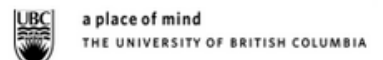


# PATIENT ENGAGEMENT IN CAN-SOLVE CKD: PRIORITIZING TOGETHER FOR FUTURE IMPACT

## ACTION REPORT

JULY 2023



# ACKNOWLEDGEMENTS

## Our Team

We are an interdisciplinary team of researchers, knowledge users, and patients with an interest in patient engagement in research.

## This project was funded by

The Canadian Institutes of Health Research.

## Thank you

To all of our participants.



# TABLE OF CONTENTS

<b>1</b>	Study Summary
<b>2</b>	Methods
<b>3</b>	Phase 1: Systematic Review
<b>4</b>	What We found
<b>6</b>	Phase 2: Multiple Case Studies
<b>8</b>	Preliminary Findings
<b>10</b>	The Deliberative Dialogue Process
<b>11</b>	Deliberative Dialogue Participants
<b>12</b>	Deliberative Dialogue Discussions
<b>14</b>	Blue Sky Thinking
<b>15</b>	Next Steps
<b>16</b>	Contacts & Request for Feedback

# STUDY SUMMARY

**HOW CAN WE  
GET PATIENTS  
MORE INVOLVED  
IN RESEARCH?**

## BACKGROUND

The overarching goal of this study is to improve patient engagement in research by investigating organizational factors that contribute to patient engagement and enhance engagement-capacity within health research networks (HRNs).

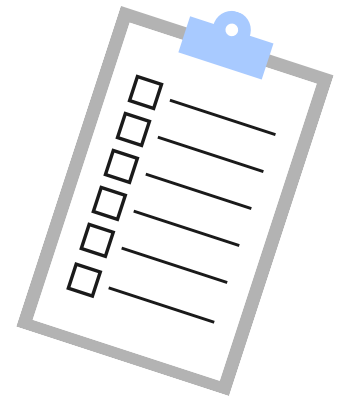
We use "**patient**" as an umbrella term defined by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR). The term "patient" may include individuals with personal lived experience of a health issue, informal caregivers, family, friends, and community members.

In Canada, HRNs are typically funded through CIHR, including the CIHR SPOR initiative, or through specific funding initiatives such as the Networks of Centres of Excellence program. Networks receive significant funding to generate the infrastructure, resources and supports needed to enact large-scale research agendas. There is a timely opportunity to explore how these networks function and support the engagement of patients.

Specifically, this work has **two principal objectives**:

- 1)** To examine the organizational factors that contribute to engagement-capacity for patient engagement in health research networks.
- 2)** To develop indicators of engagement-capacity for patient engagement in health research networks.

# METHODS



We have engaged **6** pan-Canadian networks in our research. These networks were selected as they are focused on key problematic health issues and are at varied points in their funding lifecycle.

## NETWORKS:

- **CREST.BD**
- **AGE-WELL**
- **Can-SOLVE CKD**
- **CANet** (Cardiovascular Network of Canada)
- **CDTRP** (Canadian Donation and Transplantation Research Program)
- **SPOR Evidence Alliance**

## RESEARCH PHASES:

Phase 1: Systematic Review of the literature

Phase 2: Multiple Case Studies ← **We are here**

Phase 3: Development of Indicators of Engagement-Capacity

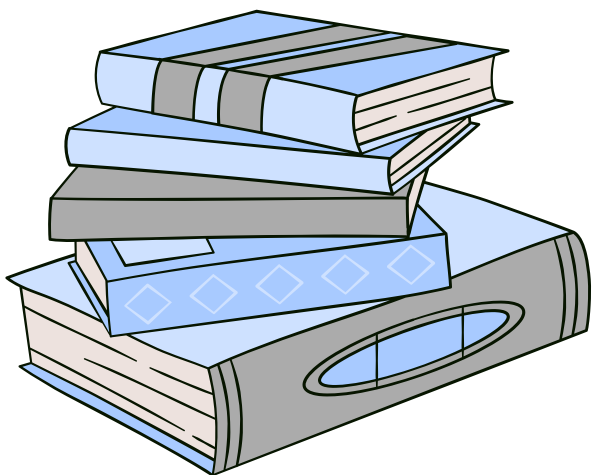
# PHASE 1: SYSTEMATIC REVIEW



The purpose of this systematic review was to describe organizational factors that contribute to engagement-capacity in health research networks and organizations; and to identify processes and structures that contribute to effective and meaningful patient engagement.

