

# DEVELOPMENT OF A PROVINCIAL FRAMEWORK TO ADVANCE PATIENT AND FAMILY ENGAGEMENT **IN KIDNEY CARE AND RESEARCH**

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# Introduction

- Patient and family engagement is key to achieving a health care system that is responsive to patients, and improving patient outcomes.
- Resources to practically embrace authentic patient and family engagement in kidney care and research are scarce.

### Aim

To co-create a framework to guide patient and family engagement activities in the provincial renal network

## Methods

- ✤ A working group of 16 patient partners and health professionals was formed to develop the provincial patient and family engagement framework.
- An environmental scan was conducted to inform the development of the framework content:
- Review of national and international patient engagement resources in health care and research; and
- $\checkmark$  A series of interviews with the leads, project managers as well as patient partners of BC Renal committees and key activities.
- Input from stakeholders such as The Kidney Foundation of Canada—BC & Yukon Branch and other provincial partners in patient and Indigenous engagement was incorporated.

## Results

### efits of Patient Engagement

Kidney care professionals identified the following benefits:

**Our patient** 

partners

identified

benefits:

the following

- Adding unique perspectives and expertise
- Focusing effort on what matters most
- Advocating collectively for new therapeutics and resources
- Enhancing accountability in advancing person- and family-centred care
- Understanding how health professionals and patients can work together in the kidney health system
- Meeting others who are impacted by kidney disease
- Empowering to be part of the kidney care planning process
- Strengthening ability to promote awareness of kidney disease.

# Results

# **BC** Renal Patient & Family **Engagement Framework**

### What:

A guide for patient and family engagement in BC Renal committees and activities

take place across these

domains:

#### Why:

Having patients and families as active partners supports optimal patient outcomes and experience.

How: Five principles guide every step of our engagement process.

**Seven-Step Cycle of Patient** and Family Engagement



To download the BC Renal Patient & Family Engagement Framework or infographic:

and families



O



# Results

Feedback on the development process:

This was a great experience for me to be involved in. Although it was a lot of information to take in, I learned so much. - Patient partner 0

This has been the most satisfying experience because it has been all about providing patients and families a voice within the interdisciplinary team. A large gap, within what a grand step, as they are the only reason we are all here to begin with...."

- Kidney care professional

# Conclusions

- The collaborative development process reflects our commitment to involve patients and families as active partners and facilitates culture change for integrating patient and family engagement in kidney care and research.
- It primes the integration of effective partnerships among health professionals, patients and families to optimize patient outcomes and experiences.

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And across the International Association for Public Participation (IAP2)'s Spectrum of Public Participation



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