



Program Report: Can-SOLVE CKD Network Presents an Inclusive Method for Developing Patient-Oriented Research Tools

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Abstract

Purpose of program: Given the growing interest in patient-oriented research (POR) initiatives, there is a need to provide relevant training and education on how to engage with patients as partners on research teams.

Sources of information: As part of its mandate to develop appropriate training materials, the patient-oriented renal research network, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD), established a training and Mentorship Committee (TMC).

Methods: The committee brings together a unique combination of Indigenous and non-Indigenous patient partners (including caregivers, family members, and living donors), researchers, as well as patient engagement and knowledge translation experts, combining a multitude of perspectives and expertise. Following an assessment of training needs within the network, the TMC undertook the co-development of 5 learning modules to address the identified gaps. Subsequently, the committee divided into working groups tasked with developing content using a consultative and iterative approach informed by the DoTTI framework for building web-based tools for patients. In addition, the TMC embodied the guiding principles of inclusiveness, support, mutual respect, and co-building as set out by the Patient Engagement Framework through the Strategy for Patient-Oriented Research (SPOR) of the Canadian Institutes of Health Research.

Key findings: The 5 new modules include: A Patient Engagement Toolkit, Storytelling for Impact, Promoting Kidney Research in Canada (KidneyPRO), Wabishki Bizhiko Skaanj Learning Pathway, and Knowledge Translation. The TMC's approach to developing these modules demonstrates how a diverse group of stakeholders working together can create tools to support high-quality POR. This also provides a roadmap for other health research entities interested in developing similar tools within their unique domains.

Limitations: The landscape of patient engagement in research is constantly evolving. This underscores the need for sustained resources to keep POR tools and training relevant and up-to-date. Sustaining such resources may not be feasible for all research entities.

Implications: Collaborative approaches integrating patients in the development of POR tools ensure the content is relevant and meaningful to patients. Broader adoption of such approaches has great potential to address existing gaps and enhance the Canadian POR landscape.

Abrégé

Objectif du programme: L'intérêt croissant pour les initiatives de recherche axée sur le patient met en évidence le besoin de sensibiliser les chercheurs et d'offrir une formation pertinente sur les façons d'impliquer les patients comme partenaires dans les équipes de recherche.



Sources: Dans le cadre de son mandat consistant à élaborer des documents de formation appropriés, le réseau dédié à l'avancement de la recherche en santé rénale axée sur le patient, le réseau CAN-SOLVE CKD (*Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease*), a créé un Comité de formation et de mentorat (CFM).

Méthodologie: Le CFM réunit une combinaison unique de patients partenaires autochtones et non autochtones (incluant soignants, membres des familles, donneurs vivants), des chercheurs et des experts de l'application des connaissances et de l'implication des patients à la recherche, ce qui permet de conjuguer une multitude de points de vue et d'expertises. Après une évaluation des besoins en formation dans le réseau, le CFM a entrepris l'élaboration conjointe de cinq modules d'apprentissage pour combler les lacunes mises en évidence. Le comité s'est ensuite divisé en groupes de travail chargés d'en élaborer les contenus par le biais d'une approche consultative et itérative guidée par le cadre de perfectionnement DoTTI pour la création d'outils Web destinés aux patients. De plus, le CFM a intégré les principes directeurs d'inclusion, de soutien, de respect mutuel et de co-création énoncés dans le Cadre d'engagement des patients de la stratégie de recherche axée sur le patient (RAP) des Instituts de recherche en santé du Canada.

Principaux résultats: Les cinq nouveaux modules sont: une trousse d'outils sur l'implication des patients, le partage de récits qui ont un impact, la promotion de la recherche dans le domaine rénal au Canada (*KidneyPRO -Promoting Kidney Research in Canada*), le cheminement d'apprentissage Wabishki Bizhiko Skaanj et l'application des connaissances. L'approche adoptée par le CFM pour développer ces modules a montré comment un groupe diversifié d'intervenants qui travaille ensemble peut mener à la création d'outils pour soutenir une RAP d'excellente qualité. Ces travaux ont également fourni une feuille de route pour d'autres entités de recherche en santé qui souhaiteraient élaborer des outils similaires dans leurs domaines respectifs.

Limites: L'implication des patients dans la recherche est en constante évolution. Cette étude souligne le besoin de ressources durables pour garder les outils et les formations en RAP pertinents et à jour. Le maintien de telles ressources pourrait ne pas être possible pour toutes les entités de recherche.

Implications: Les approches collaboratives qui impliquent les patients dans le développement d'outils de RAP garantissent que les contenus soient pertinents et significatifs pour les patients. L'adoption à plus grande échelle de telles approches a le potentiel de combler les lacunes existantes et d'améliorer le domaine de la RAP au Canada.

Keywords

chronic kidney disease, patient-oriented research, patient engagement, training, storytelling, indigenous cultural safety, knowledge translation

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What was known before

There is an increasing number of institutions dedicated to patient-oriented research (POR), yet few tools and training materials to support meaningful inclusion of patient partners as co-leaders of research. To address this gap, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) established a Training and Mentorship Committee (TMC), tasked with identifying

and developing tools to support POR within this national research network.

What this adds

This manuscript describes how patients, researchers, health care providers, and policymakers can work together to develop meaningful POR tools. Examples are provided in the context of Can-SOLVE CKD's TMC, describing the

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TMC's approach for developing, implementing, and evaluating 5 novel POR modules. These include: (1) the Patient Engagement Toolkit, which includes a suite of resources targeted to help teams communicate, identify a common vision and shared goals, and define roles for patients within the research team. (2) Storytelling for Impact, which seeks to empower patient partners to tell their healthcare stories for impact. (3) Promoting Kidney Research in Canada (KidneyPRO), which is a self-paced online learning module providing learners with foundational knowledge on kidney research in Canada; supporting patients in meaningful engagement as partners and participants in research; and increasing awareness for kidney research opportunities. (4) Wabishki Bizhiko Skaanj Learning Pathway, which provides learners with a better understanding of Indigenous experiences and perspectives in health, research, and education and guides researchers and patient partners how to look, listen, learn, and lead. Finally, (5) a Knowledge Translation (KT) module, which enhances the understanding of the importance of KT, whereby knowledge gained through research is synthesized, shared, and applied in clinical practice.

