners of Diabetes Action Canada and Can-SOLVE-CKD met in Winnipeg to further develop an Indigenous-focused Patient-Oriented Research Training program. In May 2018, many members of the Indigenous Patient Circle participated in the Diabetes Action Canada Annual Workshop and contributed to the understanding of where research, education and knowledge translation activities must focus to improve health outcomes for Indigenous persons living with diabetes.

The Indigenous Patient Circle will have Patient Partner presence at the upcoming Diabetes Canada annual conference in October 2018. In the fall of 2018, they will also participate in an important meeting in Winnipeg for the planning of a national project to create an Indigenous Diabetes Health Atlas with guidance of Indigenous research leaders from across Canada.

Keynote Interactive Address – Maureen O'Neil

Diabetes Action Canada was very pleased to welcome Maureen O'Neil, President of the Canadian Foundation for HealthCare Improvement as our Keynote Speaker. She began her talk with a summary of the spread and scale-up across Canada of the very successful INSPIRED Chronic Obstructive Pulmonary Disease (COPD) program. This initiative started with one site in Nova Scotia. It enables the chronic care of individuals with COPD to move from the hospital to the home with transformation impact on patient experience and outcomes as well as the sustainability of healthcare. This program is an intensive home care approach that provides the right services at the right time to patients with COPD, improving self-management and reducing

the need for inpatient hospital admissions. Maureen indicated that too often people with chronic diseases like COPD end up in acute or longterm care facilities because the care they need is not available in the community. Teams formed by coalitions of hospitals, health regions/systems, primary care organizations and community partners provide the INSPIRED community-based services. These services are being scaled up in multiple provinces at over 50 sites and by 2021 to reach 5,800 patients avoiding \$688 million in acute care costs.

For the majority of her Keynote, Maureen engaged in a very successful interactive discussion with the Workshop participants. She addressed questions from the floor and then encouraged others in the audience to provide their views. We focused on how a program like INSPIRED could inform the goals and projects of Diabetes Action Canada. Maureen encouraged all the members of our SPOR Network to advocate for the necessary change in our health care system to improve the outcomes of persons living with chronic conditions like diabetes and its complications. We were truly inspired by her leadership and the impact of the Canadian Foundation for HealthCare Improvement on improving outcomes for Canadians living with chronic conditions. The experiences share with the INSPIRED programs were highly relevant to our diabetes-related activities.

Maureen's Keynote discussion set the stage for the discussion in our breakout sessions.

Summary of Advice from the Goal-Directed Program Breakout Sessions

Each participant at the Workshop was assigned three breakout sessions of their choice. The breakout sessions were led by four Research Goal-Directed Programs (Retinopathy Screening, Innovations in T1D, Indigenous Peoples Health, Digital Health for Diabetes Research and Care) and one Enabling Research Program, Training and Mentoring Program. Prior to the Workshop, Program Leads provided a one page summary of their goals and projects to date. During the sessions, the participants discussed their views of these goals and projects and advising about their potential impact on the most serious health challenges experienced by persons living with diabetes. On the last day of the Workshop, the Program Leads reported back on the advice they received and their anticipated next steps to address these important recommendations.

The following summarizes the key themes emerging from all the participant feedback at the Workshop. Appended are the individual reports from the Workshop sessions.

ACCESS to Effective Care Paths

Although evidence-based guidelines are available, and pockets of successfully integrated care paths exist, e.g., Aboriginal Youth Mentorship Program, Tele-ophthalmology sites for diabetic retinopathy screening, a large gap remains in accessing screening for complications and providing the right care at the right time for persons living with diabetes. Hence, the prevalence

of T2D and preventable complications such as blindness and amputations remain all too frequent. Diabetes complication rates remain highest among the most vulnerable and high needs communities who do not have access to fundamental necessities to promote wellness. Food security is a major challenge – access to affordable healthy foods must be tackled. Access to internet services in the north and remote areas remains a major challenge for connecting communities to health services. Access to community services and home visits by health professionals who can navigate the complex health system for persons living with diabetes and other chronic conditions must be provided to improve self-management. Design, implementation and access to end-to-end care paths for comprehensive and sustained prevention of foot ulcers, cardiac and renal risk factors, vision loss, and hypoglycemia remain the key concerns of persons living with diabetes and their care-providers. Use of digital health information to assist in navigation of the health system by both patients and health care providers would improve access to customized care paths.

