



Canadian Breast Cancer Network
Réseau canadien du cancer du sein

BREAST CANCER

THE LIVED EXPERIENCE



BREAST CANCER

THE LIVED EXPERIENCE

ACKNOWLEDGEMENTS

The Canadian Breast Cancer Network would like to acknowledge and thank the hundreds of Canadian women who so openly and honestly shared their experience of being diagnosed with breast cancer. Your insights have painted a vivid picture of what it truly means to have breast cancer, what is needed to manage and cope with this diagnosis, and what needs to be improved to better the lives of people and families affected by all stages of this disease. Your resilience and willingness to share your personal story is a testament to who you are, and we sincerely thank you for sharing this with us.

This report is dedicated in loving memory of Laurie Kingston, who was key in the development of the survey for people living with metastatic breast cancer. Laurie's own experience of living with this stage of the disease was integral in helping to ensure that information gathered through this survey can help improve the lives of others.

We also acknowledge the input of Diana Ermel and Wendy Panagopoulos for guidance and leadership in the development of the early stage survey. Their personal experience, expertise as health care professionals, and connection with the breast cancer community were integral in developing a survey that was relevant and framed in a manner that truly captures the lived experience.

We would also like to recognize the health care professionals, many who go above and beyond to improve the lives of their patients. Countless survey

respondents shared how appreciative they are of their health care team and the support, guidance, and care that they have received from them. While there are areas of improvement that are identified throughout this report that relate specifically to health care professionals, they are mostly reflective of systematic improvements that need to be made.

The Canadian Breast Cancer Network would also like to acknowledge with gratitude the generous unrestricted grants provided by the following funders who made this project possible: Full Circle Foundation for Wellness, Pfizer Canada, Novartis Pharmaceuticals Canada Inc., Hoffman-La Roche Limited, Astra Zeneca, Amgen Inc., Healthy Cravings, and United Awareness Group. In addition, thank you to our partner organizations, health care professionals, and individuals who circulated and promoted the surveys.

This report is authored by the Canadian Breast Cancer Network; written by Jenn Gordon, Rebecca Armstrong, Niya Chari, and Wendy Hall; and edited by Cathy Ammendolea, Diana Ermel, and Wendy Panagopoulos. The design and layout were beautifully created by Unika Studio.

The Canadian Breast Cancer Network has been working for 24 years to voice the views and concerns of Canadians with breast cancer. As the patient-directed national organization, we continue our commitment to be the national voice of patients and survivors and ensure that the lived experience is heard and considered by decision makers across the country.

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EXECUTIVE SUMMARY

In 2017, the Canadian Breast Cancer Network (CBCN) undertook two surveys of Canadians who have experienced a breast cancer diagnosis to better understand the lived experience of patients and what opportunities exist to improve support for patients, survivors and their families and minimize the impact of this disease. There were 278 people diagnosed with early stage breast cancer, defined as stage I, II, or III for the purpose of this report, and 180 people living with metastatic breast cancer, or stage IV breast cancer, who responded to these surveys.

The purpose of these surveys was to capture the lived experience of Canadians who have received a breast cancer diagnosis and the entire spectrum of this experience, from detection through to survivorship or living with metastatic breast cancer. The intent is to use this data to voice the needs of breast cancer patients to decision makers, health care professionals, community organizations, and health charities. CBCN also intends to use this information to inform our own work to better support the needs of patients through education and advocacy.

The lived experience of Canadians diagnosed at an earlier stage is shared alongside people living with metastatic breast cancer. There are some shared similarities experienced by both groups, but there are also significant differences in priorities and experiences at various points in this process. Understanding the similarities and differences between these two groups is key to better addressing the unique needs of patients with various stages of breast cancer.

This report shows that while patients feel supported and well cared for in certain aspects, there are still significant opportunities for improvement. CBCN has identified five overarching factors that could greatly improve health outcomes and the quality of life of Canadians who experience a breast cancer diagnosis.

1. Improved Educational Resources: The quality and availability of patient education has increased over the past couple of decades; however, there are still some patient-friendly educational resources that are lacking. These include: specific resources for newly diagnosed metastatic breast cancer patients; decision aids that support breast cancer surgery and post-surgery decisions; navigation of financial resources; treatment timelines and recovery expectations; private insurance navigation; and information on dying-well.

2. Increased Access to Treatments: This challenge was specifically identified and vocalized by people living with metastatic breast cancer; but as new treatments move into the early stage setting, this will also be a concern for early stage patients. Efforts need to continue to shorten the drug approval process time, increase equitable access to new medications for all Canadians, and ensure equitable access for take-home oral cancer medications.

3. Increased Access to Information: Information available to patients about their health and treatment has increased; however, there is still information that isn't always communicated to patients that would help them make informed decisions about their health. This includes information about breast density, palliative care options, and information around clinical trials.

4. Integrated Systemic Supports: The health care system as a whole is responsible for many of the services and supports that patients need to achieve optimal health and manage their breast cancer; however, these supports can be challenging to navigate and are sometimes lacking. Supports that need to be addressed at a systemic level include developing survivorship care plans for early stage patients, patient navigation, communication tools to support general practitioners during the diagnosis process, access to psychosocial professionals, and increased Employment Insurance Sickness Benefits.

5. Increased Awareness and Understanding of Metastatic Breast Cancer: A lack of accurate statistics and overall awareness of metastatic breast cancer makes it challenging to truly understand the impact of this disease and also leaves people living with an incurable form of breast cancer feeling isolated and disconnected. Accurate statistics and increased awareness would help further the understanding of the impact of this stage of breast cancer and better support those with it.

Addressing these gaps, means improving the lives of hundreds of thousands of Canadians. This report will intensely examine the lived experiences of patients and how their insight can be used to improve the experience of breast cancer patients now and in the future.

Experiencing a breast cancer diagnosis is overwhelming. While overall survival for those diagnosed at an earlier stage is relatively high, the impact is still significant given that 5,000 Canadians die from metastatic breast cancer each year. Twenty-five percent of all cancers diagnosed in Canadian women will be breast cancer, meaning that 1 in every 8 women will receive this diagnosis in her lifetime. In 2017, over 26,000 women in Canada were diagnosed with breast cancer. While progress has been made in reducing breast cancer deaths, 13% of all female cancer-related deaths will still be a result of breast cancer¹.

Given that breast cancer continues to impact a large portion of the Canadian population, it's imperative to understand the lived experience of patients and what opportunities exist to improve support for patients, survivors, and their families and minimize the impact of this disease.

In 2017, the Canadian Breast Cancer Network undertook two surveys of Canadian breast cancer patients to better understand their lived experience. There were 278 people diagnosed with early stage breast cancer (defined as stage I, II or III for the purpose of this survey), and 180 people living with metastatic breast cancer (also referred to as stage IV) who responded to this survey. Patients shared very honest and specific information about what it's like receiving a breast cancer diagnosis in Canada and can be improved to better support Canadians going through this experience.

This report addresses each stage of a patients' experience; from how their cancer was detected, to the process of being diagnosed, through treatment and then living after and with a breast cancer diagnosis. This report also looks at the impact on families, the financial burden of cancer, and the psychosocial impact and effect on overall well-being.

The lived experience of Canadians diagnosed at an earlier stage is shared alongside people living with metastatic breast cancer. There are some shared similarities experienced by both groups, but there are also significant differences in priorities and experiences at various points in this process. Understanding the similarities and differences between these two groups is key to better addressing the unique needs of patients with various stages of breast cancer.

¹ Canadian Cancer Society <http://www.cancer.ca/~media/cancer.ca/CW/publications/Canadian%20Cancer%20Statistics/Canadian-Cancer-Statistics-2017-EN.pdf>

INTRODUCTION



METHODOLOGY AND DEMOGRAPHICS

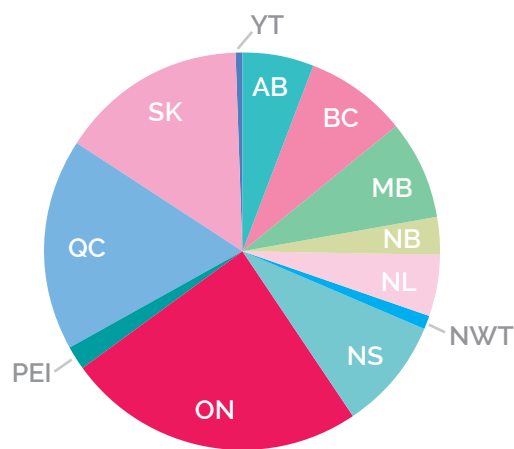
The information for this report was collected through two online surveys published in 2017 in both English and French by the Canadian Breast Cancer Network. The surveys were circulated to individuals and groups through social media, digital newsletters, and www.cbcn.ca. These surveys were limited to people who are currently living in Canada who had experienced a breast cancer diagnosis. One survey was specifically for people who had received an early stage breast cancer diagnosis, defined as stage I, II or III; the other survey was specifically for people who had experienced a metastatic breast cancer diagnosis, also known as stage IV breast cancer. Both surveys consisted of a combination of multiple choice questions and open-form questions that allowed respondents to share their personal experience.

The overarching limitation in both surveys is the homogeneity of the respondents. All respondents identified as female; given that breast cancer primarily affects women, this is to be expected. However, approximately 100 men are diagnosed with breast cancer in Canada each year, but their experiences are not captured through this survey.

In addition, most respondents were Caucasian; the French-Canadian community was also well represented. However, racial or ethnic groups outside of these lacked representation. The majority of respondents were well-educated, having some type of post-secondary schooling, and the majority had an annual household income of \$60,000 or more.

EARLY STAGE

The **provincial/territorial representation** of respondents was generally reflective of the disbursement of the Canadian population: Alberta 6%; British Columbia 8%; Manitoba 8%; New Brunswick 3%; Newfoundland and Labrador 5%; Northwest Territories 1%; Nova Scotia 9%; Nunavut 0%; Ontario 24%; Prince Edward Island 2%; Québec 17%; Saskatchewan 15%; and Yukon 0.41%.



Most respondents, 80%, were currently in a **relationship**, and 100% of respondents identified as female. The majority, 98%, identified as heterosexual; 1% as homosexual; and 1% as bi-sexual. No one identified as having a sexual orientation outside of these three.

When asked which **racial or ethnic group** people most identified as, respondents indicated the following: African-Canadian 0%; Asian 1%; Caribbean 0%; Caucasian 76%; Indigenous Peoples 3%; French Canadian 16%; Hispanic/South American 0%; Middle Eastern or North African 0%; Pacific Islanders 0%; South Asian 0%; Other 4%.

Respondents identified their highest **level of education** as follows: elementary school 1%; secondary school 13%; college or college equivalent 38%; university undergraduate 30%; university masters 16%; and university doctorate 2%.

Respondents identified their total **annual household income** as follows: Less than \$20,000 (2%); \$20,000 - \$39,999 (8%); \$40,000 - \$59,999 (9%); \$60,000 - \$79,999 (11%); \$80,000 - \$99,999 (14%); \$100,000 - \$149,999 (14%) and \$150,000 or higher (16%). Twenty-five percent preferred not to say.

AGE AT DIAGNOSIS

A TOTAL OF



278 people
responded to the **EARLY STAGE SURVEY**

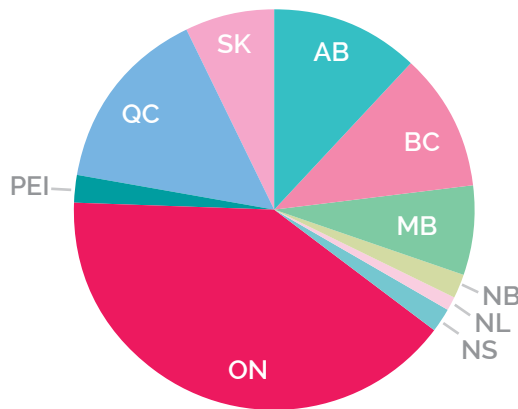


180 people
to the **METASTATIC SURVEY**



METASTATIC

The **provincial/territorial representation** of respondents was generally reflective of the disbursement of the Canadian populations except for Ontario, which was significantly larger: Alberta 12%; British Columbia 11%; Manitoba 7%; New Brunswick 2%; Newfoundland and Labrador 1%; Northwest Territories 0%; Nova Scotia 2%; Nunavut 0%; Ontario 40%; Prince Edward Island 2%; Québec 15%; Saskatchewan 7%; and Yukon 0%.



Most respondents were currently in a **relationship**, 81%, and 100% of respondents identified as female. The majority, 96%, identified as heterosexual; 2% as homosexual; and 2% as bi-sexual. No one identified as having a sexual orientation outside of these three.

When asked which **racial or ethnic group** people most identified as, respondents indicated the following: African-Canadian 0%; Asian 0%; Caribbean 0%; Caucasian 86%; Indigenous Peoples 2%; French Canadian 7%; Hispanic/South American 0%; Middle Eastern or North African 0%; Pacific Islanders 0%; South Asian 1%; Other 5%.

Respondents identified their highest **level of education** as follows: elementary school 0%; secondary school 17%; college or college equivalent 38%; university undergraduate 31%; university masters 12%; and university doctorate 2%; and 2% preferred not to say.

Respondents identified their total **annual household income** as follows: Less than \$20,000 (5%); \$20,000 - \$39,999 (7%); \$40,000 - \$59,999 (9%); \$60,000 - \$79,999 (14%); \$80,000 - \$99,999 (11%); \$100,000 - \$149,999 (18%) and \$150,000 or higher (8%). Twenty-eight percent preferred not to say.



PATIENT PROFILE

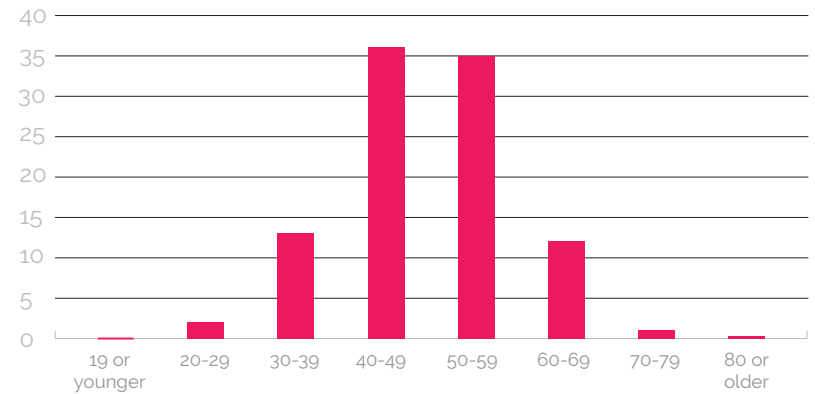
PATIENT PROFILE

EARLY STAGE

AGE AT DIAGNOSIS

The majority of respondents, 71%, were in their 40s or 50s when they were diagnosed with breast cancer; however, 2% were in their 20s, 13% were in their 30s, 12% were in their 60s, and 2% were over the age of 70.

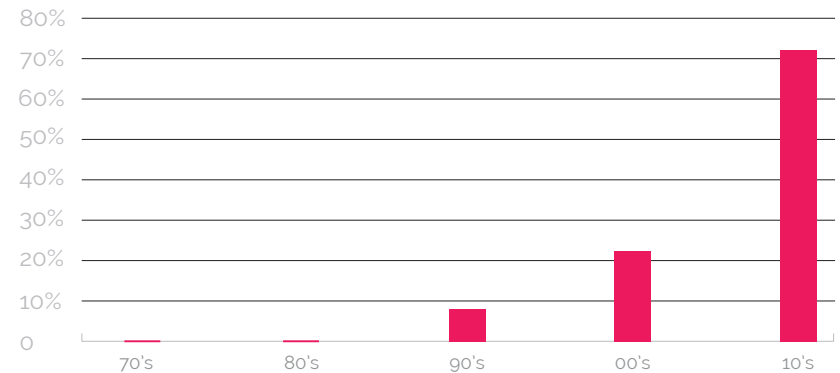
AGE AT TIME OF DIAGNOSIS



YEAR OF DIAGNOSIS

Most respondents, 71%, were diagnosed in 2010 or later; 21% of respondents were diagnosed between 2000 and 2009; 8% were diagnosed before 2000.

WHAT YEAR WERE YOU DIAGNOSED WITH BREAST CANCER?



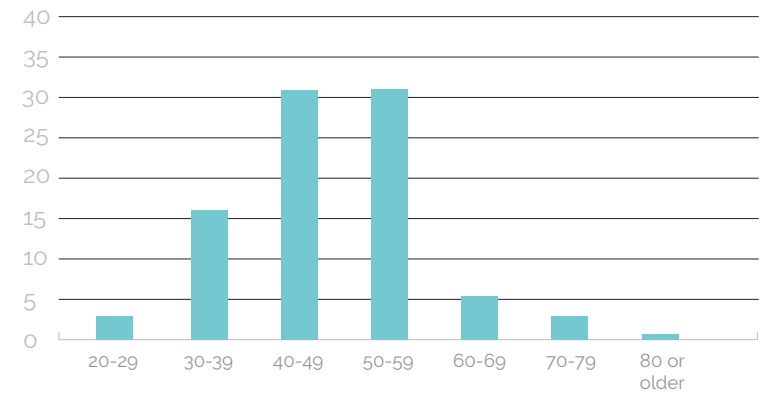
PATIENT PROFILE (CONTINUED)

METASTATIC

AGE AT DIAGNOSIS

The majority of respondents, 62%, were in their 40s or 50s when they were diagnosed with breast cancer; however, 3% were in their 20s, 16% were in their 30s, 15% were in their 60s, and 4% were over the age of 70.

