A report of
RCN survey
results from
2014-2018

THE EXPERIENCE OF PATIENTS WITH CANCER AT DIAGNOSIS AND DURING TREATMENT

September 2018

Réseau de
cancérologie
Rossy

Rossy
Cancer
Network

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Centre universitaire de santé McGill
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Hôpital général juif
Jewish General Hospital

Centre hospitalier de St. Mary
St. Mary's Hospital Center

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ABOUT THE ROSSY CANCER NETWORK

The Rossy Cancer Network (RCN) is a partnership among McGill University's Faculty of Medicine, the McGill University Health Centre (MUHC), the Jewish General Hospital (JGH) and St. Mary's Hospital Center (SMHC), dedicated to improving the quality of care for patients with cancer.

Launched in 2012, thanks to a transformative gift from the Rossy Family Foundation, the RCN is proudly supported through the fundraising efforts of McGill University along with the Cedars Cancer Foundation of the MUHC, the Jewish General Hospital Foundation and St. Mary's Hospital Foundation.

Here is what we're doing to support our partner hospitals in providing cancer care of the highest possible quality – safe, effective, timely, efficient, well-coordinated and above all, person-centred:

MEASURING AND REPORTING PERFORMANCE

We report on measures that matter to patients, such as delays for treatment, access to new therapies, and the patient experience. We publicly report these measures on the RCN website and ensure that these are shared with healthcare professionals in all three partner hospitals.

DRIVING QUALITY IMPROVEMENT INITIATIVES

We work hand-in-hand with healthcare staff to make lasting improvements to patient services at the three partner hospitals.

CONNECTING HEALTHCARE PROFESSIONALS

We have in place cancer-type specific and supportive care teams — groups of clinicians across different hospitals working to address issues in a multi-disciplinary way. We organize an annual meeting and other events to encourage sharing of best practices and research findings.

FUNDING RESEARCH AND EDUCATION

We support research aimed at improving quality of care for individuals with cancer. We participate in training the next generation of healthcare professionals to enhance skills and outcomes.

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THE PATIENT EXPERIENCE

Navigating the healthcare system after a cancer diagnosis can be a difficult experience for individuals with cancer and their families. To enhance the patient experience, we need to understand that **all interactions that occur within and beyond the healthcare system can affect patients' perceptions of care.**

The Rossy Cancer Network's vision is to support our partner hospitals in providing world-class cancer care based on a person-centred approach in the design of care services.

To deliver care based on patient needs and preferences, **we need meaningful insights into the patient experience.** The feedback that we receive from patients is used to identify gaps in services, gain knowledge of issues that negatively affect patient care, and design service improvements based on patient values.

As part of a broader effort to understand the patient experience within the RCN partner hospitals, we chose to use a standardized survey. The Ambulatory Oncology Patient Satisfaction Survey (AOPSS) was developed and validated by the National Research Corporation (NRC Health). It is also used across Canada and in the United States, allowing us to compare our results with those of other patients in other provinces.

The survey evaluates overall care, as well as **six specific care domains** that are important to the patient experience.

Data presented in this report represent the patients' perspectives of their cancer care experience.

> *The entire experience was terrifying. Suddenly I had cancer. The following six months was a whirl of episodes that I had no control over.*
>
> JGH patient

> *I like to have my situation well explained. Being kept in the dark is the worst situation I could face. I think doctors could spend a bit more time making things clearer so that we can plan our lives better.*
>
> MUHC patient

CARE DOMAINS

RESPECT FOR PATIENT PREFERENCES

Were my healthcare providers sensitive to my unique needs and preferences?

ACCESS TO CARE

Did I wait too long to see my doctor or to receive my treatment? Was my wait time made comfortable?

PHYSICAL COMFORT

Was I told how to manage side effects and symptoms?

COORDINATION AND CONTINUITY OF CARE

Did I receive confusing information? Did I always know who was in charge of my care?

INFORMATION, EDUCATION AND COMMUNICATION

Did I receive clear information about treatments, test results, nutrition and more?

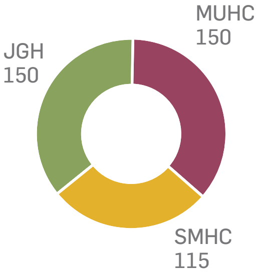
EMOTIONAL SUPPORT

Were my worries addressed?

ASKING PATIENTS FOR FEEDBACK

Each year, we mail out surveys to 1660 patients treated at our three partner hospitals. The 100-item survey also has an open-ended question where patients are encouraged to describe their experiences and perceptions in their own words. Over the last five years, approximately 3300 patients responded to the survey.

The survey is mailed every three months to 415 patients aged 18 years or older who have a confirmed cancer diagnosis and who have received active treatment as an outpatient within the last six months at one of the RCN partner hospitals.



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

Treatment is defined as either:

- Surgery
- Radiation therapy
- Chemotherapy (oral, intravenous (IV) or both)

- Completed surveys are returned to NRC Health in pre-stamped return envelopes, and NRC Health compiles the results. Responses are completely anonymous.
- Roughly 20% to 40% of patients receiving the survey reply, which is a good response rate for mailed out surveys.

