

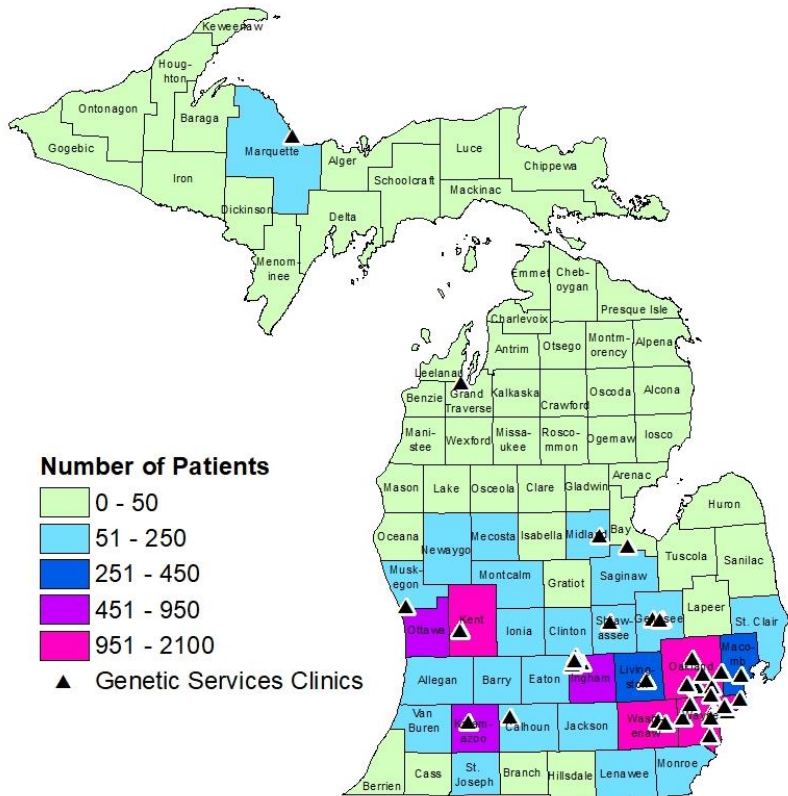
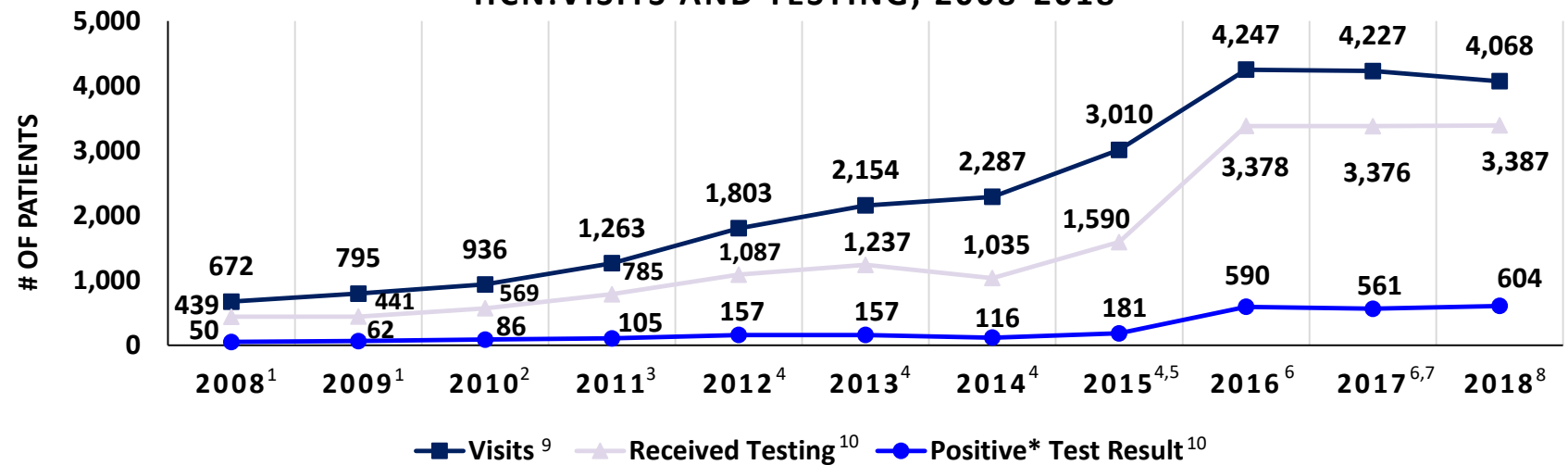
# Findings from the Hereditary Cancer Network (HCN) Database 2016-2018

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, 2018**. Nine partner institutions currently contribute de-identified data on all BRCA gene-related and Lynch syndrome (LS)-related genetic counseling patient visits.

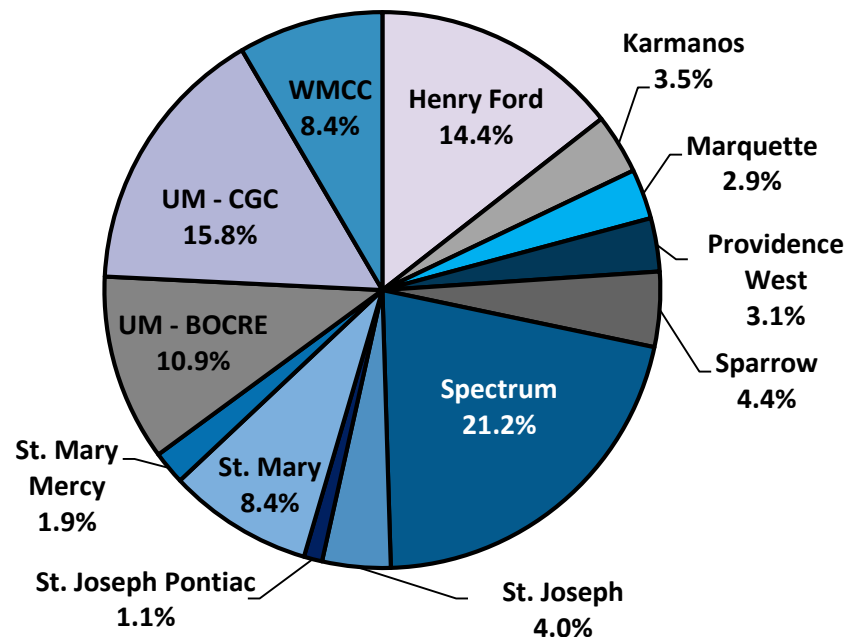
This report is a summary of the patient populations of **partner clinics that have provided patient visit data for patients seen between 2016 and 2018** that are at risk for either Hereditary Breast or Ovarian Cancer Syndrome (HBOC) or LS-related cancers.

There was a total of **12,542** records for 2016-2018, and data were extracted July 23, 2020 and includes: demographic information, personal and family history of hereditary cancer, and genetic testing. Please contact Jessica Fritzler at [FritzlerJ1@Michigan.gov](mailto:FritzlerJ1@Michigan.gov) for any questions.

