

KidneyLink Visioning Workshop

Summary Report

July 5, 2022

What is the purpose of this report?

This report summarizes the major themes identified during breakout group discussions at the KidneyLink visioning workshop held July 5, 2022. A total of 42 attendees joined the workshop virtually via Zoom. Participants included patient partners, researchers, and health care providers from seven provinces. The full list of participants is found in Appendix 1 and the meeting agenda has been included in Appendix 2.

The workshop objectives were to:

- Understand the community's needs and the value KidneyLink can add
- Develop a vision for refreshing KidneyLink that reflects the perspectives of researchers, patients, and our partners
- Understand how we can maximize KidneyLink's uptake among Canada's kidney community
- Learn how we can empower patients, researchers, and others to become advocates for KidneyLink in their own networks

Pre-workshop preparation

In advance of the workshop, a detailed information package was prepared to provide participants with a common understanding of the history and current state of KidneyLink. This information package contained the following items: discussion questions; video overview of KidneyLink; SWOT analysis; KidneyLink timeline; environmental scan; pre-meeting survey results. These documents are attached in Appendix 3, and the introductory slides presented at the workshop are attached in Appendix 4. Participants were asked to review the materials, reflect on the discussion questions and come prepared to share their feedback.

Workshop Discussion

Question 1: What is the value of the KidneyLink model to patients, researchers, and the broader community?

Participants in the breakout groups identified several areas where KidneyLink can value to the kidney community in Canada.

- **Connection:** For many participants, KidneyLink's core value lies in the connection opportunities it provides. At the most basic level, the site can support patient engagement by making it easy to get involved in studies. It also has the potential to enhance equity, diversity, and inclusion in kidney research by creating opportunities to engage under-represented groups and patients who are located outside major centres. Another highlighted aspect of connection is peer support, including linkages to other patient partners who can act as mentors. Finally, connection can also take place between researchers and patients to open up and strengthen communication between these groups. These connections can help to level the playing field and reduce hierarchies within research projects.

- **Information sharing:** A key theme was bridging knowledge gaps and promoting access to information about current research. By sharing engagement opportunities for prospective studies, and knowledge translation content about completed work, KidneyLink can help patients, researchers, and clinicians understand the kidney research initiatives underway in Canada. In this way, KidneyLink can provide increased visibility for research projects, supporting investigators' recruitment and knowledge translation efforts.
- **Education:** The third general area in which participants see value in the KidneyLink model is education. From the patient perspective, education about research is critical to building skills and lowering barriers to participation. Education also helps increase patients' excitement about research, demystifies the research process, and makes research participation less intimidating. Participants highlighted that the site's education mandate can also support researchers, many of whom seek to incorporate the patient voice while avoiding tokenism. Curated educational resources can enhance researchers' skills in this area and can help direct them to individuals and organizations that can offer support for patient-oriented research.

Question 2: Imagine an ideal KidneyLink platform. What are the features and functions that would meet your needs/expectations?

According to workshop participants, the following features are key components of maximizing the value of KidneyLink:

- **Stories:** Information and opportunities on KidneyLink should be relatable – the site must be inviting and patients should see themselves reflected. To humanize the platform, stories are key. We must hear from patients about why they are involved and what it means to them. This can best be captured by video. Researcher stories are equally important and should not be overlooked. They can play an important role in explaining why it is important to get involved in research. Seeing researchers' faces and hearing their stories can help humanize them and lower potential barriers to patient participation. Success stories are also an important part of demonstrating value at the project level to show researchers that KidneyLink is worth their time.
- **Accessibility:** We must find ways to connect with and include those in remote areas or with low levels of connectivity. The site must also include content in both English and French. It will be important as well to consider the use of other languages (including Indigenous languages) to support participation of under-represented communities and foster equity, diversity, and inclusion.
- **Ease of access:** The current user registration and login system presents a significant barrier to participation. Patients and researchers need more information on the homepage to provide context and a sense of what the site is about before committing to use it. Most participants prefer to see research opportunities in publicly viewable parts of the site. A login area could be considered to support the creation of user profiles and peer-to-peer connections, but this should be optional and positioned as a value-add.
- **Clarity/ease of use:** KidneyLink should be easy to navigate and include robust filters and search functions. Several participants indicated the value of being able to filter opportunities/information by disease-specific keywords and location. Making KidneyLink easy to use will allow visitors to focus on the

information and resources that are important to them. The site must be written in lay language that is equally accessible to patients and researchers. The site should also be very clear about what the expectations of patients are if they choose to get involved (e.g., what is the commitment, what kind of skills are required, etc.) It must also be clear that there are many levels of participation, and the benefits of their involvement should be clearly explained.

- **Closing the loop:** Participants emphasized the importance of showing examples of the input patients provide to research teams and how their suggestions are followed. Patients want to feel like they are making a difference and the site should demonstrate how their involvement is beneficial and impactful. KidneyLink should also focus not just on prospective research studies, but on supporting knowledge translation and mobilization. The site should ideally communicate what is happening in kidney research, what the results and updates are, and how the outcomes can influence policy and practice.
- **Connection to partners:** KidneyLink should integrate with the Kidney Foundation and other patient-focused organizations to maximize the benefit to the broader community.
- **Sense of community:** The site should foster connections with other patients, caregivers, and family members and support closer integration of Canada's kidney community.

Question 3: How do we maximize uptake of KidneyLink across the community? What are the barriers and how do we overcome them?

- **Eliminate login requirement:** This is the most common barrier identified by participants. We must find other ways to collect usage data and ensure that the site's core content is accessible to all.
- **Consider connectivity:** We must find ways to bring the KidneyLink model to those living in areas with lower levels of connectivity. Participants proposed making presentations to health care providers outside of urban centres and distributing hard-copy mailouts. Another suggestion was to schedule appointment times at nursing stations.
- **Marketing and awareness:** Lack of awareness of KidneyLink is a major barrier to uptake. A more robust approach to marketing and outreach is needed, targeting both researchers and patients. Examples mentioned by workshop participants include: posters in dialysis clinics and CKD clinics, working with renal chapters throughout provinces, patient-oriented Facebook groups, email blasts, and paid advertising on social media and other channels. It is also critical to work with partners to promote KidneyLink – this could include provincial renal programs, national patient groups, informal patient networks, and organizations such as the Kidney Foundation of Canada and the Canadian Society of Nephrology.
- **Integration into care:** When patients are seen in the clinic they should be offered information about KidneyLink. This will require engagement of physicians and other frontline staff (e.g., in-centre dialysis staff, dietitians, pharmacists, and nurse practitioners). These groups must be empowered to share consistent, reliable information about KidneyLink and research involvement in a way that will build trust and credibility with patients.
- **Community focus:** Several participants noted the need to dispel perceptions that KidneyLink is exclusively for Can-SOLVE CKD. The site must be positioned as being for and by the community. Patient partners have

noted confusion at whether they are eligible to participate if they are not members of Can-SOLVE CKD.

Question 4: What does success for KidneyLink look like and how do we evaluate success?

Workshop participants described many examples of success, with several key themes emerging across the breakout groups:

- Basic metrics for success include: increasing the number of research projects that are engaging patients as research partners; increasing the number of patients who join a research project from KidneyLink; increasing the number of patients and researchers who access resources to support patient-oriented research. Some of these can be tracked through the KidneyLink website; for others, it will be important to close the loop with research coordinators to identify participants referred from KidneyLink at specific timepoints.
- Success should be measured as the downstream effect of participation, not just in specific numbers. Metrics of user engagement are helpful, but the real measure of success is whether we achieve a transformative impact on research participation and the culture of kidney research.
- For Indigenous people, success will be achieving health equity and the ability to feel safe when participating in research.
- KidneyLink will be successful when it is seen as a major recruitment tool and researchers include it in their applications due to the large community attached to it. Ideally, acceptance of a manuscript or success of a grant application will be linked to the involvement of patients and KidneyLink will play a big part in facilitating these connections.
- KidneyLink should aspire to become the go-to source for kidney research information in Canada. Success will be demonstrated by patients and providers talking about the site in dialysis clinics and nephrologists referring their patients.
- Measuring success requires breaking outside the “Can-SOLVE CKD bubble” and talking to the entire kidney community. We must be careful to avoid confirmation bias and the echo chamber effect when evaluating our efforts.
- A successful KidneyLink website will be seen by users as easy to read and welcoming. People want to feel welcomed in the choice of images, colours, and language.
- Having a KidneyLink champion at each nephrology research centre to upload studies and research opportunities is an aspirational goal.

