



# DIABETES ACTION CANADA STRATEGIC PLAN

Approved by Steering Council – February 18, 2021

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## PREAMBLE

As Diabetes Action Canada (DAC) entered its fifth year, the Steering Council struck a Strategic Planning Committee to envision the future and make recommendations for the next phase our SPOR Network in Diabetes and its Related Complications. Simultaneously, our Research and Enabling Groups were asked to engage in a strategic visioning exercise and report on their plans to build upon their achievements, assets and network collaborations. All were requested to focus on sustainability plans with or without the opportunity for CIHR SPOR Network continued funding.

Our SPOR Network is comprised of Patient Partners, researchers, diabetes specialists, primary care practitioners, nurses, pharmacists, data specialists, and health policy experts. We have been honoured by the engagement of our Indigenous community partners who have imparted a deeper understanding of Indigenous ways that has influenced all of our activities. Although the COVID-19 pandemic has disrupted many of our endeavours, we continue to connect and pivot toward addressing the immediate challenges of persons living with diabetes while maintaining the momentum achieved to date. DAC also recognizes the critical importance and value of our sponsor partners, in particular Diabetes Canada and JDRF. The following summary outlines the 8-month process from June 2020 to February 2021 that led to this complete report and final recommendations.

### *Process Summary*

The Steering Council launched the Strategic Planning Committee in June 2020 and the following steps were undertaken to prepare this report:

- Articulation and agreement on the Terms of Reference including Committee membership, overall mandate and timeframe for completion (see **Appendix 1**).
- Revision of the Core Principles for DAC first published in the 2016 CIHR SPOR Network proposal (see **Appendix 2**)
- Reports from the strategic planning meetings of the Diabetes Action Canada Research and Enabling Groups (see **Appendix 3**)
- Review of internal reference documents, including the 2019 External Scientific Review, relevant for strategic planning (see **Appendix 4**)
- Approved launch of the 3 Working Groups with mandates that include key questions to guide discussion and recommendations (see **Appendix 5**)
- Working Group reports with recommendations presented to the Steering Council and Operations & Management Committee members for feedback and further discussion

## STRATEGIC PLANNING COMMITTEE MEMBERS

### STEERING COUNCIL

*Sasha Delorme  
Ross Gray, Co-Chair  
Malcolm King  
Terry Sullivan, Co-Chair*

### MANAGEMENT

*Jean-Pierre Després  
Gary Lewis  
Tracy McQuire  
Catharine Whiteside*

### INTERNAL STAKEHOLDERS

*Marley Greenberg, Patient Partner  
Ruth Ndjaboue, Trainee  
Peter Senior, Investigator  
David Wells, Patient Partner*

### EXTERNAL STAKEHOLDERS

*Dave Prowten, JDRF  
Laura Syron, Diabetes Canada*

### ADMINISTRATIVE SUPPORT

*Allison Hardisty  
Mildred Lim*

- Draft consolidated Report circulated to DAC Research and Enabling Group Leads, Patient Partners and Steering Council for editing and final recommendations
- Steering Council approves final Strategic Planning Report

## MISSION

Our mission is to develop patient- and research-informed innovations in equitable health care delivery designed to prevent diabetes and its related complications and to achieve the Quadruple Aim goals (improve: patient experience; population health outcomes; health professional experience; health system cost).

### Building and Sustaining the Impact of Diabetes Action Canada

- **through meaningful relationships with...**
  - our Patient Partners
  - Canadian diabetes organizations – DC, JDRF and others (e.g., Diabète Quebec, NIDA)
  - provincial and territorial health system leaders and policy decision-makers
  - public and private sector supporters
- **through strategic Patient-Oriented Research, knowledge translation (KT), and training & mentoring that...**
  - engages our Patient Partners in all stages of co-design, implementation and evaluation
  - improves wellness for those in Canada living with diabetes who are most vulnerable to adverse health outcomes
  - builds capacity in and provides a platform for multi-disciplinary, trans-sectoral collaboration
  - creates data-informed and technology-enabled learning health system solutions that fill the gaps in diabetes care and prevention
- **through the continued development and application of unique digital health infrastructure assets including our ...**
  - National Diabetes Repository
  - Connect1d
  - Teleophthalmology and AI analytics
  - Virtual care models

## A. BUILDING AND SUSTAINING MEANINGFUL RELATIONSHIPS

### 1. Build More Meaningful Patient Partner relationships with...

#### a) Researchers

Successful patient-oriented research means that Patient Partners are driving the research with questions about health challenges that matter most to persons living with diabetes. Although our SPOR Network research community has learned a great deal from our Patient Partners there is still more to be accomplished in establishing effective 2-way communication and engagement between researchers and our Patient Partners.

#### RECOMMENDATIONS

- i) Build a trusting relationship with mutual respect and understanding of the importance of Patient Partner experiential knowledge in co-designing research projects:
  - Incorporate the framework developed by the “do’s and don’ts committee,” that reflects the experiences (positive and negative) of Patient Partners in the Network, into the researchers’ integral commitment to the Network;
  - assign a Patient Partner Liaison for every research team who will be the main point of contact between researchers and Patient Partners who, together, will define the ground rules for regular check-ins and assessment of Patient Partner experiences;
  - improve communication between Patient Partner and researchers about the feasibility, relevance and outcomes of projects in language that is easily understood by both parties.
  - ensure Patient Partners are fully engaged from the outset of each project so that research questions are truly patient-driven (not just ratified);
  - improve technology-enabled two-way communication with researchers enabling consultation across distances that includes modalities outside of videoconferencing and reflects Patient Partner preference.

#### b) Each other and Network Governance/Management

Patient Partner diversity is necessary and requires exploration and understanding of what works, for whom and under what conditions. National representation requires effective communication and engagement across distances. Contributing to, and working constructively with, the SPOR Network Governance and Management teams is essential.

#### RECOMMENDATIONS

- ii) Enhance existing Patient Circles:

- Establish a systematic and effective process for engaging and onboarding the right persons for the right activities reflecting the experiential knowledge of individuals with different types of diabetes, age range, geographic location, ethnic diversity and languages spoken (including outside of English and French);
  - Articulate and promote opportunities for leadership, mentoring and advocacy roles to empower Patient Partners within the Circles to more effectively engage and collaborate with both the Network Executive, research teams and advocacy partners;
  - Define and expand the communications role of the Patient Circle Liaison on the DAC Operations & Management Committee
- iii) Provide professionally supported peer mentoring, including Sharing Circles (Indigenous approach), and increased training/coaching that is patient-led to empower Patient Partner participation and bridge knowledge gaps

#### c) Canadians Living with Diabetes and National Diabetes Organizations

Continued Patient Partner recruitment should focus on populations that are currently under-represented including young persons (<25 y), persons of colour whose first language is neither English or French, and those from provinces outside Ontario and Quebec. To communicate new evidence for solutions addressing the health challenges of all persons living with diabetes in Canada, more collaborative relationships should be developed between our Patient Partners and diabetes organizations that have advocacy as a core mission. By working more closely with these organizations and identifying research gaps that DAC could address, a complimentary advocacy effort would be established to effectively engage our Patient Partners.

#### RECOMMENDATIONS

- iv) Seek further connections and establish in-person communications with people from populations not currently well represented among Patient Partners. Design a process to reach into their communities through local diabetes education centres, primary care, community health centres and local culturally-relevant community leaders and associations;
- v) Develop joint strategies with national diabetes organizations (Diabetes Canada, JDRF, NIDA) to assist in recruiting Patient Partners to act in government relations and/or liaison roles with policy decision-makers

## 2. Build and Sustain Relationships with National Diabetes Organizations

The opportunity to work together with Diabetes Canada and JDRF on implementing common goals is now more important than ever for engaging all stakeholders – but particularly with health system and policy decision-makers. Further deliberation about the design of an effective partnership, where our strategies align, is in order for all three organizations. Diabetes 360° represents a strategic window of opportunity around which to continue building this partnership.

### RECOMMENDATIONS

- vi) Explore partnering with Diabetes Canada and JDRF to work collaboratively on achieving clarity of purpose and synergy for advocacy by:
  - defining the roles for each organization
  - identifying how to strategically fill research and KT gaps to optimize impact on improving diabetes prevention and care
  - clarifying how best to disseminate outcomes for health system leaders and policy decision-makers;
  - managing the expectations and facilitating the engagement of Patient Partners in advocacy roles; and
  - communicating with one voice about the widening gaps in diabetes care and complications prevention exacerbated by the COVID-19 pandemic.
  
- vii) Identify and agree upon the top (limited number of) priorities for patient-oriented research activities, aligned with Diabetes 360°, that will have the most impact in improving health of people living with diabetes in Canada or at risk of developing diabetes (Type 1 or Type 2). Together, present these priorities to the Provincial/Territorial Health Ministers.

## 3. Build and Sustain Relationships with Public and Private Sectors

Diabetes Action Canada is now consolidating projects under the theme of data-informed and technology-enabled collaborative care with emphasis on virtual diabetes care teams. This is particularly important during the COVID-19 pandemic and the acceleration of the necessary use of virtual platforms and remote monitoring. All the Provinces and Territories have prioritized digital health, chronic disease management (that includes diabetes), mental health and addictions, frail seniors and youth. Many Canadian industries are developing relationships with research organizations that align with digital health and artificial intelligence (AI) organizations including the [Vector Institute](#) in Ontario, the [Alberta Machine Intelligence Institute](#) and [Mila](#) in Quebec.

### RECOMMENDATIONS

- viii) Identify local health system leaders and policy decision-makers willing and able to champion demonstration projects at the outset of co-design with Patient Partners and other stakeholders, in collaboration with SPOR SUPPORT Units as appropriate. Engage in governance and support knowledge translation activities that will result in change to practice and policy;
- ix) Lead patient-oriented research related to diabetes and its complications in Canada, continuing to seek sponsorship support from both public and private sectors, while minimizing the risk of commercial goals-driven influence by the private sector in this context;
- x) Collaborate with Diabetes Canada and JDRF on strategies for securing support for goals the organizations have prioritized jointly while acknowledging the unique fund-raising that must be conducted by each organization. Engage in joint prospect clearance as necessary while taking advantage of opportunities to fundraise together to maximize private sector investment



## B. BUILDING AND SUSTAINING IMPACT THROUGH STRATEGIC PATIENT-ORIENTED RESEARCH, KNOWLEDGE TRANSLATION AND TRAINING & MENTORING

### 1. Meaningful Patient Partner Engagement

As a patient-oriented research Learning Health System organization, DAC brings together key stakeholders, specifically Patient Partners, with health system researchers into a knowledge-to-practice framework that aims to improve the wellness and health of people living with diabetes. It functions most effectively as a facilitatory, catalyst organization focused on achieving the Quadruple Aim, (i.e., to improve patient experience, population health, cost of health care, and the experience of healthcare providers) by facilitating meaningful Patient Partner engagement in research, knowledge translation and training and mentoring activities.