COMMUNICATION and LEARNING – overcoming the barriers

Understanding the barriers and limitations experienced by persons living with diabetes and their care-providers including family, community health workers, health professional teams and local health authorities requires effective communication and learning. Digital assistance in accessing information by persons living with diabetes and for communicating with health providers, e.g., mobile phone app – *bant*, would be preferred by some, although not all individuals. Privacy and security are critically important to ensure health data are managed safely and for specific purposes including diabetes-related research.

The projects now underway, supported directly or indirectly by Diabetes Action Canada, engage many communities, health professional services and provincial health systems. Internal communication among the Program Leads is essential to integrate research objectives and their implementation. For instance, foot care to prevent amputation and retinopathy screening include both rural and inner-city Indigenous communities, but the Indigenous Peoples Health Program has yet to be involved in these projects. Improved communication and learning among the research Goal-Directed Program Leads and investigators would enhance networking and the scope and scale of our projects. Further, our Programs are collaborating with other SPOR Networks including Can-SOLVE CKD and the Primary Integrative and Health Care Innovation SPOR Networks. Similarly, improved communication and learning among our SPOR Networks, and SPOR SUPPORT Units, are necessary for optimizing collaboration in the context of designing and implementing new models of care and prevention for chronic disease management.

IMPLEMENTING QUALITY STANDARDS to achieve improved health outcomes

The evidence-based diabetes clinical practice guidelines recently released by Diabetes Canada are up-to-date and highly informative. Health quality standards for diabetes and its complications management are not uniformly available in each province and territory. For

instance, Health Quality Ontario has published excellent quality standards for diabetic foot care, but has not published standards for comprehensive diabetes care. Diabetes quality standards for Indigenous Communities are variable across Canada. The Diabetes Action Canada Indigenous Peoples Health Program in collaboration with the National Aboriginal Diabetes Association could lead the development of quality standards customized for Indigenous Peoples. Although the challenges faced by Indigenous communities are complex and varied, there is increasing recognition that First Nations, Inuit and Métis Peoples possess the knowledge, determination and resilience rooted in their varied traditions and cultures to meet those challenges. Diabetes quality standards for Indigenous Peoples must be based on the Truth and Reconciliation recommendations and aided by culturally-appropriate care in the maintenance and enhancement of their health and well-being.

ADVOCATING FOR CHANGE – connecting with health system decision-makers

The major health care and prevention challenges experienced by persons living with diabetes and their care-providers require multi-sector (federal, provincial, municipal) and public-private (e.g., food industry) engagement and commitment to achieving collective impact. Diabetes Action Canada’s projects must focus on “how” to implement, scale and spread effective solutions within health care systems (in each Province and Territory) that fulfill the Quadruple Aim goals. A key question arising from Patient Partners, Steering Council members and Investigators at our Workshop is ***“Who can and will advocate for the necessary policy and funding changes that will enable the wide-spread adoption of these solutions”?*** It was agreed that advocacy is needed, and that a role of Diabetes Action Canada is to identify and work with stakeholders and influencers in both the public and private sectors who can and will advocate for change. It was also recognized that our health system research deliverables must include the design and evaluation of solutions for transferring knowledge/evidence into policy and practice. Building patient-oriented research capacity in this field of knowledge transfer is essential for the development and implementation of a “learning health system” and the accompanying change management required to achieve improved outcomes for persons living with diabetes.