Action Plan

The feedback provided by workshop participants will be extremely valuable in shaping the revised vision and next steps for KidneyLink. From now until the end of 2022, we anticipate the following actions:

- We will convene a working group comprising a representative sample of Canada’s kidney community. This group will meet 1-2 times per month and will be accountable for the development and implementation of the Phase 2 KidneyLink vision. Individuals who are interested in participating in this working group should

contact Graham Pollock (gpollock@cansolveckd.ca).

- At the direction of the working group, the feedback from this workshop will be compiled into a comprehensive vision for Phase 2 of KidneyLink. Additional feedback to inform this vision may be sought via focus groups and interviews with specific individuals and organizations.
- An implementation plan will be created to outline the steps by which the Phase 2 vision will be translated into tangible improvements to KidneyLink. This process may include the identification of needs requiring the support of an external vendor. The working group will lead the development of an RFP and selection of a vendor (as necessary) and will manage the vendor relationship throughout the duration of any re-development work.
- In consultation with the working group, a detailed marketing and outreach plan will be developed. Promotional materials will be refreshed to reflect the new KidneyLink vision and messaging. Awareness events and webinars will be planned along with paid advertising campaigns, as appropriate. We will also work with partners to leverage their audiences and networks.
- An evaluation framework will be developed to define key outcomes and indicators that will be tracked as part of KidneyLink Phase 2.

Appendix 1

List of Participants (n=42)

Participant	Role(s)	Organization	Province
Selina Allu	<ul style="list-style-type: none"> Knowledge Translation Broker 	Can-SOLVE CKD Network	AB
Julie Babione	<ul style="list-style-type: none"> Human-Centred Design Research Associate 	University of Calgary	AB
Mary Beaucage	<ul style="list-style-type: none"> Patient Partner Co-Chair, Indigenous Peoples' Engagement and Research Council Co-Chair, Patient Governance Circle Member, Can-SOLVE CKD Executive Committee 	Can-SOLVE CKD Network	ON
Helen Chiu	<ul style="list-style-type: none"> Quality Lead, Patient-Centred Performance Improvement 	BC Renal	BC
David Collister	<ul style="list-style-type: none"> Project Lead Researcher Health Care Provider 	University of Alberta	AB
Charles Cook	<ul style="list-style-type: none"> Patient Partner Member, Patient Governance Circle 	Can-SOLVE CKD Network	ON
Arlene Desjarlais	<ul style="list-style-type: none"> Patient Partner Co-Chair, Indigenous Peoples' Engagement and Research Council, Member, Patient Governance Circle 	Can-SOLVE CKD Network	MB
Isabelle Flett	<ul style="list-style-type: none"> Patient Partner Member, Indigenous Peoples' Engagement and Research Council 	Can-SOLVE CKD Network	MB
Linnea Franson	<ul style="list-style-type: none"> Patient Partnership & Training Manager 	Can-SOLVE CKD Network	BC

Leah Getchell	<ul style="list-style-type: none"> • Patient Partnership & Training Lead 	Can-SOLVE CKD Network	ON
Amanda Green	<ul style="list-style-type: none"> • Communications Coordinator 	Can-SOLVE CKD Network	BC
Michelle Hampson	<ul style="list-style-type: none"> • Medical Writer 	Can-SOLVE CKD Network	NS
Oksana Harasemiw	<ul style="list-style-type: none"> • Research Coordinator 	Seven Oaks Hospital	MB
Heather Harris	<ul style="list-style-type: none"> • Executive Director 	Can-SOLVE CKD Network	BC
Sunny Hartwig	<ul style="list-style-type: none"> • Researcher • Health Care Provider 	University of Prince Edward Island	PEI
David Hillier	<ul style="list-style-type: none"> • Patient Partner • Co-Chair, Patient Governance Circle 	Can-SOLVE CKD Network	ON
Grace Jauod	<ul style="list-style-type: none"> • Finance Manager 	Can-SOLVE CKD Network	BC
Pantea Javaheri	<ul style="list-style-type: none"> • Research Coordinator 	University of Calgary	AB
Joanne Kappel	<ul style="list-style-type: none"> • Project Lead • Researcher • Health Care Provider 	University of Saskatchewan	SK
Lydia Lauder	<ul style="list-style-type: none"> • National Director, Programs & Public Policy 	Kidney Foundation of Canada	ON
Loretta Lee	<ul style="list-style-type: none"> • Patient Partner 	Can-SOLVE CKD Network	AB
Adeera Levin	<ul style="list-style-type: none"> • Co-Principal Investigator • Researcher • Health Care Provider 	Can-SOLVE CKD Network	BC

Kelly Loverock	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle 	Can-SOLVE CKD Network	ON
Cynthia MacDonald	<ul style="list-style-type: none"> • Project Manager 	Can-SOLVE CKD Network	BC
Dennis McCann	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle 	Can-SOLVE CKD Network	BC
Lorraine McLeod	<ul style="list-style-type: none"> • Associate Director, Diabetes Care & Research 	First Nations Health and Social Secretariat of Manitoba	MB
Michael McCormick	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle 	Can-SOLVE CKD Network	ON
Susan McKenzie	<ul style="list-style-type: none"> • Patient Partner 	Can-SOLVE CKD Network	ON
Alicia Murdoch	<ul style="list-style-type: none"> • Project Manager 	Can-SOLVE CKD Network	BC
Linxi Mytkolli	<ul style="list-style-type: none"> • Lead - Patient Engagement and Knowledge Mobilization 	Diabetes Action Canada	ON
Thomas Ng	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle 	Can-SOLVE CKD Network	BC
Winnie Pearson	<ul style="list-style-type: none"> • Patient Partner 	Can-SOLVE CKD Network	AB
Graham Pollock	<ul style="list-style-type: none"> • Communications & External Relations Lead 	Can-SOLVE CKD Network	BC
Marian Reich	<ul style="list-style-type: none"> • Patient Partner 	Can-SOLVE CKD Network	ON

Jim Scholey	<ul style="list-style-type: none"> • Co-Principal Investigator • Researcher • Health Care Provider 	Can-SOLVE CKD Network	ON
Melissa Schorr	<ul style="list-style-type: none"> • Researcher • Health Care Provider 	University of Calgary	AB
Craig Settee	<ul style="list-style-type: none"> • Indigenous Peoples' Engagement and Research Council Coordinator 	Can-SOLVE CKD Network	BC
Dwight Sparkes	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle 	Can-SOLVE CKD Network	NL
Leanne Stalker	<ul style="list-style-type: none"> • National Director of Research 	Kidney Foundation of Canada	ON
Nancy Verdin	<ul style="list-style-type: none"> • Patient Partner 	Can-SOLVE CKD Network	AB
Hans Vorster	<ul style="list-style-type: none"> • Patient Partner • Co-Chair, Patient Governance Circle 	Can-SOLVE CKD Network	ON
Cathy Woods	<ul style="list-style-type: none"> • Patient Partner • Member, Patient Governance Circle • Member, Indigenous Peoples' Engagement and Research Council 	Can-SOLVE CKD Network	MB

