



DIABETES ACTION CANADA ANNUAL REPORT

2019-2020

[Abstract](#)

Submitted to CIHR prior to October 30th, 2020



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SPOR Network – Annual Report

April 1, 2019 – March 31, 2020

Introduction

This is a guide and template for preparing the SPOR Network Annual Report, to be completed and submitted to CIHR (along with all accompanying Excel tables). This report is intended to capture information regarding progress towards meeting stated goals, milestones, and expected results.

The information provided in this report will be used to:

- Inform CIHR's decisions regarding funding conditions of the grant, including its funding level and duration;
- Inform CIHR reporting on the aggregate results of the SPOR investment to federal decision-makers;
- Assist CIHR in communicating progress and results to stakeholders; and
- Support the federal evaluation of the SPOR Initiative.

Reporting focuses on assessing progress towards the achievement of identified objectives, outcomes and impacts. CIHR, like other research funding organizations, seeks to demonstrate the value-add of its research investments and the return on those investments. High quality reporting is a critical input to these ends. Please include pertinent contextual information that will help situate your progress, in particular changes in context, challenges, and successes that have occurred during the 2019-2020 fiscal year.

Instructions

The sections of this template are as follows:

- Section 1: Contact Information
- Section 2: Performance Highlights and Milestones
- Section 3: Governance
- Section 4: Patient and Stakeholder Engagement
- Section 5: Research Program
- Section 6: Linkages across SPOR
- Section 7: Research Capacity, Training and Mentoring
- Section 8: Advancing Knowledge
- Section 9: Relevance to Indigenous Peoples
- Section 10: Partnerships and Collaborations
- Section 11: Financial Overview and Work Plan
- Section 12: Impact Stories
- Section 13: Other Successes and Challenges

- Questions labelled as “Mandatory” must be completed. All other questions are optional, and can be completed at your discretion.
- Please be specific in your written report and complete all questions asked.
- Please respect the word limits provided in each section.
- Please save a copy of this report for your records.
- Please ensure all excel financial tables are completed and submitted with this report.

If you have any questions about this template, please contact SPOR-SRAP@cihr-irsc.gc.ca.

1. CONTACT INFORMATION (Mandatory)

1.1 – Please select the Network for which this report is being completed.

Choose an item.

1.2 – Who prepared this report?

Please provide the contact information of the person responsible for this report.

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1.3 – Who is responsible for this report?

Please provide the contact information of the person responsible for approving the content of this report.

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2. PERFORMANCE HIGHLIGHTS AND MILESTONES (Mandatory)

This section is intended to provide a high-level description of the progress and accomplishments of your Network during the reporting period.

2.1 – In the space below, please include a plain language summary including the following:

- A summary of key accomplishments of the Network during the reporting period, specifically including:
 - progress made towards the attainment of stated objectives; and
 - the implications of these key accomplishments in terms of impacts (if any impacts have been realized).
- Opportunities, challenges and how they were mitigated, changes in context and course corrections
- The Network's focus and expected outcomes for the 2020-2021 fiscal year.

(Maximum 1000 words)

2.1 Summary of Key Accomplishments

Access to Screening for Risk of Diabetes Complications

Collaboration with the SPOR Evidence Alliance (“*Diabetic Retinopathy Screening: A Systematic Review with ‘Best Fit’ Framework Synthesis*”) revealed the challenges and the facilitators for addressing the problem that up to 60% of persons with diabetes lack timely screening to prevent blindness. Marginalized populations (lower socioeconomic, new immigrants, Indigenous) are disproportionately underserved. We have demonstrated that tele-retina screening is a cost-effective solution for blindness prevention. Therefore, our Patient Engagement team with Patient Partners co-designed a project to interview persons with diabetes from 3 ethnolinguistic minorities in their native language. This revealed their lack of understanding of the need for screening, fear of retina imaging and inability to attend because of competing responsibilities. A second project reported patient satisfaction with tele-retina screening, but the inability of primary care physicians to organize or track timely screening. These studies point to the urgency for more effective, culturally sensitive and data-informed approaches to retinopathy screening and blindness prevention. Collaborating with the Ontario Ministry of Health, we are now working on a data-informed population-based model for comprehensive tele-retina screening in Community Health Centres focused on the marginalized.

Scaling up Prevention and Self-Management to Reduce Inequities

The Indigenous Youth Mentorship Program (IYMP), co-developed with Indigenous youth and elders, has rippled out to include 49 sites across Manitoba, Saskatchewan, Northern Ontario and inner city Toronto with a knowledge translation video published in YouTube and widely distributed across Canada <https://www.youtube.com/watch?v=Q6QmkbF1yRg>. Additional 5 years of funding was acquired from the CIHR Pathways program to ripple out IYMP across 5 provinces. Planning for strategic long-term visioning and sustainability has been launched in collaboration with the Leap Pecaut Centre for Social Impact <https://leap-pecautcentre.ca>.

The Community Partnership Program for Diabetes Self-Management for Older adults funded by a PIHCI program grant with Diabetes Action Canada was launched in Ontario, Quebec and PEI using the scalability assessment tool validated by 12 community-based primary health care teams published by our KT group in 2018. The Governance Steering Committee of this interdisciplinary project consists of patient partners, regional and provincial policy decision-makers and researchers engaged in a collective impact approach fostering effective relationships between diverse primary care and community-based intersectoral partners. This study has already revealed the unique barriers and facilitators in each provincial site informing

policy decision makers about next steps in adopting and scaling this program for improving health outcome for seniors with diabetes and multiple co-morbidities.

Liberating Health Data for Improving Diabetes Outcomes

Our National Diabetes repository (NDR) is a novel, secure analytics platform that contains de-identified electronic medical record data from over 120,000 persons with diabetes and the same number of age-matched controls from primary care networks in 6 provinces. <https://repository.diabetesaction.ca>. The Research Governing Committee consists of 50% patient partners and 50% primary care physicians and researchers who review and approve projects. To demonstrate the value of the NDR, the following 3 impact projects were funded: Impact of government-funded insulin pump programs on insulin pump in Type 1 Diabetes in Canada; Diabetes care among people with schizophrenia; Identifying high risk patients for Type 2 diabetes complications. Diabetes Action Canada co-hosted a workshop with the Fields Institute for Research in Mathematical Science and the Vector Institute for Artificial Intelligence (AI) to demonstrate the utility of NDR data for mathematical modelling and machine learning (ML) analytics. New projects using NDR data are now underway using ML/AI focused on predictive analytics for early detection of risk for diabetes complications.

Engaging and Empowering Patient Partners

In Canada, clinical trials in Type 1 Diabetes (T1D) research have suffered from the inability to recruit subjects in a timely fashion leading to delay in completion and even discontinuation. This is not due to lack of potential participants, but failure to engage persons with T1D through effective communication. To bridge this gap, our T1D Patient Partners are guiding the development of an opt-in digital platform, called ConnectT1D, for recruiting, contacting and regularly engaging persons living with T1D interested in contributing to clinical research. To ensure ConnectT1D was truly patient-oriented, extensive co-design was undertaken with members of the T1D community, that included workshops with the [T1D ThinkTank](#) and Patient Partner-led smaller working groups and interviews. The product presents clinical research information in an easy to understand dashboard. When participants register through e-consent, they will complete a short questionnaire about their demographics, location and research interests. Once enrolled, they are matched clinical research opportunities and can explore additional information. In later phases of the project, researchers will directly engage the participants in research opportunities for co-designing patient-oriented studies. The official launch with a social media campaign is scheduled for October 2020.

Network Performance Evaluation

In late 2019, we commissioned an External Scientific Advisory Committee of experts to engage in a 2-day comprehensive, independent review. It concluded that “the activities and

accomplishments of Diabetes Action Canada are consistent with the stated goals and have evolved in a thoughtful and robust manner and are likely to fulfill the goals, given sufficient time and resources”. We acted on the recommendations of the external reviewers with positive outcomes. A second evaluation was a detailed Network evaluation of connectivity, health and results/impact that demonstrated good progress to date and collaborations resulting in 26 new research grants adding \$36 million investment toward our mission.

Opportunities

- Expand investigators to include data science and privacy law experts and health system researchers
- Build core theme of data-informed digital diabetes health services and expand investigators to include data scientists with expertise in mathematics, AI, ML and epidemiology
- Develop demonstration projects co-designed with SPOR SUPPORT Units across Provinces and Territories

Challenges

- To establishing more meaningful engagement of policy decision-makers and health system leaders, work more closely with the SPOR SUPPORT Units to align our joint activities with the stated priorities of the provincial and territorial Ministries of Health and Health Authorities

Focus and Expected Outcomes for 20-21

Enhancing Patient Engagement – more financial and administrative support for projects designed by Patient Partners.

Strategic Planning for SPOR 2.0

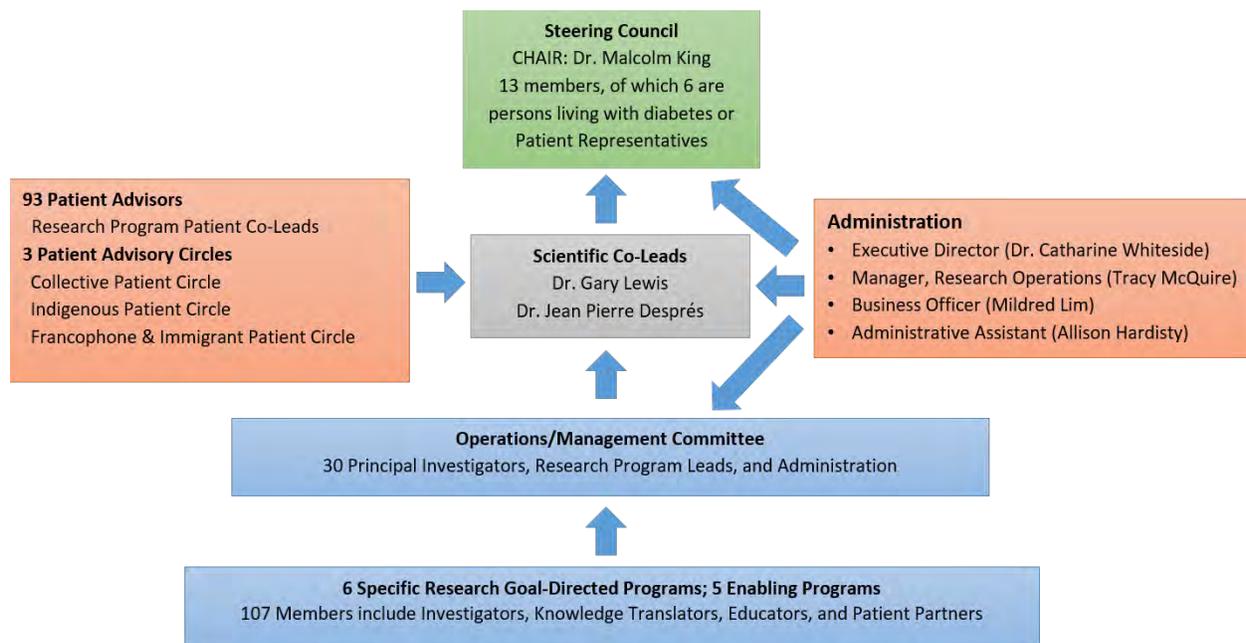
- **Repeat Network Performance Analysis** - demonstrate maturity of collaboration and impacts using defined indicators
- **Continued strategic partner building and fund-raising to sustain and grow major projects** - e.g., opening our NDR to all investigators across Canada

3. GOVERNANCE

This section is intended to summarize the status of the overall governance structure and decision-making bodies of your Network as of the end of the reporting period.

3.1 – If there have been any changes to your governance structure since the 2018-2019 fiscal year, please append a graphical representation.

Since reporting in 2018-19 we have added additional Patient Partners to our governance structure. For a complete list of Diabetes Action Canada members please refer to Appendix 1.



3.2 – Please provide a brief summary, including tangible examples, of the ways in which the governance structure is operating in an effective and efficient manner.

(Maximum 250 words)

On the recommendation of our Steering Council ad hoc committee on Performance and Evaluation, we conducted two major evaluations.

Valeria Rac, lead for our Health Technology Assessment (HTA) and Network Analytics Research Program and Mathieu Ouimet, our KT Science and Public Policy expert, conducted a Network Evaluation in three key areas: Connectivity, Network Health and Results. The analysis demonstrated a high degree of connectivity and new collaborations, and outcomes emerging with high potential for impact. Among our members, the two most discussed topics were research and Patient Partner Participation. Interdisciplinary collaboration has strongly motivated their active engagement in our Network. A second Network Evaluation is currently underway to inform Phase 2 planning of Diabetes Action Canada.

An independent evaluation was conducted by an External Scientific Advisory Committee composed of national and international experts in diabetes and/or patient-oriented research. The Committee met with representatives of our all our Research and Enabling Groups, our Patient Partners, Steering Committee members, and management staff. The overall assessment indicated good progress toward achieving our stated goals within the first 3 years. The Committee provided recommendations for immediate action and future directions. Acting on these recommendations, Diabetes Action Canada has enhanced both internal and external communication, more clearly defined the role of Patient Partners and conducted an independent evaluation of capacity development. We have extensively revised our logic models for all 11 Research and Enabling programs and are using them as tools to measure research objectives, strategic communications, and evaluation of outcomes and impact.

3.3 – Please provide a summary of the governance-related challenges / lessons learned during the reporting period, including the strategies and/or actions taken to address the challenges.

(Maximum 250 words)

Our performance evaluations revealed that our Network members and stakeholders found our communications content lacking in accessibility and effectiveness. They advised that communications should be more understandable, exciting and in modern formats. Therefore, we contracted a communications lead, Krista Lamb, formally with Diabetes Canada, to assist in preparing our lay audience communications and social media. Our newsletter and website communications have been revamped, Twitter followers have tripled with daily impressions doubling from 192 to 400 impressions/day.

As part of the Diabetes Action Canada governance, three Patient (advisory) Circles operate at arm's length from the Steering Council and Operations and Management Committee. However, we have experienced limited communication with Patient Partners among these governance bodies. To improve communication, we now have Patient Partners from the Collective Patient Circle attending our monthly Operations and Management meetings acting as ambassadors for the Patient Partners. Two additional Patient Partners have joined the Steering Council. This has been extremely helpful in improving communication and increasing engagement with our Patient Partners and leadership.

Establishing closer relationships with provincial health policy decision-makers remains a challenge. Therefore, senior management initiated closer relationship building with SPOR SUPPORT Units (AB, ON, QC, Maritimes) to align future joint projects with provincial health strategies.

To plan for sustainability, senior management continued to meet bi-monthly with each of our Research and Enabling Program leads, including their Patient Partners throughout 2019-20.

Presentations to all our NGO and Industry sponsors featured our key accomplishments and initiated discussion about renewed funding.

4. PATIENT AND STAKEHOLDER ENGAGEMENT (Mandatory)

This section is intended to summarize engagement over the reporting period.

4.1 – Patient Engagement

The answer to the question below will provide a high-level overview of key *patient engagement* activities during the reporting period. SPOR defines “patient” as individuals with personal experience of a health issue and informal caregivers, including family and friends.

What are the key achievements or outcomes of the patient engagement activities conducted by the Network during the reporting period?

(Maximum 500 words)

Our core success factor has been the impact of Patient Engagement on influencing our researchers, research topics/design/deliverables, stakeholders including health care providers and advocacy organizations. Below are some key achievements:

- In December 2019, Diabetes Action Canada held its first member’s forum, meant to gather feedback on our Network in an informal setting. The forum was very well attended by our Patient Partners who provided suggestions on how we can improve communication, knowledge translation and research planning. Among these suggestions, Patient Partners were eager to see more dynamic, lay language communications to relay research outcomes. In response to this, we completely revamped our communications plan, to include more social media, podcasts (to be released in Fall 2020), webinars (released in summer 2020) and lay language stories with both investigators and Patient Partners contributing to content.
- ‘Citizen science’ has emerged as an important aspect of our Network over the last year with our Patient Partners becoming more engaged in, and now leading, important projects. For example, after meeting in person in the Fall of 2019, our Indigenous Patient Circle designed a project to create videos that feature interviews with

Indigenous people living with diabetes. These are meant for both knowledge translation and education. This proposal was curtailed temporarily during the pandemic but will be initiated in 2020-21. Our Innovations in Type 1 Diabetes (T1D) Research Group has started a Patient Partner led project to understand the barriers to and facilitators for using insulin pump technology. This proposal has now received ethics approval with our patient Partner, Kate Farnsworth, as the lead PI. The Collective Patient Circle has also launched a 'Dos and Don'ts' Committee for Patient Engagement based on experiences from the Collective Patient Circle and other Patient Partners when working with researchers in our organization. This is a new project that will be lead completely by the Circle and its members.

- In 2019 our **Patient Engagement** Program received funding from the CIHR Catalyst Project competition to identify patient-derived research questions that can be answered using our National Diabetes Repository. This demonstrates the ability of our Patient Partners to actively plan research questions, and the value of Networking among our research programs.
- The **Innovations in T1D Program** working very closely with Patient Partners has developed *Connect1D* – a novel digital platform for connecting Canadian researchers and those living with T1D using a patient-centered design (see impact story 3). This project has evolved significantly since its inception with the user interface completely transformed in response to patient feedback.
- Our **Patient Engagement Program** and **Diabetic Retinopathy Screening Program** collaboratively developed a project to identify and understand the barriers and enablers experienced by ethno-cultural minorities with high risk of diabetic retinopathy (i.e., immigrants from South Asia, China and Africa [Francophone]), related to diabetic retinopathy screening in Ontario and Quebec. These results, about to be published, will enable the design of fit-for-purpose interventions that will specifically address the barriers experienced by these marginalized groups.

4.2 – On a scale of 1 to 5, where 1 = INFORM and 5 = EMPOWER, please indicate the level to which the Network is engaging stakeholders.

Level of Engagement

Inform – To provide stakeholders with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

Consult – To obtain stakeholder feedback on analysis, alternatives and/or decisions.

Involve – To work directly with stakeholders throughout the process to ensure that concerns and aspirations are consistently understood and considered.

Collaborate – To partner with stakeholders in each aspect of the decision including the development of alternatives and the identification of the preferred solution.

Empower – To place final decision-making in the hands of stakeholders.

| Stakeholder type | INFORM 1 | CONSULT 2 | INVOLVE 3 | COLLABORATE 4 | EMPOWER 5 | Not Applicable |
|---|--------------------------|--------------------------|-------------------------------------|-------------------------------------|-------------------------------------|--------------------------|
| Health System/Care Practitioners/Public Health Practitioners ¹ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patients / Consumers of Health System/Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Study Stakeholders (who are formally listed in the grant application) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Health System/Care Managers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Health System/Care Professional Organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Federal/Provincial Representatives (including policy-makers) | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Community/Municipal Organizations (including policy-makers) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

¹ Examples of Health System / Care Practitioners / Professionals include those employed by hospitals, hospital networks, health authorities or other large healthcare systems.

| | | | | | | |
|--|--------------------------|--------------------------|--------------------------|-------------------------------------|-------------------------------------|--------------------------|
| Consumer Groups/Charitable Organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Industry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The media | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Researchers / Academics (excluding study stakeholders) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Research funding organizations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Other – Please Specify | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4.3 – Please describe the nature and extent of the Network’s engagement with stakeholders in activities related to the question above, during the reporting period, using up to three examples.

(Maximum 250 words)

Diabetes Action Canada works diligently with stakeholders to scale and spread our research activities:

- 1) Diabetes Canada held its annual Professional Conference in Winnipeg Manitoba in October 2019. Diabetes Action Canada kicked off the event by hosting a pre-conference trainee day. This was the most successful Trainee Day yet with 29 attendees. On October 4th, 2019 Diabetes Action Canada hosted a symposium on the *Role of Patient-Oriented Research in the Development of New Models of Care*. This symposium featured three talks from our Network highlighting successful patient engagement, including personal impact stories from our Indigenous Patient Circle.
- 2) Our Foot Care to Prevent Amputations Program, in September 2019 published a study in the Canadian Medical Association Journal (CMAJ), reporting staggering statistics on the rise of lower limb amputations and the associated cost. This received attention from both media and government and has led to some fruitful collaborations with the Conference Board of Canada, CorHealth Ontario, Wounds Canada and academic institutions within Toronto (i.e., St. Michael’s Hospital and University Health Network) to tackle this issue through a coordinated approach.
- 3) Diabetes Action Canada’s National Diabetes Repository launched its inaugural grant competition in April 2019. Investigators submitted proposals to address patient-oriented research questions and three research proposals were awarded \$15,000 each.

Our Research Governing Committee (consisting of 50% Patient Partners) and Scientific Advisory Committee reviewed the proposals and selected projects based on Diabetes Action Canada priorities including what matters most to persons living with diabetes, innovative use of data/techniques, and team-based research.

4.4 – In the space below, please provide the top three benefits / advantages that were experienced by your Network through engaging stakeholders during the reporting period, using specific examples.

(Maximum 250 words)

In 2019-20 we have continued to work closely with our stakeholders as we grow our Network. Some examples include:

- 1) A top research priority is the development and launch of *Connect1D* – a digital platform to connect researchers and those living with Type 1 Diabetes (T1D). JDRF has co-funded this project and is deeply engaged in its implementation. Monthly meetings with the team at JDRF have enabled joint communication plan to facilitate recruitment to *Connect1D* through websites, social media channels, and investigators. We are confident that our strong partnerships will accelerate knowledge translation and uptake of this platform.
- 2) In collaboration with the Canadian Primary Care Sentinel Surveillance Network, Diabetes Action Canada has established the first National Diabetes Repository of primary care longitudinal EMR data. Now with representative data from 6 provinces our team is actively working with each province to expand the data holdings, and meeting regularly with local health authorities, federal data stewards, and SPOR SUPPORT Units. The goal is to use the National Data Repository as a tool for improving quality outcomes for persons with diabetes including reducing their risk of costly complications.
- 3) Diabetes Action Canada has undertaken a series of Network evaluative activities that have led to important insights and recommendations that will improve the impact of our research, enhance communication and to help us plan strategically for the future. As part of these activities we have had extensive stakeholder engagement with our Patient Partners, investigators, external scientific experts, sponsors and SPOR SUPPORT Units.

4.5 – In the space below, please provide a summary of the challenges / lessons learned in engaging stakeholders during the reporting period, including the strategies and / or actions taken to address the challenges.

(Maximum 500 words)

Engaging Health System and Policy Decision-Makers

To fulfill our mandate, we understand the necessity of engaging key leaders and influencers within local, Provincial/Territorial and Federal governments. For our projects to achieve impact on practice and policy, we are making significant efforts to engage policy decision-makers in meaningful ways, and we have some exemplary successful programs. For example our Aging, Community and Population Health Research Group has established a governance framework for its multi-provincial *Community Partnership Program for Diabetes Self-Management for Older Adults in Canada* project that includes high level health policy decision-makers from the Ministries of Health in Ontario, Alberta, Quebec and PEI on its Steering Committee co-chaired by Catharine Whiteside. <https://achru.mcmaster.ca/research-studies/achru-community-partnership-program-diabetes-self-management-older-adults---canada> This Committee meets twice a year to receive updates on progress, and results that are immediately relevant for planning the next phase of spread and scale of this highly successful health care intervention. Diabetes Action Canada now recommends that this model of governance be adopted for all new projects enabling engagement of health system and policy decision-makers in the knowledge translation of our patient-oriented research projects.

Strategic Partnering to Promote Advocacy Necessary for Health Care Transformation

To enable the spread and scale of new models of healthcare for Canadians with diabetes designed by our SPOR Network, it is not sufficient to simply publish scientific papers. Knowledge translation into practice and policy requires advocacy through effective communication to the right influencers at the right time. Therefore, Diabetes Action Canada has aligned with Diabetes Canada and JDRF to design the National Diabetes 360 Strategy <https://www.diabetesstrategynow.ca>. This relationship was instrumental for Diabetes Action Canada being invited to witness twice during the House of Commons Standing Committee on Health in 2018 as they deliberated on diabetes in Canada. In May 2019, this Committee reported to the House of Commons “A Diabetes Strategy for Canada” in which a number of recommendations from Diabetes Action Canada were published including exploring options for establishing a national diabetes registry for people living with Type 1 and Type 2 diabetes.

<https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-23/> Our National Diabetes Repository and *Connect1D* platform are the precursors for developing provincial diabetes registries necessary to transform diabetes care in Canada. We will continue to work closely with our NGO partners as they advocate on behalf of Canadians with diabetes and the translation of the evidence generated by our SPOR Network into practice and policy.

SPOR Network Program – Uncertainty

Unfortunately, the COVID-19 pandemic delayed the anticipated announcement by CIHR about the opportunity for continued funding for the SPOR Networks. This has impacted our ability to work effectively with our stakeholders, in particular with existing and new funding sponsors, to plan for a sustainable future. We have also started to become concerned with our member engagement as announcements on the future of our Network are delayed. Without a clear path our investigators and personnel are starting to consider other options for their future and this can greatly impact our ability to achieve our mission effectively and evolve our Network despite the momentum built in 2019-20.

5. RESEARCH PROGRAM (Mandatory)

CHANGES

5.1 – If applicable, please provide a summary of the changes to your research program over the reporting period, as well as a rationale for these changes.

(Maximum 500 words)

Diabetic Retinopathy Research Program

Our goal is to establish a framework for timely retinal screening for all Canadians with diabetes according to evidence-based guidelines. In collaboration with tele-ophthalmology services, our investigators have expanded screening services in focused areas across many provinces and published the cost-benefit of this approach. In 2019-20, our studies demonstrated the underlying causes of insufficient screening, particularly among the most marginalized (e.g., new immigrants), where practice accountability is held within primary care. Based on the success of the UK in eliminating diabetes as the most common cause of blindness (still the case in Canada), we have launched a new population-based screening project in Community Health Centres (CHCs) in Toronto. This project, funded by philanthropy, uses analysis of linked EMR and

provincial administrative data to find those who need screening. Then, working with the CHCs we are studying how to most effectively deploy tele-ophthalmology screening of these patients. Diabetes Action Canada envisions this data-informed population surveillance approach will become the new focus of this research program in collaboration with SPOR SUPPORT Units and provincial Ministries of Health.

Foot care and Limb Preservation – in Ontario

Our investigators in Foot Care and Prevention of Lower Extremity Amputation in Sept 2019 reported that the prevalence of amputations in Ontario, due mainly to diabetes-related complications, has risen in the last decade. By contrast the number of heart attacks and strokes have declined. In part, the amputation rate coincides with a rising prevalence of diabetes and an aging population. We know from experience in Denmark that 85% of the amputations could be prevented by timely and effective prevention and treatment of diabetic foot ulcers. Although the Ontario Ministry of Health (after the 2019 provincial election) abandoned the World Economic Forum project in value-based health care focused on prevention of diabetic foot ulcers, Diabetes Action Canada has taken up this project in collaboration with the Conference Board of Canada and CorHealth Ontario. We organized a workshop of stakeholders in February 2020 to launch the planning of a multi-centre value-based investigation of the most cost-effective approaches to identifying persons with high risk of developing foot ulcers and enabling early, cost-effective intervention for limb preservation. Sponsored funding for this project is anticipated in 2020-21. CorHealth Ontario is simultaneously developing a networked provincial clinical framework for limb preservation.

James Lind Alliance Approach - Premature

In our SPOR Network application, we described a Patient Engagement project that would be fashioned after the James Lind Alliance in the UK. After 3 years of working with Patient Partners across Canada and establishing our successful Patient (advisory) Circles, as well as the direct and meaningful involvement of many of them in our research, training and KT projects, we now know that attempting to create a James Lind Alliance framework is premature. Further, the resources necessary to replicate this approach is well beyond our current budget. The UK model is fully supported by the National Institute for Health Research and is not disease specific. CIHR could address this opportunity in Phase 2.

PROGRAM STATUS

5.2 – Please summarize the progress of your research program over the reporting period, including the total number of completed, ongoing and new research projects, for each category.

(Maximum 500 words)

When Diabetes Action Canada was funded there was a total of 24 projects categorized into 10 themes. Throughout our funding term we have added 6 new projects (with accompanying inter-institutional agreements) under 2 new themes. Within some of our research projects, namely **Knowledge Translation**, **Patient Engagement**, and **Training and Mentoring** we have many smaller projects that feed up to the larger project theme. Below is more specific information for this funding term:

Completed projects:

Health Technology Assessment (1): The initial Network Evaluation completed in Fall of 2019, provided a mid-term examination of Diabetes Action Canada in three key areas: Network Connectivity, Network Health and Network Results. The second is currently underway.

New projects:

Patient Engagement and Knowledge Translation (1): The projects mentioned below feed up to the one funding theme of the Network.

- **Patient Engagement:** Six research projects were launched in response to our findings that patient engagement work largely fails to include people from under-represented groups. These projects investigate two key areas: 1) the facilitators and barriers of ethno-cultural minority groups in screening for diabetes complications and 2) understanding research partnerships with Indigenous Communities.
- **Knowledge Translation:** In collaboration with the Quebec SPOR SUPPORT Unit, our KT program continues to focus on building capacity in KT and developing KT tools in diabetes.

Projects ongoing:

Clinical trials (8):

- **Innovations in T1D (6):** In the original application, 9 clinical trials were funded. Four of these trials are completed and published (three in 2017, one in 2018) and one new study initiated (*Connect1D*). The remaining six clinical trials are at various levels of investigation with all having ethics approval and recruitment either completed or nearly completed.
- **Additional SPOR clinical trials (2):** Diabetes Action Canada has co-funded two SPOR clinical trials. Our **Foot Care (1)** program was awarded an iCT investigating a multidisciplinary chiropodist-based approach to reduce diabetic foot complications. Our

Aging, Community and Population Health (1) program received a PIHCI grant, to scale a diabetes self-management intervention for older adults. The former has completed planning and will initiate in 2020 and the latter is currently gathering data from the intervention.

Enabling Programs (5): Governance and Administration (2), Sex and Gender (1), Training and Mentoring (2) have operational roles to facilitate the research of our goal-directed programs.

Goal-Directed Programs (8):

- We continue to be deeply involved in digital health initiatives. Our **Digital Health** (2) program is currently expanding the National Diabetes Repository to demonstrate its utility. The *bant* mobile application is evolving to respond to the needs of the diabetes community.
- Our **Diabetic Retinopathy Screening** (3) national tele-ophthalmology program continues. Work on a novel, comprehensive artificial intelligence-based program to grade the images collected is progressing well, with additional funding secured.
- Our **Indigenous Health** (3) research program is scaling the successful resilience-based community driven Indigenous Youth Mentorship Program (IYMP). Preliminary discussions with Leap Pecaut are underway to transition IYMP from academia to non-profit. The training program in cultural safety has been developed and trainees are piloting the content.

5.3 – Please identify if any stages of/projects within your research program are "Not on Track". Explain why and what actions will be taken to address the situation.

(Maximum 500 words)

All of our projects are on track with 4 exceptions of projects described below.

Topical pirenzepine for treatment in type-2 diabetes – Dr. Paul Fernyhough

Dr. Fernyhough's trial, after many delays, received research ethics approval in Canada in August 2019 – three years later than initially anticipated. Recruitment for the trial began in September 2019, but many subjects who were pre-screened were deemed ineligible based on the original study criteria. By the time the clinical trial was put on hold due to COVID-19 pandemic, 3 participants were enrolled in the study and continue to be monitored remotely. There are plans underway to support phase 2 of this clinical trial in the USA in 2020, with pre-submission deemed favourable by the FDA, and a full submission currently being prepared for Fall 2020.

Effect of SGLT2 Inhibition on Improving the glycemic performance of single and dual hormone artificial pancreas configuration – Dr. Bruce Perkins

Dr. Perkins clinical trial has experienced many delays and as such has been revised as a pilot study with half the initial funding being directed to the *Connect1D* project. REB approval was obtained in early 2019 and the interventional part of the study was initiated in August 2019 with recruitment of 28 participants expected to be concluded before January 1st 2021. Prior to the COVID-19 pandemic nearly all participants were recruited.

Comparison of dual-hormone artificial pancreas, single hormone artificial pancreas, and sensor-augmented pump therapy in outpatient settings – Dr. Rémi Rhabasa-Lhoret

This NIH-funded trial continues to be delayed due to design flaws in the initial study protocol. The project team felt that it would not be able to conduct a 15-week multicenter study with 100 participants in such a short time and the protocol and timeline needed to be adjusted. Furthermore, the development of the automated system took longer than expected causing the most significant delays. Although this NIH funded grant was included in the match for our application, there are no CIHR funds assigned to this study. We are hopeful that the NIH will continue to support this important clinical trial that is expected to be well underway within the coming years.

Sex and Gender Support for the SPOR Network in Diabetes and its Related Complications – Dr. Paula Rochon

This research support program has had difficulty in recruiting and retaining post-doctoral fellows to complete this important work. The most recent post-doctoral fellow, was leading projects with our Patient Partners and her unexpected departure impacted salaries, patient partner compensation, respondent honoraria, and other expenditures.

Aboriginal Youth Mentorship Program in Northern Ontario – Dr. Nancy Young

The Indigenous Youth Mentorship Program requires considerable community engagement to customize the program according to cultural practices, knowledge sharing methods and Elder engagement for each site. For this IYMP to be successful the right relationships with the community need to be established and Dr. Young is currently working in Northern Ontario to find the right home for this project.

5.4 – Please provide examples of the roles patients have played in the various research projects undertaken by the Network, specifying the stages of the research process in which patients were involved.

(Maximum 250 words)

The roles that patient partners assume in research projects have become increasingly diverse and now cover all stages of the research process.

Research Planning

Our Patient Partners have become increasingly active in co-developing research questions to be more meaningful to the community. Our Patient Partners have also provided feedback on research proposals, particularly on the relevance of the study, important challenges that might arise for people living with diabetes, and considerations that may influence study aims and/or design.

Research Implementation

Patient Partners have increasing responsibilities as members of research teams within our organization. These responsibilities include, but are not limited to, the following:

- providing recommendations on study aims/goals and protocols;
- designing surveys/questionnaires;
- tailoring proposed programs based on geographic regions;
- providing feedback on the burden of participation in studies, including appropriate number of in-person visits and sample collection that study subjects should undergo;
- creating consent and assent forms to ensure questions are comprehensible and necessary for the study;
- providing ideas to promote recruitment into studies to attract ethnic minorities and different gender groups; and,
- interpreting results in a manner that mattered most to patients and caregivers.

Knowledge Translation

Patient Partners are invaluable during knowledge translation to increase understanding and uptake of our research findings among the community. Patient Partners have actively consulted on the design and user-interface of our web and mobile applications leading to more accessible research products. They have also helped create lay language documents, infographics, and social media content.

SEX AND GENDER-BASED ANALYSIS (SGBA)

5.5 – If you have incorporated any SGBA considerations or analyses into your research and Network activities, please describe them below. Include a description of the extent of SGBA conducted, and what impact it has had on the Network.

(Maximum 250 words)

From the outset, Diabetes Action Canada has been committed to integrating SGBA in all its activities. This manifested through the establishment of the Sex and Gender Research Enabling Program. Co-led by Dr. Paula Rochon and Dr. Robin Mason of Women's Xchange, a

women's health knowledge translation and exchange centre based out of Women's College Hospital, the Program supports individual investigators on the integration of SGBA in all research activities and builds capacity in SGBA across our Network and other SPOR entities. The Sex and Gender Enabling Program activities include:

- Individualized SGBA consultation, proposal and manuscript review with feedback provided to investigators (89 consultations to date).
- Educational presentations on SGBA during our Annual Workshops, patient oriented research trainings, OSSU IMPACT award workshops, training and mentoring workshops.
- Development of a series of online education modules, *The Health Researcher's Toolkit: Why Sex and Gender Matter*.
- Development and publication of a tool to assess the quality of SGBA integration in research proposals.

These activities help to ensure that all of DAC's strategies and interventions for the prevention and treatment of diabetes-related complications are sensitive to sex and gender considerations, thereby improving patient care, scientific output and avoiding data waste.

Further, the Sex and Gender Enabling Program has engaged a group of patient partners, and recruited from each of our research programs, a designated Sex and Gender Facilitator, to enable more direct input into the studies undertaken. This is important to furthering integration of SGBA in research, knowledge generation and dissemination.

*****Questions 5.6, 5.7, and 5.8 are to be completed by the Chronic Disease Networks only. *****

The Sex and Gender Champion is intended to be an integral member of the Network with the support and decision-making power required to influence the integration of SGBA throughout the research program.

5.6 – In the space below, briefly summarize the role of the Sex and Gender Champion within the Network and the impact(s) this has had on the integration of SGBA into the program of research.

(Maximum 250 words)

The Sex and Gender Research Enabling Program includes Sex and Gender Champions, Drs. Paula Rochon, Robin Mason and Paula Harvey and coordinator, Jennifer Akerman. Collectively, the Sex and Gender Champions contribute through diverse activities expertise and knowledge of

women's health issues, sex and gender research methodologies, education, and knowledge translation to increase research capacity across our network, and enhance understanding and commitment to integrating SGBA as well as other key identity-related considerations into diabetes patient-oriented research.

To learn about the impact of the support provided by the Sex and Gender Champions, they completed a series of short interviews with our investigators over the Summer of 2019. The results of the project, titled "*Reporting on Sex and Gender Integration within Diabetes Action Canada: Interviews with Key Investigators*," reflected both the overwhelming need to include a sex and gender lens in health research and the positive results from support by the Sex and Gender Enabling Program Champions to take these differences into account. Success was demonstrated through positive reviewers' comments on submitted grant proposals, success in receipt of grant funding, and studies that planned for and showed disaggregation, analysis and reporting of data by sex and gender.

The interviews were also developed into a series of short narratives that were shared on social media, the Women's Xchange, and Diabetes Action Canada websites, thereby contributing to increasing awareness of the relevance and resulting impact of integrating sex and gender into health research studies.

5.7 – In the space below, from the perspective of the Sex and Gender Champion, please provide a summary of any successes achieved or challenges / lessons learned that can be provided as guidance to other Sex and Gender Champions.

(Maximum 250 words)

We have increased both the knowledge and skills of our investigators and research staff to integrate sex and gender considerations into their research activities. We have provided individualized and collective support on study designs and methods, reviewed and provided feedback on proposals and manuscripts, developed education modules and other tools, and collected relevant, useful resources on an accessible website.

With a more sophisticated understanding of sex and gender we recognize that research must also consider other key identity factors that 'intersect' with sex and gender, the "plus" in SGBA+. An intersectional sex and gender lens in research helps reveal where there may be inequities related to health, health care and treatments related to the intersection of sex and gender with race, age, geographic location, newcomer status, Indigenous identity and other

social determinants. The Sex and Gender Champions will meet this challenge through continued education, support, presentations, and the development of two new online education e-modules to add to [The Health Researcher's Toolkit](#), "Intersectionality Explained," and "Sex and Gender Considerations for Research with Indigenous Communities."

One challenge we faced was our capacity to meaningfully engage with our non-bilingual Francophone members. Hiring a bilingual research coordinator has improved the dissemination of bilingual knowledge products and increased our capacity to provide educational presentations to our francophone investigators and patient partners.

It has also been challenging to consistently engage patient partners. Instead, patient partners have been called upon intermittently to review and provide feedback on online modules, presentations, and a planned qualitative study.

5.8 – As a result of the guidance provided by the Sex and Gender Champion, please provide in the space below, three specific examples of any sex-disaggregated data collected, any vulnerable groups identified, and how this shaped the impact of your research.

(Maximum 250 words)

The following projects received guidance from the Sex and Gender Research Consultation Service:

- (I) **Dr. Monica Parry's CIHR project grant titled "PEP-CT Clinical Trials Decision Aid Project Designed to Improve Patient Engagement Partnerships in Clinical Trials".** The project involves sex-disaggregated data by including both men and women, and using the genesis-praxy questionnaire to assess gender. The sample size accommodates a sex-based analysis on any sex/gender differences in usability and uptake. Vulnerable groups were identified through use of a demographic questionnaire (gender, Indigenous status, persons identifying as a visible minority or having a disability). Outcomes will be reported for the total sample and separately for men and women.

- (II) **Dr. Alana Weisman and Gillian Booth's project titled "Impact of government-funded insulin pump programs on insulin pump use in Canada".** The project involves sex-disaggregated data, specifically investigating the effect of sex on insulin pump use, and the correlation between sex, availability of government funding for insulin pumps, and insulin pump use. This work is ongoing with planned additional

involvement with the Sex and Gender Research Consultation as they finalize their analyses.

- (III) **Dr. Gary Lewis’s Federal New Frontiers Transformation grant proposal.** The consultation was critical in the successful articulation of SGBA detailed in the application itself, as well as the supplementary sections. Additional input was also provided in the development and integration of SGBA in the research proposal. It was noted that that the involvement of Drs. Rochon and Mason, two of Canada's foremost experts on SGBA, as co-investigators strengthened the application.

6. LINKAGES ACROSS SPOR

This section is intended to provide information related to collaborations across SPOR (i.e., SUPPORT Units, other Networks and Innovative Clinical Trials). Interaction means the Network has either worked collaboratively on a joint project or provided services to the SPOR-funded entity.

6.1 – Which of the following SPOR-funded entities have been involved in Network activities during the reporting period, and in what capacity?

| SPOR-Funded Entity | Research activities | | | | | KT activities | Capacity development activities | Patient engagement activities | Governance activities |
|-------------------------------------|-------------------------------------|---|-----------------------------|--|-------------------------------------|--------------------------|---------------------------------|-------------------------------|--------------------------|
| | Involved throughout | Development of the research idea / question | Development of the protocol | Data collection phase/project implementation | Interpretation of the results | | | | |
| SPOR SUPPORT Units | | | | | | | | | |
| Alberta SPOR SUPPORT Unit (AbSPORU) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| BC SUPPORT Unit | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The George & Fay Yee Centre for | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | | | | | |
|--|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
| Healthcare Innovation (CHI; Manitoba) | | | | | | | | | |
| Maritime SPOR SUPPORT Unit (MSSU) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Newfoundland and Labrador SUPPORT Unit (NL SUPPORT) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Northwest Territories SPOR SUPPORT Unit (Hoti ts'eeda) | <input type="checkbox"/> |
| Ontario SPOR SUPPORT Unit (OSSU) | <input checked="" type="checkbox"/> |
| Quebec SUPPORT Unit (Unité de Soutien SRAP du Québec) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Saskatchewan Centre for Patient-Oriented | <input type="checkbox"/> |

| | | | | | | | | | |
|--|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
| Research (SCPOR) | | | | | | | | | |
| SPOR Networks | | | | | | | | | |
| ACCESS Open Minds | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| CHILD-BRIGHT Network | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| Chronic Pain Network | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| Diabetes Action Canada | <input checked="" type="checkbox"/> |
| IMAGINE-SPOR Chronic Disease Network | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| Can-SOLVE CKD Network | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| Other SPOR-funded entities | | | | | | | | | |
| Innovative Clinical Trial (iCT) Grant Recipients | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| SPOR Evidence Alliance | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (e.g., Collaborati | <input checked="" type="checkbox"/> |

| | | | | | | | | | |
|---------------------------------------|--|--|--|--|--|--|--|--|--|
| on Grant Recipients) – Please Specify | | | | | | | | | |
|---------------------------------------|--|--|--|--|--|--|--|--|--|

6.2 – Please describe up to three successful (significant and beneficial) collaborations (as noted in 6.1) you have had with other SPOR-funded entities during the reporting period including the nature, extent and value-add of these interactions.

(Maximum 250 words)

The Ontario SPOR SUPPORT Unit has provided critically important funding to IC/ES enabling our collaboration necessary for the provincial data analytics required to identify persons with diabetes who have not received retinopathy screening. This project, in collaboration with the Ontario Community Health Centres, will launch the population surveillance approach to comprehensive retina screening necessary to eliminate diabetes as the most common cause of blindness in working age Canadians.

In collaboration with the SPOR Evidence Alliance the following project was completed “Diabetic Retinopathy Screening: A Systematic Review with ‘Best Fit’ Framework Synthesis” and the manuscript was submitted for peer review. The purpose was to understand the facilitators and barriers influencing diabetic retinopathy screening attendance and to examine factors that promote program success in the Canadian context. This is the first comprehensive analysis of its kind in Canada and provides convincing evidence for the design of new models of successful screening.

In collaboration with Can-SOLVE CKD (SPOR Chronic Disease Network in Chronic Kidney Disease) and their Indigenous Patient Engagement and Research Council, our Indigenous Peoples Patient Circle members have created a new training platform to enable respectful partnerships with Indigenous People in research. This learning pathway, named Wabishki Bizhiko Skaanj aims to enhance the Indigenous perspective and support partnerships that consider existing racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health, and culturally safe health research practices. This learning pathway will ultimately change the way that researchers approach and engage members of the Indigenous Community.

6.3 – In the space below, please provide a summary of any challenges encountered in the Network’s collaborations with other SPOR-funded entities during this reporting period, including the strategies and/or actions taken to address them.

(Maximum 500 words)

SPOR SUPPORT Units

Diabetes Action Canada has established important collaborative relationships with the Ontario (population-based health data analytics), Manitoba (Indigenous Youth Mentorship Program), Alberta (diabetic risk factor EMR dashboard and analytics), Quebec (knowledge translation) and Maritimes (teaching and mentoring) SPOR SUPPORT Units. Following the announcement of the opportunity for the SPOR SUPPORT Units to apply for Phase 2 funding, Diabetes Action Canada immediately prepared customized proposals for potential collaboration and proactively reached out to these Units to build closer working relationships. This process has continued and now includes Newfoundland-Labrador and British Columbia. These proposals focus on the spread and scale of our successful models of improving health care for persons with diabetes who are most vulnerable to adverse outcomes and align with the eligibility criteria for Phase 2, i.e., application of health data, creating learning health systems, building capacity and patient engagement.

SPOR Networks

We continue to meet quarterly with the Directors of all the SPOR Networks and Nancy Mason-MacLellan and her team to share information, coordinate collaboration and create new opportunities for networking. Following the Ottawa meeting in February 2020 with the SPOR SUPPORT Unit leads, we were encouraged to learn about the interest in establishing more networked activity across the provinces in Indigenous Health, KT, Patient Engagement, Capacity Building and more. Diabetes Action Canada strongly endorses this concept and is eager to engage and support this effort along with the other Networks.

As Diabetes Action Canada works more closely with the provinces, focus on vulnerable populations and chronic disease management have emerged as common themes. The health system approach to persons with multiple chronic conditions must be holistic, comprehensive and integrated with social services to address all the determinants of health. Improved collaboration among the SPOR Networks could address this challenge more effectively.

SPOR National Data Platform

Diabetes Action Canada has committed to collaboration with the Health Data Research Network (HDRN) Canada and its SPOR National Data Platform. Our National Diabetes Repository of primary care EMR data is ready for linkage with provincial administrative health and related data for the purpose of initiating predictive analytics and the tracking of health interventions and outcomes in the context of patient-oriented population health research. In 2019-20, our Digital Health Research Program initiated a project with the HDRN Data Access Support Hub in collaboration with CIHI to identify missing data in key datasets necessary to track risk factors for diabetes and other chronic disease and health outcomes. Diabetes Action Canada recognizes the critical importance of developing data-informed digital diabetes health service models with the provinces and collaborating with the SPOR National Data Platform will be essential to achieve this goal.

SPOR Evidence Alliance

Diabetes Action Canada was the first SPOR Network to collaborate with the Alliance on co-designing and implementing a systematic review that was completed in early 2020. Both parties learned the value of strategic collaboration on enabling the development of the most appropriate queries, literature search and evaluation to provide meaningful analysis and results.

7. RESEARCH CAPACITY, TRAINING AND MENTORING (Mandatory)

This section is intended to summarize the training and mentoring opportunities provided by the Network.

7.1 – Please identify the number and type of training and capacity building activities held by the Network during the reporting period. Add rows as needed. Indicate 0 if none.

It is understood that some of these activities may overlap and that ‘double counting’ may occur in this section.

| Training/capacity building activities | Total # of activities | # of activities co-developed with patients | # of activities co-led and/or co-delivered with patients |
|---------------------------------------|---------------------------|--|--|
| Web-based learning | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Participatory workshop | 6 training workshops | 5 | 4 |
| Lecture or seminar | Click here to enter text. | Click here to enter text. | Click here to enter text. |

| | | | |
|--------------------------------------|---------------------------|---------------------------|--|
| Course at post-secondary Institution | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Thesis supervision | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Mentorship | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Community of Practice | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Other – Please Specify | | | |
| Internship Awards Program | 2 awards offered | 0 | 0 |
| Postdoctoral Awards Program | 4 awards offered | 0 | Patient partners are on the Review committee |
| KT Scholarship Awards Program | 3 awards offered | 0 | Patient partners are on the Review committee |

7.2 – Please identify the type and number of individuals participating in training and capacity building activities held by the Network during the reporting period. Add rows as needed. Indicate 0 if none.

For this question, estimates are acceptable although exact figures are preferred.

| Type of participants | Total # of participants | # participating in activities co-developed with patients | activities co-led and/or co-delivered with patients |
|--|---------------------------------|--|---|
| Network Staff | (see other below) | | |
| Patients | 17 | 17 | 12 |
| Researchers / Academics | 24 | 24 | 20 |
| Trainees – Post Health Professional Degree (MD, BScN, DDS) | Resident 3 Medical student 1 | Resident 2 Medical student 1 | Resident 2 Medical student 1 |
| Trainees – Postdoctoral fellows (post Ph.D.) | 13 | 10 | 7 |
| Trainees – Students (doctoral students) | 40 | 28 | 27 |
| Trainees – Students (masters students) | 11 | 11 | 11 |
| Trainees – Students (undergraduate students) | 2 | 2 | 2 |
| Clinical Scientists | 2 | 2 | 2 |

| | | | |
|---|------------|------------|--------------------|
| Health System / Care Practitioners / Professionals ² | 3 | 3 | 3 |
| Policy-Makers ³ | 0 | 0 | 0 |
| Other – Please Specify | | | |
| Project coordinators (3 DAC, 1 other) | 4 | 4 | 3 (2 DAC, 1 other) |
| Data manager | 1 | 1 | 1 |
| Research assistants | 3 | 3 | 3 |
| Research professionals | 3 | 3 | 0 |
| TOTAL | 127 | 111 | 94 |

7.3 – Please provide examples of unique and innovative training/mentoring that occurred during the reporting period – include both the successes realized and challenges faced.

(Maximum 500 words)

On April 12-13, 2019, our Training and Mentoring Program offered its first Indigenous learning pathway workshop entitled: “Starting the journey towards culturally safe patient-oriented research with Indigenous communities” (in English) in Winnipeg, Manitoba with 28 participants. This workshop was co-designed by trainees in our *Diabetes Research Envisioned and Accomplished in Manitoba* (DREAM) research project and Elders/knowledge keepers from Winnipeg. The planning team followed the Can-SOLVE CKD Wabishiki Bizhiko Skaanj Learning Pathway as a template: <https://www.cansolveckd.ca/learning-pathway>.

The aim was to provide experiential learning for trainees, patient partners and researchers about Canada’s history with Indigenous people and its impact on relationships between non-Indigenous and Indigenous people today. It provided guidance on how to appropriately and respectfully engage Indigenous People in the research process. The following content was offered: the KAIROS Basket Exercise; Tipi Teachings with Elders; the OCAP principles (Ownership, Control, Access and Possession); ethical data collection and management. Presentations by Indigenous researchers focused on how to do research the right way with Indigenous Peoples and included personal stories from Indigenous patient partners from the Can-SOLVE Network.

On March 10-11, 2020, the Diabetes Action Canada Training and Mentoring Program in collaboration with the Indigenous Peoples Health Program, Patient Engagement Program and

² Examples of Health System / Care Practitioners / Professionals include those employed by hospitals, hospital networks, health authorities or other large healthcare systems.

³ Examples of Policy-Makers include those employed by municipal, provincial and federal governments.

Sex and Gender Program hosted its second Indigenous learning pathway workshop (in French) entitled: “Progresser vers la recherche axée sur le patient adaptée à la réalité culturelle des peuples autochtones” in Wendake, Québec with 21 participants. This workshop included presentations from experts in research engaging Indigenous communities such as Melanie Vincent, researcher and consultant at GRIPMA (Groupe de recherche et d’interventions psychosociales en milieu autochtones) who delivered a talk on identity valorization and cultural safety. There were also presentations from our researchers with case studies on cultural safety and sex and gender in Indigenous communities. The KAIROS Blanket exercise was offered again and very much appreciated by all participants. The second day of the workshop included a conference on tools and resources on research principles and engagement with Indigenous peoples in research, First Nation protocols and historical context and OCAP principles in research.

Both workshops were a great success with attendees having gained valuable knowledge and awareness of histories of Indigenous peoples and the impact of colonization and racial biases on Indigenous health. Learnings included how to appropriately engage communities to conduct research in true partnership with Indigenous communities.

Trainee comments:

“I think it was really eye-opening and the experiential aspect of that learning was huge for when it comes to something like cultural safety training. It was also really great that there were elders who were involved [in the training], who were able to tell their stories. And we were all just really capable of sharing our experiences. Or thoughts and concerns, and everything that come up as we moved through the day. So, it was a very open space for that.”

“The blanket exercise was useful as well as the OCAP lecture. The whole two days were interesting so it is really hard to choose an aspect!”

7.4 – Please provide three examples of the benefit / value gained by the trainees resulting from the training and capacity building activities held by the Network during the reporting period.

(Maximum 500 words)

Since our Training and Mentoring programs have launched we have seen some remarkable results among those who have participated. In 2019-20 we launched a formal, independent evaluation of our training and mentoring program and received some preliminary results that

suggest all stakeholder groups found the programs well organized, relevant, and useful for those interested in conducting patient-oriented research. The Diabetes Action Canada training awards are perceived to be appropriately targeted to early career investigators. Those in the mentoring program report that the relationships are largely positive, productive, and career advancing. The full report will be available in 2020, with a publication to follow.

With this evaluation we started to more thoroughly track the career progression of our trainees who received awards. Already we have seen a number of trainees, namely Martin Sénéchal, Xiaolin Wei, Anne-Sophie Brazeau and Marie-Claude Tremblay become co-investigators within our organization leading collaboration on key projects with a strong focus on patient engagement. These early career investigators have produced a number of peer-reviewed papers with credit to Diabetes Action Canada (see attached KT report) and are now poised to be the next generation of patient-oriented researchers.

We have a number of testimonials from those who have participated in our programs and below are excerpts from post event evaluations. Key takeaways are that our programs, offered in both French and English, provide opportunities for trainees and researchers that are unique and valuable as the landscape of research in Canada is changing to be more person-centred and inclusive of vulnerable and/or minority populations.

Trainee comments on our Training and Mentoring Program:

“Diabetes Action Canada Training and Mentoring Program is providing training for trainees in different areas that they wouldn’t otherwise get. Grant writing, patient-oriented research, opportunities for trainees to be face to face with other trainees, practical experience in grant writing. I think that’s the most valuable. Diabetes Action Canada Training and Mentoring program has also hosted two meetings on cultural safety that have given trainees exposure to indigenous health research, and I think that’s really valuable as well. I would see those as the strengths. They’re filling a gap in the research space that no other group is doing in Canada.”

“Well, I think just providing this opportunity in the first place is amazing. To be able to give a new project, opportunities to collaborate with people, opportunities to go with the funding to be able to go to conferences is something that as a post-doc it is not easy to find. So, it really helps build that for my diabetes experience, but also for my overall career.”

“The leadership training I was able to attend as part of the DAC-TM Program equipped me with the skills needed to pursue and successfully receive a promotion.”

“I have been able to leverage the Program's mentorship to strengthen my ability to write grant proposals.”

8. ADVANCING KNOWLEDGE (Mandatory)

This section is intended to provide information on knowledge translation (KT) products and events, which are based on research findings and are intended to transmit research findings to knowledge users.

8.1 – Please identify the number and type of KT products and events developed by Network members during the reporting period – indicate 0 if none. Add rows as needed.

| KT product or event | Produced by the Network | Supported by (produced by others in collaboration with) the Network |
|--|-------------------------|---|
| Plain language publications | 35 | 8 |
| Peer-reviewed journal articles | 20 | 8 |
| Books / book chapters | 0 | 0 |
| Reports / technical reports | 9 | 5 |
| Educational materials | 2 | 0 |
| Social media campaign(s) ⁴ | 1 | 0 |
| Conference or symposia presentations (e.g., keynote address, guest speaker, conference workshop chair, poster presentations) | 95 | 0 |
| KT-related workshops | 3 | 1 |
| KT-related meetings | 23 | 0 |
| KT-related webinars | 0 | 2 |
| Online KT tools | 0 | 0 |
| Other – Please Specify Media appearances | 4 | 0 |

⁴ A social media campaign consists of a coordinated marketing effort to reinforce or assist with a Network goal using one or more social media platforms. Campaigns differ from everyday social media efforts because of their increased focus, targeting and measurability. Please do not list the number of posts or tweets.

8.2 – Please provide the references for your peer-reviewed journal articles, books and book chapters using the KT Product Report Template provided with this report.

8.3 – Please identify the type of audiences reached by the Network’s KT products and events. Check all that apply. Add rows as needed.

| | |
|---|-------------------------------------|
| Health System/Care practitioners/Public health practitioners | <input checked="" type="checkbox"/> |
| Patients / Consumers of health system/care | <input checked="" type="checkbox"/> |
| Study Stakeholders (who are formally listed in the grant application) | <input checked="" type="checkbox"/> |
| Health System/Care Managers | <input checked="" type="checkbox"/> |
| Health System/Care Professional Organizations | <input checked="" type="checkbox"/> |
| Federal/Provincial Representatives (including policy-makers) | <input checked="" type="checkbox"/> |
| Community/Municipal Organizations (including policy-makers) | <input checked="" type="checkbox"/> |
| Consumer Groups/Charitable Organizations | <input checked="" type="checkbox"/> |
| Industry | <input checked="" type="checkbox"/> |
| The media | <input checked="" type="checkbox"/> |
| Researchers / Academics (excluding study stakeholders) | <input checked="" type="checkbox"/> |
| Research funding organizations | <input checked="" type="checkbox"/> |
| Other – Please Specify | <input type="checkbox"/> |

8.4 – Please provide three examples of the value-add / knowledge gained by the audience(s) as a result of these KT products and events.

(Maximum 500 words)

In 2019-20 Diabetes Action Canada conducted a series of evaluative activities with various stakeholders ranging from Patient Partners and funding sponsors to policy decision-makers. The feedback collected was very informative as we plan for Phase 2 of our Network. A consistent message from one in all our evaluations was the need to improve communications. We took immediate action and made significant investment into improving our social media and lay communications. We hired a communications consultant and within months revamped our Twitter, LinkedIn, News, and Newsletters now focused more deliberating on reaching lay

audiences. Our monthly Newsletter now features Patient Partner personal impact stories. Our social media communications better highlight patient-oriented research and why it is important. Since implementing our new communications strategy, we have seen gratifying results. Since our 2018-19 annual report, our Twitter followers have doubled and our daily impressions tripled. Our followers are more engaged with retweets and their content sharing has tripled with enhanced commentary. Our highest uptake twitter feeds are about new research publications from our SPOR Network investigators and our Patient Partner personal impact stories. Our communications now attract increased attention from many of our partners and stakeholders in the diabetes community and we anticipate continued growth of our outreach.

