

ASSOCIATION OF
CANCER CARE CENTERS

**ASSESSING THE
STATUS OF BRCA TESTING AND
CHALLENGES FACED BY PATIENTS
AND CANCER CARE TEAMS:**

BRCA TESTING REASSESSMENT



Summary of Survey Findings

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INTRODUCTION

The Association of Cancer Care Centers (ACCC) is dedicated to improving the quality of care for patients with early-stage or metastatic breast cancer by advocating for the appropriate adoption of validated genetic testing, including but not limited to germline BRCA1/2 testing. In response to the evolving landscape of genetic testing and the increasing body of evidence, ACCC aims to promote informed treatment decisions and enhance the patient experience.

In March 2018, a survey of germline BRCA1/2 testing was conducted, where 95 oncology practitioners from across the country participated¹. The survey suggested that germline BRCA1/2 testing rates were lower than expected and that institutional and patient-related barriers prevented many patients from being tested. This prompted a quality improvement initiative in 15 sites across the United States, aimed at increasing the rates of germline BRCA1/2 testing for patients with early stage or metastatic breast cancer.

In October 2023, ACCC once again surveyed oncology practitioners, this time sampling 115 care providers from across

the United States to reassess the status of germline BRCA1/2 testing and the challenges faced by cancer care teams. The aim of this survey was to understand the current state of germline BRCA1/2 testing, given changes over the past 5 years that have included revisions in clinical guidelines and the COVID-19 pandemic. It should be noted that the survey sample did not include the same oncology providers as in 2018. Where possible, this report documents the differences in the two cohorts to convey comparability.

To comprehensively gauge the current state from the patient's perspective, an additional survey was conducted in October 2023, involving individuals recently diagnosed with breast cancer. This survey aimed to evaluate patients' experience with germline BRCA1/2 testing and subsequent follow-up. Since no prior patient survey had been conducted to appraise the experience of patients with breast cancer in relation to germline BRCA1/2 testing, there are no available comparisons for the results obtained from this survey. Survey methodology can be found in Appendix 1.

CHANGES IN BRCA1/2 TESTING BETWEEN 2018 AND 2023

Over the past 5 years, there have been some important changes to the germline BRCA1/2 testing practice that should be noted when considering the survey results. Changes in clinical guidelines (eg, National Comprehensive Cancer Network (NCCN²) and the American Society of Breast Surgeons (ASBrS³)) have resulted in expanded criteria for testing to certain breast cancer patients or those with a personal history. For patients with newly diagnosed breast cancer, testing for germline BRCA1/2 and other mutations is recommended in certain instances to guide treatment and inform decisions around surgery, radiation, and systemic therapy. Metastatic breast cancer is now a testing criterion for germline BRCA1/2, regardless of age, due to the availability of targeted treatments that are dependent on genetic test results. A broader range of indications for germline BRCA1/2 and other genetic tests has meant that the number of patients referred for genetic testing in 2023 far exceeds those in 2018.

With the changes in clinical indications, insurance providers are adjusting their coverage qualifications to make genetic testing more accessible to those who need it, although there is often a time lag to allow insurance companies an opportunity for data review and coverage decisions. Genetic mutation testing has now become faster and less expensive than it was in 2018. Counseling services are also available remotely via telephone and/or video for those who do not have local access to a certified genetic counselor.

The impact of COVID-19 was felt throughout the healthcare system and genetic testing was no exception. At the beginning of the pandemic, the use of genetic testing dropped sharply⁴ and many on-site genetic counselors were laid off until telehealth options became available. The volume of patients using remote options for genetic counseling has increased as patients appreciate the ease and convenience of telehealth, including less time away from work and the ability to provide biological samples from home.

CHARACTERISTICS OF SURVEY RESPONDENTS - PROVIDERS

To be eligible for the 2023 provider survey, respondents had to meet the following criteria: working in a facility that provides care for cancer patients; and currently having interaction with breast cancer patients. Of the 115 respondents in 2023, 44% were oncologists, 16% were genetic counselors and 15% were oncology nurses or nurse navigators. The remaining 25% included surgeons, advanced practice providers, social workers, and case managers.

In 2023, just over half (55%) of respondents were from urban settings, 28% were suburban and 16% were from rural locations. In total, 38 states were represented. No location setting

information was available for the individuals who responded to the 2018 survey.

In 2023 the respondents worked in a variety of different settings, including community cancer programs (36%), academic/NCI cancer programs (23%), hospital (22%) and private practices (17%). In 2018, 76% of the respondents worked in hospital-based outpatient cancer centers. The remainder worked in integrated health systems (6%), hospital-employed physician practices (5%), freestanding cancer centers (4%), and physician-owned practices (4%).

CHARACTERISTICS OF SURVEY RESPONDENTS - PATIENTS

Eligibility criteria for patients taking the survey included: 18 years of age or older; and diagnosed with breast cancer in the past year. All 61 respondents were female. Of these, 62% were between 18 and 45 years of age, 25% were 46-60 years old and 13% were over 60 years old. Respondents reported a variety of different stages at diagnosis and types of breast cancer (Figures 1, 2). Note that respondents could only choose one option for each of the cancer stage and type questions.

More than half (57%) of the patient sample were from suburban locations, one third (33%) were urban, and 10% were rural. Most respondents (77%) reported that most of their care was received at a hospital or hospital clinic and 21% reported that care was provided in a private clinic or doctor's office. All respondents had some form of health insurance, whether employer-based (61%), Medicare or Medicaid (30%), private insurance (11%), or other (3%).

FIGURE 1. Please indicate the stage at which your cancer was diagnosed.

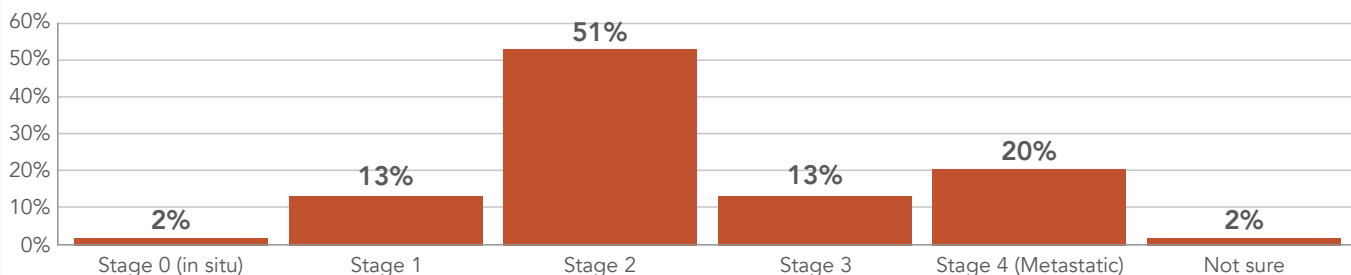
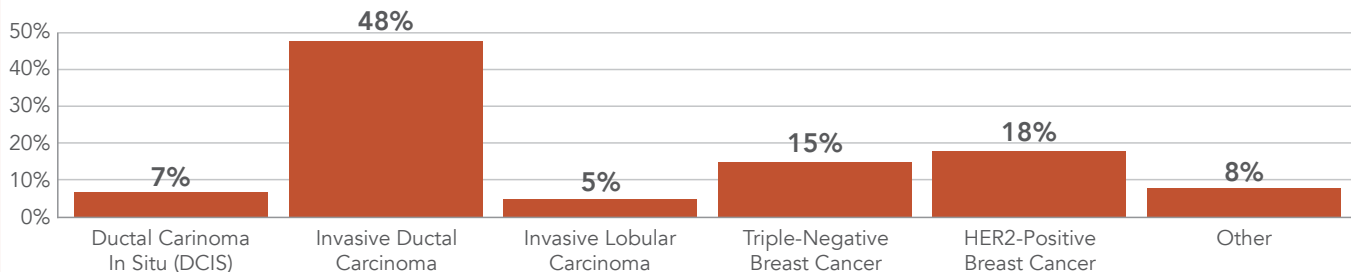


FIGURE 2. Which type of breast cancer were you diagnosed with?

