




Patient & Family Engagement Framework



BC Renal plans and monitors the delivery of kidney care services to a diverse population living in various settings and communities across BC. As a provincial network, we operate on the unceded traditional and ancestral land of many Indigenous peoples, including First Nations, Métis and Inuit people. Our main office is located on the traditional and ancestral territories of the Musqueam, Squamish and Tsleil-Waututh Nations, and the Métis Chartered Community of the Lower Mainland Region.

The framework has been approved by the BC Renal Executive Committee on June 6, 2019.

Acknowledgements

Special thanks to the BC Renal Patient & Family Engagement Framework Working Group. Their commitment and effort was central to the development of this framework. The group included:

- patient partners
- physicians
- registered nurses
- a pharmacist
- a social worker
- a dietitian
- a Provincial Health Services Authority (PHSA) representative
- BC Renal staff

We also received valuable input from:

- the health authority renal programs
- the Patient Voices Network
- PHSA Indigenous Health
- the Kidney Foundation of Canada—BC & Yukon Branch

Table of Contents

Background and Purpose	1
Strategic Alignment and Scope.....	1
Benefits of Patient Engagement.....	2
Guiding Principles for Engagement: PRISM	3
Engagement Model	4
Engagement Process	7
Appendix: Patient Engagement Examples in BC Renal	13

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➔ [Accountability](#) ➔ [Patient and Family Engagement](#)



Contact us at patientengagement@bcpra.ca

IMPORTANT INFORMATION

For information about the use and referencing of BC Renal guidelines/resources, refer to <http://bit.ly/28SFr4n>.



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Background & Purpose

Our patients and community are at the core of what we do. Person- and family-centred care is a shared priority of the BC Ministry of Health, the Provincial Health Services Authority (PHSA), BC Renal and our health authority renal programs. The Patient and Family Engagement Framework was informed by:

- a comprehensive review of existing patient engagement resources in health care and research across Canada and beyond
- a series of interviews to understand the benefits, challenges and supports required to enable patient engagement in BC Renal

This framework is a guide for patient and family engagement in BC Renal committees and activities. Our ultimate goal is to optimize patient experience and outcomes.

Strategic Alignment & Scope

The framework is our commitment to involve patients and families as active partners. This includes design, planning, implementation and evaluation of kidney care services. The framework corresponds with the BC Ministry of Health and Accreditation Canada's approach to person- and family-centred care. It also supports the values of [PHSA](#) and [BC Renal](#).

This framework will apply to patient engagement across:

- BC Renal provincial committees
- Provincial and regional projects supported by value-add funding
- The Patient Records and Outcome Management Information System (PROMIS)
- BC Kidney Days and other educational events sponsored by BC Renal
- Research and other key activities supported by BC Renal

Benefits of Patient Engagement

Kidney care professionals identified the following benefits:

- Adding unique perspectives and expertise that enables us to identify new improvement opportunities
- Focusing effort on what matters most
- Enabling patient partners to be ambassadors who can enhance awareness of existing kidney health resources and how we work together as a provincial network
- Advocating collectively for new therapeutics and resources when needed
- Enhancing accountability in advancing person- and family-centred care together

Our patient partners identified the following benefits:

- Having the opportunity to learn more about kidney disease and kidney care planning and delivery
- Understanding how health care professionals and patients work together at different system levels
- Meeting others who have lived experience of kidney disease
- Empowering to be part of the kidney care planning process
- Knowing what can be anticipated in their own care
- Strengthening ability to increase awareness about kidney disease with other kidney patients and communities

The *2018 BC Ministry of Health's Patient, Family, Caregiver and Public Engagement Framework* identifies other benefits: supporting better, long-lasting decision making; managing risk effectively; and improving population health outcomes and patients' experiences while reducing costs ([Triple Aim](#)).

