

# PATIENT AND FAMILY ENGAGEMENT IN A PROVINCIAL KIDNEY NETWORK: WHAT HAVE WE LEARNED SO FAR?

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## Introduction

- ❖ Patient and family engagement is about putting patients at the forefront of decision making about their care at the individual care, program and system levels. It is key to achieving a health system that is responsive to patients, and improving patient outcomes.
- ❖ Few practical resources for purposeful and meaningful engagement exist.
- ❖ To support culture change for person- and family-centred kidney care, BC Renal, a provincial kidney network in Canada, adopted a formalized approach to patient and family engagement in 2019.

## Results

Figure 1 BC Renal Patient & Family Engagement Framework

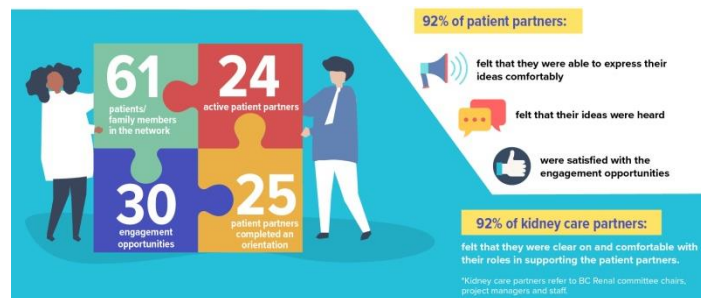
What:	Why:	How:
A guide for patient and family engagement in BC Renal committees and activities	Having patients and families as active partners supports optimal patient outcomes and experience.	Five principles guide every step of our engagement process.

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



## Methods

- ❖ A working group of patient partners and health professionals guided the development of a provincial patient and family engagement framework as well as the integration of patient voices in various ways across BC Renal.
- ❖ In addition to literature review, interviews were conducted to understand the benefits, challenges and supports required to enable meaningful engagement from various perspectives.
- ❖ As the framework was being developed, the working group also provided overall direction on the curation and development of related resources, outreach activities and evaluation.
- ❖ A set of engagement experience surveys was conducted with patient partners and health professionals in June 2020. Process measures were also captured.



### From patient partners:

"I am able to share a voice from all aspects of a patient's kidney journey...to help other CKD patients better their journey. It is my way of 'paying it forward'."

"I feel rewarded by what we're accomplishing. I feel heard (and heard the views of others), which is what had me get involved in the first place."

"I value and enjoy participating in the committee. Even just listening gives me a better understanding and appreciation of the work and progress put into our care. Because I have a better understanding, it helps me help others. I also find the people in the group are friendly and sincere. Thank you!"

### From kidney care partners:

"It is remarkable how much the patients influence our work. They provide valuable insight into what matters most, and I have learned so much from them."

They have contributed to development of materials, have provided insight into new items to include on the work plan. They help bring a patient focus to conversation at committee meetings – very good for focusing on that perspective."

"'Patient perspective' is a real and valuable thing, often allowing visibility into concepts and ideas that may not naturally occur to administrators and even care providers."

- ❖ Improvement opportunities identified include:
  - Clearer communication about roles and expectations of patient partners in their specific committees and groups;
  - Looping back to the patient partners regarding their influence on various efforts.

Our engagement opportunities generally take place across these domains:  
With input from patients and families  
Co-design with patients and families  
Capacity-building with patients and families  
And across the International Association for Public Participation (IAP2)'s Spectrum of Public Participation

The BC Renal & Family Engagement Framework and infographic are available at <http://www.bcrenal.ca/patientandfamilyengagement>

## Conclusion

- ❖ A series of supportive strategies are enabling impactful patient and family engagement in kidney care within the provincial network.
- ❖ These early efforts prime the culture change for patient- and family-oriented kidney care and research to advance patient outcomes and experiences.

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