

# Racial Differences in the Utilization of Genetic Counseling Services among Patients in the Hereditary Cancer Network Database

**Background:** Harmful mutations in the Breast Cancer (BRCA), or *BRCA1* and *BRCA2* genes, substantially increase the risk of developing hereditary breast and ovarian cancer (HBOC) over the course of a lifetime. Additionally, a *BRCA1* or *BRCA2* mutation increases the risk for pancreatic and prostate cancer. Variations in *MLH1*, *MSH2*, *MSH6*, *PMS2* or *EPCAM* genes are associated with Lynch syndrome (LS). LS is an inherited disorder that increases the risk for colorectal, endometrial, and ovarian cancer. Genetic counseling with a board certified and/or eligible genetics provider is the recommended first step for anyone with a personal or strong family history of these cancers. The individual may then be referred for genetic testing as appropriate. Early identification of HBOC or LS can help reduce the impact of cancer and save the lives of family members who may also be at risk.

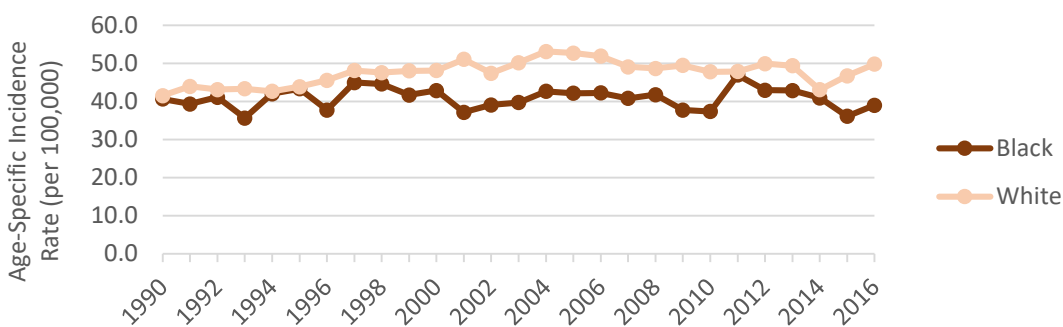
In 2012, it was estimated that over 57 percent of young breast cancer survivors in Michigan had not received genetic services and the top barrier was that no one had ever recommended these services.<sup>1</sup> Recent studies have found that Black women are less likely to receive a physician recommendation for genetic counseling compared to White women, and this difference remained after adjusting for mutation risk.<sup>2</sup> Additionally, the rate of risk reducing surgeries among BRCA carriers has been found to be much lower among Black women compared to White and hispanic women.<sup>3</sup> It is important to examine these racial disparities further to help drive decisions for program planning.

**Methods:** The Hereditary Cancer Network (HCN) Database started collecting non-identifiable information for patients seeking counseling for HBOC in 2008 and for LS starting in 2015. Eighteen clinics have contributed information to this database. This database only contains information on patients who present at a clinic participating in the HCN and therefore may not be representative of all genetic counseling performed in the state. Data was analyzed for 29,367 individuals who sought genetic counseling between 2008 and 2017. This report examined racial differences between White (N=24,201) and Black patients (N=2,217). Frequencies are reported for various characteristics and  $\chi^2$  tests were performed to assess for differences amongst the two races. Incidence and mortality rates are provided by the Michigan Cancer Surveillance Program (MCSP).

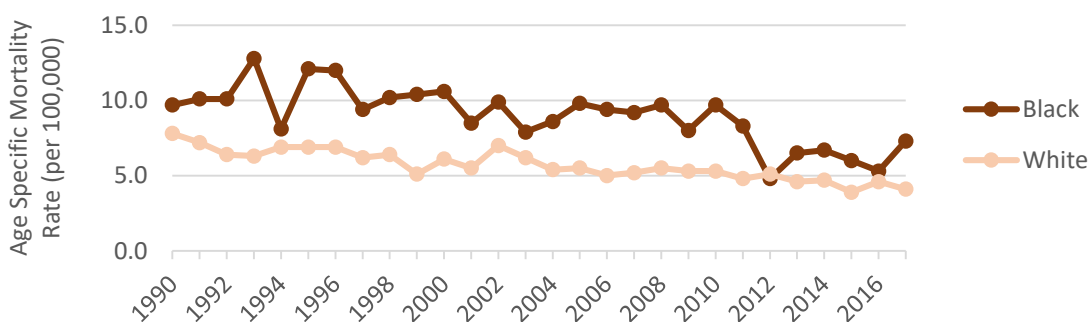
## Incidence and Mortality Rates for Young Breast Cancer by Race

- The overall age-specific incidence rate for young female breast cancer for the state of Michigan is 46.7 per 100,000 females (Data not shown).
- From 1990 to 2016 the age-adjusted incidence rate for White women has been consistently higher compared to Black women.
- From 1990 to 2016 the age-adjusted mortality rate for Black women has been generally higher compared to White women.