NOTES

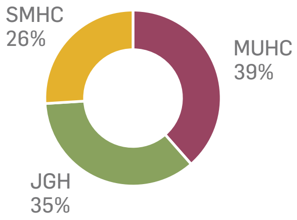
- All quotes in this report were taken from the general comments section on the survey and were not solicited.
- An extra question was added to the survey to understand why and how patients go about getting information about their cancer.
- Numbers may not always add to 100% due to numerical rounding.
- The data are reported by fiscal year. For example, 2014 represents data from patients mailed questionnaires between April 2013 and March 2014.
- Data for year 2018 are incomplete. Only quarters 1 and 2 are reported, corresponding to surveys mailed between April 2017 and September 2017.
- Canadian averages are provided by NRC Health using the most recent data collected from at least five institutions across Canada.
- Data may be influenced by major changes in the healthcare system, including the creation in 2014 of new multi-institutional healthcare networks (CIUSSS) encompassing the JGH and SMHC, as well as by the merging of MUHC services and staff in 2015 at a new location at the Glen Site.

WHO ANSWERED THE SURVEY?

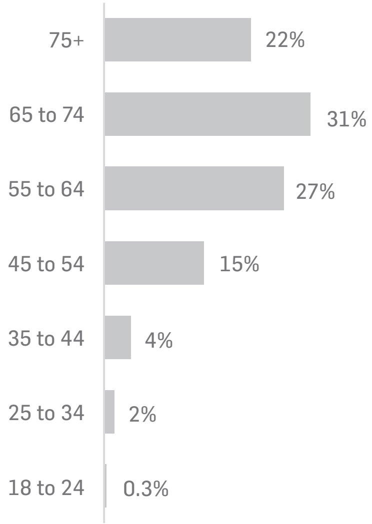
More than half of patients responding to the survey are female (60%) and half of the respondents are over the age of 65. The survey was sent to patients with all types of cancers but we received more replies from women with breast cancer.

BY GENDER

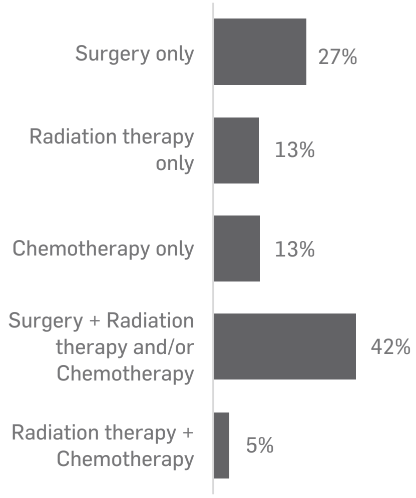
BY HOSPITAL

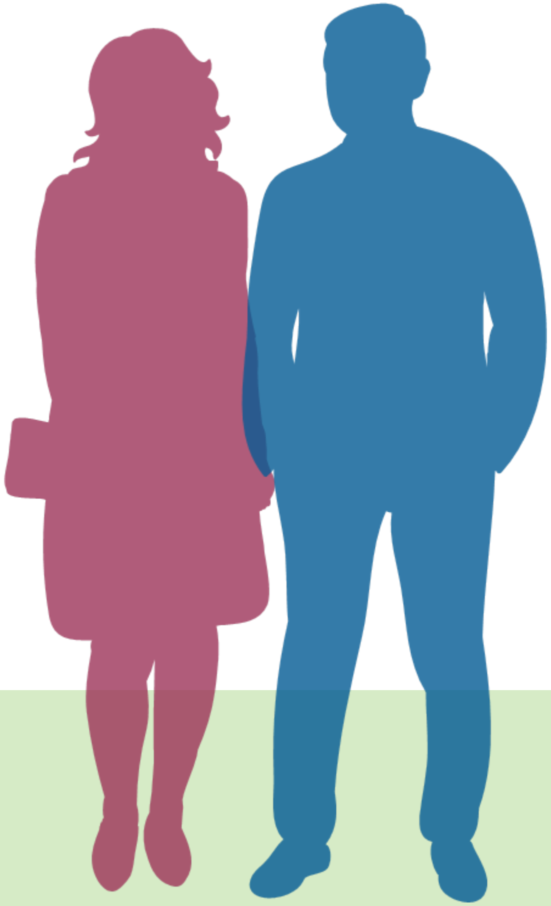


BY AGE

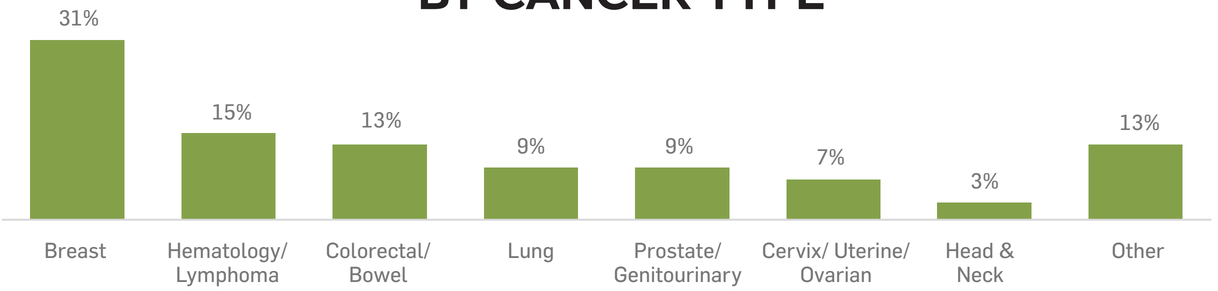


BY TREATMENT TYPE





BY CANCER TYPE



WHAT WE LEARNED

SATISFACTION LEVELS ARE GENERALLY HIGH

Patients treated within the RCN partner hospitals give very high ratings to the overall quality of cancer care they received:

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

SOME AREAS NEED IMPROVEMENT

While overall satisfaction is high, the survey results point to specific areas where care could be improved. RCN partner hospital patients give the highest ratings to care domains of Respect for Patient Preferences and Physical Comfort, and lower ratings to Emotional Support — an area of care that is also rated low in other parts of Canada.