EVALUATING OUR IMPACT – establish external, independent review

The Steering Council has clearly articulated the need for cogent and timely evaluation of the projects underway supported by Diabetes Action Canada. Clear deliverables must be identified for each activity and the outputs and outcomes must address the stated Mission of Diabetes Action Canada. The management of Diabetes Action Canada expects that our Programs and Project Leads will be producing outputs and intermediate outcomes that can be reported at our 2019 Annual Workshop. Critical evaluation of progress and deliverables over the next year will stimulate our Program Leads to address the challenges of access, communication and learning, implementing quality standards and advocating for change. This evaluation will be highlighted in the 2019 Annual Diabetes Action Canada Report to CIHR.

In the SPOR Network application, we stated that a Scientific Advisory Committee composed of national and international experts would be established. The purpose of the Committee would be to provide external evaluation of the overall Network activities and recommendations for future directions. The timing for this external review mid-point in our Network activities would coincide with the planning for renewal of the SPOR Network.

WORKSHOP EVALUATION

A Workshop evaluation survey was conducted immediately following the event. Participants were offered the opportunity to fill out the survey in writing before they left the event or through email contact. The same survey was provided in both the paper and web-based format. The detailed report with comments from the participants is appended.

Of the 34% of participants who completed the survey, over 90% indicated that they strongly agreed or agreed that;

- The duration of the Workshop was just right;
- The Workshop addressed the theme of “Enabling Effective Care Paths for People Living with Diabetes”;
- The Breakout Sessions were helpful;
- There was opportunity to express their views and/or have questions addressed; and,
- Holistically, the presentation and discussion items were informative.

The comments from the participants were particularly helpful and indicated that there was considerable improvement in the venue based on our learning from the previous two annual Workshops. Further, many good recommendations were provided for the Workshop planning committee to consider for next year.

APPENDIX 1: Reports From the Workshop Breakout Sessions

Diabetes Action Canada Annual Workshop – Diabetic Retinopathy Goal Group

THEME #1: Improving Patient Experience in Healthcare System

Our interest was focused on **Patient Partner Feedback** and to hear about barriers that they have experienced when trying to have Diabetic Retinopathy screening. The most frequent barriers are:

- ACCESS: Inconvenient screening times 9-5, location, long wait times, transportation
- COST: Patient perceived or real costs; Capital costs of the equipment and personnel/training
- INDIGENOUS CONCERNS: time of year, language of care delivery, cultural awareness
- IMMIGRANT CONCERNS: lack of trust of system, fear of results affecting job, immigration status
- AWARENESS / EDUCATION GAPS
- FEAR / DENIAL

Our tele-retina screening program has been developed to address some of the well known barriers (Access- screening centers are open on weekends or after regular hours in CHCs and closer to patients home; tele-retina screening exam is fully covered - no extra fee to patient). We recognize the challenges of accessing immigrants and indigenous communities. Currently, our research project in collaboration with the Ottawa and Laval groups will enable us to understand how different vulnerable populations with higher risks of developing diabetic retinopathy experience barriers to screening and how we can increase DR screening attendance among people living with diabetes and belonging to ethnocultural minorities.

During the workshop, the point was made quite strongly that there needs to be a trusted community champion for a program to succeed. If one person in the community has a negative experience, the story of it can spread quickly through the community, resulting in the community reluctance to continue or engage in the program. The trusted community champion can spread the word about the program and encourage community members to attend screening, which helps to better facilitate our work, addresses language barriers and cultural awareness to get information directly to patients. We believe that the program is adaptable to accommodate personal views, beliefs and values as we reach out to different communities among the diverse population across Canada. Now we are exploring a group called the RANGERS who are indigenous people. Potentially, the Rangers are able to help us get diabetic retinopathy screening into Indigenous communities. We are actively working to close the gap in awareness and education of local health professionals. Furthermore, patients play a crucial role in disseminating knowledge about the screening program and their personal experience.