### HCN: VISITS AND TESTING, 2008-2018

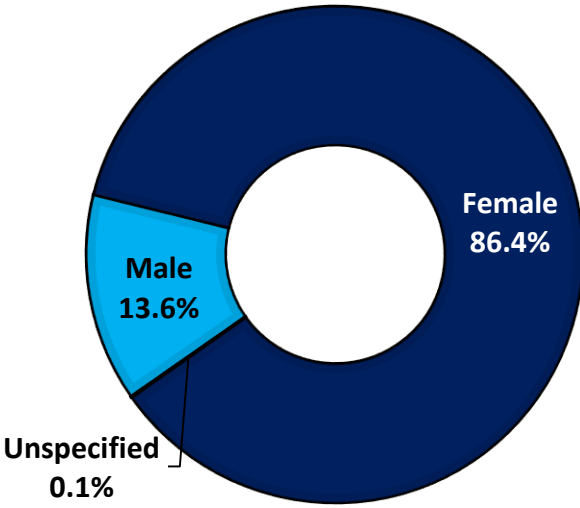


### Percent of Cases found in the HCN by Clinic, 2016-2018

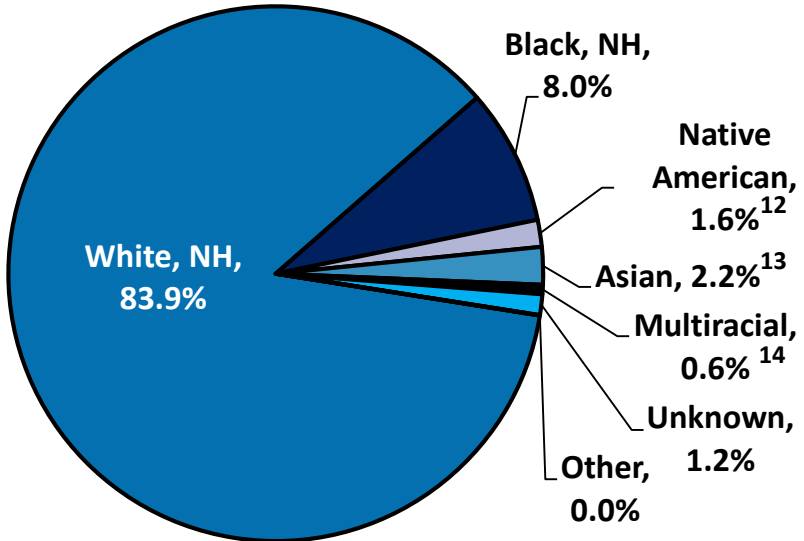


<sup>1</sup> At this time, 5 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>2</sup> At this time, 6 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>3</sup> At this time, 7 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>4</sup> At this time, 9 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>5</sup> Data for 2015 is incomplete. <sup>6</sup> At this time, 13 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>7</sup> Data for 2017 is incomplete. <sup>8</sup> At this time, 8 of the 14 clinics entered data into the HCN database. <sup>9</sup> 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. <sup>10</sup> 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.

## Gender, 2016-2018

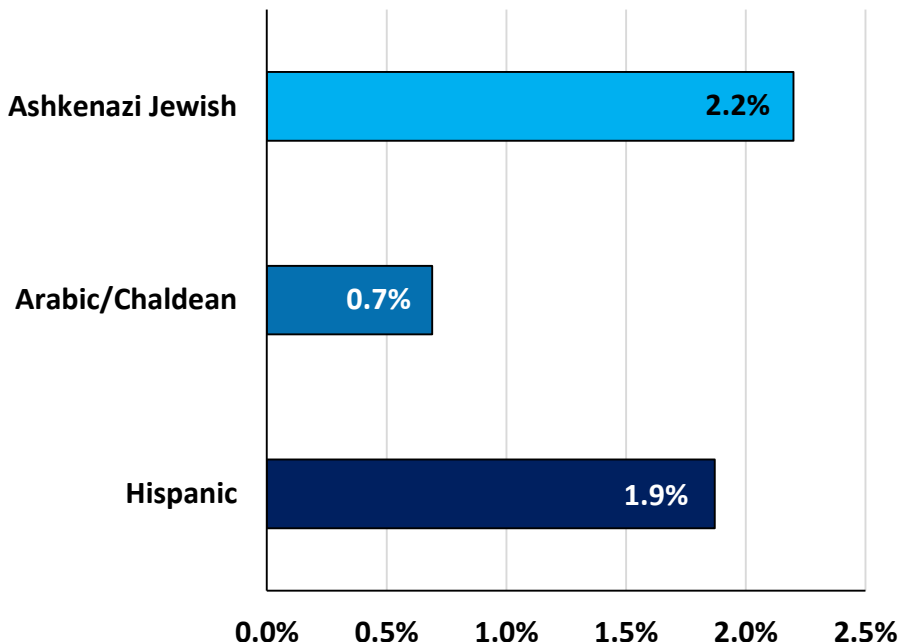


## Race, 2016-2018

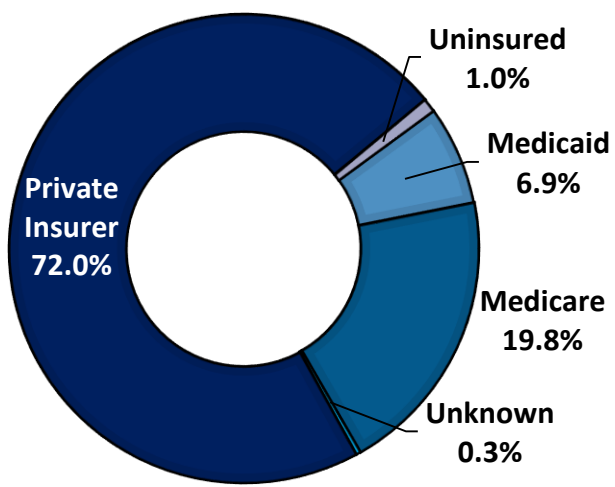


- The majority of patients in the HCN Database are female (**86.4%**) and identify as White, non-Hispanic (**83.9%**).
- Most patients in the HCN Database are between 46 and 55 years of age (**24.1%**), between 56 and 65 years of age (**24.4%**) or are older than 65 years of age (**20.2%**).
- Only **2.2%** of patients in the HCN Database identify as Ashkenazi Jewish.
- The majority of patients in the HCN Database are insured through a private insurer (**72.0%**), and there are more than twice as many patients who are on Medicare (**19.8%**) compared to Medicaid (**6.9%**).

