Findings From the HCN Database

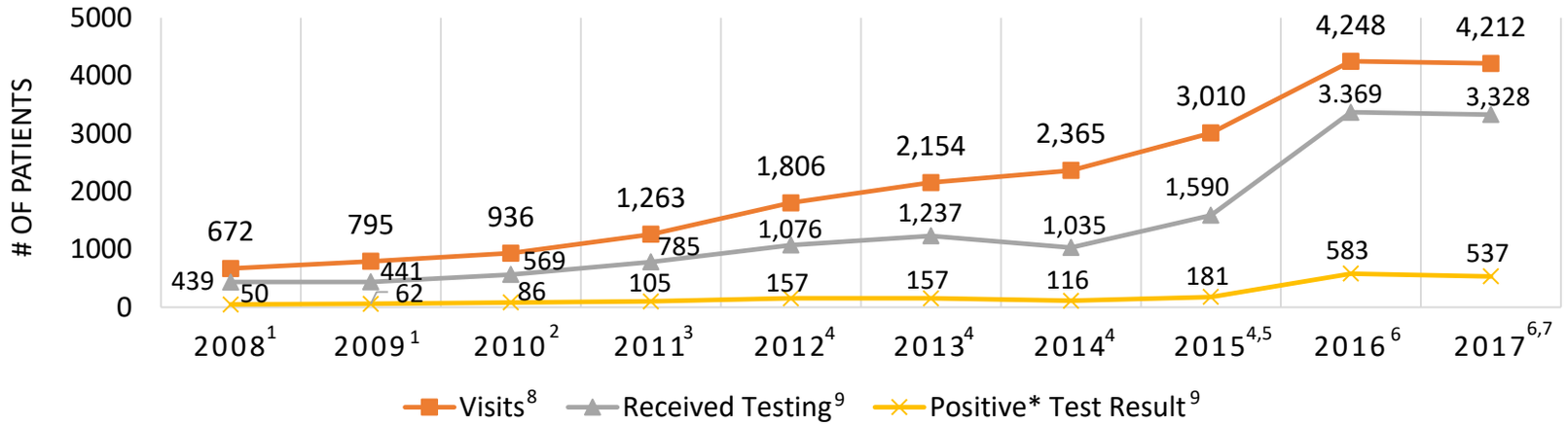
Hereditary Cancer Network, 2016-2017

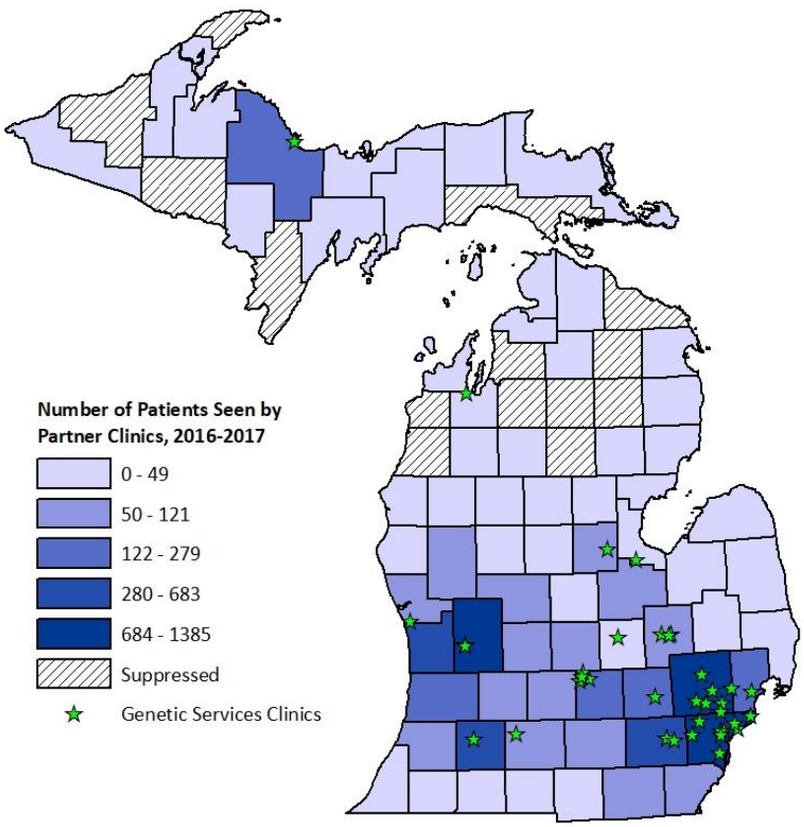
The following data were collected from the Michigan Department of Health and Human Services (MDHHS) Hereditary Cancer Network (HCN) between January 1, 2016 and December 31, 2017. Thirteen partner institutions currently contribute de-identified data on all BReast CAncer (BRCA) gene-related and Lynch syndrome (LS)-related genetic counseling patient visits.

A total of 11,678 records have been entered into the HCN database since 2015, with a total of 8,465 records for 2016-2017. These data were extracted July 19, 2019 and included: demographic information, personal and family history of hereditary cancer, and genetic testing.

