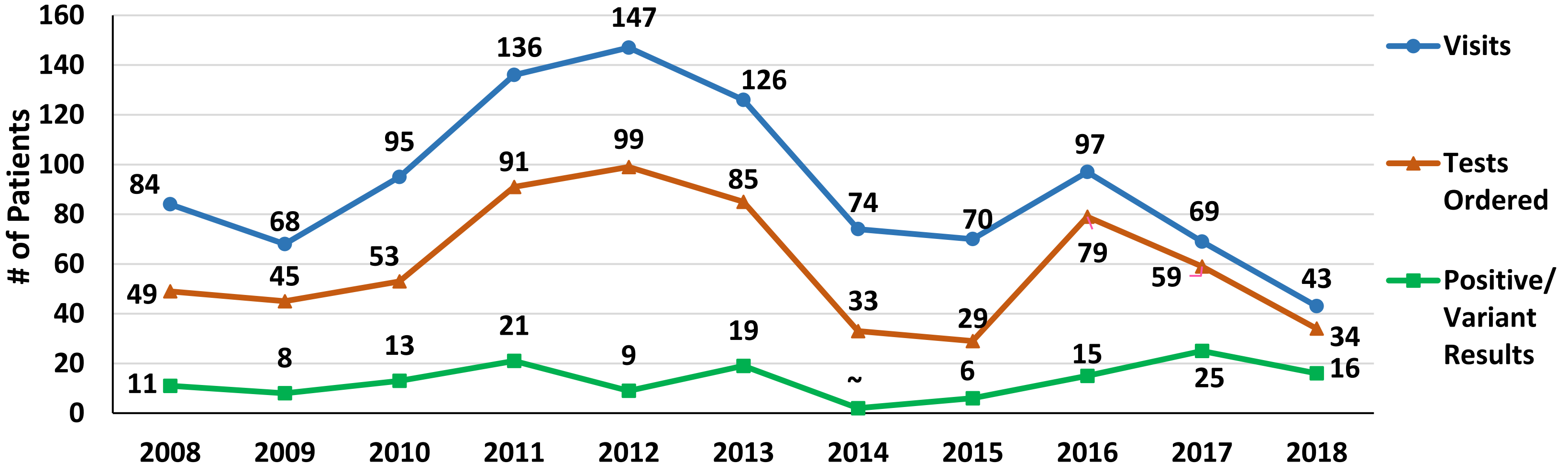
The American Indian Population: Genetics Services Surveillance, 2008-2018

Background: Cancer rates among American Indian populations tend to be greater compared to the general population, particularly lung, colorectal, gallbladder, stomach, liver female breast cancer and kidney cancer.[1,2] American Indians also have the lowest cancer survival rates in the country, mainly because they are consistently getting screened too late.[1] A study exploring cancer between 2012 and 2016 found that compared to white men, American Indian men had higher rates of myeloma, liver, stomach, kidney, colorectal, and lung cancer.[2] This same study also found that compared to white women, American Indian women had higher rates of liver, stomach, kidney, colorectal and cervical cancer. When looking for information regarding the American Indian population and hereditary cancer, the published scientific studies are sparse. Research conducted among Utah's population of breast cancer cases between 2010 and 2015 showed that 19.9% of American Indian breast cancer patients met National Comprehensive Cancer Network (NCCN) guidelines for genetic testing while 81.1% of ovarian cancer cases met guidelines for testing, however, it was not determined how many of these patients pursued genetic counseling and testing. This suggests that further research is needed to identify what cancer genetic counseling and testing rates look like among this population.

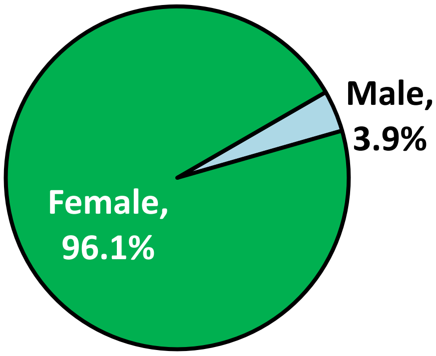
Methods: The following data were collected from the Michigan Department of Health and Human Services (MDHHS) Hereditary Cancer Network (HCN) database between **January 1, 2008, and December 31, 2018**. **During this time frame, there were 1,009 individuals who identified as American Indian when reporting race**. The 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 MDHHS*, which means data may not be representative of Michigan's American Indian population. Frequencies and chi-square analyses were performed between those who identified as American Indian versus those who do not identify as American Indian using SAS 9.4. Significant values were set at $p < 0.05$.

Please contact Jessica Fritzler at FritzlerJ1@Michigan.gov for any questions.

