

2023

THE CANADIAN BREAST CANCER NETWORK'S TNBC PROJECT

Identifying the informational, educational, and support needs
of Canadians diagnosed with triple negative breast cancer



Canadian Breast Cancer Network
Réseau canadien du cancer du sein

ACKNOWLEDGEMENTS

The Canadian Breast Cancer Network (CBCN) is pleased to acknowledge and thank the hundreds of Canadians diagnosed with breast cancer who shared experiences about themselves and their needs for informational, educational, and support resources regarding their diagnoses. They told us not only what topics and resources were

This report is dedicated in the loving memory of Joni Sawler who served on CBCN's Triple Negative Breast Cancer (TNBC) Project Advisory Committee. Joni also participated in the project interview process and recounted her experiences and evaluation of resources available to her. Her responses were invaluable in formulating focus group and assessment questions. She was relentless in making the point that TNBC patients need well-informed advocates. Joni Sawler was truly a model for advocacy.

of importance to them, but how to tailor these supports and ensure that they are easily accessible. Their responses to our assessment provide guidance to us on what is needed and how to improve what is currently available.

We were fortunate to have had a superb Project Advisory Committee who lent their time and expertise to this

effort. Our project began with six one-hour interviews with this committee, all of whom helped hone and shape the focus of this project. Joni Sawler, Rhonda Singer, and Rebecca Dahle shared their experiences from the patient perspective while Dr. Karen Gelmon, Dr. David Cescon, and Dr. Sandeep Sehdev provided input from the healthcare professional perspective. We are most grateful to each member of the committee for their interest and participation.

The Canadian Breast Cancer Network expresses our sincere appreciation to the women who enthusiastically participated in the project's informant interviews and focus group discussions. Their open and honest sharing provided depth and breadth to our understanding of the unique needs of individuals diagnosed with triple negative breast cancer.

We would also like to recognize the tremendous contributions of Jenn Gordon, Cathy Ammendolea, and Niya Chari to the TNBC Project.

CBCN acknowledges with gratitude, the generous unrestricted grants provided by Gilead Sciences Canada and Merck Canada that supported this project and the development of this report.





This report is authored by the Canadian Breast Cancer Network. It was written by Kathleen Swiger and Bukun Adeggbembo, edited by Carly Gregory, and translated to French by Claire Fennebresque. Scott Richter, Ph.D provided statistical consulting and analysis of the data. The design and layout of the report were done by Carly Gregory.

The Canadian Breast Cancer Network exists to ensure the best quality of life for people in Canada diagnosed with breast cancer. CBCN is Canada's leading patient-directed breast cancer health charity that voices the views and concerns of breast cancer patients through the promotion of information sharing, education, and advocacy activities.

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EXECUTIVE SUMMARY

In **2022**, the Canadian Breast Cancer Network (CBCN) conducted interviews, focus groups, and launched an online assessment to identify the unique educational, informational, and support needs of Canadians diagnosed with triple negative breast cancer (TNBC). The online assessment was open to all Canadians who had been diagnosed with breast cancer. **981** people completed the English-only survey – **18.9%** were TNBC patients and **81.1%** were non-TNBC patients. The mean age of all the respondents was **59.5** years old,



while the mean years since diagnosis was **5.62**. While all provinces and territories were represented, **41.7%** lived in Ontario, **21.7%** lived in British Columbia, **7.6%** were from Alberta, and **6.2%** were from Quebec.

The potential outcomes emerging from this project are focused on implementing what has been learned from this assessment regarding identifying the needs of Canadians diagnosed with TNBC. Potential outcomes include:



- *Increasing public awareness of TNBC by highlighting the unique lived experience of Canadians living with TNBC.*



- *Identifying needs and gaps in care for TNBC patients and developing resources that address these needs and gaps.*



- *Recommending concrete ways to address barriers to optimal care for those diagnosed with TNBC.*



- *Facilitating informed exchanges between patients and their healthcare team, advocacy groups, payers, and decision makers.*

As analysis and discussion continues, updates in other areas of interest can be used to improve the lives of Canadians diagnosed with triple negative breast cancer. Additionally, having included the views and perspectives of individuals diagnosed with all types and subtypes of breast cancer in our quantitative assessment, we have the opportunity to understand the larger breast cancer population's educational, informational, and support needs so that we can work to improve the lives of all Canadians who have been diagnosed with breast cancer.

INTRODUCTION



Triple negative breast cancer (TNBC) is a type of breast cancer that is characterized by the absence of [three receptors](#) (proteins located in or on the cell): estrogen (ER), progesterone (PR) and human epidermal growth factor receptor 2 (HER2). These proteins can bind with something in or on the cell surface and cause that cell to react. In ER+, PR+, and/or HER2+ cancers, treatments have been developed to prevent, impede, or stop cancer growth by targeting those receptors. However, in triple negative breast cancer patients, those receptors are not present and therefore require different types of therapies.

In addition to the different treatment needs of TNBC patients, the age demographics of those diagnosed with TNBC are unique in that while most cases of breast cancer occur in those over the [age of 50](#), TNBC is more likely to be diagnosed in [younger patients](#). Additionally, this subtype has also been found to be higher in Black and Hispanic women.

While the TNBC population represents about **10 to 20%** of the [breast cancer population](#), it is important to assess the specific needs of this sub-type of breast cancer. Their needs are often overlooked because they represent a small population. Breast cancer is not a monolithic disease, with many different types, subtypes, and treatments based on these specific types and subtypes. Increasing awareness of TNBC within the breast cancer community and to the public at large would enhance understanding of and provide a voice for those diagnosed with TNBC. As a result, the Canadian Breast Cancer Network (CBCN) began a TNBC Project in 2021 that focused on better understanding the unique needs of Canadians diagnosed with TNBC. The goals of the project were to:

- **Identify the unique educational, informational, and support needs of Canadians diagnosed with TNBC.**
- **Compare these needs to those diagnosed with other types of breast cancer to determine differences in needs and concerns.**
- **Disseminate the findings to advocates, survivors, healthcare professionals, and government officials.**
- **Use the findings to develop future materials, programs, and services that are specifically focused on the TNBC population.**



CBCN's TNBC project components included:

Project Advisory Committee:

A Project Advisory Committee was formed in November 2021. The committee consisted of 3 patients diagnosed with TNBC, 3 Medical Oncologists who were familiar with TNBC, the Board Chair of CBCN, the Director of Operations of CBCN and the TNBC Project Lead. The committee met virtually in mid-November 2021 to be briefed on the project, as well as again virtually in late April 2023 to review the study findings to date.

Key Informant Interviews:

In January 2022, 7 90-minute interviews were conducted with identified key informants. Interviews were conducted using an approved interview format with the Project Advisory Committee and 1 additional physician who specialized in psycho-oncology. Notes from the interviewed were summarized and used to inform the focus group discussion guide.

Focus Group Discussions:

5 focus groups were conducted virtually during February and March 2022. Each group had 5 to 6 participants; 1 focus group was conducted with only metastatic breast cancer patients. Groups were representative of the regions of the country and discussions were conducted in English. Key findings from the focus group discussions were incorporated into the quantitative assessment.

Quantitative Assessment:

A quantitative assessment was drafted and reviewed internally with CBCN staff during April 2022. The assessment was launched online in early May and closed in mid-June 2022. Data analysis began in mid-September 2022 and is ongoing. This summary report represents the top-line view of the findings to date. The information found in this report is based on the data analysis from the online quantitative assessment component of the overall TNBC Project.



METHODOLOGY & DEMOGRAPHICS

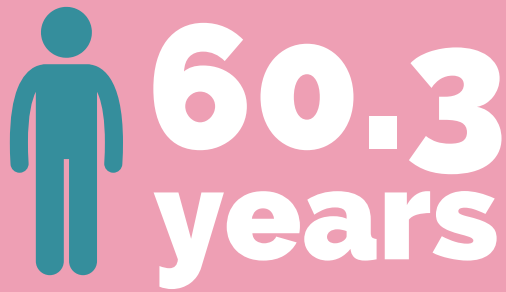
The information found in this report was based on the analyzed data from the online quantitative assessment component of the overall TNBC Project. The online assessment was limited to people currently living in Canada who had experienced a breast cancer diagnosis. It was launched in early May 2022, closed in mid-June 2022, and was available only in English. Promotion for the assessment was done online through social media (paid and organic) and e-blasts.

Data analysis began in mid-September 2022 and is on-going. This summary report represents the top-line view of the findings to date.

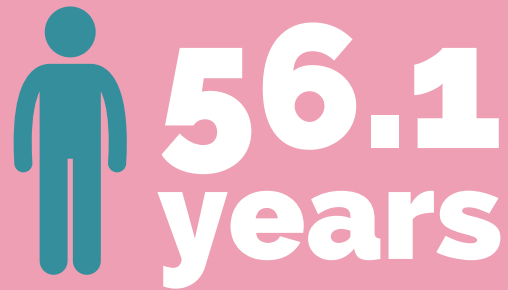
A total of **1012** Canadians who had been diagnosed with breast cancer responded to the assessment. **981** individuals completed the assessment: **185** respondents had been diagnosed with TNBC or **18.9%**; **796** respondents or **81.1%** had been diagnosed with other types of breast cancers.

The mean age of all respondents was **59.5** years. The mean age of TNBC respondents was **56.1** years and the mean age of non-TNBC respondents was **60.3** years. The difference of mean age between the TNBC group and non-TNBC group is statistically significant. This means that the difference between the mean age of the two groups in our survey is not due to chance and is likely to be found within the larger breast cancer population. This finding reflects what we know of TNBC being more likely to be diagnosed in younger women.

