



Diabetes Action Canada

Strategy for Patient-Oriented Research Network

Network Evaluation Report

Executive Summary

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## **EXECUTIVE SUMMARY**

The Diabetes Action Canada (DAC) Strategy for Patient-Oriented Research (SPOR) Network, formed in 2016, is supported by funding from the Canadian Institutes of Health Research (CIHR) and numerous academic partners, and public and private sponsors. The Network was just over three-quarters of the way through their initial 5-year funding cycle at the end of 2019-20. It has membership from across Canada consisting of Patient-Partners, Researchers and Clinicians. Building on the initial network evaluation, which examined the DAC SPOR Network and its stage of development up to the end of fiscal 2018-2019,(1) the goal of this second-cycle analysis is to provide an evaluation of the DAC SPOR Network, using the State of Network Evaluation framework, and to determine its stage of development with three key themes: Network Connectivity, Network Health and Network Results (2) and the Canadian Academy of Health Sciences (CAHS) preferred framework and indicators to measure network results and return on investment in health research.(3)

A variety of methods was used to study these Network themes. A cross-sectional network survey of members was conducted to examine Network Connectivity assessing the frequency of interactions, the topics discussed 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 CAHS preferred framework and indicators using bibliometric methods, social network analysis, review of relevant documentary sources, knowledge translation activities and media reporting.(3)

### **Network Connectivity**

The DAC SPOR Network has a membership of 185 individuals, an increase of 35 new members since the end of fiscal 2018-19. Network members were surveyed again this

year and 51.9% (96/185) of members responded. Using an undirected social network analysis approach 76.5% of the inter-individual relationships were examined. This cross sectional survey captured 458 more inter-individual relationships (N=2,763) than the 2019 survey (N=2,305) with the average number of relationships within the network around 30 ties. Prior to the members joining the DAC SPOR Network. Only 482 inter-individual relationships previously existed with at least 2,281 new relationships being created through the network. Members most commonly connect on an annual or quarterly basis. The 2020 survey found a decrease in centralization to 0.68 (2020) from 0.84 (2019) out of a maximum of 1.00, indicative of an evolution towards a more equal distribution of inter-individual relationships in the network. The DAC SPOR Network membership is still primarily based out of Québec and Ontario.

The most common topics discussed in the 2020 survey were scientific research (94%) followed by governance and coordination (88.1%) and management and operations (88.1%) then patient engagement (87%), training and mentoring (78.4%) and transfer of research (77.3%). Very few exchanges involved the commercialization of research (17.3%). Regionally, scientific research, patient engagement, management and operations and commercialization of research were discussed the most by members from Ontario, training and mentoring by a member from the Maritimes, and governance and operations and transfer of research findings by members from Québec.

## **Network Health**

The Network Health evaluation was explored through semi-structured interviews of selected members of the DAC SPOR Network. Fifteen members selected from across the researchers, clinicians, Patient Partners as well as members of the leadership of the network were interviewed. Joining the DAC SPOR Network was considered an “opportunity” to acquire funding and to engage in “networking” to impact the lives of individuals living with diabetes, to do something “meaningful” and to have the professional benefit of joining a national network to influence “policy”. Many participants stated that joining the network had exceeded their expectations. A greater and more meaningful

integration of Patient Partners was brought up by some as an opportunity to meet expectations and overcome some challenges for the network. Globally, people were enthusiastic about what the network has done with regard to patient engagement. When asked to comment on the Network's evolution respondents pointed to four major themes: increased focus on patients, progression, and maturity and expansion. Patient Partner involvement was cited as one that is positive, deep-rooted in the Network's structure and embedded more "organically" and intuitively in members' mentalities. Interviewed members almost unilaterally recognized the DAC SPOR Network's "progress" since the creation of the network and the broadening of membership and diabetes-related research groups. New collaboration opportunities, easier access to other researchers and policy makers, and a sense of belonging at an individual level were identified by members as a benefit of joining the network. There is a perception of an accelerated pace and expansion with access to a diversity of members as well as a perceived societal benefit of collaborating with Patient Partners. Barriers to participation included time allocation to other professional responsibilities, and external barriers such as funding, engaging policy makers, political or institutional barriers, including access to data across the Canada due to different provincial data management practices and regulations.

The overall level of satisfaction with the network grew from the first cycle to the second cycle of the evaluation. Participants recognized the network's management as a success factor and the "willingness of diverse researchers at all stages of their career" to work together and the "freedom" inherent within the DAC SPOR Network as important to capacity building. One area for improvement to develop a more in-depth Patient Partner involvement recognizing that some improvements have been made since the beginning of the DAC SPOR Network.

Interviewee's indicated that the COVID-19 pandemic had put tremendous strain on sustaining parts of the DAC SPOR Network research enterprise. Members were presented with "both, and opportunity and a threat". The COVID-19 has not impacted all of the research programs equally. Those that conduct research involving field work, face-to-face meetings and recruiting new patients into studies have been more affected.

