Creating a Clinical Risk Assessment Tool to Promote Cancer Genomics

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**Michigan’s Cancer Genomics and Provider Education Timeline**

- **2003**: Cancer genomics and provider education objectives in state genetics plan (2003-2008)
- **2004**: Cancer chart reviews on family history provider practices (2003-2004)
- **2005**: Health Plan primary care provider chart reviews on family history collection (2005-2007)
- **2006**: CDC Cooperative Agreement: Genomics Applications in Practice and Prevention (2008-2011)
- **2007**: Draft hand held provider tool created (2009)
- **2008**: Tool named “Cancer Family History Guide”©(2010)
- **2009**: Provider focus groups on tool (2009)
- **2010**: Finalized tool and received copyright (2010)
- **2011**: Impact of tool on cancer genetic referrals measured (2011)
- **2012**: Began dissemination of tool (2010)
- **2013**: Genomics goal and objectives in state cancer plan (2009-2015)-Includes provider education
- **2015**: Michigan’s Cancer Genomics and Provider Education Timeline

*Family history provider practice focus groups and key informants (2003-2008)*

*Genomics & Public Health Summit (2005) – primary care provider education top goal for cancer genetics*
Genomics Applications in Practice and Prevention (GAPP): Translation Programs in Education, Surveillance, and Policy

• **Goal:** move human genome applications into health practice to maximize health benefits and minimize harm through non-research activities

*Promoting Cancer Genomics Best Practices through Surveillance, Education and Policy Change in the State of Michigan*

• **Ultimate Impact:** A reduction in early cancer deaths (before age 50) through statewide surveillance and implementation of systems of care for inherited breast, ovarian, colorectal and other Lynch syndrome (HNPCC) related cancers that use best practice recommendations for family history assessment, cancer genetic counseling and testing
Our Program’s Goals
2008-2011

- Develop and implement a model for surveillance of inherited cancers and use of relevant genetic tests; and share with other cancer registries and national programs
- Identify model provider education programs to increase use of appropriate screening, counseling and evidence-based genetic tests; and share with public health and/or clinical practice organizations
- Identify a model health insurance policy for BRCA1 & 2 cancer genetic testing; and share with health plans in Michigan and other states

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- 853 charts reviewed from cancer patients reported to Michigan Cancer Surveillance Program (MCSP)
- 82% documented presence or absence of family history of cancer
  - 30% had positive family history of cancer
  - Over 80% documented relationship to patient and gender of affected family member
  - Over 94% missing age of onset/diagnosis of affected family member’s cancer
- Resulted in mandatory family history reporting for MCSP starting in 2007

Family History Provider Collection
Chart Reviews (2005-2007)

- 668 Primary Care Provider charts reviewed by Michigan Health Plan
  - 60% from Family Practice
  - 25% from Internal Medicine
  - 15% from Pediatrics
- Providers **are** collecting family history information.
- 92% of charts documented family history
  - 42% documented family history of cancer
  - 93% documented relationship of affected
  - Over 98% of charts never documented age of onset of affected
Key Informants and Focus Groups:
Family Health History Collection (2003-2008)

Common Themes Identified for Michigan Providers:

– Do not believe they see patients with high-risk cancer family history
– Do not feel confident in ability to identify high-risk family history
– Uncertain where to refer
– Would use a pocket tool in practice
Family History Collection by Primary Care Providers – Findings from Other Studies

- Average duration of family history discussion, 2.5 minutes (Acheson et al, 2000)
- Presence or absence of colorectal cancer and breast cancer are noted in 40% of charts (Medalie et al, 1998)
- Only 29% of primary care providers feel prepared to take family history and draw pedigrees. (Suchard et al, 1999)
- Even when family history collected, often do not assess risk in the family (Sweet et al, 2002; Frezzo et al., 2003)
Development of Cancer Family History Guide©

How can we help providers to:

• Identify who is at risk?
• Determine level of risk?
• Ensure proper screening?
• Ensure proper preventive services?
• Improve health outcomes?
• Possibly even save health care resources?
Development of Cancer Family History Guide©

- Modeled after standard obstetrical pregnancy wheel
  - Same size
  - Same concept as hand held pocket tool
- Developed by 3 board-certified genetic counselors employed at MDCH
- Input from CDC Office of Public Health Genomics and Cancer Genomics Best Practices Steering Committee
- Recommendations based on national publications
  - 2005 USPSTF BRCA Recommendation
  - Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Guidelines for Lynch syndrome
  - National Comprehensive Cancer Network (NCCN) Guidelines
  - Society of Gynecologic Oncologists (SGO) Education Committee Statement
Focus Groups

- Focus groups with draft tool in September-October 2009
- 2 family practice and 2 oncology groups at 4 different institutions
- Each group consisted of 10-20 physicians
- No identifiable information collected
- No honorarium provided
- Informed consent, written information, brief introductory presentation, and tutorial given
- Audio recorded and themes transcribed
Focus Group Feedback

Six Focus Group Questions:
1. Is there a need for such a tool in your daily practice? Do you already have such a tool?
2. Is overall design clear, appropriate, user-friendly?
3. What would you change about aesthetics of tool?
4. Does tool function accurately and provide useful information?
5. Are any critical pieces lacking?
6. How likely are you to use this tool in practice?