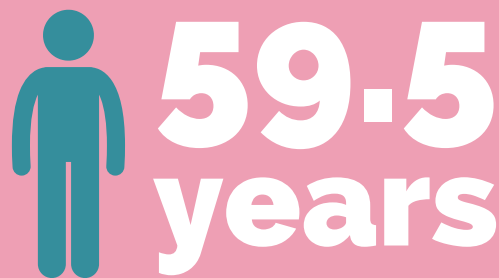
Mean Age of Non-TNBC Respondents



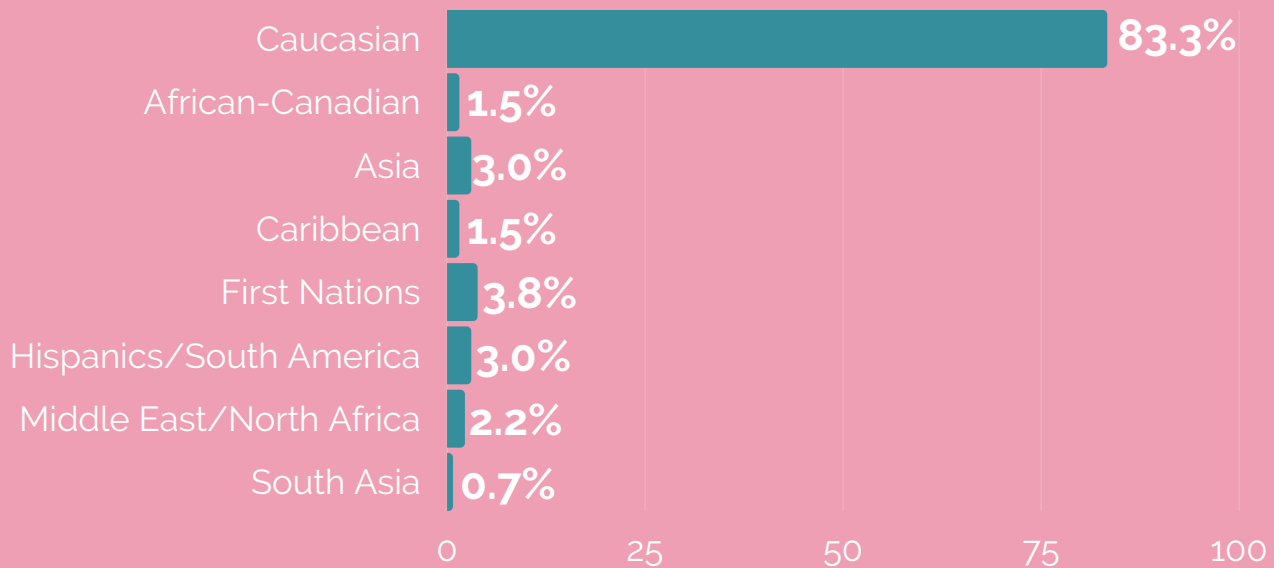
Mean Age of TNBC Respondents



Mean Age of All Respondents

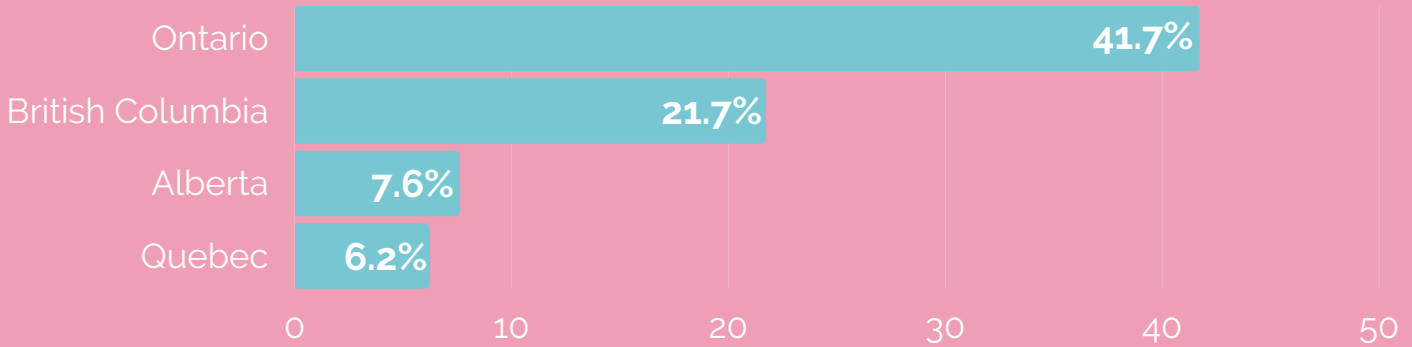


Respondents' Race/Ethnicity



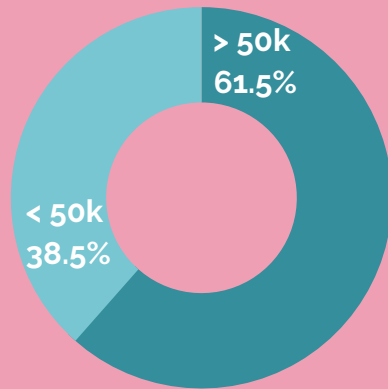
All provinces and territories were represented; however, Ontario, British Columbia, Alberta and Quebec had the largest percentage of respondents

Provinces with the Largest Percentage of Respondents



Other pertinent personal data included

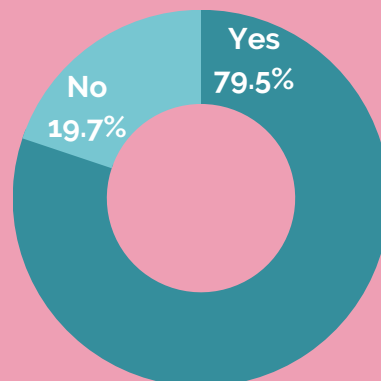
Percentage of Respondents With Incomes Greater or Lesser Than \$50K



61.5% had incomes greater than \$50K.

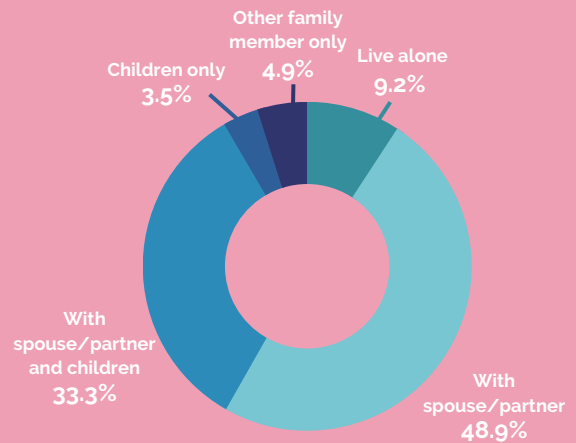
Percentage of Respondents Who Have or Don't Have Private Insurance

79.5% had private insurance; 19.7% did not.

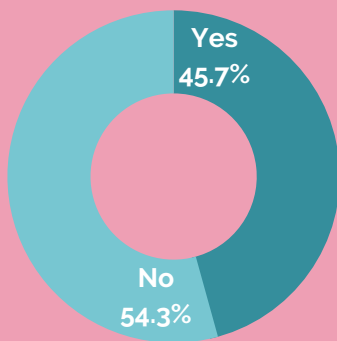


Percentage of Respondents Living With Others

48.9% lived with only their spouse/partner



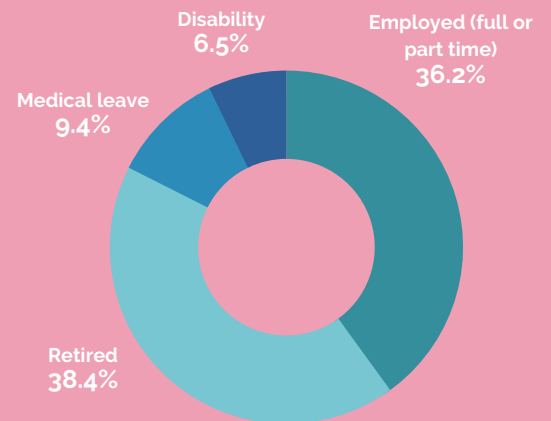
Percentage of Respondents Who Have or Don't Have Children in the Home at Diagnosis



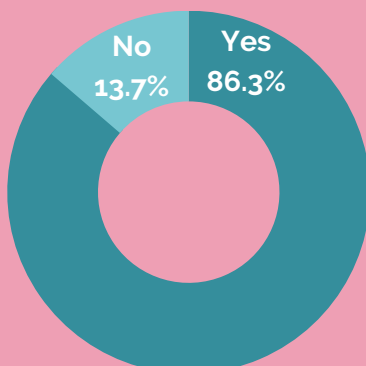
45.7% had children in the home at time of diagnosis

Respondents' Working Status (%)

Only 36.2% were currently employed



Percentage of Respondents Who Have Higher than a College-Education Level



86.3% have a college-education level equivalent or more

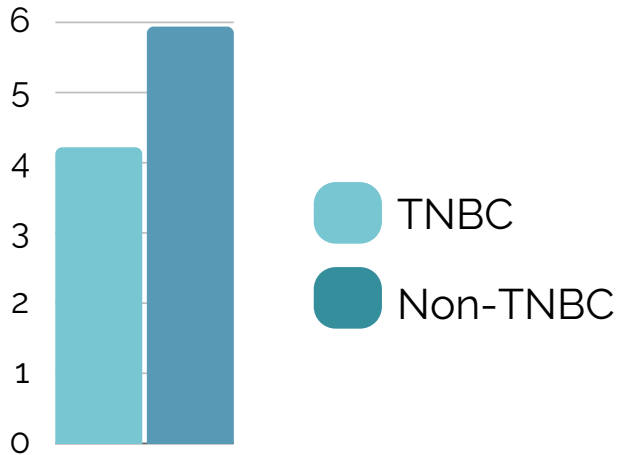
Limitations and Strengths

There were some limitations of the data which may impact the generalizability of our findings. The survey was launched online and only available in English, therefore limiting participation to English readers. Other limitations included under-representation across racial/ethnic groups (**83.3%** of respondents were Caucasian) and across geographic areas (**63.4%** of responses came from 2 provinces). Additionally, **86.3%** held a college-education level degree equivalent or higher and **79.5%** of all respondents had private insurance.