This collaborative review process was conducted in partnership with the SPOR Evidence Alliance, which seeks to support rapid-learning health systems in improving patient and health system outcomes.

- Screening was conducted using Distiller SR, a systematic review software
- 6 research team members took part in the screening process
- 3 levels of screening and 1 level of data extraction was conducted
  - 1) Rapid title screen
  - 2) Title and abstract screening
  - 3) Full text screening

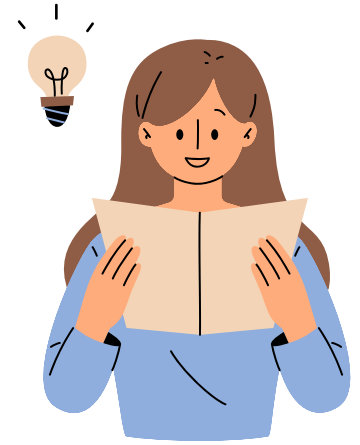


## **The studies we chose had to meet these criteria:**

- Peer-reviewed
- Written in English
- Published between Jan 1980-April 2022
- Described processes and experiences of patient engagement in health research network activities

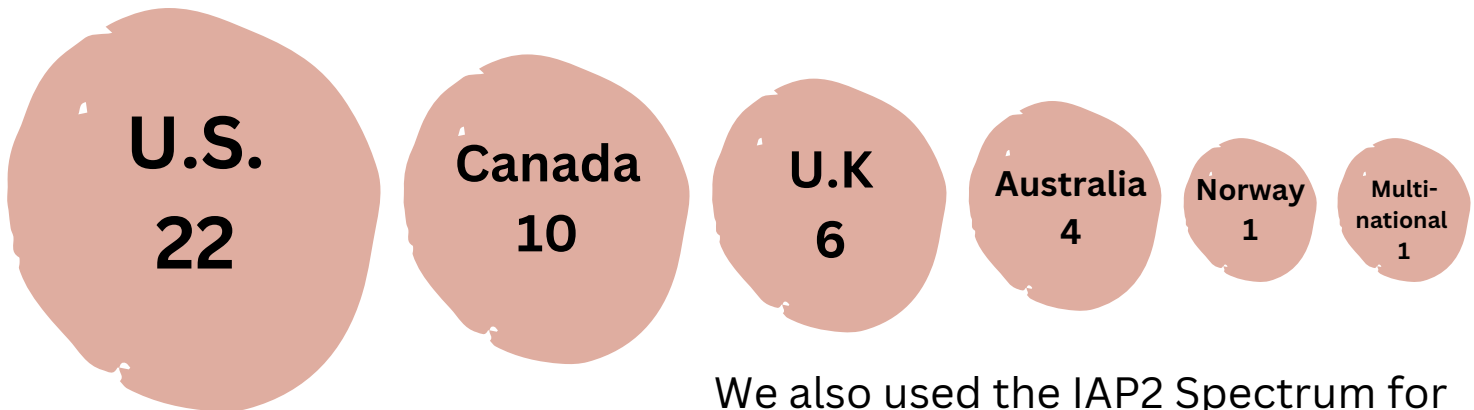
# WHAT WE FOUND

The systematic review yielded articles for analysis.



The included articles were published between the years of **2000 and 2022**, with most (**41%**) being published in the years **2017–2020**.

The 44 articles were published in the following countries:

A blue, torn-edge rectangular graphic containing three lines of text. Each line consists of an engagement level followed by a number. The text is white and bold.