Our Foot Care Program investigator, Dr. Charles de Mestral published a landmark paper in the CMAJ (September 2019) reporting new evidence that lower-limb amputation rates for those with diabetes in Ontario are rising over the last decade. This strongly highlights the urgent need for improvements in care and access to resources to reverse this devastating complication. This paper, with an accompanying commentary written by another lead researcher in our Network, Dr. Bruce Perkins, received considerable media attention with a feature on CTV news. Now with data to support the need for a coordinated approach to diabetic foot care and lower limb preservation there is new collaboration among Diabetes Action Canada, Wounds Canada, the Conference Board of Canada, and CorHealth Ontario to plan for establishing value-based preventative foot care. with a particular focus is on those in lower SES and vulnerable populations who experience the highest rate of lower limb amputation due to lack of timely prevention and treatment.

Considering the increase in prevalence of diabetes and its complications in Canada, our Knowledge Translation Research Program conducted an environmental scan to document the existing knowledge translation (KT) tools for preventing diabetes complications and to make them accessible to knowledge users (e.g. patients, caregivers and health professionals). The tools/initiatives selected from this scan, focus on diabetes complications management and have relevance to all types of diabetes. To ensure that tools/initiatives selected were easily understood and user-friendly, four Patient Partners from our Network were involved in this research project and helped plan the web presentation of these tools. We are now looking to improve accessibility of the most useful KT tools for use by patients, caregivers, health

professionals, and relevant stakeholders that will avoid unnecessary duplication and move knowledge into action promptly for better patient care.

9. RELEVANCE TO INDIGENOUS PEOPLES (Mandatory)

The following questions will gather information about activities that include / focus on / are relevant to Indigenous Peoples.

9.1 – Please identify Network research projects that include, either exclusively or as a specific focus, Indigenous Peoples as [partners in the research](#).

| Name of Research Project | Nominated Principal Investigator |
|--|----------------------------------|
| Indigenous Youth Mentorship Program | Nancy Young |
| Rural Indigenous Community Screening for Diabetes Complication for Prevention and Early Intervention | Jon McGavock |
| National Training in Culturally Safe Diabetes Education | Barry Lavalee |
| Indigenous patient circle priority setting activities and video development | Alex McComber |
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9.2 – Please describe how Indigenous Peoples have been involved in the governance and the management of the Network, including the management of research projects.

(Maximum 250 words)

Our Diabetes Action Canada Indigenous Peoples Health Program is led by an Indigenous scholar (Dr. Alex McComber) and a settler scientist (Dr. Jon McGavock) with interests in preventing Type 2 diabetes among Indigenous youth and enhancing patient engagement. Alex, a member of the Kanien'kehá:ka (Mohawk), Bear Clan, coordinates the activities of the Indigenous Patient Circle, organizing regular gatherings to establish research priorities in Indigenous health related to diabetes and its complications and connects with other Indigenous research groups across Canada. He is PI of the Network Environment for Indigenous Health Research team grant housed within Kahnawake and McGill University. He has helped develop research priorities within the program through several face to face meetings with the Indigenous Patient Circle,

which are regularly reported to our Network Operations and Management Committee, to both inform and to seek advice about collaboration with the other Research Program Leads. Our Indigenous Patient Circle works closely with investigators, to discuss the important challenges among their communities and how research teams can engage Indigenous Patient Partners in a culturally sensitive and respectful way.

Dr Barry Lavallee (Metis/Saulteaux, Bear/Makwa clan) leads development and evaluation of cultural safety training for primary care providers working with Indigenous people living with diabetes. His entire research team is Indigenous and provides lectures and direction to our Network on anti-racism within clinical care and research activities.

Dr. Malcolm King (Mississaugas of the Credit First Nations) chairs our Steering Council, and Roslynn Baird (Cayuga), Director of the Indigenous Diabetes Health Circle, is a Steering Council member.

9.3 – Please include examples of which Indigenous voices (e.g. Elders, youth, leadership, Knowledge Holders, etc.) are engaged in Network activities.

(Maximum 250 words)

(Maximum 250 words)

Our Indigenous Patient Circle consists of 12-persons with representation from Anishinaabe, Haudenosaunee/ Kanien'keha:ka, Nēhiyawēwin, Innu, Inuit, Coast Salish and Oji-Cree nations, Indigenous scientists and health care providers as well as Indigenous community-based organizations that provide diabetes care and education services. Among these members we have four persons identified as Elders and Wisdom Keepers within their communities. Elders on the patient circle include Barbara and Clarence Nepinak (Treaty 1 Territory, Anishinaabe, Bear Clan) and Robert Fenton (Anishinaabe, Thunderbay area) who provide guidance to Dr. McComber and the Circle.

In addition, our Indigenous Youth Mentorship Program (IYMP) resilience-based approach to wellness was co-developed with Indigenous youth, community Elders from across Canada. This team is funded by a CIHR Pathways to Equity Component 3 team grant. Youth and Elders sit on the national advisory circle and community members in Winnipeg and northern Manitoba, providing guidance and leadership for decision making on the team. Each site community team (n=49) for within IYMP is led by a young adult health leader and community champion,

who work and are members of the Indigenous community. The program is customized to incorporate the learnings Indigenous teachings and cultural practices in each relevant to each community and young adult leaders complete a two-day hands-on training every year with Elders and Indigenous scholars including the leadership training, and mentoring and ceremonial activities designed and provided by young Indigenous leaders and elders that they bring back to teach to children in their community.

9.4 – Please indicate which Indigenous methodologies (e.g., Indigenous storytelling) and methods (e.g., Indigenous sharing circles, traditional Indigenous protocols) have been integrated into Network activities and describe the context in which this occurs (e.g. for training opportunities, as a research method, to enhance knowledge translation, etc.).

(Maximum 250 words)

The Indigenous Patient Circle is guided by a vision that emerged from a collective PATH exercise completed in 2016. Priorities from our Patient Circle include a focus on culture for wellness; building a national community to tackle disparities in diabetes and supporting holistic models of care. Gatherings are regularly organized to refine these goals and communicate the perspectives of our Indigenous Patient Circle to our programs. These gathering always include sharing circles for patients, researchers and providers to: (1) share their stories of health care experiences; (2) review research proposals; and (3) develop a strategy to collate current best practices.

The IYMP is guided by the framework developed by Indigenous scholar Dr. Heather McRae and is based on the Indigenous medicine wheel framework and includes the teachings of two leading Indigenous scholars, Drs. Martin Brokenleg and Verna Kirkness. Evaluation of the program includes storytelling and sharing circles. These are also included in the intervention component.

At our annual gatherings, Indigenous scholars and Elders are involved in the program. We have hosted two Cultural Safety workshops (2019 and 2020), in Winnipeg and the Huron Wendat community of Wendake. These events bring patient partners, trainees, and scientists together with Indigenous scholars and Elders to support training in cultural safety and equity. Activities include the Kairos blanket exercise, sessions with Elders, sharing circles, lectures on ethics/OCAP and cultural safety from Indigenous scholars from across Canada. These activities

have also been added to the trainee workshop held annually before the Diabetes Canada Annual meeting.

9.5 – Using the table below, please indicate the amount of both CIHR and partner funding that supports Network research activities and non-research activities for Indigenous Peoples over the reporting period. Express data as both the absolute amount (\$) and as a percentage of the total funding from either CIHR or from partners. In the Subtotal and Total rows of the table, please express the percentages as those of the combined funding from both CIHR and partners.

| Source of Funds | Contributions that support Network Activities for Indigenous Peoples | | | | | |
|-------------------------|--|-------------------------|-----------------------|-------------------------|------------------------------|-------------------------|
| | Cash Contributions | | In-kind Contributions | | Cash + In-kind Contributions | |
| | Amount (\$) | % of Total Contribution | Amount (\$) | % of Total Contribution | Amount (\$) | % of Total Contribution |
| Research Activities | | | | | | |
| CIHR | 80,950.00 | 42% | | | | |
| Partners | 113,950.00 | 58% | | | | |
| Subtotal | 194,900.00 | | | | | |
| Non-Research Activities | | | | | | |
| CIHR | | | | | | |
| Partners | 141,150.44 | 100% | | | | |
| Subtotal | 141,150.44 | | | | | |
| All Activities | | | | | | |
| Total | 336,050.44 | | | | | |

10. PARTNERSHIPS AND COLLABORATIONS (Mandatory: 10.1 only)

This section provides details on partnerships, collaborations and additional research developed or undertaken during the reporting period.

Partnerships are defined as a collective venture between a SPOR Network and an external organization having a contract or other formal agreement/arrangement between the Network and the external organization.

Collaborations are defined as a collective venture between a SPOR Network and an external organization without having a contract or other formal agreement/arrangement between the Network and the external organization.

10.1 – Please provide the name and details of each new partnership formed during the reporting period that were not listed in the Grant Agreement and provide their financial and in-kind contributions. Add rows as needed.

Do not include funding partners listed in the Grant Agreement.

| Name of Funding Partner | Amount of funding received during reporting period (\$) | Estimate of amount of in-kind support during reporting period (\$) |
|---|---|--|
| Private Donor (through Toronto General & Western Hospital Foundation) | 20,000 | Click here to enter text. |
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10.2 – Please describe the key achievements that resulted from having formed partnerships and collaborations.

For this question, please consider **all** partnerships (including those listed in the Grant Agreement) and collaborations that are **presently active** (including those formed during previous reporting periods).

Please note this information on collaborations is different from what is outlined in section 6.

(Maximum 500 words)

Diabetes Action Canada, and particularly our Patient Partners, has worked closely with Diabetes Canada on its new [National Diabetes 360 Strategy](#). The prevalence of diabetes is rising among Canadians along with its preventable complications. PHAC recognizes diabetes as an indicator of health inequality as the marginalized who are most strongly affected by social determinants demonstrate higher rates of adverse health outcomes. In 2018, we joined Diabetes Canada and JDRF to witness to the House of Commons Standing Committee on Health about the urgent need for improved access to prevention and treatment for Canadians with diabetes and its related complications. The [report in April 2019](#) reflected our recommendations including the adoption of the 360 Strategy, exploring options for establishing a national diabetes registry, and that the Government of Canada provide funding through the CIHR for research into preventing and treating T1D and T2D. We are poised to lead the implementation of the Diabetes 360 Strategy in each province and territory with continued support for our SPOR Network.

In 2019-20 we partnered with the [Alliance for Healthier Communities](#) that manage the Ontario Community Health Centres (CHCs) that serve vulnerable populations, e.g., new immigrants, persons with low SES. Together we are developing a new population surveillance approach to diabetic retinopathy screening focused on identifying those who are at risk of undetected, vision-threatening eye disease. Our goal is to spread this data-informed population approach among all the CHCs in Ontario demonstrating the value of using the analysis of linked EMR and provincial administrative data to identify and reach out pro-actively to unscreened persons with diabetes to prevent blindness.

In 2019, we established collaborative relationships with [The Fields Institute for Research in Mathematical Sciences](#) and [Vector Institute for Artificial Intelligence \(AI\)](#) to explore the use of our National Diabetes Repository data for modelling and predictive analytics for risk of diabetes and its complications. Following a joint workshop in June 2019 ([report here](#)), modelling of a risk calculator for diabetes complications has emerged, and a project that applies large-scale physiological simulation modelling to predict individual responsiveness to drug treatments for specific diabetes complications. We have expanded our Diabetes Action Canada co-investigator team to include trans-sectoral expertise in these fields of mathematics and AI to enhance our ability to design data-informed digital diabetes health services.

In 2019, Diabetes Action Canada established a new collaboration with the [Conference Board of Canada Value-Based Health Care division](#). Our investigators have launched the planning of a value-based health care project focused on improving diabetic foot care to prevent lower limb amputation involving four sites in Ontario: Unity Health (St. Michael's Hospital); the University Health Network; The Ottawa Hospital; and, the Indigenous Diabetes Health Circle. Each site will contribute in-kind resource and the Conference Board is soliciting sponsorship for cash contribution to support this project. Our goal is to reduce amputations and health care cost.

11. FINANCIAL OVERVIEW AND WORK PLAN (Mandatory)

11.1 – Please append a completed financial reporting template (using the template provided) that shows expenditures over the reporting period.

Submitted Friday August 14th, 2020. Please refer to 'Financial Review_annual report template 2019-20' – 'Expenditures 2019-2020' tab

11.2 – Please append an updated budget to project future Network expenditures.

Submitted Friday August 14th, 2020. Please refer to 'Financial Review_annual report template 2019-20' – 'Prospective Budget' tab

11.3 – Please append an updated work plan, including Network objectives and projected activities for future years.

Please see Appendix 2: Diabetes Action Canada Logic Models.

12. IMPACT STORIES (Mandatory)

12.1 – If available, please provide up to three impact case studies demonstrating improved patient outcomes/experiences, access to care and quality, and/or efficiency and effectiveness of health system. Please refer to the guide found in Appendix A.

(Maximum 500 words each)

Project #1 - Description and Impact Statement

Title: Evaluation of the National Diabetes Repository (NDR) for Advanced Predictive Analytics of Health Outcomes and Liberating Data - Preliminary Results – Anticipated Completion – March 2021

The use of health data to identify persons with diabetes at high risk for adverse health outcomes is limited by barriers of privacy, security and amount of information necessary for the application of advanced predictive analytics. Improving access to the right care at the right time for persons with diabetes at risk for complications, clinicians and policymakers require better data-informed clinical decision tools.

In collaboration with, and co-funded by the Fields Institute for Research in Mathematical Sciences and the Vector Institute for Artificial Intelligence, Diabetes Action Canada co-hosted a workshop on June 17, 18, 2019 to evaluate the use of our NDR electronic medical record (EMR) data for mathematical modelling and machine learning (ML) of diabetes health outcomes. The proposal for the Workshop was presented to our NDR Governance Committee, composed of 50% Patient Partners, who reviewed the objectives and approved the use of the de-identified and encrypted NDR data. In advance of the Workshop, the NDR data were prepared in the Centre for Advanced Computing in Kingston for use by participants. During the Workshop, researchers in computer science, mathematics, public health, epidemiology, population health, primary care and diabetes, collaborated to design a project using these data for analysis of risk factors and health outcomes with novel mathematical algorithms ([see report](#)). Subsequently, two mathematical modelling projects stemmed from this workshop. The first is the design of a risk calculator to identify persons with diabetes at high risk of developing complications. The second is to identify persons at risk for progressive diabetic kidney disease and the treatment to which they are most likely to respond.

This experience set in motion new collaboration with experts in mathematics, computer science and machine learning. In addition, our Diabetes Digital Health team learned how to better prepare data for advanced analytics and is expanding the NDR to include full EMR information and diagnostic images, e.g., retinal scans, for immediate use by ML and artificial intelligence (AI) researchers. To create effective clinical decision tools, better data sharing is necessary to create learning health environments. Therefore, Diabetes Action Canada collaborated with the Schwartz Reisman Institute for Technology and Society to co-host a solution Workshop on March 5, 6, 2020 entitled *Liberating Health Data in a Digital World: Implications for Law, Technology, and Patient Outcomes*. Participants came from a variety of policy sectors, academic

and clinical disciplines, privacy law, non-profit organizations, health care institutions and Patient Partners. The common goal was improving the health and autonomy of diabetes patients in Ontario through better access to and analysis of data stored in the health system including ML/AI. Our Patient Partner voices were heard clearly and their concerns and advice are reflected in the Report https://boundless.utoronto.ca/wp-content/uploads/SRI-Liberating-Health-Data-v3_FINAL-accessible_NoRestriction1.pdf. We addressed diabetes-specific data challenges, and more generally how data liberation could improve health and save lives. The outcomes generated the framework and blueprint for a path forward for Diabetes Action Canada and our collaborators in using powerful new technologies to improve the lives of persons with diabetes.

Project #2 – Description and Impact Statement

Title: Understanding Barriers to Diabetic Retinopathy Screening – Final Results – Completion Date – March 2020

Diabetic retinopathy remains the most common cause of blindness in working-aged Canadians, but may be preventable with early detection. Prevention begins with screening on a regular basis to detect and treat sight threatening diabetic retinopathy. Diabetes Canada has developed excellent evidence-based guidelines that recommend annual retinopathy screening. In Ontario, over 455,000 (40%) of individuals with diabetes have not received retinopathy screening in the past two years. For new immigrants, persons living in poverty, Indigenous Peoples, and younger adults, this number rises to 60%. A recent Diabetes Action Canada study, in collaboration with the Ontario Telehealth Network employing tele-retina screening in Ontario Community Health Centres, identified 37% of persons with diabetes who had never received screening and of these 9% had treatable vision-threatening eye disease. Unlike the UK, where a population approach to retinopathy screening has eliminated diabetes as the most common cause of blindness, nowhere in Canada has this been established. Therefore, Diabetes Action Canada set out to understand the barriers to screening experienced by a subset of vulnerable persons with diabetes, i.e., new immigrants, and by family physicians whom the health system has made accountable for diabetic retinopathy screening.

Co-funded by Diabetes Action Canada and Bayer Pharmaceuticals Canada, in collaboration with the Ottawa Hospital Research Institute, our Patient Engagement experts and Patient Partners designed a project to interview new immigrants with diabetes across 3 ethnolinguistic

minorities (South Asian, Chinese, French Speaking persons of African descent) in their native language to understand their reluctance to undergo retinopathy screening. The barriers included: lack of understanding why screening is important; fear that the test itself may be harmful as it requires eye drops that blur the vision; and, inability to get to the testing site due to work and family obligations. These findings point to the critical importance of providing education and health care for persons with diabetes in their own language and support for patient-centered access to care. In addition, health professionals must learn to engage patients with cultural sensitivity and awareness of the limitations of language barriers and competing personal obligations. A second project in collaboration with Women's College Hospital Institute for Health Systems Solutions and Virtual Care, was designed to identify the barriers perceived by patients and family physicians for referral for tele-retinal screening. The results indicate that tele-retina screening was well received by patients. Family physicians believed diabetic retinopathy screening was adequate, despite evidence to the contrary in their practices, and referral requires additional effort on their part to ensure that timely screening is achieved. These outcomes point to the urgent need for more effective, culturally sensitive and data-informed approaches to diabetic retinopathy screening and treatment.

Collaborating with the Ontario Ministry of Health and funded by a philanthropic donor, we are now working on a data-informed population-based solution for identifying persons with diabetes in Community Health Centres who have not received screening in the past two years and instituting tele-retina screening. In addition, co-funded by the Université de Montréal and Diabetes Action Canada, our investigators are pioneering the use of machine learning and artificial intelligence to establish automated, comprehensive retina image diagnostics for cost-effective population-based screening in Canada.

Project #3 Description and Impact Statement

Title: [Connect1d: A Digital T1D Registry to Accelerate Patient-Oriented Research, Policy, and Clinical Care](#) – Evaluation Phase completion – October 2022.

Persons with Type 1 Diabetes (T1D), who number 1 in 100 Canadians usually acquired in childhood or adolescence, experience a life sentence of 24/7 self-management of insulin treatment and blood sugar monitoring. It is striking that in Canada we have no means to connect with and learn from persons with T1D about their quality of care and state of wellness.

Without meticulous care and prevention, they are at risk of insulin-induced coma and sudden death, and in the longer-term blindness, kidney failure and lower extremity amputation. Diabetes registries, as established in Sweden, are fundamental for implementing high quality, evidence-based care and prevention of adverse health outcomes. In Canada, we cannot accurately assess the number of Canadians living with T1D, the quality of their care or wellness status and how to connect with them to develop patient-oriented T1D research.

Our Digital T1D Registry project, funded by JDRF and Diabetes Action Canada, brought together key stakeholders including persons living with T1D, clinicians, researchers, human factor biomedical engineers, and diabetes NGOs from Canada and the USA. A Patient Partner co-led this project and worked with over 30 other Patient Partners from across Canada to understand their perspective, values and needs. Involved from the outset, they were instrumental in the creation of our new virtual platform and led focus groups and interviews of persons living with T1D to advise about the feasibility and utility of the design and content of this interactive platform they named *Connect1d*. Through this process urgent health challenges including lack of access to mental health services and the necessity for diabetes data for improving self-management were identified. We also learned that many persons with T1D are enthusiastically interested in research but are unable to find relevant information or opportunities to participate. A similar gap in communication was identified by T1D researchers who reported limited access to potential patient participants as a barrier to design and recruitment for clinical studies. Therefore, *Connect1d* was developed for persons with T1D to directly access information about research studies and experience precision matching of their eligibility for recruitment into clinical trials. In addition, *Connect1d* will collect registry data that is current, dynamic, private and secure. Our Patient Partners report their voices have been heard and that knowledge translation of their lived experience will enable the use of *Connect1d* to communicate with researchers who have listened to what matters most to them.

Engagement of Canadian T1D researchers and clinicians is critical for success. Diabetes Action Canada has established a consortium of 85 T1D researchers and clinicians from 7 provinces who provide quarterly updates on patient-oriented studies under active recruitment. This information will keep persons with T1D and their health care providers up to date on Canadian research projects and evidence-based knowledge about T1D through our trusted source.

Connect1d will be launched in the Fall of 2020 and evaluated iteratively to continually improve its performance from the perspective of persons living with T1D and the clinicians and researchers engaged with them.

13. OTHER SUCCESSES AND CHALLENGES

13.1 – If there are any successes and/or challenges you would like to highlight (research-related or otherwise) that were not captured elsewhere in the report, please include them here.

Please see additional information as requested by CIHR

- Appendix 3: Diabetes Action Canada Sustainability Plan
- Appendix 4: Evaluation of the Diabetes Action Canada Training and Mentoring Program
- Appendix 5: Diabetes Action Canada Network Evaluation Report
- Appendix 6: Diabetes Action Canada External Review
- Appendix 7: Patient Engagement Strategy

CONCLUSION

This completes the 2019-2020 SPOR Network Annual Report. Thank you for supporting CIHR in its commitment to collecting and disseminating information on the outputs and impacts of the research it funds.

The SPOR Team

Strategy for Patient-Oriented Research (SPOR)
Canadian Institutes of Health Research / Government of Canada
SPOR-SRAP@cihr-irsc.gc.ca

Appendix 1: Diabetes Action Canada Members

DIABETE ACTION CANADA - Principal Investigators (n=15)

| Name of Principal Investigator | Role and Institute |
|--------------------------------|---|
| Després, Jean-Pierre | <p>Co-Scientific Lead – Diabetes Action Canada <i>Professor, Department of Kinesiology, Faculty of Medicine, Université Laval</i> <i>Director of Research in Cardiology, Québec Heart and Lung Institute Research Centre</i> <i>Director of Science and Innovation, Alliance santé Québec</i> <i>Scientific Director – International Chair on Cardiometabolic Risk</i></p> |
| Lewis, Gary F. | <p>Co-Scientific Lead – Diabetes Action Canada <i>Professor, Director, Division of Endocrinology and Metabolism, Department of Medicine and Department of Physiology, University of Toronto</i> <i>Director, Banting and Best Diabetes Centre, University of Toronto</i> <i>Sun Life Financial Chair in Diabetes</i> <i>Drucker Family Chair in Diabetes Research</i></p> |
| Brown, D. Adalsteinn | <p><i>Dean, Dalla Lana School of Public Health, University of Toronto</i></p> |
| Bélanger, Mathieu | <p><i>Associate Professor, Department of Family Medicine, Université de Sherbrooke;</i> <i>Director of Research, Centre de formation médicale du Nouveau-Brunswick;</i> <i>Epidemiologist, Vitalité Health Network</i></p> |
| Brent, Michael | <p><i>Associate Professor & Chief, Retina Service</i> <i>Department of Ophthalmology and Vision Sciences, University of Toronto</i> <i>Milton Harris Chair in Macular Degeneration Research</i></p> |
| Cafazzo, Joe | <p><i>Executive Director, University Health Network Biomedical Engineering;</i> <i>Healthcare Human Factors; Centre for Global eHealth Innovation</i> <i>Wolfond Chair in Digital Health</i> <i>Associate Professor, University of Toronto Institute of Biomaterials and Biomedical Engineering, and Institute of Health Policy Management and Evaluation</i></p> |
| Carpentier, André | <p><i>Professor, Department of Medicine Centre de recherche du CHUS, Université de Sherbrooke</i> <i>Director of the Province of Quebec Research Network on Cardiometabolic Health, Diabetes and Obesity</i></p> |
| Farkouh, Michael | <p><i>Vice-Chair Research & Professor of Medicine, Department of Medicine, and Director, Heart & Stroke Richard Lewar Centre of Excellence, University of Toronto</i> <i>Peter Munk Chair in Multinational Clinical Trials, University Health Network</i></p> |
| Fernyhough, Paul | <p><i>Professor and Head, Department of Pharmacology & Therapeutics</i> <i>Professor, Department of Physiology & Pathophysiology, University of Manitoba</i></p> |

| | |
|--------------------------|--|
| | <i>Director, Division of Neurodegenerative Disorders, St. Boniface Hospital Albrechtsen Research</i> |
| Greiver, Michelle | <i>Associate Professor, Department of Family and Community Medicine, University of Toronto Gordon F. Cheesbrough Research Chair in Family and Community Medicine and Director, University of Toronto Practice-Based Research Network (UTOPIAN), North York General Hospital</i> |
| Légaré, France | <i>Tier 1 Canada Research Chair in Shared Decision Making and Knowledge Translation Professor, Department of Family Medicine and Emergency Medicine, Université Laval</i> |
| Maberley, David | <i>Professor, Ophthalmology and Visual Sciences, University of British Columbia</i> |
| McGavock, Jon | <i>Associate Professor, Department of Pediatric and Child Health, University of Manitoba CIHR Applied Health Chair, Co-Lead DREAM Theme Lead PI for the Aboriginal Youth Mentorship Program Intervention and Vigor Trials</i> |
| Perkins, Bruce | <i>Professor, Department of Medicine, and Institute of Health Policy, Management and Evaluation, University of Toronto The Sinai Health Sam and Judy Pencer Family Chair in Diabetes Director of Diabetes Clinical Research, Division of Endocrinology and Metabolism, University of Toronto</i> |
| Rochon, Paula | <i>Professor, Department of Medicine, and Institute of Health Policy Management and Evaluation, University of Toronto, Retired Teachers of Ontario Chair in Geriatric Medicine, Vice President Research, Women's College Hospital</i> |

DIABETES ACTION CANADA - Co Investigators (n=77)

| Name of Co-Investigator | Role & Institute |
|--------------------------------|--|
| Al-Omran, Mohammed | <i>Head, Division of Vascular Surgery, St. Michael's Hospital Professor, Department of Surgery, University of Toronto</i> |
| Andersson, Neil | <i>Professor of Family Medicine, McGill University. Scientific Director, Community Information and Epidemiological Technologies (CIET), and Participatory Research at McGill (PRAM).</i> |
| Bhattacharyya, Onil | <i>Senior Scientist, Women's College Research Institute Frigon-Blau Chair in Family Medicine Research, Women's College Hospital Associate Professor, Department of Family & Community Medicine, and Institute of Health Policy, Management and Evaluation, University of Toronto</i> |

| Name of Co-Investigator | Role & Institute |
|--------------------------------|---|
| Blondin, Denis P | <i>Assistant Professor, Faculty of Medicine & Health Sciences, Université de Sherbrooke Researcher, Centre de recherche du Centre hospitalier universitaire de Sherbrooke</i> |
| Booth, Gillian | <i>Scientist, MAP Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Adjunct Scientist, Institute for Clinical Evaluative Sciences (ICES) Professor, Department of Medicine and the Institute of Health Policy, Management and Evaluation, University of Toronto</i> |
| Boucher, Marie-Carole | <i>Clinical Associate Professor, Ophthalmology department, Université de Montréal Surgical retina specialist, Maisonneuve-Rosemont University, Ophthalmology Center</i> |
| Brazeau, Anne Sophie | <i>Assistant Professor, Program Director of Dietetic Education and Practice, McGill University</i> |
| Butalia, Sonia | <i>Associate Professor, Departments of Medicine and Community Health Sciences, University of Calgary</i> |
| Campbell, David J T | <i>Assistant Professor, Departments of Medicine, Community Health Sciences and Cardiac Sciences, University of Calgary</i> |
| Campbell, Melanie | <i>Professor, Department of Physics, Cross Appointments: School of Optometry and Department of Systems Design Engineering. University of Waterloo</i> |
| Chaudhary, Varun | <i>Vitreo-retinal surgeon, Chief of Ophthalmology & Associate Professor of Surgery, Hamilton Regional Eye Institute, McMaster University.</i> |
| Cherney, David | <i>Professor, Department of Medicine & Division of Nephrology, University of Toronto</i> |
| Cross, Karen | <i>Plastic, Reconstructive and Aesthetic Surgeon, St. Michael's Hospital Assistant Professor, University of Toronto Adjunct Professor, Ryerson University</i> |
| Cruess, Alan F | <i>Professor, Department of Ophthalmology and Visual Sciences, Dalhousie University Member, Board of the Canadian National Institute for the Blind Member, Board of Vision Loss Rehabilitation Canada</i> |
| Dasgupta, Kaberi | <i>Professor of Medicine, McGill University Director, Centre for Outcomes Research and Evaluation, Research Institute of the McGill University Health Centre</i> |
| de Mestral, Charles | <i>Assistant Professor, Department of Surgery Vascular Surgeon, St. Michael's Hospital Scientist, Li Ka Shing Knowledge Institute, St. Michael's Hospital Adjunct Scientist, Institute for Clinical Evaluative Sciences</i> |

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| Name of Co-Investigator | Role & Institute |
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Appendix 2: Diabetes Action Canada Logic Models 2019-20

Diabetes Action Canada Logic Models 2019-20

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Preamble

As Diabetes Action Canada enters its final year of funding we have undertaken a series of evaluative activities that have led to interesting insights and recommendations that, when actioned, will improve the impact of our research networks and help us plan strategically for the future.

During this reporting period, Diabetes Action Canada, at the recommendation of the Steering Council, invited three reviewers from Canada and the USA to evaluate our research Network and to provide an independent perspective about our performance. The external reviewers had some key recommendations with a large focus on how we strategically communicate our research objectives. As part of the external review process, the reviewers were provided with the logic models submitted previously to CIHR as part of our reporting requirement. The reviewers recommended that we use these logic models more as tools to measure research objectives and for evaluative purposes, as well as for strategic communications. Therefore, in preparation for this 2019-20 report to CIHR we revised the guidelines for creating these logic models and met with each of our Research Programs to discuss how to use their logic model more strategically. The results, are found below and will also be used as part of the strategic planning process undertaken by Diabetes Action Canada for 2020-2021.

Governance

Program Lead: Catharine Whiteside

Admin Team: Tracy McQuire, Mildred Lim, Allison Hardisty

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|---|--|---|
| 1 | Develop appropriate project funding inter-institutional agreements and memorandum documents | <p><u>2019-20</u> New IIAs: Nil Amendment of IIA: 7</p> <p># of Institutions with IIAs: 13</p> <ul style="list-style-type: none"> a) Ontario – UHN, Unity Health Toronto, Laurentian, McMaster, WCH b) Quebec – Université de Sherbrooke, Université Laval, Université de Montreal, Polytechnique de Montréal, Institut de recherches cliniques de Montréal c) Manitoba - First Nations Health and Social Secretariat of Manitoba, University of Manitoba d) BC - UBC | <p>Network operations are compliant with Tri-Council Agency policies on financial responsibility and accountability.</p> <p>Project summaries are prepared and available for review by CIHR.</p> <p>Researchers and academic institutions across Canada are supported to engage in new or strategically modified research activities.</p> | Collaborating investigators are provided the resources required to design, implement and evaluate new care pathways that translate evidence into practice and inform health policy to improve the health outcomes of those living with diabetes. | Diabetes Action Canada has established the infrastructure for a truly national research consortium with working collaboratively with Provinces and Territories to improve health outcomes for persons living with diabetes. |
| 2 | Operational management | <p>Administrative team provides support for the following network functions:</p> <ul style="list-style-type: none"> - Inter-institutional agreement negotiation and implementation - Financial oversight and management | Administrative team coordinates operational management activities of the Network to ensure research progress and | Investigators, Patient Partners, academic partners and funding partner relationships are maintained to ensure continued engagement of all stakeholders. | A learning health environment is establishing with contributions from researchers, patient partners, public and private |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|--|--|---|
| | <ul style="list-style-type: none"> - Communications and social media - Organizational management for 11 programs - Event planning, implementation and execution - Annual Diabetes Action Canada Workshop - Meeting support and documentation - Investigator networking and collaboration facilitation - Patient Partner relations - External Research Partner relationship development - SPOR entity networking - Fundraising initiatives <p>Operational Management Committee active with 30 Program Co-Leads and Principal Investigators from the 11 Programs that meet monthly with Scientific Co-Leads and Administrative team.</p> | <p>enable scaling and spreading of successful outcomes.</p> <p>Leaders of 11 research, education and KT programs are engaged in Diabetes Action Canada network activities with Patient Partners to achieve collective impact</p> <p>Research leads among the 11 programs of complementary areas of research are offered new opportunities to collaborate and to secure future funding.</p> | <p>Stakeholders are active partners in decision making and implementation of evidence-based improvements.</p> | <p>partners to improve the health outcomes of Canadians living with diabetes.</p> <p>Diabetes Action Canada has established a sustainable organizational management model to enable activities beyond the CIHR SPOR funding term.</p> |
| <p>3 Steering Council Activities</p> | <p>Steering Council comprised of external health and policy experts and Patient Partners is the highest level of governance for Diabetes Action Canada and meets quarterly (twice a year face-to-face).</p> <p>Committees of the Steering Council active in the following areas:</p> | <p>Patient Partners are integral to governance of Diabetes Action Canada.</p> <p>Research, education and KT activities are aligned with</p> | <p>The research activities of Diabetes Action Canada are advised by health system leaders and policy experts to facilitate knowledge translation into practice and policy. .</p> | <p>Knowledge is translated into practice and policy to improve health and health system outcomes.</p> <p>Health care experiences of those living with diabetes</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|--|--|
| | <ul style="list-style-type: none"> - Finance and Audit Standing Committee - Nominations and Governance Standing Committee - Strategic Partnerships and Innovations Committee <p>Ad hoc committee on Network Performance Evaluation initiated to advise on approach for formal evaluation of the research activities and processes for the Diabetes Action Canada completed its work in November 2019.</p> <p>External scientific review conducted in Nov 2019 and report issued in December 2019.</p> <p>Terms of reference for all committees complete.</p> <p>Minutes and action items recorded and tracked.</p> | <p>the mission and vision for Diabetes Action Canada.</p> <p>Diabetes Action Canada administration is advised by health system leaders and policy decision-makers about strategic directions for new research activities and implementation of ongoing research projects.</p> <p>Approach to network analytics and return on investment for Diabetes Action Canada advised by the Steering Council. .</p> <p>External review articulated the core successes and areas for improvement enable strategic planning for SPOR 2.0</p> | <p>Research is patient-oriented with Patient Partners advising on research, education and KT goals and design.</p> <p>Evidence of impact of Diabetes Action Canada enables policy decision- makers to support the scale and spread of new evidence-based care pathways.</p> <p>Diabetes Action Canada has an evidence-based approach to planning for the future.</p> | <p>are improved through application of evidence-based practice.</p> <p>Improved quality of life for Canadians and their caregivers with reduced use and cost of health services – all impacting the quadruple aim framework (improved population health, reduced cost, improved patient experience, improved provider experience).</p> |
| 4 | <p>Branding and communication</p> <p>Communications lead hired in June 2019.</p> <p>Open Forum</p> | <p>Internal and external stakeholders and sponsors have access to comprehensive resources</p> | <p>Diabetes Acton Canada is recognized and respected as a national catalytic consortium for patient-oriented</p> | <p>Diabetes Action Canada influences health system leaders and policy decision-makers by publishing and</p> |

Diabetes Action Canada Logic Models 2019-20

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|--|--|---|
| | <p>Communication plan for internal and external stakeholders complete and updated to reflect renewed vision</p> <p>Website launched (2016) and updated (2019).</p> <p>Twitter account active with 608 followers.</p> <p>LinkedIn account active with 278 followers.</p> <p>One social media campaign launched</p> <p>Regular news stories published (~1/week).</p> <p>Quarterly Newsletters published and shared with subscribers.</p> <p>Summary annual report published and shared with sponsors.</p> <p>Diabetes Action Canada member’s open forum held in December 2019 with multiple feedback items on communications that have and will be implemented before the end of our funding term.</p> <p>News release to Research Canada on Diabetes Action Canada and patient-oriented research completed.</p> | <p>documenting Diabetes Action Canada activities.</p> <p>Network members are informed of accomplishments, funding opportunities, new partnerships, and other news.</p> | <p>research in diabetes that is inclusive of patient perspectives.</p> | <p>publicizing evidence-based research findings that successfully informs internal and external stakeholders.</p> |

Diabetes Action Canada Logic Models 2019-20

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|---|---|
| <p>5 Budget Management</p> | <p>CIHR and match funding are assigned to network activities.</p> <p>Funds dispersed on payment schedule as indicated in inter-institutional agreements.</p> <p>Financial reports obtained by each funded program and submitted to CIHR on an annual basis.</p> <p>Detailed expense budgets created for each funded research project.</p> <p>Financial reporting monitored by Administrative team for internal assessment of budgeted expenditures</p> | <p>Diabetes Action Canada is compliant with Section 4.2 of original funding agreement with CIHR.</p> <p>Expenses are compliant with Tri-Council Agency financial policies and approved by CIHR.</p> | <p>Diabetes Action Canada demonstrates financial responsibility and accountability to internal and external stakeholders.</p> | <p>Diabetes Action Canada has created the financial infrastructure to become a sustainable national patient-oriented research network.</p> |
| <p>6 Partnership development with Sponsors</p> | <p>Stewardship reports are submitted to funding sponsors based on funding agreement.</p> <p>Annual progress reports issues to funding sponsors.</p> <p>One new funding partner in 2019-20</p> <ul style="list-style-type: none"> - Philanthropic donor for project in diabetic retinopathy screening <p>Relationship management of funding partners through close collaboration with the Toronto General and Western Hospital Foundation development team.</p> | <p>Support from funding sponsors enables expansion of research activities and patient engagement.</p> <p>Sponsors are kept up to date about Network activities and outcomes.</p> <p>Sponsors are engaged in advising about future</p> | <p>Diabetes Action Canada promotes and expand its research activities through continued support from external sponsors</p> <p>Funding partners are active stakeholders in the knowledge translation of research outcomes.</p> | <p>Diabetes Action Canada has created and maintained the relationships with funding sponsors for sustaining a national patient-oriented research network focused on diabetes and its related complications.</p> |

Diabetes Action Canada Logic Models 2019-20

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---------|---------------------------------|---|------------------------------|
| | | | strategic directions for Diabetes Action Canada. | |
| | | | | |

Aging, Community and Population Health

Program Leads: Maureen Markle-Reid, Jenny Ploeg, Ruta Valaitis

Program Coordinator: Tracey Chambers

Research Goal:

- To further test the Aging, Community and Health Research Unit (ACHRU) - Community Partnership Program (CPP) for Diabetes self-management for older adults, in diverse Canadian primary care and community settings, with diverse populations and across jurisdictions, and plan for scale-up.

Objectives:

- To examine the effectiveness of the CPP compared to usual care on health outcomes and service costs of patients with diabetes and one or more chronic conditions and their family/friend caregivers using a cross-jurisdictional, multi-site pragmatic randomized controlled trial.
- To examine how best to implement the CPP intervention across diverse target populations and community settings.
- To examine patient, caregiver, provider and manager experiences with the CPP intervention.
- To identify factors associated with high service use in the CPP target population.
- To examine the scalability of the CPP and develop a scale-up plan.
- To examine patient and caregiver engagement with the research process.

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|--|---|---|
| 1 Proposal submitted to SPOR Operating Grant PIHCI Competition for Aging, Community & Health Research Unit (ACHRU) | \$1,846, 062 in SPOR Operating Grant funding secured through PIHCI Programmatic grants competition. Includes funding (\$846,062) from 5 partners (Diabetes Action Canada, Fonds de recherché de Quebec-Sante, Reseau-1 –Quebec, Scarborough Health Network | Program is designed to address the specific needs of patients and practitioners and promotes adherence to the program. | Increased knowledge across all study sites (patients, providers, managers, policy makers) regarding innovative model of care. | Improved quality of life for aging Canadians who participated in the intervention and their |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|--|--|---|
| <p>Community Partnership Program (CPP) for Diabetes Self-Management for Older Adults – Canada.</p> | <p>Foundation, McMaster Institute for Research on Aging) and in-kind contributions (\$654,563) from 11 collaborating partners.</p> <p>Interdisciplinary research team consists of 31 investigators; comprised of 23 researchers, 4 patient partners, 2 knowledge users, 2 clinicians, & 16 collaborators/partners across 4 provinces (ON, AB, QC, & PEI).</p> | <p>Decision makers and knowledge users are engaged in the strategic direction of the research, from planning, to implementation, and evaluation from the outset.</p> <p>Project development and implementation occur in partnership with high level health policy decision-makers</p> | | <p>caregivers with reduced use and cost of health services – all impacting the quadruple aim framework (improved population health, reduced cost, improved patient experience, improved provider experience).</p> |
| | <p>Governance Steering Committee: Using a collective impact approach, multi-stakeholder Steering Committee was established with representation from AB, ON, QC, and PEI provincial government, and Patient Partner representation.</p> <p>Current Steering Committee includes 2 patient and public research partners, 7 regional and provincial policy/decision-maker representatives, and 14 research team members across 4 provinces.</p> <p>3 Steering Committee Meetings were held</p> <ul style="list-style-type: none"> - Jan. 22, 2019 - June 14, 2019 - December 2, 2019 | <p>Fostered collaboration between health and community care services to develop patient-oriented outcomes to achieve the quadruple aim.</p> <p>Fostering relationships between diverse primary care and community-based intersectoral partners.</p> <p>Building relationships with other provincial health systems.</p> <p>Increased knowledge of factors affecting sustainability and</p> | <p>Steering committee will assist in identifying backbone organizations and funding strategy to support scale-up of CPP in different regions throughout Canada.</p> <p>Steering committee will participate in planning of provincial forum in 2021 to begin to implement scalability strategies.</p> | <p>Stakeholders are engaged to promote scale-up of intervention to diverse populations (inclusive of high users), to ensure widespread benefit and improve patient experience with intervention targeting high user population (65+, diabetes community-dwelling, one or more chronic condition).</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---|---|---|
| | <p>2 Focus groups with Steering Committee members will assess their engagement in the program, adaptations required, & plan for scale-up.</p> | <p>scalability of the program across 3 provinces (e.g. alignment with provincial priorities).</p> <p>Fostering champions among Steering Committee members to advise on scalability of the Program and identify other stakeholders to support scale-up in the future (e.g., Diabetes Action Canada).</p> | | |
| | <p>Local Community Advisory Boards (CABs) Local CABs established across 6 study sites (1 in PEI), consisting of patient/public research partners (older adults with diabetes and multiple chronic conditions, family caregivers), local/regional policy makers, health and social service providers / managers from community or primary care, a research team member & provincial research coordinator.</p> <p>Training & orientation materials developed and available to support patient and public research partners’ participation in study activities.</p> | <p>Identified frameworks & tools to inform scale up process, assessment of scalability of the Program, and development of a scale-up plan in respective regions.</p> <p>Explore considerations for ongoing program implementation, adaptations & scale-up: 6 CAB meetings across 6 sites & 1 CAB focus group.</p> | <p>Members of CAB become champions to scale intervention.</p> <p>Guidelines, tools and training materials are adopted in partner institutions practice for promoting optimal aging.</p> <p>Decision and policy makers who participate in CAB apply guidelines in developing standard of care for aging.</p> | <p>Use of guidelines, tools and training materials yield improved health care for aging Canadians who participated in the intervention.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|--|--|---|
| | <p>Regular meetings of local community advisory boards (CABs) over the life of the project.</p> <p>1-2 CAB focus groups per site over the life of the project.</p> | | | |
| | <p>Engagement of Patient and Public Research Partners (PPRPs): 2 PPRPs are strategically involved in all aspects of this Program to ensure patient-oriented research</p> <p>Interviews and surveys at 2 points in time to measure engagement of PPRPs</p> | <p>Patients and caregivers involved in generating knowledge for study protocol</p> | <p>Patient and Public research partners and policy makers contribute to scale-up assessment</p> | |
| <p>2 Study Process</p> <p>Study 1: Population-based analysis using CIHR/CIHI Dynamic Cohort (high user) databases linked with provincial (Ontario, Alberta) databases</p> | <p>Team includes 16 researchers from 2 provinces, (ON and AB) and 2 patient/public research partners</p> <p>Sub-grant agreement with University of Alberta completed</p> <p>2 data sharing agreements (CIHI and ICES) completed</p> <p>Analysis of administrative databases - CIHI High ED User Cohort & ICES identified characteristics of older adults with diabetes and multi-morbidity who are high users of the health system i.e., Social Determinants of Health (age, sex, household income, rurality), health status measures (prescription medications, chronic conditions)</p> | <p>Characteristics of high users will be used to examine the cost, effectiveness and implementation of the intervention with the high user group of older adults compared to non-high users.</p> | <p>Increased use/integration with primary and community-based services for sites who participated in intervention.</p> <p>Sub-group analysis (including analysis of high-users), yields better understanding of characteristics of this sub-group and if the group benefitted more or less from the intervention, to help inform future resource allocation.</p> | <p>Reduction in acute care service use/costs for those participating in intervention related to other populations segmented into high healthcare needs.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|--|---|--|
| | <p>and health service use (e.g., GP/specialist visits). High users defined as top 10% for ED visits.</p> <p>Findings from analyses informed and validated the eligibility criteria for the clinical trial – STUDY 2a</p> <p>7 meetings (Sept 2018–Jan 2019)</p> <p>- planning, discussion and interpretation of analysis; 4 meetings involved patient partners (orientation to the project, interpretation of results, feedback on poster)</p> <p>Plain language document created</p> <p>Webinar created</p> <p>Poster created</p> | | | |
| <p>STUDY 2a: pragmatic RCT to test theory-informed (Bandura’s Social Cognitive Theory) self-management intervention (consistent with current MOHLTC & CIHR policies)</p> | <p>Identified and secured 6 sites for intervention (2 sites in each of Ontario, Quebec, & PEI).</p> <ul style="list-style-type: none"> - 1 clinical partner and 1 community-based partner secured for each of 6 sites - Site-specific requirements gathered and modifications incorporated into intervention <p>Approval from 7 research ethics boards across 3 provinces and 6 study sites.</p> | <p>Capacity for patient-oriented research is enhanced amongst trial participants including health practitioners and community partners.</p> <p>Quadruple aim indicators measured to demonstrate patient, caregiver, and provider experience.</p> | <p>A learning health environment within the intervention sites is established that is changing practice as the study is evolving.</p> <p>Healthy aging at home is promoted in a health care and community setting which addresses the local context for those regions receiving the intervention.</p> | <p>Improved quality of life and self-management & access to community health and social services, for older adults with diabetes and other chronic conditions participating in the intervention, and their</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|---|--|
| | <p>7 sub-grant agreements / data-sharing agreements with collaborating organizations & clinical and community-based partners secured by McMaster University.</p> <p>20 PI-led planning meetings (May, 2018 -Jan, 2019) with co-lead investigators & clinical and community partners, including 1 In-person planning meeting of co-lead investigators from ON, PEI and QC in Quebec (Nov, 2018).</p> <p>Site visits by lead investigators to community-based and clinical partner sites.</p> <p>Quadruple aim indicators established to demonstrate improved patient, caregiver, and provider experience -Identified and confirmed all PREMs/PROMs used to assess effectiveness of intervention. -Guided by implementation science framework, identified implementation outcomes and measures.</p> <p>5 Inter-professional, collaborative intervention teams established – 1 team for each study site (*1 team for 2 sites in PEI) that involves collaboration between one primary care partner and one community partner at each site. Each intervention team is comprised of 1 registered nurse, 1 registered dietitian or nutritionist (in Quebec) and a manager from the clinical partner site</p> | <p>Staggered trial launch across all study sites from July-Dec, 2019.</p> <p>As of March 13, 2020, Recruitment across 6 study sites is 83% of 264 older adult participants.</p> <p>218 Time 1 baseline survey interviews completed.</p> <p>Ongoing collection of Time 2 outcome measures.</p> <p>Change in intervention teams’ knowledge, awareness & delivery of person-centred care for older adults with diabetes and multimorbidity; collaboration, care coordination, system navigation.</p> <p>Change in patients’/caregivers’ knowledge and awareness of self-management of diabetes and other chronic conditions; system</p> | <p>Contributions to scientific knowledge and literature regarding pragmatic clinical trials, multimorbidity, characteristics of high system use, patient/stakeholder engagement and scale-up.</p> | <p>family caregivers in ON, QC, and PEI.</p> <p>Improved health outcomes, and patient, caregiver and provider experience for those experiencing the intervention programing.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|------------------------------|
| | <p>and 1 community program coordinator from the community-based partner site.</p> <p>Interventionists’ training curriculum developed and available in French and English including: Program objectives, population, underlying principles and assumptions, roles, intervention components, patient-centred care and multimorbidity, clinical assessment, self-management, medication review, mental health, physical activity, healthy eating, cultural safety, caregiver support, team-based care, care-coordination & system navigation.</p> <p>Virtual (on-line) platform developed to house/deliver training materials to intervention teams across 6 sites, to provide the CPP for seniors with diabetes and their caregivers.</p> <p>1 lead trainer/co-investigator secured for each province.</p> <p>Assessment of interventionists’ learning needs across 6 sites conducted by research coordinators.</p> <p>8-hours of training by PIs from McMaster, for 3 Lead trainers/co-investigators, 4 director/managers, and 3 provincial research coordinators across ON, PEI and QC</p> | <p>navigation, care coordination, for those receiving intervention.</p> <p>Ongoing support for intervention teams to deliver the CPP & address training needs and issues related to delivery of the CPP.</p> <p>Explored considerations for ongoing program implementation & scale-up: -Time 1 Focus Groups with 3 of 5 Intervention teams; interviews with 4 of 6 managers.</p> <p>10 Focus Groups with Intervention teams (2 per team) over the life of the project & 2 interviews with each clinical and community-partner manager in each site over the life of the project planned.</p> <p>48 Post-intervention interviews: 8 patient /caregiver CPP recipients per site at each of 6 sites.</p> | | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|------------------------------|
| | <p>1-day (8 hours) tailored training for 5 intervention teams across 3 provinces by the lead trainer and a co-investigator in each province, to deliver the CPP program (intervention).</p> <p>Increased capacity of Providers / intervention teams, i.e., 6 registered nurses, 3 registered dietitians, 2 nutritionists and 6 community program coordinators across 3 provinces and 6 sites, in multi-morbidity, self-management, mental health, system navigation, care coordination & team-based care.</p> <p>Intervention teams deliver up to 3 home visits, phone visits & up to 6 wellness sessions to 132 trial participants across 6 study sites.</p> <p>Coordinated, patient-centered care provided to 132 trial participants and their family/friend caregivers (22 participants/site x 6 sites) - 27 trial participants completed CPP as of Mar 31/20.</p> <p>Monthly case conferences held by intervention team members (nurse, dietitian/nutritionist, program coordinator) in 6 study sites, for the duration of the intervention.</p> | <p>5-10 Peer-Reviewed publications to disseminate study results expected.</p> <p>3 conferences to disseminate study results expected.</p> <p>Policy Forum in the final year of the project to support program scale-up planned.</p> | | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|--|---|--|
| | <p>Monthly outreach meetings between intervention teams and research team members across 6 study sites for the duration of the intervention.</p> | | | |
| <p>2 STUDY 2b: Provincial scale-up planning</p> | <p>Scalability assessed in populations, geographic regions, and community-based settings in each of four provinces (Ontario, Quebec, PEI).</p> <p>Draft template of program scale-up plan identifying adaptations required for implementation in each province.</p> <p>Backbone organization(s) identified in different settings.</p> | <p>OSSU & Collaborative for Health and Aging will provide methodological support and build capacity.</p> | <p>Organizational & Provincial commitment to scaling-up the CPP.</p> <p>Program is scaled-up or implemented in different regions throughout Canada with the support of backbone organization(s).</p> <p>Practice and Policy outcomes are tracked.</p> | <p>In future scale up efforts the intervention will be targeted to those sub-groups that benefited most.</p> <p>New knowledge is developed and shared related to scalability assessment, planning for scale-up, and experience in scaling up the intervention.</p> |

Assumptions

- Ability to complete the trial in all sites, after COVID 19 pandemic.
- Continued funding for the Program
- Recruitment (ability to stop and re-start the study)
- Ability to secure required human resources (i.e. intervention team)
- Intervention teams available to re-start intervention

External Factors that affect the program:

- Engagement of participants on the Steering Committee
- Cost of the intervention differs across the sites
- COVID 19 pandemic

Diabetic Retinopathy Screening

Program Co-Leads: Michael Brent, David Maberley and Debbie Sissmore (Patient Partner)

Program Co-Investigators: Marie Carole Boucher, Melanie Campbell, Varun Chaudhary, Alan Cruess, Sherif El Defrawy, Mahyar Etminan, Bernard Hurley, Stephen Kosar, Jason Noble, Tom Sheidow, David Wong

Program Coordinator: Olivera Sutakovic

Research Goals:

1. Prevent blindness in working age Canadians living with diabetes by implementing a tele-retina screening program
2. Tele-ophthalmology screening of Diabetic Retinopathy among at risk populations: an economic analysis
3. An Implementation Science Based Approach to Increase Diabetic Retinopathy Screening (DRS) Attendance by Persons with Diabetes in ethnocultural minority settings
4. Increasing Diabetic Retinopathy Screening through the Teleophthalmology Program (TOP): supporting implementation and identifying opportunities for scale up in Ontario
5. Investigating the role of artificial intelligence (AI) in retinal image analytics and its potential for application in clinical contexts in Canada
6. Establish tele-retinal screening sites in urban and rural sites in BC

