2019 DIABETES ACTION CANADA ANNUAL WORKSHOP

Summary Report

Abstract

Diabetes Action Canada conducted its Annual Workshop on May 31st, 2019 – June 1st, 2019. The theme for the event was “Telling Our Stories about Patient-Oriented Research Outcomes and Challenges to Envision the Future”

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Diabetes Action Canada 2019 Annual Workshop Report

Theme: *Telling Our Stories about Patient-Oriented Research Outcomes and Challenges to Envision the Future*

Preamble

By all accounts, our 2019 Diabetes Action Canada Annual Workshop on May 31 and June 1, was the most successful so far. We were thrilled to bring our team that spans the nation, together in person to connect, network, and learn from each other. In total we had 112 participants at our event, including 29 Patient Partners, 41 Investigators and 8 guests, including Tia Moffat, Project Lead CIHR-SPOR Major Initiatives, Norm Rosenblum, Director, and Mary-Jo Makarachuk, Assistant Director of the CIHR Institute for Nutrition, Metabolism and Diabetes.

This year we presented our tangible research outcomes in a variety of activities including, interactive poster session, rapid-fire oral presentations, plenary sessions, breakout sessions, and keynote address. All these activities were tailors to our diverse audience of Patient Partners, Policy Decision-Makers, CIHR leaders, investigators and knowledge users from many disciplines. This year, we were also honoured to hear the stories of our Patient Partners and their experiences living with diabetes and advising on research projects. This patient narrative was a compelling reminder of the why Diabetes Action Canada is so motivated to create research outcomes that are applicable to those living with diabetes. The feedback we received from our Workshop was very positive with comments lauding the diversity of activities, the opportunities to participate in break-out sessions, and the inclusion of Patient Partner stories.

Workshop Rationale and Planning

The outcomes of our 2018 Diabetes Action Canada Annual Workshop clearly outlined the strategic directions for our SPOR Network for the remainder of our first 5 years of funding. These included:

- **Access** - to effective care paths
- **Communication and Learning** – overcoming barriers
- **Implementing Quality Standards** – to achieve improved outcomes
- **Advocacy for Change** – connecting with health care decision-makers
- **Evaluating our Impact**

To establish a theme for our 2019 Workshop that would lead to meaningful outcomes, we struck a Planning Committee composed of both an Academic Lead and a Patient Partner lead member from each of our 11 Programs. Based on critical evaluation of our project outcomes to date and the strategic directions identified above, we recognized two major gaps in our performance. First is the lack of meaningful engagement of front-line health care workers and community partners in the co-design of some of our projects. Second is the difficulty in engaging policy decision-makers from the outset of project design and implementation. Diabetes Action Canada has recognized that both of these strategic partnerships are required to generate evidence for enabling change in health care practice and policy. Access to effective and timely care paths for the prevention of diabetes complications remains the most urgent challenge articulated by our Patient Partners and substantiated by the continued high prevalence of blindness, kidney failure, heart failure, and lower limb amputations caused by diabetes. The Planning Committee recommended that our plenary sessions focus discussions on these gaps so that other members of our Network learn more about best practices for engaging policy decision-makers, and about designing projects that will lead to improved access to effective care paths.

After three years of project activities, our 11 Programs have many outcomes with impact to report as well as clarity on the directions of ongoing projects. To demonstrate these outcomes, the Planning Committee recommended that we invite all the Programs and their trainees to submit posters for presentation. In addition to the traditional poster presentation format, our Patient Partners selected projects to highlight in mini-oral presentations to further inform the audience and enable collective engagement of the participants.

Most importantly, the Annual Workshop was an opportunity for our Patient Partners to share their stories. To start our event each day and after the lunch session on Friday, Patient Partners shared brief narratives, prepared in advance, about their experiences in the health care system. The purpose was to provide further insight into the many challenges faced on a daily basis by persons living with diabetes and their caregivers as they struggle with the 24/7 self-management required to sustain health.

Finally, the Workshop included the opportunity for some of our Programs to hold breakout sessions to directly interact with participants, including Patient Partners and investigators. This forum enabled the participants to give valuable feedback on ongoing projects and strategic directions necessary to achieve outcomes with impact.

The Workshop proceedings were conducted in both English and French with simultaneous translation using personal headsets as well as dual slide projection in both languages. All the written materials were also provided in both languages.

Many thanks to all who participated in the planning including the Committee members and our wonderful staff – Tracy McQuire, Mildred Lim and Jessica Antwi. Also special thanks to Conrad Pow and Holly Witteman for their contributions.