Appendix 2

KidneyLink Visioning Workshop Agenda

Time	Agenda Item
9:00-9:05	Welcome and Land Acknowledgment
9:05-9:15	Introduction to the session
9:15-9:20	Transition to breakout group
9:20-9:25	Breakout group introductions
9:25-9:40	Breakout Group Question 1: “What is the value of the KidneyLink model to patients, researchers, and the broader community?”
9:40-9:55	Breakout Group Question 2: “Imagine an ideal KidneyLink platform. What are the features and functions that would meet your needs/expectations?”
9:55-10:10	Breakout Group Question 3: “How do we maximize uptake of KidneyLink across the community? What are the barriers to adopting KidneyLink as a recruitment/engagement tool and how can these be overcome?”
10:10-10:25	Breakout Group Question 4: “What does success for KidneyLink look like? What are the metrics of success and how do we evaluate them?”
10:25-10:30	Summary and next steps

The workshop objectives are to:

- Understand the community’s needs and the value KidneyLink can add
- Develop a vision for refreshing KidneyLink that reflects the perspectives of researchers, patients, and our partners
- Understand how we can maximize KidneyLink’s uptake among Canada’s kidney community
- Learn how we can empower patients, researchers, and others to become advocates for KidneyLink in their own networks

Breakout Room Discussion Questions

1. What is the value of the KidneyLink model:
 - a. To patients?
 - b. To researchers?
 - c. To the broader community?
2. Imagine an ideal KidneyLink platform. What are the features and functions that would meet your needs/expectations?
3. How do we maximize uptake of KidneyLink across the community?
 - a. What are the barriers to adopting KidneyLink as a recruitment/engagement tool?
 - b. How can we overcome these barriers?
4. What does success for KidneyLink look like?
 - a. How do we evaluate success?
 - b. What are the metrics of success for researchers? For patients?

Breakout Room Participants

Role	Room 1	Room 2	Room 3	Room 4	Room 5	Room 6
Facilitator/ Notetaker	Alicia Murdoch	Amanda Green	Craig Settee	Graham Pollock	Leah Getchell	Selina Allu
Participants	David Collister David Hillier Joanne Kappel Loretta Lee Thomas Ng	Arlene Desjarlais Michelle Hampson Pantea Javaheri Michael McCormick Jim Scholey	Isabelle Flett Oksana Harasemiw Cynthia MacDonald Dennis McCann Linxi Mytkolli Melissa Schorr	Mary Beaucage Heather Harris Sunny Hartwig Lorraine McLeod	Julie Babione Adeera Levin Kelly Loverock Winnie Pearson Marian Reich Hans Vorster Cathy Woods	Helen Chiu Charles Cook Lydia Lauder Susan McKenzie Leanne Stalker Nancy Verdin

APPENDIX 3

VISIONING WORKSHOP PRE-MEETING PACKAGE



KidneyLink

Connect to kidney research innovation

In this package:

- **Visioning Workshop discussion questions**
- **Video overview of KidneyLink**
- **SWOT Analysis**
- KidneyLink timeline
- Environmental scan
- Pre-meeting survey results

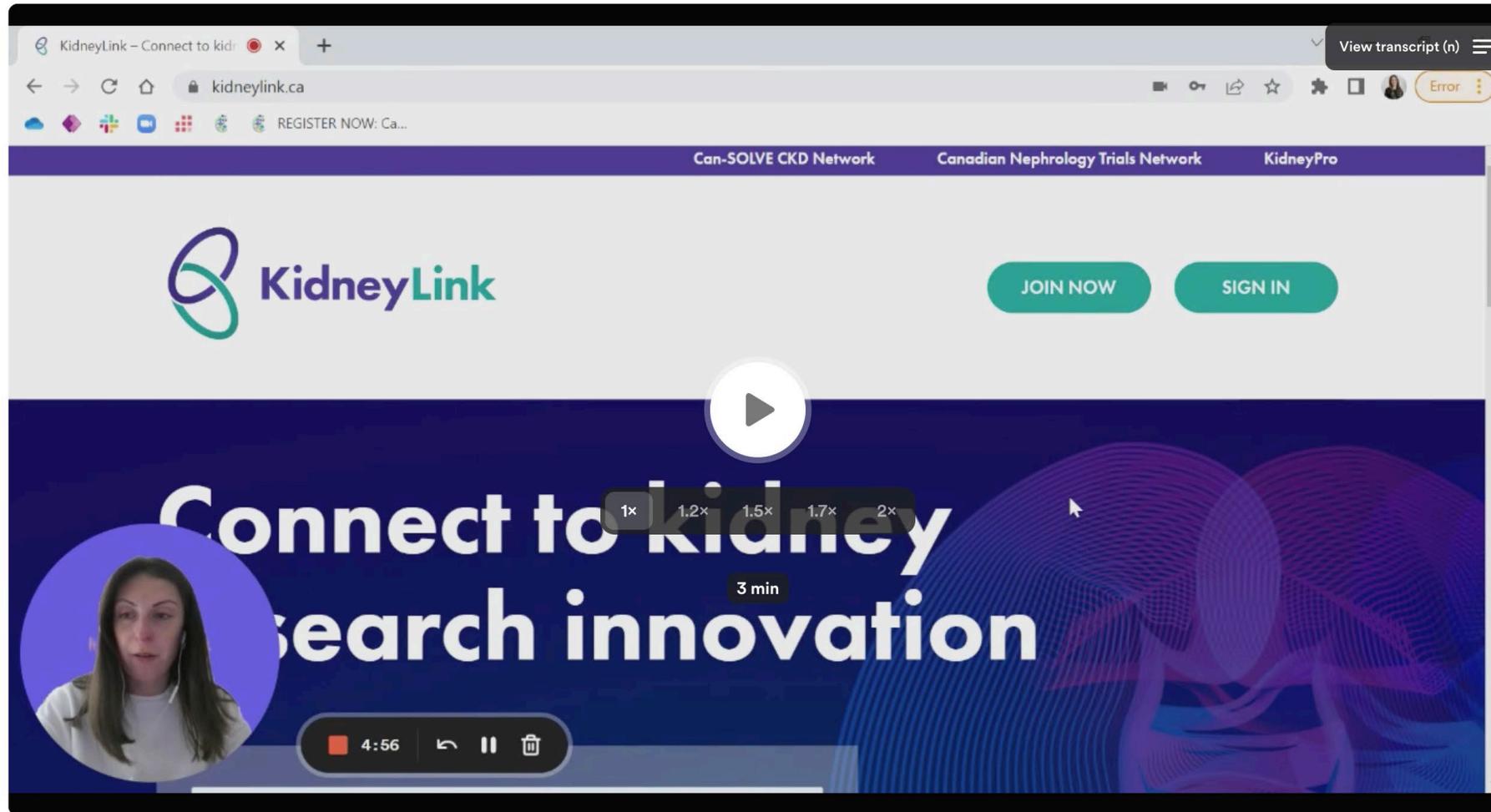
Bolded items are recommended pre-reading for the meeting on July 5. All others are optional.

Discussion questions

- 1. What is the value of the KidneyLink model:**
 - To patients?
 - To researchers?
 - To the broader community?
- 2. Imagine an ideal KidneyLink platform. What are the features and functions that would meet your needs/expectations?**
- 3. How do we maximize uptake of KidneyLink across the community?**
 - What are the barriers to adopting KidneyLink as a recruitment/engagement tool?
 - How can we overcome these barriers?
- 4. What does success for KidneyLink look like?**
 - How do we evaluate success?
 - What are the metrics of success for researchers? For patients?