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|--|--|---|---|
| 1 | Ontario tele-retina screening scale-up in selected regions | Partnerships established with Ontario Telehealth Network, Community Health Centers (CHC), LHINs Joint business proposal between Ontario Telemedicine Network (OTN) and Diabetes Action Canada – Diabetic Retinopathy (DR) group “Scaling Up Diabetic Retinal Screening in Ontario: A Pan-Ontario Plan to Close the Screening Gap” | Clients of community health services have increased knowledge and access to tele-retinal screening. Increased screening for diabetic retinopathy in | Increase in clients for diabetic retinopathy screening at the recommended intervals. Clients of community care are notified at regular intervals for diabetic retinopathy screening. | People living with diabetes receive efficient best practice for diabetic retinopathy prevention Vision loss due to diabetic retinopathy is reduced among those participating |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|--|--|---|
| | <p>Dedicated ophthalmologists-retinal champion chosen in different regions.</p> <p>Steering Committee for Tele-Ophthalmology Screening, Canadian Retina Research Network established.</p> <p>A Tele-Ophthalmology symposium dedicated to Tele-Ophthalmology program and DAC was held during Canadian Ophthalmological Society annual meeting in Québec City, June 16, 2019.</p> <p>Business case for project OPEN <i>“Digitally enabling population health management in Ontario: Diabetic Retinopathy as a First Use Case”</i></p> <ul style="list-style-type: none"> - Continuous effort to secure funds for project Open (applied to PORHSIP; PHAC; CIHR and private donation) <p>Tele-retina screening program expanded from 6 sites in the TCLHIN (South Riverdale CHC, Parkdale CHC, Anishnawbe Health Toronto, Flemingdon CHC), and Manitoulin Island to 74 sites in Ontario</p> <ul style="list-style-type: none"> o Toronto Central - 12 mobile sites & 4 static (Mt Sinai, TGH, SMH, WCH) o Hamilton Niagara - McMaster & 9 sites o South West - Western University London o South East – Kingston | <p>Indigenous communities in Toronto and Manitoulin Island Ontario</p> <p>Experts are empowered to oversee diabetic retinopathy screening in their geographic location, and ensure timely care to those who need it.</p> <p>Increase in citizen and practitioner awareness of tele-ophthalmology screening program</p> <p>Standardized delivery of diabetic retinopathy screening across Ontario that can be scaled and coordinated nationally.</p> <p>Knowledge translation of return on investment and economic impact of diabetic retinopathy screening research findings to date, to an international audience</p> | <p>Clients in rural or limited access areas have increased opportunities to participate in diabetic retinopathy screening at the recommended intervals.</p> <p>Plan articulated to decision and policy makers for improved access to retinopathy screening using tele-retina for individuals living with diabetes in Ontario</p> <p>Experts scale DRS program in their regions through a coordinated approach.</p> <p>Continued collaboration nationally, to develop a scalable and sustainable diabetic retinopathy screening program</p> <p>Continued Knowledge Translation, and feed back to/from international experts on the benefits of diabetic retinopathy screening</p> | <p>in regular tele-retinopathy screening versus those who did not across sites in ON.</p> <p>Evidence is generated to highlight need for population-based approach to deliver better outcomes while improving equity and the cost of care delivery for diabetic retinopathy screening.</p> <p>Evidence applied to develop first a provincial and then national tele-ophthalmology strategy.</p> <p>Evidence generated us applied by policy and decision and makers when supporting and planning community based care in diabetic retinopathy screening.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) | |
|------------|---|--|--|--|--|
| | <ul style="list-style-type: none"> o Central East – Scarborough o Central West – Brampton o Central – Black Creek CHC o North East Sudbury – Manitoulin Island 13 sites o North West – Thunder Bay 2 sites <p>Meaningful outputs for retinal screening currently measured:</p> <ul style="list-style-type: none"> o Screening data from Toronto tele-ophthalmology screening program o Screening data from Manitoulin Central Family Health Team <p>In 2019, 9 papers published in high-impact major journals, media appearance on national news broadcasted the work on Diabetic Retinopathy Screening.</p> <p>In 2019 in Ontario over 2,500 patient with diabetes were screened using tele-retina, many are from vulnerable population</p> <p>Evidence-based Canadian guidelines for tele-retina screening for diabetic retinopathy generated: recommendations from the Canadian Retina Research Network (CR2N) Tele-Retina Steering Committee</p> | <p>Knowledge generated from our research projects pointed to the major barrier for DRS: Inability to identify and contact people living with diabetes directly and offer them access to Diabetic Retinopathy Screening exam.</p> <p>Collaborations among ophthalmologists established and a research network with interest in Diabetic Retinopathy Screening has been ongoing.</p> | <p>Increase in physician referral to tele-retinal screening for those living with diabetes in Ontario.</p> <p>Community health data linked with administrative data to identify individuals who have not been screened in 425 days, and refer for diabetic retinopathy screening.</p> <p>Increase in diabetic retinopathy screening sites in regions generating more evidence of cost- and improved access to for our most vulnerable populations</p> <p>Expanded collaboration amongst participating ophthalmologists, as the DRSP expands nationally</p> <p>Evidence-based Guidelines for Diabetic Retinopathy Tele-Screening adopted in Canada by ophthalmologists.</p> | | |
| 2 | Cost-effectiveness analysis on pilot diabetic retinopathy screening project | Findings from this study suggest that Tele-retinal screening is a more cost-effective means of screening for Diabetic | Plan for Tele-retina screening scale-up across Ontario to increases access | Tele-retina screening is adopted as cost-effective method for preventing blindness across Canada | Vulnerable populations have improved rates of diabetic retinopathy |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|--|--|--|
| | <p>Retinopathy than the standard of care screening, in urban and rural under-screened communities</p> <p>Manuscript published in Canadian Journal of Ophthalmology demonstrated the use of portable retina cameras to reduce cost, improve outcomes, access, and patient satisfaction</p> | <p>for vulnerable diabetic population</p> | <p>as part of a National Diabetes Strategy.</p> | <p>screening and intervention.</p> <p>Generated evidence on tele-retina screening as a cost effective method is applied by decision-makers; provide support to community based health care programs to improve screening and treatment of diabetic retinopathy.</p> |
| <p>3 Patients are engaged in identifying the barriers and facilitators to diabetic retinopathy screening among ethnocultural minorities and Indigenous communities</p> | <p>Patient Partners integrated in the project design, engaged in research program.</p> <p>Through structured patient interviews and focus group, barriers and facilitators of diabetic retinopathy screening were identified from the perspective of vulnerable persons living with diabetes – immigrants across 3 ethnolinguistic minority groups (South Asian, Chinese and French speaking persons from African descent). Manuscript submitted for publishing in Canadian Medical Association Journal</p> <p>On-line survey for diabetic patients in urban and rural settings with the title: “Understanding the Impact of</p> | <p>Guided by patient partners and their personal experience goals and objectives of the research program established</p> <p>Collaboration established in Quebec with University of Laval, and Ottawa Health Research Institute, and partnered with community organizations</p> | <p>Project outcome is highly meaningful and relevant to ethnocultural minorities’ living with diabetes.</p> <p>Barriers are recognized and solutions identified to enable comprehensive screening of individuals at high risk for retinopathy</p> <p>Evidence-based clinical care guidelines are established to design fit-for-purpose diabetic retinopathy screening and interventions for vulnerable populations</p> | <p>Persons at-risk of developing diabetic retinopathy have reduced barrier to screening and customized care pathways</p> <p>Ethnolinguistic minority groups (South Asian, Chinese and French speaking persons from African descent), have increased understanding and participation rates in</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|---|--|---|
| | <p>Diabetic Macular Edema and Barriers to Treatment” completed and report written</p> | | <p>Generated knowledge from the study guided by patients experience led us to next phase: A CIHR Grant application studying attendance of newcomers to Canada with diabetes, for Tele-retina screening, to reduce the likelihood of preventable blindness in Canada</p> | <p>diabetic retinopathy screening.</p> |
| <p>4 Diabetic retinopathy screening scale up through family health teams (FHT) in collaboration with WIHV and BeACCoN</p> | <p>The project, with patient partners consultations, defined plan to:</p> <ol style="list-style-type: none"> 1. Describe patient and provider perceptions of the Tele-retina screening 2. Test patient engagement strategy for the Tele-retina screening 3. Test providers strategies for increasing DRS rates through Tele-retina screening 4. Identify the intervention(s) with the greatest potential to increase screening rates across Ontario. <p>The Patient Engagement project at Black Creek CHC site established.</p> <p>The Patient and Physician engagement component at Women’s Collage Hospital established.</p> | <p>Collaboration established with SPOR PIHCl Network (BeACCoN) and OSSU (WIHV)</p> <p>Barriers and enablers for referral of diabetic retinopathy screening by family health teams are determined.</p> <p>Evidence supports the strategy for a population-based approach to Diabetic Retinopathy screening (Project OPEN). Using administrative data, identify</p> | <p>Barriers for practitioners to adopt tele-retina screening as part of diabetes complication prevention planning addressed.</p> <p>Through continued collaboration with primary care physicians at FHTs, and solo family physicians, individuals in their practices at high risk for complications are identified and timely referral through the SCOPE Program is enabled to receive the specialist intervention necessary to preserve vision.</p> | <p>Increase in the number of practitioners who refer to the diabetic retinopathy screening program.</p> <p>Vision loss due to diabetic retinopathy screening is reduced among those who participated in the screening versus those who did not, thereby improving patient outcomes with early intervention and easier access to tele-retinal screening.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|--|---|--|
| | <p>Seamless Care for Optimizing Patient Experience (SCOPE) and Primary Care Diabetes Screening Working Group established.</p> <p>The study results found that patients liked Tele-retinal screening in terms of its timelines and convenience; providers were less clear on the value of Tele-retinal screening and lacked awareness about the program</p> | <p>unscreened individuals living with diabetes, and invite them for Tele-retinal screening, facilitate timely treatment and follow-up to prevent vision loss</p> | | <p>Tele-retina screening is adopted by primary care practitioners as part of standard practice for diabetes complications screening health plan administered through primary care</p> |
| <p>5 Investigating the role of artificial intelligence (AI) in retinal image analytics and its potential for application in clinical contexts in Canada</p> | <p>Business case “Enabling Expanded Diabetic Retinopathy Screening with Artificial Intelligence” established for support of the University of Montreal and Polytechnique Montreal collaboration with Diabetes Action Canada</p> <p>Database of biomarkers relevant to diabetic retinopathy diagnosis created from 200 publically available images</p> <p>Image database has been annotated and validated by nine retina specialists</p> <p>Evaluation if fundus image quality underway using deep learning algorithms.</p> <p>Further funding secured by Diabetes Action Canada and University of Montreal</p> <p>New collaboration agreement established with and artificial intelligence private sector company IMAGIA</p> | <p>Collaboration established with Polytechnique Montreal Offices of Innovation and Partnership; Montreal Institute for Learning Algorithms (MILA); Centre universitaire d’ophtalmologie (CUO) Maisonneuve-Rosemont; University of Montreal to establish a curated retina image database for reference using machine learning analytics and AI diagnostics</p> <p>Unprecedented resource created for artificial</p> | <p>A new approach to automated retinal image analytics using Artificial intelligence established, that is more comprehensive for diagnosing eye disease in persons with diabetes than current commercially available systems</p> <p>Establish a Canadian retina images database that can be analyzed by machine learning algorithms</p> <p>Develop a specific Canadian clinical image data bank comprised of color fundus photos and Optical Coherence Tomography images pertaining to diabetic macular edema</p> | <p>Patients have improved access to high quality ophthalmological care by increasing clinician productivity and reducing image reading times</p> <p>A national consortium for comprehensive diabetic-related eye disease is developed that leverages advanced technology to deliver high-value retinal photos and OCT image analysis across Canada</p> <p>Compare the variability of the labelling method with</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|---|---|
| | | <p>intelligence applications to diagnose diabetic retinopathy</p> <p>Train a predictive model to predict the severity of the diabetic retinopathy of fundus images.</p> | <p>Demonstrate via a peer-reviewed article the validity and reliability of the image labelling method for diabetic retinopathy automated diagnosis.</p> <p>Reduced time for the technician, physicians and the patients during image capture by ensuring quality and readable images are captured</p> | <p>the standard global diagnostic one automated diabetic retinopathy.</p> <p>Diabetic retinopathy screening is streamlined to maximize the time and cost savings for technician, physician and patient.</p> |
| <p>6 Tele-retinopathy sites established in British Columbia</p> | <p>Two additional tele-retina sites established: 1) Urban site: Vancouver’s Downtown Eastside 2) Rural site: Bella Bella</p> <p>Gathering with Indigenous Patient Partner Circle on Mar 22, 2019 on First Nations reserve outside of Calgary to learn of barriers and enablers to diabetic retinopathy screening for Indigenous communities.</p> <p>Ongoing British Columbia tele-retina screening work continued throughout the Province this past year, enhanced considerably by the implementation of a new software solution to data management and image storing processes.</p> | <p>Increased access to screening for diabetic retinopathy in Indigenous communities in British Columbia</p> <p>Collaborations established with Indigenous Peoples Health Group and Patient Circle with representation across Canada</p> <p>Customized screening models for diabetic retinopathy developed for</p> | <p>Tele-retina screening has increased early detection of diabetic retinopathy high risk individuals within British Columbia</p> <p>Understand barriers to Indigenous people accessing eye care services.</p> <p>Increased access to screening for diabetic retinopathy screening in vulnerable populations in British Columbia</p> | <p>Diabetic Tele-retina screening is adopted in British Columbia as a cost-effective solution to improve health outcomes and prevent blindness in patients with diabetes.</p> <p>This software allows evaluation of data from interested communities to assist in identifying gaps in service and/or programming and to</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|---|
| | <p>In 2019, program in British Columbia has been focused on imaging in diabetic retinopathy:</p> <ul style="list-style-type: none"> - A systematic review was conducted on the use of Optical Coherence Tomography Angiography (OCTA) in diabetic retinopathy that was published in the Canadian Journal of Ophthalmology - In collaboration with the University of Amsterdam, HemoCell Software - a high-performance framework for dense cellular suspension flows - was used to analyze blood flow through diabetic microaneurysms. Our work was the first to demonstrate mathematically why microaneurysms are often not visible with OCTA imaging when they are visible with fluorescein angiography | <p>Indigenous Communities in planning phase.</p> <p>Evidence generated and used as valuable reference for Tele-retina programs interested in considering how to integrate the use of this new technology in screening endeavours.</p> <p>A new software solution to the data management and image storing processes</p> | | <p>potentially deliver screening services more efficiently.</p> |

Assumptions:

To enable our work, we need continues funding (obtain new funds by applying for grant opportunities - CIHR, PHAC, industry or private donations)

Continues collaboration with our Patient Partners to advise the research team on project protocols and implementation.

Participants will be enrolled in the study.

Provincial and federal governments will continue to support the priorities even if there is a change in party.

Digital Health to Improve Diabetes Care

Project Leads: Michelle Griever, Joe Cafazzo

Program Co-investigators: Onil Bhattacharyya, Gillian Booth, Neil Drummond, Arnaud Duhoux, Serge Dumont, Jean-Francois Ethier, Julie Gilmour, Shivani Goyal, Eva Grunfeld, Ilana Halperin, Huang Huaxiong, Noah Ivers, Liisa Jaakkimainen, Peter Juni, Tara Kiran, Anita Layton, Lorraine Lipscombe, Marie-Thérèse Lussier, Donna Manca, Geetha Mukerji, Doug Mumford (Patient Partner), Andrew Paterson, Phil Segal, Peter Selby, Baiju Shah, Diana Sherifali, Karen Tu, Xiaolin Wei, Don Willison, Rose Yeung

Program Coordinator: Conrad Pow

Research Goal:

- To enable improved access to personalized and connected diabetes care by implementing integrated digital health solutions

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|--|--|--|
| 1 | Establishing the National Diabetes Repository | <p>Technical Committee established during proof-of-concept initiation.</p> <p>Initial business case completed for proof-of-concept: <i>“National Diabetes Repository”</i>.</p> <p><u>Sustainability Plan completed for years 3 to 4 for <i>“National Diabetes Repository”</i></u></p> | <p>Researchers have access to a first-of-its-kind research tool holding a unique Canadian data set on diabetes without administrative barriers 15 data sharing and transfer agreements</p> <p>Researchers have access to advanced computing through a remote secure analytical</p> | <p>Researchers have access to Canadian specific primary care data to generate targeted research questions to address gaps in primary care in the prevention, screening and management of diabetes.</p> <p>Researchers have access to the most comprehensive population management tool to facilitate</p> | <p>Private and public investment has been leveraged to create a new repository (recommended by the OECD analysis of health quality indicators) focused on the use of health data to improve self-management of</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|--|
| | <p>Primary care data from six provincial practice based networks with over 100,000 patients living with diabetes in the repository:</p> <ul style="list-style-type: none"> - University of Toronto Practice-Based Research Network (UTOPIAN) - Eastern Ontario Network (EON) - Southern Alberta Primary Care Research Network (SAPCRen) - Northern Alberta Primary Care Research Network (NAPCRen) - Manitoba Primary Care Research Network (MaPCReN) - Réseau de recherché en soins primaires de l'Université de Montréal (RRSPUM) - Atlantic Practice-Based Research Network (APBRN) <p>A novel, secure analytics platform that contains de-identified data derived from primary care EMR data received from Practice-Based Research Networks and Canadian Primary Care Sentinel Surveillance Network (CPCSSN) established.</p> | <p>virtual environment to ensure security of data.</p> <p>The repository is poised to scale and is able to receive expanded data holdings from additional practice-based research networks and solo practitioners.</p> <p>Patient partners play a key role in the governance of the National Diabetes Repository and how the data is used for research.</p> <p>Primary care data is available for targeted research purposes to understand diabetes trends in Canada and identify gaps in health care delivery and systems.</p> <p>Capacity in patient-oriented research with health data is developed for both patient partners and researchers.</p> | <p>pragmatic research on diabetes in Canada.</p> <p>Data in repository is used to facilitate advances in knowledge generation and application of artificial intelligence.</p> <p>Patient-oriented research is poised to advance application of data science.</p> <p>Stakeholders in health data are active partners in expanding the repository into other province and territories</p> <p>Diabetes Action Canada Digital Health research program is functioning as a back-bone catalyst for other research programs to reach their research goals.</p> <p>Create an interface within the NDR with digital diabetes health services in primary care.</p> | <p>diabetes, both type-1 and type-2</p> <p>Persons living with diabetes are true partners in how primary care health data is used in research to improve patient experiences with diabetes and the health care system.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|--|--|------------------------------|
| | <p>Secure Analytical Virtual Environment established to enable data analytics remotely.</p> <p>Data dictionary established and Standard Operating Procedures established.</p> <p>Infrastructure to collect patient-reported outcomes measures (PROMs) and patient-reported experience measures (PREMs) in place.</p> <p>Patient partner co-Lead established.</p> <p>Research Governing Committee established with 50% patient partners and 50% primary care physicians and researchers.</p> <ul style="list-style-type: none"> - Training materials completed and iteratively improved - Publication In Press with CMAJ OPEN <p>Knowledge disseminated at key conferences and meetings</p> <ul style="list-style-type: none"> - Diabetes Canada Professional Conference 2017, 2018 - North American Primary Care Research Group (NAPCRG) - SPOR SUMMIT - DFCM Conference | <p>The repository is used to advance the research agenda of the other goal-directed research programs within Diabetes Action Canada.</p> | <p>Work with EMR vendors to secure a viable option for routine data extracts and transfers in the NDR.</p> | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|---|--|---|---|
| | <ul style="list-style-type: none"> - LKS-DASH Summit <p>Dedicated website linked to Diabetes Action Canada parent site with established work flow and access to apply online to use data.</p> <p>Secure Analytical Virtual Environment currently hosts two research projects simultaneously. A manuscript from one research project has been submitted to Journal of Medical Internet Research Protocols.</p> | | | |
| 2 Application of the National Diabetes Repository in patient-oriented research | <p>2019 Inaugural Grant Competition completed</p> <ul style="list-style-type: none"> - Three \$15k grants to demonstrate the value of the repository awarded. <p>Fields Institute for Research in Mathematical Science and Vector Institute for Artificial Intelligence collaborated with DAC to host a joint workshop to evaluate the utility of the National Diabetes Repository for advanced analytics.</p> <ul style="list-style-type: none"> - Event held on June 17 and 18, 2019. - Age matched controls added to the data set <p>Plan to establish a completely de-identified Machine Learning ready data set: a subset of NDR database consisting of carefully curated data elements in a format suitable for Machine Learning</p> | <p>Reduces barrier for AI researchers to the use and learn from the repository data set.</p> <p>The utility of the repository for mathematical modelling and machine learning analytics is assessed and the adjustments made to increase functionality</p> | <p>Innovative use of our platform/data by AI researchers and mathematicians.</p> <p>Build capacity to AI and machine learning for diabetes for post-docs (who are currently learning with US data).</p> | <p>The value of capabilities of the data are demonstrated with tangible evidence-based results.</p> <p>Expanding the suite of analytic software in the NDR required for image analysis.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|---|---|
| 3 | Expansion of the National Diabetes Repository data holdings | <p>Plan to hold free text clinic notes from participating PBRNs underway</p> <ul style="list-style-type: none"> - Discussions with UTOPIAN and APBRN held <p>Proposals created to integrate EMR data from Maritimes (MaRNeT)</p> <p>Discussions ongoing to strengthen Quebec data in the repository</p> <p>Efforts underway to recruit data from BCPCReN (British Columbia Primary Care Research Network)</p> <p>Recruitment of Community Health Care data in to the National Diabetes Repository via UTOPIAN</p> <p>Recruitment of solo practitioners to provide data into the repository</p> <ul style="list-style-type: none"> - Recruiter hired in 2019-20 for 6 months to assist with recruitment - Data sharing agreements have been executed with solo practitioners in the peel region of Ontario | <p>Evaluate and improve the free text de-identification algorithm to preserve privacy.</p> <p>Implement a National Language Processing (NPL) toolkit that enables recognition and automatic encoding of clinical information in narrative patient reports in NDR</p> <p>Data from Nova Scotia, New Brunswick, and PEI will be available in the repository</p> <p>Enhance the data collected from Réseau de recherche en soins primaires de l'Université de Montréal (RRSPUM)</p> <p>Collaboration established with the Quebec SPOR SUPPORT Unit and INESSS</p> | <p>More insight into the patient's medical condition, enabling AI to refine algorithms using the free text variables.</p> <p>Partners who were reluctant to contribute text data will have more confidence in the privacy of data</p> <p>Data holdings are more representative of the Canadian population.</p> <p>National coordination of EMR data collection and data dictionary to ensure data is useful for research purposes.</p> <p>The National Diabetes Repository is strengthened as a core component of Diabetes Action Canada as opportunities for continued funding become available</p> <p>Data from new immigrant, vulnerable and lower</p> | <p>Patient privacy is protected with less risk for identifiable PHI contained in the NDR.</p> <p>Time and cost-saving for researchers and artificial intelligence applications preparing the data from clinical notes.</p> <p>Researchers have a more accurate data set to investigate diabetes related complications, resulting in better health outcomes for those living with the condition.</p> <p>More national representativeness in the repository.</p> <p>Diabetes Action Canada has meaningful connections and</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|---|--|
| | | <p>Collaborations established with the BC SPOR SUPPORT Unit</p> <p>Community health centre PBRN is being established</p> <p>Data collected outside of academic research centres</p> | <p>socioeconomic communities will be available for research purposes.</p> <p>Increased awareness of solo practitioners on the use of primary care data in research and quality improvement initiatives in diabetes.</p> | <p>expanded research presence in BC.</p> <p>Populations at risk of diabetes complications are represented in the National Diabetes Repository</p> <p>The repository has more comprehensive data set.</p> |
| <p>4 Strategic and sustainability planning for the National Diabetes Repository</p> | <p>Strategist hired to assist in planning - Six month term</p> <p>National Diabetes Repository Vision Session to define the next phase of the National Diabetes Repository completed.</p> <p>Value proposition Sustainability and Business Plan drafted for planning purposes</p> <p>Privacy Hackathon with the Schwartz Reisman Institute for Technology and Society conducted a two-day session to identify, articulate and scope the privacy-related challenges that patient-oriented and population health researchers face today in accessing, integrating and</p> | <p>Ground works established for determining the best options for growth and sustainability for the National Diabetes Repository.</p> <p>Novel collaboration with scholars in law, privacy, artificial intelligence and data science to tackle challenges in data privacy and usage for research purposes.</p> <p>The root causes of “blockages” in accessing and linking data experienced by</p> | <p>Sustainable funding model and through key strategic partnerships is obtained.</p> <p>The National Diabetes Repository has name recognition as a valuable source of data in diabetes and its related complications.</p> <p>Policy and decision makers interpret the use of data differently, still preserving privacy, but also enabling more applications for research</p> | <p>The National Diabetes Repository is a sustainable enterprise and key component for next iteration of DAC.</p> <p>Researchers have more flexibility in the use of data for patient-oriented research in diabetes.</p> <p>Privacy laws, policy, data usage and consent have more comprehensive definitions and can be</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|---|--|--|---|
| | analyzing data, both for treatment and research purposes. | DAC and its researchers in matters of privacy law and policy and sensitivity to public concerns about data use and consent are uncovered | Innovative and practical solutions are generated that both protect fundamental patient and public interests and support robust treatment and research | applied more effectively to research in diabetes. |
| 5 Diabetes patient-centred health informatics, <i>bant</i> mobile application for diabetes clinical research | <p>Patient engagement strategy established and iteratively improved.</p> <p>Android version of <i>bant</i> deployed in 2018.</p> <p><i>bant</i> is Bluetooth enabled to instantly connect with continuous glucose monitors.</p> <p><i>bant</i> is integrated with provincial personal health data in Alberta to enable patient access to their personal health records in addition to data collected by the mobile application.</p> <p>eConsent platform developed to facilitate consent to be contacted and consent to participate in clinical research underway with pilot project complete with The Hospital for Sick Children in Toronto.</p> | <p>Patient Partners and caregivers are integral to designing <i>bant</i> to meet the specific needs of the diabetes community.</p> <p>Patients have access to their health data and can share it as they so choose.</p> <p>Patients are presented their health data in a lay user-friendly comprehensive dashboard that is easily interpreted.</p> <p><i>bant</i> can access additional provincial and territorial lab</p> | <p>Patient and public uptake of the <i>bant</i> is perceived as the mobile application of choice for Canadians to improve self-management among those living with diabetes to reduce disease burden on both patient and health care resources in Canada.</p> <p>Patients have access to a dynamic mobile self-management tool that enables their input in how new research questions should be investigated, how to improve interactions the with healthcare system, and the preferred management tools for both persons</p> | <p>A novel consortium of Patient Partners, primary care, specialist care, and digital health engineering experts who would otherwise by working independently are now collaborating to improve quality outcomes for those living with diabetes, achieving collective impact.</p> <p>Patient and public engagement increases the generation and uptake of new evidence</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|---|---|
| | <p>Work plan to establish a virtual care module within <i>bant</i> as part of a ‘digital diabetes clinic’ to enable remote visits for those with T1D having difficulty managing their diabetes.</p> <p>Partnerships established with TELUS, Ontario Telehealth Network, TidePool.</p> <p>Proposal to JDRF to use <i>bant</i> as the platform for the T1D Registry: “<i>Type-1 Diabetes Registry: A Patient Oriented Tool to Advance Discovery and Pragmatic Research in Canada</i>”.</p> | <p>data and personal health data databases to provide those living with diabetes access to their health data.</p> <p><i>bant</i> functions as an information delivery system linking consenting patients with investigators.</p> <p>Decision-makers and knowledge users are engaged in enabling patients to access to their personal health data.</p> | <p>living with diabetes and their caregivers to connect.</p> <p>Patients are empowered with their health data and active partners in deciding their involvement in clinical research, health care path, treatment and self-management approach.</p> <p>A virtual patient network is established through <i>bant</i> to facilitate clinical research and set targeted research priorities in Canada.</p> <p>Evidence is gathered to inform policy decision-makers about current health system gaps in diabetes care and management.</p> <p>Evidence of improved self-management using <i>bant</i> is collected.</p> <p>Patients have increased access to researchers, and health care teams.</p> | <p>that is meaningful and relevant to the community, while reducing wasted resources.</p> <p>The rate of scientific advances generated from clinical research are accelerated in Canada.</p> <p>The patient experience is transformed to facilitate bidirectional data sharing between patient and care provider empowering patients to act as partners in deciding their health care delivery and treatment paths.</p> <p>Evidence is gathered to enable patient advocacy groups to lobby for reform in health care policy in the management</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
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| | | | | <p>and prevention of diabetes.</p> <p>Improved quality of life and patient experiences with the Canadian health care system are achieved.</p> <p>A learning health environment is established with advances in digital health changing practice in the digital era.</p> |
| 6 bant- FedDev Ontario P3 Commercialization | <p>Modernization of bant’s iOS app and expansion to Android.</p> <p>Integration of bant with TELUS Health’s Personal Health Record (PHR).</p> <p>Integration of bant with SecureKey’s block chain solution for identity management.</p> | <p>Increased number of bant users globally.</p> <p>A proof-of concept integration demonstrating that patient reported data collected through a mobile app can be shared with a PHR.</p> <p>A proof-of- concept integration demonstrated that we can federate identity to help consumer gain access</p> | <p>Increased number of patients being supported by an evidence-based self-management tool.</p> <p>Deploy of the integrated solution in Alberta (As MyAlberta), to increase the number of Albertans with diabetes self-management support.</p> <p>Deploy of the integrated solution in Ontario, to increase the number of Ontarians who can view their A1c</p> | <p>An improvement in the ability for Canadians living with diabetes to self-manage and influence their chronic disease journey.</p> <p>A reduction in the number of diabetes complications Albertans confront.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|-------------------------|---|--|--|---|
| | | | to OLIS data, such as A1c, to empower improved self-care. | data in context of their daily diabetes self-management. | Scale the conceptual model of patients with diabetes seeing their lab data in bant across provinces, to enable improved diabetes self-management. |
| 7 | Diabetes Virtual Clinic | <p>Establish a multi-stakeholder committee to understand the barriers and enablers of virtual diabetes programs.</p> <p>Enhance bant with a virtual diabetes clinic and develop a model that can be scaled across Canada.</p> <p>Develop framework for the creation of a AI-enabled coaching program.</p> | <p>Increased awareness around the challenges and opportunities of delivering virtual diabetes programs amongst Ontario decision makers, through the CIHR workshop.</p> <p>Establish partnerships to develop the virtual diabetes clinic.</p> <p>Secured a grant and associated partnerships (Vector, HHS).</p> | <p>Increased awareness around the challenges and opportunities of delivering virtual diabetes programs amongst Ontario decision makers, through a publication on the CIHR workshop.</p> <p>Develop the virtual clinic and demonstrate a feasible model to be scaled and evaluated pragmatically.</p> <p>Increased awareness in the scientific community around the feasibility of using diabetes consumer data for AI-enabled health coaching.</p> | <p>Increase awareness of the unique provincial and federal barriers and enablers to diabetes virtual care.</p> <p>Prevent diabetes complications by enabling patients living with diabetes to receive timely and personalized care.</p> <p>Revolutionize the way patients receive diabetes support, improving diabetes outcomes and reducing costs.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|---|---|---|
| 8 | Connect1d: A patient-led digital T1D registry | <p>Codesign and develop a platform that enables patient and research engagement in T1D research, and drives the ongoing collection of data across Canada.</p> <p>Conduct a pan-Canada evaluation of Connect1d with patients, researchers, and providers.</p> <p>Conduct an evaluation of Connect1d to better understand its ability to drive engagement and data collection.</p> | <p>Established a series of workshops to co-design the solution.</p> <p>Establish study design and collaborators.</p> <p>Establish study design and collaborators.</p> | <p>Launch the platform and increase awareness and engagement in T1D research.</p> <p>Increase awareness around the perspectives of the T1D research across Canada.</p> <p>Collect data on the effectiveness of Connect1d.</p> | <p>Improve Canada’s ability to respond to the needs of individuals living with T1D by using up to date and representative data to drive policy changes, care delivery, and research priorities.</p> |

Assumptions

- Although the SPOR Network will be eligible for application for continued funding in 2021, there is no guaranteed funding for continued data collection and/or maintenance of the NDR through this revenue source. Therefore, a plan for diverse revenue generation and support is required, from both public and private sectors.
- Innovation and future strategic thinking about the NDR uses, users and output of the data are key.
- Strategic partnerships from a variety of sectors are necessary to foster the Diabetes Action Canada profile and the use of NDR for public good, including analytic support for patients, researchers, government and other health professionals.
- The participation of patients and others affected by diabetes is a necessity. The mission of Diabetes Action Canada and the development of the NDR rests on patient involvement. This is a unique partnership in the data science environment in Canada and globally; thus, continued patient engagement must be fostered and maintained.
- Champions and influencers who support the growth and utilization of the NDR must be nurtured for its continued public and private support.
- Advocacy groups, such as Diabetes Canada and JDRF must continue to be involved.

External Factors

- Change in political landscape – introduction of legislation

Diabetes Action Canada Logic Models 2019-20

- Technology – Redundant or new data standards
- Health and Wellness – Pandemic
- Funding – Funds are repurposed or clawed back and/or change in accepted expenses
- Social – Change in acceptance of opt-out consent for data sharing

Foot Care to Prevent Lower Extremity Amputations

Program Co-Leads: Mohammed Al-Omran, Thomas Forbes

Program Co-investigators: David Campbell, Karen Cross, Charles de Mestral, Ahmed Kayssi, AnnMarie McLaren

Program Coordinator: Abdelrahman Zamzam

Research Goal:

Preventing lower limb amputation for those living with diabetes through a community-based multidisciplinary approach.

- Determine the economic burden of foot complications in diabetic population in Canada.
- Promote an enhanced foot screening program to be implemented across Canada.
- Develop a patient oriented care path for people with diabetic foot ulcer.
- Improve quality of life for high risk diabetic patients with effective allocation of health services.

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|---|---|---|
| 1 | Economic burden of diabetic foot ulcers in Toronto. (<i>From the General Medicine Inpatient Initiative (GEMINI) Database</i>) | Meeting presentations: <ul style="list-style-type: none"> - Annual Meeting of the Society for Vascular Surgery in Boston (2018) - Canadian Society for Vascular Surgery Annual Scientific Meeting in Montreal (2018) - Wounds Canada Conference in London (2018) - World Congress of Cardiology & Cardiovascular Health in Dubai (2018) | Health care resource burden in Toronto associated with those living with diabetic foot ulcers identified. Gaps in health care path in for those with diabetic foot ulcers in 7 hospitals are identified. | Reduction in acute care service use/costs associated with treatment of diabetic foot ulcers in Toronto. Patients have increased access to the community health and foot screening programs in Toronto. | Improved patient experience with prevention program in place to target high-user, high-risk population across Canada as part of a Provincial Diabetes Strategy with the potential for scaling. Evidence generated applied by decision makers when supporting community based |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|--|
| | <p>Manuscript published Vascular (May 2020).</p> <p>Participation on National Task Force on best practices for prevention and treatment of diabetic foot ulcers</p> <ul style="list-style-type: none"> - Led by Wounds Canada - Report and guidelines available Spring 2019 | <p>Evidence generated to highlight need for community-based diabetic foot ulcer prevention strategies.</p> <p>Health policy and decision-makers are informed of evidence and urgent need for diabetic foot ulcer prevention strategies.</p> <p>Change in awareness of economic burden of diabetic foot ulcers.</p> <p>Strategic partnerships are established to reduce the economic and emotional burden of diabetic foot ulcers.</p> | <p>Evidence leads to change in the guidelines to help reduced burden on health care resources in ON.</p> <p>Evidence informs reformed treatment pathways for diabetic foot ulcers in Toronto</p> | <p>health care programing for foot care for those living with diabetes.</p> <p>The economic burden of diabetic foot ulcers in reduced among hospitals in Toronto.</p> |
| 2 | <p>Reducing diabetic foot through a multidisciplinary chiropodist-based intervention</p> <p>CIHR funding for study received through innovative clinical trail SPOR operating grant competition. Study details include:</p> <ul style="list-style-type: none"> - 4 provinces - 2,200 participants with diabetes and chronic kidney disease on dialysis - In collaboration with Can-SOLVE CKD | <p>Evidence generated on impact of quality of life for those living with diabetic foot ulcers.</p> <p>Evidence e generated for rate of lower limb amputations,</p> | <p>Evidence informs health policy and decision makers to address need for diabetic foot screening in high risk populations.</p> <p>Evidence is collected on the benefits of a chiropody-led versus hospital-led intervention and the cost associated</p> | <p>Rate of lower limb amputations reduced for those living with diabetes who are at high risk of developing foot ulcers.</p> <p>Reduced burden on health care resources in Canada.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---|--|--|
| | <p>A steering committee organizes bi-weekly meetings to finalize the protocol.</p> <p>Final decisions are being taken regarding standardized intervention, sample size and the included centers from different provinces from which requirement will commence.</p> <p>Launching of the trial is expected in 2020.</p> | <p>hospitalization, and hospital readmissions.</p> <p>Chiropody-led Intervention designed to treat highest risk patients for developing the foot ulcer complications associated with diabetes in multiple Provinces with multiple health care streams for treating diabetic foot ulcers.</p> <p>Patients involved in generating knowledge for study protocol.</p> <p>SPOR Networks collaborating to support innovative clinical research.</p> | <p>with each treatment path to make informed decisions on developing a foot care pathway in Toronto based hospitals.</p> <p>Treatment plans led by chiropody as the main point of care for diabetic foot ulcers are demonstrated to be cost-effective and patient –oriented to promote adherence to screening program.</p> <p>Patients and caregivers have increased access to foot care through community health and social services in multiple provinces.</p> <p>Quality of life improved among caregivers and individuals within patient population.</p> | <p>Evidence is applied to reform the treatment of diabetic foot ulcers in a patient-oriented and informed manner thereby increasing adherence to treatment and prevention plans.</p> |
| 3 | <p>Quality Improvement Initiative for patients with complex diabetic foot ulcers from hospital admission to rehabilitation</p> | <p>Implement a consolidated, interdisciplinary comprehensive best practice care model led by a combined medical, surgical and chiropody teams with a pre-</p> | <p>The efficacy and economic effectiveness of the care pathway is compared to existing data using parameters (i.e. amputation rate, adverse cardiovascular outcomes, length of hospital stay, length of ICU</p> | <p>Evidence generated to support reorganization of hospital services to Improve quality of life for high risk diabetic patients with reduced use and cost of health services – all impacting</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|---|--|
| | <p>Pathway launched Oct 2018 and preliminary data collected for almost 100 encounters.</p> | <p>established rehabilitation disposition pathway and well-defined follow up planning for patients with complex diabetic foot ulcers at Unity Health Toronto.</p> <p>Chiroprapist engaged from hospital admission to rehabilitation to track patients to ensure right treatment at right time.</p> <p>Hospital resources in St. Michael's Hospital are reallocated to improve care and monitoring of those with diabetic foot ulcers.</p> <p>Hospital services that were previously working in silos on the same issue are now collaborating to develop patient-oriented outcomes to achieve the quadruple aim.</p> | <p>stay, re-admission rate, and cost of care).</p> <p>Program is scaled within Ontario hospitals and community care to reduce risk of amputation for those with diabetic foot ulcers.</p> <p>Change in how individuals who have diabetic foot ulcers enter the health care system and how practitioners treat the condition.</p> <p>Patients have improved care, monitoring and screening to reduce diabetes complications through and multi-disciplinary and coordinated approach.</p> | <p>the quadruple aim framework (improved population health, reduced cost, improved patient experience, improved provider experience).</p> <p>People with diabetic foot ulcers have a defined care path that is patient oriented.</p> <p>Evidence generated demonstrating the reduced economic burden of diabetic foot ulcers for those who participate in pathway leading to a well established and defined bundled care funding model.</p> <p>Those who participate in the pathway have reduced chances for lower extremity amputation due to diabetic foot ulcers.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|--|--|
| 4 | A nationwide study describing foot exam characteristics for diabetic patients in contemporary settings. | <p>Define foot ulcer/foot complication key words that could be searched in the free text of those patients with a documented foot exam.</p> <p>Key healthcare practitioners (champions) contributing to the repository to be identified.</p> <p>Design focus group and/or survey of healthcare practitioners with the aim to better understand knowledge, interest and motivators for achieving annual foot exams for all diabetic patients.</p> <p>Describe current foot exam (frequency and results) among patients seen by practitioners contributing data to the National Diabetes Repository.</p> | <p>The frequency and characteristics of foot exams performed at the primary care level by practitioners participating in the National Diabetes Repository is better understood.</p> <p>Understand barriers and facilitators to foot exam among practitioner contributing data to the National Diabetes Repository</p> <p>Explore practices involving foot exam among diabetic patients identified through the National Diabetes Repository.</p> <p>Collaborative relationship established between research programs of Diabetes Action Canada.</p> | <p>Specialty practitioners have better understanding of the preventative measures undertaken by primary care physicians in preventing diabetic foot ulcers based on information collected in the National Diabetes Repository.</p> <p>Evidence produced to suggest best practices for diabetes foot exams at the primary care level.</p> | <p>Provide evidence to highlight gaps in foot screening, to improve patient experience through advocating regular foot screening practice.</p> <p>Increased implementation of standard foot exams among primary care physicians for those who are at risk of diabetic foot ulcers.</p> |
| 5 | Characterizing the Burden of Diabetic Foot Ulcers (DFU) across Canada | Explore the burden of DFU across Canada using the CIHR-SPOR Dynamic Cohorts of High-Cost High-Intensity User of Health Care | Acute hospital care utilization and cost of diabetes-related amputation is compared with | Key factors contributing in increased health cost for DFU patients are highlighted and mitigation plans to | Evidence is generated to support enhancements in the current health care system that |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|---|--|
| | with linkage to CIHI hospitalization and emergency room visit records | <p>other complications of diabetes (stroke and myocardial infarction) across Canada.</p> <p>Patient-level differences are characterized between high-intensity, high-cost DFU patients and average-intensity, average-cost DFU patients across Canada.</p> | reducing burden on health care resources in Canada are considered | would support the needs of those at high risk for developing diabetic foot ulcers. |

Assumptions:

Additional funding will be obtained to establish centers of excellence across the GTA adopting this model.

Health Technology Assessment and Network Evaluation

Program Lead: Valeria Rac

Program Co-investigators: Mathieu Ouimet

Program Coordinator: Jim Bowen

Research Goals:

1. Examine the network connectivity, health, and results and impact for the Diabetes Action Canada CIHR SPOR Network over the lifetime of the research network
2. Prevent blindness in working age Canadians living with diabetes by implementing a diabetic retinopathy screening program through primary care, supported by Tele-Retina, and driven by provincial level data.
3. Reduce lower extremity limb amputation rates in patients living with diabetes through the development of a diabetic foot care pathway ensuring continuity of care from primary, tertiary and homecare services.

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|---|---|
| 1 | Mapping the evolution of the Diabetes Action Canada Network: A Social Network Analysis. | <p>Research study was conducted collaboratively by Université Laval and University Health Network members of Diabetes Action Canada.</p> <p>A Network Evaluation report was provided to Diabetes Action Canada in October 2019 and presented to the Steering Council and the report was subsequently provided to CIHR.</p> | <p>Diabetes Action Canada internal exchanges and coordination (cohesion and brokerage) were mapped since the beginning of the network.</p> <p>Cohesive subnetworks within the Network were identified and will be the examined prospectively over subsequent years</p> | <p>Diabetes Action Canada improved operational management and communication to promote connectivity and the collaboration.</p> <p>Application of SNA Methodology refined to examine a CIHR SPOR Network and its connectivity and collaboration.</p> | Diabetes Action Canada is functioning as a learning health system with stakeholders from academic institutions, sponsors, government, and community working together to improve the |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|---|---|
| | <p>Lawarée J, Rhéaume A, Ouimet M, Bowen J, Bielecki J, Rac V. Diabetes Action Canada. Strategy for Patient-Oriented Research Network. Network evaluation report. Provided to Diabetes Action Canada. Version 2.0. October 25, 2019. (pp. 62)</p> <p>Three manuscripts are planned to be submitted to one journal to be determined outlining the methods, the social network analysis and network return on investment</p> <p>System-network analysis (SNA) questionnaire administered to DAC members. Of the 150 Diabetes Action Canada members, consisting of patient partners, researchers, administration, council members and co-leads, 64 (42.6%) completed the survey.</p> | <p>Network connectivity assessed to understand the efficacy and impact of collaboration.</p> <p>Primary discussion elements between the Network members was research and patient engagement.</p> <p>The network is centralized with the administration occupying a central position in the Network</p> | <p>The second cycle of the network evaluation will be conducted in 2020 to examine longitudinal changes to the network with respect to membership, connectivity, resources and results. The analysis will also will explore impact of COVID-19 on DAC and the network flexibility to modify the research focus to incorporate research questions relevant to COVID-19</p> <p>Research subnetworks are defined and established to promote interdisciplinary and interprovincial, national and international collaboration</p> <p>Expansion of Network membership across the country.</p> | <p>lives of those living with diabetes.</p> |
| 2 | <p>Diabetes Action Canada Network Health Analysis</p> <p>As a part of the Network Evaluation semi-structured interviews of Diabetes Action Canada members were conducted examining:</p> <p>1) the perceived purpose of the network</p> | <p>Network health assessed to understand impact and its ability to sustain continuous enthusiasm, commitment and engagement of its members to work together as a</p> | <p>Network members promote continuous improvement of performance including network risk assessment (risk stratification) and risk mitigation strategies for various network’s projects/initiatives.</p> | <p>Diabetes Action Canada improves health system outcomes through evidence based practices.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---|--|------------------------------|
| | <p>2) extent the network met members' expectations</p> <p>3) describe the outcomes of the network</p> <p>4) success factors for effective interactions</p> <p>5) perceived barriers and/or factors that limited interactions</p> <p>The semi-structured interviews were completed with 18 Diabetes Action Canada members.</p> <p>A cross-sectional survey of the network members was conducted to examine the members' satisfaction and experience with Diabetes Action Canada</p> <p>Survey results were available from 64 members (42.6%).</p> <p>The ability for the Network to obtain funding in collaboration with other Network members and build infrastructure was examined.</p> <p>Sustainability and ability of the network to create a value beyond individual members was also evaluated.</p> | <p>network to achieve shared vision, mission and goals.</p> <p>Barriers to effective interactions and collaborations within the Network were identified.</p> <p>Recommendations made regarding the communications, location and multidisciplinary nature of the Network. Will track multidisciplinary nature in next SNA and semi-structured interviews</p> <p>Since the beginning of the Network, further grant funding has been obtained from CIHR and other funding sources. Approximately \$36M additional research funding has been secured by Network Principal Investigators and Co-Investigators.</p> | <p>Network results assessed to understand lasting societal impact through influence on patient outcomes, care guidelines, research and health policy</p> | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|--|---|
| <p>3 Network Results and Impact (Return On Investment (ROI) and Internal Rate of Return (IRR) Analyses)</p> | <p>Adopted the Canadian Academy of Health Sciences (CAHS) framework to guide the ROI/IRR evaluation of the DAC Network.</p> <p>Assessment of the ROI based on the relevant 66 items of the CAHS framework were evaluated. Some items were not currently relevant based on the age and the type of the Network.</p> <p>Network evaluation framework developed to examine the knowledge translation products since the inception of the Network in 2016.</p> | <p>Impact of research activities under the following categories are tracked and assessed: 1) advancing knowledge; 2) capacity building; 3) informing decision-making (policy-makers and individual clinicians); 4) health impacts; and, 5) broad economic and social impacts.</p> <p>CAHS methodology was refined in context of the DAC-SPOR Network. The monetary value of the DAC outputs will be considered as the Network matures.</p> <p>Modifications to knowledge translation tracking processes have been adopted by Diabetes Action Canada.</p> <p>Network results assessed to understand what outcomes have resulted in significant societal impact through influence on patient outcomes, care guidelines, research and health policy.</p> | <p>Health research impacts identified in the health industry, other industries, government, public information groups.</p> <p>Tangible evidence is generated to demonstrate impacts as it relates to healthcare access, prevention, treatment, and the determinants of health.</p> <p>Diabetes Action Canada has generated evidence of its research impact and can apply this evidence by engaging the decision makers, health professionals and citizens.</p> <p>Diabetes Action Canada evaluated with real time feedback and development and application of methods to associate monetary value attached to relevant research study impact.</p> <p>Specific impact assessed of Diabetes Action Canada on a particular population (i.e. Indigenous, other</p> | <p>The funding provided to Diabetes Action Canada results in tangible and quantifiable outputs that have influenced patient outcomes including enhanced quality of life of those individuals with diabetes in Canada, culturally aligned clinical care, modification to health policy, informed decision making, broad societal impact on GDP</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|---|---|--|
| | | | | ethnically diverse communities, women) or domain/category or audience. | |
| 2 | Health Technology Assessment – Diabetic Retinopathy Screening | <p>Work plan created for health technology assessment for projects with Diabetic Retinopathy Screening</p> <p>Pilot study examining costs associated with the mobile tele-ophthalmology program in Ontario complete. Manuscript published:</p> <p>Stanimirovic A, Francis T, Shahid N, Sutakovic O, Merritt R, Brent MH, Rac VE. Tele-retina screening of diabetic retinopathy among at risk populations: an economic analysis. Can J Ophthalmol 2020;55 (1):8-13. Available from: https://doi.org/10.1016/j.jcjo.2019.06.008</p> <p>Above economic model being expanded to include long-term consequences of treatments and impact on vision loss averted, quality of life and healthcare resource utilization. By Stanimirovic A, Francis T.</p> <p>Mixed Methods study “Insights into the implementation of Tele-retina screening among those who identify of women of lower SES”</p> | <p>New and existing technologies generated by Diabetes Action Canada evaluated for benefits and the cost that would accrue to the system, the healthcare providers, and their patients.</p> <p>Medical, economic, social, ethical and organizational implications of technologies are assessed and managed.</p> <p>Opportunities and challenges when applying innovative, system-disruptive health technologies to the system and society assessed.</p> <p>Evidence generated in pilot study to suggest that diabetic retinopathy screening by Tele-Retina is less costly and more effective in screening for DR in an at risk population in Ontario.</p> | <p>Pan-provincial collaboration for Diabetic Retinopathy Screening</p> <p>Collaborate with other researchers within Diabetes Action Canada to examine the diabetic retinopathy and diabetic foot ulcers</p> <p>Pilot study in diabetic retinopathy screening expanded to assess program beyond Ontario.</p> | <p>Evidence generated is applied by decision-makers when supporting community based health care programs to improve screening, treatment of diabetic retinopathy with a change in the health system that ultimately will reduced blindness in patients with diabetes.</p> <p>Evidence augmented with information on safety, effectiveness and cost effectiveness of new health technologies and programs to prevent blindness secondary to diabetic retinopathy.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|--|------------------------------|
| | <p>explores gender disparity in the provision of Tele-Retina program of diabetic retinopathy screening. Protocol has been submitted to UHN REB and manuscript has been drafted for publication targeted to Implementation Science. DAC Research Fellow - Stanimirovic A Investigator under supervision of Rac V.</p> <p>Protocol developed entitled “Guiding Primary Care Diabetic Retinopathy Screening in Canada through the use of Provincial Healthcare Administrative Data” designed to examine the use of provincial level data to identify individuals in need of DRS.</p> <ul style="list-style-type: none"> In Ontario, community health centres are participating in the study and data linked from the Institute for Clinical and Evaluative Sciences (ICES) has been evaluated to identify patients using provincial administrative datasets in collaboration with Diabetes Action Canada Members, Dr. Michael Brent at UHN and Dr. Baiju Shah at ICES. <p>Grant submissions for funding of this study were made to:</p> | <p>Expanded utilization of economic model to include long-term outcomes, evaluate future interventions and to guide future research.</p> <p>HTA capacity to support research initiatives across the DAC Network including involvement of patient partners in technology assessment</p> | | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|---|---|
| | <p>Public Health Agency of Canada (PHAC) Letter of Intent submitted Diabetic Retinopathy study examining administrative data from 3 Provinces (Alberta, BC and Ontario) submitted in September 2019. Funding not provided.</p> <p>CIHR Project Grant submission pending for Diabetic Retinopathy Screening using administrative data. Co-Principal Investigators: Dr. Valeria Rac, Dr. Michael Brent, Mrs. Debbie Sissmore (Patient Partner) and Petra O'Connell (Policy Maker). Funding decision pending.</p> | | | |
| <p>3. Health Technology Assessment – Diabetic Foot Care and Limb Preservation</p> | <p>Participation in University Health Network Diabetes Foot Care and Limb Preservation Pathway Working Group since September 2019 as methodological leads.</p> <p>The following research Protocols have been written:</p> <ol style="list-style-type: none"> 1. Diabetes Wound Care and Amputation of the Lower Limb at University Health Network (UHN) Burden of Disease Evaluation. Principal Investigator: Dr. Valeria Rac. | <p>Expanded multidisciplinary work and involvement of patient partners and policy makers related to diabetic foot care pathways across health sectors and support of research design, implementation, analysis and interpretation.</p> <p>Collaboration across cities, hospitals and provinces related to best practices and care pathways associated with diabetic foot care and limb preservation programs.</p> | <p>Collaborate with other researchers within Diabetes Action Canada to examine diabetic foot care and the development of care pathways within and across institutions</p> <p>HTA applied to evaluation of chronic wounds and the long-term relative effectiveness and cost-effectiveness of new technologies and devices, or services, or care pathways for wound care across Diabetes Action Canada research programs.</p> | <p>Evidence generated is applied by decision-makers when supporting community based health care programs to improve screening, treatment of diabetic foot care.</p> <p>Improved continuity of care pertaining to diabetic foot care and a reduction in lower limb amputation rates and improved quality</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---|--|---|
| | <p>2. Diabetic Foot Care and Limb Preservation Pathway: Developmental Evaluation Study. Principal Investigator: Dr. Valeria Rac.</p> <p>Engagement with wound care group at Unity Health, St. Michael’s Hospital concerning wound care pathways and technology assessment.</p> <p>In collaboration with Unity Health, The Ottawa Hospital and Indigenous Diabetes Health Circle and Dr. Val Rac is a steering committee member and member of the research team that will be developing a study grant proposal to the Conference Board of Canada.</p> <p>Working with fellow Diabetes Action Canada Network investigator, Dr. Karen Cross from Unity Health – St. Michael’s Hospital, a study of the MIMOSA technology has been submitted for funding to evaluate the telemonitoring and in-home use of this medical imaging device for the use of screening for diabetic foot ulcers. (https://mimosadiagnostics.com/)</p> | <p>Funding and submission of research studies to Research Ethics Boards</p> | | <p>of life for those with diabetes.</p> |

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| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---------------------------------|--|------------------------------|
| | Dr. Rac is also a Co-investigator on the Diabetes Action Canada CIHR SPOR Network Transformation Grant Submission. | | | |

Indigenous Peoples Health

Program Co-Leads: Jon McGavock and Alex McComber (Patient Partner)

Program Co-investigators: Neil Andersson, Barry Lavalley, Nancy Young

Research Goals:

- Partners with members of Indigenous communities to establish research priorities in Indigenous health, build capacity on respectful engagement of Indigenous peoples in patient-oriented research
- Prevent diabetes and its complications among Indigenous youth through the Indigenous Youth Mentorship Program (IYMP) – a multi-generational and resiliency-focused empowerment program.

| Activities | | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|--|---|--|---|
| 1 | Patient engagement with the Indigenous communities | <p>Indigenous Patient Circle established.</p> <p>Indigenous Patient Circle collaboration with the Indigenous Peoples' Engagement and Research Council at Can-SOLVE CDK SPOR Network established.</p> <p>Wabishki Bizhiko Skaanj Learning Pathway established and iteratively improved.</p> | <p>Capacity in patient-oriented research built among Patient Partners and researchers through respectful engagement of Indigenous Peoples.</p> <p>Researchers have enhanced their knowledge and awareness of racial biases, Indigenous voices and stories, the impact of colonization</p> | <p>Indigenous Patient Partners are critically important collaborators on all research activities.</p> <p>Evidence is generated jointly with Indigenous Patient Partners to advocate for change with decision-makers on current diabetes care delivery.</p> <p>Improved Patient Partner experiences in diabetes research.</p> | <p>Indigenous Patient perspectives are integral to research planning within Diabetes Action Canada and steer projects toward outcomes that are relevant and useful for those living with diabetes.</p> <p>Increased access to diabetes care and prevention of complication for Indigenous</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---|--|--|
| | <p>Gatherings held in November 2016, August 2017, March 2019, May 2019, Oct 2019</p> <p>Proposal created to investigate priorities identified by the Indigenous Patient circle.</p> <ul style="list-style-type: none"> - Philanthropic donors currently being engaged to fund proposed activities <p>PATH exercise and strategic planning document finalized.</p> <p>Partnerships with the National Aboriginal Diabetes Association (NADA), Indigenous Diabetes Health Circle, and Diabetes Canada are established.</p> <p>Partnerships with SPOR entities, such as Can-SOLVE CKD, Quebec SPOR Support Unit, Manitoba SPOR SUPPORT Unit, Saskatchewan SPOR SUPPORT Unit, BC SPOR Support Unit.</p> | <p>on Indigenous health, and culturally safe health research practices.</p> <p>Patient Partners leaders in generating new knowledge and research questions that are meaningful and relevant to the community.</p> <p>Diabetes Action Canada research programs and activities adapt to the specific needs articulated by Indigenous Patient Partners and their communities.</p> <p>Diabetes Action Canada researchers have opportunities to engage with Indigenous Patients Partners to better serve the Indigenous communities.</p> | <p>Capacity in patient-oriented research in diabetes is strengthened with researchers having access to Indigenous Patient Partners and strategies for culturally sensitive and effective engagement.</p> <p>Networking among organizations in Indigenous health leads to increased knowledge sharing among the Indigenous communities and their health and advocacy groups to respond to patient needs collectively.</p> <p>Priorities for research are established and documented via video recordings.</p> | <p>communities in both rural and urban areas.</p> <p>A culture shift towards patient-oriented research in diabetes is achieved with improved representation and equity of Indigenous perspectives.</p> <p>Indigenous Patient Partners are active partners in deciding how health care is investigated for them and delivered effectively in their communities.</p> <p>Evidence derived from Patient-oriented research is translated into new recommendations for decision makers to reform current provincial and national diabetes strategies among the Indigenous communities.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|---|--|---|--|
| | | | | | Indigenous people living with diabetes who participate the programs have better outcomes and better experiences with their healthcare. |
| 2 | Indigenous Youth Mentorship Program (IYMP) rippling | <p>Relationship building with Indigenous communities and elders in Alberta, Manitoba, Ontario, and Quebec.</p> <p>First IYMP urban site opened in downtown Toronto.</p> <p>Team gatherings Aug 2016, Nov 2017, Mar 2019.</p> <p>Program rippled out from 5 sites in Manitoba to 49 sites across Manitoba, Saskatchewan, Northern Ontario and Toronto.</p> <p>Young adult health training completed.</p> <p>Code of ethics document finalized.</p> <p>Program materials and delivery adapted to each community to reflect regional practices and cultures.</p> | <p>Leaders in Indigenous health and wellness are collaborating to create inroads within the Indigenous communities.</p> <p>Local relationships are built within Indigenous communities to enable rippling of program across the country.</p> <p>IYMP co-developed with Indigenous youth and Elders within each community to meet its own unique needs, teachings and cultural values.</p> <p>IYMP is available to Indigenous youths in certain regions both rural and urban areas.</p> | <p>Increased self-esteem, reduced weight gain and healthier dietary choices are achieved among those who participate in program.</p> <p>Indigenous youths are empowered and promote 'living the good way' within their communities.</p> <p>Healthy inclusive environments are generated by adolescents, mentored by Elders, for children in Indigenous communities.</p> <p>Partnering with Leap Pecaut will provide access to long-term visioning, strategic business planning, and potentially access to more funds to grow an independent and sustainable organization.</p> | <p>Health outcomes associated with diabetes and its complications improve in Indigenous communities who participate in IYMP.</p> <p>Reduced rates of type 2 diabetes in Indigenous youth in Canada among those who participate in IYMP</p> <p>Indigenous Peoples are integrally involved in the development and delivery of health care in their communities.</p> <p>A learning health environment is establishing within our Network to</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|------------------------------|--|--|---|---|
| | | <p>KT video published in YouTube and distributed widely.</p> <p>Additional 5 year funding received by CIHR Team Grant: Pathways Implementation Research Team – Component 3 to ripple out IYMP.</p> <p>Discussions with Leap Pecaut Centre for Social impact underway to move IYMP from academia to a not-for profit organization.</p> | <p>Health lifestyles are promoted in a culturally appropriate manner.</p> <p>Increased involvement of community health departments and workers in program.</p> <p>Diabetes Action Canada expertise in training & mentoring and sex & gender leveraged to secure additional grant funding, create new training programs and address inequity among populations within the Indigenous communities.</p> | <p>Fireside chats with Elders to understand Indigenous models of governance.</p> <p>Development of an Indigenous model of governance for the team to adopt following completion of grant funding when IYMP becomes a non-for-profit.</p> <p>Large gathering held to determine transition model.</p> | <p>improve the health outcomes of Indigenous Peoples with diabetes by providing evidence to improve how our healthcare system can better serve diverse communities.</p> <p>IYMP will be a stand-alone, self-funded, non-for profit organization delivering culturally safe programming across Canada.</p> |
| 3 | Diabetes Integration Project | <p>Trauma-informed training module for health care practitioners on 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.</p> <p>Tool was piloted with trainees and documents/videos were created for phase 2 of the pilot.</p> | <p>Researchers and health care teams have access to a community-based tool for understanding and implementing culturally sensitive practices when working with Indigenous Peoples to promote wellness and healing.</p> | <p>Tool is piloted with practicing physicians working in rural communities, evaluated and refined based on their experiences.</p> <p>Researchers and health care teams apply this training in their health care interactions with Indigenous Peoples.</p> | <p>Wellness and health are supported by research and health care teams with a culturally sensitive lens resulting be better health outcomes among Indigenous People.</p> <p>A new online module for trauma informed, culturally safe care will be released and</p> |

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| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---------------------------------|--|--|
| | Indigenous student was hired to create on-line platform for phase 2 of the pilot | | | available to non-Indigenous health care providers to improve their ability to work with Indigenous people living with diabetes |

Assumptions and External Factors:

- Ability to maintain face-to-face interactions post COVID-19 with members of the Indigenous communities

Innovations in Type-1 Diabetes

Program Co-Leads: Bruce Perkins, Peter Senior, Kate Farnsworth (Patient Partner)

Program Co-investigators: Anne-Sophie Brazeau, Sonia Butalia, David Cherney, Kaberi Dasgupta, Michael Farkouh, Paul Fernyhough, Ahmed Haidar, Benoit Lamarche, Remi Rabasa-Lhoret, Rayzel Shulmann, Alanna Weisman

Program Coordinator: Tracy McQuire

Research Goals:

1. Target improving health outcomes for persons living with T1D while simultaneously reducing the burden of long term care, including diabetes-related complications, on the Canadian health care system.
2. Design and implement a National T1D ‘Registry’ for engagement in clinical trials and monitoring outcomes
3. Improve health outcomes for T1D through technology-assisted tools and other customized self-management processes

| Activities | | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|--|--|--|
| 1 | Patient Engagement with individuals living with T1D | Patient Partner co-Lead established Collaboration agreement with the T1D Think Tank Patient Partners engaged in research program governance and working groups Joint Insight Session with Diabetes Action Canada and the T1D Think Tank – Nov 2018. | Those living with T1D are equal partners in research operations and decisions. Capacity in patient-oriented research in T1D is increased Goals and objectives of research program guided by patient input. | Increased number of investigators apply the principles of patient-oriented research when planning research. Diabetes Action Canada is a trusted resource for patient engagement on clinical trials for T1D. | Persons living with T1D are true partners in planning and implementing clinical research in T1D. The T1D Community is empowered to participate in research and have their |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|---|---|--|
| | | <p>Approach to Patient Engagement presented at Diabetes Canada Conference Oct 2019.</p> | <p>Opportunity created for researchers to interact with people living with T1D, share experiences and communicate in innovative and engaging ways</p> <p>Patient-led communities for T1D are connected with Diabetes Action Canada.</p> | <p>Project outcomes are highly meaningful and relevant to the T1D community with respect to improving self-management</p> | <p>experiences influence health care paths and advocacy</p> <p>Trust is established between patients, their practitioners and researchers, who are all interested in connecting with their peers and each other.</p> |
| 2 | <p>Establish a Type-1 Diabetes Registry proof-of-concept in Canada (Connect1D)</p> | <p>Multi-stakeholder Steering Committee established comprised of six Patient Partners, researchers and data specialists (July 2018-Dec 2018)</p> <p>Funding proposal to JDRF “Type-1 Diabetes Registry: A Patient Oriented Tool to Advance Discovery and Pragmatic Research in Canada” to reallocate funding</p> <p>Patient-led focus groups and interviews conducted at various stages of project design to ensure platform utility.</p> | <p>Patient input influenced significant changes in project planning and implementation away from using health data through EMR toward creating a platform for patient-collecting reported data through eConsent.</p> <p>Virtual community established providing opportunities for those living with T1D to connect with researchers and their peers</p> | <p>Diabetes Action Canada and T1D patient advocacy and community groups work collaboratively to recruit individuals to Connect1D as active participants in T1D research in Canada.</p> <p>Strategic partnerships with T1D advocacy groups, champions, and influencers to build virtual community interested in T1D research</p> | <p>Connect1D, when scaled nationally, will provide the most accurate health information for those living with T1D.</p> <p>Data derived from Connect1D is made available for research will identify gaps in care and address specific needs in different areas of Canada.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|--|--|---|
| | <p>Branding, design and technical development complete.</p> <ul style="list-style-type: none"> - Project rebranded to Connect1D <p>Regular meetings with JDRF to discuss joint communication plans to launch the Connect1D platform</p> <p>Project jointly funded by JDRF and CIHR</p> <p>Project start date September 2018</p> <p>Protocol for National validation study complete</p> <p>Study design for evaluation underway.</p> <p>Network of researchers and health-care practitioners involved in T1D care established and notified through quarterly newsletters in progress of projects.</p> | <p>to have their voices heard, for their stories be told, for their data to be used to benefit the T1D Community, and for them to facilitate scientific advances in T1D.</p> <p>The T1D community in Canada is empowered in their participation in clinical research.</p> <p>Strategic partnerships with JDRF and the T1D Exchange (US) established.</p> | <p>Increased awareness in Connect1D in Canada among both research and patient community in T1D leads to increased users.</p> <p>Increase in awareness of the research that is currently underway in T1D among the T1D Community.</p> <p>Increase in the users of the Connect1D platform (both researcher and community members) as evidence is generated demonstrating its effectiveness</p> <p>The T1D community has increased access to current clinical research opportunities.</p> <p>Research in T1D is facilitated by improving recruitment through communication with the T1D Registrants by researchers.</p> <p>Capacity in patient-oriented research in T1D in Canada is increased.</p> | <p>Researchers will have unprecedented access to potential clinical research participants, expediting scientific advances and informing action plans for improved health care in T1D in Canada.</p> <p>Those living with T1D have unprecedented access to researcher opportunities enabling increased participation of those interested in research but outside academic centres.</p> <p>Evidence generated is applied by decision-makers when considering virtual care opportunities in chronic disease management.</p> <p>Patient-oriented design and uptake of the Connect1D</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|--|--|---|
| | | | | | platform demonstrates the value of including community members in the design and implementation of research. |
| 3 | Facilitate new patient-oriented research in T1D | <p>Consulted on 8 grant applications for the SPOR JDRF/CIHR iCT grant competition</p> <ul style="list-style-type: none"> - 3 SPOR JDRF/CIHR iCT grants awarded for a total of \$5.6M. <p>Supported 14 patient-oriented research projects 2016-20</p> <ul style="list-style-type: none"> - 1 projects awaiting funding decision - 3 projects funded - 10 projects not funded <p>A research consortium for T1D researchers established with 94 researchers subscribing to communications and interested in patient-oriented research.</p> | <p>Capacity in patient-oriented research is increasing among researcher in T1D.</p> <p>Diabetes Action Canada is recognized as a trusted source for connecting researchers to Patient Partners.</p> <p>Patient Partners are actively engaged in generating new knowledge in T1D in Canada.</p> | <p>Patient engagement is recognized as a necessary component of clinical research projects in T1D in Canada.</p> <p>Increase in researchers seeking Patient Partners for their research planning and implementation.</p> | Scientific advances in T1D are more relevant to the patient population in Canada and provide the evidence-base for advocacy groups to address the needs of the T1D community in Canada. |
| 4 | Clinical Trial: Effect of SGLT2 Inhibition on Improving the glycemic performance if single and dual hormones | Design modified to be compliant with FDA and Health Canada use of artificial pancreas therapy using currently available equipment. Maintaining “no objection” status for use of investigational | Design established for analysis of feasibility and efficacy of combined SGLT2i therapy and artificial pancreas treatment | Evidence established for longer term impact intervention on cardio-metabolic risk factors and prevention of hypoglycaemia | Algorithm controlling the artificial pancreas system will be safely applied in Canada for insulin therapy in both |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|--|--|---|--|--|
| <p>artificial pancreas configuration</p> | <p>devices and investigational medication throughout the study.</p> <p>Study methodology refined to use commercially available empagliflozin (SGLT2i) rather than investigational SGLT2i (available only through contracts with pharmaceutical companies).</p> <p>Study protocol changes incorporated single hormone artificial pancreas technology rather than dual hormone artificial pancreas system. Further adjustment of the protocol to maximize remote training, follow-up and management of participants as a response to COVID-19 pandemics.</p> <p>Artificial pancreas algorithm obtained for testing from Eli Lilly (agreements in place).</p> <p>Collaboration agreements established with investigators in various academic institutions.</p> <p>Submitted to Health Canada for approval.</p> <p>Protocol modified from a 4-year study to a 3-year study and budget modified to reflect this change.</p> | <p>established using quantitative outcome measures.</p> <p>Empagliflozin (SGLT2i), a therapy typically associated with T2D, available for treatment with T1D as part of an artificial pancreas system.</p> <p>Design established for analysis of short term impact of intervention on cardio-metabolic risk factors and prevention of hypoglycaemia analyzed in men and women with T1D.</p> <p>Technology only available in the US is tested for clinical usability and safety in Canada in response to patient desires for more efficient management of T1D.</p> <p>Network of researchers in T1D is established to the expand testing of clinical usability and</p> | <p>analyzed in men and women with T1D.</p> <p>Further design of studies in artificial pancreas systems in Canada to advance the application and adoption of this technology in Canada.</p> <p>Dual versus single hormone artificial pancreas technology investigated to advance knowledge in the controversial area of efficiency and safety in treating T1D.</p> <p>Therapies in T1D will advance with an algorithm able to provide fully functioning communication between a sensor on a continuous glucose monitor and an insulin pump with direct communication to a processing unit for dosing of insulin feedback and a safe and effective closed loop system.</p> <p>Collaboration among researchers, patients and commercial medical</p> | <p>predictable and unpredictable situations.</p> <p>The artificial pancreas technology will adhere to the specifics required by the Canadian Health Care System and be available to Canadian patients with T1D.</p> <p>Engaged stakeholders and researchers work collaboratively to ensure optimal efficiency and safety of the artificial pancreas system making it a viable management option for any Canadian living with T1D.</p> <p>Evidence for new standards of care for T1D established that may include SGLT2i therapy.</p> <p>People living with T1D have increased access to advances</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---|--|---|
| | <p>REB approval obtained at host and collaborating institutions.</p> <p>Interventional part of the study was initiated in August 2019 (FPFV) with recruitment of 28 participants expected to be concluded before January 1st 2021 (LPFV) and LPLV before June 31st 2021.</p> | <p>safety of the artificial pancreas system to make it ready for clinical use in Canada.</p> <p>New knowledge is generated to support the application of artificial pancreas technology in Canada.</p> <p>Incorporating participant feedback about virtual communication and visiting the research office at the time of global pandemics and beyond, while still focusing on individualized participants needs and safety</p> <p>Identified procedures which can be done virtually and explored alternatives and resources for those which cannot be done over the internet (e.g. bloodwork)</p> <p>Redesign of the protocol and education tools to enable</p> | <p>device partners achieve efficient translational research evidence into clinically viable artificial pancreas solution which will fulfil all requirements for Health Canada of the pre-clinical testing needed for the device approval.</p> <p>Research evidence is applied to enable increased access to artificial pancreas technology in Canada.</p> <p>If proven beneficial, adjuvant treatment with SGLT2 inhibitors in T1DM glucose management can be used as adjuvant other APS, not only one used in this study. It will also open possibility of broader research on use of SGLT2 inhibitors in T1DM along with other technologies.</p> <p>Further explore possibilities of virtualized care in research in different other projects and expanding clinical research beyond the physical hospital environment</p> | <p>in technology and disease management.</p> <p>Concept of virtual management of participants in research, conforming with all safety rules, enabling to overcome patients' inertia to research projects caused by time commitment requirements</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|--|---|---|
| | | | virtualized research participants care | maintaining the research quality, monitoring and safety | |
| 5 | Clinical trial: Development of proteomics-based biomarkers for beta cell and adipose tissue dysfunction in T2D | <p>Longitudinal samples from the following acquired and analyzed:</p> <ul style="list-style-type: none"> - 12 individuals with pre-diabetic - 5 individuals with T2D undergoing bariatric surgery - 70 individuals with gestational diabetes - 70 healthy controls <p>Samples acquired and analyzed from 60 men and women with normal glucose tolerance or pre-diabetes with PET/CT measures of dietary fat partitioning and cardiac function. Candidate protein biomarkers tested for ability to predict disease onset and progression evaluated and compared to currently used indicators</p> <ul style="list-style-type: none"> - Results led to invalidation of diabetes beta cell proteomic biomarkers by Caprion | <p>Use of proteome-based biomarkers to predict change in glucose homeostasis in pre-diabetes and T2D validated.</p> <p>Predictive models for diagnosing T2D or prediabetes based on functional imaging biomarkers of cardiac effects of SGLT2 inhibitor canagliflozin in patients with T2D and class III heart failure improve ability to screen and prevent T2D onset and progression.</p> <p>Biomarker combinations that were deemed invalid (Caprion) are not commercially available.</p> | <p>Assessment of beta cell and adipose tissue function using yearly oral glucose and lipid tolerance tests over 4 years in men and women with pre-diabetes and T2D completed.</p> <p>Evidence is applied to use predictive biomarker combinations to reduce the onset of T2D.</p> | <p>Improved patient outcome with predictive biomarkers triggering interventions earlier in disease onset and/or progression.</p> <p>Demonstration of actionable mechanisms for better T2D risk assessment and prevention.</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---------------------------------|--|------------------------------|
| | <p>Imaging and metabolic phenotype database established and samples available for testing.</p> <p>Funding from Janssen (\$200K) obtained to conduct proof-of-concept trial on the effect of canagliflozin (SGLT2 inhibitor) in cardiac metabolism and function in subjects with T2D. This was later withdrawn due to incapacity of Janssen and CHUS to achieve contractual agreement.</p> <p>REB approval obtained</p> <p>Proof of concept calagliflozen completed 2018</p> <p>Biomarker analysis started in Spring 2018</p> <p>Application is in preparation for CIHR's Team Grant competition on Mechanisms of Diabetes and Translational Solutions.</p> <p>Manuscript to Diabetes on the 60 men and women with pre-diabetes vs. normal glucose tolerance demonstrating the mechanisms by which increased postprandial fatty acid exposure to lean organs occur in prediabetes submitted.</p> | | | |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|--|---|--|---|--|
| 6 | Clinical trial: Targeted lifestyle modification for secondary prevention of diabetes complications | <p>Valid tools made available to primary care clinicians and patients for rapid assessment of diet and food behaviours identifying barriers and facilitators for eating healthy.</p> <p>Web-based 24h recall developed to assess diet quality</p> <ul style="list-style-type: none"> - five publications in 2017-19 - 15 abstracts presented 2016-2019 <p>Diet screener developed to assess diet quality in primary care</p> <ul style="list-style-type: none"> - One publication 2019, 3 abstracts presented 2018-2019 <p>Assessment of discrepancy between web-based diet assessment tools and field measures</p> <ul style="list-style-type: none"> - one publication is 2017 <p>Validation of relationship between lifestyle choices, physical exercise, nutrition, fitness to predict cardiovascular health men and women complete</p> <ul style="list-style-type: none"> - 21 abstracts presented in 2016-2018 | <p>Behaviours identifying barriers and facilitators for healthy eating determined.</p> <p>Valid tools available for clinicians and patients to measure physical activity, diet and other lifestyle behaviours relevant to risk of complications.</p> <p>Tools integrated into the PULSAR, for the study of Sustainable Health in Québec.</p> <p>New data generated to assess relationship between physical activity and cardiovascular fitness related to biological cardiovascular disease for risk factors.</p> <p>Decision and policy-makers (Quebec Ministry of Health) engaged as funders and</p> | <p>Development of diet quality assessment tools and capacity has led to the funding a new population-based study, which aim to track and study over time the dietary habits of the Quebec adult population (NutriQuebec Project).</p> <p>Research tools developed for primary care scale and spread as part of a comprehensive diabetes screening program.</p> <p>Research tools and evidence applied in public health initiatives for the province of Quebec.</p> <p>Decision and policy-makers are active partners in research and implementation of evidence based improvements to primary care in the province if Quebec.</p> | <p>Clinicians use evidence-based tools to improve diabetes screening and prevent onset of T2D.</p> <p>Research tools are integral to a comprehensive diabetes screening program applied in primary care as part of a Quebec Provincial Diabetes Strategy and then later a National Diabetes Strategy</p> <p>Research tools are integrated into PULSAR as part of a transdisciplinary research effort at Laval University on sustainable health, with focus on vulnerable populations including patients with diabetes</p> <p>Improved health outcomes for those who participate in</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|--|--|
| | | <p>Interactive web-tools developed to integrate diet assessment tools to address needs in primary care to assess diet, food behaviours and physical activity</p> <p>High throughput procedures to assess lifestyle vital signs applied in primary care setting</p> <ul style="list-style-type: none"> - 17 papers published between 2017-19 <p>Study outcomes have led to the funding a new population-based study, track and study over time the dietary habits of the Quebec adult population (NutriQuebec Project)</p> | <p>partners in the generation of new knowledge</p> | | <p>the intervention for those at risk of developing T2D.</p> |
| 7 | <p>Clinical trial: Topical pirenzepine for treatment in type-2 diabetes</p> | <p>Research ethics approved for Phase 1 of study in Australia</p> <p>Phase 1 of project completed in Fall 2018</p> <p>Phase 2 budget re-evaluated and additional funds secured by WinSanTor Inc and Diabetes Action Canada as a 1:1 funding match contribution.</p> | <p>Data on the efficacy of topical pirenzepine in preventing and/or reversing peripheral neuropathy in individuals with T2D available for clinical decision making</p> | <p>Evidence of topical pirenzepine as a safe therapeutic for those living with T2D is applied. Study to advance to Phase 3 in clinical trial.</p> <p>Evidence is generated for non-invasive treatment of diabetic neuropathy to prevent/reverse sensory loss and/or pain</p> | <p>Phase 3 of clinical trials commences in Canada, USA and Europe.</p> <p>Topical pirenzepine, proven to increase quality of life for those with T2D, becomes a treatment option for those living with T1D</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|---|---------------------------------|--|---|
| | <p>Health Canada submitted for Phase 2 of study in early April 2019 – clearance given to initiate trial by late April 2019</p> <p>REB for Phase 2 of study submitted and approval July 17, 2019. Contract approval August 26, 2019.</p> <ul style="list-style-type: none"> - Institutional authorization August 28, 2019. <p>Recruitment for Phase 2 began in September 2019 and end in late 2020.</p> <p>Multiple subjects pre-screened but ineligible by original study criteria.</p> <ul style="list-style-type: none"> - Six subjects screened. - Two were screen failures. - One terminated early in March 2020. - Three patients are active in the study. These are being monitored remotely. - Two had appointments for screening but were canceled due to COVID-19 lockdown March 14, 2020. | | <p>Trial treatment and data collection period will end by summer 2021</p> <p>Phase 2 clinical trial in USA in type 2 diabetic patients initiated by WinSanTor in early 2021. Completed by late 2021.</p> | <p>Sensory loss, pain, diabetic foot ulcers and lower extremity amputations are reduced with use of topical pirenzepine</p> <p>The data from the UHN (Toronto) study will be combined with WinSanTor run trial data from at least 4 other sites in Canada. This will be combined with USA phase 2 trial data for permission to move from phase 2 to phase 3. The phase 3 is on track to begin in early 2022 onwards if funding in place. This funding could originate from a combination of SPOR, CIHR, WinSanTor, Clinical Trials Ontario and a partner(s) from big pharma. The phase 3 could be a</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|--|---|
| | | <ul style="list-style-type: none"> - Clinical research likely to resume in the second half of June 2020 (delay in milestones). <p>IND pre-submission to FDA by WinSanTor to support a phase 2 trial in USA in early 2020.</p> <ul style="list-style-type: none"> - Reviewed favorably and pirenzepine formulation given NCE and fast-track status by FDA. <p>Full submission of IND to FDA is expected by Fall 2020.</p> | | | <p>combined study with type 1 and type 2 patients.</p> |
| 8 | <p>Clinical trial: Comparison of dual-hormone artificial pancreas, single hormone artificial pancreas, and sensor-augmented pump therapy in outpatient settings</p> | <p>Personnel recruited (8) to develop automated system existing artificial pancreas system based on Oregon University platform.</p> <p>Agreement for licensing artificial pancreas algorithm from Eli Lilly completed in May 2018.</p> <p>Agreements to use automated system previously established with academic institutions and pharmaceutical companies complete.</p> <p>Automated system adapted for use in clinical trial.</p> | <p>Feasibility and efficacy dual-hormone and single hormone artificial pancreas treatment established using qualitative and quantitative measures.</p> <p>Design established to analyze short term impact of intervention on cardio-metabolic risk factors and prevention of hypoglycaemia analyzed in men and women with T1D.</p> | <p>Longer term impact intervention on cardio-metabolic risk factors and prevention of hypoglycaemia analyzed in men and women with T1D.</p> <p>Studies in both dual and single hormone artificial pancreas systems in Canada will advance the application and adoption of this technology in Canada.</p> <p>Dual versus single hormone artificial pancreas technology investigated to advance knowledge in the</p> | <p>Algorithm controlling either a single or dual hormone artificial pancreas system will be safely applied in Canada for insulin therapy in both standard and non-standard situations.</p> <p>The artificial pancreas technology will adhere to the requirements of the Canadian Health Care System and Canadian patients with T1D.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|---|---|--|--|--|---|
| | | <p>Automated system and algorithms for artificial pancreas adapted and incorporated into system platform.</p> <p>Study plan augmented to account for the meal and exercise control as part of qualitative measures gathered for feasibility of single versus dual hormone artificial pancreas systems.</p> <p>Health Canada approval obtained.</p> <p>Research ethics board approval obtained.</p> | <p>Technology only available in the US is now being tested for clinical usability and safety in Canada in response to patient desires for more efficient management of T1D.</p> <p>Network of researchers in T1D is established to expand testing of clinical usability and safety of the system to make it ready for clinical use in Canada.</p> <p>New knowledge is being generated the support the application of artificial pancreas technology in Canada.</p> | <p>controversial area of efficiency and safety in treating T1D.</p> <p>Therapies in T1D will improve with an algorithm able to provide fully functioning communication between a sensor on a continuous glucose monitor and an insulin pump with direct communication to a processing unit for dosing of insulin feedback and a safe and effective closed loop system.</p> <p>Research evidence Including iterative algorithm development is applied to enable increased access to artificial pancreas technology in Canada.</p> | <p>Engaged stakeholders and researchers work collaboratively to ensure optimal efficiency and safety of the artificial pancreas system making it a viable management option for any Canadian living with T1D.</p> <p>People living with T1D have increased access to advances in technology and disease management.</p> |
| 9 | <p>Clinical trial: Vigorous physical activity for glycemic control in type-1 diabetes trail (VIGOR)</p> | <p>Analysis of the effects of vigorous exercise in controlling glucose levels in T1D complete. Study published</p> <ul style="list-style-type: none"> - Rempel et al. Scientific Reports, Oct 2018; 8 15879 <p>Additional manuscript submitted</p> | <p>Leveraged existing relationships/networks to create novel multi-province working group with stakeholders from across the country engaged in VIGOR study design, implementation and evaluation.</p> | <p>Evidence on vigorous exercise and T1D management is applied in clinical settings.</p> <p>Patients are partners in the establishing research objective in T1D for Canada.</p> | <p>People living with T1D use evidence generated to make appropriate lifestyle choices to improve blood glucose levels.</p> <p>A new research network in Canada dedicated to exercise</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|--|--|---|
| | <p>Created Canadian Diabetes Exercise Network (CaDEN) website.</p> <p>Relationship established with JDRF and Diabetes Canada.</p> <p>Project Management provided by Manitoba SPOR Support Unit – George and Fay Yee Centre for Healthcare Innovation</p> <p>Relationship established with James Lind Alliance to support research priority setting exercise in Canada for T1D.</p> <p>Repository of patients interested in exercise and diabetes research created:</p> <ul style="list-style-type: none"> - Survey created - RedCAP database created to hold registry data - Recruitment started in Summer 2018 | <p>People living with T1D are integral in setting research priorities that are relevant to their challenges in living with the condition.</p> <p>Relationship established with the T1D Community.</p> <p>Capacity is built for funders to understand patient-oriented research and its methodologies.</p> <p>Patient advocacy groups (Diabetes Canada and JDRF) are engaged in generating research knowledge by disseminating the survey to learn about patient priorities for T1D research.</p> <p>SPOR funded entities work collaboratively to define research priorities in T1D for Canada.</p> | <p>Capacity in patient-oriented research is strengthened by better connection between funders, patient partners and researchers in T1D. Regular interaction between these network members facilitated patient-oriented research training, scientific training and reciprocal knowledge dissemination.</p> <p>Persons interested in participating in research for T1D are available for recruitment to clinical trials, regardless of their association to academic hospitals or centres.</p> <p>Established preferred attributes for exercise interventions for persons living with type 1 diabetes.</p> <p>3-5 clinical trials of exercise and type 1 diabetes are collaboratively designed and prepared for funding applications as a joint effort between patient partners and scientists</p> | <p>and type 1 diabetes to support multi-centre clinical trials.</p> <p>3-5 clinical trials of exercise and health outcomes co-designed with patient partners.</p> <p>Patient-oriented research is established in the T1D Community and necessary to setting research priorities that are relevant to the community</p> <p>Scientific advances are expedited with researchers, patients, advocacy groups and funders working collaboratively plan, implement and evaluate clinical research.</p> <p>Researchers have unprecedented access to</p> |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|----|---|---|--|--|---|
| | | <p>Top ten research priorities for those living with T1D are identified and inform future projects in the patient-oriented research.</p> <p>8 centres have participated in a grant application to codevelop clinical trials in the area of exercise and type 1 diabetes</p> | | <p>Relationship building within the T1D Community, Diabetes Action Canada and JDRF enables research in T1D and expediting scientific advances.</p> | <p>potential clinical research participants, expediting scientific advances and informing action plans for improved health care in T1D.</p> |
| 10 | <p>Clinical trail: The effects of DPP-4 Inhibitor therapy on renal sodium handling and renal hemodynamics in type 2 diabetes</p> <p>(Project Complete)</p> | <p>Additional funding for study secured by pharmaceutical company Merck.</p> <p>Analysis of renal and systemic hemodynamic function, neurohormones, and free radical mediators that are modified by DPP-4 inhibition to prevent progression of diabetic nephropathy complete. Study published</p> <ul style="list-style-type: none"> - Lovshin, JA et al, Cherney,D. Diabetes Care, 2017 Aug; 40(8): 1073-1081 | <p>Evidence generated on renal and cardiovascular function undergoing DPP-4 inhibition</p> | <p>Evidence on use of DPP-4 is applied in clinical setting</p> | <p>Use of DPP-4 inhibition in clinical setting improves health outcomes for those living with T2D.</p> |
| 11 | <p>Clinical trial: CNS-mediated effects of insulin and GLP-1 on intestinal and hepatic lipoprotein particle production in humans</p> <p>(Project Complete)</p> | <p>Additional funding for study secured by CIHR Project scheme grant</p> <p>Postdoctoral fellow awarded Diabetes Action Canada fellowship for this work</p> | <p>Evidence generated on the effects of endogenous insulin and GLP-1 on intestinal and hepatic lipoprotein particle production in humans</p> | <p>Evidence applied in clinical decision making for human males with T2D demonstrating insulin resistant.</p> | <p>Evidence informs alternate therapies for human males with T2D demonstrating insulin resistant..</p> |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Impacts (2022 and beyond) |
|------------|--|---------------------------------|--|------------------------------|
| | <p>Endogenous glucose production and lipid concentrations evaluated during a pancreatic clamp in 10 healthy subjects receiving intranasal glucagon. Study published</p> <ul style="list-style-type: none"> - Xiao C., et al. Diabetes, Obesity and Metabolism, Jul 2018;20(7):1751-1754. <p>Endogenous glucose production evaluated during a pancreatic clamp in 7 overweight or obese insulin-resistant men receiving intranasal insulin lispro. Study published</p> <ul style="list-style-type: none"> - Xiao C. Arteriosclerosis, Thrombosis, and Vascular Biology, Sept 2017;37:1776–1781. | | | |

Assumptions :

- **Activity 4:**
 - o Continual funding of this research project
 - o Further interest of research subjects in the APS and the trial
 - o No major malfunction of the equipment which would result in severe consequences for the study subject
 - o Continual Health Canada approval of the current (and possibly future) devices and medication used in the research project
 - o Continual manufacturing of equipment similar to that used in the study

- Post-study usability of the algorithm by general population depends on the interest of the commercial partner to manufacture APS or incorporate the algorithm into their own hardware

External Factors

- **Activity 4:**

- Rapid successful advance in development of different management/treatment options for T1DM can affect future use of the APS in targeted populations
- Market oversaturation with semi-automated APS
- SGLT-2 remain safe adjuvant treatment for diabetes (i.e. no major global scale side effect will be discovered)

Knowledge Translation

Program Co-Leads: Sophie Desroches, Monika Kastner, France Légaré

Program Co-investigators: Adalsteinn Brown, Antoine Groulx, Michael Hillmer, Helene Lee-Gosselin, Lori MacCallum, Paul Oh, Mathieu Ouimet, Monica Parry, Marie-Pascale Pomey, Rabdoul Roudsari, Sraron Straus, Erin Strumpf, Marie-Claude Tremblay, Brigitte Vachon, Catherine Yu

Research Goals: The Knowledge Translation (KT) Enabling Program has established an integrated program with Diabetes Action Canada with the main objective to facilitate the application of research findings into healthcare practices. Our team supports members of Diabetes Action Canada for contributing to science and practice on how to better move knowledge into practice. KT research goals are to:

- Improve the knowledge base on patient-oriented KT research in diabetes and its related complications
- Develop strategic partnerships with different stakeholders to disseminate the work done by Diabetes Action Canada members
- Facilitate the support for new models of care that will result in better outcomes and a better experience for individuals living with diabetes.

| Activities | | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|---|--|--|---|---|
| 1 | Small working group (SWG1): KT scholarship program | Scholarship requirements, and selection criteria established for program. Partnership with KT Canada established. Patient Partner and peer review process for applications and progress reports established. KT Training Awardees selected in 2017-18 - Four awardees – 2 PhD and 2 Post doc fellows | Building capacity in patient-oriented research in knowledge translation. Building KT capacity within the DAC network. Patient Partners are actively engaged in reviewing research projects and input | Develop and foster strategic partnerships to effectively disseminate evidence being generated by Diabetes Action Canada. Research findings in patient oriented research in diabetes are communicated through | A learning health environment is established within our Network to promote patient-oriented research and KT that is applicable to the needs of our diverse members' population. |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|--|---|---|---|
| | <ul style="list-style-type: none"> - Completed 6 month and 12 month progress reports <p>Program evaluated and deemed successful</p> <p>Based on evaluation, the 2019-2020 KT Diabetes Action Canada Scholarship Program was developed.</p> <p>A partnership with KT Canada reaffirmed. Partnership with the Quebec SPOR Support Unit was established.</p> <p>Application criteria, including a clearly defined Knowledge Translation as well as a Sex and Gender component, were established. Documentation was updated and adapted.</p> <p>The 2019-2020 scholarship program was launched. Applications were collected. Scholarship candidates' applications were reviewed in detail by researchers and patient partners. Their applications were then ranked.</p> <p>KT Training Awardees selected in 2019-20</p> <ul style="list-style-type: none"> - Three awardees (2 PhD and 1 post doc fellow) - Training in partnership with KT Canada (seminar series, and end of grant KT course) | <p>in study design and suggestions used to modified program.</p> <p>Diabetes Action Canada enabling research programs Sex and Gender; Training and Mentoring, network with KT to build capacity. Awardees exposed to communication of research findings amongst traditional and non-traditional channels.</p> <p>Change is awareness of KT applications and tools in patient oriented research and diabetes research.</p> | <p>various channels, thereby increasing the audience.</p> <p>Peer-reviewed publications in KT and patient-oriented research increase and evidence generated is applied in new research.</p> <p>Possibility of further development of research projects or of collaboration with the former awardees on new research projects.</p> | <p>Former awardees have developed a deeper understanding of the role and importance of knowledge translation in diabetes research.</p> <p>Former awardees continue participating to knowledge translation in diabetes research initiatives as demonstrated by grant application, papers or mentoring of trainees.</p> |
| 2 | SWG2: Environmental scan of effective knowledge | Protocol for environmental scan published. | Knowledge gaps in preventing diabetes | Patient-oriented research findings generated from |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|---|--|---|
| <p>translation strategies to prevent diabetes complications</p> | <p>Four patient partners from four provinces recruited to the project.</p> <p>Governance established.</p> <p>Data extraction complete.</p> <p>Preliminary report presented at SPOR Summit 2018.</p> <p>The Environmental Scan was completed on 31 March 2019. The results of the scan were presented at the 2019 DAC Annual Workshop. The results of the scan were posted to the DAC Website.</p> <p>A paper presenting the results of the Environmental Scan was submitted to the Canadian Journal of Diabetes in April 2020.</p> <p>DAC KT co-investigator (Monika Kastner) planning next phase of the environmental scan and the development of KT tools to benefit those living with diabetes.</p> <p>A renewed vision for the KT Enabling Program in the context of DAC renewal is being considered within the KT team (Monika Kastner, Catherine Yu, Sophie Desroches, and France Légaré).</p> | <p>complications are identified for both those living with diabetes and health care practitioners.</p> <p>A comprehensive inventory of effective KT strategies to help prevent diabetes complications is readily available to inform different stakeholders (i.e. patients, caregivers, health professionals) about the existing KT initiatives/tools available.</p> <p>Repository of KT tools are available to expedite research findings into practice to improve diabetes care.</p> <p>Building capacity in KT in diabetes patient-oriented research achieved.</p> | <p>Diabetes Action Canada are communicated to policy and decision makers and translated into clinical practice guidelines and healthcare practice.</p> <p>Diabetes Action Canada recognized as a reputable source of evidence-based knowledge and KT tools in diabetes and its related complications.</p> <p>Renewed vision for the KT Program increasing the translation of research findings to policy and decision makers in multiple provinces and in collaboration with other investigators in the field.</p> <p>Patient-oriented research tools in KT are developed in consultation with those living with diabetes and directly</p> | <p>in health care decision making and person centered care for those who use the KT tools.</p> <p>People living with diabetes have better outcomes and better experiences with their healthcare as a result of applying the KT tools.</p> <p>Demonstrable proof about the efficacy (positive or negative) of the developed KT tool.</p> <p>Networks of knowledge and expertise on implementing KT tools in different provinces established and accelerating the translation of information to policy and decision makers</p> <p>Canadian KT community is strengthened with cross-jurisdictional working</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|--|--|--|---|
| | | | <p>Relationships within and outside of the DAC KT Team were strengthened and new collaborations formed.</p> <p>A renewed vision of the KT Enabling Program under new leadership is developed.</p> | <p>applicable to those living with diabetes.</p> <p>Implementation of aforementioned KT tools in clinical sites in Ontario and Quebec simultaneously with evaluation of the effectiveness of the tool.</p> | <p>relationships, and partnerships with practice based research networks.</p> <p>Sustainability and scaling up of the KT tools identified to enable the increased access to the right people at the right time.</p> |
| 3 | SWG3: Patient priority identification following the James Lind Alliance method | Project not yet initiated as deemed not a priority for established and ongoing project development with active Patient Partner participation. In addition, this has been done by other team members of this SPOR network, see John McGavock, | | | |
| 4 | SWG4: Real-world implementation of interprofessional shared decision making | <p>Interprofessional shared decision-making intervention material translated from English to French.</p> <p>Systematic review of literature completed.</p> <p>Study protocol prepared.</p> <p>Evaluation of facilitators and barriers to scaling up diabetes shared decision making tool (<i>MyDiabetesPlan</i>) in primary care complete.</p> | <p>Patients and providers are encouraged to practice shared decision-making in diabetes care.</p> <p>Tools in interprofessional shared decision making for those living with diabetes are accessible and useful to managing the condition.</p> | <p>New research activities for the KT group are aligned with the needs articulated by knowledge users.</p> <p>Increased opportunity for Diabetes Action Canada research programs to contribute to the science of scale-up.</p> | <p>Diabetes Action Canada, Knowledge Users and Patients, co-design research projects to directly address the needs of all stakeholder and satisfy the quadruple aim goals.</p> <p>Research evidence is more effectively disseminated to</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|---|---|--|--|---|
| | | <p>Relationships with Ontario provincial ministries and with primary care sites developed.</p> <p>Collaborative relationship with Collectif pour les Meilleures Pratiques et l'Amélioration des Soins et Services+ (CoMPAS+) and Institut national d'excellence en santé et en services sociaux (INESSS) developed.</p> <p>Collaborate with former DAC trainee and expert in the field of scale up and scalability assessment, Ali Ben Charif.</p> <p>Proposal created by Catherine Yu and Monika Kastner to France Légaré and Sophie Desroshes on reimagining the DAC KT Enabling Program within the context of DAC renewal.</p> | <p>Renewed vision for DAC KT Enabling Program builds on proven successes from the first funding term of DAC KT Enabling Program.</p> <p>Scale up for the shared decision making tool (<i>MyDiabetesPlan</i>) to more primary care practices.</p> | <p>Greater integration of the DAC KT Enabling Program into the operations of the other DAC Research Programs.</p> <p>Implementation and evaluation of scale up strategy for the shared decision making tool (<i>MyDiabetesPlan</i>) will influence primary care in diabetes for those practices that use the tool.</p> | <p>policy-makers for timely decisions in diabetes care.</p> <p>Strengthening of the connections between the Enabling and Research programs. And development of connections where none had previously existed.</p> <p>Shared decision making tool has demonstrable impact on shared decision making between physician and patient in a clinical context.</p> |
| 5 | SWG5: Contribute to the science and practice of scale-up and spread | <p>Collaboration established with Quebec SPOR SUPPORT Unit</p> <p>Scalability assessment tool created, published and translated into French</p> <p>Tool validated with 12 Community-Based Primary Health Care (CBPHC) teams across Canada</p> <p>Publications:</p> | <p>Different stakeholders (patients, clinicians, researchers, decision makers) and DAC members have tools to effectively evaluate the potential of evidence-based practice or innovation to be scaled up.</p> | <p>Access to Community Based Primary Health Care is improved in regions using scalability tools for addressing the needs of vulnerable populations and for chronic disease prevention and management.</p> | <p>Development and testing of novel approaches for scaling in shared decision-making in home care, health care and community services sectors are established as part of a National Diabetes Strategy.</p> <p>Scalability assessment and the science of scale up</p> |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|---|--|--|--|
| | <ul style="list-style-type: none"> - Assessment of scalability of evidence-based innovations in community-based primary health care: a cross-sectional study. Ben Charif A, <i>et al.</i> CMAJ Open. 2018 Nov 2;6(4):E520-E527. - Essential items for reporting of scaling studies of health interventions (SUCCEED): protocol for a systematic review and Delphi process. Gogovor A, <i>et al.</i> Syst Rev. 2020 Jan 11;9(1):11. - Effective strategies for scaling up evidence-based practices in primary care: a systematic review. Ben Charif A, <i>et al.</i> Implement Sci. 2017 Nov 22;12(1):139 - The pitfalls of scaling up evidence-based interventions in health. Zomahoun HTV, <i>et al.</i> Glob Health Action. 2019;12(1):1670449. - Assessing the scalability of innovations in primary care: a cross-sectional study. Ben Charif A, <i>et al.</i> CMAJ Open. 2020 XX;X(X): XXX-XXX <p>CIHR foundation grant: Project Title: Scaling up shared decision making for patient-centred care</p> <ul style="list-style-type: none"> - Principal Investigator: Légaré France <p>CIHR Grant on Patient Oriented Scale Up: Patient-oriented scale up and spread for enhanced patient-centered care (Beleno R, Légaré F and Ben Charif A).</p> | <p>Diabetes Action Canada has access to KT expertise to enhance the scale and spread of their research findings.</p> <p>Building capacity in KT in diabetes patient-oriented research is enhanced.</p> <p>Scability assessment tool is iteratively improved.</p> <p>Patient engagement becomes integral in the science and practice of scale up.</p> <p>Novel networking and collaboration of DAC KT co-investigators on scaling up of KT shared decision making tool.</p> | <p>Decision makers are engaged in scaling up innovations in healthcare for persons living with diabetes.</p> <p>Partnerships with key stakeholders are fostered to disseminate knowledge.</p> <p>Primary care physicians using the scalability tool have better outcomes for their patients living with diabetes</p> <p>Increase in community-based primary care physicians using the scalability tool to scaling up evidence-based interventions.</p> | <p>influences the translation of knowledge to community-based primary care.</p> <p>DAC investigators have the capacity for scaling up (or down) effective research initiatives across this country</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|---|--|---|--|---|
| 6 | SWG6: Diabetes Action Canada network evaluation and impact analysis | <p>Study protocol completed and submitted for ethics review.</p> <p>Collaboration established with Health Technology Assessment and Network Evaluation lead, Dr. Val Rac.</p> <p>Patient partner recruited to project.</p> <p>First DAC Network Analysis report completed and shared with leadership.</p> <p>Network analysis publication expected in 2020</p> | <p>Diabetes Action Canada network internal exchanges and collaborations are mapped prospectively.</p> <p>Subnetworks within Diabetes Action Canada are identified and examined.</p> <p>Research impact on decision-makers, health professionals and patients are assessed and recommendations for improvements are made</p> <p>Further Network Analyses will demonstrate the impact of DAC and inform strategic planning for DAC renewal.</p> | <p>Diabetes Action Canada demonstrates how the development and growth of its network is creating return on investment in patient-oriented research and collective impact.</p> <p>Strategies developed for DAC to better engage and influence policy and decision makers in research initiatives.</p> | <p>The value of the network established by Diabetes Action Canada is communicated successfully to all stakeholders including health system and practice leaders.</p> <p>Demonstration of the efficacy of our Network and its outcomes to knowledge users and policy decision-makers to bridge the gap with provincial and federal governments.</p> <p>Establish connections with policy and decision makers.</p> <p>Begin actively lobbying and attempting to influence policy.</p> |
| 7 | SWG7: Develop effective KT strategies in diabetes in a continuous professional development context taking | <p>Collaboration established with Medecins Francophone Canada, Institut de Savoir Montfort, Quebec SPOR SUPPORT Unit, Maritime SPOR SUPPORT Unit.</p> | <p>Building capacity for patient oriented research in KT, specifically in diabetes, sex and gender and mental</p> | <p>Strategies to manage mental health challenges, particularly depression, are established and incorporated</p> | <p>Primary care practitioners who were trained have tools to improve quality of life for those living with diabetes and</p> |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---|--|--|--|
| <p>into account sex and gender issue</p> | <p>Collaboration with Diabetes Action Canada Sex and Gender research program established.</p> <p>Four Patient Partners recruited to project</p> <p>Training for healthcare professionals in diabetes and depression with a particular focus on sex and gender.</p> <p>Implementation of training workshops with health professionals on diabetes and depression as well as on the influence of Sex and Gender on clinical practice.</p> <p>Data collected (January 2020).</p> <p>Data analysis underway.</p> <p>Publication expected in 2020</p> <p>Workshops (4) completes - 139 people trained</p> <p>Trainee Alexe Deom Tardif (MSc Public Health) will graduate in october 2020</p> | <p>health (depression) - an area of particular concern for our Patient Partners.</p> <p>Diabetes and mental health strategies are developed with Diabetes Action Canada research programs to address this joint priority articulated by our Patient Partners.</p> <p>Primary care physicians participating in the study, become more aware of the sex and gender considerations when treating those living with diabetes.</p> <p>Building capacity in KT and patient oriented research; a Master student will graduate in October 2020).</p> | <p>into diabetes health planning for those who use the intervention.</p> <p>Strategic partnerships with psychiatry researchers and community mental health support services are established to increase impact of Diabetes Action Canada and help address the concern of its Patient Partners.</p> | <p>struggling in their self-management.</p> <p>Assessing impact on integration of sex and gender in continuous professional development and how it has changed the behaviours of practitioners and outcomes for patients.</p> <p>Development of knowledge and expertise on integration of sex and gender in continuous professional development context.</p> |
| <p>8 Collaboration with Aging, Community and Population</p> | <p>Funding secured through SPOR PICHIN grant competition.</p> | <p>Intervention is implemented in Quebec based PBRNs and</p> | <p>Intervention is scaled across PBRNs in Quebec as community-based program</p> | <p>Older Canadians with diabetes in Quebec have access to community-based</p> |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---|---|---|--|
| <p>Health to scale intervention in Quebec</p> | <p>Two PBRN sites in Quebec are secured to pilot intervention.</p> <p>Scalability assessment of intervention complete.</p> <p>Completed Phase 1 and began Phase 2 of the Quebec Portion of ACHRU-CPP (Study 13), Diabetes Self-Management in Older Adults.</p> <p>Data collection underway in two PBRN sites in Quebec.</p> | <p>modified for these sites to maximize uptake and impact.</p> <p>Diabetes Action Canada programs have access to expertise in KT to enhance research activities.</p> <p>Diabetes Action Canada research programs have opportunities for new strategic partnerships in Quebec.</p> | <p>to increased quality of life for both caregivers and older adults with diabetes.</p> <p>Begin Phase 3, Planning for Scale Up, of the Quebec Portion of ACHRU-CPP (Study 13).</p> | <p>programs to promote healthy aging at home.</p> |
| <p>9 COMPAS+ Navigation guide for patients living with T2D</p> | <p>Partnership established with Diabetes Quebec.</p> | <p>New quality improvement activities in the prevention and management of chronic disease, including diabetes are catalyzed in Quebec.</p> <p>Strategic partnership with Diabetes Quebec will increase access of guide to policy and decisions makers.</p> <p>Integral component for strategic planning for the</p> | <p>Partnerships with key stakeholders are fostered to disseminate knowledge.</p> | <p>People living with diabetes will have increased access to tools to improve their lived experience</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|----|---|--|---|---|--|
| | | | next phase of the KT enabling program | | |
| 10 | Delivery of preconception care education by pharmacists to women with diabetes | <p>Online education modules launched entitled “Preconception Care in Women with Diabetes: What Do Pharmacists Need to Know?.</p> <p>Online education program launched through Diabetes Pharmacists Network.</p> | <p>Capacity building among pharmacists in counselling women of child-bearing age with diabetes being established.</p> <p>Pharmacists are becoming integral to the circle of care for women with diabetes.</p> | Optimal preconception care for women with diabetes to ensure healthy outcomes for mother and child is promoted. | Pharmacists involved in identifying gaps in the health system for preconception women with diabetes and influence practice guidelines to fill these gaps. |
| 11 | Supporting and empowering pharmacists to improve the care of people with diabetes across Canada | <p>Collaborations established with pharmacists, researchers and experts.</p> <p>Publications about the Network:</p> <ul style="list-style-type: none"> - Guest Editor - Canadian Journal of Diabetes 2017;41(6) - MacCallum L, Lewis G. Creation of a Diabetes Pharmacists Network in Canada. Can J Diabetes 2017;41(6):571-575 - Editorial - MacCallum L, Dolovich L. Follow-up in community pharmacy should be routine, not extraordinary. Can Pharm J 2018;151(2):79-81. - Simpson SH, MacCallum L, Mansell K. Pharmacy practice and diabetes care. Can J Diabetes 2017;41(6):549-550 | <p>Best practices are promoted through publications and novel education initiatives to support pharmacists in the care of people with diabetes.</p> <p>Online community is engaged in generating new knowledge on the role of medications in diabetes and the role of the pharmacist in diabetes care and management.</p> | Strategic partnerships are established to increase impact of Diabetes Pharmacists Network in achieving common goals of improved management for those with diabetes. | <p>Pharmacists as a primary point of contact for people living with diabetes are integral in improving outcomes.</p> <p>Pharmacists who exemplify best practices through networking, education, and knowledge translation initiatives are empowered and supported.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|----|---|---|---|---|--|
| | | <p>Banting & Best Diabetes Centre (BBDC) Guidebook for Pharmacists on Diabetes Management Launched a practice tool designed to help health care providers safely and effectively use SGLT2 inhibitors in their practice.</p> <p>Annual meeting Diabetes Pharmacists Network meeting held in conjunction with Diabetes Canada Conference</p> <p>Academic publications – 9 in 2017-18</p> | | | |
| 12 | Evaluating the KT activities within the DAC network | <p>A written report for DAC outlining findings of the evaluation</p> <p>A set of recommendations outlining how the KT goal group could enhance their involvement in DAC research activities to optimize the uptake of knowledge they produce for use in their CIHR funding renewal</p> <p>Peer-reviewed publication in an open-access journal</p> | <p>Convene a project team to conduct the evaluation</p> <p>Identifying all research projects that were conducted and/or supported by the DAC network since the inception of the program</p> <p>Develop and administer an online survey to all DAC network principal and/or co-investigators of the identified research studies.</p> | <p>Map the research activities conducted via the DAC network since its inception, and identify the KT activities considered in each (i.e., knowledge dissemination, implementation, sustainability, scalability, whether an integrated knowledge user collaborative strategy was employed, and if any of these activities were evaluated to determine the</p> | <p>Strengthen the DAC network’s potential for sustainable and scalable impact</p> <p>Identify opportunities to leverage the influence of the DAC-KT goal group across the DAC network</p> <p>Generate outputs that can strengthen the DAC network’s preparation for the SPOR renewal</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|----|---|--|--|---|--|
| | | | | uptake of knowledge produced) Identify gaps in KT activities and opportunities for enhancing the uptake of knowledge generated via the DAC network Identify the KT experiences and needs of the DAC network and its investigators | |
| 13 | Collaboration with the Foot Care and Prevention of Amputations Research Program | Award received by postdoctoral fellow Virginie Blanchette | Collaboration across Foot Care and Prevention of Amputations Research Program and KT enabling program Specific project of the postdoctoral fellow | Increased experience of shared decision-making for patients with foot diseases | Reduced amputation for patients with foot diseases |
| 14 | Overall management activities | Contribution and participation in meetings: <ul style="list-style-type: none"> - Operation and management committee meetings (1/month) - Project coordinators meetings (1/month) - Patient engagement group meetings (ad hoc) | Increased collaboration with investigators, coordinators, and members of other goal groups | Develop and foster strategic partnerships | Strengthening of the connections between the Enabling and Research programs in preparation for the SPOR renewal. |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|--|---|---|------------------------------|
| | <ul style="list-style-type: none"> - Health Informatics Goal Group meetings (quarterly) - DAC annual workshop planning activities meetings (2/year) Participation in DAC annual workshop | Increased collaboration with patient partners | | |

Assumption

- Funding continues to support KT activities in 2020-2021
- Additional funding will be obtained to pursue KT activities beyond 2021
- Participants will continue to enroll in studies
- Patients partners will continue to advise the research team
- Provincial and federal governments will continue to support the priorities even if there is a change in party

External Factors

- COVID-19 pandemic; research activities and funding were affected and will still be for the next year
- Staff turnover during the last years
- Difficulty to recruit new staff (i.e. administrative staff, research assistants)
- Research coordinator on sick leave since almost a year, and difficulty to hire a replacement due to union’s collective agreement rules

Patient Engagement Enabling Program

Program Co-Leads: Joyce Dogba, Holly Witteman

Program Co-investigators: Marie-Claude Tremblay, Jon McGavock, Alex M. McComber

Patient Partners (starting from 2020): Dana Greenberg, Nadia Tabiou

Project Coordinator: Olivia Drescher

Ultimate Goal: To include and support people living with diabetes as active partners in health research to maximize the benefits of research for Canadians and their communities

Research Goals:

- ***Specific Goal 1:*** Create a diverse and inclusive pan-Canadian community of people living with diabetes (all types) and their families, research partners of the Diabetes Action Canada Network
 - ***Expanded Goal 2:*** Support Diabetes Action Canada in patient engagement practices in research
 - ***Expanded Goal 3:*** Identify good practices in engaging patients in research and in care, including those from minority groups
 - ***Expanded Goal 4:*** Understanding the barriers and facilitators to engagement in the education of health professionals, including within minority groups
 - ***Expanded Goal 5:*** Contributing to the advancement of partnership science
-

Specific Goal 1: Create a diverse and inclusive pan-Canadian community of people living with diabetes (all types) and their families, research partners of the Diabetes Action Canada Network

| | Activities | Outputs (SMART) | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|--|--|--|---|---|
| 1.1. | <p>Recruit persons living with diabetes and caregivers to participate in research</p> | <p>At least 1 Organization (Network) of People living with Diabetes is approached (by e-mails) especially out of the provinces of Quebec, Manitoba and Ontario every year</p> <p>(indicator: The updated list of Patient Partners is available)</p> <p>Approximately 10 persons living with diabetes are referred to DAC every year to join the Network as Patient Partners</p> <p>At least 8 Recruitment interviews are carried out by the Patient Engagement Coordinator every year</p> <p>At least 8 new Patient Partners are recruited to join the Network as Patient Partners every year</p> <p>At least 2 Patient Partners are recruited out of the provinces of Quebec, Ontario and Manitoba every year</p> | <p>Diabetes Action Canada’s address book grows richer</p> <p>The Patient Partners members’ list is increasing in numbers</p> <p>The recruitment process becomes continuous</p> | <p>New relationships are established with at least three Network of People living with Diabetes</p> <p>Strategic partnerships are established with patients, patient advocacy groups, clinicians, and health care practitioners across Canada to respond to patient needs and support an infrastructure of patient-oriented research.</p> | <p>DAC reflex (the response to think of DAC as a key player in discussions about diabetes)</p> <p>DAC becomes point of reference for information about research on diabetes with the different communities of persons living with diabetes</p> <p>Increased numbers of visits of the website</p> <p>Word of mouth increases number of referrals</p> |

| | Activities | Outputs (SMART) | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|---|---|--|--|---|
| | | To maintain a baseline of 75 active Patient Partners every year (including a yearly turnover of 5 Patient Partners) | | | |
| 1.2. | <p>Foster a community of patient-oriented research within Diabetes Action Canada with Patient Partners as key stakeholders in the research decision-making process</p> | <p>The three Patient Partner Circles established are functional:</p> <ul style="list-style-type: none"> - Collective Patient Circle; - Francophone and Immigrant Patient Circle; and, - Indigenous Patient Circle. <p>The established Terms of reference and governance are revised yearly if necessary</p> <p>The established Policy for Patient Partner engagement compensation is revised if necessary</p> <p>Materials adapted to maximize accessibility of information for persons in need of accommodations in every meeting of Diabetes Action Canada.</p> <p>Culturally relevant and accessible materials co-constructed as needed to maximize patient</p> | <p>Every Diabetes Action Canada researcher has the opportunity to engage with Patient Partners for his/her research activities.</p> <p>Feedback obtained on research projects gathered from diverse Patient Partners representing diverse communities and populations within Canada</p> <p>Relationships are built with people living with diabetes and their communities.</p> <p>Patient Partners are engaged in the generation of new knowledge and planning research questions that are</p> | <p>Capacity for patient-oriented research in diabetes is strengthened with researchers having access to Patient Partners and engagement facilitation.</p> <p>Patient engagement is integrated optimally in all network activities and programs.</p> <p>Patient Partners are critically important collaborators on all research activities.</p> | <p>Patient perspectives are integral to research planning and steering projects toward outcomes that are relevant and useful to all Canadians living with diabetes.</p> <p>A learning health environment is established within our Network to improve the health outcomes of those living with diabetes by providing evidence to improve how our healthcare system can better serve diverse patient populations.</p> <p>Evidence derived from patient-oriented research is translated into new recommendations for policy</p> |

| | Activities | Outputs (SMART) | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|---|---|---|---|--|
| | | <p>participation and understanding for persons with diabetes likely to be underserved.</p> | <p>meaningful and relevant to the diabetes community.</p> <p>Opportunities to enhance patient engagement within research programs are identified.</p> | | <p>decision-makers to reform current provincial and national diabetes strategies.</p> |
| 1.3. | <p>Build capacity for patient engagement in research on diabetes and its related complications in collaboration with the Training & Mentoring Enabling group of Diabetes Action Canada</p> | <p>In-person or online training are available both in French and English</p> <p>Training sessions are offered to Patient Partners</p> <p>Needs for additional training (for example in administrative skills) are identified</p> <p>Resources for additional training are advertised on the DAC website</p> <p>Meetings are scheduled with the Training and Mentoring Enabling group of Diabetes Action Canada to discuss the trainings</p> | <p>Patient partners skills in patient-oriented research is enhanced yearly</p> <p>Every Patient Partner has received the training in patient-oriented research at least once</p> <p>Patient partners' knowledge, skills and behaviours regarding patient-oriented research are enhanced</p> | <p>Trainings help Patient Partners better participate in DAC meetings</p> <p>The Training and Mentoring and Patient Engagement Enabling Groups increase their collaboration</p> <p>DAC collaborates actively with the SPOR Support Units to update training courses</p> | <p>Each DAC Patient Partner is equipped to actively engage in patient-centered research.</p> <p>Patient partners' sense of self-efficacy regarding their involvement in research is improved</p> |

| | Activities | Outputs (SMART) | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|--|---|--|--|-------------------------------------|
| | | Annual update of new training courses developed by SPOR support units | | | |
| 1.4. | <p>Mobilize diverse groups of people who bring a variety of backgrounds, expertise, ideas, types of diabetes, and personalities</p> <p>Ensure engagement of people more vulnerable to developing the complications of diabetes including immigrants and Indigenous peoples</p> | <p>DAC members (patients and researchers) are sensitized to equity, diversity and inclusion.</p> <p>Wherever possible, official DAC communications are produced in both English and French and adapted (e.g. for the blind).</p> <p>Recruitment efforts are made to achieve diversity within Patient Partners (province of residence, rural vs urban, sex, type of diabetes, language, minority, underserved).</p> <p>Maintaining equity, diversity and inclusion (EDI) is one of DAC's guiding principles.</p> <p>People who live in situations that make them more vulnerable to the development of diabetes complications are well identified within DAC</p> <p>They are represented in Partner Patient Circles. A spokesperson is appointed if necessary.</p> | <p>DAC members are sensitized to issues of equity, diversity and inclusion (EDI)</p> | <p>Opportunities to collaborate in patient engagement projects with other SPOR entities emerge</p> | |

| | Activities | Outputs (SMART) | Immediate Outcomes (2019-20) | Anticipated Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|---|--|---|--|--|
| | | <p>A systematic assessment of the level of inclusion of these individuals is carried out annually within DAC.</p> <p>Researchers are intentional in applying the principles of equity, diversity and inclusion (EDI) in the recruitment of their students.</p> | | | |
| 1.5. | <p>Involve Patient Partners at every <i>level</i> (governance, tactical and operational) of the Network and in all <i>phases</i> of the research process (planning of studies, conducting the studies, disseminating the studies' results, and implementing results of studies)</p> | <p>At least two Patient Partners are recruited to Diabetes Action Canada governance committee, leadership roles within research projects and various research activities within the Network.</p> <p>The inclusion of patient partners in research projects is becoming common practice.</p> <p>Goal directed and Enabling Programs are Co-led by Patient Partners.</p> | <p>Patient Partners are actively engaged in the operations, management, and research activities in our network.</p> | <p>Patients are active partners in deciding how solutions to health care are developed, investigated and delivered in Canada</p> | <p>Evidence is generated jointly with Patient Partners to advocate for change with policy decision-makers on current diabetes care delivery.</p> |

