

SPOR Network in Diabetes and its Related Complications

May 2016 Workshop

Summary Report

Summary

In May 2016, 79 researchers, patients,¹ healthcare providers and decision-makers came together at a two-day workshop for the *SPOR Network in Diabetes and its Related Complications* (SPOR Diabetes Network). The high-level objectives of the workshop were to (i) build capacity to perform patient-oriented diabetes-related research, (ii) begin to establish the new partnerships and relationships that will be essential for the Network's success and (iii) advance planning by establishing a common understanding of the most important deliverables, priority activities and key opportunities for the Network.²

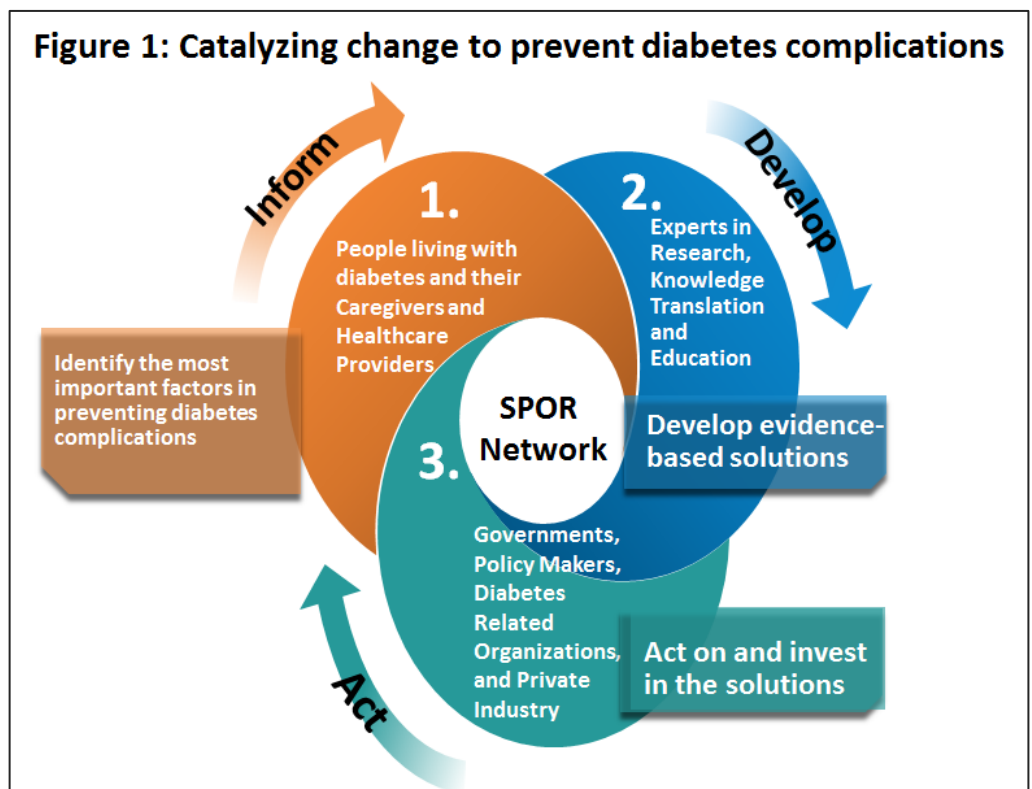
The workshop began with a statement of the strategic vision of the SPOR Diabetes Network:

- Transformer la trajectoire de santé pour tous les canadiens (enfants, femmes, hommes) ayant à vivre avec le diabète
- Transform the health trajectory for all Canadian men, women and children with diabetes at risk for complications

Over the two days of the workshop, large and small group discussions were used to help define important deliverables and develop work plans. The voices of people with diabetes were a guiding

force at the workshop, and in all the work of the SPOR Diabetes Network (Figure 1). Health innovations, which are developed and tested through research, are expected to be better and stronger when the groups and individuals who are involved in delivery or receipt are also partners in design and implementation.