KidneyLink video overview

Click image below to view



The screenshot displays a web browser window with the URL kidneylink.ca. The page features a navigation bar with links for "Can-SOLVE CKD Network", "Canadian Nephrology Trials Network", and "KidneyPro". The main content area includes the KidneyLink logo and two buttons: "JOIN NOW" and "SIGN IN". A video player is embedded in the center, showing a play button and the text "Connect to kidney research innovation" with a "3 min" duration. The video player interface includes a progress bar, a volume icon, and a "4:56" timestamp. A circular inset in the bottom left corner shows a woman speaking. The browser's address bar and various icons are visible at the top.

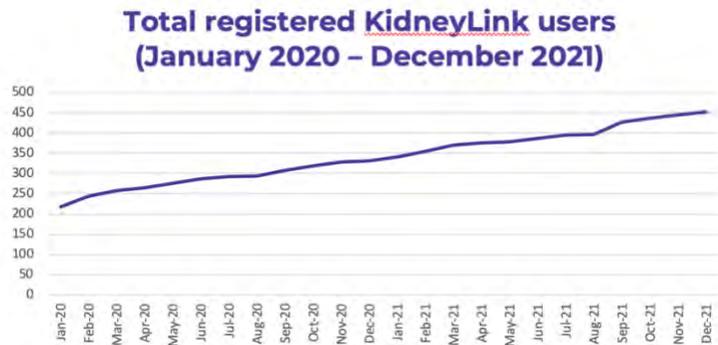
Briefing Note: KidneyLink

What challenges does KidneyLink face?

KidneyLink is foundational to Can-SOLVE CKD’s Phase 2 proposal. The Phase 2 grant states: *“Phase 2 will build upon (KidneyLink) to expand and enhance its role as a coordinating hub for patient engagement, education, and knowledge mobilization.”* However, several challenges complicate KidneyLink’s ability to meet the needs of Phase 2.

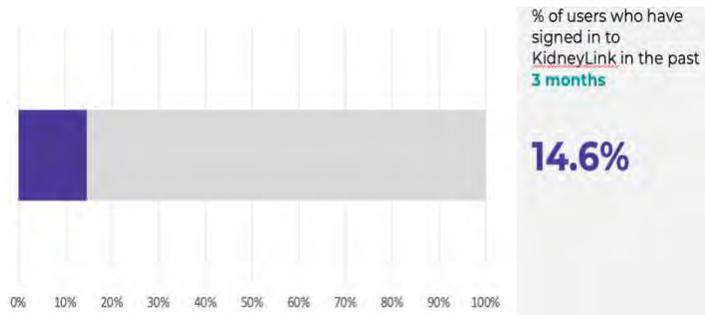
User registration

The site struggles to recruit and retain engaged visitors. As of June 2022, KidneyLink has 491 registered users, representing a tiny segment of the Canadian kidney community. A user base in the thousands will likely be required to achieve the site’s vision of meaningfully increasing patient participation in kidney research.



User retention

A strong majority of KidneyLink accounts are inactive, based on a review of usage data. 70% of users have logged in ≤ 1 time, and these accounts provide no ongoing value. During a recent three-month period, only 14% of registered users accessed their accounts.



Site construction

Up to six new functions for KidneyLink are identified in the Phase 2 proposal: integration with CNTN; registration portal for CGNR and National Patient Network; connection point for Research Ambassadors Program; knowledge mobilization hub for Canadian kidney research; home of Can-SOLVE CKD training resources.



However, the site is not currently equipped to perform many of these actions.

Marketing and outreach

The slow growth of user registration suggests current outreach efforts have plateaued in their effectiveness at driving new awareness and participation. Additional strategies, tactics, and partnerships will be required to reach new audiences and increase participation.

What is working well?

Despite the challenges noted above, certain elements of the KidneyLink model are promising and present opportunities to improve the site's performance over baseline.

Email notifications

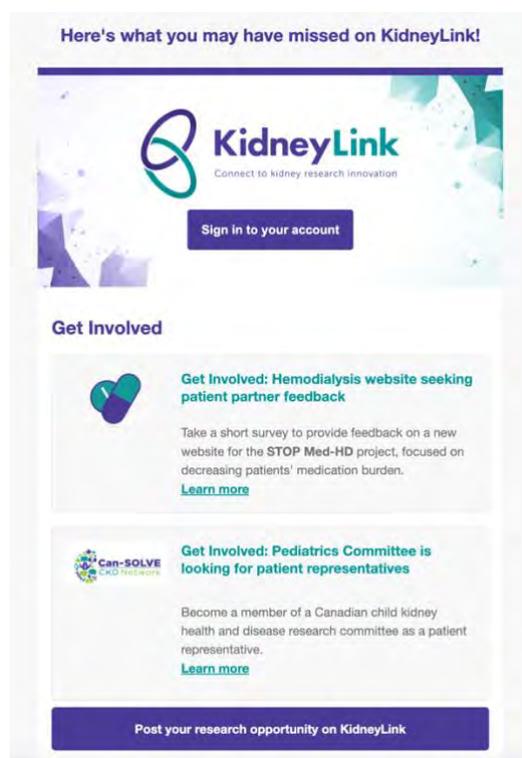
71% of registered users opted in to receive biweekly email updates featuring new KidneyLink opportunities.

These emails are very well read with an average open rate¹ of 42.6% and an average click rate² of 7.3%. Both rates are significantly above average for non-profit email marketing³. Only 13 users have unsubscribed since the notifications launched in 2020, suggesting that the format is an effective way to share KidneyLink information with users.

One key to the success of these emails is the direct pathway they offer to KidneyLink content. A user clicking an email link is taken directly to the requested post without being prompted to log in to a KidneyLink account. Removing this barrier to the user's path appears to increase the visibility of KidneyLink content. Examining a sample of top KidneyLink posts from 2021 reveals that the majority of pageviews are from non-logged in users (i.e., those who clicked an email or social media link to an individual post) rather than those who are logged in to a KidneyLink account.

KidneyLink promotional tactics to date:

- "Get Involved" page on cansolveckd.ca
- Spotlight in Can-SOLVE CKD monthly newsletter
- Social media posts
- Promotional video
- Cards, posters distributed at events
- Biweekly notification emails
- Partner outreach (KFOC, BC Renal, CIHR, PKD Foundation, etc.)
- Awareness webinars (CKD Clinic Network, KFOC BC/Yukon, National Patient Network)



¹ Percentage of successfully delivered emails opened by subscribers

² Percentage of successfully delivered emails registering at least one click

³ <https://mailchimp.com/resources/email-marketing-benchmarks/>, accessed February 8, 2022.



Research opportunities

KidneyLink posts fall into three categories: Research Opportunities, News, and Events. Research Opportunities are by far the most popular posts by every metric. They generate roughly twice as many pageviews as News and Events, and users spend up to 20% longer on Research Opportunity pages compared to the other content types. Nine of the 10 most popular content items posted to KidneyLink in 2021 were Research Opportunities. However, only about 25% of KidneyLink posts are Research Opportunities, demonstrating the need to identify and post more content of this type.

User engagement

While KidneyLink's user base is small and must grow to achieve the site's objectives, those who do log in to the site demonstrate strong engagement by many metrics. Returning visitors spent an average of 4:30 on the site and visited an average of 7.6 pages per session, both of which are significantly greater than commonly accepted web standards⁴. These data suggest that KidneyLink is delivering value to its users, but we must find ways to increase the size of the audience and the rate at which they return to the site.

Targeted partner outreach

Following a September 2021 meeting with the PKD Foundation of Canada, we provided KidneyLink background information that was shared prominently through the foundation's newsletter. In the subsequent 10 days, KidneyLink saw 33 new user registrations, roughly 30% of the site's total sign-ups during 2021. This example shows the potential opportunity offered by our partners' networks to increase KidneyLink awareness and participation.

What is not working well?

