Réseau de cancérologie Rossy
Rossy Cancer Network

The experience of patients with cancer at diagnosis and during treatment: A report on the results of the Rossy Cancer Network survey from 2014-2018

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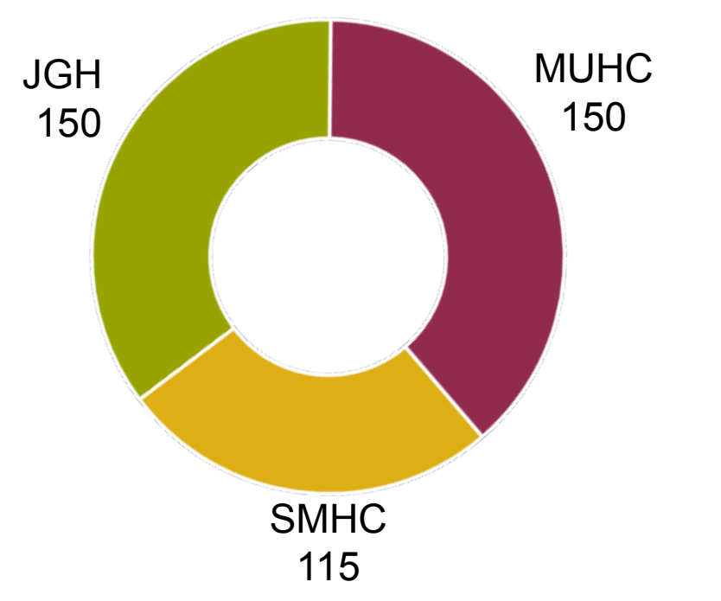
Objectives

- To report patient experience data from the RCN-partner hospitals.
- To highlight person-centered quality improvement intiatives led by RCN.

Methods

- AOPSS (Ambulatory Oncology Patient Satisfaction Survey - NRC Picker)
  - ~100 questions with 1 open-ended item
- Mailed every 3 months to 415 adult patients (April 2013-September 2017)
- Must have received therapeutic treatment (surgery, radiation therapy, chemotherapy (oral or intraveinous) as an outpatient in the last 6 months.
- N = 3278 participants

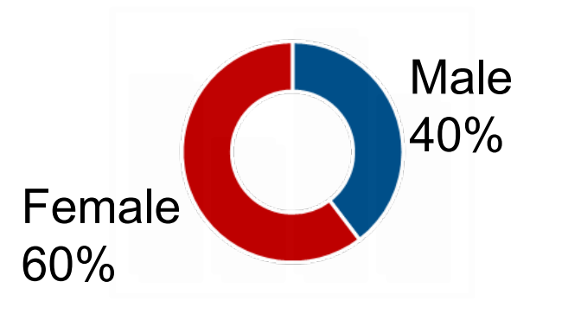


The sample size was selected to roughly reflect the proportion of outpatients seen at each institution.