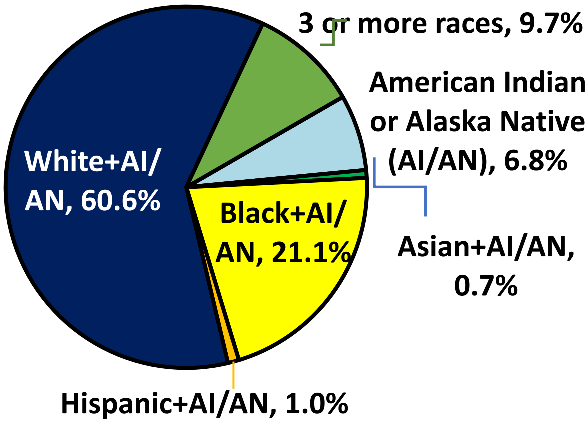
Visits and Genetic Testing, 2008-2018



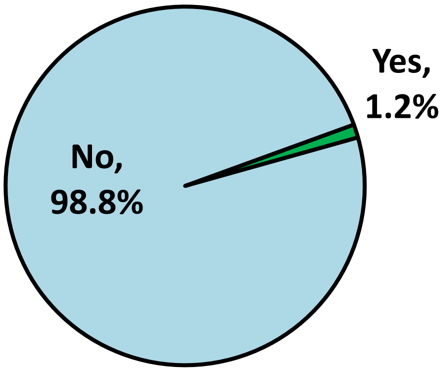
Gender, 2008-2018



Race, 2008-2018



Ashkenazi Jewish, 2008-2018



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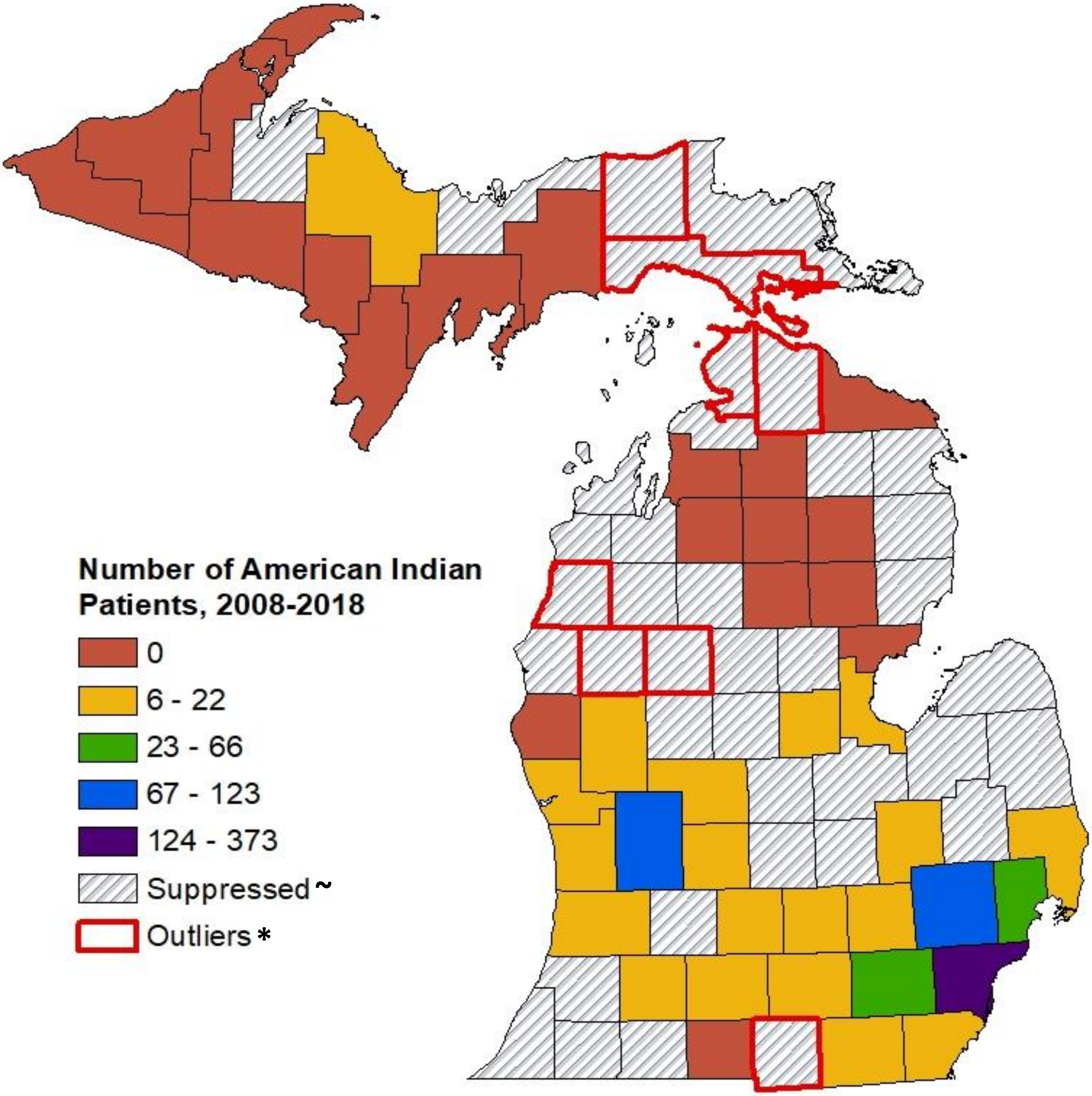
* HCN Clinical Partners: Beaumont Cancer Genetics Program, Beaumont Center for Hematology and Oncology, Henry Ford Health System Cancer Genetics Program, Karmanos Cancer Institute Cancer Genetic Counseling Service, Informed DNA Telephone Genetic Counseling Services, Mid-Michigan Hereditary Cancer Clinic, 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. ~ Data are suppressed if count is less than 6.