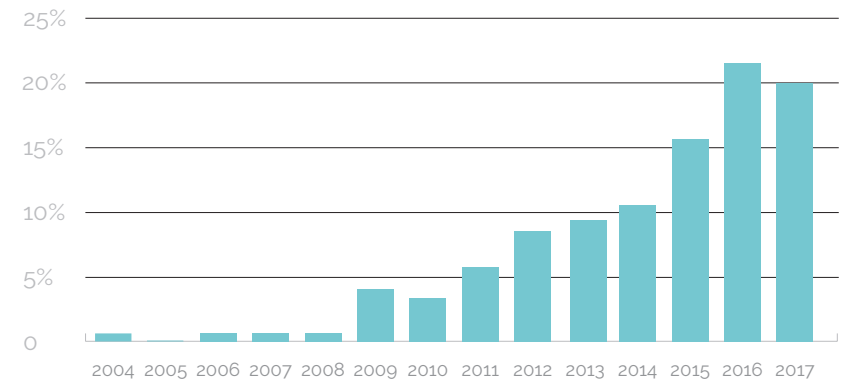
AGE AT TIME OF DIAGNOSIS



YEAR OF DIAGNOSIS

Respondents were diagnosed with metastatic breast cancer between 2004 and 2017

YEAR OF DIAGNOSIS



PATIENT PROFILE (CONTINUED)

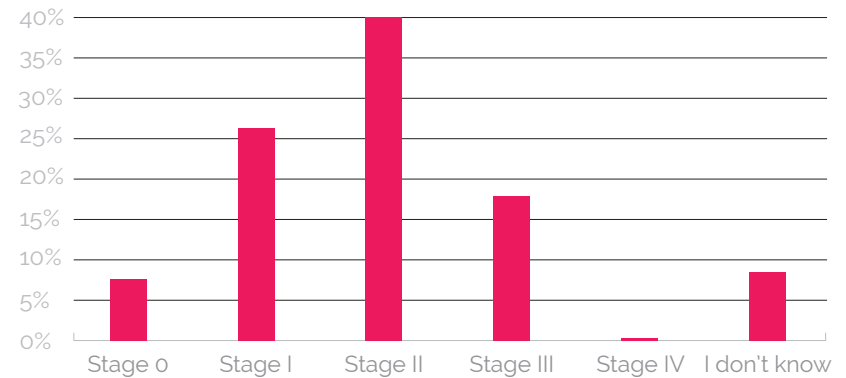
EARLY STAGE

STAGE AT DIAGNOSIS

A small number, 7%, of respondents were diagnosed at stage 0, while 26% were diagnosed stage I, 40% were diagnosed stage II, 18% were diagnosed stage III and 8% didn't know what stage they were at the time of diagnosis.

While most respondents knew the stage of breast cancer that they were diagnosed with, 33% didn't know the grade of their cancer. Of the respondents who did know, 15% indicated their cancer was grade 1, 22% indicated it was grade 2, and 30% indicated it was grade 3.

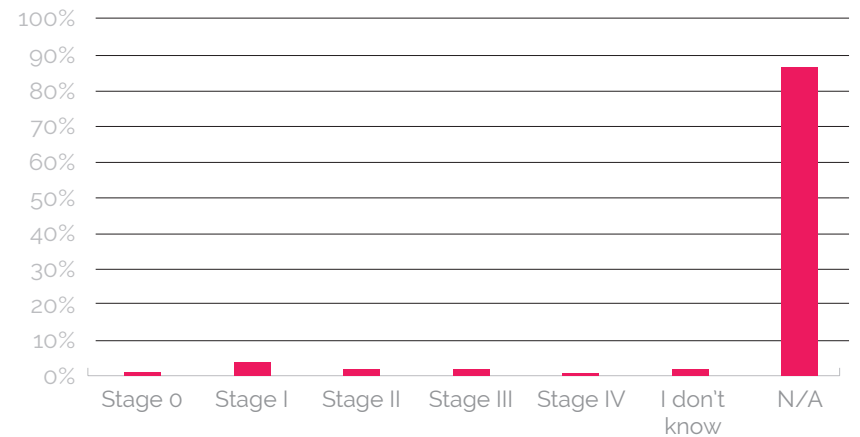
STAGE AT DIAGNOSIS



RECURRENCE

The majority of respondents, 92%, had only been diagnosed with breast cancer once; however, there were 8% who had experienced a recurrence. Of those who had experienced a recurrence 0.5% recurred stage 0, 4% stage I, 2% stage II, 2% stage III. The survey for early stage patients only captured those who recurred with stage 0 through stage III. Women who were initially diagnosed with early staged breast cancer and experienced a recurrence at stage IV are captured in the metastatic survey.

STAGE OF CANCER RECURRENCE



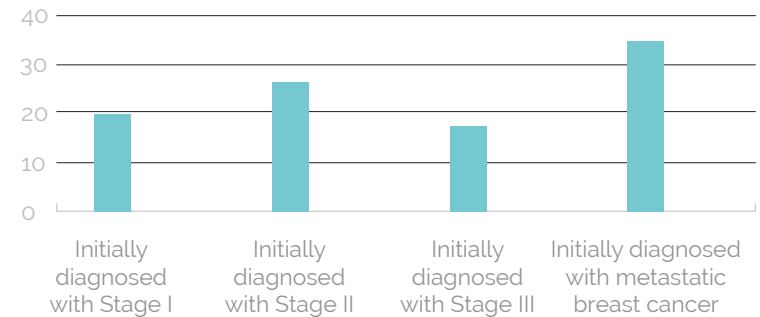
PATIENT PROFILE (CONTINUED)

METASTATIC

PREVIOUS BREAST CANCER DIAGNOSIS

Of the respondents, 35% were diagnosed with metastatic breast cancer de novo, meaning their initial diagnosis was metastatic breast cancer. However, 65% had previously been diagnosed with an earlier stage breast cancer; with 20% previously having stage I; 27% stage II; and 18% stage III.

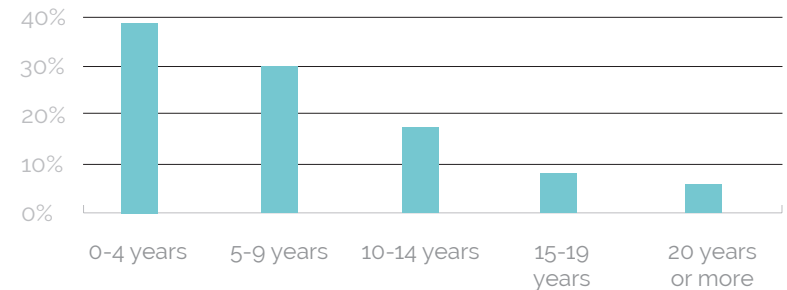
PREVIOUS BREAST CANCER DIAGNOSIS



TIME BETWEEN ORIGINAL DIAGNOSIS AND METASTATIC DIAGNOSIS

The majority of people, 39%, who experienced a recurrence did so between 0 and 4 years from their initial diagnosis; 30% recurred between 5 and 9 years; 17% recurred between 10 and 14 years; 8% recurred between 15 and 19 years; and 6% recurred after 20 years or more.

TIME BETWEEN ORIGINAL DIAGNOSIS AND METASTATIC DIAGNOSIS



PATIENT PROFILE (CONTINUED)

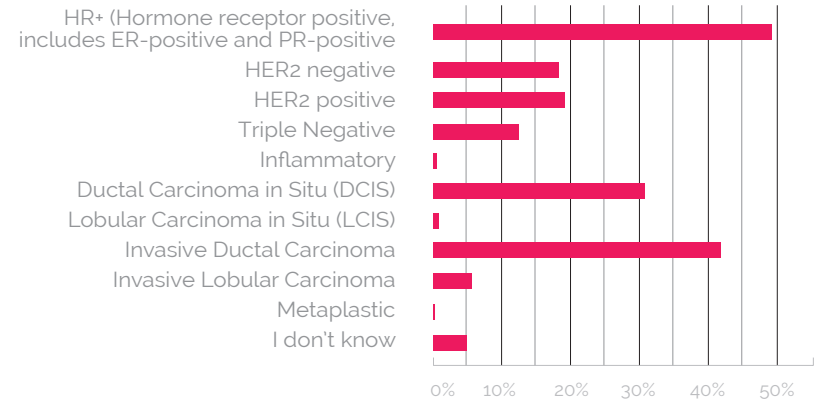
EARLY STAGE

BREAST CANCER SUB-TYPES

The majority of respondents, 42%, had Invasive Ductal Carcinoma, with 31% having Ductal Carcinoma in Situ (DCIS), 6% Invasive Lobular Carcinoma, 2% Lobular Carcinoma in Situ, 1% Inflammatory breast cancer, and 0.35% metaplastic breast cancer.

Forty-nine percent of respondents indicated they had hormone receptor positive breast cancer; 19% had HER2-positive breast cancer; and 12% had triple negative breast cancer.

BREAST CANCER SUB-TYPES



BRCA MUTATION STATUS

Five percent of respondents have a BRCA1/2 mutation, while 50% indicated that they didn't have this mutation, and 45% didn't know if they had a mutation or not.



PREGNANCY

Four respondents, approximately 2%, were pregnant at the time of diagnosis.



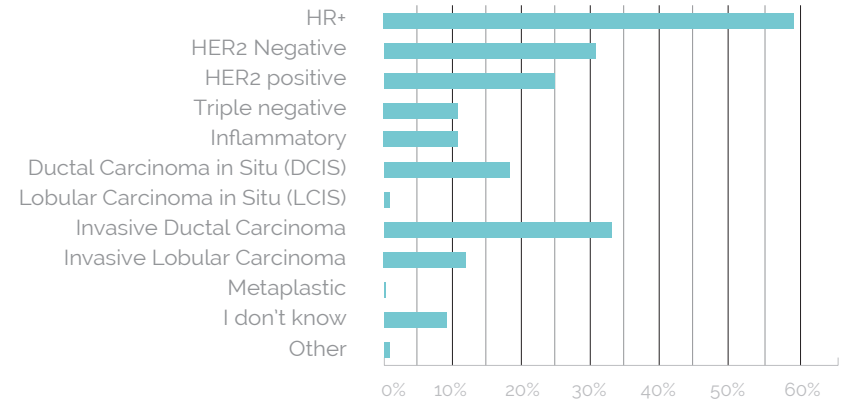
PATIENT PROFILE (CONTINUED)

METASTATIC

BREAST CANCER SUB-TYPES

Women with hormone receptor positive breast cancer accounted for 59% of respondents; 25% had HER2-positive breast cancer; and 12% had triple negative breast cancer.

BREAST CANCER SUB-TYPES



BRCA MUTATION STATUS

Eight percent of respondents have a BRCA1/2 mutation, while 59% indicated that they didn't have this mutation, and 33% didn't know if they had a mutation or not.



PREGNANCY

Two respondents, approximately 1.5%, were pregnant at the time of diagnosis.





DETECTION

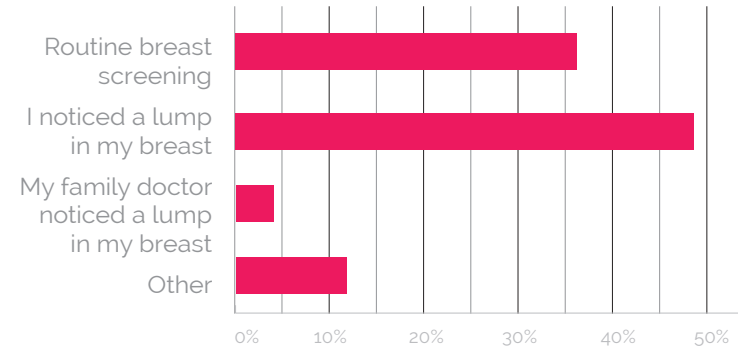
DETECTION

EARLY STAGE

HOW BREAST CANCER WAS DETECTED

Breast cancer is often detected through regular screening; however, many respondents were too young to be included in the screening programs or noticed a lump themselves between screening. In fact, the majority of respondents, 48%, noticed a lump and then followed up with their doctor. Routine breast screening detected breast cancer in 36% of the respondents; family physicians detected a lump in 4% of the respondents; and 12% of respondents had their breast cancer detected through some other manner, most often by noticing discharge from their nipple or a retracted nipple.

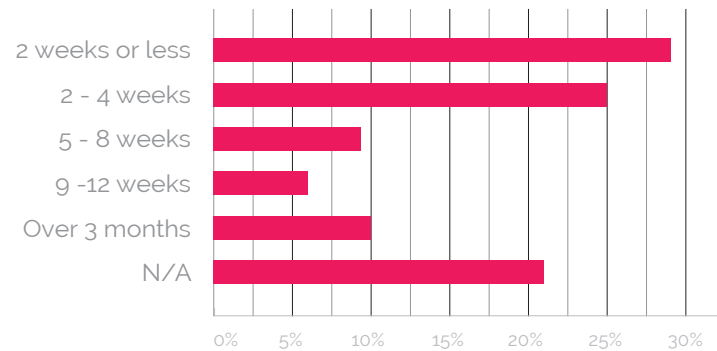
HOW BREAST CANCER WAS FIRST DETECTED



TIME TO RECEIVE DIAGNOSIS

Over 80% of respondents visited their family doctor about their concerns. The majority, 28%, were told within two weeks of their visit that they had breast cancer; 25% waited between 2 and 4 weeks to receive a diagnosis; 9% waited between 5 and 8 weeks; 6% waited between 9 and 12 weeks; 10% of respondents had to wait 3 months or more to receive a diagnosis.

TIME TO RECEIVE DIAGNOSIS



"I am 34 with no family history of breast cancer. Because of this, I felt I was not taken seriously when I found my lump. I feel I waited too long for the initial screening. The process of just getting to the screening was long and horrible." - Rachel

"It felt like forever but looking back it was actually fast." - Aimee

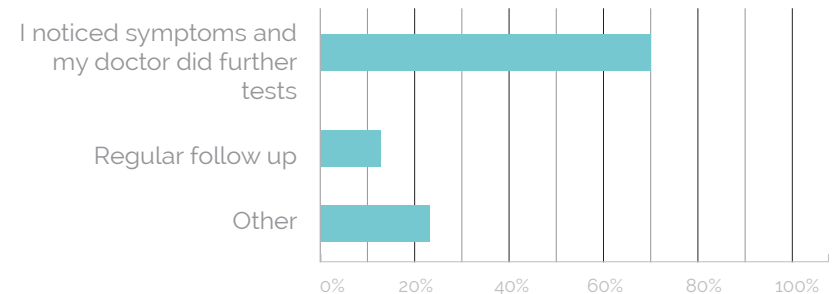
DETECTION (CONTINUED)

METASTATIC

BREAST CANCER SUB-TYPES

The majority of respondents, 65%, detected their own metastases by noticing symptoms then following up with their doctor who did further testing. Regular follow-up was responsible for detecting metastatic breast cancer in 12% of respondents; 23% reported having their cancer detected in another means.

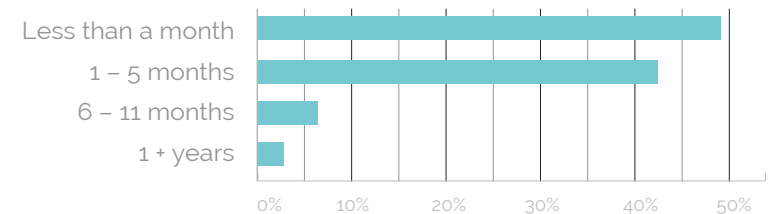
HOW BREAST CANCER WAS FIRST DETECTED



TIME TO RECEIVE DIAGNOSIS

The majority of respondents, 48%, received a confirmed diagnoses of metastatic breast cancer within a month of seeing a health care professional; 43% waited between one and five months; 6% waited between 6 and 11 months; and 3% waited over a year to receive a confirmed diagnosis of metastatic breast cancer.

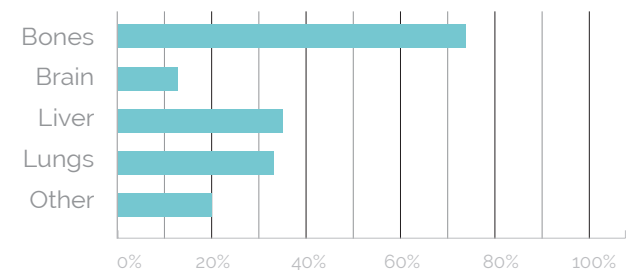
TIME TO RECEIVE DIAGNOSIS



SITES OF METASTASIS

The most common site of metastasis was the bone, with 72% of respondents having bone metastases; 35% had liver metastases; 32% had lung metastases; 12% had brain metastases; and 20% had metastasis in other parts of the body.

SITES OF METASTASIS





DIAGNOSIS

DIAGNOSIS

EARLY STAGE

INFORMATIONAL NEEDS RELATED TO DIAGNOSIS

Just over half of respondents, 56%, were provided with paper copies of information to help explain their diagnosis, while 37% weren't provided with anything in writing to explain their diagnosis, and 7% of respondents don't remember.

