

Diabetes Action Canada: A paradigm shift in Research

By: Erika Opingari

Imagine a national network of talented researchers, dedicated patients, and one vision: to transform the health outcomes of diabetes. With Diabetes Action Canada, this has become a reality. Launched in 2016, Diabetes Action Canada is a Strategic Patient-Oriented Research (SPOR) Network sponsored by the Canadian Institutes of Health Research (CIHR). Its mission is to transform the health outcomes of patients living with diabetes and address disparities in diabetes care. By promoting communication and collaboration among healthcare providers, researchers, and patients, the Network can study and implement solutions for the most important health concerns identified by persons living with diabetes.

Canada's SPOR program is a national, multidisciplinary network with the objective of fostering evidence-informed health care and applying research knowledge to improve healthcare systems. Provinces across Canada co-invested with CIHR in order to build the capacity and infrastructure for this transformative approach to research. In 2015, there was further investment to support national networks in chronic disease, including diabetes, chronic kidney disease, chronic pain, gastrointestinal disease, and childhood disability. As the Director of the Banting and Best Diabetes Centre, and nominated principal applicant for the CIHR SPOR Network grant, Dr. Gary Lewis spearheaded the establishment of Diabetes Action Canada as one of the SPOR Networks in Chronic Disease. He credits much of his achievement to the



Photo by: Krystal Jacques-Smith

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support and guidance of Dr. Catharine Whiteside, former Dean of Medicine at the University of Toronto and current Executive Director of the Network.

Dr. Lewis believes Diabetes Action Canada exemplifies an exciting and emerging

paradigm shift in research, moving away from competition between individuals and groups and instead encouraging effort towards the common goal of collective impact; improving the care of patients with diabetes.

"The beauty of the Network is that it is not restricted to drawing on expertise from one hospital, or even one university. It's not about personal or institutional ego; it's all about serving patients suffering from a very serious disease, and finding the best resources to do so," explains Dr. Lewis. "With SPOR and Diabetes Action Canada, we have no boundaries or restrictions. We pool resources from across the country and collaborate to achieve our goals; breaking down these barriers that are huge impediments to medical advancement."

To secure the CIHR SPOR Network grant of \$12.45 million over a period of five years, the Network had to include investigators from five provinces across Canada, match the funding through external sources, and incorporate persons with diabetes in their governance and advisory committees. While pulling the Network and resources together was challenging, Dr. Lewis describes it as being an organic process that started with two cores: one here in Toronto, and the second in Quebec City, led by Dr. Jean-Pierre Després from the Université Laval. Together, Dr. Lewis and Dr. Després are co-scientific leads for the Network.

In just under two years, the Network has grown to include over 80 dedicated investigators across Canada, conducting research with a focus on primary care and developing the informatics framework needed to have an impact on improving health and preventing diabetes complications. Each project focuses on outcomes in alignment with the Quadruple Aim, which includes: 1) improved health at the population level, 2) improved patient experience and outcomes for individuals, 3) improved experience for health professionals, and 4) reduced or improved costs. Over time, Diabetes Action Canada has expanded its research network to include other investigators and increase the scope and scale of their projects with the advice of patients, their families, and caregivers.

The Network functions with multiple stakeholders (federal, provincial, health ministries, industries, academia), and involves a multidisciplinary team of experts in health economics, health policy, implementation science, pragmatic clinical trials, and knowledge translation. The

Network leads are working simultaneously at both research and policy levels, in order to achieve results that will truly impact the lives of Canadians living with diabetes. By partnering with key delivery systems, such as the Ontario Telemedicine Network, Diabetes Action Canada can evaluate primary care outcomes of evidence-based programs on a larger scale. Precise evaluations of evidence-based programs can then be used to influence policy and primary care practices.

"It's a very exciting and different method of research; it's right at the interface of health care delivery and research", says Dr. Lewis, "We are developing new, innovative healthcare delivery mechanisms to impact a problem, and using resources across the country to do it."

Essentially, Diabetes Action Canada—and by extension SPOR—is contributing to the development of a learning health system. This refers to iterative models of care that evolve and can be evaluated fairly quickly, ultimately allowing researchers, patients, and healthcare providers to learn what actually works. The learning health system allows for high priority patient concerns to be linked to evidence-based solutions in the clinical setting. This is an emerging concept that provincial ministries of health are now adopting, and a part of the future for Diabetes Action Canada.

"Diabetes Action Canada aspires to be front and center in enabling this learning health system to evolve," says Dr. Whiteside, "And I think that's the great opportunity for academic medicine."

Not only is Diabetes Action Canada leading the way in the evolution of the Canadian health system, but it is also challenging the traditional view of patient involvement in research. One of the key principles and distinguishing characteristics of SPOR and its affiliated networks is that patients are integrally involved in the planning, directing, and guiding of research projects. Canadians across the country living with diabetes are recruited as patient advisors and incorporated into the governance system. They meet regularly to advise the network on high priority areas in need of further research, such as lower extremity amputations.

The patient advisory circles are reflective of the community population, and thus include various demographics such as new immigrants, Francophones, and Indigenous peoples. Given that Indigenous research has been done with the full participation and leadership of the community, the Indigenous patient advisors are most deeply engaged in the Network and are leading the way. While some patient advisors may have been unsure of their role initially, they are starting to take ownership and realize the benefit they can have to the organization. They now see a role for themselves in disseminating and communicating research information to others living with diabetes. The development of patient roles in research and the consequent sense of patient empowerment is extraordinary and a testament to the value of Diabetes Action Canada.

Looking forward, one of the biggest challenges will be the sustainability of the Network at the end of the current five year funding period. As of now, it is not known whether there will be an opportunity for a renewal or extension of CIHR funding. While the loss of funding is an issue of great concern, the Network is working diligently at various levels to create sustainability. It is developing important relationships with health ministries, academic institutions, and organizations such as Diabetes Canada and Juvenile Diabetes Research Foundation, to enable continued impact in the future.

As I listened to Dr. Lewis and Dr. Whiteside, I couldn't help but feel a sense of great pride and excitement for the future of research and healthcare in Canada. In many ways, this SPOR Network is transcending conventional barriers and paving the way for a new approach to research. It is establishing shared resources and expertise across the nation to create results that will have direct impact on the lives and care of persons with diabetes. It captures the true power of networking and the boundless possibilities that can be achieved through collaboration.