Involve **11**  
Collaborate **31**  
Empower **2**

We also used the IAP2 Spectrum for Public Participation to group the articles based on the degree of decision-making latitude and empowerment given to patients and partners engaged in research.

We excluded articles where activities only met the lowest 2 levels of engagement (Inform and Consult) and instead focused on the levels of Involve, Collaborate, and Empower.

The **44** articles were further analyzed to elicit information relating to the lifespans of HRNs from start up through to scaling and sustaining. Factors that were found to contribute to engagement capacity are listed below:

## **PHASE 1:** INITIATION & DEVELOPMENT

- Clear goals and motivation for involving patients.
  - An organizational culture that values and supports patient engagement.
  - Time and budget allocated to building relationships.
- 

## **PHASE 2:** IMPLEMENTATION & OPERATIONS

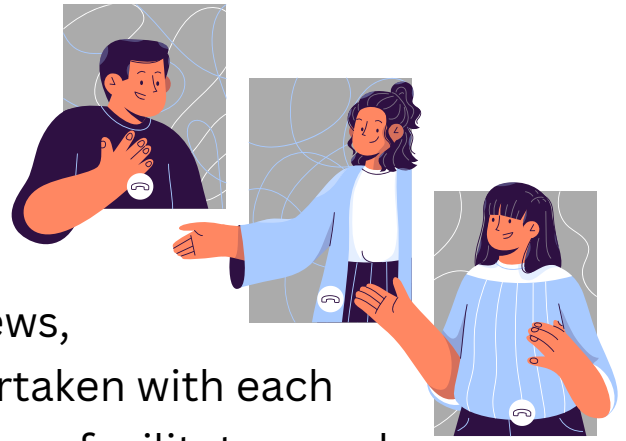
- Processes for patient partner recognition and continuous and open communication regarding compensation.
  - The use of frameworks can help to clearly define roles and ensure governance structures are responsive to patient needs.
  - Ongoing opportunities for relationship and trust building.
- 

## **PHASE 3:** SCALING, SUSTAINING, AND FOSTERING ENGAGEMENT

- Reliable funding to sustain long-term engagement.
- Ongoing recruitment of patient partners and the development of roles to meet demands and networks' evolving needs.
- Attention to and support of EDI (equity, diversity and inclusion) in terms of patient engagement.



## PHASE 2: MULTIPLE CASE STUDIES



Documentary analysis, qualitative interviews, and deliberative dialogues are being undertaken with each of the research networks to examine barriers, facilitators and organizational supports related to patient engagement. During this phase, we are studying each network in isolation and will then cross-examine these to generate new and integrated understandings of engagement-capacity and supports for patient engagement in HRNs.

### LEARNING THROUGH INTERVIEWS

To recruit participants for interviews, we shared a summary of this research with our partners and asked that they share with those in their networks. Interviews took place over zoom and ranged from 45 minutes to 2 hours in duration. Data analysis was guided by the Qualitative Description approach, with data being coded and then analyzed thematically.

### HOW IS THIS DATA ANALYZED?

When data is analyzed, researchers review the information in detail, looking for similarities, differences, or areas where information is conflicting or unclear. A researcher will identify important issues or statements (a process called coding) and will then group these together to create themes. Analyzing this type of data is very time consuming and can take months and sometimes years. After the data is analyzed, researchers describe the data, often using direct quotes to give examples or draw attention to important issues.



**39**

To date we have conducted 39 interviews with 5 different HRNs

**CanSOLVE  
CKD**

**CDTRP**

**AGE-WEL**

**CREST.BD**

**SPOR  
Evidence  
Alliance**

## **We talked to:**

- Patient partners
- Researchers
- Clinicians
- KT specialists
- Network leaders
- Community members
- Research assistants
- Trainee researchers

The interviews explored experiences and perspectives of patient engagement within each health research network and will determine what organizational factors are perceived to contribute to meaningful patient engagement.