However, a major strength of our data and findings is that our study population of TNBC (**18.9%**) and non-TNBC patients (**81.1%**) mirrors the distribution of TNBC (**10 to 20%**) in the general population, so we can expect that the findings are reflective of the general population. We also had representation from all provinces and territories and all racial/ethnic groups. Additionally, our findings from the assessment echoed what was shared by the women on the Project Advisory Committee, the key informants, and those in the focus groups, so while there are limitations, we are still able to draw conclusions about, and make recommendations from, the data.

PATIENT PROFILE

Time Since Diagnosis



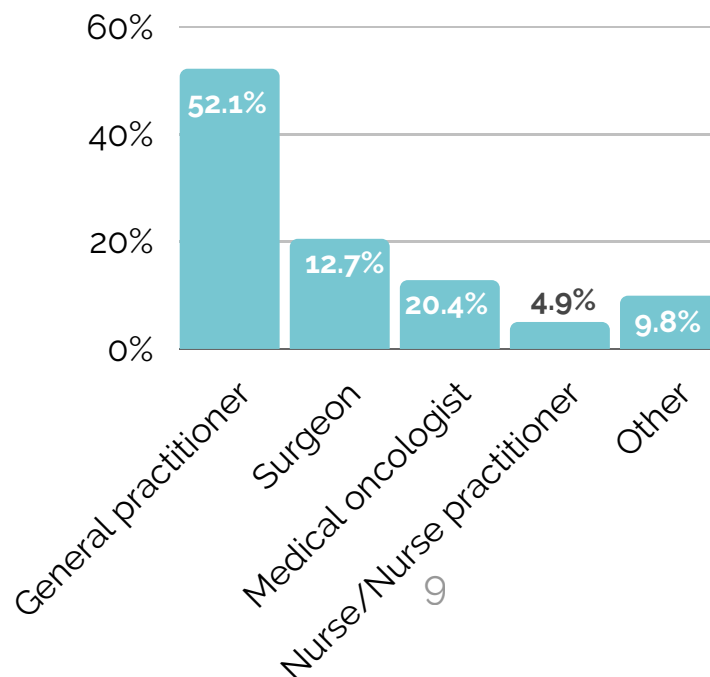
Time since diagnosis in years

The mean years since diagnosis for all respondents was **5.62**

Almost **two-thirds** of the TNBC respondents were diagnosed since **2018**.

Receiving Diagnosis

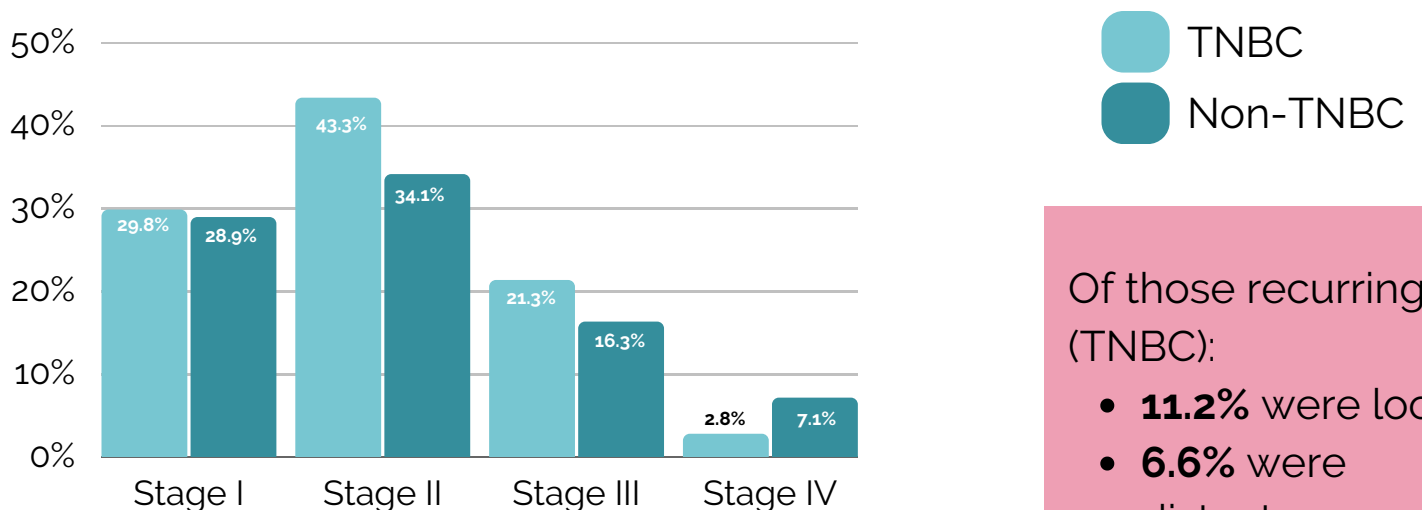
Both TNBC and Non-TNBC Respondents Reported Receiving their Diagnosis from the Following Healthcare Providers



61.5% of all respondents received a pathology report; **82%** of those who received the report had their healthcare provider review it with them. **63%** of TNBC patients (versus **61%** of non-TNBC patients) received a pathology report; **87%** of TNBC patients who received a pathology report (versus **81%** of non-TNBC patients) had their healthcare provider review it with them.

Stage of Diagnosis

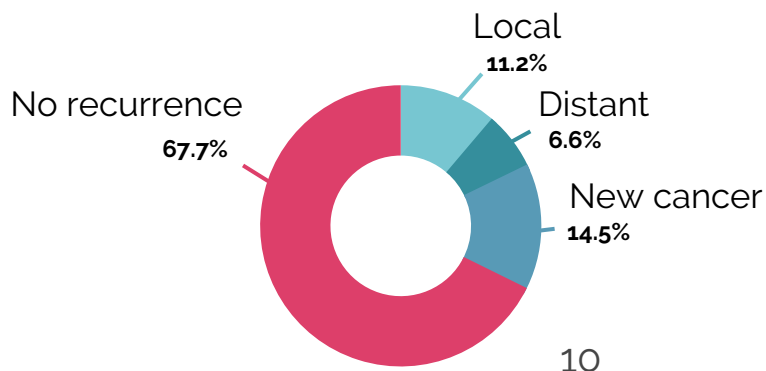
Stage at Initial Breast Cancer Diagnosis



Of those recurring (TNBC):

- **11.2%** were local
- **6.6%** were distant
- **14.5%** were a new cancer

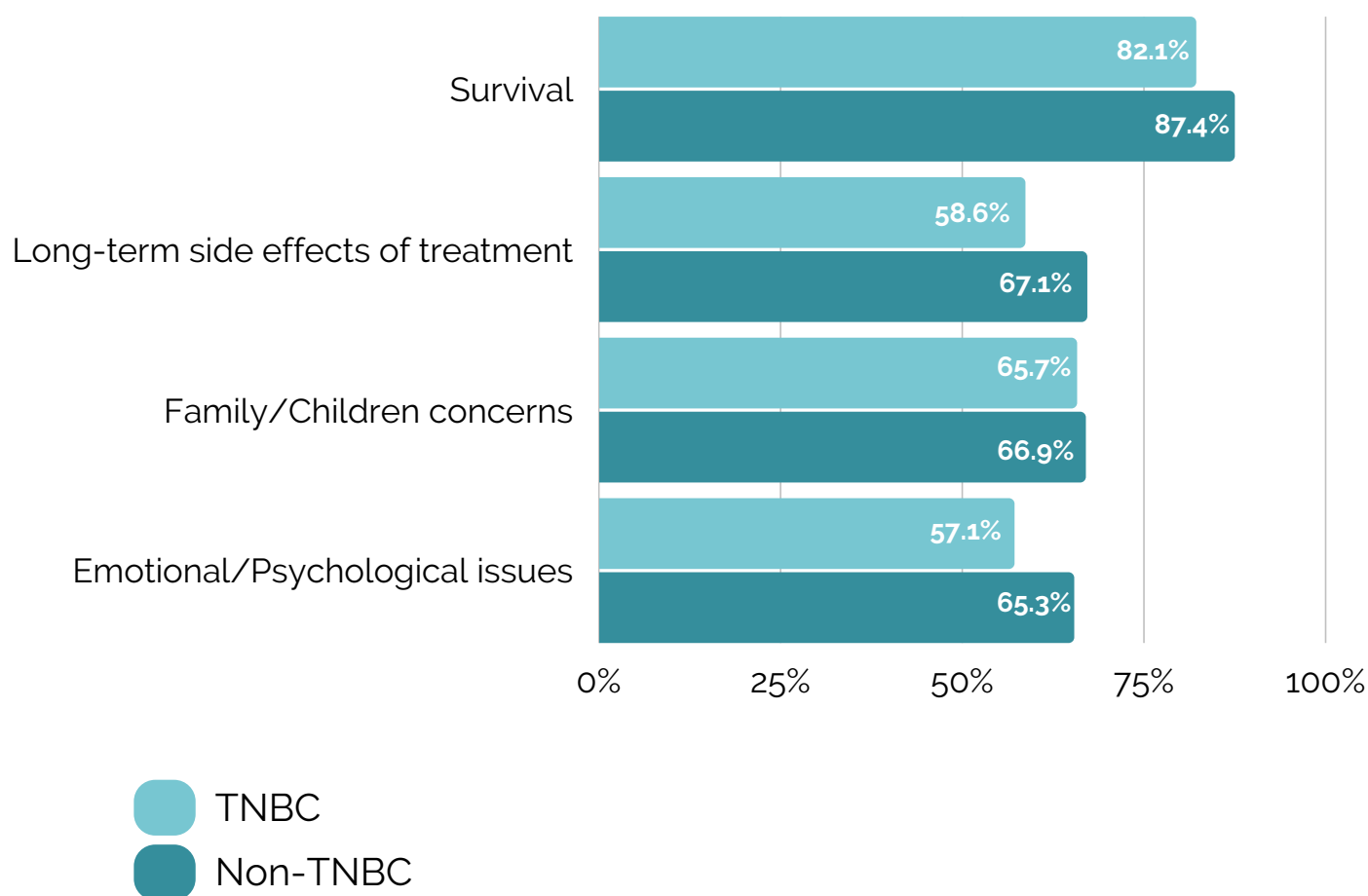
Percentage of Respondents with TNBC Who Experienced a Recurrence