Diabetes Action Canada Annual Workshop 2019 - Planning Committee

Member	Program
Dogba, Joyce	Patient Engagement
Drescher, Olivia	Patient Engagement
Bélanger, Mathieu	Training and Mentoring
Gaudreau, André	Training and Mentoring
Murray, Michelle	Training and Mentoring
Griever, Michelle	Digital Health to Improve Diabetes Care
Mumford, Doug	Digital Health to Improve Diabetes Care
Pow, Conrad	Digital Health to Improve Diabetes Care
Farnsworth, Kate	Innovations inT1D
McQuire, Tracy	Innovations inT1D/Administration
Senior, Peter	Innovations inT1D
Rac, Valeria	HTA and Network Evaluation
Bowen, Jim	HTA and Network Evaluation
Ploeg, Jenny	Aging, Community and Population Health
Chambers, Tracey	Aging, Community and Population Health
Tang, Frank	Aging, Community and Population Health
Desroches, Sophie	Knowledge Translation
Sutakovic, Olivera	Diabetic Retinopathy
Zamzam, Abdelrahman	Foot Care and Prevention of Lower Extremity Amputation
De Mestral, Charles	Foot Care and Prevention of Lower Extremity Amputation
McComber, Alex	Indigenous Peoples Health
Sadi, Pusha	Indigenous Peoples Health
McGavock, Jon	Indigenous Peoples Health
Mason, Robin	Sex and Gender
Antwi, Jessica	Administration
Lim, Mildred	Administration
Whiteside, Catharine	Administration

Pre-workshop POR Training – Day #0

Prior to the Workshop, we held a one-day Patient-Oriented Research Training session co-facilitated by our Patient Partners Howard English and André Gaudreau and led by Michelle Murray. Among the attendees were Dr. Jean-Pierre Després, the co-Scientific Lead for the Network, Dr. Holly Witteman and Dr. Peter Senior, Diabetes Action Canada Steering Council members. POR Training is a requirement for all members of Diabetes Action Canada and a fun and interesting opportunity for a diverse group to share their perspectives and contribute to research planning in a meaningful way. This training has been adapted from the CIHR curriculum on Patient-Oriented Research to include many hands-on and interactive activities to illustrate patient-oriented research concepts, share personal perspectives on research and build trusting relationships.

The Workshop Proceedings and Outcomes – Day #1

On May 31st our Workshop began with a welcome by our Steering Council Chair, Dr. Malcolm King and opening ceremony acknowledging the land by Spiritual Elders Barb and Clarence Nepinak, members of our Indigenous Patient Circle.

The Workshop proceedings started with stories from our Patient Partners, describing their experiences living with diabetes and working with Diabetes Action Canada. We then held a series of rapid-fire oral poster presentations to highlight tangible research outcomes within our network.

Plenary Session #1

"Advocating for change in the health system by connecting with decision-makers" was the topic of our first plenary session based on the gap in our Network performance identified over the previous year. Thank-you to our presenters, Maureen Markle-Reid, Mathieu Ouimet, Joe Cafazzo, Valeria Rac and our respondent Diane Finegood and facilitated by Gary Lewis. The experience of these investigators in working with policy decision-makers provided important advice to the members of our Network. These included the following:

- Understand who is the right policy decision-maker with authority to act on evidence;
- Know the problem that the policy decision-maker has prioritized for collaboration;
- Engage the policy decision-maker(s) early on to assist in co-designing the project that will be most relevant and timely for action; and,
- Be flexible in approaching policy decision-makers as they must focus on immediate challenges in the health care system.

Diane Finegood summarized and commented on the difference between "complicated" challenges, e.g., diabetes complications and their management, versus "complex" challenges, e.g., health care systems. In enabling knowledge translation into practice and policy, Diabetes Action Canada must work within both complicated and complex environments. Important points were made about the necessity for the patients' voice to be heard through Patient

Reported Experience and Outcome Measures to reinforce the urgency and necessity for action by policy decision-makers. Finally, the challenges faced by our national SPOR Network in trying to engage provincial health system policy decision-makers was addressed by Diane who encouraged us to connect through the new SPOR National Data Platform project. In addition, she recommended more strategic connections with the National Alliance of Health Research Organizations (NAPHRO) whose mandate is “ to facilitate coordination, communication, strategic alignment, convergence, and quality leadership through inter-provincial and national efforts”.