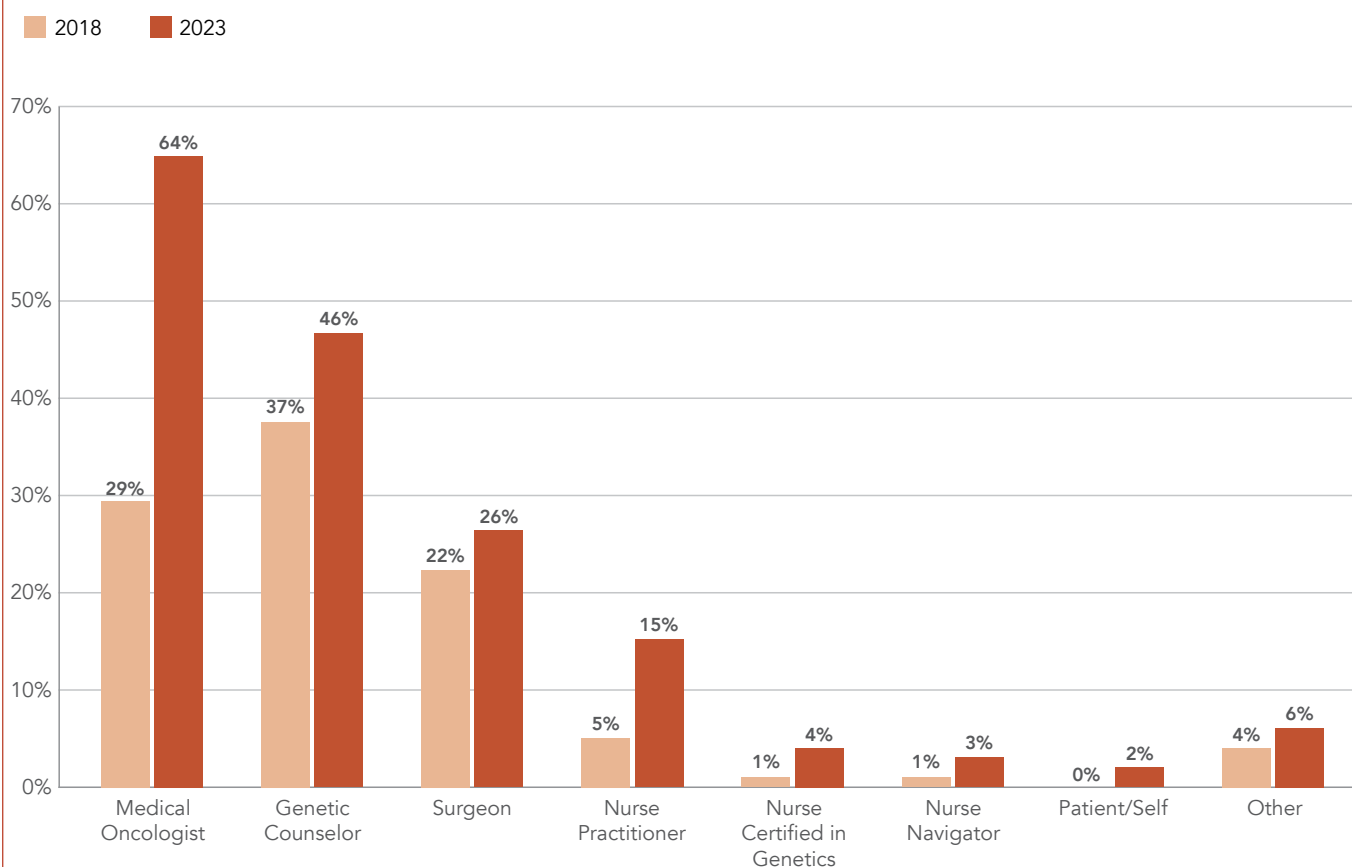


USE OF BRCA1/2 MUTATION TESTING

In 2023, 64% of survey respondents reported that the medical oncologist was the provider who most often initiated tests for germline BRCA1/2 mutation while 46% reported that it was the genetic counselor. The next most often cited providers were the surgeon (26%) and nurse practitioner (15%). These figures were all higher than in 2018, when medical oncologists accounted for only 29% of order initiators, more than doubling by 2023 (**Figure 3**). This finding may suggest that medical

oncologists are assuming a more active role relative to genetic counselors, but it may also be a result of the recent changes in testing criteria which has expanded the use of genetic testing to inform treatment decisions. The increase in genetic testing initiation among medical oncologists may also reflect state licensure laws that preclude genetic counselors from ordering tests in their own name.

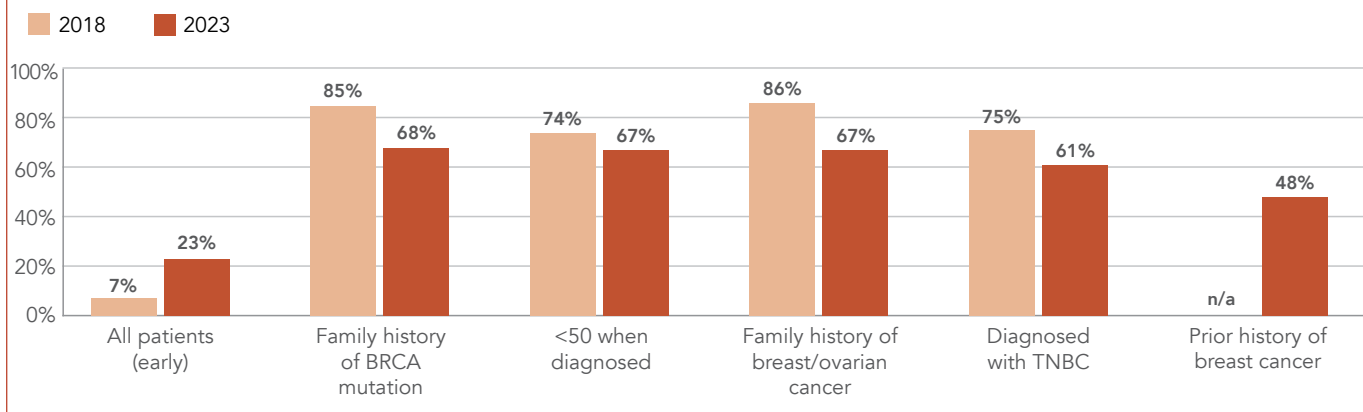
FIGURE 3. Who initiates orders for a BRCA1/2 mutation test at your cancer program?



In the 2023 survey, almost a quarter (23%) of care providers reported that they routinely ordered germline BRCA1/2 testing for all of their early-stage breast cancer patients. This number represented a three-fold increase over the findings in 2018 (7%). The remaining categories saw fewer respondents ordering germline BRCA1/2 testing in 2023 than in 2018,

specifically for patients who were younger than age 50 when diagnosed, had a family history of either BRCA mutation or breast/ovarian cancer, or had been diagnosed with triple negative breast cancer (**Figure 4**). It should be noted that for this question, even if respondents selected 'all patients', they were able to select the other options as well.

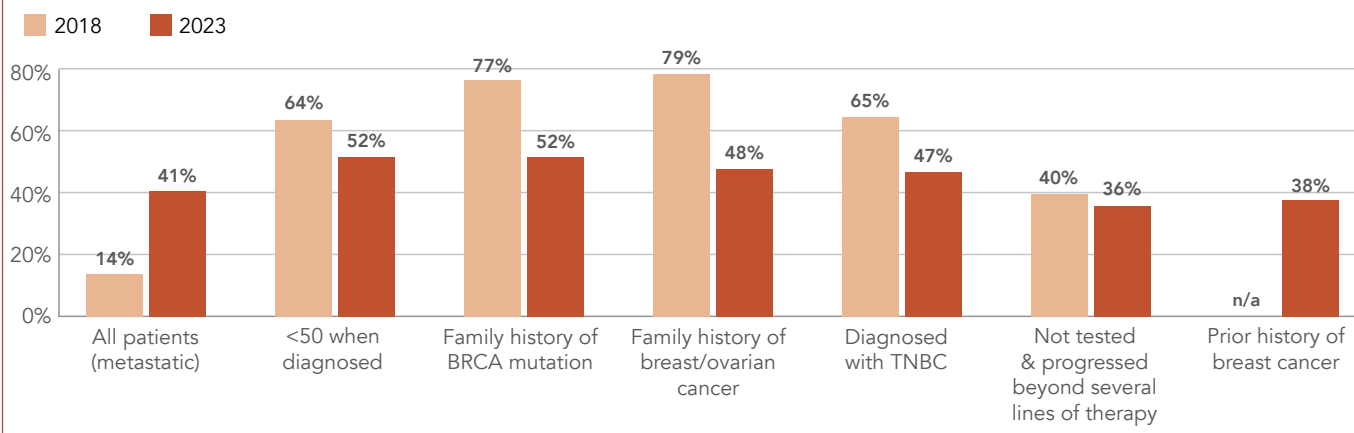
FIGURE 4. For which of the following patients with early breast cancer do you routinely order BRCA mutation testing?