Implications for Future Research/Policy

The TMC presents an innovative way in which a diverse set of health research stakeholders can co-create training and capacity development tools. Other health research networks may consider similar approaches when developing new education and training materials for POR. The modules described in this manuscript can be used by networks and organizations beyond the renal community to build capacity for meaningful POR.

Introduction

An increasing number of institutions dedicated to POR have emerged in several countries including the United Kingdom, the United States, and Canada over the last decade.¹⁻³ As these initiatives are being created, it is essential to provide teams that include patients, researchers, clinicians, and other health care providers with relevant training and education to work as partners on research teams.⁴⁻⁶

In 2011, the Canadian Institutes of Health Research (CIHR) established the Strategy for Patient-Oriented Research (SPOR) and subsequently funded 5 long-term disease research networks including the Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) Network.³ The Can-SOLVE CKD network received funding for 18 research projects focused on chronic kidney disease (CKD), spanning basic science, clinical, and population health research.⁷ To facilitate a patient-centered approach within the network, Can-SOLVE CKD established a Training and Mentorship Committee (TMC) in May of 2016, tasked with creating the tools necessary to help patients, researchers, clinicians, and decision makers engage together in kidney research.⁸ This

manuscript describes the TMC's approach for developing, implementing, and evaluating novel POR tools.

Methods: The TMC Approach

Vision & Objectives

The TMC was guided by the vision that engaging patients in research as participants, partners, and leaders, will help better the lives of those living with kidney disease. With the overarching goal of building capacity for a 'POR-ready' CKD community, the TMC sought to improve communication; establish trust; promote understanding of general research concepts; level the playing field between researchers, patients, clinicians, decision makers, and other stakeholders; and establish processes, tools, and resources to integrate patients as research team members.

Core Values

The TMC embedded principles of adult education,^{9,10} Indigenous values,¹¹ and cultural safety¹² into the way it conducted itself. During the development of the modules, Indigenous patient partners noted the connection between the network's guiding principles of *Looking, Listening, Learning, and Leading*.¹³ These principles involve *looking* within to observe and examine racial identities, privileges, and biases; *listening* to diverse voices and stories; *learning* about the impact of systemic racism and colonialism on health; and *leading* through genuine partnerships with individuals and communities. To further achieve its goals of creating a collaborative environment, the TMC adopted and expanded upon Kirkness and Barnhardt's 4 Rs,¹⁴ which include *Respect, Relevance, Reciprocity, and Responsibility*. The iterative nature of the TMC's work resulted in an additional R, *Reflection*. These core values (Figure 1) were critical for ensuring equitable partnerships between researchers and nonresearchers and challenging the dominance of "expert knowledge" by actively engaging, exchanging, incorporating, and valuing diverse perspectives from all stakeholders on the TMC.

Membership and Organization

From inception to the time of publication, the TMC has engaged a diverse group of participants. The composition of the TMC evolved to include 4 patient partners (including caregivers, family members, and living donors). Additionally, the was supported by 8 staff members of the Can-SOLVE CKD core operations team and 5 researchers, including experts in education, evaluation, and KT. The members' age range was 18 to 60 years with a 17:5 female to male ratio and included a mix of ethnic backgrounds including 4 Indigenous members. During in-person meetings, the group was also supported by an Indigenous Knowledge Keeper. This diversity