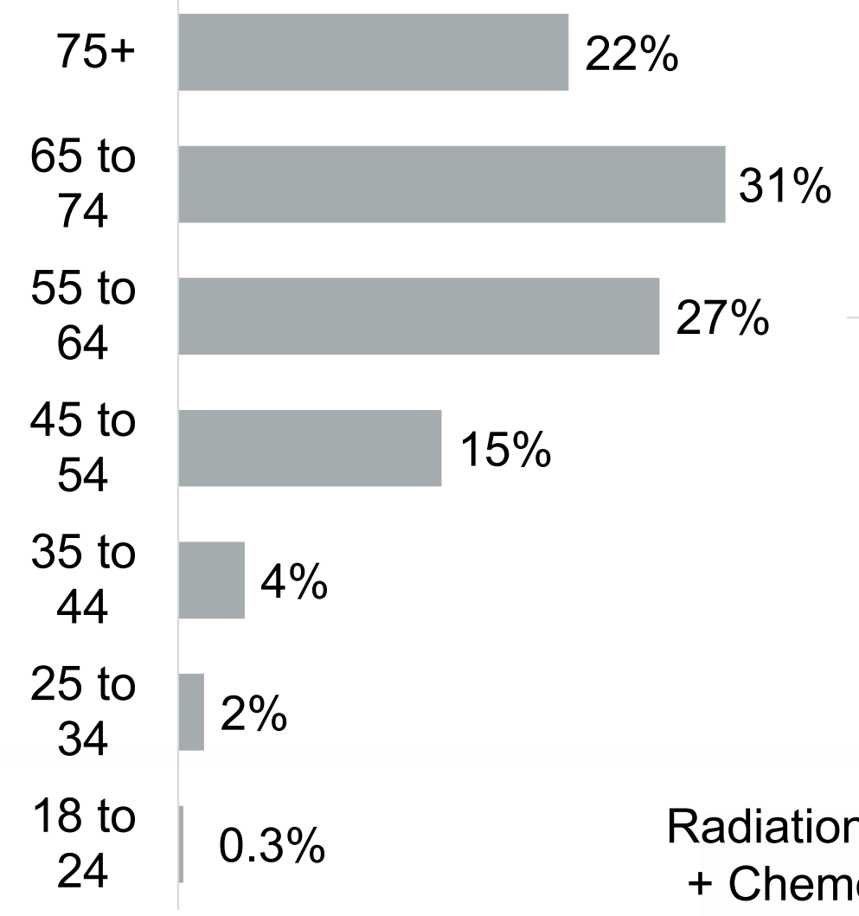
Results

WHO ANSWERED THE SURVEY?