In the case of patients with metastatic breast cancer, 41% of care providers reported in 2023 that they routinely ordered BRCA mutation testing for all patients. This figure was also about 3 times higher than in 2018, when only 14% reported ordering BRCA testing for all patients with metastatic breast cancer. Again, fewer respondents reported ordering testing for patients in specific categories: younger than age 50 when diagnosed, with family history of BRCA mutation or breast/ovarian cancer, diagnosed with triple negative breast cancer,

or progressed beyond several lines of therapy (**Figure 5**). This finding is likely related to changes in guidelines, requiring germline BRCA1/2 testing for any patient with metastatic disease. Decreases in ordering for the other traditional testing categories may be affected by the higher priority assigned to those needing germline BRCA1/2 results for surgical or systemic treatment decisions. It should be noted that for this question, even if respondents selected 'all patients', they were able to select the other options as well.

FIGURE 5. For which of the following patients with metastatic breast cancer do you routinely order BRCA mutation testing?



In 2023, only 23% of providers reported that more than half of patients with early breast cancer had germline BRCA mutation testing. This number was up from 2018, when only 18% of providers reported the same. Among patients with metastatic breast cancer, 34% of providers reported in 2023 that more than half of patients had received germline BRCA1/2 testing, also up from 2018 when 13% of providers reported the same among patients with metastatic breast cancer (Figure 6).

In 2018 providers reported a tendency to order an expanded sequencing panel for germline BRCA1/2 testing—85% for patients with early breast cancer and 80% for those with metastatic disease. Those figures dropped in 2023, with only 62% and 75% ordering the expanded sequencing panel, respectively (Figure 7).

FIGURE 6. What is the percentage of patients, managed and treated at your center in the past three months, who have ever had germline BRCA1/2 mutation testing?

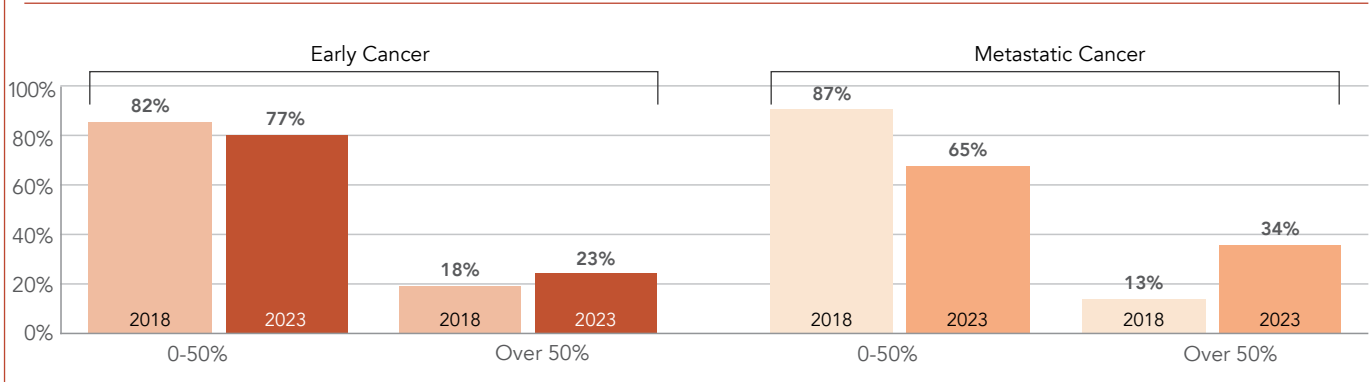
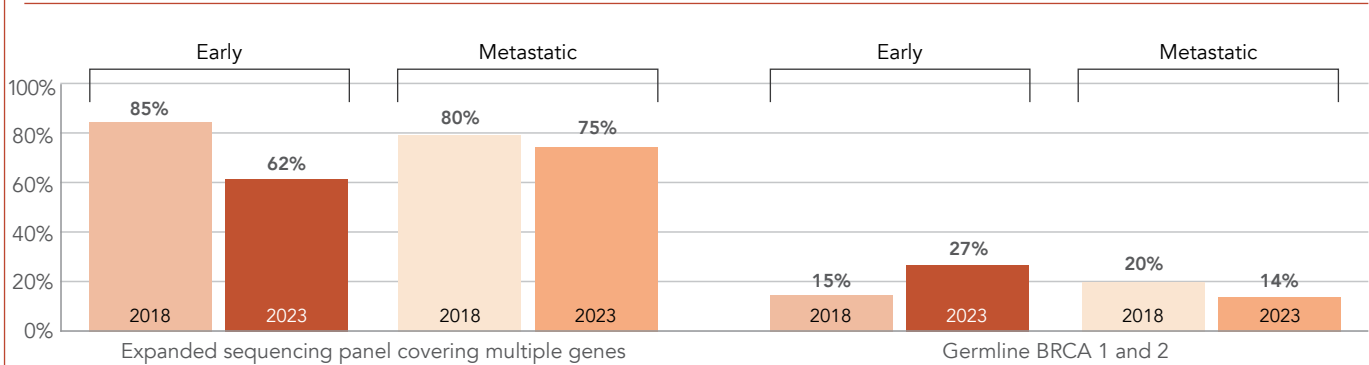


FIGURE 7. What germline BRCA test do you usually order for your patients?



When queried about BRCA1/2 testing guidelines, 76% of providers reported in 2023 that they followed the National Comprehensive Cancer Network (NCCN) guidelines, 7% followed the American Society of Clinical Oncology (ASCO) guidelines, 7% followed protocols developed by their institution/multidisciplinary team, and 4% followed the American

Society of Breast Surgeons (ASBS) guidelines. Two percent (2%) reported using no specific guidelines for BRCA mutation testing. Across each category, these findings were less than those found in 2018, however in 2018 the methodology was different, allowing for multiple responses (**Table 1**).

TABLE 1. Which guidelines do providers follow for BRCA1/2 mutation testing?

GUIDELINE	2018*	2023
National Comprehensive Cancer Network (NCCN)	95%	77%
American Society of Clinical Oncology (ASCO)	31%	7%
A protocol developed by your institution/multidisciplinary team	8%	7%
American Society of Breast Surgeons (ASBS)	17%	7%
No specific guidelines	3%	2%

*In 2018, respondents could choose more than one guideline

The 2023 BRCA1/2 patient survey revealed a very high level of awareness of germline BRCA1/2 testing among patients, with 91% of respondents reporting being very familiar or somewhat familiar with this method of identifying cancer risk. Patients in this sample overwhelmingly (95%) reported that a healthcare provider had discussed genetic testing with them. The few patients (5%) who did not discuss genetic testing all reported that it was not suggested that they meet with anyone to talk about it.

Conversations with patients about genetic testing happened mainly in person, at the hospital or cancer clinic (86%) or over the phone with someone from the hospital or cancer clinic (14%). To learn more about genetic testing for cancer risk, including germline BRCA1/2, patients reported using a variety of different means including from a doctor or nurse (84%), online/websites (51%), documents like brochures or pamphlets (33%), support groups or other patients (20%), and friends or family members (18%).

The majority of patients in the sample (95%) did undergo genetic testing – 48% at diagnosis, 33% before treatment and 13% during treatment. A mere 5% of patients reported having no genetic testing. When asked specifically about germline BRCA1/2 mutation testing, 82% of patients reported having had the test (**Figure 8**).

The reasons provided to patients by their care team for having germline BRCA1/2 testing varied, as shown below (**Figure 9**). More than half of patients cited reasons that included understanding future risk (theirs and their family's) and informing their treatment plan.