Guiding Principles for Engagement: PRISM

To enable authentic and meaningful patient and family engagement in BC Renal, we, as staff along with health care professionals and patient partners involved in BC Renal activities, embrace the following guiding principles in every step of our engagement process:



- **Partnership**

We support patients and families to actively work alongside health care professionals ensuring equal¹ voices and shared responsibility for a mutually beneficial partnership rooted in trust.

- **Responsiveness**

We commit to acknowledging and responding to the voices of patients and families. This includes being clear about the purpose of engagement upfront. It also means embracing open and honest communications throughout the entire process.

- **Inclusiveness**

We embrace equity and diversity. We respect unique beliefs, values, lived experiences, geographical locations, ethnic and cultural differences. Patients, families and communities are at the centre of all that we do.

- **Support**

We provide adequate support as well as a flexible process for patients and families to contribute. This includes shared learning, training, mentorship, expense reimbursement, offering multiple ways for patients and families to participate, and may include financial compensation.

- **Mutual Respect**

We co-create² a culturally safe, relevant and responsive environment. All viewpoints are considered and respected. We all share a vested interest in better kidney health.

¹ All patient partners and health care professionals involved in an engagement opportunity can contribute and have their voices heard in the process.

² Everyone, health care professional or patient partner, involved in the engagement opportunity will share the responsibility to ensure that individual patient partners can participate safely and actively depending on the level of engagement required.

Engagement Model

BC Renal engages patients and families based on the International Association for Public Participation (IAP2)'s Spectrum of Public Participation (Figure 1). It is a tool that helps with planning and communicating expectations of engagement, and outlines levels of participation. Engagement techniques that correspond to each level are identified. Each level of participation offers a different promise to the patient partners about how their input will influence the decision.

“Inform” is relevant to all engagement opportunities. All partners will need adequate information to effectively contribute. In some cases, patients will participate at the “consult” level (e.g., reviewing and providing input on a draft document). In other cases they will participate at the “empower” level (e.g., speaking as a panelist at an event). From the start, all participants should be clear about the level at which they will be engaged.



It is crucial to consider the context when engaging patients and families from specific populations. For example, when engaging with Indigenous peoples (First Nations, Métis, Inuit),

actively reaching out to building relationships with Indigenous leaders, communities and individuals will be key. This will promote trust and collaboration. It is important to seek guidance from and work with partners such as PHSA Indigenous Health and First Nations Health Authority who are knowledgeable, involved and can provide insights, connections and information.