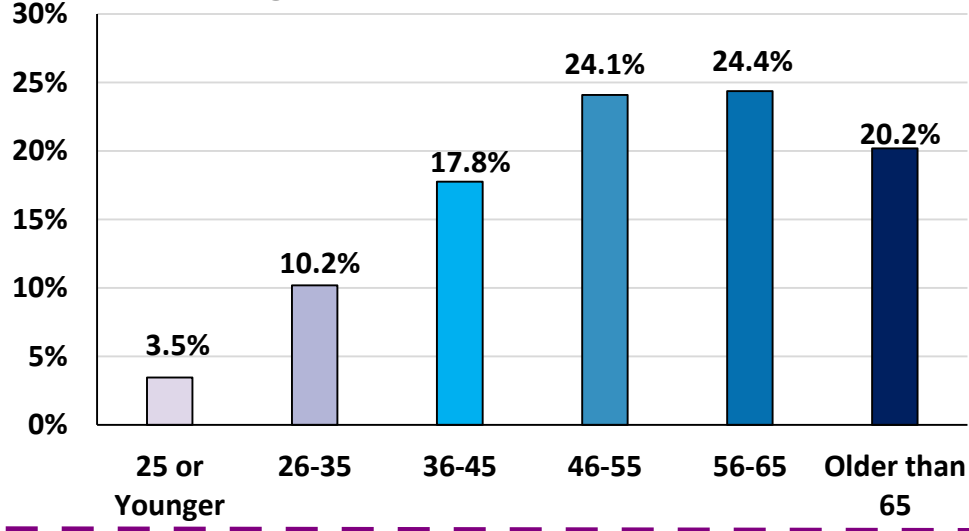
## Ethnicity & Ancestry, 2016-2018



## Insurance, 2016-2018

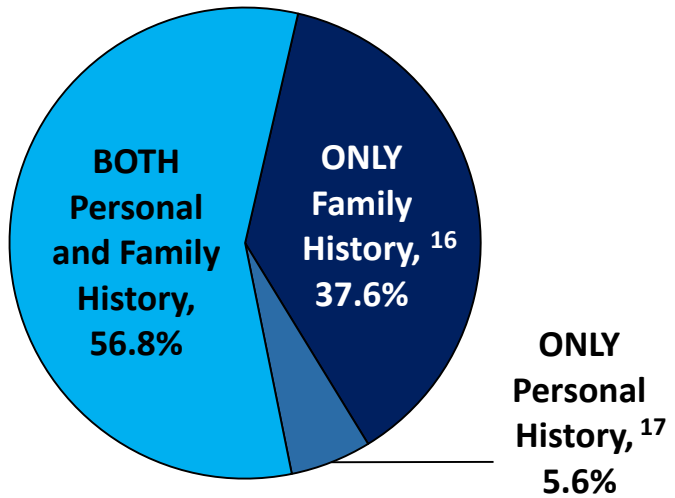


## Age at First Visit, 2016-2018

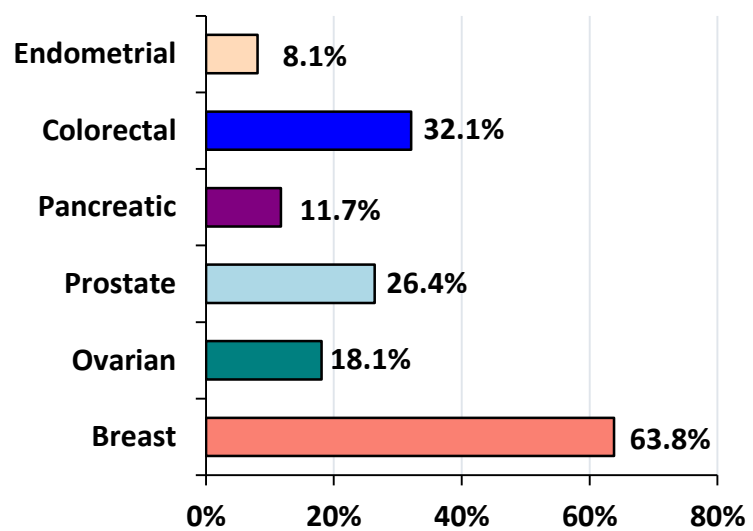


<sup>11</sup> Data for 2017 is incomplete. <sup>12</sup> Native American category includes those who identify as Black and Native American (0.30%), White and Native American (0.88%) and some other race and Native American (0.28%). <sup>13</sup> Asian category includes those who identify as Asian (2.18%), and Hawaiian (0.02%). <sup>14</sup> Multiracial category includes those who identify as Black and some other race (0.01%), White and Asian (0.13%), White and Black (0.37%) and White and some other race (0.05%).

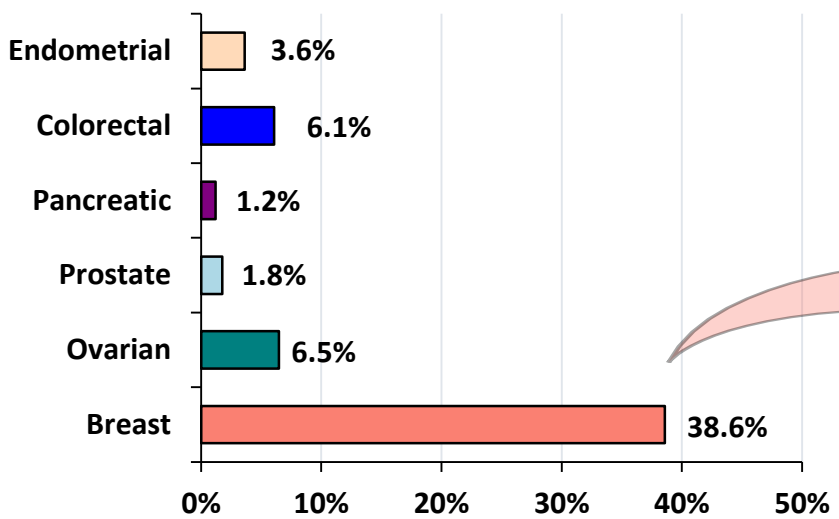
**History of Cancer, 2016-2018**



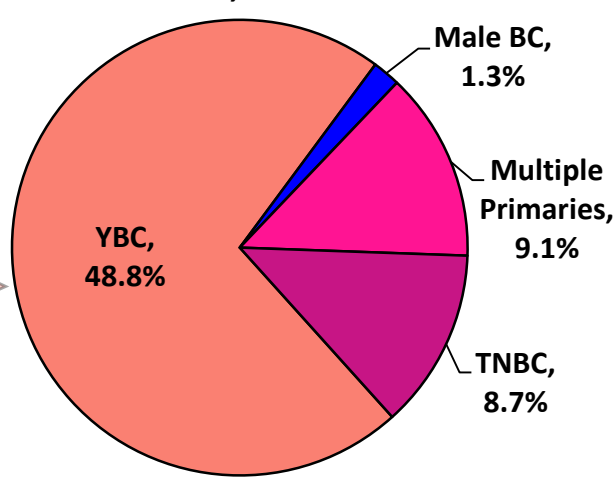
**Type of Cancer among Family Members, 2016-2018**