**Age-Specific Incidence Rate for Female Breast Cancer Age 50 or Younger by Race from Michigan Cancer Surveillance Program, 1990-2016**

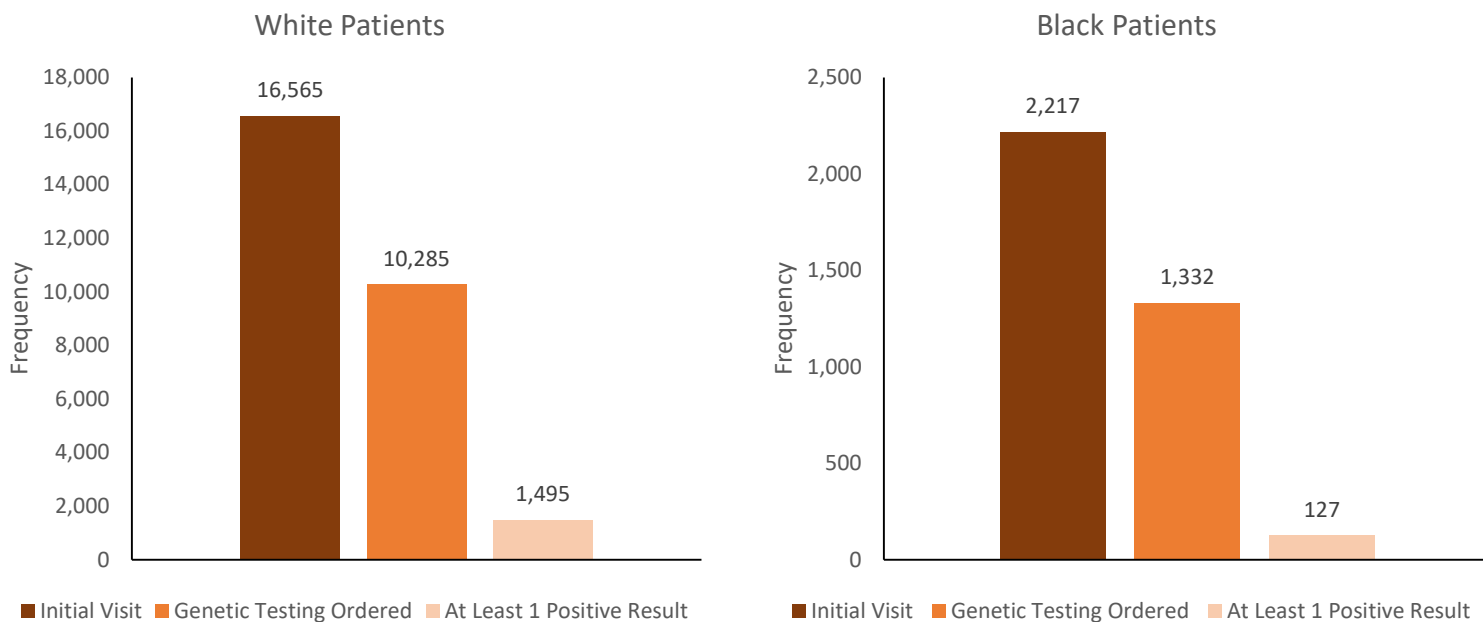


**Age-Specific Mortality Rate for Female Breast Cancer Age 50 or Younger by Race from Michigan Cancer Surveillance Program, 1990-2016**



