

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

MAY 2023

## A DELIBERATIVE DIALOGUE SESSION PRIMER



# 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



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# 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).

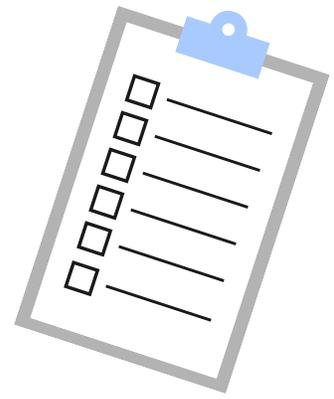
We use "**patient**" as an umbrella term defined by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR). The term "patient" may include individuals with personal lived experience of a health issue, informal caregivers, family, friends, and community members.

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

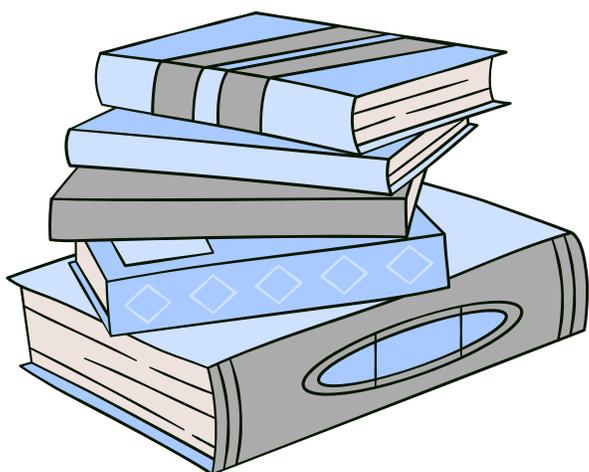
# PHASE 1: SYSTEMATIC REVIEW



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**

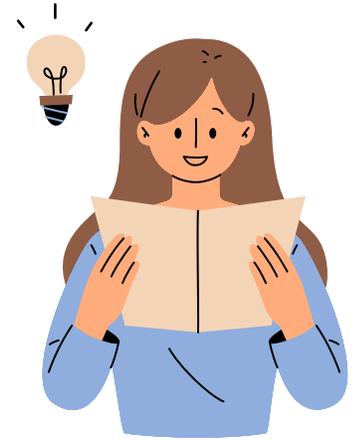


**The studies we chose had to meet these criteria:**

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

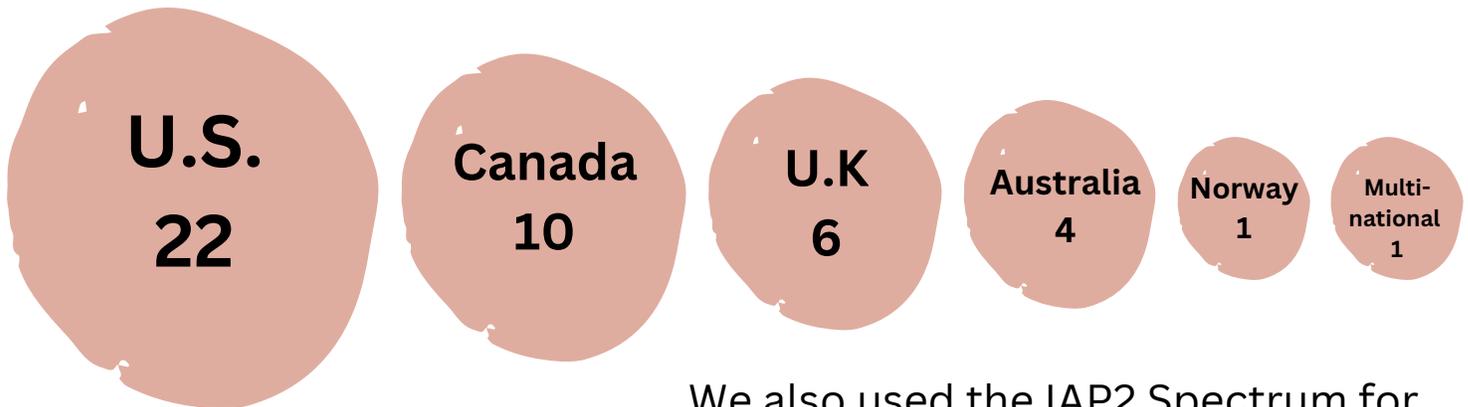
# WHAT WE FOUND

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:



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 explore 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