The American Indian Population: Genetics Services Surveillance, 2008-2018

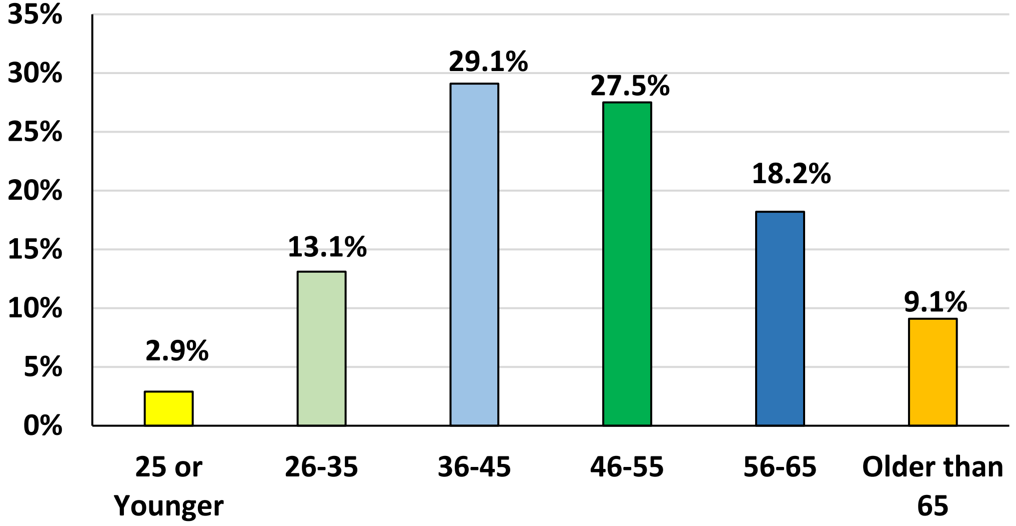


- There were eight counties that were considered outliers for the number of patients seen versus the number of patients who pursued genetic testing:
  - Cheboygan, Emmett, Hillsdale, Lake, Luce, Mackinac, Manistee and Osceola counties
- Out of the 63 counties where American Indian patients reside, 38 (60.3%) had genetic testing rates below 75%.

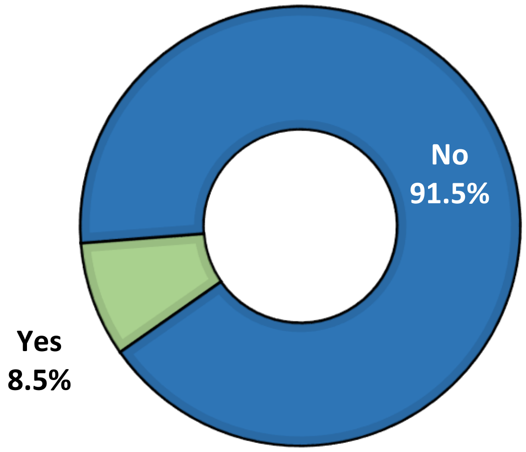
~ Data are suppressed if count is less than 6. Counties are considered outliers if the incidence rate is greater than the outlier cutoff of Q3 + (IQR*1.5), where Q3 refers to the third quartile, and IQR refers to the interquartile range (Q3-Q1). These counties are outlined in red in the maps.

