



# Diabetes Action Canada & Type-1 Diabetes Think Tank Collaborative Insight Session

Summary Report

## Theme

“Every 1 matters! Engaging people living with type 1 diabetes to set research priorities that are meaningful and relevant to the T1D Community”

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# T1D Think Tank and Diabetes Action Canada Insight Session Report

## Executive Summary

Diabetes Action Canada's Innovations in Type-1 Diabetes (iT1D) Research Program wished to create a stronger connection with people living with type-1 diabetes (PLwT1D) to co-create research questions and projects that address the needs and concerns of the T1D community. With this in mind, it seemed a natural fit to collaborate with the Type-1 Diabetes Think Tank Network (T1DTTN) to learn from patient narratives and understand their experience in healthcare and quality of life. On November 30<sup>th</sup>, 2018 Diabetes Action Canada and the T1DTTN came together to hold its first collaborative activity called an Insight Session. This event was a full-day workshop that brought researchers, health care professionals (HCPs), PLwT1D, and other stakeholders together to learn new skills in communication, share experiences and discuss research conceptually and projects in progress. Diabetes Action Canada and the T1DTTN planned this session collaboratively with PLwT1D, HCPs, and administrators. The theme for the event was ***“Every 1 matters! Engaging people living with type 1 diabetes to set research priorities that are meaningful and relevant to the T1D Community”*** and occurred at the Globe and Mail Building in Toronto, ON. In attendance were 18 people living with T1D and family members/caregivers, 13 researchers, and 12 HCPs and researchers.

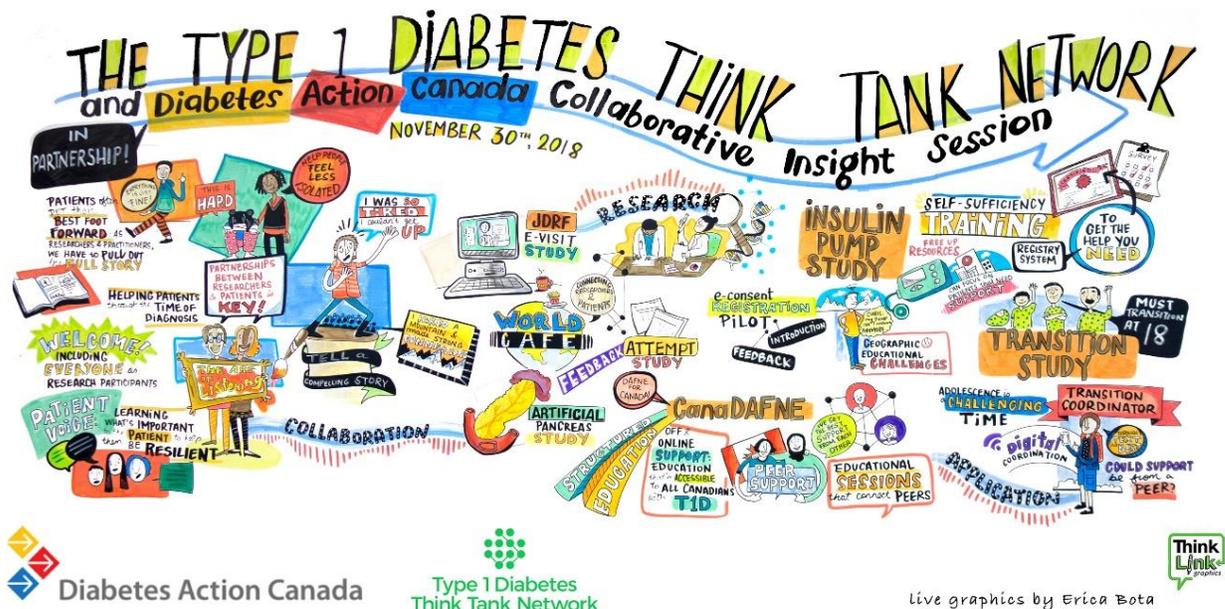
The event focussed on four main activities:

- 1) **SOAR story telling framework workshop:** The group learned the SOAR (situation, obstacle, action, result) storytelling framework to communicate thoughts and experiences in a way that will engage others. This framework was used throughout the day for PLwT1D and researchers to communicate their personal experiences and research ideas.
- 2) **Research World Café:** PLwT1D rotated between round tables that each had researchers presenting different projects that focused on T1D-related health questions. Spending 15 minutes at each table, PLwT1D provided feedback on research projects that were already funded. Researchers were to explain their projects using the SOAR framework and small group discussions were held.
- 3) **T1D Registry Introduction and eConsent Registration Pilot:** The T1D Registry project was introduced to the audience and a draft prototype registration process was demonstrated on mobile phones. Feedback was collected, both virtually (using live polling) and verbally (open discussion).
- 4) **Research Pitches:** Researchers used the SOAR framework to pitch new research ideas to PLwT1D.

