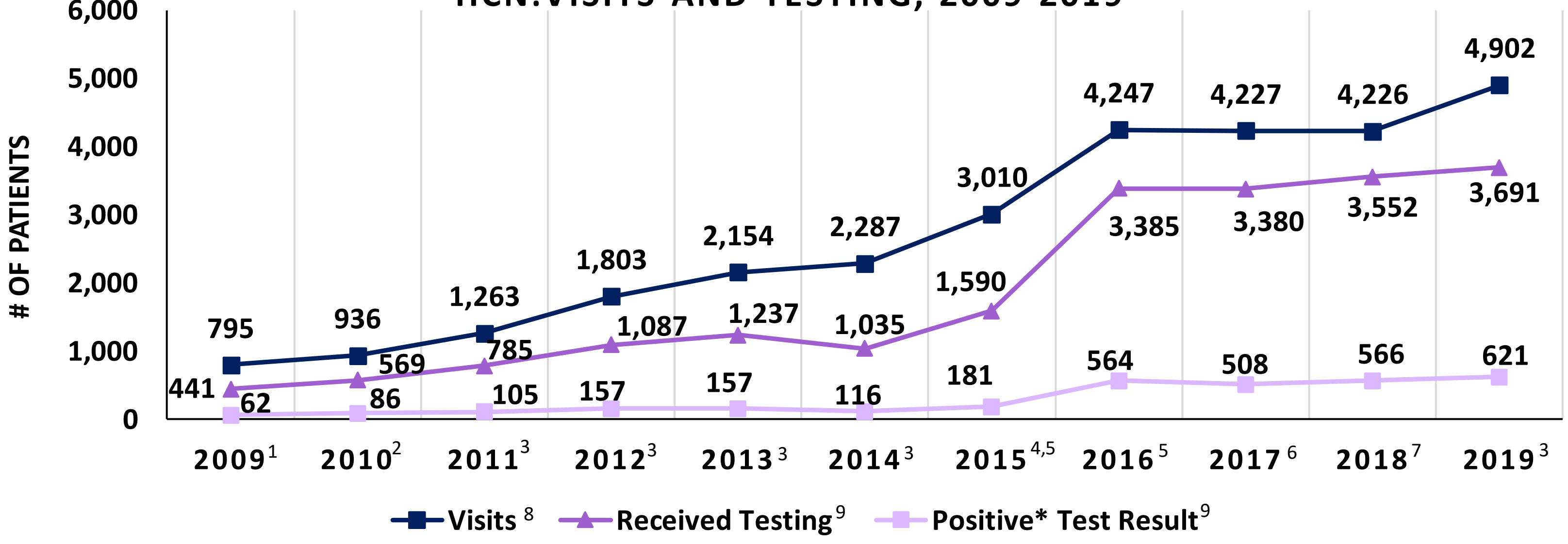
Surveillance Data from the Hereditary Cancer Network (HCN) Database, 2016-2019

The following data were collected from the Michigan Department of Health and Human Services (MDHHS) Hereditary Cancer Network (HCN) database between **January 1, 2016, and December 31, 2019**. Nine partner institutions currently contribute de-identified data on all Breast Cancer (BRCA) gene-related and Lynch syndrome (LS)-gene related genetic counseling patient visits.

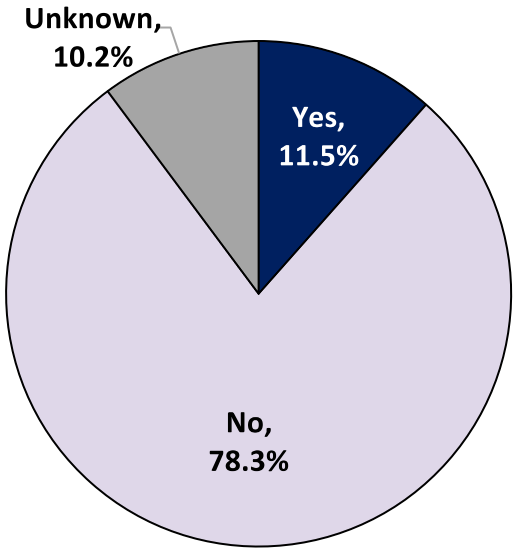
This report is a summary of the patient populations seen at **partner clinics that have provided patient visit data for patients seen between 2016 and 2019** that are at risk for either Hereditary Breast or Ovarian Cancer Syndrome (HBOC) or LS-related cancers**.**

There was a total of **17,763** records for 2016-2019, data were extracted February 1, 2022, and includes: demographic information, personal and family history of hereditary cancer, and genetic testing. Please contact Jessica Fritzler at **FritzlerJ1@Michigan.gov** for any questions.