#### RECOMMENDATIONS

- xi) Focus on co-designing research projects with Patient Partners that address their most urgent health concerns and ensure each research team has at least two Patient Partners;
- xii) Develop a systematic approach to initiate and support more Citizen-led investigation with researchers who are committed to this endeavour;
- xiii) Provide evidence, using accurate indicators, for the diabetes research community (and the research community at large) that meaningful patient engagement is essential for achieving pragmatic research outcomes with optimal impact;
- xiv) Establish proactive communication and knowledge sharing approaches between Patient Partners, both across the Network and with all SPOR entities (Networks, SUPPORT Units);

### 2. Trans-Sectoral Collaboration to Achieve Learning Health Systems

DAC aims to continue its role in promoting and leading approaches to develop digital and virtual health systems that are vital to our Learning Health System, and to create a connected empathic environment with the necessary support to facilitate and reach vulnerable populations. Health system transformation by designing and iteratively developing data-informed, digital health solutions to establish comprehensive virtual care is the single unifying theme of almost all of DAC's current research programs. Although it does not have the resources to address the broad scope of social determinants of health, we recognize the importance of health promotion beyond disease management. Therefore, a strategic direction for the Network is to embrace the contribution of lifestyle modification that includes physical activity and nutrition as key to improving the health and quality of life of those living with diabetes or at risk of developing this condition, and to support initiatives by other organizations working in this space.

In addition, if there is an opportunity for application to CIHR for continued funding of the SPOR Networks, the concept of ‘networking’ with basic scientists for the purpose of establishing the continuum of knowledge translation into practice must be considered. DAC could attract basic science researchers who are willing to collaborate with our multi-disciplinary teams (‘coalition of the willing’) and explore meaningful engagement of value to our Patient Partners.

#### RECOMMENDATIONS

- xv) Focus on developing cost-effective, evidence-based, solutions for improving health promotion and care of persons with, or at risk of, developing diabetes and secondary prevention of its complications (blindness, lower limb amputations, renal failure, cardiovascular disease) by building upon our most successful patient-oriented research projects to date;
- xvi) Build collaborations with researchers in chronic disease (e.g., circulatory, renal, mental health disorders) and a full spectrum of multi-disciplinary health professionals to develop integrated digital health solutions for persons with diabetes and multi-morbidity who are most vulnerable to adverse health outcomes;
- xvii) Prioritize research on:
  - mental health conditions experienced by persons with diabetes, including but not limited to distress, anxiety and depression;
  - understanding the impact of age, co-morbidities, sex and gender, socio-economic factors, and cultural environments on living with diabetes;
  - perspectives and challenges of young persons living with diabetes;
  - effective chronic disease management, in which diabetes is applied as the most important unique identifier of persons at highest risk for adverse health outcomes. Design primary and integrated digital health care solutions for persons with complex chronic conditions that promote early intervention and avoids the necessity for acute care, enabling meaningful cost savings based on health technology and economic assessment;
- xviii) Extend the Network patient-oriented research expertise to include basic science researchers with relevant interest and desire to collaborate with DAC’s multi-disciplinary teams.

### 3. Collaborative Development and Application of Digital Health Infrastructure

A major goal of DAC is to advance the use of health data analytics for improving wellness and health outcomes for persons living with diabetes. The successful creation of our National Diabetes Repository of primary care electronic medical record information from six provinces is unique in Canada and is now being utilized in studies to create risk assessment and clinical management tools and has proven to be a

valuable asset to AI research. Another major milestone is the recent launch of Connect1d, our patient-driven digital platform that allows researchers to easily engage people living with T1D from across Canada and enables rapid recruitment of diverse patients into research, through an interactive registry. Our tele-retinopathy screening projects in Ontario and Quebec, herald the opportunity to develop automated, AI image analytics and a cost-effective national retinopathy screening program. The COVID-19 pandemic has accelerated our planning of virtual care demonstration project development that must address the inequitable access to timely care and prevention.

#### **RECOMMENDATIONS**

- xix) Evolve the co-development and application of our digital assets to enable health system innovation across Canada to improve the health of persons living with diabetes working in collaboration with Patient Partners, health system leaders, policy decision-makers and all necessary stakeholders;
- xx) Apply the technology-enabled collaborative care model to co-design, implement and evaluate virtual care programs that can be spread and scaled in every Province and Territory;
- xxi) Evolve DAC digital assets into provincial diabetes registries that provide the platform for continuous quality improvement and cost-effective prevention and care of diabetes and prevention of diabetes complications.

## **CONCLUSIONS AND FUTURE DIRECTIONS**

DAC has established successfully the first national patient-oriented research network and is poised to spread and scale solutions for improving the health of all persons living with diabetes in Canada. Our next steps will be to implement the strategic recommendations articulated in this report starting with scenario planning with and without the opportunity for application for continued funding from CIHR for our SPOR Network. Key elements of implementation to continue to build and sustain the impact of DAC will be strategic partnering with Diabetes Canada, JDRF, SPOR SUPPORT Units and public and private sector sponsors. New funding and collective impact governance will be necessary tactics to ensure we achieve our vision of transforming the health trajectory of persons in Canada living with diabetes at risk of complications.

## APPENDICES

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| Appendix 2 | Core Principles for Diabetes Action Canada (first published in the 2016 CIHR SPOR Network proposal)     |
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## Appendix 1 - Terms of Reference of Strategic Planning Committee

### **Purpose and Rationale**

Diabetes Action Canada has successfully established a Network of patient-oriented Researchers, Patient Partners and Trainees supported by a management structure and governance in keeping with the original mandate of the CIHR SPOR Network Program in Chronic Disease. Our projects have demonstrated the importance of focusing on what matters most to our Patient Partners and engaging them in all aspects of our research, knowledge translation, and training and mentoring activities. We have been honoured by the engagement of our Indigenous community partners who have imparted a deeper understanding of Indigenous ways that has influenced all of our activities. Although the COVID pandemic has disrupted many of our endeavours, we continue to connect and pivot toward addressing the immediate challenges of persons living with diabetes during this unprecedented time while maintaining the momentum achieved to date.

The COVID disruption has delayed the June announcement of the CIHR Strategic Plan. Although the SPOR Program was to figure prominently in this Plan, there is no certainty about its future and continued funding from Health Canada. Nevertheless, assuming that the SPOR Program will continue in some fashion, we must not only sustain but continue to evolve our Network. Therefore, it is time to initiate strategic planning for the future of Diabetes Action Canada. The societal and economic changes resulting from the COVID pandemic have revealed the urgent need to address gaps in the health care for persons living with diabetes, particularly those who are marginalized and/or suffering the burden of multiple chronic conditions. Access to preventative and timely treatment supported by data-informed and technology-assisted innovation has never been more urgent and critically important for successful implementation of effective virtual diabetes care. Hence, the way forward for Diabetes Action Canada is clear. We are in a position to lead the innovative changes in health care for Canadians with diabetes to improve outcomes that matter most to them and assist policy decision-makers and health system leaders in making the necessary and right decisions.

The following describes the draft ToRs for a Strategic Planning Committee that will report to the Steering Council of Diabetes Action Canada. The initial goals for the Committee are the following with the understanding that iterative development of further goals may emerge during the process of planning.

### **Initial Goals**

1. Based on current and future envisioned needs of Canadians living with diabetes, articulate the Patient-Oriented Research principles and objectives for the next 5 years of Diabetes Action Canada.
2. Establish an information gathering process both internal and external to Diabetes Action Canada to guide analysis of the current structure and function of the Network, and prepare a gap analysis based on the above principles and objectives.

3. Recommend a change management strategy for re-organizing and supporting the current research and enabling programs into a collective impact framework focused on the envisioned objectives for Diabetes Action Canada 2.0.
4. Identify the key stakeholders and partners that Diabetes Action Canada will need to achieve these objectives and the governance model that will best build and support these relationships.
5. Based on the assumption that CIHR SPOR 2.0 funding for Networks will be considerably reduced, formulate a plan for creating a backbone management organization that would optimally support the Network to achieve the 5 year objectives.
6. Recommend a process and timeframe for implementation of the Strategic Plan guided by CIHR SPOR Program announcements.
7. Establish closer collaboration, integration and alignment between DAC and the NGOs with respect to external challenges, e.g., building strategic partnerships with government and policy decision-makers.

**Members of the Committee:**

Steering Council – 4 members (2 Patient Partners) – including the Chair of the Cttee

Management – Gary Lewis, Jean-Pierre Després, Cathy Whiteside, Tracy McQuire

Internal Stakeholders – 2 Patient Partners, 2 Investigators, 1 Trainee

External Stakeholders – 2 Sponsors (2 NGOs)

*Administrative Support* - Mildred Lim, Allison Hardisty

**Process (timeframe 8 months):**

1. Steering Council reviews and approves (with revisions as necessary) draft ToRs and membership of the Committee at an ad hoc meeting 3<sup>rd</sup> week in May
2. Members of the Committee and Chair are recruited by early June and meetings commence
3. Committee reports and seeks feedback at each quarterly meeting of the Steering Council (commencing in July 2020)
4. Interviews of internal and external stakeholders and content experts completed no later than September
5. Interim report presented to the Steering Council in end October 2020
6. Final report to Steering Council in early 2021.

**Meeting Schedule:**

Monthly meetings will be scheduled for the full Committee; Working Groups may meet more frequently during their tasks.

## **Appendix 2 - Core Principles for Diabetes Action Canada (first published in the 2016 CIHR SPOR Network proposal)**

### **Patient and Community Engagement**

- Recognize that Patient Partners are knowledge experts based on their lived experience and their engagement is essential for learning health systems research.
- Meaningful and respectful engagement of Patient Partners and Communities is enabled in all SPOR Network activities.
- Patient Partners are representative of all Canadians living with all types of diabetes (Type 1, Type 2, Gestational) and its complications.
- Commit to follow the Tri-Council principles and guidelines for research involving the First Nations, Inuit and Metis Peoples of Canada. [https://ethics.gc.ca/eng/tcps2-eptc2\\_2018\\_chapter9-chapitre9.html](https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html)

### **Focus on Equity, Diversity and Inclusion**

Commitment to adopt the Tri-Council goals that include:

- Supporting equitable access to funding opportunities for all researchers and trainees;
- Promoting integration of equity, diversity and inclusion-related considerations in all research design and practices;
- Increasing equitable, diverse and inclusive participation in all research activities including on research teams;
- Collecting the data and conducting the analyses needed to include equity, diversity and inclusion considerations in decision-making.

[https://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/index\\_eng.asp](https://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/index_eng.asp)

### **Pan-Canadian in Scope and Scale**

- Impact of research outcomes related to improving the health of persons living with diabetes reach all areas of Canada, from heavily populated areas into rural regions with particular attention on the most marginalized and vulnerable.
- Research, knowledge translation and capacity building encompass what matters most to persons living with all types of diabetes (Type 1, Type 2, Gestational).

### **Nimble and Adaptable Strategic Decision-Making**

- Take advantage of opportunities to advance the mission and goals of the Network.
- Timely decision-making to engage new directions will enhance performance, outcomes and impact.

