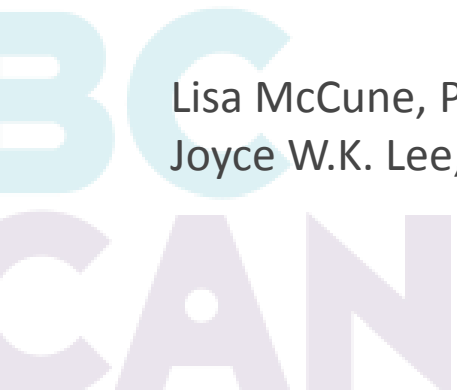


Patient and family engagement in cancer care: getting involved with your care and with cancer care service planning in BC

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Patient Experience Program

Engagement

Engage patients and families in organization decision making:

- Recruit, screen, orient, support patients and families to engage in organizational decision making.
- Enhance knowledge and skills at BC Cancer to effectively engage patients and families in organizational decision making

Education

Patients and families receive the right information at the right time:

- Right format (in-person, print, multi-media), right language, right time.
- Enhance knowledge and skills at BC Cancer to effectively deliver patient education.

Experience

Understand patient experience with care:

- Outpatient cancer care survey 2019.
- Common department Questionnaires.
- Discussion groups with hardly-reached groups.

www.bccancer.bc.ca/getinvolved

The Beryl Institute: Patient Experience is...

Patient Experience Defined:

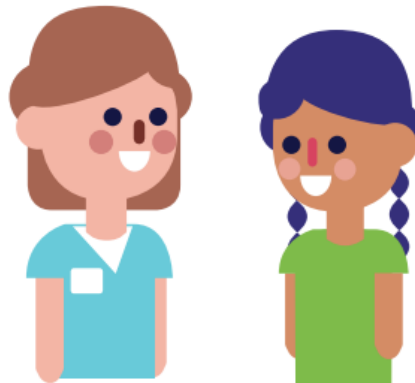
The sum of all **interactions**, shaped by an organization's **culture**, that influence patient **perceptions** across the **continuum** of care.

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Patient experience matters

- Services are appropriate
- Reduced medication errors
- Improved symptom management
- Act on what is most important to each patient

**“What
matters
to you?”**



“It gives me the opportunity to share with my provider what matters to me - my health, health care, making every day a gift and telling them my medical history. It opens up amazing doors and lets people know that someone cares and that their voice can and will be heard”

- Patient

Picker Dimensions: A framework for understanding and measuring patient experience



<http://www.nationalresearch.com/products-and-solutions/patient-and-family-experience/eight-dimensions-of-patient-centered-care/>

Respect for patients' values, preferences and expressed needs

- Patients want to be kept informed regarding their medical condition and involved in decision-making.
- Patients indicate that they want hospital staff to recognize and treat them in an atmosphere that is focused on the patient as an individual with a presenting medical condition.

Emotional support & alleviation of fear & anxiety

- Fear and anxiety associated with illness can be as debilitating as the physical effects.

Physical Comfort

- The level of physical comfort patients report has a tremendous impact on their experience. From the patient's perspective, physical care that comforts patients, especially when they are acutely ill, is one of the most elemental services that caregivers can provide.

Information, communication & education

- Patients often express the fear that information is being withheld from them and that they are not being completely informed about their condition or prognosis.

Continuity and transition

- Patients often express considerable anxiety about their ability to care for themselves after discharge.

Coordination & integration of care

- Patients, in focus groups, expressed feeling vulnerable and powerless in the face of illness.
- Proper coordination of care can ease those feelings.

Involvement of family and friends

- Patients continually addressed the role of family and friends in the patient experience, often expressing concern about the impact illness has on family and friends.

Access to care

- Patients need to know they can access care when it is needed.
- Attention must also be given to time spent waiting for admission or time between admission and allocation to a bed in a ward.

Discussion: In small groups, talk about the topic on your card

What went
well?

What
would you
like to
change?



Doing to....
Doing for....
Doing with....

WE CAN

Engagement is...

“...a process by which people are enabled to become *actively and genuinely involved* in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action *to affect change*.”

- World Health Organization

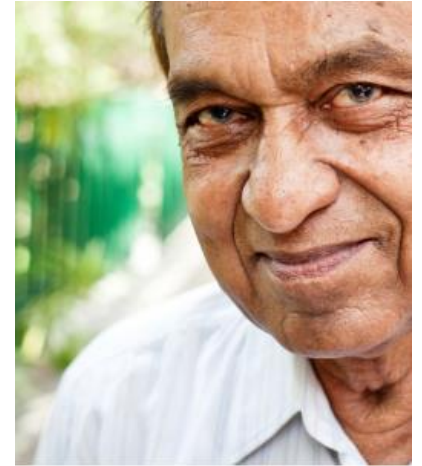
Benefits of Patient and Family Engagement

- 1 Health services that are accessible and responsive to the needs and preferences of patients and families
- 2 Improved understanding of how people navigate health services
- 3 Improved understanding of supports and barriers experienced by patients and families
- 4 Greater job satisfaction for health professionals
- 5 Improved health outcomes for patients

Which ones are meaningful to you?