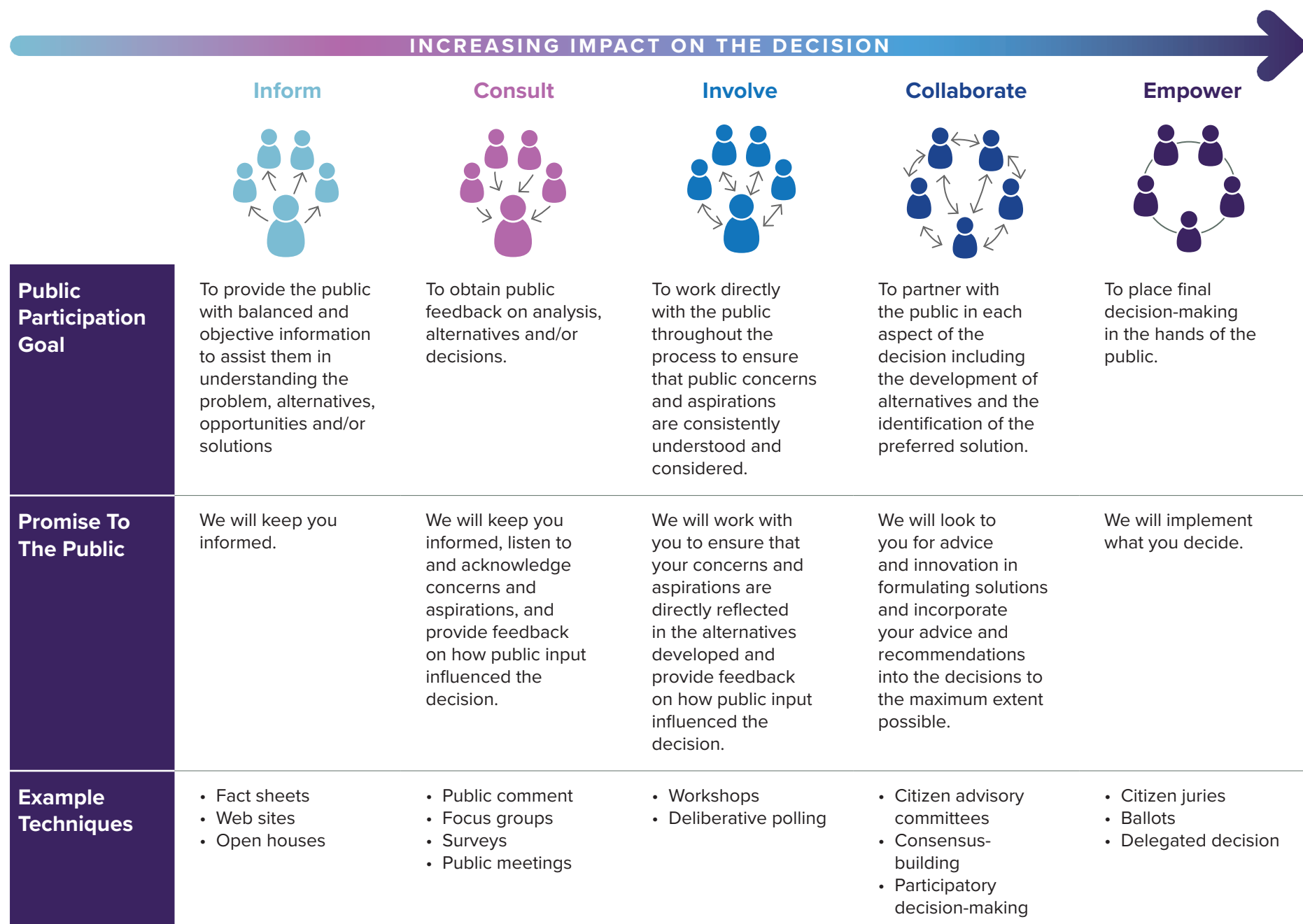


Figure 1 IAP2 Spectrum of Public Participation ©International Association for Public Participation www.iap2.org (adapted from the International Association for Public Participation by the BC Patient Safety & Quality Council)



At BC Renal, patient and family engagement opportunities generally take place in these domains:



With input from patients and families

Input from patients and families is sought on content, care processes, alternatives and/or decisions



Co-design with patients and families

Working in collaboration with patients and families to plan, design or improve services and systems



Capacity-building with patients and families

Strengthening partnerships in educational and research opportunities



For reference, a list of BC Renal patient and family engagement examples is included in the appendix. The list identifies the levels of engagement and domains described above.

Engagement Process

Effective engagement of patients and families in health care and research requires a purposeful and organized approach. Simply wanting to get patients' input may result in tokenistic engagement and not achieve appropriate or meaningful feedback. A 7-step circle of engagement (described below) is a guide for effective engagement (Figure 2).

While kidney care professionals and patient partners with content knowledge and lived experiences lead the work, dedicated BC Renal staff are available to help. They provide guidance, project management and administrative support. This support can include orientation and training (e.g., facilitation training, cultural safety training via PHSA Indigenous Health). While the process is generally described here, additional tools and resources are available. Together, we make authentic and meaningful patient and family engagement happen.



Figure 2 Seven-step Circle of Patient & Family Engagement (adapted with permission from the Patient Voices Network supported by the BC Patient Safety & Quality Council) In practice, the process between step 4 and step 7 may be more dynamic than distinct steps (as indicated by blue shade). As patient engagement is a continuous learning process, these steps may be iterative and may overlap each other.