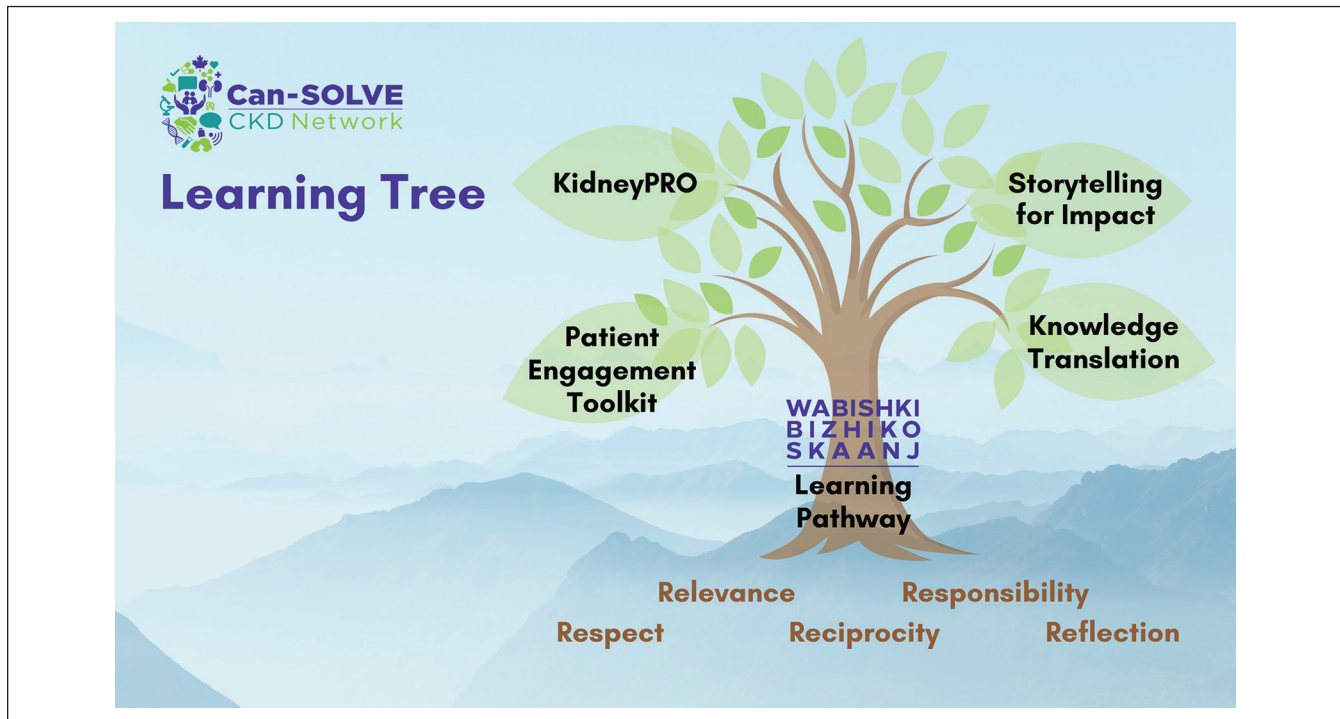


Figure 1. Can-SOLVE CKD Learning Tree.

Note. The 5 patient-oriented research learning modules are analogous to tree branches. Rooted across all modules are the values of; *Respect*—honoring the feelings, rights, perspectives, and traditions of network members; *Relevance*—ensuring responsiveness to the priorities and learning needs of various members of the network; *Reciprocity*—promoting exchange of ideas, experiences, and knowledge and recognizing the importance of relationships when engaging in patient-oriented research; *Responsibility*—being accountable to the vision and mission of the network and promoting the values of patient engagement in all network activities and; *Reflection*—thoughtfully evaluating the learning needs of network members and soliciting ongoing feedback from stakeholders to ensure relevance of the educational materials and resources offered. Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease.

promoted inclusiveness of unique perspectives and helped drive a culture change in the national kidney research community.

Communication and Interaction Among Committee Members

The activities of the committee were determined and prioritized in a collaborative manner. To promote a collegial and inviting atmosphere, the TMC engaged in formal and informal team building activities during face-to-face meetings as well as during remote virtual interactions. In-person meetings were held on an annual basis, along with quarterly meetings by web conference, to discuss curriculum development, evaluation, and KT. During the first 2 annual in-person meetings, the committee discussions centered around understanding the learning needs of network members, consulting with experts in adult education, and brainstorming ideas to determine what specific learning content would best fit the needs of the network.

Identifying Gaps in POR

Shortly after the inception of Can-SOLVE CKD, patient partners and researchers within the network participated in a

CIHR-developed training program for POR. This involved several regional workshops across the country.⁴ After the first round of regional training sessions, the TMC surveyed the participants on their satisfaction with the CIHR modules. While the feedback was positive, participants (both researchers and patients) indicated that the training lacked specific resources for meaningful patient engagement in kidney research. Members of the network identified the following priorities: educational resources on patient engagement, skill development in storytelling, information on Canadian kidney research, how to engage respectfully with Indigenous communities, and better understanding of integrated KT.

Developing the POR Modules

The TMC created working groups tasked with developing learning modules to address each of the priorities identified by the network. After a creative activity where members of the committee used the metaphor of a tree with 5 branches, these modules were eventually referred to as learning branches (Figure 1). The intention of the Can-SOLVE CKD Learning Tree metaphor was to convey the interconnectivity of the learning branches, and how the TMC processes, rooted in the core values articulated by the 5 Rs, served as the foundation of a culturally sensitive pan-Canadian POR capacity building ecosystem.

The working groups, composed of patients and researchers, came together with the understanding that while all team members had an equal voice, particular attention should be paid to patients' feedback, as they are at the heart of POR. Furthermore, to ensure elements of Indigenous learning were included in each module, an attempt was also made to include at least one Indigenous member in each working group. This inclusive approach was essential for ensuring the learning branches were relevant, accessible, and meaningful for patient partners and addressed the learning needs of the broader Can-SOLVE CKD network.

The working groups applied a modified DoTTI (Design and development, Testing early iterations, Testing for Effectiveness, Integration, and implementation) approach for the development of the learning branches.¹⁵ Following the design and development of each learning branch by its respective working group, prototypes were presented to the entire TMC for feedback. After this internal consultation process and prior to implementation, the revised prototype was subject to additional consultation and testing with patient partners. How this process informed the final development and integrated evaluation plan of the learning branches was illustrated in a recent publication.¹⁶

The Can-SOLVE CKD Learning Branches

Patient Engagement Toolkit

This learning branch was designed to support the development of teams composed of patient partners and health research team members (primary investigators, research staff, KT brokers, etc). It involved the development of a toolkit with a suite of resources targeted to help teams communicate, create a shared vision and common goals, and define roles for patients within the research team (Table 1).

Storytelling for Impact

This 8-week, peer-led course was created to provide coaching and tools to support patients tell compelling and impactful personal health stories (Figure 2). Storytelling was deemed an effective strategy to help research teams and others better understand the patient experience.^{17,18} Critically, stories shared to date focused on select moments of care and included a call to action with the aim of improving outcomes for patients. TMC patient partners also voiced an interest in hearing researchers' stories, noting that the sharing of stories by patients and researchers alike could create a sense of reciprocity and help build trust. In response to this request, plans were put in place to adapt the course for storytelling by researchers.

KidneyPRO: Promoting Kidney Research in Canada

KidneyPRO¹⁶ was created to primarily help patients understand kidney research and increase their understanding of the

research process. This learning branch sought to provide a general introduction to Canadian health research, and more specifically, an overview of the Canadian kidney research landscape. Information distinguishing participating in research (ie, enrolling as a subject in a clinical trial) from partnering on a research team was included, as well as a distinct section describing why a focus on Indigenous health was essential in kidney research. While one subsection of KidneyPRO discusses kidney research, other sections could be useful for patients and researchers interested in other domains of health research.

