Re-Envisioning the Canadian Nephrology Trials Network: A Can-SOLVE-CKD Stakeholder Meeting of Patient Partners and Researchers

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Abstract
Purpose: The Canadian Nephrology Trials Network (CNTN) was formed in 2014 to support Canadian researchers in developing, designing, and conducting prospective studies in nephrology. In response to the changing landscape and needs within the Canadian nephrology research community, an interest in further growth and development of the network was identified. In the following report, we describe the process undertaken to re-envision the network through the creation of 3 new committees and how the committees are facilitating change and growth within the CNTN for future sustainability.
Sources of information: To understand areas for improvement and capacity building, the organization charged with overseeing the CNTN, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD), began by conducting an environmental scan. As well, 2 informal surveys were sent to nephrology professionals (who were members of the CNTN and the Canadian Society of Nephrology) and patient partners (from Can-SOLVE CKD).
Methods: In September 2018, 44 CNTN members and other stakeholders from across Canada (including patient partners and representatives from research funding agencies) convened for a 2-day visioning workshop in Mississauga, Ontario. The agenda for this workshop was largely based on the results from the informal surveys. CNTN leadership participated and chose other workshop participants through informal stakeholder mapping and purposeful recruitment. Patient partners were recruited to participate in the workshop through advertisement within the Can-SOLVE-CKD patient council. The survey results and discussion questions were presented to participants at the workshop who, in turn, discussed in large- and small-group session ways in which the CNTN might be expanded.
Results: Surveys of patient partners indicated that they would like to see greater involvement of patients in the research process. Surveys of researchers indicated that they wanted more support and resources for coordinating prospective trials. The themes which emerged from the workshop discussions were peer review, engagement, and training. These themes were broadened and formally re-named to Scientific Operations, Communications and Engagement, and Capacity Building. A working committee, each co-led by a nephrologist with research experience and a patient partner, was created to advance each of these identified themes. An executive committee was created to provide overall strategic leadership and governance to the network. The Scientific Operations Committee conducts peer reviews; provides letters of endorsement after peer review; and holds semi-annual in-person meetings where researchers can present their proposals and obtain feedback from multiple stakeholders, including patients. The Communications and Engagement Committee publishes a quarterly newsletter, engages the community on Twitter, and reaches out to community sites and new nephrologists to engage them in research. The Capacity Building Committee conducts webinars to encourage patient partners to develop their own research questions and is developing a hub-and-spoke model to improve research collaboration.
Limitations: We did not conduct formal stakeholder mapping. Only attendees of the visioning workshop provided input, and not everyone’s comment or opinion was included in the workshop report. Perspectives were limited to the sample of people who attended the workshop or were surveyed and may not reflect perspectives of all stakeholders in nephrology research in Canada. We did not use formal qualitative methodology to summarize the workshops.
Implications: Renewed areas of focus and related committees within the CNTN could lead to an increased capacity for nephrology research, increased engagement and collaboration with researchers, a higher likelihood of funding with rigorous peer review, and more clinical trials and multicenter collaborative prospective research being conducted in Canada.
Abrégé

Présentation: Le Réseau canadien d’essais cliniques en néphrologie (RCEN) a été créé en 2014 pour soutenir les chercheurs canadiens dans le développement, la conception et la réalisation d’essais prospectifs en néphrologie. Un intérêt à poursuivre la croissance et le développement du réseau a été identifié en réponse à l’évolution des besoins de la communauté canadienne de la recherche en néphrologie. Dans ce compte rendu, nous décrivons le processus entrepris pour redéfinir le réseau grâce à la création de trois nouveaux comités, et nous discutons de la façon dont ceux-ci facilitent l’évolution et la croissance du RCEN afin d’assurer sa pérennité.

Sources: Can-SOLVE CKD (Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease), l’organisation qui supervise le RCEN, a d’abord procédé à une analyse contextuelle afin de cerner les aspects à améliorer et les occasions de renforcement des capacités. Deux sondages informels ont été envoyés à des professionnels en néphrologie (membres du RCEN et de la Société canadienne de néphrologie) ainsi qu’à des patients partenaires (de Can-SOLVE CKD).