1. Engagement Planning

This is the first step—co-building an engagement plan with kidney care professionals and patient partners who have the relevant content knowledge and lived experiences for the work. Communicating the overall aim of the work and roles/expectations of patient partners early on with all involved will have the most impact.

The engagement plan supports communication and should be part of the project charter or plan where applicable. A list of questions for the planning team to address in the plan is provided in the panel on page 9. For more information, you can also refer to the *BC Ministry of Health's Patient, Family, Caregiver and Public Engagement Planning Guide* that articulates a step-wise approach to engagement planning based on the IAP2 planning protocol: <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/engagement-planning-guide.pdf>

2. Recruitment & Selection

The next step is to match each engagement opportunity with the lived experience, interest, skill set and availability of patient partners. With a clear aim for the engagement opportunity, BC Renal staff can prepare a recruitment posting. This posting includes a role description along with background and other relevant information. Interested patient partners who apply will be interviewed by BC Renal staff and a project/ committee lead or designate. The goal is to ensure the opportunity is a good match for them.

Through this process, we leverage our provincial renal network, and various partner networks for better reach (e.g., Patient Voices Network, Kidney Foundation of Canada-BC & Yukon Branch, PHSA Indigenous Health, Can-SOLVE CKD Network). We may also proactively reach out to people whose voices might be missed using familiar but not always inclusive channels (e.g., Indigenous peoples and ethnic minority groups, those living in rural communities, immigrants, patients with mental health challenges).



Engagement Planning

Including both patient partners and health care professionals from the beginning enhances the effectiveness of an engagement plan. Below is a series of questions your planning team can discuss and address from the start. It is a good idea to review periodically during the engagement process.

- ✓ **What is the overall aim of the work?**
- ✓ **Why do we want to engage patient partners in the work?**
 - What aspects of the work will benefit most from the input of patient partners?
 - Do we have support and buy-in from key leaders, decision-makers, and/or committee members who are directly involved in this opportunity? If not, do we have a plan in place to address and build commitment among key stakeholders?
- ✓ **What are the steps to accomplish the overall aim of the work?**
 - For each step, what are the engagement objectives and level of engagement required?
 - What would be the appropriate engagement techniques or methods to use in achieving the objectives?
- ✓ **What are the patient roles in this work?**
 - Who will be the patient partners for this work? What lived experience, expertise and attributes would be helpful?
 - What are the expected benefits to patients from being part of this work?
- ✓ **What information do patient partners need to be able to participate fully?**
 - Do we have any background documents (e.g., terms of reference) that we can share to allow volunteers to better understand the goals, priorities and current focus of the work?
 - Who is the 'point person' who will communicate with and support the patient partners throughout this engagement?
- ✓ **What financial and human resources are required to support the patient partners (e.g., expenses and honorarium or other incentive)?**
 - The latest guidance document on patient partner expense and honorarium can be found on BC Renal website.
- ✓ **How will we know that we have a successful engagement?**
 - How do we know if the engagement technique is effective?
 - What measures would help indicate progress?
- ✓ **What is the best way to keep in touch and “close-the-loop” or share key results or outcomes during and after the engagement?**

3. Orientation & Preparation

Prior to getting involved, BC Renal staff will provide an orientation to all patient partners. The patient partners will be asked to sign a volunteer agreement and other documents. These documents outline shared expectations related to conduct, ongoing support, media release, conflict of interest, privacy and confidentiality. Each patient partner will be:

- introduced to a key contact for the work;
- briefed about the committee and/or project they are matched with;
- introduced to their specific role on the team by the project manager and/or support staff.

During preparation, communication should be centered on the patients' views about the engagement opportunity and how it would impact them directly.

4. Patient Partner Participation & Support

Ongoing communications between the patient partners and key contact is needed throughout the engagement.

Supporting patient partner participation may include:

- creating a safe and friendly environment for dialogue;
- soliciting patient voices during discussions;
- debriefing with individuals or groups after meetings by the committee or project leads and key contact.

