Program Report: KidneyPRO, a Web-based Training Module for Patient Engagement in Kidney Research

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Abstract

Purpose of report: Over the recent years, there has been increasing support and traction for patient-oriented research (POR). Such an approach ensures that health research is focused on what matters most: improving outcomes for patients. Yet the realm of health research remains enigmatic for many patients in Canada who are not familiar with research terms and practices, highlighting the need for focused capacity-building efforts, including the development of novel educational tools to support patients to meaningfully engage in the research enterprise. The need for disease-specific training in POR was identified by the network dedicated to advancing patient-oriented kidney research in Canada, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD), during the early years of the network’s inception. In this report, we describe the development of KidneyPRO, an online learning module that orients patients and families to kidney research in Canada, and outlines ways to get involved. In line with the Patient Engagement framework of the Strategy for Patient Oriented Research, KidneyPRO was co-developed with the network’s patient partners.

Sources of information: The need for KidneyPRO was identified through a review of feedback from network participants of Canadian Institutes of Health Research’s (CIHR) Foundations in Patient-Oriented Research Module 2—Health Research in Canada and a network-wide survey of Can-SOLVE CKD that was conducted in June 2017 and assessed training needs of key stakeholders. This 2017 survey ranked the need for tools providing introductory knowledge on Canadian kidney research as third in the network’s top 5 capacity-building priorities.

Methods: At Can-SOLVE CKD, a dedicated multi-stakeholder team was formed from the Training & Mentorship Committee (the network’s core infrastructure for POR capacity building) to determine the learning objectives, content, and user interface. The team consisted of 3 patient partners, Director of Research for the Kidney Foundation of Canada, a kidney clinician-scientist, the network’s Patient Partnerships & Training Lead, Can-SOLVE CKD’s Indigenous People’s Engagement and Research Council Coordinator, and a project coordinator. With permission, content from CIHR’s Foundations in Patient-Oriented Research, along with resources from the Kidney Foundation of Canada’s research arm and network project teams, was used to form the basis of the tool. The working group adapted a DoTTI (Design and development, Testing early iterations, Testing for Effectiveness, Integration, and implementation) framework and iteratively identified, created, and refined the content and user interface in consultation with the Training and Mentorship Committee and the Can-SOLVE CKD Patient Governance Circle.

Key findings: In this article, we describe the development, deployment, and evaluation of KidneyPRO, a web-based training module that helps patients understand general, patient-oriented, and kidney-specific research within Canada. KidneyPRO aims to support patient engagement in studies as partners and/or participants and empower them to take part in the research process in an active and meaningful way. It was co-designed and vetted by patients, which helps to ensure clear, useful content and a user-friendly interface. In addition, the module includes links to kidney research opportunities within the Can-SOLVE CKD Network and beyond. A literature review established that KidneyPRO fills an important gap in kidney-specific POR. Ongoing collection of website metrics and postcompletion surveys from users will be used to evaluate the effectiveness of the tool.
Limitations: As an online tool, people who do not have adequate Internet access will not be able to use KidneyPRO. Currently, the tool is not compliant with all Web Content Accessibility Guidelines. Given how the landscape of patient partnership in research is constantly evolving, the content in KidneyPRO needs to be updated on a regular basis.

Implications: Canadians with or at high risk of CKD now have access to an educational tool when seeking to engage as partners and/or participants in innovative kidney research.

Abrégé

Objet du rapport: Depuis quelques années, la recherche axée sur le patient (RAP) bénéficie d’un soutien et d’un attrait croissant. Cette approche permet de garantir que la recherche se concentre sur ce qui compte vraiment: améliorer les résultats des patients. La recherche en santé demeure toutefois énigmatique pour les nombreux patients canadiens qui ne sont pas familiers avec la terminologie et les pratiques de la recherche. Ce constat met en évidence le besoin d’efforts ciblés pour renforcer les capacités, notamment en développant des outils éducatifs pour inciter les patients à s’impliquer significativement dans la recherche. Le besoin de formation spécifique aux maladies rénales dans la RAP a été identifié par Can-SOLVE CKD, le réseau dédié à l’avancement de la recherche en santé rénale axée sur le patient au Canada, dès les premières années de sa création. Dans ce rapport, nous discutons du développement de KidneyPRO, un module d’apprentissage en ligne qui oriente les patients et les familles vers la recherche en santé rénale au Canada et qui présente les différentes façons de s’impliquer. Conformément au Cadre d’engagement des patients de la Stratégie de recherche axée sur le patient, KidneyPRO a été élaboré avec la participation des patients-partenaires du réseau.