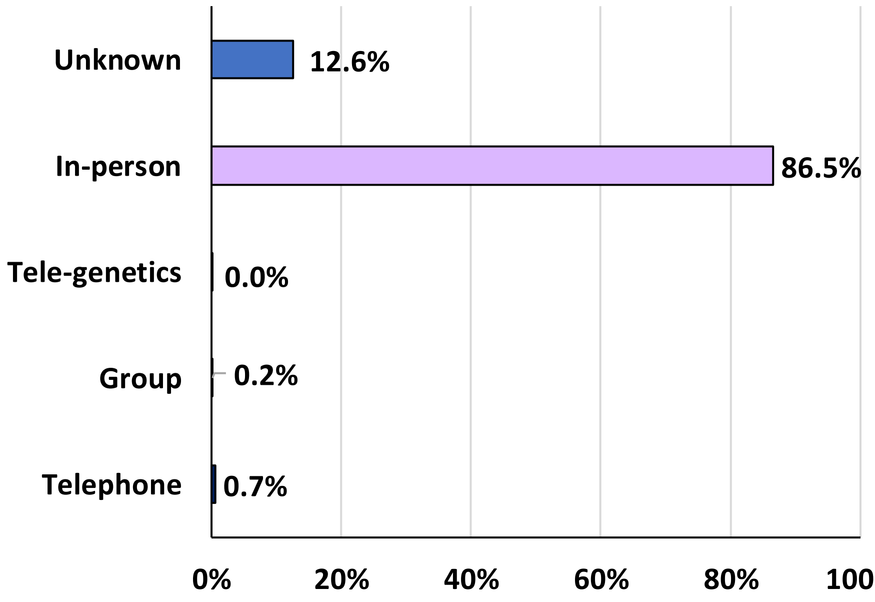
HCN:VISITS AND TESTING, 2009-2019



Cascade Screening, 2016-2019



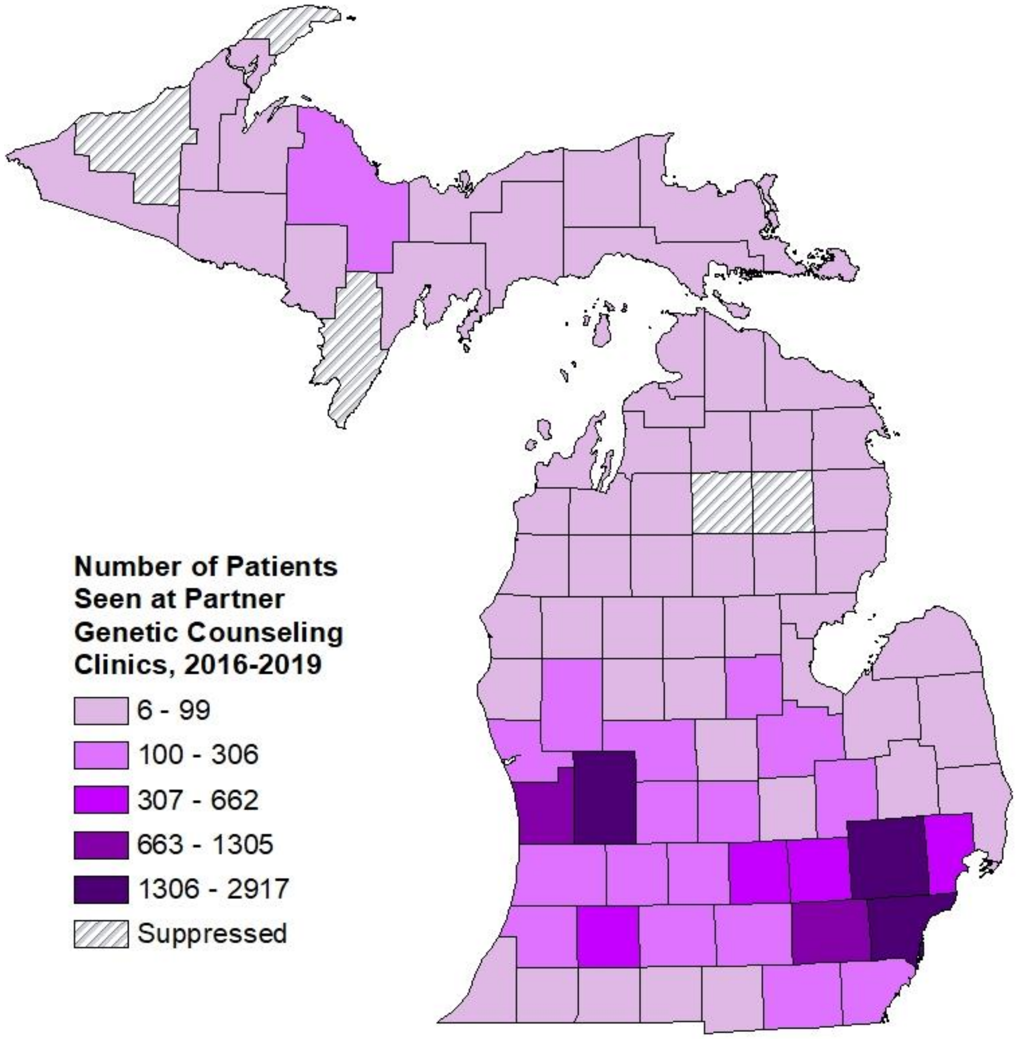
Type of Counseling, 2016-2019



---

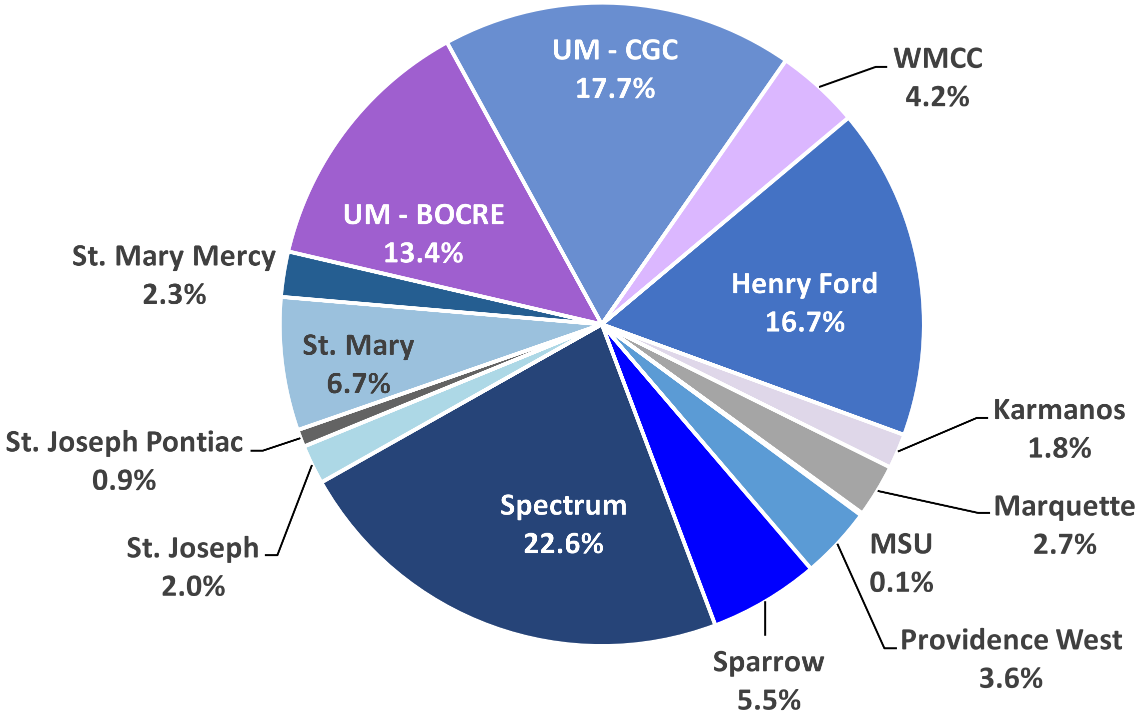
[1] At this time, 6 of the 14 clinics entered data into the BRCA Clinical Network Database. [2] At this time, 7 of the 14 clinics entered data into the BRCA Clinical Network Database. [3] At this time, 9 of the 14 clinics entered data into the BRCA Clinical Network Database. [4] Data for 2015 are incomplete. [5] At this time, 13 of the 14 clinics entered data into the BRCA Clinical Network Database. [6] Data for 2017 are incomplete . [7] At this time, 8 of the 14 clinics entered data into the HCN database. [8] Visit dates before 2015 were pulled from the BRCA Clinical Network Database, the precursor to the HCN Database. Visit date is defined as the initial visit the patient made for genetic counseling with the clinic. [9] Previous to 2015, data were collected on BRCA testing only. As of 2015, data on testing were collected on 19 clinically actionable genes. *Positive test result refers to a genetic test result being Pathogenic or Likely Pathogenic.

Surveillance Data from the Hereditary Cancer Network (HCN) Database: Location & Clinic Participation, 2016-2019



- Most genetic counseling clinics in Michigan that are partnered with the Cancer Genomics Program are in Wayne and Oakland counties, so that is where most patients are receiving these services.
- The second largest genetic counseling clinic that enters data into the HCN database, Spectrum, is in Kent County, so a high proportion of patients are receiving cancer genetic services in that region.

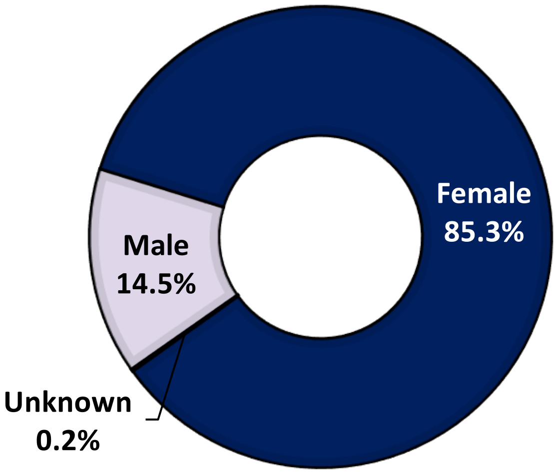
Percent of Cases found in the HCN, 2016-2019*



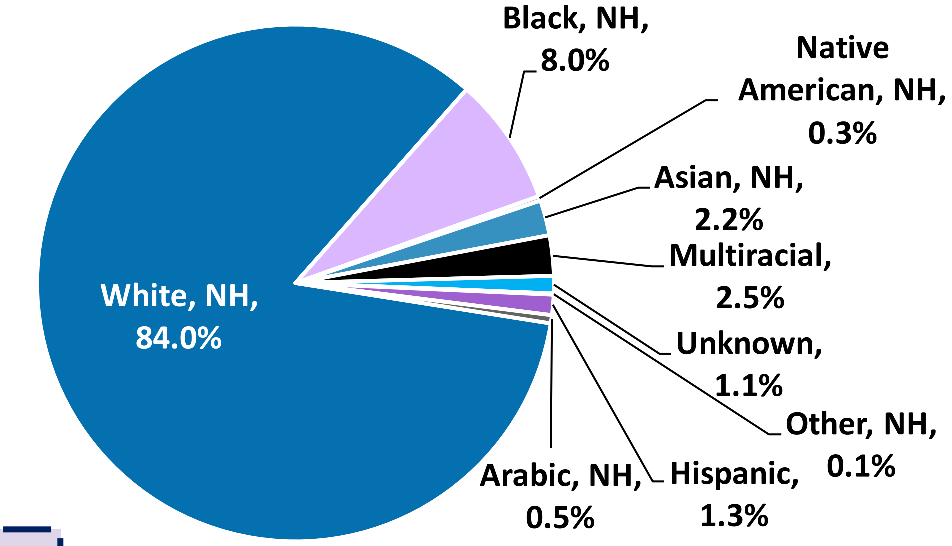
*See page nine for full names of each clinic partner

