



2020 DIABETES ACTION CANADA VIRTUAL WORKSHOP

Summary Report

Abstract

Diabetes Action Canada conducted its Annual Workshop as a virtual event throughout the month of July 2020. The theme for the event was “Envisioning our Future Through Patient Engagement”

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Table of Contents

Preamble.....	2
Workshop Rationale and Planning	3
Diabetes Action Canada 2020 Annual Workshop Planning Committee	4
July 8th, 2020 Plenary Session: Patient Engagement the Next Generation.....	5
July 15th, 2020 Research Spotlight – National Diabetes Repository	6
July 22nd, 2020 Research Spotlight – T1D and AI in Diabetic Retinopathy Screening	7
July 29th, 2020 Research Spotlight – Patient Engagement and Knowledge Translation	9
Concluding Remarks.....	10
Special Acknowledgements	10
Appendix 1: Summary of Participant Evaluation	12

Diabetes Action Canada 2020 Annual (Virtual) Workshop Report

Theme: Envisioning our Future Through Patient Engagement

Preamble

Earlier this year, Diabetes Action Canada was well underway in planning its fifth (and final) in-person Annual Workshop for its initial funding term. Our 2019 workshop, was deemed the best yet in featuring the impact of Patient Partner engagement in research and its tremendous value in shaping research in diabetes. Since then, Diabetes Action Canada has undergone a series of evaluation activities to identify opportunities and gaps in our Network, to build on all the work we have accomplished and to inform the planning for the next iteration of our SPOR Network. Based on the recommendations gathered from our evaluative activities, and considering the success of our previous workshop, the theme for this year's annual face-to-face Workshop was identified as ***Envisioning the Future Through Patient Engagement*** with a focus on strategic planning for the next phase of our research Network with an emphasis on patient engagement.

Since March 2020, along with research organizations across the country, Diabetes Action Canada has been greatly impacted by the COVID-19 pandemic. To sustain the momentum of our Network, we have pivoted in many ways to continue our research projects and connect meaningfully with our Patient Partners. Therefore, we reactivated our Workshop Planning Committee to organize a series of virtual meetings, in lieu of the in-person event, to communicate our research success and impacts, feature the great work of our trainees, and set the stage for strategic planning for SPOR Phase 2.

In the month of July, weekly webinars were held featuring Diabetes Action Canada funded and/or supported research projects presented by Patient Partners, investigators, trainees and staff. Each webinar featured a research theme in diabetes and its complications and the critical importance of patient and public engagement to inform, plan, and implement projects. These webinars were open to the public and were widely publicized over email and social media among members, Patient Partners, and many stakeholders. This was the first time Diabetes Action Canada has communicated its research projects to such a broad audience. The feedback received was very positive, especially among Patient Partners who have asked for more opportunities to learn about the diversity of research activities within the Network. We were also pleased to see that partners from JDRF, Diabetes Canada, Alberta Health Services, Nova Scotia Health, INESSS, CPCSSN and Fighting Blindness Canada were regular attendees for these webinars. In addition, members of the CIHR SPOR team, Nancy Mason MacLellan, Manager for Major Initiatives and Sobia Hafeez, Associate, also tuned in.

Workshop Rationale and Planning

We have always understood that our core success factor has been the impact of Patient Engagement on our researchers, research topics/design/deliverables, stakeholders including health care providers and advocacy organizations (Diabetes Canada, JDRF). We have learned a great deal about Patient Engagement since our inception, but we also know we can improve on how we work with our Patient Partners to co-design projects, conduct research and disseminate knowledge to the community. Originally for 2020, we had planned to feature several successful examples of patient engagement within our Network and how Patient Partner input had pivoted research towards more meaningful goals that matter most to the community of persons living with diabetes. As a virtual event, we wanted to retain this theme of patient engagement and, demonstrate its application across more projects that are funded and/or supported by Diabetes Action Canada. Therefore, the virtual workshop kicked off with a plenary session featuring patient engagement, followed by weekly ‘Research Spotlights’ with a specific research theme. To gather content for the research spotlights, an open call to our Research Programs was released in May with submissions due at the end of June. Overall, 21 submissions were received and the Workshop Planning Committee selected presentations for the first series.