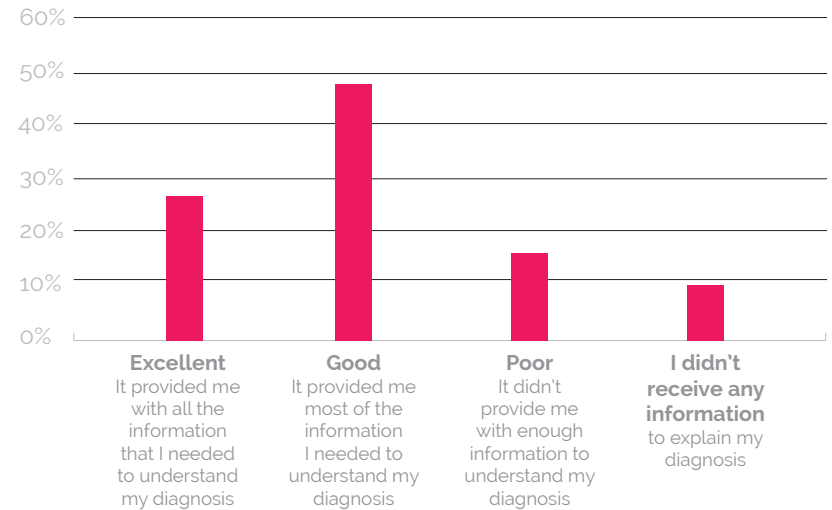
The majority of respondents, 76%, indicated that the information that they received to explain their diagnosis was either excellent or good, and that it provided them with all or most of the information that they needed to understand their diagnosis. Some patients, 15%, found that the information was lacking and it didn't provide them with enough to understand their diagnosis; 9% didn't receive anything.

Respondents also indicated that hard copies were the best format for receiving information about their diagnosis: 65% indicated this, while 33% preferred information digitally, and 2% indicated that they didn't want any information.

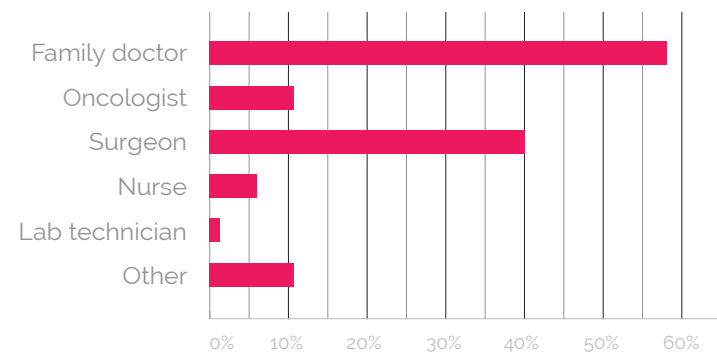
Patients interact with a variety of health care professionals through the process of being diagnosed, but patients most often receive their diagnosis from their family doctor, with 57% of respondents indicating that this was the case for their diagnosis. Surgeons, 40%, were also often the health care professional who delivered the news of a breast cancer diagnosis. Only a small number, 11%, were told they had breast cancer by an oncologist, with 6% being told by a nurse and 2% being told by a lab technician. Over 11% of respondents were told by another health care professional including, gynecologists, radiologists, or someone from a breast health clinic.

Given that most patients are told about their breast cancer diagnosis by the family doctor, it's important that these physicians are provided with tools and resources that best support their ability to clearly communicate information about this diagnosis to their patients. Many patients leave their physician's office without anything in writing that informs them of their diagnosis, support resources, or the next steps in terms of where they have been referred to for care. Many patients are verbally told about their diagnosis and next steps; however, having something in writing would eliminate some of the confusion about where they can connect.

QUALITY OF INFORMATION PROVIDED TO EXPLAIN DIAGNOSIS



HEALTH CARE PROFESSIONAL THAT DELIVERED THE BREAST CANCER DIAGNOSIS



DIAGNOSIS (CONTINUED)

METASTATIC

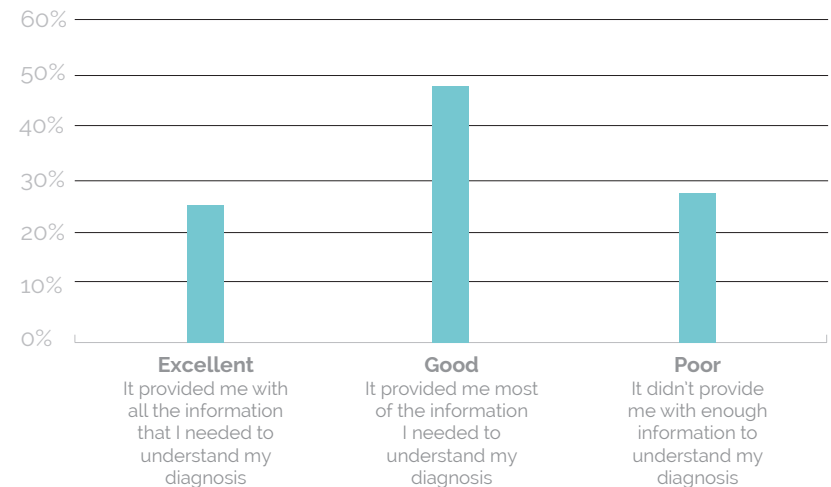
INFORMATIONAL NEEDS RELATED TO DIAGNOSIS

Just over half of respondents, 51%, were provided with paper copies of information to help explain their diagnosis, while 44% weren't provided with anything in writing to explain their diagnosis, and 8% of respondents don't remember.

The majority of respondents, 72%, indicated that the information that they received to explain their diagnosis was either excellent or good, and that it provided them with all or most of the information that they needed to understand their diagnosis. However, 28% found that the information was lacking and it didn't provide them with enough to understand their diagnosis. Most respondents, 64%, indicated that digital resources, were the best format to receive information about their diagnosis; while 36% preferred information that was in hard copy formats.

Respondents indicated the information they were given from their doctor, 49%, and patient organizations websites, 50%, were the best sources of information to help them understand their diagnosis. Booklets and brochures at the cancer centre and blogs or videos from other patients were rated as the next best source of information.

QUALITY OF INFORMATION PROVIDED TO EXPLAIN DIAGNOSIS



"The online information has improved and been very helpful over the past couple years. Where I find a need is through the initial diagnosis. The oncology department doesn't provide much information re metastatic breast cancer; it's mostly for early stage." - Anonymous

DIAGNOSIS (CONTINUED)

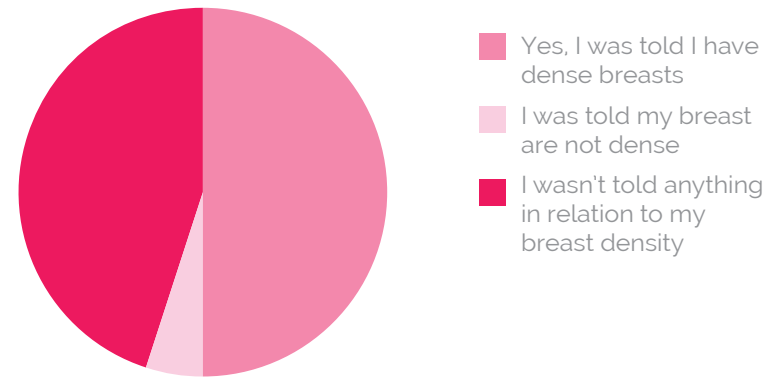
EARLY STAGE

BREAST DENSITY

Research continues to demonstrate that women with dense breast tissue are at an increased risk of developing breast cancer². Coincidentally, dense breast tissue also interferes with the reliability of traditional mammograms, making it hard to differentiate between cancer and dense breast tissue. Women need to be informed of their breast density and provided with appropriate alternatives for screening, aside from traditional mammography.

Exactly half of patients who responded, 50%, were told they had dense breasts, while 45% weren't told anything in relation to their breast density, and 6% were told that they didn't have dense breasts.

WERE YOU TOLD YOU HAVE DENSE BREASTS?



² Boyd, N., Guo, H., Martin, L., Sun, L., Stone, J., Fishel, E., Jong, R., Hislop, G., Chiarelli, A., Minkin, S., and Yaffe, M. (2007, Jan.). Mammographic density and the risk and detection of breast cancer. *New England Journal of Medicine*, 356:227-236. <http://www.nejm.org/doi/full/10.1056/NEJMoa062790#t=article>

DIAGNOSIS (CONTINUED)

METASTATIC

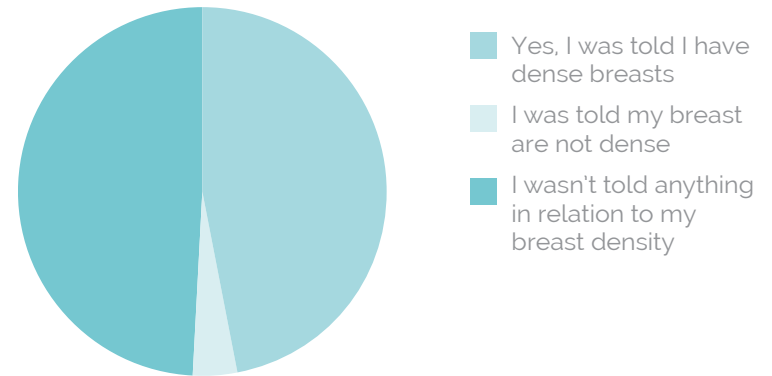
BREAST DENSITY

Research continues to demonstrate that women with dense breast tissue are at an increased risk of developing breast cancer². Coincidentally, dense breast tissue also interferes with the reliability of traditional mammograms, making it hard to differentiate between cancer and dense breast tissue. Women need to be informed of their breast density and provided with appropriate alternatives for screening, aside from traditional mammography.

Almost half of patients who responded, 47%, were told they had dense breasts, while 49% weren't told anything in relation to their breast density and 4% were told that they didn't have dense breasts.

"Had very tender spot in breast for a long while (maybe a couple of years) Regular mammograms failed to pick up anything. Finally, a lump was noticed which lead to further testing." - Anonymous (metastatic breast cancer patient)

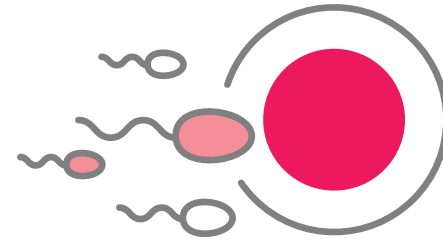
WERE YOU TOLD YOU HAVE DENSE BREASTS?



EARLY STAGE

FERTILITY

The majority of respondents, 90%, indicated that they were not planning on having any children, or additional children in the future; however, 6% did plan on having children in the future and 4% were undecided. More than 18% of respondents reported that someone in their health care team had a conversation with them about fertility.

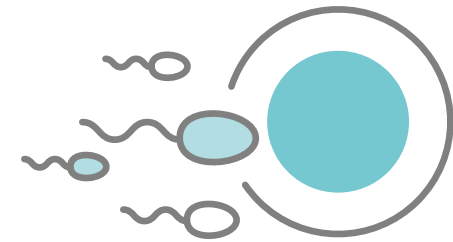


DIAGNOSIS (CONTINUED)

METASTATIC

FERTILITY

The survey for metastatic patients didn't directly address the question around fertility and fertility options.



DIAGNOSIS THE LIVED EXPERIENCE OF A BREAST CANCER DIAGNOSIS

The experience of being diagnosed is unique for each person. Complex factors impact how each person receives and reacts to a breast cancer diagnosis. Given this appropriate consideration, several gaps and needs were consistently identified by respondents when reflecting on what supports or resources were lacking at the time of diagnosis.

NAVIGATION

Patients consistently mention the need for some type of guidance on navigating the process of being diagnosed with breast cancer, making treatment decisions, and finding the necessary supports and access points within the system.

"I felt there wasn't much guidance regarding procedures that were available to me. There wasn't enough communication between specialists. I really needed to advocate for myself and I'm not sure everyone would be able to take on that role."

- Yvonne

PSYCHOSOCIAL SUPPORT

Patients also identify the need for access to various emotional support resources, including professional counsellors or social workers, as well as peer support groups and community resources.

"Emotional support: I didn't have any idea what I was in for, and what the next year would look like for me. I wish I had been referred to a social worker or therapist early on." - Anonymous

TIMELINES FOR THE TREATMENT PROCESS (EARLY STAGE)

Many respondents who had an early stage breast cancer diagnosis indicated that having some type of estimated timeline, or even a better understanding of the treatment process from the start, would have been helpful.

"Definitive time frames for treatment steps."

"How recovery from cancer and treatments would really look" - Anonymous

RESOURCES FOR YOUNG WOMEN

The younger respondents in the survey continue to express what this group has shared for years - that they need specific resources and supports tailored to their unique needs. This group of patients is often more financially vulnerable, may have young families, and experiences isolation within their peer group. This group also had greater challenges receiving a diagnosis given that they are often considered "too young" to have breast cancer.

"Information for young women, resources to help deal with raising small children, and financial information (are important.)" - Aimee

"I was 26 when diagnosed with stage II. It took 7 months of being told I was too young and had no family history. So while I was in remission, I would have thought my symptoms would have been taken seriously but my GP fluffed off my sore back as just needing a chiropractic alignment. I didn't put two and two together when thinking of how a sore back could be related to my breast cancer. New symptoms arose

(nodes on my scalp and a numb chin) and I told my oncologist. I was in an MRI less than 36 hours later." (metastatic breast cancer patient) - Katie

"GP assumed my lump was "hormonal" due to my young age, and suggested a "wait and see" approach. Three and a half months later pain forced the issue for me and I pushed for further investigation. I was sent to have cyst drained and it was a whirlwind from there." - Jordana

"It is an isolating experience being a young(ish) person living with a terminal illness." - Vesna (metastatic breast cancer patient)



TREATMENT

TREATMENT

EARLY STAGE

UNDERSTANDING TREATMENT OPTIONS

The majority of respondents, 89%, shared that their doctor explained their treatment options to them; there were, however, 11% who indicated that their treatment options weren't explained to them. For those whose options were explained, 74% said they were explained in a way that they could understand; 18% of respondents could somewhat understand what was being explained; and 3% didn't understand their treatment options.

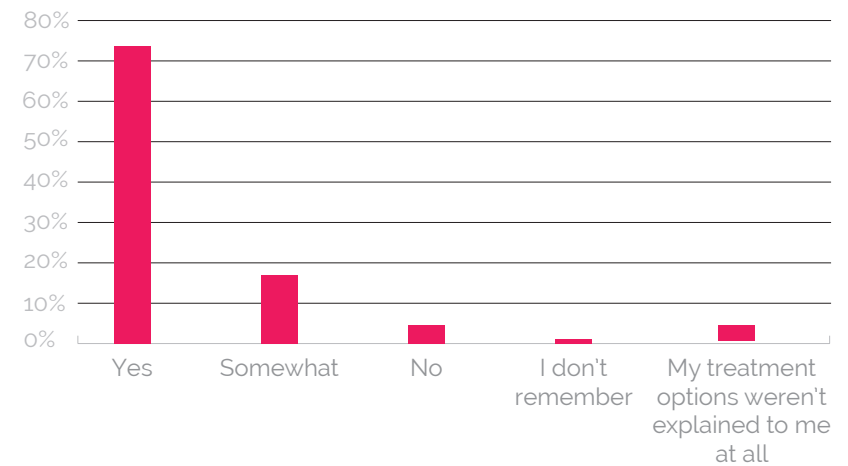
The majority, 67% of respondents were given the opportunity to be involved in the decision-making process for treatments; 19% were sometimes; and 14% weren't given this opportunity.

Many respondents, 54%, indicated that they were very comfortable participating in treatment making decisions, with 33% being somewhat comfortable. Only 10% were uncomfortable participating in treatment decisions, and 2% were uninterested.

It's important to highlight that every single respondent from the metastatic survey who added additional comments around understanding treatment options expressed concern over whether new treatments would be accessible to them.

"When I turn 65 I will no longer have private insurance. I will not be able to afford the medication I currently take, never mind any future medication that I may require." - Shelley

WERE THE TREATMENT OPTIONS EXPLAINED IN A WAY THAT YOU COULD UNDERSTAND?



TREATMENT (CONTINUED)

METASTATIC

UNDERSTANDING TREATMENT OPTIONS

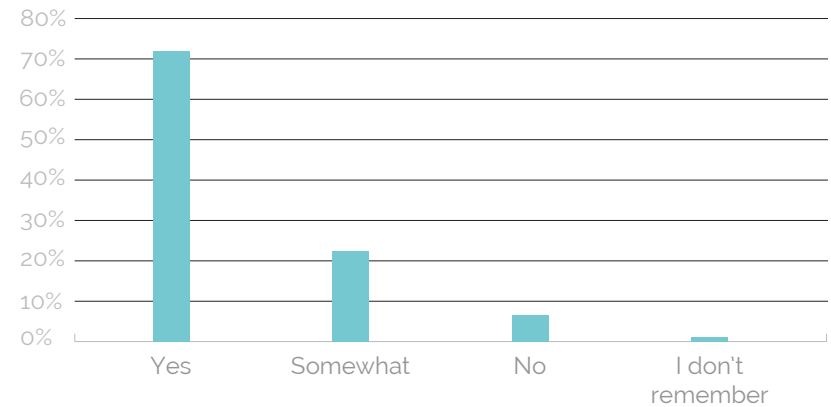
The majority of respondents, 89%, shared that their doctor explained their treatment options to them; there were, however, 10% who indicated that their treatment options weren't explained to them and 1% who don't remember. For those whose options were explained, 71% said they were explained in a way that they could understand; 22% of respondents could somewhat understand what was being explained; 6% didn't understand their treatment options; and 1% don't remember.

The majority, 72% of respondents were given the opportunity to be involved in the decision-making process for treatments; 18% were sometimes; and 10% weren't given this opportunity.