Expanded Goal 2: Support Diabetes Action Canada in patient engagement practices in research

| Activities | | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------------|---|--|--|--|---|
| 2.1. | Support Patient Partners in developing guidance for researchers on what to do and what not to do when collaborating with Patient Partners | <p>Guidelines for patient engagement are developed by Patient Partners with the support of the Patient Engagement Enabling Program.</p> <p>Patient Partners are recruited to Diabetes Action Canada governance committee, leadership roles within research projects and various research activities within the Network.</p> <p>Goal directed and Enabling Programs are Co-led by Patients Partners</p> | <p>Researchers have the instinct to consult with patients about their engagement practice.</p> <p>Patient Partners are systematically consulted for all major Network decisions.</p> | | The response: Patient voice exists within DAC |
| 2.2. | Support Patient Partners in developing a mechanism to provide feedback to researchers | <p>Ongoing performance evaluation is implemented by the Patient Engagement Team.</p> <p>Systematic feedback occurs for all DAC meetings involving Patient Partners.</p> <p>Patient partners know who to contact in case of dissatisfaction.</p> <p>Follow-up is done with Patient Partners who decide to leave the network.</p> | <p>Capacity is built in meaningful patient engagement among researchers and Patient Partners.</p> | | |
| 2.3. | Support Patient Partners in developing a mentorship program for other Patient Partners | <p>Patient Partners are informed of mentorship opportunities</p> <p>Patient Partners who wish to be mentors are trained</p> | | | |

| | Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------|---|--|--|--|--|
| | | <p>Patient Partners are approached by the Patient Engagement Group to become mentors.</p> <p>The SPOR Support Units are consulted and contribute to the mentoring program</p> | | | |
| 2.4. | <p>Ensure that researchers take the Patient-Oriented Research training</p> | <p>A logbook is maintained with the list of trained researchers.</p> <p>Invitations for online or in-person training sessions are sent to researchers.</p> <p>If necessary, the network leadership sends a personalized invitation to researchers who have yet to receive training.</p> <p>Training is mandatory for trainees.</p> <p>A training date is set for any new researcher who wishes to join the network.</p> <p>An update of the training should be done every 5 years.</p> | | | <p>A culture shift towards patient-oriented research in diabetes is achieved among researchers</p> |
| 2.5. | <p>Collect patients' priorities regularly</p> | <p>Patient Partners' concerns are regularly raised, either directly at meetings within the Circles or indirectly at other meetings of the network.</p> | <p>A research priorities list is updated annually.</p> | <p>Diabetes Action Canada research programs and objectives adapt to the needs articulated by Patient Partners.</p> | |

| Activities | Outputs | Immediate Outcomes (2019-20) | Anticipates Intermediate Outcomes (2020-22) | Ultimate Outcomes (2022 and beyond) |
|------------|--|------------------------------|---|-------------------------------------|
| | <p>A place to identify concerns (forum, James Lind Alliance) is defined jointly with the Knowledge Translation group.</p> <p>The concerns expressed are transformed into research questions.</p> | | | |

Expanded Goal 3: Identify good practices in engaging patients in research and in care, including those from minority groups

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---|--|--|---------------------------|
| <p>3.1. Project Evaluating Meaningful Patient Engagement</p> <p>Investigate meaningful patient engagement and establish measureable indicators to demonstrate impact.</p> | <p>Collaboration with UBC established for Patient Engagement in Research Scale (PEIRS) project to translate evaluation tools to French.</p> <p>Annual periodic survey evaluation of the Patient Engagement Enabling group</p> <p>Occasional (quarterly) interviews with Patient Partners to uncover and address tokenistic commitments.</p> | <p>Meaningful evaluation tools are accessible in both French and English.</p> <p>Patient partners are engaged in the development of tools for evaluation.</p> <p>Measurement tools are routinely used within DAC to assess patient engagement.</p> <p>Gaps in patient engagement in underrepresented</p> | <p>The experience of Patient Partners within DAC is increasingly improved / Patient Partners testimonials reflect their satisfaction.</p> <p>Indicators to assess meaningful patient engagement are developed and validated.</p> | |

| Activities | | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|---|---|--|--|---|
| | | | populations at risk of developing diabetes are identified. | | |
| 3.2. | Research Partnerships with People Living with type 2 Diabetes: Practices and Issues with Immigrants in Quebec | The scientific article written by postdoctoral student Séraphin Balla is submitted for publication. | The stakes of partnerships with people from ethnocultural minorities in Quebec are better understood within DAC. | Lessons learned from this study are translated into practice within DAC. | |
| 3.3. | Understanding Research Partnerships with Immigrant Patients from Ethno-cultural Minorities: A Realist Review | A literature review on the challenges of partnerships with patients from ethno-cultural minorities is completed within 18 months. | A practical guide from this literature review is produced for DAC researchers. | | Ethnocultural minorities are increasingly involved in research partnerships. They are less and less considered « hard-to-reach » |
| 3.4. | Understanding Research Partnerships with Indigenous Communities: A Realist Review | A literature review on the challenges of partnering with Indigenous people is completed within 18 months. | A practical guide from this literature review is produced for DAC researchers. | | Indigenous people are increasingly involved in research partnerships. |
| 3.5. | Engaging Indigenous patient partners in patient-oriented research: Lessons from a one-year initiative | | | | They are less and less considered « hard-to-reach » |
| 3.6. | Project: " stigmatization related to diabetes and engagement in research among ethno-cultural | The scientific article is submitted for publication. | A knowledge transfer plan derived from the results of this study is available and implemented. | | |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---------|-----------------------------------|---|------------------------------|
| minority immigrants: a qualitative study". | | | | |

Expanded Goal 4: Understanding the barriers and facilitators to engagement in the education of health professionals, including within minority groups

| Activities | Outputs | Immediate Outcomes (2018-19) | Anticipates Intermediate Outcomes (2019-21) | Ultimate Outcomes (2021 and beyond) |
|--|--|---------------------------------|---|--|
| 4.1. Development and evaluation of video learning modules to capitalize on Patient Partners' expertise | The modules are operational and tested in the Laval University course entitled 'MMS-IV : Médecin, Médecine et Société IV; thème : le pas vers la pratique et l'externat' | | | |

Expanded Goal 5: Contributing to the advancement of partnership science

| Activities | Outputs | Immediate Outcomes (2018-19) | Anticipates Intermediate Outcomes (2019-21) | Ultimate Outcomes (2021 and beyond) |
|---|--|---------------------------------|---|--|
| 5.1. Strategy for Patient-Oriented Research (SPOR) Patient and Public Engagement (PPE) Evaluation Framework Project | <p>Knowledge gaps in engaging patients in research are identified.</p> <p>A framework for evaluating Patient engagement is jointly developed with the research team within 12 months</p> | | | |

| Activities | | Outputs | Immediate Outcomes (2018-19) | Anticipates Intermediate Outcomes (2019-21) | Ultimate Outcomes (2021 and beyond) |
|------------|--|-----------------|---------------------------------|---|--|
| 5.2. | Understanding Research Partnerships with Immigrant Patients from Ethno-cultural Minorities: A Realist Review | See section 3.3 | | | |
| 5.3. | Understanding Research Partnerships with Indigenous Communities: A Realist Review | See section 3.4 | | | |
| 5.4. | Translation and cultural adaptation of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective | See section 3.1 | | | |

Training and Mentoring

Program Co-Leads: Mathieu Bélanger, André Carpentier

Program Co-investigators: Denis Blondin, Neeru Gupta, Caroline Jose, Monica Parry, Marten Sénéchal, André Tchernof

Program Coordinator: Michelle Murray

Program Goal:

- Building Capacity in the next generation of diabetes researchers across Canada in Patient-Oriented Research (POR) methods pertaining to all CIHR pillars by developing and organizing training and mentoring opportunities for graduate students (MSc and PhD), postdoctoral fellows and health professionals in POR in diabetes and its related complications.

| Activities | | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|--|---|--|---|---|
| 1 | Patient-oriented research (POR) training | <p>Patient-oriented research training materials completed in both English and French.</p> <p>Strategic partnerships established with Quebec Cardiometabolic Health, Diabetes and Obesity Research Network (CMDO) and Diabetes Canada.</p> <p>Collaboration established with Maritimes and Quebec SPOR SUPPORT Units, Diabetes Research Envisioned and Accomplished in Manitoba (DREAM) and Can-SOLVE CKD Network.</p> | <p>Capacity is being built in patient-oriented research among all Diabetes Action Canada members.</p> <p>Training and mentoring opportunities are available for graduate students, postdoctoral fellows and health professionals in patient oriented research.</p> | <p>Patient-oriented research capacity is strengthened with supporting evidence on the impact of the training program.</p> <p>Mutual understanding of the research process in patient-oriented research is achieved for both Patient Partners and researchers who participate in the training.</p> <p>Strategic partnerships are developed and fostered to effectively</p> | <p>Culture shift towards patient-oriented research is achieved among Diabetes Action Canada investigators and collaborators, both nationally and internationally.</p> <p>Patient-oriented research is integral to health care decision-making and person-centered care among those who have taken the training.</p> |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|--|--|--|---|
| | <p>Membership with SPOR Network Training and Mentoring Committee.</p> <p>Patient partners are engaged in delivery of POR training and have contributed to developing an online patient decision tool for POR training. DAC also supports the development, translation and testing of this tool and a POR decision tool for investigators. Training session feedback yielded a positive response from its participants.</p> <p>CMDO Winter Camp – 4-day French Camp:</p> <ul style="list-style-type: none"> - 4 sessions (2017, 2018, 2019, 2020) - 66 participants trained <p>Diabetes Canada Trainee Day:</p> <ul style="list-style-type: none"> - 3 in conjunction with Diabetes Canada Professional Conference (2017, 2018, 2019) - 68 participants trained <p>POR training workshops delivered:</p> <ul style="list-style-type: none"> - 4 in English (January 27-28, 2017, March 3-4, 2017, May 3, 2018, May 30, 2019) - 48 participants trained - 5 in French (February 11-12, 2017, March 22, 2017, March 15-16, 2018, March 15, 2019, February 8, 2020) | <p>Diabetes Action Canada enabling research programs: Patient Engagement, Indigenous People Health, Sex and Gender and KT Programs collaborate to offer curriculum content that is relevant to Diabetes Action Canada membership.</p> <p>Training and mentoring activities are leveraged among the SPOR SUPPORT units in both the Maritimes and Quebec, and the other SPOR Networks as part of pan-Canadian patient-oriented research training committee.</p> <p>Program evaluated and iteratively improved based on participant and Patient Partner feedback.</p> | <p>disseminate POR training generated by Diabetes Action Canada.</p> <p>All members, collaborators and trainees of Diabetes Action Canada are trained in patient-oriented research training and apply the principles when conducting new and existing research projects.</p> | <p>People living with diabetes have better outcomes and better experiences with their healthcare from those who have been trained and apply the principles of patient-oriented research.</p> <p>Creation of a Network-of Networks for POR training in Canada that includes diabetes and its related complications along with the Networks in other chronic diseases.</p> <p>Diabetes Action Canada is integral in scaling patient oriented research training across the country through collaboration with the SPOR National Training Entity.</p> |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|------------|---|-----------------------------------|--|------------------------------|
| | <ul style="list-style-type: none"> - 73 participants trained <p>Learning Pathways Training Workshops:</p> <ul style="list-style-type: none"> - 1 in English (April 12-13, 2019) - 28 participants trained - 1 in French (March 10-11, 2020) - 21 participants trained <p>Total of training sessions offered: 18 sessions</p> <p>Total participants trained by category:</p> <ul style="list-style-type: none"> - 47 patient partners - 3 family members - 151 trainees - 65 researchers and research professionals - 2 clinical scientist - 12 healthcare professionals - 3 decision-makers/administrators in healthcare - 6 DAC staff and Steering Council - 2 members of other Networks - 13 Others (1 Diabetes Canada staff, 5 research assistants, 6 coordinators, 1 data manager) <p>Total of participants trained: 304</p> | | | |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|--|---|--|---|
| | | Independent formal evaluation to understand impact of Research Program completed. Final report submitted June 1, 2020. Revised report submitted June 30, 2020. | | | |
| 2 | Mentorship, Internship and Fellowship programs | <p>Mentoring scholarship requirements and selection criteria established for program.</p> <p>Internship scholarship requirements and selection criteria established for program.</p> <p>Fellowship scholarship requirements and selection criteria established for program.</p> <p>Partnership with Diabetes Canada established.</p> <p>Patient Partner and peer review process for applications established.</p> <p>Mentorship Program Awardees selected:</p> <ul style="list-style-type: none"> - 4 awarded in 2017 - 3 awarded in 2018 <p>Internship Program Awardees selected:</p> <ul style="list-style-type: none"> - 3 awarded in 2018 - 2 awards in 2019 <p>Post-Doctoral Awardees selected:</p> | <p>Building capacity in patient-oriented research for diabetes and its related complications for members of Diabetes Action Canada.</p> <p>Patient Partners are actively engaged in reviewing program applications and selecting projects for award.</p> <p>The success of the trainees/mentees in obtaining external funding in patient-oriented research and publications in patient-oriented research is understood.</p> | <p>Capacity is strengthened with evidence of trainee successes in patient-oriented research in diabetes and its related complications among those who received awards</p> <p>Capacity is maintained through framework of SPOR education and mentorship.</p> <p>Patient-oriented research findings generated from Diabetes Action Canada are translated into clinical practice guidelines and healthcare practice.</p> <p>Diabetes Action Canada recognized as a reputable source of evidence-based knowledge and KT tools in diabetes and its related complications.</p> | <p>Culture shift towards patient-oriented research is achieved among those trainees/mentees early in their careers.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|--|--|--|---|
| | | <ul style="list-style-type: none"> - 1 in 2017 (in collaboration with Diabetes Canada) - 1 in 2018 (in collaboration with Diabetes Canada) - 4 in 2019 (Training and Mentoring Fellowship Program) <p>Total: 18 awards</p> <p>Mentorship awardee produced 8 publications (2 in 2018-19, 5 in 2019-2020, 1 in 2020-21)</p> <p>Post-doctoral awardees produced 5 publications (3 in 2017-18, 2 in 2018-19)</p> <p>Quantitative evaluation framework to track trainees and mentees who have completed their programs created.</p> | | | |
| 3 | Utilizing virtual interactive cases to develop trainee’s knowledge and clinical reasoning skills | <p>Four Virtual interactive cases complete and validated. In the process of being updated.</p> <p>Cases integrated into the Quality Education and Safety Committee (QUEST), which is part of the Banting and Best Diabetes Centre</p> | Capacity is being built in POR curriculum for Nurse Practitioners, primary care providers and diabetes educators with exposure to real-life clinical scenarios across the life span. | Trainees understand social determinants of health as it relates to diabetes care. This also includes sex and gender differences in diabetes care, management and risk of complications (e.g., cardiovascular disease). | Culture shift towards patient-oriented research for nurse practitioners, primary care providers and diabetes educators is achieved by those who participated in the training. |

Diabetes Action Canada Logic Models 2019-20

Assumptions:

- Additional funding will be obtained
- Participants will enroll in future training sessions
- Trainees (graduate students (MSc and PhD), postdoctoral fellows) will apply for Mentorship, Internship and Postdoctoral Fellowship awards
- Patient Partners will co-facilitate training sessions and participate in the peer review process for applications
- Facilitators will prepare and deliver training sessions

External factors:

- Other SPOR Networks and Support Units that offer and deliver training opportunities
- Other institutions that offer Mentorship, Internship and Postdoctoral Fellowship opportunities

Sex and Gender

Program Co-Leads: Paula Rochon, Robin Mason

Program Co-Investigator: Paula Harvey

Program Coordinator: Jennifer Akerman

Research Goals:

- (1) Enhance capacity of Diabetes Action Canada research teams to integrate sex and gender- based analysis* in all their activities
- (2) Provide sex and gender-based analysis plus (SGBA+) support to DAC and other SPOR Program investigators

*Expanded in 2019 to include other identity related factors, the ‘+’ of SGBA+

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|---|---|--|---|
| 1 | Development of Women’s Xchange online modules; The <i>Health Researcher’s Toolkit: Why Sex and Gender Matter</i> | Completed: 7 e-modules on applying a sex and gender lens in health research: <ul style="list-style-type: none"> - Activism and Evidence - Why do Sex and Gender Matter - Inclusive Sex and Gender Data Collection in Survey Research - Sex-Specific Analyses and Reporting in Clinical Trails - Integrated Mixed Methods - Concept Mapping: Gendered Perceptions of Intimate Partner Violence | Change in awareness by DAC researchers and patient partners, CIHR, Ministry of Health and the other SPOR funded entities of The Health Researcher’s Toolkit | The Health Researcher’s Toolkit eLearning modules are adopted as essential training for DAC researchers and patient partners. Increased understanding of how diabetes is experienced by men, women, boys, girls, people of diverse genders. | DAC investigators first learn to integrate in their health research studies. DAC investigators adapt SGBA+ into their health research studies. |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---|--|---|---|
| | <ul style="list-style-type: none"> - Beyond Sex and Gender: Making Research More Participatory for Vulnerable Populations <p>In development: Two new e-modules</p> <ul style="list-style-type: none"> - Intersectionality Explained - Sex and Gender Considerations for Research with Indigenous Communities | <p>Increased understanding of what intersectionality means and why it is important in health research studies.</p> | <p>A better understanding of how sociodemographic identity factors intersect with sex and gender to influence the lived experience of people with diabetes.</p> | |
| <p>2 Development of essential metrics for the assessment of sex and gender in research proposals</p> | <p>Journal article, “Essential Metrics for the Assessment of Sex and Gender Integration in Health Research Proposals Involving Human Participants” complete and published</p> <ul style="list-style-type: none"> - Day, S., PLoS One, 2017; 12(8): e0182812 <p>Revision of Essential Metrics to incorporate the ‘+’ in SGBA+</p> | <p>Increased awareness of the metrics throughout the DAC Network.</p> | <p>DAC promotes use of the metrics. The metrics are used by DAC investigators to improve their research proposals.</p> <p>Sex and gender considerations are strengthened in DAC investigators’ proposals.</p> | <p>Diabetes Action Canada is a leader in the integration of SGBA+ in research.</p> <p>DAC affiliated investigators receive funding for their studies.</p> <p>Evidence generated from DAC studies inform treatment plans and self-management behaviors; many diabetes-related complications are avoided.</p> |

| | Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|---|--|---|---|--|
| 3 | Increase outreach/dissemination of Sex and Gender Enabling Group resources and activities | Publications appear in social and other media outlets; growth in Twitter followers | Communication strategy implemented | Increased awareness of relevance of SGBA+ in diabetes research | Diabetes Action Canada is recognized as a leader in the integration of SGBA+ in research. |
| 4 | Patient partners are engaged in Sex and Gender Enabling Group activities. | <p>Quarterly newsletter for Sex and Gender Research Enabling Group Patient Partners</p> <p>Quarterly webinars to update Sex and Gender Enabling Group Champions on current research, areas for collaboration, and feedback.</p> <p>Collaboration with Patient Partners to review knowledge products and provide feedback (English and French)</p> <p>Develop study protocol for a qualitative research project, “Exploring Gendered Patient Experiences Through Patient-Led Interviews”.</p> | <p>Patient partners have an understanding of sex and gender and their relevance in health research.</p> <p>Patient partners engage in sex and gender enabling group’s research and decision-making processes.</p> <p>Research Ethics submission approved.</p> | <p>Patient partners are actively engaged in research, knowledge generation and dissemination on the implementation of SGBA+.</p> <p>Improved patient partner experience in diabetes research.</p> <p>Increased understanding of the experience, management and treatment of diabetes among diverse populations of men, women and gender diverse people.</p> | <p>Cultural change as SGBA+ is integrated into patient-oriented research.</p> <p>Study findings inform treatment plans and self-management behaviors; many diabetes-related complications are avoided.</p> |
| 5 | Study to explore the impact of integrating a sex and gender lens in DAC research proposals. “Reporting on Sex | Ethics approval obtained. Interviews completed, edited by communications specialist to produce short narratives, and shared with investigators for their approval. | Communications strategy implemented to share narratives on social media outlets and | Narratives increase awareness of the positive impact integrating sex and gender has on research studies. | Narratives contribute to the growing body of knowledge about the impact of |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|--|---|--|--|--|
| and Gender Integration within Diabetes Action Canada: Interviews with Key Investigators.” | | Women’s Xchange and Diabetes Action Canada websites. | | integrating sex and gender in diabetes research. Development of a knowledge translation and communication strategy to actively promote SGBA+ in all research activities undertaken by Diabetes Action Canada. |
| 6 Development of quality standard checklist and reporting template | Quality Standard Checklist and Reporting Template completed (Feb. 2020). | Increased awareness of quality standard checklist with DAC investigators and their home institutions. | Greater number of proposals integrate SGBA+ into their study design. | Diabetes Action Canada adopts a standardized SGBA+ reporting process drawing on existing tools. |
| 7 Provide SGBA+ consultation on research projects from Diabetes Action Canada investigators. | Consulted on 45 research projects with approximately 1/3 of these submitted by Diabetes Action Canada affiliated investigators. | Researchers access SGBA+ expertise to ensure that gender and sex biases are addressed in their research protocols. Research proposals are strengthened and more competitive with integration of SGBA+ lens. | Capacity in applying SGBA+ considerations in patient-oriented research is strengthened. Diabetes Action Canada is recognized as a reputable source of evidence-based knowledge in SGBA+ in diabetes and its related complications. Study proposals submitted by DAC investigators receive funding. | Robust evidence is generated to inform better healthcare policy and practices for those living with diabetes. Patient-oriented research findings generated from Diabetes Action Canada are used by policy decision-makers and knowledge users |

| Activities | Outputs | Immediate Outcomes (2019-2020) | Anticipated Intermediate Outcomes (2020-2021) | Impacts (2021 and beyond) |
|---|--|--|--|---|
| | | <p>Diabetes Action Canada research programs Innovations in T1D, Indigenous Health, KT and Training and Mentoring, collaborate with the sex and gender enabling program to strengthen research proposals and leverage new research funding.</p> | | <p>and transferred into healthcare practice.</p> <p>Culture change is achieved in our healthcare system in managing diabetes and screening for complications that accounts for the patient experiences in each sex and gender population.</p> |
| <p>8 Collaboration and networking with DAC programs, the Ontario SPOR SUPPORT Unit (OSSU), and other SPOR entities</p> | <p>Consultations and presentations provided to DAC investigators with Indigenous youth project, data access and management executive council, patient oriented research training, applicants for DAC awards, training and mentoring. Most recent presentation: “Sex and Gender Considerations in Research Indigenous Communities” for DAC Francophone Training and Mentoring Group (Wendake, Quebec, March 2020).</p> <p>Presentations to OSSU IMPACT award applicants.</p> <p>Correspondence initiated with Kidney Disease, SPOR Chronic Disease Network’s sex and gender champion.</p> | <p>Greater uptake of resources on the Women’s Xchange website, including The Health Researcher’s Toolkit.</p> <p>Increased awareness of SGBA+ and how to apply this lens in health research.</p> | <p>OSSU and other SPOR programs integrate SGBA+ in their research studies.</p> | <p>Patient-oriented research consistently integrates SGBA+, resulting in study findings applicable to the needs of Canada’s diverse population.</p> |

| Assumptions | External Factors |
|--|--|
| CIHR SPOR funding continues and Diabetes Action Canada’s funding is renewed Patient Partners will engage and collaborate Investigators will be motivated to learn/change Knowledge change leads to behaviour change Staff with necessary skills and abilities can be recruited and hired | COVID-19 priorities dominate and prevent Diabetes Action Canada related activities Change in political leadership at provincial or federal level leading to changes in funding priorities Staff turnover Rate of turnover among patient partners Competing research priorities |

Appendix 3: Diabetes Action Canada Sustainability Plan

1. Value Proposition

Diabetes Action Canada has established a clear value proposition that genuinely engages members and stakeholders who share our vision and mission for achieving collective impact. The core success factor of Diabetes Action Canada is Patient Partner engagement. Through the experiential knowledge of our Patient Partners all of our activities are guided to focus on what matters most to persons living diabetes. We now recognize that the KT gaps in diabetes research reside predominantly in two areas. For persons living with Type 1 diabetes the gap is the lack of a cure for this life-long autoimmune disease and the need for further fundamental research and its translation into clinical practice. For all persons with Type 1, Type 2 or gestational diabetes, the gap is lack of access to timely and effective care and prevention of complications that address both social determinants and biologic risk. The health outcomes for anyone with chronic conditions are worsened considerably with coincident diabetes. When coupled with social determinants such as poverty, new immigrant status, frailty in the aged, Indigenous status, diabetes becomes an inequality indicator for adverse health outcomes. Therefore, our vision has resonated with our Patient Partners, researchers, educators and stakeholders who have created a successful collaborative network and experienced its value achieving more than the sum of its parts.

Vision: to transform the health trajectory for all Canadian men, women and children with diabetes at risk of complications.

What we aspire to achieve is outlined in our mission statement that has been embraced by all our members and fulfilled through their projects. The outputs, outcomes and impacts of these activities as stated in our logic models reflect our mission.

Mission: 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 outcomes; health professional experience; health system cost).

2. Successful Governance

Our Steering Council (composed of over 50 % Patient Partners), Patient Partner Circles (Engagement), Operations Management Committee of our 11 Research and Enabling Group co-leads along with Patient Partner Representatives, form an inclusive, transparent and cohesive governance and management organization. This structure has functioned to support and guide the Network leadership and management through our Network startup and establishment phases. Now, our Network has matured to the point of producing outcomes with impact and is ready to continue to spread and scale our evidence-based models within each province and territory.

3. Business Plan for Sustainability and Growth

Diabetes Action Canada is currently engaged in a detailed strategic planning process to define our future priorities for sustained patient-oriented research activities. We are already focusing our collaborative activities in specific provinces (Alberta, Ontario, Quebec, Newfoundland-Labrador) where opportunities to collaborate on designing, implementing and evaluating data-informed digital diabetes learning health models of care and prevention are underway. We will adapt our governance model to provide the backbone governance, leadership, management and communication for a network-of-network collaboration among the provinces and territories over the next 5 years. The business model we are developing will support this nimble organizational structure and function and will support and continue to develop the collaborations among our members that have resulted in over \$40 million in new peer-reviewed research funding in the first 4 years of our SPOR Network. We will build on this model to achieve the collective impact necessary to fulfill our Mission and Vision.

4. Strategic and effective partnering with public and private stakeholders

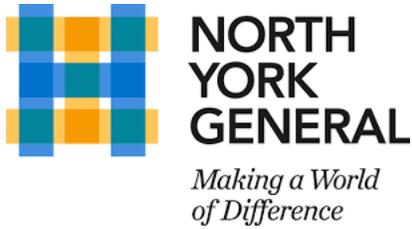
We are continuing to build strategic relationships with Diabetes Canada, JDRF, Fighting Blindness and a number of the SPOR SUPPORT Units. Our goal is to be recognized as a meaningful partner for the implementation of a National/Provincial/Territorial Diabetes Strategy with associated shared resource for the spread and scale of our transformative models of chronic disease health care and prevention.

The administrative headquarters for Diabetes Action Canada is based out of Toronto General Hospital at the University Health Network (UHN) and University of Toronto – part of the largest Health Science Network in North America. The Toronto General Hospital houses the Banting and Best Diabetes Centre (BBDC) and is recognized nationally and internationally for its

diabetes research and care. Our Scientific co-lead, Dr. Gary Lewis, is also the Director for the BBDC and whenever possible synergizes the activities of Diabetes Action Canada and the BBDC. Because of this unique collaborative structure, we are able to work closely with the Toronto General and Western Hospital Foundation (TGWHF) at UHN and their successful development team to garner interest from private industry and philanthropic donors who have been personally affected by diabetes. The TGWHF has named diabetes as a strategic priority for UHN as the 100th anniversary of insulin is approaching in 2021 and has just established a Diabetes Campaign that will support our Diabetes Action Canada projects.

In addition, we are engaging our previous private sector sponsors, e.g., Bayer, Astra Zeneca, SunLife, as well as a host of new potential sponsors. e.g., Novo Nordisk, Boehringer Ingelheim, for new investment. We are also working closely with our investigators as they apply for new funding from CIHR and other sources for ongoing research related to diabetes and its complications within our Network. We are confident that Diabetes Action Canada will continue to be strongly supported through these evolving strategic relationships among both public and private sector stakeholders.

Appendix 4: Evaluation of the Diabetes Action Canada Training and Mentoring Program



**Evaluation of the Diabetes Action Canada (DAC) Training and
Mentoring Program:
A mixed-methods study**

FINAL REPORT

June 19, 2020

Prepared by:

DAC-TM Program Evaluation Research Team, North York General Hospital

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EXECUTIVE SUMMARY

Background and Rationale

The Diabetes Action Canada Training and Mentoring (DAC-TM) Program launched in January 2017 with the goal of building capacity in the next generation of diabetes researchers in Canada in Patient-Oriented Research (POR). Since then, the DAC-TM Program has facilitated POR training to several hundred graduate students, researchers, patient partners, and other DAC members, as well as provided strategic mentorship awards to promising early career investigators.

In December 2018, the research team at North York General Hospital (NYGH) was awarded a grant by the DAC-TM Program to conduct a formative evaluation of the Program. We formed an Integrated Knowledge Translation (IKT) team consisting of our NYGH research team and DAC-TM members to design the evaluation study using a sequential, mixed-methods research design aimed at identifying areas of success, opportunities for improvement, and ultimately to help realize impact and sustainability of the DAC-TM Program.

Methods

Between October and December 2019, we administered an online survey to a wide range of DAC-TM stakeholders and knowledge users, including mentees (award holders), their mentors and supervisors, other participants of DAC-TM who attended various training events, and developers of the Program, to understand the Program functioning, scope, and potential impact. This was followed by a rigorous qualitative interview study conducted between January and March 2020 to gain a more in-depth understanding of stakeholders' perceptions, experiences, and insights about the DAC-TM Program.

Finally, we used a meta-matrix method to triangulate the quantitative survey and qualitative interview data to facilitate our interpretation of the research findings and to create this report.

Results

Our analysis of 82 completed surveys and 22 in-depth interviews from a wide range of DAC-TM Program stakeholders has revealed consistent patterns of their perceptions and experiences about the Program. All stakeholder groups reported that the DAC-TM Program met their needs, goals, and expectations. The training sessions were perceived to be well organized, convenient educational opportunities to gain new knowledge about POR and become integrated into a community of practice of POR researchers who study diabetes and its complications in Canada. The content of the training was perceived to be useful and moderately relevant to participants, although improvements could be made to help address the training needs of the broader DAC community. There is broad support for and appreciation of the mentorship awards, which are perceived to be appropriately targeted to early career investigators. The mentor-mentee relationships were perceived to be positive, productive, and career advancing overall, but could benefit from more strategic design and to promote better connectivity to foster mentor-mentee relationships. Additionally, feedback about opportunities to network and forge new connections with patients, award holders, and senior researchers through the DAC-TM Program was mixed and represents another opportunity for improvement to strengthen capacity building.

Recommendations

Key Strengths

1. The DAC-TM training sessions are high quality, and mentees are receiving valuable training that is useful to their work

2. The DAC-TM Program provides real POR education (using the CIHR POR curriculum) and research opportunities to its participants
3. Program awards and mentorship program are flexible and fairly unstructured with minimal formal requirements
4. The core training sessions of the Program has the ability to connect participants from across the entire DAC Network

Key Opportunities for Improvement

1. Increase the availability and accessibility of the Program events, training sessions, other opportunities and awards training sessions through a marketing strategy
2. Tailor some of the training session content to meet the training needs of the broader DAC community
3. Create more structure and strategic design of the awards to maximize the benefits realized from mentorship opportunities
4. Provide more clarity around the design and effectiveness of the mentorship program to strengthen the DAC-TM Program overall
5. Provide more direction for mentors and mentees to facilitate their expectations, define their roles, and to provide more opportunities for engagement
6. Provide more opportunities for mentees to connect with other potential mentors within the DAC-TM Program and the entire DAC network
7. Develop a more systematic strategy to recruit new participants into the Program
8. Improve communication and coordination across the DAC-TM Program subgroups and between Program members, administrators and participants
9. Formally track how the DAC-TM Program can benefit the mentees and patient partners, which is needed to expand the DAC-TM program and promote its sustainability moving forward

Conclusions

We used findings from this formative evaluation study to identify key strengths and opportunities to improve the DAC-TM Program, which can be used to help enhance the functioning and long-term sustainability potential of the Program as it moves toward building capacity in the next generation of diabetes researchers in Canada in Patient-Oriented Research (POR).

BACKGROUND

Diabetes Action Canada (DAC) is a pan-Canadian research organization that was launched in 2016. Funded jointly by the Canadian Institutes of Health Research's (CIHR) Strategic Patient-Oriented Research (SPOR) program, non-profit organizations (e.g. Diabetes Canada, JDRF), and private sponsors. The DAC Network consists of a diverse team of patient partners, researchers, diabetes specialists, primary care practitioners, nurses, pharmacists, data specialists, and health policy experts committed to improving the lives of persons living with diabetes. It focuses on bringing patients, their caregivers and researchers together to identify the health concerns of those living with diabetes and to co-create research projects that address these concerns. To do so, it partners and collaborates with university research teams across Canada, non-profit organizations, and provincial governments to plan, execute and evaluate research projects focused on improving patient outcomes and experiences.

In January 2017, the DAC Training and Mentoring Program (DAC-TM) was launched with the goal of training mentees at various stages of their career (Master's, PhD, Postdoctoral fellowship, health care professional mentees and early career investigators) who are interested in Patient-Oriented Research (POR) in diabetes and its complications. The Program includes training sessions on the fundamentals of POR, intensive training sessions for graduate students and postdoctoral fellows, the Intercentre Mentorship award for early career investigators, the Intercentre Internship competition for graduate students, postdoctoral fellows, and research professionals and two Postdoctoral Fellowship salary awards per year. The goal of the DAC-TM program is to promote networking and optimal integration of early career investigators into the DAC Network and the Canadian diabetes research community.

In December of 2018, our evaluation team was awarded funding to conduct a formative evaluation of the DAC-TM Program. Formative program evaluation in particular takes place during a project's implementation or early years with the aim of improving its design and performance. As Hulscher et al. (2002) note, formative evaluation allows "evaluators and implementers to (a) describe the intervention in detail, (b) evaluate and measure actual exposure to the intervention, and (c) describe the experience of those exposed" (p. 40) — concurrently. This report outlines in detail our approach, findings and recommendations based on our evaluation.

Objectives

Our main objective was to conduct a formative evaluation of the DAC-TM Program to help identify areas of success and opportunities for improvement, and ultimately to help realize impact and sustainability of the DAC-TM Program.

METHODS

Overview

Our objectives were addressed using a sequential, mixed-methods research design [Cresswell & Clark 2011]. Prior to Phase 1, we formed an Integrated Knowledge Translation (IKT) team consisting of our NYGH research team and DAC-TM members to help design the study and provide guidance and feedback throughout. We also conducted individual in-depth telephone interviews with the DAC-TM Program Leads and Coordinator to obtain background information and contextual details about the Program. Furthermore, we collected and reviewed a range of DAC-TM Program documents to deepen our understanding of the history, structure, and current functioning of the Program (Appendix A). In Phase 1, we administered a survey to a wide range of stakeholders and knowledge users associated with the Program (DAC-TM Program developers, mentors, mentees (award holders), and other training participants) to understand the Program's functioning, scope and potential impact. In Phase 2, we sought a more in-depth understanding of the perceptions and experiences of these knowledge users through one-on-one qualitative interviews.

PHASE 1: Survey

Objectives

Our primary objective was to evaluate the DAC-TM Program by administering an online survey to a wide-range of DAC-TM knowledge users (mentees, their mentors and supervisors, participants of DAC-TM who attended the various training events, and developers and organizers of the Program) aimed at identifying their perceptions and perspectives of their experiences in participating in the training program.

Population and Recruitment

We used a purposive sampling strategy to recruit individuals who participated in the DAC-TM Program between 2017 and 2019 to participate in our study. 245 potential participants were eligible: mentees (n = 16), mentors (n = 25), other training participants (n = 193), and individuals who were involved in the development, governance and organization of the DAC-TM program (n = 6). Recruitment involved two phases. In Phase I, a DAC-TM coordinator disseminated an email to all eligible participants to introduce our study and to prompt their consideration to participate in our study. In Phase II, all eligible participants were sent an email invitation, which included a link to the survey via an online survey platform (SurveyMonkey). For all four surveys, participants had a choice to complete the survey in English or French. The informed consent process was embedded within the online survey whereby the first page of the survey asked potential participants to review the study information and accept or decline consent to participate. Upon consenting, participants were taken to the first survey question. For those who declined, they were asked to provide their reason. We used Dillman's follow-up strategy to maximize our response rates (i.e., three reminders, two weeks apart followed by personalized email to non-responding mentor and mentee participants) [Dillman et al. 2009]. Our study received research ethics approval from the North York General Hospital Research Ethics Board (full board review approval number: 18-005; December 18, 2018).

Survey Development

We developed an online survey in consultation with our IKT team, including consultation with a DAC-TM coordinator to inform our understanding of the DAC-TM Program, including its objectives, development, structure, organization, and target audience/participants (Appendix B). We also used a number of knowledge translation and implementation science frameworks, including RE-AIM [Glasgow et al. 1999] and Proctor [Proctor et al. 2015] as well as educational frameworks [Organisation for Economic

Cooperation and Development (OCED), 2019] to build a matrix of key evaluation questions and indicator domains (Appendix C), which helped us to build the final set of survey questions. Our IKT team helped us to refine and modify these questions according to our four different knowledge user types: 1) DAC-TM mentees; 2) their mentors or supervisors; 3) other participants who engaged in DAC-TM Program activities and training events; and 4) DAC-TM Program developers.

Survey items consisted of a combination of Likert scale and open-ended (free text) questions and included four sections: 1) Demographics; 2) Goals, needs and expectations of the DAC-TM Program; 3) Engagement in DAC-TM training activities; and 4) Satisfaction, feasibility, and fit with other academic and life commitments. For the mentee survey, we also included a section to identify their research activities and to learn about their mentor-mentee relationship. For the mentor survey, we included a section to learn about their mentorship experience. The surveys were pilot tested with three individuals to ensure their coherence and understandability, and the appropriateness and consistency of interpretation of questions. Each of the four surveys were available in both English and French.

Data Collection and Analysis

The quantitative portion of the evaluation survey (Likert-type data) was analyzed using descriptive statistics (frequencies, means) in SPSS, and plotted as bar graphs. Open-ended questions (qualitative data) was analyzed using content analysis and triangulated with quantitative assessments to support data interpretations [Elo & Kyngas 2008, Miles et al. 2013, Wendler 2001].

Outcomes

All four surveys included measures of the following components: (i) participant demographics, (ii) context of participation (iii) process of their program participation; (iv) program fidelity (e.g., did the program function as intended?); (v) impact of the program (i.e., knowledge and skills gained, etc.); (vi) impact of the research conducted; and (vii) overall satisfaction with the program. The mentee survey also collected data on their research productivity while participating in the DAC-TM Program including research outputs (what was planned/done); the mentee's planned and current career activity(ies) and future plans. The mentor survey also collected data about their time commitment to and strategies for communicating with their mentee.

Outputs

Survey findings were used to in part inform the interview guide for PHASE 2 qualitative interviews and final recommendations.

PHASE 2: Qualitative Interviews

Overview

We employed descriptive qualitative methodology to deepen our understanding of the Phase 1 quantitative survey results to identify specific areas of success and areas for improvement, and to generate in-depth knowledge about factors that contribute to the impact and sustainability of the DAC-TM Program. A qualitative approach was selected to leverage the strengths of this methodology in capturing contextual information related to stakeholder perspectives, and because of the emphasis in qualitative research on understanding meanings, perceptions, and experiences participants have of different phenomena of interest.

Our primary method of data collection was individual in-depth interviews conducted by research staff with qualitative research expertise. In-depth semi-structured interviews are used extensively in qualitative research as a way of accessing the subjective perspectives of participants on phenomena of interest and are a useful way of gaining access to the meaning-making activities, thoughts, perceptions, beliefs, and understandings of individual social actors [Marshall & Rossman 1999]. The format helps to forefront the participants' views on the topic rather than that of the researcher, because participants are able to frame and structure their responses as they see fit.

Population, Sample Size and Recruitment

Our sample was selected using purposive and maximum variation sampling. Purposive sampling is virtually synonymous with qualitative research and involves selecting participants who are most likely to have experience with and insights about the topic of study. Maximum variation sampling seeks to capture the widest possible range of perspectives on the topic of study and allows researchers to understand how phenomena are experienced by participants in different circumstances and settings [Miles & Huberman 1994]. These sampling approaches ensured that we included individuals who cover the spectrum of positions, perspectives, and opinions about the DAC-TM Program, and has the great benefit of facilitating the development of well contextualized analysis of study findings.

All DAC-TM Program developers, mentors, mentees, and other training program participants (patient partners, DAC members, and graduate students), including Phase 1 participants who had already volunteered to be interviewed (25 in total) were sent study information letters by email and invited to contact the research team if they were interested in being interviewed. Interviews were scheduled with participants who met our sampling criteria.

Interview Questions

We developed separate interview guides for each group of key stakeholders and knowledge users (DAC-TM Program developers, mentors, mentees, and other training program participants) based on analysis of the surveys, input of team members with expertise in qualitative research, and informed by the objectives of this project. The questions were designed to: elicit participants' perspectives on the DAC-TM Program objectives and how well these had been achieved; their goals and intentions for becoming involved with the Program; experiences with the Program and at specific training events; and perceptions of the Program strengths, opportunities for improvement, and sustainability. The interview guides were reviewed and refined by the study team through three iterations prior to the start of qualitative data collection and revised again after every 3-4 interviews had been completed to ensure that topics of interest were being adequately explored.

Interview Sessions

We conducted the in-depth, semi-structured interviews between January and March 2020. All of the interviews were conducted by telephone by two members of the research team who are trained qualitative interviewers, using the interview guides to provide broad topic areas to guide the discussion. The interviews averaged 30 minutes in length (range 20-60 minutes). All of the interviews were digitally recorded and transcribed verbatim by an external transcription service for analysis.

Data Collection and Analysis

In keeping with the iterative process of qualitative methodology, data analysis occurred in conjunction with data collection. The interview data were analyzed according to

standard thematic analysis techniques [Braun & Clarke 2006]. Comparisons within and across interviews were conducted (the constant comparison technique) in order to continuously monitor emerging themes and general areas for further exploration [Charmaz 2014].

The interview transcripts and field notes were independently reviewed by two members of the research team with qualitative methodological expertise to generate a list of descriptive in-vivo codes that emerged from the data. The analysts independently attached the codes to segments of the text in each transcript through line-by-line readings, and then compared the codes in a sample of five transcripts to ensure consistent application of the coding framework and discuss any discrepancies. The descriptive codes were then grouped into broad topic-oriented categories and all text segments belonging to the same category were compared within and between transcripts. The topic oriented categories were further refined and formulated into fewer analytic categories through an inductive, iterative process. Versions of the analysis were reviewed with the research team at regular intervals, and the final analytic framework, representing themes that reflect patterns and regularities of responses in the coded transcripts, was discussed among all authors until we reached consensus on its validity and applicability.

Outputs

Data triangulated from surveys and qualitative interviews were used to generate a set of recommendations that can be used to optimize the DAC-TM Program and to ensure its long-term sustainability.

Triangulation of Quantitative (Survey) and Qualitative (Interview) Data

We used a meta-matrix method to triangulate survey and interview data to facilitate our interpretation of findings [Miles et al. 2013, Wendler 2001]. The meta-matrix approach provides analytic methods to support interpretations from disparate data sources. These methods include creating a matrix to note commonalities and contradictions of themes emerging from the data, noting reflections, isolating patterns and processes, and gradually building generalizations [Wendler 2001]. This strategy is particularly helpful for converging data from multiple sources, recognizing patterns, confirming findings, and to uncover contradictions or discrepancies in the data.

RESULTS

PHASE 1: Survey

Participant Characteristics

Table 1 shows the characteristics of 82 participants who completed the online evaluation survey between October 25 and December 10, 2019: DAC-TM Program mentees (n = 14), mentors (n = 15), developers (n = 6) as well as other individuals who attended training activities (herein referred to as “Other”) offered between January 2017 and October 2019 (n = 47). The majority of respondents were female (54%) from Québec or Ontario (79%) and were between 25-44 years of age (61%). Participants were mostly researchers or scientists (39%) and graduate students (22%) working in university or college settings (52%); 18% of participants (n = 15) were patient partners.

Table 1: Participant characteristics

| Demographics | All (n = 82) | Mentees n = 14/16 (88%) | Mentors n = 15/25 (60%) | Other n = 47/193 (24%) | DAC-TM Developers n = 6/6 (100%) |
|--------------------------------------|-----------------|-------------------------------|-------------------------------|------------------------------|--|
| Province | | | | | |
| West (BC, MB, SK, AB) | 11 (13.4) | - | 3 (20) | 7 (14.9) | 1 (16.7) |
| Central (QC, ON) | 65 (79) | 12 (86) | 11 (73) | 39 (83) | 3 (50) |
| Atlantic (NFL, PEI, NS, NB) | 6 (7.3) | 2 (14.3) | 2 (13.3) | - | 2 (33.3) |
| Age range | | | | | |
| 20-34 | 22 (26.8) | 4 (28.6) | - | 18 (38.3) | - |
| 35-54 | 37 (45.1) | 10 (71.4) | 9 (60) | 14 (29.8) | 4 (66.7) |
| 55-74 | 20 (24.3) | - | 6 (40) | 12 (25.5) | 2 (33.3) |
| 75+ | 3 (3.7) | - | - | 3 (6.4) | - |
| Sex | | | | | |
| Female | 44 (53.7) | 10 (71.4) | 6 (46.7) | 26 (55.3) | 2 (33.3) |
| Male | 36 (43.9) | 4 (28.6) | 8 (53.3) | 20 (42.6) | 4 (66.7) |
| Other | 1 (1.2) | - | - | 1 (2.1) | - |
| Highest degree held | | | | | |
| Bachelor’s degree or College diploma | 14 (17) | - | - | 13 (27.7) | 1 (16.7) |
| Master’s degree | 26 (31.7) | 1 (7.1) | 2 (13.3) | 22 (46.8) | 1 (16.7) |
| PhD | 14 (17) | 6 (42.9) | 5 (33.3) | 3 (6.4) | - |
| Postdoctoral fellowship | 19 (23.2) | 7 (50) | 5 (33.3) | 5 (10.6) | 2 (33.3) |
| Other (MD, PharmD, Secondary) | 4 (4.9) | - | - | 3 (6.4) | 1 (16.7) |

| Current primary employment role | | | | | | |
|--|-----------|-----------|-----------|-----------|----------|--|
| Researcher or scientist | 32 (39) | 10 (71.4) | 11 (73.3) | 8 (17) | 3 (50) | |
| Graduate student | 18 (22) | - | - | 18 (38.3) | - | |
| Clinician or resident | 5 (2.4) | 4 (35.7) | - | 1 (2.1) | - | |
| Patient | 9 (11) | - | - | 7 (14.9) | 2 (33.3) | |
| Decision makers | 4 (4.9) | - | - | 1 (2.1) | - | |
| Other | 14 (17) | - | 1 (6.7) | 12 (25.5) | 1 (16.7) | |
| Setting | | | | | | |
| University or College | 43 (52.4) | 9 (64.3) | 9 (60) | 21 (44.7) | 4 (66.7) | |
| Hospital | 8 (9.8) | 3 (21.4) | 2 (13.3) | 3 (6.4) | - | |
| Research Institute | 14 (17) | 2 (14.3) | 4 (26.7) | 8 (17) | - | |
| Government | 1 (1.2) | - | - | 1 (2.1) | - | |
| Other | 13 (15.9) | - | - | 11 (23.4) | 2 (33.3) | |
| Not applicable | 3 (3.7) | - | - | 3 (6.4) | - | |
| DAC-TM Award type | | | | | | |
| POR Intercentre Trainee Internship Award | 10 (12.2) | 4 (28.6) | 6 (40) | NA | NA | |
| POR Early Career Investigator Mentorship Award | 14 (17) | 7 (50) | 7 (46.7) | NA | NA | |
| Postdoctoral Fellowship | 4 (4.9) | 3 (21.4) | 1 (6.7) | NA | NA | |
| Did not respond | 1 (1.2) | - | 1 (6.7) | | | |
| Primary role within DAC-TM Program | | | | | | |
| Mentee/Graduate student | 36 (43.9) | 14 (100) | - | 22 (46.8) | - | |
| Mentor/Supervisor | 12 (14.6) | - | 11 (73.3) | 1 (2.1) | - | |
| Developer/Organizer | 8 (9.8) | - | - | 5 (10.6) | 3 (50) | |
| Patient partner | 15 (18.3) | - | - | 14 (29.8) | 1 (16.7) | |
| Investigator | 6 (7.3) | - | 4 (26.7) | 2 (4.3) | - | |
| Other | 5 (6.1) | - | - | 3 (6.4) | 2 (33.3) | |
| DAC-TM participation status | | | | | | |
| Ongoing | 9 (11) | 9 (64.3) | - | NA | NA | |
| Completed | 5 (6.1) | 5 (35.7) | - | NA | NA | |

Mentee Survey

Of 16 eligible mentees who were invited to participate in the evaluation study, 14 completed the survey (88% response rate). Of these, 71% were women and 50% were 35-44 years of age living in Ontario or Québec (86%). At the time of they completed the survey, the majority of mentees held a postdoctoral fellowship (50%) or a PhD (43%) and reported having a position as a researcher or scientist (71%) at a university or college (64%). The awards received by mentees through the DAC-TM Program were a *Patient-Oriented Research (POR) Early Career Investigator Mentorship Award* (50%), a *POR Intercentre Trainee Internship Award* (29%) or a *Postdoctoral Fellowship* (21%). 64% of

mentees reported that their DAC-TM Program training was ongoing at the time they completed the survey.

i. Mentee goals, needs and expectations of the DAC-TM Program

To a large extent, the DAC-TM Program helped mentees gain new knowledge about POR (mean 4.25; SD 0.866), interact with patients (mean 4.00; SD 0.739), and expanded their networks (mean 4.29; SD 0.726). Mentees also understood the goals of the DAC-TM Program from the outset (mean 4.00; SD 0.392). For the remainder of factors (Table 2a; Figure 1) the DAC-TM Program met mentees' goals, needs and expectations to a large extent (mean range 3.46-3.93).

Mentees also indicated that the DAC-TM Program allowed for flexibility to meet their needs and provided access to experienced researchers and to expand their network:

- *"The flexibility of the DAC-TM program was exceptionally valuable and facilitated my ability to tailor the opportunities to meet my individual needs. Many other programs are prescriptive around how/when recipients engage and this limits the potential growth of award recipients" [P2].*
- *"En me donnant un accès simple et illimité aux chercheurs chevronnés (By giving me simple and unlimited access to experienced researchers) [P8]*
- *"Le programme de mentorat a permis d'élargir mon réseau, de valider des pratiques et d'en développer de Nouvelles (The mentoring program has allowed me to expand my network, validate practices and develop new ones)" [P11]*

Table 2a: Extent to which the DAC-TM program met mentee goals, needs and expectations

| Goals, needs and expectations of the DAC-TM Program were met* | N | Mean (SD) |
|--|----|--------------|
| Gained new knowledge about POR | 13 | 4.25 (0.866) |
| Gained new knowledge about Diabetes | 12 | 3.77 (0.927) |
| Interacted with patients | 13 | 4.00 (0.739) |
| Learned how to integrate sex and gender in your research | 13 | 3.46 (1.613) |
| Increased your confidence to conduct POR research in Diabetes | 13 | 3.92 (1.115) |
| Expanded your networks | 14 | 4.29 (0.726) |
| Initiated research collaborations | 14 | 3.93 (0.917) |
| Increased your research productivity | 14 | 3.71 (0.914) |
| Was made aware of the expectations of the DAC-TM Program from the outset | 14 | 3.93 (0.730) |
| Understood DAC-TM goals from the outset | 14 | 4.00 (0.392) |
| DAC-TM Program met my needs | 14 | 3.79 (0.699) |
| DAC-TM Program met my expectations | 14 | 3.64 (0.745) |

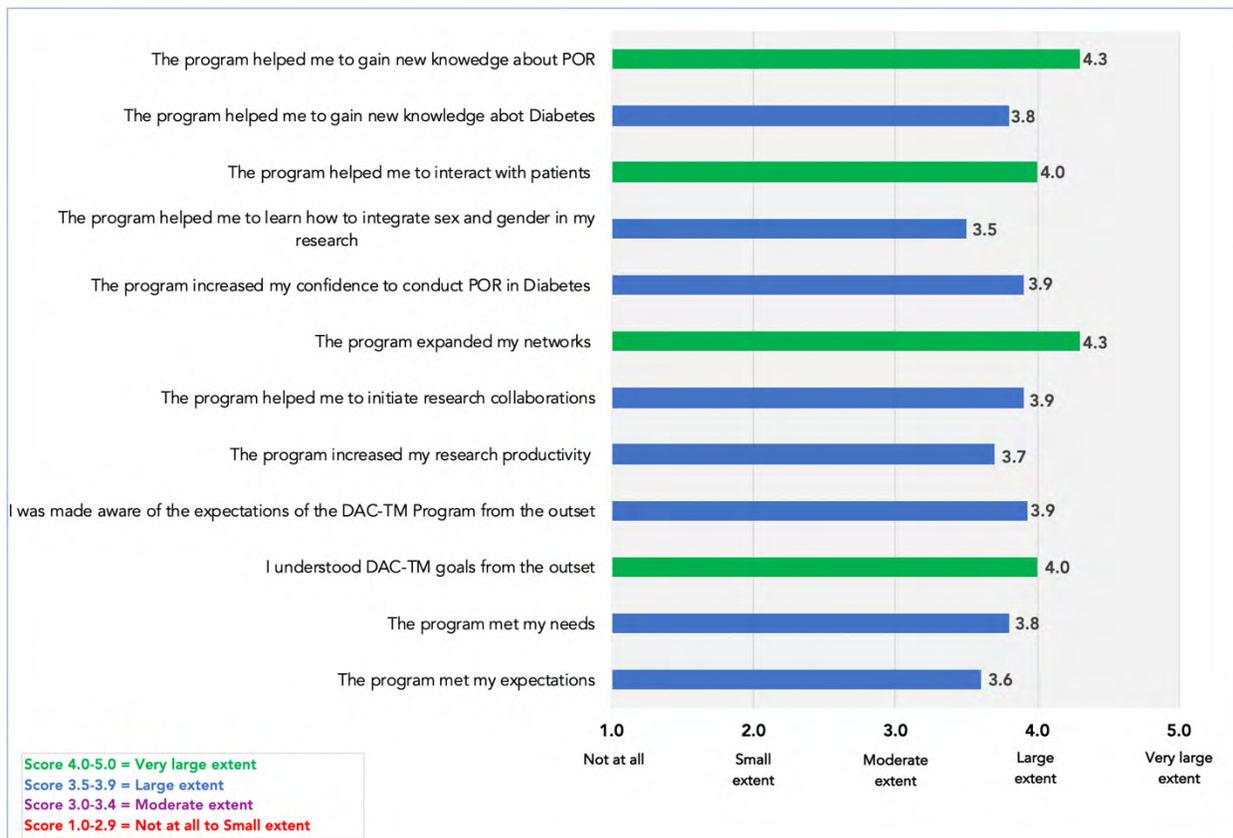
*Green = Very large extent (score 4.0-5.0)

*Blue = Large extent (score 3.5-3.9)

*Purple = Moderate extent (score 3.0-3.4)

*Red = Not at all to Small extent (score 1.0-2.9)

Figure 1: Extent to which mentees achieved their goals



ii. Mentee engagement in DAC-TM activities

Table 2b shows the DAC-TM training activities attended by mentees. The most attended events were the *POR Training pre-DAC Annual Workshop* that was held in Toronto on May 3, 2018 (n = 6), on May 30, 2019 (n = 4), and the *Third Annual Trainee Day Pre DAC Professional conference* that was held in Halifax on Oct 10, 2018 (n = 3); two mentees indicated not attending any of the activities.

Mentees found the training events useful overall (mean 3.93; SD 0.730), but indicated moderate agreement for finding the materials (covered at the training event) relevant for their work (mean 3.79; SD 0.802) or their intention to apply what they've learned in their work (mean 3.64; SD 0.745). Mentees gained knowledge about POR at the training events (mean 4.21; SD 0.802), but to a moderate extent about Diabetes and its complications (mean 3.43; SD 0.646) or research methods (mean 3.43; SD 0.852).

Table 2b: Mentee engagement in DAC-TM activities

| Engagement in DAC-TM activities* | N | Mean (SD) |
|--|----|--------------|
| I found the training event(s) useful overall | 14 | 3.93 (0.730) |
| The material covered in the training event(s) was relevant for my work | 14 | 3.79 (0.802) |
| I gained knowledge about POR at the training event(s) | 14 | 4.21 (0.802) |
| I gained knowledge about Diabetes and its complications at the training event(s) | 14 | 3.43 (0.646) |
| I gained knowledge about research methods at the training event(s) | 14 | 3.43 (0.852) |
| I will apply what I've learned at the training event(s) in my work | 14 | 3.64 (0.745) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

iii. Mentee research activities

Table 2c shows that mentees thought that their research (resulting from their DAC-TM Program participation) represents POR to a large extent (mean 3.64; SD 0.929), and the impact of their research on patients to a moderate extent (mean 3.3; SD 0.994). Some mentees indicated that it's too early to measure the impact of having patient partners

while others have already engaged patients as partners to help design their intervention or to involve them as part of the project team or as an expert:

- *“All of the diabetes-related projects I am currently engaged in have patient partners as part of the core project team (who meet monthly to discuss progress and future plans)” [P2]*
- *“I am engaging with patient partners to design and develop an online tool for use by patients” [P4]*
- *“Vont être consulté comme participant / expert (will be consulted as participant/expert)” [P7]*

Mentees indicated that the DAC-TM Program provided career growth or advancements (as a result of their participation in the Program) to a moderate extent (mean 3.43; SD 1.158), while others indicated that the leadership training provided them with the skills to receive a promotion, strengthened their ability to write grant proposals, and provided protected time to do research:

- *“The leadership training I was able to attend as part of the DAC-TM Program equipped me with the skills needed to pursue and successfully receive a promotion” [P2]*
- *“I have been able to leverage the Program’s mentorship to strengthen my ability to write grant proposals” [P3]*
- *“Obtention de l’entente 250 de la RAMQ, permettant d’avoir 50% de mon temps en recherche (Obtaining of the RAMQ 250 agreement, allowing to have 50% of my time in research)” [P7]*

Table 2c: Mentee research activities

| Mentee research activities* | N | Mean (SD) |
|--|----|--------------|
| Extent to which your research (resulting from participation in the DAC-TM Program) represents POR; (12 respondents [86%] indicated involving patients in their research) | 14 | 3.64 (0.929) |
| Extent to which your research (resulting from participation in the DAC-TM Program) had impact on patients | 14 | 3.29 (0.994) |
| Extent to which your participation in the DAC-TM Program led to any career growth or advancements | 14 | 3.43 (1.158) |

*Green = Very large extent (score 4.0-5.0)

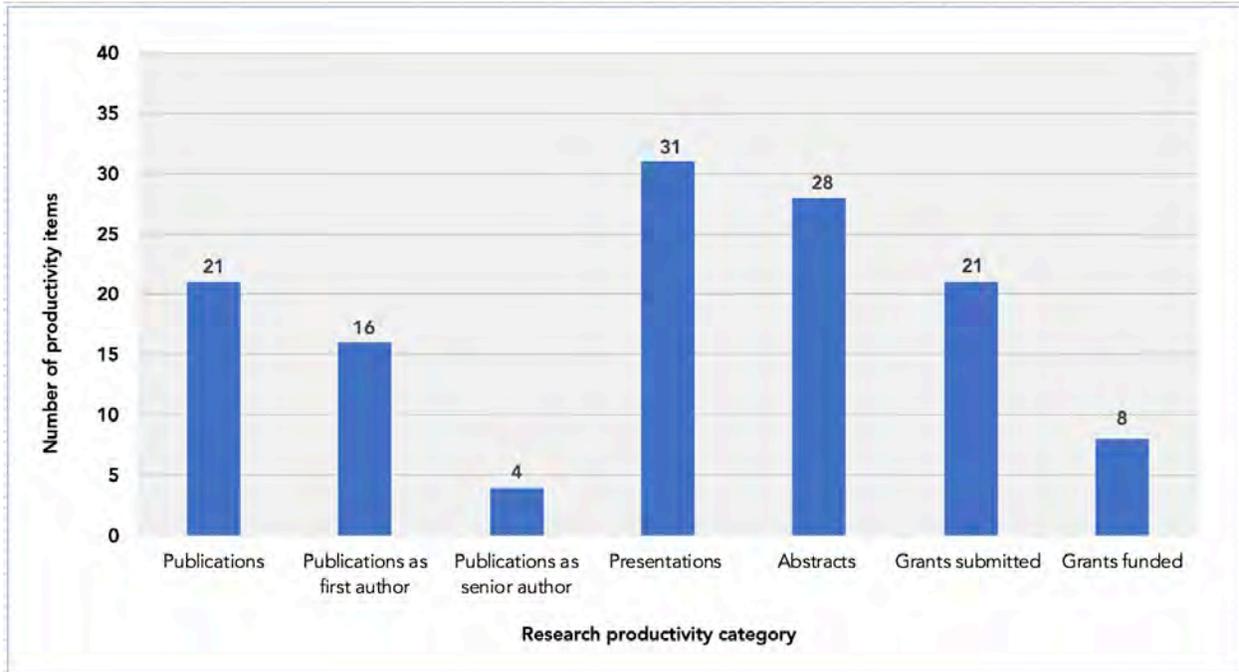
*Blue = Large extent (score 3.5-3.9)

*Purple = Moderate extent (score 3.0-3.4)

*Red = Not at all to Small extent (score 1.0-2.9)

When asked about their research productivity, mentees reported 31 publications (24 as first author; 10 as senior author), 38 presentations, 34 submitted abstracts, and 29 grants of which 14 were funded (Figure 2).

