



# Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD): Form and Function

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Can-SOLVE CKD Network

## Abstract

**Purpose of review** This article serves to describe the Can-SOLVE CKD network, a program of research projects and infrastructure that has excited patients and given them hope that we can truly transform the care they receive.

**Issue** Chronic kidney disease (CKD) is a complex disorder that affects more than 4 million Canadians and costs the Canadian health care system more than \$40 billion per year. The evidence base for guiding care in CKD is small, and even in areas where evidence exists, uptake of evidence into clinical practice has been slow. Compounding these complexities are the variations in outcomes for patients with CKD and difficulties predicting who is most likely to develop complications over time. Clearly these gaps in our knowledge and understanding of CKD need to be filled, but the current state of CKD research is not where it needs to be. A culture of clinical trials and inquiry into the disease is lacking, and much of the existing evidence base addresses the concerns of the researchers but not necessarily those of the patients.

**Program overview** The Canadian Institutes of Health Research (CIHR) has launched the national Strategy for Patient-Oriented Research (SPOR), a coalition of federal, provincial, and territorial partners dedicated to integrating research into care. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) is one of five pan-Canadian chronic kidney disease networks supported through the SPOR. The vision of Can-SOLVE CKD is that by 2020 every Canadian with or at high risk for CKD will receive the best recommended care, experience optimal outcomes, and have the opportunity to participate in studies with novel therapies, regardless of age, sex, gender, location, or ethnicity.

**Program objective** The overarching objective of Can-SOLVE CKD is to accelerate the translation of knowledge about CKD into clinical research and practice. By focusing on the patient's voice and implementing relevant findings in real time, Can-SOLVE CKD will transform the care that CKD patients receive, and will improve kidney health for future generations.

## Abrégé

**Objectif de la revue:** Le présent article décrit le réseau Can-SOLVE CKD, un réseau basé sur un programme de projets et d'infrastructures de recherche qui ont soulevé l'enthousiasme des patients et qui nourrissent leur espoir de voir une réelle réforme des soins qu'ils reçoivent.



**Contexte:** L'insuffisance rénale chronique (IRC) est un trouble complexe qui affecte plus de quatre millions de Canadiens et qui engendre au système de santé canadien des coûts annuels de l'ordre de 40 milliards de dollars. Les données probantes sous-tendant les soins en IRC sont rares, et dans les branches où ces données existent, leur intégration à la pratique clinique se montre insuffisante. Ces problèmes sont aggravés d'abord par la grande variabilité du pronostic de la maladie, puis par la difficulté de prévoir quels patients seront les plus susceptibles de développer des complications. Ces lacunes de connaissances et de compréhension de l'IRC doivent manifestement être comblées; cependant, force est de constater que la recherche actuelle sur l'IRC est inadéquate. Outre l'absence d'une culture médicale qui encourage les essais cliniques, les données recueillies rejoignent les préoccupations des chercheurs sans nécessairement refléter celles des patients.

**Présentation du programme:** Lancée par l'Institut de recherche en santé du Canada (IRSC), la Stratégie de recherche axée sur le patient (SRAP) consiste en une coalition de partenaires fédéraux, provinciaux et territoriaux visant l'intégration des résultats de la recherche dans les soins prodigués aux patients. Le réseau Can-SOLVE CKD (Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease) est l'un des cinq réseaux de recherche pancanadiens sur les maladies chroniques soutenus par la SRAP. L'objectif du réseau Can-SOLVE CKD est tripartite : on souhaite que, d'ici 2020, tous les Canadiens atteints d'IRC (ou à haut risque de développer la maladie) 1- reçoivent les meilleurs soins; 2- obtiennent des résultats de santé optimaux; 3- aient l'occasion de participer à des études cliniques pertinentes (et ce, sans égard à leur âge, leur sexe, leur ethnicité ou leur lieu de résidence).

**Objectif du programme:** L'objectif principal du réseau Can-SOLVE CKD est d'accélérer l'application des connaissances sur l'IRC, tant en recherche qu'en pratique clinique. En s'intéressant aux préoccupations des patients et en appliquant en temps réel les résultats pertinents de la recherche, Can-SOLVE CKD transformera la façon dont seront soignés les patients atteints d'IRC et améliorera la santé rénale globale des générations futures.

## Keywords

patient-oriented research, patient engagement, chronic kidney disease, clinical trials, biomedical research, nephrology, knowledge translation

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## What was known before

The evidence base for informing effective kidney care is limited, and the translation of existing knowledge to routine clinical care is slow. Canada's Strategy for Patient-Oriented Research (SPOR) has raised awareness of the need to generate knowledge that is more relevant to people affected by kidney disease and to accelerate the translation of evidence into improvement in kidney health and care.

## What this adds

Patient-oriented research focuses on priorities and outcomes that matter to patients, seeking to engage them throughout the research process and to generate results that can accelerate improvements in kidney health and care. The Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) Network embraces a national partnership strategy with researchers, patients, policy makers, and other partners across Canada to transform kidney research and care.

## Introduction

Chronic kidney disease (CKD) is a complex disorder that affects more than 4 million Canadians and costs the Canadian health care system more than \$40 billion per year.<sup>1</sup> The majority of people with CKD have multiple comorbidities, placing them at high risk for complications. However, people with CKD are often excluded from clinical studies related to kidney disease.<sup>2</sup> Given this, the evidence base for guiding care in CKD is small, and even in areas where evidence exists, uptake of evidence into clinical practice has been slow.

Compounding these complexities are the variable prognoses among patients with CKD and difficulties predicting who is most likely to develop complications over time. As such, health care professionals are unable to accurately inform patients of pertinent information such as time to dialysis or death and trajectories of disease progression. Although progress has been made, many knowledge gaps remain, notably the underlying disease mechanisms, the epidemiology and burden in different locations, and genetic and environmental interactions.