Wabishki Bizhiko Skaanj Learning Pathway

A particularly unique and important learning branch was the Indigenous cultural safety learning pathway, named *Wabishki Bizhiko Skaanj* (pronounced wah-bish-kih biish-ih-goo skaa-nch) which means "White Horse" in Anishinaabe.¹⁹ Citing an Elder, the Indigenous working group lead, Helen Robinson-Settee once said, "We have been researched to death. But it is our responsibility to research ourselves back to life."¹⁹ This fourth branch aimed to enhance researchers' and network members' knowledge and awareness of racial biases, Indigenous voices and stories, the impact of colonization on Indigenous health, and promote cultural safety. As expressed by Indigenous members of the TMC, given the past negative experiences with research, they deemed taking an active role in Indigenous research to be important.

Knowledge Translation

This learning branch was developed to enhance the understanding of the importance of KT, whereby knowledge gained through research is synthesized, shared, and applied in clinical practice or health decision-making.²⁰ The objective of this branch was to introduce learners to the principles of KT within the context of health research using kidney disease and Can-SOLVE CKD-specific examples. Included with this effort were frameworks such as the knowledge-to-action cycle helping research teams plan their KT strategies and activities (Figure 3).²¹ To address gaps in understanding KT processes and practical KT needs, self-paced e-learning modules have been in development on Articulate 360 (<https://articulate.com/360>), a web-based, interactive platform. In addition, members of the KT learning branch and the Can-SOLVE CKD KT Community of Practice developed need-based workshops and mini-modules on a variety of topics, including: understanding KT and the different types of KT; communicating research to different audiences and using different formats (oral presentations, posters); distilling key messages from publications; using plain language to communicate; learning how to collaborate on publications; and promoting patient engagement in integrated KT.^{21,22}

Table 1. Opportunities for Partnering With Patients in Research.

Research Process Steps	Identifying and Prioritizing Research Question	Study Design	Development of Grant Proposal	Study Preparation and Administration	Data Collection	Analyzing and Interpreting Data	Dissemination of Results	Implementation	Monitoring and Evaluation
Roles for Patient Partners	Consult on research topics and collaborate to develop priorities. Clarify the research question and affirm its importance	Inform study design, and aid in designing the detailed protocol Ensure the methods selected are appropriate for patients Co-develop patient recruitment strategies Ensure the research and methods proposed are ethical Define outcome measures	Identify areas where patients and the public could be involved Advise on lay summaries Identify costs of involvement, expenses Become a co-applicant Draft and revise study materials and protocols	Assist with writing patient agreement and consent forms Review ethics and operational applications prior to submission Develop research up-downline patient-friendly Review and comment on proposed questionnaires and data collection methods	Assist with the recruitment of study participants Assist with conducting interviews and surveys	Assist the research team in developing themes from data Consult with research team on interpretation of data Develop more appropriate interpretation of findings to help interpret the data	Advise on ways to disseminate results Author/co-author manuscripts, newsletters, and other appropriate information outlets Jointly present the findings with researchers Help distribute results within informal networks Produce summaries	Increase the likelihood that results of research are implemented by the findings in a patient-friendly and accessible fashion Develop patient information services/interventions within hospitals, clinics, etc.	Continue involvement with the study to maintain focus and address issues as they arise Collaborate with researchers to evaluate the research process Reflect on roles, responsibilities, and lessons learned that could inform future studies and research procedures
Complementary Skills	Participating in group discussions Active listening Setting goals and priorities Creative thinking Researching information Critical thinking Initiative	Participating in group discussions Sharing and promoting materials Teaching, training, or mentoring Writing and editing documents/reports	Planning and organization Learning by listening Participating in group discussions Researching information Managing people and delegating tasks Creative thinking Taking notes Writing and editing documents/reports	Planning and organization Communication Writing and editing documents/reports Learning by listening Participating in group discussions Adaptability/flexibility Time management Budget management	Leading meetings, discussions, or activities Teaching, training, or mentoring Interviewing others Interpersonal skills Attention to detail	Analytical thinking Problem solving cooperatively Active listening Participating in group discussions Attention to detail	Teaching, training, or mentoring Sharing and promoting materials Writing and editing documents/reports Communication Leading meetings or discussions Public speaking Graphic design Presentation skills	Setting goals and priorities Creative/strategic thinking Graphic/web design Sharing and promoting materials Leading activities	Evaluating and solving problems cooperatively Leading meetings or discussions Participating in group discussions Active listening Critical thinking Organization

Note. This chart outlines the ways Can-SOLVE CKD patient partners use transferrable skills to contribute at various research stages.
*Additional information may be found in reference.¹



Figure 2. Storytelling for Impact. Can-SOLVE CKD patient partner, Cathy Woods, used a portion of her written story developed through the Storytelling For Impact module as part of her introduction as co-master of ceremonies at the 2018 SPOR Summit.

Implementation of the Learning Branches

The learning branches were rolled out between 2017 and 2021. As each branch was completed, it was launched within the network to an engaged audience of patients and research team members (Table 2). Dissemination of the tools within the network was made possible through the Can-SOLVE CKD monthly newsletter and social media, as well as through presentations at the various scientific meetings of the kidney community (ie, the Canadian Society of Nephrology) and beyond (eg, diabetes and Indigenous health). The TMC also leveraged dedicated time and expertise of the KT broker of the Can-SOLVE CKD network to support and advise on appropriate dissemination strategies. Word of these learning branches spread across the kidney community, and beyond Can-SOLVE CKD, with other research networks requesting tools and presentations with the goal of applying similar modules in their own contexts.