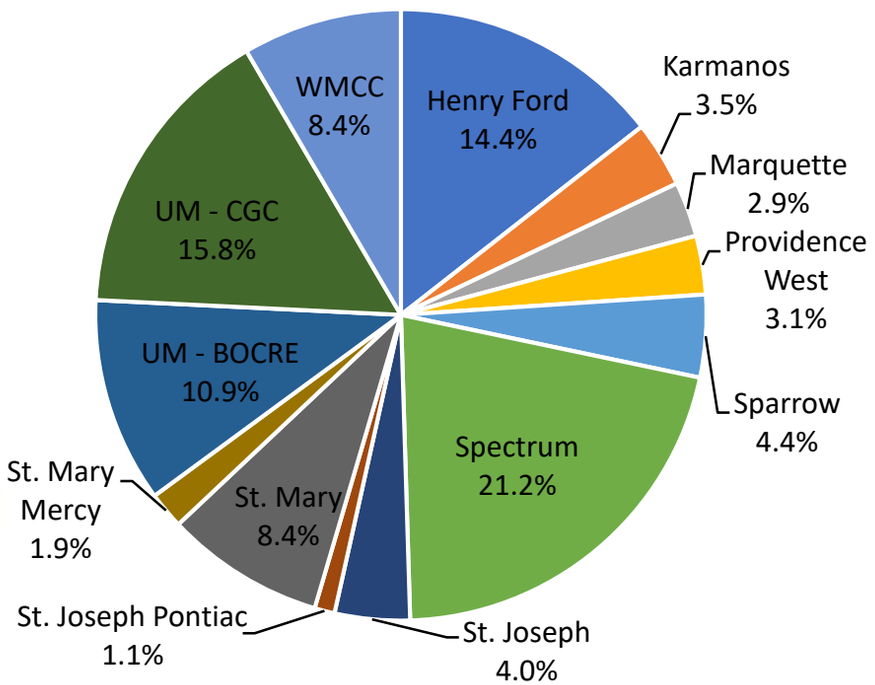
This report is a summary of the patient populations of **all thirteen partner clinics currently contributing** that are at risk for either Hereditary Breast or Ovarian Cancer Syndrome (HBOC) or LS-related cancers**.** Please contact Jessica Fritzler at FritzlerJ1@Michigan.gov for any questions.

HCN: VISITS AND TESTING, 2008-2017





Percent of Cases found in the HCN by Clinic, 2016-2017



[1] At this time, 5 of the currently participating clinics entered data into the BRCA Clinical Network Database. [2] At this time, 6 of the currently participating clinics entered data into the BRCA Clinical Network Database. [3] At this time, 7 of the currently participating clinics entered data into the BRCA Clinical Network Database. [4] At this time, 9 of the currently participating clinics entered data into the BRCA Clinical Network Database. [5] Data for 2015 is incomplete. [6] At this time, 13 of the currently participating clinics entered data into the BRCA Clinical Network Database. [7] Data for 2017 is incomplete . [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.

Hereditary Cancer Network: Demographics, 2016-2017 [10]

Table 1. HCN Patient Demographics, 2016-2017

N = 8,465

	N	%
Gender		
Female	7,360	87.0%
Male	1,101	13.0%
Race/Ethnicity		
White, non-Hispanic	7,096	83.8%
Black, non-Hispanic	655	7.7%
Hispanic	132	1.6%
Arabic/Chaldean	55	0.7%
Native American [11]	159	1.9%
Asian [12]	178	2.1%
Multiracial [13]	50	0.6%
Other	~	~
Unknown	137	1.6%
Age at First Visit (years)		
25 or Younger	317	3.7%
26 – 35	855	10.1%
36 – 45	1,528	18.1%
46 – 55	2,035	24.0%
56 – 65	2,057	24.3%
Older than 65	1,673	19.8%
Ashkenazi Jewish Ancestry	182	2.2%
Primary Insurance Status		
Medicaid	568	6.7%
Medicare	1,575	18.6%
Medicaid and Medicare	86	0.7%
Private Insurer	6,176	73.0%
Uninsured	86	1.0%
Unknown	~	~

- The majority of patients in the Hereditary Cancer Network Database are female (**87.0%**) and identify as White, non-Hispanic (**83.8%**).
- Most patients in the Hereditary Cancer Network Database are between 46 and 55 years of age (**24.0%**), between 56 and 65 years of age (**24.3%**) or are older than 65 years of age (**19.8%**).
- Only **2.2%** of patients in the Hereditary Cancer Network Database identify as Ashkenazi Jewish.
- The majority of patients in the Hereditary Cancer Network Database are insured through a private insurer (**73.0%**), and there are more than twice as many patients who are on Medicare (**18.6%**) compared to Medicaid (**6.7%**).

[10] Data for 2017 is incomplete. [11] Native American category includes those who identify as Black and Native American (0.4%), White and Native American (0.9%) and some other race and Native American (0.3%). [12] Asian category includes those who identify as Asian (2.1%), and Hawaiian (0.02%). [13] Multiracial category includes those who identify as Black and some other race (0.01%), White and Asian (0.12%), White and Black (0.40%) and White and some other race (0.06%). ~Data are suppressed if the frequency count is less than 6.