Hereditary Cancer Network Database: Demographics, 2016-2019 [10]

Gender, 2016-2019

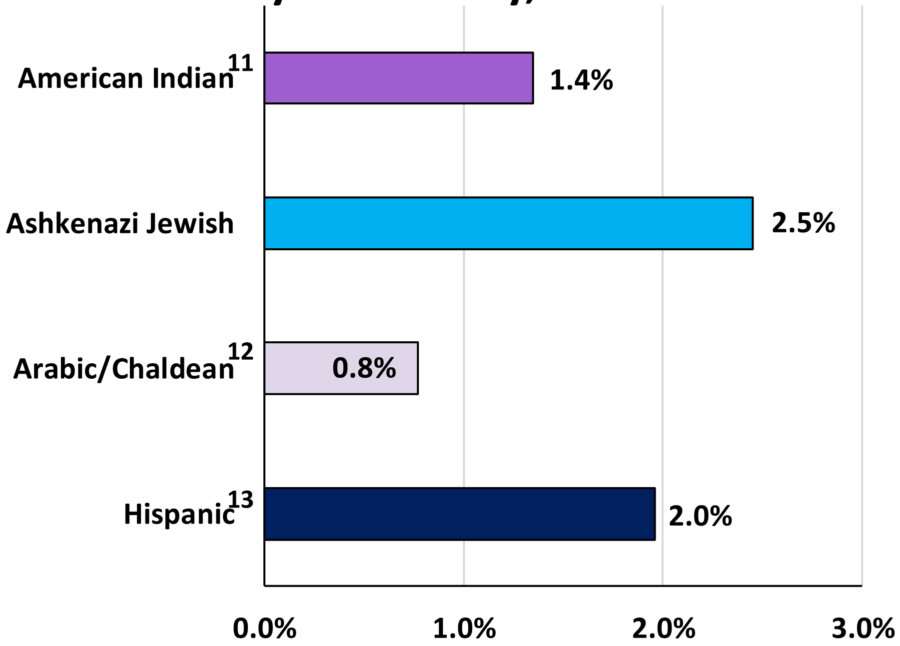


Race, 2016-2019

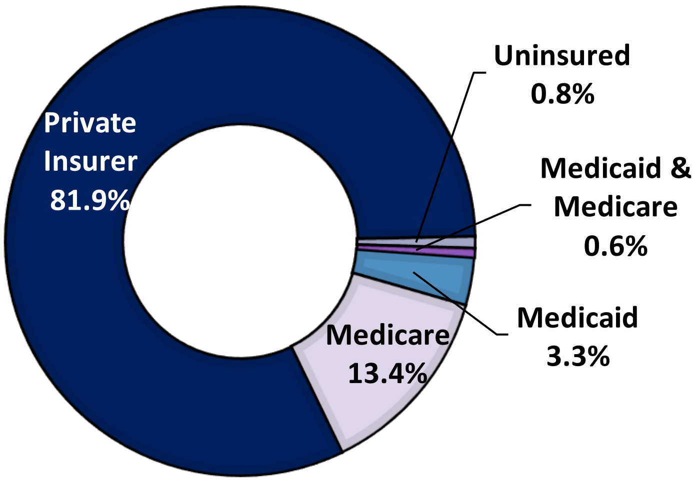


- ➢ Most patients in the HCN Database are female (**85.3%**) and identify as white, non-Hispanic (**84.0%**).
- ➢ Most patients in the HCN Database are between 56 and 65 years of age (**24.0%**), between 46 and 55 years of age (**23.6%**) or are older than 65 years of age (**20.9%**).
- ➢ Only **2.5%** of patients in the HCN Database identify as Ashkenazi Jewish.
- ➢ Most patients in the HCN Database are insured through a private insurer (**81.9%**), and there are more than four times as many patients who are on Medicare (**13.4%**) compared to Medicaid (**3.3%**).

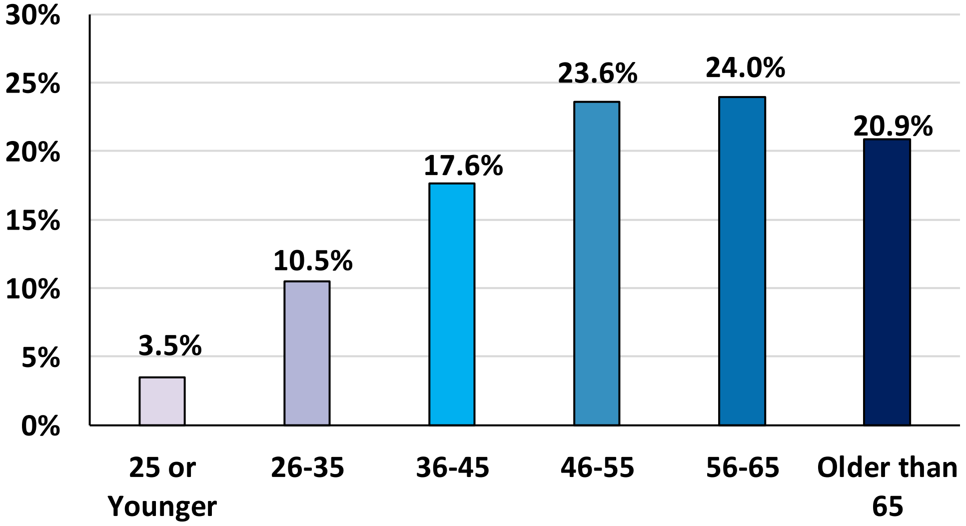
Ethnicity & Ancestry, 2016-2019



Insurance, 2016-2019



Age at First Visit, 2016-2019

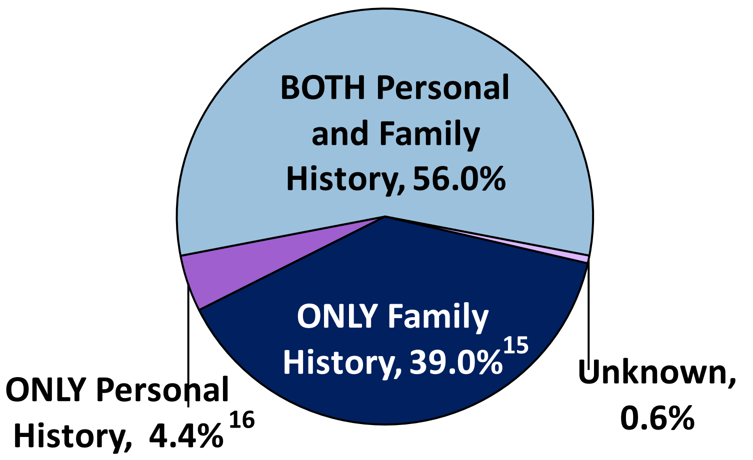


---

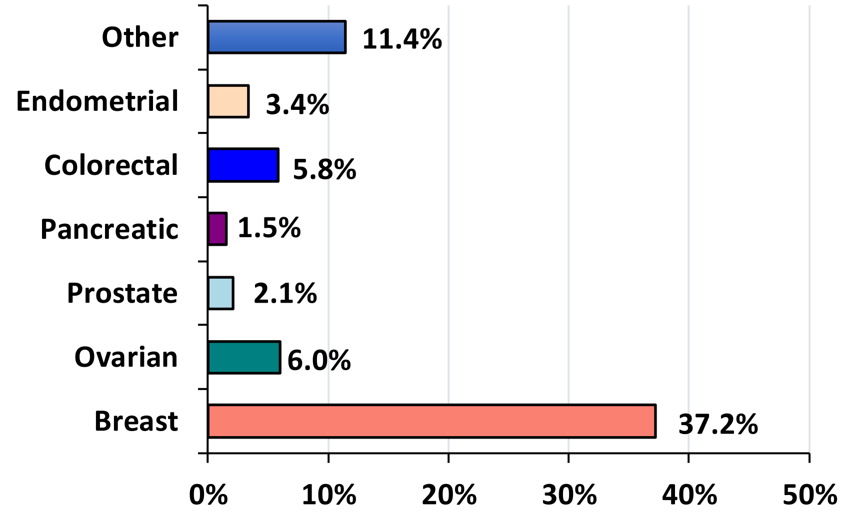
[10] Data for 2017 is incomplete. [11] Native American category includes those who identify as Native American (0.3%), Black and Native American (0.2%), white and Native American (0.6%), Hispanic and Native American (<0.03%), and 3 or more races where Native American was indicated (0.3%). [12] Arabic/Chaldean category includes those who identify as Arab (0.5%), and white and Arab (0.2%). [13] Hispanic category includes those who identify as Hispanic (1.3%), white and Hispanic (0.6%), Hispanic and Black (<0.03%), Hispanic and Arab (<0.03%), Hispanic and Asian (<0.03%), Hispanic and Native American (<0.03%) and 3 or more races where Hispanic was indicated (0.07%).