Figure 2: Mentee research outputs (n = 14)



iv. Mentor-mentee relationship

Mentees met with their mentors/supervisors monthly (36%), weekly (29%) or bi-monthly (29%). Table 2d show that mentees indicated strong agreement for all factors related to the effectiveness of the mentor-mentee relationship during their participation in the DAC-TM Program (mean score range 4.43-3.79).

Table 2d: Mentor-mentee relationship

| Mentor-mentee relationship* | N | Mean (SD) |
|--|----|--------------|
| My mentor was responsive to me | 14 | 4.57 (0.852) |
| My mentor was knowledgeable about POR | 14 | 4.71 (0.469) |
| My mentor was supportive of my work and training | 14 | 4.79 (0.426) |
| I had adequate time to meet with my mentor | 14 | 4.43 (0.852) |
| My mentor provided opportunities to network with other mentees and researchers | 14 | 4.50 (0.650) |
| My mentor provided me with guidance and career advice | 14 | 4.50 (0.650) |
| My mentor helped me to meet my milestones | 14 | 4.43 (0.852) |
| My mentor supported me by reviewing materials (e.g., protocols, papers, presentations) | 14 | 4.50 (0.855) |
| My mentor provided skill building opportunities (e.g., papers, grants, presentations) | 14 | 4.43 (0.938) |
| Overall satisfaction with the mentorship you received | 14 | 4.29 (0.825) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

Mentee satisfaction with the DAC-TM Program

Table 2e and Figure 3 show that overall, mentees were satisfied with the DAC-TM Program (mean 4.36; SD 0.633) and had a positive experience (mean 4.43; SD 0.646). They were also satisfied with the DAC-TM Program delivery and the organization of the various activities that were delivered (mean for both 4.00; SD 0.679). They found the information provided during the training activities were useful for their research (mean 4.07; SD 0.616) although moderately relevant (mean 3.86; SD 0.770). Mentees indicated that the DAC-TM Program provided opportunities to engage with their mentors/supervisors (mean 4.29; SD 0.914) and patients (mean 3.93; SD 1.072). However, they had fewer opportunities to network with DAC investigators (mean 3.79; SD 0.893) and other DAC-TM mentees (mean 3.36; SD 1.151) (Figure 3). In terms of fit with their lifestyle, mentees reported that the travel needed to participate in the DAC-TM Program was reasonable (mean 4.07; SD 0.917) but the program fit with their other academic activities and life commitments to a moderate extent (mean 3.86, SD 0.770; mean 3.57, SD 0.756; respectively).

Table 2e: Mentee satisfaction with the DAC-TM program

| Satisfaction, feasibility & fit of the DAC-TM Program with other commitments* | N | Mean (SD) |
|--|----|--------------|
| I was satisfied with the program delivery (i.e., the way info and activities were provided) | 14 | 4.00 (0.679) |
| The various activities of the program (i.e., meetings, workshops) were well organized | 14 | 4.00 (0.679) |
| The travel needed to participate in the program was reasonable | 14 | 4.07 (0.917) |
| The information provided during the activities were <u>relevant</u> to my research | 14 | 3.86 (0.770) |
| The information provided during the activities were <u>useful</u> for my research | 14 | 4.07 (0.616) |
| The DAC-TM training provided me with the opportunities to engage with patients | 14 | 3.93 (1.072) |
| I had adequate opportunities to network with other DAC-TM mentees | 14 | 3.36 (1.151) |
| I had adequate opportunities to network with DAC investigators | 14 | 3.79 (0.893) |
| I had adequate opportunities to meet with my mentor/supervisor | 14 | 4.29 (0.914) |
| Overall, I had a positive experience | 14 | 4.43 (0.646) |
| Overall, I was satisfied with the DAC-TM Program | 14 | 4.36 (0.633) |
| Extent to which the DAC-TM Program fit within my other academic activities/commitments | 14 | 3.86 (0.770) |
| Extent to which the DAC-TM Program fit within my life commitments (e.g., work, travel, time) | 14 | 3.57 (0.756) |

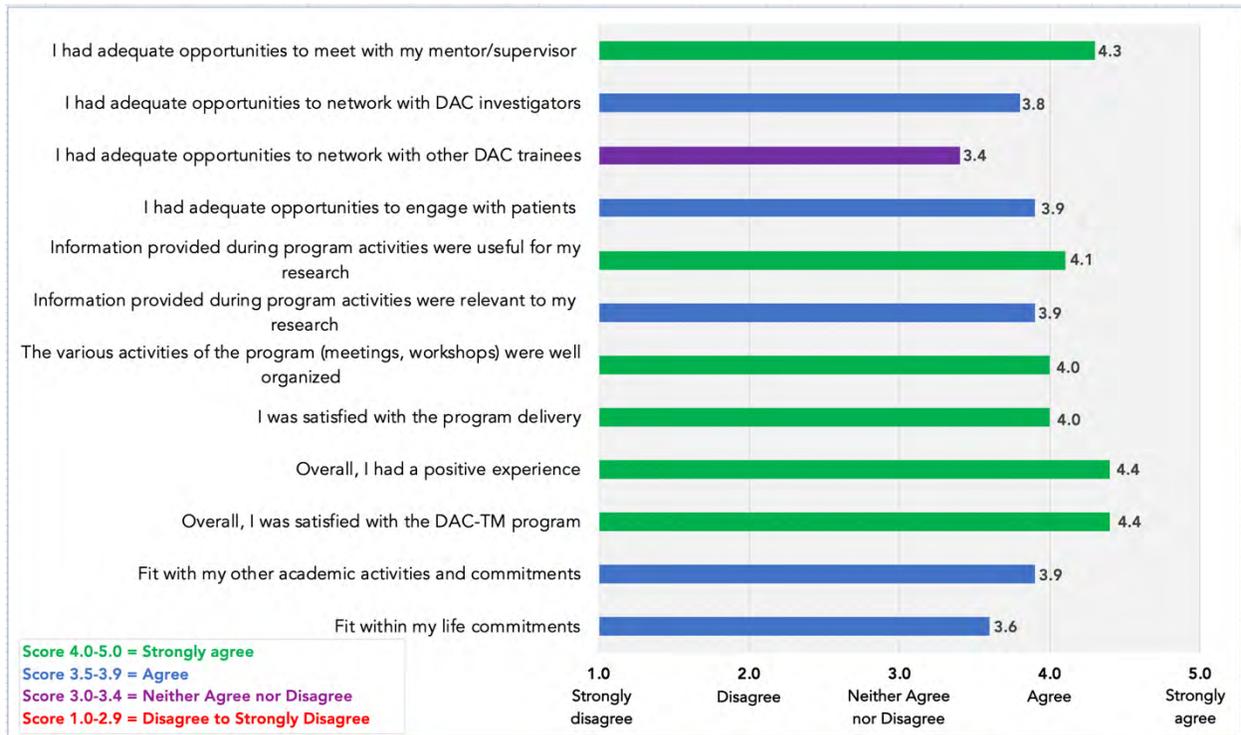
*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

Figure 3: Mentee satisfaction with the DAC-TM Program



Mentor Survey

Of 25 eligible DAC-TM Program mentors who were invited to participate in the evaluation study, 15 completed the survey (60% response rate). Of these, 53% were men and 60% were 35-44 years of age living in Ontario (40%) and Québec (33%). Most mentors hold a PhD (33%) or postdoctoral fellowship (33%), and work as a researcher or scientist (73%) at a university or college setting (60%). The majority of mentors trained students with a *POR Early Career Investigator Mentorship Award* (47%) or a *POR Intercentre Trainee Internship Award* (40%). The most common goals for mentors in terms of their participation in the DAC-TM Program were to increase capacity to do POR (67%) and to network (60%). Other goals included providing mentees with mentorship and to advance their research skills and career.

i. Mentor goals, needs and expectations of the DAC-TM Program

Table 3a and Figure 4 show that mentors understood the goals of the DAC-TM program to a large extent (mean 3.73; SD 0.961). To a moderate extent, mentors were aware of the DAC-TM Program expectations (mean 3.47; SD 0.915), and perceived the Program to meet their needs (mean 3.40; SD 0.632) and expectations (mean 3.33; SD 0.724). The Program also expanded their networks (mean 3.60; SD 0.910) and allowed them to gain new knowledge about POR (mean 3.625; SD 1.387). They did not gain as much new knowledge about Diabetes (mean 2.64; SD 1.151), improve their mentoring skills (mean 3.13; SD 0.990) or increase their research productivity (mean 2.73; SD 1.100); but these were not the goals of the DAC-TM Program. Several mentors pointed out that currently, none of the DAC-TM Program activities are targeted toward mentors, but would be useful to provide information, advice and training:

- “À ma connaissance, aucune activité n'est réservée aux mentors/superviseur de stagiaire (To my knowledge, no activity is reserved for mentors / intern supervisor” [P10]

- “Peut-être serait-il utile de rencontrer tous les mentors une fois par année pour leur donner des infos, des conseils et de la formation? (Perhaps it would be useful to meet with all mentors once a year to give them info, advice and training?)” [P10]

Table 3a: Mentor goals, needs and expectations of the DAC-TM Program

| Needs and expectations of the DAC-TM program* | N | Mean (SD) |
|--|----|--------------|
| Extent to which you gained new knowledge about POR | 13 | 3.62 (1.387) |
| Extent to which you gained new knowledge about Diabetes | 14 | 2.64 (1.151) |
| Extent to which you improved your mentoring skills | 15 | 3.13 (0.990) |
| Extent to which you expanded your networks | 15 | 3.60 (0.910) |
| Extent to which you increased your productivity | 15 | 2.73 (1.100) |
| Extent to which the DAC-TM Program met your needs as a mentor | 15 | 3.40 (0.632) |
| Extent to which the DAC-TM Program met your expectations as a mentor | 15 | 3.33 (0.724) |
| I was made aware of the expectations of the DAC-TM Program | 15 | 3.47 (0.915) |
| I understood the goals of the DAC-TM Program | 15 | 3.73 (0.961) |

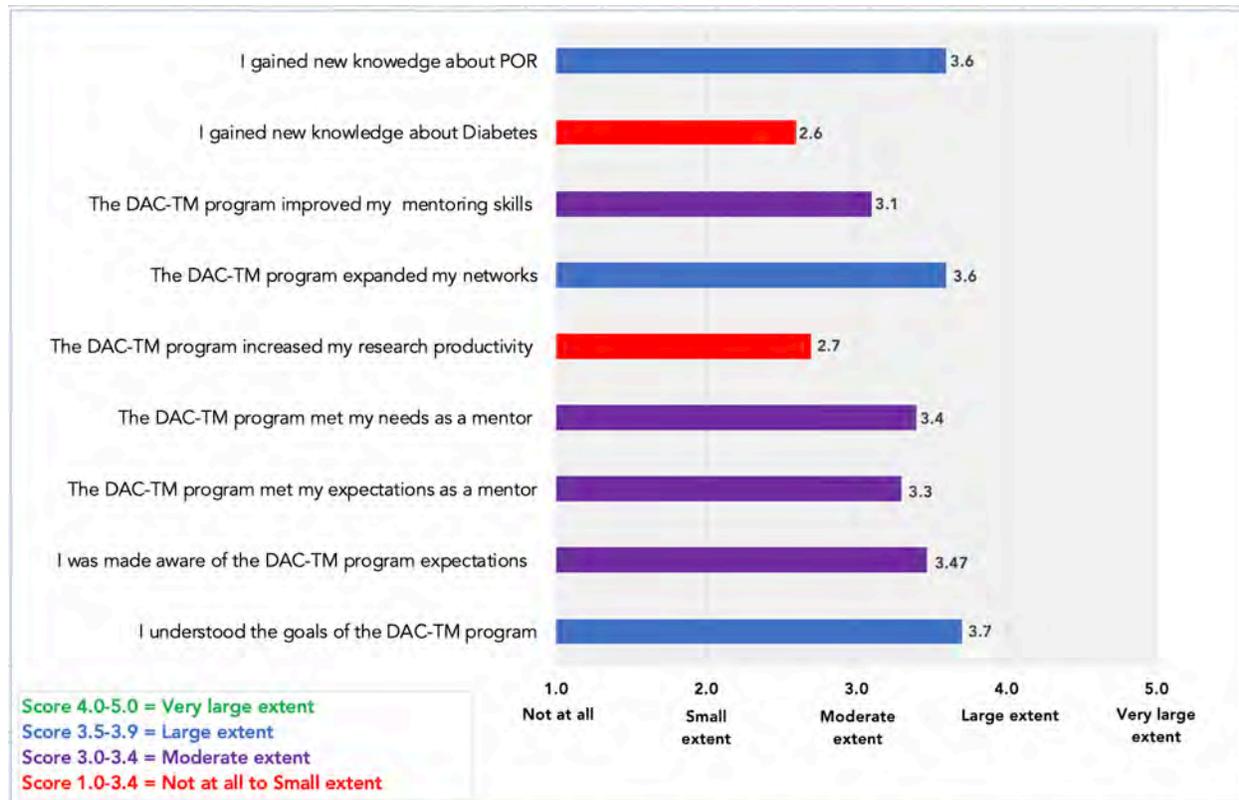
*Green = Very large extent (score 4.0-5.0)

*Blue = Large extent (score 3.5-3.9)

*Purple = Moderate extent (score 3.0-3.4)

*Red = Not at all to Small extent (score 1.0-2.9)

Figure 4: Mentor goals, needs and expectations of the DAC-TM Program



ii. Mentor engagement in DAC-TM activities and events

Attendance by 10 mentors across the DAC-TM Program training activities was widespread; 5 mentors did not attend any of the events. The most attended events were the *POR Training pre-DAC Annual Workshop* that was held in Toronto on May 3, 2018 (n = 3), on May 30, 2019 (n = 3).

Table 3b shows that mentors found the materials covered at the training event relevant for their work (mean 3.79; SD 0.802). They found the training events useful overall (mean 3.57; SD 0.852), gained knowledge about POR (mean 3.50; SD 0.760) and intended to apply what they've learned (mean 3.50; SD 0.760) to a moderate extent. They gained knowledge about Diabetes (mean 2.93; 0.730) or research methods (mean 3.14; SD 0.663) to a small extent, but these were not the goals of the DAC-TM Program.

Table 3b: Mentor engagement in DAC-TM activities

| Engagement in DAC-TM activities (<i>level of agreement about statements</i>) * | N | Mean (SD) |
|--|----|--------------|
| I found the training event(s) useful overall | 14 | 3.57 (0.852) |
| The material covered in the training event(s) was relevant for my work | 14 | 3.71 (0.726) |
| I gained knowledge about POR at the training event(s) | 14 | 3.50 (0.760) |
| I gained knowledge about Diabetes and its complications at the training event(s) | 14 | 2.93 (0.730) |
| I gained knowledge about research methods at the training event(s) | 14 | 3.14 (0.663) |
| I will apply what I've learned at the training event(s) in my work | 14 | 3.50 (0.760) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

iii. Mentorship experience

Table 3c and Figure 5 show that mentors enjoyed their experience (mean 3.85; SD 0.801) and that the DAC-TM Program provided mentees with the opportunity to advance their career (mean 4.00; SD 0.707). Overall, mentors perceived that their mentees had a good experience (mean 4.08; SD 0.760). They thought that their mentees gained new knowledge in POR (mean 4.08; SD 0.641) and Diabetes (mean 3.85; SD 0.689). Mentors also indicated that their mentees had opportunities to advance their research

productivity (mean 3.85; 0.801) and applied learnings from the program (mean 3.77; SD 0.725). However, mentors' expectations for their role were less clear (mean 3.23; SD 0.725) as was receiving adequate support to take on the mentor/mentorship role (mean 3.08; SD 0.760).

Table 3c: Mentorship experience

| Mentor-mentee relationship* | N | Mean (SD) |
|--|----|--------------|
| The expectations for my role as a mentor/supervisor were made clear | 13 | 3.23 (0.725) |
| I received adequate support to take on the mentor/supervisor role | 13 | 3.08 (0.760) |
| Overall, I enjoyed my experience as a mentor/supervisor via the DAC-TM Program | 13 | 3.85 (0.801) |
| My mentee(s) gained new knowledge in POR | 13 | 4.08 (0.641) |
| My mentee(s) gained new knowledge about Diabetes and its complications | 13 | 3.85 (0.689) |
| My mentee(s) have applied learnings from the DAC-TM Program in their work | 13 | 3.77 (0.725) |
| DAC-TM provided my mentees with the opportunity to advance their research productivity | 13 | 3.85 (0.801) |
| The DAC-TM Program provided my mentees with the opportunity to advance their career | 13 | 4.00 (0.707) |
| Overall, my mentee(s) had a good experience in the DAC-TM Program | 13 | 4.08 (0.760) |

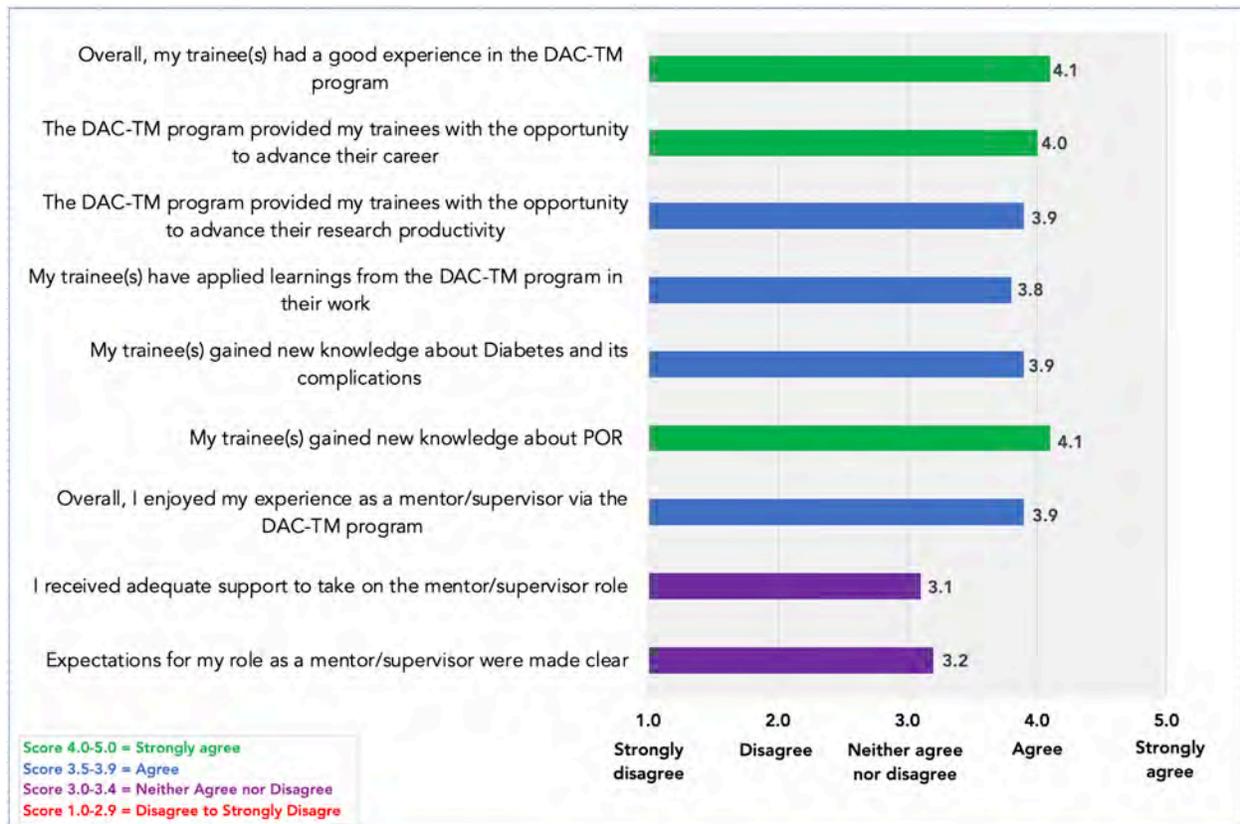
*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

Figure 5: Mentorship experience



iv. Mentor satisfaction with the DAC-TM Program

Overall, mentors were satisfied with the DAC-TM Program and had a positive experience (mean for both 4.08; SD 0.760). Mentors were in agreement with all other factors related to their satisfaction and fit of the DAC-TM Program with their other academic activities and life commitments (mean range: 3.54-3.92) (Table 3d).

Table 3d: Mentor satisfaction with the DAC-TM Program

| Satisfaction, feasibility & fit of the DAC-TM Program with other commitments* | N | Mean (SD) |
|--|----|--------------|
| I was satisfied with the program delivery (i.e., the way info and activities were provided) | 13 | 3.69 (0.630) |
| The various activities of the program (i.e., meetings, workshops) were well organized | 13 | 3.69 (0.751) |
| The travel needed to participate in the program was reasonable | 13 | 3.69 (0.855) |
| The information provided during the activities were <u>relevant</u> to my research | 13 | 3.77 (0.725) |
| The information provided during the activities were <u>useful</u> for my research | 13 | 3.62 (0.506) |
| The DAC-TM training provided me with the opportunities to engage with patients | 13 | 3.77 (0.832) |
| I had adequate opportunities to network with other DAC-TM participants | 13 | 3.77 (1.013) |
| I had adequate opportunities to meet with my mentee(s) | 13 | 3.92 (1.038) |
| Overall, I had a positive experience | 13 | 4.08 (0.760) |
| Overall, I was satisfied with the DAC-TM Program | 13 | 4.08 (0.760) |
| Extent to which the DAC-TM Program fit within my other academic activities/commitments | 13 | 3.54 (1.198) |
| Extent to which the DAC-TM Program fit within my life commitments (e.g., work, travel, time) | 13 | 3.38 (1.121) |
| Extent to which you think the DAC-TM Program meets its intended program goal to strengthen POR capacity in Canada for diabetes and its complications | 13 | 3.77 (0.927) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

Other DAC-TM Program Participant Survey

Of 193 other DAC-TM Program participants who attended various training activities and events between 2017-2019 and were invited to participate in the evaluation study, 47 completed the survey (24% response rate). Of these, 51% were women and 60% were 25-44 years of age living in Québec (57%) and Ontario (26%). At the time they completed the survey, 47% of these participants held a Master's degree, 21% held a Bachelor's degree, 11% held a Postdoctoral fellowship, and 6% held a PhD. The majority identified themselves as graduate students (38%), patients (15%) or researchers and scientists (11%) at the time they completed the survey.

i. Goals, needs and expectations of other DAC-TM Program participants

Table 4a and Figure 6 show that other DAC-TM Program participants gained knowledge about POR (mean 3.93; SD 0.884) but moderately so for gaining knowledge about Diabetes (mean 3.02; SD 1.185). Respondents understood DAC-TM Program goals from the outset (mean 3.74; SD 0.706) and were aware of the expectations of the Program (mean 3.74; SD 0.706). They also interacted with patients (mean 3.51; SD 1.121), increased their confidence to conduct POR research in Diabetes (mean 3.58; SD 0.889) and expanded their networks (mean 3.80; SD 0.930) to a large extent. However, the extent to which they learned how to integrate sex and gender in their research (mean 2.98; SD 1.271), initiated research collaborations (mean 2.97; SD 1.141) and increased their research productivity as a consequence of attending training events (mean 2.91; SD 1.329) was reported to be smaller.

Table 4a: Goals, needs and expectations of other DAC-TM Program participants

| Goals, needs and expectations of the DAC-TM Program* | N | Mean (SD) |
|--|----|--------------|
| Extent to which you gained new knowledge about POR | 43 | 3.93 (0.884) |
| Extent to which you gained new knowledge about Diabetes | 43 | 3.02 (1.185) |
| Extent to which you interacted with patients | 41 | 3.51 (1.121) |
| Extent to which you learned how to integrate sex and gender in your research | 40 | 2.98 (1.271) |
| Extent to which you increased your confidence to conduct POR research in DM | 38 | 3.58 (0.889) |
| Extent to which you expanded your networks | 44 | 3.80 (0.930) |
| Extent to which you initiated research collaborations | 34 | 2.97 (1.141) |
| Extent to which you increased your research productivity | 32 | 2.91 (1.329) |
| I was made aware of the expectations of the DAC-TM Program from the outset | 46 | 3.63 (1.329) |
| I understood DAC-TM goals from the outset | 47 | 3.74 (0.706) |
| Extent to which the DAC-TM Program met your needs | 46 | 3.63 (0.903) |
| Extent to which the DAC-TM Program met your expectations | 47 | 3.66 (0.939) |

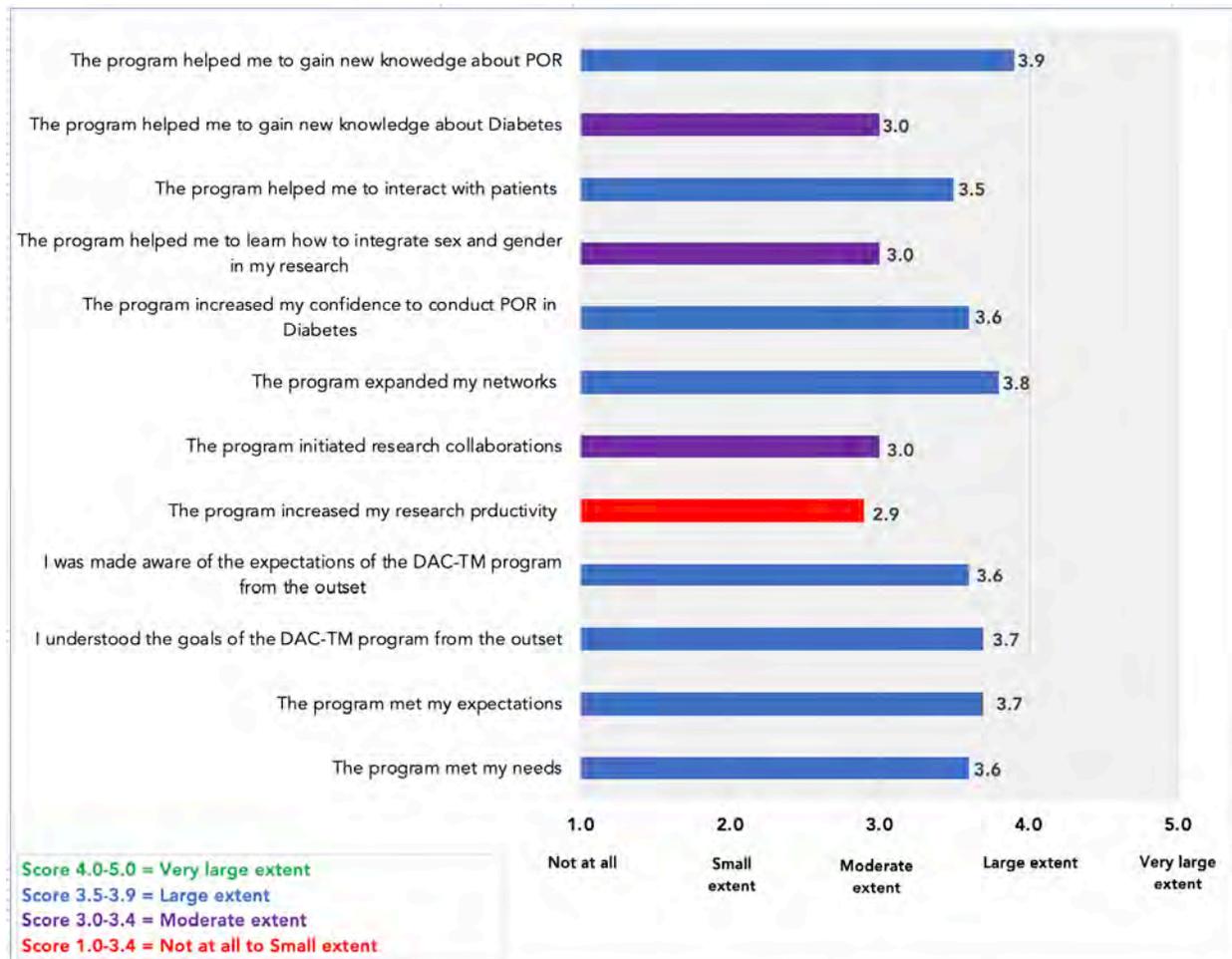
*Green = Very large extent (score 4.0-5.0)

*Blue = Large extent (score 3.5-3.9)

*Purple = Moderate extent (score 3.0-3.4)

*Red = Not at all to Small extent (score 1.0-2.9)

Figure 6: Goals, needs and expectations of other DAC-TM Program participants



ii. Engagement of other DAC-TM Program participants in training activities and events

The most attended events by other DAC-TM Program participants were the *DAC Trainee Day Pre-Diabetes Canada Professional Conference* that was held in Edmonton between Oct 31 - Nov 1, 2017 (n = 11), the *Fourth Annual Trainee Day Pre-Diabetes Canada Professional Conference* that was held in Winnipeg on October 2, 2019 (n = 11), the *POR Training pre-DAC Annual Workshop* that was held in Toronto on May 3, 2018 (n = 8) and on May 30, 2019 (n = 7), the *Québec SPOR SUPPORT Unit in collaboration with DAC* held in Québec on March 15, 2019 (n = 5), and the *Learning Pathway Training (DREAM Team and Can-SOLVE CKD)* held in Winnipeg between April 12-13, 2019 (n = 5).

Table 4b shows that participants found the training events useful overall (mean 4.32; SD 0.594), the material relevant for their work (mean 4.09; SD 0.952) and gained knowledge about POR (mean 4.17; SD 0.761). They also reported gaining knowledge about Diabetes (mean 3.55; SD 1.017) and research methods (mean 3.87; SD 0.924) and intending to apply what they've learned in their work (mean 3.98; SD 0.872).

Table 4b: Engagement of other DAC-TM Program participants in training activities

| Engagement in DAC-TM activities* | N | Mean (SD) |
|--|----|--------------|
| I found the training event(s) useful overall | 47 | 4.32 (0.594) |
| The material covered in the training event(s) was relevant for my work | 47 | 4.09 (0.952) |
| I gained knowledge about POR at the training event(s) | 47 | 4.17 (0.761) |
| I gained knowledge about Diabetes and its complications at the training event(s) | 47 | 3.55 (1.017) |
| I gained knowledge about research methods at the training event(s) | 47 | 3.87 (0.924) |
| I will apply what I've learned at the training event(s) in my work | 47 | 3.98 (0.872) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

iii. Satisfaction of other DAC-TM Program participants about the program

Table 4c shows that overall, other DAC-TM participants were very satisfied with the Program (mean 4.36; SD 0.640) and its delivery (mean 4.21; SD 0.750), had a positive

experience (mean 4.5; SD 0.619), and were satisfied with the organization of the various activities (mean 4.19; SD 0.741). They found the information provided during the training activities were relevant (mean 4.02; SD 0.766) and useful (mean 4.0; SD 0.834) for their research and expressed having adequate opportunities to network with other DAC-TM mentees (mean 4.15; SD 0.722). Participants also reported having opportunities to engage with patients (mean 3.81; SD 0.970) and network with DAC investigators (mean 3.94; SD 0.818), perceived the travel needed to participate in the DAC-TM Program as reasonable (mean 4.19; SD 0.741), and expressed that the Program fit within their other academic activities (mean 3.70, SD 1.121) and life commitments; mean 3.62, SD 0.968).

Table 4c: Satisfaction of other DAC-TM Program participants with the program

| Satisfaction, feasibility & fit of the DAC-TM Program with other commitments* | N | Mean (SD) |
|--|----|--------------|
| I was satisfied with the program delivery (i.e., the way info and activities were provided) | 47 | 4.21 (0.750) |
| The various activities of the program (i.e., meetings, workshops) were well organized | 47 | 4.19 (0.741) |
| The travel needed to participate in the program was reasonable | 47 | 4.19 (0.741) |
| The information provided during the activities were <u>relevant</u> to my research | 47 | 4.02 (0.766) |
| The information provided during the activities were <u>useful</u> for my research | 47 | 4.00 (0.834) |
| The DAC-TM training provided me with the opportunities to engage with patients | 47 | 3.81 (0.970) |
| I had adequate opportunities to network with other DAC-TM mentees | 47 | 4.15 (0.722) |
| I had adequate opportunities to network with DAC investigators | 47 | 3.94 (0.818) |
| Extent to which the DAC-TM Program fit within my other academic activities/commitments | 47 | 3.70 (1.121) |
| Extent to which the DAC-TM Program fit within my life commitments (e.g., work, travel, time) | 47 | 3.62 (0.968) |
| Overall, I had a positive experience | 47 | 4.45 (0.619) |
| Overall, I was satisfied with the DAC-TM Program | 47 | 4.36 (0.640) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

DAC-TM Program Developers

Of 6 eligible DAC-TM Program developers or organizers, all participated in the evaluation survey (100% response rate). Of these, 67% were men age 35-54 years living in Québec (50%), New Brunswick (33%) and Manitoba (17%). Their primary employer roles were researcher, scientist or clinician scientist (50%) or patient (33%); while their primary DAC roles were DAC-TM Program developer (50%) or patient partner (33%).

i. Goals, needs and expectations of DAC-TM Program developers

DAC-TM Program developers indicated that to a large extent, the program is achieving most of its goals (mean score range 4.17-4.50) and strengthening POR capacity in Canada for diabetes and its complications (mean 4.50; SD 0.548) (Table 5a).

Table 5a: Goals, needs and expectations of DAC-TM Program developers and organizers

| Extent to which DAC-TM is achieving the following goals for its participants:* | N | Mean (SD) |
|--|---|--------------|
| Gain new knowledge about POR | 6 | 4.50 (0.548) |
| Increased knowledge about Diabetes | 6 | 3.33 (0.516) |
| Increase capacity for POR research in Diabetes | 6 | 4.17 (0.753) |
| Increase research skills | 6 | 4.00 (0.632) |
| Provide networking opportunities | 6 | 4.33 (0.516) |
| Promote research collaborations | 6 | 4.33 (0.816) |
| Provide opportunities to engage with patients | 6 | 4.33 (0.816) |
| Strengthen POR capacity in Canada for Diabetes and its complications | 6 | 4.50 (0.548) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

ii. Satisfaction of DAC-TM Program developers/organizers about the program

DAC-TM Program developers were very satisfied with the way the various training activities have been delivered (mean 4.33; SD 0.516) including the three awards they offer (mean score 4.17 for all three). They were satisfied with the Program overall (mean 4.33; SD 0.516), believe that it is providing a positive experience for mentees (mean 4.50; SD

0.548) and mentors (mean 4.17; SD0.753), and that it will be sustainable in the long-term (mean 4.50; SD 0.837) (Table 5b).

Table 5b: Satisfaction of DAC-TM Program developers/organizers about the program

| Satisfaction, feasibility & fit of the DAC-TM Program with other commitments* | N | Mean (SD) |
|--|---|--------------|
| I am satisfied with the way the various training activities within the DAC-TM Program have been delivered (i.e., the way information and activities were provided) | 6 | 4.33 (0.516) |
| I am satisfied with the way the Internship Program has been delivered to date (2017-2019) | 6 | 4.17 (0.408) |
| I am satisfied with the way the Mentorship Program has been delivered to date (2017-2019) | 6 | 4.17 (0.408) |
| I am satisfied with the way the Postdoctoral Fellowship Program has been delivered to date (2017-2019) | 6 | 4.17 (0.753) |
| Overall, I think the DAC-TM Program is providing a positive experience for mentees | 6 | 4.50 (0.548) |
| Overall, I think the DAC-TM Program is providing a positive experience for mentors/supervisors | 6 | 4.17 (0.753) |
| The DAC-TM Program is achieving its intended purpose (i.e., to build capacity for POR research in Diabetes) | 6 | 4.50 (0.548) |
| The DAC-TM Program will be sustainable in the long-term | 6 | 4.50 (0.837) |
| Overall, I am satisfied with the DAC-TM Program | 6 | 4.33 (0.516) |

*Green = Strongly Agree (score 4.0-5.0)

*Blue = Agree (score 3.5-3.9)

*Purple = Neither Agree nor Disagree (score 3.0-3.4)

*Red = Strongly Disagree to Disagree (score 1.0-2.9)

PHASE 2: Qualitative Interviews

Participant Characteristics

Between January and March 2020, a total of 22 DAC-TM Program stakeholders participated in in-depth interviews. We endeavored to explore the full range of potential variation in perspective within the study's social milieu of focus and deliberately sought to include participants from the following key stakeholder groups: program developers, mentors, mentees (DAC-TM Program award holders) and other training program participants, including DAC members, patient partners, and graduate students. The interview participants came from across Canada and many were French speaking. Our sample included senior investigators with DAC who have been involved with the network since its inception and helped launch the TM program, as well as graduate students who have become involved with the DAC-TM Program more recently. In total, 5 mentees, 6 mentors, 5 program developers and 6 other people who attended the program's training activities between 2017-2019 agreed to contribute their insights and feedback for our analysis.

Key Findings

The following sections present an overview of our key findings about the program successes, factors that contribute to the impact and sustainability of the DAC-TM Program and specific areas for improvement from the participants' perspectives. As is typical in the presentation of qualitative research findings, we include some representative quotations from interview participants to illustrate our points. However, given that the sample of interview participants are drawn from small, potentially easily identifiable sub-groups of DAC-TM Program stakeholders, we have slightly modified the wording of some quotations to preserve the confidentiality and privacy of these individuals.

i. Strong Support for the Training and Awards Programs

According to the interview participants, a great success of the DAC-TM Program is the training sessions offered to DAC members, mentees (award holders), patient partners, and other program participants, both for the knowledge about POR that these sessions provide and the resulting impact of this training on the participants. The people we spoke to shared very positive feedback about the training they had attended and explained it was a highly valued educational opportunity to learn about POR and how it could be authentically incorporated into their work.

Participants strongly praised the content and organization of the training sessions, which they felt embodied POR values by including both researchers and patient partners as educators and learners. The training was widely perceived to have been designed with an equal focus on researcher and patients' needs in mind. For example, interview participants praised the experiential, hands-on, immersive format of the training sessions, and highlighted the value of conducting the training in person, which allowed for more personal engagement between the patients and researchers than would have been possible through an online format. The in-person engagement was seen to greatly increase all participants' understanding of the roles, responsibilities, interests, and potential contributions of researchers and patients on research teams. Furthermore, participants felt empowered to openly discuss their commonalities and differences as part of the learning process. Of note, we heard that the training gave patient partners a platform through which to have a voice and to become more comfortable about their own role in POR.

The availability of training in English and French, and opportunities to learn about cultural safety with regard to POR with First Nations communities, were highlighted as particularly useful training options. In particular, the graduate level trainees praised the opportunity

to receive education on areas where they were otherwise lacking in support, such as POR, Indigenous engagement, and grant writing.

- *"[DAC-TM] is providing training for trainees in different areas that they wouldn't otherwise get. So, grant writing, patient-oriented research, opportunities for trainees to be face to face with other trainees and to get a firsthand experience, practical experience in grant writing and patient-oriented research. I think that's the most valuable. [DAC-TM] has also hosted two meetings on cultural safety that have given trainees an exposure to indigenous health research, and I think that's really valuable as well. I would see those as the strengths. They're filling a gap in the research space that no other group is doing in Canada." [P18]*
- *"I think it was really eye-opening and the experiential aspect of that learning was huge for when it comes to something like cultural safety training. It was also really great that there were elders who were involved [in the training], who were able to tell their stories. And we were all just really capable of sharing our experiences. Or thoughts and concerns, and everything that come up as we moved through the day. So, it was a very open space for that." [P2]*

The mentees (award holders) and other training program participants we spoke to told us they would definitely attend more events if they were available and geographically accessible. Many praised the convenient timing and location of training events (for example, scheduled to occur immediately prior to the annual DAC Workshop) and the general organization of each training day. Others lauded the diligence of Program developers in conducting regular micro-evaluations of the different training activities, getting participant feedback on components that faltered or didn't work, and taking action to improve these aspects of the training. As one participant explained:

- *"The main activity, I would say, of both of these Trainee Days was going through the proposal with each other in a supportive, but critical way... I was really excited about doing that because I was excited to have my proposal reviewed and get some constructive feedback. I had a really good time actually critiquing other people's proposals. But the first year, it was just a little bit confusing getting it arranged to break out into the group of who reviewed who's. They improved upon that massively in 2019 because they put everybody into groups of five, maybe six. There wasn't any confusion of going to multiple groups, you stayed in your small group and everybody had received the same thing. So that worked out a lot better." [P10]*

A second area of strength identified was the DAC-TM Program awards, which participants agreed are appropriately targeted and provide an invaluable funding opportunity to early career investigators. We heard from mentors and senior DAC members that financial support options for early career investigators are somewhat limited, and that this group

is positioned to maximally benefit from the training and networking opportunities presented through the DAC-TM Program. Our analysis of interviews with the mentees supported this perspective; we heard from several mentees that they believe their career prospects and ability to compete in grant competitions have been boosted by holding a DAC-TM Program award.

Overall, the DAC-TM Program awards seem to function as a needed boost or step into the world of POR research in diabetes and its complications for early career investigators, which is consistent with the Program's stated goal to build POR capacity among the next generation of diabetes researchers in Canada. The mentees we spoke with described how the funding they received enabled them to continue projects they would not have been able to work on otherwise, or to apply for other, bigger awards that have brought them recognition and opened new doors for them in the field. Similarly, some mentee interviewees attribute their involvement with the DAC-TM Program as an award holder to connections made with other researchers that have led or could lead to other projects in the future, although not all had this experience.

- *"Well, I think just providing this opportunity in the first place is amazing. To be able to give a new project, opportunities to collaborate with people, opportunities to go with the funding to be able to go to conferences is something that as a post-doc it is not easy to find. So, it really helps build that for my diabetes experience, but also for my overall career." [P22]*

ii. Impact of the DAC-TM Training and Awards Programs

Many of the stakeholders we interviewed shared the perspective that participating in the DAC-TM Programs have positively impacted their work. A goal of our qualitative inquiry was to understand and account for why this may be the case. What we have learned is that the DAC-TM Program training sessions serve to help early career investigators, patient partners, and graduate students feel integrated into a community of practice and that participating in the DAC-TM Program training is contributing to a culture shift among researchers who study diabetes and its complications in Canada, as we explain below.

Many participants who previously had little or no experience with research into diabetes and its complications in the context of POR told us they felt informed and welcomed by the community of researchers and patients they encountered at the training sessions. The patients living with diabetes that we spoke with shared that DAC-TM Program training had equipped them with tools with which to articulate their experiences and find productive, empowered roles within the field of diabetes research. Likewise, graduate student interviewees who were taking their first steps into the world of diabetes research expressed that they felt tremendously supported at the training events and activities. Finally, even some of the mentors explained the benefit of having a forum via the training sessions through which to connect with other researchers who were perhaps more experienced than they or experienced in a complimentary field.

- *"I enjoyed the panel presentation and the pub scientifique. it was really cool because then you had a chance to kind of extend some of the social connections you made during the day. We also got introduced to some of these researchers who are big names in Canadian Diabetes research. Then there was an opportunity to also interact with them as well not just as a panel but in a pub-social type atmosphere." [P10]*
- *"And then I realized that the patient partner was kind of important for a researcher because they need them for their experience and all the professional personnel were very happy to have us with them. So, I didn't know how important it was before, because I had thought there was a big difference, you know, like with the patients and the professionals. But I could see that we have experience that they don't have. And they need [our experience] to help them." [P19]*
- *"I think the thing is that, you know, the ability to get exposure to a broad cross section of the membership of Diabetes Action Canada was excellent. And to meet new people from across the country. And also, to put a face to a name so that when you're on teleconferences with respect to other items within the network, you know who you're talking to from a visual and that you've spent time with them in the program." [P17]*

Overall, the DAC-TM Program training sessions seem to have successfully established a meaningful, applicable foundation or introduction to POR in the minds of the interviewees. Multiple participants suggested that participating in DAC-TM Program training has produced a "culture change" in how they think about their work; their conceptualization of research projects and appropriate methodologies has shifted to

include a sensitivity or commitment to a POR approach; they now understand the importance and value of including patients and families in the research process.

iii. Expanding DAC-TM Program Access and Options

We learned from the Program developers, organizers, and senior DAC members that one of the main intentions of the DAC-TM Program was to leverage pre-existing resources, opportunities, and connections to support the training and mentoring activities. Feedback from the majority of all interview participants suggests that this intention has been achieved. Strategic partnerships with other SPOR groups have enabled the DAC community to gain access to valued training opportunities, and some mentees have forged new connections within the DAC Network.

That said, interview participants also told us that this reliance on pre-existing resources has somewhat limited the Program. Interviewees frequently proposed increasing the availability and accessibility of the training events. We heard the following suggestions: increase the frequency of training, double all training sessions in both English and French, and use web-based tools to make remote access to training available for participants who are constrained by geography, mobility, and life circumstances (for example, parents of young children, and those with health issues that preclude travelling without great difficulty).

We heard that the heterogeneity of training events and activities is very useful for first-time participants and those who are new to POR. However, several participants with more experience as researchers shared that the content at the DAC-TM Program training events they have attended was not as relevant or useful to them as it could have been (for example, grant-writing seminars were highlighted as valuable by graduate students

but more experienced researchers told us they would have appreciated more practical examples of POR in action).

Some interviewees from all stakeholder groups involved in the training component of the DAC-TM Program suggested that training events and workshops could increase in sophistication. We were told that the target audience for training (including DAC members, mentees, graduate students, and patient partners) is diverse and, therefore, participants at training sessions have different backgrounds, research knowledge, skills, and learning needs. Interviewees noted that a more complex design in the delivery of the training might better accommodate this diversity of needs. One interviewee proposed that participants be grouped by knowledge needs and skill levels for the training sessions in a way that still maintains the diversity of perspective but ensures that individual training needs are met. Likewise, interviewees requested more frequent examples of how the POR content being learned could be applied to their respective situations and research projects. Of note, this feedback was not an indictment of the usefulness of what is currently being presented in the DAC-TM Program training, but rather, was presented as suggestions for the next step the Program could take – a more facilitated learning that participants who are less experienced in POR could directly apply to their work, and those with more experience could use to innovate POR methods.

Increasing the tailoring of some training events and activities, as well as providing accessible, on-line training for certain offerings, may help to address the training needs of the broader DAC community.

- *"[DAC-TM] needs to evolve the training from one day to some update half-day sessions. More applicability. I think there needs to be some sort of readjustments in how we deliver. Because an hour or a day-long meeting is not accessible for many people. So I think we need to work with other perhaps chronic disease networks for modules. And hopefully incorporate some of the online tools that have been designed in some of the training sessions." [P21]*

iv. DAC-TM Program Capacity Building and Mentoring

We learned from the DAC-TM Program developers that a primary goal of the DAC-TM Program is to build POR capacity in the next generation of diabetes researchers in Canada. Participant feedback suggests that the DAC-TM Program is achieving great successes through the training sessions but could do more to achieve this goal through the mentoring component of awards. While Program participants consistently praised the training, interviewees did not describe having experienced a consistent and guided capacity building process through their involvement with the DAC-TM Program. Often the mentees received very little guidance and direction from DAC-TM Program leadership and their projects were predominantly self-directed with input from their mentor within the Program. Almost all of the mentees we spoke to applied for the DAC-TM Program awards with a current supervisor with whom they had a pre-existing relationship; furthermore, they stated that upon receiving funding from the Program, very little about their relationship with and the work they did with that supervisor changed. This was not universally the case; some participants stated that their existing relationships were strengthened or solidified. But we heard that this was a result of working together more, and not necessarily due to the design and requirements of the DAC-TM Program awards. Some interviewees appreciated this opportunity while others acknowledged the lost potential to forge connections and receive mentoring from a new contact within the DAC community.

The minimal guidance and direction provided by the DAC-TM Program to mentees and mentors is seen as providing flexibility and freedom by those whose expectations of Program involvement were to obtain supplementary funds or enhance their knowledge of POR. In contrast, other mentees and mentors who expected a more facilitated fellowship experience identified this as an area for improvement. We heard that some mentees and mentors felt disconnected from the Program as a result of the same minimal

guidance and direction, in that they don't relate to the DAC-TM Program as a meaningful part of their journey as researchers, nor to the identity of their projects. Of note, the mentors we spoke with shared similar feedback that the relationships forged with new DAC-TM Program mentee contacts were not particularly deep nor as fruitful as some of their other mentoring experiences.

Interviewees suggested changes such as clearer communication from DAC-TM Program leadership at the start of their project/mentoring relationship, pairing mentees with mentors they are not familiar with, and providing facilitated channels through which mentees could keep in touch with one another and become familiar with each other's work outside of the annual DAC-TM Annual Workshop. Another interesting suggestion we heard was to use the training events as a forum through which mentees, graduate students, and patient participants are paired with a more senior researcher in the field that they have never worked with before for a brief but facilitated mentorship experience. This might be particularly useful for members of the DAC community who struggle with networking. For example, the graduate students we spoke with valued the opportunity to network with other trainees at the DAC-TM Program training sessions, but did not share much feedback about how they benefited from interacting with more senior researchers, patient partners, and other members of the DAC community given the lack of explicit one-on-one time offered.

Triangulation of Quantitative and Qualitative Results

Following the completion of our data analysis activities for the surveys and interviews, we used a meta-matrix approach to converge findings from the two data sets and support our identification of the main areas of success, opportunities for improvement and sustainability potential of the DAC-TM Program. In particular, we looked at commonalities, discrepancies, and patterns in the survey and interview data sets.

For the most part, the qualitative findings confirmed and deepened our understanding of the quantitative findings, as is to be expected. For example, the mentees who participated in surveys reported that the relationship with their mentors was very effective. In the interviews, we learned that many award holders continue working on POR projects with their current supervisor, thus in some cases it is pre-existing mentoring relationships that are being strengthened and projects-in-progress that are being advanced through the DAC-TM Program award opportunity versus new connections or projects. As another example, the survey respondents from all stakeholder groups reported the training sessions to be useful and indicated that they gained new knowledge about POR, yet many indicated it was only moderately relevant to their work. The interview findings make clear that the training provides a highly valued, well organized, and convenient educational opportunity for participants, however the training needs of this heterogeneous group vary based on existing knowledge and experience, and thus the content presented is not equally valued by all participants.

Comparing the two data sets revealed that there are a few contradictions in the survey and interview findings, particularly as they relate to perceptions and experiences of networking and capacity building in the DAC-TM Program. For example, the mentees and other training program participants who completed surveys both reported that the Program has enabled them to expand their networks. However, they also report having few opportunities to work with DAC investigators and engage with patients and other award holders. Furthermore, the other training program participants indicated on the surveys that their participation in the Program had not really resulted in the initiation of new research collaborations or increased their research productivity. We heard similar mixed feedback about networking and capacity building from these stakeholder groups in the interviews, with some participants sharing that the DAC-TM Program has provided

them with access to experienced researchers to expand their network and opportunities to engage with mentors and patients, and others expressing the difficulties they faced in forging new connections within the DAC Network and developing fruitful mentoring and working relationships. We suspect that this discrepancy between the survey results and interview findings about networking and capacity building relates in part to the way specific survey questions were worded. However, given the mixed feedback on these topics from the qualitative interviews, it is also likely that the experiences and perceptions of DAC-TM Program participants vary considerably and that the survey results are reflective of this.

DISCUSSION

Summary of Findings

We have conducted a formative evaluation of the DAC-TM Program to identify areas of success, opportunities for improvement, and ultimately to help realize impact and sustainability of the DAC-TM Program. Our analysis of quantitative data from online surveys and qualitative data from interviews collected from stakeholders including DAC-TM Program developers, mentors, mentees (award holders), and other training program participants has revealed consistent patterns related to perceptions of and experiences with the program.

In summary, all stakeholder groups report that the DAC-TM Program is largely meeting their needs, goals, and expectations. The training sessions are perceived to be well organized, convenient educational opportunities to gain new knowledge about POR and to become integrated into a community of practice of POR researchers who study diabetes and its complications in Canada. The content of the training is relatively useful and moderately relevant to participants; tailoring some training events and activities and providing accessible, on-line training for certain offerings may help to address the training needs of the broader DAC community. Furthermore, there is broad support for and appreciation of the mentorship awards among stakeholders. The awards are perceived to be appropriately targeted to early career investigators and experiences of these mentoring relationships are largely positive, productive, and career advancing, but could benefit from more strategic design and to promote better connectivity to foster mentor-mentee relationships. Stakeholders shared mixed feedback about their opportunities to network and forge new connections with patients, award holders, and senior researchers through the DAC-TM Program. Therefore, pairing award holders with new mentor contacts, providing facilitated channels through which mentees can connect

with each other, and creating brief, facilitated mentorship experiences between training program participants and senior researchers may strengthen capacity building within the DAC-TM Program.

Next Steps and Supporting the Sustainability of the DAC-TM Program

Training Sessions

We learned that the DAC-TM Program training sessions follow the CIHR POR curriculum and are continuously refined based on feedback from participants. This structure and rigor seem to be strengths that contributes to participants' perspectives that they have attended high quality, valuable training that is useful to their work.

Program Awards

In contrast, the interview participants articulated that the DAC-TM Program awards are flexible and fairly unstructured with minimal formal requirements. This is cited by some as an advantage; flexibility and the opportunity to pursue ideas and be open to new projects, is valuable for early career investigators. However, some participants have shared that their experiences of the DAC-TM Program mentor-mentee relationships have lacked depth, and others have told us that they have not been able to collaborate with their mentor/mentee as effectively as they would have had a project been developed in advance with a specific role for the mentee, or had opportunities for engagement been specifically defined in advance. Thus, creating more structure and strategic design of the awards may help to maximize the benefits realized from these opportunities.

Mentorship

Compared to the training program, which provides very real POR education and research opportunities to its participants, the mentorship program received mixed feedback from interview participants. Therefore, it may be worth rethinking the mentorship component

of the DAC-TM Program. Several of the stakeholders we interviewed expressed that they are uncertain about the design and subsequent effectiveness of the mentorship component. Its self-directed design, while sometimes beneficial in the flexibility it offers, does not often facilitate mentor-mentee relationships beyond those already in place. Many of the mentors we interviewed described their mentorship role as something they would have been doing anyway, not as an activity inspired by the DAC-TM Program. Likewise, we learned that the award holders did not often connect with mentors with whom they would not have become connected anyway. The mentor-mentee relationships were often described to us in generically positive terms or discussed as poorer than average due to a lack of facilitated expectation and direction from the DAC-TM Program.

On the flip side, the graduate level mentees we interviewed repeatedly expressed the desire for a stronger mentorship element of the Program. Similarly, some award holders pointed out the lost potential in the mentorship component as something that would really serve graduate students well if it were more robustly designed and had stronger facilitation. While mentors themselves had few comments about the mentorship component, other program participants expressed a clear desire for a strengthening of this aspect.

Expanding the Network

For the DAC-TM Program to exist, researchers, students and patients across the DAC Network must collaborate, so the Program facilitates new collaborations by necessity. However, these collaborations (to date) seem to be limited within the DAC Network. Given that the DAC-TM Program does not seem to have a systematic strategy in place for recruiting new participants, this is an option for future expansion. Several interviewees explained that DAC-TM Program training sessions and awards are primarily advertised

through word of mouth by DAC members and PIs to the students, young investigators, and patients in their circle of contacts. While this mechanism has been adequate in engaging participants so far, due to the DAC Network's relatively small and interconnected circle, we were told that this marketing strategy has limitations: the pool of award applicants has shrunk because award holders cannot apply twice, potential applicants don't always hear about events and opportunities until it is too late to apply, and the Program is losing the opportunity to reach out to and engage more patient partners who may benefit from and contribute to the Program.

Formal Tracking

To expand the program and promote sustainability moving forward, the DAC-TM Program would benefit from formally tracking the mentees and patient partners who benefit from Program resources by attending training sessions, and actively promoting other events and awards to these groups, along with their supervisors and other collaborators. This would ensure that the pool of potential participants from within DAC is not exhausted and would facilitate formal monitoring and evaluation of the Program impacts (in terms of participant outputs, new collaborations, etc.) in the future.

Communication and Coordination Across the Network

While at one level of engagement, participants from across the DAC Network are connected through core training sessions, at another level, participants of all types described limited communication and coordination across DAC-TM Program subgroups and between DAC-TM Program members and participants. Mentees did not feel as though they were kept in the loop of the DAC community outside of training events; mentors who felt invested in the development of the DAC-TM Program did not feel consulted on decisions made in the evolution of its execution; and some administrators

did not feel as though they were being given the appropriate information from other parts of the DAC Network to efficiently manage the Training and Mentoring Program.

