

Genetic Counseling Referrals Among Cancer Registry Patients Who Meet NCCN Guidelines: An Ohio Study

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The National Cancer Institute estimates that more than 519,000 women will be diagnosed with breast, colorectal, endometrial, or ovarian cancer in 2021, making up approximately 27 percent of all new cancer cases.^{1,2,3,4} Although most cancers occur sporadically, approximately 10 percent of these cases will be due to a hereditary cancer predisposition syndrome caused by an inherited genetic variant. Therefore, an estimated 76,000 newly diagnosed patients with cancer will have a hereditary cause for their disease. Identifying these individuals early can have a significant impact on their future health by determining their risk for additional cancers, altering cancer-screening recommendations, offering risk-reducing options, and potentially identifying gene-based anticancer treatment options.

Genetic testing became available in 1996 for the *BRCA1/2* genes associated with hereditary breast and ovarian cancer syndrome for breast and ovarian cancers. These are the most widely recognized indications for testing.⁵ Another important milestone in cancer genetics occurred in 2000, as providers could now test for two of the five genes known to be associated with Lynch syndrome, a hereditary condition that accounts for up to 3 percent of all colon and endometrial cancers.⁶ Historically, clinicians have been more aware of guidelines for referral in breast and ovarian cancers than any other types of the disease, which is reflected in genetic counseling referral patterns.

To help clinicians identify individuals at risk for hereditary cancer, the National Comprehensive Cancer Network (NCCN) created its guidelines in 1999 that continue to be updated today.⁷⁻¹¹ Several studies have analyzed the efficacy and utility of the NCCN Guidelines® in clinical practice. One such study, by Febbraro et al., evaluated the number of women with breast, endometrial, or ovarian cancer who met NCCN Guidelines and who were referred for genetic counseling between 2004 and 2010.¹² The study found that the overall referral rate was 21.7 percent and that patients with breast cancer were more likely to be referred for genetic counseling than those with endometrial or ovarian cancer.¹²

The overall referral rate for genetic counseling increased from 36 percent in 2013 to 66 percent in 2018. The proportion of patients with breast cancer who were referred for genetic counseling showed a substantial increase, from approximately 49 percent in 2013 to 75 percent in 2018.

Numerous other studies and abstracts have looked at evaluating genetic counseling uptake. Bellcross et al. evaluated a large genetic counseling integrated site system and found that, of the 684 individuals considered at high risk for hereditary breast and ovarian cancer syndrome, only 20 percent were referred for genetic counseling.¹³ A 2012 Michigan study showed that only 23 percent of women with a family history of breast cancer diagnosed at age 50 or younger received genetic counseling.¹⁴ Additionally, a study in the *Journal of Clinical Oncology* found that only 15 percent of women with ovarian cancer discussed genetic testing, and only 11 percent had genetic testing done.¹⁵

An Ohio Study

Ohio Partners for Cancer Control's Comprehensive Cancer Control Plan laid out the state's cancer genetics objective from 2015 to 2020, which was to increase the overall number of individuals who receive genetic counseling at an Ohio Cancer Genetics Network site by 20 percent.¹⁶ One strategy identified to help meet this goal included promoting collaboration among

genetic counselors and cancer registrars to identify individuals appropriate for genetic counseling. The Ohio Department of Health contracted with five Ohio-based health systems to gather registry data on individuals who meet NCCN genetic counseling referral guidelines for select cancer diagnoses. These participating health systems included the Arthur G. James Cancer Hospital and Richard J. Solove Research Institute at The Ohio State University, OhioHealth, and Mount Carmel Health System in Columbus, as well as TriHealth in Cincinnati and ProMedica in Toledo, Ohio.

This study was created to support Ohio Partners for Cancer Control's state cancer plan objective and to determine a statewide benchmark for Ohio Cancer Genetics Network sites by evaluating genetic counseling referral data for individuals who meet NCCN criteria and who are identified by cancer registry data at the five participating health systems. In this article, we discuss our experience in collaborating with various cancer registrars and lessons learned on how to obtain accurate data. The information shared here may serve as a platform for future assessment of potential methods to increase genetic counseling referral and uptake of these services among populations who are at high risk for hereditary cancers.

Materials and Methods

This study is a continuous prospective quality review that will incorporate new data annually as they become available at each participating health system. This is an Ohio-based multicenter initiative, and data were shared only in aggregate form, without patient identifiers, among participating health systems. The study's population is listed below. Eligible individuals with cancer in 2013 to 2018 who met NCCN genetic counseling referral criteria and who were identified by a cancer registrar's database from the five participating health systems were asked to participate in the study. The study was approved by each participating health system's institutional review board (IRB) and the Ohio Department of Health's IRB.

Study Population

Based on NCCN 2013 referral criteria and adjusted with NCCN updates, the study's inclusion criteria were:

- Females with breast cancer ages 18 to 50 years old
- Females with triple-negative breast cancer ages 51 to 60 years old
- Males with breast cancer ages 18 years or older
- Females and males with colorectal cancer ages 18 to 49 years old
- Females with fallopian tube, ovarian, or primary peritoneal cancer ages 18 years or older (these cancers are referred in combination as "ovarian cancer")
- Females with endometrial cancer who were diagnosed at 18 years to 49 years old.