Hereditary Cancer Network Database: Cancer Surveillance, 2016-2019[14]

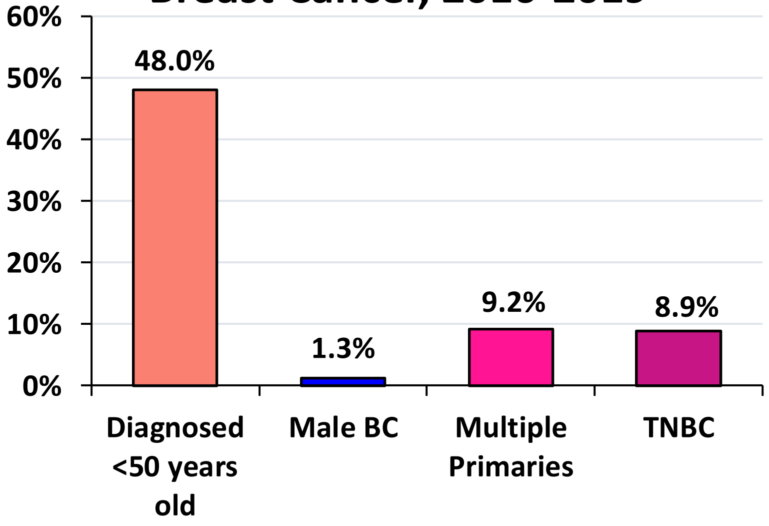
History of Cancer, 2016-2019



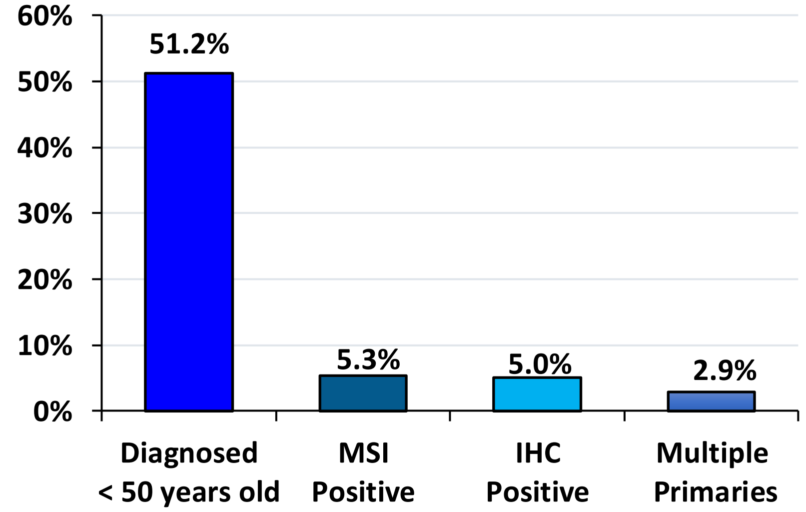
Type of Cancer among Patients, 2016-2019[17]



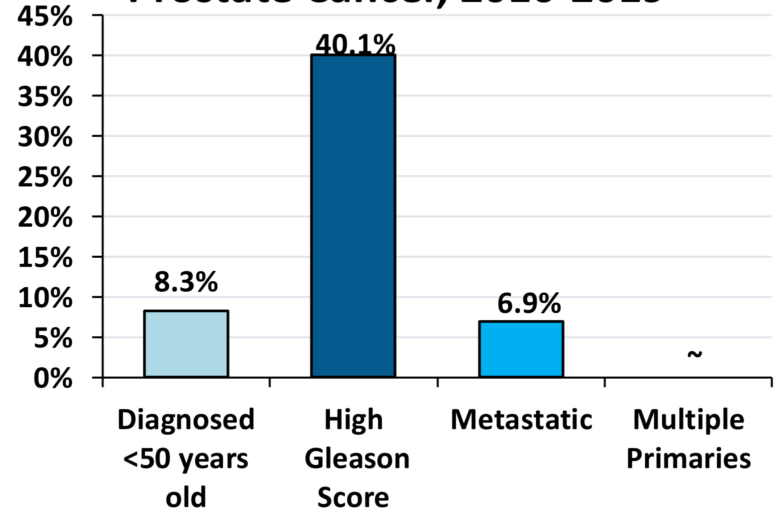
Breast Cancer, 2016-2019[18]



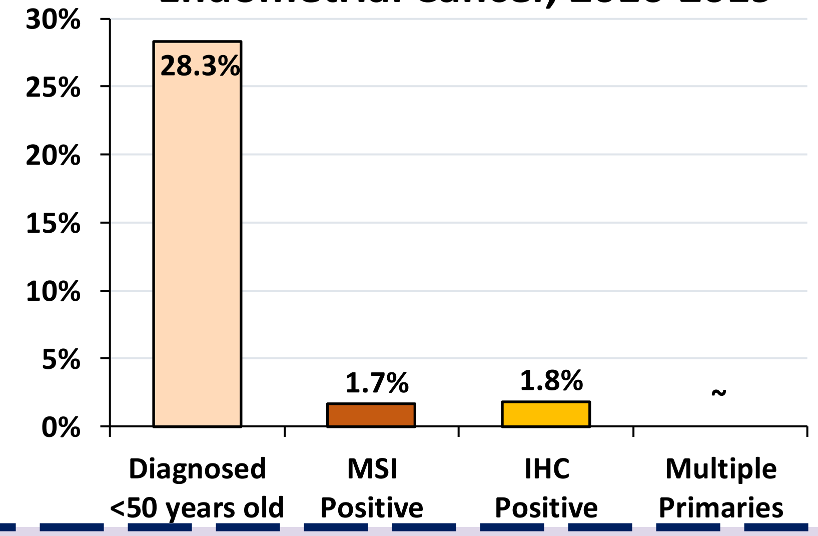
Colorectal Cancer, 2016-2019[19]



Prostate Cancer, 2016-2019[20]



Endometrial Cancer, 2016-2019[21]



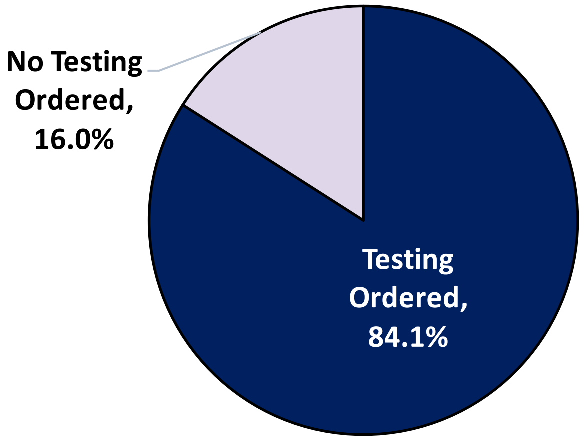
- **56.0%** of patients in the HCN Database have a personal and family history of cancer.
- **Almost half** of those with breast cancer had a diagnosis occur before the age of 50.
- **5.8%** of patients in the HCN Database had colorectal cancer at least once, of those, **51.2%** were diagnosed at age 50 or under.
- **2.1%** of patients in the HCN Database had prostate cancer at least once, of those **8.3%** were diagnosed at age 50 or under.
- **3.4%** of patients in the HCN Database had endometrial cancer at least once, of those **28.3%** were diagnosed at age 50 or under.