In the spirit of leveraging pre-existing resources, the DAC-TM Program would benefit from keeping open communication lines between and across its participants, such that they are more likely to be integrated long term into a more coherent and cohesive operation of the DAC Network.

Strengths and Opportunities to Consider for the DAC-TM Program

Based on the collective findings of our surveys and interviews, Table 6 provides a summary of factors representing the strengths that could be leveraged and opportunities for improvement across the various aspects of the DAC-TM Program that the goal group committee can consider for the future roll-out of the DAC-TM Program.

Table 6: Strengths to be leveraged and opportunities for improvement in the DAC-TM Program

| Program Aspect | Strengths to be Leveraged | Opportunities for Improvement |
|--------------------|--|---|
| Training Sessions | <ul style="list-style-type: none"> • Training sessions follow the CIHR POR curriculum and are continuously refined based on feedback from participants • Participants perceive the sessions to be of high quality, and believe that they are receiving valuable training that is useful to their work • Provides very real POR education and research opportunities to its participants | <ul style="list-style-type: none"> • Increase the availability and accessibility of the training sessions • Tailor some content of the training sessions to address the training needs of the broader DAC community |
| Program Awards | <ul style="list-style-type: none"> • Program awards are flexible and fairly unstructured with minimal formal requirements • Early career investigators value the Program’s flexibility, and the opportunity to pursue ideas and openness to new projects | <ul style="list-style-type: none"> • Creating more structure and strategic design of the awards may help to maximize the benefits realized from mentorship opportunities |
| Mentorship Program | <ul style="list-style-type: none"> • Perceived as beneficial in the flexibility it offers | <ul style="list-style-type: none"> • Participants are uncertain about its design and subsequent effectiveness • A lost potential since it is something that would really serve graduate students well if it were more robustly designed and had stronger facilitation • Mentors described their mentorship role as something they would have been doing anyway, not as an activity inspired by the DAC-TM Program • Graduate level mentees and other program participants expressed a clear desire for strengthening the mentorship aspect of the Program |

| | | |
|--|--|---|
| Mentor-Mentee Relationship | - | <ul style="list-style-type: none"> • Mentor-mentee relationships have lacked depth - the self-directed design does not often facilitate mentor-mentee relationships beyond those already in place • Lack of facilitated expectation and direction from the Program • Award holders did not often connect with mentors with whom they would not have become connected anyway • Inability to collaborate with their mentor/mentee as effectively as they would have if a project has been developed in advance with a specific role for the mentee, or had opportunities for engagement been specifically defined in advance |
| Expansion of and Collaboration within the DAC-TM Network | <ul style="list-style-type: none"> • The Program facilitates new collaborations by necessity • The DAC-TM Program training sessions and awards have been advertised through and participants engaged primarily via word of mouth (by DAC members and PIs to their students, young investigators, and patients) in their circle of contacts | <ul style="list-style-type: none"> • Collaborations (to date) are limited within the DAC Network only • The Program does not have a systematic strategy in place for recruiting new participants • The current marketing strategy to engage the Network's relatively small and interconnected circle has limitations: <ul style="list-style-type: none"> ○ The pool of award applicants has shrunk because award holders cannot apply twice ○ Potential applicants don't always hear about events and opportunities until it is too late to apply |
| Formal Tracking | - | <ul style="list-style-type: none"> • To expand the Program and promote sustainability moving forward, the DAC-TM Program would benefit from formally tracking the mentees and patient partners in terms of: <ul style="list-style-type: none"> ○ Who would benefit from Program resources by attending training sessions ○ Actively promoting other events and awards to mentees and patient partners along with their supervisors and other collaborators • These activities would: <ul style="list-style-type: none"> ○ Ensure that the pool of potential participants is not exhausted ○ Facilitate formal monitoring and evaluation of the program impacts (in terms of participant outputs, new collaborations, etc.) in the future |

| | | |
|--|---|--|
| <p>Communication and Coordination across the Network</p> | <ul style="list-style-type: none"> • At one level of engagement, participants from across the DAC Network are connected through core training sessions | <ul style="list-style-type: none"> • Participants of all types described limited communication and coordination across DAC-TM Program subgroups and between Program members and participants: <ul style="list-style-type: none"> ○ Mentees did not feel that they were kept in the loop of the DAC community outside of training events ○ Mentors who felt invested in the development of the DAC-TM Program did not feel consulted on decisions made in the evolution of its execution ○ Some administrators did not feel as though they were being given the appropriate information from other parts of the DAC Network to efficiently manage the training and mentoring program • In the spirit of leveraging pre-existing resources, the DAC-TM Program would benefit from keeping open communication lines between and across its participants, such that they are more likely to be integrated long term into a more coherent and cohesive operation of the DAC Network |
|--|---|--|

Knowledge Translation

Project-Wide Knowledge Translation

We adopted an integrated knowledge translation (IKT) strategy in this project. IKT is a collaborative approach whereby all knowledge users are partners in the entire research process from setting objectives, shaping the study design and its execution, interpreting the findings, and informing a KT strategy and next steps. Our IKT team includes (i) two researchers with expertise in program evaluation, qualitative and mixed-methods research (Kastner, Dainty); (ii) two research staff and a trainee; (iii) a clinician scientist with expertise in diabetes (Greiver); and (iv) members of the DAC-TM Program including two patient partners. Engaging all knowledge users in this way ensures that our findings reflect their perspectives and expertise, and will increase the relevance, applicability and impact of the evaluation results to best inform Program sustainability and next steps [Kothari & Wathen 2013]. We met via teleconferences quarterly over the course of the 24-month study period.

End-of-Project Knowledge Translation

We will use a wide range of passive and active end-of-grant knowledge translation (KT) approaches to disseminate our findings. First, we will present findings of this study at competitive academic conferences. Second, we will publish the results of this study in a peer reviewed journal. Third, we will work with DAC and DAC-TM Program members to develop more active strategies for disseminating findings, including how and to whom to disseminate this final report. In all these strategies, we will ensure that the messages will be clear, simple and tailored to the needs of each audience group, whether these are individuals (researchers, patients, or policy or decision makers) or organizations (e.g., DAC, SPOR, CIHR), including how they prefer to receive this information.

Conclusions

We conducted a formative evaluation of the DAC-TM Program using a sequential, mixed-methods design. In total, we involved 82 survey and 22 qualitative interview participants representing a wide range of stakeholders and knowledge users associated with the Program, including DAC-TM Program developers, mentors, mentees (award holders), and other training participants. We have used the findings from this evaluation to identify key strengths and opportunities to improve the training sessions, award programs, mentoring component, and general collaboration of this Program within the broader DAC Network. Findings from this work can be used by the DAC-TM goal group to enhance the functioning and promote sustainability of the Program as it moves forward with its goal to build capacity in the next generation of diabetes researchers in Canada in Patient-Oriented Research (POR).

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APPENDIX A

DAC-TM Program documents reviewed for background/context

1. Survey of DAC members to support creation of Training & Mentoring Program Strategy [copy of original survey and final report]
 - DAC members and Patient Engagement Group participants surveyed in Feb 2017 to ascertain their existing knowledge, learning needs, barriers to learning, and potential solutions and strategies to training in patient-oriented research in diabetes and its complications. The results of this survey informed the finalization of the training and mentoring strategy of DAC.
2. Training & Mentoring Strategy document (Nov 21, 2016)
 - Includes information about the objectives and guiding principles of the program, the program team, and details about the training and mentoring plan.
3. Performance Management Strategy for Training & Mentoring Program (v. March 2017)
 - Includes information about outputs/activities/participants, target goal, and outcomes
4. POR Training participant evaluation survey reports
 - Oct 31, 2017
 - March 15-16, 2018 (French)
 - May 3, 2018
 - Oct 10, 2018
5. List of POR webinars, videoclips, and courses (v. Oct 2018)
6. Research grant/funding reports for award holders (2017-2019)
7. Mentorship award reports for award holders (2017-2019)

APPENDIX B

PHASE 1 master survey

| Survey section | Question category | Question | Options (if applicable) | Response type | Likert scale anchors (if applicable) | Survey target: •Mentors •Trainees •DAC-TM developers •Other |
|-----------------|------------------------------|--|---|-----------------------|--------------------------------------|---|
| I. Demographics | Sex | 1. What sex were you assigned at birth? | • Female • Male | Dropdown menu options | NA | All |
| | Gender | 2. What best describes your current gender identify? | • Female • Male • Other • Prefer not to answer | Dropdown menu options | NA | All |
| | Age range | 3. What is your age? | • 20-24 • 25-34 • 35-44 • 45-54 • 55-64 • 65-74 • 75-84 • 85+ | Dropdown menu options | NA | All |
| | Role | 4. What is your current primary employment role? (i.e., we recognize that you may have multiple roles, please indicate your primary role) | • Researcher or Scientist • Clinician Scientist • Clinician (physician, nurse, pharmacist, dietitian, OTPT, etc) • Manager, director • Policy-maker • Graduate student • Other: _____ | Dropdown menu options | NA | All |
| | Setting of employment | 5. What is the setting of your primary employment? | • University or College • Hospital • Research Institute • Government • Other: _____ | Dropdown menu options | NA | All |
| | Role within DAC | 6. What is your current role within the DAC program? | • DAC-TM Trainee • DAC-TM Mentor • DAC-TM developer/organizer • DAC Investigator • Other: _____ | Dropdown menu options | | All |
| | Degree | 7. What degree(s) do you currently hold? (please select all that apply) | • Master's degree • PhD • Postdoctoral Fellow • Other: _____ | Dropdown menu options | NA | All |
| | Graduate training level | 8. Which graduate degree did you work on while you participated in the DAC-TM program? | • Master's degree • PhD • Postdoctoral Fellow • Other: _____ | Dropdown menu options | NA | • Trainees • Other participants |
| | DAC-TM award type | 9. Which DAC-TM award type are you currently participating in or have completed? | • POR Mentorship award • POR Trainee Internship award • Post-doctoral Fellowship Program | Dropdown menu options | NA | • Trainees • Mentors |
| | Awareness of DAC-TM | 10. How did you learn about the DAC-TM program? | NA | Open-ended | NA | • Mentors • Trainees • Other participants |
| | Program participation status | 11. What is your current status in the DAC-TM program? | • Ongoing • Completed date: _____ | Open-ended | | Trainees |

| | | | | | | |
|---|--|--|---|-----------------------------|--|---|
| II. Your goals, needs and expectations of the DAC-TM program | Goals | <p>1. What were your goals for participating in the DM-TM program? (please choose all that apply)</p> | <ul style="list-style-type: none"> • Gain new knowledge about POR • Gain new knowledge about Diabetes • Increase capacity to do POR in Diabetes • Improve research skills • Networking opportunities • Engage with patients • Other: _____ | Dropdown menu options | NA | All |
| | | <p>2. To what extent did you achieve your goals in the following categories?</p> <p>If you are currently still going through the program, please think about to what extent you think you will reach your goals in these categories?</p> | <ul style="list-style-type: none"> • Gained new knowledge about POR • Gained new knowledge about Diabetes • Interacted with patients • Learned how to integrate sex and gender in my research • Increased my confidence to conduct POR research in Diabetes • Expanded my networks • Initiated research collaborations • Increased my research productivity (e.g., presentations, publications, research funding) • Other: _____ | Likert scale | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | Trainees |
| | | | <ul style="list-style-type: none"> • Gained new knowledge about POR • Gained new knowledge about Diabetes • Improved my mentoring skills • Expanded my networks • Increased my productivity (e.g., presentations, publications, research funding) • Other: _____ | Likert scale | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | Mentors |
| | Needs | <p>3. Overall, to what extent did the DAC-TM program meet your needs? (specific to your award opportunity)</p> <p>Please provide any additional comments: _____</p> | NA | Likert scale | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | |
| | Expectations of the DAC-TM program | <p>4. To what extent did the DAC-TM program meet your expectations?</p> <p>If you are currently still going through the program, please think about to what extent you think the DAC-TM program will meet your expectations?</p> <p>Please provide any additional comments: _____</p> | NA | Likert scale; Open-ended | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | <ul style="list-style-type: none"> • Mentors • Trainees • Other participants |
| | | <p>5. Please indicate your level of agreement with the following statements about the DAC-TM program</p> | <ul style="list-style-type: none"> • I was made aware of the expectations of the program • I understand the goals of the program | Likert scale | 1 = Strongly Disagree 2 = Disagree 3 = Neither Agree nor Disagree 4 = Agree | |
| III. Your engagement in DAC-TM activities | Participation in DAC-TM program activities (use of available activities) | <p>1. Which of the following DAC-TM activities did you participate in during your training? (please select all that apply)</p> | <ul style="list-style-type: none"> • Winter Camp (French program) • POR Training session • Learning Pathways Training • Trainee Day • DAC Annual Workshop | Dropdown menu options | NA | All |
| IV. Trainee research activities | Productivity | <p>1. Please enter a number for each of the following research outputs that directly resulted from participating in the DAC-TM program:</p> | Total number of publications: _____ Publications as first author: _____ Publications as senior author: _____ Presentations: _____ Grants submitted: _____ Grants funded: _____ Other: _____ | Open-ended | NA | Trainees |
| | Potential impact on patients | <p>2. Has the work you completed during your DAC-TM program had any direct impact on patients?</p> <p>If Yes, please explain: _____</p> | <ul style="list-style-type: none"> • Yes • No | Binary; Open-ended | NA | Trainees |
| | Career growth | <p>3. Has your participation in the DAC-TM led to any career growth or advancements?</p> <p>If Yes, please elaborate: _____</p> | <ul style="list-style-type: none"> • Yes • No | Binary; Open-ended | NA | Trainees |
| | | | | | | |

| | | | | | | |
|--|--|--|--|-------------------------------------|---|----------|
| V. Mentor-Trainee relationship | Frequency of interactions | 1. During your DAC-TM program participation, how often did you meet with your mentor/supervisor? | <ul style="list-style-type: none"> • Every week • Every two weeks • Every month • Every 2-3 months • Every 6 months | Dropdown menu selection | NA | Trainees |
| | Quality of interaction | 2. Thinking about the mentorship you received during your participation in the DAC-TM program, please rate your level of agreement about the following statements: Please provide any additional comments: _____ | <ul style="list-style-type: none"> • My mentor was responsive • My mentor was knowledgeable • My mentor was supportive • I had adequate time to meet with my mentor • I was given the opportunity to network with other trainees and researchers | Dropdown menu selection | NA | Trainees |
| | Trainee satisfaction | 3. Overall, how satisfied were you with the mentoring you received by your mentor/supervisor? | NA | Likert-type | 1 = Not at all Satisfied 2 = Slightly Satisfied 3 = Moderately Satisfied 4 = Very Satisfied 5 = Extremely Satisfied | Trainees |
| | Mentor satisfaction | 4. Thinking about the mentorship you provided through the DAC-TM program, please rate your level of agreement about the following statements: Please provide any additional comments: _____ | <ul style="list-style-type: none"> • The expectations for my role as a mentor were made clear • I received adequate support to take on the mentoring role • Overall I enjoyed my experience as a mentor via the DAC-TM program | Likert-type | 1 = Strongly Disagree 2 = Disagree 3 = Neither Agree nor Disagree 4 = Agree 5 = Strongly Agree | Mentors |
| VI. Satisfaction, feasibility, and fit with other academic and life commitments | Experience | 1. Please indicate your agreement with the following statements about your experience with the DAC-TM program: Please provide any additional comments: _____ | <ul style="list-style-type: none"> • I was satisfied with the program delivery (i.e., the way information and activities were provided) • The various activities of the program (i.e., meetings, workshops) were well organized • The travel needed to participate in the program was reasonable • The information provided during the activities were relevant to my research • The information provided during the activities were useful for my research • The DAC-TM training provided me with the opportunities to engage with patients • I had adequate opportunities to engage with other DAC-TM trainees • I had adequate opportunities to meet with my mentor • Overall, I had a positive experience • Overall, I was satisfied with the DAC-TM program | Dropdown menu selection; Open-ended | NA | All |
| | Fit with academic and life commitments | 2. To what extent do you think the DAC-TM program: Please provide any additional comments: _____ | <ul style="list-style-type: none"> • Fits within your other academic activities and commitments? • Fits within your life commitments (e.g., work, travel, time, etc) ? | Likert-type; Open-ended | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | Trainees |
| | Inclusiveness of program participants | 3. To what extent do you think the DAC-TM program: Please provide any additional comments: _____ | <ul style="list-style-type: none"> • Includes culturally and socially diverse trainees? • Engages patients (i.e., included them in the program activities)? • Engages Indigenous patients? (i.e., included them in the program activities)? | Likert-type; Open-ended | 1 = Not at all 2 = Small extent 3 = Moderate extent 4 = Large extent 5 = Very large extent | All |

APPENDIX C

Domains of key evaluation questions that were used to develop the surveys

| Evaluation Domain: Name | Evaluation Domain: Description according to framework | Outcome(s) to be measured |
|---------------------------------------|---|---|
| Reach / Penetration / Adoption | <p><u>Reach/Penetration</u> RE-AIM: Reach of the target population; The absolute number, proportion, and representativeness of individuals who are willing to participate in a given initiative, intervention, or program.</p> <p>Proctor: Level of institutionalization? Spread? Service access?</p> <p><u>Adoption</u> RE-AIM: Adoption by target staff, settings, or institutions. The absolute number, proportion, and representativeness of settings and intervention agents (people who deliver the program) who are willing to initiate a program.</p> <p>Proctor: Uptake; utilization; initial implementation; intention to try</p> | Number of people (mentors, mentees, other) who <u>participated</u> in the DAC-TM program |
| | | Number of people who <u>attended</u> the various DAC-TM Program training opportunities and programs available |
| | | Number of people who were aware of the DAC-TM program |
| | | Number of people who were <u>eligible</u> to participate in the various DAC-TM Program training opportunities and programs available? |
| | | Characteristics of participants who attended the various training opportunities and programs available |
| | | Success of DAC-TM Program partnerships |
| | | Number of people who were involved in delivering the program |
| Efficiency | <p>OCED/DAC Network: Efficiency measures the outputs -- qualitative and quantitative -- in relation to the inputs. It is an economic term which signifies that the aid uses the <u>least costly resources possible in order to achieve the desired results</u>. This generally requires comparing alternative approaches to achieving the same outputs, to see whether the most efficient process has been adopted.</p> | Efficiency of the program |
| Feasibility / Acceptability | <p><u>Feasibility</u> Proctor: Actual fit or utility; suitability for everyday use; practicability</p> <p><u>Acceptability</u> Proctor: Satisfaction with various aspects of the innovation (e.g. content, complexity, comfort, delivery, and credibility)</p> | Satisfaction with the program |
| | | Feasibility of participating in program (fit with academic and personal life) |

| | | |
|-------------------------------|---|---|
| Effectiveness / Impact | RE-AIM: The impact of an intervention on important outcomes, including potential negative effects, quality of life, and economic outcomes. | Program-level Effectiveness of the DAC-TM |
| | OCED/DAC Network: A measure of the extent to which an aid activity attains its objectives. The positive and negative changes produced by a development intervention, directly or indirectly, intended or unintended. This involves the main impacts and effects resulting from the activity on the local social, economic, environmental and other development indicators. The examination should be concerned with both intended and unintended results and must also include the positive and negative impact of external factors, such as changes in terms of trade and financial conditions. | Effectiveness of program delivery |
| | | Individual level Effectiveness of the program to meet the needs of its participants |
| | | Effectiveness of the program to communicate important concepts in POR/Diabetes research to trainees |
| | | Effectiveness of program to advance the trainee's productivity |
| | | Effectiveness of the program to lead to positive impacts on patients via the trainee's research project |
| | | Career advancements |
| | | Engagement in the program |
| | | Effectiveness of Mentor/Supervisor; Trainee-Mentor interaction and relationship |
| | | Mentor/supervisor experience and satisfaction |

| | | |
|---------------------------------------|---|---|
| Implementation and Fidelity | <p>RE-AIM: Implementation consistency, costs, and adaptations made during delivery. At the setting level, implementation refers to the intervention agents' <u>fidelity</u> to the various elements of an intervention's protocol, including <u>consistency of delivery as intended and the time and cost of the intervention</u>. At the individual level, mplementation refers to <u>clients' use of the intervention strategies</u>.</p> <p>Proctor: Marginal cost; cost-effectiveness; cost-benefit</p> | Fidelity |
| | | Learning needs |
| | | Program engagement |
| | | Participant responsiveness and demand for the DAC-TM program |
| | | Program details that may influence implementability |
| | | <p>Implementation cost</p> <p>Is the DAC-TM program being delivered on budget?</p> <p>What aspects of the participatory elements of the Program could be done differently next time to cut costs while still delivering achievements?</p> |
| Use of the DAC-TM program by trainees | | |
| Maintenance / Sustainability | <p>RE-AIM: Maintenance of intervention effects in individuals and settings over time; The extent to which a program or policy <u>becomes institutionalized as part of</u></p> | Sustainability beyond funding period |
| Relevance / Appropriateness | <p>Proctor: Perceived fit; relevance; compatibility; suitability; usefulness; practicability</p> <p>OCED/DAC Network: The extent to which the aid activity is suited to the priorities and policies of the target group, recipient and donor.</p> | <p>To what extent are the objectives of the DAC-TM Program still valid? Are the things you (DAC-TM program) are doing meeting the objectives?</p> <p>Does the DAC-TM program need to adjust their objectives to meet any changes that are taking place or coming up in the Diabetes and/or POR context? Is it meeting the need?</p> |

Appendix 5: Diabetes Action Canada Network Evaluation Report



Diabetes Action Canada

Strategy for Patient-Oriented Research Network

Network Evaluation Report

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Version 2.0

25 Oct 2019



EXECUTIVE SUMMARY

The Diabetes Action Canada (DAC) Strategic Patient-Oriented Research (SPOR) Network, formed in 2016, is supported by funding from the Canadian Institute of Health Research (CIHR) and numerous academic partners, and public and private sponsors. The Network is just over two-thirds of the way through their initial 5-year funding cycle and has membership from across Canada consisting of Patient-Partners, Researchers and Clinicians. The following report provides a mid-term examination of the DAC SPOR Network using a State of Network Evaluation framework on three key themes: Network Connectivity, Network Health and Network Results.(1)

A variety of methods were used to study these Network themes. A cross-sectional network survey of members was completed to examine Network Connectivity to assess the frequency of interactions and the topics discussed during them and how networking effectively facilitates interactions and collaboration among its members. Network Health was assessed through semi-structured qualitative interviews, a membership survey inquiring about satisfaction and experience with the Network and a review of funding and infrastructure to evaluate Network Sustainability. Finally, Network Results and Impact were examined using of the Canadian Academy of Health Sciences (CAHS) preferred framework and indicators to measure returns on investment in health research.(2)

The DAC SPOR Network includes several interconnected individuals with different status, function and location, with each of the 150 individuals on the official membership list having at least one relationship in the DAC SPOR Network. Within these relationships, the exchanges within the Network show that the two most discussed topics between members are research and patient engagement, that are at the core of the Network's vision and mission statement.

New collaborations are considered to be one of the DAC SPOR Network's key success factors and for many members it was a significant motivating factor to join the Network. These new collaborations have generated identifiable benefits and have enabled members to improve the quality and relevance of their research, to have access to key players and to benefit from new professional opportunities. The development of new

collaborative links has also brought benefits to the DAC SPOR Network as a whole, for example by creating new funding opportunities and increasing the network's competitiveness and visibility. Aligned with these new collaborations, DAC SPOR Network members have been contributed to 26 new grants leading to over \$36 million in additional funding over the past 3 years from CIHR (N=18) and other funding sources including the Canadian Foundation for Pharmacy Innovation, Centre de recherche sur les soins et les services de première ligne de l'Université Laval (CERSSPL-UL), CIHR/NSERC, MEDTEQ, North York General Hospital Foundation and the Public Health Agency of Canada.

Communication within the DAC SPOR Network is an essential condition for members' involvement in the network's activities. As identified in the interviews, ensuring smooth communication between members and finding ways to engage their participation in network activities are ongoing challenges for large networks such the DAC SPOR Network. Overall, surveyed members were very satisfied or satisfied with the Network and considered the activities innovative (40.6%) or very innovative (20.3%) compared to other networks.

Network Results and Impact were examined across the 5 domains of the CAHS framework which include: advancing knowledge; capacity building; informing decision making; health impact; and economic and social impact. Collaboration within the DAC SPOR Network, through the advancement of knowledge over the past 3 years, was further examined through the 59 peer reviewed publications published in the areas of medicine; biochemistry, genetics and molecular biology; nursing, agricultural and biological sciences; and pharmacology, toxicology and pharmaceuticals by Network members. The number of publications was 27 in fiscal 2017-18 and 32 in fiscal year 2018-19, aligned with the maturing of the Network. Of the papers with bibliometric data 44% (25/57), were published in high-quality outlet journals and at the time of the analysis, have been cited 528 times in other publications. These papers have involved 238 co-authors with international collaboration from 10 other countries in 33.3% of the publications.

Fulfilling its commitment to support capacity building related to health research, the DAC SPOR Network has funded 16 individuals, as either graduate students or post-doctoral fellows, and has provided salary support for 15 research staff to support the investigators and co-investigators across the country. Network participation has also grown over the past 3 years to now include 80 co-investigators.

The DAC SPOR Network members have engaged discussions with decision makers related to health and research policy at all levels of government across the country with the purpose to inform policy makers about the Network and its overall provincial and national research initiatives as well as studies related to diabetes and aging, indigenous health, digital health systems, diabetic retinopathy and foot care. The activities of DAC SPOR Network members related to informing health and research policy will be captured more comprehensively over the remaining reporting periods.

Patient Partner participation is an aspect of the Network with significant progress. The DAC SPOR Network currently has 75 Patient Partner participants involved many of whom are members of the 3 Patient Partner Circles. Patient Partners contribute to the Network governance as members on 15/27 (56%) of the advisory and planning groups within the DAC SPOR Network, have participated in the majority (73%) of the workshops and training sessions, including acting as facilitators and co-designers of the curriculum.

As the DAC SPOR Network is still evolving, the health, economic and social impact of the research and network activities remain to be fully realized, as may be expected based on the age and the stage of development the network. It is anticipated that as projects and different initiatives mature the Network will have further opportunity to influence healthcare and research policy as well as economic and societal wellbeing in Canada.

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NETWORK INTRODUCTION

The Diabetes Action Canada (DAC) Strategic Patient-Oriented Research (SPOR) Network 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 outcomes; health professional experience; health system cost) with a vision to transform the health trajectory for all Canadian men, women, and children with diabetes at risk for complications.*(3) Supported by funding from the Canadian Institute of Health Research (CIHR) for a 5-year grant beginning in 2016, the DAC SPOR Network is just over two-thirds of the way through their initial funding cycle. Network membership consists of Patient-Partners, Researchers and Clinicians from across Canada. Governing the DAC SPOR Network is a Steering Council and Operations/Management Committee, Scientific Co-Leads supported by an Executive Director and administration team. The Patient-Partners, who form an integral part of the Network, are organized into three (advisory) Circles: Collective Patient Circle; and Indigenous Patients Circle; Francophone and New Immigrants Circle. Research activities of the Network are coordinated through Research Goal Oriented Groups and Enabling programs. Initially, the activities of the DAC SPOR Network were organized into 8 Goal Groups however, as the Network has evolved and grown, additional groups/programs have been added. Currently the DAC SPOR Network is organized as follows. The *Research Goal Oriented Groups (N=6)* are: 1) Diabetic Retinopathy Screening; 2) Indigenous Peoples Health; 3) Innovations in Type 1 Diabetes; 4) Digital Health for Diabetes Research and Care; 5) Foot-care to Prevent Amputations; and, 6) Aging Community and Population Health. The *Enabling Programs (N=5)* are: 1) Patient Engagement; 2) Training and Mentoring; 3) Knowledge Translation 4) Sex and Gender; and, 5) Health Technology Assessment and Network Analytics. The DAC SPOR Network's efforts extend across 3 of the 4 pillars of Canadian Health Research (excluding basic biomedical sciences) with the potential to influence several areas of Canada's health system and to improve the health and well-being of Canadians as well as economic and social prosperity.

NETWORK EVALUATION

Many important aspects were considered for the DAC SPOR Network evaluation including: 1) the number and diversity of actors coming from different stakeholder groups, and how they connect and view their roles; 2) DAC SPOR Network continual emergence and evolution; 3) the timing to effectively develop and organize the Network activities to demonstrate results with impact; 4) recognition of the “chain of impact” – the Network’s impact on its members, the members’ impact on their local communities and the members’ collective impact on their broader environment; and, 5) the relevance of the structure and function of the Network on the approach to evaluation that must be revisited periodically.

The DAC SPOR Network was evaluated using a State of Network Evaluation framework on three key themes:(1)

- 1) **Network Connectivity**, which is the essential attribute for all networks. It is important to understand if the network effectively facilitates interaction among its members that results not only in open and effective channels for active knowledge exchange but also for collaborative action and impact. Network connectivity has two dimensions: i) membership (individuals and organizations); and, ii) structure (how connections between members are structured and what flows through those connections);
- 2) **Network Health** reflects the network’s ability to sustain continuous enthusiasm, commitment and engagement of its members to work together to achieve shared vision, mission and goals. Network health has three dimensions: i) resources (external funding to sustain itself); ii) infrastructure (internal systems and structures that support the network – e.g., communication, processes, regulations); and, iii) advantages (capacity for joint value creation). In addition to these three dimensions defined by the framework, we further explored the experiences of the DAC SPOR members with the Network itself, the extent to which the DAC SPOR Network met their expectations as well as key success

factors and perceived barriers for effective interactions and collaborations within the Network; and,

- 3) **Network Results**, which is usually expressed as an overarching goal of achieving a particular change with a significant societal impact. Network results have two dimensions: i) interim outcomes that capture network performance and progress; and, ii) final intended goal/impact.

Since networks typically move through stages of development including catalyzing, launching, organizing, performing and adapting and transitioning or transforming stages, we assessed the current stage of DAC SPOR Network using the results of our evaluation.



Figure 1. States of Network Development (adapted from (1))

NETWORK CONNECTIVITY

This section of the report presents the key findings that are related to the connectivity within the DAC SPOR Network. More precisely, we summarize the findings of a cross-sectional network survey conducted among DAC's members. This portion of the Network evaluation was reviewed and approved by the Université Laval's Research Ethics Board (2018-336-A-1/08-05-2019). All gathered data were anonymized and stored according to the Board's regulations. Members of the research team also signed a formal agreement to ensure that all data remained confidential.

Cross-sectional network survey

The method in brief

Using the Qualtrics's web-based survey platform, from May to July 2019, we conducted a cross-sectional survey among the 150 members identified through the DAC SPOR Network's administrative database. The survey population includes individual stakeholders (patient representatives, researchers, administrative employees, chair council members, co-leads, etc.) that were formally involved in the DAC SPOR Network between April 1, 2018 and March 31, 2019. The survey questionnaire included two questions aimed at measuring the frequency of the relationships between DAC SPOR Network's members and the topics discussed during these exchanges. The cross-sectional network data were analyzed with Pajek and VOSviewer.

Participation rates

From the 150 individuals included in the survey population, after three reminders, 64 (42.6%) completed the questionnaire. Four more individuals solely completed the first block of questions aimed at measuring the relational frequency. In this study, the relational data were considered as symmetric. This means that when a respondent indicated that he or she had a relationship with a DAC SPOR Network member and the member did not confirm the relationship either because he or she did not participate in the survey or because he or she could not confirm the relationship for other reasons (e.g., could not recall), the relationship was entered into the relational database. In social

network analyses where data are considered symmetric, the response rate is often higher for relationship reporting than for topics discussed during relationship interactions. In this study, the relational response rate was 70.3% for data on the frequency of relationships, and 67.3% for data on topics discussed during interactions.(4)

DAC Network Visualization

Figure 2 provides a visualization of the whole Network according to the regional location of members. The regional location refers to five geographical areas (The Maritimes, Quebec, Ontario, Manitoba-Saskatchewan and Alberta-British Columbia). The member's location was determined on the basis of the survey responses (n=61) and administrative data (n=74) on the basis of their institutional affiliation, i.e., the location corresponding to the city where their main employer is located (university, research centres, companies, etc.). Location information was not available for 15 Patient Partner members, as personal home addresses were not obtained from DAC SPOR Network administrative data for privacy reasons. In Figure 2, colors correspond to the regional location, and bubbles represent members. The size of bubbles is the number of relations that a member has with other actors of the DAC SPOR Network. Figure 2 shows the numerical importance and centrality of Ontarian members. It can be seen that there are two main regional hubs in the network, namely Ontario (n=79; 52.7%) and Québec (n=33; 22%), while Alberta-British Columbia (n=9; 6%), the Maritimes (n=7; 4.7%) and Manitoba-Saskatchewan (n=7; 4.7%) have fewer members and relations.

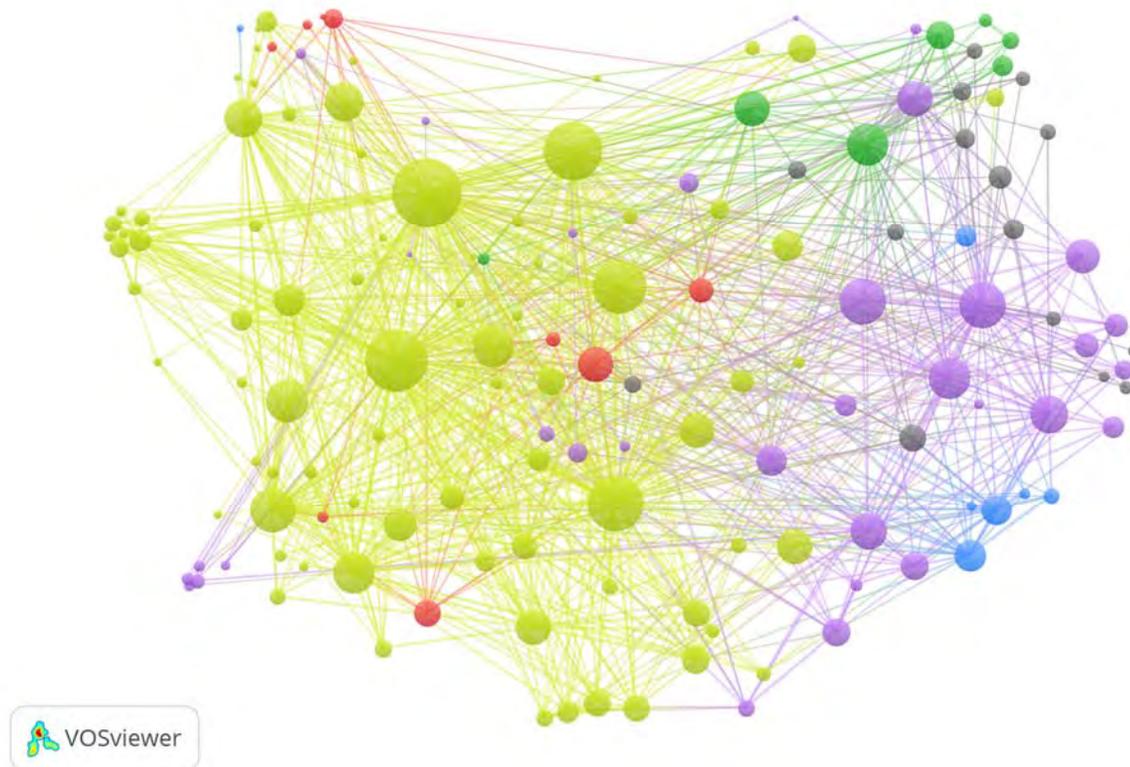


Figure 2. DAC SPOR Network based on the regional location of members (n=150, Density= 0.20; Centralization= 0.78)

Legend (Regional location):

- | | | | |
|--|---|---|---|
|  = Ontario |  = Québec |  = The Maritimes |  = Unknown |
|  = Alberta-British Columbia |  = Manitoba-Saskatchewan | | |

Findings for the relational frequency

In order to measure the relational frequency, a roster including the name, picture and affiliated group(s) for each member was presented to the participants. They were asked to indicate how often they interacted with each of the individuals who are (or were) formally involved in the DAC SPOR Network. It was specified that, for the sake of this project, an interaction was defined as any recalled direct conversation between two individuals, of any length, through any means of communication (e.g., face-to-face, telephone, email, chatting, texting), that occurred within the context of DAC-related

activities between April 1, 2018, and March 31, 2019, inclusively. For each listed individual, participants were asked to indicate the frequency of the relationship on the following 5-point scale: (1) **daily**, multiple times a day, most days in the last 12 months; (2) **weekly**, multiple times a week, most weeks in the last 12 months; (3) **monthly**, from time to time, most months in the last 12 months; (4) **quarterly**, a few times during the last 12 months; or (5) **yearly**, only once during the last 12 months.

The data show that the majority of the 3,113 inter-individual ties that were captured in the survey were sporadic, namely yearly (n= 934; 40.7%) or quarterly (n= 860; 37.3%), while monthly (n= 363; 15.8%), weekly (n= 104; 4.5%) or daily (n= 41; 1.8%) relations were much less frequent (Figure 3).

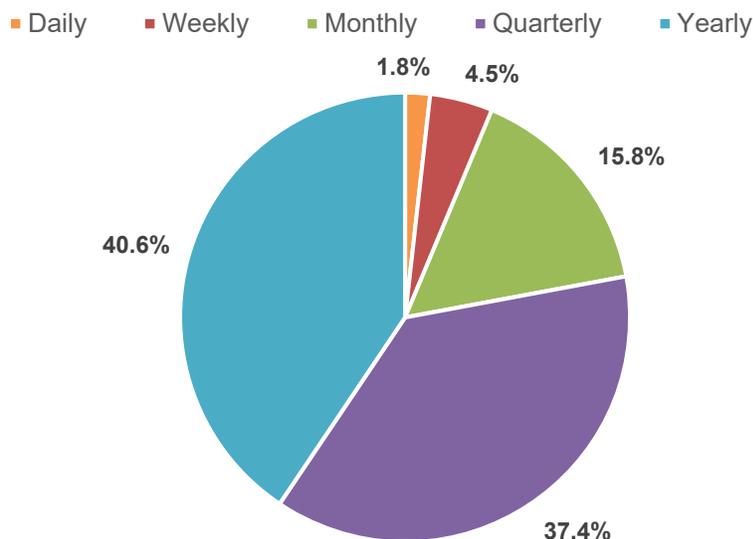


Figure 3. Distribution of ties based on the relational frequency

Figure 4 provides a visualization of both sporadic and frequent relations using a technique that optimizes the relations within a cluster (i.e., the primary function in DAC), thus positioning each actor close to the ones who have the same primary function. Based on administrative data, each actor was assigned to one of the following primary functions: research, patient partner, governance (e.g., Steering Council, sponsor partner) and administration (e.g., executive director, DAC SPOR Network’s employees

or project coordinators/managers). Figure 4 provides another way to see that most ties in the DAC SPOR Network were sporadic (i.e., yearly or quarterly). From the sporadic tie network presented in Figure 4, it can be seen that many ties linked individuals whose primary function in the DAC SPOR Network is engaging patient partners in research activities or whose primary function is governance or administration. Sporadic interactions between Patient Partners and administrative actors are also numerous. Frequent relations, that were much less frequent than sporadic ones during the survey period, were largely concentrated between researchers and administrators. People whose primary function in the DAC SPOR Network is governance have few connections with Patient Partners, researchers and administrators. Figure 4 also shows a pattern of frequent triadic relationships among patient partners, administrators and researchers.

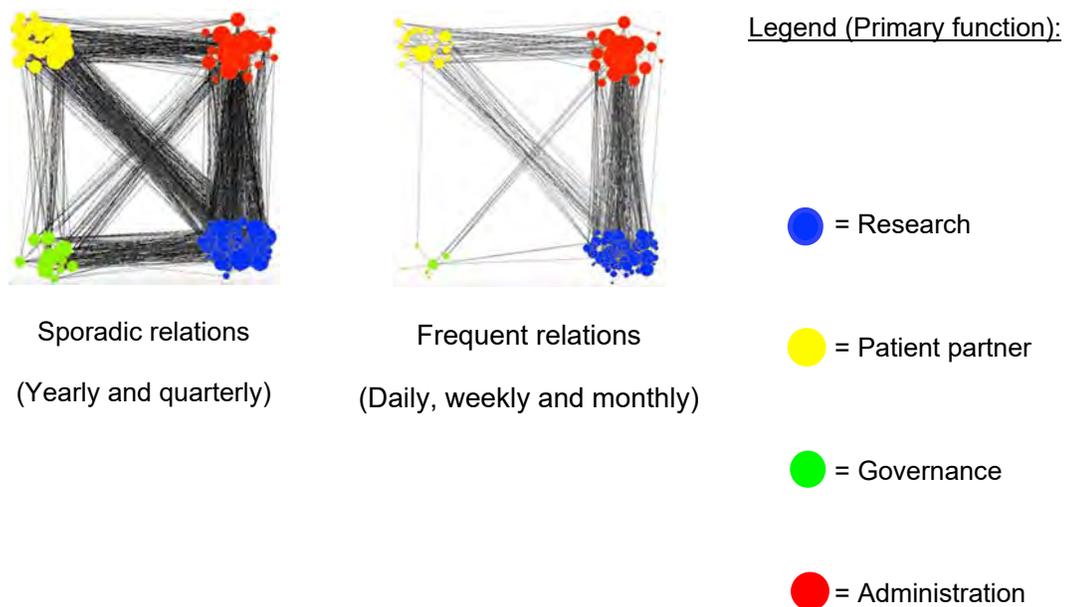


Figure 4. Relational frequency between members according to their primary function (Kamada-Kawai, Optimize Inside Cluster Only)

Discussion topics

After indicating the frequency of their relationships with each listed DAC SPOR Network member, participants were asked to indicate the topic(s) they discussed during their exchanges with each individual using the following mutually exclusive categories (i.e., participants could tick all categories) that were adapted from published social network analysis of health care networks:(5-7)

1. "Scientific research" refers to the research process (e.g., grant application, protocol writing, data collection, data analysis) or traditional ways to disseminate research findings (e.g., publications, conferences);
2. "Training" refers to student supervision, training or any other educational activity;
3. "Patient engagement" refers to Patient Partners' participation within the DAC SPOR Network (e.g., participation in research committees, collaboration in the research process, management and/or recruitment of Patient Partners);
4. "Management and operations" refer to the management of project or activity implementation (i.e., recruitment, reporting, coordination of services and resources);
5. "Governance and coordination" refer to the strategic decision making for the whole Network (e.g., defining the overall mission and objectives of the DAC SPOR Network, program evaluation and planning) or for specific groups (e.g., creating a new group, monitoring projects, coordinating researchers);
6. "Commercialization of research findings" refers to the commercialization of research products (e.g., licensing, consultancy, intellectual property protection and/or technology transfer processes);
7. "Transfer of research findings" refers to the dissemination of research results to external actors, excluding commercialization of research and scientific publications (e.g., guidelines, policy briefs, media articles, presentations to decision makers etc.);
8. "Other" items not included in the above categories, without further description.

During this last fiscal year, overall, the top three most frequent topics discussed during the inter-individual relationships were scientific research (n= 1,190 ties; 21.9%), patient

engagement (n= 1,081 ties; 19.9%), and management and operation (n= 947 ties; 17.5%). It should be noted that training (n= 506 ties; 9.3%), transfer of research findings (n= 338 ties; 6.2%) and commercialization of research (n= 45 ties; 0.83%) were discussed in much fewer relationships than management and operation (n= 947 ties; 17.5%) and governance and coordination (n= 663 ties; 12.2%) (Figure 5). Other items (n= 655 ties, 12.1%) were identified; however, in the survey, further opportunity to provide additional details was not available.

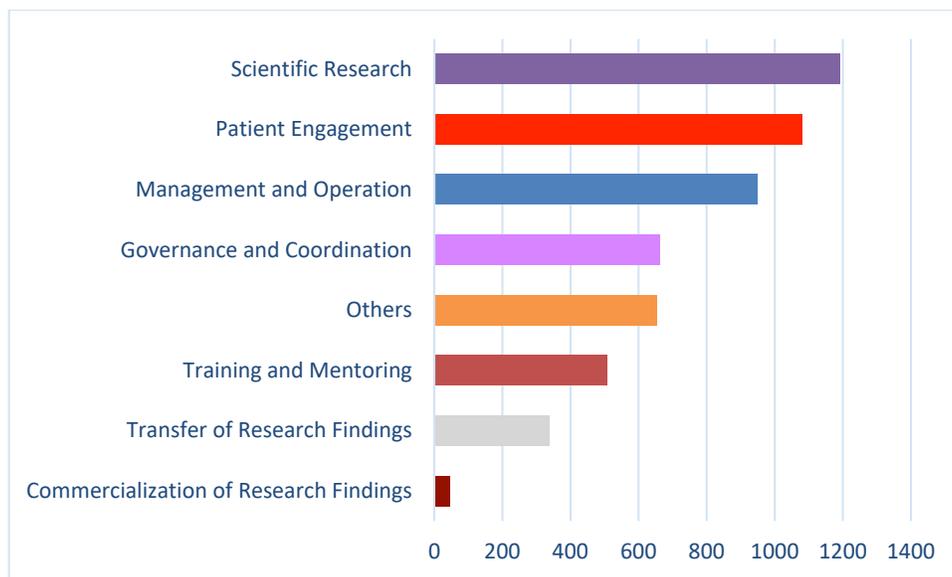
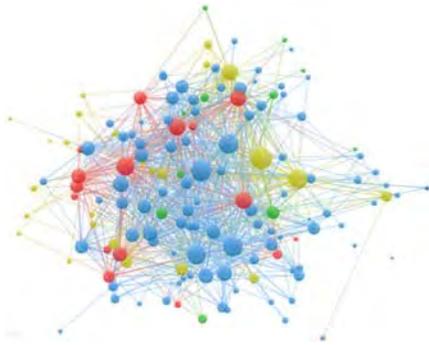
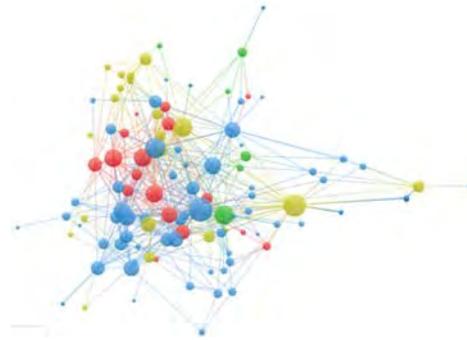


Figure 5. Distribution of ties according to the discussion topics

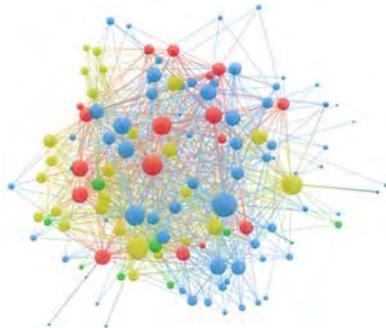
Figure 6 presents a visualization of the distribution of the relations according to the topic discussed, including the density and the centralization scores for each discussion topic network. Density refers to the proportion of ties in a network that are activated (e.g., 0.10 or 10% of the ties in the research topic network are activated), while centralization is a measure of the extent to which the ties in a network are concentrated around few highly connected individuals. Both measures can take a minimum value of 0 and a maximum value of 1. The color of vertices in Figure 6 corresponds to individuals' primary function, while the size of vertices corresponds to the weighted degree centrality of each actor (i.e., the number of direct ties a person has in a network).



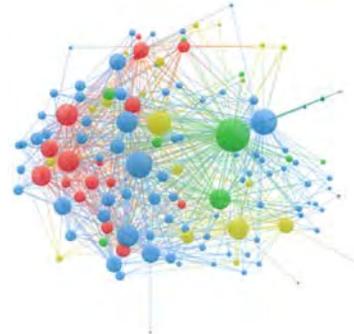
Scientific research
(Density = 0.10; Centralization= 0.59)



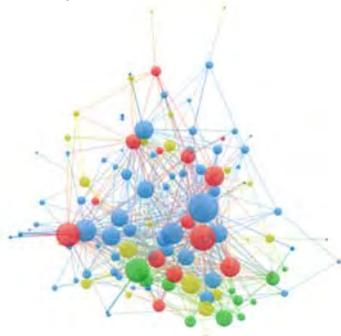
Training
(Density= 0.04; Centralization= 0.31)



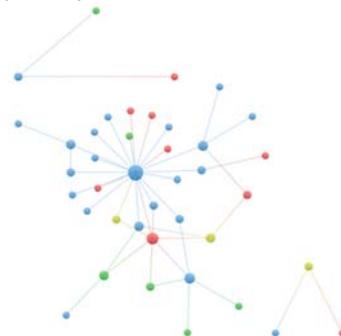
Patient engagement
(Density= 0.09; Centralization= 0.47)



Management and operation
(Density= 0.08; Centralization= 0.78)



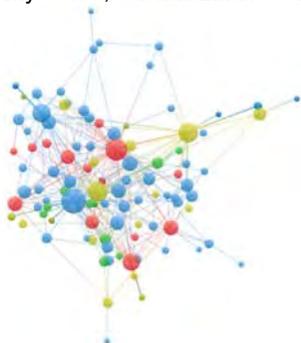
Governance and coordination
(Density= 0.05; Centralization= 0.38)



Commercialization of research Findings
(Density= 0.004; Centralization= 0.13)

Individual's primary function in DAC SPOR Network:

- = Research
- = Patient partner
- = Governance
- = Administration



Transfer of research findings
(Density= 0.03; Centralization= 0.37)

Figure 6. Discussion topic networks
(Vos Mapping Method)

When considered as a whole, the DAC SPOR Network (shown in Figure 2) for the last fiscal year had a density of 0.20 meaning that 20% of the potential direct ties were activated. This result should be interpreted with caution for two reasons. First, the quantity of ties in a network is not necessarily an indicator of performance. What might matter more is the nature of the relationships. A highly dense network in which everyone talks to everyone might not be efficient. Second, large networks that include many people such as the DAC SPOR Network rarely show high density scores.⁽⁸⁾ When looking at the networks of discussion topics, Figure 6 provides an alternative way to see that research, patient engagement and management & operations were the three most frequent topics discussed in the DAC SPOR network, with density scores of 0.10, 0.09, and 0.08 respectively.

As for network centralization, the DAC SPOR Network as a whole (shown in Figure 2) had a fairly high centralization score (0.78) indicating that the distribution of ties within the DAC SPOR Network is overall concentrated around few highly connected individuals. The DAC SPOR Network as a whole is as centralized as the subnetwork of members who discussed management and operation issues (0.78). The other discussion topic networks are much less centralized.

Location of Central Actors

We conclude this part of the report by addressing an important aspect of the DAC SPOR Network, namely the geographic variable. From a purely administrative point of view, the CIHR grant that enables the DAC SPOR Network to operate is mainly administered in Ontario (e.g., the Nominal Principal Applicant of the DAC SPOR Network and his administrative team are located in Ontario). Several other DAC SPOR Network members are also located in Ontario. Table 1 presents the top 10 most central individuals in the DAC SPOR Network as a whole and in the discussion topic networks. The individuals are identified solely by the name of the region where they reside, as adding more personal attributes to this table would have made it too easy for the readers to put a name on some of the listed individuals. Overall, the results presented in Table 1 show that among the 10 most connected individuals in the DAC SPOR Network as well as in the discussion topic networks, several are located in other regions. This is particularly

the case in Quebec and Manitoba-Saskatchewan, where people with several links in the network reside.

Conclusions

Four conclusions can be drawn from the analysis of the cross-sectional network survey data. First, it is clear that the DAC SPOR Network does not exist only on paper and includes several interconnected individuals with different status, function and location. It is important to mention that each of the 150 individuals on the official membership list has at least one relationship in the DAC SPOR Network. Second, the data on links and exchanges within the network show that the two most discussed topics within the network - research and patient engagement - are at the core of the Network's vision and mission statement. Third, the DAC SPOR Network is overall quite centralized and people responsible for its administration occupy a central position in the Network. Finally, relationally speaking, some topics occupied a more peripheral place in the network, such as training and mentoring, research transfer and commercialization of research.

Table 1. The top 10 central actors in the DAC SPOR Network as a whole and in the discussion topic networks

| Rank 1-5 | Residence location | Number of ties | Rank 6-10 | Residence location | Number of ties |
|--|--------------------------|----------------|-----------|--------------------------|----------------|
| DAC SPOR Network as a whole | | | | | |
| 1 | Ontario | 203 | 6 | Quebec | 136 |
| 2 | Ontario | 188 | 7 | Quebec | 126 |
| 3 | Ontario | 181 | 8 | Ontario | 115 |
| 4 | Ontario | 167 | 9 | Quebec | 111 |
| 5 | Ontario | 151 | 10 | Manitoba-Saskatchewan | 110 |
| Discussion topic network: Scientific research | | | | | |
| 1 | Manitoba-Saskatchewan | 102 | 6 | Manitoba-Saskatchewan | 61 |
| 2 | Quebec | 69 | 7 | Ontario | 59 |
| 3 | Quebec | 67 | 8 | Ontario | 51 |
| 4 | Quebec | 67 | 9 | Quebec | 51 |
| 5 | Ontario | 62 | 10 | Ontario | 44 |
| Discussion topic network: Training | | | | | |
| 1 | Quebec | 53 | 6 | Ontario | 28 |
| 2 | Ontario | 46 | 7 | The Maritimes | 27 |
| 3 | Quebec | 36 | 8 | Ontario | 25 |
| 4 | Manitoba-Saskatchewan | 32 | 9 | Quebec | 24 |
| 5 | Manitoba-Saskatchewan | 31 | 10 | Ontario | 23 |
| Discussion topic network: Patient engagement | | | | | |
| 1 | Quebec | 83 | 6 | Ontario | 49 |
| 2 | Manitoba-Saskatchewan | 69 | 7 | Ontario | 42 |
| 3 | Ontario | 59 | 8 | Quebec | 40 |
| 4 | Ontario | 58 | 9 | Manitoba-Saskatchewan | 40 |
| 5 | Ontario | 56 | 10 | Quebec | 39 |
| Discussion topic network: Management and operations | | | | | |
| 1 | Ontario | 127 | 6 | Ontario | 48 |
| 2 | Manitoba-Saskatchewan | 71 | 7 | Alberta-British Columbia | 48 |
| 3 | Manitoba-Saskatchewan | 64 | 8 | Quebec | 47 |
| 4 | Quebec | 63 | 9 | Ontario | 46 |
| 5 | Ontario | 49 | 10 | Quebec | 46 |
| Discussion topic network: Governance | | | | | |
| 1 | Quebec | 65 | 6 | Quebec | 37 |
| 2 | Ontario | 49 | 7 | Ontario | 32 |
| 3 | Ontario | 46 | 8 | Manitoba-Saskatchewan | 32 |
| 4 | Alberta-British Columbia | 45 | 9 | Ontario | 31 |
| 5 | Ontario | 37 | 10 | Manitoba-Saskatchewan | 30 |
| Discussion topic network: Commercialization of research | | | | | |
| 1 | Quebec | 21 | 6 | Ontario | 3 |
| 2 | Ontario | 7 | 7 | Quebec | 3 |
| 3 | Quebec | 5 | 8 | Quebec | 3 |
| 4 | Ontario | 4 | 9 | Quebec | 2 |
| 5 | Ontario | 3 | 10 | Alberta-British Columbia | 2 |
| Discussion topic network: Transfer of research findings | | | | | |
| 1 | Quebec | 59 | 6 | Ontario | 21 |
| 2 | Ontario | 39 | 7 | Ontario | 16 |
| 3 | Manitoba-Saskatchewan | 32 | 8 | Ontario | 14 |
| 4 | Ontario | 30 | 9 | Quebec | 13 |
| 5 | Quebec | 24 | 10 | Ontario | 13 |

NETWORK HEALTH

The assessment of the health of the DAC SPOR Network was conducted through qualitative interviews and a survey to explore network experience and a review of relevant internal and external documentary resources to assess additional funding obtained through grants awarded to DAC SPOR Network Investigators either as a Principal Investigator or Co-investigator, to examine network sustainability.

Semi-structured interviews

The method in brief

Between May 3rd 2019 and July 15th 2019, we conducted 18 semi-structured interviews (most by phone) with a purposive sample of 18 DAC SPOR Network members from the different groups. The interview guide was closely modelled on the *CDC Evaluation Interview Guide*, a questionnaire developed to evaluate the impact of specific communities on individual members, organizations, and public health (9). The interview guide included 18 open-ended questions designed to achieve the following objectives: i) to describe the perceived purpose of the DAC SPOR Network from the members' perspective; ii) to assess the extent to which the DAC SPOR Network met member expectations; iii) to describe outcomes associated with the DAC SPOR Network; iv) to identify key success factors for effective interactions and collaborations within the DAC SPOR Network; and, v) to identify perceived barriers and/or other factors that limited interactions and collaborations within the DAC SPOR Network. All interviews were recorded and transcribed verbatim. NVivo was used to analyze the data using a thematic analysis approach based on a predefined codebook. All interviews were coded by Ashley Rhéaume and audited by Mathieu Ouimet.

Six dominant themes emerged from the coding process: (i) DAC SPOR Network's mission and objectives; (ii) members' motivations for joining the DAC SPOR Network; (iii) members' expectations with regard to the DAC SPOR Network; (iv) Network collaborations; (v) outcomes and factors of effectiveness; and, (vi) participation barriers. These themes were captured by the questions included in the interview guide and

reflect the overarching research objectives. In this section, we report on the interview findings that are related to network health (collaboration, communication, etc.). As with the Network connectivity, the semi-structured interviews portion of the Network evaluation was reviewed and approved by the Université Laval's Research Ethics Board (2018-336-A-1/08-05-2019). All gathered data were anonymized and stored according to the Board's regulations. Members of the research team also signed a formal agreement to ensure that all data remained confidential.

Networking as one of the key missions and factors of success of the DAC SPOR Network

When participants were asked to summarize the overarching purpose and mission of the DAC SPOR Network, almost unilaterally, they stated that the Network aimed to prevent, reduce and treat diabetes-related complications. Interview data show that achieving this objective requires first and foremost the creation of a network that links several actors in diabetes research and care with the intent to spearhead and scale-up research projects—with the guidance of Patient Partners—to ultimately improve the lives of people living with diabetes. As one participant said:

“DAC is, first and foremost, a network [Its objective] is to bring people to work together as a network because people are stronger together, than they are in their own laboratories. So, that's it! The objective is to create a networking effect among many research teams across Canada.”

When interviewees were asked to name the factors and circumstances that contribute to the DAC SPOR Network's success, three principal themes emerged: 1) leadership; 2) networking; and, 3) patient-oriented research. As shown by the words cloud below, “people” that are interconnected in the “network” are considered at the heart of the network's success, along with “leadership”.

identified – benefits for policy makers – but it was based on the view of only one participant. By creating links between experts in a broad range of fields, the DAC SPOR Network has cultivated opportunities for cross-learning and cross-fertilization. Consequently, research initiatives are more likely to take on a multidisciplinary and/or inter-sectoral dimension. For example, a participant said:

“I think at the individual level, it's certainly strengthened, I would say, the quality of the research that we're doing because we're connecting now with people who have expertise in some of those areas that we didn't have.”

