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
www.kidneypro.ca

KidneyLink
Connect to kidney research innovation
www.kidneylink.ca

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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@cansolveckd   www.cansolveckd.ca

KidneyLink – kidneylink.ca

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

Adele Mansour
Research Assistant

Send an email

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KidneyPro – kidneypro.ca