PATIENT INSIGHTS ARE BEING USED TO IMPROVE CARE

Throughout this report, we have highlighted initiatives supported by the RCN to enhance the delivery of care, based on patient feedback. But the survey shows that patients still have unmet needs. Patients need more information at the time of diagnosis and during treatment. They want more support to figure out how to pay for extra costs. They want their travel concerns taken into account during treatment planning. Patients also feel that their worries or concerns are not sufficiently addressed.

Our aim is to raise awareness of issues that matter to patients and inspire healthcare providers and the designers of healthcare services within our network to provide patients with the best care experience.

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.

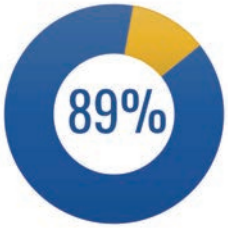
SURVEY LIMITATIONS

While the AOPSS survey can help us learn from patients and their experiences, we also need to consider the following limitations:

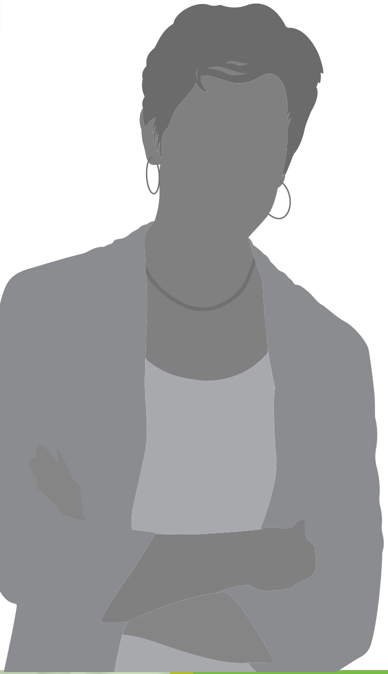
- The time between treatment and receiving the survey can be as long as six months, so patients may not remember everything accurately.
- A higher proportion of patients with breast cancer replied to the survey, which can bias the results.
- It does not tell us about the range of encounters that patients experience while receiving care.
- The survey is not designed to detect improvements that were targeted to specific patient groups or hospitals.
- Every patient experience is unique, is evolving and is the sum of many factors, which are unlikely to be measured by a one-time survey.

HOW ARE WE DOING OVERALL?

Overwhelmingly, patients are satisfied with their care and would recommend their hospital to friends and family.

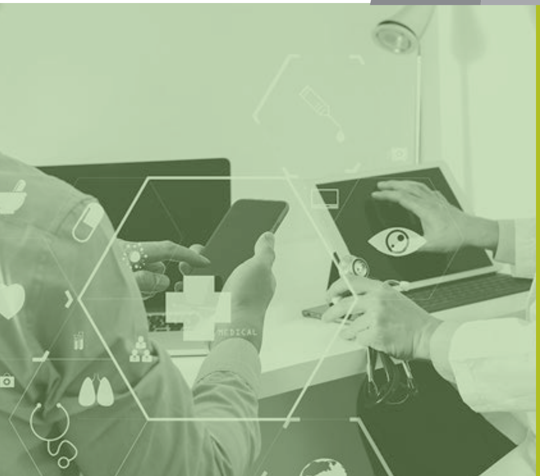


were satisfied
with their care



would recommend
their hospital

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



> *I am very pleased with the cancer care I am receiving. The doctor and clinical team are doing an excellent job. The wait times are always acceptable, very rarely too long. The team and oncologist are very professional. I fully understand the treatment I am receiving. The pharmacist is also always very accessible and helpful.*
>
> MUHC patient

> *The cancer care services are excellent. All the staff from the nurses in the treatment room, to the secretaries at the reception desk, the volunteers, the doctors and pivot nurses treat all patients with respect and compassion. I would not want to go to any other hospital and would recommend this hospital to anyone.*
>
> SMHC patient

> *The oncology team is marvelous. They are always available and listen to the patients. I live very far away but I go to this hospital because the care is exceptional. I am entirely satisfied with the care that I receive and I thank life for having put this team on my path.*
>
> JGH patient

PATIENT EXPERIENCE BY CARE DOMAIN

OVERALL TRENDS

The RCN scores slightly lower than the Canadian average across all care domains.

The domain scores have remained relatively unchanged over the past five years, with the exception of Access to Care.

ACCESS TO CARE

Each year that RCN patients were surveyed (from 2014-2018), there was a significant increase in the percentage of patients who reported positive experiences in the Access to Care domain.

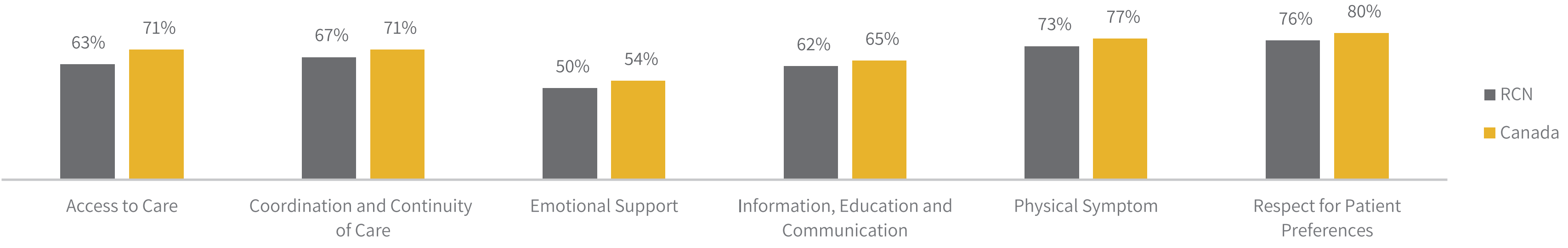
The changes over the years are mainly due to efforts made to improve the waiting room experience for patients receiving chemotherapy or radiation therapy (see Access to Care section, page 10).