Table 2. Personal and Family History of Cancer, 2016-2017

N = 8,465

	N	%
Personal History of Any Cancer	5,302	62.6%
Personal History of Breast Cancer	3,337	39.4%
Diagnosed at age 50 or under [16]	1,640	49.1%
Male Breast Cancer [16,18]	51	1.5%
Multiple Primaries [16]	277	8.3%
Triple Negative Breast Cancer [16]	295	8.8%
Personal History of Ovarian Cancer [17]	541	6.4%
Personal History of Prostate Cancer [18]	124	1.5%
Personal History of Pancreatic Cancer	94	1.1%
Personal History of Colorectal Cancer	541	6.4%
Less than 50 years of age [16]	270	49.9%
Personal History of Endometrial Cancer [17]	308	3.6%
Less than 50 years of age [16,17]	88	28.6%
Known Familial Mutation	1,082	12.8%
No Personal History, Only Family History [19]	3,163	37.4%
Only Personal History of Cancer, No Family [20]	515	6.1%
Genetic Testing Ordered	6,905	81.6%
At Least 1 Pathogenic* Result [16]	1,189	17.2%
At least 1 Negative** Result [16]	5,373	77.8%
At least 1 Unknown Result [16]	9	0.1%
At least 1 Variant*** Result [16]	168	2.4%
Single Site [16]	877	12.7%
Genetic Testing Ordered Prior to Visit [16]	143	2.1%

- **62.6%** of patients in the HCN Database have a personal history of some type of cancer.
- **37.4%** of patients in the HCN had family history of cancer, but no personal cancer.
- Of those who have a personal history of cancer, **39.4%** have had breast cancer at least once.
- **Almost half** of those with breast cancer had a diagnosis occur at or before the age of 50.
- Only **1.5%** of patients in the HCN Database are males with breast cancer.
- **6.4%** of patients in the HCN Database had colorectal cancer at least once, with **49.9%** being diagnosed at age 50 or under.
- **12.8%** of patients in the HCN Database had a known familial mutation before the visit.
- **81.6%** of patients in the HCN database received genetic testing.
- Of those who received genetic testing, **17.2%** had at least one positive result.
- Only **12.7%** of patients had single site testing.
- **2.1%** of patients had genetic testing completed before they had genetic counseling.

[15] Data for 2017 is incomplete.
[16] Number and percent displayed is a subset of the previous bolded category.
[17] Female only.
[18] Male only.
[19] 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.
[20] No family history of breast, ovarian, prostate, pancreatic, endometrial, or colorectal cancer but has a personal history of one of these cancers.
~Data are suppressed if the frequency count is less than 6.
* 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).

Table 3. Genetic Test Results by Selected Characteristics, 2016-2017

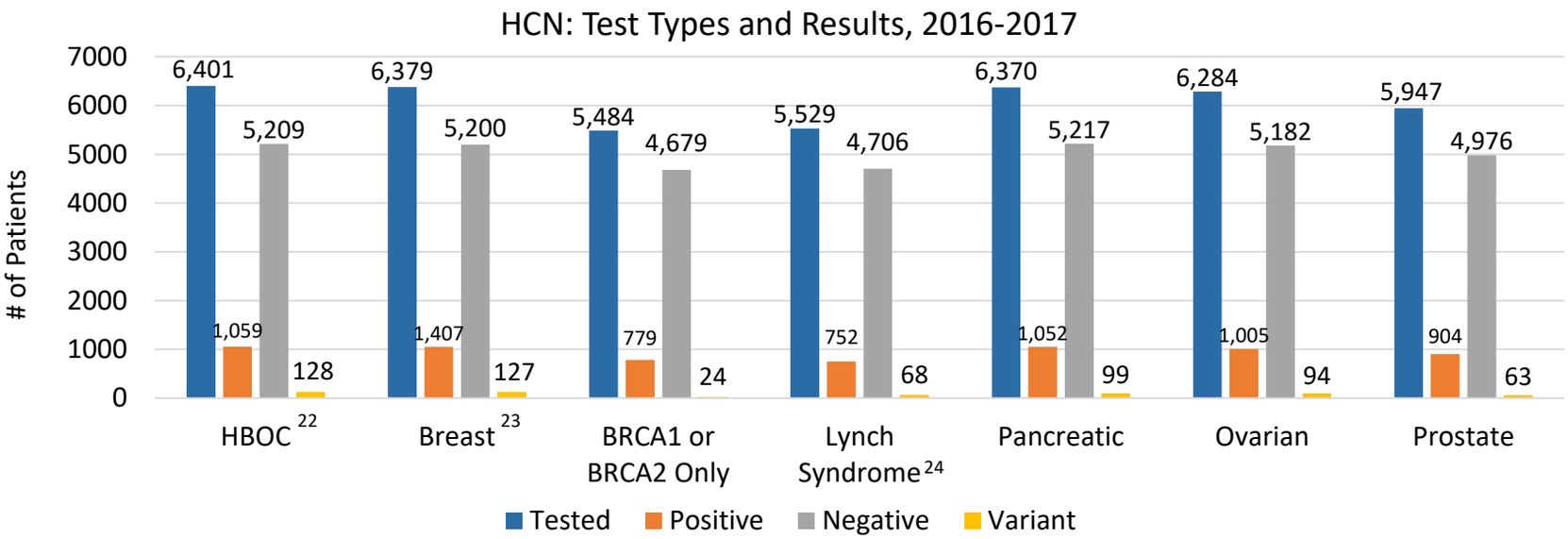
Test Result	Personal History of Breast, Ovarian, Prostate, Pancreatic, Endometrial, or Colorectal Cancer ONLY		Family History of Breast, Ovarian, Prostate, Pancreatic, Endometrial, or Colorectal Cancer ONLY	
	N	%	N	%
Negative**	367	71.3%	1,669	52.8%
Positive *	43	8.3%	504	15.9%
Variant ***	19	3.7%	35	1.1%

- With those that have a personal history of Breast, Ovarian, Prostate, Pancreatic, Endometrial, or Colorectal Cancer only, **367** (71.3%) had a negative test result and **43** (8.3%) had a positive result.
- With those that have a family history of Brest, Ovarian, Prostate, Pancreatic, Endometrial, or Colorectal Cancer only, **1,669** (52.8%) had a negative test result and **504** (15.9%) had a positive result.