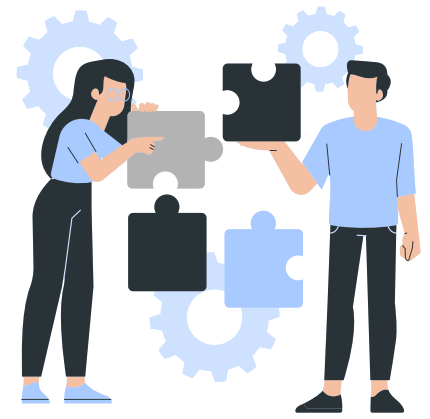
# PRELIMINARY FINDINGS



## INSIGHTS FROM ACROSS NETWORKS:

- The networks were at their best as an environment for patient engagement when they encouraged and allowed patient partners to be more than “patients.”
- The patient partners, as individuals, felt they had the most to contribute when they were seen as whole people, beyond the category of patient.
- Participants regarded establishing personal connections and relationships within the network as vitally important to its functioning.
- The importance of Equity, Diversity, and Inclusion (EDI), with particular attention given to diversity.
- Compensation is a key factor for expanding the capacity of HRNs as engagement-capable environments.
- HRN staff dedicated to patient engagement is crucial and facilitates long term engagement.

# PRELIMINARY FINDINGS



## Can-SOLVE CKD Interview Insights:

- 12 interviews to date.
  - With patient partners, network staff, leadership, IPERC members, researchers, and clinician researchers.
- The context of Can-SOLVE is shaped by the historical and contemporary realities of Canadian colonialism.
- The network actively grapples with issues of health inequity and disparity facing Indigenous peoples in Canada.

## Main Interview Themes:

Network interviews centered around six main themes:

- Facilitators of engagement
  - Partnerships that reinforce the value of the 'whole person.'
- Collective vision and power sharing in the network
  - The network as a 'collective project' with an ongoing process of power-sharing.
- Cultural safety and humility
  - Infused and integrated across the whole network.
- Inclusion and diversity
  - Central to the democratic vision of the network.
- Compensation and recognition
  - Key factor for expanding the capacity of Can-SOLVE as an engagement-capable environment.
- Engagement supports
  - Central to fostering organizational capacity and allowing relationships with patient partners to be built and maintained.

# THE DELIBERATIVE DIALOGUE PROCESS

Deliberative dialogue meetings can include a variety of activities, including guided discussion, consensus methods, and voting. During the meeting, we invited all participants to contribute, creating an inclusive space to discuss issues and potential actions.