Impact of Diagnosis

A breast cancer diagnosis can have a significant impact on many aspects of a person's life beyond physical health. A diagnosis of triple negative breast cancer can especially have an impact on day-to-day life due to generally being more aggressive, with a poorer prognosis than other breast cancers. While we are aware of how a diagnosis impacts physical health, we wanted to determine what was impacting patients' lives in areas such as mental, psychological, emotional, social, financial, and more.

Percentage of Patients Who Reported Various Concerns



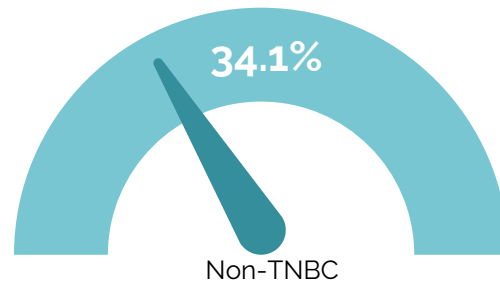
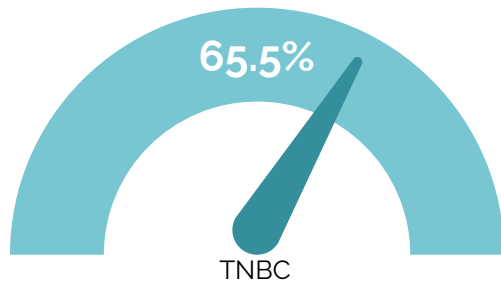
Genetic Testing

Genetic testing involves obtaining a sample of a person's DNA to help confirm a suspected genetic condition or to assess a person's chance of developing or passing on a genetic disorder. Instances where the passing of abnormal genetic material that is associated with breast cancer is known as hereditary breast cancer from a parent to a child. About 5 to 10% of breast cancer cases are believed to be hereditary, but recent studies have shown this number to possibly be higher in patients with TNBC.

In hereditary breast cancer, the most well-known genes that have been found to increase one's risk of developing breast cancer are mutations of the BRCA1 and BRCA2 genes. Having a mutation in the BRCA1 or BRCA2 gene comes with a 45 to 85% risk of developing breast cancer over the course of one's life. With a BRCA1 mutation, the type of breast cancer is more likely to be triple negative, with 60 to 80% of breast cancers in women with mutated BRCA1 genes being TNBC. Additionally, patients diagnosed with TNBC younger than **60** years old are more likely to have a BCRA1 or BRCA2 mutation, with 10 to 30% of patients with TNBC having one or the other.

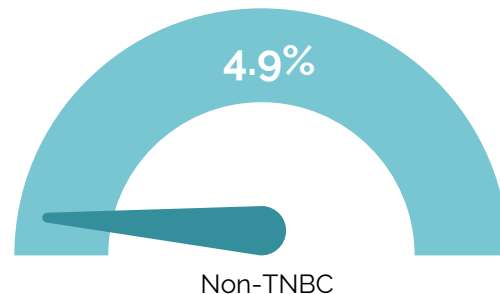
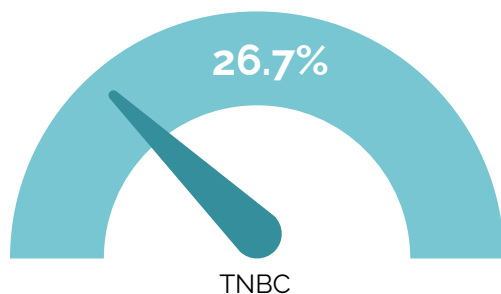


Percentage of Respondents Who Reported Testing for BRCA1 and BRCA2 Genetic Mutations



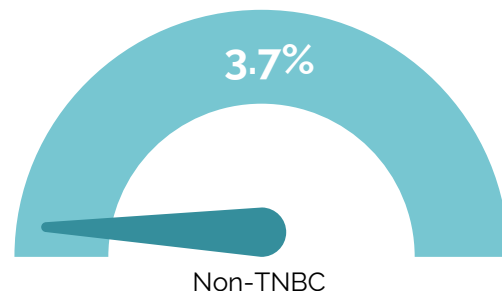
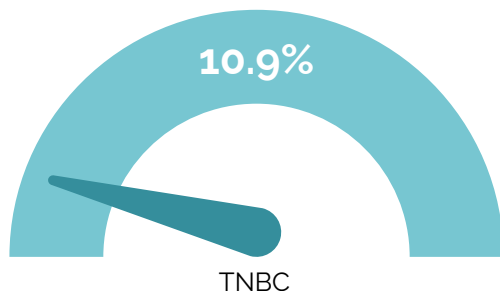
65.5% of TNBC patients reported testing for BRCA1 and BRCA2 genetic mutations (versus **34.1%** of non-TNBC patients).

Percentage of Respondents With and Without TNBC Who Had a BRCA1 Mutation



Of those who had been diagnosed with TNBC and who were tested, **26.7%** had a BRCA1 mutation (versus **4.9%** of non-TNBC patients).

Percentage of Respondents With and Without TNBC Who Had a BRCA2 Mutation



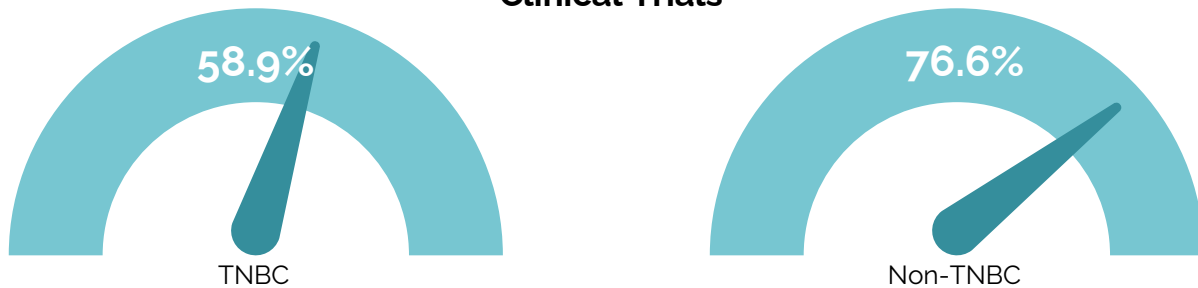
10.9% of TNBC patients had a BRCA2 mutation (versus **3.7%** of non-TNBC patients). This is in line with statistics in the general population where on average, 10 to 30% of women diagnosed with TNBC have a BRCA1 or BRCA2 mutation.

51.1% of TNBC patients (versus **31.7%** of non-TNBC patients) reported that they received additional genetic testing other than testing for a BRCA1 or BRCA2 gene mutation.

Clinical Trials

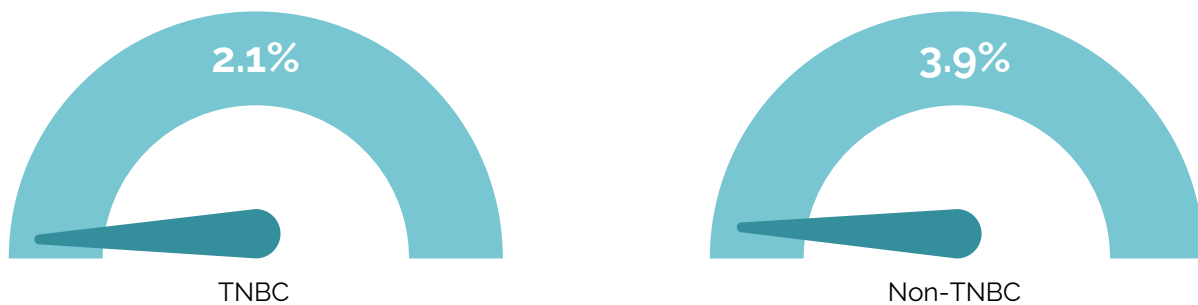
Since there are fewer targeted treatment options for patients with TNBC, clinical trials may fill the gap as an effective option for better treatment. **26.2 %** of all TNBC patients had previously participated in a clinical trial versus **12.3%** of non-TNBC patients. At the time of taking the survey, **12.8%** of TNBC patients stated that they were currently enrolled in a clinical trial. This is compared to **7.2%** of non-TNBC patients who reported the same.