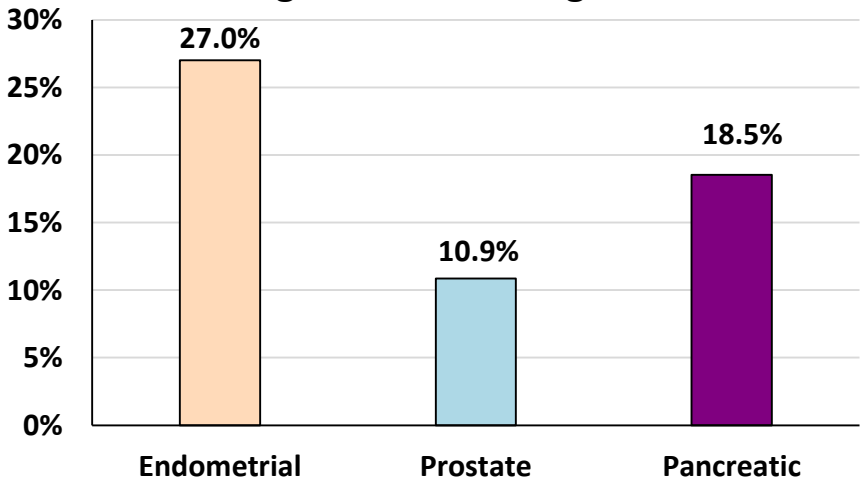
**Type of Cancer among Patients, 2016-2018 <sup>18</sup>**



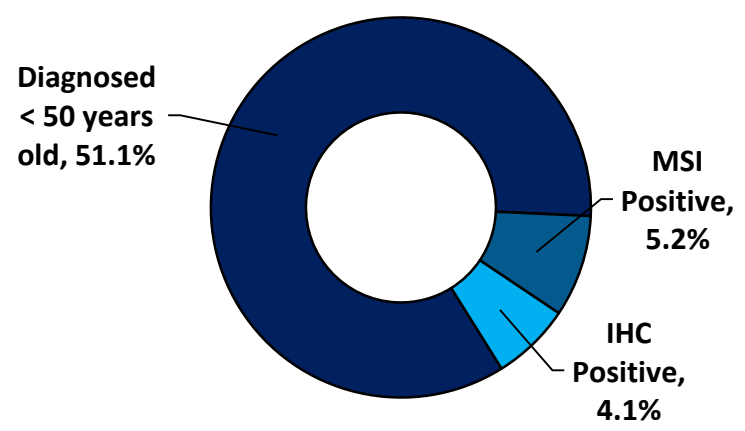
**Breast Cancer, 2016-2018 <sup>19</sup>**



**Cancer Diagnosed Before Age 50, 2016-2018**



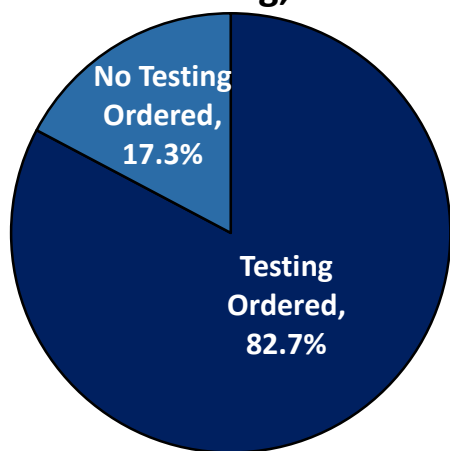
**Colorectal Cancer, 2016-2018**



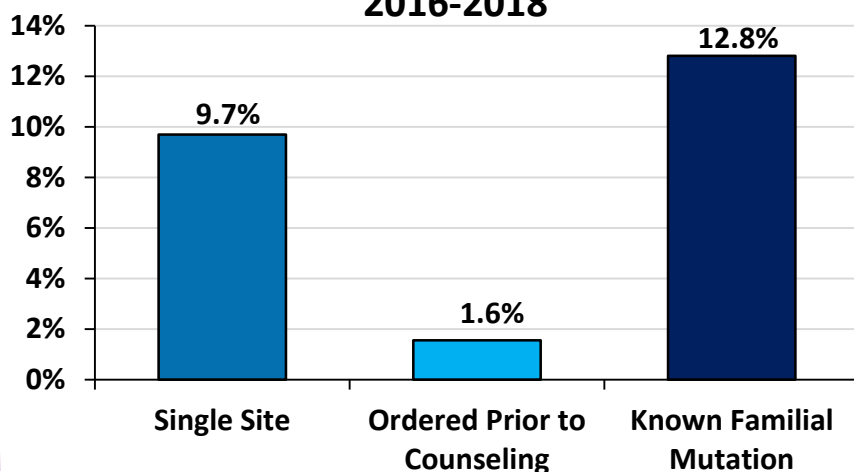
- 56.8% of patients in the HCN Database have a personal and family history of some type of cancer.
- 37.6% of patients in the HCN had family history of cancer, but no personal cancer.
- **Almost half** of those with breast cancer had a diagnosis occur at or before the age of 50.
- Only 1.3% of patients in the HCN Database are males with breast cancer.
- 6.1% of patients in the HCN Database had colorectal cancer at least once, with 51.11% being diagnosed at age 50 or under.

<sup>15</sup> Data for 2017 is incomplete. <sup>16</sup> 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. <sup>17</sup> No family history of breast, ovarian, prostate, pancreatic, endometrial, or colorectal cancer but has a personal history of one of these cancers. <sup>18</sup> Type of cancer among patients who have a personal history of cancer. <sup>19</sup> Characteristics of breast cancer patients: Young Breast Cancer (YBC), Male Breast Cancer, Multiple Primaries, and Triple Negative Breast Cancer (TNBC).