The reasons provided by the few (5%) patients who did not have genetic testing were that: “genetic testing was not offered as an option to me,” and “it would not change my treatment plan”.

FIGURE 8. Have you had genetic testing specifically for BRCA1/2 mutations related to breast cancer risk?

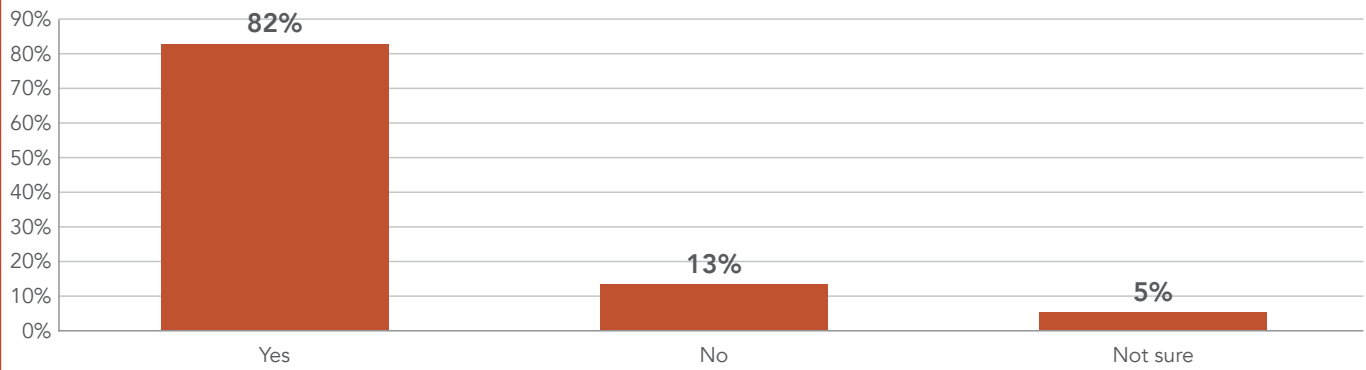
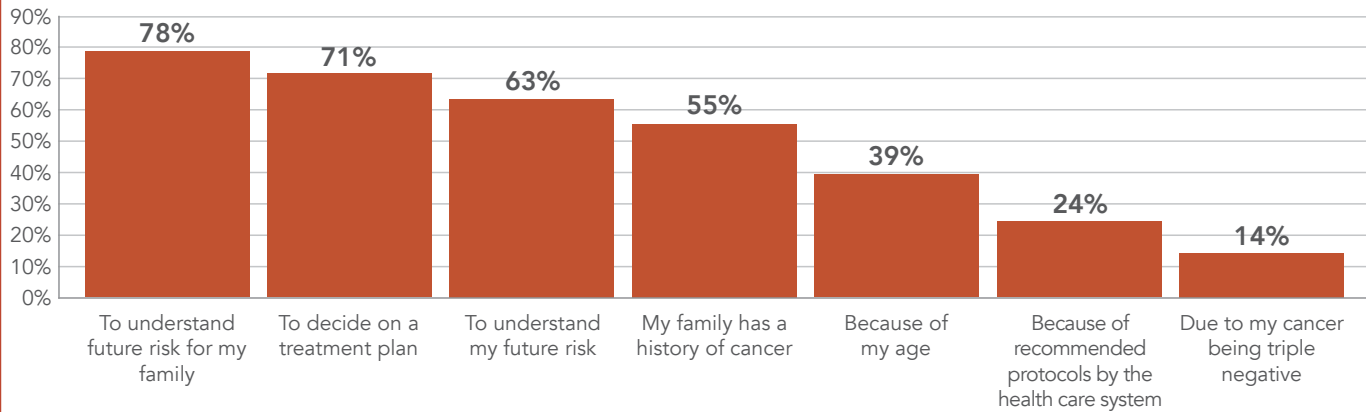


FIGURE 9. What were the reasons provided by a care team for you to have BRCA1/2 testing?



CHALLENGES AND BARRIERS TO GERMLINE BRCA1/2 MUTATION TESTING

The most commonly cited challenge to offering routine germline BRCA1/2 testing were patient concerns and fears, the top challenge both in 2018 and 2023. Other challenges were related to the availability of genetic counselors, turnaround time, and reimbursement for testing or counseling (**Figure 10**).

An additional question was included in the 2023 survey to better understand the institutional challenges that impact genetic testing (eg, germline BRCA1/2). The results suggested

that providers considered access to tumor boards and clinical expertise as challenges, and that patient preference to at-home options also had an impact on their genetic testing practice (**Figure 11**). It is unclear whether the “at-home options” refer to direct-to-consumer genetic testing products like 23andMe, or telehealth genetic counseling where the counseling is provided online, and clinical testing involves patients sending their saliva samples directly to the genetics diagnostic laboratory.

FIGURE 10. What challenges do you encounter at your center for offering routine BRCA mutation testing to your patients with breast cancer?

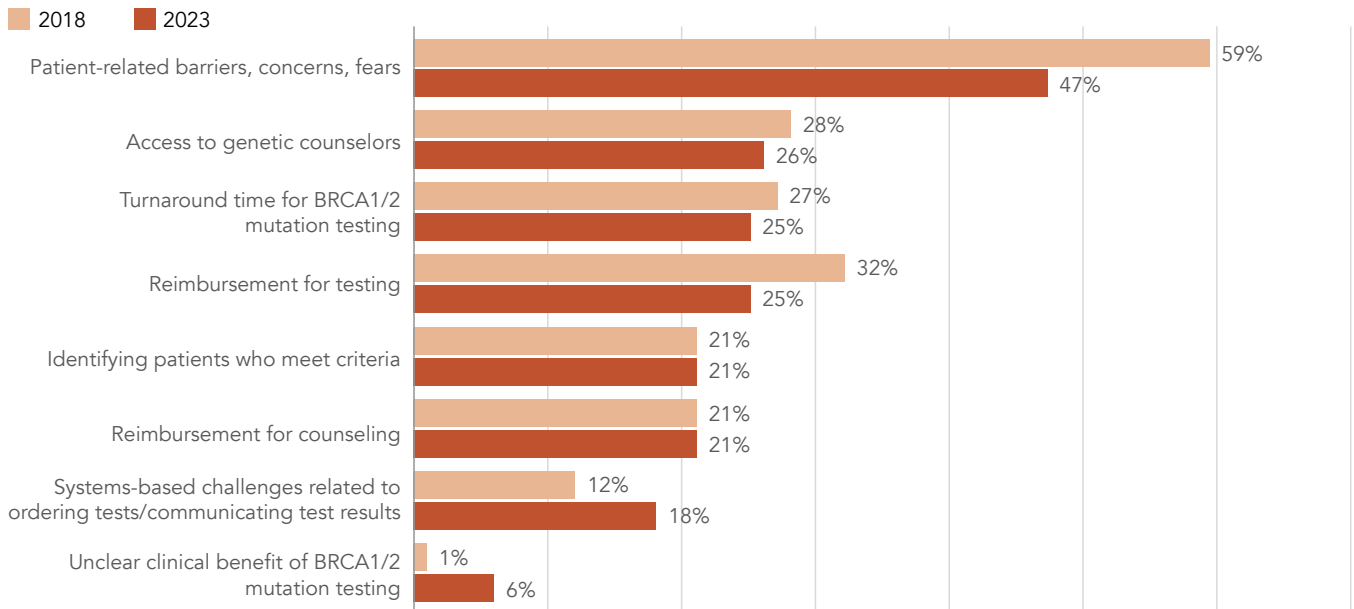
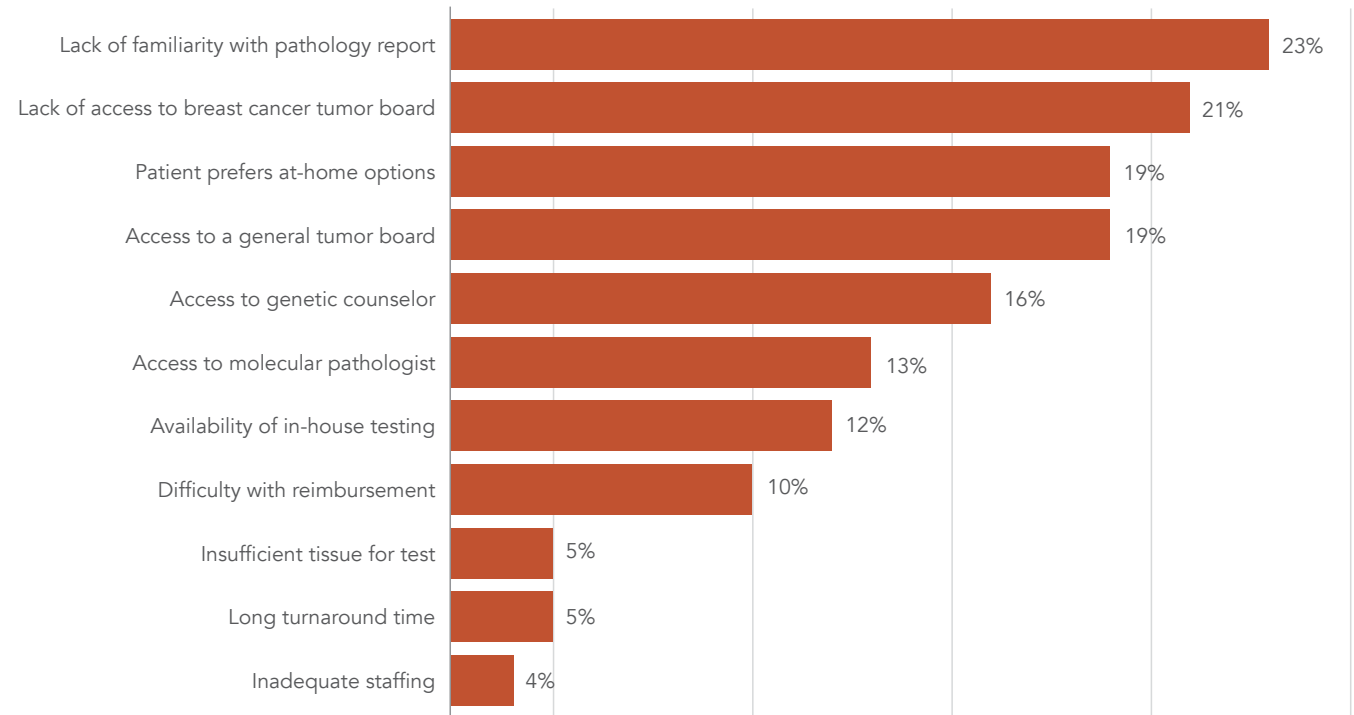