Méthodologie: En septembre 2018, 44 membres du RCEN et autres intervenants de partout au Canada (notamment des patients partenaires et des représentants d’organismes de financement de la recherche) se sont réunis à Mississauga (Ontario) pour un atelier de réflexion de deux jours dont l’ordre du jour reposait largement sur les résultats de sondages informels. Les dirigeants du RCEN participaient à l’atelier et ont sélectionné d’autres participants par l’entremise d’une cartographie informelle des intervenants et d’un recrutement ciblé. Les patients partenaires ont été recrutés par le biais de publicités dans le conseil des patients de Can-SOLVE-CKD. Les résultats des sondages et les sujets de discussion ont été présentés aux participants lors de l’atelier, et ces derniers ont pris part à des discussions en petits et grands groupes sur les façons d’élargir le RCEN.

Résultats: Des sondages auprès de patients partenaires ont révélé que ceux-ci aimaient voir plus de patients participer au processus de recherche. Des sondages menés auprès de chercheurs ont montré à eux qu’ils souhaitaient davantage de soutien et de ressources pour coordonner les essais prospectifs. Les discussions ont permis de dégager les thèmes de l’évaluation par les pairs, de l’engagement et de la formation; lesquels ont été élargis et officiellement renommés Activités scientifiques, Communications et engagement, et Renforcement des capacités. Un groupe de travail, mené conjointement par un néphrologue avec de l’expérience en recherche et un patient partenaire, a été créé pour faire avancer chacun des thèmes. Un comité de direction a été créé pour assurer la direction stratégique et la gouvernance du réseau. Le comité Activités scientifiques dirige les évaluations par les pairs; fournit des lettres d’approbation après celles-ci; organize des réunions semestrielles en personne où les chercheurs peuvent présenter leurs propositions et obtenir des commentaires de plusieurs intervenants, y compris de patients. Le comité Communications et engagement publie un bulletin trimestriel, mobilise la communauté sur Twitter et communique avec les sites communautaires et les nouveaux néphrologues pour les inviter à participer à la recherche. Le comité Renforcement des capacités organise des webinaires pour encourager les patients partenaires à développer leurs propres sujets de recherche et élaborer un modèle de plateforme visant l’amélioration de la collaboration en recherche.

Limites: Nous n’avons pas fait une cartographie officielle des parties prenantes. Seuls les participants à l’atelier ont fourni leurs commentaires; et ce ne sont pas tous les commentaires et opinions qui ont été inclus dans le compte rendu de l’atelier. Les perspectives sont celles des participants à l’atelier ou des personnes sondées; elles pourraient ne pas refléter les points de vue de tous les intervenants de la recherche en néphrologie au Canada. Nous n’avons pas utilisé de méthodologie qualitative officielle pour résumer les ateliers.

Conclusion: Le renouvellement des domaines d’intervention et la création de comités connexes au sein du RCEN pourraient entraîner un accroissement de la capacité de recherche en néphrologie, une hausse de l’engagement et de la collaboration avec les chercheurs, une plus grande probabilité de financement grâce à une évaluation rigoureuse par les pairs, et un nombre accru d’essais cliniques et de recherches prospectives multicentriques réalisés en collaboration au Canada.

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What Was Known Before
Patients and researchers in the nephrology community saw the value in creating a national network to support nephrology research across Canada through the Canadian Nephrology Trials Network. But both stakeholder groups acknowledged that there was room to improved upon the existing infrastructure.

What This Adds
This report describes how stakeholders identified and created new avenues for improving upon the CNTN to create more robust infrastructure to support trials in Canada.

Background/Purpose of Program
Randomized controlled trials (RCTs) are critical to understanding the causal relationship between interventions and outcomes. Kidney patients are often excluded in big trials, and the number of RCTs in this population lags significantly behind other medical disciplines.1,2 This led to the establishment of the Canadian Nephrology Trials Network (CNTN) in 2014.3 The network consisted of researchers in the field of nephrology from across the country who reviewed and provided feedback to investigators on their proposed prospective trials. This was accomplished through regular executive committee meetings and investigator meetings, whereby peers provided support in identifying site investigators for the conduct of multicenter studies.