Over the past few years, several resources have been developed by various organizations including the provincial SPOR support units (eg, <https://absporu.ca/patient-engagement-2>), other SPOR networks (eg, <https://imaginespor.com>), and international organizations like the Patient Centered Outcomes Research Institute (PCORI).² Much like the tools included in the TMC's patient engagement toolkit, these organizations developed resources for introducing patients and researchers to the concepts of patient engagement, for recruiting and training patient partners in research, as well as for sustaining research teams with diverse stakeholders. Importantly, however, the TMC's Storytelling for Impact, KidneyPRO, and Wabishki Bizhiko Skaanj learning branches remain unique contributions in the POR capacity development scene.

Evaluation of Learning Branches

Alongside the development of the learning branches, the TMC implemented an evaluation plan for each learning branch. The evaluation plan sought to: (1) provide the quantitative measures needed to inform annual CIHR reporting; (2) promote broader awareness and uptake of each of the branches across the network and greater Canadian kidney community; (3) ensure network staff members and patient partners were engaged in the appropriate trainings and have a record of trainings completed; and (4) enable continuous improvement of the learning branches.

An evaluation expert was contracted from the Center of Excellence on Partnerships with Patients and the Public (<https://ceppp.ca/>) to support the development of logic models for each learning branch, including a data collection plan capable of ascertaining the impact and reach of each learning branch on an ongoing basis. Featured in this data collection plan were descriptions of the specific evaluation indicators to be collected for each branch, when and where they would be collected, and by whom. Evaluation plans were tailored to the objectives and expected outcomes of each of the learning branches, as well as considering the intended audience, and implementation plan. An example for the evaluation scheme developed for the KidneyPRO learning branch was previously published.¹⁶

The evaluation plans were set to monitor the uptake of the tools by assessing content downloads, browsing patterns, and interactions with the webpages of the various learning branches. Learning modules like KidneyPRO were designed with integrated quizzes to measure learning curve and provide certificates of completion. Short learner feedback and satisfaction surveys were integrated across modules.

To support the intended evaluation plan for each learning branch, specific output formats were generated, including: (1) a crossover chart aligning collected indicators, such as the number of people who completed the training and their professional capacity, to the annual CIHR reporting needs, (2) branch-specific data visualization dashboards to guide strategic planning and responsiveness to evolving needs of the Can-SOLVE CKD network, and (3) maintenance of accurate training records within the Can-SOLVE CKD internal database.

The TMC also recognized the fact that the needs of the kidney community would evolve over time. Therefore, a plan was outlined to review each learning branch yearly and ensure the content remained relevant and up to date. The evaluation tools were set to launch in 2022.

Lessons Learned and Future Directions

The development of the Can-SOLVE CKD Learning Tree has been a dynamic and iterative process. The TMC was hopeful the work of this group would help create an environment where patient partnership in research becomes the norm. This following section of the article provides a brief overview of some of the lessons learned.