To start the webinar series, we highlighted some of our most effective approaches to patient engagement. The plenary session was intended, in part, to help inform the strategic planning now launched by Diabetes Action Canada. Despite the delays in decisions and announcements by CIHR, we assume that the SPOR Program will continue in some fashion after 2021. Therefore, we must not only sustain but continue to evolve our Network. The Diabetes Action Canada Steering Committee has established a Strategic Planning Committee that will report its recommendations for our next phase of Diabetes Action Canada by early 2021. To assist this Committee, we have asked each Research Program to conduct a virtual strategic planning session with a 3 to 5-year horizon with report to the Strategic Planning Committee. These sessions will occur in August and September and be staggered to enable maximum participation among investigators and Patient Partners within each Research Goal-directed group and those within our Enabling Research groups to contribute.

In each subsequent week in July, ‘Research Spotlights’ were conducted. Each session opened with a personal impact story from one of our Patient Partners, followed by research project presentations. Each webinar had an option for dial-in direct simultaneous French or English translation, depending on the principal language used for the webinar. Prior to each webinar all participants were emailed links to the slides in both French and English and for those who missed the email the information was provided in the chat function of the Zoom platform. All webinars were recorded and after receiving consent from the presenters, the videos were posted on our [Diabetes Action Canada YouTube channel](#). It is worth noting that not all Patient

Partners were comfortable with having their personal impact story widely available after the webinar itself, so some of these were edited out of the videos prior to posting.

In total, over the four webinars, there were 171 distinct attendees. Among these attendees were 31 Diabetes Action Canada members, 23 Patient Partners, 12 trainees, and 19 external stakeholders from organizations like JDRF, Diabetes Canada, Fighting Blindness Canada, and Alberta Health Services, to name a few. We also had representatives from the CIHR SPOR management team, at every session.

Diabetes Action Canada 2020 Annual Workshop Planning Committee

We thank the members of the Workshop Planning Committee for taking the time to first plan an in-person event and then a virtual event for our 2020 Workshop. A special mention and thank-you to our Patient Partner Ron Beleno, who was instrumental in helping navigate the Zoom platform prior to the webinars, participated as co-host during each webinar, and assisted with video editing thereafter. The following are a list of all those who participated and their affiliation within our Network.

Member	Program
Dogba, Joyce	Patient Engagement
Delgado, Pascual	Patient Engagement – Collective/Francophone Patient Circle
Drescher, Olivia	Patient Engagement
Remy, Daniele	Patient Engagement – Francophone Patient Circle
Wells, David	Patient Engagement – Collective Patient Circle
Bélanger, Mathieu	Training and Mentoring
Gaudreau, André	Training and Mentoring
Murray, Michelle	Training and Mentoring
Griever, Michelle	Digital Health to Improve Diabetes Care
Pow, Conrad	Digital Health to Improve Diabetes Care
Butalia, Sonia	Innovations inT1D
Farnsworth, Kate	Innovations inT1D
McQuire, Tracy (CHAIR)	Innovations inT1D/Administration
Bowen, Jim	HTA and Network Evaluation
Rac, Valeria	HTA and Network Evaluation
Beleno, Ron	Aging, Community and Population Health
Chambers, Tracey	Aging, Community and Population Health
Granann, Rebecca	Aging, Community and Population Health
Ploeg, Jenny	Aging, Community and Population Health
Kastner, Monica	Knowledge Translation
Mills, Thomas	Knowledge Translation

Sissmore, Debbie	Diabetic Retinopathy
Sutakovic, Olivera	Diabetic Retinopathy
De Mestral, Charles	Foot Care and Prevention of Lower Extremity Amputation
Zamzam, Abdelrahman	Foot Care and Prevention of Lower Extremity Amputation
Delorme, Sasha	Indigenous Peoples Health
McComber, Alex	Indigenous Peoples Health
McGavock, Jon	Indigenous Peoples Health
Nepinak, Barb	Indigenous Peoples Health
Akerman, Jennifer	Sex and Gender
Mason, Robin	Sex and Gender
Lim, Mildred	Administration
Whiteside, Catharine	Administration