## WHAT WE HAVE LEARNED SO FAR



### 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

## **CanSOLVE-CKD Interviews**

- 12 interviews to date
  - Patient partners, network staff, leadership, IPERC members, researchers, 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 inequality and disparity facing indigenous peoples of Canada



## Facilitators of Engagement

Partnerships that reinforced the value of the **'whole person'**

*"Everyone is so passionate about what they do and it's really evident and it's more than, like sometimes I'm up at night thinking about people or projects or like it kind of, it's not healthy sometimes, but **it's not just a job, like these are people, these are lives and, you know, you're reminded of how important it is** and you can see that within these networks, at least Can-SOLVE anyways."*

## Collective vision and power sharing in the network

Participants viewed the network as a 'collective project' and is seen as an ongoing process of power-sharing.

“I think it’s really evolved ... It’s not us and them. Like it’s we, you know, they [patients] are on every working group, they are a part of all of our governance structures. It really has morphed from let’s make sure we get the patient perspective and that’s maybe more tokenistic cause I mean you have to start somewhere, right, in the fabric to what we do. To the point where we have patient partners as part of our research operations committee. Right, we’re viewing budgets and Gantt charts and project timelines and being really critical in a good way. I think what I’ve seen and why I love this kind of work is because it holds researchers to account at a different level, at a new level.”

## Cultural safety and humility

Cultural safety and humility are infused and integrated across the network

“In one of our evaluation criteria it said something about it was the truth and reconciliation, so does your project address some of the truth and reconciliation commission, you know, the calls to action and I guess one of the patient partners thought well, we’ll just put an if applicable in brackets and then of course the Indigenous member said well no, it’s not if applicable, this should be for all projects.

So, no one held back in that meeting, their feelings, everything was very vocal, and it was a conversation that should’ve been had.”

## Inclusion and Diversity

Striving for diversity and inclusion was central to the 'democratic' vision of the network

I think it's really important to be able to bring in new voices and hear what they say ... it's really important I think to have voices come in from the outside and maybe see things differently than we do. Cause we're so into it, right, we don't necessarily and, you know, we're so entrenched in it and we're so in favor of it that, you know, there may be things that we might just overlook because of the bias that we have."

## Compensation and Recognition

Compensation was a key factor for expanding the capacity of Can-SOLVE as an engagement-capable environment.

*“I feel like I probably could argue like both sides for like always paying versus not always paying patient partners. Anyway, ... **it opens the door to who can participate ... where is the line between altruism and wanting to give back versus paying people for their expertise/lived experience you know, that they’re bringing to this professional environment.** I know that I have heard patients say it’s not felt great to be the only person around a research table who’s not getting paid for their contributions. So, paying people for their time is important. I think it comes down to individuals ... it has to be an individual conversation and I think you give people the option”*

## Engagement Supports

Dedicated engagement support was central to fostering organizational capacity. Network staff were crucial links at the hub of organizations, allowing relationships with patient partners to be built and maintained over time.

“I think what I have to say is like the underestimation of the importance of engaging with research coordinators. So, we’ve often engaged with the PI’s who are important but **it’s the researcher coordinators who, for the lack of a better word, do the engagement with the patients, who are sending the emails, who are building the relationships, who are asking the questions,** so I think that they are a bit of a, have gone as a bit of an unrecognized bunch of key people that we need to support for this to work.”

Positions were seen as vulnerable to high turnover

“The challenge too is those are high turnover positions ... so that can be hard because then you’re kind of starting from scratch and **building those relationships kind of over and over again.**”

Dedicated support helped foster ‘**institutional memory**’, referring to the ability of an organization to maintain its practices, culture, knowledge, and momentum as a collective project independent the individuals that staff it.

“So sometimes, one of the things we always talk about is as a group or as an individual you could be a strong personality, you could be a good leader, but can you affect change. I would say that IPERC as a group has affected change. They have direct access to people in power in the network. So, **they’re not just a standalone thing that does their own thing. Their opinions, their guidance is sought and actually put to action because they truly have support.**”

# 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.

## WHAT TO EXPECT AT THE MAY 9TH SESSION

- Since this workshop is part of a larger research study we will begin the session by discussing the informed consent process
- Attendance and participation in the session is completely voluntary and participants are free to leave the session at any time
- The session will involve 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 will summarize discussions and priorities and send to participants for review and feedback

# 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 - Engagement-Capacity Indicators**

To do this we will be holding a multi-network deliberative dialogue session. If you are interested in attending this future event, please let us know. We will also reach out when we begin the planning process.



# QUESTIONS?

# COMMENTS?



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