The American Indian Population: Genetics Services Surveillance, 2008-2018

Age at First Visit, 2008-2018

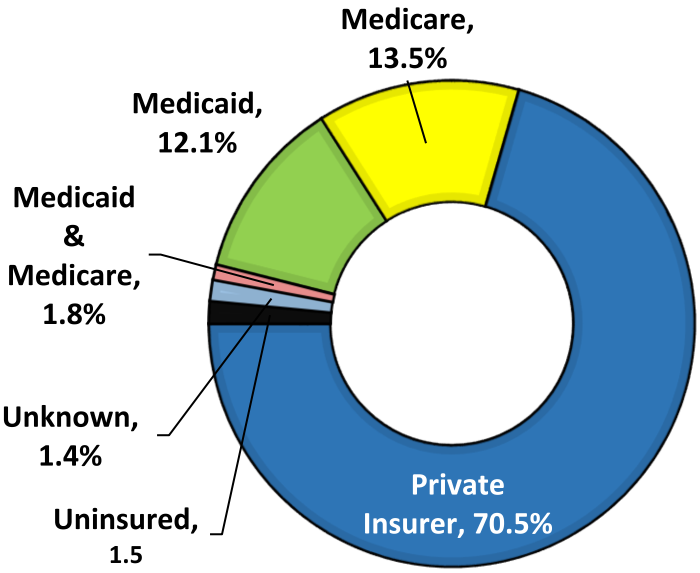


Known Familial Mutation, 2008-2018

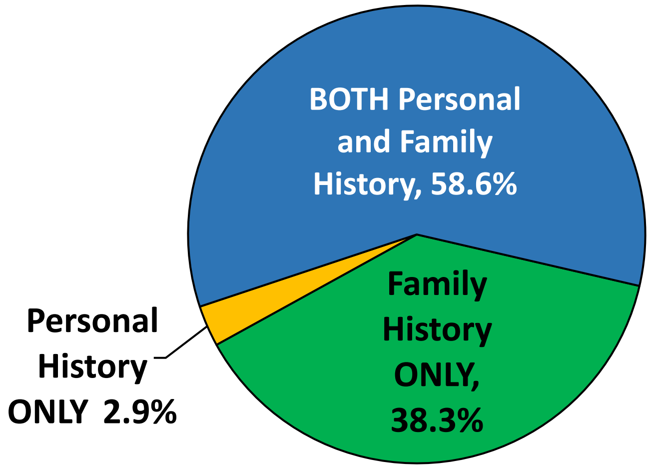


- Most American Indian patients in the database are between 36 and 45 years of age (**29.1%**) or between 46 and 55 years of age (**27.5%**).
    - American Indians were more likely to be at or under the age of 50 at the time of their appointment compared to white, Black, or other populations (**59.4% vs. 46.8%; data not shown**).
        - This difference was greatest between white (**59.4% vs. 45.1**%) and Black patients **(59.4% vs. 53.0%; data not shown**).
- American Indians were less likely to have a KFM compared to white, Black, or other populations (**8.5% vs. 11.8%**).
        - When broken down by race, however, American Indians were more likely to have a KFM compared to Black patients (**8.5% vs. 4.2%; data not shown**).
- Most American Indian patients had insurance through a private insurer (**70.5%**), followed by Medicare (**13.5%**).
    - American Indian patients were more likely to have Medicaid compared to white, Black, or other populations (**12.1% vs. 5.7%**).
        - This differences was greatest between American Indians and white patients (**12.1% vs. 4.4%; data not shown**).
- Most American Indian patients had both a personal and family history of cancer (**58.6%**).
    - American Indians were less likely to have only a personal family history of cancer compared to white, Black, or other populations (**2.9% vs. 4.7%**).

Insurance, 2008-2018



History of Cancer, 2008-2018



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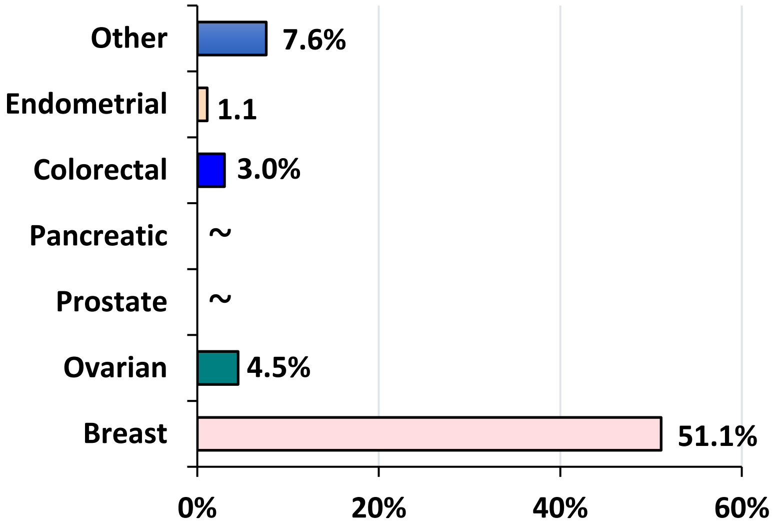
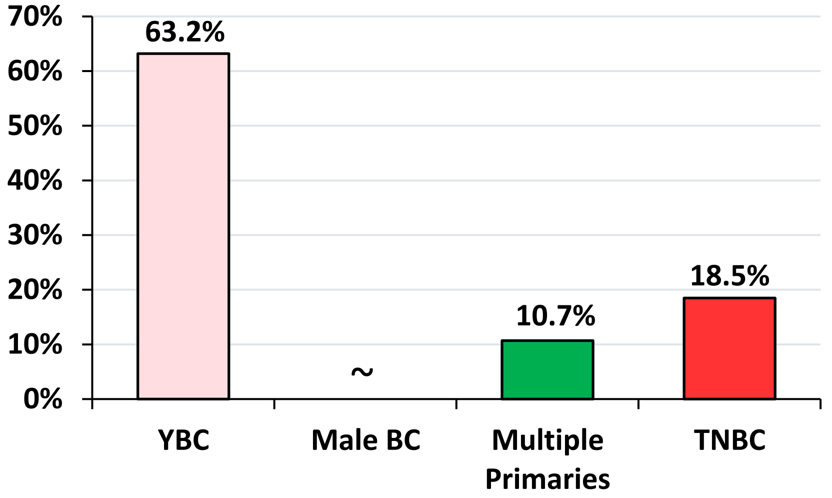
The American Indian Population: Genetics Services Surveillance, 2008-2018

Type of Cancer among American Indian Patients, 2008-2018



- **51.1%** of American Indians were diagnosed with breast cancer, which was significantly greater than other populations (**45.3%; data not shown**).
  - When broken down by race, the biggest difference is between American Indian and white patients (**51.1% vs. 44.2%; data not shown**).
- **1.1%** of American Indians were diagnosed with endometrial cancer, which was significantly less than other populations (**2.6%; data not shown**).
  - When broken down by race, the biggest difference is between American Indian and white patients (**1.1% vs. 2.7%; data not shown**).
- 4.5% of American Indians were diagnosed with ovarian cancer.
  - When broken down by race, Black patients were significantly less likely than American Indians to be diagnosed with ovarian cancer (**2.3% vs. 4.5%; data not shown**).

Breast Cancer Characteristics among American Indian Patients, 2008-2018 [a]



- **63.2%** of American Indian patients had a breast cancer diagnosis occur at or before the age of 50.
  - American Indian patients were more likely to be diagnosed at a younger age compared to other populations (**63.2% vs. 52.6%**).
    - When broken down by race, the biggest difference is between American Indian and white patients (**63.2% vs. 50.8%; data not shown**).
- **18.5%** of American Indian breast cancer patients were diagnosed with Triple Negative Breast Cancer (TNBC).
  - American Indians were more likely to be diagnosed with TNBC compared to other populations (**18.5% vs. 8.8%**).
    - When broken down by race, the biggest difference is between American Indian and white patients (**18.5% vs. 7.8%; data not shown**).