Many respondents, 68%, indicated that they were very comfortable participating in treatment making decisions, with 29% being somewhat comfortable. Only 3% were uncomfortable or uninterested in participating in treatment decisions.

It's important to highlight that every single respondent from the metastatic survey who added additional comments around understanding treatment options expressed concern over whether new treatments would be accessible to them.

WERE THE TREATMENT OPTIONS EXPLAINED IN A WAY THAT YOU COULD UNDERSTAND?



"I worry that in the future, a drug that may work for me won't be accessible to me based on provincial formulary." - Jordana

"I have concerns that the next best line of treatment won't be available here." - Anonymous

TREATMENT (CONTINUED)

EARLY STAGE

FACTORS THAT INFLUENCE TREATMENT DECISIONS

Unsurprisingly, reducing the risk of recurrence for early stage patients and overall survival/progression free survival for metastatic breast cancer patients were the most important factors when considering treatment options. Progression free survival wasn't ranked as high by metastatic patients as overall survival, but it was still a very important consideration. While it may not extend life, progression free survival allows patients to have their disease controlled which provides a much better quality of life. Quality of life and side effects were the second and third most considerations for both groups.

When considering treatment options, respondents indicated that reducing the risk of cancer coming back and effectiveness of the treatment were the most important considerations, with over 90% of respondents indicating that these were both very important.

Respondents also indicated that quality of life was a key factor in selecting treatments, with 58% of respondents indicating that this was very important and 28% indicating that it was important.

Minimal side effects were also an important factor, with 32% indicating this was very important and 39% indicating it was important. Many respondents brought up concerns around needing to better understand the long-term side effects of cancer treatments

"Quality of life during and after treatment" - Jody

"I only wanted to reduce my risk of recurrence as much as possible. Everything else was secondary."

- Anonymous

"I am a mother to 3 children. I wanted to be aggressive in order to increase my chances of survival." - Trisha

"I wanted a treatment that had the best chance of beating the cancer the first time." - Gillian

"I now worry about any side effects the treatments may have on me long term. At the time of treatment, I felt the doctors chose the best treatment for me." - Sheilagh

"Although I was told about the side effects, I was not told about longer term side effects. I felt that I took the responsibility of being informed and did more searching so I asked the right questions." - Anonymous

TREATMENT (CONTINUED)

METASTATIC

FACTORS THAT INFLUENCE TREATMENT DECISIONS

Unsurprisingly, reducing the risk of recurrence for early stage patients and overall survival/progression free survival for metastatic breast cancer patients were the most important factors when considering treatment options. Progression free survival wasn't ranked as high by metastatic patients as overall survival, but it was still a very important consideration. While it may not extend life, progression free survival allows patients to have their disease controlled which provides a much better quality of life. Quality of life and side effects were the second and third most considerations for both groups.

When considering treatment options, respondents indicated that overall survival (88%) and progression free survival of 6 months or more (82%) were the very important considerations when considering treatment options. Progression free survival of 3 to 5 months was very important to 59% of respondents and important to 25% of respondents. Progression free survival of less than 3 months was still very important to 52% of respondents and important to 21% of respondents.

Quality of life was ranked as very important consideration by 58% of respondents, and rated as important by 33%.

Minimal side effects were ranked as an important consideration by 40% of respondents but only ranked as very important by 24% of respondents.

The concept of accessibility of new treatment options also came up numerous times when metastatic respondents were asked about factors that influence decision making. Many indicated that whether or not a treatment was covered provincially could decide what treatment they choose.

"Always quality of life. If I am to suffer greatly then, no, that is not what I want." - Kay

"Effectiveness is most important and then all other things being equal - least side effects."

- Jordana

"Quality of life over quantity." - Shelley

"Being able to manage side effects and try to prevent permanent neuropathy in feet and hands from getting worse." - Marie

"Not having private health insurance and possibility of needing oral chemo as an Ontario resident where it is NOT covered/ subsidized." - Tricia

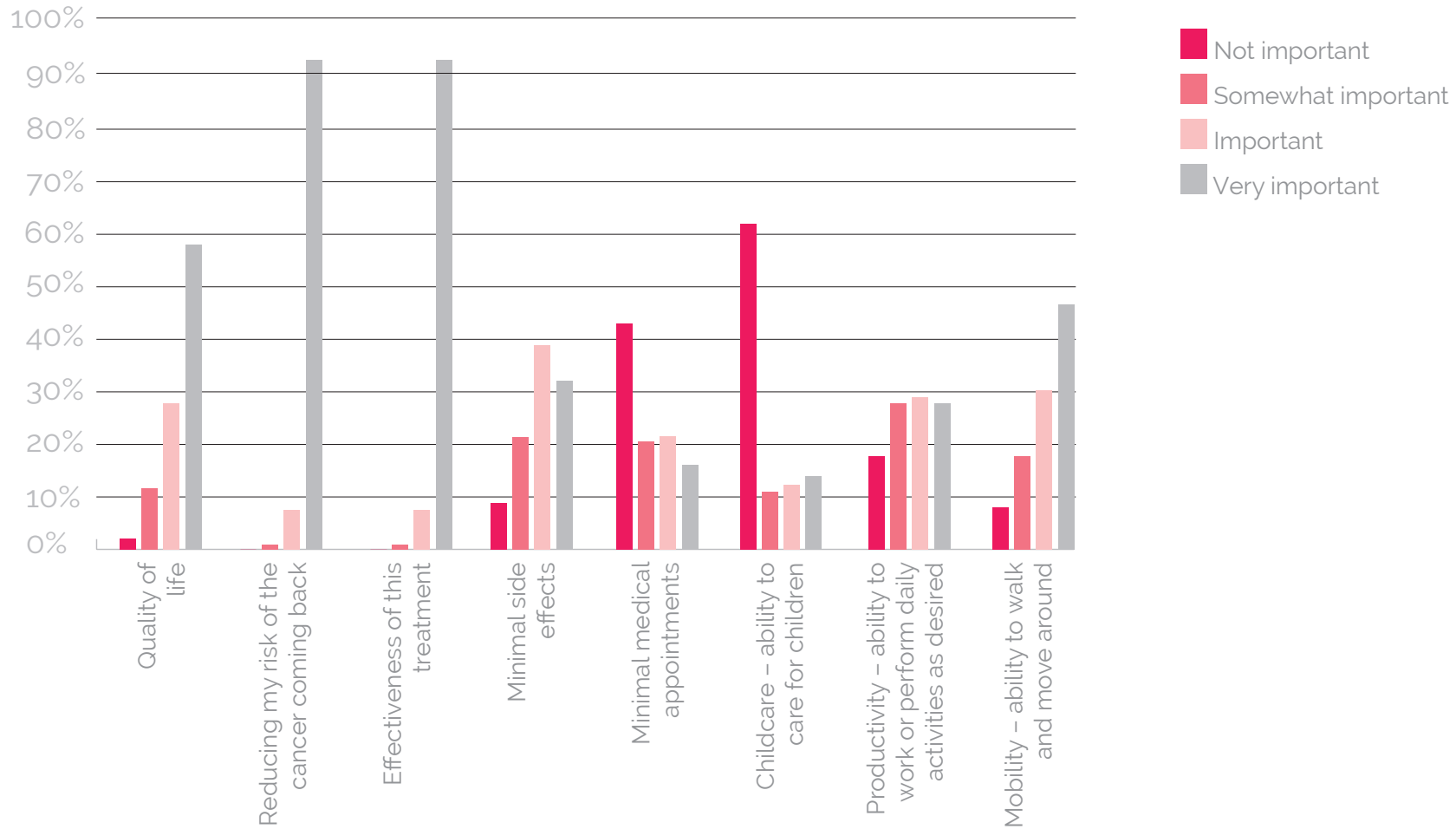
"Accessibility to new drugs- not limiting choices." - Anonymous

TREATMENT (CONTINUED)

EARLY STAGE

FACTORS THAT INFLUENCE TREATMENT DECISIONS (continued)

WHEN CONSIDERING TREATMENT OPTIONS HOW IMPORTANT ARE THE FOLLOWING?

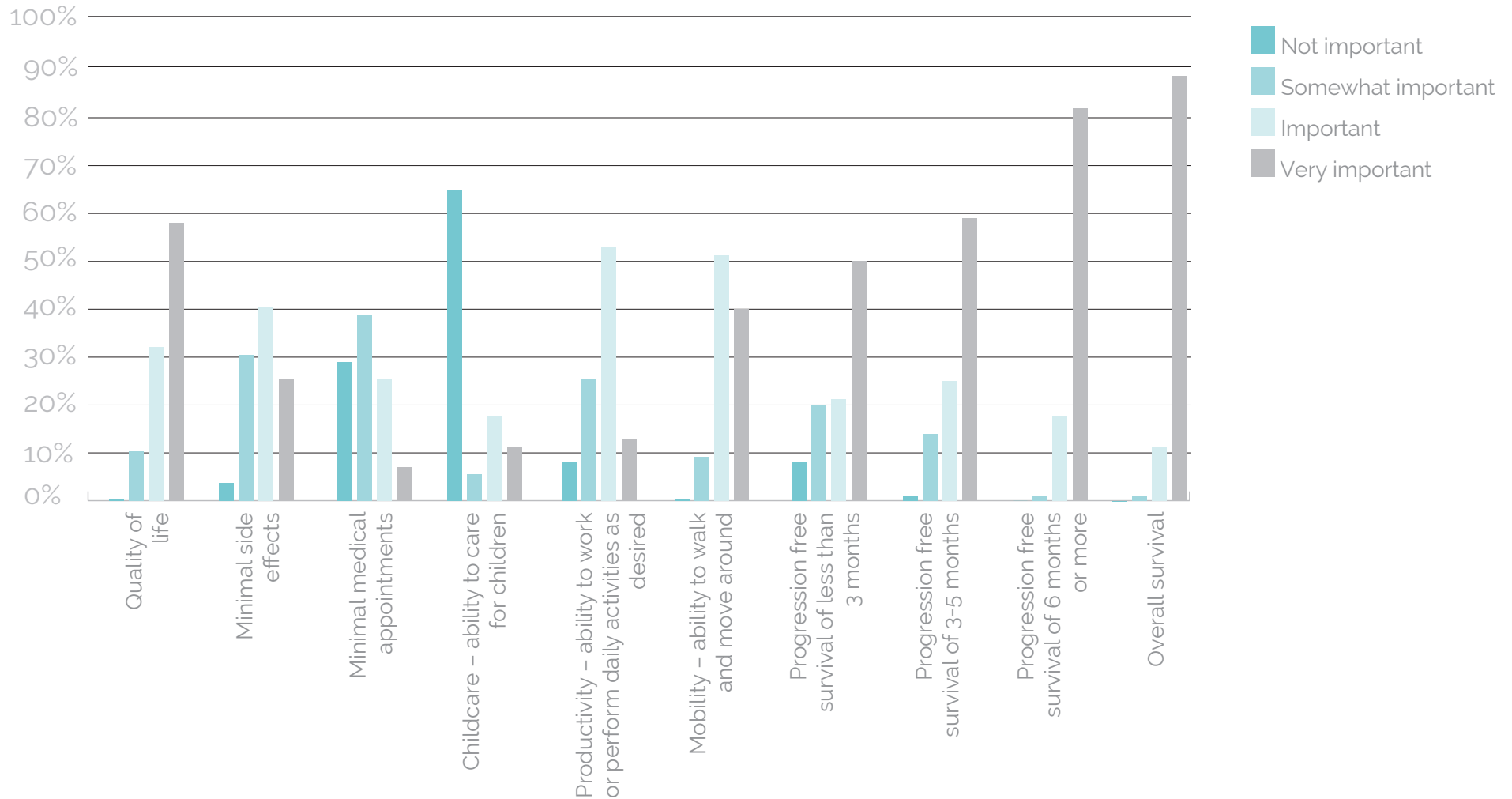


TREATMENT (CONTINUED)

METASTATIC

FACTORS THAT INFLUENCE TREATMENT DECISIONS (continued)

WHEN CONSIDERING TREATMENT OPTIONS HOW IMPORTANT ARE THE FOLLOWING?



TREATMENT CONSIDERATIONS FOR EARLY STAGE

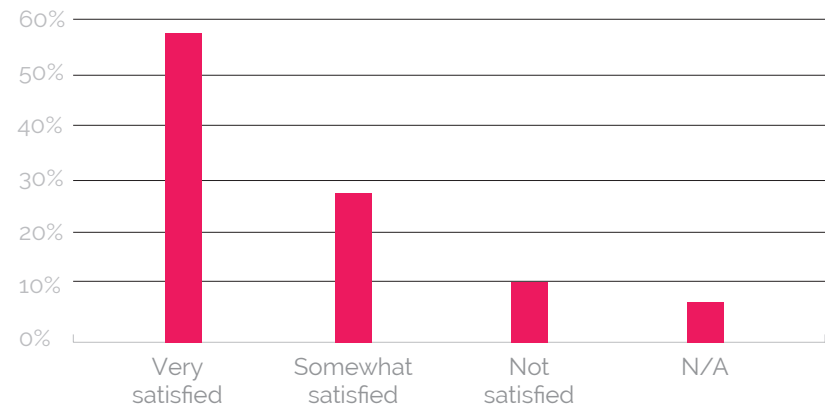
SURGERY

Breast cancer surgery in the treatment of breast cancer plays a very different role in early stage breast cancers and metastatic breast cancers. In the early stage setting it is used as a curative form of treatment; whereas in the metastatic setting it may be used more so as a symptom management tool or to reduce the cancer burden in a patient. Given these vastly different objectives for the use of breast cancer surgery, the survey mainly captured data in the early stage setting regarding the decision making involved in choosing a type of surgery and decisions around reconstruction, living flat, or using a prosthesis.

Most respondents, 76%, had only the one surgery to remove their breast cancer, while 24% required more than one surgery.

When asked about the information available to help patients decide about having a lumpectomy or mastectomy, if the choice was given, 56% of respondents indicated that they were very satisfied with the information available, and 28% indicated they were somewhat satisfied. There were 10% of respondents who were not satisfied at all.

IF YOU HAD SURGERY, HOW SATISFIED WERE YOU WITH THE QUALITY OF THE INFORMATION TO HELP YOU DECIDE ABOUT HAVING A LUMPECTOMY VS. MASTECTOMY



"I had five minutes to make a decision about whether to have lumpectomy or mastectomy. I didn't really have much information to base the decision on." - Anonymous

TREATMENT (CONTINUED)

TREATMENT CONSIDERATIONS FOR EARLY STAGE (CONTINUED)

HORMONE THERAPY

Patients diagnosed with early stage breast cancer often report challenges adhering to hormone therapy for the recommended duration due to side effects. Of those respondents who were prescribed hormone therapy, 81% of them took the medication for the amount of time recommended by their doctor; however, 19% did not. For those who discontinued hormone therapy early, 93% said it was due to side effects, while 3.5% indicated it was due to cost and 3.5% indicated it was due to pregnancy or trying to get pregnant. Toxicity still seems to be the greatest factor in compliance to hormone therapy for early stage patients.



BREAST RECONSTRUCTION, LIVING FLAT, AND USING PROSTHETICS

Respondents accessed information about breast reconstruction, prosthetics, and living flat from a variety of sources including their doctor (31%), online websites (35%), and at the cancer centre (26%).

When asked about the quality of information to make a decision about breast reconstruction, prosthetics, or living flat, 24% of respondents said they were very satisfied, while 25% were somewhat satisfied. Of participants who looked for this information, 18% were not satisfied with the quality of information they received to help them make an informed decision.

"I really wish the whole mastectomy and reconstruction was explained more." - Anonymous

"What were my surgical and treatment options? No one told me about breast reconstruction until after lumpectomy and nurse navigator thankfully told me." - Susan

TREATMENT (CONTINUED)

TREATMENT CONSIDERATIONS FOR EARLY STAGE (CONTINUED)

WHEN ASKED WHAT THE DECIDING FACTOR WAS ABOUT WHETHER TO LIVE FLAT, HAVE BREAST RECONSTRUCTION, OR USE A PROSTHETIC, RESPONDENTS SHARED THE FOLLOWING:

LIVING FLAT

"I wanted to be done with surgeries and tests so I opted for a double mastectomy with no reconstruction. Flat works for me." - Anonymous

*"My surgeon tried to persuade me not to go flat. I had to insist. It should be presented as a valid option!"
- Dianne*

"I knew that radiation was part of my course of treatment, and with the type of cancer I had, immediate reconstruction was not for me. I am not interested in any more surgery than necessary. I also had a friend that had reconstruction that went bad in so many ways. Reconstruction is not that important to me." - Jackie

RECONSTRUCTION

"I was a good candidate and I was offered an immediate reconstruction. It was an easy decision to have immediate reconstruction. I've never regretted it." - Susan

*"Normalcy. I hated the prosthesis."
- Anonymous*

"I had no desire to live flat. My vanity wanted to look as normal as possible, perhaps a psychological attempt to BE normal. I did not want to look like I'd had cancer. I tried prosthetics, but found them very limiting in fashion and convenience. I still had a certain style of clothing I wanted to be able to wear. I still wanted to look normal, naked. Or as close to it as I could. Reconstructive surgery was my best option for the outcome I was looking for." - Anonymous

NOT HAVING RECONSTRUCTION

"No one deciding factor. It's a very complicated decision. So far I have not had reconstruction (unilateral mastectomy) but still may in the future." - Anonymous

"The deciding factor was I did not feel strong enough after 4 months of chemo to go directly into a 12-hour surgery. I chose delayed reconstruction plus I knew I would need radiation. Now I am thinking of just living flat because I want to focus on feeling stronger and healthier. Plus, it is so hard on my family when I'm recovering. Just want some normal for a while." - Andrea

Respondents indicated that there was a lack of information to help with informed decision-making around breast cancer surgery, as well as information to better support decision-making around reconstruction, living flat, or using a prosthetic.