Consensus that Tool:
1. Needed and does not currently exist
2. Clear and intuitive design
3. Needed no changes except font colors and bold contact information
4. Functions accurately and is useful
5. Could use more specific definitions (i.e. define relative; exact number of polyps, etc)
6. Would be used in their clinical practice with exception of one provider group that is paperless
**Cancer Family History Guide©**
**Examples of Focus Group Comments**

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “This is very unique.”</td>
<td>• “Better if a web-based tool or PDA- lots of people would prefer web based or incorporate into EMR.”</td>
<td>• “So this is for paternal history too?”</td>
</tr>
<tr>
<td>• “Very easy to use the second and third time.”</td>
<td>• “I don’t know if we would use it- might be better for PCPs.”</td>
<td>• “Add definition of 1st degree relative.”</td>
</tr>
<tr>
<td>• “Can we take this with us today?”</td>
<td>(comment from oncology group)</td>
<td>• “A few more instructions would be good.”</td>
</tr>
<tr>
<td>• “We use the OB wheels and we won’t part with them so this is the same idea.”</td>
<td>• “This wouldn’t see the light of day in my office.”</td>
<td>• “Why age 50?”</td>
</tr>
<tr>
<td>• “Very easy and helpful. It’s hard to know automatically when to refer for genetic counseling.”</td>
<td>• “Do guidelines address if smoking status changes risk assessment?”</td>
<td>• “If they’re yellow, what do we do? We always struggle with this gray area.”</td>
</tr>
<tr>
<td>• “Even though it’s not electronic, it’s very cool.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cancer Family History Guide©
For More Information

www.migeneticsconnection.org

Information on Cancer Genetic Testing and Counseling:

MCGA Guide to the Genetic Testing and Counseling Process
http://www.migeneticsconnection.org/cancer/guide_1.html

MDCH Cancer Genomics Terminology Sheet

Michigan’s Informed Consent Law for Genetic Testing

MCGA Cancer Genomics Services Directory of Clinics
http://www.migeneticsconnection.org/cancer/directory.html

US Preventive Services Task Force (USPSTF) Evidence Based Recommendations on BRCA testing for breast cancer
http://www.ahrq.gov/clinic/uspstf/uspsbrca.htm

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)
http://www.egappproject.org


Tumor Gene Expression Profiling in Women with Breast Cancer
http://hdl.handle.net/1853/18782

CDC National Office of Public Health Genomics site on genetic testing for colorectal cancer and Lynch Syndrome
http://www.cdc.gov/genomics/testing/EGAPP/recommendations/lynch.htm

Or call 1-866-852-1247
Cancer Family History Guide©
Finalized in 2010

• Revised tool based on focus groups feedback

• Requested and received copyright
  – approved in April 2010

• 2500 tools successfully printed and delivered
  – in July 2010

• Second printing of 9500 tools requested in October 2010
  – Awaiting delivery
Cancer Family History Guide©

Dissemination

- 2997 tools disseminated and/or requested
  - Michigan cancer reporting facilities
  - All Oakwood Hospital providers
  - Disseminated at key Michigan events
    - Michigan Cancer Consortium annual meeting
    - Michigan Association of Health Plans Pinnacle Awards and Summer conference
    - Michigan Association of Genetic Counselors
    - Michigan Cancer Genetics Alliance
    - Hereditary Cancer Provider conference

- Key national events
  - CDC Family History workshop
  - CDC Division of Cancer Prevention and Control
  - Cancer Control PLANET webinar
  - Today

- Examples of requests received
  - Two Michigan local public health departments
  - Michigan State University College of Nursing
  - Out-of-state providers in 12 other states
  - Four other state health departments
    - 500 requested from Washington State Department of Health
  - One out-of-state tumor registry
  - National ovarian cancer advocacy group
Cancer Family History Guide©

Evaluation

- Michigan Cancer Consortium (MCC) Breast Cancer Advisory Committee
  - 688 surveys on family history of breast and ovarian cancer completed by women waiting for clinical visits
  - Compared 5 risk assessment tools to determine appropriate referral to cancer genetics
  - Same 71 women (13%) identified appropriate for referral by Cancer Family History Guide and B-RST
    - Lowest referral rate compared to other tools rates (18-54%)
  - Cancer Family History Guide and B-RST identified same 28% of women at moderate risk

- Oakwood Hospital & Medical Center based in Dearborn, Michigan
  - New provider referrals to cancer genetics measured since May 2010 (6 months prior to dissemination)
  - Oakwood Communications sent tools to 700 Oakwood providers in October 2010
  - New provider referrals to cancer genetics to be measured until April 2011 (6 months after dissemination)
  - Interest from 3 other health systems to measure impact of tool on cancer genetic counseling referrals
  - Other ideas?
Summary:
Creating a Clinical Assessment Tool to Promote Cancer Genomics

Data → Public Health Action → Dissemination & Evaluation

• 94-98% of Michigan medical charts without documented age of cancer diagnosis for affected family members
• Key informant interviews and focus groups revealed providers:
  – Do not believe they see patients with high-risk cancer family history
  – Do not feel confident in ability to identify high-risk family history
  – Are uncertain where to refer
  – Would use a pocket tool in practice

• Pocket tool incorporates USPSTF and EGAPP guidelines
• Assists providers in:
  – Collecting cancer family history
  – Assessing the risk of hereditary cancer
  – Proceeding with referral and/or increased surveillance based on guidelines

• ~3000 tools requested to date
• 700 Oakwood Health System physicians
  – Cancer Genetics Clinic to monitor new provider referrals before and after dissemination
• 200 cancer reporting facilities
• 20 Michigan health plans
• Others

Please contact genetics@michigan.gov to order tools