Registration system

Most KidneyLink pageviews come from users who directly click on a specific opportunity via email or social media, not from those who log in and navigate through the website. This confirms what we have heard anecdotally from some researchers and patients that the requirement to register creates a barrier to participation. This in turn amplifies the existing problem facing the site of building and retaining an audience.

The registration system was implemented to enhance evaluation efforts, and it has been mostly effective in this regard. It allows us to track the site's overall reach and communicate to researchers the number of potential participants they can access by posting their studies. It also collects basic user-reported demographic information (primary professional role, province of residence, Indigenous status). Furthermore, the registration form allows users to opt in to

⁴ <https://www.spinutech.com/digital-marketing/analytics/analysis/7-website-analytics-that-matter-most/>, accessed February 8, 2022



receive email notifications, which are one of the most successful aspects of the KidneyLink model to date.

However, while these functions are valuable, they are not irreplaceable. We can find alternate ways of collecting this information and facilitating email subscriptions. Ultimately, the registration system's value in data collection must be measured against the user engagement challenges it presents. Presently, the data suggest that users are more likely to interact with KidneyLink when registration/login is not required.

“Community” and “Learn” sections

KidneyLink is divided into three main sections: **Get Involved** (for searching research opportunities), **Community** (for connecting with the National Patient Network), and **Learn** (for accessing information about kidney disease and patient-oriented research. In 2021, Get Involved received 1,543 pageviews, compared with 110 for Community and 94 for Learn. All three pages are listed prominently in the site's main navigation menu, yet the latter two were unable to generate significant engagement. This will be a critical issue to resolve for Phase 2, as KidneyLink is intended to serve as a hub for the National Patient Network and the Can-SOLVE CKD Training & Mentorship Committee resources.

Offline visibility

The COVID-19 pandemic has disrupted plans to increase KidneyLink awareness in CKD clinics and at in-person events. Expanding our marketing efforts beyond purely online channels is critical to increasing awareness and usage of the site to levels that will meet our needs.

Environmental Scan Report of Research Connection Tools

Organization (created by)	Kidney Health Gateway (NephCure US)	Patient and Researcher Connection Site (Saskatchewan Centre for Patient Oriented Research)	Connect1d Canada (Diabetes Action Canada)	REACH BC (Michael Smith Health Sciences BC)
Types of information and opportunities	Research participant opportunities	Patient partnership and research participant	Research opportunities, research outcomes	Patient partnership and research participant
Registration required? Y/N	No (Yes, if you want detailed info)	No	Yes	Yes
Type of connection	Research team contact information or allow information to be shared with research team (if you created an account)	Research team contact information or allow information to be shared with research team	Research team contact information	Research team contact information or allow information to be shared with research team
Study information posted	Brief description; disease type under investigation; age range; study goal; time commitment; drug or intervention name; locations	Position type; number available; organization; overview; knowledge, experience, skills required; time commitment; location; what to expect; supports available (i.e. honoraria); deadline; contact info	Broad inclusion/exclusion; personal data that will be collected; location; ethics approval certificate; compensation; time commitment (inc. number of visits and duration); recruitment deadline; contact info	Study purpose; time commitment; procedures required; broad inclusion/exclusion; compensation; funding agency; recruitment deadline; locations; contact info
Website	https://kidneyhealthgateway.com/trials-research/	http://qi.hqc.sk.ca/scpor-connection-site/	https://connect1d.ca/	https://app.reachbc.ca/login

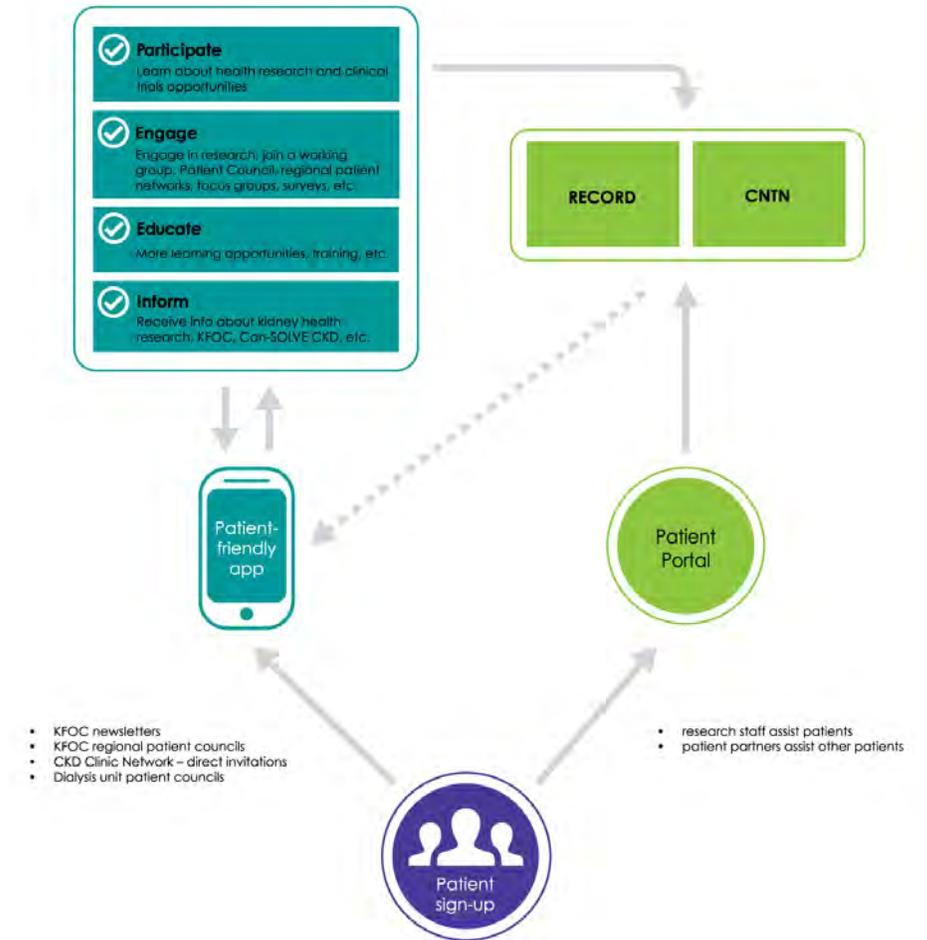
KidneyLink Timeline

January 2018

Can-SOLVE CKD develops a vision for a “patient portal” that will provide a point of entry for all patients interested in better understanding kidney research in Canada

Patients will be able to enter to portal through a patient-friendly app to:

- Register their interest in learning more about kidney research
- Register their interest in being approached about specific studies
- Register key information about themselves that would help researchers recruit
- Register their interest in participating in activities for knowledge translation



KidneyLink Timeline

May 2018

- A group discussion is facilitated at the Can-SOLVE CKD annual meeting to understand patient preferences and integrate with RECORD and CNTN

July 2018

- A request for proposals is issued to identify a vendor that will build the patient portal