Negative implications were cited such as delays and interruption of research, change in activity to virtual webinars, uncertainty and impacts on the Patient Partners. The participants recognized the support and preventative management of the central administrative team during the pandemic.

Network sustainability was assessed by evaluating the additional funding the investigators of the network have received from new CIHR grants. Since the establishment of the Network, new CIHR funding totalling \$32,081,840 has been obtained with \$48,887,076 when accounting for partner funding. Other granting agencies have also contributed \$2,543,267. DAC SPOR Network members received new funding through eight grants from CIHR in fiscal 2019-2020 for a total of \$2,056,808. To further support the sustainability of the network, closer strategic relationships with the provincial SPOR SUPPORT Units and the Canadian Primary Care Sentinel Surveillance Network were established. Engagement with Diabetes Canada and the Juvenile Diabetes Research Foundation was strengthened to support the National Diabetes 360 strategy at a national level.

## **Network Results**

The impact of the DAC SPOR Network with respect to advancing knowledge was examined through a bibliometric analysis of the peer-reviewed literature published by the network members since April 2017. Ninety-six articles were published with 27 peer-reviewed publications in fiscal 2019-2020. The peer-reviewed publications have been cited 1,395 times as of December 23, 2020 with increase of 867 citations since the first-cycle network evaluation in August 2019, and an average citation rate of 15.2 citations per article, up from 9.3 citations at the time of the last evaluation. Of the peer-reviewed literature, 36.8% were published in high quality outlet journals. An additional 137 authors contributed to the published articles with representation of authors from multiple provinces in 21.9% of the 96 publications, in six (22.2%) of the 27 articles from fiscal 2019-2020. International research collaboration across 14 countries was identified with 29.2% of articles' authors being from outside Canada.

The broader impact of the DAC SPOR Network on informing decision making was identified during this second-cycle of the network evaluation as where nine of the identified publications were cited in either clinical or social care guidelines. Furthermore, the survey reported that 47.9% (46/96) of survey respondents engage with policy makers and that of these contacts 54.3% (25/46) were related to DAC SPOR Network activities. Over the previous fiscal year two DAC SPOR Network members were interviewed by local television networks in Toronto and three have contributed to Apple Podcasts providing public information related to their research and diabetes care. These are the first television interviews and podcasts associated with the DAC SPOR Network.

Support of undergraduate and graduate students, and post-doctoral fellows with funding and training and mentoring opportunities by the network continues. Funding support from all sources totalled \$680,606 and four training workshops were provided in 2019-20.

Ninety-one Patient Partners are member of the network with participation in three patient circles. Patient Partner engagement with research activities has resulted in 2 co-author publications and 2 reports over the past fiscal year. Patient Partners participated in over half of the 30 workshops over the 4-year life span of the DAC SPOR Network and have co-facilitated five of the annual DAC workshops.

The DAC SPOR Network's potential influence on the overall health of Canadians is emerging as studies are maturing, and completed studies such as those evaluating diabetic retinopathy screening are leading to improved eye health in those individuals living with diabetes. Studies pertaining to lower-extremity amputations and diabetic retinopathy have identified unmet health service needs and provided information that could results in changes to the health system and health policy if acted upon. Studies examining food insecurity and hospital admissions for individuals living with diabetes found that individuals that were food insecure were more commonly admitted to hospital suggesting that addressing food insecurity issues could reduce the hospital burden of diabetes. In another study, examining lesbian, gay, or bisexual (LGB) care for individuals with cardiometabolic disorders, hospitalization costs were 54% (95% CI 8-119) higher

than heterosexual counterparts. These studies could lead to the opportunity of co-designing and implementation of initiatives to address the unmet health service needs which could lead to improved health and well-being with additional societal and economic benefits.

The DAC SPOR Network is growing and maturing with new relationships being developed, funding secured through these relationships, and research collaboration, now including more Patient Partners, leading to peer reviewed publications. Following the State of Network Evaluation framework, the DAC SPOR Network is at an early mid-phase 4 stage of network development, with a focus on performance and adaptation and with a deepening of the involvement of the network in patient engagement and research. The DAC SPOR Network activities, with its diverse membership, is beginning to influence decision making through clinical and social guidelines and maturing studies, with opportunities to impact health policy and the overall well-being of Canadians. New funding has been obtained through additional CIHR and other grants to grow the research enterprise and sustain activities. There is a need to expand the network so as to be more representative of all provinces across the country and to enhance the involvement of Patient Partners throughout the research process. Further engagement with health policy makers at a regional, provincial and national level would help support diabetes care initiatives and implementation of health policies based on the evidence created by the DAC SPOR Network members.

1. Lawaree J, Rheume A, Ouimet M, Bowen J, Bielecki J, Rac VE. Network Evaluation Report. Toronto, ON; 2019 22 Oct 2019. Report No.: Version 2.0.
2. Network Impact and Center for Evaluation Innovation. Framing Paper: The State of Network Evaluation. 2014.
3. Panel on Return on Investment in Health Research. Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research. Ottawa, ON, Canada 2009.