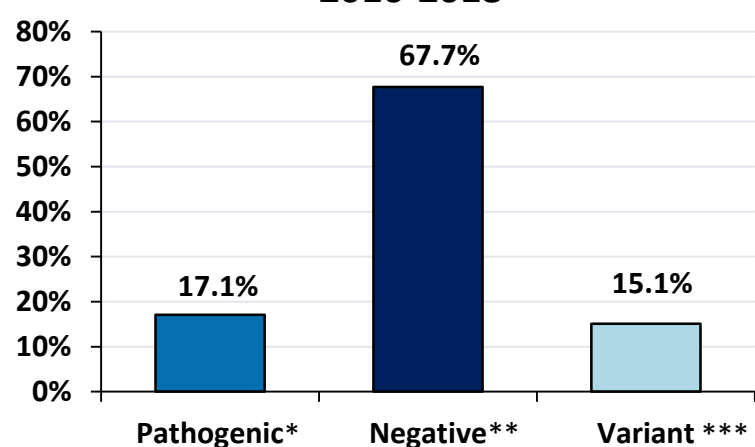
## Genetic Testing, 2016-2018



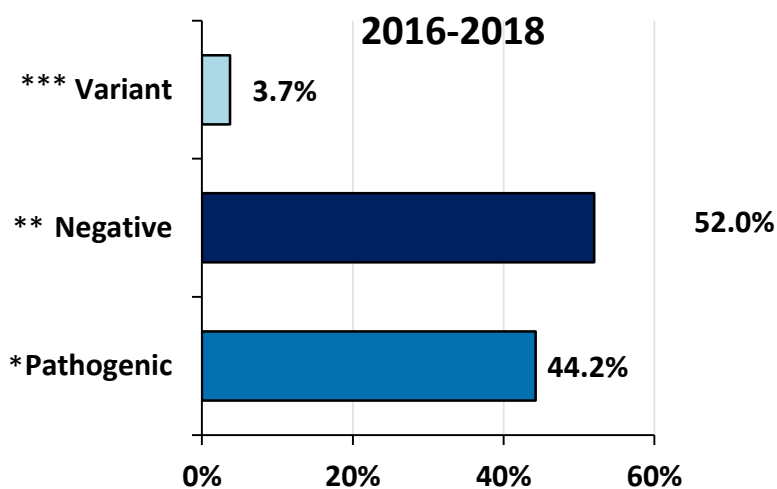
## Characteristics of Genetic Testing Performed, 2016-2018



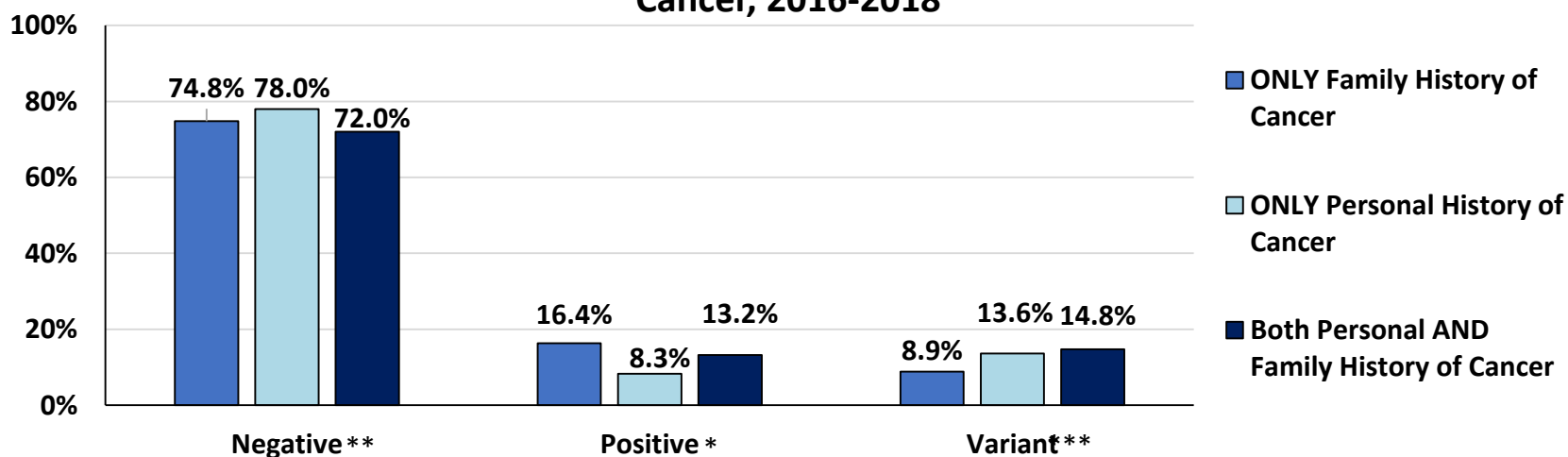
## Genetic Testing Results, 2016-2018



## Genetic Testing Results among those with a Known Familial Mutation, 2016-2018



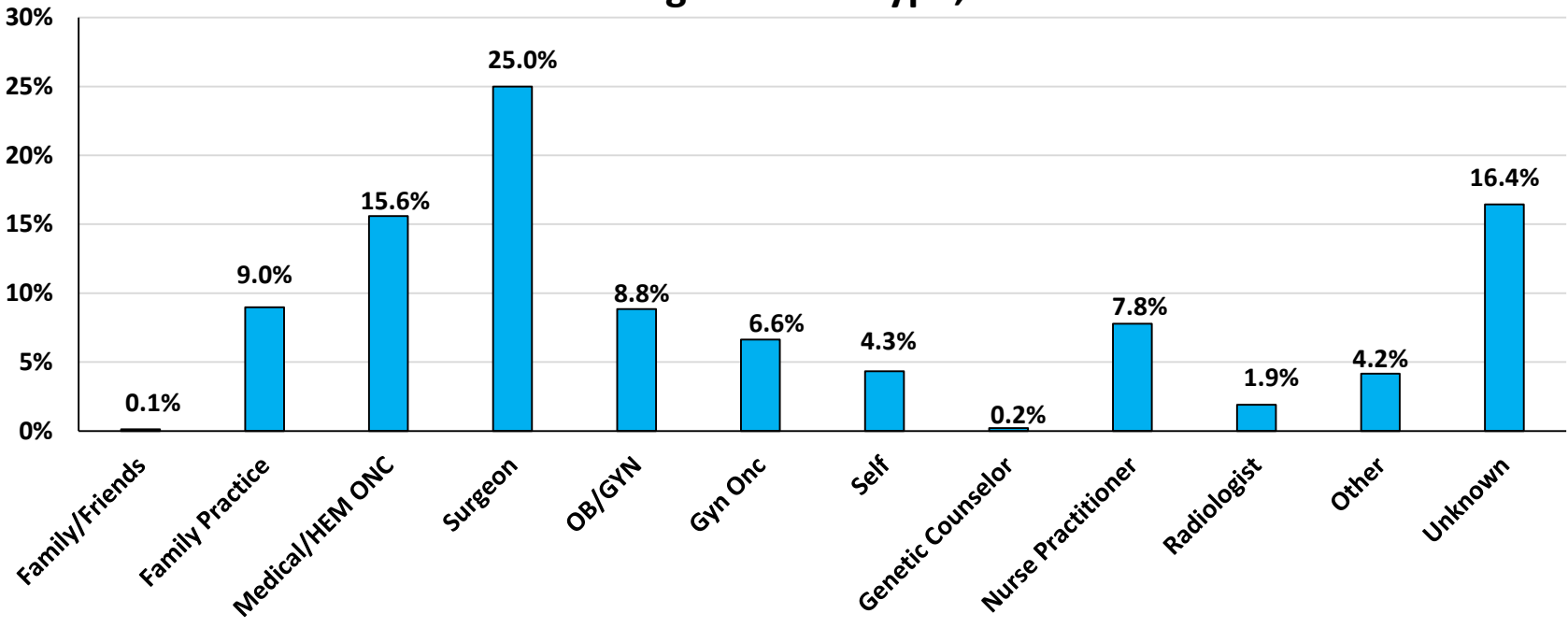
## Genetic Test Results among those with Personal or Family History of Cancer, 2016-2018



- 82.7% of patients in the HCN database received genetic testing.
  - Of those who received genetic testing, 18.0% had at least one positive result.
- 12.8% of patients in the HCN Database had a known familial mutation before the visit.
  - 45.1% of those with a known familial mutation that received genetic testing had at least one positive result.