Table 4. Genetic Test Results by Selected Characteristics, 2016-2017

Test Result	Single Site		Known Familial Mutation	
	N	%	N	%
Negative **	467	53.2%	553	51.1%
Positive *	399	45.5%	465	43.0%
Variant ***	6	0.7%	8	0.7%

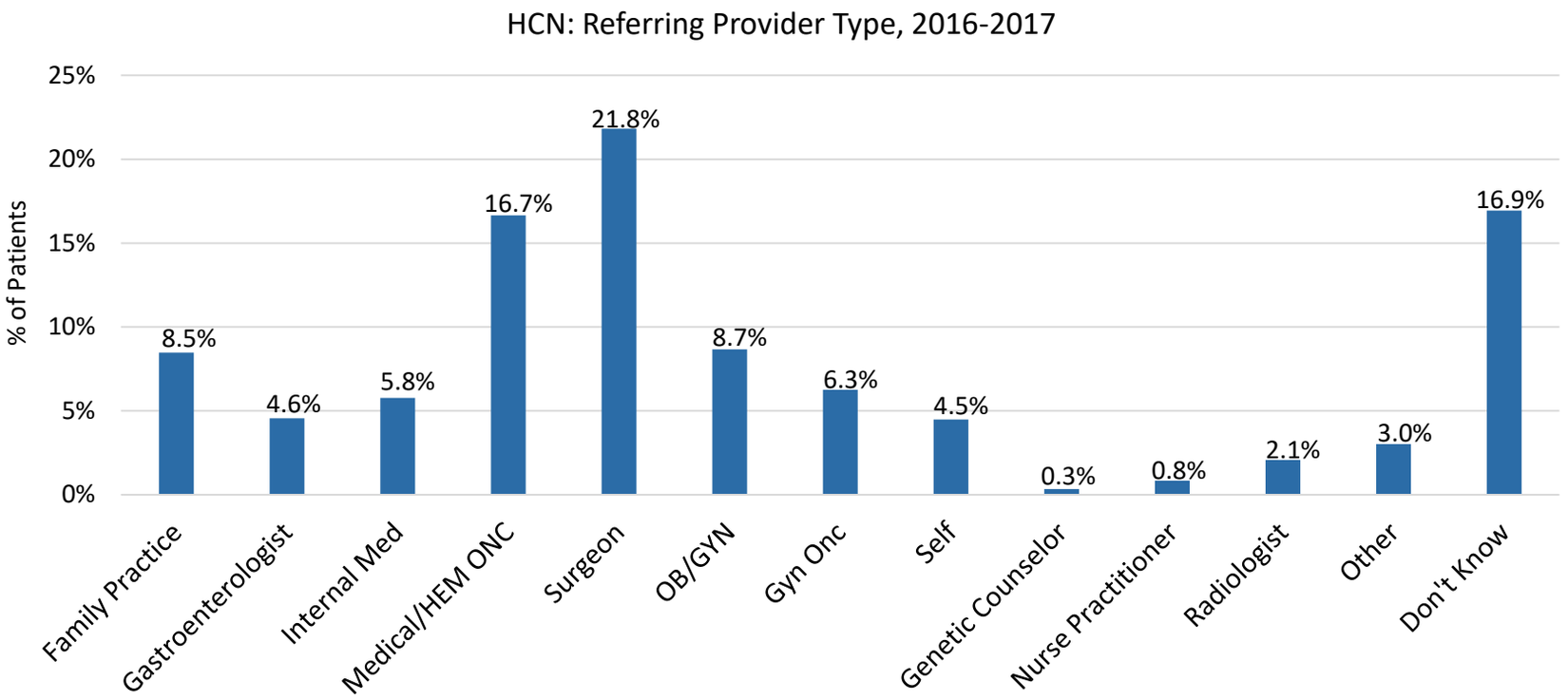
- Of those who had single site testing, **467** (53.2%) had a negative result and **399** (45.5%) had a positive result.
- Of those with a known familial mutation, **553** (51.1%) had a negative result and **465** (43.0%) had a positive result.