July 8th, 2020 Plenary Session: Patient Engagement the Next Generation

The first of the July series of webinars was held on July 8th, 2020 deemed the plenary session as it highlighted our organization's most successful approaches to patient engagement and had relevance to all our research activities. Every project highlighted the research engagement of our Patient Partners. A key takeaway from this session was that, as a SPOR Network, we have learned and continue to learn a considerable amount about Patient Engagement, but we can still improve on how we effectively and meaningfully engage our Patient Partners in research. Below is a list of the topics and presenters for this plenary session:

- **Strengthening the Collaborations Between Patient Research Partners and Researchers**
 - Presented by: Sasha Delorme on behalf of the Collective Patient Circle
- **A Digital Platform to Accelerate Research and Build Community**
 - Presented by Shivani Goyal
- **Answering questions that matter to people living with diabetes using the Canadian National Diabetes Repository**
 - Presented by: Holly Witteman and Dana Greenberg
- **Engaging Patient and Public Research Partners in the Aging, Community & Health Research Unit (ACHRU) Community Partnership Program for Diabetes Self-Management for Older Adults – Canada.**
 - Presented by: Ron Beleno and Rebecca Granann
- **Barriers and enablers to attending diabetic retinopathy screening experienced by immigrants to Canada from multiple cultural and linguistic minority groups**

- Presented by: Joyce Dogba

***Moderator:** Tracy McQuire

The webinar had 118 people registered with 97 attendees. Of those who registered 26 were francophone. The following summarizes the attendees:

- 21 Diabetes Action Canada investigators
- 19 Patient Partners
- 14 Diabetes Action Canada personnel
- 11 Trainees
- 13 External stakeholders including JDRF, Alberta Health Services, Nova Scotia Health, CPCSSN, Abbott and Fighting Blindness Canada
- 3 representatives from CIHR
- 2 members of the Diabetes Action Canada Steering Committee
- 35 other members of the community

The slides for this webinar in both English and French can be found [here](#)

The video for this webinar in English only can be found [here](#)

We promoted this event through social media and the webinar agenda information received 3,255 impressions and this particular webinar had a total of 7817 impressions on Twitter.

July 15th, 2020 Research Spotlight – National Diabetes Repository

The second webinar in the series highlighted the National Diabetes Repository and its use as a valuable research tool for those interested in applying data science to their investigation in diabetes and its related complications. The following is a brief description of the session and a list of presenters:

The National Diabetes Repository was launched only two years ago and today we are seeing an increase in researcher awareness and interest in applying this novel tool to investigating diabetes in Canada. In this session we will learn of projects lead by Diabetes Action Canada investigators, Alanna Weisman, Michelle Griever and Braden O'Neill that have successfully used the data within the repository to answer questions that are of interest to the patient communities, policy makers and researchers.

- **Personal Impact Story:** Conrad Pow
- **The Impact of Government-Funded Insulin Pump Programs on Insulin Pump Use in Canada: A Cross-Sectional Study Using the National Diabetes Repository**

- Presented by: Alanna Wesiman
- **Trends in diabetes medication use in Canada, England, Scotland and Australia: a repeated cross-sectional analysis (2012-2017)**
 - Presented by: Michelle Griever
- **Diabetes care among people with schizophrenia: a cohort study using the Diabetes Action Canada National Diabetes Repository**
 - Presented by: Braden O'Neill

***Moderator:** Conrad Pow

The webinar had 67 people registered with 65 attendees. Of those who registered 9 were francophone. The following summarizes the attendees:

- 13 Diabetes Action Canada investigators
- 14 Patient Partners
- 7 Diabetes Action Canada personnel
- 7 Trainees
- 7 external stakeholders including JDRF, Alberta Health Services, Indigenous Diabetes Health Circle, TELUS and Fighting Blindness Canada
- 2 representatives from CIHR
- 3 members of the Diabetes Action Canada Steering Committee
- 14 other members of the community

The slides for this webinar in both English and French can be found [here](#)

The video for this webinar in English only can be found [here](#)

We promoted this event through social media and this webinar received a total of 6,471 impressions in Twitter.