---

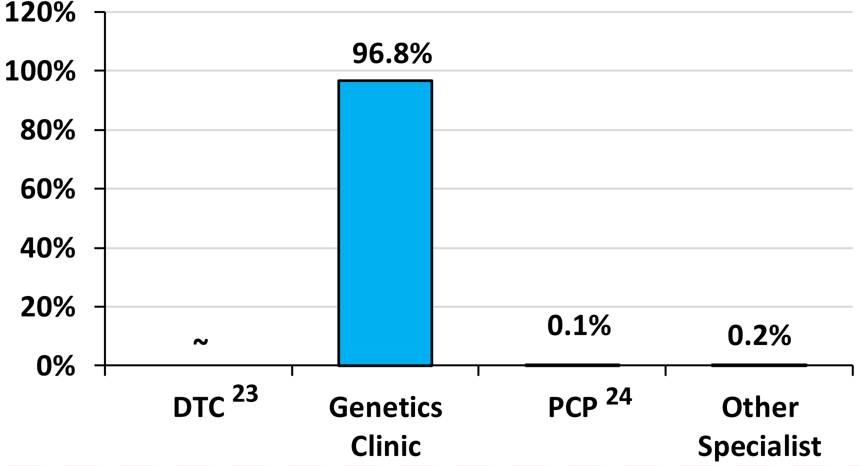
[14] Data for 2017 is incomplete. [15] No personal history of breast, ovarian, prostate, pancreatic, endometrial, or colorectal cancer but has at least one family member with a history of one of these cancers. [16] No family history of breast, ovarian, prostate, pancreatic, endometrial, or colorectal cancer but has a personal history of one of these cancers. [17] Type of cancer among patients who have a personal history of cancer. [18] Abbreviations: Young Breast Cancer (YBC), Male Breast Cancer (Male BC), and Triple Negative Breast Cancer (TNBC). [19,21] Abbreviations: Microsatellite instability (MSI) positive and Immunohistochemistry (IHC) positive. [20] Definitions: High Gleason Score is a Gleason score of 7 or greater and Metastatic is defined as prostate cancer diagnosed at a regional or distant stage. ~Data are suppressed if count is less than 6.

Hereditary Cancer Network Database: Genetic Testing, 2016-2019 [22]

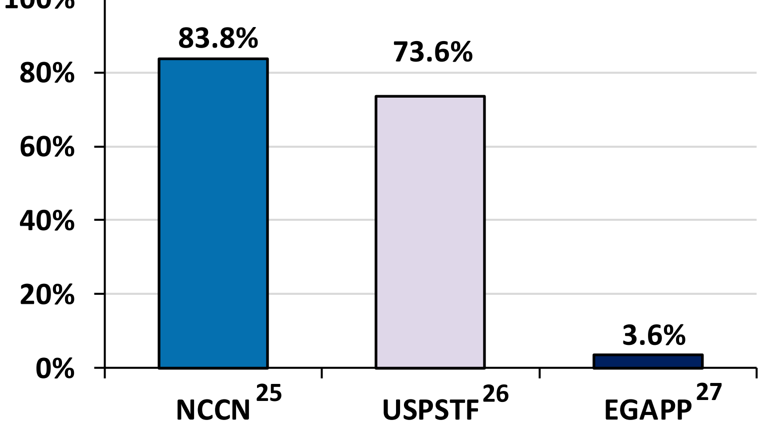
Genetic Testing, 2016-2019



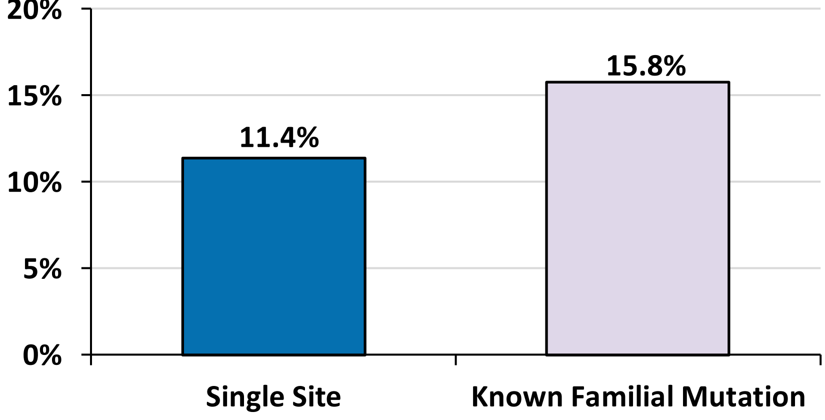
Who Ordered Genetic Testing, 2016-2019



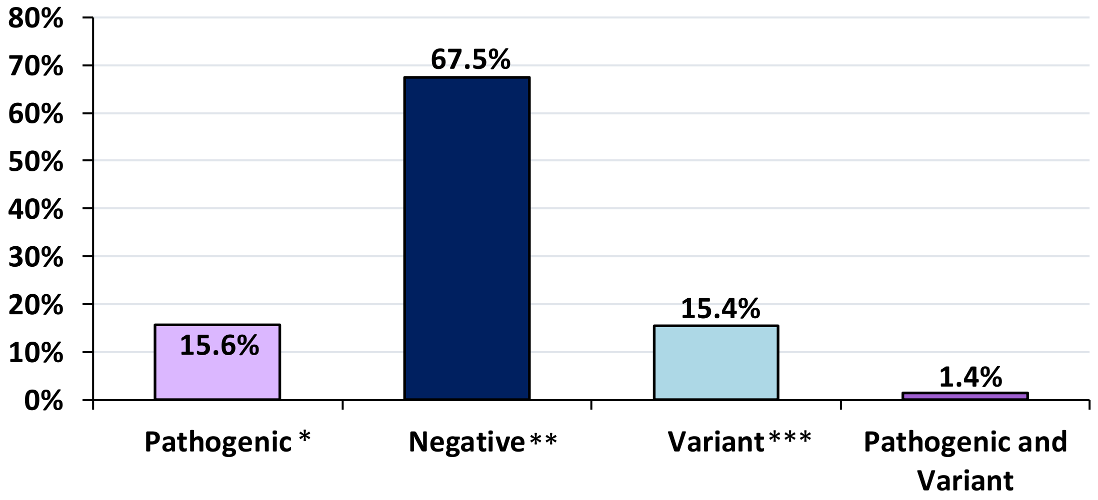
Patients Who Met Guidelines for Testing, 2016-2019



Characteristics of Genetic Testing Performed, 2016-2019



Genetic Testing Results, 2016-2019



BRCA 1 or 2 positive

841 (5.6%)

HBOC related gene positive

882 (5.9%)

MMR gene positive

428 (2.9%)

LS related gene positive

305 (2.0%)

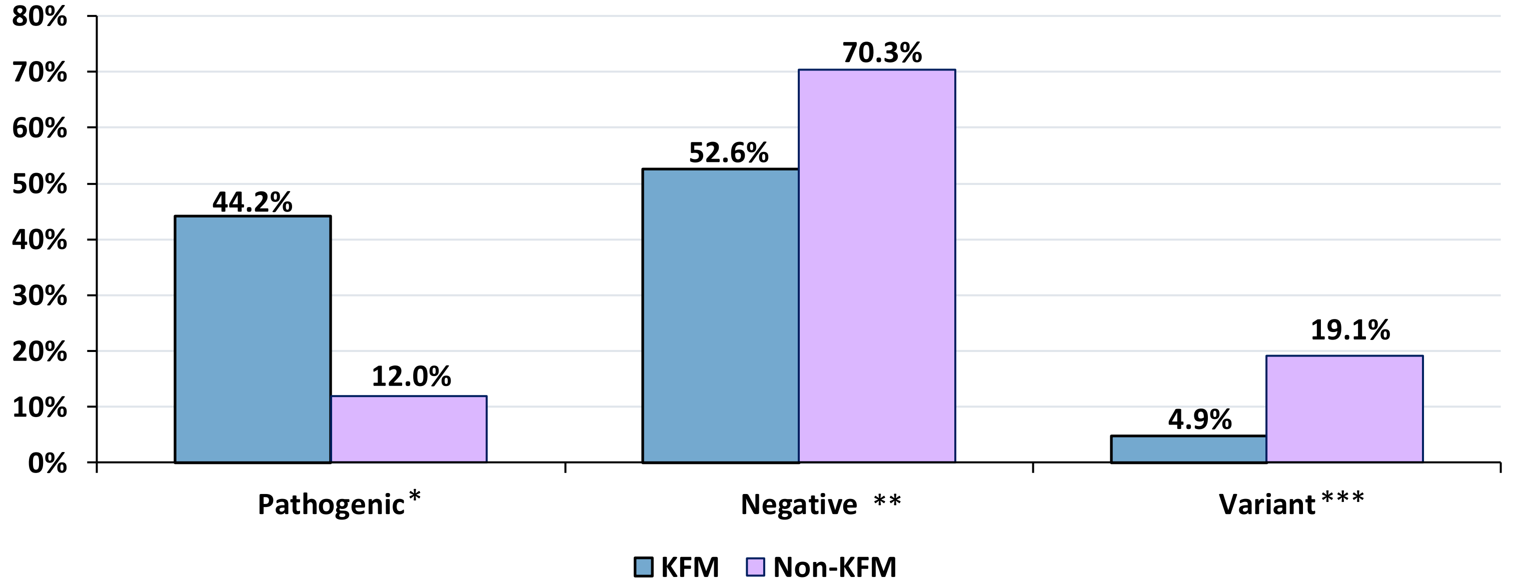
- **84.1%** of patients in the HCN database received genetic testing.
  - Of those who received genetic testing, **15.6%** had at least one positive result.
- **15.8%** of patients in the HCN Database had a known familial mutation before the visit.
- Of those with a positive genetic test result, **11.5%** had a positive result in a gene related to HBOC and **4.9%** had a positive result in a gene related to LS.
- **83.8%** of those in the HCN database met NCCN criteria for genetic testing for HBOC or LS, **73.6%** met USPSTF criteria for genetic testing for HBOC, and **3.6%** of colorectal and endometrial cancer patients met EGAPP guidelines for genetic testing for LS.