Patients and caregivers were active participants in all workshop discussions, and portions of the agenda were



¹ As outlined by the Canadian Institutes of Health Research (CIHR), the term “patient” under the Strategy for Patient-Oriented Research (SPOR) is understood to include individuals with personal experience of a health issue and informal caregivers, including family and friends.

² More detailed objectives illustrating alignment with the SPOR Logic Model are presented in the Appendix A.

dedicated to bringing in their lived-experience expertise and advice. Governance, including the role of patients in strategic oversight of the network, and specific performance commitments were emphasized, both by CIHR and by the Network Leads.

In the afternoon of the second day of the workshop, the SPOR Diabetes Network's five Goal Leads made presentations which synthesized advice and ideas into actionable plans. The workshop concluded with a discussion of how the five teams of the Network will work together, and with external partners, to make the impact of the SPOR Diabetes Network greater than the sum of its parts.

Motivation, Goals and Teams of the SPOR Diabetes Network

(see also Appendix B)

Academic Co-Leads Jean-Pierre Després and Gary Lewis presented the ambitious vision and objectives of the SPOR Diabetes Network.

Notre motivation première...
...nous mettre au service de la population!

- Les 3 millions de personnes ayant à vivre avec le diabète et ses complications
- Les personnes à risque
- Briser le fossé entre l'état des connaissances et la façon dont on prend en charge/aide les patients avec le diabète
- Mettre la science de tout un collectif de chercheurs au service de la population
- Faire différemment et mieux avec et pour les patients ayant le diabète

The network will do things differently – with and for patients with diabetes:

- 3 million people live with diabetes and its complications
- High risk individuals
- Fill the gap between what we know and what we do
- A unique network of multidisciplinary scientists to better serve the population

History in the making...
...let's build this together!

Réseau SRAP sur le diabète et ses complications,
Ce n'est que le début...

The SPOR Diabetes Network has established five Goal teams which mobilize researchers, healthcare providers, decision makers and people with diabetes to work together on strategic goals:

- **Patient, Practice and Population Based Diabetes Complications Risk Management**
Establish informatics including a National Diabetes Registry – Goal Lead: Dr. Frank Sullivan
- **Clinical Trials Network**
Establish a clinical trials network to test new therapies including novel medications, artificial pancreas and mobile phone apps to facilitate diabetes management – Goal Lead: Dr. Bruce Perkins

- **Retinopathy Screening**

Create a national retinopathy screening program for diabetic eye disease to prevent visual impairment – Goal Lead: Dr. Michael Brent

- **Knowledge Translation**

Facilitate effective knowledge translation to help bring research findings from the SPOR Diabetes Network into practice – Goal Lead: Dr. France Légaré

- **Training and Mentoring**

Build Canadian capacity for patient-oriented research through training and mentoring, Goal Leads: Dr. André Carpentier and Dr. Mathieu Bélanger

The Strategy for Patient-Oriented Research (SPOR)

(see also Appendix C)

Phil Sherman, Scientific Director of the CIHR Institute of Nutrition, Metabolism and Diabetes, provided an overview of CIHR's Strategy for Patient-Oriented Research (SPOR) – “a coalition of federal, provincial and territorial partners, including patients, researchers, health practitioners, provincial/territorial health authorities, policy makers, academic health centres, charities, and the pharmaceutical sector, working together to generate and translate high quality, relevant research into practice.” Provincial SPOR SUPPORT Units are working together on activities to support patients as active partners in research, and will create important resources for the SPOR Diabetes Network to draw upon. To-date CIHR has funded seven national SPOR Networks including the SPOR Diabetes Network. The SPOR CAN-SOLVE CKD NETWORK, which is focused on chronic kidney diseases and is led by Adeera Levin, is expected to be a particularly important partner for the SPOR Diabetes Network.