July 22nd, 2020 Research Spotlight – T1D and AI in Diabetic Retinopathy Screening

This session featured work from some of the Diabetes Action Canada awardees from our 2019-20 competitions as well as other trainees conducting projects within our various research programs. The presenters for this session stretched across the country with representation from Ontario, Manitoba, Alberta and Quebec. The following topics were featured during this webinar:

- **Person Impact Story: Debbie Sissmore**

Debbie is the Patient Partner co-lead for the Diabetic Retinopathy Screening Program and serves on the Diabetes Action Canada Steering Council. She has been living with type 1 diabetes (T1D) for 50 years. Due to diabetic retinopathy, she completely lost her eyesight 25 years ago.

- **Restructuring Type 1 Diabetes and Exercise Research in the Context of Patient Engagement**

- Presented by: Nika Klaprat

Interested in type 1 diabetes and exercise? Nika Klaprat, is engaging researchers and individuals living with type 1 diabetes (patients and caregivers), to increase capacity for patient-oriented research in type 1 diabetes and exercise by determining a core set of variables to measure in all trials, identifying preferences for attributes of exercise programs, and co-designing research protocols.

- **Narrative inquiry into understanding the type 1 diabetes lived experience and its motivations in seeking diabetes health services and education in Alberta**

- Presented by: Jamie Boisvenue

For many living with type 1 diabetes insulin pumps are the chosen path for insulin replacement therapy, but is it the best for everyone? Jamie Boisvenue will describe how hearing the life stories of people living with type 1 diabetes on pump or multiple daily injections, could have an impact on diabetes health seeking behaviours in Alberta.

- **Artificial Intelligence for Diabetic Retinopathy Screening**

- Presented by: Gabriel Lepetit-Aimon & Clément Playout

Diabetic retinopathy is a complication that is of great concern for all members of the diabetes community. Investigators that are part of Diabetes Action Canada are currently working to scale and spread the tele-ophthalmology screening in Ontario, BC and Quebec, but what about the increased workload of grading these images? Learn about this innovative approach grading retinal images for automated diabetic retinopathy diagnosis using machine learning and artificial intelligence from our trainees Gabriel Lepetit-Aimon and Clément Playout.

***Moderator:** Tracy McQuire

The webinar had 50 people registered with 45 attendees. Of those who registered 10 were francophone. The following summarizes the attendees:

- 11 Diabetes Action Canada investigators
- 7 Patient Partners
- 8 Diabetes Action Canada personnel
- 5 Trainees
- 5 external stakeholders including JDRF, Alberta Health Services, TELUS and Fighting Blindness Canada
- 1 representative from CIHR
- 1 member of the Diabetes Action Canada Steering Committee
- 11 other members of the community

The slides for this webinar in both English and French can be found [here](#)

The video for this webinar in English only can be found [here](#)

We promoted this event through social media and this webinar received a total of 6,504 impressions in Twitter.

July 29th, 2020 Research Spotlight – Patient Engagement and Knowledge Translation

The final installment of our July webinar series was a French session that featured the work of Diabetes Action Canada post-doctoral fellowship awardee, Dr. Ruth Ndjaboue, Knowledge Translation fellowship awardee, Choumous Mannobi and trainee, Alexe Deom Tardif. The following are the topics with description for this webinar:

- **Person Impact Story:** Sylvie Dostie

Sylvie resides in Quebec and has been living the type 1 diabetes for 51 years. She is a retired administrative assistant at the Research Center of the Center Hospitalier Universitaire de Quebec. She has recently joined Diabetes Action Canada and loves to share her story.

- **A patient-initiated research project to improve diabetes management and care**

- Presented by: Ruth Ndjaboue

A recent study by Diabetes Action Canada researcher and recipient of the 2019-21 postdoctoral fellowship award, Dr. Ruth Ndjaboue, focuses on the expertise of those most closely involved in the diabetes community – persons living with diabetes. Aimed at helping health professionals and those living with or affected by the disease better understand how to improve self-management and care, Ndjaboue had some surprising results to share.

- **Needs analysis and co-design of a tele-nutrition platform for the therapeutic management of patients with chronic diseases**

- Presented by: Choumous Mannobi

Since the pandemic, there is a growing interest in telehealth and an increase in political will towards digital care. Our Knowledge Translation scholar, Choumous Mannoubi is working to developing a tele-nutrition platform to optimize remote therapeutic management for those living with chronic disease.