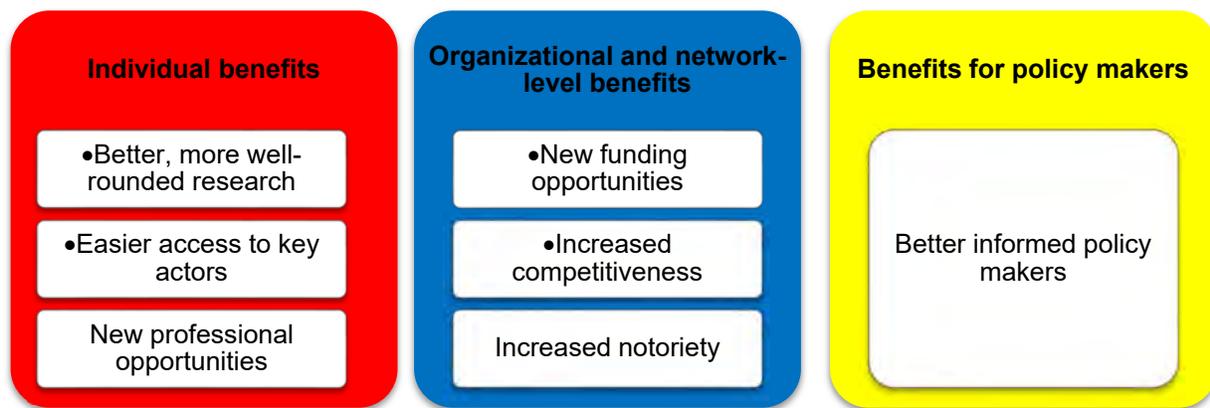


Figure 10. Categories of benefits of collaboration

Organizational and network-level benefits

As the DAC SPOR Network continues to expand across Canada, more sustained collaborations between members and other organizations increase the Network’s clout in the academic and medical spheres. This level of notoriety—compounded with the conception of competitive, multidisciplinary grants—generates new funding opportunities for the DAC SPOR Network members. A participant said:

“I think the benefits can be found on multiple levels. So, certainly, it helps the network gain visibility. It helps make the network known outside the academic arena or even within organizations that we know of like Diabetes Canada and other large organizations. So it helps Diabetes Action Canada gain notoriety on another level.”

Another participant said:

“Then for the network, in terms of funding, I think it's great for us to be connected to people that maybe aren't funding DAC right now, but could be funding it in the future.”

Informing policy decision-makers

According to one interviewee, newfound connections with policymakers and stakeholders allow the DAC SPOR Network members to present their research findings and/or other contributions to decision-makers at the local, provincial and national level. These connections facilitate the process of knowledge translation (KT). More precisely, this participant said:

“The more they can leverage their ability to get policymakers around the table, the better off we are at trying to translate our work and to change policy, which is great. That also helps the network because if we can do research that's going to be.... where the results are going to be on the desk of people who are making policy decisions or determining where funding should go to improve the health of a province, or the health of a country.”

Members' participation and engagement in the DAC SPOR Network's activities

Participants cited a number of barriers which hindered participation. However, they recognized that many factors lay outside the DAC SPOR Network's control. Some also noted that certain barriers (i.e., lack of funding, competing priorities) were common to most large organizations. Certain respondents spoke about barriers that were specific to their own personal circumstances (i.e., accessibility issues, geographical distance). When asked to provide potential solutions to mitigate said barriers, many participants remarked that most issues were inherent to research organizations and therefore not so easily remedied.

One obvious and concrete way to foster the creation and maintenance of links in a network is for its members to participate in the Network's activities. Communication—or lack thereof—was a common theme among a few respondents. Accordingly, better and more sustained communication between individuals and groups would allow for a

higher degree of coordination and provide more opportunities for members to express their concerns and/or dissatisfaction. One respondent said:

“We could place a greater emphasis on communication. Maybe we could hire a communications expert for the network, the partners, the researchers and the administrative side. We could perhaps devote a part of the budget to that aspect.”

Conclusions

The interviews highlighted certain elements and issues that could not be identified in a survey with almost exclusively closed-ended questions. Three conclusions can be drawn from the analysis of the interview data. First, the qualitative data generated by the interviews show that networking exists not only within the DAC SPOR Network, as demonstrated by the results of the cross-sectional survey, but that this networking has facilitated new collaborations that have generated identifiable benefits. These new collaborations are considered to be one of the DAC SPOR Network's key success factors. Several participants also mentioned networking as a factor that motivated them to join the DAC SPOR Network.

Second, the interview data revealed how participants perceive the benefits of the new collaborations generated within the DAC SPOR Network. These collaborations have generated new opportunities for members and their respective communities. More precisely, these collaborations have enabled them to improve the quality and relevance of their research, to have access to key players and to benefit from new professional opportunities. The development of new collaborative links has also brought benefits to the DAC SPOR Network as a whole, for example by creating new funding opportunities and increasing the network's competitiveness and visibility.

Finally, the interview data highlighted the issue of communication within the DAC SPOR Network, an essential condition for members' involvement in the network's activities. As one participant reminded us, the DAC SPOR Network is a "network of networks". The analyses of the cross-sectional survey data also reminded us that the DAC SPOR Network is a large network (150 members) with multiple relationships of different kinds. The cross-sectional survey data also showed that individuals whose main function in

the DAC SPOR Network is management and operations occupy a central place in the network of interactions. Ensuring smooth communication between members and finding ways to ensure their participation in network activities are ongoing challenges for large networks such the DAC SPOR Network.

Survey

As a component of the cross-sectional network survey, the DAC SPOR Network's members were asked about their satisfaction and experience with the DAC SPOR Network over the past year during the period of April 1, 2018 to March 31, 2019. A 7-point Likert scale was used to evaluate the member's experience with the network. The members were asked about their level of satisfaction with the DAC SPOR Network's products or services (Figure 11), potential for achievement of overarching objectives (success)(Figure 12), the ability for the network to compete with other formal health-care related research networks (Figure 13) and with management or leadership of the network (Figure 14). Lastly, the members were asked how innovative they considered the DAC SPOR Network to be relative to formal health-care related research networks (Figure 15). The member's responses are outlined below in the following Figures. In general, members were either very satisfied or satisfied with the network (Figures 11 to 14) and considered the DAC SPOR Network to be innovative (40.6%) or very innovative (20.3%) compared to other networks (Figure 15).

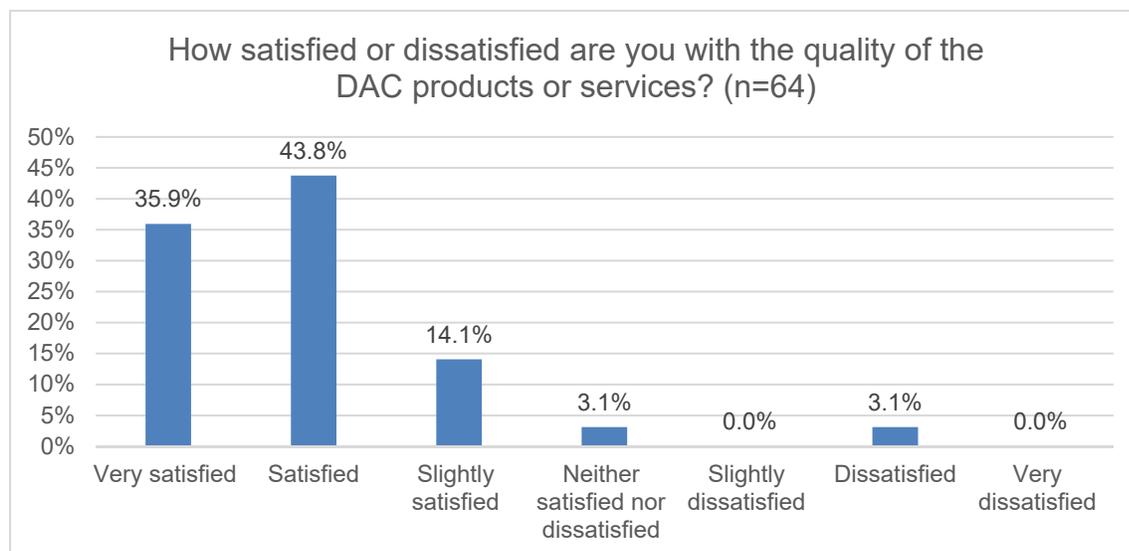


Figure 11. DAC SPOR Network members level of satisfaction products or services

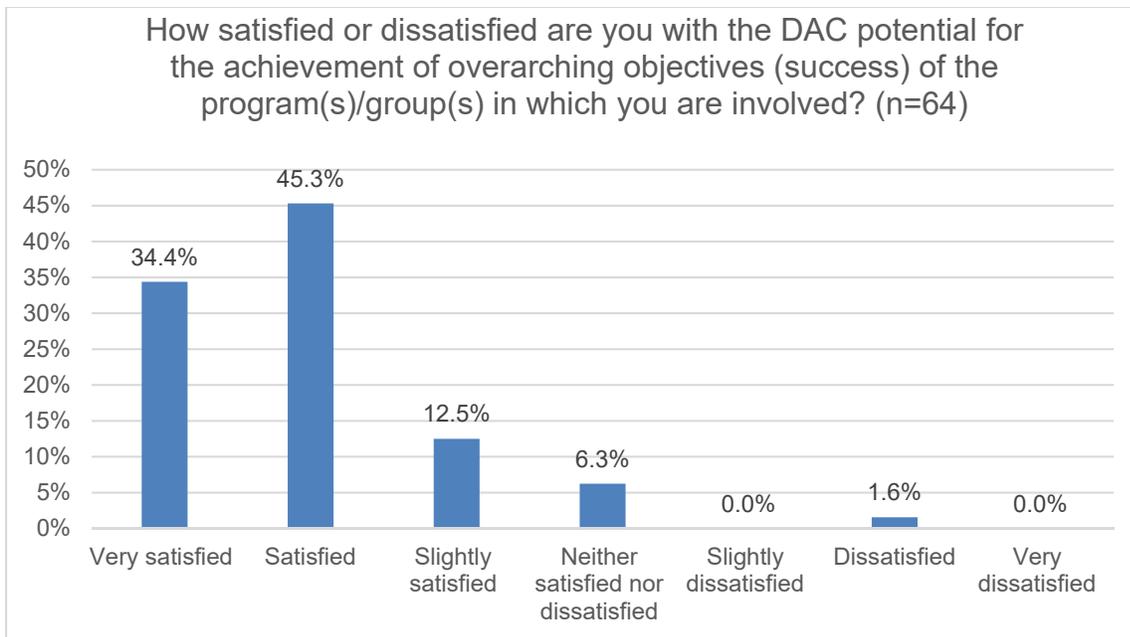


Figure 12. DAC SPOR Network members level of satisfaction with potential to achieve overarching objectives

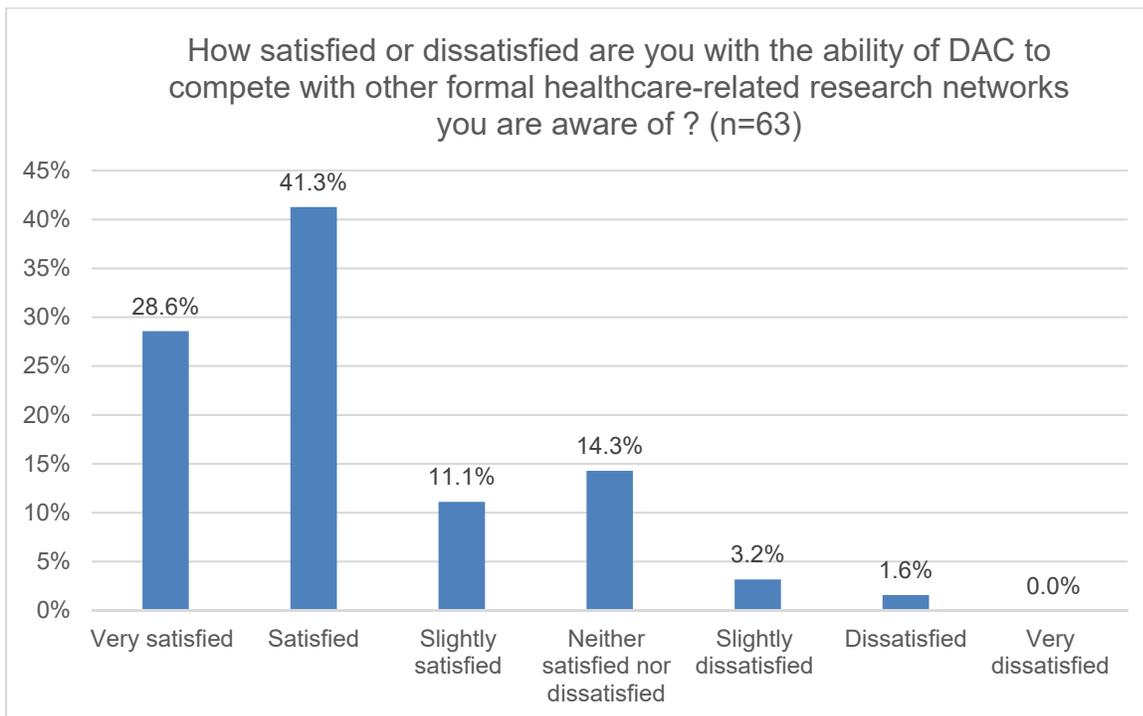


Figure 13. DAC SPOR Network members level of satisfaction with ability of network to compete

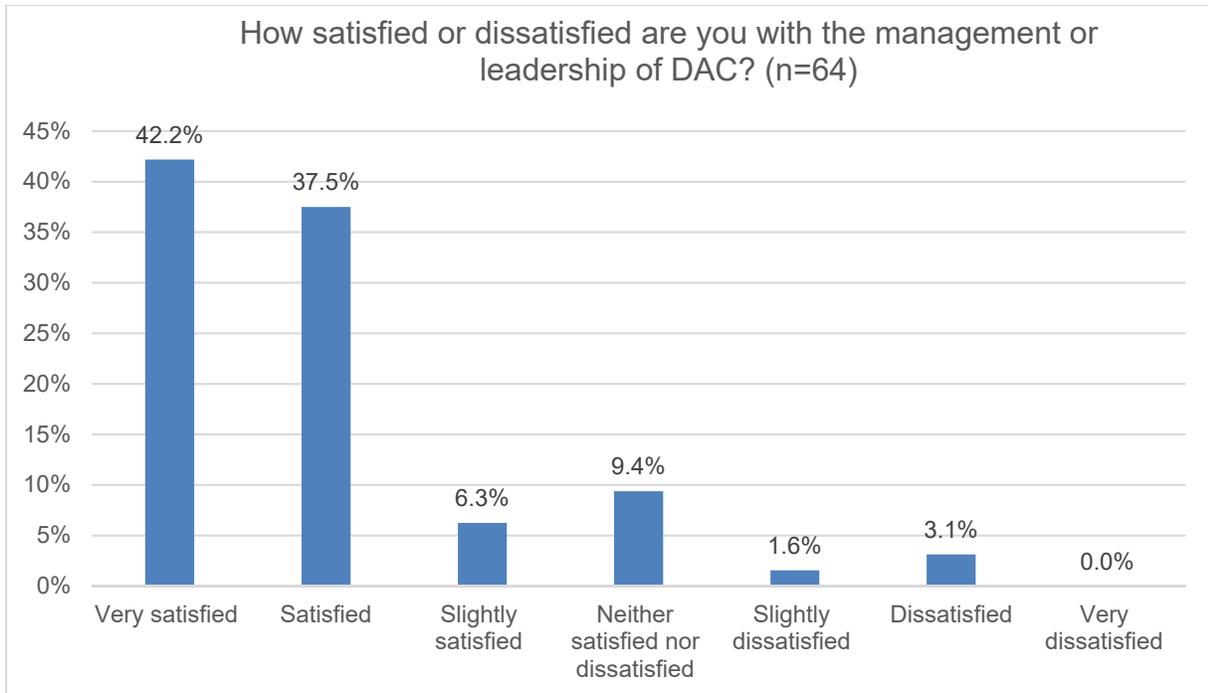


Figure 14. DAC SPOR Network members level of satisfaction with management or leadership

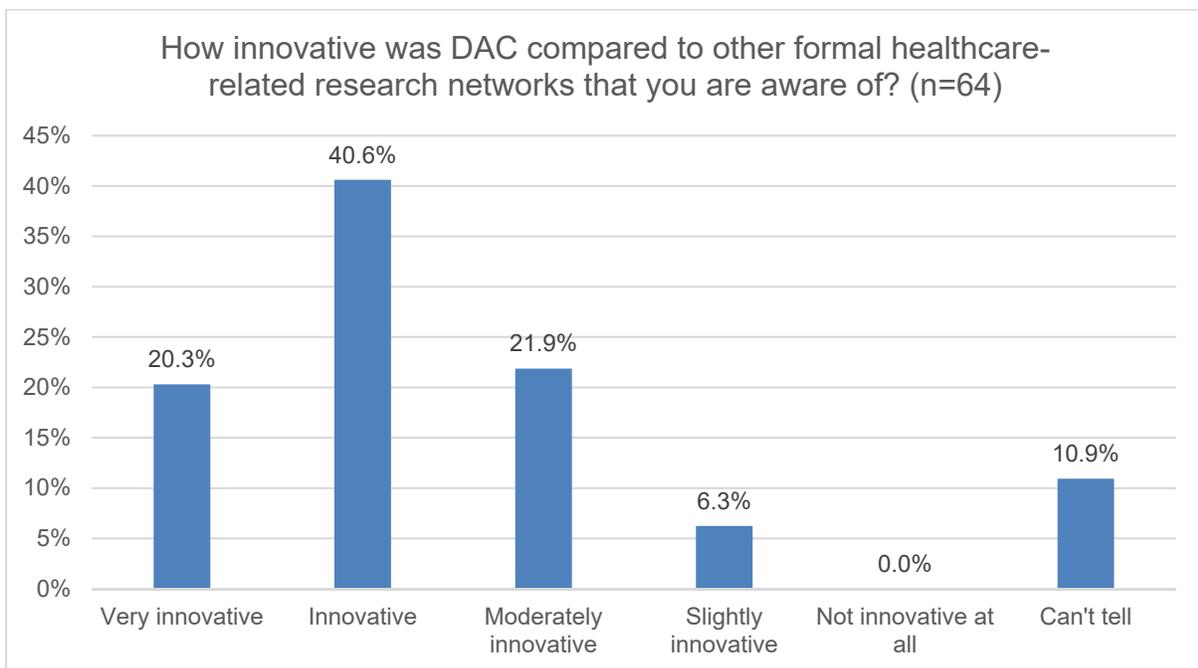


Figure 15. DAC SPOR Network innovation compared to other formal healthcare-related research networks.

Network Sustainability

We reviewed relevant internal and external documentary resources to further explore network health by assessing the initial resources provided by the CIHR, Network infrastructure, and capacity of the Network for joint value creation in terms of additional funding obtained by DAC SPOR Network members. Information regarding new funding awards was obtained through DAC Annual Reporting before March 31, 2019 to determine the incremental funding obtained. The information reported was then reviewed in the CIHR Funding Decisions Database and the Canadian Research Information System. Funding from granting agencies other than CIHR was also reported by the Investigators. Where necessary, clarification was requested from the DAC SPOR Network Investigators about the funding amounts obtained.

Initial Resources and matching funding

In 2016 the DAC SPOR Network in diabetes and its related complications was awarded \$12,500,000 in funding from CIHR. The grant funding provided by CIHR has been \$9,401,904 as of March 31, 2019; with \$912,721 in funding year 2015/16, \$3,469,402 in funding year 2016/17, \$2,663,848 provided in funding year 2017/18 and finally in the last complete funding year of 2018/19, \$2,355,958.

In addition to the CIHR funding, matching funding has been obtained, equaling \$21,586,678, from a variety of organizations, corporations and private donors. Of these funds \$13,368,139 are restricted, \$2,814,935 is unrestricted funds and in-kind matching funds equivalent to \$5,623,723.

Infrastructure

The DAC SPOR Network has established a core internal governance and communication infrastructure. The highest level of governance within Diabetes Action Canada is the Steering Council which meets quarterly to ensure that the vision and mission of the Network are being fulfilled. Guiding the Network, is the Steering Council Executive, consisting of the Chair of the Steering Council, the Chair of the Standing Committees, the Scientific Co-Leads and the Executive Director, who review relevant

reports and set the agenda for the Steering Council meetings. The DAC SPOR Network Strategic Partnerships and Innovation Standing Committee also meets quarterly and is responsible for advising about both internal and external partnerships with researchers, organizations, corporations or government.

The Governance and Nomination Committee meets annually and recruits and nominates members of the Steering Council and DAC SPOR Network Standing Committees. This committee is also responsible for the overall evaluation of performance of the Steering Council and academic performance of co-leads. Finance and Audit Committee meets semi-annually and is responsible for budget development and trouble-shooting financial- related issues. Finally, with respect to oversight of the research of the Network, the Operational and Management Committee, consisting of the core Principal Investigators and additional co-leads of the Research and Enabling Groups, meets monthly to provide strategic, critical and innovative thinking to the implementation of programs and projects and advises the Steering Council regarding the strategic directions of the Network. An administrative team, consisting of an Executive Director, Manager of Research Operations, Business Officer, and an Administrative Assistant, as well as Program Coordinators or Managers associated with each of the Research Groups, supports the daily activities and research activities of the DAC SPOR Network.

Additional Research Funds obtained by Diabetes Action Canada SPOR Network members

As described above in the semi-structured qualitative interviews, the funding of the DAC SPOR Network has provided the opportunity for collaboration between scientists and institutions. The collaborations have enabled DAC SPOR Network's members to establish new research teams and to apply for additional funding to support research initiatives aligned with the goals of the Network over the last 3 years. The funding associated with these grants has provided \$36,496,062 in incremental research funding (Table 2).

Table 2. Grants awarded with Diabetes Action Canada members as principal investigator and/or co-investigators

| | Granting Agency Funding | CIHR partner(s) | Applicant partner(s)* | Total Research Funding |
|---|-------------------------|--------------------|-----------------------|------------------------|
| CIHR grants with DAC Member(s) as one of the PIs (N=15) | \$11,492,496 | \$3,843,990 | \$2,881,750 | \$18,218,236 |
| CIHR grants with DAC Member(s) only as Co-PIs (N=3) | \$6,121,864 | - | \$9,829,900 | \$15,951,764 |
| CIHR grants subtotal (N=18) | \$17,614,360 | \$3,843,990 | \$12,711,650 | \$34,170,000 |
| Other Granting Agencies (N=8) | \$2,326,062 | - | - | \$2,326,062 |
| Total | \$19,940,422 | \$3,843,990 | \$12,711,650 | \$36,496,062 |

*not including Diabetes Action Canada funds

CIHR has been the primary funding source for additional grants. Further, CIHR funding has been obtained through the awarding of 18 grants consisting of 9 operational (12-20), 3 patient engagement (21-23), 3 project grants (24-26), and 1 team grant (27), 1 planning and dissemination grant (28), and 1 development grant.(29) Of these grants, 15 (83%) had one or more DAC SPOR Network member as a Principal Investigator. Across all CIHR grants awarded 12 (67%) had multiple DAC SPOR Network members contributing to the application.

The total funding associated with these CIHR grants is \$34,170,000, of which \$17,614,360 has been provided by CIHR, with a required matches of \$3,843,990 provided by a CIHR partner, such as the Juvenile Diabetes Research Foundation (JDRF),(12, 15, 17) and \$12,711,650 provided by organizations identified as partners by the applicants that are contributing a cash match to these research projects. For two of these grants, Diabetes Action Canada is an applicant partner providing \$895,062 in

funding (from unrestricted sponsor funds) and this funding is not included in Table 2.(16, 20)

Other funding organizations have also contributed support for research being conducted by DAC SPOR Network members including: the Canadian Foundation for Pharmacy Innovation, Centre de recherche sur les soins et les services de première ligne de l'Université Laval (CERSSPL-UL), CIHR/NSERC, MEDTEQ, North York General Hospital Foundation and the Public Health Agency of Canada. The total value of these grants is \$2,326,062 (Table 2).(30-36)

NETWORK IMPACT

Introduction

In January 2009 The Canadian Academy of Health Sciences (CAHS) released the report *Making an Impact. A Preferred Framework and Indicators to Measure Returns on Investment in Health Research.*(2) This framework has the “payback model” developed by Buxton and Hanney in 1996 as its foundation.(37) The model was adapted by the Canadian Institutes of Health Research (CIHR) initially in 2005 and, the 2008 following the CAHS report in order to evaluate return on investment (ROI) in health and biomedical research.(2) The anticipated impact of research activities is described across all 5 Pillars: Biomedical Research, Clinical Research, Health Services Research, Population and Public Health Research and Cross Pillar Research evaluated across 5 domains. A schematic of the CAHS framework is presented in Figure 16.

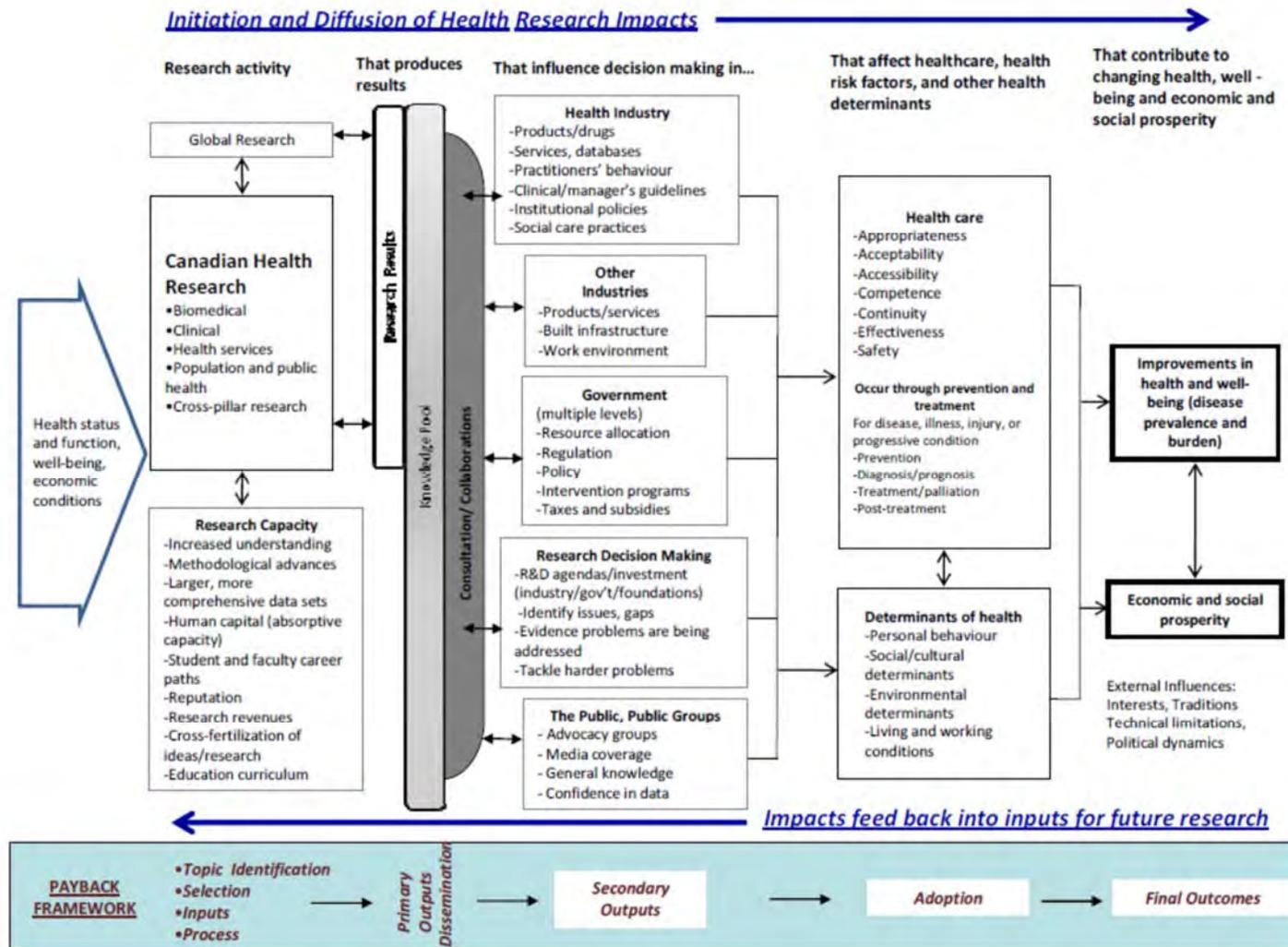


Figure 16. The Canadian Academy of Health Sciences impact framework (2)

The CAHS framework uses five main domains to track health research impact: 1) advancing knowledge; 2) capacity building; 3) informing decision-making; 4) health benefits; and, 5) broader economic benefit.(2) Each of the domains is then divided into categories in which 66 indicators of research impact are described.(Appendix A)

Methods

The CAHS framework for ROI for health research was applied to the DAC SPOR Network activities since April 1, 2016 to March 31, 2019 and forms the basis of this analysis. Data for the activities were obtained from a review of relevant documentation including; DAC SPOR Network annual reports covering 2016-17, 2017-18 and 2018-19, the DAC SPOR Network website (3), knowledge translation reporting for each fiscal year, peer reviewed publications, and bibliometric analyses. For application of the CAHS framework, the DAC SPOR Network is considered as a Research Group. The CAHS framework Indicators within each domain were evaluated to determine which indicators were appropriate for the evaluation of the DAC SPOR Network based on the level of consideration recommended in the CAHS report and also based on the maturity of the DAC SPOR Network and its research activities. The following outlines the indicators, within each domain, that were examined to consider the feasibility and appropriateness for a research Network level analysis. Where there was some possible ambivalence related to the indicators, relevant stakeholders were consulted to clarify the use of the metric. Some relevant indicators were deferred for future analysis, due to lack of maturity of the Network and the early nature of research projects. The domains and indicators primarily examined for this evaluation were advancing knowledge, capacity building and informing decision- making. Evaluation of the indicators within health benefits and broader economic benefit domains were deferred.

Of all the CAHS indicators (N=66), bibliometric data is needed for at least 18 (27%) to assess research impact.(2) This evaluation was conducted with the assistance of an academic medical librarian. To complete this assessment, a combination of information from PubMed, SCOPUS and SCOPUS- SciVal and Google Scholar was used to obtain bibliometric data. Benchmarking metrics were obtained from the SCOPUS SciVal analysis to compare the DAC SPOR Network to relevant other entities including

scholarly output within Endocrinology, Diabetes and Metabolism, Nephrology and Ophthalmology within the SCOPUS datasets. Targeted literature searches were completed within Google Scholar or SCOPUS to identify publications stating funding from DAC. For the purposes of the co-author analysis, VOSviewer and Pajek social network analysis software were used to analyze and illustrate the DAC SPOR Network co-author publication interactions. Full-text publications were obtained and reviewed to abstract and calculate additional metric information including the number and provincial location of the DAC SPOR Network authors, and the number and country of residence of international authors. All abstracted data was managed in Excel.

Advancing Knowledge

Over the 3-year life span of the DAC SPOR Network, there have been 59 peer reviewed articles published. DAC SPOR Network Investigators and research staff reported 48 papers; an additional 11 articles were identified where DAC SPOR Network funding has been acknowledged. The number of publications by fiscal year examined in this analysis is 27 in fiscal 2017-18 (38-64) and 32 in fiscal year 2018-19.(64-96) In addition to the peer-review publications, 32 poster presentations and 63 oral presentations have been presented at conferences and meetings. Other KT products that have been produced by the DAC SPOR Network members include 1 book chapter and 10 reports. The reporting of research findings has been spread across the various DAC SPOR Network groups.

Citations

For a bibliometric analysis of citations for the DAC SPOR Network, data is available in SCOPUS for 57 (97%) publications at the time of this analysis. The DAC SPOR Network peer review publications were cited 528 times with 48 of the identified 57 papers (84%) being cited at least once by another paper with an average citation rate of 9.3 citations per article (min – max: 0 – 119). This surpasses an average citation rate for Endocrinology, Diabetes and Metabolism of 4.7 citations per paper as identified in the SCOPUS SciVal analytics.

Field Analysis

Publication across multiple fields of study occurred across the DAC SPOR Network over the past 3 years. The following 5 topics of study within the scope of the publications (N=57) were evaluated using SCOPUS SciVal: Medicine (56.2%); Biochemistry, Genetics and Molecular Biology (18%); Nursing (15.7%); Agricultural and Biological Sciences (5.6%) and Pharmacology, Toxicology and Pharmaceutics (2.2%) with other topics comprising of the remaining 2.2%. The topics of publication and relative proportion of the DAC SPOR Network publications is depicted in Figure 17 from the SCOPUS SciVal analysis.

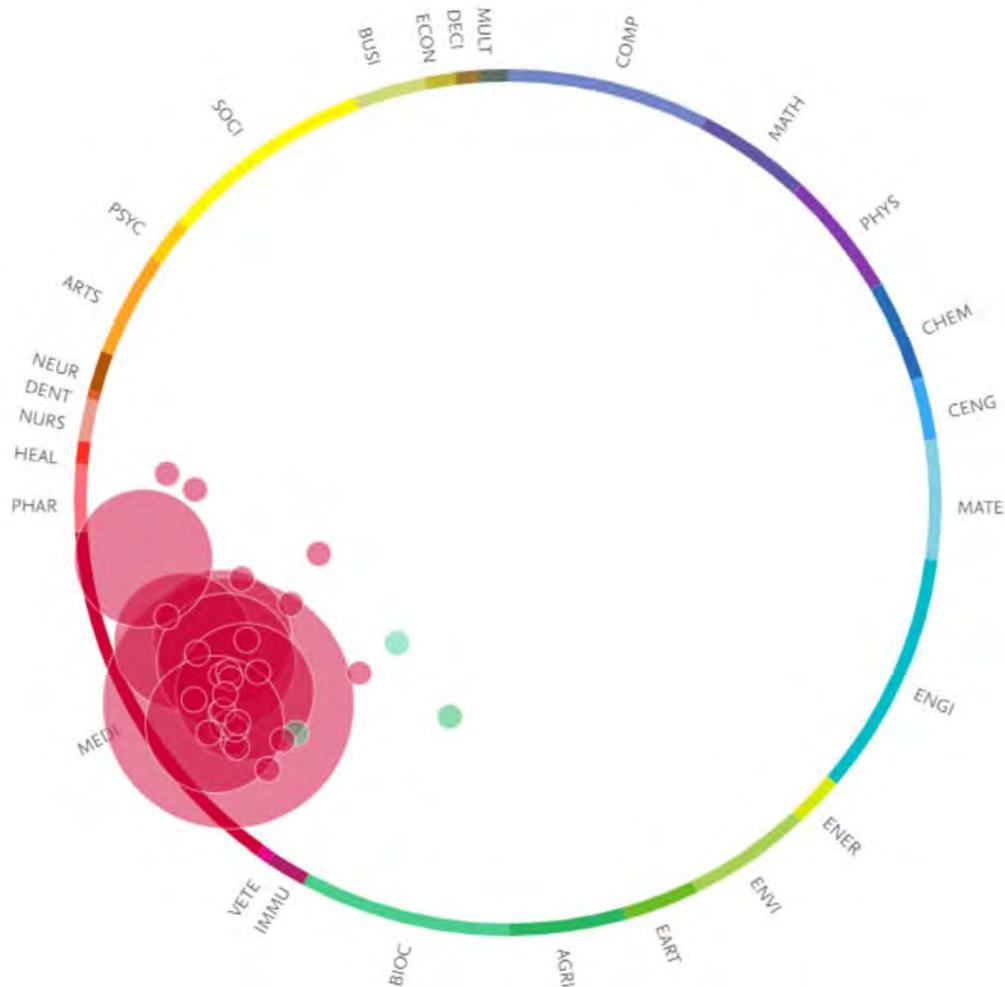


Figure 17. Diabetes Action Canada investigators topics analysis for top 100 topics by scholarly output – SCOPUS SciVal as of September 16, 2019.

Quality

The SCOPUS SciVal analysis was based on 57 (97%) of the peer reviewed journal articles as 2 articles published by DAC SPOR Network members have not been indexed in SCOPUS at the time of the analysis.(65, 74) Of the papers included in the analysis, 44% (25/57) have been published in high-quality outlet journals, as defined as being within the top 10 % of journals by SCOPUS CiteScore. Compared to all publications indexed within SCOPUS for disciplines aligned with the DAC SPOR Network research, the percentage of articles published within the top 10% of journals are 19.5% for Endocrinology, Diabetes and Metabolism, 23% for Nephrology and 17% for Ophthalmology.

Co-authorship

An analysis of the 57 peer-review papers indicates that 238 DAC SPOR Network and non-network authors have contributed to the publications across 20 clusters and 1298 links between authors and total link strength of 1581. The co-authorship social network analysis, with the author weighted by number of publications, is depicted in Figure 18.

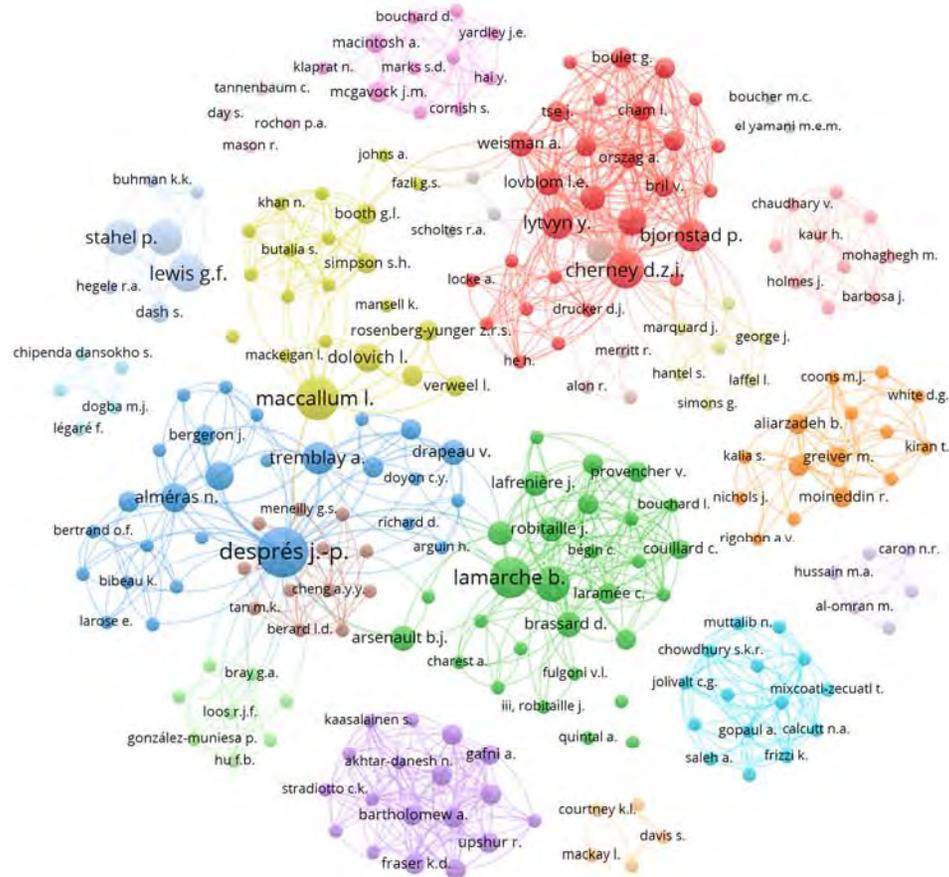


Figure 18. Co-author network diagram for DAC SPOR Network publications April 2017 – March 2019 (N=57)

National collaboration, as identified in the SCOPUS SciVal as all authors from the same country occurred in 31.6% of publications, with international collaboration in 33.3% and only institutional collaboration in 33.3%. In addition to the SCOPUS SciVal analysis, further details were abstracted directly from all 59 published articles by the DAC SPOR Network investigators to examine collaboration. For all publications, over one-third of the publications were collaborations with multiple DAC SPOR Network members (N=20, 33.9 %). Further examining of the representation across Canada by province for all identified publications (N=59), representation from multiple provinces within the project teams occurred for 18 published papers (30.5%). International collaboration within the DAC SPOR Network has involved co-authors from Brazil, France, Germany, Israel, Japan, the Netherlands, Scotland, Spain, United Kingdom and the United States.

Capacity Building

Graduate Students

The DAC SPOR Network has supported graduate students over the past 3 years through the provision of funding and training opportunities. Funding has been provided to 16 individuals over the first two granting periods for the network. This support has consisted of 7 mentorship awards (\$70,000), 3 internship awards (\$30,000), 4 Knowledge Translation scholarships for 2 PhD students (\$38,000) and 2 post-doctoral fellows (\$80,000), and 3 post-doctoral fellowships, two funded through the DAC SPOR Network and 1 through an industry partner (\$250,000) for a total of \$468,000. Other funding through CIHR funds provided to investigators for student support and stipends totaled \$404,701.

Training opportunities have been provided for graduate students through the DAC SPOR Network with trainees participating in 10 workshops and training sessions coordinated through the DAC SPOR Network.

Research and Research-related staff

Along with the capacity building associated with the training of graduate students and fellows in the DAC SPOR Network the number of research staff hired to support the investigators and co-investigators consists of a team of 15 individuals across Canada with a variety of academic backgrounds. The centrality of the individuals whose primary function is operations and administration was revealed in the cross-sectional network survey.

Investigators and Co-Investigators

Over the past 3 years the DAC SPOR Network has maintained the same number of Principal Investigators (N=16) with only one change in a named Principal Investigator, where investigator roles were switched with a Co-Investigator from within the same goal group. The number of Co-investigators has increased from an initial group of 8 researchers to now a collaboration of 80 researchers across the country (Figure 19).



Figure 19. Number of investigators within the DAC SPOR Network over time

Using information from the DAC SPOR Network web-page the health professional background of the DAC SPOR Network members consists of physicians with predominantly specializing in endocrinology, family medicine, ophthalmology and vascular surgery.(Figure 20)

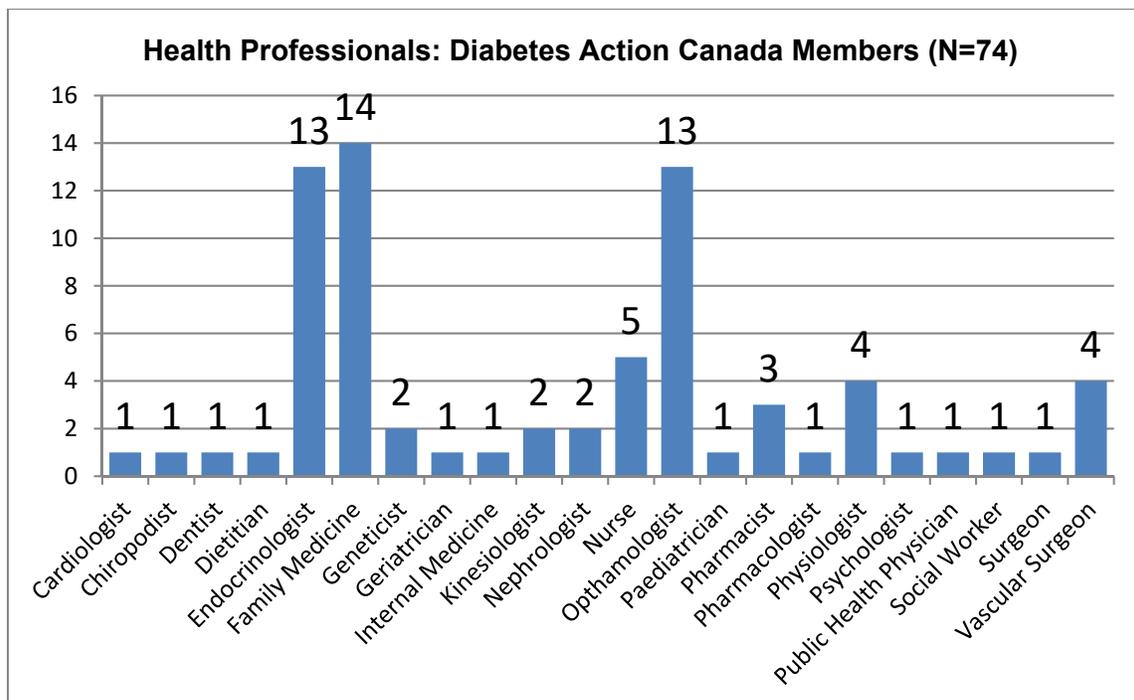


Figure 20. Health professions of DAC SPOR Network members

Informing Decision-Making

Clinical, Service and Social Care Guidelines

Two of the CAHS indicators within the informing decision-making domain involve the evaluation of the use of the research within clinical, service and social care service guidelines. A search of the 57 DAC SPOR Network publications and the associated 528 citing papers from SCOPUS SciVal identified that none of the 57 publications from the DAC SPOR Network Investigators has been incorporated into a clinical practice guideline as of 31 Mar 2019. The relatively short time span of the DAC SPOR Network may account for the lack of its publications being cited in guidelines,

Consulting to Health and Research Policy

The CAHS framework outlines an indicator related to Research Policy and consulting to policy makers. Within the scope of the DAC SPOR Network, it was considered that this indicator should be expanded to include consulting not only to research policy, but also to health policy. To evaluate this indicator, the meetings with various levels of government with the DAC SPOR Network Executive Director were reviewed as an initial feasibility of this indicator. For future network evaluations, this indicator will be expanded to include consultation to policy makers for the Principal Investigators, Leads and Co-leads of programs associated with the DAC SPOR Network.

Since 2016, the Executive Director of the DAC SPOR Network has had 27 meetings with policy makers in attendance. These meetings have been at a Municipal (N=1), Regional (N=1), Provincial (N=21), National (N=2) and International (N=2) level of government. The purpose of the meetings with policy makers have been to discuss the DAC SPOR Network and its overall research initiatives, digital healthcare systems, diabetic retinopathy, indigenous health, aging or foot care.

At this stage of the DAC SPOR Network life-cycle, the discussion with policy makers has been initiated. The influence of the DAC SPOR Network on health policy will be monitored, as the research activities and results, conducted at either a provincial or national level, provide direction for change in existing health systems across Canada.

This will be monitored by identifying when DAC SPOR Network related research cited within public policy documents.

Health Product Industry Engagement

Academic and industry collaboration, consultation and clustering/co-location are CAHS indicators that can be evaluated in relation to the activities of the DAC SPOR Network. The Network has Academic-corporate collaboration that was identified in 5.6% of the publications within the SCOPUS SciVal bibliometric data. Industry support has been provided by 7 corporations and two new strategic partnerships established with 2 other corporations. This relationship development is important for the sustainability of the Network for ongoing innovation and funding. Diversity of funding sources within the Network is a reflection of overall network health.

Patient Partner & General Public Engagement

The CAHS framework outlines 2 indicators regarding the impact of research on the General Public, neither of which fully provides the ability to examine the impact of a Patient Oriented Research Network. A broader scope of indicators is needed to examine the impact and engagement of the Network with the public. The DAC SPOR Network currently has 75 Patient Partner participants involved many of whom are members of the 3 Patient Partner Circles. Patient Partners contribute to the Network governance as members on 15/27 (56%) of the advisory and planning groups within the DAC SPOR Network that provide strategic direction and project approval, research project design, educational activities including running of workshops, preparation of grant applications and publications.

Since the creation of the DAC SPOR Network, 22 workshops have been implemented covering a variety of topics and educational material. Participation by Patient Partners has occurred in the majority (73%) of the training sessions. Patient Partners have co-facilitating 5 Patient-Oriented Research Training Workshops and co-designed the curriculum.

Health Impact

Based on the stage of development and maturity of the Network with many of the projects yet to be completed, the ability of the Network activities to have a measurable health impact at this time is limited. Careful review of the indicators outlined within the domain of health impact suggested that the outcomes of the DAC SPOR Network should be evaluated on a per project basis to identify changes in health status or determinants of health.

One project that is maturing, with early potential to impact modifiable risk factors, is the Indigenous Youth Mentoring Program (IYMP). Initial study results have shown that children and youth who have participated in the program experience increased self-esteem, reduced weight gain, reduced waist circumference, and healthier dietary choices, compared to those not in the program. The analysis of the IYMP reports up to a 12% reduction in risk factors associated with developing metabolic syndrome.(97) The IYMP is being rippled out to reach more Indigenous youth across the country.

The broader implementation of programs developed through research activities of the DAC SPOR Network members has the potential for contributing to the overall improvement of health of Canadians.

Broad Economic and Social Impact

As with the Health Impact domain, the ability at this time to assess impact of the DAC SPOR Network on broader economic and social aspects in Canada is beyond the scope of the current analysis. As the DAC SPOR Network's research and innovations mature, the ability to quantify some of their commercialization, health benefits and overall social impact will emerge. It may be necessary to prospectively collect additional primary data alongside some of the project outcomes in order to facilitate measurement of the indicators within this domain. These measures include quality of life, satisfaction with care, healthcare resource utilization, wait-times and coordination of care. Revision of the metrics collected by the DAC SPOR Network members will be discussed with the

Network's administrative team to facilitate the capture of data relevant to the CAHS economic and social impact indicators.

SUMMARY

This evaluation of the DAC SPOR Network provides a baseline assessment of the connectivity, health and impact of the collaboration between Patient Partners and researchers over the past 3 years. This SPOR Network is still evolving and entering the Perform/Adapt state of network development.(1) The findings within this report provide the context where the vitality of the Network is apparent and also gives direction where improvement can occur over the next few years.

At the core of the development of a network is the creation of relationships and communication pathways between members. The DAC SPOR Network consists of 150 interconnected Patient Partners, researchers, administration and Steering Council members. Amongst many of these members, the frequency of communication is on a quarterly or yearly basis. However, within the Network there exists a triad of more frequent connectivity among Patient Partners, administrators and researchers. Scientific research, patient engagement and management and operations are the most frequently discussed topics. These observations are aligned with the mission and vision of the DAC SPOR Network.(3)

Discussion of training, transfer of research findings and commercialization of research occurs less frequently. As many of the research projects and initiatives have been implemented over the past few years, it is anticipated that these topics will be more frequently discussed as the Network matures. Both the survey and network impact analysis from this evaluation indicate a less frequent focus on commercialization of research.

The qualitative interviews highlight that new collaborative relationships have been developed within the DAC SPOR Network and that new opportunities for working together across the country have developed over the past 3 years. This observation is further supported by the quantitative analysis of the Network's health and the generation

of collaborative efforts to design new research projects that have attracted further funding that align with the Network's objectives. Improved communication across the Network, as may be expected in large national initiatives separated by vast geography, was identified as an area where further effort should be made to support the collaboration.

The members of the DAC SPOR Network are collaborating and publishing together as a result of the new relationships that have been formed through the Network. The publications have been in high-impact journals across several disciplines. The value of this collaboration is reflected in the successful public sector funding of new projects and some private sector research support. The SPOR Network funding from CIHR has enabled the research staff and trainees to grow the capacity to support expansion of the Network's initiatives.

The health, economic and social impact of the research and network activities remain to be fully realized, as may be expected based on the age and the stage of development of the DAC SPOR Network.(1) This is anticipated to be seen over time as projects mature and have an opportunity to influence healthcare and research policy. In order to evaluate the impact of the DAC SPOR Network research impact, prospective data aligned with the CAHS metrics and indicators within the individual studies must be captured.(2)

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Appendix A. CAHS framework impact, categories and indicators(1)

| Framework Impact | Category | Indicator |
|--|--------------------------|---|
| Advancing Knowledge (N=11) | Quality | Relative citation Impact |
| | | Highly cited publications |
| | | Publications in high-quality outlets (or desired outlets) |
| | Activity | Share of publications |
| | | Publication counts |
| | Outreach | Co-author analysis |
| | | Field analysis of citations |
| | Contextual/Structural | Relative activity index |
| | Aspirational Indicators | Expanded relative citation index |
| | | Relative download rate |
| Research diffusion | | |
| Graduated research students in health-related subjects | | |
| Capacity Building (N=7) | Personnel | Numbers of research and research-related staff in Canada |
| | | Levels of additional research funding |
| | Infrastructure | Infrastructure grants (\$) |
| | | % of activity grants with infrastructure support |
| | Aspirational Indicators | Receptor capacity |
| Absorptive capacity | | |
| Informing Decision Making (N=18) | Health Related | Health Care - Use of research in guidelines |
| | | Public Health - Survey of public health policy makers |
| | | Social Care - Use of research in guidelines |
| | | Other - Researcher reported use of findings outside health |
| | | Health Related Education - Research cited in ongoing health professional education material |
| | Research | Research Funding - Citation analysis of successful funding applications |
| | | Research Policy - Consulting to policy |
| | | Research Policy - Requests for research to support policy |
| | | Research Education - Research used in curricula for new researchers |
| | Health Products Industry | Number of patents licensed |
| | | Clustering/ co-location |
| | | Consulting to industry |
| | General Public | Collaboration with industry |
| | | Use of research in stage reports by industry |
| | | Advocacy Groups - Research cited in advocacy publications |
| | Aspirational Indicators | Public Education - Public lectures given |
| | | Media - Media citation analysis |
| | Health (N=19) | Health Status |
| Morbidity to include functional impacts - Prevalence | | |
| Morbidity to include functional impacts - Incidence | | |
| Mortality - PYLL | | |
| Quality Adjusted Mortality - Quality Adjusted Life Years (QALYs) | | |
| Determinants of Health | | Quality Adjusted Mortality - PROMs |
| | | Modifiable Risk Factors - Example: obesity; alcohol consumption |
| | | Social Determinants - Example: education levels; social cohesion |
| | | Environmental Determinants - Example: air pollution levels |
| | | Acceptability - Example: self-reported patient satisfaction |
| | | Accessibility - Example: wait times |
| | | Accessibility - Example: appointment statistics |
| | | Appropriateness - Example: adherence to clinical guidelines |
| | | Competence - Civil law suits against health system |
| | | Continuity - Self-reported continuity of care |
| | | Effectiveness - Example: re-admission rates |
| | | Efficiency - Actual vs. expected hospital stay |
| | | Efficiency - Cost input versus output |
| | | Safety - Example: adverse drug effects |
| | | Safety - Example: hospital-acquired infections |
| Broad Economic & Social (N=11) | Activity Impacts | Economic rent (Labour rents) |
| | Commercialization | Licensing Returns (\$) |
| | | Product Sales revenues (\$) |
| | | Valuation of Spin Out Companies (\$) |
| | Health Benefit | Economic rent (Producer rent and spillover effects) |
| | | Health Benefit in QALYs per health care dollar |
| | Well-Being | Health Benefit in PROMs per health care dollar |
| | | Annual report of HRSDC |
| | | Happiness |
| | Social Benefit | Level of Social Isolation |
| Socioeconomic Status | | |

Appendix 6: Diabetes Action Canada External 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 7: Patient Engagement Strategy

Patient Partners:

How are Patient Partners involved?

There are two ways to be actively involved:

- 1 Join a Patient Circle
- 2 Get involved in a research team

What can you expect when you become a Patient Partner of the network?

- Support • Mutual Respect • Collaboration
- Inclusiveness • Core Competencies

What does it mean to be engaged and contribute as a Patient Partner?

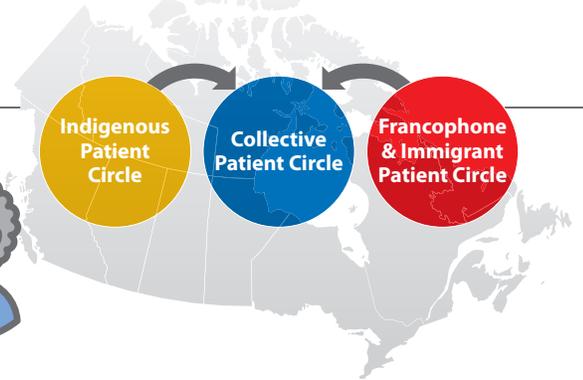
Diabetes Action Canada aims to integrate the patient perspective into every step of the research process including developing research questions, defining research objectives, collecting data and evaluating results. Overall the Patient Partner's role will vary according to the contributions each individual is prepared to offer.



What are Patient Circles?

Patient Circles are composed of a diverse group of people affected by diabetes from across Canada. There are **THREE** Patient Advisory Circles:

- THE COLLECTIVE PATIENT CIRCLE
- THE FRANCOPHONE AND IMMIGRANT PATIENT CIRCLE
- THE INDIGENOUS PATIENT ADVISORY CIRCLE



What does it mean to be part of the Collective Patient Circle?

- Be part of a group of 10 – 15 people
- meet approximately 8 times per year
- one in-person meeting, others by phone or video conferencing
- meetings will be in English

What does it mean to be part of the Francophone and Immigrant Patient Circle?

- Be part of a group of 6 – 8 people
- meet approximately 4 times per year
- one in-person meeting, others by phone or video conferencing
- meetings will be in French



What does it mean to be part of the Indigenous Patient Circle?

- Be part of a group of 6 – 8 people
- meet approximately 4 times per year
- one in-person meeting, others by phone or video conferencing
- meetings will be in language determined by members

How will the Patient Circles connect with each other?

Two members from each of the Francophone and Immigrant and Indigenous Circles will also be members of the Collective Patient Circle. These designated patient partners will represent the interests of their respective Circles, as well as liaise between their Circles and the Collective Patient Circle.



Patient Partners helping guide Diabetes Action Canada's operation and administration

Patient Partners can also be a part of the Steering Council and Research Committee to collaborate with Diabetes Action Canada administrators, researchers and practitioners in directing (steering) the organization, its operations and its research objectives. Some examples of activities in this regard are:

- Advising on internal policies
- Working as full members of governance committees



Patient Partners as Research Team Members

As the field of patient-oriented research grows, research teams are looking for Patient Partners to collaborate throughout the research process in such areas as priority setting, study design, analysis and knowledge translation. Members of the Patient Circles may also be involved directly with research teams by bringing expertise from their lived experience with diabetes to research projects.



Are Patient Partners compensated? YES. In recognition for their time spent and valuable expertise, all Patient Partners that are members of Patient Circles or research teams will be compensated for their participation and contribution.

For More Information:

- On our Patient Compensation Policy please [click here](#) for English or [here](#) for French
- On SPOR Network Directors Task Force -Patient Engagement Compensation Policy please [click here](#)



Diabetes Action Canada
Preventing complications. Transforming lives.

Strategy for Patient-Oriented Research / Stratégie de recherche axée sur le patient
SPOR * **SRAP**
Putting Patients First / Le patient d'abord