In 2016, the Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD)4 network assumed sole responsibility of funding and oversight for the CNTN. Can-SOLVE CKD is 1 of 5 long-term disease networks formed as part of the Canadian Institutes of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR).5 Can-SOLVE CKD supports initiatives involving a patient-oriented research approach that focus on improving outcomes for patients. This explicitly involves including patients in the design and implementation of the research process. Integrating and expanding CNTN was a key component in the SPOR grant application. Soon after assuming responsibility for the CNTN, Can-SOLVE CKD began seeking ways to expand the network’s capacity, with input from patient partners. This report describes how CNTN and Can-SOLVE members came together to develop a new, collaborative sustainability strategy and vision for the CNTN.

Sources of Information
With funding and additional resources from Can-SOLVE CKD, work began to re-envision the CNTN. Can-SOLVE CKD staff conducted an environmental scan of 11 national and international research networks (Australian Kidney Trials Network,6 Canadian Cancer Clinical Trials Network,7 Canadian Critical Care Trials Group,8 the Canadian Trials Network,9 Canadian Clinical Trials Coordinating Center,10 International Society of Nephrology—Advancing Clinical Trials,11 Canadian Stroke Prevention Intervention Network,12 CHILDNEXPH,13 Children’s Oncology Group,14 Children’s Cancer and Blood Disorders (C17),15 and Canadian Immunization Research Network)16 to compare and contrast their activities, governance, membership, and patient engagement. The results of the environmental scan are included within the vision workshop report (Supplementary Material 1).

This environmental scan revealed many examples of networks around the world that help build capacity and support quality clinical trials. Other ideas identified from this scan included facilitating collaborations between researchers, helping to develop relationships between researchers and patient partners and facilitating knowledge translation. Four of the 7 networks (Australian Kidney Trials Network, Canadian Cancer Clinical Trials Network, Canadian Critical Care Trials Group, and the Canadian Trials Network) supported quality-investigator-initiated trials by offering support in the development and review of clinical trial protocols, and all 7 networks offered capacity building through the posting of research resources and hosting of educational workshops, webinars, or networking events.

Can-SOLVE CKD then sought to plan a visioning workshop. Can-SOLVE CKD network staff created 2 informal surveys (Supplementary Material 2 and 3) that were distributed prior to the workshop to help inform the agenda and discussion. The questions within the survey were derived from barriers and potential solutions explored in the 2014 workshop.3 Physician members of the Canadian Society of Nephrology and CNTN were invited by email to complete an online survey on their current use of CNTN offerings and services, as well as their thoughts on the future growth of the CNTN. Can-SOLVE CKD patient partners were invited to complete an online survey on their awareness of clinical trials and involvement in the clinical trials process.

Methods
In September 2018, Can-SOLVE CKD organized a meeting of 44 stakeholders from across Canada for a 2-day visioning workshop in Mississauga, Ontario. Stakeholders included patient partners (N = 11), researchers (N = 22), administrators, funders, and the Ontario Renal Network. The purpose of the workshop was to engage stakeholders in developing a collaborative vision and sustainability strategy for CNTN.
Potential participants were identified through existing CNTN membership and Can-SOLVE CKD leadership and staff. The results of the surveys and environmental scan were presented to the attendees to set the stage prior to any discussions at the workshop.

Can-SOLVE CKD staff developed a set of questions, included within Supplementary material 1, intended to generate a dialogue about the future direction of CNTN, including the future focus of the CNTN; the role of the patient partners; the role of industry and the value of CNTN to the Canadian nephrology community. These topics were discussed independently in small groups of 6 participants and then a summary of each group’s discussion was presented to the larger group. This was followed by a Strengths, Weakness, Opportunities, and Threats (SWOT) analysis conducted with the full group to better understand the network’s current state and participants’ visions for growth and development of the network over the next 5 years. Each table had an assigned notetaker who also took notes during the larger group discussions. Summaries were discussed further in large- and small-group sessions over the remainder of the 2-day workshop. Figure 1 shows the information flow and process.