EMOTIONAL SUPPORT

Emotional support is low across the RCN and Canada. Only 50% of patients rated their experience as positive, consistent with the rest of Canada.

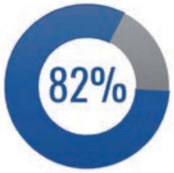
Responses from patients in the RCN partner hospitals are similar to those of others in Canada. Efforts were made by the RCN over the past five years to improve access to care and other specific areas with lower patient satisfaction. Emotional support remains an area in which patients signal a need for improvement.

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



ACCESS TO CARE

Most patients have their first treatment scheduled quickly but some report waiting too long in the waiting rooms on the day of treatment.

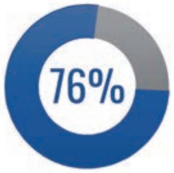


Did not have to wait too long for first treatment appointment

Received all services needed in past 6 months for cancer care

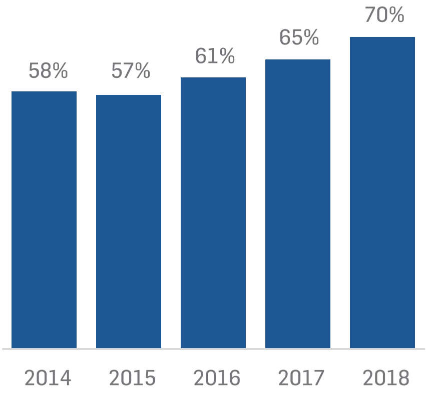
Felt care provider considered travel concerns in treatment plan

SURGERY



Given enough info about how long to wait until the day of surgery

PERCENTAGE OF PATIENTS WHO REPORTED POSITIVE EXPERIENCES IN ACCESS TO CARE OVER TIME



THE WAITING ROOM EXPERIENCE

RADIATION THERAPY

CHEMOTHERAPY

67%
Waited longer than expected for radiation therapy

73%
Waited longer than expected for IV chemo treatment

68%
Felt care provider did everything to make radiation therapy wait comfortable

65%
Felt care provider did everything to make IV chemo wait comfortable

> *The wait time for oncologist appointments is unacceptable. In the past 3 years, my average wait time has been 3 hours.*
>
> SMHC patient

> *When waiting for treatment, and the chairs for chemo are full, it would be nice to be informed of the expected delay.*
>
> JGH patient

> *Radiation should have a system letting us know how long the wait is.*
>
> MUHC patient

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

> *I would appreciate for the blood draw and the chemo to be on the same day. That would prevent us from coming to the hospital twice (loss of work days, parking cost).*
>
> MUHC patient

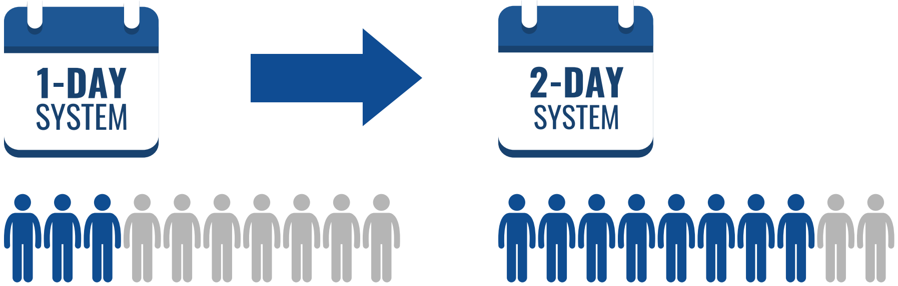
> *It is not helpful to make patients do the blood test one day and treatment the next. Many people have a big distance to travel and it is not convenient. If someone requires assistance they can't always have someone available. It is more difficult and exhausting.*
>
> SMHC patient

> *My only problem is the long time I have to wait to start my chemotherapy treatment after my blood test (about 3 hours). Totally unacceptable.*
>
> MUHC patient

SEPARATING BLOOD TESTS AND CHEMOTHERAPY REDUCES WAIT ON THE DAY OF TREATMENT BUT ADDS EXTRA INCONVENIENCES FOR SOME PATIENTS

A two-day system (blood tests on separate day from chemotherapy appointment) was put in place to improve patient safety, reduce wait time on the day of treatment and use the chemotherapy clinic more efficiently. This change requires most patients to visit the hospital twice, which is still not ideal.

In both the one-day and the two-day system, patients continue to report having to wait too long to see their oncologist on the day of their scheduled appointment.



3/10 patients waited 30 minutes or less for their chemo treatment

8/10 patients waited 30 minutes or less for their chemo treatment

MAKING CHANGES TO THE WAITING ROOM EXPERIENCE

A waiting room management system was implemented in radiation oncology at the MUHC, which has reduced line-ups and waiting at the registration desk.