FIGURE 11. Which of the following challenges impact genetic testing (eg, BRCA1/2) practices at your institution?



PATIENT ENGAGEMENT AND THE CARE TEAM

The vast majority of patients in the survey (96%) reported that either their cancer doctor or other health provider discussed the results of their genetic tests with them during treatment discussions. Furthermore, most patients (91%) agreed (definitely or somewhat) that test results were explained by their cancer doctor or healthcare provider in a way that they could understand. A further sign of good engagement is the finding that most patients (80%) felt like they had been involved in decisions about how to use their genetic test results (definitely or somewhat) (**Figure 12**). Decision-making may reflect a broader set of discussions around topics like treatment

decisions, which have many different considerations in addition to genetic test results.

When asked about the psychosocial support available during and after discussions about their genetic test results, the results were not as positive. Just under half (48%) of patients reported that there was a nurse or nurse navigator present in the room during treatment discussions with their cancer doctor. Further, just over half (58%) reported that after these discussions, they had the opportunity to meet with someone to talk about their concerns or fears (**Figure 13**).

FIGURE 12. Patient Engagement in Discussions About Genetic Test Results

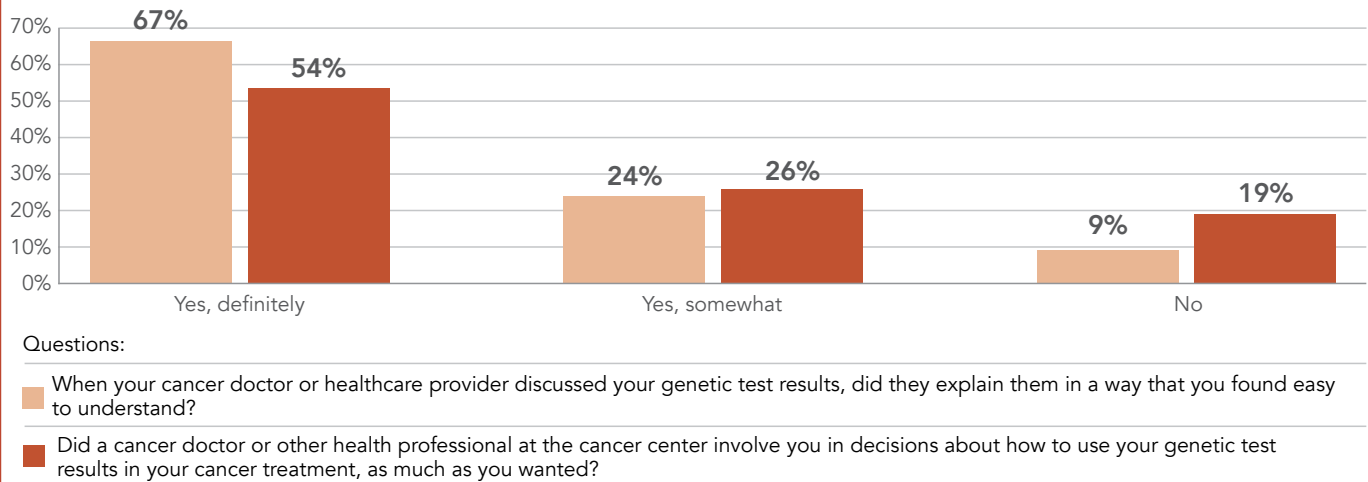
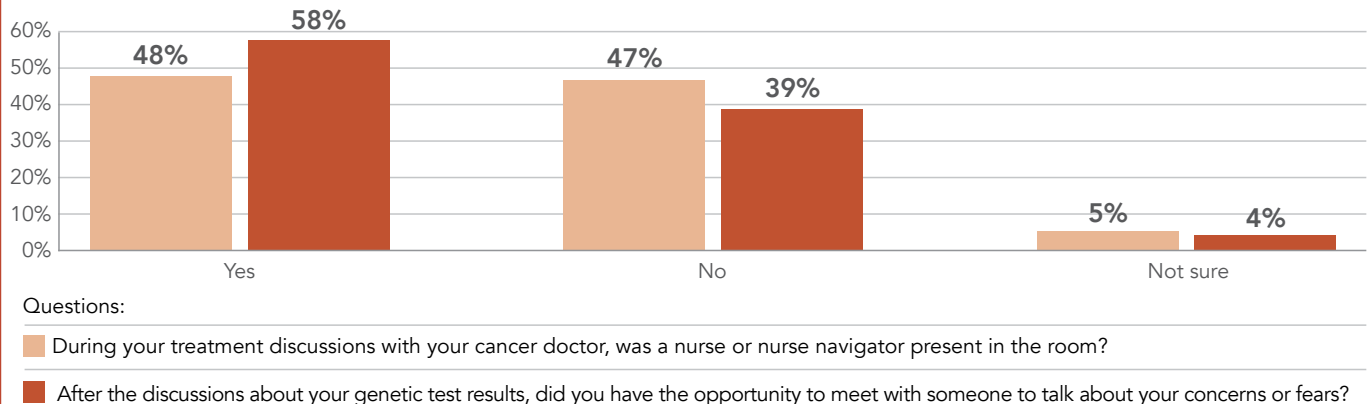


FIGURE 13. Availability of Psychosocial Support for Patients Around Genetic Test Results



ROLES AND RESPONSIBILITIES

The results from the provider survey suggest that a wider variety of options were used for genetic counseling in 2023 than were in 2018. When asked about access to genetic counselors, in 2023 only 8% of providers reported that they had no routine access to a genetic counselor at their site, down from 15% in 2018 (**Figure 14**). Slightly more providers reported routine use of tele-counseling in 2023 (19%) than in 2018 (16%). Although there is no comparative data from 2018, the fact that 23% of providers reported using “multiple sources” is indicative of the wider range of options currently available.

