The State Of Michigan Leads the Way for Others

November 14, 2014
BRCA Symposium

Debra Duquette, MS, CGC
Michigan Department of Community Health
duquetted@michigan.gov; 517.335.8286
Mission:

MDCH will protect, preserve, and promote the health and safety of the people of Michigan with particular attention to providing for the needs of vulnerable and under-served populations.

Vision:

Improving the experience of care, improving the health of populations, and reducing per capita costs of health care.
Improved health outcomes and an enhanced quality of life for the people of Michigan through appropriate use of genetic information, technology, and services

First state genetics plans in US to identify need for cancer genetics in public health!

www.michigan.gov/genomics

Genomics Goal:

Increase availability of cancer-related genetic information to the Michigan public and decrease barriers to risk-appropriate services

First in US to have entire goal for genomics in state comprehensive cancer control plan!

http://michigancancer.org/
Healthy People 2020 (HP 2020)

- Started in 1979
- 10-year national objectives for promoting health and preventing disease
- HP 2020 marks first time for genomics objectives
- Encourage collaborations across sectors, guide individuals toward making informed health decisions, and measure the impact of prevention activities
- Works to achieve increased quality and years of healthy life and the elimination of health disparities.
Primary care providers should screen women with a family history of breast, ovarian, fallopian tube or peritoneal cancer to identify those potentially at increased risk for a BRCA mutation. Women with a significant family history receive genetic counseling, and, if indicated, they be offered genetic testing

(Grade B Recommendation)

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

(Grade D Recommendation)

http://www.uspreventiveservicestaskforce.org/uspstf/uspsbrgen.htm
“…no important health problem will be solved by clinical care alone, or research alone, or by public health alone - But rather by all public and private sectors working together”

JS Marks. Managed Care 2005;14:p11
Supplement on “The Future of Public Health”

Impact: A reduction in the young breast cancer death rate and the ovarian cancer death rate.
Public Health Genomics
Implementation to Save Lives: From National Vision to State Success

https://www.youtube.com/watch?v=OfjkY1ILxbE&feature=youtu.be

- 2014 video created by CDC and Genetic Alliance
- Highlights Michigan as model for other states
- Importance of Partnerships!
Importance of Federal Funding for Michigan BRCA Efforts

CDC Awards Programmatic Funding to Support Breast Cancer Genomics

CDC funded three state health departments for a three-year cooperative agreement, "Enhancing Breast Cancer Genomic Practices through Education, Surveillance, and Policy," as part of a broader effort by CDC to support the Education and Awareness Requires Learning Young (EARLY) Act, section 10413 of the Patient Protection and Affordable Care Act.

About the Cooperative Agreement

This funding catalyzed the adoption of evidence-based recommendations for breast cancer genomic tests and other related interventions into health practice in a way that maximizes health benefits and minimizes harm to individuals and populations. Funding enhances the state health departments' capacities to promote applications of evidence-based breast cancer genomics best practices through education, surveillance, and policy, and thus address the needs of young women at high risk for developing breast cancer. Funded applicants will develop or enhance activities related to promotion of breast cancer genomics, for example:

- Increase appropriate BRCA 1/2 counseling and testing.
- Increase insurance coverage of BRCA 1/2 and related clinical interventions for appropriate women.
- Develop educational programs to increase the public and health care provider's knowledge about family history, risk assessment, and the appropriateness of BRCA 1/2 counseling and testing.

About the Awardees

CDC received applications from eight state health departments. With available resources, CDC was able to fund health departments in Georgia, Michigan, and Oregon. The remaining applications...
CDC Funding Announcement


• 3 year cooperative agreement (2011-2014) awarded to three projects
  – Authorized from Affordable Care Act
  – State health departments and Tribal governments eligible

• **Purpose:** develop or enhance activities related to breast cancer genomics
  – Promote use of BRCA1/2 clinical practices as recommended by USPSTF and NCCN

• **Must** conduct programs in policy plus surveillance and/or health education
  • **Cannot** use funds for research, clinical practice or lobbying

![Figure 1: BRCA Counseling, Testing and Clinical Services](image)
 CDC Funding Announcement


- **5 year** cooperative agreement awarded to four projects
  - Authorized from Affordable Care Act
  - State health departments and Tribal governments eligible

- **Purpose:** Enhance state health department’s capacities to promote and apply evidence-based breast and ovarian cancer genomics guidelines in public health practice
  - Develop, enhance and evaluate education, surveillance and policy/systems change
  - Emphasis on partnerships
  - Focus on HBOC but may also include Lynch syndrome
  - May identify target populations disproportionately affected by HBOC and lack genetic services
MDCH Cancer Genomics Outcomes, 2014-2019