It is important to proactively solicit input and feedback from patient partners. Where barriers exist for some patient partners (e.g., literacy, language, biases and stereotyping for marginalized groups), more creative approaches must be sought to enable participation. The key contact for the patient partners will regularly check in with them and others involved.

BC Renal also offers opportunities for ongoing training and coaching on an as-needed basis. We reimburse any related expenses and may offer honoraria to patient partners. This supports participation and shows our appreciation. For the most current guidance and forms, please visit BC Renal website or contact patientengagement@bcpra.ca.

5. Analyze and act on the input

Committee or project team leads consider all input from patient partners based on the agreed-upon level of engagement and/or other evidence or information. They incorporate this information into the decision-making and the work we do together. The lead will acknowledge patient voices, ensure objectivity by validating with all key stakeholders, and respond to and act upon the feedback received, where possible.

6. Report and closing the loop

Committee or project leads report successes, challenges and learnings from the engagement process within the team and in the final project report or annual report where applicable. This is a crucial step that is often missed. To demonstrate commitment to person- and family-care and to build trust, it is important to let the patient partners and other partners involved know how various input is incorporated and how the aim of the project has been met. Sometimes, it may not be possible or appropriate to implement all recommendations. In these cases, it is helpful to explain to those involved how other factors played a role and the rationale for the decision. Some patient partners may choose to play an active role in incorporating the input. As part of our commitment to transparency, it is good practice to publicly communicate how patients and families are engaged in the process, along with the outcome and impact of the engagement.

7. Evaluate

Along the way, the committee or project team gathers and shares feedback so we can learn from one another to improve the process as we go and for future engagement. A number of tools for gathering feedback from patient partners and others are available. How the feedback will be gathered (e.g., survey, interviews), analyzed and shared will depend on the specific purpose of the evaluation. We strongly encourage all those involved in the engagement process to reflect on the work, discuss learnings and celebrate successes during and at the end of the work. Feedback on the engagement should also be included as part of reporting.

For further information about the engagement process or assistance, contact patientengagement@bcpra.ca

Monitoring Progress for Improvement

This framework is a living document. It will be reviewed and updated over time to ensure it aligns with our principles and supports continual improvement in patient and family engagement. Evaluation will be supported by:

- Gathering feedback from health care professionals, patient partners and others who are involved in any patient engagement activities within BC Renal (using existing questionnaires);
- Reporting of process indicators that measure the usefulness of this framework and corresponding resources;
- Capturing stories and experiences to illustrate the impact of various engagement activities.


These evaluation activities will guide ongoing improvement and prompt future review of the framework with kidney care professionals, patient partners and BC Renal staff who use it.

Feel free to get in touch with any feedback and suggestions at any time: patientengagement@bcpra.ca!


Thank you for your commitment to authentic and meaningful patient and family engagement with BC Renal!




Appendix: Patient Engagement Examples in BC Renal

PROJECT/ GROUP	DESCRIPTION	IAP2 LEVEL(S) OF ENGAGEMENT
 With input from patients and families: Input from patients and families is sought on content, care processes, alternatives and/or decisions		
<u>Modality Choice Education</u>	BC Renal Kidney Care Committee developed standardized education resources to help patients discern treatment options for advanced kidney disease. During the pilot phase of those resources, patient participants were interviewed and asked to complete a survey before and after the education session using the resources. Feedback from the interviews and survey responses were used to further improve the resources.	Consult and Involve
<u>Dialysis Options in BC Brochure</u>	A brochure was developed in several languages (English, Chinese and Punjabi) to provide information for patients considering dialysis options. It includes detailed information about clinical, lifestyle, financial and self-management considerations. It is intended as a starting point for discussion with family and care providers to support patients in making the best decision for them. During the development of this brochure, a series of focus groups with patients were conducted. There was also a review with the patients with respect to language level and cultural appropriateness.	Consult and Involve
<u>Hemodialysis Welcome Guide</u>	BC Renal Hemodialysis Committee developed a welcome guide for those who are starting to receive treatment at in-centre or community hemodialysis units. During the development of the guide, committee members interviewed patients for their input on the content and format of the guide to ensure that the final version is relevant and easy to use.	Consult
<u>Vascular Access Education Materials</u>	To understand education needs related to vascular access, members of BC Renal Hemodialysis Committee (Vascular Access Educators Group) gathered feedback from patients with recent experiences of receiving an arteriovenous fistula or a catheter for hemodialysis. A subset of patients from all health authorities participated in the interviews. Information gathered from the interviews were used to update existing vascular access education resources.	Consult