In 2023, genetic counseling consults were most often ordered by the medical oncologist (89%), surgeon (54%), or nurse navigator/nurse practitioner (44%). Since 2018, the tendency for medical oncologists to refer patients grew considerably (from 47%) as did the tendency for nurse practitioners and navigators, and genetic counselors themselves (**Figure 15**). The referral from genetic counselors themselves may be a recommendation that happens during a tumor board or other meetings of the clinical team.

FIGURE 14. Do you have access to, and routinely utilize, a genetic counselor?

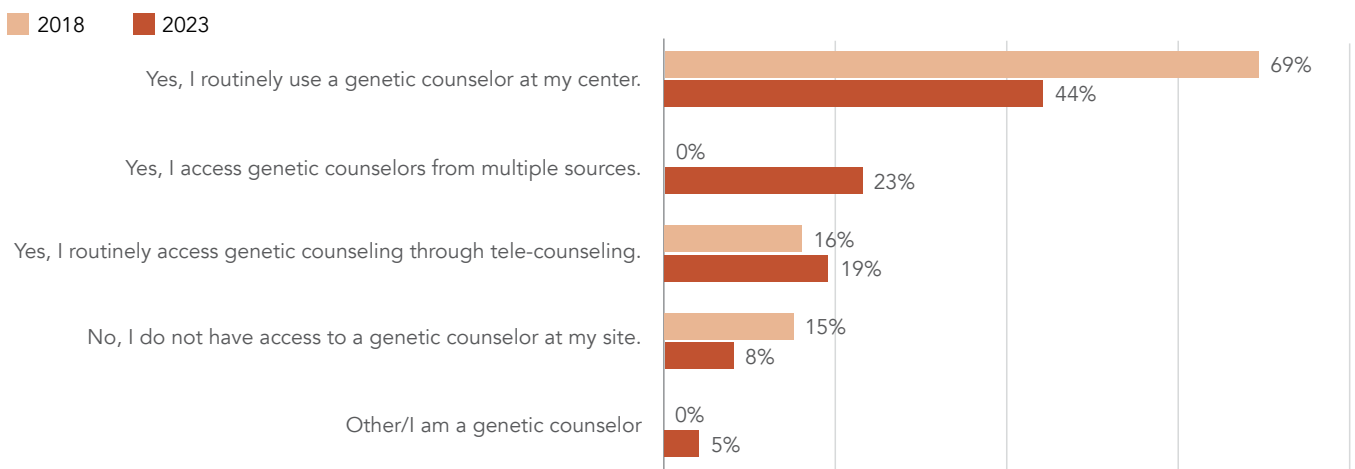
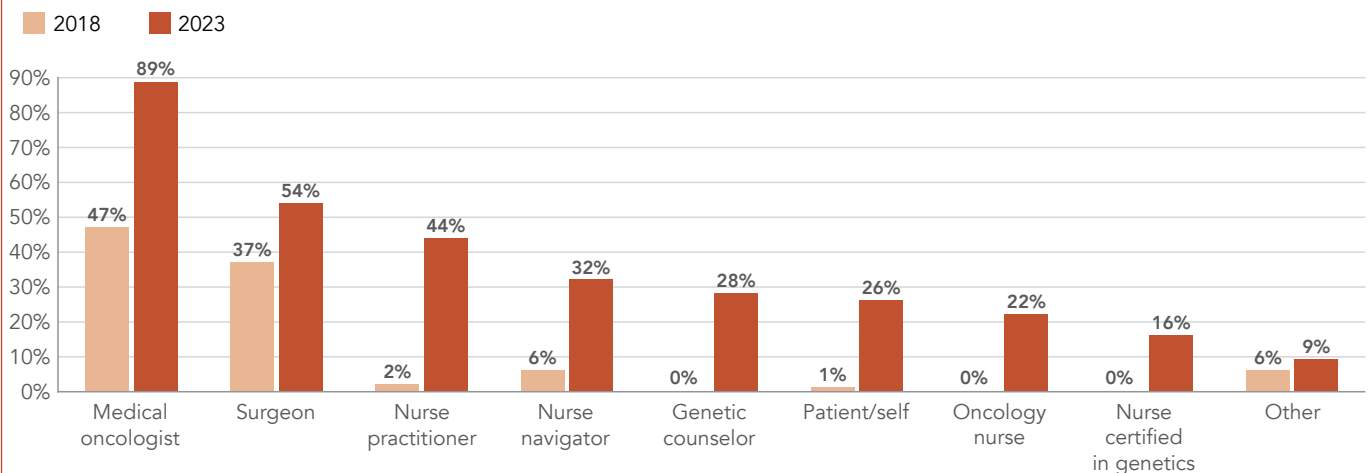


FIGURE 15. Which roles commonly refer patients for genetic counseling services at your center?



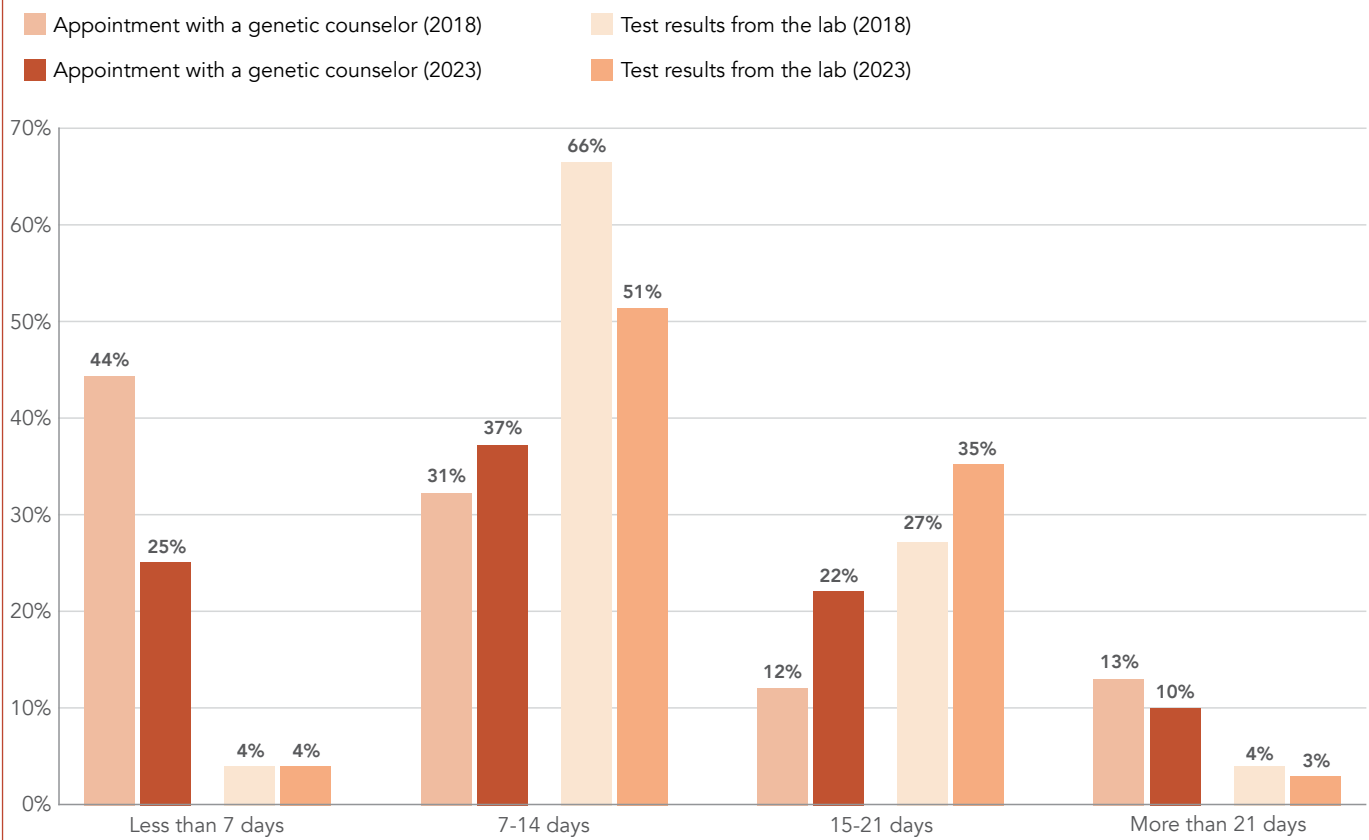
Note: In 2023, respondents could choose more than one response

Among centers that reported providing access to a genetic counselor in 2023, 62% of providers reported two weeks or less wait time to get an appointment with a counselor (down from 75% in 2018). Reported turnaround for receipt of BRCA germline test results from the lab varied, with 55% of respondents indicating an average time of less than two weeks (down from 70% in 2018) (**Figure 16**).

qualifying for genetic testing with the expanded testing criteria in 2023 compared to 2018. Wait times may also be affected by the type of tests that are ordered, with ‘stat’ (eg, urgent or rush) panels taking priority and available more quickly. Another factor in longer turn-around times for test results may be associated with the process of testing for remote genetic services, for which test kits are shipped to and from the patients, which adds a variable in completing sample collection and thus timing to receive results.