THEME #2: Scaling-up Successful Community- Based Program

THEME #3: Solutions to Improve Diabetes Self-Management

THEME #4: Strategic Partnerships for Sustainability

Our biggest challenge is to identify and directly contact people living with diabetes but are without evidence of retinopathy screening. We have been working closely with the UHN Network - Digital Health group on enabling a population health management approach in Ontario to help us to identify people with diabetes who have not had an eye exam in the past 1-2 years and to establish a mechanism to notify such individuals. We asked our **Patient Partners for Feedback**: If you were to get a letter from your doctor or ophthalmologist that it is time to get your eyes screened would it be helpful or would it risk offending or upsetting you? We received a positive response, a reminder letter would help.

Diabetes Action Canada Annual Workshop – Digital Health Group

THEME #1: Improving Patient Experience in Healthcare System

Feedback:

- Need to be clear about why we are gathering data and what the Repository is for?
- Make data dictionary available on-line with summary of data quality.
- Patients want their experiences with the health system captured, and the results or outcomes of their treatment made available to them.
- Are we trying to be too much for too many?
- Patients want to access data via mobile apps.
- Patients want a dashboard view.
- Patients want us to capture data for a handful of patients and then test it.
- *bant* is planned to add peer to peer networking. Patients might feel that they are speaking to their physician. Who is monitoring the information being provided? What if someone mentions suicide, for example? What do we do?
- You asked “why are we doing what has already been done?” Our answer is:
 - Multi-sectoral
 - Social economic data
 - Admin data
 - Clinical decision support
 - Pan Canadian

Action Items:

- Data dictionary needs to be made available with summary of data quality

THEME #2: Scaling-up Successful Community- Based Program

Given time constraints this theme was not addressed.

THEME #3: Solutions to Improve Diabetes Self-Management

Feedback:

- Patients want their experiences with the health system captured, and the results or outcomes of their treatment made available to them.
- Patients do not want to be burdened with data entry.
- Patients want to access data via mobile apps.
- Patients would like *bant* used for appointment reminders, alert for physician, as a platform for clinical trials information and recruitment and for consenting patient for research studies.

Action Items:

- Organise small focus group to gather information on patients opinion of *bant*

THEME #4: Strategic Partnerships for Sustainability

Given time constraints this theme was not addressed.

We are planning to apply for a grant through MOHLTC to fund the project.

Diabetes Action Canada Annual Workshop – Innovations in Type-1 Diabetes

The Innovations in Type-1 Diabetes (T1D) Goal Group presented the following three goals for the research program at the Annual Workshop:

- 1) Improve the health outcomes of those living with T1D across all ages
- 2) Design and implement a pan-Canadian T1D Registry
- 3) Improve health outcomes for T1D through technology-assisted tools, and customized self-management processes

With each of the listed goals, we discussed progress to date (i.e. JDRF/CIHR funded clinical trials) and future plans (i.e. Insight Session with the T1D ThinkTank and building a T1D registry)

THEME #1: Improving Patient Experience in Healthcare System

We heard from our patients that connection within the Type-1 Diabetes community is important for peer-to-peer mentoring and learning strategies to manage the disease. This type of forum can also be useful for informing patients on current research in T1D and engaging participation in research among the T1D community. This has been successfully implemented in the US through the T1D Exchange, but has yet to surface in Canada. A type of communication platform has been incorporated into the successful JDRF/CIHR projects but these are currently limited to small groups.

THEME #2: Scaling-up Successful Program

When we discussed building a precise T1D registry during our breakout session, we received a lot of input on strategies for identifying people who may wish to register. Connecting with pharmacies may be a useful strategy as pharmacists are often the only healthcare interaction for those living with diabetes in remote areas. We also discussed connecting with registries that currently exist and partnering with industry and charitable organizations to inform the T1D community of a T1D registry. We also discussed the behaviors of different sex and gender groups and strategies for engaging hard to reach groups (i.e. young adult males).