Percentage of Respondents Who Reported Not Being Given the Option of Clinical Trials



58.9% of TNBC patients and **76.6%** of non-TNBC patients reported that no clinical trial was shared as an option to them.

Percentage of Respondents Who Were Not Interested in a Clinical Trial



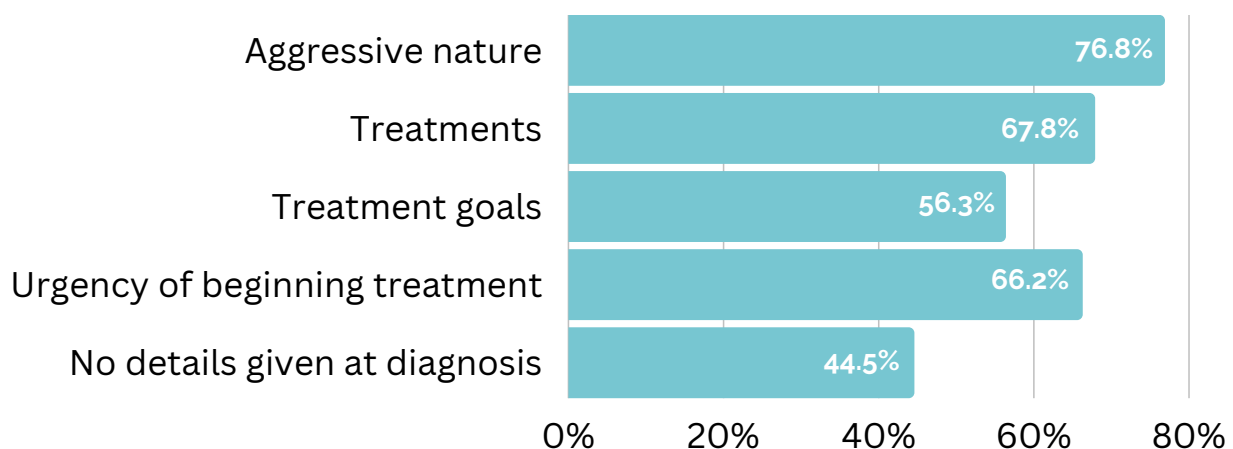
2.1% of TNBC patients said they were not interested in a clinical trial versus **3.9%** of non-TNBC patients.

KEY FINDINGS

TNBC Awareness

Lack of awareness was one of our key findings when asking TNBC patients about their knowledge of TNBC. At diagnosis, **70.6%** of TNBC patients were not aware of the term triple negative breast cancer. This meant that the majority of women who were diagnosed with TNBC only learned about it at diagnosis. **69.9%** of TNBC patients said that the person giving them their diagnosis used the term: triple negative breast cancer. **54.5%** reported being provided with specific details about what a TNBC diagnosis meant. This included details about: the aggressive nature of TNBC (**76.8%**), treatments (**67.6%**), treatment goals (**56.3%**), and the urgency of beginning treatment (**66.2%**). In retrospect, TNBC patients said that more information on the long-term side effects of treatment and post-treatment follow-up should have been included in the discussion at diagnosis.

Details Given at Diagnosis (in 54.5% of TNBC Patients)



Treatment Decision-Making

Including patients in the treatment decision-making process can build trust and may improve treatment adherence. **87.3%** of all patients said they were included in the decision-making process. Of those who were involved in decision-making, **81.2%** felt they were provided with sufficient information to make decisions and **87.3%** reported they felt either very comfortable or comfortable in making treatment decisions.

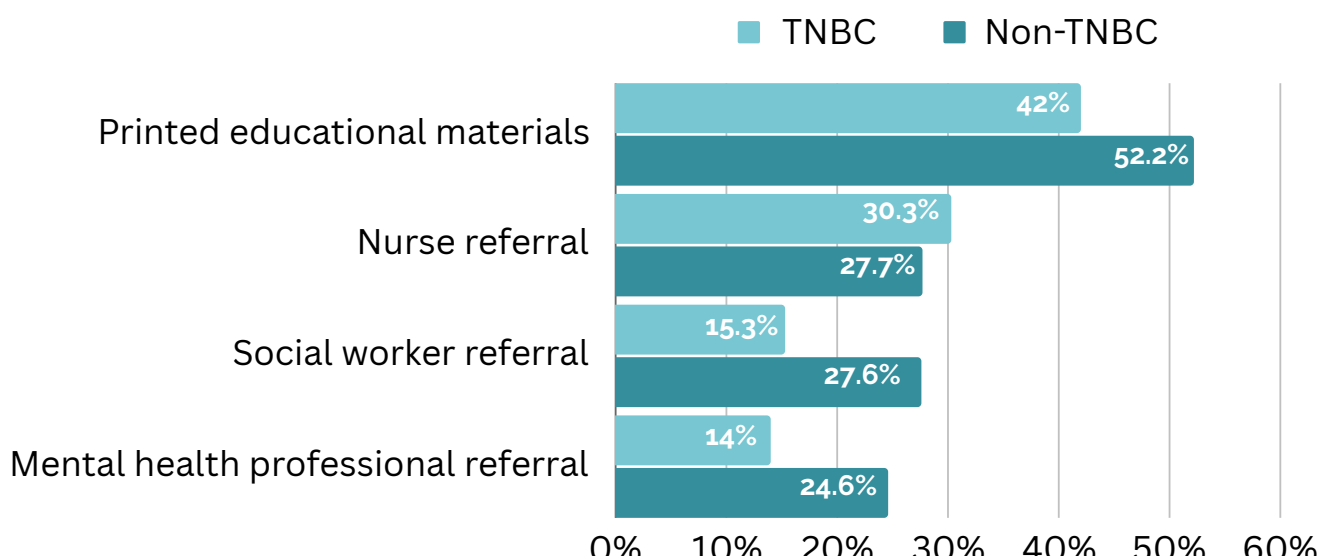
For all patients, the most important concerns in making treatment decisions were efficacy of the treatment (**76.3%**) and quality of life (**60.4%**). Both TNBC and non-TNBC respondents were asked if they discussed their treatment concerns with their doctor at diagnosis. **70.6%** of TNBC patients (versus **60.7%** of non-TNBC patients) said they had. As a result of the discussion, **42.0%** of TNBC patients were given printed educational materials (versus **52.2%** of non-TNBC patients); **30.3%** were referred to a nurse (versus **27.7%** of non-TNBC patients); **15.3%** were referred to a social worker (versus **27.6%** of non-TNBC patients); and **14.0%** were referred to a mental health professional (versus **24.6%** of non-TNBC patients).

87.3% of patients said they were included in the decision-making process

81.2% felt they were provided with sufficient information to make decisions



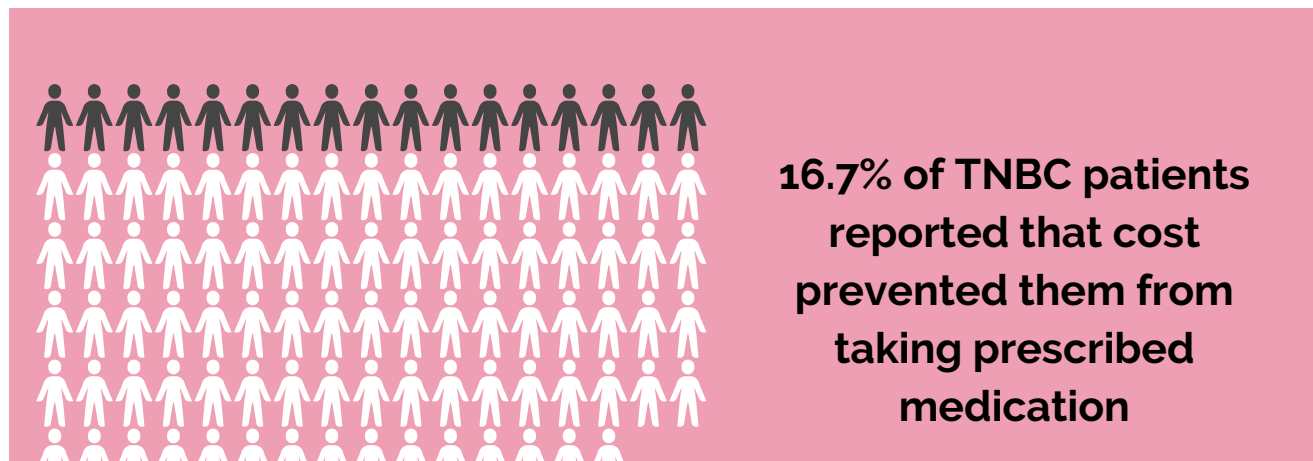
Percentage of Respondents Who Were Given Various Types of Resources After Discussion of Treatment Concerns With Doctor