### **Strategic Partnering to Overcome Translational Barriers and Achieve Long-term Sustainability**

- Collaborative relationships with key stakeholders, including other SPOR elements, are established to enable translation of evidence into practice and policy.
- Shared value is created with both public and private sectors.

### **Accountable Network Governance and Management**

- Governance is designed to fully integrate Patient Partners, healthcare providers and policy decision-maker advisors with researchers.
- Management oversees and facilitates network performance that enables translation of outcomes into feasible clinical application considering important determinants of equity, efficacy, cost-effectiveness and transparency.

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## **WORKING GROUPS**

1. Meaningful Patient Partner and Community Engagement
2. Patient-Oriented Learning Health Systems Research
3. Engaging and Influencing Health System and Policy Decision-Makers



### Appendix 3 - Reports from the Strategic Planning Meetings of the Diabetes Action Canada Research and Enabling Groups

Research Group: Aging Community and Population Health

Participants:

|                         |  |
|-------------------------|--|
| Jenny Ploeg             | Principal Investigator & Professor, School of Nursing, McMaster University   |
| Maureen Markle-Reid     | Principal Investigator & Professor, School of Nursing, McMaster University   |
| Rebecca Ganann          | Co-Lead Investigator & Assistant Professor, School of Nursing, McMaster University                                       |
| Ron Beleno              | Patient & Public Research Partner (Ontario)  |
| Lynne Mansell           | Patient & Public Research Partner (Alberta)  |
| Frank Tang              | Patient & Public Research Partner (Ontario)  |
| Jean-Sebastien Paquette | Co-Investigator, Laval University & Groupe de Médecine de Famille Universitaire de Saint-Charles-Borromée                |
| Catherine Freeze        | Policy Analyst, Health Policy and Programs Section, Health and Wellness PEI  |
| Janet MacIntyre         | Co-Investigator, Faculty of Nursing, University of Prince Edward Island  |
| Robyn Connors           | Provincial Research Coordinator, University of Prince Edward Island  |
| Ethel Macatangay Doyle  | Patient Care Director-Nephrology and Chronic Disease, Scarborough Health Network   |
| Clint Gunn              | Patient Care Manager-Multi-Care Kidney Clinic, Home Dialysis & Family Medicine Teaching Unit, Scarborough Health Network |
| Jacqueline Chen         | Clinical Leader Manager, St. Michael's Hospital  |
| Tracy McQuire           | Manager, Research Operations, Diabetes Action Canada – CIHR SPOR Network   |
| Laurie Kennedy          | Administrator, Aging, Community & Health Research Unit, McMaster University  |
| Tracey Chambers         | Provincial Research Coordinator, Aging, Community & Health Research Unit, McMaster University                            |

#### **Responses to the Strategic Planning Questions**

The focus of the meeting was on older adults with diabetes and other chronic conditions.

1. The top Patient-Oriented Research Priorities for the next 5 years that will transform health outcomes for older adult Canadians living with diabetes, were identified as follows.

### **System integration**

- **Improving integration** between primary care, home and community care and hospital-based care, particularly for older adults with diabetes and multimorbidity
- **Timely access to and use of administrative data** that reflects social determinants of health, PROMs and PREMs to 1) identify at-risk groups, 2) inform intervention design and adaptations, 3) evaluate different approaches to service delivery
- **Helping patients navigate** multiple layers of the health care system

### **Service delivery models**

- **Scaling and spreading** interventions for older adults with diabetes
- **At-home care** for patients with diabetes and multimorbidity
- **Targeted strategies** to engage those with diabetes and multimorbidity who are often from **marginalized, vulnerable populations**
- **COVID-related**
  - Exploring feasibility, acceptability and effectiveness of **virtual approaches** to interventions for older adults with diabetes in this “new normal” environment
  - **Addressing social isolation** for patients in the context of the pandemic

### **Self-management and decision support**

- **Evidence-based self-management tools** for those who want to manage their own chronic diseases with guidance from professionals
- **Provide data to patients** about their own progress in easy-to-understand ways
- **Decision support** related to: Living environments (where to live, etc.); Options to best manage health/chronic diseases conditions; End of life related decisions
- **New testing and monitoring devices** (interstitial fluid testing vs blood for blood sugar testing)

### **Accessibility**

- Enhancing patient access - geographic and financial - to primary health care providers (including vulnerable and isolated populations)
- Indigenous population health planning and diabetes; under-privileged population and the social determinants of health effect on diabetes management and access to care; making services available to diverse populations
- Utilizing a health equity impact assessment/approach to understand which patients are accessing care and which patients are not, to understand why some groups are experiencing disadvantage; Using data to understand where diabetes is most prevalent and prioritizing populations that need improved access.

### **Patient engagement**

- Advancing knowledge of the implementation and impact of patient engagement in research
- Advancing knowledge of how to effectively engage marginalized and vulnerable older adults as patient partners in a meaningful and feasible way
- Revisit groups that are engaged in planning now, e.g., assembly of new primary care teams, Seniors health care 5-year plan, Primary care 5-year plan (in PEI), to understand what the project has learned about diabetes and comorbidities, key transitions that

older adults with diabetes struggle with, like connecting to primary care and other services, to inform planning.

2. Key barriers to achieving these priorities were identified as follows.

#### **System/organizational support**

- **Policy and funding support** for scale-up of effective interventions
- Identification of a **backbone organization** to sustain effective interventions
- **Time and human resource** constraints e.g., primary care
- **Financial and human resources**

#### **Data access**

- Lack of **consistency of data** across provinces
- **Lack of access** to provincial health care utilization databases
- Challenges accessing data on cost of health and social services
- Lack of **timely access** to administrative data that includes relevant **social determinants of health, patient-reported experience measures**, and other data not currently collected, and that is readily accessible and quickly available to inform real-time adaptations

It was noted that, in Quebec, data access is a huge barrier to patient care and research. Electronic medical records/systems do not communicate with each other. A lack of access to data creates challenges in providing patient care, e.g. lack of access to lab values for Indigenous populations in Quebec. A lack of access to provincial databases also creates barriers for researchers who wish to collaborate. A possible solution is an initiative like **PULSAR** in Quebec, see: <https://pulsar.ca/en/home>

#### **Patient level**

- Older adults' **challenges in using virtual approaches** e.g., how to use tablets, ability to afford computers/electronic devices, data plans/access internet and hardware; the digital divide and its effect on diabetes care (e.g., digital determinants of health).
- **Addressing health inequities and social isolation** that have been highlighted and widened as a result of the COVID-19 pandemic
- **Cost** of drugs and supplies to manage care. Inconsistencies across provinces in drug and service coverage and the impact of political leadership on adoption of proven interventions.
- Meeting the **cultural needs** of large, ethnically diverse patient populations. A greater understanding of the determinants of health and cultural components of care by region is needed to better support patients with self-management, e.g., using peer-support programs like those available through Scarborough Health Network's renal program.
- Lack of understanding/misinterpretation of **equity-based questions**. Patients often misinterpret questions being asked. Increasing the validity of questions and responses would make data more meaningful.
- **Goal setting**. Integrating patient and provider goals to achieve optimal health outcomes.

### **Patient engagement**

- **Address barriers to achieving meaningful patient engagement**, e.g., financial compensation for patient partners, demonstrating impact of patient engagement on outcomes, engagement of patient research partners from vulnerable and marginalized groups

3. Anticipated key facilitators to achieving these priorities were identified as follows.

**Existing Program Governance Structure** facilitates engagement of all stakeholders in the decision-making process, including policy-/decision-makers, patient partners, and researchers; supports scale-up of the intervention and can be used to address data access issues.

### **Knowledge translation (KT)**

- A marketing and communications approach designed to reach a **lay audience** will attract more attention from key groups, including government, to facilitate scale-up of intervention.
- **KT products** targeted at specific audiences, e.g., lay language summaries

### **Value, knowledge and funding for innovation and scale up**

- **Increasing value for and knowledge** of scale-up approaches
- **Continued funding and policy support** to scale-up and sustain effective interventions
- Policy-maker/provincial **government support for innovations** for managing chronic conditions in older adults
- Invested stakeholders with the means to continue to advance ACHRU-CPP

### **Improvements to care delivery approaches**

- **Strong partnerships** between primary care and community organizations
- Targeted approaches to address **social isolation**
- **Increased knowledge** in how to effectively provide virtual care
- Increasing proportion of **older adults using technology**

### **Patient engagement**

- Continued funding to support engagement of patients as research partners
- Knowledge and experience engaging vulnerable older adults as patient research partners

4. Participants had the following comments regarding how to foster collaboration with others, including those who are within the SPOR Network and outside of the Network.

The work of the Aging, Community and Population Research Goal Group is well-aligned with Diabetes Action Canada's priorities and the SPOR SUPPORT Unit components. We have been building collaborations over the last few years, including those with other Ontario SPOR Support Unit Research Centres (IC/ES, Women's Xchange, MIRA Health and Aging Collaborative) and SPOR Networks to better understand opportunities for collaboration and opportunities to share expertise related to older adults, patient engagement, accessing data, and implementation design, evaluation and scale up. We recognize that funding for SPOR 2.0 includes working with SPOR Networks and national data platforms. We are working to understand what is of value to other networks and how we can contribute in the area of aging.

We are in the process of creating a new website to highlight the expertise within the McMaster Institute for Research in Aging (MIRA) Aging and Health Collaborative and where we can provide support and consultation. Other suggested collaborations included Age Well, the Canadian Frailty Network, and the National Dementia Strategy.

5. Recommendations for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF), to co-design the spread and scale of effective interventions arising from Diabetes Action Canada initiatives. Leadership at national and provincial levels is required to forge connections between the SPOR SUPPORT Units and Centres within the SUPPORT Units, and between SUPPORT Units and national networks.

Work to understand the barriers to connecting patients to services and which organizations can meet patients' needs is needed to drive collaborative efforts.

Create a campaign and frame requests to key stakeholders. Tailor messages based on the mandate of the group that is approached. Understand the role of Provincial and Territorial ministries and health authorities - who does strategy vs. operations, in various provinces.

6. Strategies to support long-term sustainability of our Patient-Oriented Research initiatives included the following.

Creating a business plan to present to prospective donors, to give donors the option to fund smaller parts of the larger project.

Leveraging relationships with other SPOR SUPPORT Units and their access to other provincial governments.

Aligning with a community of practice to gain exposure and avail opportunities with other governments.

### **Next Steps**

Jenny thanked the group for their time and thoughtful suggestions. A copy of the presentation from the meeting was circulated to all participants. All participants were invited to send additional comments and suggestions and were advised that they would be sent a copy of the 3-page report for their comments, before submitting to Diabetes Action Canada.

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Research Group: Diabetic Retinopathy Screening

**1. What are your top 3 patient-oriented research priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes? How do you plan to ensure that the needs of marginalized and vulnerable populations are addressed? How will you meaningfully engage Patient Partners?**

Our main goal is to increase DRS. BC and the Western provinces are more advanced in the DRS process but in Ontario we still have close to 40% unscreened people in vulnerable populations. To improve health outcomes for Canadians living with diabetes our priorities are the following.