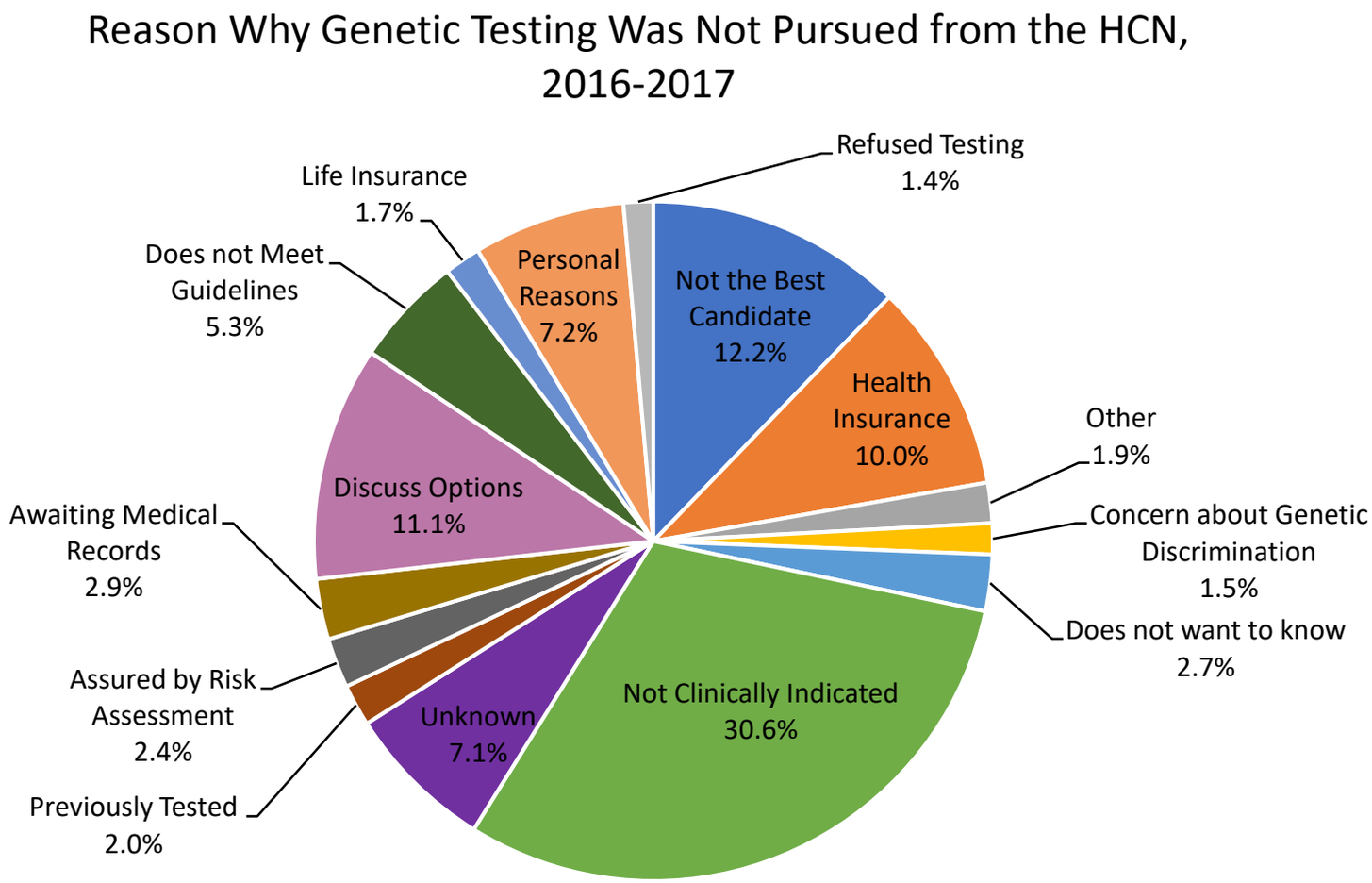
- Of those who received genetic testing, **6,401** (92.7%) were tested for genes associated with Hereditary Breast or Ovarian Cancer (HBOC) and **5,529** (80.1%) were tested for genes associated with Lynch Syndrome (LS).
- Of those who were tested for genes associated with HBOC, **1,059** (16.5%) had a positive result.
- Of those who were tested for genes associated with LS, **752** (13.6%) had a positive result.

[21] Data for 2017 is incomplete. [22] HBOC test means any of the 19 clinically actionable genes that are associated with Hereditary Breast or Ovarian Cancer. [23] Breast Test means any of the 19 clinically actionable genes that are associated with breast cancer only. [24] Lynch Syndrome Test means any of the 19 clinically actionable genes that are associated with colorectal or endometrial cancers. * 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: Select Characteristics, 2016-2017 [25]



- 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 (**21.8%**) or from a Medical Hematologist Oncologist (**16.7%**).

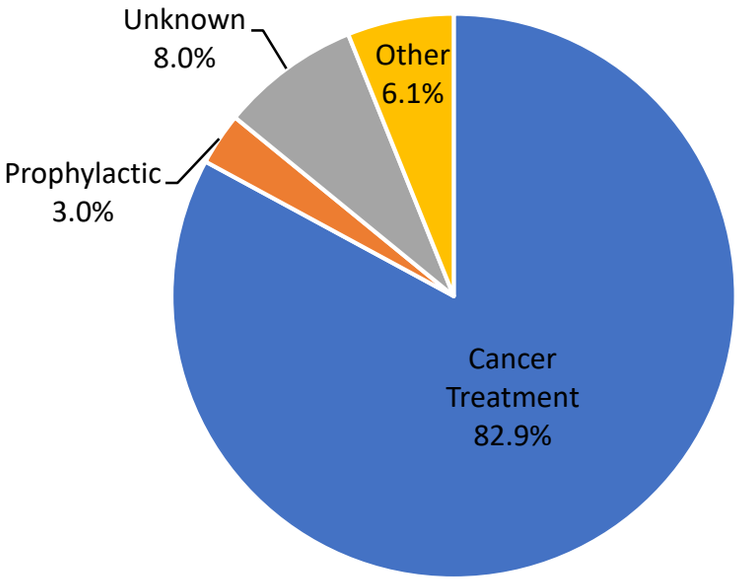


- Of those who decided to not pursue genetic testing at the time of the genetic counseling appointment, most did not receive testing because it was not clinically indicated by the physician (**30.6%**), followed by not being the best candidate for the genetic test (**12.2%**) and having some issue with coverage due to health insurance (**10.0%**).