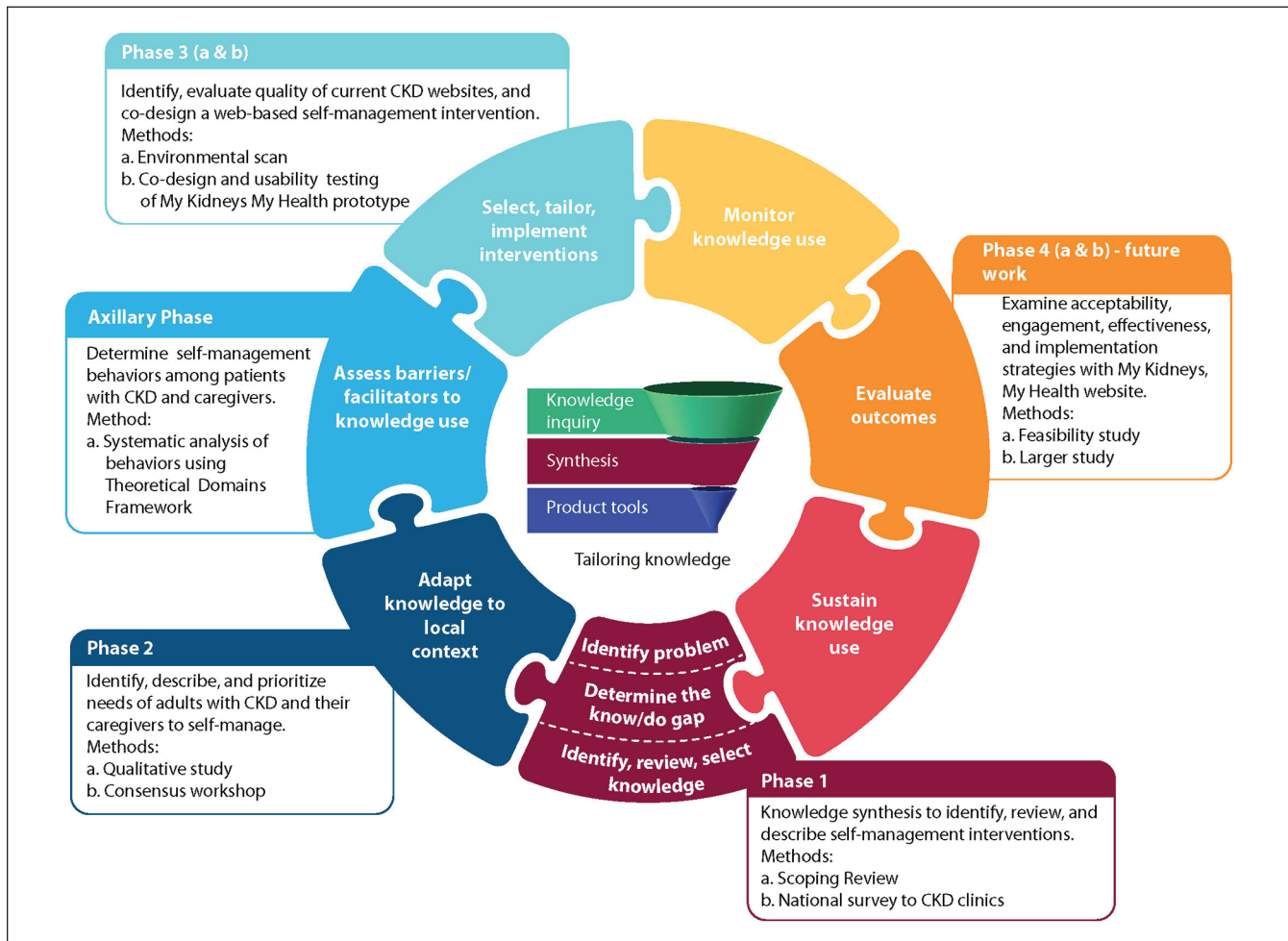


Figure 3. The knowledge-to-action framework.

Note. This image illustrates how the Knowledge-to-Action framework has been used by the Can-SOLVE CKD project “Strategies to enhance patient self-management of CKD.” (Also see Strategies to enhance patient self-management of Chronic Kidney Disease—Can-SOLVE CKD Network [cansolveckd.ca]). Can-SOLVE CKD = Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease.

Fostering a Culture of Inclusiveness and Mutual Respect

The TMC activities were guided by the belief that creating a safe space for open communication is critical for facilitating strong collaboration. TMC members were motivated to ensure all voices around the table were equally heard, and everyone’s opinion was valued. One effective approach for bringing members of the team together as equals was the use of the “talking circle.” This was suggested by our Indigenous members. Once the participants got to know each other and understood their areas of commonality, barriers fell, and collaboration was enhanced.

The Importance of Face-to-Face Meetings

Regardless of how engaged and motivated the group was, only so much could be accomplished through teleconference

and web-based meetings. Ultimately, most of the decision-making was made collaboratively and creatively during the annual day-and-a-half, face-to-face meetings in Montreal. These annual meetings ensured all members secured the dedicated time required to come together from all parts of the country and focused their attention on the tasks at hand. Setting aside dedicated time for face-to-face meetings significantly enhanced the cohesiveness of the group, serving as a time to share, bond, identify, and strive to achieve common goals. Importantly, the relationships established allowed TMC members to continue engaging remotely when in person meetings were no longer possible during the COVID-19 pandemic.

Working With Volunteers

The TMC is comprised of both patient and researcher volunteers. In the early days of the TMC, volunteers doing the

Table 2. The Can-SOLVE CKD Learning Branches.

Learning branch	Aims/goals	Main learners	Tools/products	Reference
Patient engagement toolkit	To create resources for patients and researchers engaged in patient-oriented research	All stakeholders in kidney research, including patients and researchers.	Patient Engagement Roadmap: skills and contributions chart; tips for collaboration in patient engagement; a toolkit for project leads; a glossary of terms; practical tools for teams for internal functioning as well as on roles of team members in the research process.	https://www.cansolveckd.ca/wp-content/uploads/2018/07/patient-engagement-toolkit.pdf
Storytelling for impact	To empower and equip patient partners to tell their healthcare stories for impact.	All stakeholders in kidney research, including patients and researchers.	A peer-led online course (zoom calls and independent work) resulting in an adaptable personal story.	https://www.cansolveckd.ca/news/online-training-module-supports-storytelling-with-impact/
KidneyPRO	To enhance patient knowledge on Canadian kidney research and enhance patient and researcher knowledge on patient participation and partnership in research.	All stakeholders in kidney research, including patients and researchers.	Self-paced online learning module providing foundational aspects of kidney research in Canada; supporting patients in meaningful engagement as partners and participants in research; and increasing awareness for kidney research opportunities.	https://kidneypro.ca/ https://journals.sagepub.com/doi/10.1177/2054358120979255
Wabishki Bizhiko Skaanj	To enhance researchers' and network members' knowledge and awareness of racial biases, indigenous voices and stories, the impact of colonization on Indigenous health, and promote cultural safety.	All stakeholders in kidney research, including patients and researchers.	A learning pathway guiding researchers and patient partners through interactive exercises, online training modules, webinars and online/print resources encouraging participants to look, listen, learn, and lead. Learners gain a better understanding of Indigenous experiences and perspectives in health, research and education.	https://pubmed.ncbi.nlm.nih.gov/34008136/ https://www.cansolveckd.ca/learning-pathway
Knowledge translation	To improve knowledge translation (KT) literacy and capacity for KT within the context of patient-oriented research and kidney health research.	All stakeholders in kidney research, including patients and researchers.	Online, self-paced, e-learning modules are being developed on Articulate Storyline 360 (https://articulate.com/360). Content will be presented as sub-topics/sections with interactive quizzes to allow for engagement with the content. Additionally, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease KT broker, content experts, and patient partners from the KT Community of Practice offer workshops based on ongoing needs assessment.	https://journals.sagepub.com/doi/full/10.1177/20543581211004803

