Public Health Surveillance of BRCA Testing Using Clinical Cancer Genetics Data
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Background

In 2005, the U.S. Preventive Services Task Force (USPSTF) issued the following evidence-based recommendation for BRCA1 & 2 genetic counseling and risk assessment1.

**U.S. Preventive Services Task Force BRCA Guidelines**

“Women whose family history is associated with an increased risk for deleterious mutations in BRCA1 or BRCA2 genes should be referred for genetic counseling and evaluation for BRCA testing.” (Grade B Recommendation)

USPSTF also recommends against routine referral for women whose family history is not associated with increased risk

Since 2008 the Michigan Department of Community Health (MDCH) Cancer Genomics Program has developed methods to promote translation of the USPSTF BRCA recommendation into clinical and public health practice as part of a cooperative agreement with the Centers for Disease Control and Prevention (CDC). Using 2008 Michigan Behavioral Risk Factor Surveillance data, we found that 8.7% of Michigan women appear to meet the USPSTF family history criteria for genetic referral; however, only 12.4% of these women with increased risk for BRCA mutations receive counseling, and 5.2% receive genetic testing2. In addition to other surveillance activities, evaluation of the clinical use of BRCA 1 & 2 testing is underway.

Objectives

- To establish a surveillance system for evaluating the appropriate use of BRCA counseling and testing as set forth in the USPSTF recommendation
- To form a network of cancer genetics clinics to participate in data collection
- To develop a tool for collecting and sharing de-identified patient data

Methods

MDCH genomics staff has identified and recruited cancer genetics clinics to participate in the network. They agreed to collect de-identified patient information on all BRCA 1 & 2 referrals between October 2007-March 2011.

**Examples of Information Collected**

- Demographics of patients (age, gender, race/ethnicity)
- Personal and family history of cancer
- Type of BRCA test ordered
- Reason not tested

A database was developed that features drop-down menus and tabs for easy navigation (Figure 1). MDCH genomics staff also developed a collection tool user manual and provided training on the data collection process. The network began with four pilot clinics that provided training on the data collection process. MDCH genomics staff also developed a collection tool user manual and provided training on the data collection process.

![Figure 1. Screenshot of the data collection tool.](image)

**Table 1. Demographic data, October 2007 to October 2009.**

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Clinic A</th>
<th>Clinic B</th>
<th>Clinic C</th>
<th>Clinic D</th>
<th>Clinic E</th>
<th>Clinic F</th>
<th>Clinic G*</th>
<th>Clinic H*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number (%)</td>
<td>Number (%)</td>
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<td>Number (%)</td>
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<td>Number (%)</td>
</tr>
<tr>
<td>Total Patients</td>
<td>310</td>
<td>297</td>
<td>195</td>
<td>847</td>
<td>256</td>
<td>229</td>
<td>63</td>
<td>97</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11 (3.5)</td>
<td>13 (4.4)</td>
<td>5 (2.6)</td>
<td>47 (5.5)</td>
<td>7 (2.7)</td>
<td>5 (2.3)</td>
<td>3 (4.8)</td>
<td>7 (7.2)</td>
</tr>
<tr>
<td>Female</td>
<td>299 (96.5)</td>
<td>284 (95.6)</td>
<td>190 (97.4)</td>
<td>800 (94.5)</td>
<td>249 (97.3)</td>
<td>224 (97.8)</td>
<td>60 (95.3)</td>
<td>88 (90.7)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>229 (73.9)</td>
<td>231 (77.8)</td>
<td>159 (81.5)</td>
<td>736 (86.9)</td>
<td>236 (92.2)</td>
<td>181 (79.0)</td>
<td>62 (98.4)</td>
<td>86 (88.7)</td>
</tr>
<tr>
<td>Black</td>
<td>69 (22.3)</td>
<td>55 (18.5)</td>
<td>11 (5.6)</td>
<td>51 (6.0)</td>
<td>7 (2.7)</td>
<td>16 (7.0)</td>
<td>1 (1.6)</td>
<td>4 (4.1)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (3.9)</td>
<td>10 (3.4)</td>
<td>8 (4.1)</td>
<td>58 (6.8)</td>
<td>11 (4.3)</td>
<td>31 (13.5)</td>
<td>6 (10.0)</td>
<td>6 (6.2)</td>
</tr>
<tr>
<td>Ashkenazi Jewish</td>
<td>Yes</td>
<td>14 (4.5)</td>
<td>46 (15.5)</td>
<td>9 (4.6)</td>
<td>152 (17.9)</td>
<td>28 (10.9)</td>
<td>3 (1.3)</td>
<td>2 (3.2)</td>
</tr>
<tr>
<td>Personal History of Cancer</td>
<td>Yes</td>
<td>192 (61.9)</td>
<td>174 (58.6)</td>
<td>114 (58.5)</td>
<td>505 (59.6)</td>
<td>166 (64.8)</td>
<td>132 (57.6)</td>
<td>45 (71.4)</td>
</tr>
<tr>
<td>Relative With Cancer History</td>
<td>Yes</td>
<td>288 (92.9)</td>
<td>290 (97.6)</td>
<td>192 (98.5)</td>
<td>808 (95.4)</td>
<td>246 (96.1)</td>
<td>219 (95.6)</td>
<td>51 (81.0)</td>
</tr>
</tbody>
</table>