# Genetic Counseling and Testing by Race in the Hereditary Cancer Network Database

## Genetic Counseling and Testing among Patients in the HCN Database by Race, 2008-2017

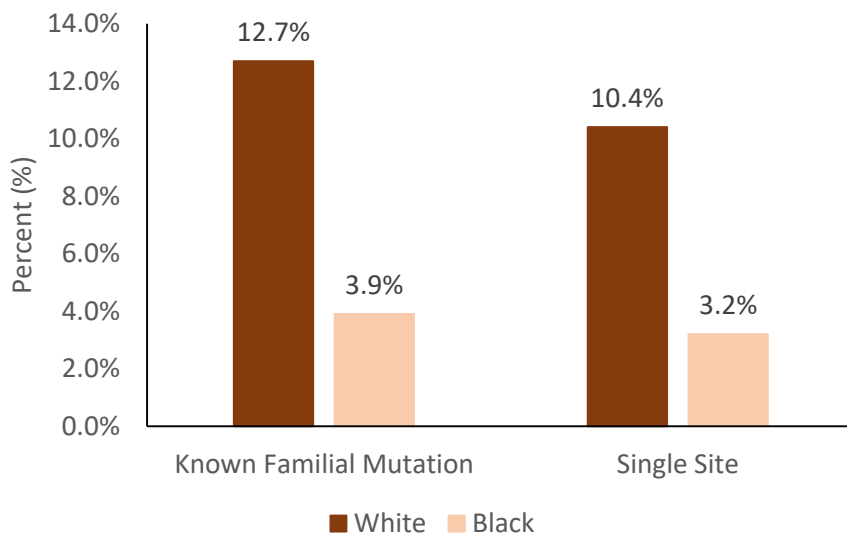


- There was a statistically significant difference between race and having a genetic test ordered.
  - A total of 16,510 (68.2%) White patients who sought genetic counseling had a genetic test ordered.
  - A total of 1,332 (60.1%) Black patients who sought genetic counseling had a genetic test ordered.
- There was a statistically significant difference between race and having a pathogenic mutation.
  - A total of 1,495 (16.0%) White patients who had a genetic test ordered had a pathogenic mutation.
  - A total of 127 (9.7%) Black patients who had a genetic test ordered had a pathogenic mutation.

## Single Site Testing in the Hereditary Cancer Network Database by Race

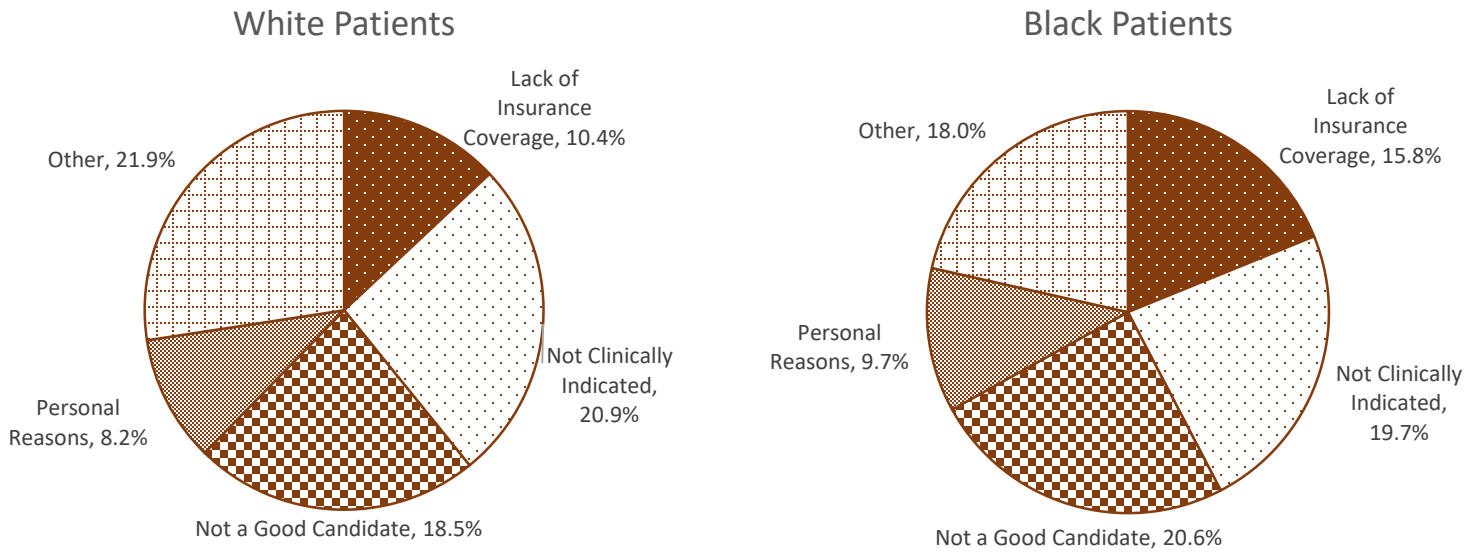
- Having a Known Familial Mutation (KFM) allows a patient to have a single site test ordered instead of a full panel test. Having a single site test is significantly less expensive compared to a full panel (approximately \$100 versus \$2,000).<sup>4</sup>
- Black patients were significantly less likely to report a KFM (3.9%) compared to White patients (12.7%).
- Black patients were significantly less likely to have a single site test ordered (3.2%) compared to White patients (10.4%).