Clearly these gaps in our knowledge of CKD need to be filled, but the current state of CKD research is not where it needs to be. A sufficient number of mechanistic targets have yet to be identified, and many trials have failed due to poor study design or challenges with recruitment. Much of the existing evidence base addresses the concerns and curiosity of researchers but does not necessarily align with the areas of highest priority to patients.<sup>3</sup>

Aligning research with patient needs and accelerating the translation of evidence into practice are now prerequisites for several health research funding competitions in the United

Kingdom and the United States.<sup>4-6</sup> In Canada, the Canadian Institutes of Health Research (CIHR) has launched the national Strategy for Patient-Oriented Research (SPOR), a coalition of federal, provincial, and territorial partners dedicated to integrating research into care. The ultimate objective of SPOR is to foster evidence-informed and patient-centered care by bringing innovative diagnostic and therapeutic approaches to the point of care, so as to ensure greater quality, accountability, and accessibility of care. As part of SPOR, CIHR is funding provincial SUPPORT (Support for People and Patient-Oriented Research and Trials) Units and national networks that will help advance patient-oriented research.<sup>7</sup>

Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) is one of 5 pan-Canadian chronic disease networks supported through SPOR. The vision of Can-SOLVE CKD is that by 2020, every Canadian with or at high risk for CKD will receive the best recommended care, experience optimal outcomes, and have the opportunity to participate in studies with novel therapies, regardless of age, sex, gender, location, or ethnicity. The network is led by a steering committee that includes a broad range of patients affected by a representative mix of medical conditions, policy makers, researchers, and charitable foundations. Its co-principal investigators are Dr Adeera Levin (University of British Columbia) and Dr Braden Manns (University of Calgary).

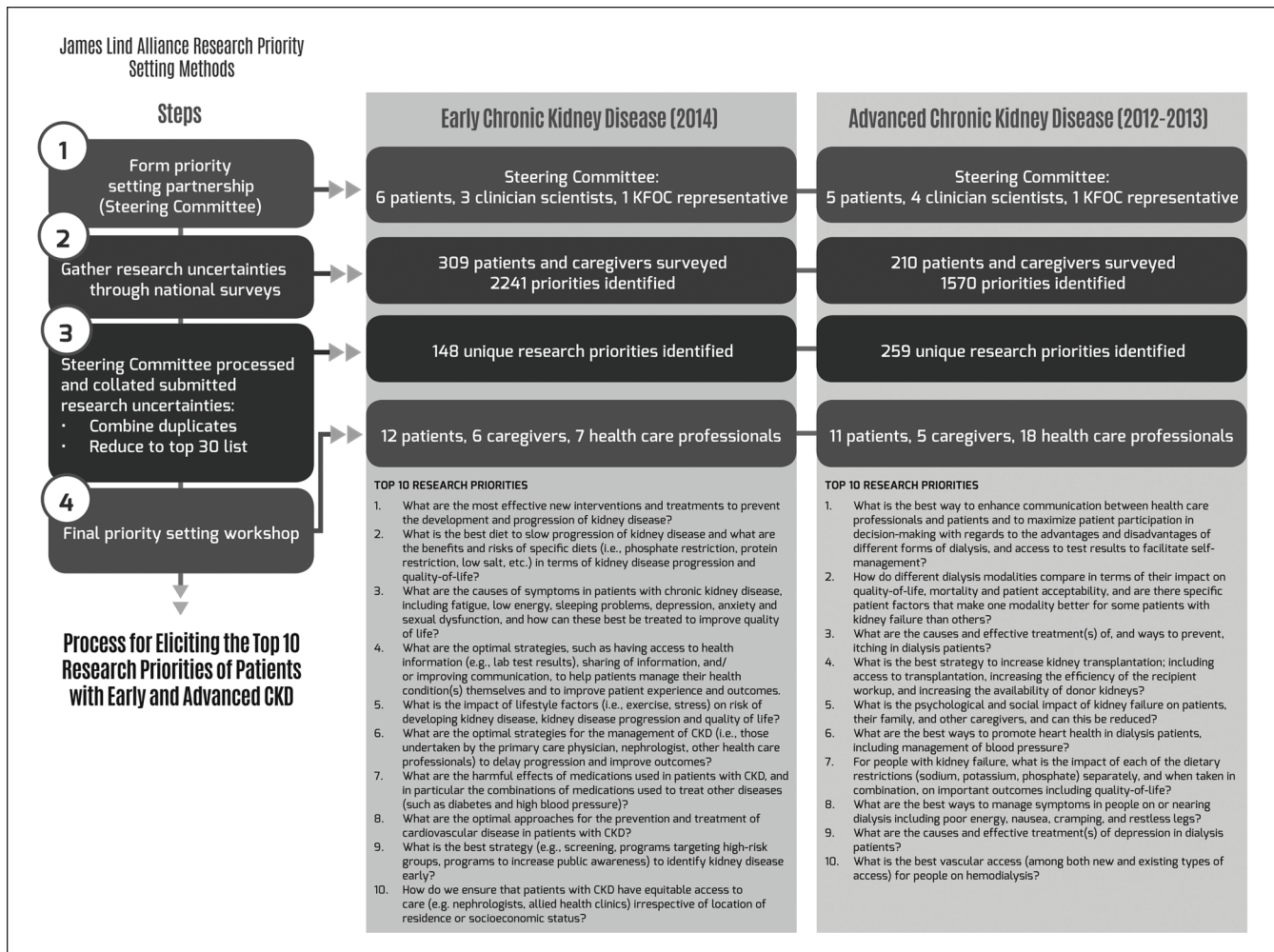
This article serves to describe the Can-SOLVE CKD Network, a program of research projects and infrastructure that has excited patients and given them hope that we can truly transform the care they receive.

## Network Objective

The overarching objective of Can-SOLVE CKD is to accelerate the translation of knowledge about CKD into clinical research and practice. To fulfill this objective, a coast-to-coast partnership of patients, health care providers, policy- and decision-makers (herein referred to as policy makers), and researchers will build on key existing human resources, core infrastructure, and research partnerships to create a sustainable network.

## Network Development

The Can-SOLVE CKD Network builds on an existing collaborative community that has emerged in Canada over the last 15 years and is committed to improving the quality of care and outcomes for CKD patients. Two planning conferences, in 2000 and 2007,<sup>8,9</sup> involved key stakeholders from the kidney community. The first led to the development of a national interdisciplinary training program (Kidney Research Scientist Core Education and National Training [KRESCENT], [www.krescent.ca](http://www.krescent.ca))<sup>10</sup> for allied health professionals, basic scientists, and clinician scientists. The second conference led to the formation in 2010 of the Canadian



**Figure 1.** Can-SOLVE CKD patient-oriented priority-setting process.

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; KFOC = Kidney Foundation of Canada; CKD = chronic kidney disease.