- **Ultimate long term outcome**
  - Reduce incidence and mortality related to hereditary cancers, including breast, ovarian and colorectal cancer

- **Short- and intermediate term outcomes** (by 2019):
  - Increase knowledge among key clinical and policy stakeholders about cancer genetic best practices; improved access to and coverage of cancer genomics best practices. **[Policy/system change]**
  - Improve ability to assess the burden of hereditary cancers and use of cancer genomics best practices; increased production and dissemination of periodic cancer surveillance reports. **[Surveillance]**
  - Increase knowledge of hereditary cancers and appropriate use of cancer genomics best practices among the public and health care providers. **[Education]**
  - Improve partnerships and coordination among key stakeholder groups regarding cancer genomics services and care. **[Partnerships]**
Example of Long-Term Outcome:
Michigan Mortality Rates for Breast Cancer in Young Women, Black and White, 1990-2012

- Decrease in breast cancer in young women incidence and mortality in Michigan from 1990-2012
  - 5.2 per 100,000 in 2010 compared to 8.7 deaths per 100,000 in 1990
- In Michigan, 2012 marked the first year since 1990 that there was not a statistical difference in black/white mortality
  - 5.2 deaths per 100,000 for young black women vs. 4.6 per 100,000 for young white women
Improve Access and Coverage for Cancer Genetic Services

- Growth of cancer genetic counseling and BRCA testing of individuals with a personal and/or family history of breast and/or ovarian cancer
- Reduced barriers for appropriate BRCA testing with continued decrease in percentage of individuals who had genetic counseling but were not able to pursue BRCA testing due to inadequate insurance
  - Reduced to 8.3% of those not testing in 2014 compared to 21.7% in 2008
  - Increased written health plan policies for appropriate BRCA counseling and testing from 4 to 15 health plans
    - Covering over 7.5 million Michigan members
Commission on Cancer (CoC) Genetic Counseling Standard

STANDARD 2.3 Risk Assessment and Genetic Counseling

Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

DEFINITION AND REQUIREMENTS

Cancer risk assessment and genetic counseling are the processes to identify and counsel patients at risk for familial or hereditary cancer syndromes. The purposes of genetic counseling are to educate patients about their chance of developing cancers, help them obtain personal meaning from cancer genetic information, and empower them to make educated, informed decisions about genetic testing, cancer screening, and cancer prevention. Identifying patients at increased risk of developing cancer because of a family history of cancer or a known hereditary cancer syndrome can have dramatic effects on early detection and cancer outcome. For this reason, cancer risk assessment and genetic counseling are rapidly becoming standards of care for patients with personal and/or family history of cancer who are at high risk of having a hereditary syndrome.

The program provides cancer risk assessment and genetic counseling on-site or by referral to another facility or community-based organization.

Cancer risk assessment and genetic counseling are performed by a cancer genetics professional who has extensive experience and educational background in genetics, cancer genetics, counseling, and hereditary cancer syndromes to provide accurate risk assessment and empathetic genetic counseling to patients with cancer and their families.

Cancer risk assessment and the potential for referral may be discussed as part of the multidisciplinary cancer conference.

Genetics professionals include people with the following:

- An American Board of Genetic Counseling (ABGC) or American Board of Medical Genetics (ABMG) board-certified/board-eligible (in some states) licensed genetic counselor
- An American College of Medical Genetics physician board certified in medical genetics
- A Genetics Clinical Nurse (GCN) or an Advanced Practice Nurse in Genetics (APNG), credentialed through the Genetics Nursing Credentialing Commission (GNCC). Credentialing is obtained through successful completion of a professional portfolio review process.
- An advanced practice oncology nurse who is prepared at the graduate level (master or doctoral) with specialized education in cancer genetics and hereditary cancer predisposition syndromes*; certification by the Oncology Nursing Certification Corporation is preferred.
- A board-certified physician with experience in cancer genetics (defined as providing cancer risk assessment on a regular basis).

*Please note, specialized training in cancer genetics should be ongoing, educational seminars offered by commercial laboratories about how to perform genetic testing are not considered adequate training for cancer risk assessment and genetic counseling.

The Cancer Committee defines the appropriate individuals who will provide risk assessment and counseling for major cancer disease sites (such as breast and colon). In addition, the program needs to have immediate access to formal genetic counseling services should identify resources for referral.