---

[22] Data for 2017 is incomplete. [23] DTC = Direct to Consumer DNA test. [24] PCP = Primary Care Physician. [25] Abbreviation: National Comprehensive Cancer Network (NCCN); guidelines for who should receive genetic testing for HBOC or LS. [26] Abbreviation: United States Preventative Services Task Force (USPSTF); guidelines for who should receive genetic testing for HBOC-related cancers only. [27] Abbreviation: Evaluation of Genomic Applications in Practice and Prevention (EGAPP); guidelines for who should receive genetic testing for LS-related cancers only. * Pathogenic/Positive result refers to a genetic test result being Pathogenic or Likely Pathogenic. ** Negative result refers to a genetic test result being Benign, Likely Benign or Not Clinically Significant. *** Variant result refers to a result that is classified as a Variant of Unknown Significance (VUS).

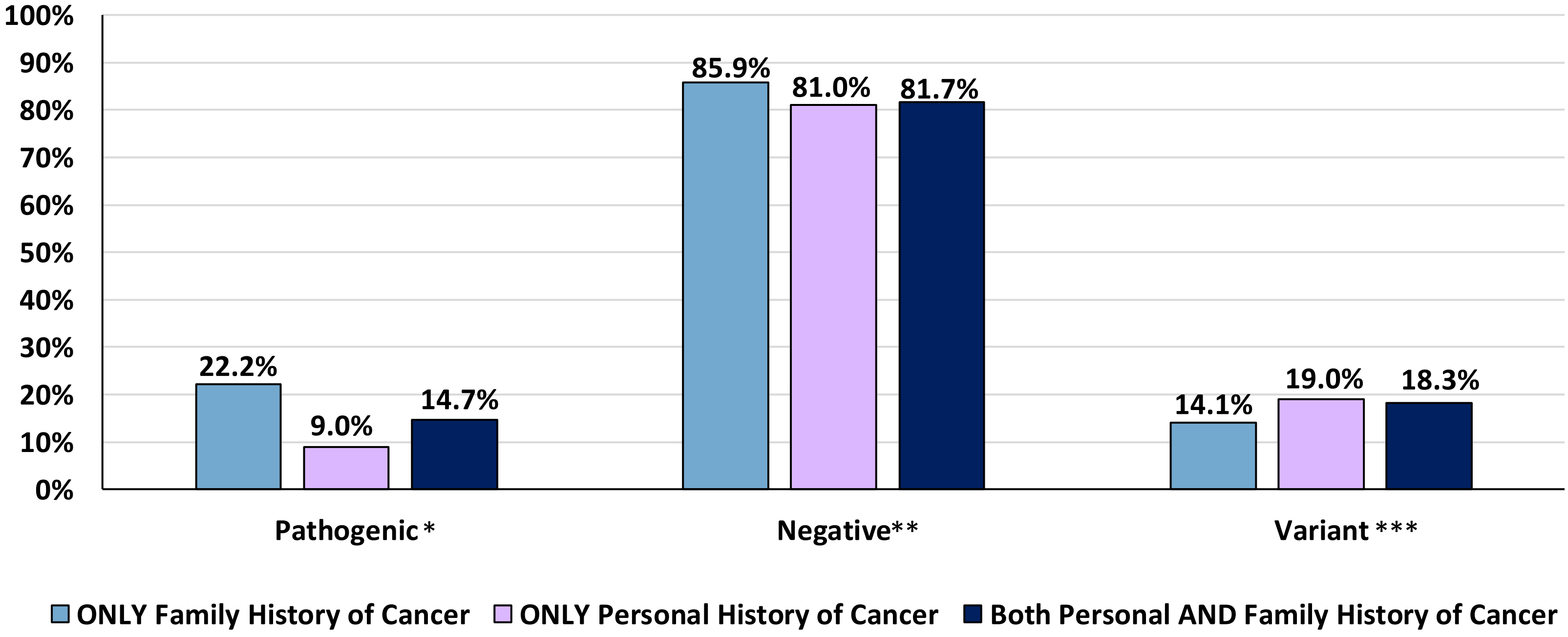
Hereditary Cancer Network Database: Genetic Testing Continued, 2016-2019 [28]

Genetic Testing Results Among Those with a Known Familial Mutation, 2016-2019



- **Forty-four percent** of patients in the HCN database with a known familial mutation (KFM) had a pathogenic genetic test result, compared to **12.0%** of those who did not have a known familial mutation.
- **Five percent** of patients in the HCN database with a KFM had a variant of uncertain significance genetic test result for HBOC, compared to **19.1%** of those who did not have a KFM.

Genetic Test Results Among Those with Personal or Family History of Cancer, 2016-2019



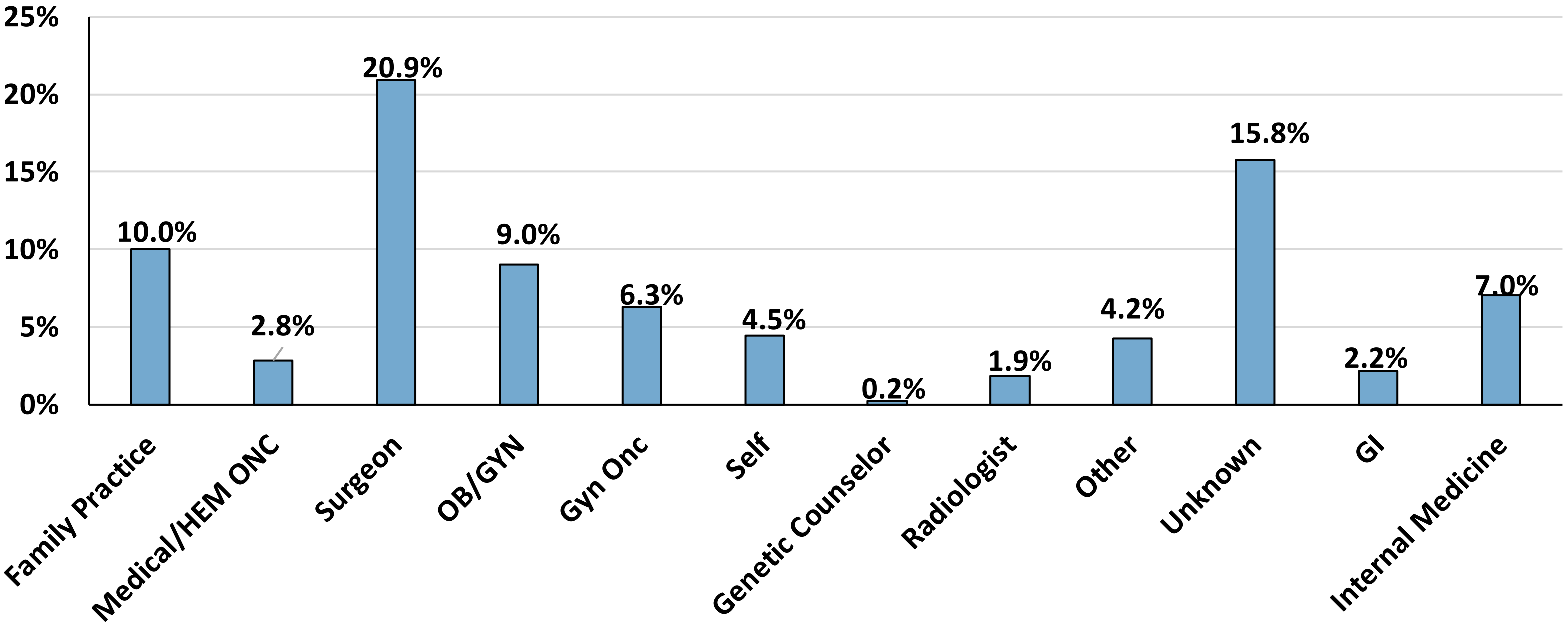
- **Fifteen percent** of patients in the HCN database with a personal and family history of cancer had a pathogenic genetic test result, compared to **9.0%** of those with only a personal history and **22.2%** of those with only a family history of cancer.
- **Eighteen percent** of patients in the HCN database with a personal and family history of cancer had a variant of uncertain significance genetic test result, compared to **19.0%** of those with only a personal history and **14.1%** of those with only a family history of cancer.