KidNey KNowledge TraNslation and Generation NeTwork ([www.CANN-NET.ca](http://www.CANN-NET.ca))<sup>11</sup> to enhance collaboration and exchange of information between researchers and knowledge users. The Can-SOLVE CKD Network, with its broad engagement of key stakeholders, is well positioned to consolidate and leverage these activities to overcome the limitations of existing networks and address the needs of all people with CKD, extending the benefits to Canadians with other chronic diseases.

### Patient-Oriented Research Program

The goal of patient-oriented research is “to better ensure the translation of innovative diagnostic and therapeutic approaches to the point of care, as well as to help the provinces and territories meet the challenge of delivering high quality, cost-effective health care.”<sup>12</sup> Patient-oriented research focuses on priorities that are important to patients,

engages patients in the research process, and produces information that can be used in meaningful ways to improve health care practice.

Using an established patient priority-setting framework by the James Lind Alliance,<sup>13</sup> a 3-year national process of patient consultation was undertaken to identify the top 10 research priorities of individuals with early or more advanced CKD, their families, and care providers (Figure 1).<sup>9,14,15</sup> Since the inception of the Can-SOLVE CKD Network in March 2014, patients have continued to meet regularly with researchers and policy makers. Two workshops were held with more than 30 patients, caregivers, Indigenous peoples, researchers, and policy makers to finalize research priorities using a modified Delphi process. These priorities informed the development of 18 multidisciplinary research projects spanning biomedical health research, and knowledge translation (KT). This research agenda forms the foundation of the network.

**Table 1.** Can-SOLVE CKD Research Themes, Priorities, and Projects.

Research themes	Research priorities	Research projects
Theme 1: Identify kidney disease earlier and support those who are at highest risk of negative outcomes	Priority 1.1: How can we identify those with or at risk for CKD earlier?	1.1A: Improving renal complications in adolescents with type 2 diabetes through research (iCARE) 1.1A: Assessment of early markers of cardio-renal risk in a longitudinal cohort of youth with diabetes (AddIT) 1.1B: Identifying diabetes and CKD in Indigenous communities
	Priority 1.2: How can we identify and treat those at highest risk for progression to kidney failure?	1.2: Defining risk and personalizing treatment of patients with glomerulonephritis and autosomal dominant polycystic kidney disease 1.2: Glomerulonephritis translational research program
	Priority 1.3: How can we identify those at highest risk for adverse outcomes?	1.3A: Integrating risk-based care for patients with CKD in the community 1.3B: Risk prediction to support shared decision making for managing heart disease (APPROACH)
Theme 2: Define best treatments to improve outcomes and quality of life	Priority 2.1: What are the best treatments to improve outcomes for patients with CKD?	2.1A: Cell therapy for advanced diabetic kidney disease 2.1A: Clinical trials of promising repurposed drugs/compounds for autosomal dominant polycystic kidney disease 2.1B: Aldosterone inhibition and enhanced toxin removal in hemodialysis patients (ACHIEVE)
	Priority 2.2: What strategies can reduce symptom burden in patients with advanced CKD?	2.2: Dialysis symptom control (DISCO) 2.2: Etiology of pruritus during dialysis 2.2: Patient-reported outcomes clustered RCT (EMPATHY)
Theme 3: Define the optimal ways to deliver patient-centered care in the 21st century	Priority 3.1: What model of care will best deliver evidence-based personalized care?	3.1A: Restructuring kidney care to meet the needs of 21st-century patients 3.1B: Targeted de-prescribing in patients with CKD to decrease polypharmacy
	Priority 3.2: How can we better enable self-management of CKD, where appropriate?	3.2: Strategies to enhance patient self-management of CKD
	Priority 3.3: What is the best way to help patients access the best treatment for their kidney failure?	3.3A: Improving patient knowledge about treatment options 3.3B: Increasing the use of living donor kidney transplantation

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; CKD = chronic kidney disease; AddIT = Adolescent type 1 Diabetes cardio-renal Intervention Trial; RCT = randomized controlled trial.

The highest priority areas identified by patients and policy makers were those pertaining to early diagnosis and prognosis—improved understanding of pathobiology and stratifying patients based on risk (Theme 1); treatment options for CKD and comorbidities, and how best to address physical and emotional symptoms (Theme 2); and optimal models of care in chronic disease (Theme 3). Table 1 illustrates research priorities and projects that patients and policy makers included within each theme, connected by a common focus on stratification and personalization. Two examples of the research projects conducted under Can-SOLVE CKD are described in Table 2. Others are available at [www.cansolveckd.ca](http://www.cansolveckd.ca).

As the network executes the projects, patients have been integrated into the research teams, bringing the patient voice to all aspects of the research: design, development, recruitment, implementation, and KT. This partnership is a new way of doing research, requiring a culture change for all involved. To help effect this change, Can-SOLVE CKD has hosted 2 training workshops to help

enable a truly effective and meaningful partnership. To date, 56 network members have received training in patient-oriented research at sessions facilitated by Can-SOLVE CKD.

## Core Infrastructure

The network's sustainability plan includes creating core national infrastructure for research, KT, and training. The national KT network for patients with kidney failure ([www.cann-net.ca](http://www.cann-net.ca)) will be expanded, as will the scope of a national network of multidisciplinary CKD clinics.<sup>16</sup> These resources will be key to disseminating results of Can-SOLVE CKD studies. A repository for biosamples across diabetes, glomerulonephritis, and polycystic kidney disease<sup>17-19</sup> will be created to support collaborative research. Current research training programs will grow. All resources will be united to create core infrastructure that is greater than the sum of its parts (Table 3).