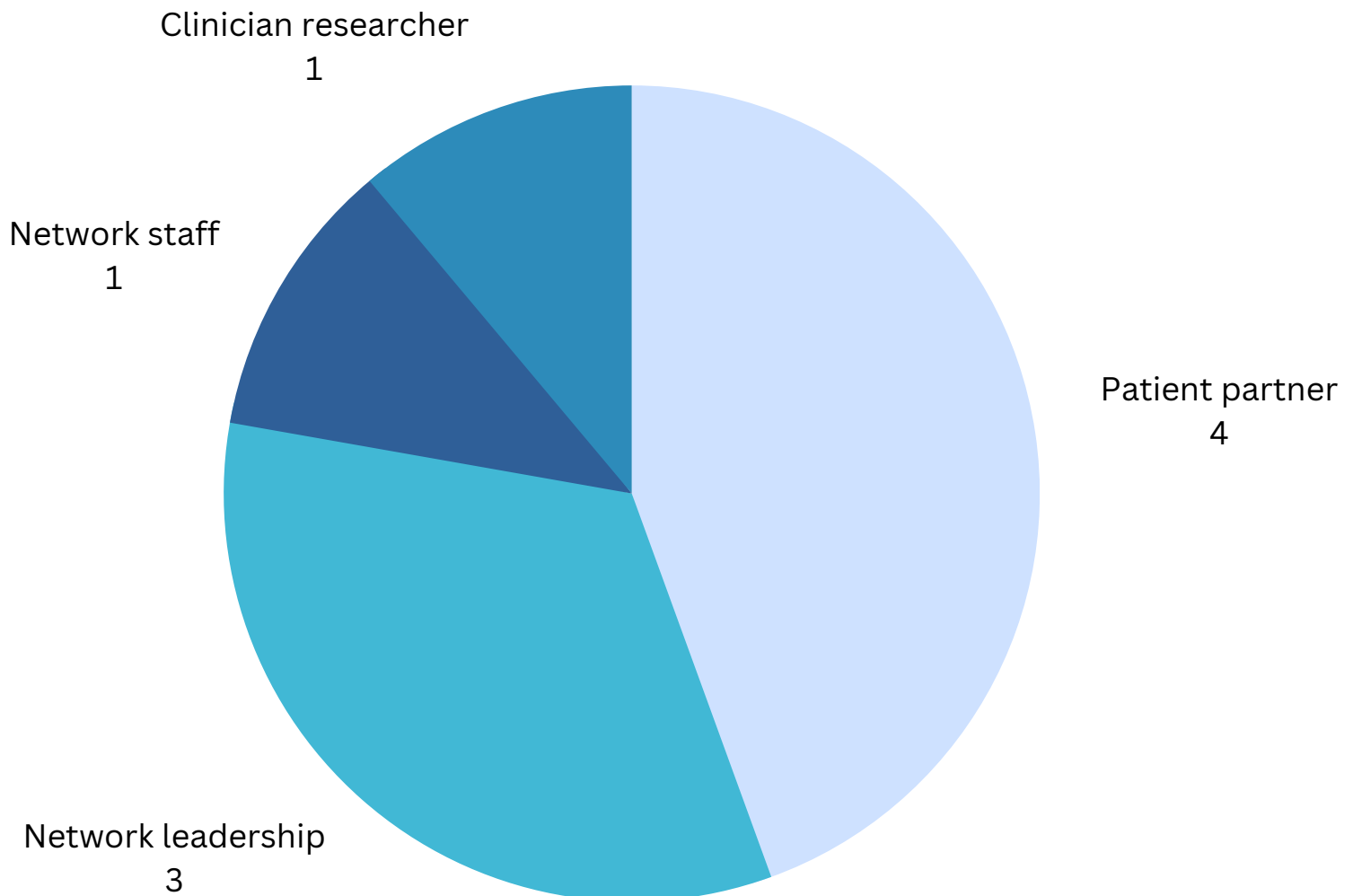
## MAY 9TH SESSION:

- Since this workshop is part of a larger research study, we began the session by discussing the informed consent process.
- Attendance and participation in the session was completely voluntary and participants were free to leave at any time.
- The session involved an overview of the study and structured discussion about organizational factors that contribute to engagement-capacity for patient engagement in health research networks.
- After the session, our team summarized discussions and priorities and developed this report. The Action Report is now being sent to participants for review and feedback.

# DELIBERATIVE DIALOGUE PARTICIPANTS

The session was planned in conjunction with the Can-SOLVE Annual General meeting and held on May 9th, 2023. Our workshop had a total of 9 participants including patient partners, network staff and leadership, and clinician researchers. The roles of the participants are displayed below.

All participants provided informed consent at the beginning of the workshop. The majority of participants have been involved with Can-SOLVE CKD between 3 and 7 years, one participant had been involved for less than one year.



# DELIBERATIVE DIALOGUE DISCUSSIONS

## We asked:

Reflecting on Phase 1: Making it Happen and looking ahead to Phase 2: Making it Matter, what is needed to advance patient engagement in Can-SOLVE CKD?

## Participants were asked to rank the determined priorities below:

Continue to work on mechanism to evaluate patient engagement (performance measures).

Develop cohorts of both patient partners and researchers that can train and mentor new members of Can-SOLVE.