**Results/Key Findings**

The surveys that were used to inform the visioning workshop were sent out to 12 patient partners, 59 CNTN members and 175 Canadian Society of Nephrology members. In total, 6 patient partners (50%) and 41 nephrologists (23%) completed their respective surveys. The CNTN and Canadian Society of Nephrology responses were pooled and presented as researcher responses. When asked “What are the core strengths of the CNTN?,” 65% of respondents felt that “reviewing clinical trials to improve the quality of science” was the most important core strength. Improving the likelihood of funding for clinical trials, promoting collaboration, enhancing the ability of sites to conduct multisite trials, and mentoring young investigators were also viewed as core strengths. In contrast, only 20% felt strongly or moderately strongly that assisting with enrolment was a core strength.

With respect to challenges, 74% of researcher respondents indicated that the acquisition of funding was moderately-to-extremely challenging. More than 50% of researchers identified each of the other issues included in the survey as moderately-to-extremely challenging, including the inability to facilitate the conduct of multisite trials, lack of engagement with community sites, lack of skilled research coordinators at sites, and inability to facilitate patient recruitment (Figure 3).

Researchers endorsed the ideas of a trials registry, which could be searched to find work by a given investigator or trials active at a particular center (71%), a registry of patients interested in clinical trials (68%), and national clinical trials coordinators to assist sites with study start-up (66%) (Table 1).

The results of these surveys allowed Can-SOLVE CKD staff to understand the perspectives of physicians and patient partners and create discussion questions for the visioning workshop.

At the in-person workshop, small groups identified SWOT issues, which were summarized by facilitators and discussed further in large- and small-group sessions. During the SWOT exercise, patient partners also expressed the need to better understand the research process, noting that they would be interested in learning about clinical trials from their physician, websites, social media, and posters in medical offices. This led to the recommendation that the structure and function of the CNTN evolve to increase support to the nephrology clinical trials community within 3 themes: peer review, engagement, and training. These themes were broadened and formally re-named as Scientific Operations, Communications and Engagement, and Capacity Building. Discussions at the visioning workshop identified strengths and opportunities for growth and development within each of these 3 themes.

A workshop report (Supplementary Material 1) was created based on the notes and was distributed to attendees. Committees were created for each of the 3 themes identified in the report: Capacity Building, Communication and Engagement, and Scientific Operations and a new Executive Committee to serve as the governing body of the entire network (Figure 4).

In the spirit of patient-oriented research, patient partners are included as members of each of the new committees, and each committee is co-chaired by a researcher and a patient partner. Can-SOLVE CKD emailed the CNTN and Can-SOLVE CKD membership, asking for those interested to...
apply to be a part of 1 of the 4 committees. The application asked individuals what committee or committees they would like to join, why they wanted to join those committees and whether or not they were interested in being a co-lead. Everyone who applied was appointed to the committee of their choice and offered the role of co-lead if they were interested. The patient partners initially involved in these committees are all affiliated with Can-SOLVE CKD.

All 3 working committees and the executive committee were formed in April 2019 and began monthly meetings. Each committee drafted terms of reference, a workplan and a mandate, which were reviewed and approved by the Executive Committee. The terms of reference set limits on the number of committee members (12 per committee) and the length of time each member serves (generally 2-4 years with an option to extend for 2 years). The network plans to

Figure 2. Core strengths of Canadian Nephrology Trials Network as reported by researcher respondents on a scale from 1 (not a strength) to 5 (very strong).