THEME #3: Solutions to Improve Diabetes Self-Management

Connecting T1D patients and caregivers with a reliable resource of diabetes management tools and education was discussed. Currently resources exist, but finding specific information can be difficult to navigate and sometimes information is unreliable. In particular, information related to alcohol consumption, athletic activity and transition of care. The key message from this discussion is that information must be easily accessible and easy to understand. This is particularly important for supporting patients in trouble shooting glycemic control. We discussed how this is something that is being implemented in the *bant* application and further consultation will be done to determine the types of information people are seeking.

THEME #4: Strategic Partnerships for Sustainability

When discussing the T1D Registry we learned that people living with Type-1 diabetes are fine to share their personal health data as long as it was not shared with pharmaceutical companies. We discussed the challenge of this as funding for such initiatives often comes, in part, from private industry. We also discussed the importance of initially focusing our efforts on building a privacy compliant tool in the T1D registry. Once we have proven the effectiveness of the registry and its use in clinical research, we can then consider scaling to Type-2 Diabetes.

Diabetes Action Canada Annual Workshop – Program Training and Mentoring

The co-Leads, Mathieu Bélanger and André Carpentier did a brief overview of the Training and Mentoring Groups activities. They presented the POR Training Sessions that have been offered since the beginning of our program as well as the funding programs we offer: 1) Mentorship Program, 2) Internship Program and 3) Post-Doctoral Fellowship. They also discussed our Patient Partner engagement and the partnerships the Training and Mentoring Group has with the CMDO, Diabetes Canada, SPOR Networks and SPOR Support Units.

THEME #1: Improving Patient Experience in Healthcare System and THEME #2: Scaling-up Successful Community- Based Program

We summarized the discussions for the three breakout sessions into four main themes: 1) Structure; 2) POR Training and Mentoring in the future; 3) Evaluation; and 4) Sustainability and Scalability. Within these themes, we indicated the main elements from our discussions concerning what we have done so far and how we could improve the Training and Mentoring program going forward.

1) Structure

- Good set of pragmatic values (i.e. not reinvent the wheel) and focus on developing a common understanding
- Develop a conceptual model
- Bidirectional communication channel between Research Programs and Patients and Indigenous Patients Circle is needed

2) POR Training & Mentoring 2.0

- Continue to cover POR 1.0 while addressing more specific needs for advanced training
 - Team work and interprofessional skills
 - Evaluation and management of research projects
 - Train the trainer
 - Front-line health care professionals
- ‘Vulgarisation scientifique’ 101 / science outreach
- Management of Patient Partners’ expectations
- Emphasis on the respect of patient partners (i.e. keeping them in the loop)
- Diversification of the media used (i.e. video clips)
- Continuing POR education of trainees
- Mentoring of young scientists by Patient Partners

3) Evaluation

- POR Training & Mentoring Goal Group meets the experts for collaborative work
 - McMaster’s Aging Community
 - CIHR collaboration grant (Monica Parry and coll.)
 - Others
- Documentation and promotion of the benefits of POR to patients, scientists and students

4) Sustainability and Scalability

- Working with other SPOR Networks
 - Common training needs of POR on chronic diseases



- Training workshops and tools
 - PICORI, Enhance, Involve
 - Professional organizations and associations
 - Health agencies and institutions
 - Universities

Others

- Consider development of general and tailored training (different needs of Patients vs Researchers)
- Consider development of Welcome Kit for new DAC members
- Improve communication of training and mentoring opportunities (dedicated space on website)

THEME #3: Solutions to Improve Diabetes Self-Management

THEME #4: Strategic Partnerships for Sustainability

Diabetes Action Canada Annual Workshop – Indigenous Goal Group

THEME #1: Improving Patient Experience in Healthcare System

The Patient Partners and stakeholders noted that collecting data only on Patients with diabetes missed half the perspective of the disease; the healthy population as well as youth need to be included in the discussion and measurements to identify protective factors. There is a lot of stigma around diabetes particularly in youth, a different lens is needed to reach this population. Story-telling and photo-voice is an important and culturally relevant tool that can be leveraged in these efforts.