Overarching Themes: Patient Partnership and Sex, Gender and Equity Considerations

(see also Appendix D)

In keeping with the CIHR SPOR principle that “Patients need to be involved in all aspects of the research to ensure questions and results are relevant and integrated into practice”, patients will be partners in all the work of the SPOR Diabetes Network. Joyce Dogba presented advice on when and how to involve patients, as well as reasons why patient partnership is important:

- Articulating the outcomes that are most important to patients and their families
Préférences des patients et des familles
- Bringing experiential knowledge
Savoir expérientiel

- Providing helpful input on language and cultural issues to make dissemination campaigns more effective
Langue accessible
- Ethical mandate: “democratization” of the research process
Mandat éthique: «démocratisation» du processus de recherche
- Reducing “waste”
Réduction du gaspillage

The SPOR Diabetes Network’s *Research and Research Users Partnership Platform* (RRUPP) will be a key mechanism to involve patients in all stages of research, from priority setting and the establishment of research questions, right through to intervention and study design, and knowledge translation.

Joe Cafazzo’s Bant mobile phone app is an exemplar of how patient advice can be combined with researcher expertise to design and implement an effective intervention for diabetes self-management. In addition to being user-friendly and widely accessible, Bant and other mobile-phone based interventions also serve as excellent systems to capture large amounts of real-time data for studies. In other words, the data that is needed for patient care and self-management is the same data that is needed for research.

Paula Rochon from the Women’s Xchange at the Ontario SPOR SUPPORT Unit noted that while “integrating sex, gender and other equity issues is crucial for equitable and effective health research, policies and programs,” a review of high impact diabetes studies found that there is significant room for improvement. Concrete examples were presented to illustrate how gender, equity and other patient-centered considerations can lead to the development of interventions that align with the needs of specific communities, e.g., a mosque-based exercise program for Muslim women. Strategies were presented to integrate sex and gender considerations into the work of the SPOR Diabetes Network. First among those is the strategy of having each of the five Goal teams identify one lead point of contact for the Women’s Xchange to work with.

Select Contributions from People with Diabetes and Their Caregivers

For most of the workshop, people living with diabetes and caregivers were active participants in discussions with researchers, healthcare providers and decision makers. By design, three hours of the workshop were allocated for patient-led or focused activities while scientific teams worked in parallel on detailed research planning.

In these discussions, patients highlighted the practical barriers that affect the lives of people with diabetes. One patient expressed the frustration of being unable to use potentially beneficial services and products using the metaphor ‘Doctors point to a door to walk through; but when we get to the

door, we find that it is filled with glass - invisible to others but a barrier for us.’ Factors including cost (e.g., for medication, devices, shoes and quality food), lack of services and/or challenges accessing available services all have real negative effects on patients.

The patient-led discussion culminated in a compelling presentation on the morning of the second day with four parts:

- Jaime Borja spoke of winning conditions for patient partnership in research (an advancement from patient collaboration) and patients’ rights to quality healthcare
- André Gaudreau presented a [plain language resource](#) for patients which he has developed and brought to copies share, and about how the costs associated with diabetes, going as high as hundreds of out of pocket dollars, affect his life
- Phyllis Woods spoke of many factors in her remote First Nations community that impact the health of communities, people with diabetes and caregivers; Phyllis noted that there isn’t an expectation that researchers can solve all the issues, but people want to be heard
- Malcolm Sissmore spoke of how family and friends function as patient advocates and partners in care for their loved ones (for example, determining what programs are available, filling prescriptions, making appointments and generally helping with decisions and activities so that people who have diabetes can focus on self-care); Malcolm noted that patient advocates also want to be, and should be, partners in research

Following the patient presentations, Malcolm King challenged all workshop participants to think about what the patients said, and about how the SPOR Diabetes Network can help to make things better. This prompted reflection and discussion about what research could and could not achieve. There was agreement that, given the innovative and uncertain nature of research, not all studies and activities that are undertaken by the SPOR Diabetes Network will have the desired outcomes. However, there was also agreement that researchers working in partnership with patients can make important contributions to improve the lives of people with diabetes.