TREATMENT (CONTINUED)

TREATMENT CONSIDERATIONS FOR METASTATIC BREAST CANCER

PALLIATIVE CARE

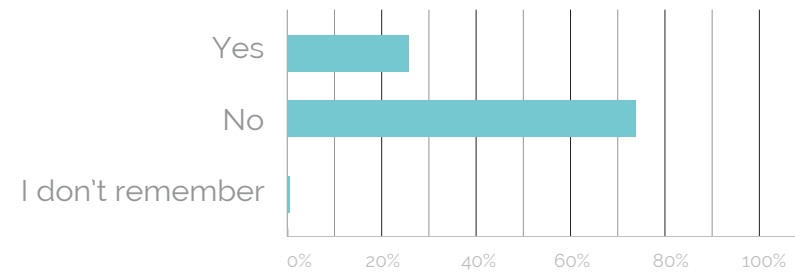
There is increasing evidence that demonstrates the importance of early access to palliative care to improve quality of life while living with metastatic breast cancer, not just at the end of life.³

When asked if anyone from their health care team had spoken to them about palliative care 26% of respondents indicated that someone had this conversation with them; 73% of respondents answered no; and 1% of respondents didn't remember.

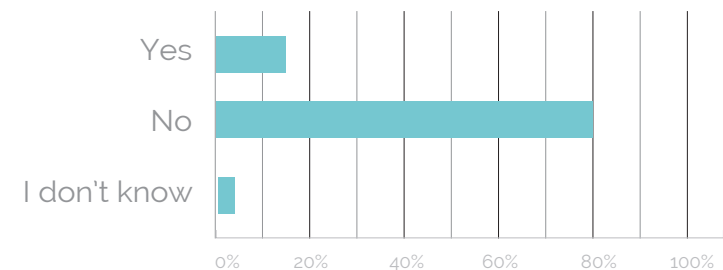
When asked if they had accessed palliative care, 16% of respondents shared that they had, while 80% indicated they had not, and 4% didn't know.

"Palliative care wasn't accessible to me unless I was at end of life" - Jordana

PATIENTS WHO HAVE HAD CONVERSATIONS ABOUT PALLIATIVE CARE WITH A HEALTH CARE PROVIDER



PATIENTS WHO HAVE ACCESSED PALLIATIVE CARE



³ Ziegler LE, Craigs CL, West RM, et al Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study BMJ Open 2018;8:e018284. doi: 10.1136/bmjopen-2017-018284

TREATMENT (CONTINUED)

TREATMENT CONSIDERATIONS FOR METASTATIC BREAST CANCER

PALLIATIVE CARE (CONTINUED)

The responses shared on palliative care continue to reinforce that the majority of patients are not being told about palliative care at the early stages of their diagnosis, or how to access it. The data from this survey doesn't explain whether this is because patients are asymptomatic and their health care team may suggest it when they are symptomatic, or whether patients are still generally being referred to palliative care at the end-of-life. However, given the evidence that supports early access to palliative care, it's important that patients are given all the information and options so that they understand what resources exist and how to access them.

"I recognized that I was palliative upon diagnosis of metastatic breast cancer, and self-identified. My health care team wasn't particularly comfortable with this. I am a health care professional with expertise in palliative care, death, and dying. I have taken narcotics for pain, so yes, I have received palliative care, although I am far from end-of-life. There is a vacuum regarding information about wellness, diet, exercise, resilience, and optimizing health for people in the early stages of MBC. There is a vast difference between me and someone in the last few months of life, but we all get lumped in together, and palliative care is supposed to address the needs of all of us. Palliative care doesn't begin to meet me where I am at." - Eileen



CLINICAL TRIALS

Interest in clinical trials continues to be significantly higher for people living with metastatic breast cancer. Although both groups share similar experiences in whether or not they were told about clinical trials and ones that may be appropriate for them, the overall interest level differs after that point. Many people living with metastatic breast cancer report seeking out information about clinical trials and also think they are something of importance and applicable to them. A significant number of respondents in both groups shared that they didn't feel they had enough information to make an informed decision about clinical trials. Many respondents living with metastatic breast cancer expressed concern about the ability to access clinical trials based on their geographical location. There was also concern about the lack of clinical trials in Canada compared to the U.S. and trials specifically for heavily pre-treated patients.

CLINICAL TRIALS

EARLY STAGE

The majority of respondents, 55%, indicated that they weren't told about clinical trials. However, 29% indicated that they were told about trials that may be appropriate for them and 20% of respondents were able to access a clinical trial.

The majority of respondents with early stage breast cancer, 71%, indicated that they didn't seek out clinical trials, while 17% said that they did. The main sources of information about clinical trials were an oncologist, online resources, or staff at a cancer centre.

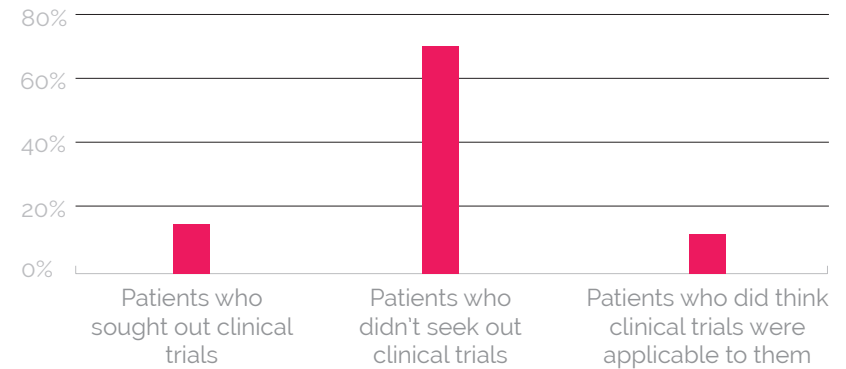
Only 19% of people felt that they had enough information about clinical trials to make an informed decision about whether to join one; 41% of respondents felt that they didn't have enough information to make this decision; 39% of patients felt that it wasn't applicable to them.

"I would have liked to be informed if I qualified for any or how I could find out about them." - TerriAnn

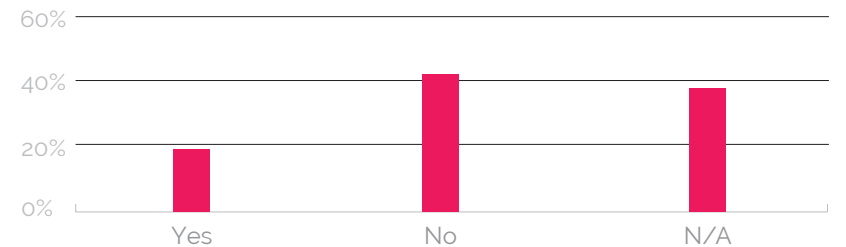
"I wish I had known more at the time about how to access them." - Anonymous

"I wasn't interested as I felt I had plenty of appointments to attend for treatment, and I didn't want to add anything else to such a busy treatment plan." - Sandy

INTEREST IN CLINICAL TRIALS



ACCESSIBILITY OF CLINICAL TRIAL INFORMATION TO MAKE AN INFORMED DECISION



"I feel that if my surgeon and my oncologist had felt that a clinical trial would have been of an advantage to me they would have discussed it." - Eleanor

CLINICAL TRIALS (CONTINUED)

METASTATIC

The majority of respondents, 59%, indicated that they weren't told about clinical trials, while 32% were told about clinical trials that may be appropriate for them; 24% were able to access a clinical trial.

The majority of respondents, 51%, didn't seek out clinical trial information; however, 40% of patients did. The main sources of information about clinical trials were their oncologist or online resources.

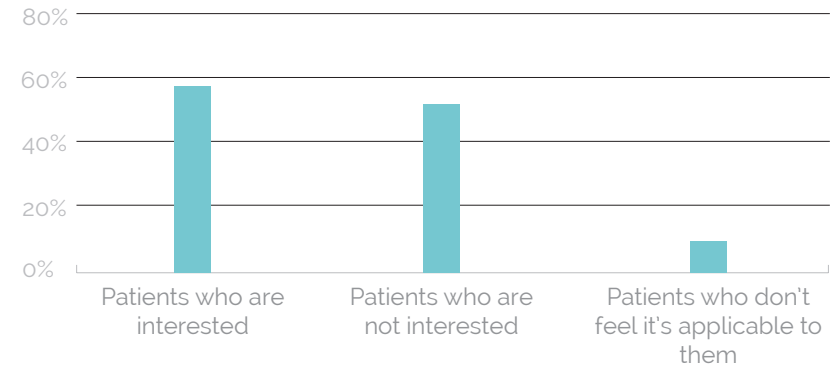
Only 33% of respondent felt that they had enough information about clinical trials to make an informed decision about whether to join one; 52% of respondents felt that they didn't have enough information to make this decision; 16% of patients felt that it wasn't applicable to them.

"I would like to be informed about any Canadian clinical trials that may apply to me. I may be able to find accommodation in another province or city if need be."

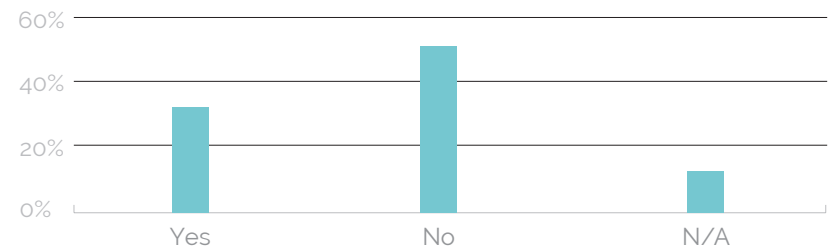
- Anonymous

"Would like to see more trials for heavily pretreated Stage IV breast cancer. The ones I would like to be involved in are U.S. only" - Brigitte

INTEREST IN CLINICAL TRIALS



ACCESSIBILITY OF CLINICAL TRIAL INFORMATION TO MAKE AN INFORMED DECISION



"I am so grateful to be on a clinical trial. These drugs are the future of MBC." - Katie

COST OF TREATMENT

Most Canadians assume that the cost of cancer treatments will be covered by the public health care system; however, this isn't always the case.

There's a stark contrast between early stage and metastatic patients when trying to access cancer medications that are covered through the public health care system. There were three times more people living with metastatic breast cancer who were prescribed medications that weren't covered through the public health care system than early stage patients. Because of this, there was a much higher number of people in the metastatic group who didn't end up taking their cancer medication because of the cost.

Both groups shared challenges around accessing support medications that were prescribed to them but weren't covered through public healthcare; although, again in this instance, the metastatic respondents were three times more likely to experience this and also had a high rate of non-compliance due to cost.

These numbers indicate a concerning reality: that cancer medications and support medications are not accessible to Canadians due to the out-of-pocket expenses. It also shows that the impact is more severe for people living with metastatic breast cancer, who need these medications to extend their life.

COST OF TREATMENT

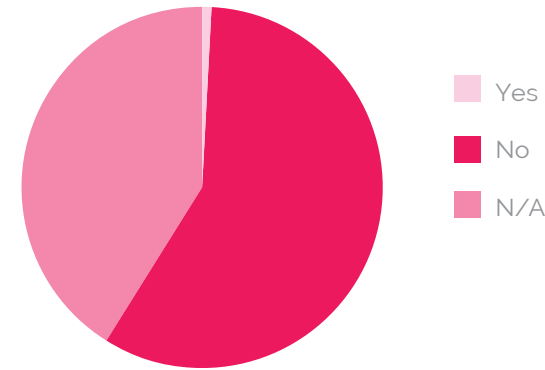
EARLY STAGE

ACCESSING CANCER MEDICATIONS

When asked if there were cancer medications that were prescribed that weren't covered through the public health care system, 14% indicated that there were. To cover these costs, respondents either used their private insurance, covered the cost themselves, or accessed a manufacturer's patient assistance program. Only a small percentage of early stage breast cancer patients, 1%, stopped taking cancer medication due to the cost.

"If you do not have private insurance, or are out of pocket until someone can help you. I'm not sure how people get through it." - Anonymous

DID THE COST OF CANCER MEDICATIONS STOP YOU FROM TAKING ANY OF THEM?

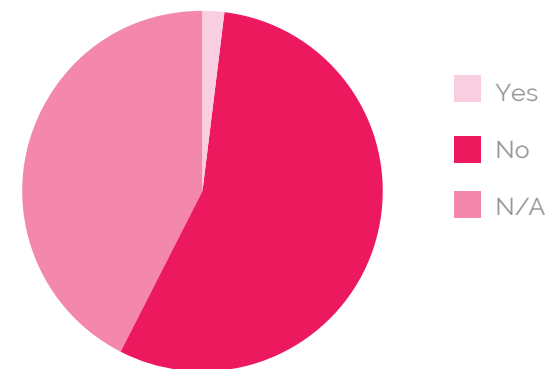


ACCESSING SUPPORT MEDICATIONS

When asked if there were support medications prescribed to help manage the side effects of treatment that weren't covered by the public health care system, 32% of respondents said yes. To cover the cost, people either paid out of pocket, used private insurance or accessed a manufacturer's patient assistance program. The cost of these support medications stopped 2% of respondents from taking them.

"Although I had access to health insurance through work, it was not 100% and included a cap on spending." - Anonymous

DID THE COST OF SUPPORT MEDICATIONS STOP YOU FROM TAKING ANY OF THEM?



COST OF TREATMENT (CONTINUED)

METASTATIC

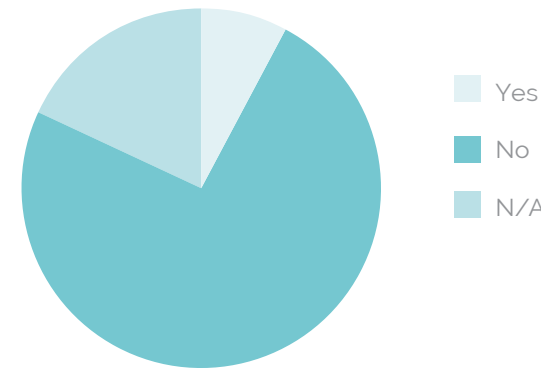
ACCESSING CANCER MEDICATIONS

When asked if there were cancer medications that were prescribed that weren't covered through the public health care system, 39% indicated that there were. To cover these costs, respondents either used their private insurance, covered the cost themselves or accessed a manufacturer's patient assistance program. There were 8% of respondents who didn't take medications to treat their cancer due to cost.

"I'm concerned with how long it takes to get a treatment approved and on the public health care lists and with the high cost of new treatments that have become available but are not yet covered under the public health care lists."

- Anonymous

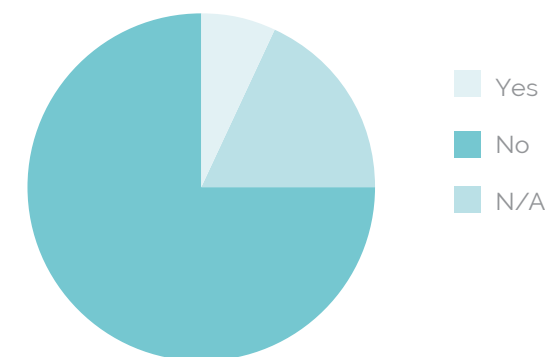
HAS THE COST OF CANCER MEDICATIONS STOPPED YOU FROM TAKING THEM?



ACCESSING SUPPORT MEDICATIONS

When asked if there were support medications prescribed to help manage the side effects of treatment that weren't covered by the public health care system, 85% of respondents said yes. To cover the cost, people either paid out of pocket, used private insurance, or accessed a manufacturer's patient assistance program. The cost of these support medications stopped 7% of respondents from taking them.

HAS THE COST OF CANCER MEDICATIONS STOPPED YOU FROM TAKING THEM?





FINANCIAL IMPACT

Receiving a breast cancer diagnosis in Canada can significantly impact the finances and financial stability of patients and families.⁴

⁴ Canadian Breast Cancer Network

<https://cbcn.ca/web/default/files/public/Reports/Economic%20Impact%20and%20Labour%20Force%20Re-Entry%20Report%20-%20E.pdf>

FINANCIAL IMPACT

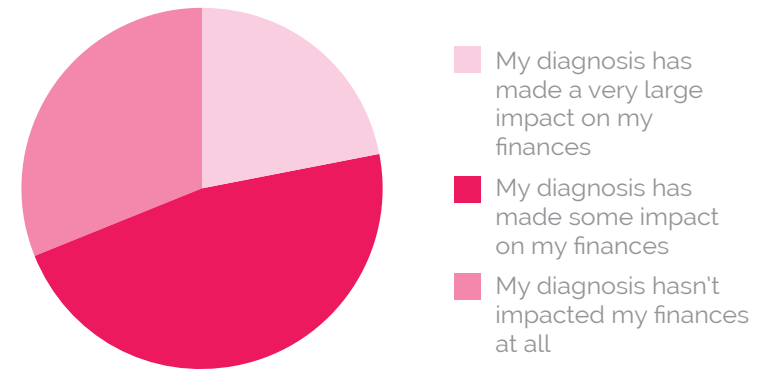
EARLY STAGE

The majority of respondents, 47%, indicated that their diagnosis has had some negative impact on their finances, with 22% reporting a large negative impact. Only 31% of respondents said that there was no impact on their finances.

