Creating a Clinical Risk Assessment Tool to Promote Cancer Genomics Best Practices in the State of Michigan

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Background

The Michigan Department of Community Health (MDCH), in collaboration with the Centers for Disease Control and Prevention National Office of Public Health Genomics, has developed a multi-faceted cancer genomics program which includes educating providers about the importance of cancer family health history.

Program activities were designed to address the Healthy People 2020 objective to:

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

Women with an appropriate family history must first be identified by the primary care provider. It is estimated that the average primary care provider has approximately **2.5 minutes to devote to family history discussion**.[1] Past MDCH projects, including two separate patient chart reviews, revealed that providers are documenting family history of cancer and recording the gender and degree of relatedness of the affected relative. However, these projects revealed that providers did not include age at diagnosis when documenting family history.[2,3]

Because age at diagnosis is a critical factor in assessing familial risks, these data suggested that providers might benefit from a tool to aid in family history collection and cancer risk assessment. We therefore sought to develop a pocket family history guide which had a cancer risk assessment function and could be used quickly by practitioners in the clinical setting.

Objective

- To create a tool that provides an algorithm-based risk assessment and subsequent recommendations for the most common hereditary cancers and:
  - allows providers to quickly obtain a risk assessment based on family history information
  - provides referral and management recommendations
  - is based on national evidence-based guidelines addressing *BRCA* and Lynch Syndrome; two known, common hereditary causes of breast, ovarian/fallopian tube/primary peritoneal, and colorectal/endometrial cancers.[4,5,6,7,8]

Methods

The Cancer Family History Guide consists of three layers with questions for determining a patient's genetic risk for cancer: number of relatives diagnosed, age of onset and the degree of relatedness. Alignment of the answers guides the provider's decisions about referral, screening, and surveillance.

A mock up was created for use in the four focus groups with providers to obtain detailed feedback about the utility, design, benefits, and suggested revisions of the Cancer Family History Guide. Each group consisted of 10-20 participants.

Six pre-developed questions were discussed with each focus group:

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

The focus group discussions were deemed exempt from MDCH Institutional Review Board approval. Due to the unique nature of the Cancer Family History Guide©, MDCH has registered and received a copyright to prevent commercial replication of the content without permission.

Results

Over 50 subspecialty and primary care providers in four focus groups evaluated the Cancer Family History Guide©. Participants were from facilities located in Southeast (Wayne, Oakland counties) and Mid-Michigan (Ingham County) and included family medicine physicians, oncology physicians, nurses and staff. **They overwhelmingly agreed that no such tool is currently available similar to the Cancer Family History Guide and that there was a need for one.** Feedback from each of the discussion questions is summarized in *Table 1*.

Table 1. *The summary of comments and suggestions from the four focus groups on the six pre-developed questions.*

Question	Summary of Feedback
1 Needed?	• Groups agreed that the Guide is needed and a similar tool does not currently exist; however, there were suggestions that it may not be useful for a paper-free practice
2 User-friendly?	• All groups agreed that the Guide was "clear", "intuitive", and "user-friendly". They also mentioned that additional instructions would be helpful with clear definitions for first and second degree relatives.
3 Design changes?	• Two groups felt the Guide needed no changes. The other two groups recommended 1) adding a contact phone number and 2) considering the needs of color-blind individuals by changing some of the color combinations.
4 Accurate?	• Two of the groups agreed unanimously that it was accurate and useful. The other two groups wanted first and second degree relatives defined.
5 Anything lacking?	• One group thought nothing was lacking. The other three groups suggested adding screening guidelines, defining multiple polyps as >10, adding risk magnifiers and adding the definition for first/second degree relatives.
6 Would you use?	• Two groups wanted to take the Guide with them that day to use. One of the oncology groups thought it would be best in a primary care setting and another group raised concerns that it was paper-based rather than electronic.

The Cancer Family History Guide has been well received with nearly 15,000 copies distributed nationally between August 2010 and July 2012. The MDCH Cancer Genomics Team has received extremely positive feedback from a variety of sources including local health departments, hospitals and clinics, areas providers, other state health departments, breast and cervical cancer control programs (BCCCP), advocacy groups and academic partners. To date, the Cancer Family History Guide has been disseminated to 21 states and the District of Columbia.

Discussion

Based on the focus group results, the Cancer Family History Guide© was further refined and suggestions incorporated, as feasible. Although several different electronic cancer risk assessment tools have also been developed, particularly to assess the risk of carrying a *BRCA* mutation based on family and/or personal history, we are unaware of any tool such as our Cancer Family History Guide that incorporates evidence-based recommendations for multiple types of cancer. The tool plays an important role in today's health care environment by making it quick and easy for providers to assess a patient's cancer risk based on family history; and will assist in achieving the Healthy People 2020 *BRCA* counseling objective.

A limited number of Guides are available at no cost. Please contact MDCH Genomics at 1-866-852-1247 or genetics@michigan.gov to order.

References

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