### Having a Known Mutation in the Family and a Single Site Test by Race, 2008-2017



# Reason Why Genetic Testing was not Pursued among Patients in the Hereditary Cancer Network Database by Race

## Reasons why Genetic Testing was not Pursued among Patients in the HCN Database by Race, 2008-2017



- There was a statistically significant difference between race and the reason for not having a test ordered.
  - Black patients in the HCN database were more likely to report lack of insurance coverage as the reason for not having a genetic test (15.8%) compared to White patients (10.4%).
  - White patients in the HCN database were more likely to be classified in the 'other' category as the reason for not having a genetic test ordered (21.9%) compared to Black patients (18.0%). This category includes having been tested already, waiting for results from a family member, being lost to follow-up, etc.

## Genetic Counseling and Testing by Race and Gender among Patients in the Hereditary Cancer Network Database

- The HCN database has a total of 26,989 females and 2,374 males.
- Black males make up only 5.1 percent of the entire database.
- There was a statistically significant difference between gender and having a genetic test ordered.

### Genetic Counseling Visits among Patients in the HCN Database by Race and Gender, 2008-2017

	Black N (%)	White N (%)	Total N (%)
Female	2,106 (95.0)	22,126 (91.4)	26,989 (91.9)
Male	111 (5.1)	2,072 (8.7)	2,374 (8.1)

- Among White men 72.7 percent had a genetic test ordered compared to 67.6 percent of Black men.
- Among White women 67.8 percent had a genetic test ordered compared to 59.7 percent of Black women.

### Genetic Testing Ordered Following the Initial Visit among Patients in the HCN Database by Race and Gender, 2008-2017

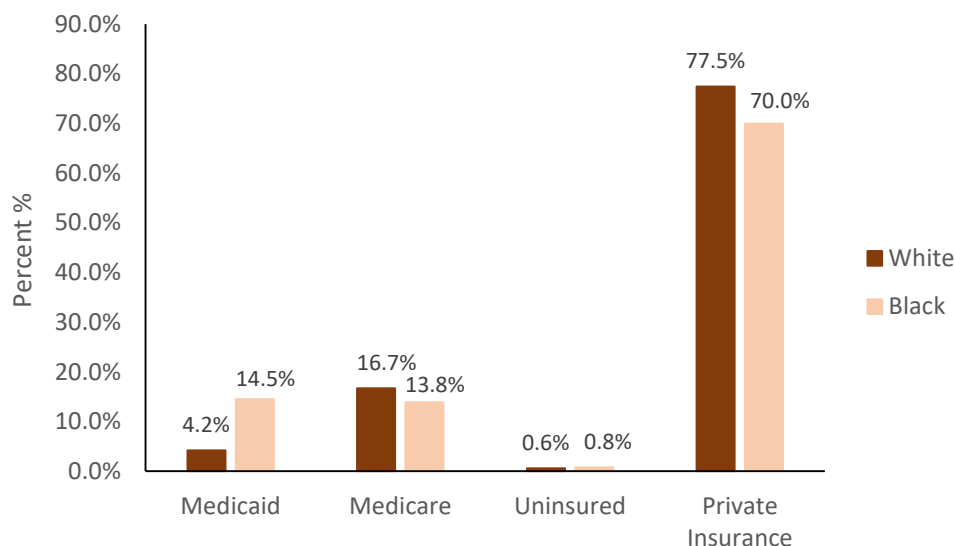
	Black N (%)*	White N (%)*	Total N (%)*
Female	1,257 (59.7)	15,000 (67.8)	18,030 (66.8)
Male	75 (67.6)	1,507 (72.7)	1,712 (72.1)

\* The percent is calculated as the proportion of patients from their respective categories who had a genetic test ordered in the Genetic Counseling Visits table above