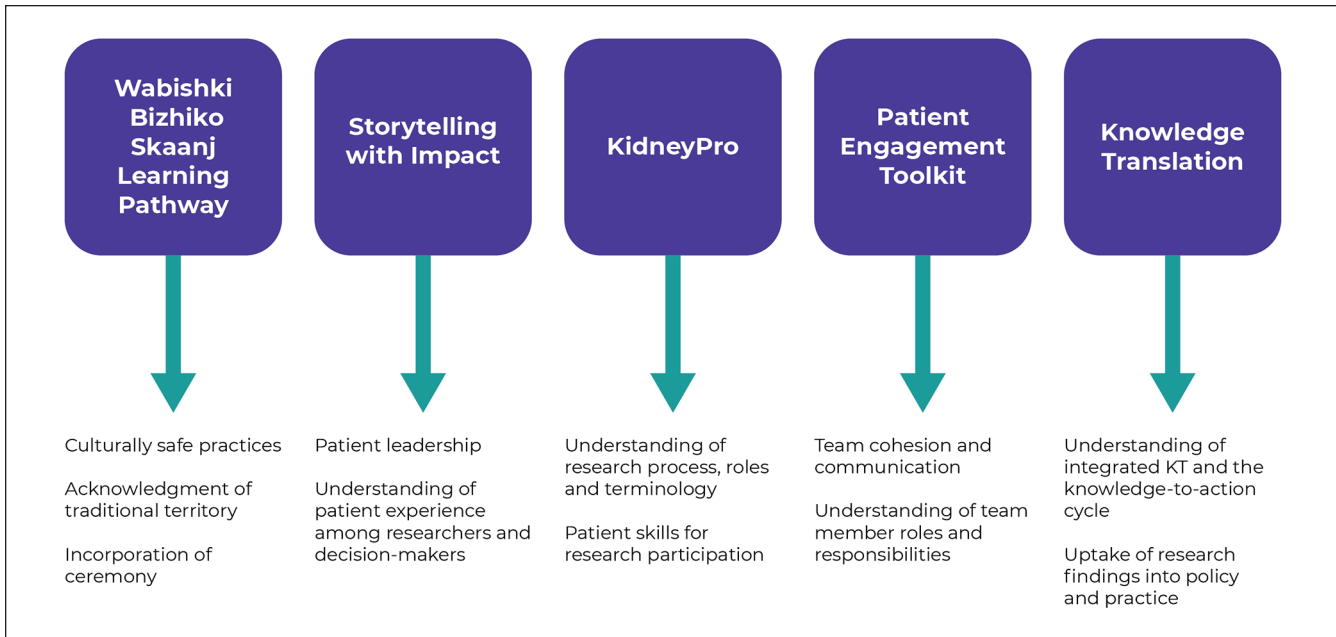


Figure 4. Network-wide culture shift.

Note. Each of the learning branches is driving cultural shifts within the Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) Network.

committee's work "at the side of their desk" were required to carve out time from their personal lives to accomplish the committee's goals. Momentum was maintained through leadership of 1 or 2 highly motivated individuals, but as time progressed and additional tasks mounted, it became clear that the time investment required to create the modules was too demanding for volunteers. Given the competing demands on volunteer committee members, the involvement of a paid coordinator became necessary for overseeing day-to-day activities and following up on outstanding actions. Among the coordinator's responsibilities were detailed note taking and retaining of all documentation so that the group discussions and decision-making would be tracked at every stage. This ensured the necessary work was accomplished and the committee stayed on track.

Managing Time and Expectations

As with any group working toward a goal, it became important to ensure team members were prepared for planning and implementation to take more time than originally expected. Given the number, complexity, and natural evolution of the modules as they were being planned, implemented, and revised, it was important that the committee allowed for flexibility in the progress and rollout of the learning branches. It was also important to discuss these expectations at the outset to ensure individuals were comfortable with the evolution of ideas. Finally, while the ideas were encouraged to evolve, it was important for the group to be reminded to stay focused on the relevant content and scope.

Recruiting Content Experts as Needed

Working with volunteers who participated because of interest and passion ensured the engagement of a group of people willing to work together. Occasionally, however, the group identified a skill or area of expertise that was not available within the TMC. In this case, the committee recruited experts to help accomplish its goals. The committee brought in experts in storytelling, evaluation, and Indigenous content to enhance its work.

Health Issues and Their Impact on Teams

When working with a group over a long period of time, and especially with people living with CKD, it was expected that some individuals would have to leave the group temporarily or indefinitely due to other commitments or health concerns. The departure of a valued colleague due to a health concern had a significant impact on the remaining members of the group, as team members became a close-knit unit. Members of the TMC learned to acknowledge the importance of the loss of a member and allow the remaining members time to grieve. The TMC membership came to understand that this is a part of healing.

A Culture Shift Within the Network

As the learning branches were being implemented within Can-SOLVE CKD, a noticeable culture shift occurred throughout the network (Figure 4). For example, the implementation of *Wabishki Bizhiko Skaanj* Learning Pathway,

along with increased leadership by Indigenous partners over the years, resulted in greater inclusion and adoption of culturally safe practices within Can-SOLVE CKD. The traditional territory was acknowledged at the beginning of each meeting, sharing circles were incorporated in many projects and initiatives and, network members had the opportunity to participate in a Sweat Lodge Ceremony and the KAIROS™ blanket exercise,²³ a key step within the *Wabishki Bizhiko Skaanj* Learning Pathway. Knowledge Keepers were invited to open and conclude many of the network's meetings and workshops. For example, Knowledge Keeper Amelia McGregor from Kahnawake First Nation opened and closed all in-person TMC meetings that took place in Montreal with a traditional blessing.

As the number of patient partners and the scope of their involvement in the network increased, there was a natural shift from historically perceived power imbalances between patients and clinicians/researchers to the development of true partnerships. This culture shift has also been seen at the network level where patient partners participate in, mentor, and lead across the network's operations and research activities.

Conclusion

To better the lives of patients with kidney disease in a meaningful way, there is a need for greater patient involvement in research as participants, partners, and leaders. Each patient brings a unique and relevant voice to the table. The TMC, on behalf of the Can-SOLVE CKD network, was assigned the responsibility of building capacity for a 'POR-ready' Canadian CKD community. The development of the Can-SOLVE CKD Learning Tree, through the collaborative process of the TMC, embodies the core values of *Respect, Relevance, Reciprocity, Responsibility, and Reflection*. The TMC presents an innovative approach in which patient partners and researchers can collaborate to create valuable tools to support POR. Other health networks can consider similar approaches when developing new educational and training materials for POR.

