The patient experience: What do patients tell us about their cancer care experience?

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Using PROMs and PREMs in cancer care

Patient-reported **outcome** measures (PROMs)

- Assess patients’ perceptions of their general or cancer-specific health status
- EQ-5D, ESAS, QoL

Patient-reported **experience** measures (PREMs)

- Assess patients’ perceptions of their interactions with the healthcare system
- Ambulatory Oncology Patient Satisfaction Survey (AOPSS), HCAHPS for in-patient care
Patient perspective

- Experience with cancer and treatment, PROMs (e.g., side effects such as fatigue)
- Experience with health care system, PREMS (e.g., satisfaction)

Why use Patient Reported Experience Measures (PREMs)?

Patients’ values and perspectives can inform the design of healthcare services

- Assess patient experience
- Inform performance improvements over time
- Support benchmarking across institutions, provinces, countries

- Individual interviews/focus groups
- Patient advisors
- Self-report questionnaires/surveys
Asking patients for feedback – AOPSS

- ~100 items + open-ended question
- ~1660 patients/year mailed survey (2013-2018) – all received treatment with last 6 months at JGH, MUHC, or SMHC

- Treatment defined as: surgery, radiation therapy, chemotherapy (oral, IV or both) or any combination of the above
Who answered the survey?

- **3,330 surveys completed** (2013-2018)
- **20-40% response rate**

### By Age

- 75+: 22%
- 65 to 74: 31%
- 55 to 64: 27%
- 45 to 54: 15%
- 35 to 44: 4%
- 25 to 34: 2%
- 18 to 24: 0.3%

### By Cancer Type

- Breast: 31%
- Heme: 15%
- GI: 13%
- Lung: 9%
- GU: 9%
- GYNE: 7%
- H&N: 3%
- Other: 13%

### By Hospital

- JGH: 26%
- MUHC: 36%
- SMHC: 39%
3 AOPSS items addressing overall satisfaction

- 98% rated their overall quality of care as excellent, very good, or good (91% excellent or very good)

- 99% agreed that their care providers did everything they could to treat their cancer

- 99% would recommend their care providers to family and friends
How are we doing by care domains?

Composite Scores (2014-2018)

% pts reporting a positive score

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<thead>
<tr>
<th>Category</th>
<th>RCN</th>
<th>Canada</th>
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<td>Access to Care</td>
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<td>Coordination and Integration of Care</td>
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<td>Respect for Patient Preferences</td>
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Questions with largest difference between RCN and Canada

- Felt provider did everything possible to make radiation therapy wait comfortable: [VALUE]% RCN vs. [VALUE]% Canada
- Felt providers were always aware of test results: [VALUE]% RCN vs. [VALUE]% Canada
- Felt involved in care decisions: [VALUE]% RCN vs. [VALUE]% Canada
- Felt care provider gave family info needed to support pt in care & recovery: [VALUE]% RCN vs. [VALUE]% Canada
- Was referred to provider for anxieties or fears: [VALUE]% RCN vs. [VALUE]% Canada
Gaps in information received

Received enough information about:

- Cancer therapies: 67%
- Physical changes: 60%
- Nutritional needs: 60%
- Changes in energy levels: 55%
- Changes in work & activities: 43%
- Changes in sexual activity: 37%
- Emotional changes: 35%
- Changes in relationships: 27%

“I wish I could have more information about current clinical trials. But my oncologist didn’t provide any.”
- SMHC patient

“I suggest that a list of paramedical services (such as nutrition, physiotherapy, lymphedema support) be given to each patient by their nurse or surgeon”
- JGH patient

“My surgery date was very delayed without adequate explanation. I did not feel involved in the decision-making process on several occasions.”
- MUHC patient
The patient experience... radiation, IV/oral chemo

“I wish I had been advised by my oncologist (and not internet searches) about the long-term side effects of chemo, not just the temporary pain, fatigue, loss or hair and nails.”
- JGH patient

“The management of side effects was not as good as the treatment planning.”
- MUHC patient

“The first chemotherapy treatment was overwhelming. There wasn’t enough information on the side effects of chemotherapy.”
- SMHC patient

- Told how to manage side effects
- Care Provider did everything they could to help with side effects

Radiation
- 74%
- 62%

IV Chemo
- 73%
- 67%

Oral Chemo
- 76%
- 67%
Survey limitations

• Time between treatment and receiving survey could be as long as 6 months → recall bias

• Breast cancer is overly represented

• Does not capture movement within the network and beyond while receiving care

• Every experience is unique, evolving, the sum of many factors, and unlikely to be captured by a one-time survey

Nevertheless, each AOPSS question offers an opportunity to improve care
From AOPSS most frequent open-ended comments (700+):

• Being **rapidly diagnosed** and initiating cancer treatment ASAP
• Receiving personalized care with the **latest and most effective therapy**
• Having **timely access** to **pertinent cancer-related information**
• Care that is **well coordinated**
• Services and support adapted to their and family’s needs
• Feeling **actively engaged** in their cancer treatment and recovery
THE EXPERIENCE OF PATIENTS WITH CANCER AT DIAGNOSIS AND DURING TREATMENT

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We would like to thank patients for taking the time to provide valuable insights into their experience while being treated at the RCN partner hospitals.

To access the report, visit: www.mcgill.ca/rcr-rcn/scorecard
Thank You