Guided small group discussions invited both positive and critical feedback on the research that was both planned and underway. The main takeaway from these discussions was that inviting PLwT1D to participate in clinical research is not enough and we must identify what is truly valuable to the community. Thoughts included a peer-peer virtual community that would facilitate peer mentoring, experience exchange, and education. Others included a T1D exclusive forum to promote advocacy for better health services and outcomes for those living with T1D. Of all the ideas, one thing was very clear. The T1D community must be heard when planning research and they must feel empowered by their participation in research.

Each activity was followed by a larger group reflection and sharing, that guided a more fulsome discussion with ideas and feedback building on individual comments. Also throughout the event, PLwT1D and researchers were invited to share their stories about their experiences with T1D.

Overall, participants rated the session very highly, with an average score between 4-5 on a 5-point scale. The participants enjoyed the opportunity for open and honest communication between PLwT1D and those investigating the disease. Participants were also inspired by the personal stories and found them an effective reminder about the difficulties faced by those people living with T1D. We learned a great deal from this session and received many suggestions for future collaborative sessions with the T1DTTN. A graphic summary was prepared throughout the day to capture the key points and discussion (Figure 1) and a summary video is currently in production and expected to be completed in the New Year.



**Figure 1:** Summary graphic for the Diabetes Action Canada and The T1D ThinkTank Collaborative Insight Session. Graphic created by Erica Bota from Think Link

### Insight Session Preparation

Diabetes Action Canada and the T1DTTN jointly planned this collaborative Insight Session with a Planning Committee that consisted of PLwT1D, HCPs and administrators from both organizations. The Planning Committee members (Table 1), met monthly from August to November to plan the agenda and event details.

**Table 1:** List of the 2018 Diabetes Action Canada Workshop and T1DTTN Planning Committee

Name	Role
Antwi, Jessica	Diabetes Action Canada Administrator
Fransworth, Kate	PLwT1D
Gregory, Lori	T1DTTN Administrator
Houlahan, Michael	T1DTTN Executive Director
McQuire, Tracy	Diabetes Action Canada Administrator

Narrandes, Renira	PLwT1D
Perkins, Bruce	Diabetes Action Canada iT1D Program Lead, HCP
Rose Yeung	HCP

## Insight Session Outcomes

### Opening Remarks

Bruce Perkins, Rose Yeung and Michael Houlahan introduced the event with a brief overview of Diabetes Action Canada and The T1D TTN.

Diabetes Action Canada is committed to improving the health outcomes and experience of persons living with diabetes. Funded by the CIHR Strategic Patient – Oriented Research (SPOR) in Chronic Disease Program, Diabetes Action Canada is committed to addressing the most important challenges and concerns articulated by persons living with diabetes. The iT1D Research Program within Diabetes Action Canada is focussed on the design and implementation of innovative research that investigates new technologies and management methods for improved quality of life for those living with T1D. Research projects are co-developed with PLwT1D to position research outcomes to be relevant and meaningful for the T1D Community. Diabetes Action Canada has many research projects underway and large projects planned over the next two years. We are seeking the feedback and advice of a large and diverse group of PLwT1D in Canada to develop our research programs towards areas of interest and concern for PLwT1D.

The T1D TTN aims to remove barriers to communication and improve relationships between PLwT1D, researchers and healthcare teams by bringing these groups together as equals, outside of the traditional hierarchical relationships in the health care and academic systems. Among its many activities, the T1D TTN holds innovative programming through Insight Sessions, designed to include the patient voice and the power of the patient narrative in health care planning. The purpose of this Insight Session was to unite PLwT1D with researchers and HCPs in a non-judgemental learning environment to share personal experiences of T1D and gather feedback on the T1D Registry and other T1D-related research projects.

### Story Telling and Effective Communication

The primary purpose of this Insight Session was to enable improved communication between those who live with T1D and those who investigate and treat persons living with T1D. The event had no hierarchical structure and created a safe environment for sharing experiences, building trust and creating mutual understanding.