Although there are numerous other criteria for genetic counseling referral, this study used only patients' cancer and age at diagnosis. This is because these criteria are the easiest for healthcare providers to identify and the most straightforward data for cancer registrars

to collect. Patients who did not meet the criteria were excluded from the study.

Statistical Analysis

Each participating health system requested data from their respective cancer registry annually from 2013 to 2018. The registry looked for patients who met the study's criteria and provided a list to the health system with patient identifiers. Each center used its own method to determine if a genetic counseling referral was made and whether or not the patient's appointment was completed. This process included query of the center's electronic health record (EHR) and/or use of internal genetics clinic databases. The patient identifiers were only used internally to match patients who had genetic counseling. For each year, the participating health systems recorded and collected in an aggregate spreadsheet the de-identified number of eligible patients referred to genetic counseling and the number of eligible patients seen for genetic counseling. Table 1, right, shows the formulas each healthcare center used to calculate percentages.

The proportions of eligible patients who were referred to genetic counseling, eligible patients who were seen by a genetic counselor, and those seen by a genetic counselor for each cancer diagnosis were summarized by year. Generalized linear mixed models were used to estimate mean predicted probabilities and evaluate trends from these referral statistics. These data were summarized over time from 2013 to 2018 for patients with breast cancer, triple-negative breast cancer, ovarian cancer (fallopian tube, ovarian, and primary peritoneal cancers), colorectal cancer, and endometrial cancer. Cancer sites were used as a random effect in our models to account for repeated measures. The mean predicted probabilities summarized in tables and plots represent the model's estimated proportion of eligible patients who were referred to genetic counseling, eligible patients seen by a genetic counselor, and those referred patients who were seen for genetic counseling across all centers for a given year. Statistical analysis was performed using statistical software SAS/STAT (version 9.4 of SAS for Windows by SAS Institute Inc. in Cary, N.C.) and RStudio (R version 3.6.0 by The R Foundation for Statistical Computing).

Patients Referred for Genetic Counseling

Data for eligible patients referred to genetic counseling are summarized in Figure 1, page 46, and Table 2, page 47. From 2013 to 2018, the five participating health systems identified 8,945 patients who met NCCN criteria for genetic counseling referral, including:

- 477 patients with breast cancer (477 females; 136 males)
- 1,956 patients with ovarian cancer
- 968 patients with colorectal cancer
- 636 patients with triple-negative breast cancer
- 475 patients with endometrial cancer.

The overall referral rate for genetic counseling increased from 36 percent in 2013 to 66 percent in 2018. The proportion of patients with breast cancer who were referred for genetic counseling showed a substantial increase, from approximately 49 percent in 2013 to 75 percent in 2018 ($p < .001$). Similarly, the proportion

Table 1. Mean Predicted Probabilities of Eligible Patients Referred for Genetic Counseling

Mean predicted probability of eligible patients referred for genetic counseling	2013 n Mean (SE) [95% CI]	2014 n Mean (SE) [95% CI]	2015 n Mean (SE) [95% CI]	2016 n Mean (SE) [95% CI]	2017 n Mean (SE) [95% CI]	2018 n Mean (SE) [95% CI]
Breast cancer (female)	581 .49 (.08) [.33, .65]	841 .54 (.08) [.38, .69]	785 .62 (.07) [.47, .76]	829 .67 (.07) [.51, .79]	912 .7 (.06) [.55, .81]	826 .75 (.06) [.6, .85]
Triple-negative breast cancer	65 .30 (.11) [.12, .56]	96 .48 (.12) [.25, .72]	155 .73 (.09) [.5, .88]	120 .67 (.11) [.42, .85]	96 .67 (.11) [.42, .85]	104 .66 (.11) [.41, .84]
Breast cancer (male)	19 .57 (.19) [.2, .87]	28 .61 (.14) [.31, .85]	23 .87 (.09) [.57, .97]	18 .46 (.16) [.17, .77]	19 .69 (.15) [.34, .91]	29 .59 (.14) [.3, .83]
Ovarian cancer	210 .3 (.08) [.16, .49]	328 .35 (.08) [.2, .53]	373 .39 (.08) [.24, .58]	320 .46 (.09) [.29, .65]	353 .51 (.09) [.33, .69]	372 .5 (.09) [.32, .68]
Colorectal cancer	91 .22 (.06) [.12, .36]	155 .29 (.05) [.2, .4]	171 .33 (.05) [.24, .45]	185 .33 (.05) [.23, .44]	162 .44 (.06) [.33, .56]	204 .51 (.05) [.4, .62]
Endometrial cancer	43 .1 (.05) [.03, .27]	69 .27 (.06) [.16, .42]	89 .29 (.06) [.18, .42]	80 .39 (.07) [.26, .53]	101 .45 (.06) [.33, .58]	93 .51 (.06) [.37, .64]

CI = confidence interval ; SE = standard error.

of patients with triple-negative breast cancer who were referred for genetic counseling increased from 30 percent in 2013 to 66 percent in 2018 ($p = .002$), and the proportion of patients with ovarian cancer who were referred to genetic counseling increased from 30 percent in 2013 to 51 percent in 2018 ($p = .001$). Increases in referrals over the same period were also seen among patients with colorectal cancer (22 percent to 44 percent, $p = .001$) and patients with endometrial cancer (10 percent to 51 percent, $p = .006$).