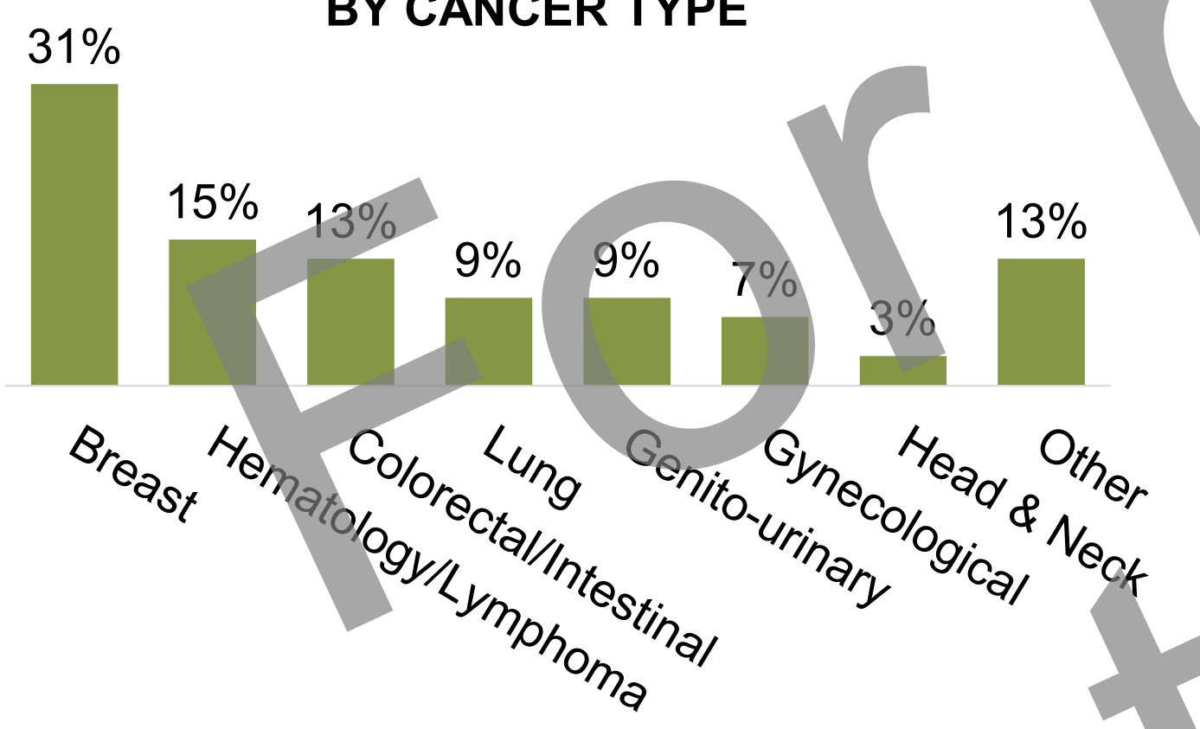
BY GENDER



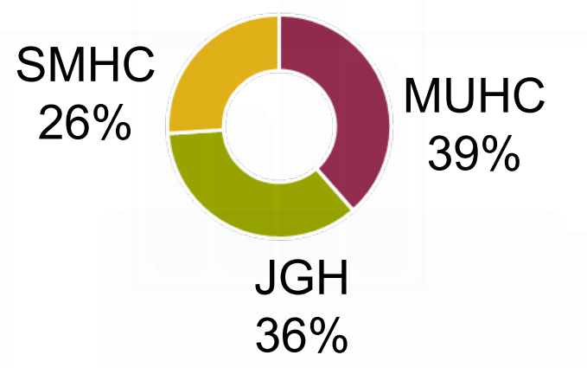
BY AGE



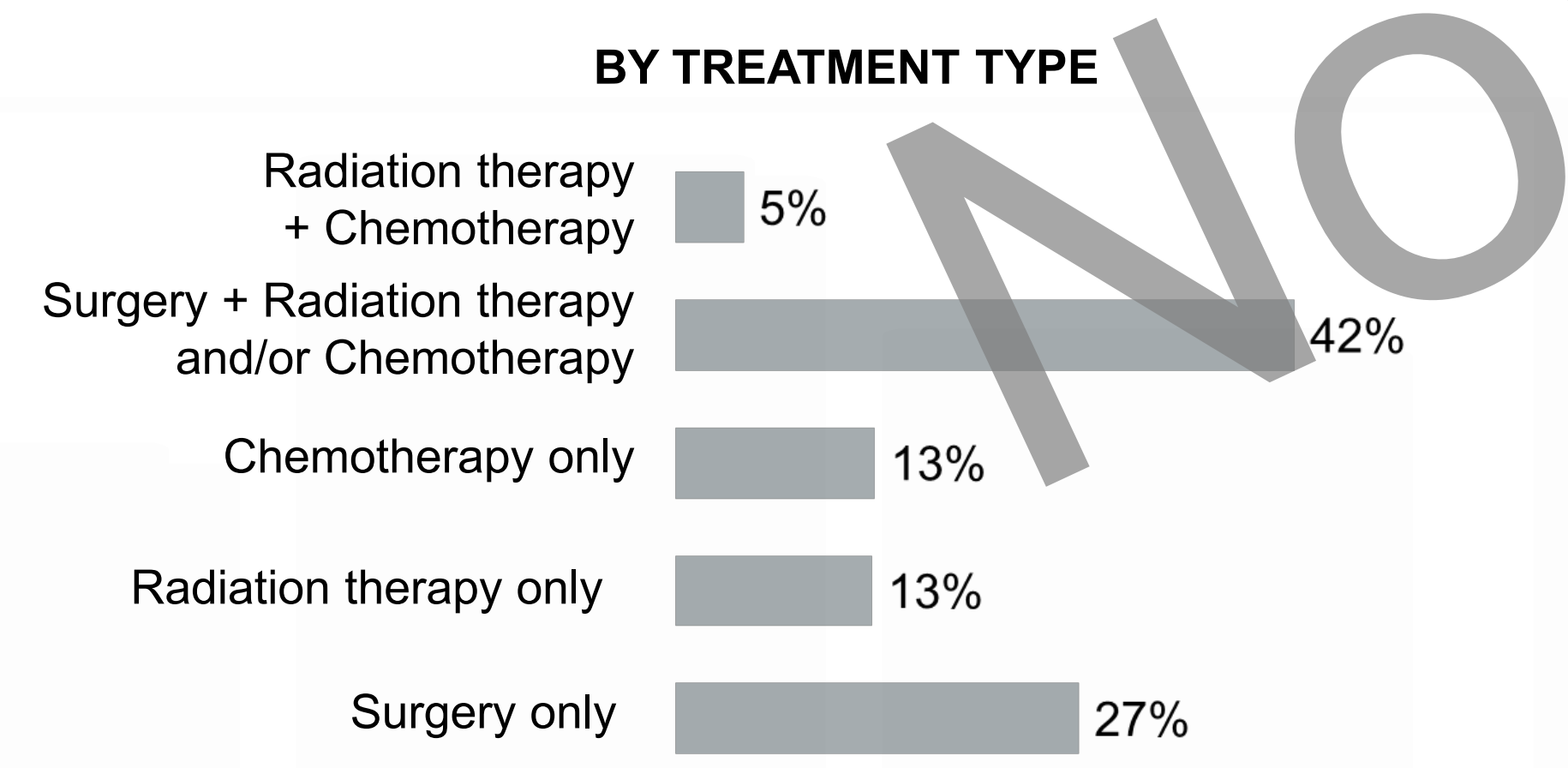
BY CANCER TYPE



BY HOSPITAL



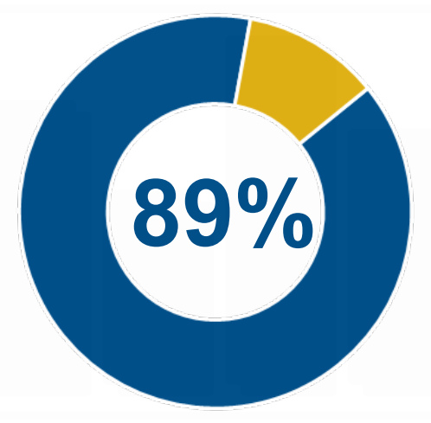