**Table 2.** Examples of Selected Can-SOLVE CKD Research Projects.

Project	Lead(s)	Issue	Research plan
1.1B: Identifying diabetes and chronic kidney disease in Indigenous communities	Dr Paul Komenda Dr Adeera Levin	Indigenous people in Canada are at high risk for CKD and progression to end-stage kidney disease. Current evidence shows Indigenous people progress to end-stage kidney disease 10 years earlier than non-Indigenous people. If CKD is detected early, progression can be delayed through earlier treatment. However, as many Indigenous people live in rural and remote communities, they face additional barriers to accessing appropriate screening, detection, and treatment.	This project will address inequities in access to CKD and diabetes diagnosis and treatment among Indigenous people across Canada, which is one of the top research priorities identified by patients and stakeholders. It has the potential to fundamentally change health care delivery for Indigenous Canadians living in remote communities who are at very high risk of diabetes and CKD. The experienced project team, based at the University of Manitoba, has piloted point-of-care screening in Manitoba Indigenous communities. They will apply their screening strategy to communities in British Columbia, Alberta, Saskatchewan, Ontario, and other areas within Manitoba. The goal is to screen 4000 individuals.
3.3B: Increasing the use of living donor kidney transplantation	Dr Amit X. Garg	Despite the advantages of kidney transplantation over dialysis (ie, improved survival and quality of life, substantial savings to the health care system), only about 40% of Canadians with end-stage renal disease are treated with a kidney transplant. The best way to improve access to kidney transplantation is unknown. There are too few deceased donors to meet the demand for kidneys, and while transplants from living donors offer many advantages (eg, superior graft and patient survival, shorter wait times, lower health care costs), Canada's rate of living kidney donation has stagnated since 2006 and is 35% lower than several Western nations.	Informed by our patient partners, we aim to improve the quality and efficiency of the donor candidate evaluation process throughout Canada. We will measure current processes, develop national consensus on the goals of an efficient evaluation process, and develop and test solutions to realize these goals. A second priority is to evaluate a multicomponent strategy launched in Ontario to support patients to improve their access to kidney transplantation with a focus on living kidney donation. This strategy includes administrative support to programs and providers, a patient-centered approach to transplant education and choice, and peer mentorship. The lessons learned will inform future initiatives in other provinces. If this multicomponent strategy is effective, it will result in improved access to kidney transplantation, better patient outcomes, and significant health care system savings. Moreover, if we see an increase in kidney transplant referrals in the multicomponent intervention, this will provide evidence to support the need for government spending on strategies to improve access to kidney transplantation.

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; CKD = chronic kidney disease.

**Table 3.** Network Core Infrastructures.

Network core infrastructures	Description
Linked Canadian biorepositories in glomerulonephritis, diabetes and polycystic kidney disease	<p>The existing core infrastructure facilities described below will expand glomerulonephritis, diabetes, and polycystic kidney disease initiatives and enable the proposed Can-SOLVE CKD projects. All initiatives will utilize a secure web-based clinical research tool to access de-identified patient data. Access to patient-specific tissue archives will be enabled by secure linkage to the web platform.</p> <ol style="list-style-type: none"> <li>1. <i>The Glomerulonephritis and Pathology Registry</i>: The Ontario Glomerulonephritis (GN) Registry will be expanded to collect information on GN patients across Canada. Both include baseline and longitudinal data on patient demographics, histology, medications, and laboratory results.</li> <li>2. <i>The AMGEN Canada Inc Renal Molecular Diagnostic Laboratory</i> dedicated to GN and diabetic nephropathy currently supports investigators in Ontario, but will be expanded nationally to facilitate analysis of gene expression and proteins in biopsies (kidney, skin, lung) urine, and blood.<sup>20-24</sup></li> <li>3. <i>The Polycystic Kidney Disease Research Registry</i> is a standardized platform adaptable to housing the proposed multidisciplinary PKD research program including a clinical database with mutation and total kidney volume data linked to a biobank of ~2000 DNA and ~500 urine samples.<sup>25-28</sup></li> <li>4. <i>The international AdDIT<sup>29</sup> research team</i> is based at Toronto's Hospital for Sick Children and includes research coordinators, technicians, and cardiac sonographers, with a proven track record of productivity.<sup>23,30-33</sup></li> <li>5. <i>The Improving Renal Complications in Adolescents With Diabetes Through Research Study (iCARE)</i> is a national network based at the Children's Hospital Research Institute of Manitoba in Winnipeg with expertise in care of youth with type 2 diabetes.</li> </ol>
National nephrology clinical trials network	<p>Linking investigators, research personnel, patients, and policy makers is critical for successful randomized controlled trials that can change practice and improve patient care. Over the past year, the network team established the CNTN (<a href="http://www.CNTN.ca">www.CNTN.ca</a>),<sup>34</sup> a key Can-SOLVE CKD infrastructure that will address research questions relevant to all stages of CKD. This will increase Canadian capacity to design and perform robust RCTs. The network will further extend CNTN capacity to answer those questions most important to patients and knowledge users.</p>
National registry of patients interested in participating in clinical trials	<p>Insufficient enrollment is a major barrier to successful RCT completion, especially in CKD, where trials are relatively infrequent and unfamiliar to patients. A patient network will be created for trials participation and treatment evaluation. We will create a registry of over 3000 consenting patients with advanced CKD who will be notified of trials for which they may be eligible. This will include planning and executing trials for participants with specific symptoms, who will be randomly selected to receive a promising therapy, with evaluation using the optimal patient-reported outcome measures.<sup>35,36</sup></p>
Laboratory for development of novel KT tools	<p>Existing KT resources (both human capital and experience) will be expanded to support the development and implementation of electronic tools (including clinical decision support systems, and patient decision aids), which will be comprehensively evaluated in multiple projects.</p>
KRESCENT multidisciplinary training and mentoring program	<p>The innovative and highly successful interdisciplinary national KRESCENT training program will add training streams for patients and policy makers. The goal of KRESCENT is to train an increased number of highly skilled scientists, with a focus on the prevention of end-stage renal disease and new treatments to improve the health of Canadians affected by kidney disease. KRESCENT is a multipartner collaboration, founded by the Kidney Foundation of Canada, the Canadian Society of Nephrology, and the Canadian Institutes of Health Research.<sup>37</sup></p>

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; PKD = polycystic kidney disease; AdDIT = Adolescent type I Diabetes cardio-renal Intervention Trial; KT = knowledge translation; CKD = chronic kidney disease; CNTN = Canadian Nephrology Trials Network; KRESCENT = Kidney Research Scientist Core Education and National Training.

## Partnerships

Engaging the partners noted in Table 4 will transform care for CKD patients across Canada. National and international disease-based advocacy and patient groups, health charities, provincial kidney care programs, community organizations, professional societies, and research and training networks are all essential to the network's success and are represented on the Can-SOLVE CKD Steering Committee. In addition to CIHR, the network is funded by more than 30 funding partners, from

foundations to individual donors, with donations ranging from several thousand to several million dollars. Many organizations are committing in-kind resources to facilitate network activities.