Private Insurance & Medications

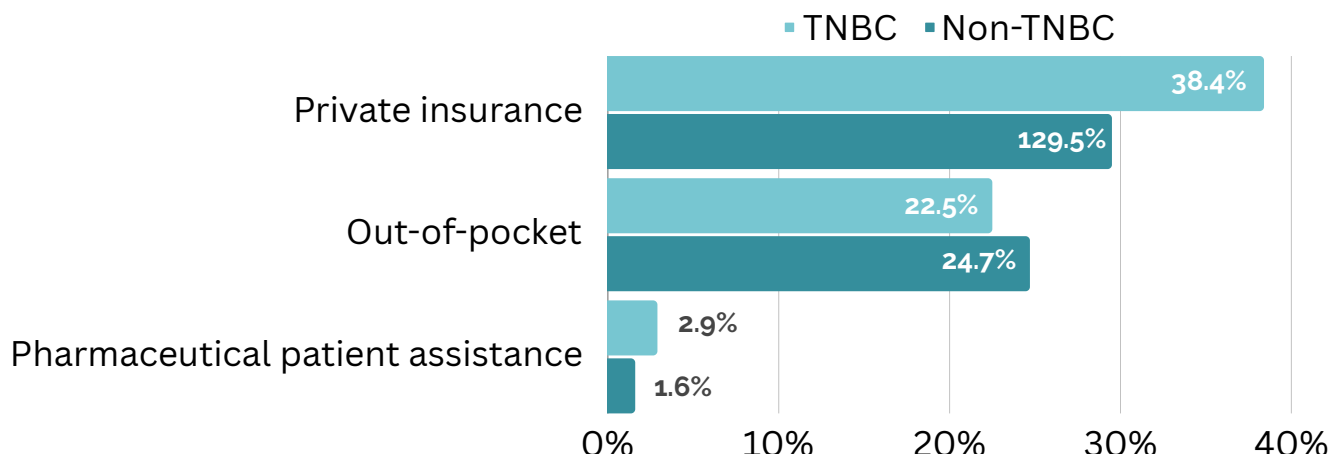
Despite Canada's universal healthcare system, cancer continues to be a [financial burden](#) on many because not all healthcare costs are covered by the public system, including certain cancer treatments. While about **80%** of all respondents had private insurance, we did ask about whether all medications were covered, and, if not, how those medications that were not covered were paid for. **40.6%** of all TNBC respondents reported that they had prescribed medications that were not covered publicly (versus **31.9%** of non-TNBC respondents). This difference is not statistically significant. This means that the difference we found between TNBC and non-TNBC patients who were prescribed medications that were not covered publicly is likely due to chance and not reflective of the breast cancer population. Said

another way, TNBC and non-TNBC patients in our survey had similar chances of being prescribed medications not covered publicly, a result we are likely to find in the larger breast cancer population.



41.9% of TNBC patients used private insurance (versus **32.1%** of non-TNBC patients) to pay for these medications; **19.4%** paid out of pocket (versus **12.1%** of non-TNBC patients) and **10.9%** of TNBC patients used pharmaceutical patient assistance programs (versus **7.9%** of non-TNBC patients). **16.7%** of TNBC and **3.3%** of non-TNBC reported that cost prevented them from taking prescribed medications and this difference was significant. This means that the difference between TNBC and non-TNBC patients from our survey likely reflects the general breast cancer population. So we can expect to find that for TNBC patients compared to non-TNBC patients even outside of this survey, cost of prescribed medications prevents them from access.

Percentage of Respondents Who Obtained Medication Coverage from Various Sources



Medications to treat the cancer itself are not the only kind of medication a patient may need. [Side effects](#) as a result of cancer treatment also need to be managed, often with medication. Regarding support medications, **58.7%** of TNBC patients had support medications that were not covered publicly (versus **42.2%** of non-TNBC patients) and this difference was significant. This means that we can expect that in the larger breast cancer population, TNBC patients, compared to non-TNBC patients, use support medications that are not covered publicly.

Private insurance was used by **38.4%** of TNBC patients and **29.5%** of non-TNBC patients while **22.5%** of TNBC patients and **24.7%** of non-TNBC patients paid out-of-pocket. **2.9%** of TNBC patients and **1.6%** of non-TNBC patients used pharmaceutical patient assistance programs. **15.0%** of TNBC patients and **3.6%** of non-TNBC patients reported that cost prevented them from taking support medications and this difference was significant. In other words, for the general breast cancer population, costs of support medications is more likely to prevent TNBC patients from access than it is to prevent non-TNBC patients.

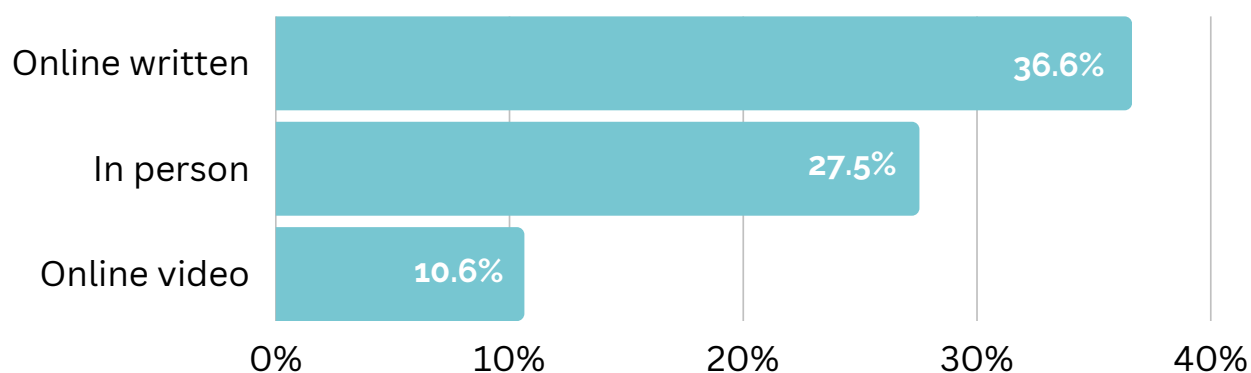
Resources & Breast Cancer Information

Preferred Format of Resources

For patients, being aware of a variety of information about their breast cancer diagnosis can help them feel empowered. Not only is it important to provide patients with more than just the basic information about their type and subtype of breast cancer, it is also important to consider the format of the information.

TNBC patients were asked about their format preferences for certain types of information. For health and medical information on TNBC, **36.6%** preferred that it was provided as online written content, **27.5%** preferred that it was discussed in person, and **10.6%** preferred it to be provided in online video format. For practical resources, such as travelling for treatment or returning to work, the majority (**45.4%**) of TNBC patients preferred that this was provided on a website, **21.5%** preferred this information to be provided as a printed resource, and **17.7%** preferred to receive this information in person.

Format Preferences for Health and Medical Information

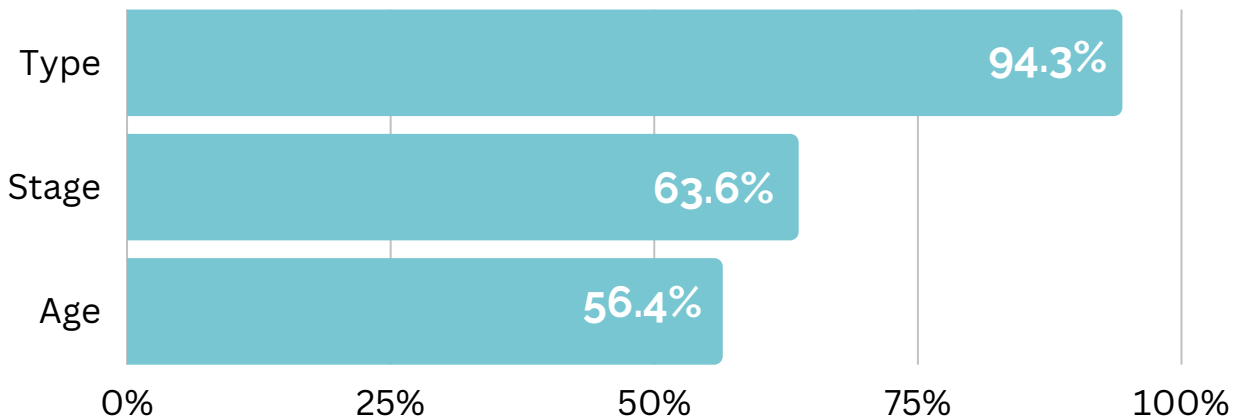


In terms of the format of the resources they actually used, online resources, for example websites, were most frequently used by TNBC patients (**77.6%**), followed by social media platforms (**49.2%**), and printed materials, for example brochures (**36.5%**).

Tailored Resources

Tailoring the type of information that patients receive can also be very beneficial in helping patients better understand their diagnosis. When asked to indicate how they wanted their educational materials and information tailored, TNBC patients reported that they wanted these materials and resources tailored to their type of breast cancer (**94.3%**), stage of breast cancer (**63.6%**), and their age (**56.4%**).

What TNBC Patients Want Their Information Tailored To



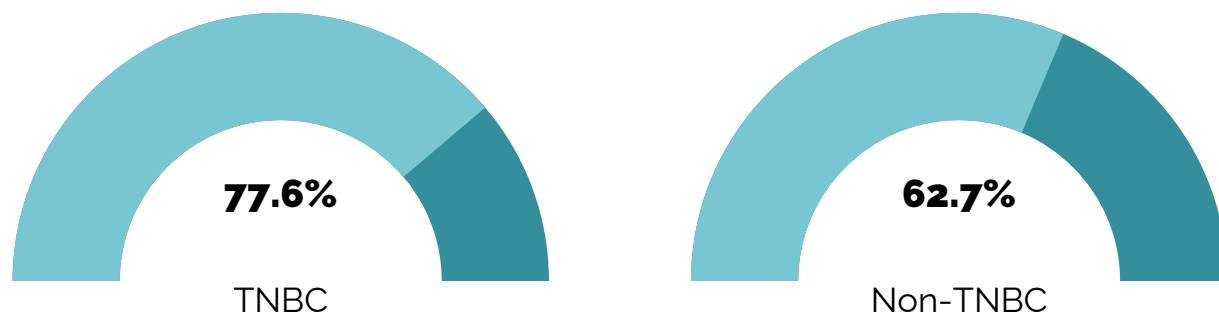
While almost **85%** of TNBC patients were able to find materials and resources on their diagnosis, **74%** said that TNBC-tailored materials were **not easy to find**. TNBC patients were also asked to rate the quality of the materials that they found, and the results were mixed: **48.4%** rated that these materials were **very good or good** while **44.6%** said they were **satisfactory or poor**.