- **Application of Knowledge Focused on Sex and Gender for People in French-language Context: Co-creation of continuing professional development training for people experiencing diabetes and depression**

- Presented by: Alexe Deom Tardif

Those living with diabetes have told us that mental health is an area of concern. Master's student, Alexe Deom Tardif will discuss the training of healthcare professionals in diabetes and depression with a particular focus on sex and gender.

***Moderator:** Olivia Drescher

The webinar had 66 people registered with 42 attendees. Of those who registered 9 were francophone. The following summarizes the attendees:

- 9 Diabetes Action Canada investigators
- 10 Patient Partners
- 10 Diabetes Action Canada personnel
- 6 Trainees
- 10 external stakeholders including JDRF, Diabetes Canada, Alberta Heath Services, INESSS, CPCSSN, Can-Solve CKD, and Fighting Blindness Canada
- 3 representatives from CIHR
- 3 members of the Diabetes Action Canada Steering Committee
- 18 other members of the community

The slides for this webinar in both English and French can be found [here](#)

The video for this webinar in French only can be found [here](#)

We promoted this event through social media and this webinar received a total of 4,357 impressions in Twitter.

Concluding Remarks

The Workshop Planning Committee along with Diabetes Action Canada leadership are very pleased with the outcome of these virtual events. So much so, that it was decided that these webinars will continue into the Fall of 2020, with each month featuring a specific research program within the Network. After considering the remaining presentations from the initial call for research, it was decided that the September series would feature Training and Mentoring, and October would feature Knowledge Translation. The former will have presentations in English and the latter in French, with simultaneous translation provided. Furthermore, through our initial webinar series, Fighting Blindness Canada has reached out and a joint webinar series in eye health and diabetes is being planned for November.

Immediately following the webinar series an email evaluation was requested from all 171 attendees. Overall the webinars were very well received with comments lauding the research projects, approach to patient and public engagement, and lessons learned as we evolve as a patient-oriented research Network. A detailed look at the evaluation responses can be found in Appendix 1.

Special Acknowledgements

In closing, we want to say a special thank- you to Patient Partners Sasha Delorme, Dana Greenberg, Conrad Pow, Debbie Sissmore, and Sylvie Dostie for sharing their stories with us. Their personal impact stories and perspectives were a moving reminder about why Diabetes

Action Canada is engaged in projects to improve the health outcomes of those living with diabetes. Also a special acknowledgement to Ron Beleno for taking the time to assist with the Zoom platform, present his research, act as co-host for the series and edit all the videos. It was a great help and very appreciated.

Appendix 1: Summary of Participant Evaluation

Diabetes Action Canada Workshop 2020 July 2020

Participant Category:

English Respondents	11
French Respondents	5

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

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
The Webinars addressed the theme, “Envisioning our Future Through Patient Engagement”	7	8	1		
The duration and frequency of the webinars were appropriate.	8	8			
The webinars were useful in communicating the research conducted by Diabetes Action Canada trainees, researchers and Patient Partners.	9	7			
The webinars provided an opportunity to ask questions and/or express your views.	5	10	1		
The simultaneous translation was effective in communicating what was presented during the webinar.	1	8	7		
I am likely to participate in future webinars	12	2	2		

Did you have any technical difficulties participating in the webinars?

Problems included the following:

- logging onto the webinar platform
- Sound wasn't clear
- Confusion about the registration process
- Internet connection problems

What was your favourite segment of the webinars?

In summary, those who replied enjoyed learning about the current research and how patient perspectives have been applied in different projects. The following are excerpts discussing specific aspects that were indicated on the evaluation form.

- Personal impact stories.
- Question & Answer period.
- AI and Diabetic Retinopathy Screening presentation.
- Dr. Alanna Wesiman's presentation on insulin pump use.
- Alexe Deom Tardif's presentation on knowledge translation.

What was your least favourite segment of the webinars?

The responses provide useful feedback on how to improve the sessions going forward. These included

- The sound quality could be improved with presenters using better microphones rather than their computer microphones.
- The email addresses for the presenters should be presented to allow follow-up questions and start collaborations.
- Sometimes the translation was difficult to follow but minor.
- The presentation of ongoing studies with little or no results at present.
- Presentations with decision-makers as speakers.