## Policy Makers

Policy makers are also integral partners and engaged in all aspects of the work: identifying health issues of strategic importance, designing and implementing interventions, and

**Table 4.** Can-SOLVE CKD Partners.

Partners	Contribution to network
KFOC	The KFOC advocates for CKD patients across Canada and will be a major partner in the Can-SOLVE CKD Network, taking an active role on the Patient Council and facilitating the training program. KFOC will also be involved in organizing patient activities, and will collaborate on the development of education and decision aid tools aimed at patients, ensuring that the Network transforms Canadian kidney care into a system that is driven by and responds to the wishes and preferences of patients and their caregivers. Can-SOLVE CKD has a direct reporting relationship to the KFOC (Figure 2).
CSN	The professional body representing over 600 nephrologists, kidney scientists, clinical and research trainees, and allied health professionals in Canada, co-hosts its annual meeting with the Canadian Association of Nephrology Administrators (administrative leads within provincial kidney care programs) ensuring ongoing links with provincial kidney care administrators (see below). KFOC has partnered with CSN on several important initiatives, including the KRESCENT program.
Provincial kidney care programs	While structures differ by province, these organizations fund or advise on care for all patients with advanced CKD in Canada.
Indigenous peoples' organizations	The team has partnered with several organizations at the national and provincial levels that address Indigenous health issues. These partners will be critical in ensuring research implementation and eventual scale-up where appropriate. Indigenous peoples' groups (eg, the Indigenous Peoples' Health Research Centre and the Centre for Aboriginal Health Education), in conjunction with IPERC, will continue to inform the research agenda, and engage patients in research and translation of our findings to clinical care.

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; KFOC = Kidney Foundation of Canada; CKD = chronic kidney disease; CSN = Canadian Society of Nephrology; IPERC = Indigenous Peoples' Engagement & Research Council.

translating findings into practice. The network has strong links with policy makers across Canada and a track record of influencing health care policy.<sup>38,39</sup> This partnership and experience will maximize the likelihood that network innovations will be scaled up if study findings are positive, or modified or discontinued if they are not shown to be effective, thus reducing costs to the health care system. Furthermore, policy makers from Indigenous communities are involved in all aspects of the initiative.

### Patient-Oriented Research Training and Mentorship

To implement a patient-oriented research network requires training of all involved—patients, researchers, policy makers—in this new way of conducting research. The Can-SOLVE CKD Network will leverage KRESCENT, the existing and highly successful national transdisciplinary program for kidney scientists ([www.KRESCENT.ca](http://www.KRESCENT.ca)), to deliver a robust, innovative, and structured teaching/mentoring program that will revolutionize kidney research training for all stakeholders in Canada by:

*Training patients and their informal caregivers* to engage as full partners in the Can-SOLVE CKD Network, and to serve as mentors for other patients, ensuring program sustainability. This will be done in conjunction with the standardized national “Foundations in Patient-Oriented Research” developed by a CIHR reference group.

*Training researchers* to develop expertise in patient-centered research and how to work in research teams effectively with patients. This will involve researchers from multiple disciplines conducting research of relevance to

Can-SOLVE CKD, including translational scientists capable of commercializing innovative discoveries, and clinical researchers able to assess the quantitative and qualitative impact of novel treatments and education on outcomes important to patients.

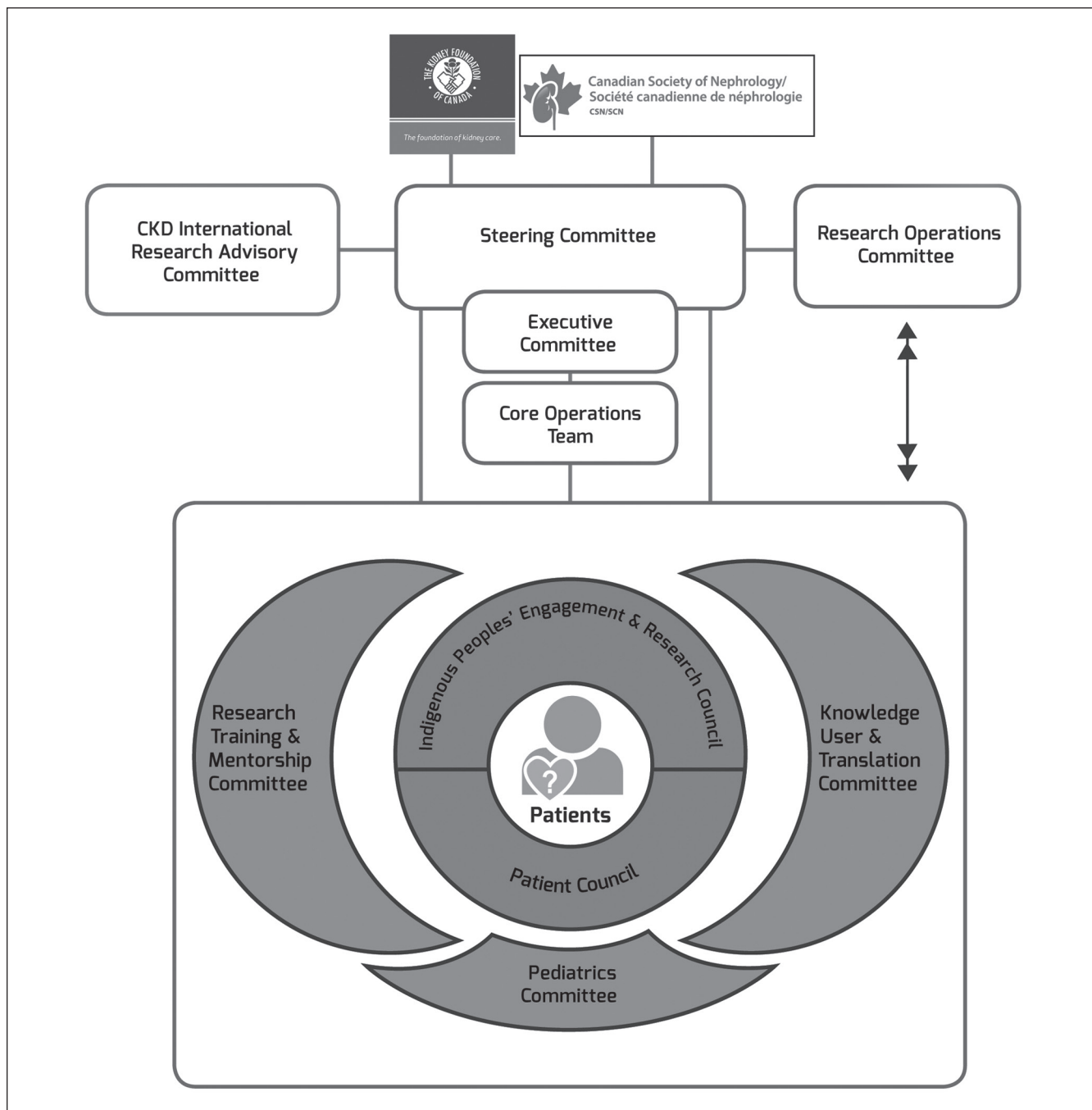
*Training nephrology health care providers* to develop skills in patient engagement and patient-oriented care. Workshops in patient-oriented care for Canadian nephrology fellows and other health care trainees attending the nephrology trainee pre-course will take place at the Canadian Society of Nephrology (CSN) annual meeting.