Other Cancer Characteristics, 2008-2018

77 patients had an “Other” type of cancer

66.2% of patients with this type of cancer were diagnosed at or under the age of 50

8.0% of patients with this type of cancer were diagnosed with multiple primaries

Ovarian Cancer Characteristics, 2008-2018

35.6% of those with ovarian cancer were diagnosed at or under the age of 50

None of these patients were diagnosed with multiple primaries

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[a] Characteristics of breast cancer patients: Young Breast Cancer (YBC), Male Breast Cancer, and Multiple Primaries.

~ Data are suppressed when counts are less than 6.

The American Indian Population: Genetics Services Surveillance, 2008-2018

Colorectal Cancer Characteristics, 2008-2018

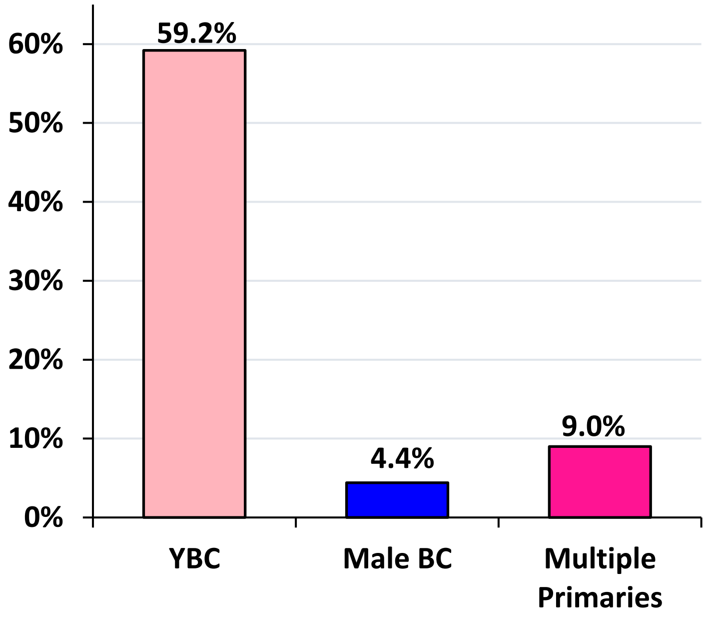
50.0% of those with colorectal cancer were diagnosed under the age of 50

Data are suppressed* for the number of patients that had absent Mismatch Repair (MMR) proteins

Data are suppressed* for the number of patients that had a high MSI histology

Data are suppressed* for the number of patients had multiple primaries

Breast Cancer among Relatives, 2014-2018 [c]



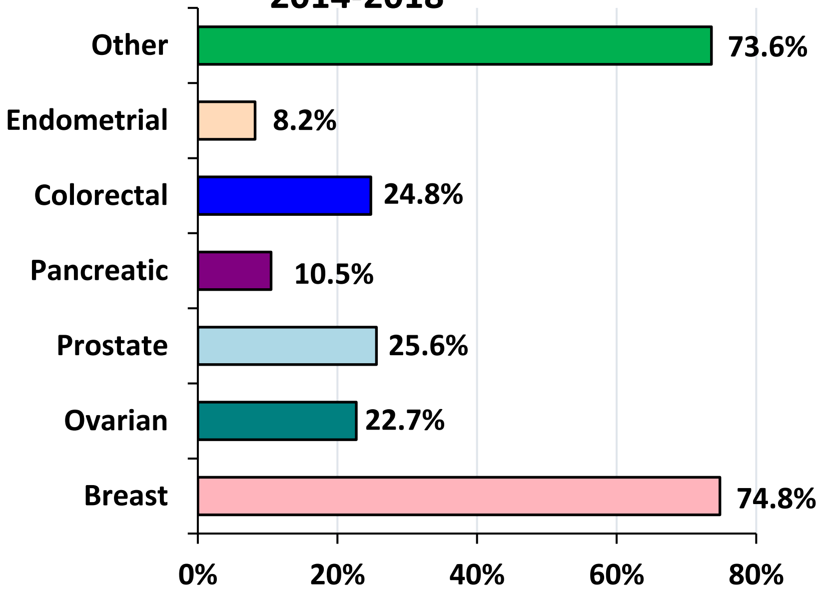
- American Indians were more likely to have a relative diagnosed with breast cancer at a young age compared to other populations (**59.2% vs. 55.0%**).
  - When broken down by race, that the largest difference is between American Indian and white patients (**54.1%; data not shown**).
- American Indians were more likely to have a male relative diagnosed with breast cancer compared to other populations (**4.4% vs. 3.0%**).
- When broken down by race, that the largest difference in relatives diagnosed with multiple primaries for breast cancer was between American Indian and white patients (**10.5%; data not shown**).