BY TREATMENT TYPE



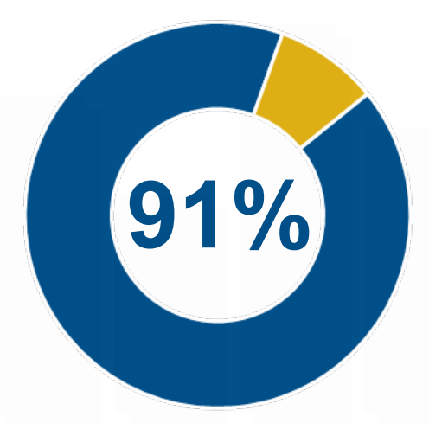
WHAT WE LEARNED

SATISFACTION LEVELS ARE GENERALLY HIGH

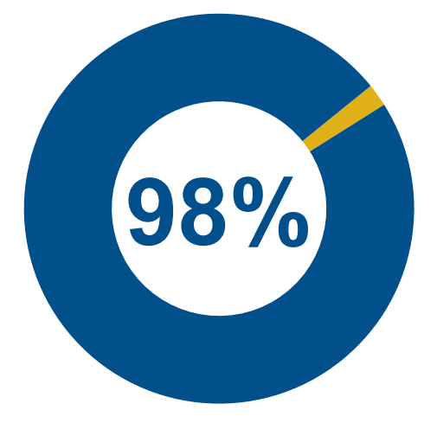
98% rate the quality of care as good, very good or excellent