[25] Data for 2017 is incomplete.

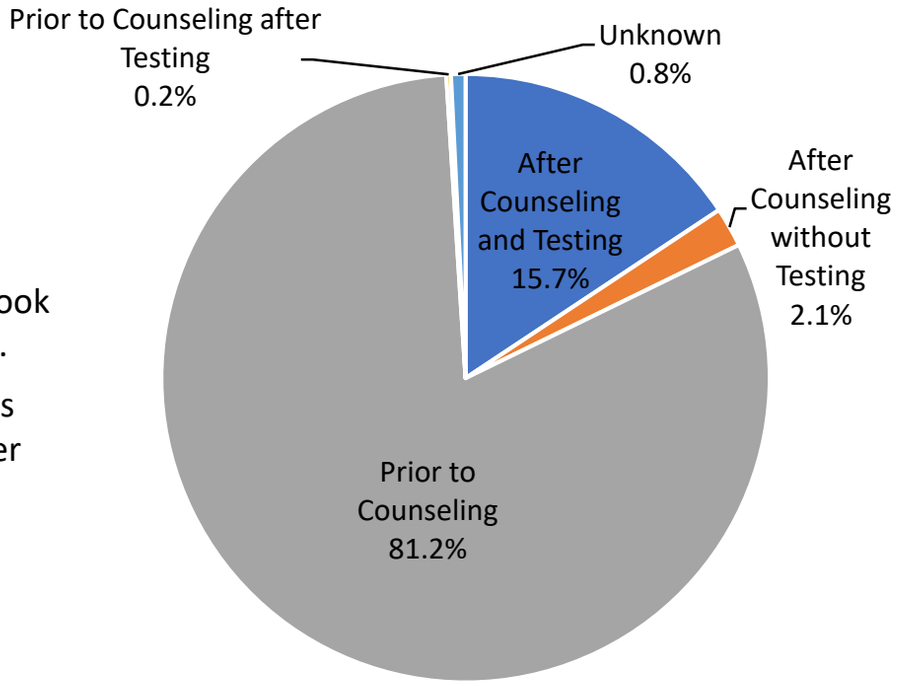
Hereditary Cancer Network: Surgeries, 2016-2017 [26]

Reasons for Patients Opting for Surgery from the HCN, 2016-2017



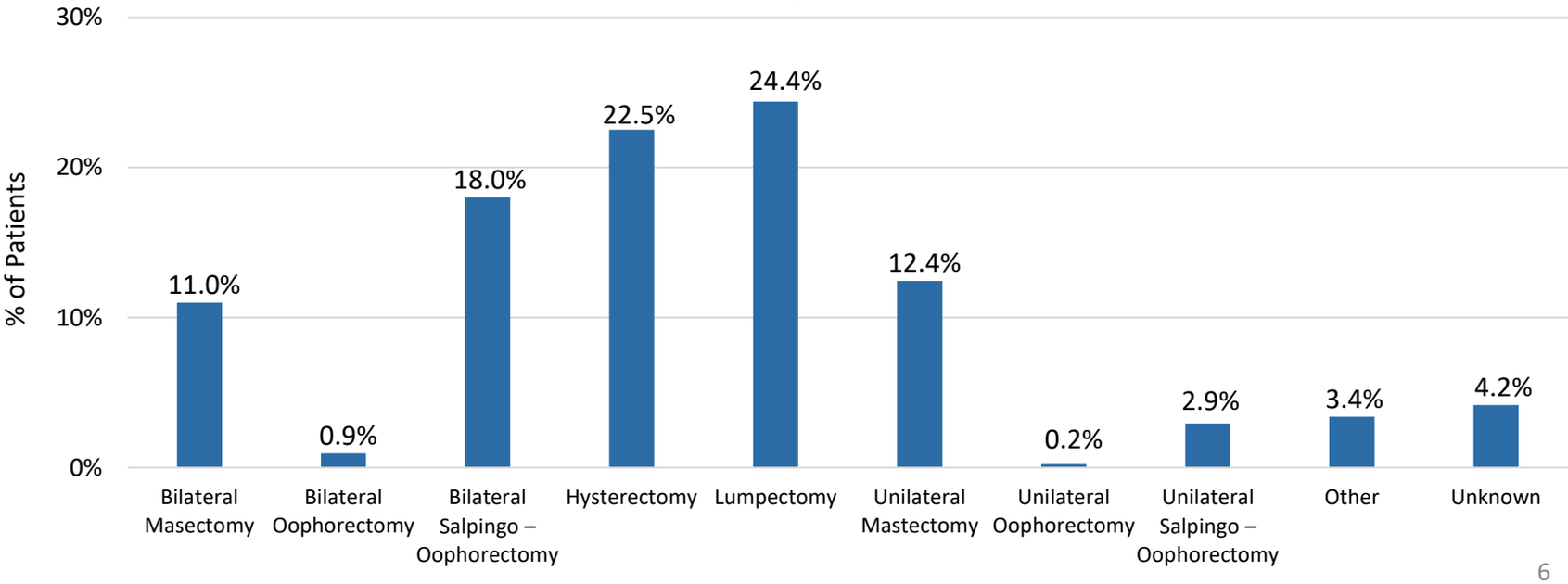
- The majority of patients seen in the HCN Database received some type of surgery for the purpose of cancer treatment (**82.9%**), with only **3.0%** of surgeries being for prophylactic reasons.