1. Expand the DRS program. Quebec teleophthalmology, led by Dr. Marie-Carole Boucher, is supported by the Quebec Ministry of Health to develop Province wide program for Diabetic Retinopathy screening.
2. The main enabler to achieve our goal is to use a data-driven approach and focus on approvals from the Government to allow us to use the Government administrative health data and existing structures to find and contact people who need to be screened.

We are planning to expand our population-based data-driven approach to screening (Project OPEN) in Ontario, Alberta and BC. This CIHR grant that we are working on with Dr. Val Rac, will help connect the country together in a National teleophthalmology program for DRS.

BC and the Western provinces are more advanced in the DRS process. They have node sites, hospitals, and optometry who can take images. The key point is to identify people through provincial databases who need screening and get provincial approval to directly contact patients if they find problems within the database. This more focused approach for DR screening may achieve higher yield in BC.

3. It is important to develop a Type 2 Diabetes registry and a Type 2 Diabetes patient App in the next round to be able to track the data.

**2. What key barriers do you envision to achieving these priorities?**

1. Putting databases together and being able to move the data across provincial borders are our biggest challenges. The goal for SPOR national data. platform is to share data access provinces, and DAC leadership is working on these challenges and focusing on integrating data within the provinces.
2. Funding for a Connect T2D registry needs a national consortium with sufficient funding to support this initiative.

We need a provincial/regional registry. MOH Ontario has declared the Digital First for Health strategy – including chronic disease management and retinopathy screening – but due to COVID, their priorities have shifted.

We will continue to work with the Ontario Community Health Centres and the Ontario Health Teams as the best way to get and link data, through IC/ES and/or with UTOPIAN and academic family health teams in Ontario.

3. We need to lobby government in each province for better access to and linkage with their administrative health data.

### **3. What do you anticipate will be the key facilitators to achieving these priorities?**

1. To achieve continued support and funding, we will be working with the public sector, SPOR SUPPORT UNIT networks, NGOs (i.e. Diabetes Canada with a focus on preventing blindness as a major diabetes complication) and private sectors as our best supporters (Bayer, Novartis). We are aware that our industry partners will need to reevaluate how they can support our research financially in the near future as they are facing the implementation of generic drugs that are coming soon that will reduce their market share of patented drugs.
2. To create a Type 2 Diabetes registry and use integrated health data we might need partner with TELUS Health and potentially other EMR service providers.

### **4. How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?**

Building collaboration between Vancouver hospitals (through collaborators Dara - working on data integration for chronic disease management, Minie Downey, Sabrina Wong –BC Population Health), and engaging government to access BC databases that can be linked to larger projects, is the main goal in the next round.

*Provincial retinal diseases program* in BC is well organize. Everyone who is getting treatments (those in more advanced stages) is in the provincial retinal disease database, and can be linked to other disease-specific databases. This linked databases can give us information about highest risk people who are losing eyesight.

Sharing of these disease-specific databases and the retinal disease registry may be a way to extract data. Using databases already available in BC (i.e. rheumatology data) we can pull data, find and engage those patients who need to be seen directly.

Dr Maberley has applied to the BC Government for a wider data pull, and for permission to contact patients directly for secondary use of data. Patients are not consented to release their contact information for research but government has allowed it for implementation of quality improvement projects. The data stays within the group partnered within the government.

In Ontario, the Ontario Telemedicine Network has DRS information in their database. The challenge is convincing the privacy commissioner to share administrative health data to allow us to identify people living with diabetes who have not had annual DRS.

We need to lobby government for better access to their data with support from the SPOR SUPPORT Units in each province.

**5. What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?**

Over the years we have tried to build collaborative relationships with CNIB and Fighting Blindness Canada. CNIB moved away from funding research and is more focused on vision rehab work. Fighting Blindness Canada is focused on basic science and retinal degeneration research, and there is very little financial support beyond hereditary vision loss pathology.

Another suggested opportunity is with Insurance companies (e.g., SunLife). This may not be feasible because our patients with the worst type of retinopathy are usually of lower socioeconomic status and most do not have 3<sup>rd</sup> party insurance.

Other provinces: Alberta has a well developed DRS program; Manitoba has a good set-up, Quebec is fast moving forward; Newfoundland has a tele-ophthalmology DRS program but Nova Scotia, New Brunswick and Saskatchewan are not active yet. Quebec is the only province with declared province-wide support for the development of a DRS program using tele-ophthalmology.

We need public health and primary care involvement to step up and help organize regional screening with ophthalmology based on the current UK model.

**6. What are your strategies for long term sustainability of your Patient-Oriented Research initiatives?**

Key recommendations:

- Population based approach
- Data-informed digital health services
- Use of technology



Research Group: Digital Health – National Diabetes Repository

**Planning session: September 14, 2020**

The National Diabetes Repository (NDR) can provide information relevant to individuals deemed to be at high risk for diabetes-related complications, building the information infrastructure to enable more timely interventions. The strategic session that was held on September 14, 2020 identified 3 priorities to focus on for the next 3 to 5 years. These include (1) collection of Patient-reported experience measures (PREMs) and patient-reported outcomes measures (PROMs); (2) novel data linkage methods and expanding the breadth of data, and (3) expanding use of the repository to more users with a focus on AI researchers.

**What are your top 3 patient-oriented research priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes? How do you plan to ensure that the needs of marginalized and vulnerable populations are addressed?**

**1. PREMs and PROMs**

- Sets the NDR apart from other databases.
- Aligned with involving patients in research.

**2. Data Linkage and Collection:**

- Expand to population-based outcomes through linkages with national and provincial administrative data sources
- Work with Indigenous Peoples and their representatives to include data, following and respecting OCAP principles.
- Expand number of practices and provinces/territories contributing data.

**3. Artificial Intelligence and Machine Learning:**

- Expand work with experts in AI and Machine Learning to identify those individuals who are high risk for the adverse outcomes arising from Diabetes.
- Members of the DAC Collective Patient Circle expressed their interest and reiterated the importance of research in this area.

**How will you meaningfully engage Patient Partners?**

- All projects submitted to the NDR require review and approval from the Research Governing Committee (RGC), which provides a decision on whether the proposed research is being conducted with the best interest of the patients in mind.
- Adding lived experience to the analysis adds meaning and depth that resonates with the population whose data these are.
- Patient involvement in the NDR will continue to operate following the patient compensation guidelines set by Diabetes Action Canada.
- Additionally, we will continue to invest in training and education for members of our RGC, including AI so that Patient Partners can better understand analytic approaches and risks of AI. This aligns with the “Support Principle” for patient-oriented research.

### What key barriers do you envision to achieving these priorities?

#### 1. PREMs and PROMs

- Physician uptake
- Technology

#### 2. Data Linkage and Collection

- Privacy legislation / Interpretation of Law
- Institutional Policies / too risk adverse = reluctance to share
- De-identified data = Difficulty to link to other datasets
- Provincial initiatives – PULSAR and PARS3
- Issue around duplication of efforts is being worked on by several organizations (e.g. CPCSSN, DAC etc.)

#### 3. AI and Machine Learning

- REB approval required, but no formal question defined
- NDR currently lacks computing power required for some data intensive tasks.

### What do you anticipate will be the key facilitators to achieving these priorities?

#### 1. PREMs and PROMs

- OCEAN Tablets and secure email – Technology enabling easier collection of data
- Diana Sherifali – identified possible funding through her research chair.

#### 2. Data Linkage and Collection

- Quebec's priorities continue to revolve around PULSAR and the PARS3 Platform. One of our options is to run small-scale tests for feasibility of both systems using dummy data. Another option would be to conduct parallel analysis., which was proven to be feasible through a recent project by Dr. Greiver which compared the trends in diabetes medications in 4 countries.
- Building on the "Inclusiveness Principle" our data focus will be expansion to include the marginalized and vulnerable and the inclusion of socioeconomic diversity (such as those from rural Canada.)
- CPCSSN = Strengthened partnerships with national EMR vendor (TELUS Health, QHR Accuro)
- Continued work with the Alliance for Healthier Communities and South Riverdale Community Health Centre to add their EMR data to our data holdings (Vulnerable Populations).
- Engaged Dr. Pauline Pariser who leads the Seamless Care Optimizing the Patient Experience (SCOPE) to recruit solo practitioners into the NDR (many participating practitioners have practices in more deprived areas.)
- Engaging Dr. Jennifer Walker to seek her advice and guidance in working with the Indigenous Communities so they will be reflected in the work being done in the NDR.

### 3. AI and Machine Learning

- Fostering relationship and building new partnerships with AI, Advanced Analytics and Industry leaders will help propel us into the next phase of the NDR. The Transformation Competition has illustrated the partnerships we need to strengthen with Doug Manuel, Peter Selby, Parminder Raina, Anita Layton
- Include securely transferring a data cut from the NDR and into a secure HPC environment at an accredited and trusted research or academic institution.
- Subject matter experts (incl. clinicians) are critical to success of the projects. Individuals who know about diabetes, its impacts will be partnered with AI researchers.

#### How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?

Diabetes Action Canada Digital Health research program is functioning as a back-bone catalyst for other research programs to reach their research goals.

Fostering relationships with:

- **Vector Institute for Artificial Intelligence** and the **Schwartz Reisman Institute for Technology and Society**. These critical collaborations will build capacity to AI and machine learning for diabetes for researchers and post-docs.
- **ICES** and **CIHI** enables identifiable cohort list disclosed from a Prescribed Entity to a health information custodian.
- **Information Privacy Commission of Ontario** - as an observer to projects.
- **Ontario Health Data Platform** - privacy-preserved linkage of large datasets in a federated high-performance environment.
- **Health Data Research Network (HDRN)** provides an opportunity incorporate health a social data from various sources across the country enabling multi-jurisdictional research.

#### What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?

Establish collaborations with:

**Quebec** - INESS and the PULSAR group and Alliance santé in Quebec City.

**Nova Scotia** - Nova Scotia Health Authority's Diabetes Registry and Maritime Family Practice Research Network (MaRNeT-FP) (EMR data from Nova Scotia, New Brunswick and PEI.)

**Newfoundland and Labrador** – NLCHI and eDOCSnl; continued expansion of Atlantic Based Primary Care Network (APBRN).

The **STOP Program** for smoking cessation at CAMH is of great interest to us as we aim to create a virtual health care initiative for diabetes care

**Diabetes Canada** – Their Diabetes 360 report, which is a framework for a national diabetes strategy highlights the need for a National Diabetes Repository and suggests that the DAC NDR is

a starting place, which should be enhanced and combined with existing and future data to provide a comprehensive view of the burden of diabetes in Canada.

### **What are your strategies for long term sustainability of your Patient-Oriented Research initiatives?**

As this was not discussed in depth at our session, we have referenced our prior visioning session which outlined 3 options for continued operations and growth. Outlined below are the options that resonated with our patient partners and the members of the NDR operations team.