---

[28] Data for 2017 is incomplete. * Pathogenic result refers to a genetic test result being Pathogenic or Likely Pathogenic. ** Negative result refers to a genetic test result being Benign, Likely Benign or Not Clinically Significant. *** Variant result refers to a result that is classified as a Variant of Unknown Significance (VUS).

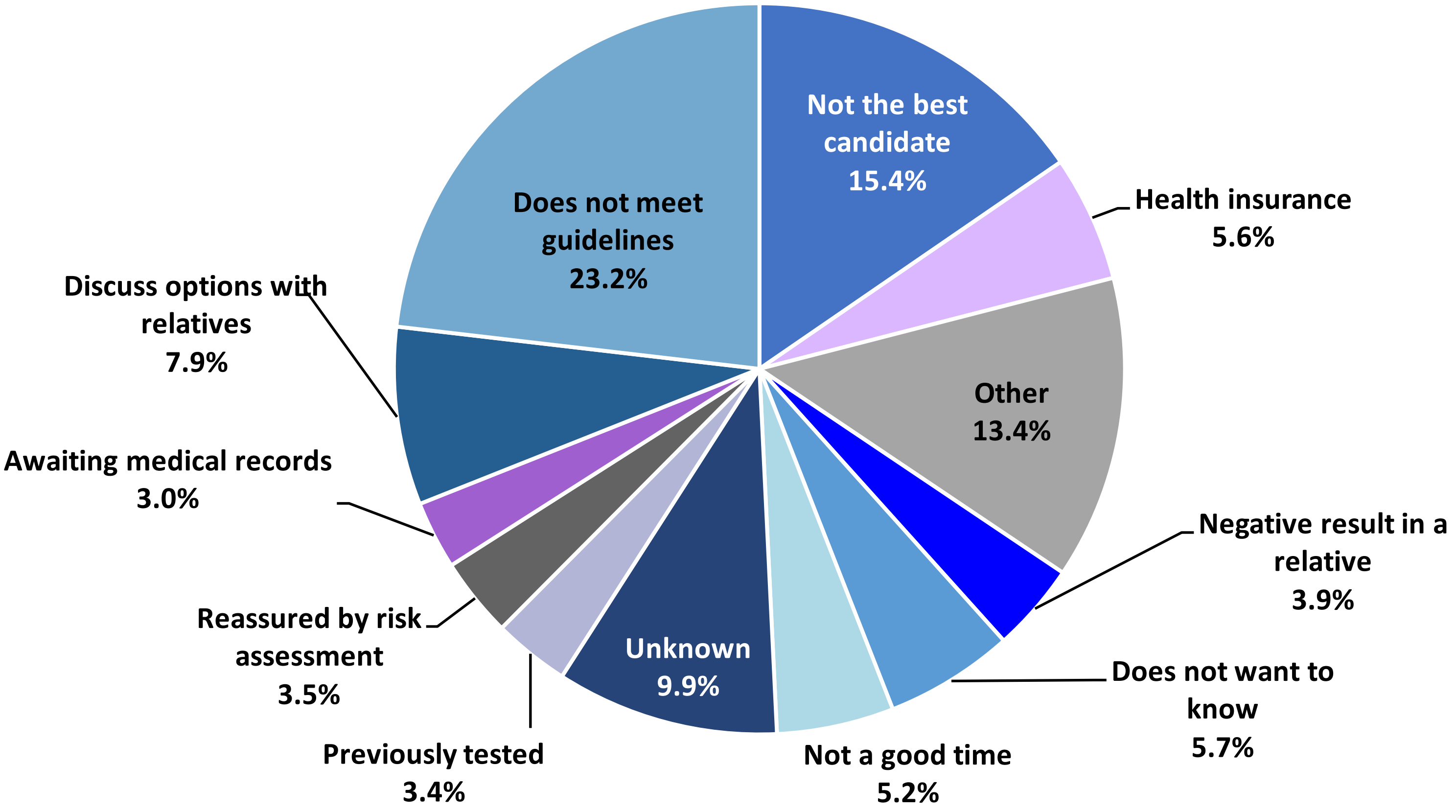
Hereditary Cancer Network Database: Select Characteristics, 2016-2019[29]

HCN: Referring Provider Type, 2016-2019



- Of those who received genetic counseling from one of the partner clinics in the HCN database, the majority were referred to counseling from a surgeon (**20.9%**) or from a family practice (**10.0%**).

Reason Why Genetic Testing Was Not Pursued from the HCN, 2016-2019



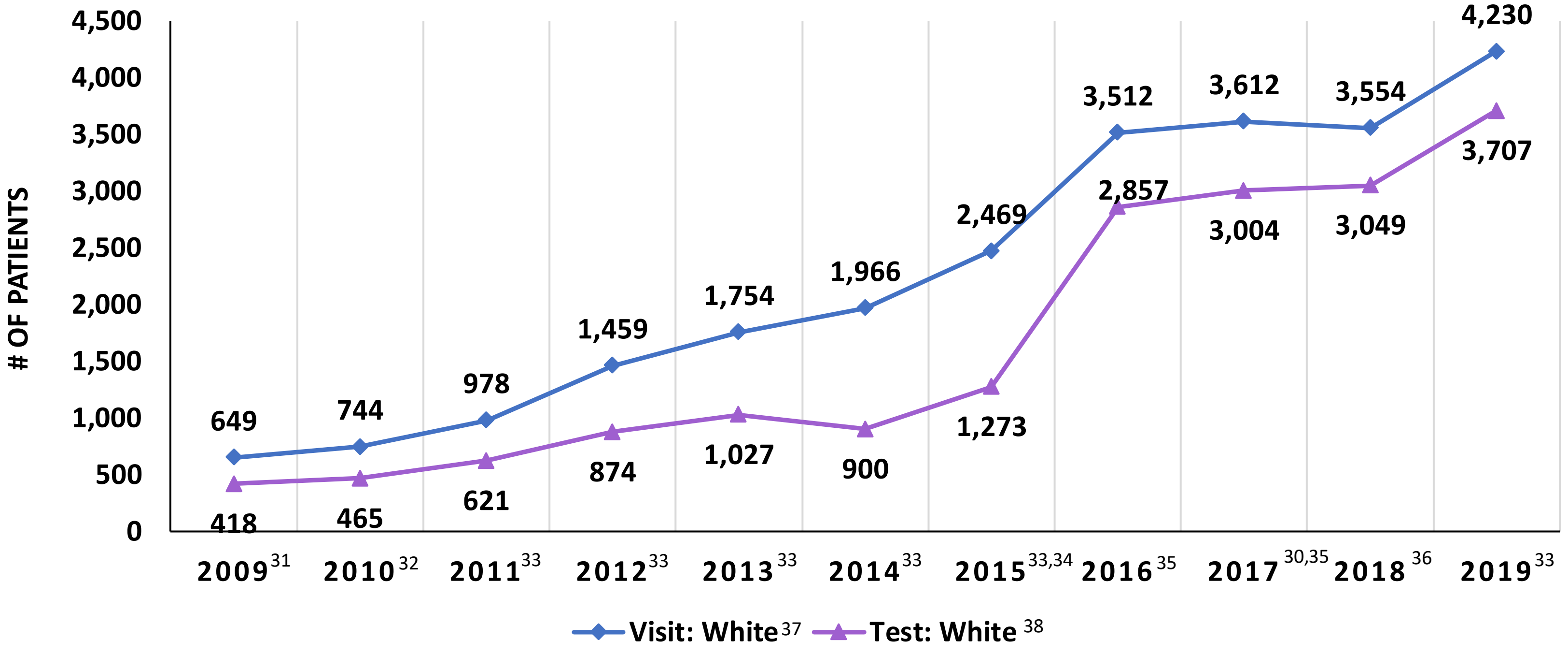
- Of those who decided to not pursue genetic testing at the time of the genetic counseling appointment, most did not receive testing because they did not meet guidelines by the physician (**23.2%**), followed by not being the best candidate for the genetic test (**15.4%**).