Regarding the functions of the RRUPP, patients remarked that technical web-based tools that other networks such as PCORI³ in the USA and INVOLVE⁴ in the UK have developed (e.g., for recruitment, publicizing research funding opportunities etc. See Appendix E) may be useful for the SPOR Diabetes Network, but noted that the first work of the RRUPP should not be focused on technology. The main priority for patients was that the RRUPP establish ways of working that allow patients to be true partners, e.g., via accessible language and shared decision making processes.

³ PCORI is the PCORI. Patient-Centered Outcomes Research Institute, www.pcori.org/

⁴ Since it was established in 1996, INVOLVE has been part of, and funded by, the National Institute for Health Research, to support active public involvement in UK National Health System (NHS), public health and social care research. the <http://www.invo.org.uk/>

People also made the point that remote First Nations communities without internet are unlikely to be helped by technology-based approaches. This is particularly important given that First Nations communities are the ones that, by all evidence, should be prioritized for more and better diabetes-related care and services. Being overly focused on technology could also result in the SPOR Diabetes Network overlooking the contributions that skilled people can make. For example, for one health intervention in a remote community, the “app” was a person. There are members of remote communities that have previously received training and have strong relationships that can be used to spread change. These skilled people continue to be present and ready to contribute, and have the expertise that is required to tailor interventions for First Nations Peoples. Planning and implementation should integrate these people, early and continuously.

In a discussion of branding for the SPOR Diabetes Network led by Lisa Chicules, words like “partnership”, “reduced complications” and “life/lives” (vs. health) and “people” (vs. patients) dominated (see Figure 2 and Appendix F). It will be important that the SPOR Diabetes Network brand isn’t one that could be mistaken as belonging to a practice network or health charity, and that it captures the idea of research being harnessed or transformed into results that have benefits for people.



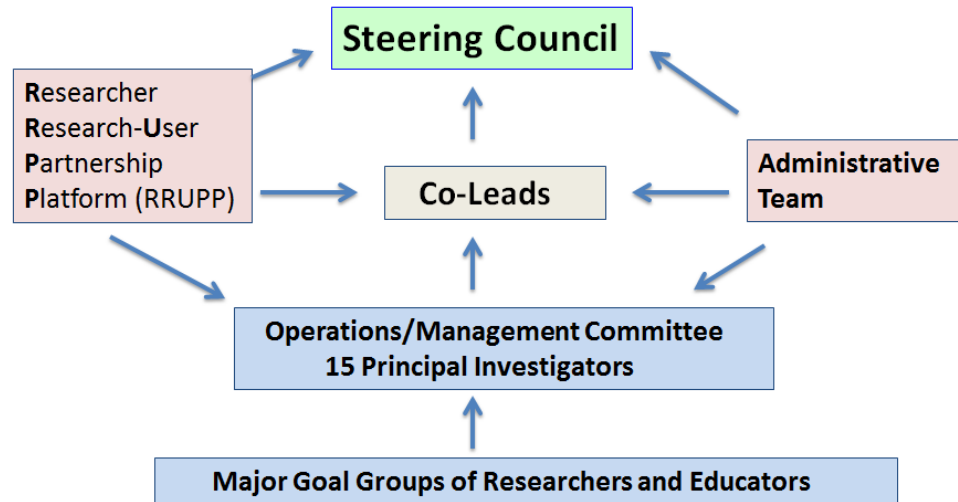
Governance, Performance and Communications

(see also Appendix G)

CIHR has high expectations for the SPOR Diabetes Network and will require consistent progress and regular performance updates. To ensure that the SPOR Diabetes Network meets or exceeds CIHR expectations, a governance structure similar to what is used by many not-for-profit corporations is being established (Figure 3).