PROJECT/ GROUP	DESCRIPTION	IAP2 LEVEL(S) OF ENGAGEMENT
Peritoneal Dialysis (PD) Assist	An assisted peritoneal dialysis (PD) program is available to those who may require home assistance to maintain PD independently. At the end of the pilot phase, participated patients were interviewed for the value of the service and explore any further support required. The feedback was instrumental to the success of expanding PD Assist provincially in 2017.	Consult
<u>Peritoneal Dialysis e-Learning Modules</u>	BC Renal PD Committee developed a set of PD e-learning modules to assist patients and families with the steps and procedures involved in PD. During its development, committee members interviewed patients and families for their input on content and format of the modules. The six modules were filmed with a patient and family caregiver from one of the PD programs and have been incorporated as part of PD education in all programs.	Consult
Peritoneal Dialysis and Home Hemodialysis (HHD) Transition Guides	Transition guides for patients are being developed to help patients transition from choosing PD or HHD at Kidney Care Clinics to starting PD or HHD respectively. Selected patients who experienced the transition from all health authorities were interviewed to inform the development of the guides. Further feedback will be gathered from patients who participated in a 6-month trial with the new guides for further improvement in the content and provincial roll out.	Consult and Involve
Baxter Amia with Sharesource Cyclor Trial	Patients on PD from Vancouver General Hospital are participating in a trial with the Baxter Amia with Sharesource cyclor. The trial will assess its clinical value, functionality and ease of use. Patient participants will be asked to provide feedback using evaluation forms at the beginning, 3 and 6 months following trial start. The feedback will be used to identify recommendations for PD program standardization and patient criteria for the implementation of Amia with Sharesource provincially.	Consult
Request for Proposal for Home Hemodialysis Machines	In the selection process for HHD machines, two patient partners were involved in the review of contract and machine demonstration. Their feedback was incorporated into the terms of the final contract.	Consult

PROJECT/ GROUP	DESCRIPTION	IAP2 LEVEL(S) OF ENGAGEMENT
<u>Patient Experience in Kidney Care</u>	As part of its commitment to improving patient care, BC Renal conducts province-wide surveys of patients to learn about their experience of care and where improvements can be made. The patient experience survey was conducted in 2009, 2012 and 2016. Results from the 2016 survey are comparable to those from the previous surveys. The results have been broken out for all modalities of care and by health authority. The goal is to identify opportunities that focus efforts to improve the patient experience across areas of care.	Consult
 Co-design with patients and families: Working in collaboration with patients and families to plan design or improve services and system		
Kidney Care Committee	The provincial committees provides expert opinion regarding non-dialysis chronic kidney disease (CKD) care in BC. It is a forum for collaboration across health authorities and disciplines. The committee guides provincial priorities for CKD care and programming, develops standards, guidelines, tools and resources, and monitors quality indicators. Patient partners and a representative of the Kidney Foundation of Canada (KFOC)—BC & Yukon Branch have been integral members of the committee since its inception in 2012. Multiple working groups with direct and immediate impacts on patients (e.g., symptom assessment and management, conservative care pathway, polycystic kidney disease best practices) also include patient members and the KFOC representative who work alongside with various kidney care professionals and administrators.	Collaborate
Transplant First Initiative	Transplant First is a joint initiative of BC Renal Kidney Care Committee, BC Transplant and KFOC—BC & Yukon Branch to promote pre-emptive transplants for patients considering renal replacement therapies. Pre-emptive transplants are those that occur before the person requires dialysis therapy to start. The focus of the initiative, launched in October 2017, is to promote living donation. This involves patients recruiting volunteer kidney donors. Working group members include two patient partners and various kidney and transplant care professionals. Through this initiative, the Living Donor Mentor Program was established by KFOC—BC & Yukon Branch to connect people considering being a living organ donor with someone who has been a living donor.	Collaborate