Face-to-face engagement opportunities among teams (with financial supports).

A better understanding of what diversity and inclusion mean for Can-SOLVE.

# DELIBERATIVE DIALOGUE DISCUSSIONS

## We asked:

- What do you think the network needs to do to advance patient engagement?
- At the organizational level, what needs to be in place to support patient engagement?

## We heard:

### Training and mentorship

- Desire to build a diverse cohort of patient partners who are formally trained to help maintain network momentum
- Need a clearly defined focus on patient engagement, patient population, and growing these to support the projects
- Desire to build a mentorship program for patient partners
- Issue of burnout among patients partners, researchers, and network employees

### Reframing what is important

- Need for an organization vision and to identify clear priorities for the network
- Can-SOLVE as training ground for patient partners and researchers that continues to build and sustain these programs
- Need for funding from sources outside of CIHR



# DELIBERATIVE DIALOGUE DISCUSSIONS

## We asked:

- What supports and structures, or different roles in the network, does Can-SOLVE need moving forward?

## We heard:

- Need to refine the onboarding and introduction activities
  - This stage can be difficult to navigate
- Need for communications supports for patient partners
  - This will promote more sustainable relationships between researchers and patient partners



# DELIBERATIVE DIALOGUE DISCUSSIONS

## We asked:

- What does an increased focus on equity, diversity, and inclusion for the network look like?
- What supports are needed to develop this network vision?

## We heard:

- Greater access to technology, staff support, and training
- First, what diversity looks like and what level of diversity the network is looking for needs to be addressed
- **Evaluation**
  - Need for different perspectives for each topic of focus and a greater diversity of experiences
  - Currently no formal mechanism for evaluating patient engagement
  - Gap between what the network is asking and what is actually being evaluated needs to be addressed
  - Difficult to measure what the network is doing and if it is making meaningful impacts

**“We cannot be all things to all people ... we gotta pick our spots and do a good job on those spots.”**

# BLUE SKY THINKING



## We asked:

- What does your vision of success for the Can-SOLVE CKD look like?

## We heard:

- Supporting more personalized medicine
- Doing meaningful and impactful research that addresses the 'so, what?' question
- Making the network more approachable and able to provide support for patients and researchers to bridge gaps in research
- Ability to provide the 'quality stamp' to other networks and types of research
- Supporting increased patient involvement and empowerment in research at all stages

**"We need a far more patient-focused agenda"**

**"We need to optimize care across the CKD spectrum from earlier detection to improved treatments, quality of life"**

# NEXT STEPS

We are continuing to engage with members of the other 5 health research networks that are involved in this study.

This includes one-to-one interviews and deliberative dialogue sessions with various stakeholders.

Once this phase has been completed with each of the networks, we will enter Phase 3 of the study.

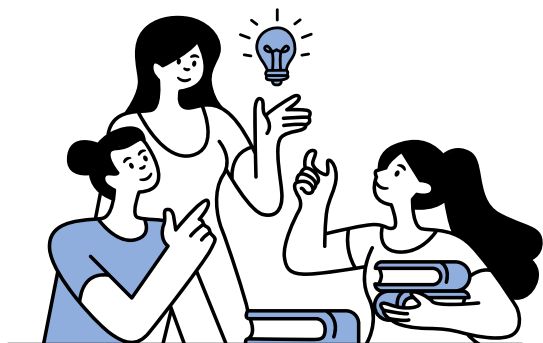


## **Phase 3: Development of Engagement-Capacity Indicators**

We will recruit participants from across the networks to participate in a multi-network deliberative dialogue session to develop indicators of engagement-capacity for patient engagement in HRNs. We will work with our network partners to identify potential participants and will seek to recruit equal numbers of patients and network investigators from each network.

# YOUR FEEDBACK MATTERS!

- Does this report reflect the content and messaging from the workshop?
- What about these results resonates strongly with you?
- What do you think is missing?
- Who do you think needs to hear these results and recommendations?
- What do you think should happen with these results?



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