*Clinics G and H display data for a one year period, October 2007 to October 2008. Only patients seen for an initial visit were included.

**Table 1.** Demographic data, October 2007 to October 2009.

The majority of patients were female (95.6%) and white (83.7%). Blacks comprised the second largest racial group (9.3%), and 11.4% of patients seen for counseling reported Ashkenazi Jewish ancestry. More than half of those counseled (59.3%) had a personal history of cancer, and the majority (95.4%) had at least one relative with a history of cancer. There were a few demographic differences by clinic. Clinics A and B saw more than twice the proportion of blacks than the other clinics, while Clinics C and D had higher proportions of Ashkenazi Jewish patients. Clinic G saw a high percentage of patients with a personal history of cancer and a relatively low percentage with a family history of cancer (Table 1).

The majority (72.1%) of patients seen for an initial counseling session received BRCA1 & 2 testing. A total of 263 patients were found to have a deleterious mutation and 72 patients had variants of unknown significance. Of the 640 patients who were not tested, the primary reason for lack of testing was that the patient was not the best test candidate in the family (25.0%). The second most cited reason for declining testing was because of inadequate insurance coverage (17.5%).

**Conclusion**

This cancer genetics surveillance network is the first of its kind and now includes all Michigan clinics with a board certified genetics professional that offer BRCA cancer genetic services. The collection methods and database tool can serve as a foundation for other state health departments working to evaluate the use of BRCA counseling and testing within their state.

Multiple demographic differences were seen across the clinics which may be due to their diverse geographic locations throughout the state. The data regarding reasons patients do not pursue testing highlights the need to test the affected relative first in order to make the test results informative for other family members and most cost-effective for the health system and insurer. Insurance status was the second most cited reason that patients declined BRCA 1 & 2 testing, showing that more education for health insurers is necessary to promote coverage of appropriate tests. We are currently addressing this issue through additional cooperative agreement activities targeting health plans.

The data obtained through this surveillance program provide a baseline measure for assessing Michigan’s progress toward meeting the following Healthy People 2020 objective:

**Healthy People 2020 Objective**

Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling.

The data will also be used to measure the impact of the MDCH Cancer Genomics Program’s efforts to educate health care providers and promote health plan policy alignment with the USPSTF BRCA recommendation.

Future activities to promote best practices include examining the logistics of linking the BRCA clinical surveillance data to the Michigan Cancer Surveillance Program. We also plan to survey patients with known deleterious mutations, identified through the clinical network, to learn more about their follow-up care and clinical decision making.

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