were satisfied with their care



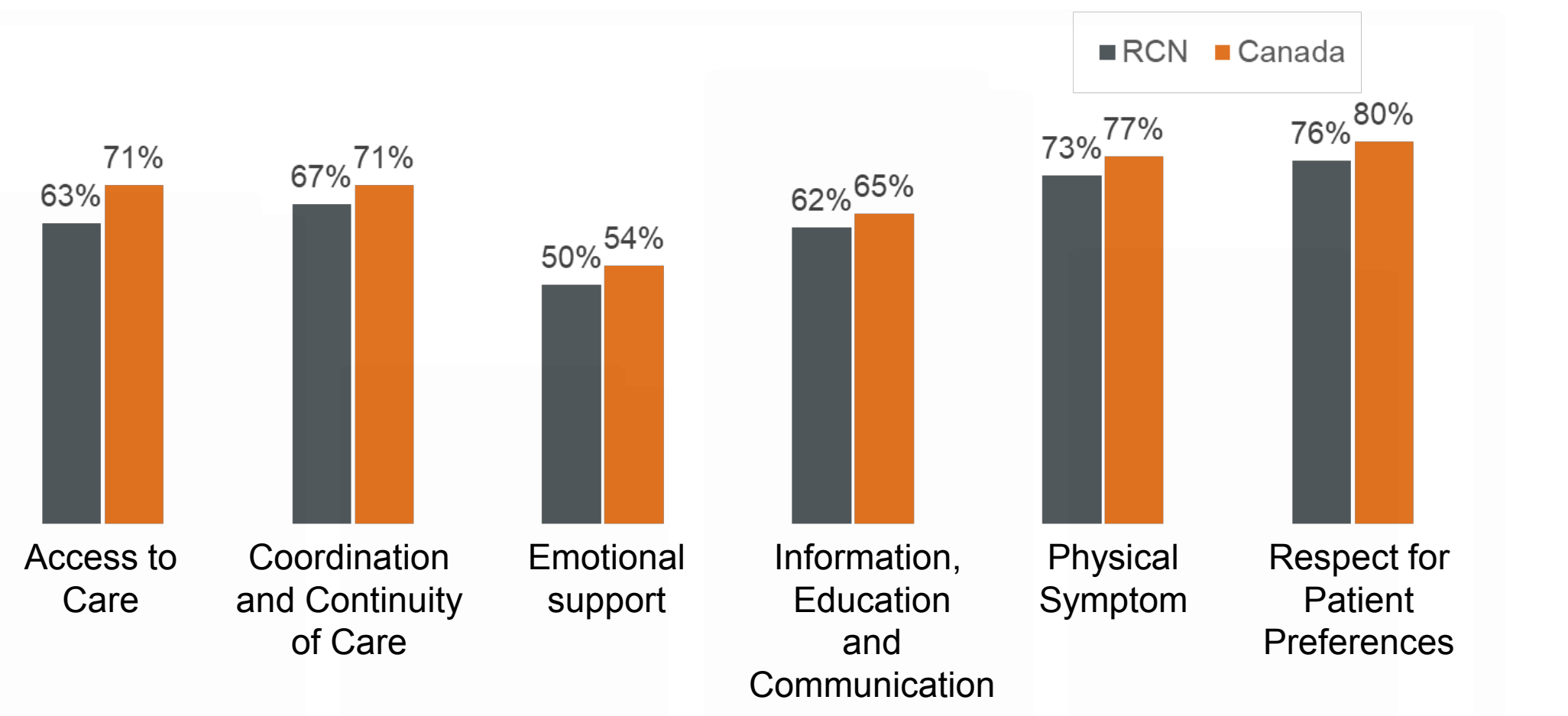
would recommend their hospital



felt their healthcare providers did everything they could to treat their cancer

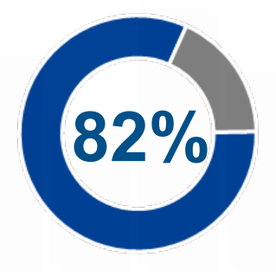
PATIENT EXPERIENCE BY CARE DOMAIN

PERCENTAGE OF PATIENTS WHO REPORTED POSITIVE EXPERIENCES WHILE RECEIVING OUTPATIENT CARE (2014-2018)

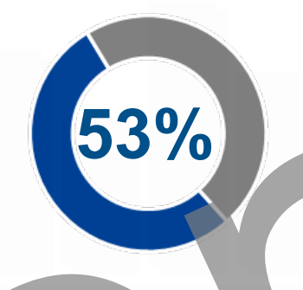


ACCESS TO CARE

- Most have first treatment scheduled quickly.
- Some report long waits on the day of treatment.