*Training policy makers* on key aspects of the full spectrum of patient-oriented research, including the use of health research data to produce evidence-based policy. This will also enable input from health care policy makers to inform future Can-SOLVE CKD priority research questions.

### Knowledge Translation

Effective KT is the foundation of the Can-SOLVE CKD Network. The evidence generated will be shared with a broad spectrum of end-users, enabling its application in real-world settings and ensuring a return on investment. The network uses an integrated KT approach whereby key end-users, including patients, caregivers, clinicians, and health policy-makers, are involved from research inception through to the dissemination and implementation of results. This approach emphasizes regular interactions with key stakeholders across all phases and also ensures that specific audiences are targeted for knowledge dissemination at the end. The team will build on the successes of CANN-NET, which has implemented a series of national KT initiatives using educational





**Figure 2.** Can-SOLVE CKD organizational chart.

Note. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease; CKD = chronic kidney disease.

tools aimed at patients and providers as well as a broad range of implementation strategies.<sup>40,41</sup>

### Governance

As a patient-oriented research network, Can-SOLVE CKD comprises several committees and councils. The organizational structure is developed around patients, as depicted in

Figure 2, including both the Patient Council and the Indigenous Peoples' Engagement & Research Council (IPERC). At least 2 patients serve on all Can-SOLVE CKD committees, thus enabling bidirectional communication between committees, the Patient Council and IPERC.

The Patient Council is the core and the heart of Can-SOLVE CKD. The Council is co-chaired by 3 patients with unique lived experience of CKD (Table 5). Membership

**Table 5.** Can-SOLVE CKD Patient Council Co-chairs.**Kate Chong**

I was born and raised in southern Alberta but have called Metro Vancouver home for the past eight years. I have worked for the PNE in a few roles over these past eight years; currently I am their Manager of Community Relations. My involvement in the community doesn't stop with my job but also into my personal life through volunteer work. The past four years, I have been involved with the Kidney Foundation of BC through events, speaking engagements, research committees and workshops.

I am a kidney patient with chronic kidney disease. I was diagnosed four and half years ago at the age of 25 with IgA Nephropathy and was functioning at 13%. I have been able to avoid dialysis and have been able to build back my function to 30-32%. I have been fortunate compared to so many, as it is not often can you improve your function. Most days I feel like a "normal" person, but there are days that I am reminded I live with this disease. I am starting to see other side effects popping up. I know there is a possibility I will decline, but I want to be able to find ways that this can be prolonged and subsequently have a higher quality of life.

Finding ways to diagnose patients earlier and to delay progression are important to me. This is one of the reasons why I got involved in the Can-SOLVE CKD initiative. Research is how we are going to move forward, find solutions and make a change. The involvement of patients has been placed front and centre in the Can-SOLVE CKD Network, engaging us in discussions, workshops and reviewing each step along the way.

My personal experience will help those who work in the field of research to understand the importance of this research and what areas are important to patients, which in the end will provide better quality of life to those living with chronic kidney disease. The experience of being able to help in research is quite rewarding, as you are working towards a future with earlier diagnosis, slowing progression of the disease and providing stronger support when the time comes for transitioning towards dialysis or transplantation. Patient involvement is imperative to the success of research as it will help researchers to know what is important.

**Michael McCormick**

At 18 years of age, I was diagnosed with chronic kidney disease. My primary disease process is FSGS; I have been on hemodialysis for over 27 years, and on home hemodialysis for the past 15 years. I have had two living-related kidney transplants, from my dad and from a cousin. Both transplants failed immediately on the operating room table with extremely aggressive reoccurrence of FSGS in the transplanted kidney. At this time, I am not on the transplant list, as it is believed that the same outcome will occur as with the first two transplants.

I work full time as a Senior Manager at the Toronto Stock Exchange, and I have recently become active with the Kidney Foundation of Canada—Ontario Branch as a Peer Support Counselor. I believe that having access to a network of like-minded, progressive patients who have a keen interest in living a productive life, despite being diagnosed with CKD, is critical. I am part of a roster of several dialysis patients that are available to be matched to new patients and have spoken publicly at York University on risk factors and treatment options for CKD. I am also a standing member of the Ontario Renal Network Patient and Family Advisory Council.

I look forward to continuing my involvement in the CKD community. Having access to shared experience is of huge value—be it in person or electronically. It is my sincere hope that the recent shift to a patient-oriented research focus will bring about significant improvements to the overall care delivered to and received by CKD patients.

**Cathy Woods**

I am a proud Anishinaabe woman, originally from Northwestern Ontario, and now living in Winnipeg, Manitoba. In late 2010, I was diagnosed with nephrotic syndrome. My family physician first noticed some irregularities in routine medical tests and sent me to a renal specialist. After a referral to a renal specialist and a kidney biopsy, I was diagnosed with Idiopathic Membranous Nephropathy.

At this point, I was overwhelmed and terrified by the thought that at some point my kidneys were going to fail. I underwent two different drug regimens, each lasting for 10 months. Nausea and fatigue were a daily part of my life. Although I was very tired and extremely ill, I still kept working and focused on eating well and exercising. Some days it took all my energy to just get myself to work. Working kept me busy and so did spending time with my grandchildren. I didn't know what was happening to my body and I knew that if my kidneys were to fail, I would not be able to do much at that point.