---

[29] Data for 2017 is incomplete.

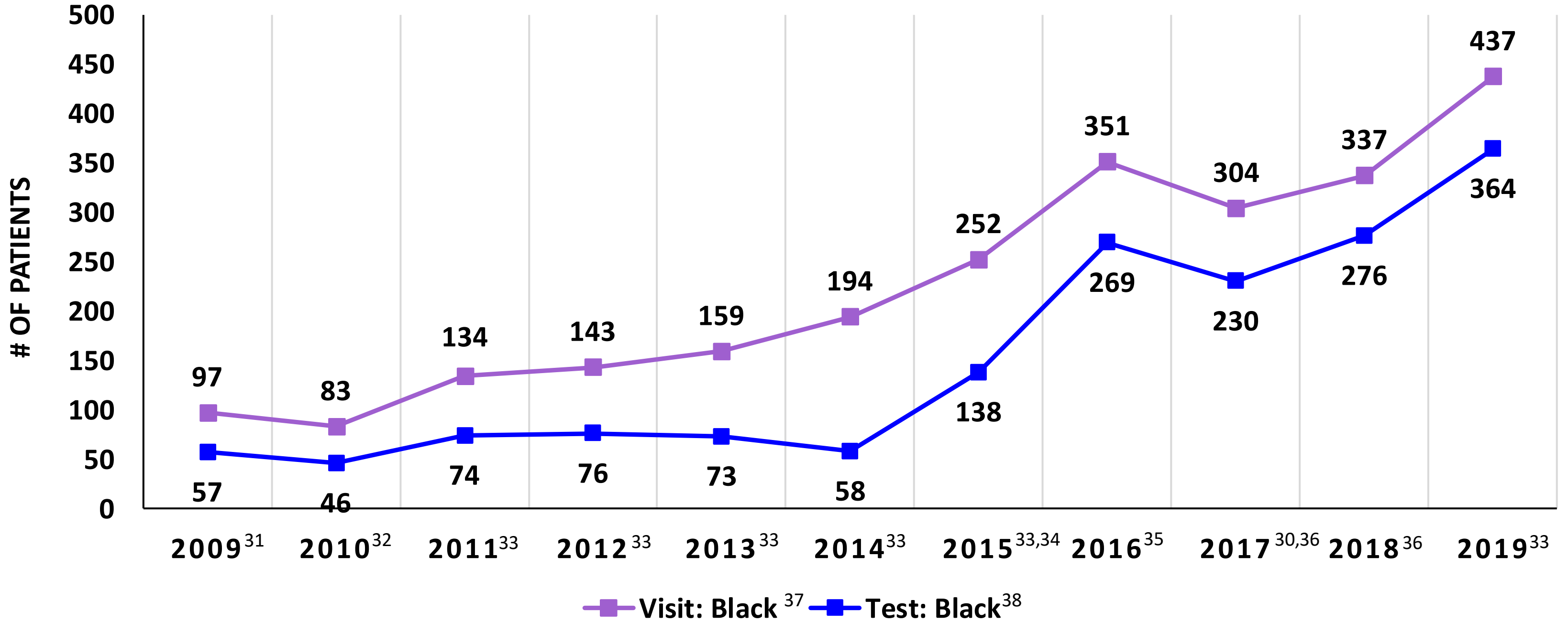
Hereditary Cancer Network Database: Time Trends, 2016-2019 [30]

TIME TRENDS BY RACE FROM THE HCN, 2009-2019



- In 2018, **3,049** white patients in the HCN received genetic testing, which was **86.0%** of those who received counseling.
- The number of white patients who received genetic testing increased to **3,707** (21.6% increase) in 2019.

TIME TRENDS BY RACE FROM THE HCN, 2008-2018



- In 2018, **276** Black patients in the HCN received genetic testing, which was **81.9%** of those who received counseling.
- The number of Black patients who received genetic testing increased to **364** (31.9% increase) in 2019.

---

[30] Data for 2017 are incomplete. [31] At this time, 6 of the 14 clinics entered data into the BRCA Clinical Network Database. [32] At this time, 7 of the 14 clinics entered data into the BRCA Clinical Network Database. [33] At this time, 9 of the 14 clinics entered data into the BRCA Clinical Network Database. [34] Data are incomplete. [35] At this time, 13 of the 14 clinics entered data into the BRCA Clinical Network Database. [36] At this time, 8 of the 14 clinics entered data into the HCN Database. [37] Visit dates before 2015 were pulled from the BRCA Clinical Network Database, the precursor to the HCN Database. Visit date is defined as the initial visit the patient made for genetic counseling with the clinic.
[38] Previous to 2015, data were collected on BRCA testing only. As of 2015, data on testing were collected on 19 clinically actionable genes.

Discussion & Summary

The Hereditary Cancer Network (HCN) is a unique database that functions as a statewide surveillance network for tracking the use of cancer genetic counseling and testing services for 19 actionable genes that are associated with Hereditary Breast and Ovarian Cancer (HBOC) and Lynch syndrome (LS) cancers in Michigan. In order to be eligible to be entered into the database, patients must have received genetic counseling from one of the clinics that have partnered with the Michigan Department of Health and Human Services.[40] Patients from these clinics can be included in the database if they have been seen for cancer genetic services by a board-certified/eligible, Michigan genetic professional or other qualified professional as recognized by the Commission on Cancer (CoC), are 18 years of age or older, and have a personal and/or family history of breast, ovarian/fallopian tube/primary peritoneal, colorectal, and/or endometrial cancer.

Key Surveillance Data:

- In 2019, the HCN database had the highest number of patients seen and tested since tracking began in 2008 with the BRCA Clinical Network Database.
- Among patients seen in 2018 and 2019, the majority were seen at Spectrum Health System.
- Among patients seen in 2019, the majority resided in Wayne (**16.6%**), Kent (**15.4%**) and Oakland (**11.2%**) counties.
- Patients with only a family history of cancer were twice as likely (**22.2%**) to have a positive genetic test result compared to those with only a personal history of cancer (**9.0%**).
- Patients with a known familial mutation were four times more likely to have at least one positive genetic test result (**40.6%**) compared to those without a known familial mutation (**11.2%**).
- In 2019, even though there were more white patients entered into the database compared to Black patients, there was a comparable proportion of those who received genetic testing (**87.6%** of white patients and **83.3%** of Black patients).

For More Information on the MDHHS Cancer Genomics Program:

Visit **Michigan.gov/hereditarycancer** to learn more about hereditary cancers. **Email:** genetics@michigan.gov

Visit **Michigan.gov/cge** to view more data on hereditary cancers. **Cancer Genomics Hotline Phone #:** 866-852-1247

Suggested Citation:
Fritzler J and Anderson B. Surveillance Data from the Hereditary Cancer Network, 2016-2019. Bureau of Epidemiology and Population Health, Michigan Department of Health and Human Services, February 2022.

---

[40] **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, Informed DNA 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

This publication was supported by the Cooperative Agreement Number 6 NU58DP006702-02-01, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

MDHHS-Pub-1490 Revision: 2/2022