

PATIENT-FOCUSED SELF-MANAGEMENT OF CKD

NEWSLETTER



ACHIEVEMENTS:

- June 21: Roy & Vi Baay Chair Event - the team presented on My Kidneys My Health implementation study and peer support scoping review
- Oct 3-4: Alberta NWSPOR Collaborative Forum - Sabrina presented on our self-management project (Can-SOLVE 1.0 project)

NEXT STEPS

- Please share any suggestions to recruit for our sexual health study
- Nov 2023: Dissemination Working Group Meeting
- Dec 11-13: Dissemination & Implementation Conference - Sabrina presenting on implementation study results
- Do you have any ideas to promote My Kidneys My Health? (e.g., events, social media outlets, etc.) - email Sabrina

PROJECT UPDATES

Over the summer, we have been working on the planning and execution of our three pillars of work.

Peer Support: The team is finalizing their manuscript for a scoping review on peer support programs, to be submitted for publication.

Sexual Health: Our survey to explore the perceptions, practices, and needs on the provision of sexual health support has launched.

- 41 respondents completed over half of the survey (42% Nurse, 22% Nephrologist, 10% Administrator, 7% Dietitian, 2% Pharmacist, 17% Other).
- Next steps:

1. Continue to recruit health care providers in CKD clinics across Canada to complete the survey (suggestions welcome).
2. Conduct interviews with those who volunteered to participate. The survey results will inform the interview guide. The aim is to further explore the experiences with sexual health support in more detail.

Engagement and Needs of Indigenous Communities in Alberta:

- We continue to explore engagement opportunities and build relationships to prepare for our study to understand kidney health priorities of Indigenous communities in Alberta.
- Knowledge Keeper Violet introduced us to Maureena, who we have welcomed onto the team as a patient partner.
- Violet and Maureena shared their experience at the NWSPOR Collaborative Forum in October.
- Next steps:
 1. Explore partnerships with communities in Alberta (e.g., Morley).
 2. Prepare ethics application with the APPROACH team, led by Dr. James

Strategy for Patient-Oriented Research



PROJECT UPDATES CON'T

My Kidneys My Health Updates:

- June to September 2023: My Kidneys My Health accessed by 1,617 users.
- Developing "Subscriber Form": website users can sign-up for website updates (e.g., new content, highlight features) - to be launched.
- Developing "Resources" tab: a page located at the top of the website, housing patient/provider resources (1 page, "how to" manual, etc.).



ENGAGEMENT ACTIVITIES

Dissemination:

Over the summer, Sabrina and Caitrin O'Connor (summer student) presented on our Can-SOLVE projects at the Roy & Vi Baay Chair event in Calgary. Sabrina presented the Can-SOLVE 1.0 final stage, the implementation study. Caitrin presented on the peer support scoping review related to our Can-SOLVE 2.0 work.

Meghan, Mo, Catherine, Violet, and Maureena presented at the NWSPOR Collaborative Forum on Patient-Oriented Research, hosted by the Alberta SPOR SUPPORT Unit. This year's theme is "Your Stories: Creating Impact Through Patient-Oriented Research." Session recordings will be posted [here](#). Sabrina presented our Can-SOLVE work, an abstract prepared by Gillian Crysdale (summer student).

Indigenous Engagement:

Over the past few months, we have been meeting with Violet and Maureena to discuss engagement in Indigenous communities in Alberta. We met with Dr. Matt James on August 8th to discuss our project and brainstorm our approach. On October 3rd, Meghan and Mo presented on our experience working with Knowledge Keepers in research (presentation led by Catherine Turner). Maureena and Violet shared their story which led to very engaging conversations.



Maureena, Meghan, Mo, Catherine, Violet, Sabrina, Presentation at NW SPOR Collaborative Forum, October 3rd, 2023

Project Check-Ins:

The Can-SOLVE ROCKeT Committee held their annual check-in call with our Self-Management Team. At the meeting, we discussed project updates, priority areas, and the 4 pillars: 1) Knowledge Mobilization/Implementation, 2) Indigenous Cultural Competency, 3) IDEA (inclusivity, diversity, equity, and accessibility), 4) Patient Engagement and Capacity Building. The ROCKeT Committee was enthusiastic about our progress made and provided helpful suggestions. It was a great discussion on how we can make our self-management work accessible and more effective.

The Dissemination Working Group will be meeting in November to review our website analytics, review website updates, and brainstorm opportunities. Sabrina will share a poll for availability soon.

We plan to hold our next full team meeting in the new year. Please stay tuned!