Endometrial Cancer Characteristics, 2008-2018

Data are suppressed* for the number of endometrial cancer patients diagnosed under the age of 50

There were no patients that had multiple primaries

Type of Cancer among Family Members, 2014-2018[b]



- When broken down by race:
  - American Indian patients were more likely to have a relative diagnosed with breast cancer compared to Asian, Arab, and other populations (**74.8% vs. 67.5%; data not shown**).
  - American Indian patients were more likely to have a relative diagnosed with ovarian cancer compared to Black patients (**22.7% vs. 18.4%; data not shown**).
  - American Indian patients were more likely to have a relative diagnosed with endometrial cancer compared to Black patients (**8.2% vs. 4.6%; data not shown**).
- **16.6%** of American Indians had a family history of relatives with both a breast and an ovarian cancer diagnosis, which was significantly greater compared to other populations (**14.0%; data not shown**).
- American Indian patients were less likely to have a relative diagnosed with colorectal cancer compared to other populations (**24.8% vs. 29.3%**).
- American Indian patients were more likely to have a relative diagnosed with some other type of cancer compared to other populations (**73.7% vs. 64.5%).**

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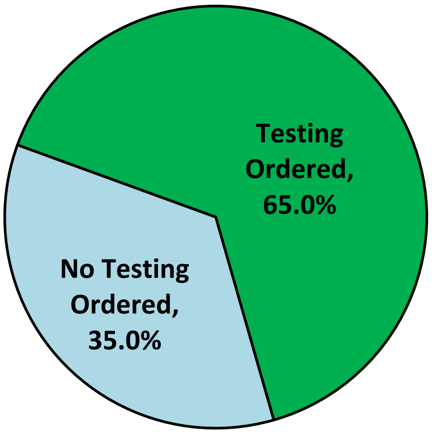
[b] Type of cancer among family members of patients who have a family history of cancer. [c] Characteristics of breast cancer among family members: Young Breast Cancer (YBC), Male Breast Cancer (Male BC), and Multiple Primaries. *Data are suppressed when counts are less than 6.

The American Indian Population: Genetics Services Surveillance, 2008-2018

Genetic Testing among American Indian Patients, 2008-2018

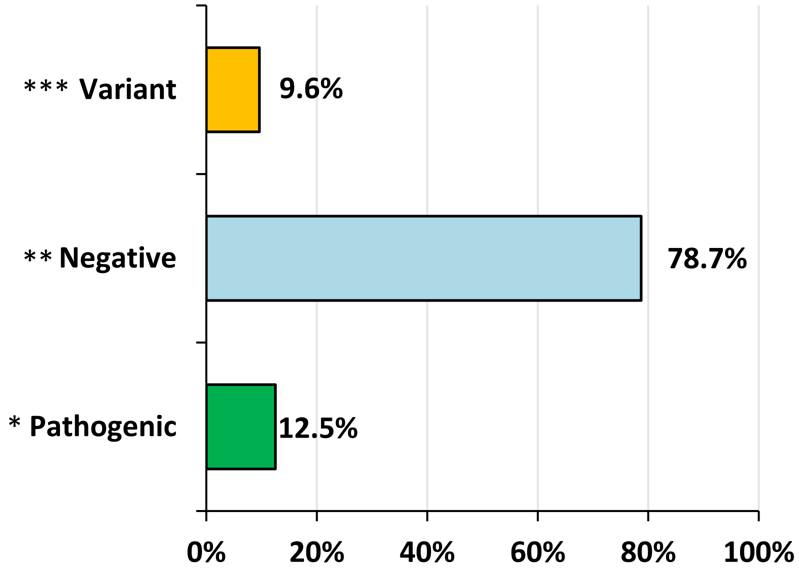


11.1% had single site testing

2.0% had testing prior to counseling

American Indian patients were less likely to receive genetic testing compared to those who did not identify as American Indian (**65.0% vs. 69.5%**), with white patients being the main driver of this difference (**70.3%**).

Genetic Test Results among American Indian Patients, 2008-2018



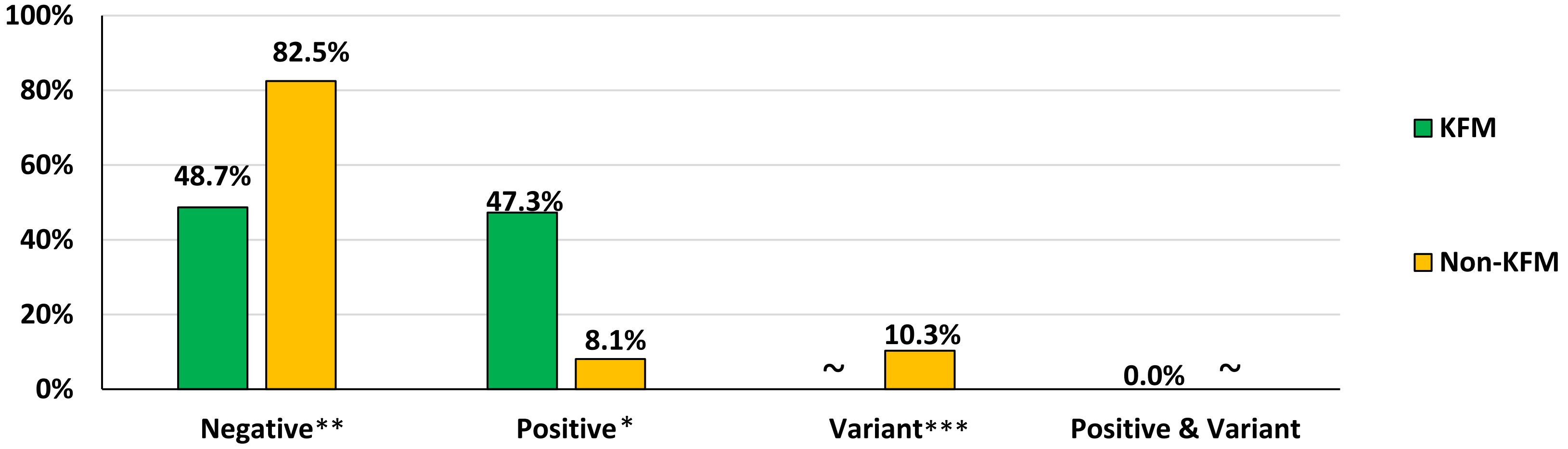
Positive Gene Results among American Indian Patients, 2008-2018