A mobile application is being developed to empower patients with their own information at the MUHC. This app will be integrated into the waiting room management system and will include wait time predictions and the ability to call patients for their appointments via their phones. This should reduce the stress of waiting and allow patients the flexibility of leaving the waiting room without worrying about missing their appointment.

> *It was a challenge to coordinate all my services. Very little information is shared between the establishments and this causes so much stress on myself, the patient.*
>
> SMHC patient

COORDINATION AND CONTINUITY OF CARE

Patients feel there is a lack of awareness of their cancer care by their family doctor and that their cancer specialists are not always aware of their medical history and test results.

Felt providers knew enough about cancer therapies

Knew who was in charge of care for each therapy

Were never given confusing or contradictory information about health or treatment

Always knew who to ask about health problems

Felt providers always familiar with medical history

Always knew next step in care

Felt providers always aware of test results

Felt family doctor knew enough about your cancer care

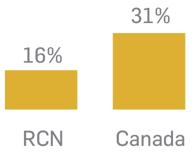
By contrast, 60% of other Canadian patients felt that their family doctor knew enough about their cancer care.

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

In the RCN, surgeons and other cancer specialists are the main care providers who tell patients about their cancer diagnosis. In other provinces, a family doctor is more likely to inform the patient about their cancer diagnosis.

CANCER DIAGNOSIS TOLD BY A FAMILY DOCTOR



HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

KEEPING FAMILY DOCTORS IN THE LOOP

During cancer treatments, many patients also visit their family doctor, who is not always kept up to date. Only 42% of patients in the RCN partner hospitals who visited their family doctor report that the doctor was aware of their cancer treatment – almost 20% less than in the rest of Canada.

Better communication can help manage side effects and help doctors stay on the lookout for complications or cancer recurrence, so an RCN initiative created an easy-to-read template that oncologists can quickly fill out to summarize a patient's diagnosis and treatment plan. The template is sent to family physicians right after diagnosis.

The template was piloted with oncologists at SMHC; 96% of the 43 family physicians involved in the pilot felt it had a positive impact on their practice. The project has since been incorporated into routine care at SMHC. The process and the template need to be revised before they can be adopted at other sites.

ENSURING FERTILITY PLANNING IS CONSIDERED BEFORE TREATMENT

Most men with cancer have no idea that chemotherapy, radiation or surgery may impact their fertility (ability to conceive a child). Often when they find out, the effects on fertility have already begun.

In 2017, an RCN-funded initiative has helped to get the message out to patients and to healthcare providers that fertility preservation needs to be planned early.

Brochures and videos, which explain how sperm preservation works, are now available in hospital oncology waiting rooms and during patient education sessions.
A standardized referral system has also been developed to help direct patients to the MUHC Reproductive Centre. The next phase is creating similar tools for women with cancer.

> *My treatment network covers 36 square kilometers in Montreal, and includes four hospitals, five public clinics 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 mobile app in collaboration with colleagues at the MUHC. The app lets patients store and share their personal health data, appointment information and receive personalized educational material.

Other apps are also being explored and the RCN is instrumental in evaluating the various electronic-health and mobile-health tools that will make a difference in the patient experience.

EMOTIONAL SUPPORT

Patients in the RCN are referred more frequently to a healthcare provider for help with anxieties and fears than other patients in Canada. But emotional support remains the domain with the lowest satisfaction scores, suggesting that patients have unmet emotional needs.

Told of diagnosis in a sensitive manner

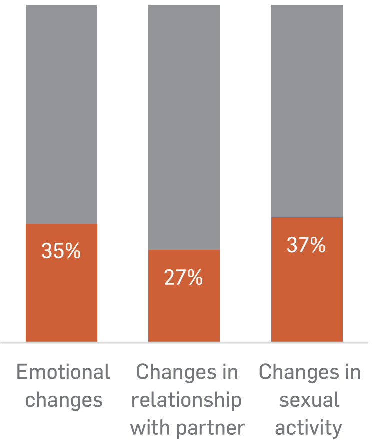
Referred to a care provider to help with anxieties and fears when first told of illness

Put in touch with other care providers who could help with anxieties and fears

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

Felt care provider went out of his or her way to help or make you feel better

RECEIVED ENOUGH INFORMATION ABOUT



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

37% learned of services **before** treatment

61% became aware **during** treatment

> *I felt that my diagnosis was rather rushed. There was no explanation of my results or of how the surgery was to take place. I would have liked to have been more supported.*
>
> JGH patient

> *In relation to the subject of sexuality and emotions, the care team, in general, doesn't talk about it. It would be important to give us a bit more time to talk about it.*
>
> MUHC patient

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

KEEPING A CLOSE EYE ON PATIENTS' EMOTIONAL AND PHYSICAL ISSUES

Regularly monitoring patients' symptoms and side effects, then acting to improve them is an important part of person-centred care.

There are many tools to assess symptoms, such as the Edmonton Symptom Assessment Scale (ESAS), which is often used in Canadian hospitals. This scale is given to patients to evaluate their physical and emotional symptoms, like pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety and well-being. The RCN supported a three-year pilot project to test the periodic use of these scales in selected clinics at the MUHC, JGH and SMHC.

Patients rate their symptoms each time they come for a doctor's appointment. If a patient reports high scores for symptoms like pain, fatigue, anxiety or depression, this triggers more questions on the form about these symptoms. The healthcare team discusses the report with patients at each visit and refers them to specialists when needed.