Sources: Le besoin pour un outil comme KidneyPRO a été établi grâce à l’examen des commentaires des participants au module 2 des fondements de la recherche axée sur le patient des IRSC et d’un sondage évaluant les besoins de formation des principaux intervenants mené en juin 2017 dans l’ensemble du réseau Can-SOLVE CKD. Ce sondage a permis de classer le besoin d’outils fournissant des connaissances de base sur la recherche en santé rénale au Canada au troisième rang des cinq principales priorités du réseau en matière de renforcement des capacités.

Méthodologie: Chez Can-SOLVE CKD, une équipe multipartite dédiée a été constituée au sein du comité de formation et de mentorat (la principale infrastructure du réseau en matière de renforcement des capacités dans la RAP) pour établir les objectifs d’apprentissage, le contenu et l’interface utilisateur de KidneyPRO. Cette équipe était constituée de trois patients-partenaires, du directeur de la recherche de la Fondation canadienne du rein, d’un chercheur clinicien en santé rénale, du responsable chez Can-SOLVE CKD de la formation et des partenariats avec les patients, du coordonnateur du Conseil de la recherche et de l’engagement des peuples autochtones (CREPC) de Can-SOLVE CKD, et d’un coordonnateur de projet. Avec les autorisations requises, le contenu des Fondations pour la recherche axée sur le patient des IRSC, de même que les ressources du bras de recherche de la Fondation canadienne du rein et des équipes de projet de Can-SOLVE CKD ont été utilisés pour constituer la base de l’outil. Le groupe de travail a adapté un cadre de perfectionnement DoTTI (Design and development, Testing early iterations, Testing for Effectiveness, Integration and implementation) puis déterminé, créé et raffiné de manière itérative le contenu et l’interface utilisateur de l’outil en collaboration avec le Comité de formation et de mentorat et le Conseil des patients de Can-SOLVE CKD.

Principaux résultats: Cet article décrit le développement, le déploiement et l’évaluation de KidneyPRO, un module d’apprentissage en ligne qui aide les patients canadiens à comprendre la recherche tant générale que centrée sur les patients ou spécifique aux maladies rénales. KidneyPRO est conçu pour soutenir l’engagement des patients en recherche, comme partenaires et/ou participants, et leur donner les moyens de s’impliquer activement et significativement dans le processus. L’outil a été co-créé et validé par les patients, ce qui contribue à garantir un contenu clair et pertinent, et une interface facile à utiliser. Le module comprend également des liens vers les différentes avenues de la recherche dans le réseau Can-SOLVE CKD et ailleurs. Une revue de la littérature a permis de confirmer que KidneyPRO comble un important vide de la RAP en santé rénale. L’efficacité du loutil sera évaluée par la collecte de données en continu sur le site Web et par des questionnaires de suivi proposés aux patients.
Limites: KidneyPRO étant un outil en ligne, son utilisation pourrait constituer un enjeu pour les personnes dont l’accès à internet est inadéquat. Aussi, l’outil n’est toujours pas conforme à toutes les directives pour l’accessibilité aux contenus Web. Enfin, la situation des partenariats avec les patients en recherche étant en constante évolution, le contenu de KidneyPRO doit être mis à jour régulièrement.

Conclusion: Les Canadiens atteints ou susceptibles d’évoluer vers l’insuffisance rénale chronique ont désormais accès à un outil éducatif lorsqu’ils cherchent à s’impliquer comme partenaires ou participants à des études innovantes en santé rénale.

Keywords
chronic kidney disease, patient-oriented research, patient engagement, patient-partner, web-based training tool, e-learning

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What was known before
Health research largely remains mysterious for many patients who are not familiar with research terms, practices, and protocols. We present a user-friendly, online learning platform called KidneyPRO, a tool designed to support patients in understanding research processes and how they can contribute in a meaningful way. It addresses a key gap in patient-oriented research (POR), as identified by patients in the Can-SOLVE CKD Network.

What this adds
KidneyPRO is a web-based training tool that was co-developed with patient partners, which helps patients understand general, patient-oriented, and kidney-specific research in Canada. KidneyPRO promotes patient engagement in studies as partners and/or participants. The tool also includes links to kidney research opportunities.

Implications for Future Research/Policy
KidneyPRO will help create a cohort of research-ready kidney patients across Canada. As POR continues to gain momentum within health research, the ability to reduce orientation time by equipping patients with foundational understanding of the research process and how they can contribute to it will allow research teams to implement POR more efficiently—ultimately improving outcomes for the CKD community. Ongoing evaluation of the impact of KidneyPRO on patient engagement in kidney research is needed to ensure it continues to respond to the needs of patients.