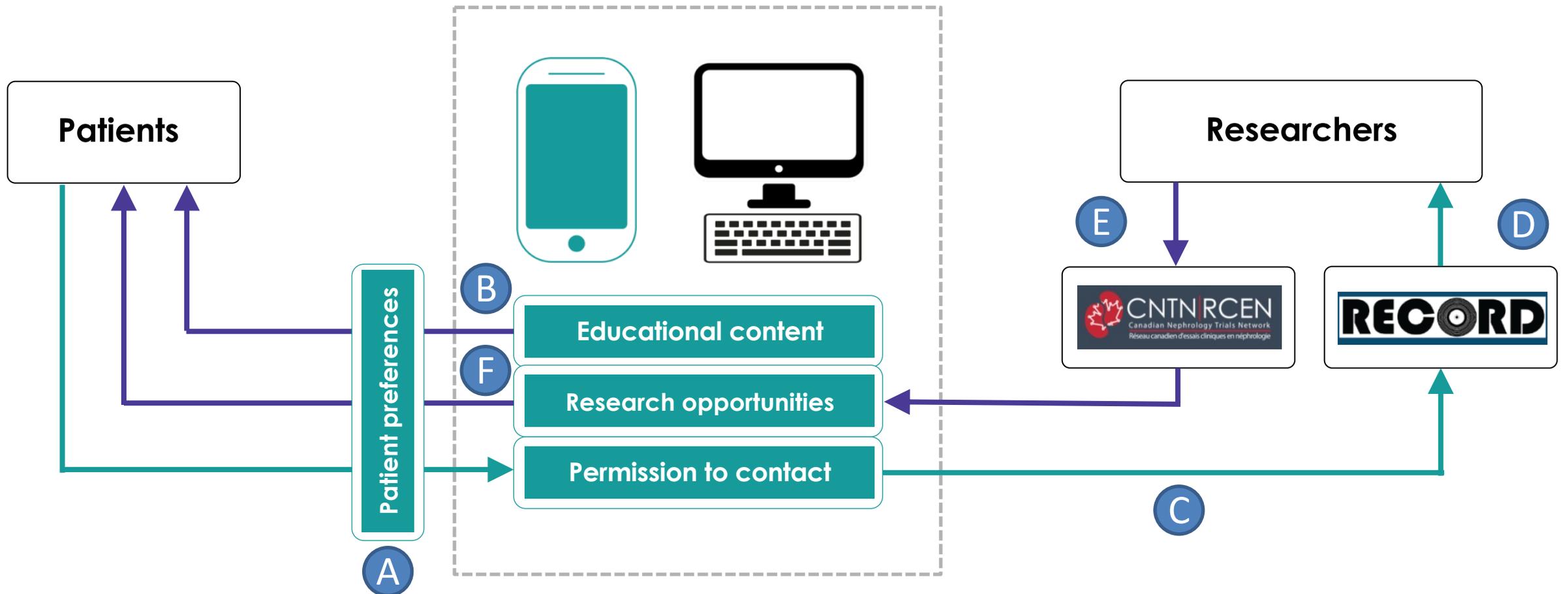
September 2018

- A vendor is selected and development work begins

KidneyLink Timeline

Can-SOLVE CKD Patient-Oriented Research Platform (September 2018)

See next slide for definitions



KidneyLink Timeline

- A. Patients create a user account and complete an intake survey in which they indicate notification preferences, topics of interest, and/or permission to contact for specific research studies. Patient preferences can be updated at any time, but must be checked at least on an annual basis. Mechanisms for automatic prompts for annual updating of preferences should be in place.
- B. After creating an account, patients can access educational content filtered according to their preferences. These resources will include text-based and multimedia content. Some content will be purpose-built and hosted within the platform; some will be curated links to resources developed and hosted by other organizations. Creation/curation of this content will be managed by Can-SOLVE CKD staff.
- C. Permission to contact info, for those who choose to provide it, will be held securely in at least one registry database being developed in parallel to this platform. Additional linkages to other registries/databases may be required at a later date.
- D. Researchers whose studies have received ethics approval can query the registry database(s). Patients who meet the study criteria based on the information provided in step A can be contacted directly by the researcher to discuss participation.
- E. Researchers whose studies have received ethics approval can post their research opportunities to the Canadian Nephrology Trials Network (CNTN) website/database. CNTN is a network of kidney researchers and centres throughout Canada working to increase the number of high quality randomized controlled trials focused on kidney disease. The development of a new website and database for CNTN is part of the scope for this project.
- F. Patients can receive notifications of new research opportunities based on the preferences indicated in step A. Patients can also receive invitations to take part in surveys, focus groups, and other research activities.

KidneyLink Timeline

December 2018

- A working group is formed to manage the project and liaise with the developer

February 2019

- The working group decides to develop a unique brand for the patient portal



KidneyLink Timeline

May 2019

- The patient portal officially launches under the name KidneyLink

The screenshot shows the top navigation bar with logos for Can-SOLVE CKD Network and SPOR (Strategy for Patient-Oriented Research). The main heading is "Announcing the launch of KidneyLink – connect to kidney research innovation!". Below this, there is a date "May 13, 2019" and tags: "Kidney research, kidney transplantation, kidneylink, Patient engagement". The main text describes the launch of KidneyLink as a new online platform connecting patients to kidney research. A "Create your account today!" link is provided. To the right, there is a "Latest News" section with a poster for an "All My Relations" information session on June 17, 2022. At the bottom right, there is a "TRIPLE I" logo.

Can-SOLVE CKD Network **SPOR** Strategy for Patient-Oriented Research Putting Patients First

Research Patient Engagement Indigenous Health About Resources News

Announcing the launch of KidneyLink – connect to kidney research innovation!

May 13, 2019 | Tags: [Kidney research](#), [kidney transplantation](#), [kidneylink](#), [Patient engagement](#)

We're excited to announce the launch of **KidneyLink**– a new online platform that connects you to the latest kidney health research across Canada! This is your chance to partner in innovation and contribute to better kidney health.

KidneyLink is an online platform that will connect you with researchers looking to work with people like you. You will receive updates regarding opportunities to get involved in research and see the impact of your participation in real time! All are welcome to join. Whether you are a person living with kidney disease, a family member, a donor, or a caregiver, your voice is important. KidneyLink will connect you with a variety of opportunities focused on different areas of kidney health. You can choose to stay up to date on the topics that matter most to you!

Learn about innovations that will transform kidney health and sign up to get involved!

[Create your account](#) today!

Latest News

All My Relations
IPERC and Learning Path
Information Sharing
17 June 2022
9:30 am – 10:00 am PST

Information session to amplify Indigenous voices
June 21, 2022

Can-SOLVE CKD
July 22 at 11:42 am

The Can-SOLVE Kidney Failure Risk Equation (KFRE) project, lead by Dr. Navdeep Tangri and patient partner Dwight Sparkes, has a new website! The website has testimonial videos about patients' experiences being diagnosed with CKD in primary care, new risk-based informational videos and a handbook. Check it out at <http://kidneyfailurerisk.com>

Can-SOLVE CKD
July 9 at 11:49 am

Glomerular Disease (glomerulonephritis) is a group of diseases that injure the part of the kidney that filters blood (called glomeruli). An international initiative called SONG-GD is conducting a survey to ask about what impacts of treatment and disease are important to patients – outcomes that you think should be reported in research in people with glomerular disease. If you are interested in participating, copy and paste this web address --> <https://songinitiative.org/projects/song-gd/>

Can-SOLVE CKD
July 4 at 10:34 am

Survey opportunity for those receiving in-centre hemodialysis (HD)- The Triple I research team is looking for volunteers with lived hemodialysis experience to participate in an anonymous survey. This survey will help the team understand what people receiving in-centre HD need and want from their health providers. People on in-centre HD, family members and caregivers of people on in-centre HD, and health care providers in HD are eligible. Copy and paste this web address to go to the survey--> <https://rsurvey.med.umanitoba.ca/redcap/surveys/?s=8TETRLRJXP>

TRIPLE I

KidneyLink Timeline

Summer 2019

- Uptake of KidneyLink is slow and several issues are identified, including a complicated registration process

1 Can-SOLVE CKD Registration
There are two steps to register for Can-SOLVE CKD.
Step 1
Register for a Canbrian Navigator Account via the hyperlink: <https://canbrian.com/canbriannavigator>
Step 2
Connect your account to the Can-SOLVE CKD organization by providing your Canbrian Navigator credentials from Step 1.

2

3 Can-SOLVE CKD Registration
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Step 2
Connect your account to the Can-SOLVE CKD organization by providing your Canbrian Navigator credentials from Step 1.