Patients Seen for Genetic Counseling

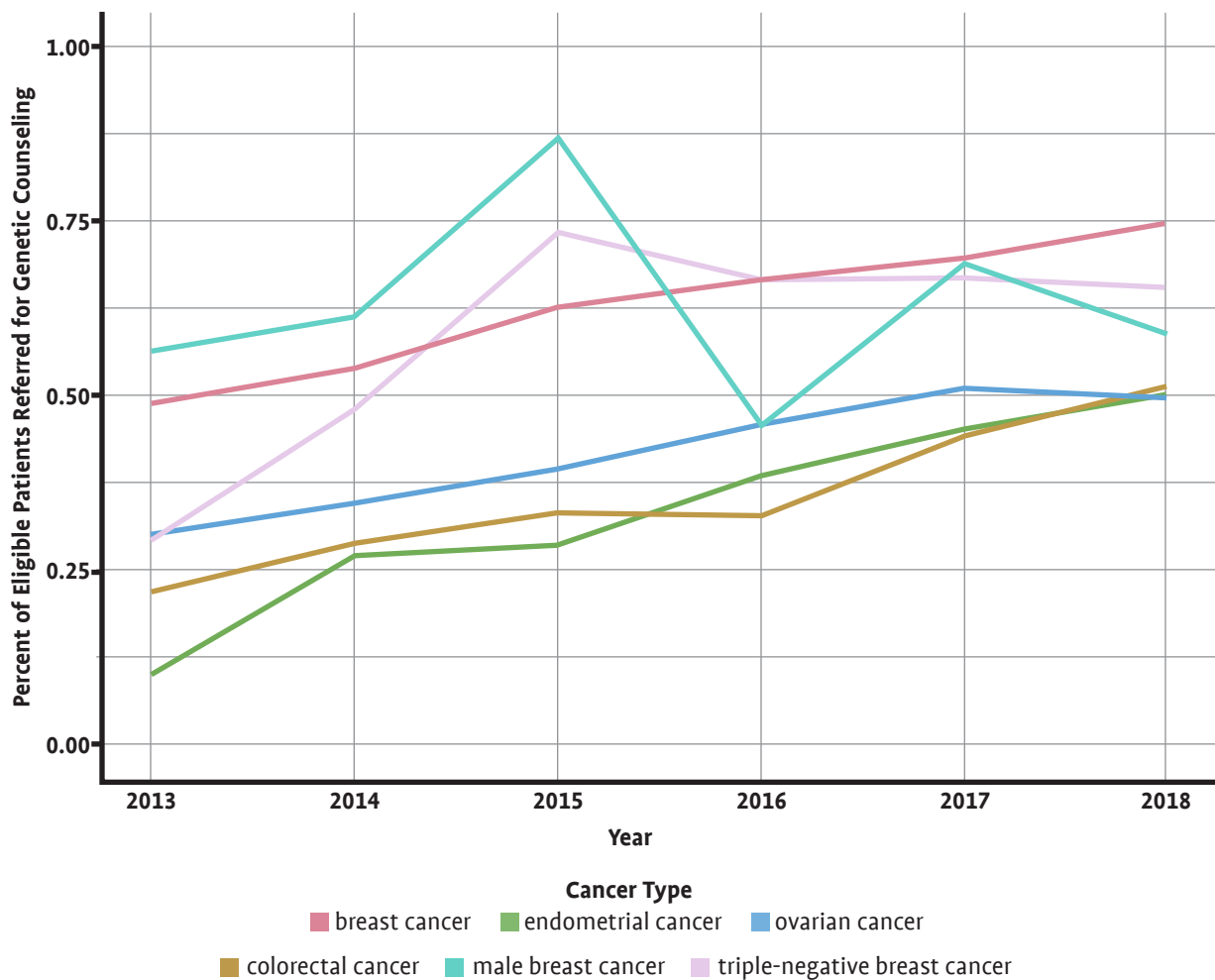
The overall rate of eligible patients who were seen for genetic counseling increased from 29 percent in 2013 to 57 percent in 2018. Proportions of female patients with breast cancer who were seen for genetic counseling gradually increased from 43 percent to 68 percent from 2013 to 2018 ($p < .0001$). Similarly, the proportion of patients with triple-negative breast cancer who were seen for genetic counseling showed a substantial increase from 27 percent in 2013 to 60 percent in 2018 ($p = .001$). Proportions of male patients with breast cancer seen for genetic counseling fluctuated between 33 percent to 52 percent from

2013 to 2018, with no overall difference detected in mean predicted probability seen across time ($p = .859$). Increases in proportions from 2013 to 2018 were also observed among patients with ovarian cancer (19 percent to 44 percent, $p = .001$), patients with colorectal cancer (15 percent to 35 percent, $p = .021$), and patients with endometrial cancer (4 percent to 30 percent, $p = .045$). See Table 2, page 47, and Figure 2, page 48.