# Insurance Status among Patients by Race in the Hereditary Cancer Network Database

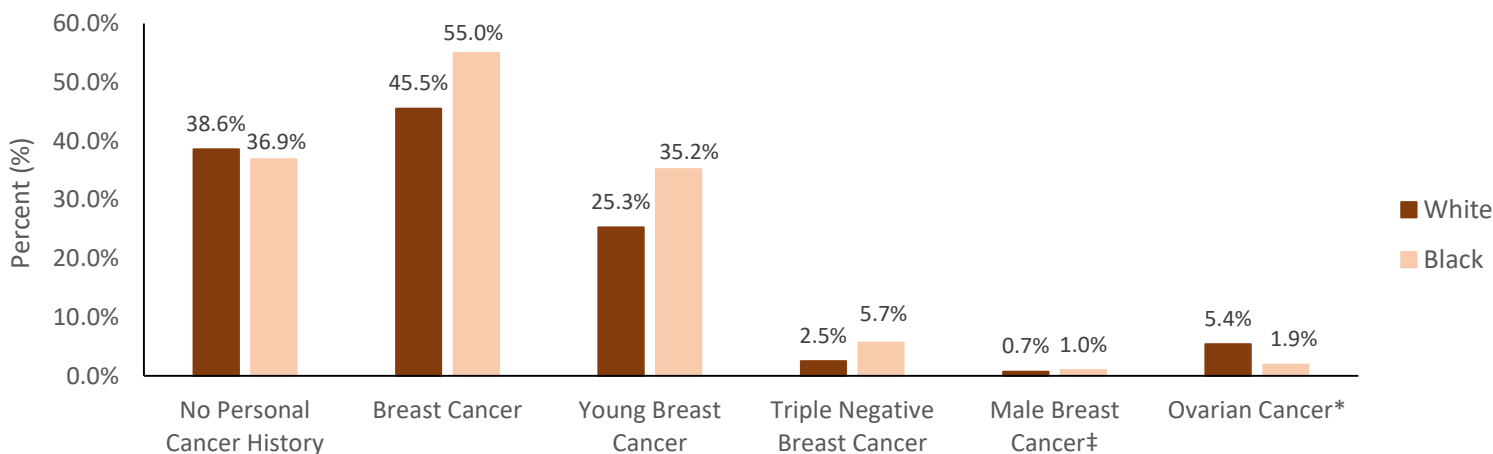
- A total of 24,201 White patients and 2,217 Black patients reported their insurance status.
- There was a significant difference between race and insurance status.
  - Among Black patients, 14.5 percent reported Medicaid as their primary insurer compared to 4.2 percent of White patients.
  - Among White patients, 77.5 percent reported having private insurance compared to 70.0 percent of Black patients.

Insurance Status among Patients in the HCN Database by Race, 2008-2017



# Cancer History among Patients by Race in the Hereditary Cancer Network Database

Personal History of Cancer among Patients in the HCN Database by Race, 2008-2017

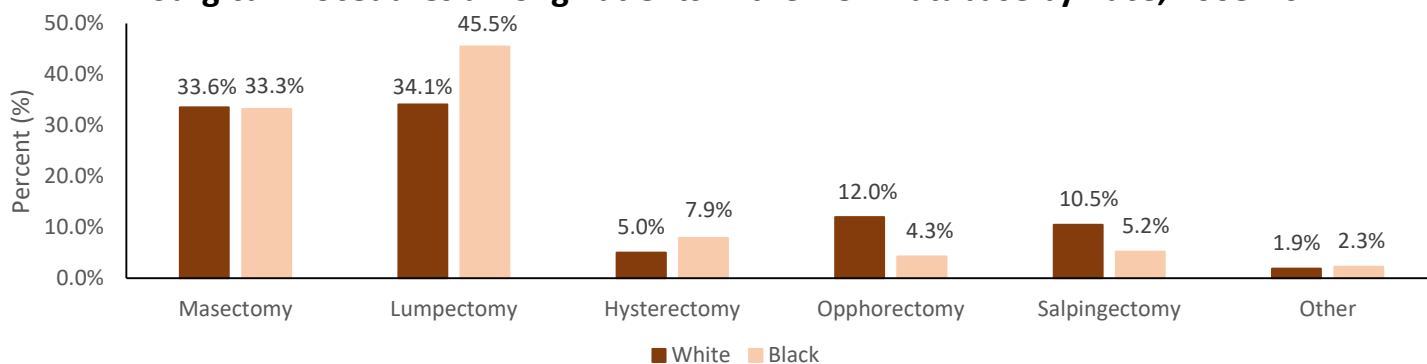


‡ Only males included in the denominator  
 \*Only females included in the denominator

- Among patients in the HCN database, 38.6 percent of White patients and 36.9 percent of Black patients reported having no personal history of any type of cancer.
- A higher proportion of Black patients reported having breast cancer (55.0%) compared to White patients (45.5%).
  - Of those with breast cancer, a higher proportion of Black patients reported having breast cancer diagnosed at 50 or younger (58.2%) compared to White patients (51.3%).
- Of those diagnosed with breast cancer, a higher proportion of Black patients reported having triple negative cancer (5.7%) compared to White patients (2.5%).
  - Data collection for this field began in 2015.
- A higher proportion of White patients reported having a history of ovarian cancer (5.4%) compared to Black patients (1.9%).

