

Background: Over recent years, there has been increasing support and traction for patient-oriented research. However, for many patients, research terms, practices and protocols are still unfamiliar. A lack of awareness of opportunities to take part in research studies presents a further barrier to participation. To empower patients to engage in kidney health research across Canada, as partners and/or as participants, the Canadian kidney research network Can-SOLVE CKD has developed two online resources in collaboration with patient partners: KidneyLink and KidneyPro.

Results: Both platforms launched in November 2019 and have seen strong initial engagement. As of September 2020, KidneyLink has 317 users and 337 unique users have visited the KidneyPro website and launched the learning module.

Conclusions: These two platforms show promise as strategies to increase patients' knowledge of, and involvement in, various aspects of research by linking them to opportunities for participation and enhancing their understanding of patient-oriented kidney research in Canada.

Thank you to the members of the KidneyPro and KidneyLink Working Groups



Online resources to educate, engage and inform patients about kidney research in Canada



KidneyPro users learn about:

- Health research in Canada
- Kidney research in Canada
- Patient participation in research
- Patient partnerships in research
- Indigenous patient partnership in research
- How to get involved in research



KidneyLink informs users about opportunities to participate in research-related activities such as:

- Focus groups
- Patient engagement opportunities
- Clinical trials
- Events to learn about current kidney research and patient oriented research

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Webinar: Patients as Investigators Webinar Series – Pt 03

This webinar is titled, "Presenting an Idea". Participants will learn the guidelines and tips to presenting their research idea to stakeholders, how to create an elevator pitch and the next steps to developing their idea.

Read More

May 21, 2020 Events, CKD



Webinar: COVID, Kidneys and Coping: Ask Your Social Worker

This webinar will give you the opportunity to ask social workers any questions you may have about coping: financial and employment supports, and anxiety about work, life and society - finding a new normal.



Survey: The Patient Reported Inventory of Self-management of Chronic Conditions (PRISM-CC)

Overview

We are currently recruiting participants to complete a ~25-minute anonymous and confidential online survey about living with chronic conditions. We are recruiting 750 people, who are 18+, speak/read English, and live with 1 or more chronic conditions (includes mental illness). Participants can live anywhere in the world, but must have internet to access the online survey.

Click [Here](#) to complete survey



Goals: The purpose of the survey is to hear what people with chronic conditions want their health care providers to ask about self-management. Participant answers to the survey questions will help our research team design a questionnaire that can be used in clinical and research settings to assess patients' ability to self-manage their chronic conditions.

Participant Info

Study Type: Survey

Commitment: 25-35 minute survey

Seeking participants from: Participants must be 18

Contact

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Send an email





KIDNEY PRO:
Promoting
Kidney Research
in Canada

0% COMPLETE



Lesson 1 of 10

Health Research in Canada

THE RESEARCH LANDSCAPE

Health Research in Canada

Kidney Research in Canada

PATIENT ENGAGEMENT IN RESEARCH

Patient Participants in Research

Patient Partners in Research

Indigenous Patient Partnership

Health research involves
asking and **answering** questions
that lead to a **healthier** Canada.