Keynote Address by Dr. Holly Witteman

“Power Dynamic and Health Research, Care and Policy “was the topic of our Keynote Address in the afternoon. This interactive session was led by Dr. Holly Witteman, Diabetes Action Canada Co-Lead for our Patient Engagement Research Program, Steering Council Member and person living with type-1 diabetes. Dr. Witteman invited Patient Partners Sasha Delorme and Alex McComber and Investigators, Maman Joyce Dogba, Jon McGavock and Peter Senior to discuss their personal experiences about understanding their power, or lack thereof, in situations where they were either at an advantage of disadvantage interacting with health professionals and the health system. We learned about power struggles based on racism, lack of cultural sensitivity, settlers control over Indigenous communities, health professional superiority in decision-making for their patients, and hierarchical perceptions between senior academics and trainees. Importantly, these stories revealed how our members have overcome these challenges, imparting important learnings for our Workshop participants. This discussion underscored the critical importance of the experiential knowledge of our Patient Partners in guiding all of our activities within Diabetes Action Canada. Continual, respectful learning from each other is essential to change the current power relationships that lead to inequities suffered by persons living with diabetes and related complications.

Breakout Sessions

Following the keynote, four of our research programs facilitated breakout sessions to gather feedback from attendees on current and future research projects. These sessions, held by our Indigenous Peoples’ Health, Digital Health, Sex and Gender and Innovations in type-1 diabetes research programs, were excellent opportunities to learn from a diverse group of stakeholders. Among those who participated included our aforementioned guests from CIHR.

Poster Sessions

In addition to the rapid-fire oral poster presentations, an interactive poster session was held at the end of Day #1. Twenty-eight posters, featuring tangible research outcomes from our Network, were presented in a traditional one-on-one poster session format. During the poster session and throughout the first day of our event, we also had an interactive display with a retinal imaging camera on site (generously provided by Topcon Canada) to demonstrate the process of teleretina screening. Twenty-six participants were screened and given the opportunity to discuss their results with either the technician (Lina Chen) taking the images or Dr. Michael Brent. All posters presented by trainees were evaluated by Patient Partners on overall poster design, content, approach to patient-oriented research, and ability to communicate research effectively to Patient Partners.

Congratulations to trainees **Ruth Ndjaboue** and **Nika Klaprat** for their Poster Presentation award. Thank-you to the Patient Partner judges André Gaudreau, Howard English, Daniele Remy, Monia Rekik, Dana Greenberg and Virtue Bajury for all their fantastic feedback!

Following the breakout sessions and concurrently with the interactive poster session, Tia Moffat and SPOR Executive Director David Clements joined our Steering Council meetings where we had an opportunity to discuss the next phase of the SPOR program and the necessity for knowing the terms and conditions from CIHR for the opportunity for renewal application.

The Workshop Proceedings and Outcomes – Day #2

June 1st, followed much of the format of the previous day with the day opening with Patient Partner stories and rapid-fire mini-oral poster presentations.

Plenary Session #2

“*Access to Effective Care Paths and Overcoming Barriers*” was the topic of our second plenary session featuring brief presentations by Maman Joyce Dogba, Ann-Marie McLaren, Michelle Griever, John McGavock and Paula Rochon facilitated by Jean-Pierre Després. Collectively, we heard about some of the important initiatives that are underway to enable improved health care experiences and the resources that Diabetes Action Canada, as a back-bone organization, has provided to facilitate this research. These presentations highlighted many of the gaps in prevention and care experienced by persons living with diabetes and related complications including:

- Cultural and language barriers for immigrants who are unable to understand the communication provided by health professionals about the necessity of diabetes complications screening and treatment;
- Lack of effective, community-based chiropody-led care paths for persons at risk for developing diabetic foot ulcers and lower limb amputations;
- Use of primary care health information to improve shared decision-making between patients and their health professionals about customized care paths based on risk of diabetes complications;
- Filling the gap in diabetes prevention in Indigenous communities by rippling out the Indigenous Youth Mentorship Program that has proven to be effective in improving resilience and a healthy lifestyle necessary for lowering the risk for developing for diabetes through an Indigenous approach; and,

- Identifying sex and gender-related challenges in health care and the importance of including research project design and evaluation elements that address these gaps in generating evidence-based solutions for improving the health outcomes of persons living with diabetes.

Breakout Session Report Back

Following our second plenary session, we asked those groups who held an interactive breakout session to report their findings. Below is a brief summary of the outcomes of these sessions.