Introduction
Adopting a patient-oriented research (POR) approach is important for ensuring that health research remains relevant and focused on what matters most: improving outcomes that are important to patients. POR means that patients are not just included as research subjects or participants but are active contributors in the research process.1-3 The premise for this approach reflects a growing desire for more individualized, ethical, democratic, and moral health care practices, as well as for a more informed and accountable research agenda; indeed, patients are the ultimate recipients of health research findings, and therefore are the most important stakeholders who should play a valuable role in the research process.4

Recognizing the value of this approach, Canadian Institutes of Health Research (CIHR) created the Strategy for Patient-Oriented Research (SPOR) in 2011.5 As a result, 5 pan-Canadian chronic disease networks were founded, one of which is focused on kidney disease, called Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD). The mission of Can-SOLVE CKD is to ensure that every Canadian with or at high risk of 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.6

As a SPOR network, Can-SOLVE CKD is committed to following the direction of SPOR’s Capacity Development Initiative7—supporting POR through proper training opportunities. As such, the network offered CIHR’s Foundations in Patient-Oriented Research Curriculum to members of the network, including researchers, health care professionals, policy makers, and patient partners. However, post-training surveys indicated that patients needed additional support to understand research processes in Canada, and especially in the context of kidney disease. Similarly, although Can-SOLVE CKD was onboarding patients as partners in research, it became clear from their questions during discussions that they needed more information about kidney research and the roles of patient partners. At the time, there were no resources or tools within the Canadian kidney research community that offered a simple overview of kidney research for patients and how they could get involved. A network-wide survey of Can-SOLVE CKD in June 2017 to assess POR training needs among the network’s key stakeholders also identified the need for more POR training tools.

In the absence of such educational resources (see Supplementary Material 1), the Can-SOLVE CKD Network sought to create a new online learning tool for patients, called KidneyPRO. Critically, the project was largely a patient-centered and patient-led initiative, which has resulted in a tool with clear language and content that directly addresses the needs of patients within the Can-SOLVE CKD Network.
Learning Objectives of KidneyPRO

KidneyPRO is a platform that allows patients to explore the breadth and depth of kidney research in Canada, to understand how patients can participate in and guide kidney research, and to become empowered to engage in kidney research. Can-SOLVE-CKD has made KidneyPRO available freely online for anyone to use. KidneyPRO is offered to new patient partners in English and in French. This tool aims to increase patients’ awareness on how they can partner in research beyond their traditional involvement in research study participants and provides links to kidney research opportunities across Canada. KidneyPRO involves 3 main components: a general introduction to the Canadian health research landscape, a more specific overview of the Canadian kidney research landscape, and information about why and how patients should become involved, including why an emphasis on Indigenous patient partnership is essential to kidney research. At the end of each module, an interactive quiz evaluates participants’ retention of the knowledge presented.

Development of the KidneyPRO Learning Modules

Once the need for KidneyPRO was identified, a working group from the Can-SOLVE CKD Training & Mentorship Committee (TMC) was tasked with creating the tool. The working group included members with diverse expertise and perspectives, including patient partners, Indigenous patient partners, researchers, and a member of Can-SOLVE CKD’s core operations team. Part way through development of the tool, a coordinator was hired to offer additional support.

The working group took a multi-phased approach akin to the DoTTI (Design and development, Testing early iterations, Testing for Effectiveness, Integration, and implementation) framework. The lifecycle of KidneyPRO development and deployment included 5 phases: design and development, testing (consultation with patients), revision, implementation, and evaluation (Figure 1).

Phase 1: Design and Development

In January 2018, the working group met in-person and spent several hours drafting an outline for KidneyPRO. Given the main target audience of KidneyPRO was to be patients with the Can-SOLVE CKD Network, the working group strived to ensure from the beginning that the tool was engaging, easy to use, and addressed the needs of patients. The vision of the working group was to introduce new patient partners to various causes of CKD; the breadth of kidney research in Canada to address CKD; researchers’ and research trainees’ projects delivered in a patient-accessible manner; patient testimonials on their experience when engaging in research; exposure to a
learning was more interactive and relied on visual tools. Interactive quiz questions at the end of each section, to help patients recall what was learned, were also added at this stage. While not all of the initially envisioned content materialized in the end product, some key features that were incorporated into KidneyPRO include videos of researchers and patients sharing their perspectives and experiences, informative content that answers many patients’ questions about research, a Glossary of Terms for easy reference, and a hyperlink to KidneyLink.