Figure 3. Main challenges for Canadian Nephrology Trials Network in overcoming barriers to randomized clinical trials as reported by researcher respondents, ranked from most to least challenging.
The Scientific Operations Committee

The Scientific Operations Committee aims to improve the quality of research proposals submitted for funding through robust peer review and to provide investigators with pre- and post-review support. Prior to formal submission to a potential funder, investigators can submit near-final research proposals for feedback through the CNTN website and within 6 weeks receive comments and potentially an endorsement letter. If the committee agrees that this research is an important topic for research and that the submitted proposal is a rigorous protocol, investigators receive a letter of endorsement to use in their funding application. The letter describes the importance of the question and the quality of the proposed research and offers support in the promotion of the study and knowledge translation after publication. Each proposal is formally reviewed by 2 researcher members and 1 patient partner member. The committee meets by video conference to discuss the proposal and the reviews. The goal of these discussions is to provide feedback to the applicant to improve the proposal as required and achieve consensus on whether or not to endorse each proposal.

As well, the Scientific Operations Committee initiated a new informal review process aiming to add value earlier in the research cycle, whereby investigators present proposals that are in early development in an online forum to the committee for feedback and assistance. The committee also assists investigators with specific questions or by identifying resources as required.

To become more visible and advance its reach, the Scientific Operations Committee hosted face-to-face events in May and November 2019, as well as 2 virtual research symposium in November 2020 and April 2021. These events continue to recruit members in preparation for those who may be ending their terms in the next year or 2.

**Table 1.** Support for Possible Expanded Services for CNTN as Reported by Researcher Respondents.

| Possible expanded CNTN services | Proportion of respondents support this option (41) |
|---------------------------------|---------------------------------------------------|
| Registry of trials searchable by investigator and center | 71% (29) |
| National clinical trials coordinator who could assist local sites with start-up | 66% (27) |
| Registry of patients interested in clinical trials | 68% (28) |
| Training of coordinators to conduct trials | 46% (19) |
| Training of coordinators to recruit at non-university sites | 46% (19) |
| Provide subsidies to community sites | 2% (1) |
| Independent data safety monitoring board for investigator-initiated clinical trials | 2% (1) |

**Note.** CNTN = Canadian Nephrology Trials Network.

![Figure 4. Change in network structure preworkshop and postworkshop.](image)
were well attended with 37 attendees in Montreal in May 2019 and 26 attendees in Washington, DC in November 2019. The first virtual event, in November 2020, had 50 attendees and the April 2021 virtual event had 34 attendees. The committee plans to hold future annual events in association with the Canadian Society of Nephrology and American Society of Nephrology meetings. These half-day events allow multiple investigators to share ideas, develop potential collaborations, learn from each other’s experiences and expertise, and connect with colleagues. Updates on ongoing trials also offer an opportunity to share insights and experiences.

**The Capacity Building Committee**

The Capacity Building Committee aims to increase the number of people and resources supporting clinical trials in Canada and to increase the number of research ideas developed by both patient partners and physicians. This committee provides training for patient partners to learn how to develop and present their research ideas at meetings; as well, it connects smaller or community sites to large research sites expand research recruitment capacity through a hub-and-spoke model.

To facilitate the development of patient-driven research ideas, a 3-part webinar series has been created to present patient partners with key points to consider when developing a research idea. Recordings of these webinars are posted on the CNTN website with general viewing access (https://cntn.ca/education/cntn-spring-virtual-research-symposium/). The 3 webinar themes include: “What is research,” “How to develop a research question,” and “Presenting your idea.” The webinars are not meant as a step-by-step guide on how to develop a research question, but act as an introduction and high-level overview of some of the considerations that investigators make in their own development process. This approach aims to entice patients to develop their own idea, with the help of CNTN investigators.

The committee has started work on the development of a hub-and-spoke model in which major research centers act as a hub, with smaller hospitals and community sites as the spokes. The major research hubs will be a point of contact for the spoke sites that wish to participate in research or to recruit and refer to the hub but are unsure of how to get started.

In the future, CNTN plans to mentor trainee researchers by providing resources on our website, promoting training and funding opportunities, and connecting trainees to mentors.

**The Communication and Engagement Committee**

The Communication and Engagement Committee was created to increase the awareness of the CNTN in the Canadian nephrology community and beyond. This ultimately means increasing membership and facilitating more collaboration with academic and nonacademic sites across Canada, as well as keeping the community informed about what is happening in the Canadian research community.