Percentage of Referred Patients Seen for Genetic Counseling

The overall proportion of referred patients seen for genetic counseling increased slightly (from 82 percent to 87 percent) from 2013 to 2018. Generally, trends in the mean predicted probabilities of referred patients seen for genetic counseling fluctuated over the study period, with no definitive increases over time. Among female patients with breast cancer, there was a slight increase (83 percent to 90 percent) from 2013 to 2018 ($p = .078$). There was no clear trend over time in the proportion of patients with triple-negative breast cancer who were referred and seen for genetic counseling; mean predicted probabilities fluctuated between 70 percent to 89 percent from 2013 to 2018 ($p = .047$). Similar

Figure 1. Percentage of Eligible Patients Referred for Genetic Counseling



fluctuating trends with no clear increase overtime were observed among patients with ovarian cancer (68 percent to 90 percent, $p = .047$), colorectal cancer (50 percent to 80 percent, $p = .061$), endometrial cancer (41 percent to 71 percent, $p = .061$), and male patients with breast cancer (59 percent to 85 percent, $p = .047$). See Table 3, page 49, and Figure 3, page 50.

Referral Increases by Cancer Type

From 2013 to 2018, all cancer sites showed an increase in patient referral, and by 2018, all cancer sites had 70 percent or more patients who completed genetic counseling when referred. Exactly what contributed to these increases were not measured as part of this study. However, our team considered factors, such as:

- Adding genetic counselors to a cancer program or practice
- Embedding genetic counselors within oncology point-of-care clinics
- Screening patients with colorectal and/or endometrial cancer universally for Lynch syndrome

- Using genetic test results for determining targeted therapies
- Increasing discussion of genetic counseling at tumor board meetings
- Performing genetic counseling grand rounds presentations
- Requiring genetic counseling for site accreditation (e.g., National Accreditation Program for Breast Centers).

Additional factors like improved insurance coverage and reduced out-of-pocket costs for genetic testing may have also played a role in increased genetic counseling appointments and follow through.

A Focus on Breast Cancer

Breast cancer started with the highest genetic counseling referral rate (49 percent) and had the highest overall increase: 75 percent by 2018. This increase excludes the study's rate increase found among patients with triple-negative breast cancer (66 percent) and male patients with breast cancer (87 percent) because these

Table 2. Mean Predicted Probabilities of Patients Seen for Genetic Counseling

Mean predicted probability of eligible patients seen for genetic counseling	2013 n Mean (SE) [95% CI]	2014 n Mean (SE) [95% CI]	2015 n Mean (SE) [95% CI]	2016 n Mean (SE) [95% CI]	2017 n Mean (SE) [95% CI]	2018 n Mean (SE) [95% CI]
Breast cancer (female)	581 .43 (.06) [.31, .55]	841 .46 (.06) [.34, .58]	785 .52 (.06) [.4, .64]	829 .61 (.06) [.48, .72]	912 .64 (.06) [.52, .75]	826 .68 (.05) [.56, .78]
Triple-negative breast cancer	65 .27 (.07) [.15, .45]	96 .36 (.08) [.22, .53]	155 .61 (.07) [.45, .74]	120 .53 (.08) [.37, .68]	96 .59 (.08) [.42, .74]	104 .6 (.08) [.43, .75]
Breast cancer (male)	19 .47 (.11) [.25, .7]	28 .5 (.09) [.31, .69]	23 .52 (.1) [.31, .72]	18 .33 (.11) [.15, .59]	19 .47 (.11) [.25, .7]	29 .52 (.09) [.33, .7]
Ovarian cancer	210 .19 (.06) [.09, .35]	328 .24 (.07) [.12, .41]	373 .31 (.08) [.17, .5]	320 .34 (.09) [.19, .53]	353 .37 (.09) [.21, .56]	372 .44 (.09) [.27, .64]
Colorectal cancer	91 .15 (.05) [.06, .3]	155 .19 (.06) [.09, .34]	171 .21 (.06) [.11, .37]	185 .25 (.07) [.14, .42]	162 .21 (.06) [.11, .37]	204 .35 (.08) [.2, .53]
Endometrial cancer	43 .04 (.03) [.01, .2]	69 .14 (.06) [.06, .3]	89 .17 (.06) [.08, .33]	80 .24 (.08) [.11, .43]	101 .16 (.06) [.07, .32]	93 .3 (.08) [.15, .5]

CI = confidence interval ; SE = standard error.

are much smaller patient populations. An average of 6 male patients with breast cancer and 21 patients with triple-negative breast cancer were included in the study in 2018 across all five health systems, resulting in more significant changes to the study's percentages by even just one patient. There were fluctuations in percentages of patients with breast cancer who were referred and seen across the individual health systems, possibly due to genetic counselor and physician staffing; the more physicians and genetic counselors on staff, the more patients can be referred and seen.