The event activities opened with a powerful video presentation created by the T1D TTN on understanding the T1D experience. This was followed by a series of stories, called ‘two-minute tales’, told by those living with T1D to help build a shared understanding of what it is really like to live with T1D. These stories were delivered in person by program facilitators, Renira Narrandes and Deanna Paolantonio, and through video using submissions from their annual video fest, link [here](#).

The group then learned of the power and effectiveness of storytelling using the SOAR (Situation, Obstacle, Action, and Result) structure. Stories are 22 times more memorable than facts alone and

participants were asked to use the SOAR framework to describe a challenge or conflict they had experienced. These stories were shared first with small table groups and then with the larger audience. The group was then asked to reflect on these stories and use the SOAR framework throughout the day to communicate both personal experience and research stories. One comment that resonated throughout the event is that patient experiences are not abstract and this simple reminder set the stage for a productive and interactive day.

## Research Café

Researchers were invited to present their funded research to the PLwT1D to get feedback on research project outcomes and design. Three studies, which are all funded jointly by CIHR and JDRF, were discussed in small table groups. The studies include:

- Bruce Perkins presented '**Combining Innovations for Type 1 Diabetes to Maximize Benefit: Artificial Pancreas and Adjunctive-to-Insulin Medications**'. This study is investigating the efficacy of SGLT2i in controlling blood glucose in those with T1D. This medication has already been proven effective in people with type-2 diabetes and has promise as part of a T1D self-management regiment.
- Gillian Booth, Lorraine Lipscombe, and Rayzel Shuman presented '**Type 1 diabetes virtual self-Management Education and support**'. This study endeavours to help PLwT1D achieve better control of their diabetes and improve their healthcare experience by providing electronic delivery of healthcare and related support services on top of usual care.
- Farid Mahmud, Yesmino Elia, and Jim Scholey presented '**Adolescent Type 1 diabetes Treatment with EMPaglifozin for hyperglycemia & hyperfiltration Trial, "ATTEMPT" Trial**'. This study is investigating the effect of SGLT2i medication, in combination with insulin, on metabolic control and kidney function in adolescence (ATTEMPT Trial), and 2) identifying young adults with T1D at risk of developing early onset complications by analyzing biomarkers that may be sensitive in predicting this risk (AddIT-SPOR).

Discussions were very active and researchers recorded the feedback collected through small table discussions. This activity was very well received and feedback on the evaluation forms indicated more time was needed for this activity.

## The T1D Registry Project

A large part of the afternoon was dedicated to collecting feedback from researchers and PLwT1D on the proposed T1D Registry. The T1D Registry is envisioned as a database of people living with T1D interested in contributing to clinical research. Registration into the T1D Registry will be accessed directly by patients through a mobile application and/or websites and consents for participation in research will be collected electronically through an eConsent platform. At this early planning stage of the T1D Registry, it was proposed that three consents will be collected: 1) consent to be part of the T1D Registry, 2) consent to be contacted for clinical research opportunities, and 3) consent to share patient-reported information in the registry, in a de-identified way, with Canadian researchers focussing on T1D. The T1D Registry is meant to fill the gap between PLwT1D and clinical research, by enabling participation of PLwT1D in research, regardless of where these individuals live or what HCPs they see for their diabetes care. The T1D Registry is also intended to expedite scientific advances in T1D and allow researchers to make evidence based recommendations in self-care and community actions.

Shivani Goyal and her team started this discussion on the T1D Registry by explaining their process of piloting the eConsent framework and collecting feedback virtually and in large group discussions. This session was recorded and has research ethics board approval for a user-experience study.

Lorraine Lipscombe then led a large group discussion on the T1D Registry that focussed on two areas of interest – value of the T1D Registry to those living with T1D and patient recruitment. The following summarizes the key takeaways from the participant feedback:

- 1) **SIMPLE MESSAGING AND REGISTRATION PROCESS:** The name for the T1D Registry needs to be changed to something simple and catchy. The positioning of this registry should start with a clear and simple value proposition for PLwT1D and then research should follow the lead that PLwT1D provided. Collecting a baseline patient-reported dataset at registration is not interesting to PLwT1D as their first interaction with the registry. Registration should be very visually pleasing, non-threatening, engender trust, clearly articulate the value of participating and have simple prompts. PLwT1D can be given the option to provide more details about their experiences and behaviours through their engagement with clinical research and surveys via the T1D Registry.
- 2) **COMMUNICATION AND PEER LEARNING:** The value to the patients was not immediately apparent in the T1D Registry. PLwT1D wish to be connected with their peers and many wish to see how their behaviours and experiences compare with others in the community. This can be done through comparative analytics or simple statistics from surveying those in the registry. Creating opportunities for PLwT1D to connect and share their personal stories and experiences may be more valuable to the community than participating in clinical research. This concept should be considered as part of the first phase of planning for the registry and researchers can use this forum to gather patient input on setting research agendas. Furthermore, an opportunity to build a community for health care professionals in T1D to share ideas and learn from patient experience is key to building a network for collaboration and shared understanding in T1D.
- 3) **ADVOCATING FOR CHANGE:** There is significant interest in using the T1D Registry to advocate for change. This requires a ‘movement’ that will need the attention of as many people living with T1D in Canada as possible, their HCPs, and government – federal, provincial and municipal. It was highlighted that the T1D voice is often lost in the bigger discussion on diabetes as a whole, and the unique needs of those living with T1D are not addressed at the policy level. This has led to inconsistent healthcare paths and benefits across the country for those who need insulin and medical devices to survive. Although Diabetes Action Canada is a research consortium and not an advocacy group, through partnership with organizations like JDRF and Diabetes Canada, the registry could provide the patient perspective and evidence-base to incite change.

## SOAR in Research Pitches

The final event for the Insight Sessions revisited the SOAR framework, with researchers ‘pitching’ their research ideas to the audience using storytelling. The following three research ideas were pitched to the audience followed by large group discussion:

- Peter Senior pitched the ‘**Insulin Pump Registry**’. This tool would enable those who wear insulin pumps access to their lab data, HCPs and education, thereby eliminating the need for routine appointments to meet eligibility criteria for coverage. This tool would also alert pump wearers of their complications screening schedule and alert HCPs of any hospital or ER visits of those wearing pumps but still experiencing complications related to their T1D.
- Rose Yeung pitched the ‘**CanaDAFNE**’ (**Dose Adjustment For Normal Eating**) study. This would adapt the already established structured self-management education programs, specifically designed for people with T1D, to the Canadian context. This program has been shown to improve glycemic control, quality of life, reduce hypoglycemia and to be cost-effective in the UK.
- Tamara Spaic pitched the ‘**Structured Transition Program in Young Adults with T1D**’ pilot study. An innovative technology-based approach to provision of diabetes care (interactive mobile application) in young adults transitioning from pediatric to adult care. Preliminary results show that young adults on a structured plan attend more clinic visits and are more satisfied with their health care than those that are not.

The discussions revealed opportunities for collaboration and methods to engage patients in research design and implementation. Researchers were available afterward for small group discussions with PLwT1D and those interested in deeper engagement with pitched studies identified themselves.

## Workshop Evaluation

An Insight Session 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. The same survey was provided in both the paper and web-based format.

Of the 43% of participants who complete the survey, all indicated an overall ranking of either 4 (somewhat agree) or 5 (strongly agree) for the following:

- The Insight session was useful
- Individuals were given the opportunity to discuss how to improve research in T1D
- New methods to integrate the patient experience into clinical research were discovered
- A shared understanding was established of the T1D Registry project and its purpose.

The written comments were extremely useful as we look to improve the research presented. The PLwT1D were keen to see further research exploring education programs for T1D management and pump programs and projects exploring mental health. The most lauded part of the session was the story sharing with all participants, despite their role, enjoying the opportunity to hear and share their experiences with T1D. The PLwT1D really enjoyed hearing researchers position their research ideas as relatable stories, and the ‘pitch session’ was another highlight for most at the event. The large group discussions and sharing back was an integral part of the Insight Session’s success and many indicated

that hearing others discuss the topics inspired their own thoughts and ideas. Finally, the feedback that was most interesting is that this Insight Session was for many, the first time PLwT1D, researchers and HCPs gathering in the same room to networking, sharing experiences and discussing research in a safe and non-hierarchical way. In sum, the event was very well received and will be an important part of Diabetes Action Canada and The T1D Think Tank's ongoing commitment to learning from the patient narrative. The learnings from this session will have a major impact on future design and development of the various research activities underway by Diabetes Action Canada researchers.