Timing of Surgeries from HCN, 2016-2017



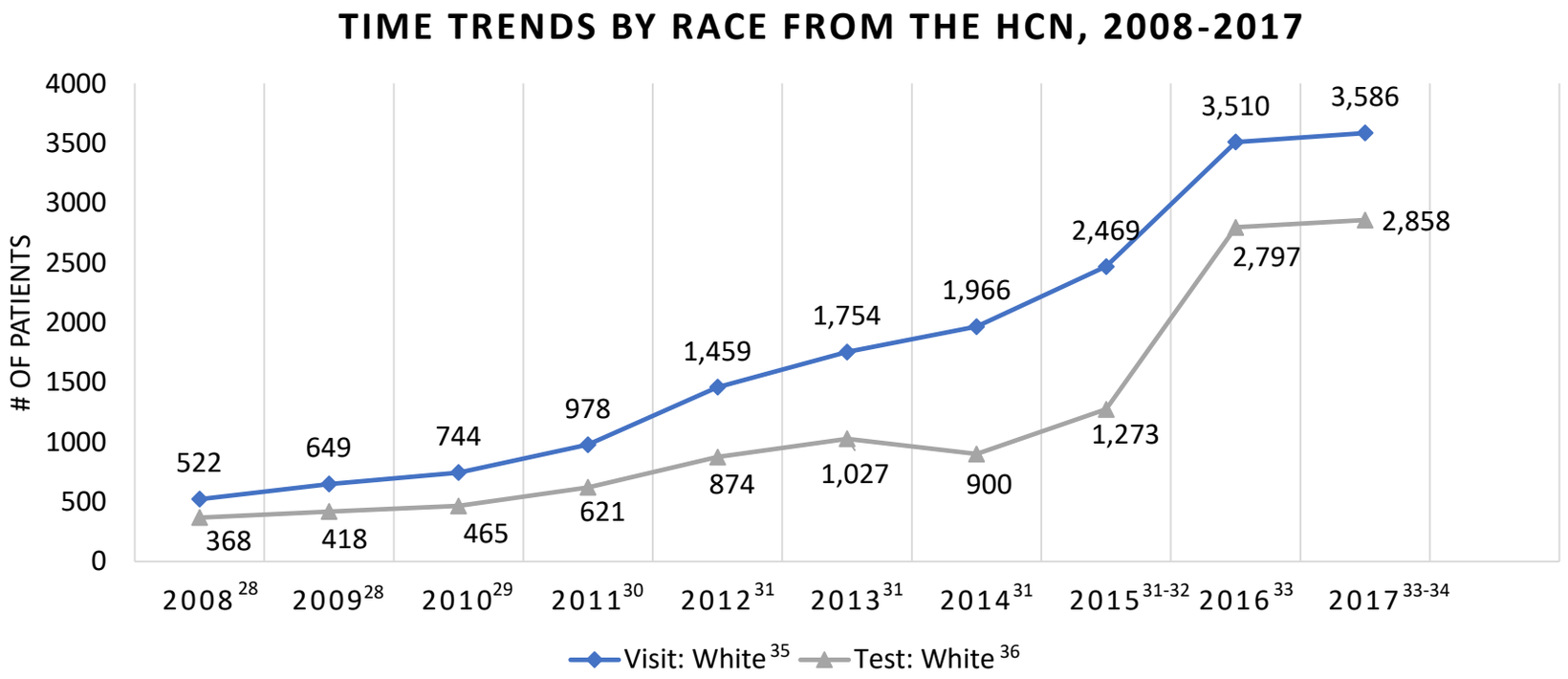
- Of those who had surgery, the majority took place prior to genetic counseling (**81.2%**).
- About **2.1%** of patients who had surgeries during this time period had surgeries after counseling, but before they had genetic testing done.

