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 family health history.

Some program activities have been designed to address the new Healthy People 2020 objective to:

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

However, before women can receive genetic counseling, those at higher risk 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] From 2003 through 2007, the MDCH Genomics Program undertook two chart review projects to ascertain Michigan provider practices regarding collection of family history relative to breast, colorectal and endometrial cancers with the following results:

- 853 oncology charts were reviewed between 2003-2004, and 80% documented the gender of the affected relative and the relationship to the patient but **over 94% did not include the age of diagnosis**.
- 668 primary care charts were examined from 2005-2007 and **98% were lacking the age at cancer diagnosis** of the affected family member.

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

The goal of designing a new pocket guide was to create a tool that provides an algorithm-based risk assessment and subsequent recommendations for the most common hereditary cancers. This cancer genomics tool allows providers to quickly obtain a risk assessment based on family history information and provide referral and management recommendations. The recommendations are based on national evidence-based guidelines addressing BRCA and Lynch Syndrome, two known hereditary causes of Breast, Colorectal/Uterine and Ovarian/Fallopian Tube/Primary Peritoneal cancers.[2,3,4]

Methods

The concept for the guide was based on the pregnancy wheel, a paper-based model used in obstetric practices for years. The wheel consists of three layers that ask important 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 and understanding about the utility, design, benefits, and suggested revisions of the cancer family history pocket guide. Each group consisted of 10-20 participants. They were provided with a pocket guide information sheet and informed consent statement prior to the discussion. Two focus groups were held with oncologists, while two were held with primary care physicians.

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 Pocket Guide©, MDCH has registered and received a copyright to prevent commercial replication.

Results

Over 50 subspecialty and primary care providers in four focus groups evaluated the Cancer Family History Pocket Guide©. The 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 there was no tool currently available like this and that there was a need for one.** Feedback on 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 in a paper-free office
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 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 instead of electronic.

Discussion

Based on the focus group results, the Cancer Family History Pocket 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 Guide that incorporates evidence-based recommendations for multiple types of cancer and can be used without the provider having to take the time to log on to a web-based application. While a decision support tool embedded within the electronic health record may be ideal for assessing cancer family history and respective risks, the cost of developing and implementing such a tool far exceeds that of our hand-held pocket tool. Thus, the tool plays an important role in today's health care environment by making it quick and easy for providers to adopt the habit of assessing a patient's cancer risk based on family history; and will hopefully assist states in meeting the Healthy People 2020 genetic counseling goal.

The Guide has been positively received with more than 2,000 copies distributed nationally between August and October 2010. Its effectiveness in changing referral patterns will be evaluated at Oakwood Hospital & Medical Center in southeast Michigan. Six months after distribution to 700 providers in the Oakwood health care system during October 2010, MDCH will review the Guide's impact through a pre- and post- assessment of call volume and referrals to the Oakwood genetic counseling clinic.

A limited number of Guides are available at no cost. Please contact genetics@michigan.gov if you would like to place an order.

References

1. Acheson LS et al. Family history-taking in community family practice: Implications for genetic screening. Genet Med 2000; 2(3):180-5.
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4. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology. Colorectal Cancer Screening. www.nccn.org

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