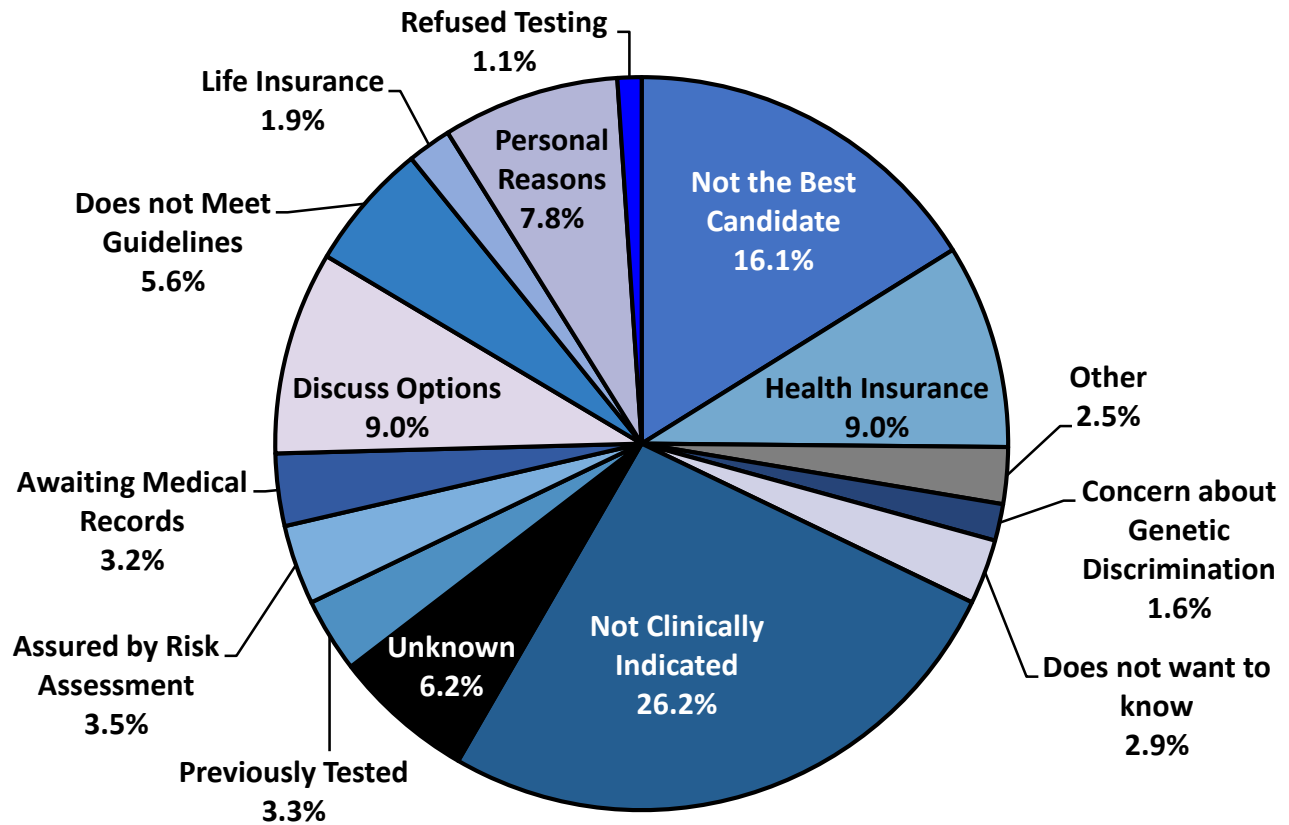
<sup>20</sup> Data for 2017 is incomplete. \* Pathogenic/Positive result refers to a genetic test result being Pathogenic or Likely Pathogenic. \*\* Negative result refers to a genetic test result being Benign, Likely Benign or Not Clinically Significant. \*\*\* Variant result refers to a result that is classified as a Variant of Unknown Significance (VUS).

### HCN: Referring Provider Type, 2016-2018



➤ Of those who received genetic counseling from one of the thirteen partner clinics in the HCN database, the majority were referred to counseling from a Surgeon (25.0%) or from a Medical Hematologist Oncologist (15.6%).

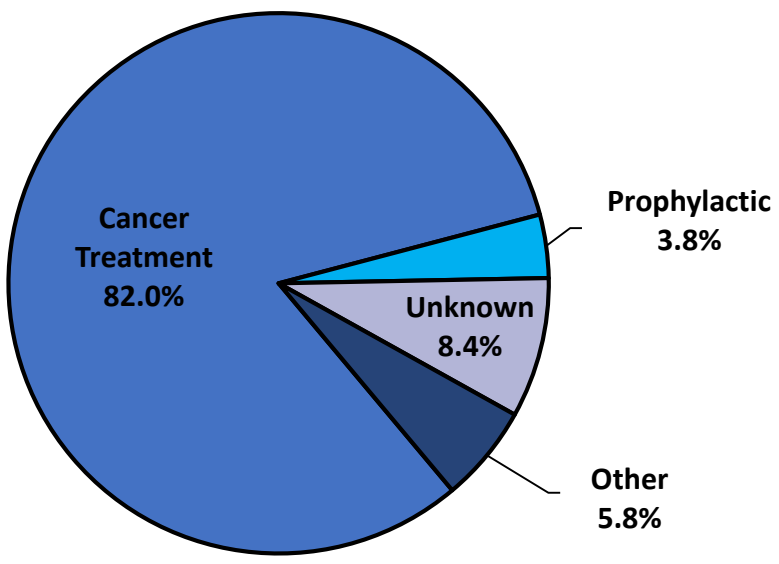
### Reason Why Genetic Testing Was Not Pursued from the HCN, 2016-2018



➤ Of those who decided to not pursue genetic testing at the time of the genetic counseling appointment, most did not receive testing because it was not clinically indicated by the physician (26.2%), followed by not being the best candidate for the genetic test (16.1%) and having some issue with coverage due to health insurance (9.0%).

