Using State Cancer Registries to Evaluate Potentially Hereditary Cancers

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Introduction

The Michigan Department of Community Health (MDCH) and the Oregon Genetics Program, in collaboration with the Centers for Disease Control and Prevention (CDC) Office of Public Health Genomics, are conducting surveillance to promote evidence-based genomics best practices. Data from their respective state cancer registries has been used to increase the understanding of statewide incidence rates and trends related to possible inherited cancers including:

BRCA1/2 related cancers:
Breast
Ovarian

HNPCC related cancers:
Colorectal
Ovarian
Endometrial

Michigan and Oregon both participate in the National Program of Cancer Registries through CDC. The state-based registries collect, manage and analyze data on cancers in their states. These registries collect data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. Michigan and Oregon are using this large set of data as a potential surveillance method to estimate the need of genetic services in the two states due to residents' personal history of cancer.

Methods

Michigan and Oregon analyzed cancer registry data from 1997-2006. The registry staff identified cases which had a primary cancer that was possibly associated with BRCA 1/2 or HNPCC in that time period (i.e. breast, ovarian, colorectal, endometrial). When ovarian cancer is discussed it includes fallopian tube and primary peritoneal cancers with ovarian diagnoses.

Genetics program staff then identified cases that had more than one multiple primary cancer of interest, such as breast-breast or breast-ovarian. These cases were identified for their likelihood of having an inherited cause.

The number of cases were examined and rates were calculated to make the numbers comparable between the states. The rates were age-adjusted to the 2000 US Standard Population. Multiple primary cancer rates were presented as crude rates.

The two states developed specific criteria to identify cancer cases that could be related to either a BRCA1/2 mutation or an HNPCC mutation. Those criteria included:

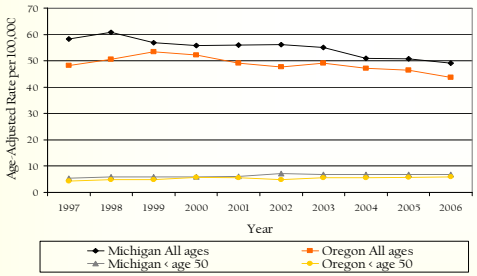
- Early-onset cancer diagnoses (before age 50)
- Males with breast cancer diagnoses
- Multiple primary cancer diagnoses related to BRCA1/2 or HNPCC

Results

The population demographics in Michigan and Oregon are quite different. In 2009, Michigan had a population just under 10 million residents and reported approximately 64,000 cases of cancer annually, whereas Oregon had under 4 million residents and reported approximately 20,000 cases of cancer annually.

Michigan and Oregon began by examining the incidence trends for each of the primary cancers of interest. Colorectal cancer trends in both states were remarkable when the rates were broken down by age group (Figure 1). The age-adjusted colorectal incidence trend among all ages appears to be decreasing, Michigan saw a decrease of 15.8% in the 10 year period and Oregon saw a 9.1% decrease. However, when the rate was calculated for those under the age of 50 the rates appear to be increasing, Michigan increased by 25.9% and Oregon by 34.1%.

Figure 1. Age-adjusted colorectal cancer incidence rates by age group for Michigan and Oregon, 1997-2006.



As was expected, male breast cancer incidence is very rare in both Michigan (1.5 per 100,000) and Oregon (1.0 per 100,000), however early-onset female breast cancer was much more common (Table 1). In a ten year period Michigan had 15,679 cases of early-onset breast cancer (42.2 cases per 100,000 women), and Oregon had 5,228 cases (41.2 per 100,000 women). Michigan had 2,093 cases of early-onset endometrial cancer (5.6 cases per 100,000 women, and Oregon had 556 cases (4.4 per 100,000 women).

Table 1. The numbers and rates for select primary cancers in Michigan and Oregon between 1997-2006

Cancer Type	Michigan N (age-adjusted rate per 100,000)	Oregon N (age-adjusted rate per 100,000)
Breast (Males)	662 (1.5)	170 (1.0)
Early-Onset‡ Breast (Females)	15,679 (42.2)	5,228 (41.2)
Early-Onset‡ Endometrial (Females)	2,093 (5.6)	556 (4.4)

‡ Early-onset is defined as before the age of 50 years

The multiple primary cases were compared between the two states and the rates were very similar except for breast cancer (Table 2). This difference is likely related to Oregon having one of the highest breast cancer rates in the country.

The highest rate of multiple primaries was for breast-breast. Michigan had a rate of 4.9 per 100,000 women and Oregon had a rate of 8.2 per 100,000 women. The second highest number and rate of multiple primaries for both Michigan and Oregon was people with two or more colorectal diagnoses.

Table 2. The numbers and rates for select multiple primaries in Michigan and Oregon between 1997-2006

Cancer Type	Michigan N (crude rate per 100,000)	Oregon N (crude rate per 100,000)
Breast-Breast*	2,498 (4.9)	1,449 (8.2)
Colorectal-Colorectal	2,234 (2.2)	642 (1.8)
Ovarian-Endometrial*	290 (0.6)	107 (0.6)
Breast-Ovarian*	202 (0.4)	112 (0.6)
Ovarian-Ovarian*	90 (0.2)	15 (0.1)
Endometrial-Endometrial*	109 (0.2)	10 (0.06)
Colorectal-Endometrial	210 (0.2) (0.4)*	63 (0.2) (0.4)*
Colorectal-Ovarian	103 (0.1) (0.2)*	34 (0.1) (0.2)*

*Rates were calculated using female population only

Discussion

Michigan and Oregon had success in using their state cancer registries to identify trends and incidence rates for specific cancers of genomics interest. To our knowledge this is the first time that multiple primaries have been investigated using state cancer registry data. Michigan has also started to use this data to educate providers about cancer genomics and the populations at risk in the state and in their facilities. Michigan and Oregon plan to continue using this surveillance method as a way to collect information on possible hereditary cancers and to track and evaluate their trends in the future as a measure of their programs' impact.

In the future, both states would like to explore the few differences they had (breast-breast and endometrial-endometrial multiple primaries) to determine the possible reasons for the discrepancies. It would also be helpful to have national statistics to compare with state results. Finally, it is unknown whether these high-risk individuals have received genetic evaluation and counseling and have had a genetic test. An important next step would be to add a required field to the cancer registry on genetic services and/or genetic test results.

The programs concluded that state registries can be used to assess the potential high-risk populations who may benefit from genetic services. The two states had similar rates which indicates this surveillance method could be used more widely by other state health departments or genomics programs for surveillance and educational activities.

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