ATM	*BRCA1*
6	6

American Indian patients were less likely to have a positive result compared to other populations (**12.5% vs. 15.8%).**

American Indians were more likely to have a positive gene result for the *ATM* gene (**20.0% vs. 5.8%**) and the *RAD51C* gene (data are suppressed) compared to other populations (**20.0% vs. 5.8%**)

Genetic Test Results among American Indian Patients with and without a Known Familial Mutation (KFM), 2008-2018



American Indian patients with a KFM were more likely to have a positive genetic test result compared to American Indian patients who did not have a KFM (**47.3% vs. 8.1%**).

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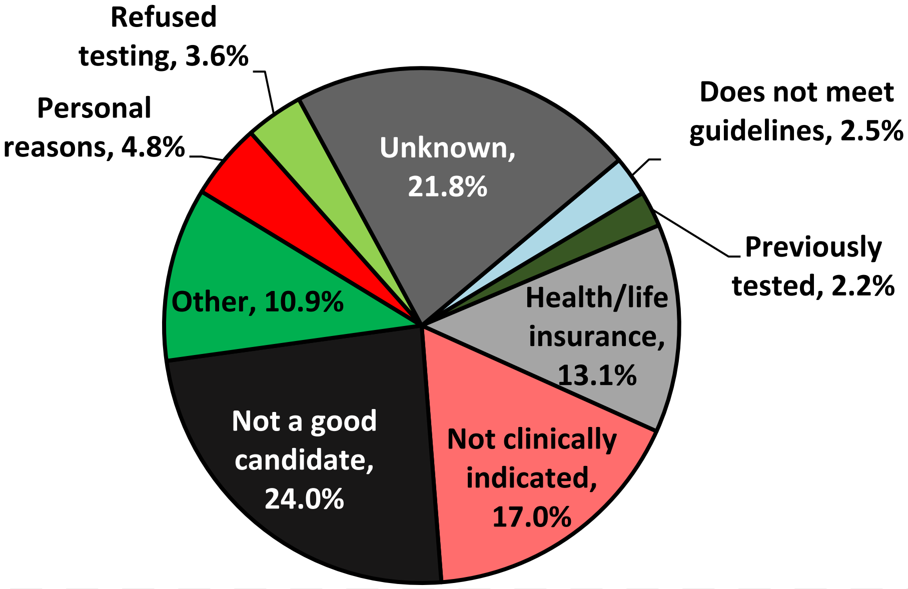
* Pathogenic/Positive result refers to a genetic test result being Pathogenic or Likely Pathogenic. ** Negative result refers to a genetic test result being Benign, Likely Benign or Not Clinically Significant. *** Variant result refers to a result that is classified as a Variant of Uncertain Significance (VUS). ~ Data are suppressed when count is less than 6

The American Indian Population: Genetics Services Surveillance, 2008-2018

Reason Why Genetic Testing Was Not Pursued among American Indian Patients from the HCN & BRCA Databases, 2008-2018

35.0% had no testing performed

American Indian patients were less likely to be considered a good candidate for testing (**24.1% vs. 19.0%**) and were less likely to say they didn't want to know their results (**0.9% vs. 2.4%**) as the reason why testing was not pursued.