Monitoring patient symptoms over a period of time allows the healthcare team to make important decisions on how to best manage symptoms. The three-year RCN-led initiative will be expanded across more cancer types in 2018. We estimate that up to 9000 patients per year will participate in routine symptom monitoring across the RCN.

806 patients with different cancer diagnoses took part in the pilot project

2/3 of patients who completed the ESAS reported that it made it easier for them to describe their physical and emotional symptoms

7/10 patients with an appointment in one of the pilot project clinics agreed to rate and evaluate their symptoms using the scale provided

9/10 healthcare providers reported that patient self-report tools improved their understanding of their patients' symptoms

> *Cancer is a traumatic experience. I am forever grateful to the caregivers who did what they could to allay my fears.*
>
> MUHC patient

> *As a first-time cancer patient, I had no prior experience to know if I would have those anxieties during treatment. The information on support services should be reinforced periodically throughout the treatment to ensure that those in need are steered In the right direction.*
>
> SMHC patient

INFORMATION, EDUCATION AND COMMUNICATION

Patients report not receiving enough information on cancer treatment options or on the physical changes that may be caused by their treatment. They also report not being informed of reasons for delays for their first consultation appointment.

Someone discussed different cancer treatments

Comfortable talking with staff about clinical trials or new treatment

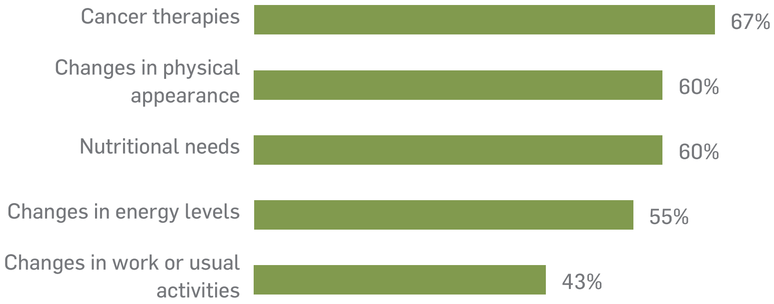
Felt provider explained understandably why tests were needed

Test results were explained understandably

Surgery results were explained understandably

Delay before first consultation appointment was explained (if applicable)

RECEIVED ENOUGH INFORMATION ABOUT:



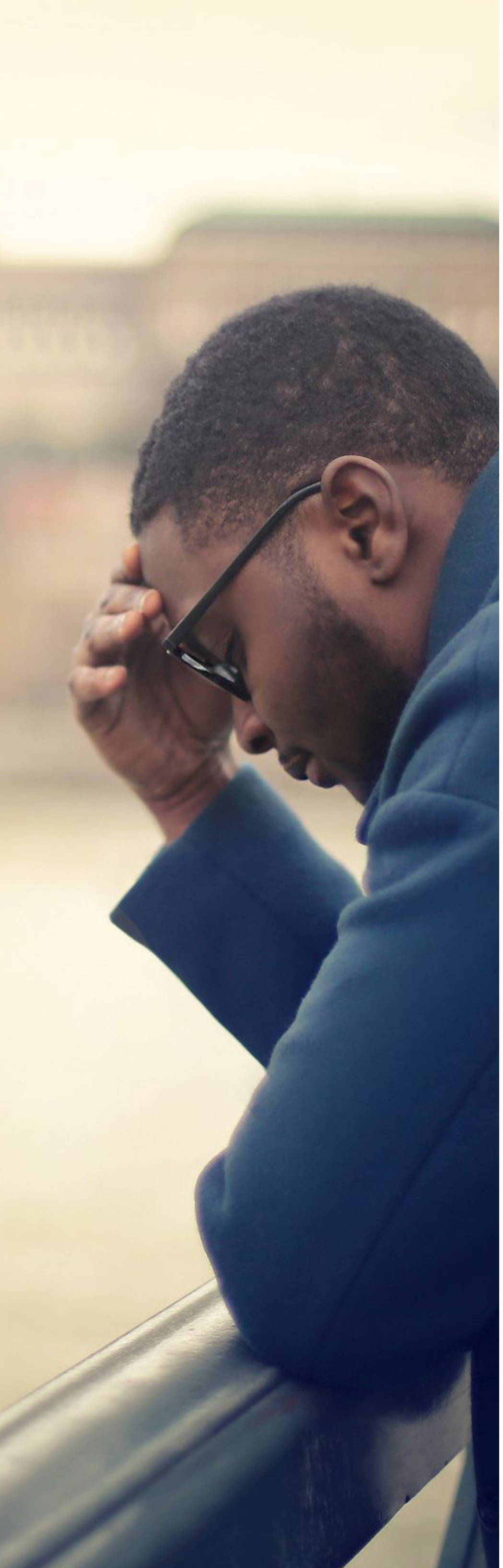
Patients differ in their preferences for cancer information. Of the patients who responded to the AOPSS survey:

- 60% self-identified as interested in information about their cancer;
- 40% self-identified as disinterested or preferring to avoid information about their cancer.

> *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, psychology, 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



HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

TALKING WITH PATIENTS ABOUT CLINICAL TRIALS

Patients report wanting more information on available treatments, so the RCN is making it easier for patients to know about the clinical trials available at the McGill-affiliated hospitals. Clinical trials give patients access to new treatments that wouldn't otherwise be available.

The RCN website has a list of over 150 active trials in the network. A patient education initiative is underway in the three partner hospitals, encouraging patients to ask their healthcare team about clinical trials. See all the trials at mcgill.ca/rcr-rcn/clinical-trials.

