Bidirectional Reporting of Michigan Cancer Registry Data: A Pilot Project

4th National Conference on Genomics and Public Health
December 9, 2010

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Outline

• Overview of the Michigan Cancer Surveillance Program (MCSP)
• Genomics and MCSP
• The Facility Specific Report
  – What cancers are included
  – What materials are in the report
  – How they were disseminated
  – Who receives the report
• Evaluation
• Future Steps
Michigan Cancer Surveillance Program (MCSP)

- MCSP has been collecting cancer data since 1985
- Reported through 2 sources:
  - National Program of Cancer Registries (NPCR)
  - National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program
- Collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment.
MDCH Genomics received a 5-year CDC cooperative agreement to incorporate genomics into chronic disease.

2003

MCSP and Genomics

Family history collection project with MCSP.

2004

MCSP decides to implement a mandatory family history element.

2005

Both discussed the possibility of creating a bi-directional reporting system using MCSP data.

2007

MDCH Genomics was awarded a 3-year cooperative agreement to apply cancer genomics best practices.

2008

Genomics and MCSP developed a bi-directional reporting system.

2009

Genomics and MCSP implemented a bi-directional reporting system.

2010
Cooperative Agreement

• Promote cancer-genomics best practices and evidence-based recommendations
  – U.S. Preventive Services Task Force
  – EGAPP
• Activities include surveillance, education, and health plan policy projects
• This project demonstrates the translation of surveillance data into education
**Multiple Primaries Methods**

- 1990-2007 cancer registry data, with at least one diagnosis in 2006 or 2007
- Proxies for cancers with a higher genetic load
- Multiple primaries defined as two or more BRCA1/2 or HNPCC- potentially related cancers that were classified as separate primary tumors
- Examples of multiple primaries: breast-breast, breast-ovarian, colorectal-endometrial, and colorectal-colorectal
Single Primary Cancers

• Number of cancer cases in 2006-2007 with a diagnosis at any age for the following:
  – Colorectal (Lynch)
  – Male Breast (BRCA)
  – Ovarian (BRCA & Lynch)

• Number of cancer cases in 2006-2007 with a diagnosis between 18-49 years for the following:
  – Female Breast (BRCA)
  – Endometrial (Lynch)
Facility-specific Profiles

Sample Hospital and Medical Center Cancer Genetics Data Report (2006-2007) on Hereditary Breast and Ovarian Cancer Syndrome (BRCA) and Lynch Syndrome

Michigan healthcare facilities are required to report all cancer diagnoses to the Michigan Cancer Surveillance Program (MCSP) within the Michigan Department of Community Health (MDCH). MDCH has compiled state-wide registry data as well as facility-specific data, in order to provide you with the number of patients at your facility who may be at risk for HBC or Lynch syndrome, also called Hereditary Non-Polyposis Colorectal Cancer (HNPCC). These patients should have a formal risk assessment by a suitably trained health care provider to discuss the appropriate indications for genetic testing. HBC accounts for approximately 5-10% of all breast cancer diagnoses and is associated with increased risk for ovarian cancer. Approximately 3-5% of all individuals with colorectal cancer will have Lynch syndrome, which is associated with an increased risk for endometrial and ovarian cancers. Proper documentation and discussion of the above and related cancers, along with demographic features suggestive of a hereditary cancer syndrome, is critical. Individuals diagnosed with early onset cancers, multiple primary diagnoses, or rare cancers are at risk for hereditary cancer syndromes and may benefit from increased cancer surveillance, genetic testing, or special medical management.

### Table 1

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Breast (female)</td>
<td>3,025</td>
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<tr>
<td>Endometrial</td>
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<td>459</td>
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</table>

### Table 2

<table>
<thead>
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<th>All ages</th>
<th>Sample 2006 - 2007</th>
<th>Michigan 2006 - 2007</th>
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</thead>
<tbody>
<tr>
<td>Colorectal</td>
<td>10,340</td>
<td></td>
</tr>
<tr>
<td>Ovarian*</td>
<td>1,544</td>
<td></td>
</tr>
<tr>
<td>Breast (male)</td>
<td>147</td>
<td></td>
</tr>
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</table>

### Table 3

<table>
<thead>
<tr>
<th>All ages</th>
<th>Sample 2006 - 2007</th>
<th>Michigan 2006 - 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple primary cancer diagnoses</td>
<td>1,985</td>
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</table>

* All ovarian cancer data also include those cases diagnosed with cancer of the fallopian tube.

Patient names associated with the reported diagnoses can be sent to a designated person in your facility upon request. If requested, the names will be disclosed to your facility using current confidentiality rules.

Prepared in 2010 by MDCH staff
Contents

• Introductory letter
• Guidelines
• Data Report
• MCGA Directory of Cancer Genetics Services
• Resources: informed consent brochure, newsletters, fact sheets
• Front cover: Resource CD, MDCH fact cards, and our new pocket guide
Dissemination of Facility Reports

- Dissemination will occur by region to 129 facilities in 2010 (excludes labs, dermatology, dental, etc)
  - Region 3/6/7 in July 2010
  - Region 5 in Sept 2010
  - Region 4 in Oct 2010
  - Region 8 in Nov 2010
  - Region 9/10 in Dec 2010

- To date 77 facilities have received reports

- 30 facilities had no cases

- 21 facilities will receive reports this month

- Up to 50 reports will be mailed out in 2011 to the SEER sites (Regions 1 and 2)
Who receives the report?

- Cancer Registrar
- CEO of Medical or Clinical Affairs
- Head of Legal Affairs
- Head of Risk Management
- Medical Director
- Head of Nursing
- Head of the Oncology Department
Evaluation

• All that we have heard back from have shared the report with others in and out of their facility
• One is using data as a baseline for their genetics program
• Several have expressed interest in grand round presentations
• A facility has requested the names of the individuals in their report so they can follow-up with the patients and provide educational materials or support
**Future Steps**

- 30 facilities had no cases of cancer in 2006-2007. For these, we will evaluate data back to 2003 and mail reports by the end of 2010.
- Present Grand Rounds to the facilities that have requested educational trainings.
- Develop an evaluation tool to be completed via phone when our educator calls to confirm receipt of the facility report.
- Write up the results of our findings to be shared nationally so other states can use this surveillance/educational project.
- Cost analysis.
Thank you!

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