Indigenous Health

Our Indigenous Peoples Health Patient Circle had an opportunity to meet concurrently with the Annual Workshop activities to further the discussions held at their southern Alberta gathering in March 2019. During the Workshop gathering, they had an opportunity to articulate their mission and set research priorities for Diabetes Action Canada research activities involving Indigenous peoples. Below is a summation of the outcomes:

Indigenous Health Patient Circle Mission: "Indigenous partners empowering holistic approaches to wellness"

Upcoming research priorities:

1. Community diabetes education - develop a diabetes educator course that is community friendly to train community members who can deliver community-friendly diabetes information;
2. Community needs survey - identify what community members want to know or wish to learn about diabetes via research using different processes (i.e. on-line survey, Facebook survey, student home visits, etc.);
3. Have youth educating other youth about the basics of living with diabetes (type 1 diabetes and type 2 diabetes) through classroom and school visits;
4. Sponsor the Kairos Blanket Exercise for the next Diabetes Action Canada meeting in 2020, to educate participants on the history of relations between Indigenous Peoples and Canada;
5. Build and nurture partnerships with the Indigenous Patient Circle and National Aboriginal Diabetes Association, Diabetes Canada and regional Indigenous health organizations (IHDC, BCFNHA, FNQLHSSC, etc.); and,
6. Develop a video of youth stories (in alliance with IYMP).

Sex and Gender

Our Sex and Gender Research Program focused their breakout session on assessing the usability of their knowledge translation tool, *The Essential Metrics for Assessing Sex and Gender*

Integration in Health Research Proposals Involving Human Participants. Participants who were part of this breakout session were contacted in advance and provided a mock research proposal in which to apply the matrix. The session consisted of recorded focus group discussion. The last phase of the session examined what is meant by an intersectional sex and gender lens and how to strengthen research proposals and study outcomes by integrating sex and gender from the outset. The data collected in this breakout session will be reviewed and used to improve the usability of the metrics. Our Sex and Gender team received Research Ethics Board approval for this session and the participants signed consent forms for their feedback to be part of a publication on the next iteration of *The Essential Metrics*.

Digital Health

Our Digital Health Research Program breakout session was the only session conducted in both French and English and had fulsome discussions in both languages. The breakout session discussed the National Diabetes Repository and the desired outcome was to generate ideas on patient-oriented research questions that could be answered using the data held within the repository. Participants in this session learned more about the breadth and depth of the data within the National Diabetes Repository and what may be accomplished by studying the data. Some takeaways from the session included the following:

1. A knowledge translation strategy is needed to inform the research community of the repository and the advantages of using the data;
2. Efforts need to be made to engage the Francophone community;
3. A control group of non-diabetic patients is necessary to test against the data in the repository; and,
4. The Diabetes Action Canada website needs to be modified to include a listing of submitted projects with status information.

Innovations in Type-1 Diabetes

The Innovations in Type-1 diabetes Research Program used their breakout session as an opportunity to gather feedback on the co-design of a digital platform for patient-oriented T1D research. The digital platform is intended to reach all Canadians living with T1D, to learn of the challenges faced in different jurisdictions across our country, and to create a platform that will facilitate the design of patient-oriented research that equitably addresses the concerns articulated by persons with T1D. During the session, the participants were split into smaller focus groups to discuss the following questions: Could patient-generated data from across Canada revolutionize diabetes research? Would it help recruit research subjects more effectively and drive novel ideas?

From the discussion, the following key themes emerged articulated by the participants.

- I want to know about studies. People living with T1D diabetes (PWD) want to know about studies that are occurring in Canada and beyond.
- I need to be able to easily determine if this study is important to me. PWDs find it difficult to decipher whether studies are relevant to their values and interests. Part of this can be attributed to the technical language used in study descriptions.
- I deserve to know the status and results of studies in which I participated. Knowledge translation back to patients is poor and infrequent.
- My study experience matters. Studies do not adequately account for participant burden or explicitly communicate the commitment required from participants (time, days off, etc.).
- How do you engage the people who struggle the most? We must make it a priority to develop tactics that reach PWDs who are isolated either by geography, socioeconomics, or disengagement.
- We want to be part of studies, but they need to be match with my life and my values, and be a joy to participate in.