Cancer risk assessment and genetic counseling involve pretest and posttest counseling. At a minimum, this counseling includes the following:

Pretest Counseling

- Collecting relevant information needed to assess a patient's personal and family medical history
  - A 3- to 4-generation pedigree, including detailed medical information about the patient's first-, second-, and third-degree relatives should be obtained
  - Gathering information about paternal and maternal family history, ascertainment bias, and consanguinity, if applicable, is necessary.
- Evaluating the patient's risk
  - One aspect of risk assessment is discussing the absolute risk that the patient will develop a specific type of cancer or cancers based on that family history. The second aspect is the risk that the patient carries a heritable or germline mutation in a cancer susceptibility gene.
- Performing a psychosocial assessment
  - Educating the patient about the suspected hereditary cancer syndrome, if appropriate
  - The provider reviews and discusses with the patient the cancer risks associated with gene mutations, including basic concepts such as genes and inheritance patterns and more advanced concepts of penetrance and variable expressivity and the possibility of genetic heterogeneity.
- Obtaining informed consent for genetic testing (if genetic testing is recommended).

Posttest Counseling

- Disclosure of the results and posttest counseling include a discussion of the results, significance, and impact of the test results, medical management options, informing other relatives, future contact, and available resources. The test results and interpretation will be communicated to the provider, lines and recommendations for cancer risk management and genetic counseling for hereditary cancer cases are available from the Agency for Healthcare Research and Quality (AHRQ) and the NCCN.

SPECIFICATIONS BY CATEGORY

All programs fulfill the standard as written.

DOCUMENTATION

The program completes the SAR.

During the on-site visit, the surveyor will discuss the process for providing cancer risk assessment and genetic counseling services either on-site or by referral.

MEASURING COMPLIANCE

Rating

(1) Compliance: The program fulfills the following criterion:
- Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

(5) Noncompliance: The program does not fulfill the following criterion:
- Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

Example of Populations in Current Need of Cancer Genetic Services

- Increase in number of cancer genetic clinics with board-certified genetic professionals in Michigan including previously underserved areas
  - 17 clinics in 2014 compared to 8 clinics in 2010
- Highest incidence of age-adjusted breast cancer in young women
  - Top five counties located in NW Lower Peninsula
- Highest incidence of age-adjusted ovarian cancer
  - Top seven counties located in NE and SE lower peninsula and ‘thumb’ area,
Example of Ability to Access Burden of Hereditary Cancers

- BRCA mutations found in 29.4% of patients with a history of both breast and ovarian cancer and 14.0% of patients with ovarian cancer
  - Data from Michigan Cancer Genetics Clinics with Board-Certified/Eligible Genetics Professionals

- Only 3.7% of Michigan ovarian cancer patients underwent BRCA genetic testing
  - Data from Michigan cancer chart reviews
  - Letter to the NY Times editor from Ovarian Cancer National Alliance cited data

- Room for improvement: reduce barriers to established beneficial services

Example of increasing knowledge of hereditary cancers among public and providers

- Cascade screening!
- Individuals of a relative with a known deleterious mutation
  - 50% risk to inherit known deleterious mutation for first degree relatives
  - Single site testing is extremely informative and much less expensive
  - Rate of single site testing has remained relatively low and steady in Michigan
- Only 12.3% of people who had BRCA counseling in Michigan cancer genetics clinics were referred because of known familial mutation

Michigan Cancer Genetics Alliance Corner
Cascade Genetic Screening: Improving Hereditary Cancer Risk Identification
By Angela Trepamer, MS, CGC, Michigan Cancer Genetics Alliance

One of the goals in Michigan’s current Comprehensive Cancer Control Plan is to “increase the availability of cancer-related genetic information to the Michigan public and decrease barriers to risk-appropriate services”. This goal is in line with the more targeted Healthy People 2020 objective to “increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling”. Through a cooperative agreement with the Centers for Disease Control, the Michigan Department of Community Health has been working to increase the number of Michigan residents receiving appropriate genetic counseling, genetic testing, and follow-up for hereditary breast and ovarian cancer syndrome (BRCA). According to data from 2011 and 2012 Michigan Behavioral Risk Factor Surveillance System surveys, there was a decrease in BRCA genetic counseling from 50% to 42% during the 2-year period. With the emphasis on increased risk communication, providers and patients will have access to the latest research and services. http://www.michigancancer.org/PDFs/Publications_Products/MCCUpdate/MCCUpdate2014/MCCUpdateJuly-Aug2014.pdf
Patient-Powered Network for Hereditary Breast and Ovarian Cancer (HBOC)

- ABOUT Network first “patient-powered” research registry created and governed by and for people affected by HBOC
- Goal to enroll 15,000 people in US affected by HBOC
- Would like representativeness among all populations
  - Part of National Patient-Centered Clinical Research Network (PCORNet) established in 2014 under the Affordable Care Act

Some of this presented work was supported by the Cooperative Agreement Number 5U58DP003798-03 from The Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the presenter and do not necessarily represent the official views of the CDC.