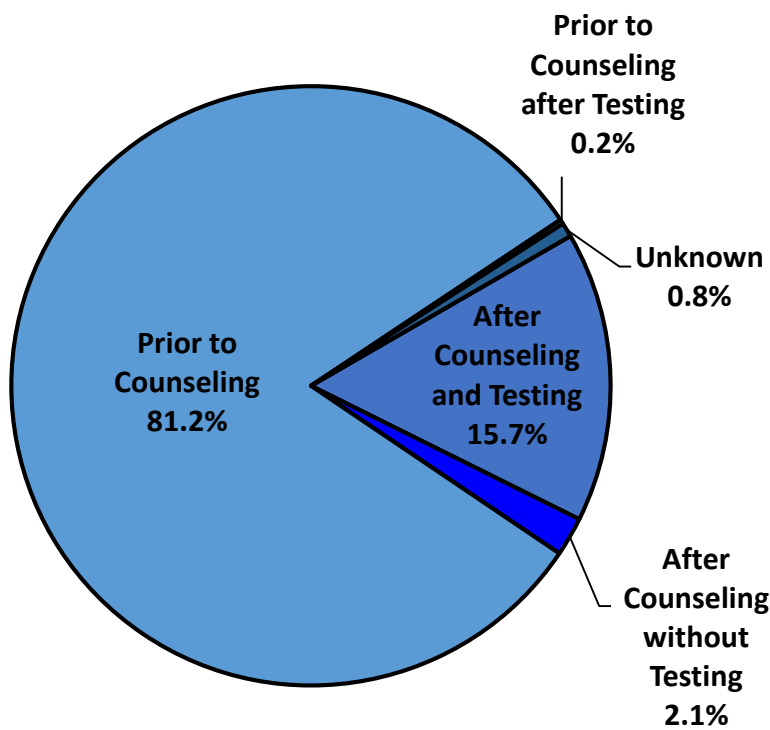
<sup>21</sup> Data for 2017 is incomplete.

## Reasons for Patients Opting for Surgery from the HCN, 2016-2018



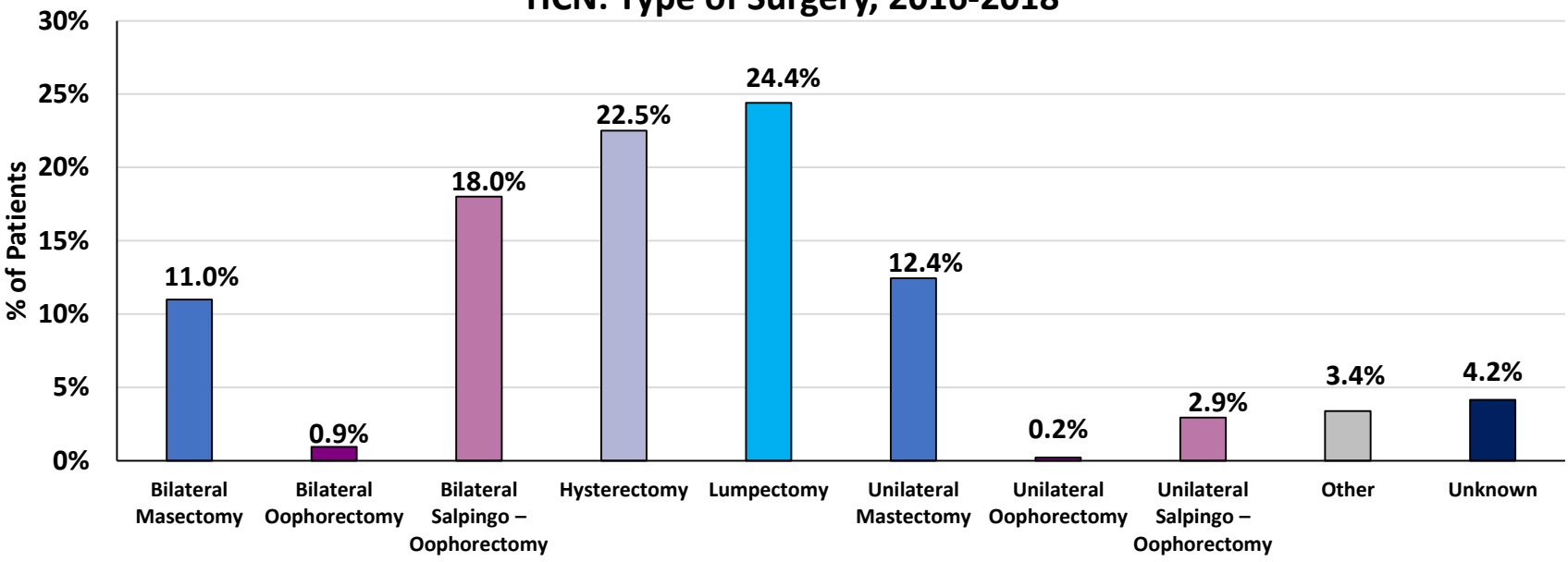
- Of those who had surgery, the majority took place prior to genetic counseling (**81.2%**).
- About **2.1%** of patients who had surgeries during this time period had surgeries after counseling, but before they had genetic testing done.

## Timing of Surgeries from HCN, 2016-2018



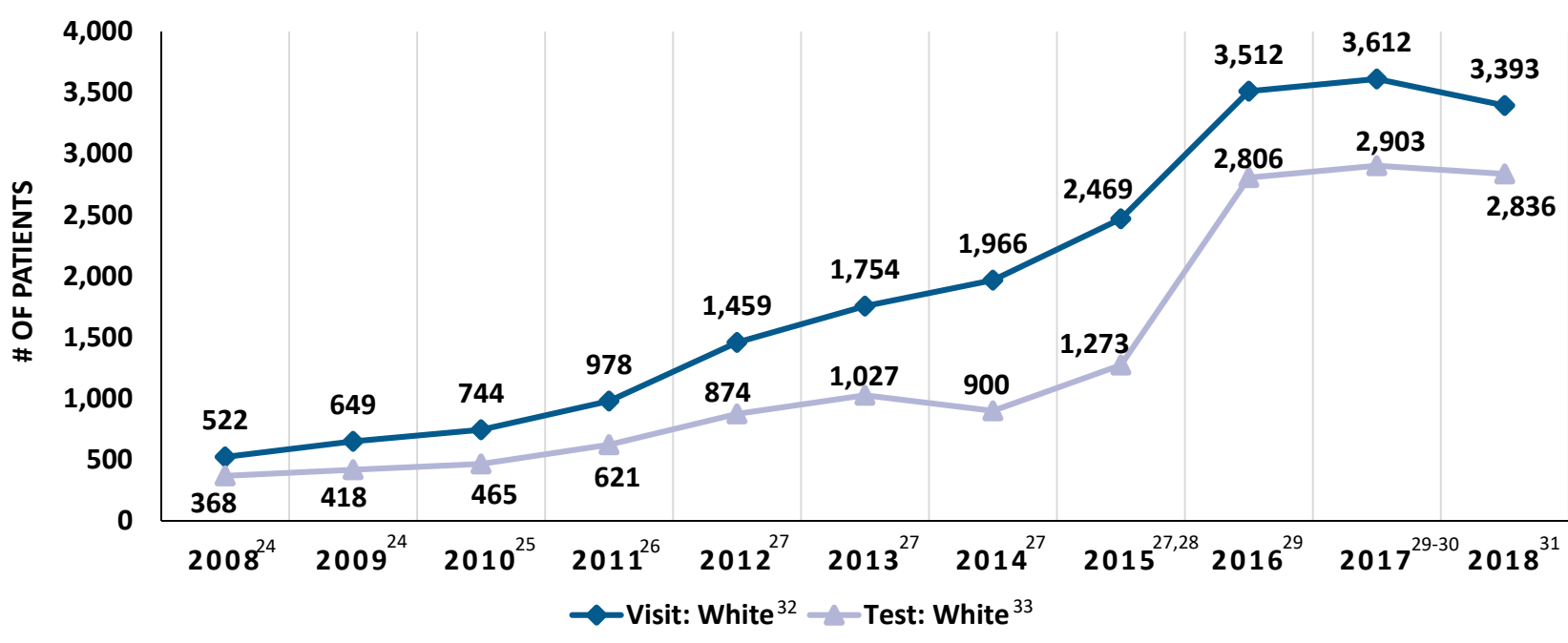
- **31.6%** of those in the HCN reported having some type of surgery.
  - The majority of patients seen in the HCN Database received some type of surgery for the purpose of cancer treatment (**82.0%**)
  - Only **3.8%** of surgeries were performed for prophylactic reasons.