THEME #2: Scaling-up Successful Community- Based Program

It is important to connect with local and culturally driven organizations that have relationships with and have been serving communities. There are scattered projects that are not attached to research questions that doing well within these communities to improve the health experience, these efforts need to be brought to the forefront and scaled up nationally. There are a lot of groups that still need to be engaged in the conversation.

THEME #3: Solutions to Improve Diabetes Self-Management

In order improve self-management in these patients with diabetes the socio-economic disparities must be addressed first. Communities must be approached with sensitivity and acknowledge the reality of people living with poor food security and access to health. There has been a loss of continuity in culture directly due to the colonization of Indigenous people and this has led to the current disparities. Research results and health implications need to be made more accessible and easy to understand to reach those who the information is relevant to. When addressing strategies for diabetes care, it is important engage women and reframe interventions so that it is relevant to the community, ex. prescribing land-based activity (fishing, hunting) instead of ‘exercise’.

THEME #4: Strategic Partnerships for Sustainability

It was felt that the development of a separate and sovereign strategy for diabetes in Indigenous people was needed and this had to sit within an Indigenous organization. A more sustainable and equitable source of funding had to be secured for the National Aboriginal Diabetes Association at the same level as Diabetes Canada, and DAC would be best served in an advocacy role. A change in policy and process is key in addressing the determinants of health which drive the rates of diabetes in Indigenous people.

APPENDIX 2: Summary of Patient Evaluation

Diabetes Action Canada Workshop 2018 May 4 – 5, 2018

Participant Category:

Patient Representative	10
Steering Council / Standing Committee	6
Principal / Co-Investigator of DAC	11
Other	6

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

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
The duration of the Workshop was just right.	12	20		1	
The Workshop addressed the themes of “Enabling Effective Care Paths for People Living with Diabetes”	12	19	2		
The Breakout Sessions were helpful.	18	13	2		
There was opportunity for me to express my views and/or have my questions addressed.	22	10	1		
On the whole, the presentations and discussion items were informative.	20	14	1		

Which segment of the Workshop did you like most?

1. I was glad to hear the patient's perspectives on the proposed research topics.
2. Interactive session with keynote
3. Breakout sessions / Small group sessions
4. T1 Innovations breakout
5. The advancement of technology with respect to enabling research
6. Retinopathy

7. Maureen O'Neil's talk. The summary presentations of the Goal-Directed Programs at the end.
8. Maureen O'Neill interactive presentation
9. All very well organized and implemented. Congratulations!
10. Breakout sessions & M O'Neil, patient engagement
11. Learning about our progress
12. Lots of opportunity for input; the input was shared back right away, a good feeling of "action" and not just discussion.

FRENCH

1. Un aperçu (overview), Session en petits groupes, rapport des cercles de patients
2. La participation patients – chercheurs – partenaires à part entière

Which segment of the Workshop did you like least?

Following are direct quotes and feedback collected by persons who attended the conference:

1. "...there was very little discussion about the actual research that is being done, as the meeting was so focused on the patients. I think it needs to strike a better balance, or perhaps be split up into days where patients aren't present... The meeting needs to find the line between inclusion and get-the-job-done-ness better."
2. "No specific subject I did not like the repeating the same issues and/or questions was redundant for me."
3. "Felt rushed as some breakout sessions went overtime."
4. "Indigenous patient breakout summary Saturday. Didn't exactly report what was learned in the Friday breakout session."
5. "Initial Patient Engagement presentation, and the relevance of the guest speaker."
6. "Training and mentoring, the content was too thin."
7. "The freezing cold main room."
8. "From 5.00 – 6.30 p.m., there was nothing for the patient participants involved in concurrent sessions."
9. "Breakout sessions"

10. "Temperature in the room was not appealing - felt the organizer was not listening. Missed Olivia as she has the understanding & sensitivity, and listens to the needs."
11. "Networking dinner not attended by many."
12. "Keynote speaker"
13. "Keynote session, I would leave that time for more brainstorming on what action items need to be taken for the next year."
14. "First day was long and heard others commenting. Perhaps spread to 2 full days with less "condensed" on first day."