#### **Incorporate as a Federal Non-Profit**

The National Diabetes Repository should remain under the custody and control of Diabetes Action Canada with the RGC intact.

Operating on a cost-recovery basis with annual base funding.

Incorporating federally would also place the NDR under Federal Privacy Legislation PIPEDA. The new entity would act as an umbrella organization to cover the Diabetes Registry.

#### **Membership-Based Entity**

Members will financially support the NDR. This model would operate under an oversight committee including members from the DAC Steering Council.

Either of these two models would create opportunities and a sustainable platform for researchers to collaborate with experts in other sectors (Government, Academia and Inter-provincial groups) and will encourage members to foster relationships to ultimately answers to the needs of the diabetic communities across Canada.

#### **Status Quo+**

Diabetes Action Canada receives continued funding to proceed with the expansion of the NDR. This will enable an immediate value-based approach for direct patient impact based on current policies and procedures. Seek grant funding or support from stakeholders.

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Approved by Steering Council – February 18, 2021

Research Group: Foot Care and Prevention of Lower Limb Amputations

Pending

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Research Group: Indigenous Peoples' Health

### **Diabetes Action Canada Strategic Planning – Indigenous Health**

Diabetes Action Canada has established a pan-Canadian Network of investigators and Patient Partners to enable the development of research questions and projects that are most meaningful to those living with diabetes. Our first funding term ends in March 2021 and we are now working with each of our research programs to plan for an application to renew our Network funding with CIHR and our other funders. We have established a Strategic Planning Committee and Working Groups, and together we are working with each of our research programs to understand what research priorities they wish to see in our next phase. The opinions of our Patient Partners are extremely important during this process so we can learn what has worked and how we can improve in order to engage those living with diabetes more meaningfully and respectfully.

We know that the Indigenous Patient Circles had a series of gatherings in 2018-19 to discuss the important challenges among their communities and how we, as research teams, can best engage in diabetes complications prevention research with Indigenous Patient Partners in a culturally appropriate and respectful manner. From these gathering your renewed mission was developed as follows: "*Indigenous partners empowering wholistic approaches to wellness*" During these sessions a number of research priorities for the Indigenous Patient Circle were identified. These include:

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. Scale the Diabetes Integration Project developed by Dr. Barry Lavalee. This trauma-informed training module for health care practitioners discusses the unique challenges encountered by Indigenous peoples and how these challenges have affected their health and experience with the Canadian health care system are being developed.
5. Support capacity building in patient-oriented research among Indigenous researchers
6. 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;
7. 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,
8. Develop a video of youth stories (in alliance with IYMP).

We wish to include these research priorities as part of our strategic plan, which will then be used to develop our application of Diabetes Action Canada phase 2.

To determine what priorities, if not all, can be included in our application for renewal the Strategic Planning Committee has developed the following questions to facilitate discussion. In this Indigenous Patient Circle meeting we are hoping to get your perspectives on at least the first three questions and if time allows the remaining.

### **Strategic Planning Questions for DAC Research and Enabling Groups**

Given the opportunity to apply for continued CIHR and matched funding for our SPOR Network:

1. What are your top 3 patient-oriented research priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes? How do you plan to ensure that the needs of marginalized and vulnerable populations are addressed? How will you meaningfully engage Patient Partners? (This question should be customized for each Enabling Group, replacing 'research' with training and mentoring, patient engagement, knowledge translation, sex & gender, health technology and economic assessment.)
  2. What key barriers do you envision to achieving these priorities?
  3. What do you anticipate will be the key facilitators to achieving these priorities?
  4. How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?
  5. What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?
  6. What are your strategies for long term sustainability of your Patient-Oriented Research initiatives?
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## Innovations in Type 1 Diabetes Strategic Planning Report

**Vision:** Enable patient-oriented research and accelerate clinical research in type 1 diabetes in Canada

**Mission:** Develop and utilize a first of its kind digital registry in Canada to connect researchers with the type 1 diabetes community.

### 1. What are your top 3 patient-oriented research priorities for the next 5 years that will transform health outcomes for Canadians living with diabetes?

**Connecting with type 1 diabetes community in Canada more holistically.** We have made great efforts to consult with members of the type 1 diabetes community – though our own Patient Partners, partnering with the T1D ThinkTank and reaching out to patient advocacy groups like JDRF and Connected in Motion, and must continue to do so for all activities in our program. We have also created a digital platform to enable the collection of patient-reported data, *Connect1d*, but its efficacy as a research tool is only as powerful as its users. We are not worried about recruiting those living with type 1 diabetes that are already engaged in other advocacy or virtual communities, but we need to implement a communication and recruitment strategy to reach those living with type 1 diabetes, but are not easy to reach. We need to understand what barriers exist for these individuals and learn how to position *Connect1d* as a trustworthy, accessible and approachable means to contribute to clinical research in Canada.

#### **Use *Connect1d* to expand clinical trials beyond institutional and jurisdictional silos.**

Researchers often plan clinical research and apply for funding with little consultation with the type 1 diabetes research and patient community. The digital platform for *Connect1d* can help researchers with shared interests connect and collaborate on potential proposals to yield stronger applications focussing on collaboration rather than competition. Through *Connect1d* the research community can also test their research questions or conduct priority setting questionnaires with the type 1 diabetes community to learn whether their research direction has relevance to the community at large.

**Generating data that will be useful for policy and practice.** We are often challenged when asked for simple demographic information about those living with type 1 diabetes in Canada. This is a function of how data is collected and shared by physicians with provincial and jurisdictional health authorities. When our Patient Partners hear this, they are surprised that their condition is often lumped together with diabetes as a whole, making it harder to advocate for the unique needs of those living with type 1 diabetes. By collecting patient reported data on the lived experience of those living with type 1 diabetes we can enable population based research on the impact of social determinant of health on living with the condition.

### 2. What are the key problems (i.e. barriers) in achieving these priorities?



**Privacy and data sharing issues.** We are asking those living with type 1 diabetes to provide personal health information to be stored in a trusted hospital-based server. For those already comfortable with sharing their data this should not be a barrier, but for those uncomfortable we have to be clear about how this data is protected and used for research.

**Redundancy among studies and resources.** We recognize that competitive research is important, but also has the potential to create silos and avoid collaboration. True collaborations take time, effort and trust and as a result can be slow to come to fruition. This can be frustrating for those who are unfamiliar with the research process and expect more streamlined approaches to research.

**Reluctance to work with industry.** We hear often from Patient Partners they are uncomfortable supporting the research efforts led by industry. This tension between the type 1 diabetes community and industry has been problematic for academic based research which has limited resources to answer big research questions. Sustainability of *Connect1d* will likely need support from industry so transparency, communication to enrolled participants and a robust governance model must be in place to help navigate this sensitivity.

**Struggles with research ethics board.** Navigating research ethics is a complicated tasks and not something easily understood by lay audiences. Although *Connect1d* itself will have approval for quality improvement and not require REB approval, research studies that use the platform will be required to have REB approval. Enlisting a ‘host’ REB to facilitates approval of studies is a potential approach (similar to what I.C.E.S has with Sunnybrook Hospital), but this may be unrealistic with University Health Network, the host academic institution for *Connect1d*. This will be a challenge to our mission to enable clinical research and will need to be considered.

### 3. What do we need to achieve these priorities (i.e. enablers and facilitators)?

**Robust governance structure with Researchers and Patient Partners as equals.** When requests for data are received by *Connect1d* they must be approved by a governance committee with representation from the main stakeholder groups including, physicians, researcher, advocacy groups and Patient Partners. This will ensure that all data usage is aligned with the best interest of all who participate in *Connect1d*

**Collaboration/Partnership with existing virtual patient networks.** These include the Montreal based VPN, BETTER study, and patient advocacy groups (JDRF and Diabetes Canada). Fostering community is an important aspect of *Connect1d*, but in the first iteration of the platform, it was decided as more of a ‘phase 2’ add-on. We would like to see how the great work already ongoing with other jurisdictional and/or national community groups can be bolstered by *Connect1d* and vice versa to drive patient-oriented research in type 1 diabetes.

**Recruitment through physician offices.** During all of our planning thus far, recruiting through physician offices has come up as a trusted conduit into *Connect1d*. This is a good idea in theory but would require buy-in from physician office, funding for human resources, and site coordination.

**Feed back to Patient Partners on research and results.** Having a mechanism that enables live feedback to those who have either participated in a research study or contributed to the planning will keep everyone informed and empower those living with type 1 diabetes to continue to contribute to the *Connect1d* platform and communicate positive user experiences. This may require training for all researcher who use *Connect1d* to ensure they are well versed in knowledge translation expectations to continue their use of the platform.

**Comprehensive communication and marketing plan.** Since participants in *Connect1d* will be self-enrolling in the first iteration of the platform, a cogent communications and marketing plan is essential to recruit and retain those living with type 1 diabetes. Social media campaigns, continued communication of research finding and community engagement will be necessary components of said plan, as well as continued communications partnerships with JDRF and other patient advocacy groups.

**4. How do you intend to foster collaboration with others in your field? This includes those who are within the SPOR and those outside of the Network?**

**Foster virtual community where researchers and type 1 diabetes community present ideas and collaborate.** During our planning discussions the stress of competing for the same resources was discussed more than once. The idea of collaborating on larger projects with multiple researchers navigating the complexities of the REB, Health Canada, and inter-institutional agreements was very attractive to the team. Using the *Connect1d* platform to not only recruit for research studies, but also highlight national assets (i.e. VPN and BETTER) can also increase awareness of valuable resources to facilitate a ‘working together’ mentality.

**5. How can we develop closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR SUPPORT Units, and NGOs (e.g., Diabetes Canada, JDRF), so that they can help co-design spread and scale of your effective interventions?**

**If we build it, they will come.** Already we have had opportunities to discuss *Connect1d* and demonstrate its use to provincial health authorities in Ontario, Quebec, and Alberta. Each time we have garnered significant interest, but without any validation or evaluation to demonstrate its effectiveness, this interest has not materialized into anything significant. Once we have generated the data needed to inspire these health authorities into action, we are can start the scale of this important work beyond self-enrollment and provide evidence needed for policy and decision makers to make informed recommendation on type 1 diabetes care and management.

**Aligning research priorities with other research groups and NGOs.** Diabetes Action Canada already works very closely with JDRF on the *Connect1d* project as they are a co-funder and key stakeholder. We have a joint communication and marketing plan for phase one and assume that JDRF will be among the first of our stakeholders to engage the digital community. Using our digital community, we can work with other SPOR entities, NGOs, governments, etc. to start providing the data needed for those living with type 1 diabetes advocacy, research questions planning, insulin pump policy, etc.