Data among patients with breast cancer also show an increase in genetic counseling appointments, with an average of 68 percent in 2018, and the highest average for referred patients who were seen by genetic counseling was at 90 percent in 2018. This study did not analyze the reasons why an individual declined a genetic counseling appointment. However, a prior study by OhioHealth looked at referral rates of newly diagnosed patients with breast cancer and existing barriers to genetic testing.¹⁸ The study found that the biggest limiting factors for patients referred to genetic counseling included physicians' not referring, timing, stress, and patients not wanting to know about their testing results.¹⁷ This study was published in 2017 and may have contributed to Ohio-

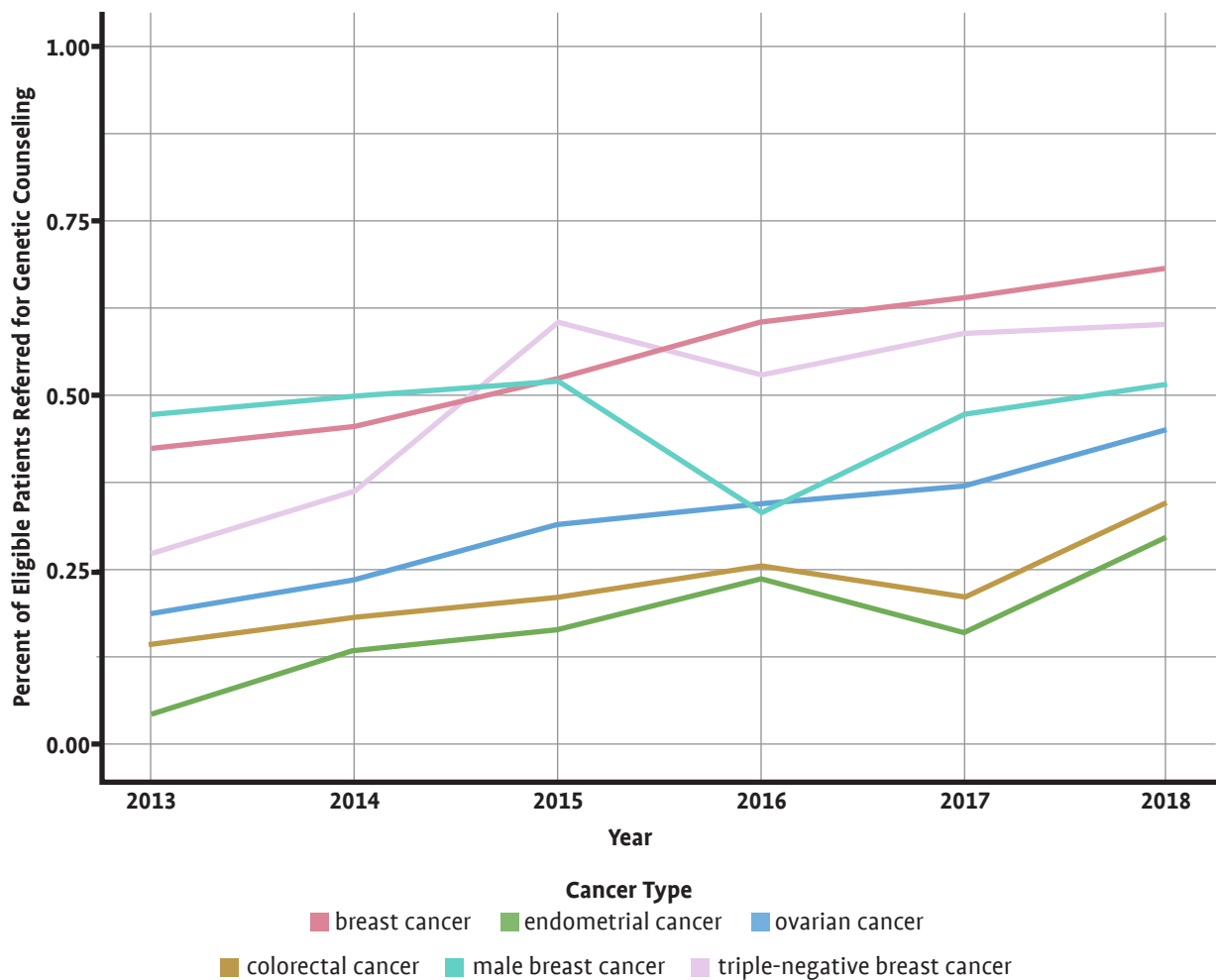
Health now having the highest overall referral rate for patients with breast cancer (94 percent in 2018).