**Phase 4: Online Launch of KidneyPRO**

An English version of KidneyPRO was officially launched in November 2019, and the tool was translated into French in the winter of 2020. KidneyPRO was highlighted on the network’s website and in the network’s monthly newsletter, as well as disseminated through the national website of the Kidney Foundation of Canada and their local branches. A permanent link was also embedded into KidneyLink.

**Phase 5: Evaluation of KidneyPRO**

Alongside the implementation of changes to the initial prototype, the TMC hired an expert from Montreal’s Center of Excellence on Partnership with Patients and the Public (CEPPP) to outline an evaluation strategy. To establish the evaluation scheme for KidneyPRO, we commenced by developing a logic model (Figure 2). A logic model is a visual illustration of a program’s resources, activities, and expected outcomes. The logic model for KidneyPRO summarized the context, general objectives, and nature of...
training offered to patient partners from the Can-SOLVE CKD Network. For the content, modalities of delivery, and dissemination plan, sources of inputs, activities, and outputs were determined. Finally, the expected results and anticipated impact of the KidneyPRO training modules were outlined. This process ultimately informed what metrics should be measured to quantify the success of each of the KidneyPRO modules in meeting its intended goals. Examples of these metrics include capturing the popularity of KidneyPRO based on the number of people navigating to the web page, downloading the learning material, and capturing social media activity and links from other published and web-based content showcasing this e-learning tool.

As the website is relatively new, many of the evaluation metrics have not yet been collected. There is ongoing data collection to assess the popularity of KidneyPRO among

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**Figure 2.** The KidneyPRO logic model for planning and evaluation.

Note. A logic model was developed to help evaluate key outcomes of KidneyPRO. This includes website metrics capturing the popularity of the module. Abbreviations in the logic model include the following: POR = Patient-Oriented research; KU/KT = Knowledge User and Knowledge Translation; CIHR = Canadian Institutes of Health Research; CKD = chronic kidney disease; PGC = Patient Governance Circle; TMC = Training & Mentorship Committee; IPERC = Indigenous People’s Engagement and Research Council.
members of the Can-SOLVE CKD Network. Preliminary data from Google Analytics suggest that between November 1, 2019, when KidneyPRO was launched, and September 30, 2020, the English version of the tool received a total of 384 pageviews and 344 unique pageviews (which is a proxy for the total number of users). In addition, the working group is currently developing a system for users to voluntarily register and consent to providing post-module feedback. The feedback will be reviewed by members of the working group and inform future changes and/or supplements to the current content to ensure KidneyPRO remains a useful resource for patient partners.

**KidneyPRO, Training Content, and Knowledge Check**

**Module 1: Health Research in Canada**

The first module of KidneyPRO provides participants with a broad overview of the 4 CIHR health research themes, which include: biomedical research, clinical research, health services research, and social, cultural, environmental, and population health research. For each of these themes, the module offers a brief description of what the research entails, how it is typically conducted, and what type of research subjects are most often involved (eg, animals vs humans).

Within this first module, there is also a general introduction to health care spending in Canada. This informs learners of the differences between “investigator-driven research,” which refers to projects conceived by individual researchers and their teams, and “priority-driven research,” which refers to initiatives created by the Government of Canada to investigate pressing health issues that are of strategic importance to Canadians. The last part of this component provides a brief overview of the health research process. Importantly, the content presented in the module is a summary of CIHR’s foundational POR curriculum.

**Module 2: Kidney Research in Canada**

The second module introduces participants to the Canadian kidney research landscape. This module commences by noting the complexity and diversity of kidney disease. It then provides examples of kidney-specific research across the same 4 themes outlined in the first module: biomedical research, clinical research, health services research, and social, cultural, environmental, and population health research.

Importantly, the learning opportunity in this module is enriched by interactive links to a selection of open-access papers published in the *Canadian Journal for Kidney Health and Disease* (CJKHD). These links allow participants who are interested in learning more about kidney-related research a chance to explore relevant academic papers. Topics captured in peer-reviewed manuscripts include genetics, diabetes, heart health, pregnancy, quality of life, health information, patient partnership, glomerulonephritis, acute kidney injury, transplant, dialysis, and the latest issue of CJKHD. Finally, this module outlines historic and current funding of kidney research in Canada. This includes an interactive map of selected kidney researchers across the country also participating in the Can-SOLVE CKD Network and descriptions of their scholarly work (Figure 3).

**Module 3: Patient Engagement in Research**

This module starts by explaining how patients participating in research as study subjects are critical for helping advance knowledge on kidney disease. Such participation, for example, helps determine whether a new drug or therapy is effective at treating a particular type of kidney disease. It includes a checklist of relevant knowledge items for patients considering participation in a study. For those interested in exploring ongoing studies and clinical trials, KidneyPRO provides access to KidneyLink.