PROVIDING HEALTHCARE STAFF WITH TOOLS TO TALK ABOUT SEX & CANCER

Patients report that sexual changes and body image are not often addressed by their healthcare team. However, this is an important issue for them during cancer treatments.

To address this concern, the RCN provided support for nurses to access a tutorial on Sex and Cancer from the de Souza Institute. This will help front-line staff discuss this topic more knowledgeably. The first cohort of nurses will take the tutorial by the end of 2018. This is only one of many learning opportunities offered through the RCN's Nursing Skills Enhancement Grants.

PREPARING PATIENTS FOR SURVIVORSHIP

Individuals with cancer may need the same amount of time recovering from treatment as they spent being treated. This makes survivorship very challenging. Patients often feel unsupported when treatment ends. So an RCN-funded initiative called Looking Forward worked with a team of cancer survivors and healthcare staff to create booklets and a self-assessment questionnaire. Important priorities include physical recovery, emotional changes, and returning to work. Looking Forward is available at mcgill.ca/rcr-rcn/resources.

HELPING FAMILIES BREAK THE NEWS TO A CHILD

Talking to a child or a teen about a family member's cancer diagnosis can be difficult. To help with the process, in 2013 the Canadian Association of Psychosocial Oncology (CAPO) developed Start the Talk — a series of online modules to give healthcare professionals, individuals with cancer and their families the tools to address cancer with children and teens.

The interactive website uses videos, images and text to convey in simple terms what cancer is, ways to help children cope and tips on how to discuss the stages of the disease.

In 2017, an RCN-funded initiative made these resources accessible to all patients across Canada by developing a French version of the modules, and launching the websites Startthetalk.ca and Parlonsen.ca.

PHYSICAL COMFORT

About 25% of individuals with cancer are not sufficiently aware of the potential side effects of their treatment and how to best manage them. For oral cancer medication, this is even more of an issue.

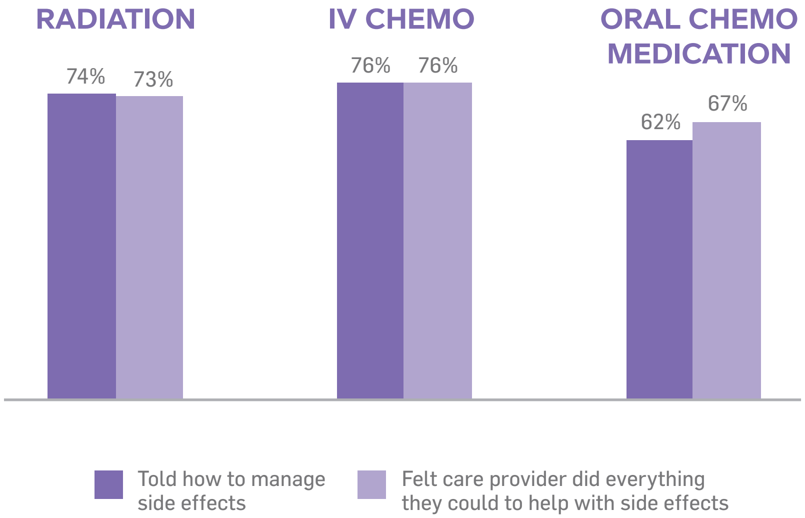
Many cancer medications are given as pills or tablets. These can be as potent as IV chemotherapy and must be taken as the doctor prescribes. Oral cancer medications can cause the same side effects as other types of chemotherapy. It is important that these be properly explained to patients and managed appropriately. Patients mainly get information about oral medications from their doctor (33%), pharmacist (31%) or nurse (27%).

Felt purpose of the oral cancer medication was clearly explained

Told in clear and understandable way how to take oral cancer medication

Told about any danger signals to watch for at home

Knew whom to talk to for any questions or concerns



DURING TREATMENT, PATIENTS REPORT DIFFERENT LEVELS OF PAIN

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

> *I wish I had been advised by my oncologist (and not by internet searches) about the long-term side effects of chemo, not just the temporary pain, fatigue, loss of 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

HOW WE ARE IMPROVING THE PATIENT EXPERIENCE

> *My husband passed away after a long hospitalization. It was very difficult because of divergent opinions by doctors. It was all in all a traumatizing experience for him and for our family. The approach to patients by doctors should be reviewed particularly during end of life.*
>
> MUHC patient

HELPING TO MANAGE SYMPTOMS WITH A PHONE CALL

Creating a hotline to avoid Emergency Department visits

Chemotherapy treatments can lead to a number of physical side effects. If they are not treated early, these side effects can get worse and lead to a trip to the Emergency Department or even to being admitted to hospital.

In the three RCN partner hospitals, there were over 3000 cancer-related visits to Emergency Departments in 2017. Many of those visits could have been prevented if symptoms were managed early.

To help patients avoid the stress and potential infections of a crowded Emergency Department and to help improve their outcomes, a new rapid-response hotline was launched at the JGH for patients concerned with symptoms that may be related to their IV chemotherapy. This Symptom Management Hotline is staffed by nurses who quickly give patients information about the best way to deal with their symptoms.

Since it was launched in early 2018, only 14% of patients calling in were directed to the Emergency Department, and almost half of the calls could be managed by self-care. The MUHC already operates a similar hotline staffed by a trained nurse. At SMHC, patients can call the Cancer Care Day Center Clinic or the in-patient unit and be directed to the appropriate resource who can answer their concerns.