A Focus on Ovarian Cancer

Studies have shown that fewer than 34 percent of patients with ovarian cancer are referred to genetic counseling and testing in the United States.^{13,18,19} Our ovarian cancer referral data showed an increase across all participating health systems from 30 percent to 51 percent, which is above the U.S. average.^{13,18,19} Low genetic counseling referral rates for ovarian cancer are perplexing given the straightforward guidelines stating that all patients with ovarian cancer meet referral criteria regardless of age and therapeutic implications.⁹

In 2013, Bednar et al. implemented a universal genetic testing initiative that included physician-coordinated testing; genetic counselors being embedded into gynecology oncology clinics; and tracking for patients with high-grade, nonmucinous epithelial ovarian cancer. This initiative surpassed an 80 percent increase in referrals.²⁰ Additionally, the initiative reviewed reasons for failure to complete genetic testing, and the most common reasons were that patients elected to pursue genetic testing elsewhere,

Figure 2. Percentage of Eligible Patients Seen for Genetic Counseling



declined genetic counseling and testing, or had financial concerns or lack of health insurance coverage for testing.²⁰

In 2014, the Arthur G. James Cancer Hospital and Richard J. Solove Research Institute at The Ohio State University evaluated whether having a genetic counselor embedded in the gynecologic oncology clinic would increase referrals and patient uptake of their appointment.²¹ Data found that only 21 percent of patients were being referred, and after the genetic counselor was embedded in the clinic (from 2014 to 2016), the referral rate increased to 44 percent.²¹ The data from our study reflects this steady increase of referrals and patients that were seen at the James Cancer Hospital.

An additional factor that could have influenced ovarian cancer referrals was the approval for PARPs in December 2014 for patients with advanced ovarian cancer who have germline *BRCA1/2* pathogenic variants. The rise in patients referred and

seen during this time may have been because providers recognized that genetic testing posed implications for anticancer therapy. Our data show that there is an increase in patients with ovarian cancer being seen by genetic counseling over time when referred. However, there is room for improvement, and sharing these data help us think about the factors that are involved in getting closer to a 100 percent rate.

A Focus on Colorectal Cancer

Our data reflects that Lynch syndrome genetic counseling referrals have lagged behind hereditary breast and ovarian cancer syndrome. Colorectal cancer had a starting overall referral rate of 22 percent that increased to 44 percent by 2018, compared to breast cancer's 50 percent starting referral rate. As Lynch syndrome testing continues to evolve and incorporates universal tumor screening by immunohistochemistry and next-generation tumor profiling,

Table 3. Mean Predicted Probabilities of Referred Patients Seen by Genetics

Mean predicted probability of referred patients seen by genetics	2013 n Mean (SE) [95% CI]	2014 n Mean (SE) [95% CI]	2015 n Mean (SE) [95% CI]	2016 n Mean (SE) [95% CI]	2017 n Mean (SE) [95% CI]	2018 n Mean (SE) [95% CI]
Breast cancer (female)	268 .83 (.04) [.73, .9]	479 .86 (.03) [.79, .92]	509 .86 (.03) [.78, .91]	585 .88 (.03) [.81, .93]	666 .9 (.02) [.84, .94]	642 .9 (.02) [.84, .94]
Triple-negative breast cancer	23 .75 (.1) [.5, .9]	48 .7 (.08) [.52, .83]	105 .89 (.03) [.8, .94]	78 .72 (.06) [.58, .83]	65 .88 (.04) [.76, .95]	67 .87 (.05) [.74, .94]
Breast cancer (male)	7 .76 (.16) [.31, .96]	19 .77 (.1) [.48, .92]	20 .61 (.12) [.34, .83]	8 .59 (.2) [.2, .9]	14 .68 (.13) [.36, .89]	18 .85 (.09) [.57, .96]
Ovarian cancer	47 .77 (.07) [.59, .89]	131 .68 (.06) [.54, .8]	168 .82 (.05) [.7, .89]	168 .76 (.05) [.64, .85]	200 .74 (.05) [.62, .83]	203 .9 (.03) [.82, .95]
Colorectal cancer	16 .75 (.15) [.34, .94]	42 .64 (.17) [.28, .89]	52 .69 (.15) [.34, .91]	56 .8 (.11) [.49, .95]	68 .5 (.17) [.19, .81]	100 .75 (.12) [.42, .92]
Endometrial cancer	4 .66 (.27) [.13, .96]	19 .58 (.19) [.21, .88]	25 .63 (.18) [.25, .89]	31 .71 (.15) [.33, .92]	45 .41 (.16) [.14, .74]	45 .61 (.16) [.26, .87]

CI = confidence interval; SE = standard error.

genetic counselors became involved in reviewing testing results and helping direct appropriate referrals at all five of this study's participating health systems. Thus, genetic counseling referrals increased at TriHealth Cancer Institute and Mount Carmel Health System.

An additional impact on colorectal cancer data comes from an Ohio-wide study called the Ohio Colorectal Cancer Prevention Initiative, which overlapped with our study period. From 2013 to 2016, the initiative enrolled patients with colorectal cancer for a large-scale, universal Lynch syndrome screening protocol that used genetic counseling and testing at no charge to patients. As a result of this initiative, Pearlman et al. found that 16 percent of individuals with colorectal cancer before age 50 had inherited cancer susceptibility.²² Thus, this initiative highlighted the importance of genetic counseling and testing in patients with colorectal cancer diagnosed before age 50.²²

However, our study's colorectal cancer data are potentially skewed because patients enrolled in the Ohio Colorectal Cancer Prevention Initiative and underwent genetic counseling and testing, but may not have been referred to our participating centers' genetics program unless testing identified a pathogenic variant.

