

PATIENT AND FAMILY ENGAGEMENT IN BC RENAL: WHAT HAVE WE LEARNED SO FAR?

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Introduction

- Patient and family engagement is key to achieving a health system that is responsive to patients, and improving patient outcomes.
- In 2019, BC Renal adopted a formalized approach to patient and family engagement as described in the BC Renal Patient and Family Engagement Framework.

Aim

To assess progress in the first year since the adoption of a formalized approach to patient and family engagement in BC Renal.

Methods

- A working group of patient partners and health professionals provides an overall direction on the curation and development of related resources, outreach activities and evaluation.
- Process measures were captured as the patient partner network grew.
- A set of engagement experience surveys was conducted in June 2020. Separate surveys were conducted with patient partners and kidney care partners (BC Renal committee chairs, project managers and staff).

Results

- The response rates were 100% for the patient partner survey, and 60% for the committee chair, project manager and staff survey.
- Most patient partners indicated satisfaction with their engagement opportunities.
- Responses from the kidney care partners were also very encouraging.
- Improvement opportunities identified include:
- Clearer communication about roles and expectations of patient
 partners in their specific committees and groups, and
- Looping back to the patient partners regarding their influence on various efforts.





Some feedback from patient partners:

- "I am able to share a voice from all aspects of a patient's kidney journey. I am able to share and discuss my experience...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!"

Some feedback 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."

Conclusions

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

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Further Information

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