**6. How might we ensure the long-term sustainability of patient-research oriented research?**

**Investigate other sources of funding to support the initial phases of the *Connect1d*.** We understand that in the second phase of the SPOR program, only the research infrastructure and select personnel would be supported. As we pursue other exciting collaborative opportunities with the T1D Exchange and potentially Tide Pool in the US we become a more attractive investment in Canada. We hope to continue the relationship with our developments team out of UHN to find funding for the initial phases of the project. At the conclusion of phase 1, we expect to be positioned as a valuable tool for conducting patient-oriented research and other research teams will wish to use or adapt the system for their own use. Beyond this, we will have to get creative on how to secure additional funding and this might be with government and/or industry partnerships. Our one key barrier is the tension between private industry and those living with type 1 diabetes and this is something that will need to be navigated carefully through the governance structure.

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**Strategic Planning for DAC 2.0 – KT Goals Group Strategic Plan v. 2.0**

December 18, 2020

- 1. What are your top 3 patient-oriented research priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes? How do you plan to ensure that the needs of marginalized and vulnerable populations are addressed? How will you meaningfully engage Patient Partners?** (This question should be customized for each Enabling Group, replacing 'research' with training and mentoring, patient engagement, knowledge translation, sex & gender, health technology and economic assessment.)
    - 1) Increase patient empowerment to engage in KT research that is relevant for diabetic patients taking into account pandemics and other uncertain factor such as change of government, etc:**
      - Current challenges/gaps:
        - Research questions are typically launched by investigators, which may not be in line with patient needs or interests
        - Patients are not driving the initiatives and may not be involved in research questions that are important to them thereby limiting their drive to be
  - 2. How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?**
    - Opportunities to collaborate across other DAC goal and enabling groups
    - Opportunities for collaboration with organizations and networks we can attach to and leverage:
      - KT Canada/KT Summer Institute
      - Practice-based Research Networks (PBRNs)
      - Diabetes Canada
      - Ministry of Health
      - Quality improvement groups
      - Primary care groups
      - QSSU/OSSU
      - JDRF (juvenile/type 1 diabetes), which is missing but they are very eager to collaborate
      - Ottawa Methods Centre has specific methods focus (and is OSSU-linked): <http://www.ohri.ca/ottawamethodscentre/about.aspx>
      - Websites that are accessed by patients: “Beyond Type 1” (<https://beyondtype1.org/>); “Waltzing with dragon”
      - SPOR-funded entities beyond DAC
- For the French session, other suggested opportunities included:**
- Collaboration between DAC and Réseau-1 Quebec, there is funding for researchers and involvement of patient partners

- Community organizations such as FADOQ or FROHQ for Jenny Ploeg's project in Quebec
- Presence of DAC at the university level in Quebec (such as Université du Québec à Trois-Rivière)
- Diabetes Québec, as well as these various variations such as Diabetes Mauricie, there are 6 communities diabetes associations
- Community Pharmacy network
- International Diabete Federation
- Centre d'amitié Autochone de la Lanaudière (also all others Autochonus friendship centers in Quebec)
- Pharmaceutical industry
- The private sector
- Links with technology compagnies
- INESSS, COMPAS project

**3. What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?**

- Create a model of engagement and ongoing collaboration; we could introduce something from KT theories, models and frameworks (e.g. iPARIHS that further highlights role of KT group in this area)
- We need align with the relevance to their current priorities (e.g., COVID-19, budget issues, elections times)
- We could study this specifically as a KT issue in terms of figuring out *how* to establish these relationship (i.e., what are barriers/enablers to stakeholders engaging with DAC)

**For recommendations during the French session, we could also consider:**

- If DAC has knowledge products that should be scaled up, targeted strategies should be developed to reach decision-makers, no need to build trust over the long term (via lobbying).
- To create added value for citizens, organizations need to communicate, to rally together. The issues related to diabetes are much broader than diabetes per se, and this requires exchanges between the different organizations involved such as community groups, decision-makers, ...
- Without overloading their agenda, we should find a way for decision-makers to become aware of the problem and to come back with possible solutions later.
- For this, in Belgium, there is a networking group/platform for collaboration with decision-makers. This platform has obtained political support, as well as field teams.
- At the level of the partners, the integration of Artificial Intelligence could be a good idea. The use of a virtual assistant for people with diabetes who could answer their questions 24 hours a day would be something to consider.

- Collaborations with organizations that are not directly related to diabetes, but by their field/specialty could be involved (e.g., the Institute of Gender and Health, or the Institute of Nutrition, Metabolism and Diabetes).
- Network for Pan-Canadian Advocacy
- PULSAR
- Following the example of the Quebec Support Unit and Réseau-1 Québec, explore the institutions and networks with which Support Units in other provinces collaborate.
- The importance of having and maintaining trusting relationships
- Have a patient partner dedicated to making connections with patients in francophone communities in other Canadian provinces (francophones outside Quebec, francophones in different provinces).

#### **4. What are your strategies for long term sustainability of your Patient-Oriented Research initiatives?**

- The challenge with any sustainability is that projects outlive the longevity of a grant, so we propose to embed an assessment of the sustainability and/or scalability potential of each DAC research project across the various DAC projects (including KT projects) – this would allow us to achieve that longevity (i.e., 5 years and long-term follow-up over these 5 years)
  - We will start by synthesising and exploring scalability assessment among all DAC innovations to evaluate their preparedness for scaling up in Canada.
  - There have already been two initiatives on this respect with the 12 CIHR-funded CBPHC teams and the Quebec College of Family Physicians
- Embed in all networks and organisations we work with
- Training and building capacity
- Strategies for supporting transition of DAC (marginalized) trainees to the POR leadership stream in Canada (e.g., obtaining a position as an early career investigator)
- We are currently undertaking an evaluation of KT activities of DAC 1.0, which will also inform gaps to address in DAC 2.0

#### **For the French session, the participants also proposed the following point:**

We also need to look for groups/organizations for which the partnership would be beneficial. Generally, we ask organizations to participate in projects in the immediate term. They agree, but once the project is completed, contact between the two parties is less frequent. We need to think differently. We should see/seek organizations interested in a long-term partnership with DAC-KT, even if there is no immediate project, so it is a win-win situation for both parties.

Research Enabling Group: Patient Engagement

**DAC Patient Engagement Strategic Planning session  
In consultation with the Collective Patient Circle  
October 21<sup>st</sup> & November 12<sup>th</sup> 2020**

**TOP 3 PRIORITIES:**

- 1) Ensure thriving, meaningful patient engagement across all DAC activities.
- 2) Identify “active ingredients” of meaningful patient engagement in research across different groups and contexts & ensure these are in place.
- 3) Initiate and support more Patient Partner-led research.

**1) Ensure thriving, meaningful patient engagement across all DAC activities.**

- Build upon prior experiences (good and bad) to ensure consistently positive experiences for Patient Partners in DAC.
- Every project must have at least 2 Patient Partners.
- We will check in with Patient Partners regularly (using methods for checking in that are preferred by Patient Partners) to assess how well/poorly teams are doing re: the ‘Do’s and Don’ts’ identified by DAC Patient Partners, and to ensure that everyone has the opportunity to contribute as they would like.
- Continue Patient Partner recruitment, with a particular recruitment focus on groups that are currently under-represented: people <25 years old, English-speaking people of colour, people in provinces outside ON & QC.
- Ensure all Patient Partners have onboarding and a mentor/group to contact.

**2) Identify “active ingredients” of meaningful patient engagement in research across different groups and contexts & ensure these are in place.**

- Different groups may require different approaches. We have a diverse set of Patient Partners. We will continue to explore to identify what works, for whom, and under what conditions.
- We particularly want to look at how to ensure meaningful relationships and good experiences across distances. This is new for a lot of patient engagement work, and videoconferencing works better for some people than others.

**3) Initiate and support more patient partner-led research.**

- Patient partners should be driving the research. We are seeing this in some studies and will build on these successes.
- We particularly want to create pathways for Patient Partners to propose research questions they wish to see answered.

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**What key barriers do you envision to achieving these priorities?**

- Time is a major hurdle to achieving all three priorities. It takes time to build relationships and meaningful patient engagement.

- Creating accurate indicators to measure paradigm shift and culture change across scientific research.

**What do you anticipate will be the key facilitators to achieving these priorities?**

- Facilitating more patient-led initiatives will help us do better in all aspects of patient engagement in the Network (f. e. in valuing expertise).
- Increasing variety of channels for 2-way communications between researchers and patient partners to foster common understanding, interest and collaboration.
- Training, coaching that is patient-led to bridge knowledge gap and empower patient partners.

**How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network? What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?**

- Contributing and fostering a culture of proactive communication and knowledge sharing across the Network and all SPOR Networks.

**What are your strategies for long-term sustainability of your Patient-Oriented Research initiatives?**

- Create patient-led protocols that are maintainable and easily reproducible.
  - Provide evidence for the diabetes science community (and scientific community at large) that patient engagement is essential to achieving superior scientific results.
-



Research Enabling Group: Sex and Gender

**Diabetes Action Canada – Sex and Gender Enabling Program Strategic Plan Input Report**  
October 15, 2020

**Background:**

The Sex and Gender Enabling Program enhances capacity of Diabetes Action Canada (DAC) research teams and individual investigators to integrate sex and gender-based analysis plus (SGBA+) in all their activities and provide SGBA+ support to DAC and other SPOR Program investigators. In response to Diabetes Action Canada's request for input into their strategic planning process, the Sex and Gender Enabling Program, based out of Women's College Hospital, hosted a strategic planning input session. The session, facilitated by Drs. Paula Rochon and Robin Mason was held on Tuesday, October 6, 2020 via Zoom and attended by Patient Partners, facilitators and DAC staff. An attendee list is attached as Appendix A.

The input collected from this input session was discussed, compiled and refined by the Sex and Gender Enabling Program leadership team. The results of this process are described below.

**1. What are your top 3 patient-oriented sex & gender priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes?**

- Equity will be an overarching principle of the work of the Sex and Gender Enabling Program. We will continue to advance the need to integrate sex and gender in all research, as well as introduce the concept of intersectionality – the inclusion of key identity factors such as age, race, and Indigeneity that constitute the “+” in SGBA+. Integrating an intersectionality lens will help us understand how individuals and groups differ in their health experiences, access to healthcare and responses to therapies, which in turn will contribute to improved treatment plans and self- management behaviours, leading to greater equity.
- Embed sex, gender and intersectionality into all DAC processes and pilot projects.
- Build capacity:
  - across the country by pursuing additional national and provincial partnerships to advance SGBA+ (eg. SPOR support units outside of Ontario).
  - to support the application of SGBA+ in French, to further engage French speaking Patient Partners and researchers.

**A. How do you plan to ensure the needs of marginalized and vulnerable populations are addressed? How will you meaningfully engage Patient Partners?**

- Continuing to advocate for and educate DAC investigators on the need to consider key identity factors in addition to sex and gender will help highlight the unique needs of specific populations. For example, examining gender and race relative to diabetes self-care highlights differences between Black women and White and Black men. Without an intersectional lens, distinctions are lost and individuals may receive

inappropriate treatment perpetuating rather than eliminating health inequities.