Special Acknowledgements

In closing, we want to say a special thank- you to Patient Partners Sasha Delorme, André Gaudreau, Dana Greenberg, Marley Greenberg, Kate Farnsworth, Conrad Pow, Shayla Hele, Pina Barbieri, Devin Cleary Gooden and Debbie Nuna for sharing their stories with us. Their stories were a moving reminder about why Diabetes Action Canada is engaged in projects to improve the health outcomes of those living with diabetes.
In the June 2019 edition of our Newsletter, a more detailed account of the day and highlights of the event are found on Twitter, #DACWorkshop2019.

Appendix 1: Summary of Participant Evaluation

Diabetes Action Canada Workshop 2019
May 31 – June 1, 2019

Participant Category:

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

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

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
The duration of the Workshop was just right.	12	13			
The Workshop addressed the theme "Telling our Stories about Patient-Oriented Research Outcomes and Challenges to Envision the Future"	14	11			
The Breakout Sessions were helpful.	10	13	1		
There was opportunity for me to express my views and/or have my questions addressed.	11	11	2		
On the whole, the presentations and discussion items were informative.	11	13			

Which segment of the Workshop did you like most?

The following are excerpts from the evaluation form. In summary the participants enjoyed the keynote address by Dr. Holly Witteman, the breakout sessions, and integration of patient stories in the event.

- I thoroughly enjoyed the breakout sessions. I think it provided a lot of value and it was really nice to be able to have more small group discussions about practical projects and give input alongside other workshop attendees.

- The session with Holly Witteman and the testimonies of people concerning powers in health
- Patient Oriented Research Outcomes, Patient stories / personal stories
- Active Patient involvement during the workshop and being able to gain a whole new understanding/perspective into what it means for patients to live with diabetes.
- Digital Health breakout session
- Story-Telling / Holly Witteman Power dynamic session
- Poster presentations, plenary session 2, research program report back
- Keynote speech with questions. Important topic to acknowledge but also discuss actively.
- I very much enjoyed the smaller breakout sessions, as well the Holly Witteman's Plenary talk and panel
- Testimonials from those living with diabetes
- Variety of presentations, themes and opportunities for Patient Partners to participate

Which segment of the Workshop did you like least?

The following are excerpts from the evaluation form. In summary, the participants felt that the first plenary and some of the poster presentations were too technical and the food could be improved.

- I thoroughly enjoyed the entirety of the workshop and really took a lot away from it, I wouldn't really remove any part of it. However, if needing to identify the lesser of the enjoyable parts, I would say the first plenary session was my least favourable.
- Dinner was too late on Friday
- Plenary session 1 – used technical language and acronyms throughout without any explanation -> this excludes patient partners in that you're only talking in academic / research language.
- Mini poster oral presentations. Some presentations used acronyms that I couldn't decipher and I felt could've been summarized better in lay terms.
- There is not much information on statistical data
- Small Workshops Focusing on Children's Parents and Close Relatives

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

The following are excerpts from the evaluation form. In summary, the participants would like more opportunity to participant in small group discussions/breakout sessions, and an opportunity for the Patient Partners to have a plenary session.

- I think the translation was amazing, and that should definitely be maintained. However, ensuring there is a better way of translating questions that are being asked of presenters in a more efficient way might be a good next step. I think it might be nice to have the opportunity to engage in more than one breakout sessions as well, it was honestly the most enjoyable part for me as I really liked having a deeper engagement with the participants in the smaller group.

- I'd like more problem-centred, small-group, round table discussion. I thought there was too much 'presentation'
- Appreciate more storytelling which may aid me in understating patients' needs
- More promotion of SPOR Training Days
- More physical activity; patient panels – presentation with open discussion following (scientists get to sit together then have open mic. Patients tell their story then sit down – UNBALANCED & UNEQUAL!
- Same sort of panel with patient partners
- More information on management of diabetes and complications

Any other comment or feedback

- This workshop was very well done and organized and I think it was one of my better workshop/conference experiences in my few short years as a trainee. I think DAC is doing amazing work, and should keep it up!
- Good job to the organization team
- I liked the poster session! Keep that for next years and encourage more participants to visit the posters.
- Does the meeting always have the be Friday and half-day Saturday? It interferes with personal time.
- Very well organized, opportunities for sharing and networking, good location, food was good
- Great conference – so well organized
- Different location for 2020 - Montreal or Quebec City; Youth with T2DM present/share their story
- Patient stories were very important and effective. Best workshop yet. It is so great to see the improvements each year. Great job everyone!
- This has been great and I have learned a lot!
- Information on diabetes prevention in Universities, and pregnant women