Who are Patient and Family Partners?

- ✓ Have experience with cancer care as a patient, caregiver, loved one, supporter
- ✓ Care about high-quality cancer care for all patients and families
- ✓ Share their experience to ensure high quality care for all
- ✓ Volunteer their time



PATIENT EXPERIENCE PROGRAM

Your Voice Matters

You are invited to join
the BC Cancer Network of Patient & Family Partners



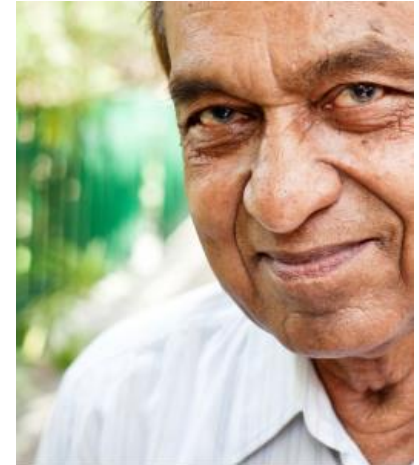
Partners share their cancer care experience in projects or in committees to improve services for all

Learn more at

www.bccancer.bc.ca/getinvolved

What do Patient and Family Partners do?

- Collaborate with health professionals to improve cancer care
- Volunteer 1 to 4 hours per month
- Share their cancer care experience in one on one and group discussions
- Participate on committees to design and review cancer care services
- Serve on patient and family advisory councils



The Patient perspective: What could you do?

You recently completed treatment. Overall you were happy with your care.

You have some ideas about how the patient experience can be improved. You would like to share your suggestions with health professionals at the cancer centre. What could you do next?

Options:

- 1) Go to the cancer centre in person and complete a comment card with your suggestions
- 2) Talk to your health care professionals about your ideas
- 3) Meet with the cancer centre manager to share your ideas
- 4) Respond to an engagement invitation posted in the network newsletter that is seeking partners to join the cancer centre redevelopment working group.



Pathway To Becoming a Patient or Family Partner

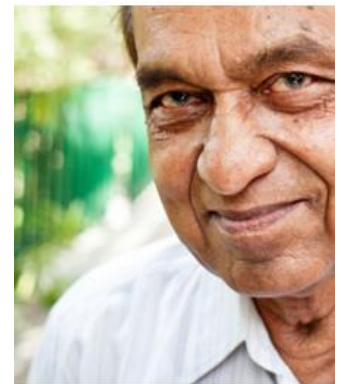


PARTNERSHIP

What do patients/families say about being Partners?

Listening, compassion, respect...

“Listening to and being listened to. The level of compassion and respect was a definite plus for both staff and family and patient members to speak freely about experiences, values, social, economic and cultural concerns.”



What do patients/families say about being Partners?

Purpose, focus, positive...

“Being actively treated for two cancers meant I was no longer able to work. Becoming a Patient Partner allowed me to regain a sense of purpose in my life. It became my new job. It allowed me to focus on something positive.”



What do patients/families say about being Partners?

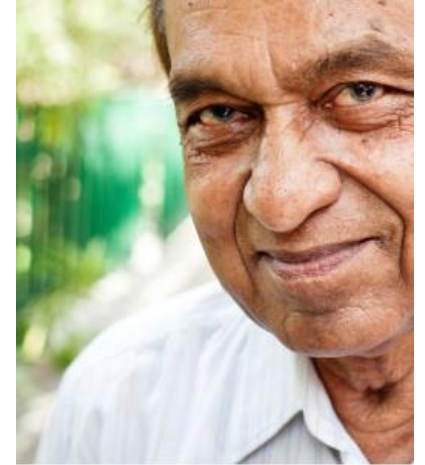
Others, hope, voice...

“I want to be able to help others find hope. Being involved with BC Cancer as a Patient Partner has given me many opportunities over this past year to contribute in health care initiatives and have my voice, the voice of a patient, heard.”



Be a Patient or Family Partner, if you...

- ✓ Have experience with cancer care as a patient or carer of a loved one with cancer
- ✓ Can share your own experience to improve care for all
- ✓ Are good at listening and working with others



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<http://www.bccancer.bc.ca/getinvolved>

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