- Leverage existing DAC organizational structures to raise awareness of SGBA+ among all investigators and Patient Partners.
- Support increasing diversity of investigators and Patient Partners to represent marginalized and under-served populations.
- Further engage French language researchers in advancing the application of SGBA+.
- Engage with Patient Partners in the language of their choice to embed them in research, knowledge generation and dissemination on the implementation of SGBA+.

**2. What key barriers do you envision to achieving these priorities?**

- Explaining complex concepts of sex and gender, intersectionality and SGBA+, as well as how to apply these to research, is challenging; investigators and Patient Partners may not recognise the need to understand these issues until facing proposal deadlines.
- Resolving critical questions, such as how to measure gender, to allow for concepts to be embedded into databases and other process/projects.
- COVID-19 and negative impacts/delays to some research projects.
- Limited bilingual capacity of the Sex and Gender Enabling Group team and access to translation services (English and French).

**3. What do you anticipate will be the key facilitators to achieving these priorities?**

- Bilingual staff (English and French).
- Development and dissemination of online educational modules, webinars, virtual meetings.
- Support of the DAC leadership to encourage integration of SGBA+ in all activities;
- Regular outreach and engagement with the Patient Partner circles.
- Develop and track indicators of success.

**4. How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?**

- Explore opportunities to connect with other chronic disease networks, the provincial SPOR support units and sex and gender researchers/facilitators across the country not already in the DAC Network

**5. What recommendations to you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g. Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?**

- Clearly define a value proposition of what we can offer other SPOR Support Units
- Develop tangible examples of successes with the Sex and Gender Enabling Program and OSSU to share with other Units

- Coordinate opportunities for DAC to engage with SPOR Support Units across all enabling programs

**6. What are your strategies for long term sustainability of your Patient-Oriented Research initiatives?**

- Enhance understanding of (perceived) benefit of sex and gender analysis for research project/researcher
    - Infographic series featuring positive examples of integrating SGBA+ in diabetes research
    - Development of SGBA+ e-learning modules for the Health Researcher’s Toolkit, including module on intersectionality
  - Continue to build messaging (and advocates for) benefits of SGBA+
    - Individual stories
    - Explore new mediums to share the message (eg. Podcasts)
    - French language capacity
  - Explore expanded funding opportunities
    - For example, expand network to include as many SPOR units across the country as possible
-

Research Enabling Group: Training and Mentoring

**DAC Training and Mentoring Strategic Planning Session – October 9, 2020**  
**Report of discussions**

TOP 3 Priorities

- 1) Develop business plan for the Training and Mentoring Program
- 2) Expend funding to undergraduate students and graduate students
- 3) Prioritize Indigenous training (Learning Pathways) and other training for vulnerable populations

1. What are the top 3 patient-oriented training and mentoring priorities for the next 5 years that will transform the health outcomes for Canadians living with diabetes? How do you plan to ensure that the needs of marginalized and vulnerable populations are addressed? How will you meaningfully engage Patient Partners?

- Consider supporting trainees at the levels of undergraduate (summer studentships) and masters in addition to the doctoral, postdoctoral and young investigators.
- Accompany trainee funding with training; trainees are able to do interesting projects with smaller grants (5K-7K).
- Linking recipients of our group's funding with patient circles.
- Identify partners which can collaborate in the offer of training or knowledge exchange.
- Concerning undergraduate and graduate initiatives, perhaps there is some kind of awareness or culture building initiative that should happen at the faculty level.
- Create links with government (federal, provincial) priorities and look into the regulation side.
- Focus awards call with a particular attention to racialized communities in engaging in POR.
- Consider offering more awards, but of lower amounts – this would allow to increase our numbers at no additional cost.
- The Learning Pathways training and Trainee Day are great successes. We hear often from our Indigenous community how appreciated and useful they find this training (Learning Pathways) and the Trainee Day provide other valuable themes and content (i.e. social media, sex and gender, etc.). We have leaders at DAC that could enable this.
- Better engagement with patient partners and better representation for Training and Mentoring. Work with patient partners to inform the entire Network.
- Provide trainees with experience/exposure/training in KT through a placement program and KT training with workshops (will need to see how KT group moves forward with its own strategic planning).
- Training and Mentoring could be the hub for trainees to get to other training opportunities.
- Need to relay to researchers the importance of integrating patient partners in the conceptualization of projects.
- In general, patient partners prefer in-person workshops and training. This said, if a good relationship is established beforehand online workshops could work.

- We could continue with a hybrid format (in-person and online). There should be at least one in-person workshop event throughout the year.
- There should be more follow-ups after POR training to see if researchers are actually engaging patient partners in their projects.

2. What key barriers do you envision to achieving these priorities?

- Several funding partners, in particular charities, are facing budget restrictions.
- Uncertainty about core DAC funding that will be secured for Training and Mentoring.

3. What do you anticipate will be the key facilitators to achieving these priorities?

- The forced move to virtual due to COVID-19 has demonstrated that virtual has many advantages, despite our Zoom overload. Perhaps Training and Mentoring can leverage that.
- Some funded programs are opened for collaboration: SPOR SUPPORT Units, CMDO
- Explore collaboration with MITACS (network centres of excellence has developed collaboration with them). They have a program (policy fellowships) to connect trainees with policy makers/government agencies (facilitate KT).

4. How do you intend to foster collaboration with others in your field, including those who are within the SPOR Network as well as those outside of the Network?

- SPOR SUPPORT Units are reorganizing to have leadership in certain areas and Malcolm King will be the lead for the Indigenous Community of practice. There could be an opportunity to expand the Learning Pathways training through other SPOR SUPPORT Units (using their funds and connections).
- Open conversation for strategic collaborating with specific diabetes research centres (i.e. DREAM, BBDC, etc.)
- Partnerships for training in research with Indigenous groups – connect with NEHR Network
- Partnerships for training for racialized communities with organizations and communities to look at the priorities in these areas.
- Joint scholarships to leverage our awards, in particular for vulnerable populations.
- Other vulnerable communities: seek help from recent DAC member recruits who do research in these areas, such as David Campbell and Ananya Banerjee to collaborate and assist with curriculum development.
- Senior groups have a real potential for capacity building.
- Collaborate with KT group and Patient Engagement group (and Patient Circles) to help set priorities for our group: for true alignment within the Network
- Collaboration with National Training Entity will be essential (new NTE to be announced in 2021). Foster collaboration and avoid redundancy = improve efficiency.

5. What recommendations do you have for establishing closer strategic relationships with provincial/territorial Ministries of Health and Health Authorities, other SPOR elements (e.g., SPOR SUPPORT Units) and NGOs (e.g., Diabetes Canada, JDRF) to co-design the spread and scale of effective interventions arising from your DAC initiatives?

- Connect trainees with knowledge users to facilitate KT and entice trainees to address questions of importance to influence practice

6. What are your strategies for long-term sustainability of your Patient-Oriented Research initiatives?

- Need business plan for sustainability: identifying the key facilitators and barriers such as availability of funds, administrative support to manage partnerships, relationships and curriculum development required to implement strategy being developed.
- Better integration of DAC programs (i.e. Sex and Gender program integrated with Training and Mentoring program, KT and Patient Engagement).

## Appendix 4 - 2019 External Scientific Review

### **DIABETES ACTION CANADA Report of External Review, November 25-26, 2019**

#### **Introduction**

Diabetes Action Canada (DAC) was funded by the Canadian government as a Strategic Patient-Oriented Research (SPOR) Network in 2016. It comprises ~175 researchers, health professionals and patient partners whose collective mission, as stated in the Network Evaluation Report included in the External Review report, is to “develop patient and research informed innovations in equitable healthcare delivery designed to prevent diabetes and its related complications and to achieve the quadruple aim goals” of improving patient experience, population outcomes, health professional experience and health system costs. Its stated vision is to “transform the health trajectory for all Canadian men, women and children with diabetes at risk for complications.” In its third year, DAC assembled an external scientific review committee to comment on progress thus far and provide recommendations for future activities:

- Cindy Bell, PhD, Executive Vice President, Corporate Development, Genome Canada
- Diane Bild, MD, MPH, Former Chief Science Officer, Patient-Centered Outcomes Research Institute
- Hertzell Gerstein, MD, Professor of Medicine, Director, Diabetes Care and Research Program and Deputy Director Population Health Research Institute, McMaster University
- Louise Potvin, PhD, Director, Centre for Public Health Research, University of Montreal and CIUSSS du Centre-Sud-de-l'Île-de-Montréal

The reviewers convened on November 25 and 26, 2019 in Toronto. They had been provided an internally commissioned Network Evaluation Report dated October 21, 2019; the DAC Summary Report 2018-2019; and access to the DAC website. During the 2-day review the committee interviewed DAC members in groups based on leadership, research areas, or function. (See attached Agenda.)

DAC's current structure and collaborative researchers are the result of a coalescence of initiatives over its first 3 years of operation, directed by the Executive Director, Dr. Catherine Whiteside, and Co-Scientific Leads, Drs. Gary Lewis and Jean-Pierre Despres. It has evolved into a network that currently comprises 21 research institutions, 29 funding partners, 75 patient partners, 99 researchers and 11 programs. These programs include 6 research goal-directed programs and 5 enabling programs.

The research programs include:

- diabetic retinopathy screening
- indigenous people's health
- innovations in type 1 diabetes
- digital health for diabetes research and care
- foot care to prevent amputations
- aging, community and population health

The enabling programs include:

- patient engagement
- training and mentoring
- knowledge translation
- health technology assessment
- sex and gender

Governance includes a Steering Council and Operations Committee, scientific co-leads, an Executive Director and an administration team.

The following sections are organized into the answers to 4 questions that the reviewers were asked to address.

**1. Do the activities undertaken by Diabetes Action Canada align with and potentially fulfill the stated mission of the SPOR program as defined by Diabetes Action Canada – to develop patient- and research-informed innovations in equitable health care delivery designed to prevent diabetes and its related complications and to achieve the Quadruple Aim goals (to improve patient experience; population outcomes; and health professional experience; and reduce health system cost).**

The reviewers concluded that the activities and accomplishments of DAC are consistent with the stated goals and have evolved in a thoughtful and robust manner that are likely to fulfill the goals, given sufficient time and resources. As population health outcomes require years of consistent program application to observe significant change, the success of DAC will be better captured and valued if based on logical intermediate outcome measures, such as number of individuals undergoing retinal screening or care by a chiropodist while also measuring and monitoring “hard” health outcomes, such as the incidence of lower extremity amputation or blindness in persons with diabetes.

**2. What are strengths of the Network and key opportunities to continue to build on these achievements?**

- The explicit and clear commitment to patient-oriented outcomes appropriately forms the basis for all DAC planning, structure development, and programmatic activities and uses patient engagement and partnership as a core activity to achieve goals.
- There is a focus on groups that suffer disproportionately from diabetes and its complications, including indigenous populations, women and immigrants.
- There is an explicit commitment to accessibility for the non-bilingual francophone population in all activities and communications, and significant efforts are made to reach out to the non-bilingual francophone population.
- The report provided to the External Review committee summarizes the results of a self-evaluation, network evaluation, plan for prospective evaluation, and programmatic plans. It concludes that funding is needed to support the SPOR Network Backbone organization, build more strategic collaborations within DAC, expand engagement of patient partners to



encompass all activities and reports, create valuable engagement opportunities for all members of the network, and more comprehensively engage health professional leaders and policy decision-makers. The reviewers endorsed these plans, several of which will be reiterated in the following sections.