Increases in wait times for genetic counseling or test results may be a function of the growth in volume of patients

FIGURE 16. What is the average time that it takes to get...?

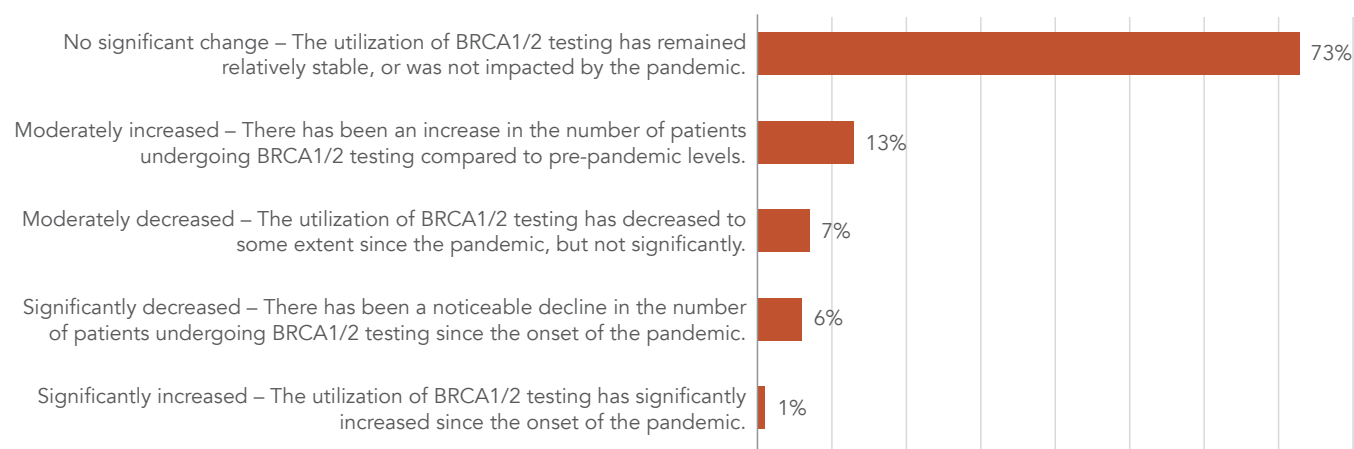


IMPACT OF COVID-19

The providers surveyed in 2023 were asked about the impact of the COVID-19 pandemic on germline BRCA1/2 testing, in light of the challenges it presented. Most respondents (73%) felt that it had no significant impact – that the utilization of germline BRCA1/2 testing remained relatively stable or was not impacted by the pandemic. A further 13% expressed that the pandemic prompted a moderate increase in testing compared to pre-pandemic levels and 7% felt that it moderately decreased testing (**Figure 17**).

When asked about the factors contributing to changes in testing with the COVID-19 pandemic, most respondents cited the increased use of telehealth, which has made genetic testing more easily available and is a trend that has continued to the present day. Coinciding with the pandemic were changes to clinical guidelines, and an increase in patient awareness, both of which have also increased the number of referrals to genetic testing. The timing of these changes has made it difficult to distinguish the true impact of the pandemic. For the factors that providers believe have contributed to changes since COVID-19 pandemic, see Appendix 2.

FIGURE 17. How has the COVID-19 pandemic impacted the utilization of BRCA1/2 testing in your practice?



SURVEY STRENGTHS AND LIMITATIONS

One of the main goals of this project was to reassess the state of germline BRCA1/2 mutation testing in 2023 compared to 2018. Comparisons between the 2018 and 2023 surveys were made possible by using the same questions on each survey. This allowed an assessment of changes in germline BRCA1/2 testing over the past 5 years which is a valuable question to the clinical community. The comparison is limited by the use of two different samples of providers not from the same institutions and by slight changes in survey methodology. It is also subject to the biases inherent in many self-report surveys, such as recall and desirability.

Although providers in the 2023 survey came from 38 states, 6 states represented almost half (47%) of the sample; these were California, Ohio, Maryland, New York, Pennsylvania, and Texas. The sample was also largely urban (55%) or suburban (28%), with only 16% of providers practicing in rural locations. This geographical response pattern may have affected the generalizability of the findings to all parts of the country. No geographic data was available in 2018 for comparisons of the samples.

Half of the sample in the 2023 provider survey was derived from a panel of physicians registered with marketing research company Sermo. These respondents were all medical oncologists. There is no reason to question the validity of their responses, but they may have been affected by factors related to the physicians' interest in participating in this type of paid research activity.

Despite the alignment in survey questions between 2018 and 2023, there were instances where the survey instructions changed, and for the same questions, respondents were able to select 'all that apply' in one survey and were asked to 'choose one' in the other. When this occurred, it was difficult to compare results side-by-side.

The patient survey had the advantage of focusing on individuals who had been diagnosed with breast cancer in the past year, which in theory, was likely conducive to better recall and reflective of experience with current practice. The questions were designed to capture similar information as the provider survey on germline BRCA1/2 genetic testing, from the patient's perspective. The sample was derived from a market research organization, Rare Patient Voice (RPV), who maintains a roster of patients willing to participate in surveys. Such a willing and captive audience may have resulted in certain biases, including a population of patients who are in otherwise relatively good health.

SUMMARY

Comparisons between the surveys of community oncology practitioners in 2018 and 2023 suggest that over the past five years, there has been a moderate improvement in germline BRCA1/2 mutation testing for breast cancer patients. A notable finding in 2018 was that 82% of respondents reported that 50% or fewer of their patients with early or metastatic breast cancer care have ever had germline BRCA mutation testing. Now, in 2023, 77% of respondents reported 50% or fewer of patients having germline BRCA1/2 testing. Compared to 2018, fewer practitioners reported that they usually ordered expanded sequencing panels covering multiple genes for patients with both early and metastatic breast cancer. Despite the lower percentages in 2023, the continued use of expanded sequencing panel testing is reassuring as it frequently identifies mutations in genes that predispose patients to other cancers and can prompt enhanced screening.

The title of the patient survey was 'Patient Perspectives on Genetic Testing in Breast Cancer', and it is possible that the survey attracted patients who had considered or undergone genetic testing, biasing the results towards higher rates of counseling and/or testing. Indeed, 82% of patients who participated reported having germline BRCA1/2 mutation testing. Conversely, if an individual with breast cancer never had genetic testing, it is possible that they assumed that the survey was not directed at them.

The patient survey had no comparator, so the results only represent one point in time. The main limitation of the patient survey was that it was based on only 61 individuals; a larger sample would have provided a more reliable set of results. The patient sample was also comprised of mainly urban (36%) and suburban (55%) respondents, with 9% from rural areas, which may also have biased the survey results. A large percent (61%) of respondents were also 45 years of age or younger and a further 21% were between 46 and 60. Only 11% were 60 and over, which might also have affected the survey results and our ability to generalize the results to germline BRCA1/2 testing in older patients. Notably, all respondents to the patient survey reported having some form of health insurance.