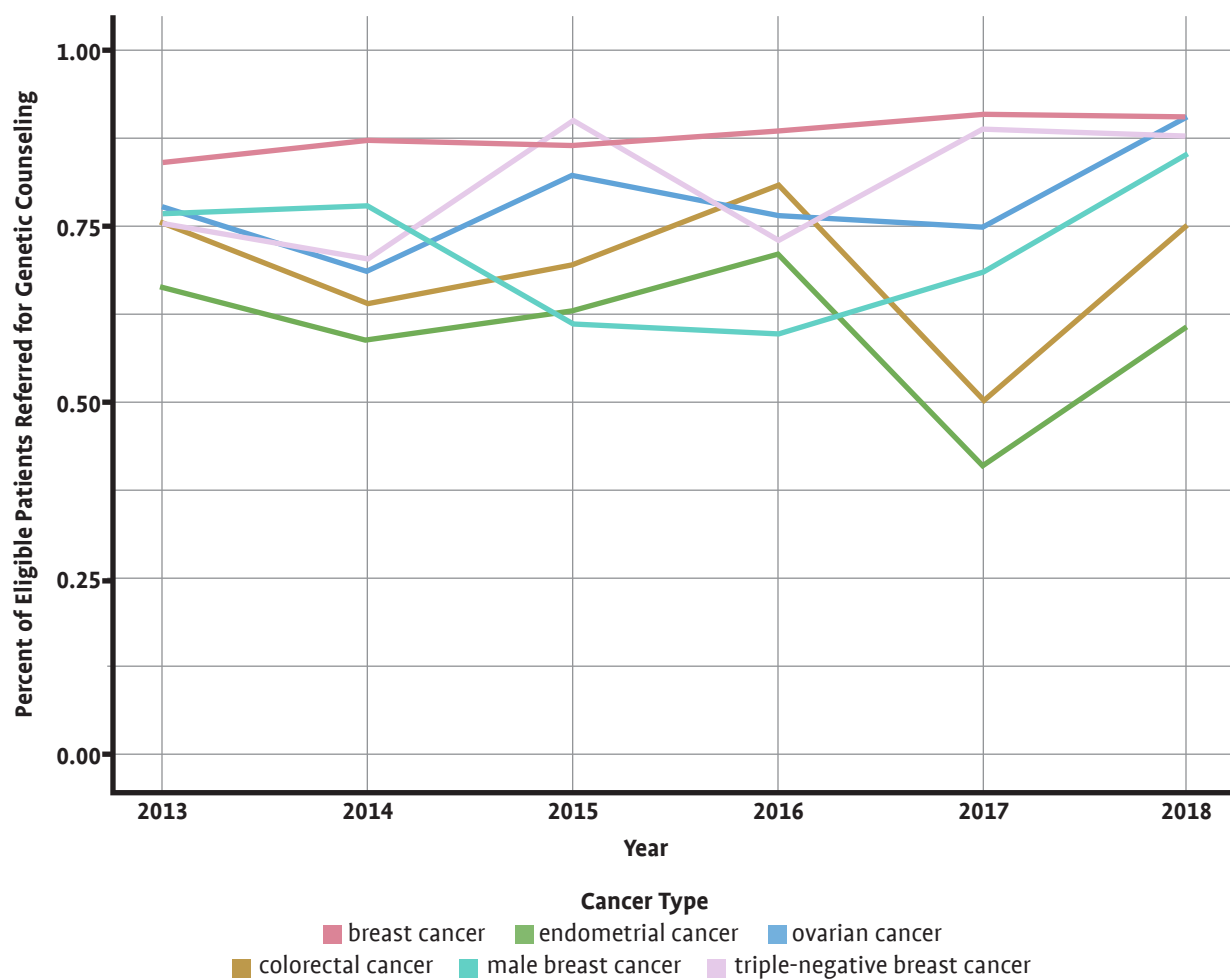
Thus, patients participating in the Ohio Colorectal Cancer Prevention Initiative could have contributed to a lower percentage of eligible patients with colorectal cancer being referred and seen by genetic counseling.

Since the addition of universal tumor screening, genetic counseling involvement in universal tumor screening, and the Ohio Colorectal Cancer Prevention Initiative study publication, our data show a rise in colorectal referrals across all five participating health systems. We also anticipate that colorectal cancer referrals will continue to increase with somatic tumor profiling and as therapeutics are approved for individuals with Lynch syndrome-related colorectal cancer.