When I was asked to attend the Can-SOLVE CKD workshop in June 2015, I was honoured and humbled to be part of this exciting initiative. This initiative has the ability and scope to be able to assist people struggling with chronic kidney disease by looking at testing and optimizing treatments and patient-focused care to improve the outcomes and quality of life for patients and their families. The research program will also identify and support those at the highest risk of developing CKD, including all Indigenous people.

What I found most fascinating about my journey is my chance to be part of something that will change the culture and focus of how we deal with those with CKD. It is my chance to give back to my community and to those who assisted me in dealing with my disease. I believe that the Can-SOLVE CKD network research projects can change the face of CKD for all by involving and including the patients and their caregivers in this process.

Note. Additional patient profiles are available at <https://cansolveckd.ca/patient-partners/patient-stories>.

includes a broad range of patients affected by a representative mix of medical conditions (eg, diabetes, heart disease, polycystic kidney disease) as well as caregivers and kidney donors. Representation is diversified in terms of age, sex, geography, and ethnic and cultural background.

IPERC serves to guide the conduct of the network's activities in accounting for the unique aspects of patient-oriented research involving First Nations, Inuit, and Métis people.

Using an ethical framework that encompasses the principles of ownership, control, access, and possession, IPERC's mandate is to ensure that Can-SOLVE CKD appropriately incorporates, addresses, and respects the unique needs and perspectives of Indigenous peoples.

All committees report to the Steering Committee through the respective committee co-chairs. The Steering Committee is ultimately accountable to the Board of Directors of the

CSN and the Kidney Foundation of Canada (KFOC). Committee Chairs are nominated by the respective committees and appointed by the Executive Committee. The Can-SOLVE CKD International Research Advisory Committee (CIRAC) provides advisory support to the network, and the Core Operations Team provides the infrastructure support to keep the network functioning on a day-to-day basis.

## Tracking the Impact of Can-SOLVE CKD

Network activities will be tracked and reported according to a performance measurement framework with a series of process and outcome measures. For example, performance-management research-to-impact frameworks are described by the Canadian Academy of Health Sciences and Alberta Innovates Health Solutions.<sup>42,43</sup> Examples of these measures include number of patient partners engaged; experiences of patients engaged in research teams; percentage of partners trained in patient-oriented research; numbers of Indigenous people screened, triaged, and treated; number of living donor and preemptive kidney transplants; and uptake of home therapies as measures of informed decision making and an appropriately resourced health care system. The network will also begin to track patient experiences formally and regularly as part of routine care.

## Conclusion

The Can-SOLVE CKD Network will provide the infrastructure necessary to drive patient-oriented research and implement evidence into clinical practice. By linking patients, caregivers, policy makers, researchers, and clinicians, the network promotes a cultural shift from care which is disease-centered and provider-focused to care which is patient-centered, informed by evidence, and coordinated across the health care system.

By focusing on the patient's voice and implementing relevant findings in real time, Can-SOLVE CKD will transform the care that CKD patients receive, and will improve kidney health for future generations.

## 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

No primary data is presented in this publication.

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## References

1. Manns BJ, Mendelssohn DC, Taub KJ. The economics of end-stage renal disease care in Canada: incentives and impact on delivery of care. *Int J Health Care Finance Econ*. 2007;7(2-3):149-169.
2. Coca SG, Krumholz HM, Garg AX, Parikh CR. Underrepresentation of renal disease in randomized controlled trials of cardiovascular disease. *JAMA*. 2006;296(11):1377-1384.
3. Jun M, Manns B, Laupacis A, et al. Assessing the extent to which current clinical research is consistent with patient priorities: a scoping review using a case study in patients on or nearing dialysis. *Can J Kidney Health Dis*. 2015;2:35.
4. INVOLVE. <http://www.invo.org.uk/>. Accessed December 7, 2017.
5. Patient-Centered Outcomes Research Institute. <http://www.pcori.org/>. Accessed December 7, 2017.
6. Tong A, Chando S, Crowe S, et al. Research priority setting in kidney disease: a systematic review. *Am J Kidney Dis*. 2015;65(5):674-683.
7. Strategy for Patient-Oriented Research. <http://www.cihr-irsc.gc.ca/e/41204.html>. Accessed December 7, 2017.
8. Harnett J, Barrett B, Belanger P, et al. Horizons 2015: Enhancing Excellence and Capacity in Kidney Research Consultation Report. 2007.
9. Hemmelgarn BR, Pannu N, Ahmed SB, et al. Determining the research priorities for patients with chronic kidney disease not on dialysis. *Nephrol Dial Transplant*. 2017;32:847-854.
10. Burns KD, Wolfs W, Bélanger P, McLaughlin K, Levin A. The KRESCENT Program: an initiative to match supply and demand for kidney research in Canada. *Clin Invest Med*. 2010;33(6):E356-E367.
11. CANN-NET. Canadian Kidney Knowledge Translation and Generation Network. <http://www.cann-net.ca>. Accessed December 7, 2017.
12. Canadian Institutes of Health Research. Canada's Strategy for Patient-Oriented Research: Improving health outcomes through evidence-informed care. Ottawa, Ontario; 2011:iii. [http://www.cihr-irsc.gc.ca/e/documents/P-O\\_Research\\_Strategy-eng.pdf](http://www.cihr-irsc.gc.ca/e/documents/P-O_Research_Strategy-eng.pdf). Accessed December 14, 2017.
13. Cowan K. The James Lind alliance: tackling treatment uncertainties together. *J Ambul Care Manage*. 2010;33(3):241-248.
14. Manns B, Hemmelgarn B, Lillie E, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol*. 2014;9(10):1813-1821.