*"I was in financial hardship and had to contact my credit card companies and speak to them about payment arrangements because we went from two incomes to one."
- Anonymous*

"I was off work for 9 months. I used all my short-term disability benefits from work, 15 weeks of EI (Employment Insurance Sickness Benefits), and a few weeks of long term disability and a gradual return to work. I was very ill and unable to look after myself during treatment and my spouse had to take every other week off without pay to look after me. We used much of our savings to supplement our loss of income during that time." - Gillian

HOW MUCH OF A NEGATIVE IMPACT HAS YOUR DIAGNOSIS HAD ON YOUR FINANCES?



FINANCIAL IMPACT (CONTINUED)

METASTATIC

The majority of respondents, 42%, indicated that their diagnosis has had some negative impact on their finances, with 40% reporting a large negative impact. Only 18% of respondents said that there was no impact on their finances.

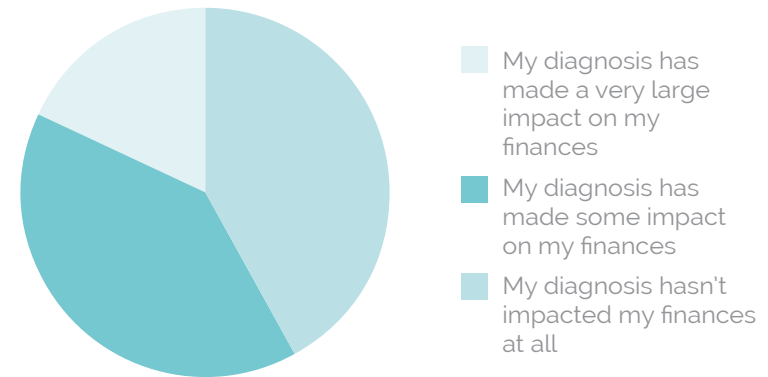
"When medications aren't covered, it is a tremendous financial burden, especially when I wasn't working."

- Anonymous

"We need help financially as well. I don't qualify for some of the disability funds to help take the burden off."

- Anonymous

HOW MUCH OF A NEGATIVE IMPACT HAS YOUR DIAGNOSIS HAD ON YOUR FINANCES?



FINANCIAL IMPACT (CONTINUED)

EARLY STAGE

ACCESSING FINANCIAL RESOURCES & SUPPORT

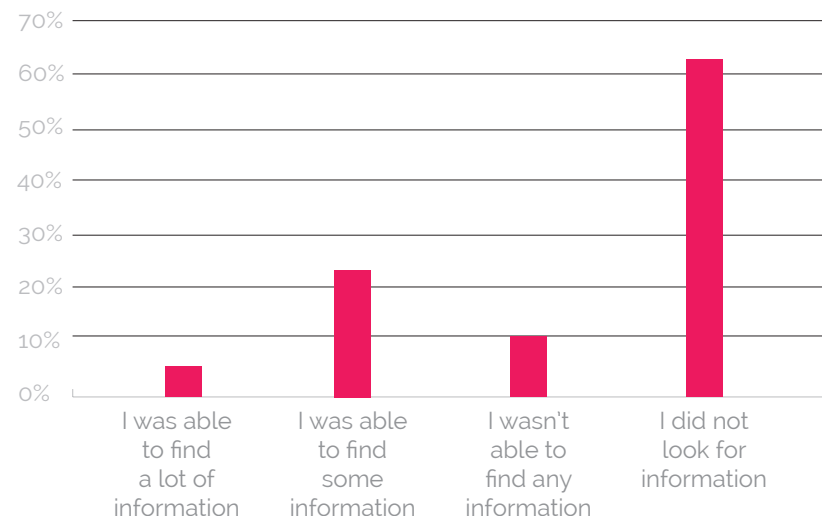
Both early stage and metastatic patients indicated that their breast cancer diagnosis has had a negative impact on their finances, with people in the metastatic group having a higher negative financial impact. The early stage and metastatic respondents also both shared that they had some challenges in finding and accessing financial resources, with increased challenges in the metastatic group.

Some respondents, 23%, indicated that they were able to find some information about financial resources, while 10% weren't able to find any information. Many, 62%, indicated that they didn't look, and only 5% reported being able to find a lot of information about financial resources and supports.

Of the respondents who looked for information about financial supports, 28% were able to access all of the financial support that they needed; 37% were able to access some financial support; and 35% weren't able to access any financial support.

"Financial security is a big issue. With no income and, so far, no government assistance, my retirement savings have been impacted. Also, I am uncertain of when I will be able to begin searching for a job again or when I will be successful in my search." - Anonymous

WERE YOU ABLE TO FIND INFORMATION ABOUT FINANCIAL RESOURCES?



FINANCIAL IMPACT (CONTINUED)

METASTATIC

ACCESSING FINANCIAL RESOURCES & SUPPORT

Both early stage and metastatic patients indicated that their breast cancer diagnosis has had a negative impact on their finances, with people in the metastatic group having a higher negative financial impact. The early stage and metastatic respondents also both shared that they had some challenges in finding and accessing financial resources, with increased challenges in the metastatic group.

Some respondents, 46%, indicated that they were able to find some information about financial resources, while 22% weren't able to find any information. Some, 29%, indicated that they didn't look and only 3% reported being able to find a lot of information about financial resources and supports.

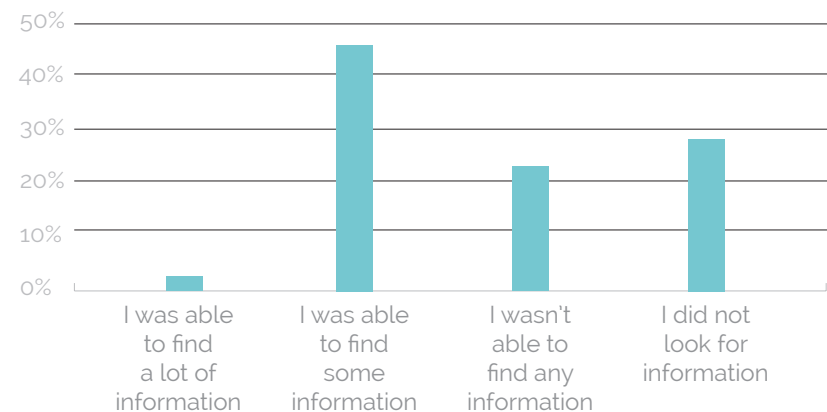
Of the respondents who looked for information about financial supports, 4% were able to access all of the financial support that they needed; 32% were able to access some financial support; and 22% weren't able to access any financial support.

"I think it would be good for the government to have concrete information related to each province outlining available supports - specifically financial / grants, etc."

- Anonymous

"Information concerning government or other aid, how to navigate insurance issues, long term disability issues, whether or not there is other funding for people on disability." - Mei-Lin

WERE YOU ABLE TO FIND INFORMATION ABOUT FINANCIAL RESOURCES?



"Just because I am not in the lowest income bracket does not mean I don't need assistance. I am excluded from all programs I have tried to access." - Tina

"How to deal with extra costs after being diagnosed. Transportation, parking. Losing weight, gaining weight and needing new clothes, shoes, wigs, makeup. How to pay for medications that are not covered by government or insurance." - Anonymous

FINANCIAL IMPACT (CONTINUED)

EMPLOYMENT INSURANCE SICKNESS BENEFITS – EARLY STAGE BREAST CANCER

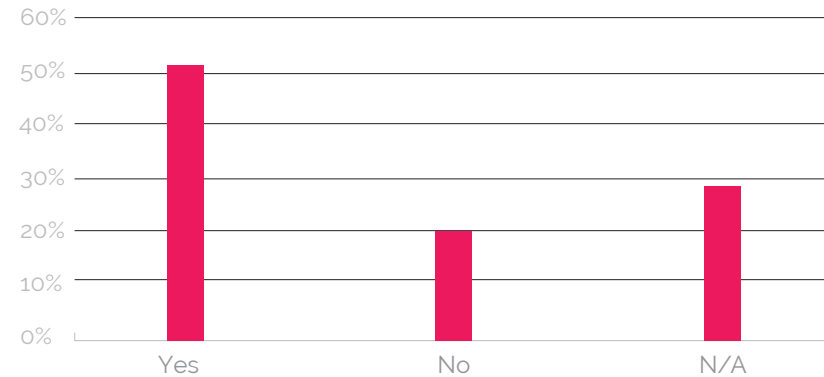
Currently the Employment Insurance Sickness Benefits program covers a maximum of 15 weeks of sick leave. Some respondents had additional support and allowances from their workplaces and some were self-employed and had no coverage

Over half of respondents, 51% indicated that they required more time off work than the 15 weeks covered by EI sickness benefits; 20% said they didn't require additional time; and 29% said EI sickness benefits weren't applicable to their situation.

"I was able to work part-time, or reduced hours, during my treatments. The full course of treatment was 60 weeks. Fifteen weeks of EI would not have covered it."
- Jackie

"15 weeks only covered time off up to my first chemo treatment. I had 6 then followed by 5 weeks radiation. Being single made it that much harder with only 15 weeks of EI sick benefits and the cost of travel etc. I had to be off work for nearly a year total."
- Anonymous

DID YOU REQUIRE MORE TIME OFF WORK THAN THE 15 WEEKS COVERED BY EI SICKNESS BENEFITS?



"HER+ treatment takes approximately 18 months. EI benefits are woefully inadequate." - Amanda



Many people diagnosed with early stage breast cancer rely on Employment Insurance Sickness Benefits to help them financially while they are undergoing treatment and recovering from breast cancer; however, the allocated time of 15 weeks is inadequate for people with a breast cancer diagnosis.⁵ Understandably, people living with metastatic breast cancer experience a significant impact on their ability to work; which directly impacts their financial health. The metastatic group also shared that there was a challenge in having employers making accommodations for them if they were willing to work.

⁵ Canadian Breast Cancer Network

<https://cbcn.ca/web/default/files/public/Reports/Economic%20Impact%20and%20Labour%20Force%20Re-Entry%20Report%20-%20E.pdf>

FINANCIAL IMPACT (CONTINUED)

EARLY STAGE

IMPACT ON EMPLOYMENT

Prior to a breast cancer diagnosis, 2% of respondents were on disability; after this diagnosis, the percentage jumped to 9%.



TRAVEL COSTS

For patients who need to travel significant distances from their home, there is an additional financial burden to dealing with a cancer diagnosis and treatment. Most respondents also commented on the challenges of the high cost of parking at cancer centres, especially if they are going on a daily basis.

The majority of respondents, 77%, travelled less than 60 kilometres for treatment, 17% travelled between 60 and 200 kilometres; and 6% travelled more than 200 kilometres.



FINANCIAL IMPACT (CONTINUED)

METASTATIC

IMPACT ON EMPLOYMENT

The majority of respondents, 47%, were employed full-time at the time of diagnosis, with only 12% employed full time at the time of this survey. Prior to their metastatic breast cancer diagnosis, 4% of respondents were on disability; after this diagnosis the percentage jumped to 30%.

For those who wished to work, 47% of employers made accommodations to allow this to happen; 16% made some accommodations; and 38% of employers did not make accommodations.



TRAVEL COSTS

For patients who need to travel significant distances from their home, there is an additional financial burden to dealing with a cancer diagnosis and treatment. Most respondents also commented on the challenges of the high cost of parking at cancer centres, especially if they are going on a daily basis.

The majority of respondents, 77%, travelled less than 60 kilometres for treatment, 17% travelled between 60 and 200 kilometres; and 6% travelled more than 200 kilometres.





PRIVATE INSURANCE

Many Canadians rely on private insurance to cover the cost of medications that aren't covered publicly. It is estimated that over 24 million Canadians have private health coverage.⁶

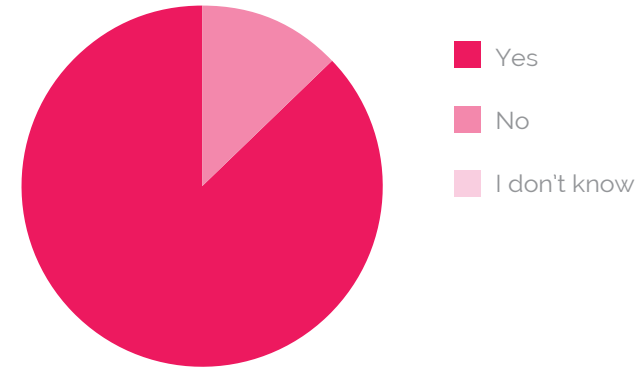
⁶ Canadian Life and Health Insurance Association [https://www.clhia.ca/web/CLHIA_LP4W_LND_Webstation.nsf/resources/Factbook_2/\\$file/2016+CLHIA+Factbook+ENG.pdf](https://www.clhia.ca/web/CLHIA_LP4W_LND_Webstation.nsf/resources/Factbook_2/$file/2016+CLHIA+Factbook+ENG.pdf)

PRIVATE INSURANCE

EARLY STAGE

At the time of diagnosis, 80% of respondents had private insurance coverage. Of the respondents who had private insurance coverage, 23% of them had challenges accessing their private insurance and 6% had a claim denied.

AT THE TIME OF DIAGNOSIS, DID YOU HAVE PRIVATE INSURANCE?

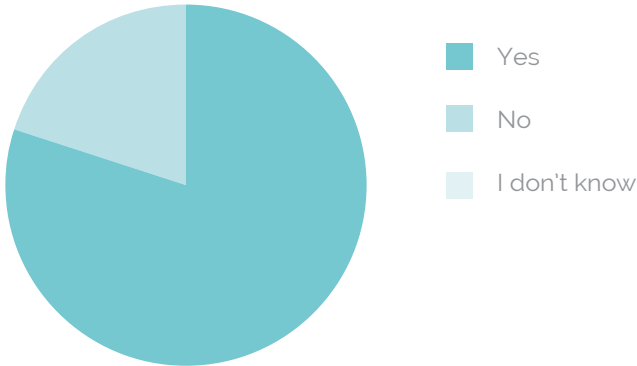


PRIVATE INSURANCE (CONTINUED)

METASTATIC

At the time of diagnosis, 87% of respondents had private insurance coverage. Of the respondents who had private insurance coverage, 13% of them had challenges accessing their private insurance and 7% had a claim denied.

AT THE TIME OF DIAGNOSIS, DID YOU HAVE PRIVATE INSURANCE?





IMPACT ON FAMILIES

The overall impact of a breast cancer diagnosis is shouldered by not only the patient, but by the families of patients. This survey focused specifically on the experience of patients, but it's important to acknowledge that there is a significant impact on partners, children, parents, and siblings. Family members will experience an emotional impact in some way or another, and often a financial impact can be significant for the family as well. There is also the psychosocial impact of watching a loved one go through cancer treatments, and for families who lose a loved one to breast cancer, there is a loss that can never be quantified or explained through a survey. The impact of this disease is significant and far-reaching.

IMPACT ON FAMILIES

EARLY STAGE

The majority of respondents, 73%, indicated that they had children at the time of diagnosis.

59% of these children were 20 or older; 31% were teenagers between the ages of 13 and 19; 17% were between the ages of 6 and 12; 10% were toddlers between the ages of 2 and 5; and 9% were infants 1 year old or younger.

When asked about information that was lacking at time of diagnosis as it relates to family, respondents shared the following insights:

"How to deal with my partner." - Anonymous

"Resources to help deal with raising small children"

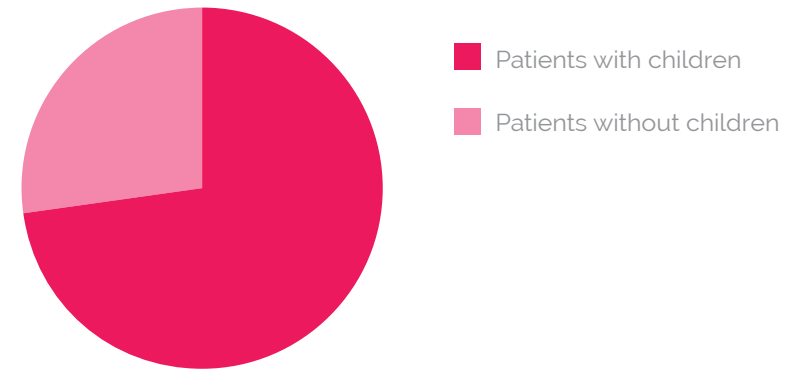
- Aimee

When asked about factors that influence treatment decisions that related to family, respondents shared the following insights:

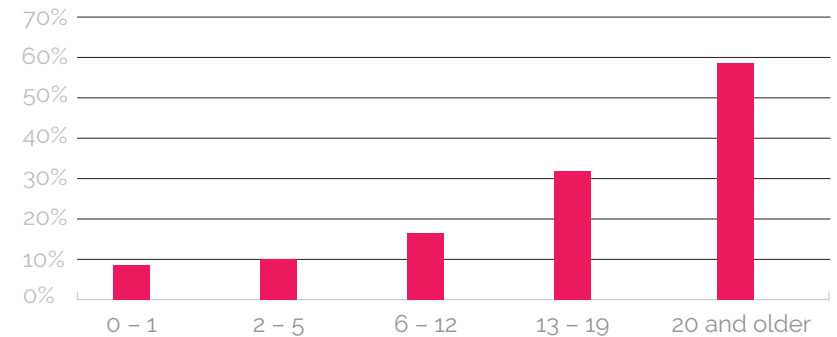
"How will my decisions affect my family." - Anonymous

"My mental health and that of my family was not addressed. Lack of recognition of the emotional toll of cancer is a huge gap." - Anonymous

PATIENTS WITH CHILDREN



AGES OF CHILDREN



IMPACT ON FAMILIES (CONTINUED)

METASTATIC

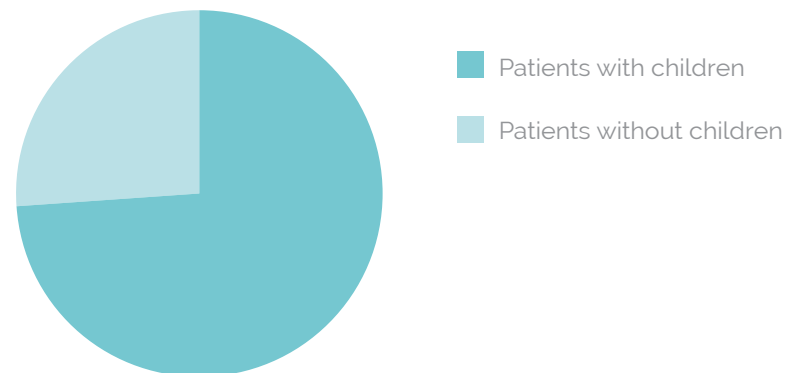
The majority of respondents, 74%, indicated that they had children at the time of diagnosis.