A Focus on Endometrial Cancer

The lowest starting referral rate among all cancer types in this study was for endometrial cancer (10 percent), but this disease site also saw an overall increase from 10 percent to 51 percent, which was the greatest increase in referral rates across all cancer sites. This increase could be attributed to participating health systems adding universal tumor screening for Lynch syndrome by immunohistochemistry on all endometrial cancers with genetic

Figure 3. Percentage of Eligible Referred Patients Seen for Genetic Counseling



counselor involvement. Additionally, the James Cancer Hospital had a study called Ohio Prevention and Treatment of Endometrial Cancer (OPTEC) from 2017 to 2020, in which all patients with endometrial cancer were enrolled and received germline and somatic genetic testing. Three centers (the James Cancer Hospital, TriHealth Cancer Institute, and OhioHealth) enrolled patients in the OPTEC study. This reduced overall endometrial cancer referrals to genetics, yet it increased the rate of patients who underwent genetic testing and could explain the inconsistent increase in referrals at these three cancer centers, as patients were not being counted for referrals to genetics.

Study Limitations

This study was performed within five Ohio-based cancer centers that had strong cancer genetics programs within major medical centers and that were led by board-certified genetic counselors. The authors acknowledge that there are cancer centers that do not have genetic counselors on staff and that may face greater barriers to genetic service uptake. Study data may not reflect

genetic counseling data for all cancer centers in Ohio. Our inclusion criteria were based on factors that could be readily identified using cancer registry data (e.g., cancer type, age). Family history of cancer and Ashkenazi Jewish heritage were not indications that could be applied accurately as a criterion for inclusion in the study due to lack of consistency in reporting this type of information and cancer registrars' inability to abstract this data consistently.

These factors contributed to a lack of uniformity within medical records and how data were gathered or stated differed among the participating cancer centers and their registrars. Patients referred to genetic counseling may not have been seen due to a multitude of reasons, including transfer of care to another health system, death before completing appointment, or patients declining their appointments. Whether these data were available to participating cancer centers or how they incorporated this information into their reporting could have differed. Additionally, due to the de-identified nature of the shared data between participating cancer centers, we could not assess if a patient was being captured

as an eligible patient at more than one cancer center. The James Cancer Hospital, OhioHealth, and Mount Carmel Health System are all in Columbus, Ohio; therefore, there is a possibility that patients may have received care at more than one location or sought a second opinion from another center due to their geographic location.

Additionally, genetic testing results can be scattered throughout the EHR and are often scanned in, as opposed to being entered in the EHR as discrete, searchable fields. Thus, tracking patients who had previous genetic counseling and testing at another cancer center was a challenge.

Another limitation of this study was that we did not stratify for triple-negative status in patients with breast cancer diagnosed at ages 18 to 50. To avoid counting twice those individuals with triple-negative breast cancer who overlapped with a breast cancer diagnoses at ages 18 to 50, triple-negative breast cancer was only specifically assessed for those diagnosed at ages 51 to 60. Therefore, we are not able to compare referral rates and appointment uptake for patients with triple-negative breast cancer at ages 18 to 60 versus patients with non-triple-negative breast cancer at ages 18 to 50. We also did not look at income, race, or other demographics to assess the level of health equity in genetic services, as these data were outside the scope of the study. It would be interesting to evaluate demographic factors in future studies on genetic testing and counseling in oncology.

Concluding Thoughts

The experience from these five Ohio-based cancer centers showed that partnering with cancer registrars can provide impactful genetic counseling data and lessons learned to improve referrals and appointment uptake among patient populations at high risk for hereditary cancer. By providing a benchmark, these data allow institutions to compare and use their cancer registry and a referral and appointment model to track their own data trends over time.

This study also revealed challenges with data not capturing patients who were enrolled in research that provided genetic counseling and testing; shared patients between participating institutions; and, most importantly, the inability to track genetic testing information within the EHR.

Furthermore, it is important to share our data with the genetic counseling community as we work to increase the number of individuals who receive these much-needed services. The participating five cancer centers will continue to collect data on all the cancers described above, in addition to other cancers (e.g., prostate and pancreatic cancers), in concordance with NCCN referral guidelines.

Finally, using these data will help further evaluate whether lack of genetic counseling compliance at an institution is at the point of referral or appointment uptake, in order to implement targeted interventions.

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Formulas Used to Calculate Percentages

$$\frac{\text{Eligible patients referred for genetic counseling}}{\text{Number of patients referred for genetic counseling}}$$
$$\frac{\text{Number of eligible patients for that category}}{\text{Number of eligible patients for that category}}$$
$$\frac{\text{Eligible patients seen for genetic counseling}}{\text{Number of patients seen for genetic counseling}}$$
$$\frac{\text{Number of eligible patients for that category}}{\text{Number of eligible patients for that category}}$$
$$\frac{\text{Referred patients seen for genetic counseling}}{\text{Number of patients seen for genetic counseling}}$$
$$\frac{\text{Number of referred patients for that category}}{\text{Number of referred patients for that category}}$$

Ethics Declaration

This study was carried out under approved protocol #2017-05 by the Ohio Department of Health Institutional Review Board. This study includes data provided by the Ohio Department of Health, which should not be considered as an endorsement of this study or its conclusions. Additionally, this publication is supported by the OSU CCTS CTSA grant number UL1TR002733 *from the National Center for Advancing Translational Sciences* and funded by a voucher CTSA citation.

Declarations of Interest and Data Availability

The authors declare no conflict of interest. Data available upon request from the authors, with appropriate institutional approvals.

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