Social Media

Social media is a tool that has risen in popularity for breast cancer patients to find resources, share their experiences, and connect with others who understand what they are going through. All respondents

in our survey reported on their use of social media, which included using it to access breast cancer information (**72.2%**), using it to connect with breast cancer organizations (**44.5%**), and using it to connect with other patients with the same diagnosis (**46.7%**).

Percentage of Respondents With and Without TNBC Who Preferred Social Media Groups Tailored to Their Type of Breast Cancer



Overall, respondents preferred that the social media groups they joined were tailored to their type of breast cancer. This was reported in **77.6%** of TNBC respondents, compared to **62.7%** of non-TNBC patients.

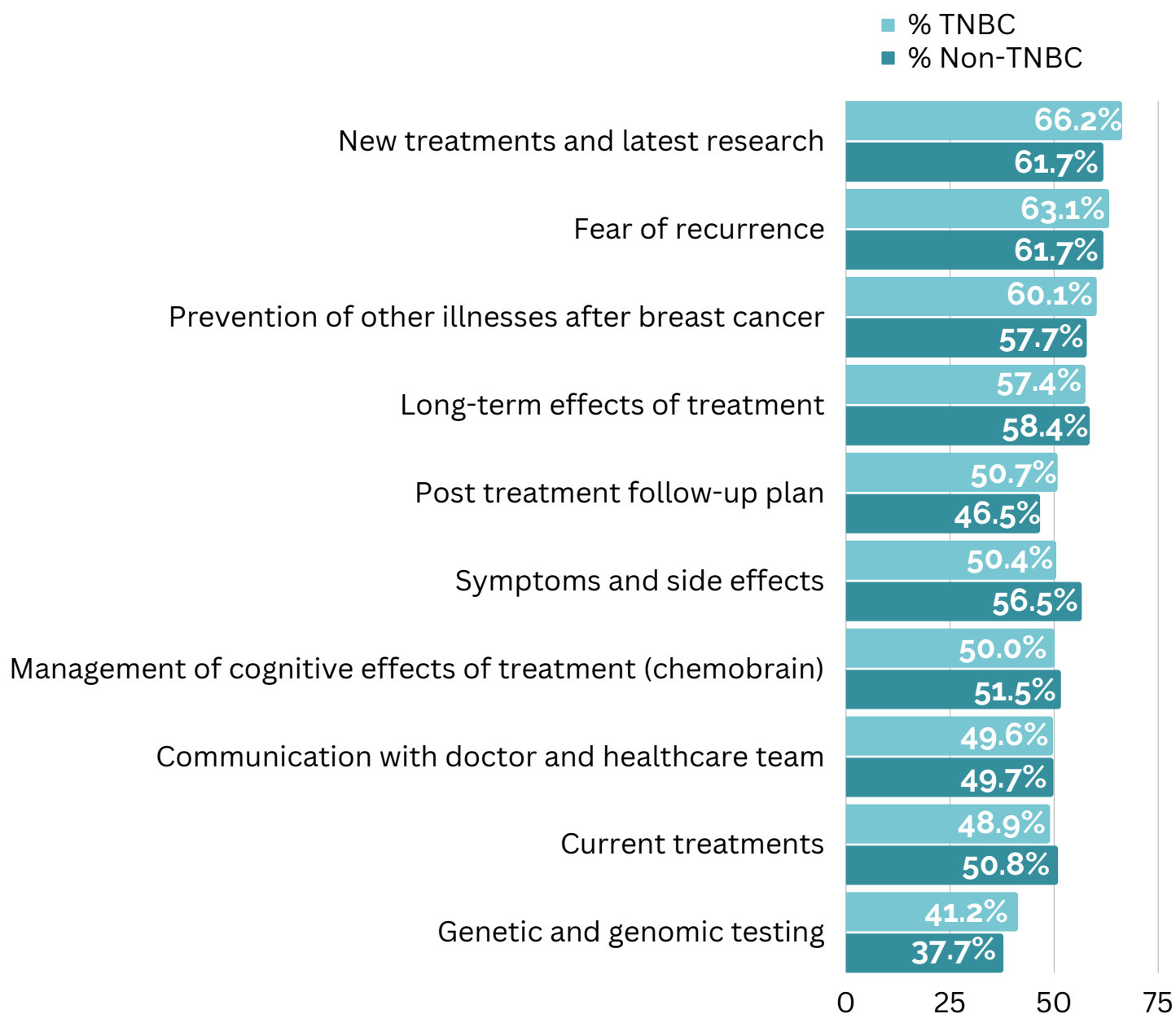
66.2% of TNBC patients reported that it was either **not easy** or **somewhat easy** to connect with other TNBC patients (versus **84.3%** of non-TNBC respondents).

Topics of Interest and their Availability

A breast cancer diagnosis comes with a lot of questions, and although it is vital to provide patients with information, it is possible to overload patients with too much information. Therefore, it is important that the information that patients receive aligns with the questions they have and the topics that they are interested in.

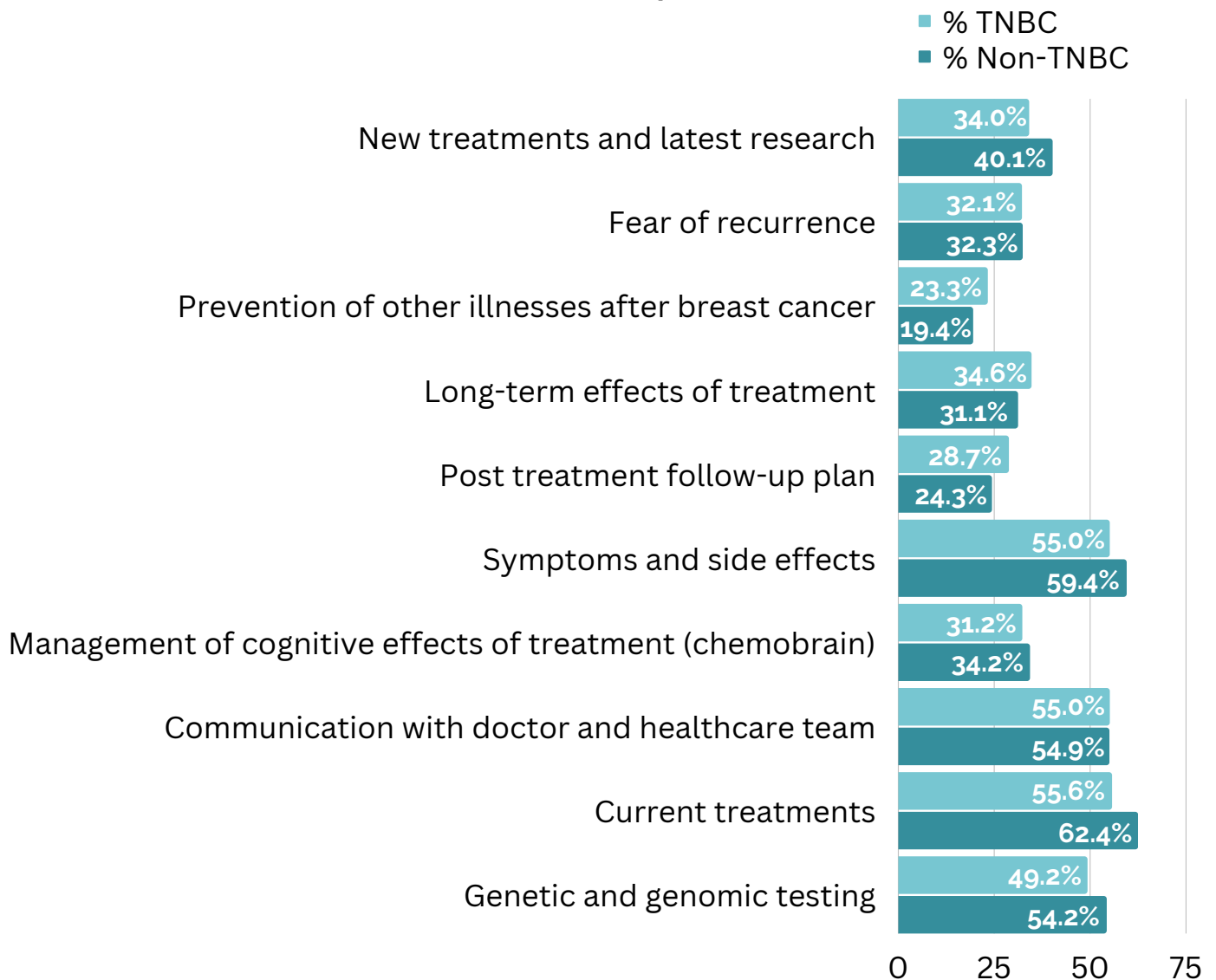
To learn more about such topics of interest, we provided both TNBC and non-TNBC patients with a list of topics and concerns that were collected from interviews, focus groups, and internal discussions. We asked them about their current interest in the given topic. The top ten topics that TNBC patients reported being **very interested** or **interested** in are shown in the table below.

Percentage of Respondents Who Were Very Interested or Interested in Various Topics



Respondents then rated whether the list of given topics and concerns were **available**, **not available**, or if they **didn't know** if they were available (for example, if they didn't look for information on the topic). The table below reflects the top 10 topics of interest among TNBC patients were available.