4

5

6

7

8 Can-SOLVE CKD User Preferences

1. I identify myself as (Please check all that apply):
 Patient/family member
 Caregiver
 Nephrology Researcher
 Research administrator/coordinator/assistant
 Policy maker
 Health Care Professional
 Other

2. I am interested in the following kidney-related topics (Please check all that apply):
 Kidney disease in general
 Glomerulonephritis - inflammation of the glomerulus (part of the kidney that filters blood)
 Nephrotic Syndrome - collection of symptoms that indicate the kidneys are not filtering properly and losing too much protein
 Polycystic kidney disease - growth of masses (cysts) within the kidneys
 Pediatric kidney disease - any kidney type of disease affecting those under the age of 18

KidneyLink Timeline

September 2019

- Can-SOLVE CKD decides to transition from the initial KidneyLink model to a simplified platform
- The simplified site will not collect user preferences or automatically link patients to studies – it will be a listing of opportunities for patients to connect with at their discretion

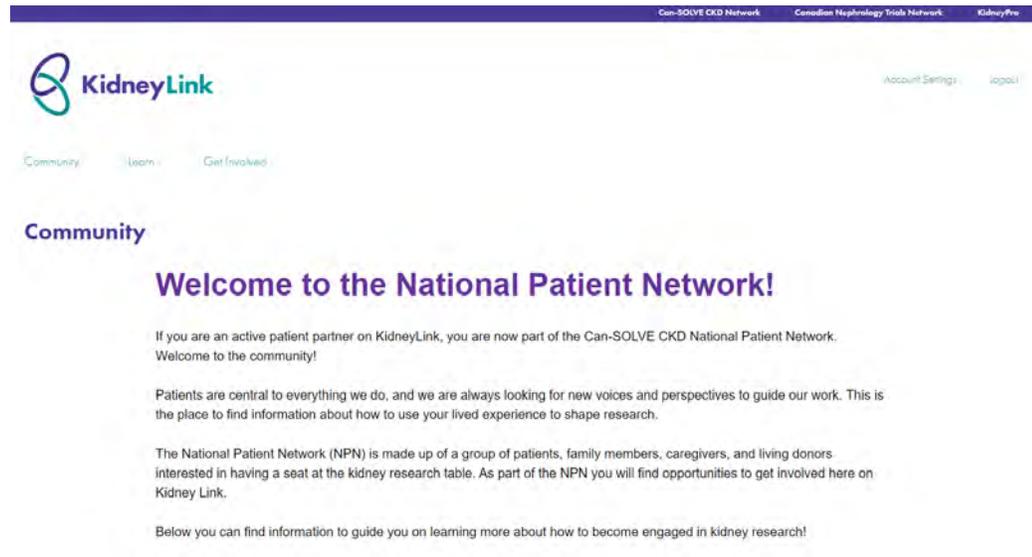
November 2019

- The second iteration of KidneyLink is developed in-house and launched
- This site features a search interface for research opportunities, news, and events

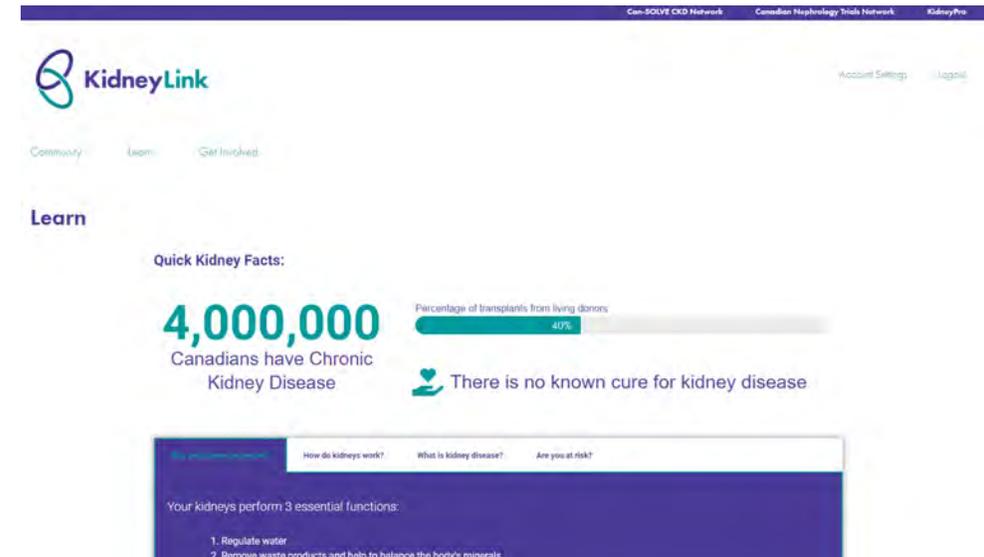
The screenshot displays the KidneyLink website interface. At the top, there is a navigation bar with links for "Can-SOLVE CKD Network", "Canadian Nephrology Trials Network", and "KidneyPro". The main header features the "KidneyLink" logo and navigation options for "Community", "Learn", and "Get Involved". A search bar is prominently displayed with filters for "Post Category", "Topic", and "Study Type". Below the search bar, there are two featured sections: "Get Involved: CDTRP 9th Annual Scientific Meeting Call for Abstracts" and "Upcoming Event: Body Image and Self-Esteem / Image corporelle et estime de soi". On the right side, there are sections for "Post your research to KidneyLink!" with an "Upload" button, and "What is patient-oriented research?" with a "KidneyPro" logo and a "Learn more" button.

KidneyLink Timeline

- In addition to a listing of research opportunities, the new KidneyLink includes **Learn** and **Community** sections
- **Learn** contains curated information about kidney health and research participation
- **Community** introduces patients to the National Patient Network



The screenshot shows the 'Community' section of the KidneyLink website. At the top, there is a navigation bar with links for 'Can-SOLVE CKD Network', 'Canadian Nephrology Trials Network', and 'KidneyPro'. Below this is the KidneyLink logo and a navigation menu with 'Community', 'Learn', and 'Get Involved'. The main heading is 'Welcome to the National Patient Network!'. The text below reads: 'If you are an active patient partner on KidneyLink, you are now part of the Can-SOLVE CKD National Patient Network. Welcome to the community! Patients are central to everything we do, and we are always looking for new voices and perspectives to guide our work. This is the place to find information about how to use your lived experience to shape research. The National Patient Network (NPN) is made up of a group of patients, family members, caregivers, and living donors interested in having a seat at the kidney research table. As part of the NPN you will find opportunities to get involved here on Kidney Link. Below you can find information to guide you on learning more about how to become engaged in kidney research!'

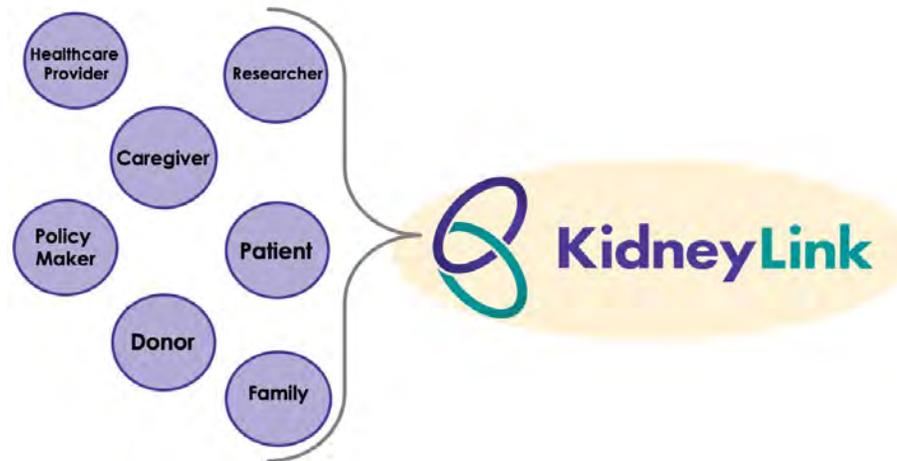


The screenshot shows the 'Learn' section of the KidneyLink website. At the top, there is a navigation bar with links for 'Can-SOLVE CKD Network', 'Canadian Nephrology Trials Network', and 'KidneyPro'. Below this is the KidneyLink logo and a navigation menu with 'Community', 'Learn', and 'Get Involved'. The main heading is 'Learn'. Below the heading is a 'Quick Kidney Facts:' section. It features a large number '4,000,000' with the text 'Canadians have Chronic Kidney Disease' below it. To the right, there is a progress bar labeled 'Percentage of transplants from living donors' with a value of '40%'. Below the progress bar, there is a heart icon and the text 'There is no known cure for kidney disease'. At the bottom, there is a section titled 'Your kidneys perform 3 essential functions:' with a list: '1. Regulate water' and '2. Remove waste products and help to balance the body's minerals'.