HCN: Type of Surgery, 2016-2017

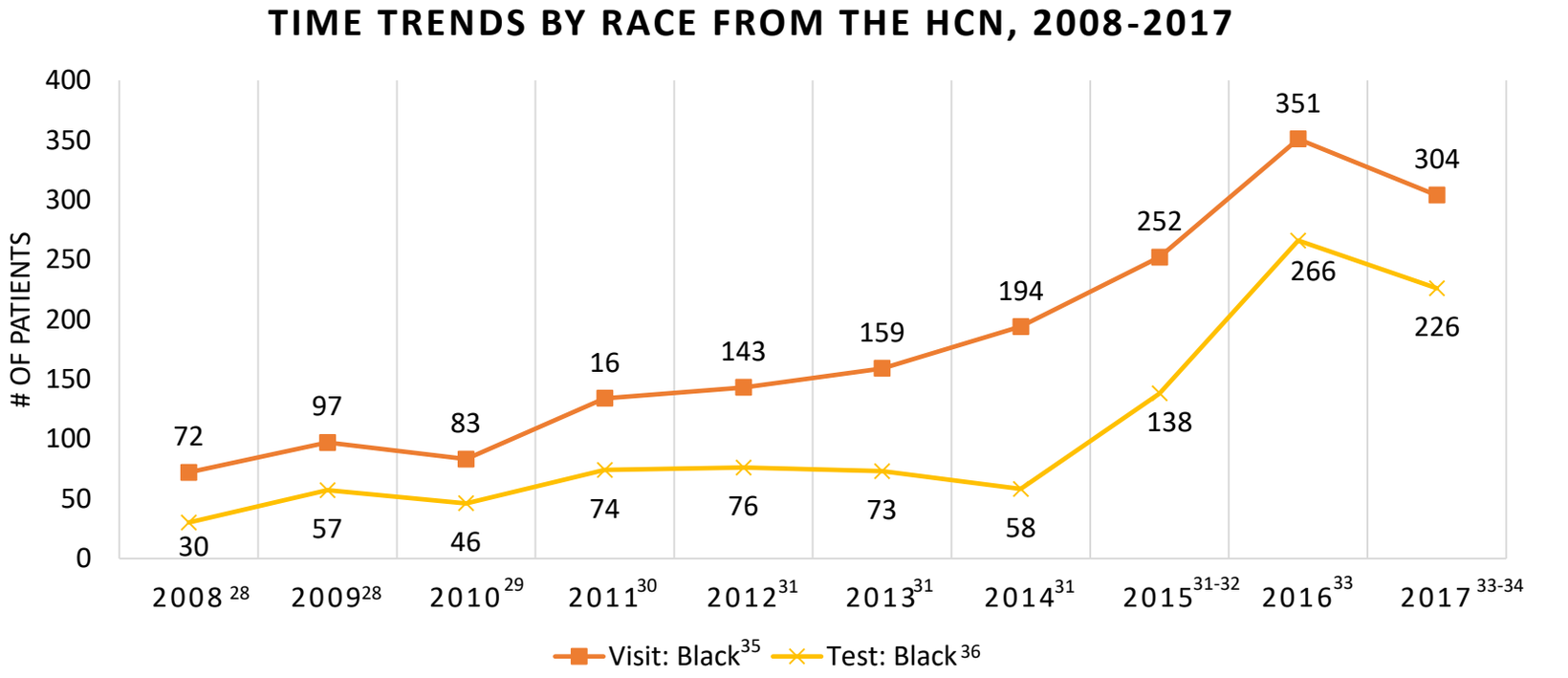


[26] Data for 2017 is incomplete

Hereditary Cancer Network: Time Trends, 2016-2017 [27]



- In 2016, **2,797** (79.7%) White patients in the HCN received genetic testing.
- The amount of White patients who received genetic testing increased to **2,858** (72.1%) in 2017.



- In 2016, **351** (75.8%) Black patients in the HCN received genetic testing.
- The amount of Black patients who received genetic testing slightly decreased to **226** (74.3%) in 2017.

[27] Data for 2017 is incomplete. [28] At this time, 5 of the currently participating clinics entered data into the BRCA Clinical Network Database. [29] At this time, 6 of the currently participating clinics entered data into the BRCA Clinical Network Database. [30] At this time, 7 of the currently participating clinics entered data into the BRCA Clinical Network Database. [31] At this time, 9 of the currently participating clinics entered data into the BRCA Clinical Network Database. [32] Data for 2015 is incomplete. [33] At this time, 13 of the currently participating clinics entered data into the BRCA Clinical Network Database. [34] Data for 2017 is incomplete . [35] 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. [36] 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[37]. 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 2016 and 2017, the majority were seen at Spectrum Health System.
- Among patients seen in 2016 and 2017, the majority resided in Wayne (16.4%), Kent (13.9%) and Oakland (11.9%) counties.
- Patients with only a family history of cancer were almost twice as likely (15.9%) to have a positive genetic test result compared to those with only a personal history of cancer (8.3%).
- There were only slightly more patients who received genetic testing for genes related to HBOC (92.7%) than who received genetic testing for genes related to LS (80.1%).
  - Both groups of individuals had approximately the same amount of positive genetic test results (13.6% and 16.5%).
- In 2016, 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 (79.7% of White patients and 74.3% of Black patients).
- 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 (72.1% of White patients and 74.3% of Black patients).

Visit www.Michigan.gov/hereditarycancer to learn more about hereditary cancers
Visit www.Michigan.gov/cge to view more data on hereditary cancers

Suggested Citation:

Fritzler J, Anderson B, and Olsabeck T. (2019). Findings from the Hereditary Cancer Network 2016-2017. Bureau of Epidemiology and Population Health, Michigan Department of Health and Human Services.

MDHHS
Michigan Department of Health & Human Services
GRETCHEN WHITMER, GOVERNOR | ROBERT GORDON, DIRECTOR

[37] 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 Cancer Genomics Best Practices Cooperative Agreement DP14-1407, 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.