- There is appropriate interconnection among the 6 goal-oriented goals groups and the 5 enabling groups.
- Surveys of the opinions of members is valuable for self-evaluation, and the high satisfaction ratings in the member surveys are encouraging.
- The current shift from a vision-directed phase of exploration, feasibility assessment, and capacity-building in the Network to development of a priority-driven strategy for future activities is timely and appropriate.
- The DAC leadership is strong and effective. Member surveys indicate a high level of satisfaction with leadership, in general. There is a generally positive culture, which is mission-driven and collaborative among groups.
- The DAC has been successful in attracting \$21.6M in matching funds for the programs and \$36.5M in leveraged funding, in addition to the \$12.5M grant from CIHR.
- There is a strong commitment to training and capacity-building to support Patient-Oriented research.
- DAC recognizes the importance of improving communications and has hired a part-time dedicated staff member to improve social media, website, and other communications.
- The Diabetes Repository is growing and currently includes 110K patients with diabetes, and a matched set of patients without diabetes. This is already providing an excellent resource for exploring data analytics.
- Resources were committed that enabled the full range of DAC members to be involved in the current review, including interviews by the External Review committee. This reflects favorably on the commitment to the evaluation and desire to strengthen the network.
- A logic map is presented in the [Full Annual Report](#), which provides a valuable framework for measuring and monitoring progress towards meaningful goals.

**3. What are the major challenges and barriers to successfully achieve the patient-oriented research goals? What are the recommendations for addressing them (e.g., change in research direction, engaging new stakeholders and decision-makers?)**

After three years of planning and growth, the network is ready to be more systematic and strategic in its development by setting up strategic goals and measurable outcomes for each area of activities, and to develop tools and formal processes to achieve them. The following are topic-based sets of issues that should be considered, along with recommendations within each topic.

Role of Patient Partners

Issues identified:

- The roles and expectations for patient partners are not completely clear. Their interaction with other team members on individual projects is variable. The patients do not always see what their value is on projects and believe that their influence is inappropriately limited. Researchers need to better understand and articulate the value of the patient perspective. There is also a risk of “instrumentalizing” the patient partners (i.e. using them for end-purposes) and inadvertently alienating them.
- Despite significant efforts, there are limitations in capacity to engage at the Network level with non-bilingual francophone patients and in engaging in a meaningful way with non-English speaking Francophone patients.
- There is a lack of representation or voice for youth with diabetes, who face unique challenges.

#### Recommendations:

- Work with patient partners to create clear expectations for patient roles. Also, designate patient co-leads for each enabling group.
- Create protocols to consistently communicate to patient partners new developments, planned projects, progress in grant funding, research results, implemented programs, and opportunities for participation. Explore and implement these communications using a variety of media, including newsletters, videos, and face-to-face meetings.
- Explore options for better engaging non-bilingual francophones in the governance of the Network and in pan-Canadian activities. Consider designating part of the budget for this effort and lobbying CIHR to recognize this as an essential additional need for a pan-Canadian network of patient-oriented research.
- Consider implementing a formal mechanism to support the development and funding of patient-initiated projects.
- Consider engaging a consultant on how to assure that training on how to optimally involve patients in all aspects of project development and implementation is put into practice. This consultant could be considered for skills in communication, facilitation and/or an ombudsmen role. The position should help establish and assure a positive culture, as well as serve as a resource person for problem-solving.
- Use Patient Circles to develop communication vehicles to other patients.
- Consult and partner with other organizations that are exploring and creating capacity for conducting patient-oriented research, such as the Patient-Centered Outcomes Research Institute (PCORI). Access materials that provide ideas and guidance, such as the PCORI Engagement Rubric (<https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>).

#### Measurable Milestones and Deliverables

##### Issues identified:

- The tables in the document entitled “Diabetes Action Canada Annual Report 2018-19” (pages 59-111) provide logic models and detailed strategic analysis on how each of the Network’s activity will contribute to

the overarching goals in the form of immediate, intermediate and longer term outcomes. Although these tables provide a clear sense of direction for the Network, plans are needed to use them in strategic communication.

Recommendations:

- Assure that the proposed logic model is followed to measure and report meaningful outcomes of the Network's activities.
- Invest in a communication project that will use the information from the logic models in communications about DAC's strategic objectives.
- Consider developing a dashboard with measureable objectives, and use it for tracking and reporting.
- Develop goals for patient-reported outcomes (PROs) and measure them as part of PROs from patient care or as focused surveys.
- Include surveys of healthcare providers to address the important goals of improving practice and the ability of providers to practice and incorporate guideline-concordant care.
- Include the scaling of programs, as appropriate, as part of outcome goals.
- Borrow from other resources, such as the PCORI Evaluation Framework (<https://www.pcori.org/sites/default/files/PCORI-Evaluation-Framework-3.0.pdf>) that provides ideas for process and outcome measures in conceptual models that may be applicable to the Network.

Scope and Growth of the Network

Issues identified:

- As Network activities are expected to mature and grow, it is unclear if such growth will occur on a broad national scale or a more intense, regional manner. Given the nature of health care systems in Canada it is not realistic to develop programs to be implemented and scaled up in all 14 healthcare systems simultaneously.

Recommendations:

- Develop a vision, plans, and a mechanism for CIHR networks to communicate, engage, and collaborate, as appropriate.
- Develop and test ideas regionally, and scale up or bring ideas from one province to others. Different approaches may be needed for different programs. If a regional approach is taken, focus on areas of greatest need, while also considering feasibility and sensitivities to equity across sectors of the population.

Governance Structure and Administration

Issues identified:

- The first three years have been combined growth and feasibility-testing. The timing is perfect to move into the phase of goal- and strategy-directed activities.

- There is a lack of clarity in how enabling programs interact with research goal-directed programs; how a program gets reviewed, approved and funded.
- The Steering Council should not focus on operational issues but rather should focus on strategic issues.
- Goal-oriented (morbidity reduction programs) and enabling programs do not always seem to interact according to articulated principles.
- There is a lack of engagement with provincial healthcare system governance, as well as with bono fide health services researchers and healthcare providers, which is necessary for the system changes to occur that will reduce morbidity and improve the lives of patients.

Recommendations:

- Separate scientific decisions from strategic decisions e.g., through the creation of a Scientific Committee to review scientific directions and develop the research strategy.
- Assure that goal-directed and enabling programs are provided with opportunities to interact on projects consistently.
- Add healthcare system research and healthcare provider membership to the Steering Council and/or relevant subcommittees so that they have appropriate input and ownership of programs and may assist with system change.

Digital Health

Issues identified:

- There is a lack of detail about how this valuable resource will grow and develop.
- There is underutilization of repository for health outcomes research.
- There is a lack of indigenous patient representation in the repository.

Recommendations:

- Develop a plan for increasing the number of patients, representativeness, and diversity of the repository.
- Develop a strategy to turn the repository into a national resource for Patient oriented diabetes research.
- Include plans to make the resource widely available to qualified researchers.

Equality, Diversity, and Inclusion

Issues identified:

- There appears to be a lack of attention to issues of rural, remote, and low socioeconomic status, while issues related to sex and gender are well-addressed in programs.

Recommendations:

- Consider how socioeconomic status and issues relevant to rural communities will be addressed in research and programs in a systematic manner.
- Devise a strategy to address the needs of these populations in both the research and in patient engagement.

Training and Mentorship

Issues identified:

- The rationale for targeting only postdoctoral fellows in the training strategy is lacking.
- There is a lack of clarity about funding for students.
- It is unclear if there is a core curriculum to train students that assures exposure to the main principles of patient-oriented research.
- It is unclear if the training program is being systematically evaluated.

Recommendations:

- Consider broadening the student base, including masters students and a variety of health professionals.
- Consider how funding for students is being managed.
- Develop and articulate a core curriculum for students and mentors.
- Institute an evaluation of the training program.

**4. Provide advice for achieving sustainability of parts or all of the Network and the opportunity for renewal application to the CIHR SPOR 2.0 program**

- Develop and, as feasible, apply and report metrics on activities to CIHR, and report on a plan for implementing this in the next phase.
- Because healthcare systems have a role in developing the agenda for research and programs, they are more likely to help sustain the Network. Therefore, develop a strategy to engage healthcare systems. Consider adding representation of healthcare systems on Steering Council. Similarly, add health services researchers to governance and goal-oriented programs.
- Develop a strategy to turn the repository into a national resource for Patient oriented diabetes research.
- Seek funding from appropriate sources that support patient-oriented research, such as PCORI.
- Offer the network and its resources for other sponsored research, including that sponsored by the biomedical research industry.

## Appendix 5 - Mandate for Working Groups

### Diabetes Action Canada - Strategic Planning Committee

#### **WORKING GROUPS' – mandate**

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The overall outcome of the work of the Strategic Planning Committee will be a report (no more than 10 pages) with recommendations to the Steering Council. The report will be based on the analysis of the submissions by the Research and Enabling Groups, the serial Network Evaluations, the 2019-20 external review and collective input from the Committee members, which includes Patient Partners. The report should address the queries and themes outlined in the Committee's terms of reference and reflect the Core Principles agreed to by the Committee. In the event that CIHR announces the opportunity for continued (competitive) funding of the SPOR Networks, any information made available about the terms and conditions for application will be taken into consideration.

To enable each member of the Committee to engage efficiently in the analysis of the materials provided by the members of Diabetes Action Canada and based on their interest and expertise, members will be invited to join three Working Groups that focus on the following central themes for Diabetes Action Canada.

1. Meaningful Patient Partner and Community Engagement
2. Patient-Oriented Learning Health System Research
3. Engaging and Influencing Health System and Policy Decision-Makers

#### **Process and Timelines**

1. The Working Groups will begin their analysis of available materials beginning in October 2020 when the reports from the Research Enabling Groups will be available.
2. The Working Group should appoint a lead (or co-leads) to assist in preparing the agendas and to chair the meetings.
3. The Working Groups will meet monthly (between October and December) during which time the Strategic Planning Committee will not meet as a whole.
4. Each Working Group will prepare a brief (no more than 3-4 pages) report with 3 -5 well-focused draft recommendations by the end of 2020.

5. The Strategic Planning Committee will meet as a whole in January 2021 to review the Working Group Reports and advise the Chairs and Diabetes Action Canada Executive about the final content of the overall report and recommendations.
6. Administrative support for each Working Group will be provided by the Diabetes Action Canada Staff (Mildred, Tracy, Cathy and Allison) who will assist in scheduling meetings, providing the materials for review and assisting in preparing the Working Group reports.