Creating an urgent care centre for individuals with cancer

The goal by 2019 is to open outpatient urgent care centres inside the existing cancer clinics in each RCN partner hospital.

This will allow patients to receive urgent care in an oncology setting that is specialized to meet their needs, while avoiding the Emergency Department.

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

Providing earlier supportive and palliative care

Patients with advanced lung cancer often report pain, difficulty breathing, poor appetite, and low mood as a result of their cancer or treatment, all of which can impact their quality of life. Research shows that for patients with stage IV lung cancer, introducing supportive or palliative care early after diagnosis helps the healthcare team control patients' symptoms better and improve their quality of life.

The RCN is currently developing a process to offer patients' early palliative care along with their cancer treatment at the three RCN partner hospitals. As part of the initiative, healthcare teams will discuss the goals of care and the patient's treatment preferences within two months of diagnosis. This will allow patients to have an earlier and better understanding of their prognosis and more awareness of end-of-life treatment options.

Using medical cannabis to manage symptoms

Medical cannabis has been approved to manage patients' symptoms such as severe pain, nausea and loss of appetite, as well as side effects from treatments. However, there is still limited knowledge about how to prescribe medical cannabis and integrate it into clinical cancer care.

That's why the RCN instituted a pilot project in 2018 evaluating the use of medical cannabis as a complementary treatment under the guidance of the MUHC Supportive Care Program. Patients are evaluated for physical and psychosocial symptoms by a physician and nurse; those who meet specific criteria can be prescribed a cannabis product in addition to other medications.

As part of this pilot project, all services are centralized and free of charge. Patients have access to highly specialized medical expertise and are regularly monitored. This improves coordination and ensures the healthcare team has the relevant information to manage patient care.

RESPECT FOR PATIENT PREFERENCES

Patients report that they are treated with dignity and respect by their healthcare providers. However, many patients want to be more involved in decisions about their care. They want their family or living situation to be taken into consideration when planning treatment and they would like to be able to discuss complementary therapies.

Treated with dignity and respect by care providers

Involved in decisions about care as much as respondent wanted

Felt family or living situation taken into account when planning treatment

Comfortable talking with care provider about alternative therapies

Felt family or friends appropriately involved in care and treatment

Felt someone discussed different cancer treatments

7/10 patients felt their doctor and care providers always listened carefully to them

> I would have liked to receive documentation when I first got my cancer diagnosis, instead of before starting chemotherapy. That would have helped me to make a more enlightened decision.
>
> SMHC patient

> Doctors need to be open to alternative cancer treatments.
>
> JGH patient

> The doctor should better explain the effectiveness and survival rate of the different cancer treatments.
>
> MUHC patient

HOW THE RCN WILL CONTINUE TO IMPROVE THE PATIENT EXPERIENCE

WE BELIEVE PATIENT VALUES AND PERSPECTIVES SHOULD GUIDE THE DESIGN OF HEALTHCARE SERVICES

The AOPSS survey is only one way that we identify issues. We also give patients a voice through focus groups and as patient advisors on project teams. Throughout this report, we provided examples of actions that the RCN has taken to enhance the patient experience. **But we know that more work needs to be done.**

EVERY STEP WE TAKE IN IMPROVING THE QUALITY OF CARE ENHANCES THE PATIENT EXPERIENCE

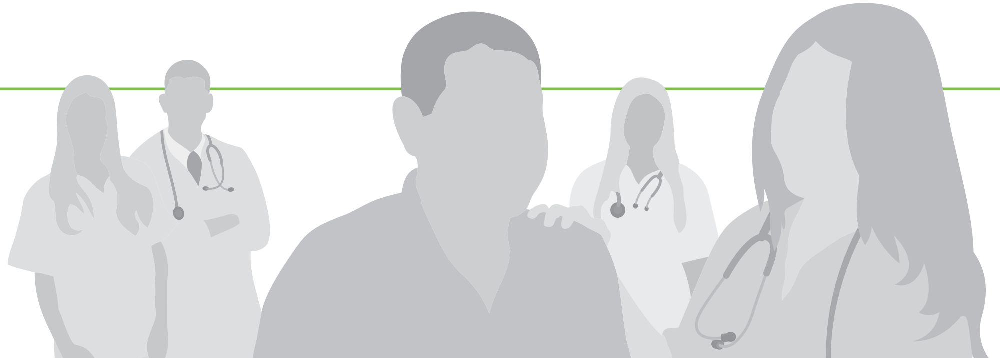
We support our partner hospitals in advancing best practices in clinical care, collaborating on clinical trials so patients have access to breakthrough treatments, supporting healthcare service innovation, and encouraging knowledge sharing between healthcare professionals across the network. All of these elements play an integral part in providing world-class person-centred care.

OUR GOAL IS TO HAVE PATIENTS EXPERIENCE THE HIGHEST LEVEL OF SATISFACTION WITH THEIR CARE

We want all patients receiving care in the RCN partner hospitals to feel that:

- They were **rapidly diagnosed** and started their cancer treatment quickly
- Their care was personalized and they received the **latest and most effective therapy**
- They received **pertinent and timely information** about their treatment and its possible side effects
- Their **care** was **well coordinated**
- They received the **services and support** they or their family **needed** to respond to their concerns
- They felt like a **partner** in their cancer treatment and recovery

> *The treatment I received has been outstanding. Everyone from the nurses, oncologists, surgeons, radiology department, phlebotomists and volunteers have made this experience truly remarkable. They have all been caring and shown tremendous dedication and compassion.*
>
> *Thank you.*



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