In 2023, patient barriers to BRCA mutation testing included fear, financial concerns, and access to genetic counselors. There were also institutional challenges including lack of access to tumor boards, limited availability of specific clinical expertise, and turnaround time for test results. Many of these barriers were no less prevalent in 2023 than they were in 2018. The results suggest that multi-pronged efforts are needed to improve the continued uptake of germline BRCA1/2 testing for improved quality of care.

The significant practice variations seen in 2018 in terms of the patients selected for routine BRCA mutation testing were again observed in 2023. The current data suggested that the majority of respondents followed the guidelines developed by the National Comprehensive Cancer Network (NCCN) or the American Society of Clinical Oncology (ASCO) for

ordering BRCA mutation testing, 7% reported using institution-specific guidelines and 2% reported using no specific guidelines at all.

The differences observed between 2018 and 2023 suggest a changing landscape related to germline BRCA1/2 mutation testing. Providers now seek out a variety of sources for clinical guidance and for genetic counseling services. The uptake of germline BRCA1/2 testing has not yet seen a steady stream of providers incorporating it into routine practice. Some of the contributing factors may be the lag between changes in testing criteria and the criteria for insurance coverage often needed to pay for the test, as well as the lack of systematic ascertainment of family history.

The patient survey results suggested a high degree of awareness and indeed utilization of germline BRCA1/2 testing. Patients were involved in discussions about testing and implications for their care, which are no doubt complicated and

uncertain. The psychosocial support available to patients still needs improvement to ensure that care is focused on patient and family needs, along with the clinical decisions around treatment.

It is reassuring that the availability and utilization of genetic counseling and testing have improved, and that referrals for testing have significantly increased for both the early breast cancer and metastatic breast cancer patient populations. Improvements are still needed in areas such as turn-around time for test results, so that treatment can be based on clinical parameters rather than feelings of anxiety or fear. With more information, patients can opt for different, more appropriate, and potentially less invasive treatment. The direction of change in germline BRCA1/2 testing has resulted in more patients getting access to genetic testing and a more targeted application of this clinical tool, likely improving treatment effectiveness, improving quality of life, and saving many lives.

REFERENCES

1. ACCC Assessing the Status of BRCA Testing and the Challenges Faced by Cancer Care Teams in the Community Summary of Survey Findings. April 2018 acc-cancer.org/docs/projects/brca/brca-initiative_survey-summary_final-v2.pdf?sfvrsn=80fe0ffb_2
2. Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic Version 2.2024 — September 27, 2023. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) nccn.org/professionals/physician_gls/pdf/genetics_bop.pdf
3. American Society of Breast Surgeons. Consensus Guideline on Genetic Testing for Hereditary Breast Cancer. February 10, 2019. breastsurgeons.org/docs/statements/Consensus-Guideline-on-Genetic-Testing-for-Hereditary-Breast-Cancer.pdf
4. London, J.W.; Fazio-Eynullayeva, E.; Palchuk, M.B.; Sankey, P.; McNair, C. Effects of the COVID-19 Pandemic on Cancer-Related Patient Encounters. *JCO Clinical Cancer Informatics*. 2020, 4, 657–665. ascopubs.org/doi/pdfdirect/10.1200/CCI.20.00068

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APPENDIX 1. SURVEY METHODOLOGY

To address the study objectives a multi-center, observational, cross-sectional study was undertaken. The methodology included two separate self-administered surveys, each delivered and administered online. One survey was geared towards healthcare providers who currently work with breast cancer patients. A second survey targeted adult patients with breast cancer.

SURVEY OF HEALTHCARE PROVIDERS

Inclusion Criteria

- Healthcare professionals employed by a cancer program or practice who provide care and/or support services to patients with breast cancer.
- Anyone who can read and answer questions in English.

Exclusion Criteria

- Healthcare professionals not employed by a cancer program.
- No professional interaction with breast cancer patients.
- Patients or caregivers.

The survey was available as an online option only. The survey was programmed in Qualtrics and a generic link to the survey was generated and distributed through the following channels:

Recruitment through ACCC membership channels included:

1. Emails to select ACCC members as an invitation to complete the survey.
2. ACCC e-Newsletters that target specific member groups (eg, interest areas, discipline).
3. ACCC created a webpage on its public website with information about the study and the survey link.
4. ACCC created a post about the survey, including the Qualtrics link, on its member-only discussion forum, ACCCeXchange.

ACCC also recruited cancer care providers through Sermo, an online knowledge-sharing platform for healthcare providers. Panel recruitment for this survey relied on those healthcare providers who have indicated that they practice in the following areas: oncology nursing; clinicians (oncology/radiology); social workers; and genetic counselors.

Those ACCC-affiliated care providers who completed the survey had the option to enter a raffle for a \$50 gift card. This was completely optional and required the participant to enter their email address. Those healthcare providers who were recruited through Sermo and who answered the survey were eligible for remuneration through the Sermo partner.

The final sample was made up of 57% ACCC members and 43% Sermo panelists.

SURVEY OF ADULT CANCER PATIENTS

The patient survey was designed for adults who have been diagnosed with breast cancer. The survey was available as an online option only. The survey was programmed in Qualtrics and a generic link to the survey was generated and distributed to adult cancer patients.

Inclusion Criteria

- Individuals over the age of 18.
- Diagnosed with breast cancer in the past year.
- Individuals who can read and answer questions in English.

Exclusion Criteria

- Participants younger than 18 years.
- Adults who have never received treatment for breast cancer.
- Adults who are not included in the stated target populations.

Cancer patient recruitment: ACCC enlisted the assistance of RPV to recruit participants for the patient survey. RPV is a knowledge platform specifically designed for patients and caregivers, offering them opportunities to participate in surveys and other research activity. Using the membership information provided, RPV screened its members for eligibility in this study, ie, individuals diagnosed with breast cancer. RPV has over 100,000 patient and caregiver members across more than 700 diseases, both rare and non-rare.

The initial contact for this study was by RPV, who sent an email to those members who had previously identified themselves as having been diagnosed with breast cancer. Those who indicated an interest were sent a follow-up email containing: a brief introduction to the study; steps that were taken to maintain privacy and confidentiality of the data; an indication of how the results would be used; with whom the data would be shared; and an assurance that the survey is completely voluntary and that respondents can leave at any time. To take the survey, participants were asked to click on a unique link in the email and were then given access to the online survey. No pen-and-paper version of the survey was used. The survey was provided in English only.

RPV offers financial incentives for members who participate in surveys. Patients who participated in this survey were eligible for payment of \$25.

APPENDIX 2. FACTORS CONTRIBUTING TO CHANGES SINCE COVID-19

The following are providers' verbatim responses to the question:

"If the utilization of BRCA1/2 testing has changed since the COVID-19 pandemic, what factors do you believe have contributed to this change? Please provide any additional information or insights related to the impact of COVID-19 on BRCA1/2 testing in your practice."

RESPONSES:

☞☞ Afraid to come in

COVID allowed for the opportunity for telehealth counseling which has slightly increased uptake of pre-test counseling.

☞☞ Also, NCCN guidelines have gotten more inclusive in the last few years so there has been opportunity to offer testing to patients that previously did not qualify for genetic testing.

☞☞ Decreased patient visits and referrals

☞☞ Decreased rates for screening mammogram, decreased patients identified with elevated risk scores

☞☞ Fear of cost report by patients

☞☞ Greater need for genetic testing for more indications and greater knowledge of different oncology services of the use of genetic testing for guiding treatment (PARPi, immunotherapies, etc.). For more than patients with breast/ovarian cancers - now trying to test all with pancreatic adenocarcinoma, patients with high grade/metastatic prostate, etc.

☞☞ Increase patient awareness

☞☞ Increased telehealth use

☞☞ More criteria for testing approved

☞☞ More testing other tumors

☞☞ Referral volumes in general for genetic testing have increased since 2020. I am not sure that this is related to COVID directly or just an increase in awareness, indications, etc.

☞☞ We are testing more often but I do not think this is related to COVID

☞☞ We saw no long term change due to COVID; we have increased testing due to additional staffing

☞☞ Ability to utilize telehealth services enables a larger population to access genetic counseling services

☞☞ Ongoing conversations, increased access to care

☞☞ Telehealth counseling availability due to pandemic



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Learn more at
acc-cancer.org/BRCA-testing-survey.

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