FRENCH

1. "Sommaires des projets des groupe de travail; sommaires des projets des boursiers"
2. "Du temps pour évaluer les résultats"

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

Following are direct quotes and feedback collected by persons who attended the conference:

1. "No need for a group dinner on Friday, or a lunch on Saturday"
2. "I hope to see more implication from the steering committee on issues affecting all projects, so the dedicated teams could address more specific questions."
3. "Increase the length of time for each break out session."
4. "More time for questions during the breakout."
5. "Education of patients to augment their self-treatment (prise en charge)."
6. "I'd like to see breakout sessions organized around groups of patients and their interests, and researchers go to them."
7. "More time for researchers and patients to mix and get to know each other. An additional day or days a bit more broken up. The content was good but there was a lot packed into 1.5 days of breakout sessions and presentations, made for a lot of information all at once and

hard to retain after a certain point. Breakout sessions tried to address too much in the time allotted.”

8. “More inter involvement with all groups and all of the patients”
9. “Foot care, Kidney and Nephrology”
10. “Policy workers, CIHR reps”
11. “Small group discussion segments need 90 minutes, not 60”
12. “More aboriginal participation / presenters / organizations”
13. “Time allocated for summary of breakout sessions could be reduced.”
14. “Longer breakout sessions, ability to visit all breakout sessions -> was sad to have missed out on important/relevant conversations”
15. “More concrete descriptions about the benefit for researcher to connect with patients, what input patients have had to research projects thus far; confirmation of this progress to date.”
16. “Perhaps a mapping session of all groups, committees, projects, etc to understand how all moving parts relate to each other, especially as new people always being added.”

Any other comments or feedback

Following are direct quotes and feedback collected by persons who attended the conference:

1. “It would be nice to see some actual output from DAC...”
2. “Hope to see more participants representing all the different regions where Diabetes Action Canada is active.”
3. “Thoroughly enjoyed the workshop. Excellent opportunity for networking.”
4. “Dinner Friday evening was snacks, not dinner. Small plates, small meal. Not appropriate for dinner time.”
5. “Overall a big improvement over last year.”

6. "Great execution of the workshops!"
7. "Some patients mentioned to me that we should be careful about the patient invited with respect to their ability to be able to express themselves. I agree with this point, assuming that we want to get the most out of their experience, we probably want to make sure they can express themselves in public."
8. "All around, was a great conference and a big undertaking to organize and host. Well done!"
9. "Re-iterate that the purpose of the breakout sessions is to provide feedback on each specific aim of DAC."
10. "The food was very patient friendly, thank you"
11. "Impressed to see how DAC has evolved positively vs first meeting."
12. "Great workshop. Great learning opportunity. MANY THANKS TO DAC and the organizers."
13. "SAME VENUE NEXT YEAR PLEASE!!!"
14. "Great meals, well organized, main room too cold!"
15. "Well organized, great networking"
16. "All participants / presenters should be more aware of language sensitivity. Please do not refer to the Indigenous as "those people" or "them" – not a positive message to the aboriginal people present"
17. "Opportunity to have POR training ahead of meeting was great."
18. "Breakout sessions had too many questions for the time; forms should be able to be submitted at the end of breakout sessions to allow for submission of any comments that may not have been time for."
19. "Very well done, very inclusive, well organized, a good feeling of "doing & improving""

FRENCH

20. "Les traducteurs en français. Merci beaucoup"