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List of Abbreviations

Can-SOLVE CKD, Canadians Seeking Solutions and Innovations to Overcome; CIHR, Canadian Institutes of Health Research; CKD, Chronic Kidney Disease; KT, Knowledge Translation; POR, Patient-Oriented Research; SPOR, Strategy for Patient Oriented Research; TMC, Training and Mentorship Committee

Ethics Approval and Consent to Participate

Not applicable.

Consent for Publication

All co-authors reviewed this final manuscript and consented to its publication.

Availability of Data and Materials

The content of the learning branches are available from: cansolveckd.ca

Declaration of Conflicting Interests

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References

1. National Institute of Health Research. INVOLVE. <https://www.nihr.ac.uk/news/nihr-launches-new-centre-for-engagement-and-dissemination/24576/>. Accessed January 25, 2021.
2. Patient-Centered Outcomes Research Institute. <https://www.pcori.org/>. Accessed January 25, 2021.
3. Canadian Institutes of Health Research. *Strategy for patient-oriented research patient engagement framework*. <https://cihr-irsc.gc.ca/e/48413.html>. Accessed January 25, 2021.
4. Bell T, Vat LE, McGavin C, et al. Co-building a patient-oriented research curriculum in Canada. *Res Involv Engagem*. 2019;5(1):7. <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0141-7>. Accessed January 25, 2021.
5. Demian MN, Lam NN, Mac-Way F, Sapir-Pichhadze R, Fernandez N. Opportunities for engaging patients in kidney research. *Can J Kidney Health Dis*. 2017;4. <http://journals.sagepub.com/doi/10.1177/2054358117703070>. Accessed January 25, 2021.
6. Manafo E, Petermann L, Mason-Lai P, Vandall -Walker V. Patient engagement in Canada: a scoping review of the "how" and "what" of patient engagement in health research. *Health Res Pol Syst*. 2018;16(1):5. <http://www.ncbi.nlm.nih.gov/pubmed/29415734>. Accessed January 25, 2021.
7. Levin A, Adams E, Barrett BJ, et al. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD): form and function. *Can J Kidney Health Dis*. 2018;5. <https://pubmed.ncbi.nlm.nih.gov/29372064/>. Accessed January 25, 2021.

8. Can-SOLVE CKD Training & Mentorship Committee (TMC) terms of reference. <https://cansolveckd.ca/wp-content/uploads/2021/05/Training-and-Mentorship-Committee-Terms-of-Reference.pdf>. Accessed January 25, 2021.
9. Taylor DCM, Hamdy H. Adult learning theories: implications for learning and teaching in medical education: AMEE Guide No. 83. *Med Teach*. 2013;35(11):1561-1572. doi:10.3109/0142159X.2013.828153.
10. Merriam SB, Baumgartner LM. *Learning in Adulthood: A Comprehensive Guide*. 4th ed. San Francisco: Jossey-Bass a Wiley Brand; 2020.
11. First Nations Perspective on Health Wellness. <https://www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness>. Accessed January 25, 2021.
12. Creating a Climate for Change Cultural Safety and Humility in Health Services Delivery for First Nations and Aboriginal Peoples in British Columbia. www.fnha.ca/culturalhumility. Accessed June 21, 2021.
13. Wabishki Bizhiko Skaanj Learning Pathway—Can-SOLVE CKD Network. <https://cansolveckd.ca/learning-pathway>. Accessed January 25, 2021.
14. Kirkness VJ, Kirkness RB, Barnhardt R. *First nations and higher education: 2001*. <http://www.ankn.uaf.edu/IEW/winhec/FourRs2ndEd.html>. Accessed January 25, 2021.
15. Smits R, Bryant J, Sanson-Fisher R, et al. *Tailored and integrated web-based tools for improving psychosocial outcomes of cancer patients: the DoTTI development framework*. <http://www.jmir.org/2014/3/e76/>. Accessed January 25, 2021.
16. Getchell L, Bernstein E, Fowler E, et al. Program report: kidneyPRO—a web-based training tool for enhancing patient engagement in kidney research. *Can J Kidney Health Dis*. 2020;7:1-10.
17. Can-SOLVE CKD Network. Online training module supports storytelling with impact. <https://cansolveckd.ca/news/online-training-module-supports-storytelling-with-impact/>. Accessed January 25, 2021.
18. Hawthornthwaite L, Roebotham T, Lee L, O’ Dowda M, Lingard L. Three sides to every story: preparing patient and family storytellers, facilitators, and audiences. *Perm J*. 2018;22:17-119.
19. Robinson-Settee H, Settee C, King M, et al. Wabishki Bizhiko Skaanj: a learning pathway to foster better Indigenous cultural competence in Canadian health research. *Can J Public Health*. 2021;112(5):912-918. doi:10.17269/s41997-020-00468-2.
20. Castellano MB. Ethics of aboriginal research. *Int J Indig Health*. 2004;1(1):98-114. <https://jps.library.utoronto.ca/index.php/ijih/article/view/28935>. Accessed January 25, 2021.
21. Elliott MJ, Allu S, Beaucage M, et al. Defining the scope of knowledge translation within a national, patient-oriented kidney research network. *Can J Kidney Health Dis*. 2021;8. <https://pubmed.ncbi.nlm.nih.gov/33889417/>. Accessed January 25, 2021.
22. Patient Engagement in Knowledge Translation—Can-SOLVE CKD Network [Webinar]. <https://cansolveckd.ca/news/webinar-patient-engagement-in-knowledge-translation/>. Accessed January 25, 2021.
23. Kairos Blanket Exercise. <https://www.kairosblanketexercise.org/>. Accessed January 25, 2021.