15. CANN-NET: *Canadian Kidney Knowledge Translation and Generation Network*. What are the research priorities of adult patients with chronic kidney disease not on dialysis, their care providers, clinicians & decision makers? 2015; <https://www.cann-net.ca/knowledge-translation/past-projects/research-priorities-of-adult-patients-with-ckd-not-on-dialysis>. Accessed December 14, 2017.
16. Levin A, Steven S, Selina A, Flora A, Sarah G, Braden M. Canadian chronic kidney disease clinics: a national survey of structure, function and models of care. *Can J Kidney Health Dis*. 2014;1:29.
17. Tonelli M, Wiebe N, Hemmelgarn B, et al. Trace elements in hemodialysis patients: a systematic review and meta-analysis. *BMC Med*. 2009;7:25.
18. Gadegbeku CA, Gipson DS, Holzman LB, et al. Design of the Nephrotic Syndrome Study Network (NEPTUNE) to evaluate primary glomerular nephropathy by a multi-disciplinary approach. *Kidney Int*. 2013;83(4):749-756.
19. Levin A, Rigatto C, Brendan B, et al. Cohort profile: Canadian study of prediction of death, dialysis and interim cardiovascular events (CanPREDDICT). *BMC Nephrol*. 2013;14:121.
20. Hodgins JB, Berthier CC, John R, et al. The molecular phenotype of endocapillary proliferation: novel therapeutic targets for IgA nephropathy. *PLoS One*. 2014;9(8):e103413.
21. Reich HN, Landolt-Marticorena C, Boutros PC, et al. Molecular markers of injury in kidney biopsy specimens of patients with lupus nephritis. *J Mol Diagn*. 2011;13(2):143-151.
22. Reich HN, Trichtler D, Cattran DC, et al. A molecular signature of proteinuria in glomerulonephritis. *PLoS One*. 2010;5(10):e13451.
23. Cherney DZ, Scholey JW, Daneman D, et al. Urinary markers of renal inflammation in adolescents with Type 1 diabetes mellitus and normoalbuminuria. *Diabet Med*. 2012;29(10):1297-1302.
24. Cherney DZ, Scholey JW, Sochetti E, Bradley TJ, Reich HN. The acute effect of clamped hyperglycemia on the urinary excretion of inflammatory cytokines/chemokines in uncomplicated type 1 diabetes: a pilot study. *Diabetes Care*. 2011;34(1):177-180.
25. Pei Y, Hwang YH, Conklin J, et al. Imaging-based diagnosis of autosomal dominant polycystic kidney disease. *J Am Soc Nephrol*. 2015;26(3):746-753.
26. Barua M, Cil O, Paterson AD, et al. Family history of renal disease severity predicts the mutated gene in ADPKD. *J Am Soc Nephrol*. 2009;20(8):1833-1838.
27. Pei Y, Obaji J, Dupuis A, et al. Unified criteria for ultrasonographic diagnosis of ADPKD. *J Am Soc Nephrol*. 2009;20(1):205-212.
28. Pei Y, Lan Z, Wang K, et al. A missense mutation in *PKD1* attenuates the severity of renal disease. *Kidney Int*. 2012;81:412-417.
29. Adolescent Type 1 Diabetes Intervention Trial. <http://www.addit-trial.org>. Accessed December 7, 2017.
30. Cherney DZ, Reich HN, Scholey JW, et al. The effect of aliskiren on urinary cytokine/chemokine responses to clamped hyperglycemia in type 1 diabetes. *Diabetologia*. 2013;56(10):2308-2317.
31. Cho YH, Craig ME, Davis EA, et al. Cardiac autonomic dysfunction is associated with high-risk albumin-to-creatinine ratio in young adolescents with type 1 diabetes in AddIT (adolescent type 1 diabetes cardio-renal interventional trial). *Diabetes Care*. 2015;38(4):676-681.
32. Maftai O, Pena AS, Sullivan T, et al. Early atherosclerosis relates to urinary albumin excretion and cardiovascular risk factors in adolescents with type 1 diabetes: Adolescent type 1 Diabetes cardio-renal Intervention Trial (AddIT). *Diabetes Care*. 2014;37(11):3069-3075.
33. Marcovecchio ML, Woodside J, Jones T, et al. Adolescent Type 1 Diabetes Cardio-Renal Intervention Trial (AddIT): urinary screening and baseline biochemical and cardiovascular assessments. *Diabetes Care*. 2014;37(3):805-813.
34. Rigatto C, Walsh M, Zalunardo N, et al. Establishing a Canadian national clinical trials network for kidney disease: proceedings of a planning workshop. *Can J Kidney Health Dis*. 2015;2:46.
35. Frobert O, Lagerqvist B, Olivecrona GK, et al. Thrombus aspiration during ST-segment elevation myocardial infarction. *N Engl J Med*. 2013;369(17):1587-1597.
36. Lauer MS, D'Agostino RB, Sr. The randomized registry trial—the next disruptive technology in clinical research? *N Engl J Med*. 2013;369(17):1579-1581.
37. Burns KD, Levin A, Fowler E, et al. The KRESCENT Program (2005-2015): an evaluation of the state of kidney research training in Canada. *Can J Kidney Health Dis*. 2017;4.
38. Culleton BF, Walsh M, Klarenbach SW, et al. Effect of frequent nocturnal hemodialysis vs conventional hemodialysis on left ventricular mass and quality of life: a randomized controlled trial. *JAMA*. 2007;298(11):1291-1299.
39. Hemmelgarn BR, Zhang J, Manns BJ, et al. Nephrology visits and health care resource use before and after reporting estimated glomerular filtration rate. *JAMA*. 2010;303(12):1151-1158.
40. CANN-NET: Canadian Kidney Knowledge Translation and Generation Network. Nurse or pharmacist-led anemia management protocol initiative. 2015. <https://www.cann-net.ca/knowledge-translation/past-projects>. Accessed December 14, 2017.
41. Manns B, Barrett B, Evans M, et al. Establishing a national knowledge translation and generation network in kidney disease: the CANadian Kidney Knowledge Translation and Generation Network. *Can J Kidney Health Dis*. 2014;1(1):2.
42. Canadian Academy of Health Sciences. Making an impact: a preferred framework and indicators to measure returns on investment in health research. [http://www.caahs-acss.ca/wp-content/uploads/2011/09/ROI\\_FullReport.pdf](http://www.caahs-acss.ca/wp-content/uploads/2011/09/ROI_FullReport.pdf). Published December 2009. Accessed December 14, 2017.
43. Alberta Innovates Health Solutions. Performance management and evaluation: defining the research-to-impact framework. [http://www.aihealthsolutions.ca/media/2012-PME\\_Framework-brochure.pdf](http://www.aihealthsolutions.ca/media/2012-PME_Framework-brochure.pdf). Accessed December 7, 2017.