62% of these children were 20 or older; 17% were teenagers between the ages of 13 and 19; 25% were between the ages of 6 and 12; 12% were toddlers between the ages of 2 and 5; and 3% were infants 1 year old or younger.

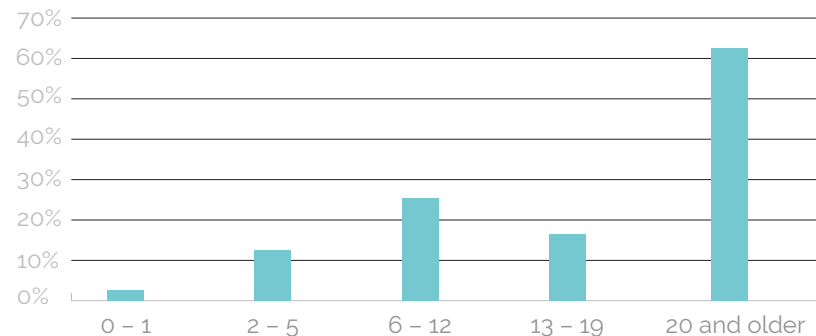
"I'm 43 now and I will be in treatments for the rest of my life. I have a very difficult time still trying to figure out how to move forward while taking advantage of all the wonderful moments I still have. I have no choice but to continue to battle this war that my body has bombarded my family and me with... the most difficult aspect is planning for my mortality and trying to keep my chin up and not burden my family. I am grateful to have survived this long. And I will continue to fight." - Marie-Carole

"It has really changed my mindset. I am living in fear every day. I have never been the sort of person who worries, but I am now. My young children have grown into teens with anxiety and I wish I knew how to help them." - Jackie

PATIENTS WITH CHILDREN



AGES OF CHILDREN





PSYCHOSOCIAL SUPPORT

Resources, programs and research addressing the psychosocial support needs of patients has increased in recent years; however, there is still a gap in patients' ability to access these programs.

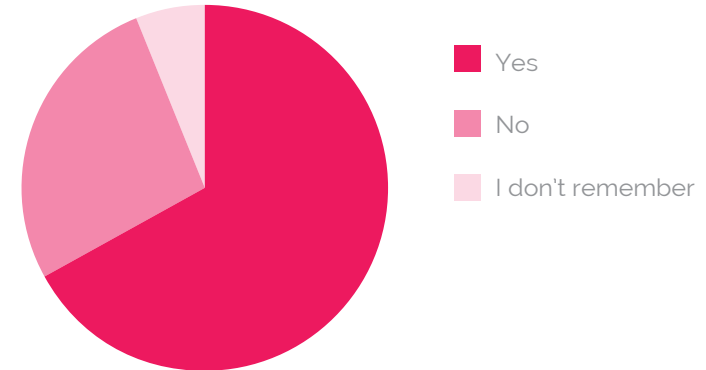
PSYCHOSOCIAL SUPPORT

EARLY STAGE

The majority of respondents, 67%, were provided with information about where to access psychosocial (emotional) support; 27% weren't provided with this information; and 6% don't remember.

"More support is needed in dealing with worry about recurrence." - Sandy

WERE YOU PROVIDED WITH INFORMATION ABOUT WHERE TO ACCESS PSYCHOSOCIAL (EMOTIONAL) SUPPORT DURING AND AFTER YOUR TREATMENT?



PSYCHOSOCIAL SUPPORT (CONTINUED)

METASTATIC

The majority of respondents, 69%, were provided with information about where to access psychosocial (emotional) support; 24% weren't provided with this information; and 7% don't remember.

Family (81%), partner/spouse (80%), children (63%), and friends (56%) were ranked as very important supports for the majority of people. Professional counsellors were ranked as very important support for 47% of respondents. Support groups (30%), social media (33%), and online discussion forms (26%) were ranked as very important supports by approximately a third of respondents.

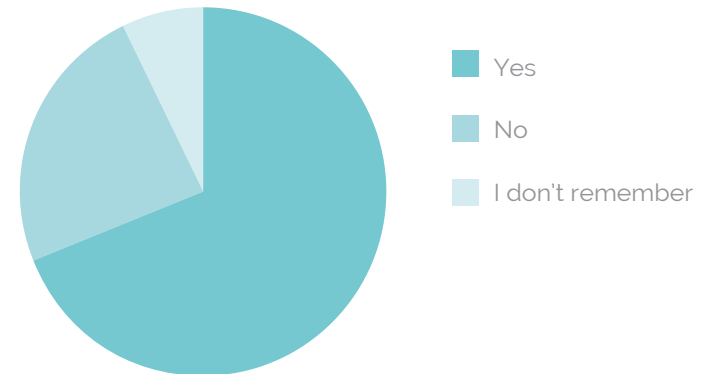
"I find there is survivorship support for early stage or right after treatment for mets then support at hospice level but pretty much nothing in the middle of these."

- Patricia

"Where to find support? How to access emotional support? It is expensive or there is a very long wait."

- Anonymous

WERE YOU PROVIDED WITH INFORMATION ABOUT WHERE TO ACCESS PSYCHOSOCIAL (EMOTIONAL) SUPPORT DURING AND AFTER YOUR TREATMENT?





MENTAL HEALTH AND WELL-BEING

There is a significant impact to the mental health of people diagnosed with any stage of breast cancer; however, many patients were able to access the information and support that they needed. There were still a small number who lacked these resources, and increased efforts to connect all patients with mental health resources should continue to help support these needs. Both groups also shared that this diagnosis had an impact on their self-confidence, with resources addressing this topic being harder to access.

The impact on body image was experienced by almost of half of both groups; however, there were increased challenges in accessing supports and information in relation to body image than there were for mental health.

MENTAL HEALTH AND WELL-BEING

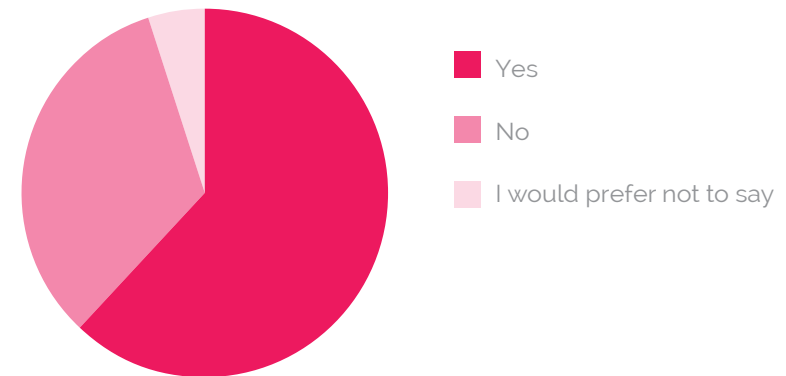
EARLY STAGE

The majority of respondents, 62%, said that they had experienced an impact on their mental health as a result of their diagnosis; 33% said they had not; and 5% preferred not to say. Most, 70%, of respondents said that they had been able to access some information about mental health after a breast cancer diagnosis, while 9% of respondents said they weren't able to access any information about this.

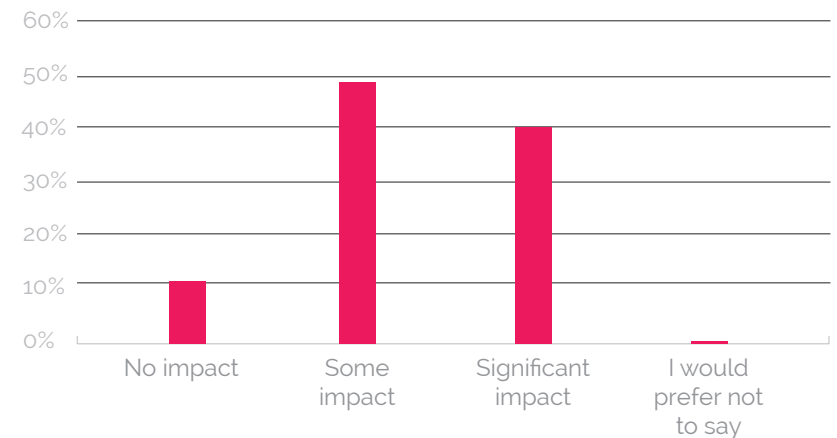
"The health care system was efficient in getting me diagnosed and treated; however, the support for my mental health during the tragedy of the diagnosis and the mastectomy was non-existent." - Anonymous

The majority of respondents, 49%, indicated that a breast cancer diagnosis had some impact on their body image, with 40% indicating it had a significant impact. Most patients were able to find resources to help support a positive body image after a breast cancer diagnosis, but 15% of respondents weren't able to find any resources to help with this.

HAVE YOU EXPERIENCED ANY IMPACTS ON YOUR MENTAL HEALTH AS A RESULT OF YOUR DIAGNOSIS?



IMPACT ON BODY IMAGE



MENTAL HEALTH AND WELL-BEING (CONTINUED)

METASTATIC

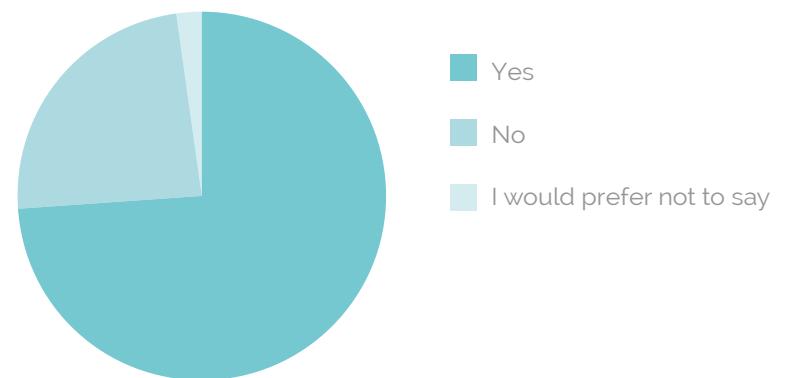
The majority of respondents, 74%, said that they had experienced an impact on their mental health as a result of their diagnosis; 24% said they did not; and 2% preferred not to say. Most, 71% of respondents, said that they had been able to access some information about mental health after a breast cancer diagnosis, while 5% of respondents said they weren't able to access any information about this.

"What's most difficult is that you can look well (although you are not well), so people, the medical teams, and even your family have unrealistic expectations of you. Also, you are living with internal fear and anxiety as to when and how this disease is going to take you down. You celebrate every small milestone and immediately question whether there will be the next. So you're internally sad all of the time and outwardly hiding it. That makes going to sleep at night difficult - negative thoughts are screaming in your head!"

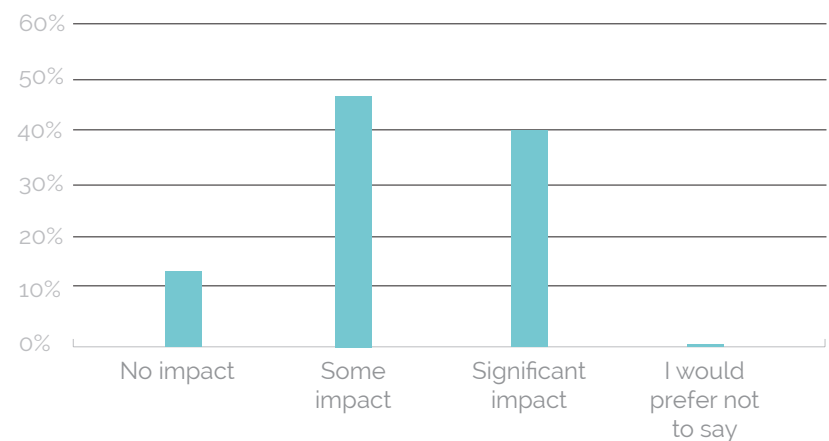
- Joan

The majority of respondents, 47%, indicated that a breast cancer diagnosis had some impact on their body image, with 40% indicating it had a significant impact. Most patients were able to find resources to help support a positive body image after a breast cancer diagnosis, but 28% of respondents weren't able to find any resources to help with this.

HAVE YOU EXPERIENCED ANY IMPACTS ON YOUR MENTAL HEALTH AS A RESULT OF YOUR DIAGNOSIS?



IMPACT ON BODY IMAGE

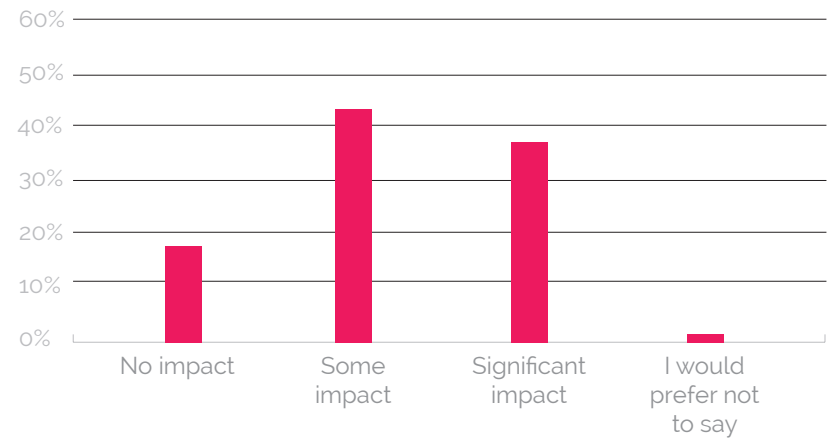


MENTAL HEALTH AND WELL-BEING (CONTINUED)

EARLY STAGE

Most respondents, 80%, indicated that that having breast cancer had either some impact or a significant impact on their self-confidence, with 11% of respondents indicating that there weren't any resources available to them to help address this.

IMPACT ON SELF-CONFIDENCE

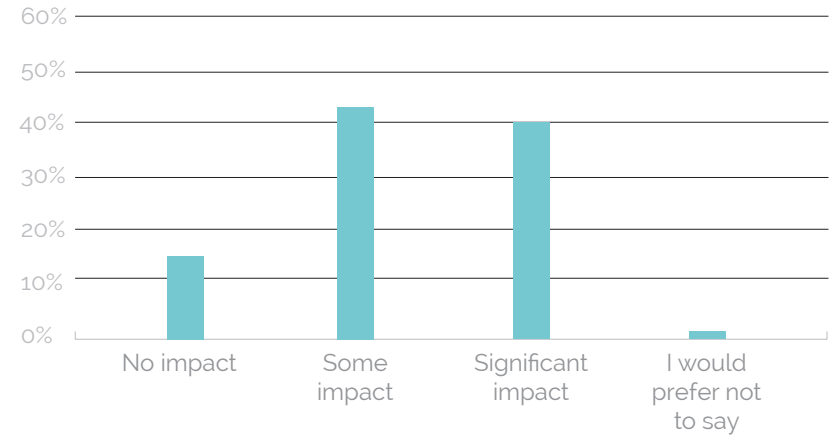


MENTAL HEALTH AND WELL-BEING (CONTINUED)

METASTATIC

Most respondents, 83%, indicated that that having breast cancer had either some impact or a significant impact on their self- esteem, with 18% of respondents indicating that there weren't any resources available to them to help address this.

IMPACT ON SELF-CONFIDENCE





EXERCISE AND NUTRITION

Many patients indicate paying closer attention to their overall health after a breast cancer diagnosis and often look at ways, through diet and exercise, to help reduce their risk of recurrence or of the cancer spreading further.