PROJECT/ GROUP	DESCRIPTION	IAP2 LEVEL(S) OF ENGAGEMENT
Integrated Palliative Nephrology	This project includes two strategies for implementing a palliative approach in kidney care: one designed to identify general knowledge from the literature and the second intended for knowledge dissemination. A working group with clinicians and patient partners is formed to drive change by developing a standardized palliative approach for those living with advanced chronic kidney disease.	Collaborate
Palliative Care Quality Metrics	To aid strategic planning and continuous quality improvement efforts in palliative care for people living with kidney disease, it is important to monitor key quality indicators that matters to patients and families, clinicians and administrators. A working group reflective of a full range of voices of the key stakeholder groups and the regions in BC was formed to develop the set of indicators through a consensus-building exercise. These quality indicators are routinely reported provincially and regionally to guide improvement since 2016.	Collaborate
Palliative Care Committee	The provincial committee works to ensure that patients living with chronic kidney disease have access to high quality comprehensive and well integrated renal palliative care. Since 2012, the membership has included patients to work alongside various kidney care professionals and administrators across health authorities. Through diverse partnerships, the committee recommends and drives the planning, implementation, monitoring and reporting activities of the renal palliative and end-of-life care work in the health authority renal programs.	Collaborate
Patient & Family Engagement Framework	BC Renal has made increased patient engagement a priority for the provincial renal network. In 2019, a working group was formed with 15 members from across the province, including patients, health professionals from each health authority, and BC Renal staff members. The framework developed by this group will guide a broad range of patient engagement in BC Renal committees and key activities.	Collaborate
<u>Regional Renal Programs (RRP) and PD Support Fund Projects</u>	BC Renal supports regional and provincial projects using funding from the value add rebates included in the provincial contracts for drugs and supplies. Some of the projects involve various levels of patient engagement at different stages in the projects. For example, one health authority developed a patient health plan template with kidney care teams and patients. Another health authority dedicated value-added dollars to developing a patient engagement framework reference guide with staff and patients.	Consult, Involve and/or Collaborate

PROJECT/ GROUP	DESCRIPTION	IAP2 LEVEL(S) OF ENGAGEMENT
 Capacity-building with patients and families: Strengthening partnerships in educational and research opportunities		
<u>BC Kidney Days</u>	BC Kidney Days brings together primarily clinicians and administrators from across BC, other parts of Canada and the United States to discuss the latest research, trends, clinical treatments and surgical breakthroughs in kidney care. The planning committee includes patient and clinician voices. Patients have also been invited to share their lived experiences, perspectives and expertise as presenters or panelists for a variety of topics in the past years.	Collaborate and Empower
<u>Congress of the International Society of Peritoneal Dialysis</u>	The 17th Congress of the International Society of Peritoneal Dialysis (ISPD) was held in Vancouver in 2018 with the focus on person-centred care. BC Renal PD Committee invited local patients on PD to share their experiences and journey on PD through presentations and workshops with health care professionals from around the world. Conference feedback indicated this collaborative approach between patient and clinical support was instrumental in creating a positive space for mutual learning and sharing.	Collaborate and Empower
<u>Can-SOLVE CKD Network</u>	The Can-SOLVE CKD Network (Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease) is a national, patient-oriented research network. BC Renal is a committed and integral partner of this largest effort to improve care for people with kidney disease through a range of research projects. Patient partners in BC and other jurisdictions are working side-by-side with researchers, clinicians, policy-makers and other partners in priority-setting, governance, conducting research and knowledge translation towards the shared goal of better kidney health and care.	Collaborate

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