Importantly, the academic Co-Leads of the SPOR Diabetes Network report into a Steering Council which has 50% patient membership. Further, the 15 member (minimum) RRUPP, which has ten patient and 5 caregiver representatives, advises both the Steering Council and the academic Co-Leads.

Figure 3: SPOR Diabetes Network Governance and Administration



Both CIHR and funding partners have performance requirements. The five year funding agreement with CIHR requires an overall work plan aligned with the available budget, annual reports on the achievement of milestones, outputs and outcomes and separate specific plans for: Patient-Engagement, Governance, Training and Mentoring and Sustainability. In addition, commitments to funding partners will require: the involvement of funding partners in the development and implementation of strategic directions, annual reporting, the development of new partnerships and additional co-investors.

Branding will be established to help communicate the vision, value and promise of the SPOR Diabetes Network. Thus far, the SPOR Diabetes Network has secured \$33 million; however, studies have already been identified that would put additional millions of dollars of investment to good use. Branding, a website, social media and newsletters will all raise awareness of the SPOR Diabetes Network and help attract additional academic and funding partners. Communications will also help with coordination of activities and delivery of education/training under the SPOR Diabetes Network.

Goal Leads Presentations

(see also Appendix H)

In the second afternoon, the five Goal Leads presented plans which integrated the discussions, advice and other inputs of the two-day workshop (see Appendix H for full content of presentations). The clarity of the plans was noteworthy. All presentations made reference to how Goal teams will learn from and build upon the work of others, both within and external to the SPOR Diabetes Network, such as:

- The *Knowledge Translation* team will make major contributions to establishing the *Research, Research Users Partnership Platform* (RRUPP) which will serve all other teams
- The *Training and Mentoring* team will focus on training for researchers (noting that the provincial SPOR SUPPORT Units are working together on training for patients); one of the *Training and Mentoring* team's first steps will be a survey of SPOR Diabetes Network members to assess what exists already vs. what is needed for researcher training
- Multiple teams commented on how they will work with the Women's Xchange to integrate sex and gender considerations into the work of the SPOR Diabetes Network, the *Retinopathy Screening* team has noted a gender issue worth exploring – men appear to wait longer for retinopathy screening and as a result have more complications
- The informatics system set up by the PPPDRM appears to have already surpassed its target of 60,000 individuals registered, and will be able to support recruitment for trials led by other teams in the short-term
- Multiple teams noted how they will work with groups outside the SPOR Diabetes Network to ensure that they build upon what exists already and do not duplicate work that has been led by others; for example, through Jean-François Éthier the PPPDRM will work with the nascent Pan-Canadian Real-world Health Data Network (PRHDN) which has already developed a plan to prepare harmonized multi-province datasets
- Multiple teams intend to use mobile apps in their work, and there was consensus about the value of sending data captured by these apps to informatics system set up by and maintained by the PPPDRM team
- The Knowledge Translation team proposed that a network-wide research ethics board approved integrated KT study be established to assess and learn from the processes and interactions of the SPOR Diabetes Network members – a show of hands indicated widespread support for this idea

Conclusions

As the first post-funding gathering of members of the SPOR Diabetes Network, the workshop was a success. The next step is to move quickly into establishing the governance structure and supports for researchers to work with patients, so that the Network can move quickly into implementation.

List and Order of Appendices

- A. Workshop Context, Objectives, Agenda and Guidelines for Goal Lead Presentations
- B. High-Level Summary of SPOR Diabetes Network Goals
- C. Overview of CIHR's Strategy for Patient-Oriented Research
- D. Brief Presentations on Overarching Themes
- E. Researchers-Research Users' Partnership Platform (RRUPP) – Examples to Build On
- F. Branding
- G. Governance, Administrative Support, Financial Management and Performance Evaluation Metrics
- H. Goal Leads Day 2 Presentations
- I. Contact Information for Attendees (provided to workshop attendees only)

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