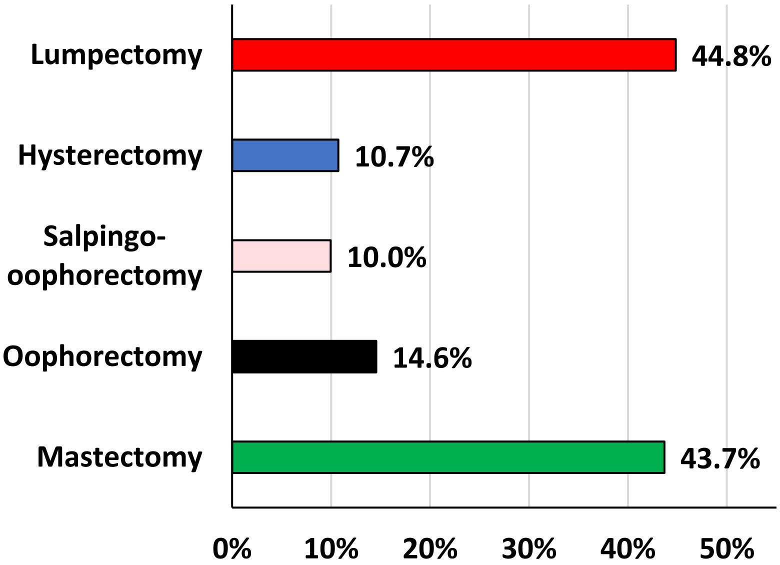
Surgeries from the HCN, 2008-2018

25.5% had surgery performed

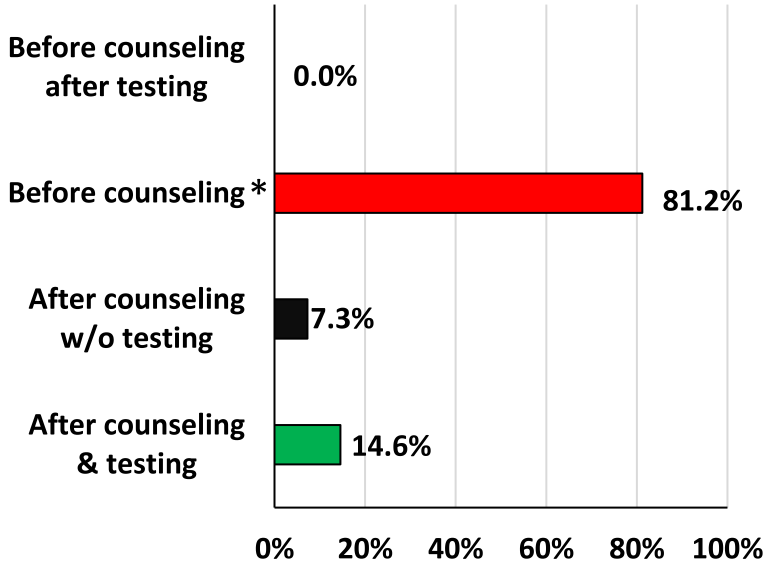
Among those who had surgery, 84.7% had surgery performed for cancer treatment

Among those who had surgery 10.7% had surgery performed for prophylactic reasons

Types of Surgeries from the HCN, 2008-2018



Timings of Surgeries from the HCN, 2008-2018



- Among those who had a surgery performed, there is a trend suggesting that American Indian patients are more likely to have a surgery performed after counseling without testing compared to other populations (**7.3% vs. 4.8%, p = 0.06**).
  - When broken down by race, American Indians had the highest proportion of patients who received survey after counseling without testing (**Black = 7.0%; Other = 5.1%; white = 4.6%**).
- American Indian patients were less likely to have the following procedures done compared to those who did not identify as American Indian:
  - Hysterectomy (**10.7% vs. 17.4%**)
  - Salpingo-oophorectomy (**9.7% vs. 16.1%**)
  - Bilateral salpingo-oophorectomy (**8.9% vs. 14.2%**)

~ Data are suppressed if count is less than 6.

* Includes procedures that are typically done before a genetic counseling appointment happens

Summary & Discussion

- Overall, American Indian patients in the HCN and BRCA databases were less likely to receive cancer genetic testing compared to other populations (**65.0% vs. 69.5%**).
  - Out of the 63 counties where American Indian patients reside, **36 (57%)** had genetic testing rates below **75%.**
- Even though the literature has shown that lung, colorectal, gallbladder, stomach, liver, female breast cancer and kidney cancer are often more common among the American Indian population, not all of these results were replicated from data collected from the HCN.
  - From the HCN, we did see that 51.1% of American Indians were diagnosed with breast cancer, which was significantly greater than white, Black or other populations (**45.3%; data not shown**).
  - However, when looking at data pulled from the cancer registry between 2009 and 2018, we see the following trends:
    - Female breast cancer was less likely to be diagnosed among the American Indian population compared to white, Black or other populations (**13.4% vs. 15.7%**).
    - Colorectal, lung cancer, kidney, and liver cancer were more likely to be diagnosed among the American Indian population compared to white, Black, or other populations (Colorectal: **10.6% vs. 8.1%;** Lung: **18.1% vs. 13.1%;** Kidney: **4.8% vs. 3.3%;** Liver: **3.4% vs. 1.5%**).
      - Data on liver, kidney and lung cancers are not available in the HCN database, due to the database focusing on Hereditary Breast and Ovarian Cancer (HBOC) and cancers associated with Lynch syndrome (LS).
- American Indian patients were less likely to have a positive genetic test result compared to other populations (**12.5% vs. 15.8%).**
  - However, American Indians were more likely to have a positive gene result for the ATM gene (**20.0% vs. 5.8%)** and the RAD51C gene (**data are suppressed**) compared to other populations.
    - Of the 20 genes collected by the HCN database, eight (40.0%) had no American Indian patents with a positive test result
- Of those who met guidelines for genetic testing, only **70%** received genetic testing.
  - Most patients who met guidelines but did not receive testing were told they were not the best candidate since most had a family member who had cancer would be tested first.
  - Patients also indicated that issues with health insurance were why they could not pursue this service.
- MDHHS Cancer Genomics Program (CGP) has worked with the Inter Tribal Counsel of Michigan (ITCM) to create a family history fact card for the American Indian population in Michigan.
  - ITCM has also asked that the MDHHS CGP to provide provider education on this topic, specifically for the populations that they serve due to the creation of this brief.

For More Information

Visit **Michigan.gov/hereditarycancer** to learn more about hereditary cancers.
Cancer Genomics Hotline Phone #: 866 852 1247
Visit **Michigan.gov/cge** to view more data on hereditary cancers.
Email: genetics@michigan.gov

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MDHHS
Michigan Department of Health & Human Services

References:

1. Haring, Rodney (2018). Roswell Park: Native American Cancer Risks. Retrieved September 2021 from: https://www.roswellpark.org/cancertalk/201804/native-american-cancer-risks
2. The Centers for Disease Control and Prevention [CDC] (2021). Cancer in American Indians and Alaska Natives in the United States. Retrieved September 2021 from: https://www.cdc.gov/cancer/dcpc/research/articles/cancer-AIAN-US.htm

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