Although there is a long history of patients participating in research studies as subjects, the concept of patient partners, who play an active role in designing and implementing the research projects, is relatively new. Therefore, a subsection of KidneyPRO is dedicated to informing patients on how they can contribute as partners within health research—acting as key drivers of POR. This interactive subsection includes quotes and video interviews of existing patient partners.

The remaining subsection of this module is dedicated specifically to Indigenous patient partnerships. In Canada, First Nations, Inuit, and Métis (FNIM) populations are disproportionately affected by kidney disease. FNIM groups also face unique barriers in accessing care. These barriers are related to racism, remoteness, or costs of care. Therefore, the Can-SOLVE CKD Network puts emphasis on engaging FNIM groups as patient partners. The module provides an overview of colonial history and clarifies the need to include Indigenous partners in the research process. Through this subsection, learners are exposed to the voices of Canadian Indigenous communities, carrying not only their experiences with systemic racism but also the rich cultural nuances of their communities, which is essential for research partnership. At the conclusion of the subsection, learners seeking additional information are provided with links to Indigenous-specific initiatives offered by Can-SOLVE CKD and IPERC.

**Module 4: Opportunities to Engage in Research as Participants and Partners**

KidneyPRO also provides a comprehensive list of resources that correspond to each theme discussed in the various
subsections. These resources allow participants to delve deeper into a topic of their choice. For example, learners can find out information about CIHR, health research training, organizations in Canada that fund kidney research, and opportunities to become patient participants and partners in kidney research projects.

Knowledge Check and Certificate of Completion

At the end of each subsection, learners are invited to take an interactive quiz that verifies their understanding of the content presented in the module. An example of one such interactive quiz is presented in Figure 4. Those completing all the KidneyPRO modules are awarded a certificate of completion.

Discussion: Strengths, Limitations, and Future Directions

KidneyPRO addresses a key gap in POR, as identified by kidney patients. While such tools were missing at the time of KidneyPRO’s conception, an updated literature review (see Supplemental Material 1) suggests that KidneyPRO is a unique resource in the landscape of e-education and e-learning tools for patient engagement in kidney research in Canada. Furthermore, its creation was largely a patient-centered and patient-led initiative, involving patients in the working group and in the consultation phase as stakeholders and end-users. This has resulted in a tool that offers clear, disease-specific information to help patients participate meaningfully in research. Moreover, the evaluation plan integrated within KidneyPRO seeks to ensure the adaptability of the online patient education modules, ensuring their relevance and responsiveness to the evolving needs of patient partners in the Can-SOLVE CKD Network.

In terms of limitations, the online nature of the tool means that users must have adequate Internet access, which limits the number of potential users. In addition, KidneyPRO is not compatible with the Web Content Accessibility Guidelines. Notably, the research landscape is constantly evolving, and therefore the content in KidneyPRO must be updated on a regular basis. KidneyPRO is hosted on the Can-SOLVE CKD domain and will be made available while the domain exists, and the KidneyPRO content remains relevant for patient partners. Sustainability and future updates of KidneyPRO are bound to depend on the availability of dedicated human and financial resources through research funding and support.
Getchell et al

from non-for-profit organization and national or regional professional societies.

The next iteration of KidneyPRO is planned in partnership with the Canadian Nephrology Trials Network.12 A new subsection will be developed to better prepare patients to co-conceive, pursue, and synthesize knowledge for upcoming clinical trials in nephrology. The working group plans to meet twice a year to review KidneyPRO content and implement updates as needed. In addition, the working group will ensure the KidneyPRO website meets Canadian Web Content Accessibility standards. The content of the website will also be provided in PDF format, allowing delivery in hard copy or electronically to patient partners without Internet access.

**Conclusion**

To foster more meaningful patient engagement in Canadian kidney research, there is a need for more resources to support
patients’ understanding of the research landscape and how they can contribute. KidneyPRO is a free, web-based, interactive educational resource that provides on-demand key introductory knowledge for patients to support their engagement in kidney research. We hope that Canadians with or at high risk of CKD will find this tool useful as the Can-SOLVE CKD Network seeks to engage new patients as partners and participants in innovative kidney research. We also hope that the iterative process of content and user interface development as well as the evaluation of KidneyPRO outlined in this report could serve groups seeking to co-develop materials for patient engagement in other health domains.

**Ethics Approval and Consent to Participate**

Non-Applicable

**Consent for Publication**

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

**Availability of Data and Materials**

The content of KidneyPRO: Promoting Kidney Research in Canada is available from: http://kidneypro.ca

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**Supplemental Material**

Supplemental material for this article is available online.

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