Did not have to wait too long for first treatment appointment



Felt care provider considered travel concerns in treatment plan

The Waiting Room Experience

Radiation Therapy		Chemotherapy
67%	Waited longer than expected	73%
68%	Felt care provided did everything to make wait comfortable	65%

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

MAKING CHANGES TO THE WAITING ROOM EXPERIENCE

➢Implementation of a waiting room management system in radiation oncology at the MUHC.

- Reduced line-ups and waiting at registration desk.

➢Development of a mobile application to empower patients with their own information at the MUHC.

- Will allow patients flexibility of leaving waiting room without missing appointments.

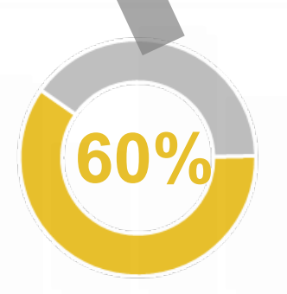
➢Implementation of a two-day system (blood tests on a separtae day from chemotherapy).

- Focuses on improved safety, reduced wait times on day of treatment.

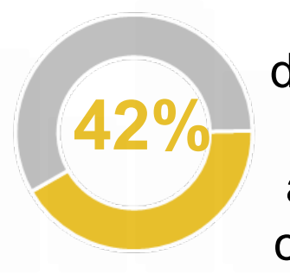
COORDINATION AND CONTINUITY OF CARE

Patients report:

- lack of awareness of their cancer care by their family doctor.
- lack of awareness of their medical history and test results by their cancer specialists.

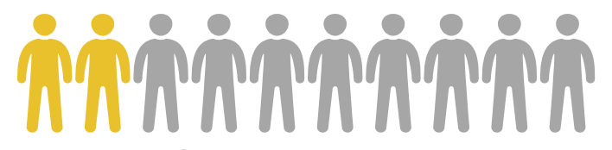


Felt providers always aware of test results



Felt family doctor knew enough about your cancer care ▸ Compared to 60% throughout the rest of Canada

37% of patients felt that their overall care was not always well coordinated



20% of patients, when diagnosed, were not provided with any contact information

> *"My treatment network covers 36 square km in Montreal, and includes four hospitals, five public and five private clinics. In looking for information on how to interact with this type of health bureaucracy while seriously ill, what I have found is that the common element in my healthcare network is me. I'm in the centre. As the centre of my healthcare network, I should hold the key to my data. And my phone is the logical infrastructure from which I should be able to access my data from my healthcare providers, just like I can securely access my banking data from different banks."*
> Laurie, MUHC patient

Laurie, a computer scientist affected by breast cancer was driven by her own experience to develop a patient-centric app in collaboration with the MUHC. The app (OPAL) lets patients store and share their personal health data, appointment information and receive personalized educational materials.

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

KEEPING FAMILY DOCTORS IN THE LOOP

➢Initiative to keep family doctors in the loop.

- Involves an easy-to-use template for oncologists to fill out with diagnostic and treatment plan information.
- Piloted at SMHC.
- 96% of the 43 family physicians involved felt it had a positive impact on their practice.
- Incorporated into routine care at SMHC.
- Adaptation required before larger-scale implementation.

ENSURING FERTILITY PLANNING IS CONSIDERED BEFORE TREATMENT

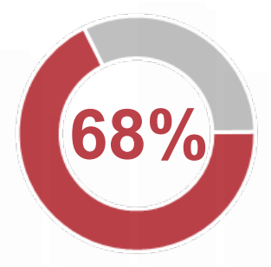
➢Development of brochures and videos on sperm preservation.

- Awareness that cancer treatment can impact fertility and fertility preservation should be initiated early.