Percentage of Respondents Who Reported Information Being Available on Various Topics

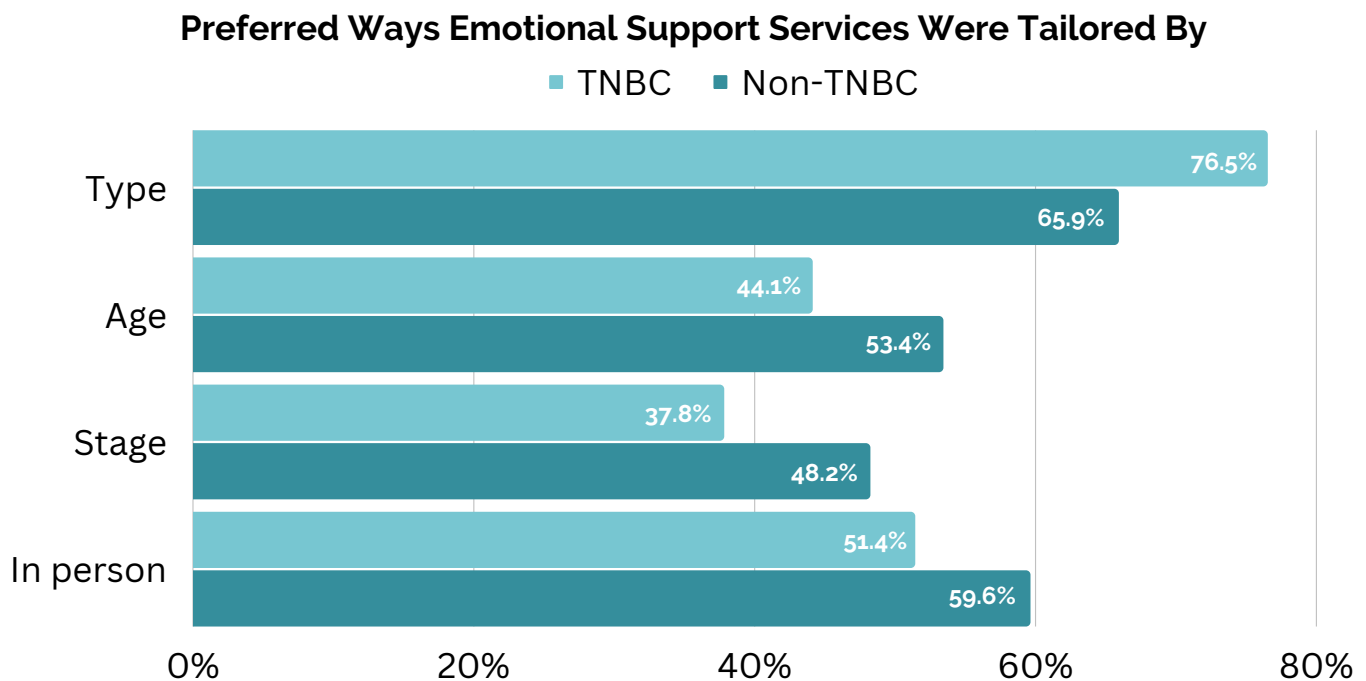


These topics align with the current issues surrounding TNBC patients. For instance, with TNBC being a more difficult subtype to treat due to less options, it makes sense for patients to want to learn more about newer treatments and the latest research that may create more treatment options and improve outcomes. As well, with TNBC being

more likely to [recur](#), it is important for patients to have access to information surrounding their subtype and the increased risk of recurrence. Through these numbers shown in the tables, it is clear that there is a major gap between what TNBC patients are interested in and what information they were able to access. For example, **60.1%** of TNBC patients showed an interest in learning more about prevention of other illnesses after breast cancer, with only **23.3%** being able to find information on this topic. By increasing access to information on these topics, we can help close these gaps.

Emotional Support

After being diagnosed with triple negative breast cancer, patients experience a range of emotions, including shock, fear, anxiety, guilt, sadness, depression, anger, and more. A variety of support services are available to breast cancer patients to address these emotional concerns.



Respondents reported that when seeking **emotional support** services, they preferred such services to be tailored to their type of breast cancer (**76.5%** of TNBC patients versus **65.9%** of non-TNBC patients); age (**44.1%** of TNBC patients versus **53.4%** of non-TNBC patients) or stage of breast cancer (**37.8%** of TNBC patients versus **48.2%** of non-TNBC patients). Additionally, the majority of respondents said they preferred in person emotional support service (**51.4%** of TNBC versus **59.6%** of non-TNBC patients).

NEXT STEPS

As a follow-up to our TNBC Project, the next steps emerging from this work are focused on implementing what has been learned from this project that will help CBCN address the needs of Canadians diagnosed with triple negative breast cancer. A list of potential next steps are as follows:



Build awareness of TNBC in the larger community. CBCN is the leading breast cancer advocacy organization in Canada and a voice for Canadians diagnosed with breast cancer. It is a credible and reliable resource for education, information, and support. Using its position and platform, CBCN can create a TNBC awareness campaign that addresses many of the needs identified in this project. Sharing some of these findings with those who visit the website and other CBCN channels will help to bring awareness to triple negative breast cancer.



Create an ongoing TNBC Advisory Committee. Containing four to five people (patients, physicians, and other healthcare professionals), this committee can assist with reviewing TNBC materials, support information development, and bring new materials to CBCN's attention. Once this committee is created, it should be announced through CBCN's communication channels and its TNBC initiatives and mandates should be shared.

Become a resource for TNBC patients. Using the list of the current topics that TNBC patients identified current interest in, their preference of how the topics should be presented, and their preference of how these resources should be tailored, CBCN can develop resources that address the needs of TNBC patients. CBCN can become a go-to for individuals looking for TNBC resources. This can include printable materials, online materials, and support resources for patients and caregivers. These materials, resources, and supports can be regularly assessed by the TNBC Advisory Committee to ensure that resources are up-to-date and continue to reflect the needs of TNBC patients.

Additional focus group discussion to address the needs of underrepresented TNBC populations. The geographic and racial/ethnic participation in the assessment limits its findings and generalizability. CBCN can conduct several focus groups with

underrepresented areas and racial/ethnic populations to better understand their needs, perspectives, and voice.

Create a dialogue with relevant stakeholders. CBCN can reach out to relevant stakeholders, including the medical community, healthcare professionals, and government officials, to share the findings of our TNBC project. Discussions with these groups will focus on mutual topics of interest. At this time, abstracts have been submitted to national and international conferences where we will communicate some of the findings from this project with the medical community and other patient advocates.

As analysis and discussion continues, updates in other areas of interest can be used to improve the lives all Canadians who have been diagnosed with triple negative breast cancer.



CONCLUSIONS



Background: In 2021, CBCN began a triple negative breast cancer project that included consulting with an advisory committee, conducting interviews, leading focus group discussions, and launching an online assessment, in order to identify the unique educational, informational, and support needs of Canadians diagnosed with triple negative breast cancer. The English-only online assessment was open to all Canadians who had received a diagnosis of breast cancer. **981** people completed the survey – **18.9%** were TNBC patients and **81.1%** were non-TNBC patients. This report provides a summary of the findings from the assessment to-date.

Personal Demographics: The mean age of all survey respondents was **59.5** years old; the mean age of TNBC patients was **56.1** years old and for non-TNBC patients, it was **60.3** years old. Mean years since diagnosis for all survey respondents was **5.62**. Mean years since diagnosis for TNBC patients was **4.22** years and for non-TNBC patients, it was **5.94** years. While all provinces and territories were represented, the majority of survey participants lived in Ontario (**41.7%**) and British Columbia (**21.7%**). The majority of the respondents were Caucasian (**83.3%**).

Medical Demographics: The majority (**43.3%**) of TNBC participants were stage II at diagnosis and **32.4%** had a recurrence since their initial diagnosis. **65.5%** of TNBC patients were tested for BRCA1 and 2 mutations; **26.7%** had a BRCA1 mutation and **10.9%** had a BRCA2 mutation. **51.1%** of TNBC patients reported that received additional genetic testing. **12.8%** of TNBC patients reported being enrolled in a clinical trial at the time of the survey.



TNBC Awareness: **70.6%** of TNBC patients had never heard of TNBC. Breast cancer is not a monolithic disease. Increased awareness of the various types of breast cancers among the breast cancer community and to the public at large would enhance understanding and provide a voice for those who have this type of breast cancer.

Treatment Decision-Making: **87.3%** of patients said they were included in the treatment decision-making process, and of these patients, **81.2%** felt they were provided with sufficient information to make decisions and **87.3%** reported they felt either very comfortable or comfortable in making these decisions. Key concerns in making treatment decisions were efficacy of the treatment and quality of life.

Private Insurance and Medications: Almost **80%** of all patients had private insurance. **16.7%** of individuals who had been diagnosed with TNBC reported that cost prevented them from taking the prescribed medications while **15.0%** of TNBC patients reported that cost prevented them from taking support medications.

TNBC Resources: Women with TNBC preferred resources and services tailored to their breast cancer type (**94.3%**), age (**56.4%**), and stage (**63.6%**) of breast cancer. TNBC patients also preferred that both the medical/health information (**36.3%**) and the practical information (**45.4%**) that they received be provided in an online format. Topics of interest for patients include information on new treatments and latest research, recurrence, prevention of other illnesses, and long-term effects of treatment. Unfortunately, patients reported limited availability of materials on these topics.

Next Steps: The next steps emerging from this work are focused on implementing what has been learned from this project that will help CBCN address the needs of Canadians diagnosed with triple negative breast cancer. Potential outcomes include: increasing public awareness of TNBC; identifying and addressing the needs and gaps in care for TNBC patients; recommending concrete ways to address barriers to optimal care for those diagnosed with TNBC; and facilitating informed exchanges between patients and their healthcare team, advocacy groups, payers, and decision makers.



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