## HCN: Type of Surgery, 2016-2018



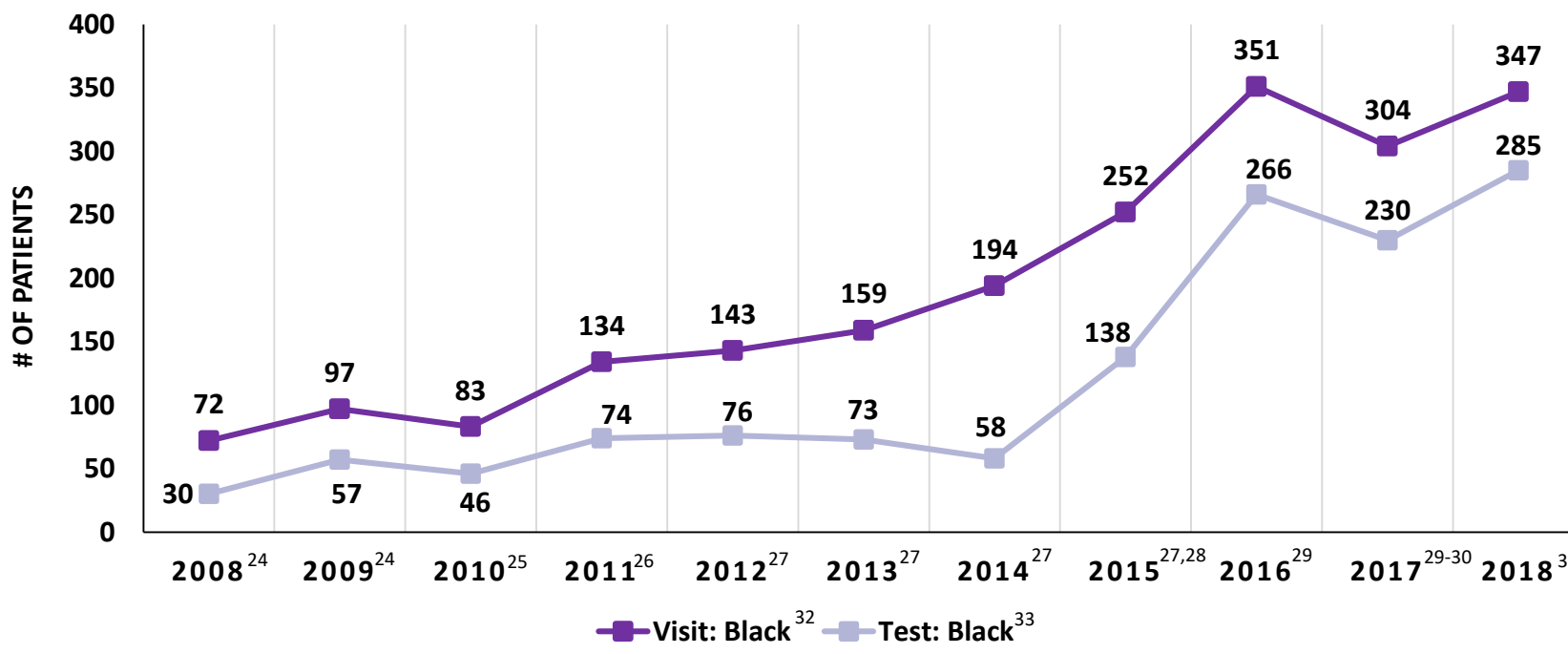
<sup>22</sup> Data for 2017 is incomplete

## TIME TRENDS BY RACE FROM THE HCN, 2008-2018



- In 2017, **2,903** (80.4%) White patients in the HCN received genetic testing.
- The amount of White patients who received genetic testing increased to **2,836** (83.6%) in 2018.

## TIME TRENDS BY RACE FROM THE HCN, 2008-2018



- In 2017, **230** (75.7%) Black patients in the HCN received genetic testing.
- The amount of Black patients who received genetic testing increased to **285** (82.1%) in 2018.

<sup>23</sup> Data for 2017 is incomplete. <sup>24</sup> At this time, 5 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>25</sup> At this time, 6 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>26</sup> At this time, 7 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>27</sup> At this time, 9 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>28</sup> Data for 2015 is incomplete. <sup>29</sup> At this time, all 13 of the 14 clinics entered data into the BRCA Clinical Network Database. <sup>30</sup> Data for 2017 is incomplete. <sup>31</sup> At this time, 8 of the 14 clinics entered data into the HCN Database. <sup>32</sup> 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. <sup>33</sup> 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<sup>34</sup>. 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 Findings:

- In 2016, 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 2017 and 2018, the majority were seen at Spectrum Health System.
- Among patients seen in 2017 and 2018, the majority resided in Wayne (16.6%), Kent (15.2%) and Oakland (12.2%) counties.
- Patients with only a family history of cancer were twice as likely (16.7%) to have a positive genetic test result compared to those with only a personal history of cancer (8.6%).
- Patients with a known familial mutation were four times more likely to have at least one positive genetic test result (45.1%) compared to those without a known familial mutation (10.5%; data not shown).
- In 2017, even though there were more White patients entered into the database compared to Black patients, approximately the same proportion of individuals in each group received genetic testing in (80.4% of White patients and 75.7% of Black patients).
- In 2018, even though there were more White patients entered into the database compared to Black patients, approximately the same proportion of individuals in each group received genetic testing in (83.6% of White patients and 82.1% of Black patients).

## For More Information:

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

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

## Suggested Citation:

Fritzler J and Anderson B. (2020). Findings from the Hereditary Cancer Network 2016-2018. Bureau of Epidemiology and Population Health, Michigan Department of Health and Human Services.



<sup>34</sup> 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

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