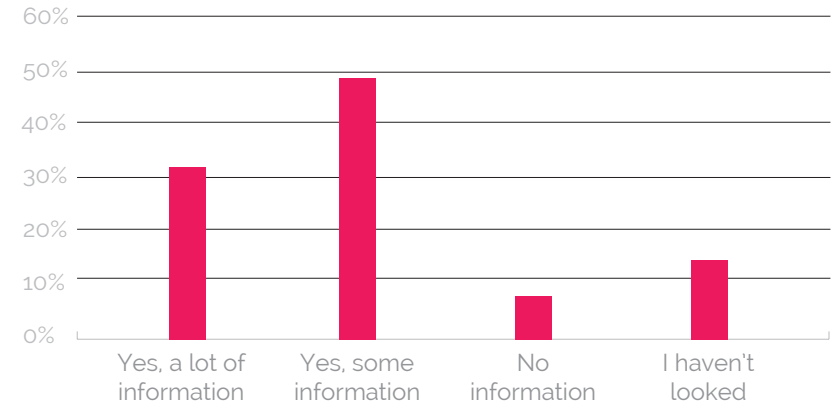
EXERCISE AND NUTRITION

EARLY STAGE

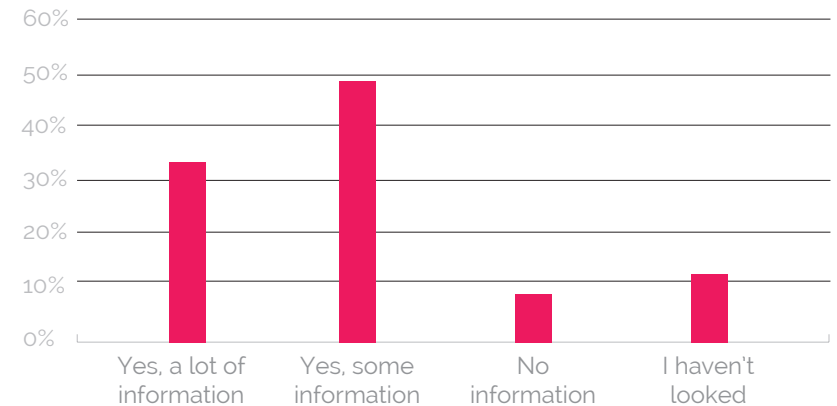
Most, 91%, of respondents indicated that they are somewhat interested or very interested in information related to nutrition after a breast cancer diagnosis, and the majority of respondents, 80%, have been able to access information about this topic.

An overwhelming majority, 95%, of patients indicated that they were somewhat or very interested in information related to exercise after a breast cancer diagnosis, and the majority, 81%, have been able to access a lot or some information on this topic.

ACCESSIBILITY OF NUTRITION RELATED INFORMATION



ACCESSIBILITY OF EXERCISE RELATED INFORMATION



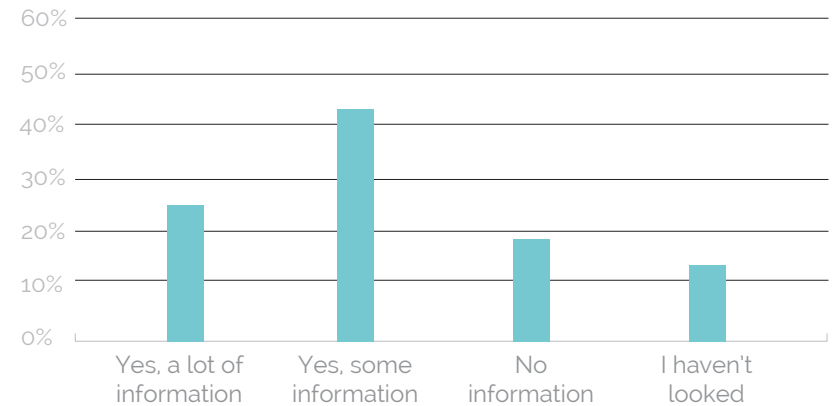
EXERCISE AND NUTRITION (CONTINUED)

METASTATIC

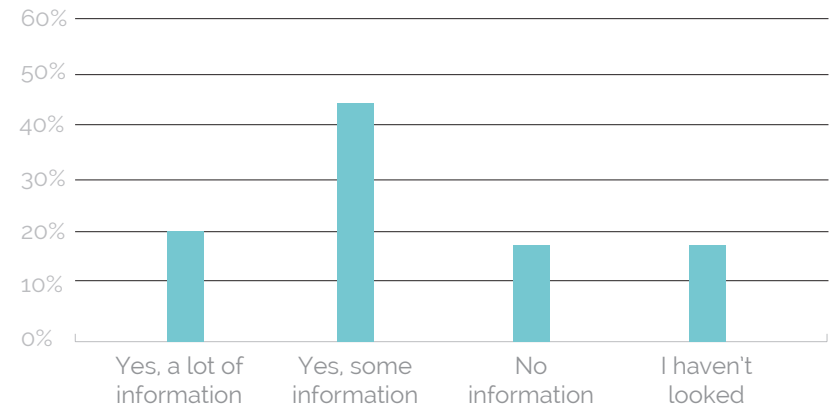
When asked about accessing quality information about nutrition as it relates to living with metastatic breast cancer, 25% of respondents said they were able to access a lot of information; 42% said they had accessed some information; 19% weren't able to access any information; and 14% didn't look for this information.

When asked about accessing quality information about exercise and living with metastatic breast cancer, 20% were able to access a lot of information; 44% were able to access some information; 18% weren't able to access any information; and 18% didn't look for information about exercise and living with metastatic breast cancer.

ABILITY TO ACCESS NUTRITION RELATED INFORMATION



ABILITY TO ACCESS EXERCISE RELATED INFORMATION





LIVING WITH METASTATIC BREAST CANCER

People living with metastatic breast cancer still feel isolated. While early stage breast cancer is generally well-understood by people and the public as a whole, metastatic breast cancer is not. This lack of awareness and understanding of the disease continues to marginalize people living with an incurable stage of breast cancer.

The patient quotes really paint a vivid picture of the challenges of living with metastatic breast cancer, and these are echoed by most of the respondents and most of the patients that CBCN has worked with for years.

There continues to be a lack of understanding that while metastatic breast cancer can't be cured, it can be treated; and as new treatment options become available, it can be managed for longer and longer, often with a good quality of life.

There continues to be gaps in accurate statistics for this patient population. There is also a need for better resources on dying-well, in a way that allows people to have conversations about a topic that can be challenging to discuss.

LIVING WITH METASTATIC BREAST CANCER

METASTATIC

When asked if there is enough information about living with metastatic breast cancer, only 37% of respondents said that there was; 53% said that there wasn't; 10% had not looked.

When asked what information was lacking about living with MBC, respondents shared the following:

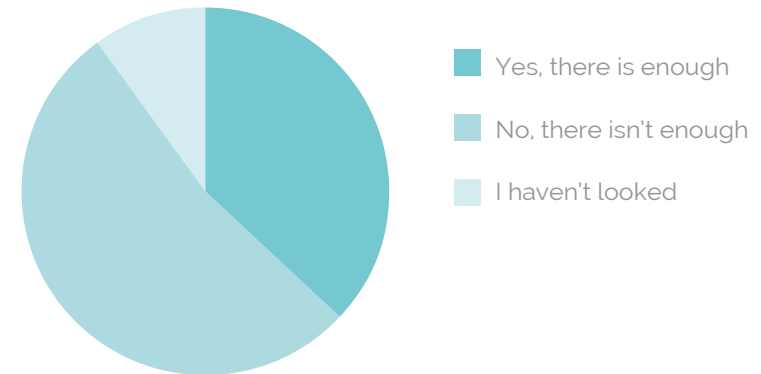
"Accurate statistics." - Lisa

"Drug approval process in language that is easy to understand." - Shelley

*"A realistic approach to the end. How to die well."
- Diane*

"Coping skills preparing for death, accessing palliative care and help in deciding when to go to hospice vs. staying at home." - Nathalie

AVAILABILITY OF INFORMATION ABOUT LIVING WITH METASTATIC BREAST CANCER



LIVING WITH METASTATIC BREAST CANCER (CONTINUED)

METASTATIC

When asked if there is enough awareness about living with metastatic breast cancer, an overwhelming majority, 89%, said there was not; only 7% thought that there was enough awareness and 4% didn't know.

"(Need) awareness that it is treatable but no cure." - Tricia

"There is a lack of awareness that patients can live many years with metastatic breast cancer and that advances have been made in treatments and continue to be made."

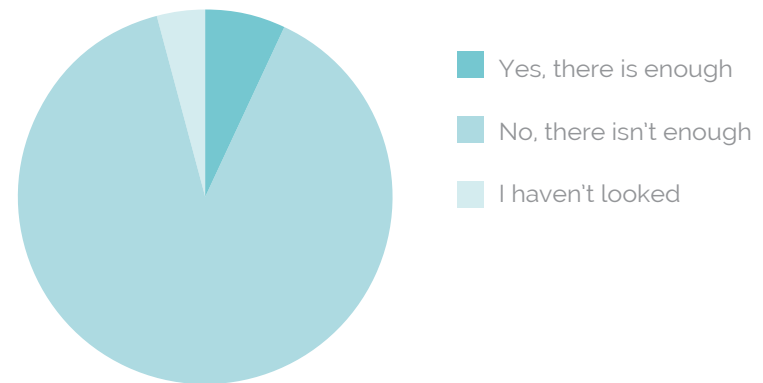
- Anonymous

"Metastatic breast cancer is incurable. Too often we have to explain to people that we are going to die from metastatic breast cancer. We are told to "be positive" and "you can fight it". War language is extremely hurtful and not supportive." - Anonymous

"I am very saddened by the lack of knowledge the general public has of this disease. It isolates us."

- Anonymous

AWARENESS ABOUT BREAST CANCER



"I find when info says it's preventable (metastatic breast cancer) with exercise and diet (it) implies I did something wrong. I was healthy, with healthy weight. It affects mental health." - Cindy



SURVIVORSHIP

LIFE AFTER BREAST CANCER

The aim with early stage breast cancer is to treat it and cure it; however, often, once a patient is finished treatment, she feels that the support that she had through her cancer team and the cancer centre is no longer available to her, and she often feels that the transition to the “new normal” can be overwhelming. In addition, patients express concern with managing the fear of recurrence, which is a common challenge for many people who have experienced an early stage breast cancer diagnosis. Many respondents expressed concern around these two specific areas.

After treatment is completed I felt very abandoned by my cancer team. It went from “hand holding” to basically a “kick to the curb”. I worry about recurrence but feel I am out of the system. - Sandy

There needs to be much more socio-emotional support for living once treatment is completed as there is none. One goes from actively being supported during treatment to NOTHING once it's over. - Anonymous

More support is needed in dealing with worry about recurrence. - Sandie

Will Canadian medical practice have the survivorship plans that are being used in the U.S.? I am not too sure my GP know how to assess symptoms for recurrence, etc. - Anonymous

“The side effects of treatments cause a lot of other health problems, which I am still dealing with and recovering from.” - Marnie

RECOMMENDATIONS



Through the information shared in this survey, Canadians who have experienced a breast cancer diagnosis have clearly identified where their needs are being met and where there are opportunities for improvement. As the national voice of Canadians affected by breast cancer, the Canadian Breast Cancer Network puts forward the following recommendations to better address the needs of patients:

1. Improved Educational Resources: The quality and availability of patient education has increased over the past couple of decades; however, there are still certain areas that lack patient friendly educational resources. These include:

- A newly diagnosed metastatic breast cancer resource that is specific to this patient population.
- A breast cancer surgery decision aid that can support early stage breast cancer patients trying to make informed decisions about their surgery treatments. In addition, a decision aid that helps support patients with decision making after breast cancer surgery around breast reconstruction, living flat and using a prosthesis is needed.
- A financial navigation tool that outlines all financial supports and programs across Canada that are accessible to breast cancer patients and families.
- A tool that informs early stage patients what to expect from a treatment timeline perspective in terms of how long each treatment will take and what a realistic recovery time is.
- A private insurance resource tool that helps patients understand their private insurance and navigate challenges with accessing coverage.
- A resource for employers to help accommodate breast cancer patients as they return to work or make accommodations for people living with metastatic breast cancer who may still wish to work.
- Resources about, and opportunities to discuss, dying well need to be available.

2. Increased Access to Treatments: This challenge was specifically identified and vocalized by people living with metastatic breast cancer; however, as new treatments move into the early stage setting this will also be a concern for this patient population.

- An expedited drug approval process is needed to decrease wait times for access to new treatments.
- Equitable access to new treatments that allows all Canadians living with metastatic breast cancer to have access to the new treatments regardless of the province they live in.
- Equitable access to take-home oral cancer medications, regardless of province.

3. Increased Access to Information: Information available to patients about their health and treatment has increased; however, there is still information that isn't always communicated to patients that would help them make better-informed decisions about their health.

- After screening, all women need to be informed of their breast density to ensure that they understand whether or not they are at an increased risk of breast cancer or if the traditional screening mammography methods will work for them.
- People diagnosed with metastatic breast cancer should be informed about palliative care, how it can improve their quality of life, how to access it, and that it's not only a resource for end-of-life care.
- Information about clinical trials needs to be more easily accessible to patients, including what trials may be available across Canada.

4. Integrated systemic supports: The health care system as a whole is responsible for many of the services and supports that patients need to achieve optimal health and manage their breast cancer; however, these supports can be challenging to navigate and are sometimes lacking. The following supports need to be addressed at a systemic level:

- A survivorship care plan needs to be developed for early stage patients to ensure that appropriate follow-up and monitoring continues throughout the patients' lives.
- Patient navigation needs to be integrated across Canada to help patients navigate the system, access the supports they need, and have their care coordinated in an integrated manner.
- General practitioners need to have the appropriate tools to effectively communicate a breast cancer diagnosis to a patient and provide them with the information that they need at that time.
- Psychosocial professionals, such as therapists and social workers, greatly impact patients' abilities to cope with a breast cancer diagnosis and to access supports to assist them and their families; these professionals are an essential part of patient care and all patients should have access to them.
- Employment Insurance Sickness Benefits, although not part of the health care system, significantly impact a breast cancer patient's health. The ability to undergo treatment and properly recover are greatly impacted by the availability of Employment Insurance Sickness Benefits, which currently aren't substantial enough to support patients throughout their entire treatment and recovery.

5. Increased awareness and understanding of metastatic breast cancer:

A lack of accurate statistics and overall awareness of metastatic breast cancer makes it challenging to truly understand the scope and impact of this stage of breast cancer.

- Accurate statistics specifically about metastatic breast cancer need to be collected.
- Greater understanding and awareness about metastatic breast cancer needs to be achieved to help mitigate the isolation of people living with this stage of the disease.

CBCN IN ACTION

As a patient directed organization, the Canadian Breast Cancer Network is committed to listening to the lived experience of breast cancer patients and survivors that was shared through these surveys, and ensuring that it informs the priorities and initiatives of the organization. Through our education and advocacy programs, CBCN will work to implement these recommendations and work with partners, key decision makers, and stakeholders to move these recommendations forward. As a result of the lived experience shared through these surveys, CBCN has already undertaken several initiatives to address some of the needs identified by patients and survivors.

Metastatic Breast Cancer Newly Diagnosed Handbook: In partnership with Living Beyond Breast Cancer, CBCN launched a resource specifically to address the needs of Canadians with metastatic breast cancer. This resource is available both digitally and in print, in English and in French, and is currently being distributed to cancer centres and community organizations across the country. This will help address an unmet need of this community for information specific to metastatic breast cancer at the time of diagnosis.

Breast Cancer Surgery Decision Aid: Information to help breast cancer patients make informed decisions about breast cancer surgery and the post-surgery options isn't equitable, with many patients sharing that there was a significant gap in information at the time of diagnosis to help with these decisions. CBCN will be launching a digital "Breast Cancer Surgery Decision Aid" in 2018, that will help navigate patients through this process with patient friendly evidence-based information.

Financial Resources Navigation Tool: Given the financial impact of a breast cancer diagnosis, many patients seek resources and support to help them throughout treatment, or after. This information can be challenging to find, which is why CBCN will launch a "Financial Resources Navigation Tool" in the fall of 2018 that will allow patients from across Canada to access a comprehensive database that will list all the financial resources and supports that exist to support breast cancer patients.

Drug Access: There continues to be significant challenges regarding drug access for breast cancer patients, specifically for metastatic breast cancer. CBCN has undertaken and continues to initiate various advocacy and awareness campaigns to highlight this issue, ensuring that the voice of patients is heard and considered by decision makers. CBCN also regularly participates in consultations about drug access and provides the patient perspective to drug approval bodies for new and emerging therapies.

Access to Take Home Medications: CBCN is proud to be a member of CanCertainty, a coalition of patients and patient groups that is committed to moving forward on the issue around take-home oral cancer medication. The work of CanCertainty has led to better coverage and accessibility for take-home cancer medications in Nova Scotia, and work continues in other provinces as well.



CONCLUSION

Receiving a breast cancer diagnosis is overwhelming, complex and experienced by individuals in many different ways. While improvements have been made in addressing the needs of breast cancer patients, there are still gaps and opportunities for increased support, resources, and care.

Early stage breast cancer patients and people living with metastatic breast cancer share some similar experiences; however, there are noticeable differences. While the informational needs at the time of diagnosis are generally well addressed for early stage patients, people diagnosed with metastatic breast cancer often experience a lack of information specific to their diagnosis. The metastatic population also experiences higher treatment related costs both for cancer medications and support medications, which creates a significantly higher rate of non-adherence to medication as a direct result of the cost. Additionally, while there is interest in clinical trials

for both groups, there is significantly more in the metastatic population; however, both groups indicated that they didn't feel they had enough information to make an informed decision about clinical trials. It's important that the difference in the experience and needs of early stage patients and metastatic patients is considered when looking to better serve breast cancer patients. Progress has been made in treatments and detection of breast cancer, but without timely and equitable access to new treatments some patients are prohibited from benefitting from these advances.

The burden of breast cancer weighs heavy on patients, families and communities. All stakeholders, including governments, private industry, health care professionals, patient organizations, patients, and caregivers needs to work together to ease the impact of this disease on Canadians.





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