KidneyLink Timeline

2020-2022

- More than 490 users register for KidneyLink
- 300 posts are added to the site
 - 163 events
 - 91 research opportunities
 - 46 news updates
- KidneyLink is described as a key component of Can-SOLVE CKD's Phase 2 research proposal – several new functions and features are envisioned



KidneyLink survey results

User experience

"The latest opportunities to engage in research projects are always kept up to date."

"I like to try and stay updated with renal research so this is why I continue to log into KidneyLink. I have participated in research and I believe this gives me a sense of purpose for living with Kidney disease."

"I login to check out the research relevant to CKD. I have participated in a few research projects through information obtained from KidneyLink."

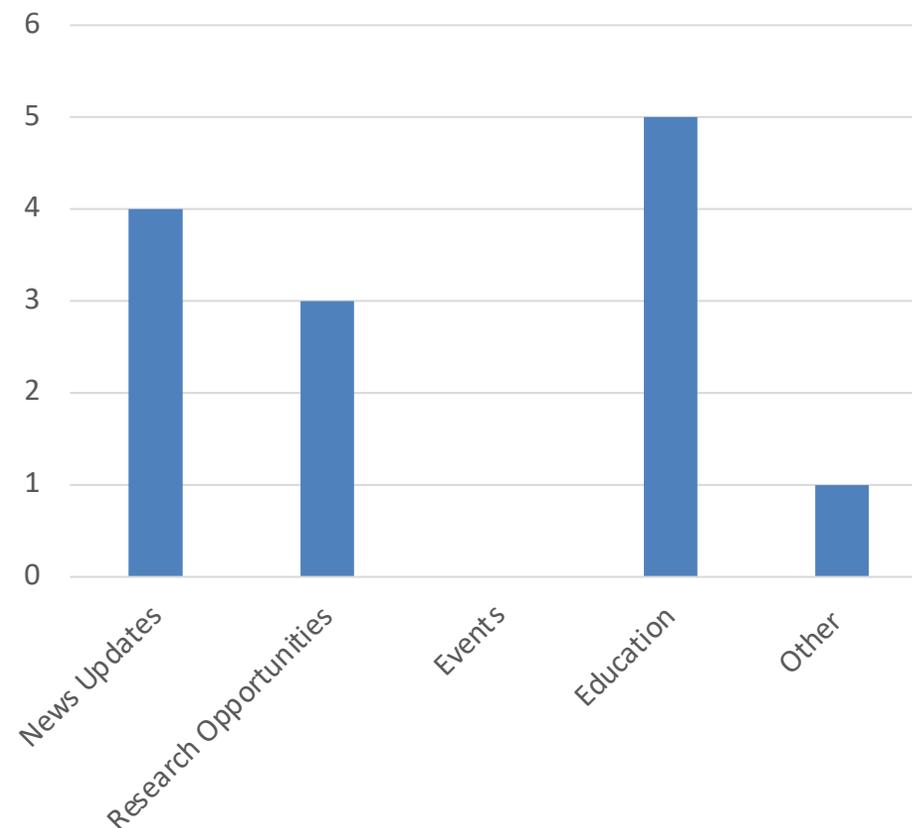
"I need to know what's new and available for me as a kidney dialysis patient."

KidneyLink survey results

How did you first hear about KidneyLink?

- “Through the Kidney Foundation of Canada”
- “Attended Module 1 SPOR training”
- "From a nephrologist I work closely with”
- "Through volunteering at BC Renal”
- "Can-SOLVE CKD newsletter”

What is the purpose of your visit?



Appendix 4

Introductory slide presentation



KidneyLink

Connect to kidney research innovation

VISIONING WORKSHOP
July 5, 2022

1

Land acknowledgment

The Can-SOLVE CKD Network acknowledges that our offices are located on the traditional, unceded territory of the Coast Salish Peoples, home of the Musqueam, Tsleil-Waututh, and Squamish First Nations.







2

Today's format

- **KidneyLink background + meeting objectives**
- **Breakout groups**
 - Four questions – 15 minutes each
- **Summary and next steps**





3

KidneyLink background

Our vision:
A "patient portal" that will provide a point of entry for all patients interested in better understanding kidney research in Canada:

- linking patients to research opportunities
- providing educational tools focused on research participation
- supporting researchers to recruit interested patient partners







4

KidneyLink background

What we've done:

- kidneylink.ca launched in November 2019
- 90+ research opportunities posted
- 490+ users registered
- Connects to KidneyPro training module
- Connects to kidney health info via KFOC
- Connects to National Patient Network info
- Bi-weekly notification emails
- Marketing via Can-SOLVE CKD and partner channels



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KidneyLink background

What we've learned:

- There is value in the model but the site and user experience can be enhanced
- Slow uptake and user retention
- Not a significant recruitment tool for researchers at this time
- Low awareness among wider kidney community



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KidneyLink background

Why we're here:

- KidneyLink is a central part of Can-SOLVE CKD Phase 2
- We recognize that the current iteration of KidneyLink is not set up to meet the needs of Phase 2
- **Can-SOLVE CKD Phase 2 offers an opportunity to build something truly transformative with and for the kidney community**



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KidneyLink background

Why we're here:

- Understand the community's needs and the value KidneyLink can add
- Develop a vision for refreshing KidneyLink that reflects the perspectives of researchers, patients, and our partners
- Understand how we can maximize KidneyLink's uptake among Canada's kidney community
- Learn how we can empower patients, researchers, and others to become advocates for KidneyLink in their own networks



8

Discussion questions

1. **What is the value of the KidneyLink model:**
 - To patients?
 - To researchers?
 - To the broader community?
2. **Imagine an ideal KidneyLink platform. What are the features and functions that would meet your needs/expectations?**
3. **How do we maximize uptake of KidneyLink across the community?**
 - What are the barriers to adopting KidneyLink as a recruitment/engagement tool?
 - How can we overcome these barriers?
4. **What does success for KidneyLink look like?**
 - How do we evaluate success?
 - What are the metrics of success for researchers? For patients?



9

00:10

Breakout groups

- You will be automatically moved into a breakout group with other participants
- We have made every effort to ensure balance among different roles (patients, researchers, partners, staff members, etc.)
- We have allocated 15 minutes to address each question – the facilitator will be responsible for keeping time and moving through the questions
- The breakout sessions will be recorded
- If you have more to say on a certain topic, please feel free to use the survey link at the end of the workshop to add additional comments
- We will reconvene after the breakouts to discuss next steps



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Next steps

- All feedback from the sessions will be reviewed by our team
- We will develop a detailed summary report to capture what we have heard, along with recommended actions
- If you have additional feedback to contribute, please use this form to provide comments: <https://cansolveckd.ca/kidneylink-workshop>
- Based on the directions identified today, we will create a working group to lead the development and implementation of the new vision for KidneyLink
- We need volunteers! If you would like to be part of this working group, please contact gpollock@cansolveckd.ca



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