➢**A standardized referral system developed to direct patients to the MUHC Reproductive Centre.**

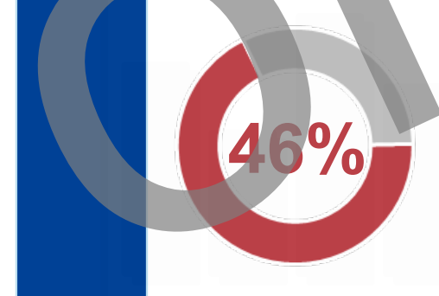
➢Next phase: creating similar resources for women with cancer.

EMOTIONAL SUPPORT



Told of diagnosis in a sensitive manner

Referred to a care provider to help with anxieties and fears when first told of illness



Always received as much help as wanted in figuring out how to pay for any extra costs

81% of patients were aware of information and support services such as Hope & Cope or Cedars CanSupport.

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

KEEPING A CLOSE EYE ON PATIENTS' EMOTIONAL AND PHYSICAL ISSUES

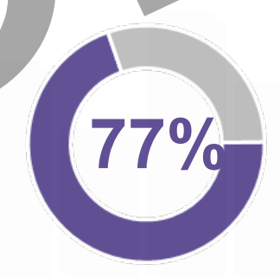
- Three-year pilot to test the use of a symptom assessment scale (ESAS).
- High scores for symptoms like pain, fatigue, anxiety or depression signal healthcare team'S discussions
- Referral to other specialists as needed.
- Expansion is planned for more cancer types: with an estimated 9000 recruited patients over a year.

806 patients took part in the pilot project

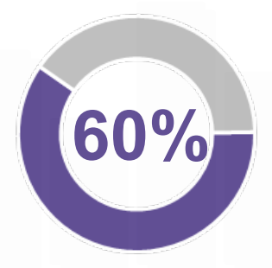
2/3 of patients who completed the ESAS reported that describing their symptoms was easier for them

9/10 healthcare providers reported that ESAS improved their understanding of their patients' symptoms

PHYSICAL COMFORT

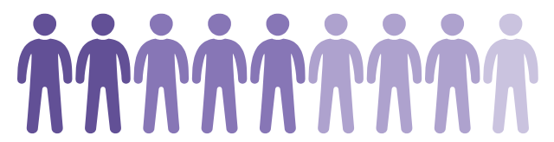


Felt purpose of the oral cancer medication was clearly explained



Told about any danger signals to watch for at home

Reported level of pain during treatment



32% no pain
26% mild pain
28% moderate pain
14% severe pain

67% of patients reported that their care provider did all they could to control pain or discomfort

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

HELPING TO MANAGE SYMPTOMS WITH A PHONE CALL

➢Creating a hotline to avoid Emergency Department visits

- Launched in early 2018.
- Since launch:
  - Only 14% of patients calling in were directed to the Emergency Department
  - Almost 50% of the calls could be managed by self-care

INITIATIVES TO BETTER MANAGE PAIN AND SUPPORT PATIENTS AT END OF LIFE

➢Providing earlier supportive and palliative care

➢Using medical cannabis to manage symptoms

- The RCN instiuted a pilot project in 2018 to evaluate the use of medical cannabis under the guidance of the MUHC Supportive Care Program.
- All services are centralized and free of charge.

Survey Limitations

- Potential recall bias in self-reporting due to survey being retrospective
- Over-representation of a group of participants (women with breast cancer)
- Survey cannot document satisfaction pertaining to all healthcare encounters
- A patient's experience is unique and evolving; it cannot be captured fully by a one-time survey

Discussion and Perspectives

- Patients' needs, values and perspectives should guide the design and delivery of care services
- AOPSS is one of many strategies used to identify gaps and issues in care
- **Every step taken to improve quality of care also contributes to an enhanced patient experience**

"The experience of patients with cancer at diagnosis and during treatment: A report of RCN survey results from 2014-2018" can be found on our website: www.mcgill.ca/rcr-rcn/scorecard

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