Communications outreach, primarily through a quarterly newsletter, was developed and currently has a reach of more than 300 contacts. The newsletter promotes CNTN events or other events that would be of interest to the network members; informs readers about ongoing studies and recent publications by network members; and reminds readers about the services offered by CNTN.

In December 2018, the CNTN joined Twitter to increase its visibility, further connect with the research nephrology community and find new members. Currently, the network has 275 followers. Twitter is used to re-tweet research news from network members and kidney research groups across Canada and the world. It is also used to promote CNTN events and the newsletter.

The committee recruits new members from community sites, new researchers and clinical trainees by participating in networking events and by directly emailing individuals who work in nephrology. Over the years, the CNTN members have been primarily research nephrologists, but the network sees the value in including more community nephrologists and other nephrology health care professionals. The Communication and Engagement Committee will be working to reach out to community sites, primarily identified by the Capacity Building Committee members in the course of their work developing the hub-and-spoke model, to see how best to help interested individuals working in nephrology at these sites to engage and participate in nephrology research in Canada.

**The Executive Committee**

The Executive Committee comprises the co-chairs of each working committee (patient partner and researcher), 6 members at large and 2 non-voting members (Can-SOLVE CKD leadership representative and CNTN project manager). The committee meets quarterly to coordinate the 3 working committees, offer guidance and leadership, and ensure that the network is moving forward in the direction that was set forward at the visioning workshop. Four co-chairs of the Executive Committee report to the Can-SOLVE CKD Steering Committee.

**Limitations**

The surveys sent to stakeholders had a low response rate, below 50%. The visioning workshop used to identify the key areas of focus in this initiative included stakeholders from across the country; however, the perspectives of our sample of 44 individuals may not be representative of all members of the nephrology community in Canada, which is large, diverse, and dispersed across many regions and disciplines. We did not use formal qualitative methodology to capture the themes emerging from the small- and large-group sessions at the workshop.
Implications

These new committees aim to foster a culture of greater collaboration within Canadian community. The goal is to help the CNTN become a better resource for investigators, patient partners, and collaborators. This will be achieved by helping investigators, through peer review, capacity building, and communications, to design and complete their research, and to disseminate and apply their results.

As Table 2 shows, many initiatives developed by these new committees aim to support the recommendations originally outlined in the re-design of the CNTN.\(^3\) For example, efforts by the Communications and Engagement Committee to upgrade the CNTN website and create a quarterly newsletter will allow the network to better promote studies and disseminate their findings. In addition, the development of the hub-and-spoke model will provide investigators with the support and resources they need to conduct trials across multiple sites. Through these mechanisms, the network aims to increase the capacity of the Canadian nephrology community to complete large collaborative prospective studies that will have a substantial impact on people living with kidney disease and other stakeholders.

Future Direction

The CNTN is currently supported by Can-SOLVE CKD through a SPOR grant, which ends in 2023, and it is currently uncertain whether a second grant will be funded. To support long-term sustainability regardless of a second grant, the CNTN is looking at collaborations with groups such as KRESCEnt and CSN, as well as discussing the idea of engaging with industry partners to continue fostering country-wide collaboration in kidney research. In the meantime and potentially beyond, CNTN will continue to act as a resource for members of the Canadian nephrology community interested in pursuing research. We will continue to engage new investigators and support them in developing relevant and effective proposals, while fostering the work of mid-career and senior investigators. We will develop quality metrics and deliverables to facilitate reporting of our progress in these endeavors.
The research landscape is changing, and the needs of today are not the needs of tomorrow. CNTN will support the growing and dynamic needs of the nephrology research community in Canada.

Ethics Approval and Consent to Participate
No ethics approval or consent to participate was required for this publication.

Consent for Publication
All authors read and approved the final version of this manuscript.

Availability of Data and Materials
Surveys used in the preparation of this workshop and questions for workshop discussion are included in the supplementary materials.

Declaration of Conflicting Interests
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