# Surgical Procedures in Patients from the HCN Database

## Surgical Procedures among Patients in the HCN Database by Race, 2008-2017



- Among patients in the HCN database, there was a statistically significant difference between races and reporting surgeries, with 27.7 percent of White patients and 20.2 percent of Black patients reported having a surgery related to Hereditary Breast or Ovarian Cancer.
- There was a statistically significant difference in the types of surgeries patients received by race. Having a lumpectomy was the most common surgery reported with 45.5 percent of Black patients and 34.1 percent of White patients reporting having the procedure.
- There was a statistically significant difference in the reported reason for surgery (Data not shown).
  - Of people who had surgery, 4.3 percent of Black patients and 8.5 percent of White patients reported they had a prophylactic surgery.

## Summary

**Methods:** Incidence and Mortality data was obtained from Michigan Cancer Surveillance Program (MCSP) and Vital Records while genetic counseling and testing information was analyzed using data obtained from the Hereditary Cancer Network. Significance was based on chi-square analyses with a significance value set to be  $p < 0.05$ .

**Conclusion:** In this analysis, a sample of patients seeking genetic counseling in Michigan is used to highlight potential racial disparities. Black patients are underrepresented in this database, especially Black men. Black patients were less likely to have a genetic test ordered, with the most frequent reason for not having a test being due to insurance coverage. Over the last 15 years, Black patients diagnosed with breast cancer at a young age have consistently had a higher mortality rate compared to White patients. Addressing the racial disparity in genetic counseling and testing is critical because this could help prevent or lessen the burden of young breast cancer and several other cancers. In turn, by preventing or lessening the burden of these cancers the mortality rate could also decrease. Several barriers need to be addressed, starting with ensuring proper referrals to genetic counselors are being made for people of all races. More education and awareness about genetic counseling, as well as the insurance coverage for counseling, is of utmost importance in addressing these racial disparities.

### For More Information:

Visit [www.Michigan.gov/hereditarycancer](http://www.Michigan.gov/hereditarycancer) to learn more about hereditary cancers

Visit [www.Michigan.gov/cge](http://www.Michigan.gov/cge) to view more data on hereditary cancers

### Suggested Citation:

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**HCN Clinical Partners:** Beaumont Cancer Genetics Program, Beaumont Center for Hematology and Oncology, Henry Ford Health System Cancer Genetics Program, Karmanos Cancer Institute Cancer Genetic Counseling Service, InformedDNA Telephone Genetic Counseling Services, Mid-Michigan Hereditary Cancer Clinic, Michigan State University Hereditary Cancer Program, Marquette General Hematology/Oncology, Munson Cancer Genetics Clinic, Sparrow Cancer Center, Spectrum Health Cancer Genetics Program, St. Joseph Mercy Hospital Cancer Genetics Program, St. John Providence Health System Cancer Genetics Program (Southfield and Grosse Pointe Woods, MI), St. Mary Health Care Lacks Cancer Center Genetics (Grand Rapids, MI), St. Mary Mercy Our Lady of Hope Cancer Center (Livonia, MI), University of Michigan Breast and Ovarian Cancer Risk and Evaluation Program, University of Michigan Cancer Genetics Clinic, West Michigan Cancer Center

### References:

1. Anderson, B et al. Barriers and Facilitators for Utilization of Genetic Counseling and Risk Assessment Services in Young Female Breast Cancer Survivors. *J Cancer Epidemiology*.
2. Jones et al, Predictors of BRCA1/2 testing among Black women with breast cancer: Population-based study. *Cancer Medicine* 2017, 6(7):1787-1798.
3. Cragun et al., Racial Disparities in BRCA Testing and Cancer Risk Management Across a Population-Based Sample of Young Breast Cancer Survivors. *Cancer* 2017, 123:2497-505
4. What is the cost of genetic testing, and how long does it take to get the results? - Genetics Home Reference <https://ghr.nlm.nih.gov/primer/testing/costresults>